

AUTISM SPEAKS, MOROCCO LISTENS

*Recording, analyzing, and documenting the
current state of autism in Morocco*

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Autism Speaks, Morocco Listens

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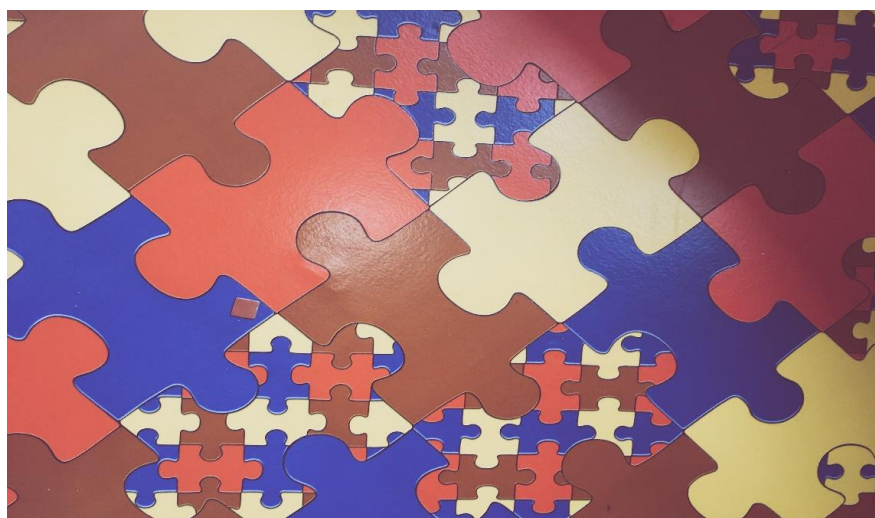
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Abstract

This project assessed the availability of resources for families of children with autism in the Rabat region of Morocco. Our sponsor, Autism Speaks, provided their 2016 survey to conduct further family interviews in 2018. Working with a translator, our team interviewed 20 families and four professionals associated with autistic children at three Moroccan non-governmental organizations. Results from these interviews indicate a number of areas for improvement in the treatment of autism in Morocco including: more cultural awareness, better government and home support, more specialized education and professional training. Our analysis of the results between the 2016 and 2018 interviews illuminated differences in resource availability between rural families and urban families in Morocco.



Autism Speaks, Morocco Listens

Executive Summary

Autism in Morocco

Authors: Angelica Pollard-Knight, Morgan Reisinger, Edith Sawyer

What is Autism?

Autism Spectrum Disorder (ASD) is a neurological disorder that affects the social and physical functioning of the diagnosed. The term “autism” refers to a complex spectrum of conditions regarding personal strengths and weaknesses of the diagnosed. Autism is an incurable disorder and symptoms usually develop between two and three years old (What is Autism, 2012). The areas in which individuals experience autism impairment include difficulty with repetitive behavior, social interaction, and verbal and nonverbal communications.

Understanding Autism

Autism remains incompletely understood in medical, public, and domestic sectors of Moroccan society. This situation is heightened due to the lack of official documentation or national research about autism. Medical diagnoses of ASD do not reflect the

complexity of the spectrum. Families of children with autism often consider the mother the most understanding of their child’s condition.

Government Support

In 2015, the Moroccan parliament adopted its first initiative to protect the rights of the disabled under the Draft Framework Law. However, law enforcement is inadequate regarding this law. Additionally, Morocco has 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).

Furthermore, the process for receiving government funding for organizations that specialize in autism care is difficult and is often inadequate for supporting a large number of families at a time.

Resource Availability

Funding of organizations that



Names of the children of the Space for Brothers organization



Wall mural painted by the children of the Yasmine Breton organization

specialize in treating children with autism significantly affects the resources that these organizations can offer. Public organizations that obtain funding from the Moroccan government often must limit the amount of families they can service at their organization. Limits in physical space organizations have adds to this. Both public and private organizations share the struggle of obtaining the necessary physical items they need to sufficiently run a schooling facility, such as chairs and tables.

Social Implications

Children with autism typically exhibit multiple characteristics that set them distinctly apart from their peers. Consequently, a social stigma has developed around individuals who exhibit these traits. Poor public perception of autism results in families feeling shame when performing daily activities. Many Moroccan families struggle to raise children with these disabilities (Galindo, Grant, Languet, & Sirry, 2016; Hachim, Martin, Miner, & Rahman, 2016).



Transportation vehicle for students at the AMAL association

Non-Governmental Organizations

Specialists in autism care

To compensate for limited governmental, medical, and educational efforts to improve the quality of life for the disabled in Morocco, non-governmental organizations (NGOs) have developed with the intention of providing awareness and resources for ASD. We worked with the following three NGOs throughout the completion of our project:

Espace al Akhawayne

Founded in September 2017, Espace Al Akhawayne's (the Space for Brothers) mission is to prepare children with autism for academic and professional integration into Moroccan society. Some of the services they provide include speech therapy, psychomotor learning, psychological support, and both individualized and group training sessions (A. Attar, personal communication, Jan. 24, 2018).



Yasmine Breton Center

A doctor diagnosed Yasmine Breton with autism disorder at the age of three. When local services could not provide the care she needed, Yasmine's mother studied possible methods of treatment for autism. Today, the Yasmine Breton Center treats more than one hundred children. The goal of this organization is to achieve concrete results regarding the development of daily living skills of the associated children (Breton).



AMAL

AAEBSM's (Association AMAL Enfants Aux Besoins Specifiques Mentaux or AMAL) mission is to support the needs of families and children affected by ASD. They aim to provide proper support regarding social integration for children, as well as alter public perception of mental disabilities to promote mutual respect and dignity for every member of society (AAEBSM, 2017).



Project Summary

In 2016, two teams of WPI students conducted a project to support Autism Speaks, an international organization aimed at advancing autism care and awareness, by performing interviews of caregivers and professionals who autism impacts in Morocco. By using caregiver and professional surveys in these interviews, these project teams gathered a substantial pool of data regarding the realities of autism in both urban and rural regions of Morocco. We analyzed only the rural data collected by these teams for the purpose of this investigation.

Our project was a similar but non-identical extension of the 2016 projects. The goal of our project, like theirs, was to collect and analyze data regarding current resources and education available for children with autism in Morocco. However, we only interviewed in the urban Rabat region. Another difference between our projects was our inclusion of targeted evaluations of experiences of professionals.

Our team utilized the caregiver survey



Our team with the officials at the Space for Brothers organization in Rabat

Autism Speaks provided previous WPI project teams in 2016. This survey allowed us to assess the attitudes and struggles of families impacted by autism. Next, our team used this information to develop an additional set of interview questions for professionals who specialize in treating autism. Our team used the combined data from caregiver and professional interviews to identify factors of treatment and governmental policy that restrict the advancement of resource availability for autism in Morocco.



Our team in the interview setting



Morgan Reisinger typing up interviewee responses

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

1. Analyzed resources and challenges for families of children with autism in the Rabat region
2. Conducted comparative analysis between 2016 and 2018 data sets
3. Conducted targeted evaluations of resources and experiences in Rabat

Our deliverables included recommendations for Autism Speaks, as well as the addition of interview results into the Autism Speaks database.

Methods

To complete objectives one and three, we conducted in-person interviews with families of children with autism at both the Space for Brothers and Yasmine Breton centers. We conducted seven interviews at the Space for Brothers, and thirteen at the Yasmine Breton center. We conducted four professional interviews at the AMAL center in Casablanca. We completed two to six interviews a day with the assistance of our associate and translator, Jihan El Ouaragli. Our family interviews took three weeks to complete, whereas our professional interviews took one day.

Results

This section describes our results in three sections that consolidate our analysis.

Public vs. Private

The Space for Brothers organization is a public organization. The Centre Yasmine Breton association, however, is private. There were many interesting differences between these types of facilities.

The key differentiating factor between public and private autism NGOs involves their funding. Public organizations receive the majority of their funding from the Moroccan government and charge families they service small amounts of money. Private organizations are funded solely by parents who pay directly for treatment.

Further, families of the private organization showed less financial instability than those of the public organization. Families associated with the Space for Brothers had to sacrifice career work and financial gain in order to care for their children more often than those associated with the Yasmine Breton center.

Another remarkable difference between public and private organizations pertains to family satisfaction with the services they receive. At the Space for Brothers, 100% of respondents indicated that they were very satisfied with the relationship they had with their service providers. Comparatively, only 54% of families at Yasmine Breton center indicated that there were very satisfied with this relationship. Despite their differences, public and private NGOs did share some similarities.

Almost every family at both organizations indicated that they did not receive additional support for their children outside of specialized NGOs. Additionally, the internet and communications between caregivers served as primary sources of information for both families and professionals at all organizations we visited.

Urban vs. Rural

The 2016 WPI teams conducted interviews of families impacted by autism in both urban and rural areas of Morocco. Our project team, comparatively, only conducted family interviews in the urban Rabat region. Through comparing the data these surveys provided, we discovered that in rural areas of Morocco, more families have children who are not enrolled in any schooling. Families of these children must travel longer to obtain a professional diagnosis as well. This suggests that professional resources are harder to obtain by families in rural regions of Morocco. Finally, families in rural areas feel they need less in-home support for their children than those in urban regions.

Results vs. Expectations

Overall, we were both surprised and unsurprised by the results of our study. The background research we conducted before arriving in Morocco prepared us for the limits families experienced regarding accessing the treatments and support they needed. However, the specifics of these limitations caught us off guard. Primarily, the Internet as the primary source of training and information received by both families and professionals was what we found the most interesting.



“AMAL” wall painting located at the organization’s center



Hands of children at the Yasmine Center



Mural that reads “To Understand Them” at the Space for Brothers

Recommendations

Through the process of our data analysis, our team concluded that Moroccans could improve areas of their society to better suit the needs of the autistic community. Areas that Moroccans could improve involve medical, educational, domestic, and informational aspects of society. Additionally, there exist actions Autism Speaks can take to make the process of data collection in Morocco more accurate. We hope that the following recommendations aid Autism Speaks in supporting the autism community in Morocco.

- Advance training opportunities for professionals specializing in autism treatment
 - Develop field practice opportunities in Moroccan universities
 - Establish medical training for proper, individualized diagnosis of ASD
- Distribute information about autism to the public in the form of informational pamphlets and online websites
- Make access to necessary governmental funding easier to obtain and maintain for people impacted by autism
- Provide more training opportunities for families of children with autism
- Establish greater networking opportunities for families of children with autism
- Emphasize seriousness of families engaging in substantial in-home training and education

There currently exist specialized schools that are successful in producing favorable results while treating children with autism in Morocco. However, there remain aspects of Morocco that can serve the needs of these children to a greater degree.

Conclusion

A mother's greatest love is her children. They want what is best for their children in every aspect of life. A thriving social life, academic resource availability, significant networks for support, and recognized human rights are all necessary for a child to live their best life. Every child with autism deserves to have access to the same opportunities as children without a disorder. Unfortunately, this is not the reality. The lack of current research and data pertaining to the specifics of autism in Morocco substantially blockades the advancement of families impacted by ASD. Limited data results in a limited national understanding of the realities of autism. This, in turn, leads to negative social implications associated with autism and other disabilities in Morocco. Without proper knowledge of and respect for disabled, it is nearly impossible to ensure their human rights are upheld.

Our project is important because it allowed us to add to the database of knowledge pertaining to autism in Morocco. We were able to listen to the stories of affected families and document the aspects of their situation that they struggle with the most. Even simply listening to these mothers instigated sincere feelings of appreciation for our concern and time. We hope that our recommendations aid Autism Speaks in their mission to provide support to families and children who live with autism in Morocco.

**Autism
Speaks,
Morocco
Listens**

Executive Summary

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Authorship

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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 Limitations with Receiving Support	Edith Sawyer and Angelica Pollard-Knight
2.5 Stakeholders	Team
2.6 Relevant Case Study	Edith Sawyer
2.7 Summary	Morgan Reisinger
3.1 Assess and Analyze Resources and Challenges for Families in Rabat	Morgan Reisinger
3.2 Conduct Comparative Analysis of 2016 and 2018 Data Sets	Morgan Reisinger
3.3 Targeted Evaluations of Resources in Rabat	Angelica Pollard-Knight and Morgan Reisinger
3.4 Logistics and Data Management	Edith Sawyer
3.5 Timeline	Edith Sawyer
4.1 Survey Analysis	Edith Sawyer
4.2 Urban vs Rural Comparative Analysis	Morgan Reisinger and Edith Sawyer

4.3 Analyzing Supplementary Information	Morgan Reisinger
4.4 Professional Interviews	Angelica Pollard-Knight and Morgan Reisinger
4.5 Summary	Angelica Pollard-Knight and Morgan Reisinger
Figures and Tables	Edith Sawyer
5.0 Recommendations and Conclusions	Morgan Reisinger

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Chapter 1 Introduction

Autism Spectrum Disorder (ASD) is a neurological developmental disorder with symptoms typically first 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 within a spectrum that people commonly identify under the umbrella term "autism." As a result, patients with autism often show a range of symptoms that present personal challenges they must deal with. Commonly cited symptoms include difficulties with concentrating, adapting to traditional school settings, and controlling impulses. Repetitive behaviors are also a common symptom of ASD. However, there are aspects of the complexities of the disorder that remain scientifically unknown. Many countries around the world are currently conducting further research on ASD and its effect on those who have the disorder (Elsabbagh, 2012).

Countries like the United States and United Kingdom conduct a substantial portion of the research on ASD (Daniels, 2012). Other areas of the world, such as Morocco, do not emulate these countries' efforts to understand and accommodate people with the disorder. Due to the lack of support from the Moroccan government, parents and professionals impacted by autism began establishing independent organizations to fulfill their needs. The goal of these organizations is to provide caregivers and teachers with effective resources necessary to care for children with autism. Moroccan families affected by autism often utilize a variety of resources, such as the Internet and word of mouth, to gain knowledge of support groups and non-governmental organizations (NGOs) in their regions. These organizations assist families by providing information and training that facilitate integration of their children into Moroccan society. However, restrictions regarding funding, training opportunities, physical resources, and the overall understanding of autism in Morocco limit the abilities of these NGOs. Parents of children with autism frequently employ resources supplied by NGOs because hospitals and public schools consistently deny these children care. Parents must receive assistance for their children from NGOs before they are eligible for additional medical and educational assistance (A. Mounir, personal communications, Jan. 21, 2018).

Moroccan NGOs collaborated with Autism Speaks, an international organization specializing in autism research and advocacy, and began 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 Morocco. Unfortunately, there exists next to no official documentation of the realities of autism in Morocco. Previous project teams from WPI have worked to gather this information through surveys and interviews in varying geographic regions throughout Morocco (Galindo, Grant, Languet, & Sirry, 2016; Hachim, Martin, Miner, & Rahman, 2016). Because the 2016 teams only had seven weeks to collect their data, there is much more to document.

The goal of our project was to collect and analyze data regarding current resources and education available for children with autism in the Rabat region of Morocco. After assessing the attitudes and struggles of families impacted by autism, we developed recommendations for the Moroccan government and Autism Speaks to better the accessibility of resources for the autistic community in Morocco. To accomplish our goal, we utilized the “caregiver needs” survey Autism Speaks provided the 2016 project teams. We interviewed families using this survey to identify resources and challenges available to children with autism in the Rabat-Salé region. The Space for Brothers (Espace al Akhawayne) organization in Rabat and Yasmine Breton organization in Salé identified and arranged meetings with the families that we interviewed. We assessed the attitudes and struggles of these families by analyzing supplementary information they shared in these interviews. Then, we conducted an analysis comparing the 2016 and 2018 data sets to identify differences in resource availability between rural and urban regions of Morocco. The trends our team identified provided the basis for the interview questions that our team designed and used to interview professionals in Casablanca. The AMAL organization connected us to these professionals. Our team used the combined data from caregiver and professional interviews to identify actions the Moroccan government and Autism Speaks can take to advance the standard of living of the Moroccan population impacted by autism.

Chapter 2 Literature Review

This chapter provides an overview of what Autism Spectrum Disorder (ASD) is, as well as the resources available for those it affects in Morocco. The first section provides a working definition for Autism Spectrum Disorder and explains common conditions associated with it. The following section evaluates the social implications that people afflicted with autism face in Moroccan society. Next, this chapter examines a cross-cultural comparison of legislations pertaining to the rights and resources of the disabled. The final section profiles the stakeholders that our team worked with in Morocco.

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 experience autism impairment 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 ASD, for example, may sway back and forth to soothe themselves, remain quiet while their peers are laughing, or not respond to their name.

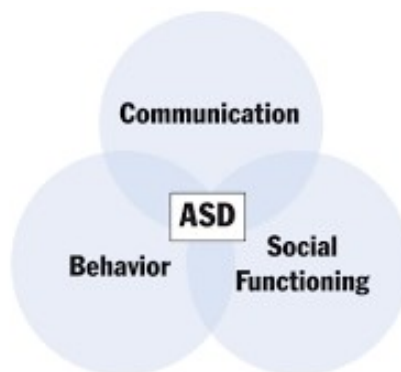


Figure 2.1 Aspects of life impacted by autism (RDH, 2014).

The diagram above represents the overlapping potential of the areas of life impaired by ASD. Autism Spectrum Disorder can disrupt a single area, two areas, or all three areas of daily functioning simultaneously. Additionally, the severity of each inhibition children with autism

deals with varies from child to child. Being that the disorder exists as a spectrum, children suffering from autism can experience any combination of hindrances or abilities in their involved areas of life (What is Autism, 2012). The resultant variety of symptoms requires thoughtful individualization of care and treatments for each child.

As the severity of autism 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 the autistic population globally (What is Autism, 2012). Unfortunately, combinations of these same characteristics frequently lead to social isolation of people with autism. Lack of proper understanding of the specifics and complexity of the disorder has resulted in a widespread stigma around ASD.

2.1.1 Physical Ailments Associated with Autism

The quantitative data discussed here exists in the limited scope of the United States. This data is 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 information regarding autism serves as the foundation of our understanding of the disorder.

Autism Spectrum Disorder is most commonly seen in 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 individuals with autism encounter.

2.1.1.1 Autism and Epilepsy

The most common condition children with autism endure is epilepsy, influencing 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 can 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, are associated with similar gene mutations.

2.1.1.2 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 mitochondrial function 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. Individuals suffering from gastrointestinal disorders may also withdraw from society and become irritable.

2.1.1.3 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. Some causes for these behaviors include

sensory aversions, anxiety, and resistance to change. Researchers have linked behavioral medications that affect metabolism and appetite to chronic overeating, another problem commonly seen in the autistic community. Medical officials associate pica, or the condition of eating nonfood items, with autism as well.

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 conditions that typically pair with ASD.

2.1.2.1 Autism and ADHD

Recent studies show that between one third and two thirds of the autistic population also have Attention Deficit/Hyperactivity Disorder (ADHD). Similar to autism, ADHD symptoms include difficulty focusing, listening, organizing, and remaining still. Consequently, the diagnosing of one of these disorders in a child can mask or postpone the diagnosing of the other (Autism and Health, 2017).

2.1.2.2 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 can instigate depression (Autism and Health, 2017).

2.2 Social Implications of Autism in Morocco

The symptoms and ailments that tend to accompany autism, detailed above, are often very apparent in individuals affected by autism. Thus, children with autism typically exhibit multiple characteristics that set them distinctly apart from their peers. Consequently, a social stigma has developed around individuals who exhibit these traits because they do not act in a manner considered appropriate to the norms of contemporary society. This stigmatization is due to the Moroccan population's lack of proper awareness of mental disabilities.

Poor public perception of autism results in families feeling shame when performing daily activities, such as use of public transportation. Various testimonies from current and past Moroccan residents support this claim; many families struggle to raise children with disabilities in Morocco (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 stigma surrounding autism 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 care for children with autism and the fight for rights of the autistic community (Morocco World News, 2016). Unfortunately, the hardships associated with autism in Morocco are undeniable and impede the social development of the individuals it affects.

Moroccans sometimes group autistic diagnoses with those of other mental illnesses. One consequence of this is that frequently, Moroccans assume that autistic individuals are unfit to make decisions or care for themselves. The misunderstanding of social interactions associated with autism and mental disorders influences this. In 2017, families protested for proper rights for children with autism in an attempt to combat these consequences of negative autistic imputations. In these protests, families called for “the provision of social and psychological care for sick children, on a continuous and permanent basis,” (الجدید العربي, 2017; New Arab). They wanted public comprehension of the illness, fair treatment from authorities, proper access to schooling, and accessible medical care. These recent protests may 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. Some agencies that assist families, in the form of non-governmental organizations (NGOs), receive funding from the government to aid in treating children with autism. However, this assistance is difficult to obtain and maintain, and is often insufficient to support families on a broad scale. Many other factors also contribute to the lack of resources available to the autistic

population in Morocco. The next section considers these factors relative to the design and integrity of this investigation.

2.3.1 Trend Toward Urbanization

Morocco is a largely urbanized country. From 2005 to 2015, the urban proportion of the country has increased from 55% to 61.2% (Urbanization, 2015; World Factbook, 2017). Much of this urban population resides in ten large cities across the country. Figure 2.2 below depicts the population for each of these ten cities, gathered in 2014.

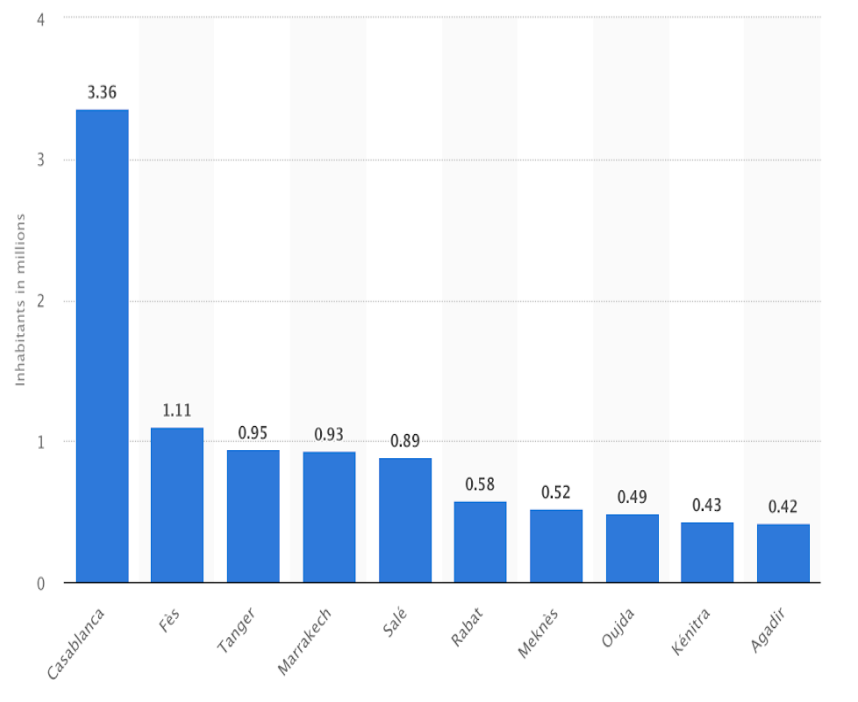


Figure 2.2 Graph of populations in millions of cities in Morocco (Morocco-Largest Cities, 2014)

Our project focuses on the Rabat region along the northwestern coast of Morocco. Casablanca, Rabat, and Salé are three cities found within this region; they are the cities we investigated throughout this project. Casablanca, the most populated city of the three, is home to over three million people. Increased urban population in regions of Morocco, at a rate of 1.92% per year, makes availability of resources to these areas a rising concern (World Factbook). 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 in both rural and urban areas of Morocco must travel long distances to access resources with limited availability. However, families living in rural regions often have to travel farther to find appropriate care. Rising urbanization suggests that this issue will continue until resources are readily available.

2.3.2 Literacy and Language

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 was important to consider while determining the way we would conduct our interviews, as well as how we would prepare for interviewees from multiple backgrounds. Language and literacy diversity in Morocco called for a translator who could both speak and read the local Darija and French.

Overall, the 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 past attempts to spread awareness among the Moroccan population. For example, brochures and pamphlets may not have been equally accessible to every segment of Moroccan society. Advocates for autism awareness must share information in multiple languages in order to ensure that Moroccan citizens from every background can understand it.

2.4 Limitations 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, the Moroccan government does not implement these laws in the manner they were intended due to factors such as limited access to necessary resources and the stigmatization of mental disabilities. An assessment done by the United Nations for recent policies and actions revealed that Morocco could provide much more for its handicapped population (Morocco: Flawed Draft, 2017).

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. Also known as Draft Law 97.13, this law is the first in Morocco to address the rights of people with disabilities. However, Morocco has also 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 (CRPD), the Draft Framework Law does not follow the legislation of the international treaty (Letter to Moroccan Parliament, 2015). Human Rights Watch, an international non-governmental organization 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, as well as the absence of 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 reports on the separation of special needs children from regular, public classrooms. This lack of proper accommodations for the disabled in an educational setting denies children with disabilities the right to fair education and is a direct violation of the rights outlined in the CRPD (Letter to Moroccan Parliament, 2015). There are aspects of the Moroccan legislation that the Moroccan government can ameliorate 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 facilitate a change in 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. The Moroccan government should enact more initiatives to ensure these laws are properly recognized and followed.

2.4.2 Regional Comparisons of Legislation for the Disabled

Morocco ranks relatively below its neighbors in effectively responding to disabled citizens. 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.). The implementation of necessary provisions in social, cultural and political aspects of Saudi Arabian society is evidence of this national dedication. Changes to the Disability Rights Act encouraged the Saudis to increase 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 states that governmental officials must 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 parts of North Africa and the Middle East. However, it is interesting to note that the dedication to accommodating the disabled through national legislation and the implementation of accessible resources is not consistent across the North African and Middle Eastern region.

2.4.3 Education and Healthcare Limitations

In Morocco, hospitals, clinics, and schools that specialize in autism or other disabilities do not exist. Professionals of mainstream facilities turn away families who seek autism information or treatment, and refer them to small NGOs that do specialize in autism and other disabilities (A. Mourir, personal communications, Jan 21, 2018). NGOs that specialize in disabilities aid families who seek information or treatment from any of these three sources. Families often receive diagnoses for their children at NGOs. Once families and children have received specialized treatment from NGOs, they may return to hospitals to receive medical care and non-specialized treatment. Hence, families are reliant on receiving treatment for their children with autism from NGOs. Still, the NGOs do not have enough resources to support all of the many families who need help.

The government sometimes 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. As a result, 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 for older children to find care.

2.5 Stakeholders

The primary stakeholders for this project were family and professional caregivers of children with autism. Over the duration of our project, families of these children were the primary source of statistical and qualitative information regarding experiences the autistic community encounters in the Rabat region. Professional caregivers, including a psychologist and special educators, provided technical insight to the current system of diagnosing and treating children with autism. The NGOs we 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.

Table 2.1 Primary project stakeholders

<i>Stakeholders</i>	<i>Interests</i>	<i>Perspectives</i>	<i>Assets</i>
Families	<ul style="list-style-type: none"> - Child's well-being - Utilizing resources and knowledge to help get the best care for their children 	<ul style="list-style-type: none"> - Further their child in personally developing, thriving, and socially integrating 	<ul style="list-style-type: none"> - Current knowledge of accessibility to local resources - Experience with social implications associated with autism in Morocco - Knowledge of child's personal difficulties
AMAL	<ul style="list-style-type: none"> - Advancing resources and awareness of autism in Morocco - Treating children with autism 	<ul style="list-style-type: none"> - Spreading autism awareness by sharing information and resources 	<ul style="list-style-type: none"> - On site offices - Connections with professionals who specialize in treating children with autism
Espace al Akhawayne (Space for Brothers)	<ul style="list-style-type: none"> - Providing training and resources to transition children with autism into society 	<ul style="list-style-type: none"> - Spreading autism awareness by sharing information and resources 	<ul style="list-style-type: none"> - On site offices - Connections with autistic families and associations in the area - Connections with professionals who specialize in treating children with autism
Yasmine Breton Center	<ul style="list-style-type: none"> - Providing training and resources to transition children with autism into Moroccan society 	<ul style="list-style-type: none"> - Offering specialized assessments and early intervention services for children with autism - Spreading awareness of autism and resources 	<ul style="list-style-type: none"> - On site offices - Connections with autistic families and associations in the area - Connections with professionals who specialize in treating children with autism
Professional Caregivers	<ul style="list-style-type: none"> - Improving the ability to accurately diagnosis autism - Improving quality of treatment for individuals with autism - Improving the medical understanding of ASD 	<ul style="list-style-type: none"> - Experiencing the advantages and disadvantages of current diagnosis and treatment methods 	<ul style="list-style-type: none"> - Insight to the current methods of diagnosis and treatment for autism in Morocco - Personal experience with treating individuals with autism

The stakeholders outlined in Table 2.1 include those we interacted with over the course of our project. These stakeholders' experiences and expertise provided us with insight to the current state of autism in Morocco.

2.5.1 Non-Government Organizations (NGOs)

To compensate for limited governmental, medical, and educational efforts to improve the quality of life for the disabled in Morocco, parents and professional caregivers of children with autism have developed NGOs. The intention of these grassroots organizations is to improve awareness ASD and provide necessary resources for those the disorder affects. Since professionals still do not fully understand the complexities of ASD, NGOs collaborate to develop a deeper understanding of how autism impacts the families it afflicts. Figure 2.3 reflects concern for these difficulties by showing a mural alongside a quote that reads “To Understand Them,” found on the wall of an NGO in Rabat, Morocco. The people who autism directly impacts are those who exhibit efforts to support the autistic community in Morocco. Section 2.5.1 introduces and discusses the three NGOs that worked with our team over the course of our project.



Figure 2.3 Painting drawn onto a wall in the Espace al Akhawayne organization that reads, “To understand Them”

2.5.1.1 AMAL

Founded in 2010, the AAEBMSM (Association AMAL Enfants Aux Besions Specifiques Mentaux) organization, otherwise known as AMAL, specializes in medical and psychological

care of people with various levels of mental disabilities. Figure 2.4 shows the AMAL logo that depicts a circle of people standing arm in arm.



Figure 2.4 Official logo of the AAEBSM (AMAL) Organization

AAEBSM's involvement focuses on, but is not limited to, children from disadvantaged backgrounds. 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 requirements of their special needs child, as well as helping children flourish in modern society. 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 every member of society (AAEBSM, 2017).

2.5.1.2 Espace al Akhawayne (Space for Brothers)

An organization founded in September 2017, Espace Al Akhawayne (the Space for Brothers) is a center with resources for the mentally disabled. Figure 2.5 shows the official logo of the Space for Brothers organization.



Figure 2.5 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. The Space for Brothers organization had only been around for five months at the time of our investigation. Still, by this time, the center had reached its capacity of fifteen affiliated families. Officials of the organization hope to expand their center in order to accommodate more families.

2.5.1.3 Centre Yasmine Breton

Medical professionals diagnosed Yasmine Breton with autism disorder at the age of three. Her mother, now the owner of the Yasmine organization, took control of her treatment. When local services could not provide the care she needed, Yasmine's mother studied all possible methods of treatment for autism. Three years later, the Yasmine Breton center for children with autism treats more than one hundred children. The goal of this organization, similar to other NGOs, is to achieve concrete results regarding the development of daily living skills of the associated children (Breton). Yasmine offers an abundance of resources for children with autism and their families. These include, but are not limited to, specialized assessment for children, speech therapy, and psychomotor learning. Yasmine also provides specialists who host

workshops and training for parents (Breton). Figure 2.6 below shows the official logo of the Yasmine Breton association.



Figure 2.6 Official Logo of Centre Yasmine Breton (Yasmine Breton Center)

2.5.2 Other Stakeholders

2.5.2.1 Professional caregivers

The professionals who the non-government organizations described above employ include special educators, speech therapists, occupational therapists, and non-specialized professionals. These professionals come from many different backgrounds and have varying levels of experience and educational backgrounds. Most professionals attended high school before they began practicing in their fields. After high school, many of these professionals continued on to study at universities or engage in specialized training programs in their field. Unfortunately, universities in Morocco emphasize only theory and not field practice. This leads to many difficulties adapting to the real work environment where these professionals labor to better the lives of children with autism (A. Attar, personal communications, Jan. 24, 2018). Hence, internships and experience are essential for learning how to effectively treat all types of autism.

2.6 Relevant Case Study: Autism Assessment in Morocco, 2016

Our investigation evaluated the methods of two 2016 WPI student teams who conducted a project similar to ours (Galindo, Grant, Languet, & Sirry, 2016; Hachim, Martin, Miner, & Rahman, 2016). This section provides a case study of their interview methodologies and reviews 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. The teams gathered qualitative and quantitative data in Casablanca, Ouarzazate, Skoura, Tiznit, Agadir, Biougra, and Taroudant. Both project teams analyzed their data and suggested possible steps to increase understanding of autism in Morocco in the future. Throughout the project, these teams experienced roadblocks. One issue they encountered included miscommunication between translators and sponsors. Miscommunications involved 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. Consequently, both teams emphasized the importance of establishing a clear relationship with translators, as well as paying for translation services.

Additionally, logistical planning and communication between participants and agencies saw challenges. This resulted in parents bringing their children to interview sites with the expectation of receiving a medical diagnosis. The teams also encountered sensitive survey questions in their questionnaire that resulted in difficulties collecting reliable data. Through their interviews with families, the teams found that a few of the questions on the survey questionnaire were culturally insensitive to the interviewed families and they suggested avoiding asking questions related to religion and the stigma around autism. Furthermore, they noted that language barriers led to inaccurate responses to survey questions by physicians and other professionals.

2.7 Summary

Autism Spectrum Disorder is complex neurological disorder seen in children all over the world. There is currently not enough data to fully understand the resources available to children with autism in Morocco. As a result, Moroccan society sees individuals with autism as incapable of caring for themselves. However, there has been a progressive movement to guarantee more rights to individuals with autism through recent legislative efforts by the Moroccan government. Unfortunately, law enforcement has not properly ensured adherence to these laws yet. Additional struggles dealt with by families of children with autism are limitations in accessing medical and educational services in their region. Non-governmental organizations formed by parents of children with autism have become the main source of treatment and care for those afflicted by ASD. To expand the quantity of data that exists regarding the treatment and reality of autism in Morocco, this investigation utilized the methodologies detailed 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 spectrum disorder in Morocco. We completed the following three objectives while in Morocco in order to effectively reach this goal:

1. Analyzed resources and challenges for families of children with autism in the Rabat region
2. Conducted comparative analysis between 2016 and 2018 data sets
3. Conducted targeted evaluations of resources and experiences in Rabat.

Figure 3.1, shown below, represents the flow of progression of this project's three primary objectives. The following sections detail the implementation of our methods of implementation for each of the objectives in the figure.

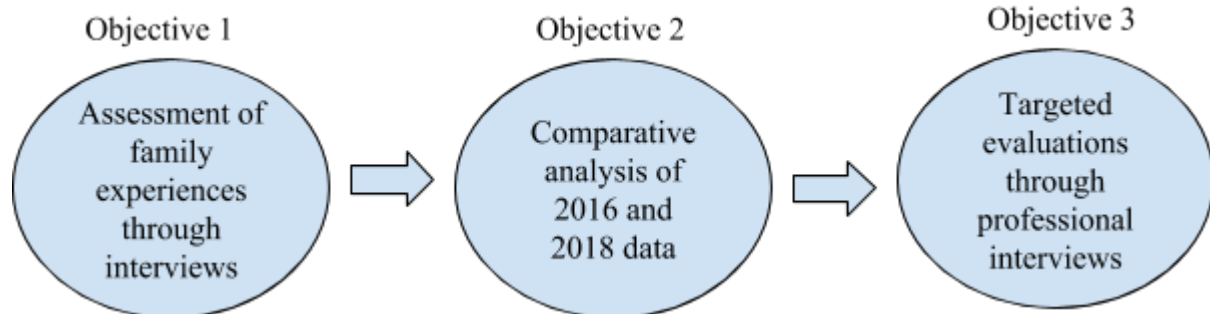


Figure 3.1 Flow chart depicting our three objectives

3.1 Assess and analyze resources and challenges for families in Rabat

The primary component of this investigation was to conduct careful interviews with families and other caregivers of children with autism using a survey tool that Autism Speaks wrote in 2016. Henceforth, this report refers to the main caregivers of these children, whether they be immediate or extended family, friends, or other, as “family.” We conducted our family interviews with families affiliated with two organizations located in the Rabat region. These

organizations are the Espace Al Akhawayne (Space for Brothers) organization located in Rabat and the Yasmine Breton center in Salé.

3.1.1 Family Interview Preparations

We used convenience sampling to determine the families we interviewed. Our stakeholder organizations, the Espace Al Akhawayne (Space for Brothers) and Yasmine Breton organizations, contributed to our pool of family stakeholders. Our translator organized and scheduled interview times for each family through these organizations. Professionals of each stakeholder organization clearly articulated the purpose of our project when they invited each family to participate in our interviews.

During our interviews, we used a caregiver survey Autism Speaks wrote in 2016. To prepare for the delivery of this survey, we compiled every multiple-choice question of its Arabic translation into a packet and printed out a copy for each respondent. We also printed out one full Arabic survey and one full English survey for our team and translator to read and reference during the interviews. Finally, in preparation, our team refined the Autism Speaks survey used in 2016, calibrated our translator, as well as ensured proper accommodations for families were available during the time of interviewing.

3.1.1.1 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. 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 pertaining to this topic (Galindo, Grant, Languet, & Sirry, 2016; Hachim, Martin, Miner, & Rahman, 2016).

Along with our associate and translator, Jihan El Ouaragli, our team reviewed the 2016 Autism Speaks survey. We compared both the English and Arabic versions to eliminate any errors pertaining to translation and comprehension. The next step was to discuss each question and its content with our translator, a native of Morocco. Our focus was on the phrasing of each question to determine if any were biased or potentially insensitive to Moroccan culture. The team also discussed the meaning of some questions and technical terms with our translator so she could communicate their content to each respondent accurately. We altered the wording of a

couple of questions in the Arabic survey to accommodate the Darija dialect spoken in the Rabat region. The final step in this process was submitting to and receiving approval from WPI's Institutional Review Board (IRB) for this project's methodology (including our refined survey).

3.1.1.2 Calibrated Translator

Before beginning our interviews, WPI hired a translator to aid our team in communicating with each organization official and interview respondent. Jihan El Ouaragli, a civil engineering student at the School Mohammadia of Engineers in Rabat, served as our translator throughout the duration of our project. Dr. Tahar El-Korchi, the co-director of our project site, recruited this translator for this study.

Prior to our first official interview with a family member, we performed a mock interview with our translator and an unaffiliated ally of the Space for Brothers organization. This ally, Amine Mounir, sat in as our respondent. This mock interview served two purposes: it saw to each interview question being clear; and it provided practice at avoiding multiple types of interview bias (Ward, 2014). Our team utilized a PowerPoint provided by Dr. Maretha de Jonge that contained useful information regarding how to avoid multiple forms of interview biases. By practicing our formal interview process and etiquette in conjunction with this PowerPoint, we familiarized ourselves with body language and tonal tendencies to avoid during the interviews.

3.1.1.3 Accommodations for Privacy

Our team worked with officials of our stakeholder organizations, the Space for Brothers and Yasmine Breton center, to stagger the arrival times for the family interviews. Staggered arrival times mitigated families having to wait all day for an interview, a problem that occurred in 2016 when many families arrived simultaneously. Additionally, we collaborated with the officials of both stakeholder organizations to convey to families that they may have to wait and encourage participating respondents to bring any necessary accommodations. It was also essential that restroom facilities were available for those who needed to wait for their interview.

3.1.2 Family Interviews

When the team executed the family interviews at the two NGO centers, we conducted one interview at a time because we had one translator. The interviews took place over a span of

three weeks. This involved two weeks interviewing at the Space for Brothers organization, and one week interviewing in the Yasmine Breton organization. Family interviews took place in the mornings and early afternoons.

3.1.2.1 Espace al Akhawayne (Space for Brothers)

The Space for Brothers is a public NGO in Rabat that specializes in treating children with autism. We conducted the family survey written by Autism Speaks to families associated with this organization in the form of in-person interviews. We conducted our interviews in this manner due to limitations with literacy and variable WiFi availability in the region. Due to limited availability of each family, our team was able to conduct only two to three interviews a day with a total of seven interviews at this organization. These interviews took between forty-five and sixty minutes to complete.

Our translator gave the packet of multiple-choice questions to each participant at the beginning of their interview session. Our translator asked each respondent if they could read Arabic. If they responded affirmatively, our translator then instructed them to read and answer each multiple-choice question. However, if any respondent could not read, our translator read each question aloud to these respondents and aided in filling out the corresponding tables before the verbal interview began. This was required four times. Many families associated with this organization could not read (J. El Ouaragli, personal communications, Feb. 4, 2018). After this process, we communicated the purpose of our interviews to the interviewees. One teammate read aloud our statement of intent in English to each respondent (see in Appendix A). Our translator then repeated this statement to the respondent in Arabic. This statement explained how we planned on conducting each interview, why we were collecting this data, and how each participant's information would be protected and kept confidential.

The interviews that our team conducted at the Space for Brothers organization involved four team member interviewers and our translator. Each family interview consisted of a respondent, translator, and every team member. In each interview, one team member read the interview questions aloud in English. A second team member was responsible for monitoring the physical demeanor, body language, and tone of the respondent throughout each interview. Our translator translated each question, in Arabic, to the families along with their responses, in English, back to our team. A third team member recorded the responses of the participant with a

laptop into an Autism Speaks database. The remaining team member electronically recorded these same responses into two Microsoft Word documents to be later referenced and analyzed by our team. One of these documents included responses to the specific questions of the Autism Speaks survey. The other document contained supplementary information families shared about their unique experiences that did not directly correlate to a survey question.

3.1.2.2 Centre Yasmine Breton

Contrary to the Space for Brothers organization, the Yasmine Breton center is a private NGO that specializes in autism treatment. This organization is affiliated with over one hundred families, so inviting families to participate in interviews was easier than at the Space for Brothers. We interviewed three to six families a day at the Yasmine Breton center with a total of 13 interviews at this organization. Each interview lasted between twenty and forty minutes. These interviews were shorter than those we conducted at the Space for Brothers because we retroactively provided the long multiple-choice questions to families.

Similar to our interview protocol at the Space for Brothers, we used the family survey written by Autism Speaks in the form of in-person interviews at the Yasmine Breton center. However, here the team gave the multiple-choice question packets to family members who arrived to their interview time early so that they could get a head start on answering our questions. We did this at the Yasmine Breton center and not at the Space for Brothers because every family interviewed at the Yasmine Breton association could read Arabic. We added a sentence to the beginning of the multiple-choice packet we used in Space for Brothers interviews. This sentence read (in Arabic): “if you do not understand any of the following questions, please leave them blank and we will discuss them in your interview.” After our translator confirmed there were no remaining questions regarding each multiple-choice packet, one team member read aloud our statement of intent before proceeding to the verbal interview.

The interviews that took place at the Yasmine center involved only three team member interviewers. Each interview involved a respondent, our translator, and every team member. Initially, one team member read aloud the interview questions in English. This team member was additionally responsible for monitoring the physical demeanor, body language, and tone of each respondent. Our translator then read each interview question in Arabic to the respondent, as well as translated their responses in English for the team members. A second team member recorded

the responses of the participant with a laptop into an Autism Speaks database. The remaining team member electronically recorded these same responses into two Microsoft Word documents to be later referenced and analyzed by our team.

3.1.3 Analyze Collected Data from Families

Prior to analyzing our family interview data, our team performed content analysis on the statistical data and personal stories from our collection of 20 interviews. We characterized this form of information as “supplementary information.” We analyzed respondents’ supplementary information separately from direct interview responses. We did this by coding each respondent’s supplemental responses. Coding involves identifying commonalities within a set of qualitative data that researchers can tally and track in a manner similar to quantitative data (Berg, 2012). To do this, we highlighted keywords, phrases, and ideas within each respondent’s supplementary information that corresponded to a common theme noted throughout our interviews. We organized this information into categories depending on common themes by compiling highlighted sections into a condensed Excel spreadsheet. By comparing the responses under each topic, the team extracted results about the overall attitudes and struggles pertaining to families impacted by autism.

We analyzed the quantitative data that corresponded to specific interview questions in a different manner than the qualitative supplementary information shared by respondents. The Autism Speaks database in which we entered each respondent’s answers processed and presented the total responses to each interview question. From the presentation of these statistics, we generated graphs and charts that depicted the percentages or exact number of respondents who answered each response. We considered the visual representations of the data pertaining to each interview question when determining aspects of our research that were crucial to understanding the realities of struggling with autism in Morocco.

3.2 Conduct comparative analysis of 2016 and 2018 data sets

In 2016, two WPI teams conducted interviews with families of children with autism all over Morocco. Their studies included interviews in both urban and rural areas, such as the Draâ and Meknes regions. Comparatively, the 2018 interviews focused only on urban areas of

Morocco where the prior teams did not collect data. The 2016 research teams characterized urban regions as having a population of over 100,000 residents (M. de Jonge, personal communications, Feb. 11, 2018). Our research contrasted the 2018 urban data with only the rural data collected in 2016. The previous project teams' results and analysis facilitated our indication which of their interviews took place in rural vs urban regions. By comparing these two sets of data, we recognized trends of the autistic experience in Morocco that occur across urban and rural regions. Our team compiled results from both years into graphs to contrast information collected across different criteria such as abilities of children, needs and priorities of families, and resource accessibility.

3.2.1 Comparison of Urban vs. Rural Morocco

Dr. Maretha de Jonge provided our team with the raw data collected by the 2016 WPI teams via a Microsoft Excel spreadsheet. This spreadsheet presented this data by simply listing the number of participants who responded to each answer, as well as the percentage of the total sample these numbers represented. Our team looked at the number of responses to each question in this 2016 data to determine if interviewees' answers exhibited noticeable differences when compared to our urban data.

3.3 Targeted evaluations of resources in Rabat

Our three-member team conducted interviews with professionals at the AMAL association for children with disabilities, located in Casablanca. These interviews pinpointed aspects of the state of autism in Morocco in order to shed light on topics that interviews conducted in 2016 and 2018 did not thoroughly investigate. Officials of the AMAL organization served as the professionals of our interviews. Our translator communicated with officials of AMAL to schedule a date for us to visit the center and perform our interviews.

3.3.1 Professional Interview Preparations

After interviewing families in objective one, our team developed targeted questions to ask professionals. We no longer used a survey Autism Speaks wrote for this portion of our investigation because the idea was to tailor each question to the specific areas of information that

were of interest. The team wrote questions for these interviews based on our results from both objectives one and two. We noted interesting pieces or trends of information in our analysis of our family data, as well as in our comparative analysis of 2016 and 2018 data. The areas of information we wanted to learn more about served as the basis for the questions we constructed. Topics pertaining to the questions we designed include the “availability of resources”, “understanding of autism in Morocco”, “autism treatment”, and “support at home”. These questions are located in Appendix C.

Before starting our professional interviews, the officials of the AMAL organization showed us around each of their three sites in Casablanca. We visited classrooms where professionals work with children to obtain an understanding of the services the AMAL association provides.

3.3.2 Professional Interviews

Our team performed convenience sampling to determine which professionals to interview. Our team traveled from classroom to classroom at one of the centers of AMAL in Casablanca and located four professionals who were willing to participate in our interviews. Each interview lasted for approximately fifteen minutes.

Our team performed our first two professional interviews simultaneously, but in different rooms. This was because our first respondent could speak English, so we did not need our translator. In order to effectively use our time in Casablanca, two team members performed an interview with the English-speaking respondent, while the remaining team member traveled with our translator to perform an additional interview in another room. In the interview with two team members, one member asked each question aloud in English while the other recorded the respondent’s responses into a Word document. In the interview with our translator, the team member asked each question aloud in English. Then, our translator asked the question again in Arabic. Our translator then translated the respondent’s answers back to the team member in English. This team member recorded this answer into a Word document. In both of these interviews, a team member placed a cell phone near the respondent in order to audio record their responses.

Our team conducted the following two interviews with all three team members present. One team member asked the questions aloud in English. Our translator then translated these

questions into Arabic. Next, she translated the respondents' answers back to the team in English. The team member who asked the questions in English also recorded the responses of the participants directly into the Word document from which they read the questions. The remaining two team members listened to the respondents and observed their body language throughout the interviews. There was a cell phone recording the audio of these interviews as well.

Sometimes, professionals gave answers that elicited further elaboration. In these instances, our team asked follow up questions. We also adapted questions based on the each professional's expertise. For example, we did not ask special educators questions regarding financial payment plans available for families.

3.3.3 Analyze Collected Data from Professionals

We transcribed the responses of each professional by listening to the audio recordings we gathered in each interview and writing down all that interviewers and interviewees said. Then, we grouped professional responses according to the categories of our questions. We coded the interview transcriptions in search for words and phrases that pertained to each of our categories. We highlighted these words and phrases and placed them into an Excel spreadsheet that displayed each question topic with its corresponding responses. From these groupings of responses, the team identified specific outcomes about the themes of our professional interviews.

3.4 Timeline

Table 3.1 displays the weekly progression of our project. We adapted this timeline from the one we proposed prior to arriving in Morocco. This was in order to accommodate for the availabilities of families and professionals that we interviewed.

Table 3.1 Timeline for the progression of our project

<i>Timeline</i>	<i>Week 0</i>	<i>Week 1</i>	<i>Week 2</i>	<i>Week 3</i>	<i>Week 4</i>	<i>Week 5</i>	<i>Week 6</i>	<i>Week 7</i>
	<i>1/8-1/14</i>	<i>1/15-1/21</i>	<i>1/22-1/28</i>	<i>1/29-2/4</i>	<i>2/5-2/11</i>	<i>2/12-2/18</i>	<i>2/19-2/25</i>	<i>2/26-3/2</i>
<i>Visit/ Meet Stakeholder Organizations</i>								
<i>Family Interviews</i>								
<i>Comparative analysis between 2016 and 2018 data</i>								
<i>Targeted Professional Interviews or Focus Groups</i>								
<i>Accumulate Findings and Write Final Paper</i>								

Chapter 4 Results and Analysis

Through the completion of our objectives, described in Chapter 3, our team collected data about the realities of living with and treating a child with autism in the Rabat region. We collected this data by performing personal interviews with twenty families. The questions our team asked during these interviews came directly from the caregiver survey Autism Speaks provided our team. In addition to recording the multiple choice and “yes/no” answers family members selected throughout the interview, our team recorded supplementary stories and anecdotes that families chose to share regarding their experiences. Section 4.1 details our analysis for both forms of information. Next, section 4.2 compares the results we collected in urban areas of Morocco in 2018 with results collected in rural areas of Morocco in 2016. We also interviewed four professionals at the AMAL association in Casablanca to further our project objectives. Section 4.3 provides a snapshot of professionals’ perceptions and experiences from working with children with autism in Morocco.

Our team reviewed and analyzed more of the interview results than we present in this chapter. This chapter only discusses the results we felt displayed our most important findings. Appendix E provides the additional graphs associated with the other interview questions not discussed here.

4.1 Survey Analysis

Our team conducted interviews at the Space for Brothers and Yasmine Breton organization centers which involved a sample of the families associated with these organizations. The Espace al Akhawayne (Space for Brothers) is a public organization located in Rabat, Morocco. The Centre Yasmine Breton is a private organization located Salé, Morocco. The methods our team utilized to conduct these two sets of interviews differed slightly in that the interviews at Center Yasmine Breton included only three team members instead of four. Section 4.1.1 includes an analysis of our data that involves a comparison between answers families gave to the interview questions at the private and public organizations. The following section displays and discusses trends that occurred throughout our public and private organization analysis.

4.1.1 Trends in public vs. private samples

The interviews that our team conducted took place in one public center and one private center that both specialize in autism treatment. The key differentiating factor between public and private autism treatment organizations is the source of their funding. Public organizations receive the majority of their funding from the Moroccan government and charge their families small fees for their services. Private organizations, on the other hand, receive their funding from parents who pay the organization either full or partial price for each service they receive. Since public organizations are government funded, they have limits to the number of families they can treat at a given time and often have long wait-lists. Private organizations are able to accommodate any family who can pay for treatment. While analyzing our results, our team identified several questions in our survey where parents' responses at public and private organizations differed. This section addresses these questions and analyzes their possible implications.

4.1.1.1 Financial Problems

Table 4.1 shows the number and percentage distributions of responses to the question, “during the past 12 months, did you have any issues (finding resources for your child) due to cost?”

Table 4.1: During the past 12 months, did you have any issues finding treatment for your child due to cost?

	<i>Space for Brothers (Public)</i>		<i>Centre Yasmine (Private)</i>	
	Number of respondents	Percentage of respondents	Number of respondents	Percentage of respondents
Yes	7	100%	7	54%
No	0	0%	6	46%
	<i>N=7</i>		<i>N=13</i>	

While 100% of respondents from the public organization answered “yes,” only 56% of respondents from the private organization indicated that they had not experienced cost-related issues while finding treatment. These results suggest that the backgrounds and resources available to families differ between those who belong to public and private organizations. Families with the financial resources that allow them to attend private organizations are less likely to experience the added difficulty of public organizations’ waitlists.

4.1.1.2 Satisfaction with Support

Over the course of our interviews, the team recognized a trend indicating there are two realms of properly treating autism that parents view as very important. One of these areas involves professional intervention in the form of specialized classes, and the other area involves care within the home. The Autism Speaks survey included questions that asked families how satisfied they were with the support their child was receiving in these two areas of life.

Table 4.2 shows the responses of parents at both public and private organizations when the translator asked how satisfied they were with their relationship with service providers who work with their children.

Table 4.2: How satisfied am I with the relationship I have with the service providers who work with my child?

	<i>Space for Brothers (Public)</i>		<i>Centre Yasmine (Private)</i>	
	Number of respondents	Percentage of respondents	Number of respondents	Percentage of respondents
Very satisfied	7	100%	7	54%
Neutral	0	0%	3	23%
Very dissatisfied	0	0%	3	23%
	<i>N=7</i>		<i>N=13</i>	

At the public organization, 100% of respondents indicated that they were very satisfied with the relationship they had with their service providers. However, only 54% of families at the private organization indicated that they were very satisfied with this relationship. These statistics indicate that the care that is provided in both public and private organizations are not identical. Through conversations with officials at these organizations, our team discovered that there are thirteen professionals to care for the fifteen children at the public Space for Brothers organization. Comparatively, there are only six professionals to care for the 100+ children associated with the Yasmine Center. Additionally, the Space for Brothers supports children in a day-long, regular school manner. The Yasmine Center, however, services each child in individualized sessions that parents pay for separately. The dissatisfaction with the relationship families have with this private service provider likely stems from the 6:100 ratio of professionals to children at the Yasmine Centre. Limited professionals implies that each educator has less time to spend treating each child.

The next survey question asked “how satisfied am I with the support my child receives to make progress at home?” Examples of progress that can result from support at home include learning how to complete household chores and retaining information from school long-term. Parents play the most substantial role in determining the amount of support their child receives within the home. Table 4.3 compares the responses parents at public and private organizations gave regarding this realm of autism treatment.

Table 4.3: How satisfied am I with the support my child receives to make progress at home?

	<i>Space for Brothers (Public)</i>		<i>Centre Yasmine (Private)</i>	
	Number of respondents	Percentage of respondents	Number of respondents	Percentage of respondents
Very satisfied	4	57%	4	31%
Neutral	1	14%	0	0%
Very dissatisfied	2	29%	9	69%
	<i>N=7</i>		<i>N=13</i>	

The majority of parents from the public pool of respondents indicated that they were very satisfied with the support their children have to make progress at home. However, the majority of parents from the private pool of respondents stated that they were very dissatisfied with this support. An interesting way to look at this comparison is by first considering the employment backgrounds of the parents at each organization. In our interviews, families at the public organization shared that they had to give up work to support their children more often than parents at the private organization. Being that mothers of children of the public organization were more likely to stop working, it is plausible that they are at home with their children more frequently than mothers of the private organization. Resultantly, mothers from the Yasmine Center likely suffer from their inability to tend to their child throughout each workday.

4.1.2 Trends in combined public and private sample

Following our comparative analysis, we performed additional analyses by combining public and private data to observe trends across our entire sample. This section presents and discusses these recurring trends.

4.1.2.1 Financial realities of paying for services

From the total sample of twenty families that this investigation interviewed, many stated that they received treatment from one or more types of professionals. Figure 4.1 illustrates how

these families responded when we inquired whether they paid no price, partial price, or full price for each of these services. Some of the families we interviewed received treatment from more than one specialist; one respondent in our sample receives treatment from seven different specialists. To accommodate for this variety, the selection of answers allowed respondents to indicate that they pay different amounts for some treatments compared to others. Respondents indicated how much they pay for each of the services they receive. This is why figure 4.1 displays twenty-three responses with a sample size of fifteen. Our sample size regarding this question is fifteen instead of twenty because five participants filled out the multiple-choice question improperly.

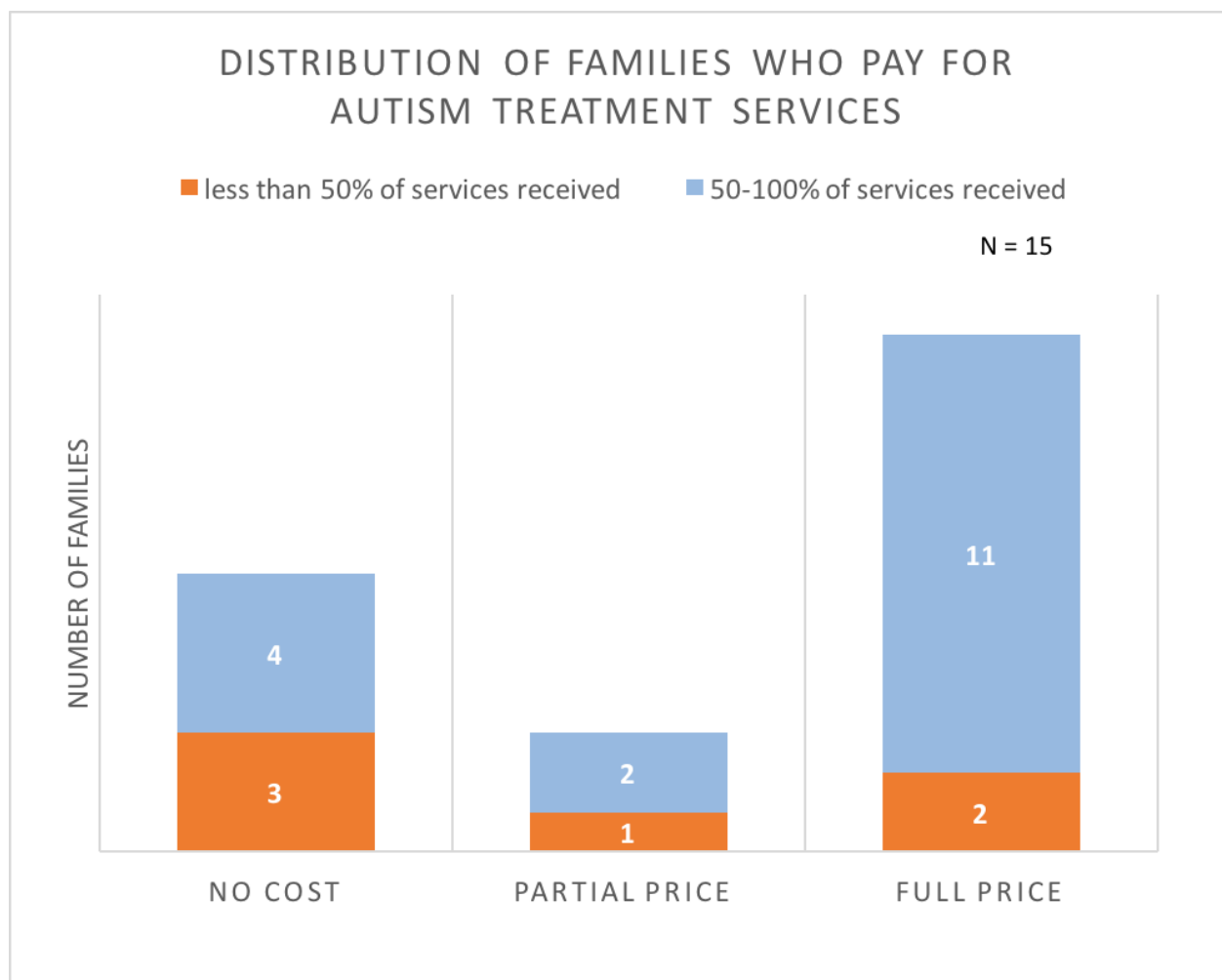


Figure 4.1: Number of families who pay no, partial, and full price for the services received

Six out of fifteen families reported that they pay varying amounts for their treatment services; one family recorded that they pay no cost, partial price and full price for their different services. From the fifteen responses, only four families reported that they received between half and all of their professional services for free. This means that eleven families must pay for treatment to some extent. Additionally, eleven families stated that they pay full price for 50%-100% of the services they received. This indicates that only four families received the majority of their treatment for less than full price. Through our interviews, families expressed that a scarcity of additional financial support from the government and academic support from schools made it nearly impossible to find affordable treatment.

Despite the fact that the results illustrated in this graph align with many personal testimonies we heard from families, there are some aspects of the question that may have contributed to inaccurate data. The survey asked families to mark which types of specialists they receive services from and whether they pay no cost, partial price, or full price for these services. In addition to the fact that the formatting for this multi-part question was difficult for understand, its phrasing does not align with the current state of autism treatment in Morocco. For example, the question does not consider the fact that many specialists at NGOs have the professional title “special educator” as opposed to specific titles including “audiologist” or “speech therapist” such are the options indicated in the survey. As a result, special educators fit the roll of many different specialists. This could have led to skewed data. Additionally, the question does not consider the fact that families who belong to public organizations pay small amounts of money for treatment from these special educators. It is unclear how these families would respond to this question and whether they believe they are paying full or partial price. We noticed that there are too many possibilities for how these families are receiving and paying for treatment that this question cannot capture their stories accurately. This is one reason why we recommend adaptations to the Autism Speaks caregiver survey in chapter five.

4.1.2.2 Lack of additional Support

Our interviews involved asking parents if they receive additional support for their child outside of support that their school/organization and home provide. The survey focused particularly on whether families receive additional academic or governmental support. Figure 4.2

displays the responses from families when the interviewer asked if they receive additional support for their child from the government or if they receive additional academic support.

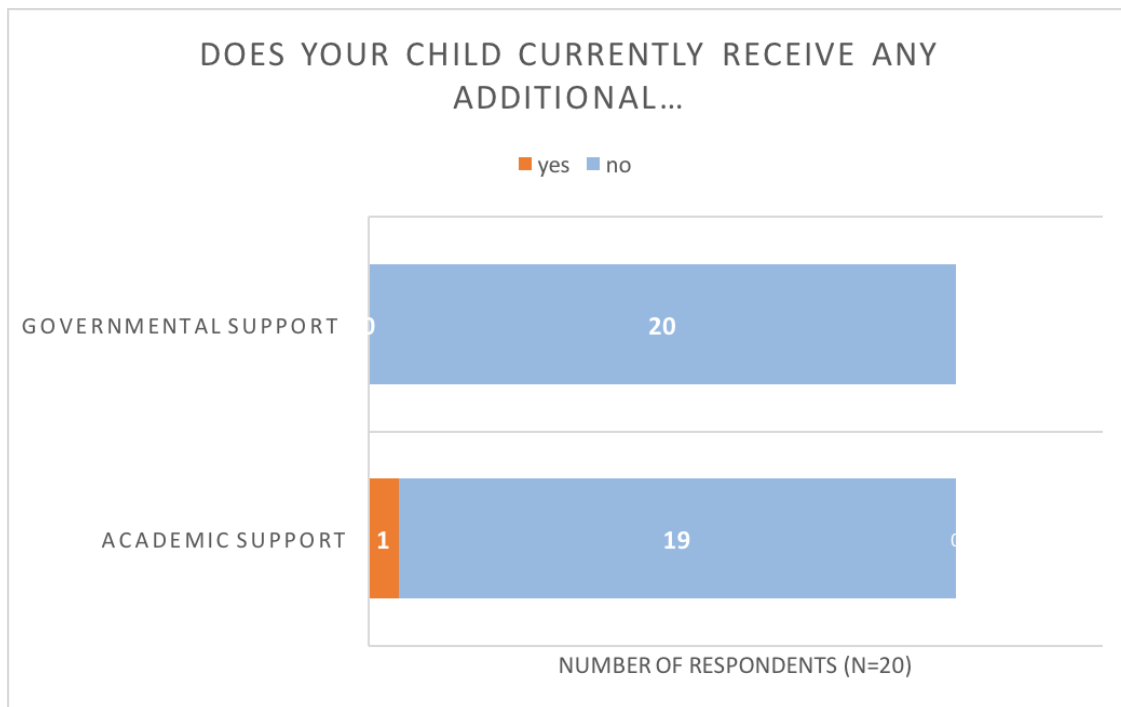


Figure 4.2: Number of families receiving additional governmental or academic support for their children

The results from our sample show that additional government and academic support are not standard practice for autism treatment in Morocco. This data complements Figure 4.1 and the associated family testimonies which suggest that most treatment options involve paying full price.

Figure 4.3 indicates the responses families gave when our team asked how often, within the past 12 months, they were frustrated in their efforts to find services for their child. The sections of the chart shown in orange signify families who answered they were frustrated in some degree while the section of the chart shown in blue indicate families who responded they were never frustrated.

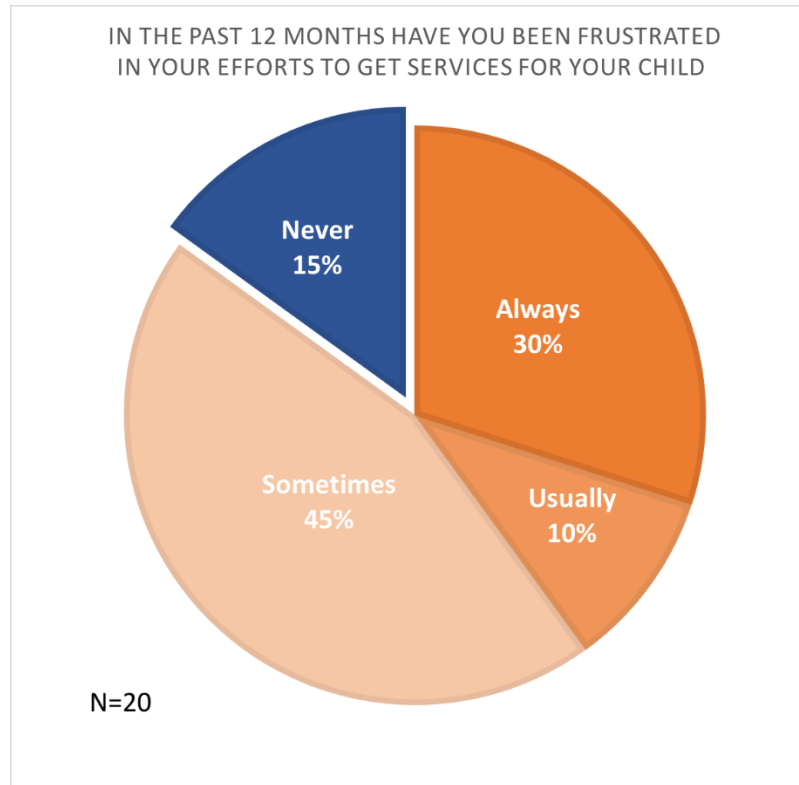


Figure 4.3: Distribution of families that responded they were either frustrated or not frustrated in their efforts to get serviced for their child within the past 12 months

Combined, 85% of respondents reported frustrations in their efforts to find services for their child. Resources for families of children with autism are not readily available or easy to obtain.

4.2 Urban vs. Rural Comparative Analysis

Two WPI project teams collected data from both urban and rural areas across Morocco in 2016. This section compares the rural data that they collected with the urban data that we collected in 2018. The rural areas in which the 2016 project teams collected data include: Draâ, Tafilalet, and Souss. Our urban data comes from family interviews in the cities of Rabat and Salé. The sample size of the rural data set is 34 and the sample size for the urban data set is 20.

4.2.1 Differences in support for autism treatment between urban and rural regions

Figure 4.4 depicts the distribution within both samples with respect to the types of schooling children with autism attend in rural and urban regions of Morocco.

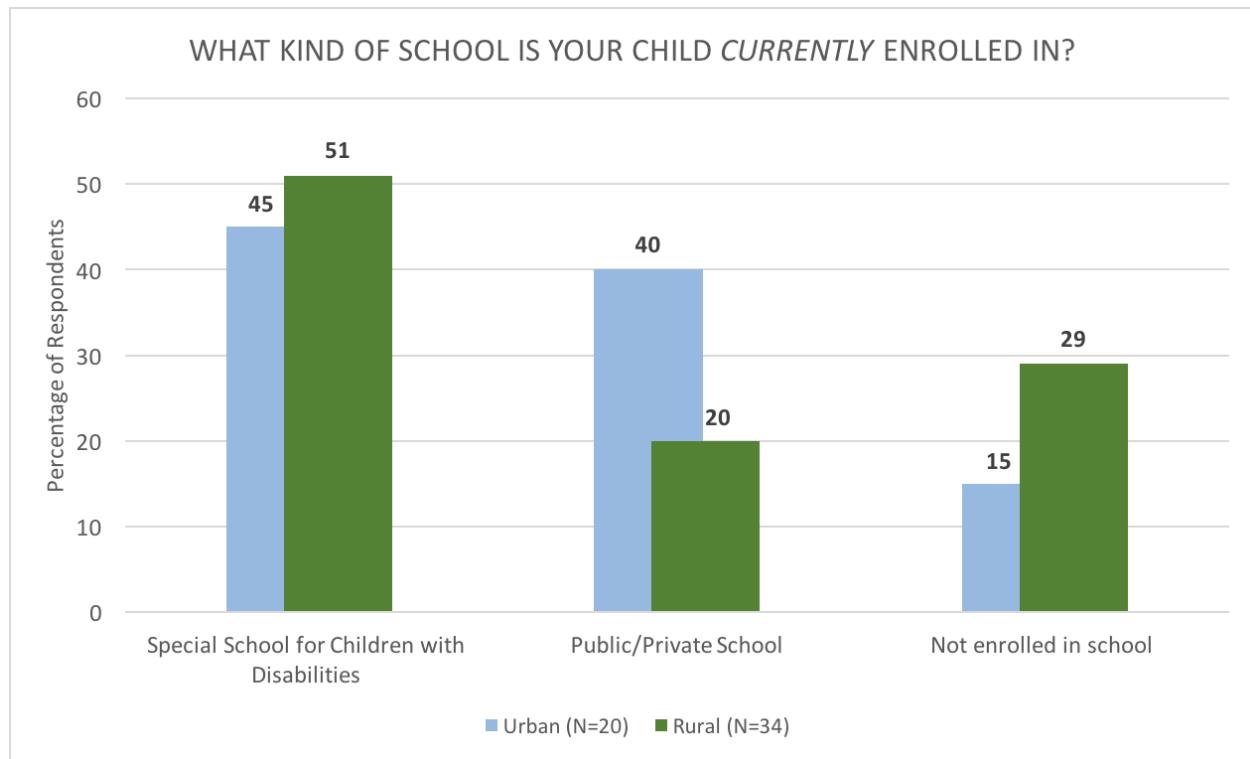


Figure 4.4: Types of schools where children with autism are enrolled in Morocco

Our data suggests that it is most common for children with autism to receive schooling at specialized schools for children with disabilities. Here, we refer to these establishments as “schools.” However, our team discovered on site that these “specialized schools” actually exist in the form of NGOs established by parents and caregivers of children with autism. Our sample of families also indicated a notable difference in the percentage of children who attend public/private school and the percentage of children who do not attend school in urban and rural regions. Nearly 30% of the children in our rural sample were not enrolled in school, and this rural population was twice as likely to not attend school compared to the urban population. However, it is important to note that, despite our urban sample coming from treatment organizations, 15% of these families’ children do not attend school. This is likely a consequence of that fact that private organizations do not function as schools but instead function in a manner

similar to scheduling appointments with a doctor. As a result, it is possible for these families to belong to an organization but not attend any school.

Despite these results, the team found a few inconsistencies between the way the Autism Speaks survey worded this question and the stories we heard from families. The three choices available for respondents leave almost no room to compensate for the unique circumstances and resources available to each family. The term “special school for children with disabilities” does not specify whether these are public NGOs, specialized programs existing within traditional schools, or possible other sources of specialized treatment. Additionally, the “public/private school” option does not allow families the opportunity to indicate if they must pay these schools additional money to provide their child with treatment.

Figure 4.5 illustrates parents’ responses to the question, “how long did you have to travel to obtain a diagnosis for your child?”

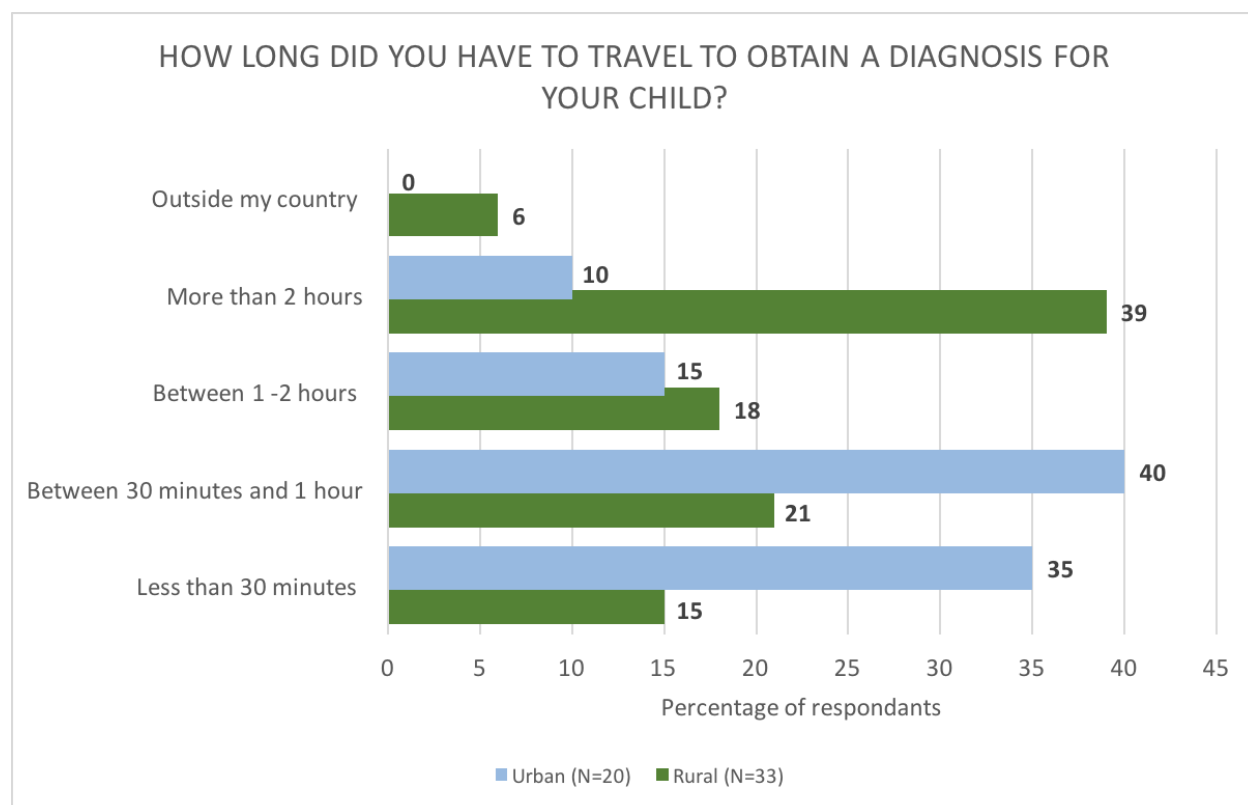


Figure 4.5: Time traveled to obtain an autism diagnosis in urban and rural regions of Morocco

As the time bins increase (located on the left-hand side of the graph), there is a shift from higher percentages of the urban populations to higher percentages of the rural populations. For example, the urban sample was more than twice as likely to only travel less than 30 minutes to obtain a diagnosis compared to the rural sample. Conversely, the rural sample was three times as likely to travel over two hours. We have no additional information regarding which outside countries families traveled to receive a diagnosis. The data illustrated in Figure 4.5 is an indication that rural areas of Morocco have less medical and educational resources for children with autism.

Figure 4.6 summarizes the responses families gave when the Autism Speaks survey asked them to identify all of the sources they turned to when seeking information about autism. This question allowed families to select all of the five answers that applied to them. Due to the nature of this question, we incorporated it into the “multiple-choice packet” we asked families to answer before the start of their interview.

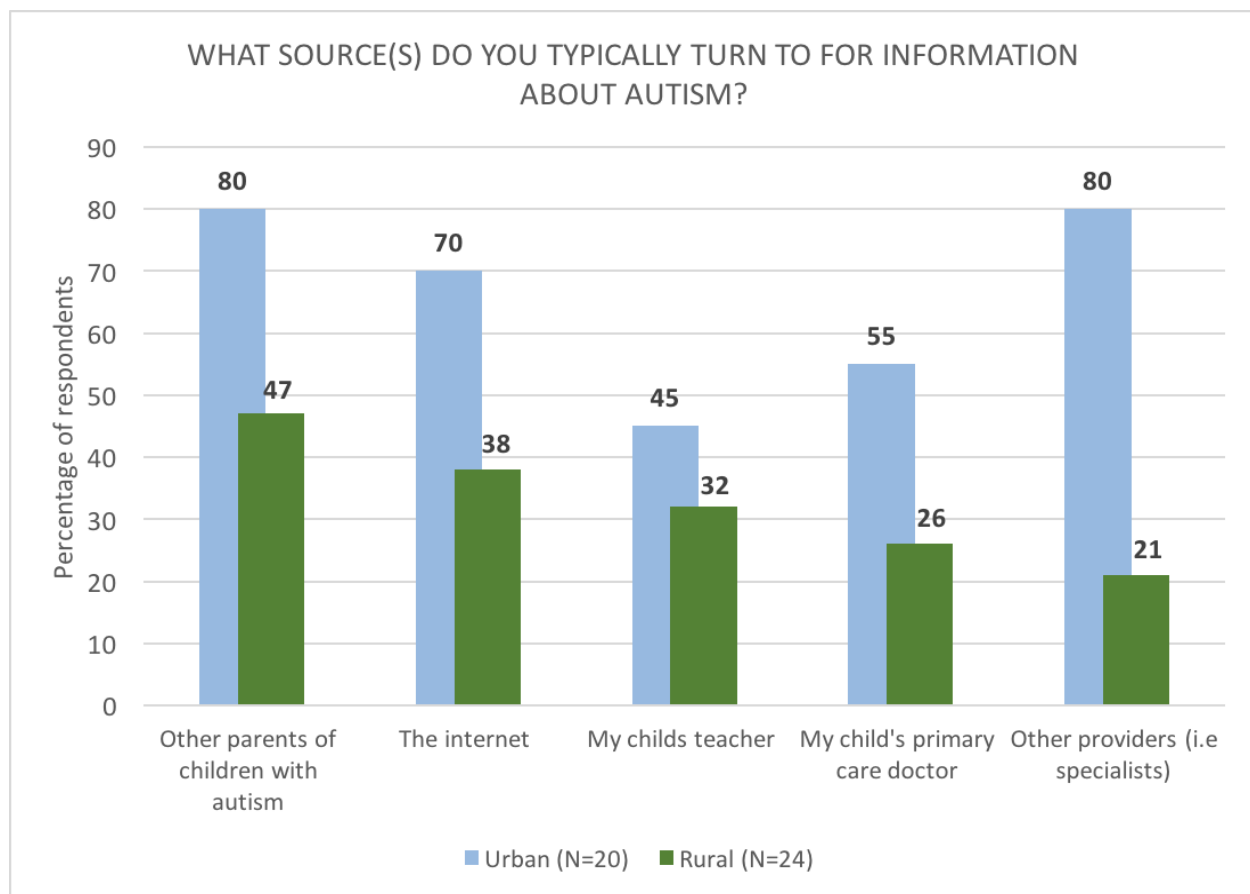


Figure 4.6: Sources of information about autism in urban and rural regions of Morocco

From the urban sample of 20 families, all 20 families responded with at least one source of information that they typically utilize. Many families chose more than one source, and the most common number of sources that urban families selected, the data's mode, was three. However, only 24 of the 34 rural family sample answered that they typically turn to any of these five sources. Of these 24 families' responses, the data's mode was only two. This suggests that a higher percentage of families in urban regions had access to multiple sources of information when compared to rural regions.

It is worth noting that 70% of families in urban areas and 38% of families in rural areas received information from the Internet about autism, making it the second most common method of getting information among the entire sample. Finally, the substantial gap in urban and rural families who responded they turned to other providers like specialists (four times greater) and primary care doctors (two times greater) reaffirms the trend discussed in Figure 4.6. Still, it is possible that the data is a result of irregularity in the way that 2016 and 2018 teams phrased this question to families. The multiple-answer nature of this question could have led to confusion and inconsistent data collection.

The Autism Speaks survey asked families from both urban and rural regions what they considered their top three priorities regarding autism treatment. Figure 4.9 illustrates the responses that families gave for this question.

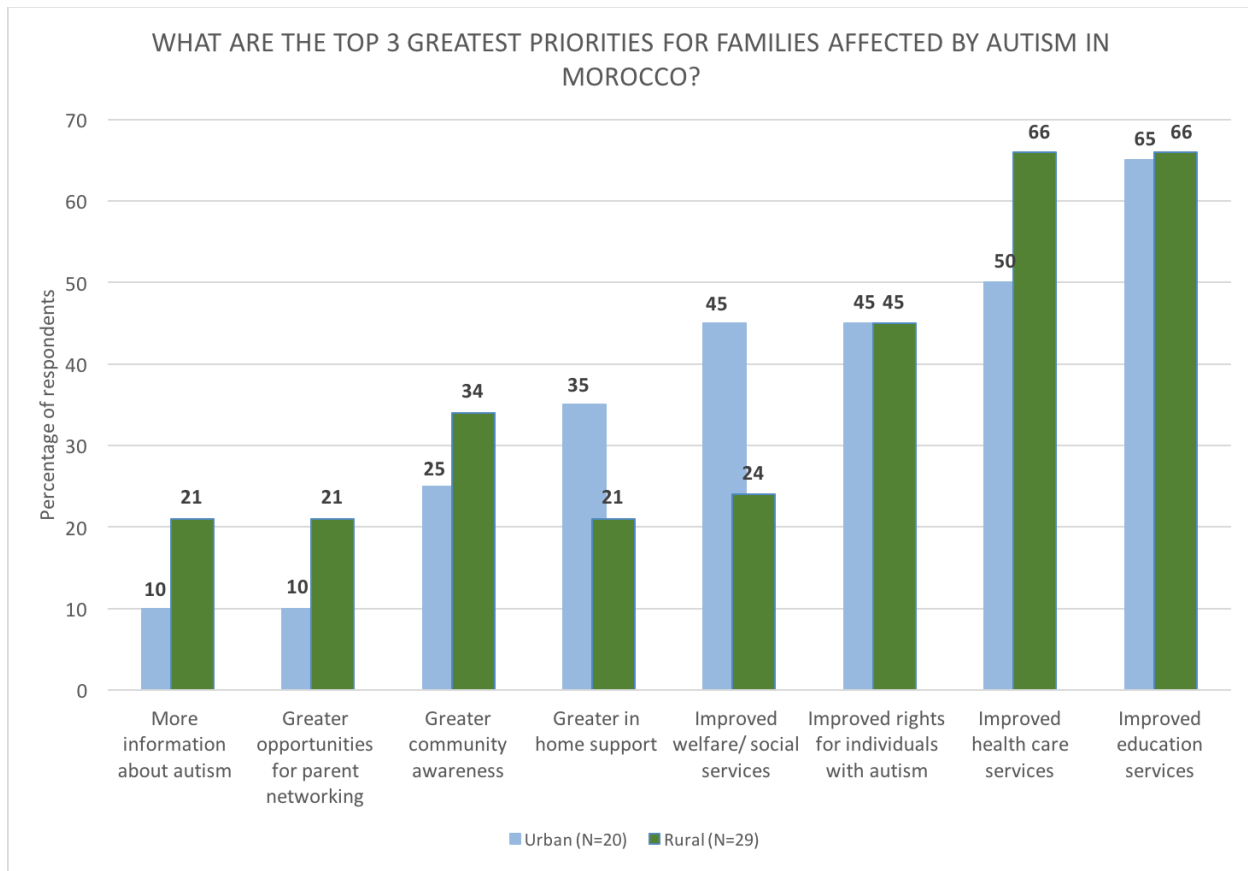


Figure 4.7: Top concerns and priorities of families for the treatment of autism in urban and rural regions

The top three concerns for autism treatment are the same across our urban and rural samples. These concerns include: improved healthcare and education services, and improved rights for individuals with autism. It is important to note that all three of these priorities involve the improvement of different aspects of life for individuals with autism.

4.3 Analyzing Supplementary Information

In order to analyze the supplementary information that our team collected during family interviews, we sorted our collection of their stories and experiences into common themes through the process of coding. Table 4.4 provides a summary of the key concepts that reoccurred throughout the supplementary information. Most “broad themes” are accompanied by “sub-themes” that give more specific insight to their relative category. The data displayed throughout the rest of section 4.3 gives examples of instances where families provided anecdotes that

support each theme. This section also only includes only interview responses from the 2018 interviews.

Table 4.4: Recurring themes of supplementary family interview information

Key Concepts	
<i><u>Broad Theme</u></i>	<i><u>Sub-theme</u></i>
Support from home	
Varying parental emotions surrounding autism	Pride in child
	Overall regrets
Varying perceptions of autism	“Normal” vs. “Autistic”
Understanding of autism	Doctors
	Public
	Families
Discrimination	Public Environments
	Traditional schools
	Family attitudes

4.3.1 Support within the home

The sample of families we interviewed often indicated receiving multiple types of support from specialists at the NGOs where they are affiliated. Interestingly, the only area of support that parents consistently mentioned as being the most important throughout our interviews was support children received in the home setting. Table 4.5 includes phrases from the 20 participants that pertain to their feelings about support for their children in the domestic setting.

Table 4.5: Examples of instances where families expressed the importance of in-home support

Support from home
<i>Education</i> in the home is important
It is <i>important to work</i> with a child at home
Necessary <i>training</i> can come from home
Home <i>life</i> is the most important thing
Home <i>support</i> is the most important thing
<i>Most substantial improvement</i> have come from families' work at home
"Support at home is 100% the <i>most important thing</i> "

Support for children of autism at home involves parental guidance and training, with or without homework or programs provided by NGOs. Thirty-five percent of the families we interviewed explicitly indicated that supporting a child's progress at home is more important than doing so in educational or social settings. No other families commented on other areas of support being the most crucial to the development of their children. The sample of our study showed that support for children with autism in the home is very important to the families of these children. Unfortunately, sometimes the parent's emotions regarding their situation can differ between homes and influence the amount of in-home support their children receive as a result. Table 4.6 lists instances where families expressed differing emotions about their child's disability.

Table 4.6: Examples of different perceptions parents have regarding their child's disability

Varying parental emotions surrounding autism	
<u>Pride in child</u>	<u>Overall regrets</u>
I am <i>proud of my child</i>	Mother regrets <i>not attending school</i> before she had a child
Proud because <i>it is God's will</i> ; mother is working towards a better life	Mother is sorry she <i>had to stop working</i> to care for her child
Father is <i>not proud of sick</i> child	

The misalignment of parental and professional perspectives regarding a child's condition exists in both directions. A parent can consider their child normal while a doctor diagnoses them with autism. Conversely, a doctor can consider a child normal while their parent believes their development is abnormal. This disagreement could be a result of the different levels of personal knowledge and experience both involved parties have with each child. This disagreement sheds light on the current level of understanding of autism in Morocco.

Mothers of children with autism show signs of great understanding of their children's conditions. They consistently show unconditional love for them despite their diagnoses. Parents have exhibited pride in their children for multiple reasons. The only source of regret we discovered in our interviews pertains to the mothers' need to stop working in the field of their degrees in order to care for their children. The consistency regarding a Moroccan mother's pride towards their child with autism indicates that mothers could play a substantial role in advancing the understanding and acceptance of autism in Morocco.

4.3.2 Understanding and Misunderstanding of Autism in Morocco

Those who spend the most time with each child with autism obtain the deepest understanding of the complexities of their condition. It is very difficult to immediately determine each symptom of an autism diagnosis because the disorder exists as a spectrum. There is no one set of symptoms or conditions associated with ASD, but instead a multitude of overlapping

affected areas of life. Any one child with autism can have a unique combination of characteristics. Table 4.7 displays comments from families that pertain to the disagreement between their perception of their child’s disorder and that of a professional.

Table 4.7: Phrases exhibiting the widely variable medical and parental perception of autism

Varying perceptions of autism
<u>“Normal” vs. “Autistic”</u>
<i>Mother thinks</i> child is normal; <i>but doctors say</i> they have autism
Twins with autism: doctors say <i>one has autism</i> and <i>one is normal</i>
<i>Doctors described</i> child as normal, <i>but mother sees</i> wrongness in the development of the child

In Morocco, there is no research on autism. Any information that people learn about autism come the Internet or from experience working with afflicted children. Thus, there still exists a vague and unclear understanding of exactly what classifies as autism. This vague understanding results in disagreements between professionals and parents regarding the condition of their child.

Aligning with this issue, nine out of the twenty interviewed families expressed dissatisfaction with the degree to which professionals and the public understand autism in Morocco. Table 4.8 below displays responses from our twenty family interviews that correlate with experiences pertaining to the understanding of autism in Morocco.

Table 4.8: Examples of autism understanding by doctors and families

Understanding of autism		
<u>Doctors</u>	<u>Public</u>	<u>Families</u>
Doctors <i>don't understand</i> autism fully	People <i>don't understand</i> (our) situation	Only the <i>mother understands</i> her child
Doctors didn't diagnose autism directly, but instead child has " <i>a little disability</i> "	Autism is <i>just being discovered</i> in Morocco	Mother should <i>always be with the child</i> because she understands him most
Doctors provide <i>no official diagnosis</i> document		Morocco doesn't fully understand the <i>child's behavior or condition</i> but the mother does
		<i>Father can't control</i> the child; mother always has to be with him

Caregiver responses in our interviews reveal that the areas of Moroccan society that suggest an incomplete understanding of autism include medical, public, and in-home. Sometimes, parents perceive the diagnoses of their children as too vague to address the specifics of their autism case. There exist multiple forms of autism, such as Asperger Syndrome and Pervasive Developmental Disorder (PDD), because autism is such an expansive spectrum of conditions. The fact that medical diagnoses of autistic patients are not more specific than "autism" or "autism spectrum disorder" suggests that there may be an incomplete comprehension of the complexities of the autism spectrum. Figure 4.8 shows that out of the twenty families we interviewed, every diagnosis their children received was either "autism disorder," "autism spectrum disorder," or "unknown."

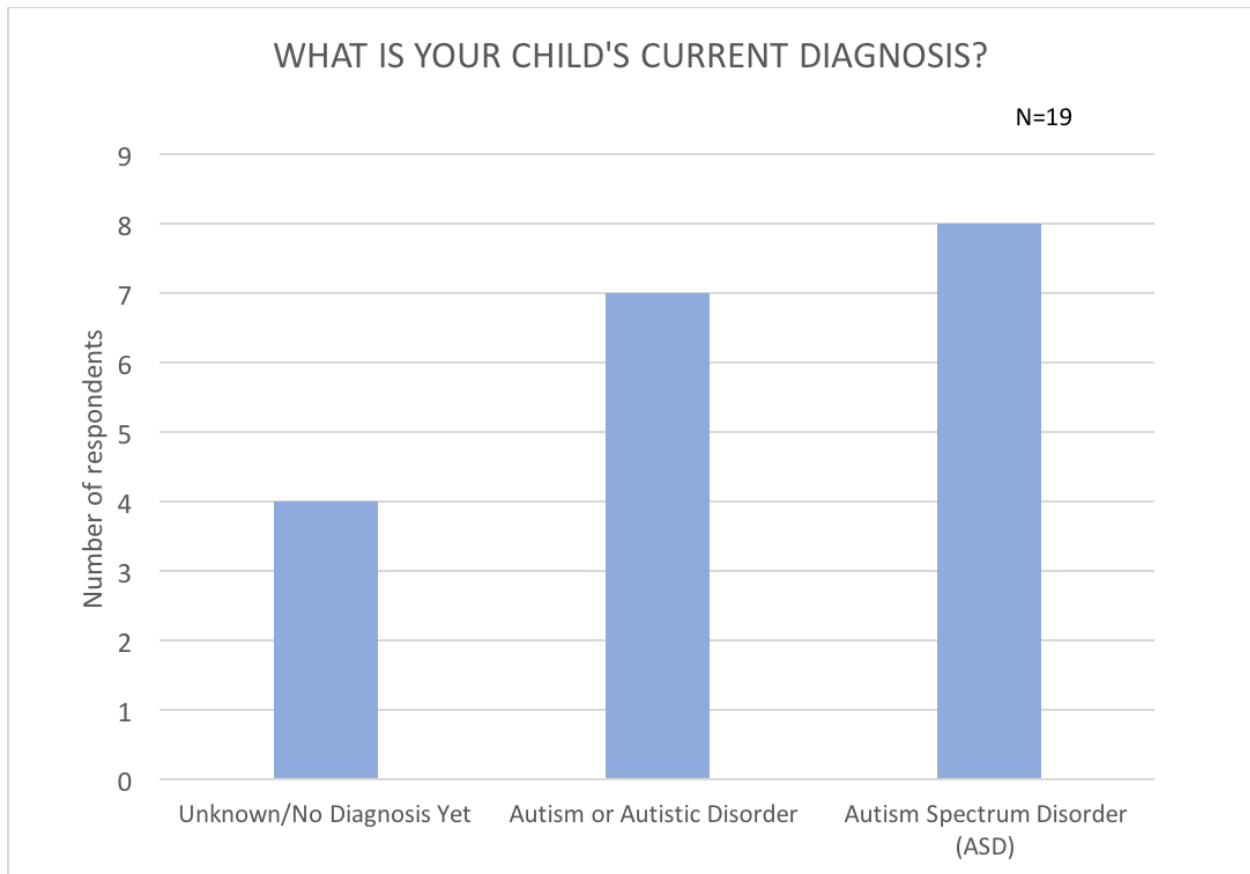


Figure 4.8: Diagnoses of children in the 2018 urban sample

In the home, as previously mentioned, there is inconsistency pertaining to the personal connections non-parental family members make with children with autism. In our family interviews, the mothers of children with autism have been the primary respondents to our questions. These mothers consistently express themselves as being as the primary caretaker of the child, as well as the person who most deeply understands their child's condition. This makes daily life especially difficult for these mothers when they encounter members of the public who do not share their perspective of their child.

Unfortunately, the lack of complete understanding of what autism spectrum disorder is in Morocco has led to instances of discrimination against those with the disorder. Discrimination against the autistic community is not limited to one aspect of life. On the contrary, those affected by autism experience discrimination in public, academic, as well as family settings. Table 4.8 below includes every instance of discrimination shared by a caregiver over the course of our family interviews. These instances of discrimination were consistently present across public and

private NGOs as well as prevalent in other aspects of daily life including extended family and friends.

Table 4.9: Instances of discrimination mentioned in family interviews

Discrimination		
<u>Public Environments</u>	<u>Traditional schools</u>	<u>Extended family attitudes</u>
People <i>push</i> child away	School <i>rejected</i> child for their <i>behavior</i>	Offered no assistance; <i>gave up</i> on mother
Bus driver <i>accused mother</i> of having disabled child on purpose to pay less for transportation	School <i>rejected</i> child because of their <i>condition</i>	Family <i>stopped talking</i> to mother
	Private school <i>questioned</i> child's <i>condition</i> ; child is no longer enrolled	Family <i>avoided</i> and <i>disproved</i> of child; family members offered no help
	School rejected child because he didn't talk; <i>had to hire private educator</i> to help in public school	Child is <i>locked in a room</i> to minimize interactions with others
		Father <i>abandoned</i> family because of <i>shame</i> of having a sick child

The patterns of rejection from our interviews that this table highlights provide evidence of the stigma associated with the ASD in Morocco. These attitudes likely stem from an improper or incomplete understanding of the complexities of the autism spectrum disorder. Morocco's public and private school systems reject children with ASD. Perhaps this is because there are insufficient numbers of adequately trained educators to deal with autism in these settings. If families wish to see any specialized help in the private or public school systems, they must pay for a private teaching assistant for their child. Schools do not offer specialized services for the

disabled themselves (A. Mounir, personal communication, Jan. 21 2018). Many families cannot afford for these private educators and are forced to take their children out of mainstream schools. It is likely that the families who cannot afford private educators must then turn to public NGOs for support because private NGOs require families to pay for each service they receive.

Furthermore, hurtful discrimination sometimes also comes from within the families of afflicted children. Frequently, families of children with autism do not understand the condition, or feel shame for having a ‘sick’ child. This leads to social isolation in the home setting. The lack of a detailed understanding of autism throughout most of Moroccan society negatively impacts those affected by the disorder in the form of social, academic, and family discrimination. Figure 4.10 displays the responses families provided when asked to rate their agreement with the statement: people discriminate against my family because I have a child with autism.

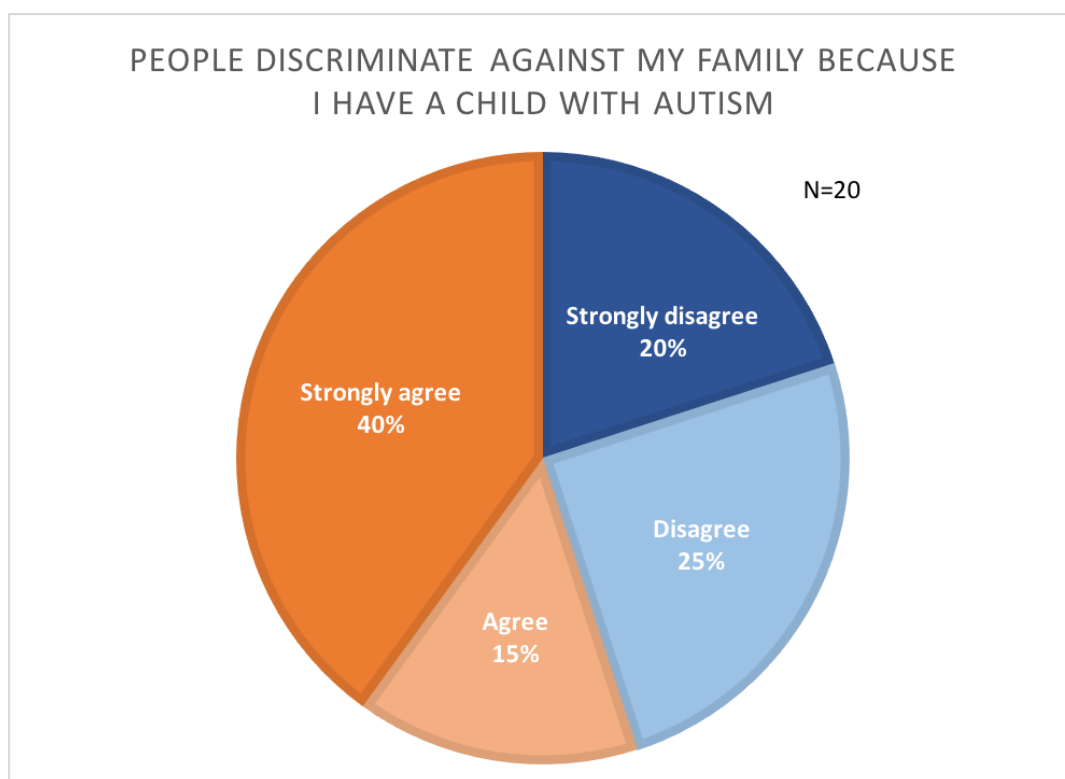


Figure 4.9: Distribution of families that responded they either agreed or disagreed that people discriminated against their family because they have a child with autism.

The graph above supports the claim that it is not uncommon for families of children with autism to experience discrimination in their day-to-day lives. Slightly more than half of the

families we surveyed share the opinion that people discriminate against their family because of their child with autism.

Chapter 5 Recommendations and Conclusion

The purpose of this project was to collect and analyze data pertaining to the resources available for and experiences of families of children with autism in Morocco. We interviewed twenty families at the Space for Brothers and Yasmine Breton organizations in order to obtain necessary data. The data we collected identified the needs of these families, as well as the realities regarding if these needs are being met. Our four professional interviews at the AMAL association in Casablanca generated data pertaining to the realities of autism treatment in Morocco. In general, Moroccan families and professionals who autism impacts do not have access to the resources they require in order to affectively care for their children. Through the process of our data analysis, our team concluded that the Moroccan government could improve areas of their society to better suit the needs of the autistic community. Areas that Moroccans can improve involve medical, educational, in-home, and informational aspects of society. Additionally, there exist actions our sponsor, Autism Speaks, can take to further their mission to support children and families affected by autism and spread awareness of the disorder. Autism Speaks can also take action to make the process of data collection in Morocco more accurate and personalized. In order to address these areas of improvement, we recommend the following:

To the Moroccan government:

- Advance training opportunities for professionals specializing in autism treatment
 - Develop field practice opportunities in Moroccan universities
 - Establish medical training for proper, individualized diagnosis of ASD
- Advance support of families of children with autism
 - Provide more training opportunities for families of children with autism
 - Establish greater networking opportunities for families of children with autism
 - Develop a cellphone app that facilitates conversations between parents of children with autism
 - Communicate seriousness of valuing in-home training and education to families
- Make access to necessary governmental funding easier to obtain and maintain for people impacted by autism.

To Autism Speaks:

- Present documented data about autism in Morocco to the Moroccan government
- Distribute information about autism to the public in the form of informational pamphlets and online websites
- Reformat the Autism Speaks caregiver survey:
 - To include multiple choice tables that are easily understood by both the interviewer and the interviewee
 - To include language translations that are consistent in formatting and question content across languages
 - To include more open-ended questions about the realities of living with a child with autism in Morocco.

Establishing greater hands-on training opportunities for professionals who work with children with autism will enhance the experience these professionals have when they first obtain a job in their field. It is important that professionals develop comprehension of the general realities of ASD before individualizing care to each child in non-governmental organizations. We propose the hands-on training process begins in universities. Specialized training in the university setting would see to professionals obtaining an overall understanding of ASD early in their career. With this understanding, professionals can effectively share this knowledge with parents of affected children at the start of family training. Training in universities can be done by officials of NGOs who are already experienced with treating autism.

Supporting the families of children with autism is as important as supporting the children themselves. Without continued support after children leave the educational setting each day, the practice they receive developing new skills suffers in conjunction with their rate of developmental improvement. Encouraging families to work with their children at home, offering training sessions for families regarding how to deal with their children, and offering opportunities for families affected by autism to meet one another will substantially benefit their community. NGOs who specialize in autism care can provide these opportunities with the assistance of governmental aid.

Autism Speaks should improve the surveys that they provided to our team to facilitate family interviews in Morocco. In particular, the formatting of questions 3.2, 3.3, and 3.4 led to

inconsistencies in respondent answers. As a result, we considered inconsistent answers as outliers and could not analyze them within our data. Additionally, it is important that each form of a particular survey is consistent across language translations. The French and English versions of the professional survey the 2016 teams used in their investigation were not identical.

Ameliorating this will ensure interviewers are collecting consistent data.

The completion of these recommendations will result in the needs of the community affected by autism being better met. We believe that the implementation of these recommendations will lead to a heightened standard of life for families and professionals impacted by autism.

5.1 Conclusions

It is not only autism that exists as a spectrum. The experiences and obstacles faced by families of children with autism exist as a spectrum as well. The financial background of family members substantially impacts their ability to obtain the services they need to care for their children. Families that cannot afford private training sessions for their children often deal with long wait lists of the limited public organizations in their area. Difficulties obtaining care has led many parents of children with autism to develop non-governmental organizations that provide the care that they need. Unfortunately, the Moroccan government is not providing support appropriate enough to facilitate the advancement of these organizations. Almost every family involved in our investigation struggled with obtaining support for themselves and their children through the means of governmental and academic aid. The needs of families affected by autism are simply not being met in Morocco. This inadequacy is likely a result of limited understanding of the realities of autism in the nation. Without substantial knowledge pertaining to the statistics of autism, the Moroccan government cannot know how many families need assistance. The lack of current research and data pertaining to the specifics of autism in Morocco substantially hinders the advancement of families impacted by ASD.

Our project is important because it added to the documented body of knowledge pertaining to autism in Morocco. Moreover, we were able to look at autism in a beneficial, non-systematic way. Interviewing a population with surveys is a great way to increase the amount of quantitative data pertaining to a topic. However, it is the elaboration of unique stories, emotions, and perspectives that sheds light on the personal dimension of a problem. We listened to the

stories of affected families and document the aspects of their situation that they struggle with the most. Even simply listening to these mothers generated sincere feelings of appreciation for our concern and time. We have been honored to work with Autism Speaks throughout the duration of this project. We hope that our recommendations aid Autism Speaks in their mission to provide support to families and children who live with autism in Morocco.

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Appendices

Appendix A: Statement of intent 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.”

Appendix B: Caregiver Surveys

English Translation of Autism Speaks' Caregiver Survey

-Autism Speaks Caregiver Needs Survey Developed by Amy Daniels & SEAN National Coordinators

* Required



Sans titre

Participant Consent Form

Dear Parent / Caregiver,

Worcester Polytechnic Institute, in partnership with Autism Speaks (www.autismspeaks.org), is conducting a survey to understand the needs of children with autism and the challenges and difficulties faced by them and their families in seeking and receiving help. While there is no immediate benefit to your participation, 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 do not anticipate any risks to your participation other than those encountered in day-to-day life.

If you agree to participate, the survey should take approximately 30 to 45 minutes to complete. Please read the questions and answers carefully. Please do not skip any questions that are relevant to you, as all information you provide is very important!

Taking part is voluntary and the survey is anonymous! This study is conducted between August-October 2016.

If you have any questions please do not hesitate to contact Hamza Hachim and Abdelrahman Sirry at hhachim@wpi.edu (Hamza) and amsirry@wpi.edu (Abdelrahman) between August 22 and October 10,

https://docs.google.com/forms/d/1Rh_hpOOqPdMDlc1z9yedNBzQ-wrMXQVIV7vyKo1WBDU/edit

1/19

2016. If you have any questions about this research project after October 2016 you can contact M.V. de Jonge at M.V.Jonge@umcutrecht.nl.

I have read the above information, and have received answers to any questions I asked. I consent to take part in the study.

1. Participant initials

Thank you!

Skip to question 2.

SECTION 0: BASIC SURVEY DATA

2. **0.1 Region (enter town or city name/district or province name)**

3. **0.2 Delivery method**

Mark only one oval.

- ☐ In person (interviewer)
- ☐ In-person (self)
- ☐ Phone
- ☐ Email
- ☐ Other: _____

4. **0.3 Format**

Mark only one oval.

- ☐ Paper
- ☐ Electronic

5. **0.4 Setting**

Mark only one oval.

- ☐ Home
- ☐ Facility
- ☐ Other: _____

6. 0.5 Facility name (enter name, if applicable)*Mark only one oval.*

- ☐ N/A
- ☐ Other: _____

7. 0.6 Date completed (enter DD/MM/ YYYY)*Example: December 15, 2012***SECTION 1: FAMILY DEMOGRAPHIC CHARACTERISTICS****8. 1.1 What is your highest level of education?***Mark only one oval.*

- ☐ No schooling
- ☐ Primary school
- ☐ Secondary School
- ☐ High school/ vocational training
- ☐ College/ University degree
- ☐ Higher than College/ University degree PHD
- ☐ Not applicable

9. 1.2 What is your spouse's highest level of education?*Mark only one oval.*

- ☐ No schooling
- ☐ Primary school
- ☐ Secondary School
- ☐ High school/ vocational training
- ☐ College/ University degree
- ☐ Higher than College/ University degree PHD
- ☐ Not applicable

10. 1.3 What is your relationship to the child*?** Henceforth referred to as "your child"**Check all that apply.*

- ☐ Mother
- ☐ Father
- ☐ Grandparent
- ☐ Other: _____

SECTION 2: AFFECTED CHILD CHARACTERISTICS

These questions pertain to the nature of the first concerns you had about your child with autism's development and his/her autism diagnosis.

11.

2.1 What is your child's current diagnosis?*Mark only one oval.*

- ☐ Autism or Autistic Disorder
- ☐ Asperger's Syndrome
- ☐ Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)
- ☐ Pervasive Developmental Disorder (PDD)
- ☐ Autism Spectrum Disorder (ASD)
- ☐ Unknown/ No diagnosis (yet)
- ☐ Other: _____

12.

2.2 What is your child's gender?*Mark only one oval.*

- ☐ Male
- ☐ Female

13.

2.3a What is your child's current age?

Write in numbers (Years)

14.

2.3b What is your child's current age?

Write in numbers (Months)

15.

2.4 What is the verbal ability of your child?*Mark only one oval.*

- ☐ Does not talk
- ☐ Uses single words only (e.g. "Bread")
- ☐ Uses two- or three-word phrases (e.g. "TV cartoons")
- ☐ Uses sentences with four or more words (e.g. "I want more juice")
- ☐ Uses complex sentences (e.g. "I am tired and I want to sleep")

FIRST CONCERN

16.

2.5 We would like to ask you a little about your child's early development. How old was your child when you first had a concern about his/her development? (Months)

17. **2.6 There are many reasons why a parent might be concerned about a child's development. Below is a list of behaviors that can cause a parent to be concerned. Think about the first concerns you had and select all that apply below. ***

Concern(s)

Mark only one oval per row.

	Yes	No
Had medical problems such as seizures, lack of physical growth, or stomach problems?	<input type="radio"/>	<input type="radio"/>
Didn't make eye contact when talking or playing with others?	<input type="radio"/>	<input type="radio"/>
Didn't respond when called or didn't respond to sound?	<input type="radio"/>	<input type="radio"/>
Didn't seem to understand nonverbal communication, such as understanding what you meant by the tone of voice you used or your facial expressions or other body language cues?	<input type="radio"/>	<input type="radio"/>
Had behavioral difficulties such as sleeping or eating problems, high activity level, wandering, tantrums, aggressive or destructive behavior?	<input type="radio"/>	<input type="radio"/>
Had problems with coordination or gross motor skills such walking?	<input type="radio"/>	<input type="radio"/>
Talked later than usual for most children	<input type="radio"/>	<input type="radio"/>
Was not talking at all?	<input type="radio"/>	<input type="radio"/>
Did not talk as well as other children that were the same age?	<input type="radio"/>	<input type="radio"/>
Some speech skills that he/she had already developed were lost	<input type="radio"/>	<input type="radio"/>
Didn't seem to understand what you or other adults said to him/her?	<input type="radio"/>	<input type="radio"/>
Had problems with fine motor skills such as using scissors or drawing with crayons?	<input type="radio"/>	<input type="radio"/>
Had difficulty playing or interacting with others, or played alone "in her/her own world"?	<input type="radio"/>	<input type="radio"/>
Insisted on sameness or had difficulties with change?	<input type="radio"/>	<input type="radio"/>
Had difficulty learning new skills such as toilet training or getting dressed?	<input type="radio"/>	<input type="radio"/>
Had difficulty learning new things such as the alphabet or numbers?	<input type="radio"/>	<input type="radio"/>
Had unusual gestures or movements such as hand-flapping, toe-walking, or self spinning?	<input type="radio"/>	<input type="radio"/>

18. 2.7 Who was the first person who had a concern that something did not seem right with your child's development?

Check all that apply.

- ☐ I was
- ☐ My spouse
- ☐ Other family member/relative
- ☐ Doctor or other health care provider
- ☐ Teacher
- ☐ Other: _____

If "other" please specify

DIAGNOSIS

19. 2.8 How old was your child when he/she was first diagnosed with autism? (Months)

20. 2.9 Who gave your child this initial diagnosis?

Mark only one oval.

- ☐ Primary care doctor
- ☐ Pediatrician
- ☐ Pediatric specialist (i.e. developmental pediatrician)
- ☐ Psychologist
- ☐ Psychiatrist
- ☐ Neurologist
- ☐ Nurse
- ☐ Team of professionals
- ☐ Other: _____

21. 2.10 How long did you have to travel to obtain a diagnosis for your child?

Mark only one oval.

- ☐ Less than 30 minutes traveling
- ☐ Between 30 minutes and 1 hour
- ☐ Between 1 - 2 hours
- ☐ More than 2 hours
- ☐ I traveled outside the country

HEALTH SERVICE ENCOUNTERS

SECTION 3: SERVICE ENCOUNTERS

These questions pertain to health, education or other services or treatments that your child with autism may have received in the past or is currently receiving to meet his/her needs.

22. **3.1 Has your child ever received any of the following services or treatments to meet his/her needs? Select all that apply. ***

Services/Treatments

Mark only one oval per row.

	Yes	No
Behavioral intervention or modification (e.g. ABA)	<input type="radio"/>	<input type="radio"/>
Sensory integration therapy	<input type="radio"/>	<input type="radio"/>
Cognitive based therapy	<input type="radio"/>	<input type="radio"/>
Occupational therapy	<input type="radio"/>	<input type="radio"/>
Physical therapy	<input type="radio"/>	<input type="radio"/>
Social skills training	<input type="radio"/>	<input type="radio"/>
Speech or language therapy	<input type="radio"/>	<input type="radio"/>
Pharmacotherapy / medication	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>
Don't know	<input type="radio"/>	<input type="radio"/>

23. **3.1 If "Other" specify**

24. **3.2 Is your child currently receiving any of the following services to meet his/her needs? ***

Mark only one oval per row.

	Yes	No
Behavioral intervention or modification	<input type="radio"/>	<input type="radio"/>
Sensory integration therapy	<input type="radio"/>	<input type="radio"/>
Cognitive based therapy	<input type="radio"/>	<input type="radio"/>
Occupational therapy	<input type="radio"/>	<input type="radio"/>
Physical therapy	<input type="radio"/>	<input type="radio"/>
Social skills therapy	<input type="radio"/>	<input type="radio"/>
Speech or language therapy	<input type="radio"/>	<input type="radio"/>
Pharmacotherapy/medication	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>
Don't know	<input type="radio"/>	<input type="radio"/>

25. **3.2 If "Other" specify**

26. 3.3 How many hours of does your child usually receive per week? **Mark only one oval per row.*

	0-2 hrs	3-5 hrs	6-8 hrs	8-10 hrs	11+ hrs	Not Applicable
Behavioral intervention or modification	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sensory integration therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cognitive based therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social skills therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speech or language therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27. 3.3 If "Other" specify

28. 3.4 Do you have to pay for this service? **Mark only one oval per row.*

	Yes, total amount	Yes, partial amount	No	Not Applicable
Behavioral intervention or modification	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sensory integration therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cognitive based therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social skills therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speech or language therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pharmacotherapy/medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Don't Know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

29. 3.4 If "Other" specify

30. 3.5 Has your child ever worked with the following providers to meet his/her developmental needs? Select all that apply.

Provider

Check all that apply.

- ☐ Audiologist
- ☐ Behaviorist
- ☐ Developmental pediatrician
- ☐ Education specialist
- ☐ Neurologist
- ☐ Nutritionist
- ☐ Psychiatrist
- ☐ Psychologist
- ☐ Other: _____

31. 3.6 Is your child currently working with the following providers to meet his/her developmental needs? Select all that apply.

Provider

Check all that apply.

- ☐ Audiologist
- ☐ Behaviorist
- ☐ Developmental pediatrician
- ☐ Education specialist
- ☐ Neurologist
- ☐ Nutritionist
- ☐ Psychiatrist
- ☐ Psychologist
- ☐ Other: _____

EDUCATION SERVICES

32. 3.7 What kind of school is your child currently enrolled in?

Mark only one oval.

- ☐ Preschool
- ☐ Public primary school
- ☐ Private school
- ☐ Special school for children with disabilities
- ☐ Home-schooled
- ☐ Not enrolled in school

33. **3.8 Does your child receive any additional academic support because of his/her developmental needs?**

Mark only one oval.

- ☐ Yes
- ☐ No
- ☐ Don't Know

34. **3.9 What type of additional academic support does your child currently receive? Select all that apply.**

Check all that apply.

- ☐ Special classroom for children with autism
- ☐ Special classroom for children with disabilities (classe intégrée, CLIS)
- ☐ In-school tutor
- ☐ In-school aide/shadow
- ☐ Tutor outside of school
- ☐ Not applicable
- ☐ Other: _____

OTHER SERVICES/ASSISTANCE

35. **3.10 Do you currently receive any training or assistance in managing or addressing your child's needs or implementing your child's treatments?**

If yes, specify in the other option

Mark only one oval.

- ☐ No
- ☐ Other: _____

36. **3.11 Does your child currently receive any special government assistance because of his/her autism?**

If yes, specify in the other option

Mark only one oval.

- ☐ No
- ☐ Other: _____

37. **3.12 Do you or any family member currently participate in any family support or advocacy group or organization because of his/her autism?**

Mark only one oval.

- ☐ Yes
- ☐ No
- ☐ Don't Know

38. **3.13 To what source(s) do you typically turn to get information about autism? Select all that apply.**

Check all that apply.

- ☐ The Internet
- ☐ My child's primary care doctor/pediatrician
- ☐ My child's teacher
- ☐ Other parents of children with autism
- ☐ Other providers (i.e. health specialists, therapists) who work with my child
- ☐ Other: _____

39. **3.14 Please indicate the first 3 training needs that you have as a parent (In order to help your child)?**

40.

41.

42. **3.15 Does your child currently participating in daily family activities inside the house (for example, washing dishes, and food preparation table)?**

Mark only one oval.

- ☐ Yes
- ☐ No
- ☐ Other: _____

43. **3.16 Does your child currently participating in family activities outside the home (for example, public transport, The mosque, visit family / friends)?**

Mark only one oval.

- ☐ Yes
- ☐ No
- ☐ Other: _____

44. **3.17 Does your child currently take part in any organized social activities (such as swimming lessons, soccer, clubs)?**

Mark only one oval.

- ☐ Yes
- ☐ No
- ☐ Other: _____

SECTION 4: PARENT/CAREGIVER PERCEPTIONS

ACCESS & UNMET NEEDS

These questions are about all the types of services children may need or use, such as medical care, dental

care, specialized therapies, counseling, medical equipment, special education, and early intervention.

These services can be obtained in clinics, schools, child care centers, through community programs, at home, and other places.

45. **4.1 During the past 12 months, did you have any difficulties or delays in getting services for your child because he/she was not eligible for the services?**

Mark only one oval.

- ☐ Yes
☐ No
☐ Don't Know

46. **4.2 During the past 12 months, did you have any difficulties or delays because services he/she needed were not available in your area?**

Mark only one oval.

- ☐ Yes
☐ No
☐ Don't Know

47. **4.3 During the past 12 months, did you have any difficulties or delays because there were waiting lists, backlogs, or other problems getting appointments?**

Mark only one oval.

- ☐ Yes
☐ No
☐ Don't Know

48. **4.4 During the past 12 months, did you have any difficulties or delays because of issues related to cost?**

Mark only one oval.

- ☐ Yes
☐ No
☐ Don't Know

49. **4.5 During the past 12 months, did you have any difficulties or delays because you had trouble getting the information you needed?**

Mark only one oval.

- ☐ Yes
☐ No
☐ Don't Know

50. **4.6 During the past 12 months, did you have any difficulties or delays for any other reason?**

If yes, please specify in the other option

Mark only one oval.

- ☐ No
☐ Don't Know
☐ Other: _____

51. **4.7 During the past 12 months, how often have you been frustrated in your efforts to get services for your child?**

Mark only one oval.

- ☐ Never
☐ Sometimes
☐ Usually
☐ Always
☐ Don't know

CAREGIVER / FAMILY IMPACT

These questions pertain to the impact that your child's autism has had on you and other members of your family.

52. **4.8 Has your child's autism caused financial problems for your family?**

Mark only one oval.

- ☐ Yes
☐ No
☐ Don't Know

53. **4.9 Have you or other family members stopped working because of your child's autism?**

Mark only one oval.

- ☐ Yes
☐ No
☐ Don't Know

54. **4.10 Have you or other family members cut down on the hours your work because of your child's autism?**

Mark only one oval.

- ☐ Yes
☐ No
☐ Don't Know

STIGMA

For the following questions, indicate the extent to which you strongly agree, agree, disagree or strongly disagree with each statement.

55. **4.11 I feel helpless for having a child with autism.**

Mark only one oval.

- ☐ Strongly disagree
☐ Disagree
☐ Agree
☐ Strongly agree

56. **4.12 I worry if other people would know I have a child with autism.**

Mark only one oval.

- ☐ Strongly disagree
☐ Disagree
☐ Agree
☐ Strongly agree

57. **4.13 Other people would discriminate against me because I have a child with autism.**

Mark only one oval.

- ☐ Strongly disagree
☐ Disagree
☐ Agree
☐ Strongly agree

58. **4.14 Having a child with autism imposes a negative impact on me.**

Mark only one oval.

- ☐ Strongly disagree
☐ Disagree
☐ Agree
☐ Strongly agree
☐ I do not wish to answer

QUALITY OF LIFE

For these next questions, we want to learn how you feel about your family and child's quality of life.

59. **4.15 For a family to have a good life together, how important is it that my child with autism has support to make progress in school?**

Mark only one oval.

- ☐ A little important
☐ Important
☐ Very important

60. **4.16 How satisfied am I with the support my child with autism gets to make progress in school?**

Mark only one oval.

- ☐ Very dissatisfied
☐ Neutral
☐ Very satisfied

61. **4.17 For a family to have a good life together, how important is it that my child with autism has support to make progress at home?**

Mark only one oval.

- ☐ A little important
☐ Important
☐ Very important

62. **4.18 How satisfied am I with the support my child with autism gets to make progress at home?**

Mark only one oval.

- ☐ Very dissatisfied
☐ Neutral
☐ Very satisfied

63. **4.19 For a family to have a good life together, how important is it that my child with autism has support to make friends?**

Mark only one oval.

- ☐ A little important
☐ Important
☐ Very important

64. 4.20 How satisfied am I with the support my child with autism gets to make friends?*Mark only one oval.*

- ☐ Very dissatisfied
- ☐ Neutral
- ☐ Very satisfied

65.

4.21 For a family to have a good life together, how important is it that my family has a good relationship with the services providers who work with my child?*Mark only one oval.*

- ☐ A little important
- ☐ Important
- ☐ Very important

66.

4.22 How satisfied am I with the relationship with the service providers who work with my child?*Mark only one oval.*

- ☐ Very dissatisfied
- ☐ Neutral
- ☐ Very satisfied

CHALLENGES & PRIORITIES

67.

4.23 We are now interested in learning what you consider to be the greatest challenges to caring for a child with autism. Please select the top 3 challenges from the list below.*Check all that apply.*

- ☐ Challenging behaviors (i.e. self-injury, aggression, tantrums)
- ☐ Daily living skills (i.e. toileting, self-feeding)
- ☐ Health problems (i.e. co-occurring physical and/or mental health conditions)
- ☐ Sleep problems (i.e. trouble falling asleep, trouble staying asleep)
- ☐ Diet/eating/feeding difficulties
- ☐ Social interaction difficulties
- ☐ Repetitive behaviors/restrictive interests/insistence on sameness
- ☐ Communication difficulties
- ☐ Safety concerns (i.e. wandering, climbing)
- ☐ Sensory issues
- ☐ Other: _____

68. 4.24 What are the greatest challenges you face in getting support for your child. Please select the top 3 challenges from the list below.

Check all that apply.

- ☐ Making sure my child receives adequate health care
- ☐ Making sure my child receives adequate education
- ☐ Making sure my child receives adequate welfare / social supports
- ☐ Making sure my child's basic rights are protected
- ☐ Making sure my family and I receive adequate respite
- ☐ Other: _____

69.

4.25 We are also interested in learning what you consider to be the greatest priorities for families affected by autism in your country. Please select the top 3 priorities from the list below.

Check all that apply.

- ☐ Improved health care services
- ☐ Improved education services
- ☐ Improved welfare / social services
- ☐ Greater rights for individuals with autism
- ☐ More information about autism
- ☐ Greater in-home support
- ☐ Greater community awareness
- ☐ Greater opportunities for parent interactions / networking
- ☐ Other: _____

Thank you for your time!

Thank you very much for filling out the survey

You helped us to investigate how to improve the care for children with autism in Morocco.

Did you know that Autism Speaks has des Trousses d'outils en Français about ...

Des stratégies à employer au domicile et des conseils pour enseigner et augmenter des comportements désirés et diminuer des problèmes de comportement.

https://www.autismspeaks.org/sites/default/files/docs/behavioral_health_treatment_french.pdf

Stratégies pour améliorer le sommeil

Caregiver Needs Survey
Developed by Amy Daniels
& SEAN
National Coordinators
Kara A.Reagon

استقصاء لاحتياجات مقدمو الرعاية
تصميم ايمي دانيالز و شون

المنظمون الوطنيون
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- أخرى (صف:)

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

- 1- _____ (غير مفعلاً)
- 2- _____.

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

الموافقة علي المشاركة:

أعزائي الآباء/ مقدمو الرعاية

(اسم الجامعة/المؤسسة/ _____) ،

بشراكة مع جمعية (Autism Speaks) (www.autismspeaks.org) ، 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- الباب الثاني : الخصائص الديموغرافية للعائلة :

1.1 - ما هو أعلى مستوى تعليمي لديك؟

- | | | |
|----------|---|---------------------|
| 0- _____ | لم اذهب للمدرسة | بشهادة / بدون شهادة |
| 1- _____ | المدرسة الابتدائية | بشهادة / بدون شهادة |
| 2- _____ | المدرسة الإعدادية | بشهادة / بدون شهادة |
| 3- _____ | المدرسة الثانوية / التكوين المهني | بشهادة / بدون شهادة |
| 4- _____ | الكلية / الجامعة المجزئات الجامعية | بشهادة / بدون شهادة |
| 5- _____ | أعلى من الكلية / شهادة جامعية "الدكتوراه" | |

2.1- ما هو أعلى مستوى تعليمي لزوجك أو زوجتك ؟

- | | | |
|----------|---|---------------------|
| 0- _____ | لم تذهب للمدرسة | بشهادة / بدون شهادة |
| 1- _____ | المدرسة الابتدائية | بشهادة / بدون شهادة |
| 2- _____ | المدرسة الإعدادية | بشهادة / بدون شهادة |
| 3- _____ | المدرسة الثانوية / التكوين المهني | بشهادة / بدون شهادة |
| 4- _____ | الكلية / الجامعة المجزئات الجامعية | بشهادة / بدون شهادة |
| 5- _____ | أعلى من الكلية / شهادة جامعية "الدكتوراه" | |
| 6- _____ | غير قابل للتطبيق | |

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.

1.2- ما هو تشخيص طفلك الحالي ؟

- 1- _____ التوحد أو اضطراب التوحد
- 2- _____ متلازمة اسبرجر
- 3- _____ اضطراب النمو المتفشي الغير المحدد (TED-NS) الاضطراب التطوري الشامل غير محدد بطريقة مختلفة
- 4- _____ اضطراب النمو المتفشي (PDD) ، الاضطراب التطوري الشامل TED
- 5- _____ اضطراب طيف التوحد (ASD) ، اضطراب من 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

4.2 ما هي القدرات اللفظية لطفلك ؟

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

السؤال الهام الأول:

5.2- برجاء الشرح عن متي كانت أولي علامات تطور الحالة المرضية لطفلك؟! كم كان عمر طفلك عندما لاحظت تطور

الحالة المرضية لديه؟

أشهر _____

6.2- هناك أسباب كثيرة وراء كون احد الوالدين قلقا بشأن نمو الطفل ، وفيما يلي قائمة من السلوكيات التي يمكن أن تسبب لأحد الوالدين القلق 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 المرحاض 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- _____ متخصص في طب الأطفال (طبيب أطفال مختص في تنمية الطفل)
- 4- _____ **اخصائي نفسي**
- 5- _____ طبيب نفسي
- 6- _____ طبيب مخص و أعصاب
- 7- _____ ممرضة
- 8- _____ فريق من المهنين
- 9- _____ أخرى (حدد: _____)

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

- 1- _____ اقل 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
		لا اعرف	10

2.3- هل يتلقى طفلك حاليا أي من الخدمات التالية لتلبية احتياجاته/ها؟	3.3- كم عدد الساعات التي يتلقاها طفلك غالبا أسبوعيا؟	4.3- هل عليك أن تدفع لقاء هذه الخدمة
1	التدخل السلوكي أو تعديلات (مثال ABA)	1. نعم، تماما 2. نعم، جزئيا 3. لا
2	علاج التكامل الحسي	1. نعم، تماما 2. نعم، جزئيا 3. لا
3	العلاج السلوكي المعرفي	1. نعم، تماما 2. نعم، جزئيا 3. لا
4	العلاج الوظيفي	1. نعم، تماما 2. نعم، جزئيا 3. لا
5	العلاج الفيزيائي	1. نعم، تماما 2. نعم، جزئيا 3. لا
6	التدريب على المهارات الاجتماعية	1. نعم، تماما 2. نعم، جزئيا 3. لا
7	العلاج اللغوي	1. نعم، تماما 2. نعم، جزئيا 3. لا
8	العلاج بالأدوية	1. نعم، تماما 2. نعم، جزئيا 3. لا
9	أخرى	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 مختص في أمراض السمع أو السمعيات		
2 مختص في السلوكيات		
3 مختص في طب الأطفال		
4 اختصاصي التعليم		
5 طبيب مختص في الأمراض العصبية		
6 مختص في التغذية		
7 طبيب نفسي		
8 مختص في علم النفس		
9 أخرى (حدد: _____)		

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

الخدمات التعليمية:

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

1. _____ مرحلة ما قبل المدرسة (الحضانة)
2. _____ المدرسة الابتدائية العامة
3. _____ مدرسة ابتدائية خاصة
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:

2. لا	1. نعم	الدعم المدرسي	
		فصول دراسية خاصة بالأطفال المصابين بالتوحد	1
		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	
		الإنترنت	1
		طبيب أطفال	2
		مدرس الطفل	3
		آباء الأطفال الآخرين الذين يعانون من التوحد	4
		غيرهم من مقدمي الخدمات (أي المتخصصين بالصحة، و المعالجين) الذين يعملون مع طفلي	5
		أخرى (حدد: _____)	6

14.3- يرجى ذكر أول 3 احتياجات تدريبية مهمة لديك؟

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 حالياً 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 حالياً في أنشطة اجتماعية منظمة (مثل دروس السباحة، الرياضة، أنشطة خاصة بالأطفال)

1. ____ نعم (حدد: _____)

2. ____ لا

4-الباب الخامس:

إدراك الآباء/ الوالي: الاحتياجات الملبة و الغير ملبة:

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 ال 12 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 ال 12 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 ال 12 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 التكلفة؟

1. ____ نعم (حدد: _____)
2. ____ لا
3. ____ لا أعلم

5.4- 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

6.4- 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 أفراد 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

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 أن 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

Packet of short answer questions our team compiled from caregiver survey

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
		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

3.1

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

اختر كل ما ينطبق:

لا	نعم	خدمات / علاجات	
<input type="checkbox"/>	<input type="checkbox"/>	التدخل السلوكي أو تعديلات (مثال ABA)	1
<input type="checkbox"/>	<input type="checkbox"/>	علاجات التكامل الحسي	2
<input type="checkbox"/>	<input type="checkbox"/>	العلاج السلوكي المعرفي	3
<input type="checkbox"/>	<input type="checkbox"/>	العلاج الوظيفي	4
<input type="checkbox"/>	<input type="checkbox"/>	العلاج الفيزيائي	5
<input type="checkbox"/>	<input type="checkbox"/>	التدريب على المهارات الاجتماعية	6
<input type="checkbox"/>	<input type="checkbox"/>	العلاج اللغوي	7
<input type="checkbox"/>	<input type="checkbox"/>	العلاج بالأدوية	8
<input type="checkbox"/>	<input type="checkbox"/>	أخرى (حدد: _____)	9
<input type="checkbox"/>	<input type="checkbox"/>	لا اعرف	10

3.2, 3.3, 3.4

2.3- هل يتلقى طفلك حاليا أيا من الخدمات التالية لتلبية احتياجاته/ها؟	3.3- كم عدد الساعات التي يتلقاها طفلك غالبا أسبوعيا؟	4.3- هل عليك أن تدفع لقاء هذه الخدمة	
1 التدخل السلوكي أو تعديلات (مثال ABA)	1. نعم 2. لا	1. نعم، تماما 2. نعم، جزئيا 3. لا	1
2 علاج التكامل الحسي	1. نعم 2. لا	1. نعم، تماما 2. نعم، جزئيا 3. لا	2
3 العلاج السلوكي المعرفي	1. نعم 2. لا	1. نعم، تماما 2. نعم، جزئيا 3. لا	3
4 العلاج الوظيفي	1. نعم 2. لا	1. نعم، تماما 2. نعم، جزئيا 3. لا	4
5 العلاج الفيزيائي	1. نعم 2. لا	1. نعم، تماما 2. نعم، جزئيا 3. لا	5
6 التدريب على المهارات الاجتماعية	1. نعم 2. لا	1. نعم، تماما 2. نعم، جزئيا 3. لا	6
7 العلاج اللغوي	1. نعم 2. لا	1. نعم، تماما 2. نعم، جزئيا 3. لا	7
8 العلاج بالأدوية	1. نعم 2. لا	1. نعم، تماما 2. نعم، جزئيا 3. لا	8
9 أخرى	1. نعم 2. لا	1. نعم، تماما 2. نعم، جزئيا 3. لا	9
10 لا اعرف			

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	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	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: _____)		

3.9

ما نوع الدعم الأكاديمي الإضافي الذي يحصل عليه طفلك حالياً؟ اختر 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 الأنترنت		
2 طبيب أطفال		
3 مدرس 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 نائماً)

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 ____)

Appendix C: Professional Survey Questions

Can we record this interview?

Professional title:

Educational background:

Number of years' worth of experience:

Type/Source of experience:

How were you trained to treat/educate children with autism?

Availability of Resources:

What training services are offered by this organization?

How much are the services for families per month?

Are there payment plan options available for low income families?

How do you share information about autism with families?

- Is this information only available for families associated with the organization?
 - Why?
- Is this information free?

Understanding of Autism in Morocco:

What do you know about autism? / What is professionally known about autism?

How is autism diagnosed? How do you classify autism diagnoses?

Have you ever had an experience where a parent disagreed with your diagnosis of their child?

Autism Treatment

It is clear through our family interviews that younger children are prioritized in receiving treatment. However, some families we interviewed claimed that their child was too young to be diagnosed/treated. Can you comment on this?

What are some things that influence if a child can or cannot be treated?

Support in the Home:

What do you consider the greatest outcome of support for children with autism in the educational setting? In the home?

Support in the home has consistently been valued by families we interviewed. How can this form of support be advanced?

Additional:

Have you ever noticed a connection between the educational background of parents associated with this organization and their satisfaction with the services they receive?

Appendix D: Professional Interview Transcriptions

Professional Interview One: Professional A

Edith: Okay, so what is your professional title?

Professional A: A Clinical Psychologist.

Edith: What is your educational background?

Professional A: Background.....I have a Master's in Psychology, and also I have a bachelor's degree in English Literature.

Edith: English Literature?

Professional A: Yeah.

Edith: And how many years of experience do you have working with autism and autism treatment?

Professional A: Now, five years.

Edith: Where did you get this five years of experience? How did you ...what were you doing?

Professional A: At this association and another association. Which specialty is just too...

[Inaudible]

Edith: Which is what?

Professional A: [Inaudible]

Edith: Okay.

Professional A: These two associations at the beginning. Then two years at the other association I stopped [there was too much work] and it is very busy. Because I also had my office in another city. So I am just at this association. And I have been here for five years.

Edith: So the first questions we are going to ask is the availability of resources for families. So what training services are offered by this organization?

Professional A: I do not know. Because I am not aware of these things. I do not interfere in these things. My job is to see the kids, to follow them and to guide parents, to inform them, and to speak about illness and the evolution of the kids in the association. And to... I do not even know how much they pay. I do not interfere in that category.

Edith: So you work with helping parents understand.

Professional A: Yes, if they have questions about the mental illness of them. They do not know how to deal with...they have preoccupations about the future of their kids and something like that. I try to guide them.

Edith: Can you elaborate more on how you share this information with families? Is it all verbal communication?

Professional A: It's verbal communication.

Edith: Do they come with you with questions? Do you have meetings or training sessions?

Professional A: No, not here. They just ask for appointment with the phycologist. They want to meet her. Because they do not know how to reduce behavior troubles and communication [of the kids].So they come and ask for appointments and I am here at this association once a week all day. And the other instructor, we meet here, just meet one day or three days at the association in general. And it is the same time, also in the beginning of the year I see parents that really want to start their kids here. I try to know the kind of trouble and the degree of mental retardness. So the story of the illness and we have a place to keep them, I dispatch in the classes.

Edith: And just sort of an extension off of that, is there any sort of written like...I want to say pamphlet or place where information about autism is written down or you said it is all verbal?

Professional A: Information for families. Ugh no. Sometimes we organize information for the families. There is another psychologist, so she comes here and they give information. They do a round table, and expressed to them how, ugh to...the method of ABA, analysis behavior.

Edith: We heard about ABA, TEACCH, and...

Professional A: And Pix. It depends on the kid. If he is not communicating, if he cannot speak. So we try to store some kind of file so that that they could communicate with Pix. We started Pix this year.

Edith: And these training sessions or these round table meetings only happens with families that are associated with these organization?

Professional A: Yes, especially those who have their kids in the association.

Edith: You said you do not know anything about what families pay to belong to this association or if there's any sort of fee for the information of services? You said you do not know anything about that?

Professional A: No.

Edith: So the next question we are going to ask is about the overall state of autism in Morocco. So what is professionally known about autism?

Professional A: **phone rings** Excuse me, it is the school nurse.

Edith: It is okay, go ahead.

20 Seconds Later

Edith: Can you give us just, I guess a quick summary of what is known about autism, sort of where the current understanding of the disorder?

Professional A: Yes, now families try to start too understand and to search by themselves about autism. So we find them some mothers who do not have high degree in education but just they go on the internet and search to know about autism. And they work with the kids at home and they do a lot of efforts. And even the states now in Morocco gives a lot of importance to autism and start to speak about it. And now people start to be aware of that kind of trouble. Ugh because when we start to put questions is when the kid do not communicate, when there is no language. Where there is troubled behavior, then there is no concentration, and no memories effect. So they start to ask if there is something wrong with the kids, then they go to the pediatrician or they go to a physiologist or an association to know. So they attend a lot of meetings and they pay for themselves to that understand more and to learn more about this and they also ask themselves about how to behave and what shall they do for the future of the kid. So there is a big preoccupation of autism now and people start too... even now... ***phone rings***

15 Seconds Later

Edith: Just now that there is a greater understanding or I guess...

Professional A: There is a great understanding. Because ugh, parents they are coming for example from Casablanca and from the cities that are very far. Where is no education, there is no means of transport, and there is no schools for that kind of trouble to take care of their children. They come here and change their life, they change their habits...everything to come here just for the benefit of the kid.

Edith: Did you learn about autism through school like when you were getting your masters, or did you learn through your experience through other organizations?

Professional A: Not a lot. I really experienced when I worked at the association and we studied just theoretically. We just learn about studies because of the autism, like what could we do for it, but not very deeply. That is the experience, I get it from here....from the association.

Edith: Thank you. So how autism is diagnosed and are there different classifications of autism?

Professional A: Normally it's not the psychologist who says that boy or that girl has autism. They have to go to a psychiatrist for kids.

Edith: Like a pediatrician?

Professional A: Yes. And they must go there. And he must observe for a lot of days for the evolution of the boy. He has to do some tests and after he would say it is autism. And sometimes they are wrong.

Edith: So an extension off of that, but also another question first: Do you know if there is, even if you are not the person that diagnosis them, are there different sort of classifications of autism and if so kind what are those. What are different names for the, like, different severities?

Professional A: Yes you can, you can just for example in my experience I could see the kids and could see if it is deep, severe, or heavy.

Edith: Is that sort of how you describe it? Like heavy or there is no like ...

Professional A: No not exactly, but I can, it is not severe. He can progress, he can learn...he can ... so in between. Like in my first sight I could see it.

Edith: And sort of going back from what you have mentioned before, have you ever experienced a situation where a doctor diagnosed a child one thing and [the] family disagreed or there was some sort of disagreement on whether the child had autism or isn't?

Professional A: Um, in general the family does not disagree, because when the diagnosis is made by a doctor, they could change doctors. But if there is the same diagnosis they would just accept and try to fight and find by themselves and learn by themselves and look where they could put their kids. The about the association is not... we do not have information here...lot of information here.

Edith: Right. Um, so something else we have learnt while talking to parents is that there has been some parents that have said their child was denied service because they were too old to receive that service. But, there were other times that they were denied because they were too young to receive that service. Do you have any idea why children that are older/younger might be, I guess prioritized for different kinds of services? Is there any sort of pattern?

Professional A: I don't understand your question.

Edith: Ugh, we have learnt from talking to families that sometimes children are too young to get services from an organization, but sometimes they are too old to get services from an organization.

Professional A: Personally, I do not know any organization about you know...I want to be able to get in contact with the organization that take care of autism and which can offer information and studies and some training about autism. Why not?

Edith: Okay, um, and then just something else that we are interested in is that we have been talking to a lot of families about the support that their child receives when they, like go to school and come to these organizations and they get professional help. And then a lot of families have been talking about how support at home is very important to them and it is kind of two-part thing. Support at school is important but then also having support to learn at home is important.

Professional A: Yes, of course.

Edith: So with both halves of that, what do you think the greatest benefit of having support at home is and then what do you think the greatest benefit of having support at school?

Professional A: They go together. School and home go together. Because if they do not education go...work here...they work a lot and take care and educate and show a lot of methods. If there is no continuity at home, then there is nothing. Because this is what I try to teach parents, it is very important to follow what the educator tell them. They must keep in contact with them. They must ask about the evolution of the kid, so that they could go together, okay, on the same line. And this is very important because we noticed that when kids go through holidays, they lose everything.

Angelica: That they learn?

Professional A: Yes.

Angelica: Like for how long? Like the months of teaching?

Professional A: Yes, things like how to eat at a table and how to eat properly and how to sit down, to be social, names of colors in terms of education.

Edith: Do you sort of have any input or thoughts on how that continuity could be stronger? Like how...ways to increase at support at home or to make it so that when children do not come to school for a few days, they do not lose all of that. Like how can...what is something that could happen to sort of increase that support at home? Do you have any ideas?

Professional A: *Shakes head no.*No.

Edith: And then the last question that we have is: Have you ever noticed any sort of connection between the educational backgrounds that parents have and how satisfied or dissatisfied they are with like the education that their children are receiving?

Professional A: Ugh, no. Because it's really rare are those parents who come and ask about the evolution of the kids. They are some parents that send their kids to an association and they do not even follow. And we have some parents who just insist on school. [Like they say] "They must go to school." They insist on their kids even if they just want to make them aware. Sometimes it is difficult. It is difficult for them to learn in a classical school and in public schools. But they do not know....and they should learn to write...until they find some problems.

Professional A: You understand?

Angelica: Mhm, yes.

Professional A: My English is very hard. **laughs**

Angelica: No, it is great.

Edith: That is the end of all the questions that we have. If there is anything else that you are dying to share with us, we would love to hear it. But other than that...

Professional A: Just to learn anything new in terms of autism, in terms of methods. I would like to share experience with Americans that are in the field. If they can offer something new about autism, so we could be aware.

Edith: So that we can stay in line with... yeah.

Edith: I think that is all we have. Thank you so much! That was really helpful.

Professional Interview Two: Educator A

Responses were recorded and translated by our translator Jihan Ouaragli. Responses were told to us by her.

Morgan: What training services are offered by this organization?

Jihan and Educator A: Specialists, auditory training, psychologists.

Morgan: How much are the services for families per month?

Special Educator: Depends on each family, military governmental help is an option. AMAL gets government funding, some pay nothing.

Morgan: How do you share information about autism with families?

Jihan and Educator A: Meetings/classes with families, classes to learn how parents deal with each child.

Morgan: Is this information only available for families associated with the organization? Why?

Jihan and Educator A: Sometimes other families join training classes. Internet, Facebook, word of mouth.

Morgan: Is this information free?

Jihan and Educator A: Depends.

Morgan: What do you know about autism? What is professionally known about autism?

Jihan and Educator A: Before, autism was not really known. Parents just closed the doors on them and didn't work on understanding them. Internet source is used for information.

Morgan: How is autism diagnosed? How do you classify autism diagnoses? What diagnoses do you work with?

Jihan and Educator A: Diagnosis come from specialists before they come here. They go see the psychologist/psychiatrist before training.

Morgan: Have you ever had an experience where a parent disagreed with your diagnosis of their child?

Jihan and Educator A: Normally, parents don't accept their child's condition. They don't come directly out and say it but professionals noticed they don't act like they don't accept it. Mostly all parents.

Morgan: It is clear that younger children are prioritized in regard of receiving treatment. However, some families we interviewed claimed that their child was too young to be diagnosed/treated. Can you comment on this?

Jihan and Educator A: Depends, younger children with autism need special training. She works with older children and knows that both young and old children have needs; priority should not exist.

Morgan: What do you consider the greatest outcome of support for children with autism in the educational setting? In the home?

Jihan and Educator A: Professionals sometimes think that the educational setting is more important for support than at home; she personally disagrees. A lot of improvements can come from this.

Morgan: Support in the home has consistently been valued by families we interviewed. How can this form of support be advanced?

Jihan and Educator A: Parents have to listen to advice from professionals and apply their advice at home; take trainings for domestic life at the center and take it seriously. Parents must contact professionals, and take advice from professionals so it could be applied at home; update their knowledge about what to do, like taking training.

Morgan: Have you ever noticed a connection between the educational background of parents associated with this organization and their satisfaction with the services they receive?

Jihan and Educator A: Parents with less education show more interest in supporting their child. Those with more education spend more time working and have less time to dedicate to assisting child.

Professional Interview Three: Educator B

Morgan: Ready? What is your professional title?

Jihan and Educator B: Just educator, not special educator.

Morgan: What is your educational background?

Jihan and Educator B: High school.

Morgan: How many years of experience do you have?

Jihan and Educator B: Ten years.

Morgan: Where did you get this experience?

Jihan and Educator B: Yes, she started with many associations. Here in Casablanca. Yes, she worked before at three associations including this one. Like four in total.

Morgan: How were you trained to treat autism?

Jihan and Educator B: When she came first to the association, there were some educators that helped her to know what she had to do and everything and then like they gave her many training and information so they could know exactly what they needed to do with the kid. That is how she learnt about autism. And like how they should like schedule and everything they do here at the association.

Morgan: What training services do you offer here?

Jihan and Educator B: They have a musician, like a professor... like a teacher, and they have like a painter here too. They give lessons and many other activities like social activities and they have like sports here too like teachers or something like that. So they have different activities....social ones.

Morgan: Yeah.

Jihan and Educator B: They have educators and they have specialists. Yeah, they have everything here.

Morgan: Okay. What do you or this organization as a whole know about autism?

Jihan and Educator B: She said like, autism like a topic before that is not really known and now the states are trying to know more about it, like to contact the other people who knows a lot, yeah. She said that the association is one of the associations really known here in Casablanca. Yes, there are others but this one is really known.

Morgan: That is big Haha.

Jihan: Yeah.

Morgan: What are some diagnoses of the children you work with?

Jihan and Educator B: She is the educator, so she like concentrating on educational background like you could see the numbers, letters and everything. So to know how to write, to read, and like she has here people, like one kid with autism. And the other with multiple illness or something like that. And have three kids and each one has a special case. But she concentrating on education...educational background like to know numbers, like to know how to read...yeah like their knowledge for colors and everything.

Morgan: What are somethings that influence if a child can or cannot be treated?

Jihan and Educator B: If they have those kinds of problems, they could contact the phycologists. She is the one... like trying to figure out what to do if they have problems with the kid's situation. Or like if it is hard to improve or something like that. She is helping a lot and talking to the kid and trying to understand what he needs. And then she tries to apply what she says.

Morgan: Have you found that younger children are more prioritized in treatment?

Jihan and Educator B: She says that it depends for the younger kids who have autism. Like they need special training and like they are working in another class. But here, she is working with an older ones. So she has kids until 19 years old. So she thinks both need like care so no one has like priority over someone. So everyone has needs and things they have to work with. Like it should give importance to both the younger and older ones. Because here she is concentrating on the educational... she is working with the older one to understand how to read and write.

Morgan: What do you consider the biggest outcome of support for a child with autism in the educational setting?

Jihan and Educator B: She said first you noticed in the kid that they really want to do work and improve, and even if they cannot do it. But they really want todo...they show desire to do that, and like if you work with them, like they are learning something, they really show improvement and they really understand. So like showing improvement is really the best thing you could notice in the kid and you could see that. Because like when they work, or you help them to know something, they really see that they are improving and everything. So that is the best thing for them is to notice that the kid is improving.

Morgan: What is the greatest outcome of supporting a child in the home setting?

Jihan and Educator B: She said if they want to have like best result they should like work at home too... at the same level that they are working here. So they should like make efforts and work with them a lot and like continue what they are doing here at home. Because like it is really important.

Morgan: Support in the home has been consistently valued by families we interviewed. How can this form of support be advanced?

Jihan and Educator B: First they should be in everyday contact with them. Keep in touch. And like the educator and the people who are working here, they should explain to them how they should work with the kid that is home. Yeah, she could understand like to do the same at home... and should like update their knowledge and like take training here and everything. So they could know what to do and the need things that they have to do.

Morgan: And last question. Have you ever noticed a difference between the educational background of parents associated with this organization and their satisfaction with the services they receive?

Jihan and Educator B: She said yes they are very satisfied. And if they were not they would not bring their kids. So she said that the level of education really influence ...like the kid's situation. Because like people who are highly educated already know the case, they already know about autism...so when they came here they already knew what they had todo. But for people who are not, like they should explain everything. And like they are the most people who do not accept the kid's condition. So they say, "My kid is normal "and, "I do not understand, what autism is?" And, "I do not want to think about it," but the other people who are really educated they already know the kid's situation, they accept it and they already look for it on the internet. They search about it. So they do not have to explain that too...like they show a lot of improvements better than the others. She said one of the parents he liked searched ugh...book for like for the kid who has autism, or something like that. And he like brought that book and bring it here to the educators and showed them he is reading that book to understand about his kid. To understand exactly about the situation and everything. And they said it really was impressive. Because to see parents who really want to know and like they didn't bring the kid here and go, but he really want to know about the kid's situation and everything. So it he was really impressive. But not like everyone, just a few of them. It depends on their educational background like if they really want to know.Yeah.

Professional Interview Four: Educator C

Jihan to Educator: Salam.

Morgan: Hello. Welcome. Marhabaan. What is your professional title?

Jihan and Educator C: She is an educator.

Morgan: What is your educational background?

Jihan and Educator C: Second year at a university. So two years. Yeah, university level.

Morgan: How many years of experience do you have?

Jihan and Educator C: Ah, she was like a teacher at normal public school. Ah, in private school, not public school. She was a normal teacher, yeah, and now she came here. Like one year of experience. She is new in field because she worked with normal kids.

Morgan: How are you trained to educate children with autism?

Jihan and Educator C: She has a certification in education from a center. So this certification was with like for the normal kids, but they did like information and training for the kids with disabilities. Like kids with autism and everything. Yeah.

Morgan: Where?

Jihan and Educator C: At the same center. Ah, another center, not here. Yeah.

Morgan: Like a disability center?

Jihan and Educator C: Yeah.

Morgan: What training services are offered by this organization?

Jihan and Educator C: She is the same as all the other ones. So the special in education, yes. But, she now working with kids with autism. But the kids who have like not fast with development, so she is working like between 11-17 years old. She is working with older kids.

Morgan: What is the youngest age of these children?

Jihan and Educator C: Five years old. They do not have like... less.

Morgan: What do you know about autism?

Jihan and Educator C: She said that she knows what autism means, like the definition and everything. She knows kids with autism need special care. And kids with autism need specialists to work with and everything. So because she is not doing the training, she is just an educator. But she is like learning about this through training at the other center. But she is trying to search like the internet to learn more about the case. But now she like specializes in education. Yeah.

Morgan: What are some of the diagnosis of the children you work with?

Jihan and Educator C: She is working with kids who are at a really advanced level. But they have like multiple illness like yeah, but they really understand. And like two kids with Tres Amis Twenty One.

Morgan: Have you ever have an experience when the parent disagreed with the diagnosis of their child?

Jihan and Educator C: Yes, she said it happened with one father. He has a girl. And he says to them, like, "The way you are behaving with the girl is not good. You should change this by saying she is normal." And he does not understand that she has something wrong. So...but she is trying. He said like he had went to doctors and he said "No, she is normal," or something like that. But she knows she is not and trying to explain that, but he is not accepting at all. So it happened with one father with the one girl. Because she says, "Yeah, she should change how she acts with the girl if you want her to improve."

Morgan: Is it clear that younger children are prioritized in terms of treatment?

Jihan and Educator C: She said no, because each case is different. And she said like the people who are really smart with working.... she said everyone need care no matter the age. So she thinks everyone have special cases and everyone have to take benefit from the training and services. Yeah....and like in her class, the youngest, is the most...the smartest one in the class. yes...she said no matter the age, the age is not the factor to influence if the kids should...she said sometimes the youngest understand better than the older one. She said if you look at the real age, for example 18 years old, but he is just five years old. So you should not say no, he is 18, he should not come here. The normal age is not exactly the age of the brain. And for example, the youngest is five but her brain is like eight. So it depends sometimes.

Morgan: Why are not there children younger than five here?

Jihan and Educator C: She does not know. You should ask the director about that. She is just receiving the kids.

Morgan: Okay. What are some things that influence if a child can or cannot be treated?

Jihan and Educator C: A problem they are facing, especially with the older kids who are like age between 15 years old or like 18 years old. Like show like they want to have a family. They are thinking about the future. They are showing how they want to have a job, they want to have a family and they want to have kids and everything. So they know like they have todo that, but trying to explain is not easy for them. So that is one of the problems they are facing because they are working with other kids here. Yeah, so that is one of their problems. They understand the environment, and they understand the society and like they are thinking about, "Yeah, they want a family, they want to marry, and they want that." They said that it is their right and they could that. And they could be like normal people and they could live their lives. And it is hard and that is one of the problems that they are facing, and to explain that to them. She said that when we came here, all the guys were here, and they were looking at that. She said they like ask....so they were thinking about that.

Morgan: What is the greatest outcome or support with children with autism?

Jihan and Educator C: She said that the most important thing that the family is thinking about is education. So when they are home they try. They are thinking that they want them to get a job and be like normal people and to be educated and everything. So they are like focusing about education. And she said like that they are now looking at talents. Because many kids have talents but families do not give importance to talents but to education. So she said that it depends on each family. They give each kid homework to do at home. So some families do not give much importance to the homework and they just do it quickly with the kids. But some families they really give importance to the kid. They take their time to help them at home. And they try to see if the kid is really learning to help them, so they help them. Yeah.

Morgan: How can support at home be advanced?

Jihan and Educator C: She said like the parents should really know the case of the kid. And they should really know about it and keep in contact with the educators, and talk to them and know a lot. Know if the kid is improving. And to know what they need and what they do not. Because like education..... she said like an example, a girl that comes here, she is really good at understanding and communication. But when it comes to writing, she is really bad at it so the parents should give her like more attention and should work with her a lot to improve.

Morgan: Okay last Question. Have you ever noticed a connection between the educational background of parents and their satisfaction with the services that they receive?

Jihan and Educator C: She said that they are no relation. But everyone here are very satisfied from the services and everything. It is because they are seeing the kid and they are improving a lot.

Appendix E: Additional Data Graphs

Autism Diagnosis

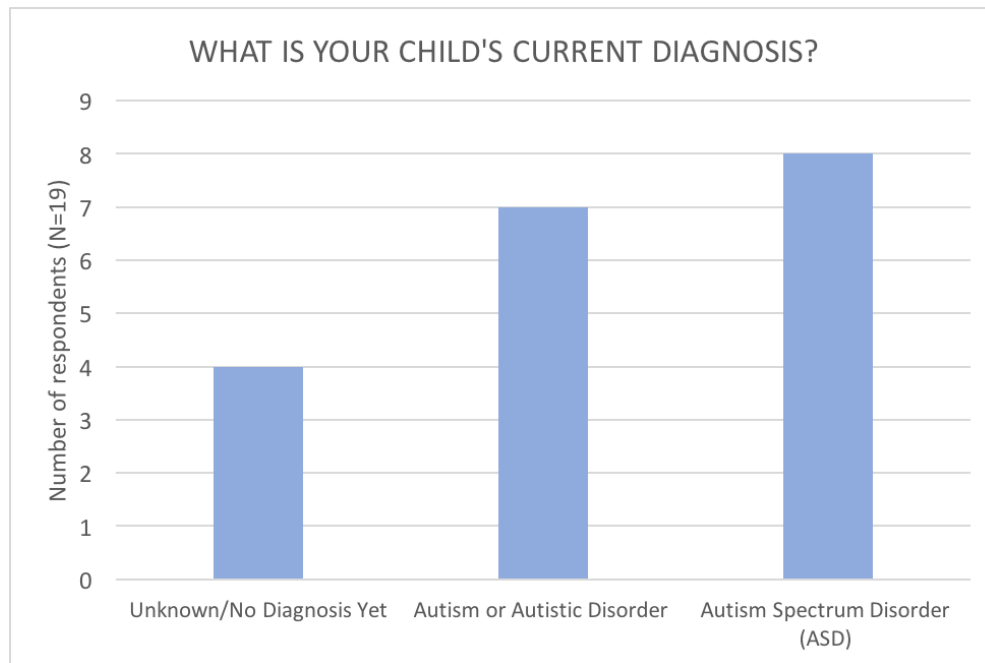


Figure A1: Distribution within our urban sample of each child's current diagnosis

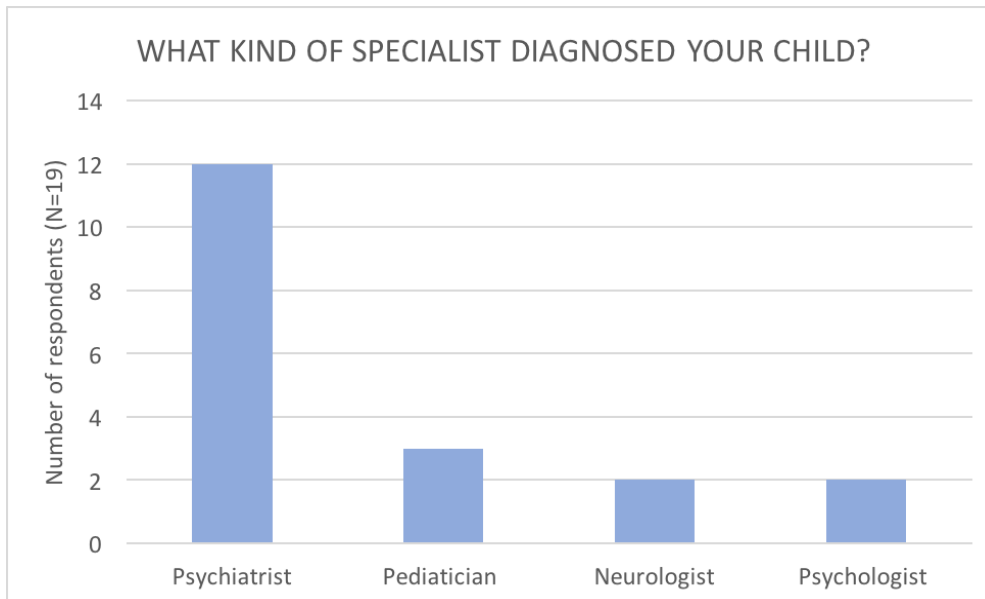


Figure A2: Distribution within our urban sample of what specialist diagnosed gave the diagnosis found in Figure A1

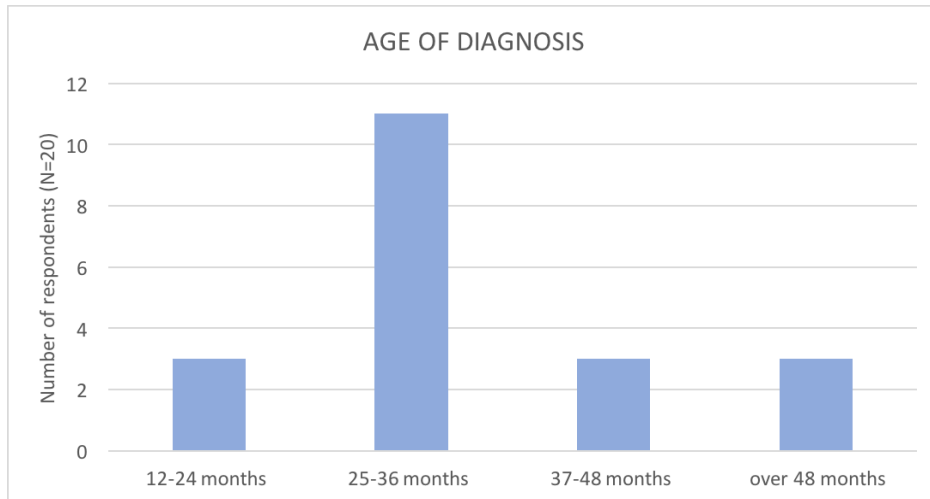


Figure A3: Distribution within our urban sample of what age children received their current diagnosis

Parent's Highest Education Level

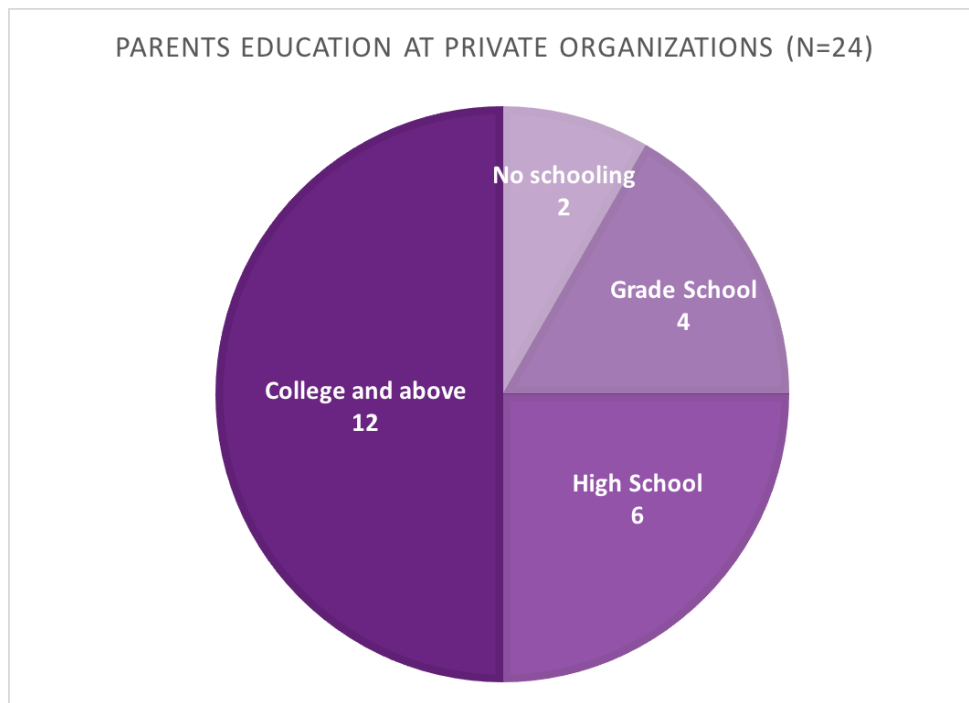


Figure A4: Highest level of education parents received within our private organization sample

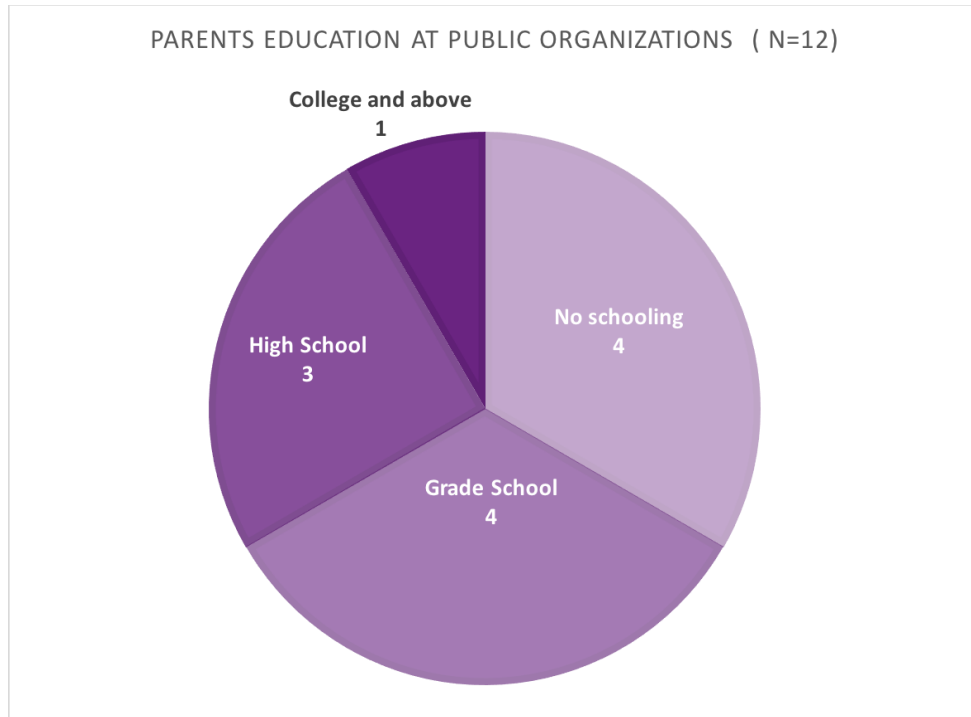


Figure A5: Highest level of education parents received within our public organization sample

Families Participating in Autism

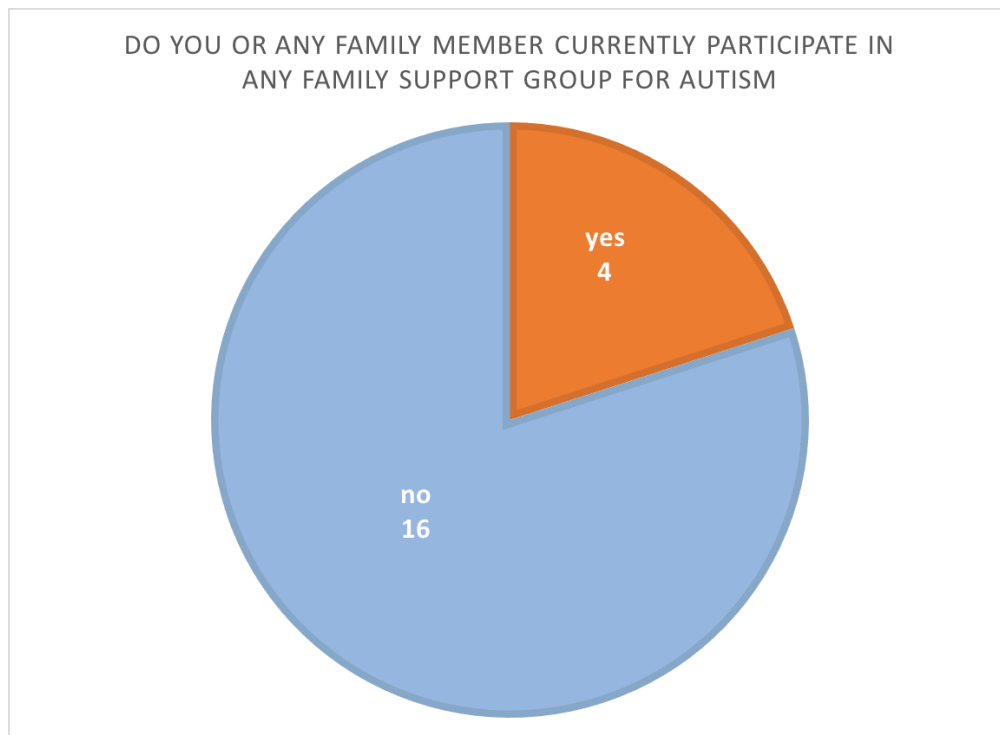


Figure A6: Number of families who participate in a support group for autism

Appendix F: Caregiver Supplementary Information Raw Coding Results

<u>Theme</u>	<u>Supporting Examples</u>	<u>Number of Occurrences</u>
“Normal” vs “Autistic”	The mother thinks the child is normal but the doctors tell her that they autism	
	A mother has twins with autism and the doctors tell her one is normal and the other has autism	
	The mother believes that the child has autism based on her internet research, but the doctors say the child is normal	
Pride	Mother feels proud of the child for the progress they have made	
	Mother feels pride with her child because the child was God’s will and she has been working toward a better life	
Regret	The mother regrets not going to school before she had the child	
	The mother is sad that she had to stop working in order to support her child	
In-home support	Maintaining educational progress within the home and outside of school is important	
	It is most helpful to work with and support the child at home, not just in school	
	Parents can facilitate lot of the necessary training to help children integrate into society at home	
	“Home life is the most important thing”	3 instances
	Mother claims that she saw the greatest amount of improvement in her child through working with them at home	

Proper age for treatment	The child was too young to diagnose when they were 9 months old	
	The child's young age (2 years) made finding treatment difficult	
	Attempting to find treatment while the child is young will cut down on the amount of delay the family experiences	
	Specialists prioritize younger children for treatment	
	Mother testifies that her child began receiving treatment at 18 months old and no longer had autism at 6 years old	
Understanding of autism	One child's doctor did not understand autism enough to diagnose the child. Instead, the doctor said the child has "a little disability"	
	The child's mother is the only person to understands their disability well	3 instances
	Doctors do not provide any official document with a diagnosis	
	The mother is expected to always be with the child because she is the only one who understands them	
	The public does not understand autism	2 instances
	The father cannot control the child	
	"Autism is just being discovered in Morocco"	2 instances
Problems acquiring services	Long waiting lists before organizations can accept families	4 instances
	Difficulties with traveling in order to acquire and maintain continual access to services	3 instances
	Financial issues affording services	5 instances
	Families do not receive any governmental assistance finding or paying for treatment	
	Mother did not know and could not find the exact kind of treatment her child needed	

	Family could not find any schools or hospitals that specialize in autism treatment	
	Mother spent a lot of time doing research and trying to find information about available services	
	“There are no special education services in Morocco other than (the organization this family belongs to)”	
	Waitlists are especially a problem in public facilities	
Aggression of children with autism	Mother of twins says the boy is more aggressive than the girl	
	Mother says that her child is very aggressive	
	Aggressive children do not make friends	
	One mother says that her child with slight autism is not aggressive	
Family attitudes	Family disapproved of the child with autism	
	Family stopped talking to the mother	3 instances
	Family did not offer any help to the mother or child	3 instances
	Family does not know how to deal with a child with autism	
Autism in public and private schools	School rejected the child for their behavior (i.e. not talking or aggression)	2 instances
	School rejected the child because the child had autism	2 instances
	Parents had to hire a private educator to keep their child enrolled in traditional school	
Discrimination	People in public push the child away from them	
	Parents locked child in a room to minimize interaction	
	Bus driver accused a mother of having a disabled child on purpose	
Most common places of support outside of NGOs	Advice from other families of children with autism	8 instances
	Internet	4 instances

	WhatsApp	2 instances
Miscellaneous	Acceptance of the child's condition	
	Lack of time to care for child	3 instances
	Career change in order to find treatment	3 instances

Appendix G: Profession Interview Raw Coding Results

<u>Major theme</u>	<u>Subtheme</u>	<u>Supporting Examples</u>
Availability of resources	<i>Training services offered</i>	Specialists
		Auditory training
		Psychologists
		Musician
		Painter
		Social activities
		Sports
	<i>Services for families per month</i>	Depends on family
		Military governmental help
		Government funding
		Pay nothing
	<i>Payment plans for low income families</i>	Yes
	<i>Share information about autism</i>	Meetings
		Classes to learn how to deal with children
	<i>Information available to families at AMAL</i>	Sometimes join training classes
		Internet
		Facebook
		Word of mouth
	<i>Information Free?</i>	Depends
Understanding Autism in Morocco	<i>Personal and professional knowledge on autism</i>	Internet
		Not really know
		Didn't understand
		Effort for knowledge

		Not known before
		Knows definition
		Special care
		Methods required for each child
	<i>How autism diagnosed, classified</i>	Go to psychologist/psychiatrist before training
		Many cases
		Special case, mental illness
		Advanced mental illness
	<i>Disagree with diagnosis</i>	Parents don't accept
		Don't directly say, mostly all parents
		Not accept her disability
Autism Treatment	<i>Priority, Younger children</i>	Learn faster
		Younger, special training
		Younger quicker to learn
		Doesn't influence organization
		Young kids learn write and read and older learn new functions like art and sports
		Educators believe both have special needs and physical age does not equal brain
	<i>Influences for treatment</i>	Psychologist main contact. Figure out needs
		Psychologist helps with needs
		Every child can't take treatment
		Parents and home environment
		THEY want to help
	<i>Older kids</i>	(15-18)
		Desires for future, job and family = not easy
Support in the home	<i>Education</i>	More important with professionals, disagrees
		Desire to improve, powerful, benefit to educator
		Importance of homework and education important, need same level
		Self-expression, art and communication, environment changing, adapting, how to make friends
		Older kids desire for family, job

	<i>Supplementary information (Older Kids)</i>	Explaining realities = hard environment
		Society = not easy
		Teachers teaching that
	<i>Value of home support</i>	Parents need to listen to advice, apply at home, training at the center, seriously
		Update knowledge on what to do
		Know needs, research, condition update, contact professionals
	<i>Home</i>	Lots of improvements
		Importance of education
		Job educated people = not east
		Ignore and neglate child's talents
		Don't prioritize homework. Not serious
	<i>Education background and satisfaction with services</i>	Less education =more support more education =less support, working, less time to dedicate to kid
		Parents satisfied
		Level of education influences child support
		Research = improvements
		Books on autism, share information on autism with organization
		Few show desire
		No relation, satisfaction, improvements shown