State of Autism in Morocco:

Gaining a better insight through data collection and analysis

By: Albert J. Languet IV, Allysa Grant, Abdelrahman Sirry, Alvaro Galindo

Faculty Advisors: Dr. Ingrid Shockey and Dr. Gbeton Sommasse

Sponsor: Autism Speaks

Submission Date: October 13th, 2016

Abstract

The situation of diagnoses, treatments, and education for autistic children in Morocco is unknown. The goal of our project is to provide our sponsor, Autism Speaks, with a report documenting the experiences for families of autistic children in Morocco. In order to achieve this goal, we conducted surveys and interviews of people affected by autism and created a database system. Our results indicate a range of access to resources, networks, trained medical professionals, education, and basic services available to families.

Executive Summary

Autism is one of the most complex and misunderstood mental disabilities in the world today. The treatment and diagnosis of autistic people, as well as education about autism spectrum disorder, are processes in Morocco that require major improvement and attention. As a result, autistic people in Morocco do not have access to the resources that they need and have a right to. There has not been much research done regarding how this disorder is affecting children in the country of Morocco. Given the current lack of research, our project was important because it allowed us to contribute by collecting data about the autistic population in Morocco, making us more familiar with the problem, while assisting future studies with data that we were unable to find. Through our project, were also able to extend understanding of the issues that autistic people struggle with every day in Morocco. Lastly, our research also allowed us to determine improvements that could be made to treatments for children in need. We also determined the qualifications of doctors in the public health sector diagnosing children with this disorder, as well as what treatments are required for autistic children. Our research enabled us to raise awareness about autism spectrum disorder in Morocco and draw the attention of the Moroccan authorities to the issues that need to be addressed.

Current state of Autism in Morocco

The literature revealed autism to be a complex illness that affects people in different ways. Through our research, we were able to determine the most effective treatments and services for autistic people. According to the CDC, Applied Behavior Analysis (ABA) is one of the most effective treatments. Other successful types of treatments have included Floortime, Treatment and Education of Autistic and related Communication-handicapped Children, occupational therapy, sensory integration therapy, speech therapy, and The Picture Exchange Communication System (PECS). Many autistic people are also advised to see a neurologist or gastroenterologist.

We know that education and resource leverage can come from strong networks of concerned stakeholders, so we wanted to know what networks existed for autism awareness and treatment. For the most part, our research indicated that online resources, websites, and communities for autistic people were the most popular. We also found communities where professionals connect and share information to be very common. Additionally, we found a number of centers with online resources that provide access to schooling, trainings, other services, as well as information collected on a database system.

Since autism in Morocco is an issue that was not discussed prior to the past 10 years, it is difficult to find statistical data. Autism Speaks celebrated its 10th year in Morocco this year. While they have announced that they have reached tremendous development in improving the social lives of autistic children, their website could provide statistical data of the achieved goals with our help. It would be beneficial to see how these various private and public interventions have influenced autistic children in a country with one of the highest autistic populations.

In the case of autism in Morocco, it is not only hard to find clear case studies , but also the evidence we found contradicts each other. This demonstrates an incentive for the Moroccan population to initiate projects such as ours, in order to finally provide viable information that will help to raise awareness regarding autism.

In sum, there are a few key points that we identified to support our work in Morocco. Firstly, Morocco faces a crisis in diagnostic services, treatments, and education. In addition to this, we were able to conclude that there needs to be a set of reliable data collected in order to lead to an understanding of autistic people and what they need in order to better their treatment, diagnosis, education, and support.

Methodology

Our goal for this project was to provide Autism Speaks with a report of statistical and ethnographic/anecdotal data on the current state, problems, and needs for families with autistic children in Morocco. Our objectives and strategies were as follows:

Objectives	Strategies
Conduct a quantitative assessment of a sample of families with autistic children	Identify sites of interest and sample participants, conduct surveys with translators, design a database
Evaluate the perspectives of experts and professionals	Conduct both online and paper surveys at agencies
Collect personal stories that reflect challenges that families with autistic children face	Gather open-ended responses during surveying, interview book author

Figure 1: Centers visited in Ouarzazate & Skoura.

Results and Analysis

The results from our survey and interviews for Autism Speaks yielded considerable data about the state of Autism in Morocco. This data is showed and explained according to the response of the families and our own interpretations based on our previous knowledge about the state of autism in Morocco as well as what we have experienced while interviewing families in different cities in the Kingdom of Morocco. Education, basic rights, and health care are the three greatest challenges in getting support for autistic children. They require a better quality of education, despite that most of the parents interviewed are happy with services provided by the school that their children are currently enrolled in. But as discussed before, their happiness is due to the fact that the education is free, and not because they are receiving the right education that will improve their children's social skills. Autistic children need more social rights, such as laws that help prevent discrimination and provide discounts for public services, such as trams or busses. Lastly, they need to be provided more specialists trained and experienced. Most Moroccan families will have to drive long distances, as well as being waitlisted, before seeing a doctor that is a specialized in working with autistic children.

The data generated by our study presents a dire situation for families and caregivers living with autistic children in Morocco. The trends clearly point to deficiencies in resources and networks, a lack of available trained medical professionals, virtually no consistent educational strategies, and poor basic services for these families. Moreover, in-depth discussions and interactions with our respondents reveals the extent to which families suffer profoundly in their daily lives as they struggle to make ends meet and simply provide a safe environment for their children. We were struck by dismal ratings in certain domains that could be addressed with modern intervention and programming that is available for autistic people elsewhere in the world.

We were also struck by the extraordinary efforts of individuals that have sacrificed their own resources to help individuals with autism. This includes a family who started a center for children with disabilities in Ouarzazate to which they donated the bottom of their house, as well as a couple of sisters in Casablanca that opened a school for autistic children. This also includes the parents who traveled long distances to meet us and share their stories with us. Another great example is Autism Speaks, which works to make the lives of autistic people better every day through research and other tools that it provides.

Recommendations

After analyzing all of the data collected in our database system, we generated the following suggestions:

- Connect sister associations in different cities by sharing information and benefits
- Through the internet and conventions, create a network that connects people to services and resources for autistic people
- Organize autism awareness and fundraising campaigns for teachers
- Organize autism awareness campaigns for the general public in order to reduce stigma
- Organize campaigns for autistic people to make public transportation services accessible to autistic people
- Initiate Co-Ops or similar projects for psychology students to collaborate with organizations for school credit in this area of expertise

- Annual conferences where professionals can interact and discuss the subject matter

We believe that implementing the above recommendations would greatly improve the conditions for autistic people and their families in Morocco. Although there are already a number of successful schools, centers, and associations for children with disabilities established in Morocco, we believe that the above recommendations are important steps that will aid in the autistic population achieving decent living standards that are in accordance with the law.

Acknowledgements

We are greatly thankful for all of the support from sponsor, Autism Speaks, who provided us assistance and guidance throughout this 7-week project. We also need to thank the American Moroccan Competencies Network (AMCN) and the “Ministère chargé des Marocains Résident à l’Etranger”. We are also grateful to our advisors, Dr. Ingrid Shockey and Dr. Gbetonmasse Somasse, for providing us with insightful guidance throughout the term. Finally, we are forever grateful for the various associations and centers for children with disabilities, as well as the families and professionals who participated in our surveying and interviewing process.

Authorship

Our report was completed with the combined effort of team members Allysa Grant, Albert Languet, Alvaro Galindo, and Abdelrahman Sirry. Each section of the report was written and reviewed equally by all four members of the team. The Abstract, Executive Summary, Acknowledgements, Authorship, List of Tables, List of Figures, Table of Contents, Introduction, Literature Review, Project Outcomes, and Works Cited were revised and edited in depth by Alvaro Galindo and Allysa Grant. The Methodology, Findings and Discussion, and Appendices were revised and edited in depth by Abdelrahman Sirry and Albert Languet.

Table of Contents

List of Figures

List of Tables

Chapter 1: Introduction

Autism is one of the most complex and misunderstood mental disabilities. While diagnoses and treatments can help, awareness can be a very beneficial factor since it is the first step to identifying and allocating resources. In Morocco, a small group of researchers and educators are trying to make progress. We collaborated with the non-governmental organization Autism Speaks. Following their direction, our mission was to obtain a better understanding of the current state of treatment, diagnosis, and education available to the autistic population of Morocco.

We explored a number of key issues, including the kinds of daily struggles faced by autism sufferers and their families. Second, we wanted to know the degree of knowledge about autism spectrum disorder in Morocco. Finally, we wanted to assess the kinds resources available to facilitate better diagnosis and education of autism. There is little research regarding how this disorder is affecting children in the country. Official and accurate data reporting the population of diagnosed children with autism spectrum disorder has not yet been released to the general public. As of now, the current treatments available are varied and are often available through specialized associations who limit their capacity. We hope that this project will enable an understanding of the perceptions and awareness shared through the families that experienced their autistic children's treatment and diagnosis processes. This was made possible through an extensive survey, interviews with professionals, and the collected stories shared by some families to show the everyday struggles of parents and caregivers. The data from our study was added to a database as a repository for future research and resource development.

Chapter 2: Literature Review

Autism is a misunderstood disorder worldwide, and resources available to families vary widely. This chapter presents a deeper context for understanding the awareness and the treatment of autism, and the efforts to address this concern across the world.

Stakeholders

Misconceptions about the reality of autism spectrum disorder (ASD) may vary across different cultures. At this time, ASD is defined as a "group of developmental disabilities that can cause significant social, communication and behavioral challenges" in an individual (CDC, 2016). However, this remains unclear to many people as they continue to misdiagnose children who require specific types of treatments in order to accommodate for their disabilities.

This disorder is "estimated global prevalence was 1 in 166 in the year 2005. Today it is listed as 1 in 68 – an increase of more than 100% in one decade" (Autism Speaks). Individuals suffering from autism face obstacles that inhibit their acceptance as citizens. For this reason, occupational and social skills therapy has been implemented for Moroccan autistic people.

In Morocco, it is estimated that over 200,000 children suffer from autism. Furthermore, Morocco leads other North African countries with a 10.5% rate of communication disorders, among them speech disorders according to E-Science central organization (Sabir, 2015). Autism was not a recognized problem in Morocco until 2005, due to the lack of professionals working with this type of disability.

Historical context for ASD awareness in Morocco

The first study that examined autism in Morocco took place in 2006 by the Virtual British Academy (Shabib, 2006). Its main objective was to study the behavior of a random sample of autistic children. The study also compared the current autistic population to that of the previous generations. It was shown that autism in Morocco had increased by 13.43%. As this study was one of the first conducted in Morocco, it did not really have any history of treatment to refer to, however, the researchers were able to introduce the problem to the Moroccan society and show the need for specialists working with this kind of disability. They also cooperated with international autism organizations, such as Autism Speaks and Autism Spectrum, in order to compare the data they have collected with the world mean average.

In 2008, Dr. Fakri F. Chzal collaborated on an experiment testing communication and language skills for over 500 children in Morocco. He states, “it is estimated that 5.62% of the Moroccan population are affected with speech disorders, 1.74% are unable to communicate in writing, 1.17% are disabled, 1.09% are affected with ENT disorders, and 0.81% have neurological disorders” (Sabir, 2015). These large numbers make it clear that we need to raise awareness so that the overall majority of the population is more aware of the problem. Going beyond raising awareness, we need to evaluate the problem in order to create an efficient solution to help autistic children develop their social and language skills.

In 2013, King Mohammed VI of Morocco organized the first international conference attended by all autism organizations in Morocco, as his government recognized the importance of the problem and the increasing number of autistic children. In this meeting, Autism Speaks announced positive improvement in the cases they have been working on. They also asserted that the Moroccan population has become more aware with the recognition of the problem, as well as become less violent towards autistic children.

In contrast, another study from early 2015 suggested that the rate of autism in Morocco has not been improving (Sabir, 2015). The study interviewed speech language therapists to collect data about autistic children’s improvement, as well as the therapist's approach to solving problems that autism presents. The study mainly focused on Rabat and Casablanca, although it failed to reach therapists in other regions. This study's results showed that Morocco, after 10 years of government and private sector involvement, remains the country with the highest percentage of autism of the North African countries.

Another compounding issue associated with autism in Morocco is the violence from and towards autistic children. The Academic Military Psychiatric Unit in Ibn Sina Hospital in Morocco sponsored research that examined autistic children’s behavior towards others (Touhami, Ouriaghli, Manoudi, & Asri, 2011). This showed that 40% of the autistic population experience behavioral problems, such as violence. Men are also 30% more likely to have a behavioral problem than women. The Academic Military explained that these violent behaviors are mainly present because the autistic population feels unwanted and unrecognized by the overall majority of the population. However, this is also as a result of violence experienced by them from the community. Autistic people generally experience violence toward them since society is often incapable of understanding how to best treat children misbehaving in such extreme ways.

Since autism in Morocco is an issue that was not discussed prior to the past 10 years, it is difficult to find statistical data. However, we can say that there has been a strong presence by international organizations such as UNICEF, INSAR, Autism Speaks, and CARE. These organizations have been working around the globe with autistic children. Autism Speaks celebrated its 10th year in Morocco this year. While they have announced that they have reached tremendous development in improving the social lives of autistic children, their website could show more could provide statistical data of the achieved goals with our help. It would be beneficial to see how these various private and public interventions have influenced autistic children in a country with one of the highest autistic populations.

In the case of autism in Morocco, it is not only hard to find clear case studies, but also the evidence we found contradicts each other. This demonstrates an incentive for the Morocco to initiate projects such as ours, in order to finally provide viable information that will help to raise awareness regarding autism.

Agents of change

Autism Speaks is a non-profit organization based in the United States and dedicated to support for autistic families since 2005. It was founded by Bob and Suzanne Wright, who were themselves the grandparents of an autistic child. They wanted a better understanding of the cause of the disorder and how to better educate others about this topic. A $25 million donation, helped fund the first steps of the organization, with a strong mission is to change the future for all who struggle with an autism spectrum disorder. They do this by funding global biomedical research for the causes, prevention, treatments and a possible cure for autism. They also raise awareness by bringing the autism community together as one strong voice to urge the government and private sector to listen to address this urgent global health crisis (Autism Speaks). Their success is recognized worldwide because of their accomplishments in raising awareness and their distinctive fundraisers with the capacity to help and make noticeable changes for the better.

Since 2005, Autism Speaks has grown tremendously. It supports research teams that travel to different parts of the world and evaluate the factors that can cause autism (genetic predisposition, environmental triggers, geography, and so forth). Just within the United States, Autism Speaks has developed an interactive map that shows all of the resources available to families with autistic children in each state. They have also implemented an entity called the Autism Response Team (ART), which helps to connect autistic individuals, their families, and their caregivers to information, tools, and resources. Families are connected to local Early Intervention Services, allowing them to make extraordinary development during early childhood phases. The services provided are cost effective, as they reduce the need for educational and behavioral support in grade school and beyond.

Autism Speaks developed one of the first programming data collection programs called Autistic Self-Advocacy Network, focused on helping autistic people to advocate on their own behalf. The goal of the Autistic Self-Advocacy Network is to ensure that autistic people receive the same rights and opportunities as everyone else, while empowering them to have a presence in society. The Autistic Self-Advocacy Network initiates "public policy advocacy, the development of Autistic cultural activities, and leadership trainings for Autistic self-advocates". It also "provide[s] information about autism, disability rights, and systems change to the public through a number of different educational, cultural, and advocacy related projects" (About, 2016).

Building support

We know that education and resource leverage can come from strong networks of concerned stakeholders, so we wanted to know what networks existed for autism awareness and treatment. For the most part, our research indicated that online resources, websites, and communities for autistic people were the most popular. Autism Speaks provides excellent lists on its website (Websites, 2016). We also found communities where professionals connect and share information to be very common. One example of a well-known online community is Network Autism, which is sponsored by The National Autistic Society (Network, 2016). Additionally, we found a number of centers with online resources that provide access to schooling, trainings, other services, as well as information collected on a database system. The National Autism Center's website is one of these mentioned above (About NAC, 2016). Below is the list of all agencies that are currently operating in Morocco in support of autism care and education:

Table 1: Member organizations of the Moroccan Association of Autistic Children

Organization Number	Organization name	Location
1	Toyor Al Gana Organization	Tangier
2	Yahia Organization	Tangier
3	Abaa w Atfal Organization	Tetouan
4	Al Hanan organization	Tetouan
5	Farah Organization	Oujda
6	Garada w Bourkan Organization	Wajda
7	Taweert Organization	Figuig
8	Maraa Organization	Fes
9	Autisme 2005 Organization	Meknes
10	Al Ghad Organization	Taza
11	Al Tahady Organization	Rabat-Sale
12	Al Mobadara Organization	Knefifra
13	Idmaj Al Tawahod	Casablanca
14	Malak Orgization	Casablanca
15	Al Amal Organization	Casablanca
16	Autisma Organization	Marrakesh
17	Tefl Al Tawahod Organization	Marrakesh
18	Ibni Organization	Agadir
19	Al Tahady Organization	Ouarzazate
20	Al Tahady Organization	Tiznit

All of these organizations are currently functioning as separate entities to provide services in distinct areas of the country. Furthermore, this has created a sort of rivalry among the ones located on the same town or city. This leads to disputes within a community fighting for one same purpose.

Government Involvement

The case for autism is gradually gaining the support it demands from the government and authorities. The current monarchy ruled by King Mohamed VI has been showing interest from the state to help this cause. A series of major reforms were applied since he ascended to the throne in 1999. These reforms have enlarged the legal space for civil society, expanding its rights as well as its role in policymaking and the public sphere. As a result of the more enabling legal environment, Moroccan civil society has undergone substantial development. To help support autism on January 27 of this year, the House of Representatives adopted Draft Law No. 64.14 on presenting legislative motions, and Draft Law No. 44.14 on submitting petitions to public authorities. The draft laws are designed to implement Article 139 of Morocco's Constitution, which gives associations the right to present motions and petitions at the local and provincial level (ICNL, 2016). This means any NGO could start operations to favor the participation of the citizens and of the associations in the enactment and the application of the programs of development.

On the other hand, the involvement of the government and authorities in Morocco's situation could be improved. Autism is rarely mentioned in the press and mass media networks, with the exception of a number of articles published annually on World Autism Awareness Day, which takes place on April 2nd each year (Morocco, 2016). Furthermore, there were no public or private structures established in Morocco to care for autistic children until 2002 (**Shabib, 2006**). The government system in Rabat is newly acquainted with the idea of autism and has not been able to accommodate for autistic people prior to this time. There is a shortage of qualified personnel working in this field, which could be addressed by the training and certification of qualified persons. Medical expenses for autistic children also rely fully on the family's budget. Some medical treatments can be expensive, making it inaccessible for marginalized communities or low-income families. The care in this country can be over 5000 Dirham (Moroccan currency, equal to about 500 US dollars) per month (Morocco, 2016). In Morocco, increasing urbanization is concentrating more on the population around the major cities, causing rural areas to lack in some public services. Between the money needed for treatment and the transportation needed to reach those in the more developed cities, it becomes very difficult for families to access what their children need. In 2014, the Global Autism Summit was held in Rabat, where the Vice President of Autism Speaks, Dr. Andy Shih, actively participated by praying for the assistance of the government, policy-makers, and professional community (Morocco, 2014). The Moroccan government has not been completely present to address the need on raising awareness and receiving support from the community in order to ultimately improve conditions for autistic people and their families.

Morocco could use the same initiatives implemented in other countries more informed of the issue that autistic people face. For instance, research on the many different aspects of autism is now being conducted by the Moroccan government (Purdy, 2008). With this information, the government will be able to fully comprehend autistic people, their cognitive behavior, and determine what they require as treatment and support. In addition to this, the National Institute of Health now provides guidelines for evaluation and treatment of autistic people (Braus, 2014). Finally, there are bills regarding autism that have more recently been enacted (Purdy, 2008). All of these establish an ideal situation for autistic people, through exemplary proper treatment, diagnosis, and education.

Best Practices for Autism Care

Through our research, we were able to determine the most effective treatments and services for autistic people according to the CDC, Applied Behavior Analysis (ABA) is one of the most effective treatments. There are a number of different types of ABA, which include Discrete Trial Training, Early Intensive Behavioral Intervention, Pivotal Response Training (PRT), and Verbal Behavior Intervention. Other successful types of treatments have included Floortime, Treatment and Education of Autistic and related Communication-handicapped Children, occupational therapy, sensory integration therapy, speech therapy, and The Picture Exchange Communication System (PECS) (Autism, 2016). Among the scientific community studying this mental disorder, these practices have proven to enhance motor skills, social skills, and cognitive ability. This is the reason why most current psychologists use these techniques to prepare individuals as functioning human beings for the future. Many autistic people are also advised to see a neurologist or gastroenterologist (Treatments, 2016). We also evaluated a case study that determined the top eight therapies for autistic children, as reported by their parents. The top eight therapies were ranked as the following: 1-Occupational therapy (39%) 2-Speech therapy (27%) 3-ABA Therapy (15%) 4-Social skills classes (8%) 5-Hippotherrapy (2%) 6-Gluten free, dairy free diet (2%) 7-Psychiatrist/Psychologist sessions (2%) 8-Floortime, RDI, PECS, PRT, swimming (a four-way tie, all having 1%). Some other therapies that received less than 1% of mentions are the following: mainstream schooling, iPad usage, vision therapy, aqua therapy, vitamin supplements, chelation, and the use of hyperbaric chambers (Top, 2016). The results of this case study shows us that the vast majority of people being affected by an autistic person worry the most for their own independence, communication, and behavior around others. We can also deduct that there is a wide variety of practices not linked to a doctor that parents have found to be useful for their children.

Summary

In sum, there are a few key points that we identified to support our work in Morocco. Firstly, Morocco faces a challenge in diagnostic services, treatments, and educational opportunities for families supporting autistic children. In addition to this, we were able to conclude that there could be more reliable data collected in order to lead to an understanding of autistic people and what they need in order to better their treatment, diagnosis, education, and support.

Chapter 3: Methodology

Our goal for this project was to provide Autism Speaks with a report of statistical and anecdotal data on the current state, problems, and needs for families with autistic children in Morocco. Our objectives were as follows:

1. Conduct a quantitative assessment of a sample of families with autistic children
2. Evaluate the perspectives of experts and agencies
3. Collect personal stories that reflect challenges that families with autistic children face

This chapter details the methods and strategies we used to gather data.

Objective 1: Conduct a quantitative assessment of a sample of families with autistic children

We conducted a detailed survey of parents of autistic children for Autism Speaks. The survey contained 5 sections with 61 questions covering parental educational level, diagnosis of the child, age when the symptoms were first noticed by the parents, schooling, academic supports, specialists working with the child, number of hours of social training, stigma, challenges, and priorities. The surveys took place at Al Amal School in Casablanca, Al Amal Center in Casablanca, Ibtissama Center in Ouarzazate, and the Cultural Center in the town of Skoura. We used a sample of convenience to identify families with autistic children, based on connections leveraged by these schools and centers. As most of our team does not speak the native language Darija or French, we were assisted in all interviews with translators that spoke Arabic, French, and English. These translators helped to deliver the data from families to the interviewer. The data was collected through two different formats: online and on paper. The online data was submitted directly through Google Forms, while the hard copies were completed before uploading them to our online database through Google Forms later on. A map of centers and our interview sites can be seen below in figure 1.

Figure 2: Map of autism centers in Morocco (Sirry, 2016)

<u>Objective 2:</u> Evaluate the perspectives of experts and professionals

In order to better understand the perspectives of experts and professionals, we interviewed a small sample of volunteers using a sample of convenience and snowball samples to identify participants. The professionals completed a survey designed to ask about their education level, the nature of their job and the number of autistic children they give their attention to. The survey also asked them about their qualifications, their degree and whether they are open to take additional classes in their career. In addition to the interviews, we were able to visit the schools and assess their facilities. We observed classrooms, teaching materials, resources and recreational areas.

<u>Objective 3:</u> Collect personal stories that reflect challenges that families with autistic children face

In order to collect personal stories from parents, we gathered open-ended responses during the surveying process in order to gain a better understanding of the experiences that families with autistic children face on a daily basis.

We interviewed Oum Kalthoum Dialmy, “parole d’autisme” book author, using an open-ended interview strategy. With the help of Dr. Tahar El Korchi, we were able to get in contact with Oum Kalthoum Dialmy and set up an appointment with her to talk about her book, as well as her experiences. Unfortunately, we were in Ouarzazate conducting family interviews when the interview with this author took place. As a result, other fellow students working with us and Autism Speaks in this same project conducted this interview. While speaking with her she discussed the reasons why she wrote the book and what challenges are Moroccan families with an autistic child regularly facing.

Additionally, we met with two coordinators from two autism centers, Mme. Touria Mabrok in Casablanca and Mme. Fatima Al Zahraa in Ouarzazate. They both shared the stories that inspired them to open centers. They also shared the benefits, the challenges, and priorities that they encounter on daily basis. A detailed description of the interview will be discussed in Chapter 4.

Finally, at the end of each survey, we asked families to share their personal stories with us. These stories reflect the day-to-day challenges that these families encounter. These stories were collected with participant permission, although remaining anonymous, and can be found in Part 3 of our findings.

Data Management and Sampling Strategy

Our sponsor, Autism Speaks, works with multiple organizations specialized in autism in the Kingdom of Morocco. We used this connection to contact families that have a child with autism enrolled in their organization. In nearby cities, such as Casablanca and Jadida, we cooperated with two organizations where they asked for volunteers who would like to take the survey. When we arrived at each of the centers, there were families waiting to be interviewed. We had at least four interviewers, so we were able to have four interviews every thirty minutes. The number of interviewed families was not always determined prior to our arrival. Since we commuted from Rabat, it was easy for us to visit the school in Casablanca every time the president of the school provided us with a number of families that were ready to take the survey.

Figure 3: The school for autistic children in Casablanca where we conducted interviews of both families and professionals (Grant, 2016).

In Ouarzazate and Skoura however, the situation was very different. Since these two cities were farther away from Rabat, all interviews had to take place in four days while we were in the south of Morocco. Autism Speaks reached out to the different organizations and cooperated with them to set up four days of interviewing. From August 21st until the first interview date on September 22nd, these organizations reached out to every family in their files to ask for volunteers for the survey.

The last step before starting our project was to determine the sample population that we needed to interview in order to have an appropriate representative number of the Moroccan population. In order to determine this population, we had to contribute a statistical analysis in order to give a correct estimation. We ended up with a sample of 183 families who participated in the survey, which was largely a sample of convenience.

Chapter 4. Findings and Discussion

The results from our survey and interviews for Autism Speaks yielded considerable data about the state of autism in Morocco. Here we present the findings by objective.

Objective 1. The survey for families and caregivers

The survey prompted parents about diagnosis, services, sources of information, challenges, and priorities. We interviewed families in the cities of Casablanca, Taroudant, Agadir, Biougra, Ouarzazate, Skoura and Tiznit. The interviews in Casablanca were completed at a school for autistic children called Amal School for Disabled Children. In Tiznit, another team collaborating with Autism Speaks conducted interviews at the Association of Nore for Autistic Children, while the interviews in Ouarzazate and Skoura took place at the Ibtisama Organization for Disabled Children and The Skoura Community Center. Lastly, at the three cities of Agadir, Biougra and Taroudant they went to smaller associations. From our sample, 95% of the participants preferred to be interviewed by students instead of filling the survey themselves. Interviews were held in cooperation with English, Arabic Darija, and French language translators who read, translated, and helped to record all interaction between the participants and the team. We analyzed the results of our survey and divided it into ten main sections: demographics, characteristics of the children, services and treatments, first diagnosis and schooling, family training and government help, source of information, access and unmet needs, family impact, stigma, and challenges. We also organized our data into three different groups based on the samples interviewed: First, the overall sample of participants interviewed. Second, the sample of participants with children specifically diagnosed with autism. Third, the sample of participants with undiagnosed children, children diagnosed with other mental disabilities, and children with unknown mental disabilities. The figure below shows the demographics of the different locations where the interviews took place:

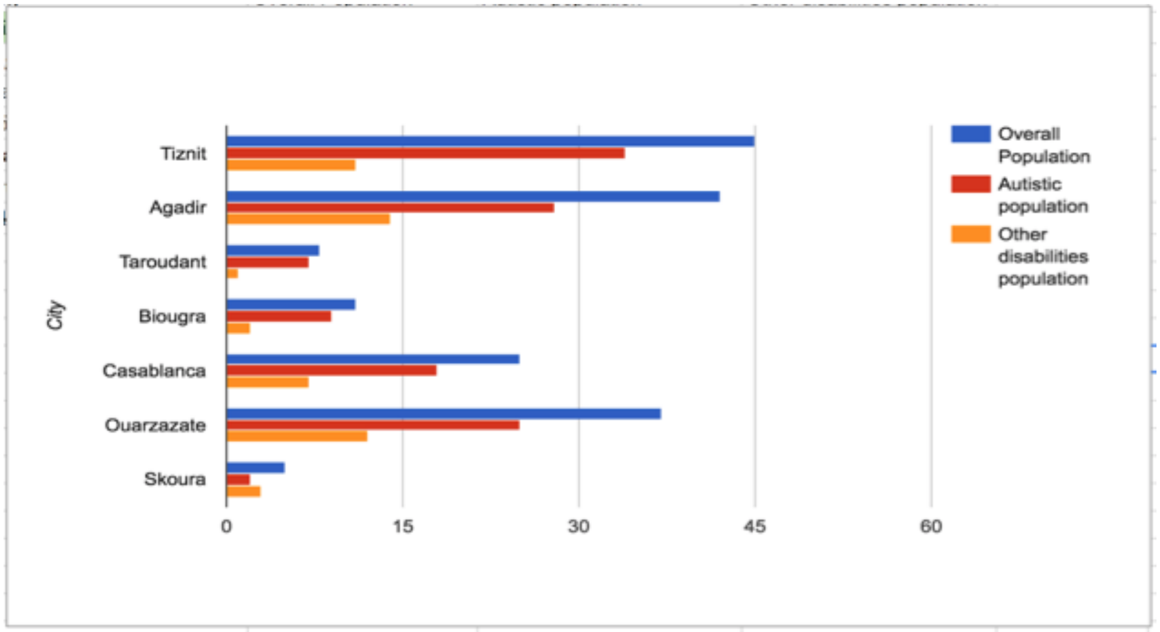

Figure 4: Participants of our survey, organized by city

Demographic characteristics

We began our survey by obtaining basic information about the families with autistic children. The first questions in the survey asked about education, relationship, gender of the child, and so forth. We interviewed 82 mothers and 48 fathers. The chart below describes the varying level of education amongst those who participated. Using the chart, and considering the ratio of fathers with respect to mothers who participated, we can infer that the fathers of the children tended to have a higher education. One father had an education level higher than a college degree. Among the parents who received no schooling the mothers have fallen into this category more frequently than the other four choices.

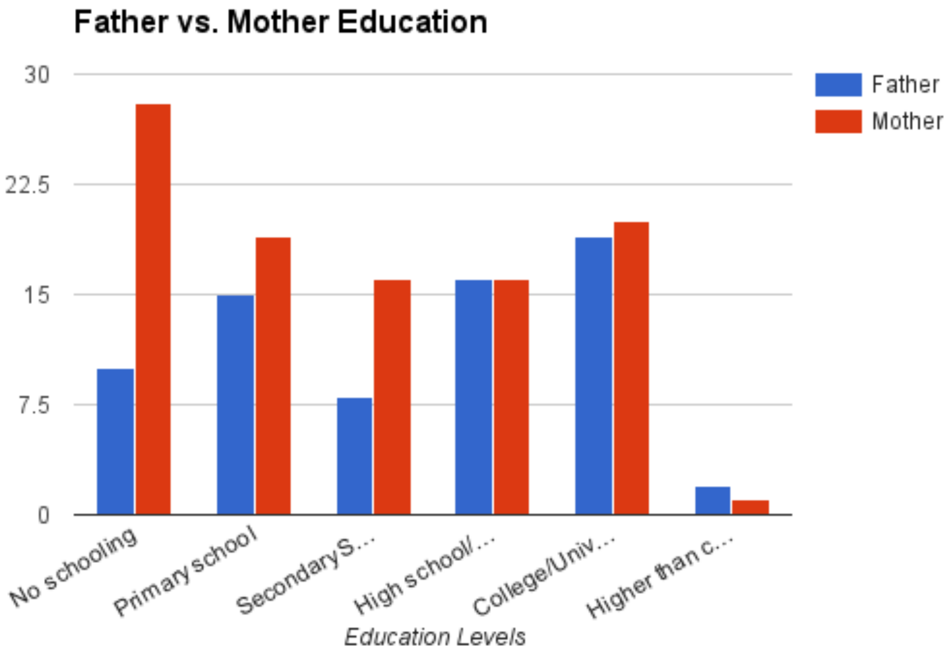

Figure 5: Educational level of interviewed sample

Characteristic of the diagnosis

Questions about accurate diagnosis of affected children indicated a broad set of complications. These findings are presented below in Figure 6. The data suggest that 39.1% of the families interviewed have a child diagnosed with autism or autistic disorder, 17.4% do not have a diagnosis for their child, and 14.7% have a child with another mental disability.

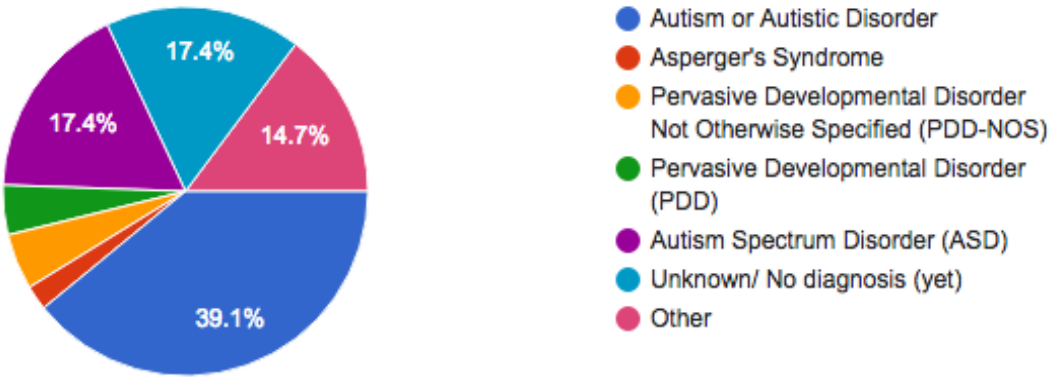

Figure 6: Diagnoses received

Our data shows that 74% of the autistic children of the survey participants are male. Looking below at the histogram (Figure 7), we can see that the ages range from 0 to 33 years old. Most of the participants' children, however, are between the ages of 3 and 12 years old.

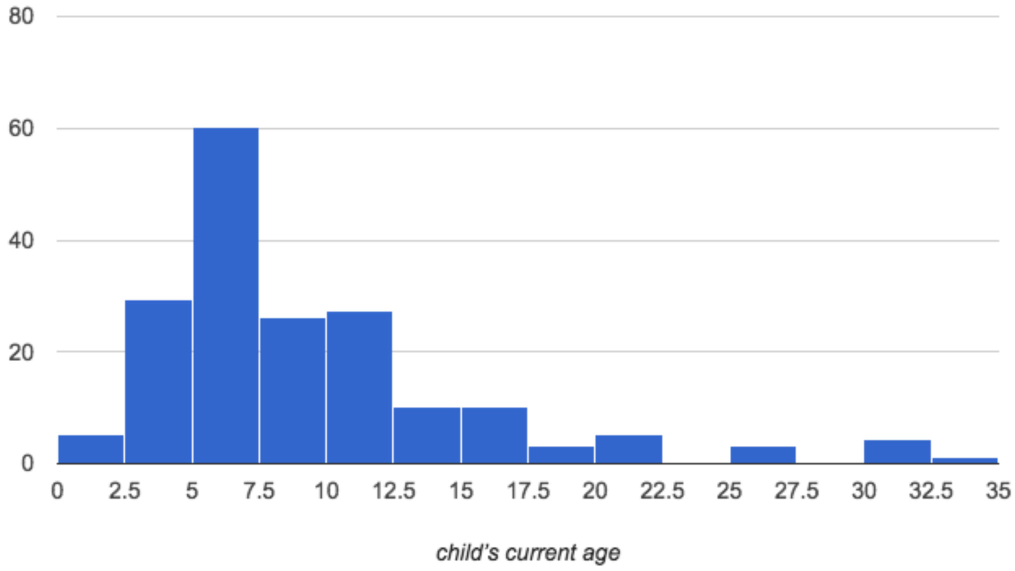

Figure 7: The ages of the children of the interviewed sample

When asked about the verbal ability of their child, most parents said that their child does not talk (33.7%) or only speaks single words (34.8%). Others reported that their child initially spoke and then regressed to non-verbal at a young age.

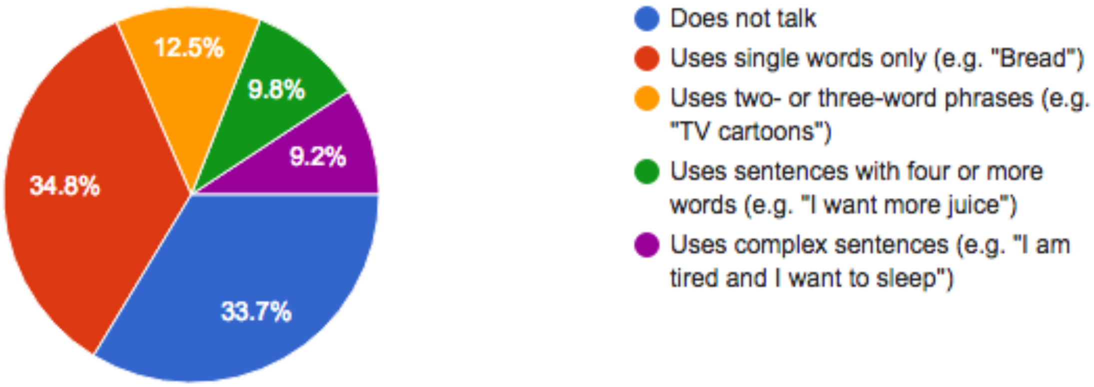

Figure 8: Speech ability of interviewed overall sample

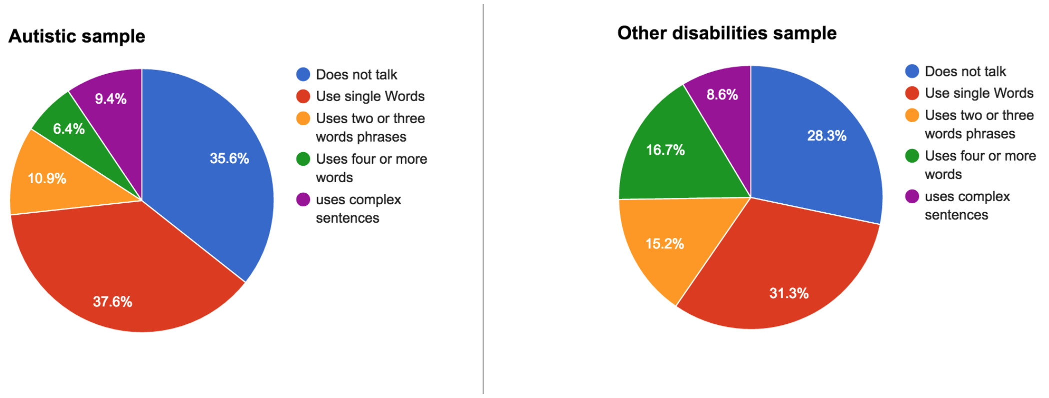

Figure 9: Speech ability of interviewed autistic sample and other/unknown diagnosis sample

From the Figures 8 and 9, we can observe that the results are similar for the autistic, non-autistic, and overall population. Most of the interviewed sample does not talk or only uses single words (68% overall, 70% autistic, and 58% other disabilities). These results reflect reports from parents indicating language therapy as one of the most-wanted therapies for their children. In Figure 10, we see that language therapy is the most common training for children with disabilities, while Table 5 demonstrates that communication difficulties is the third most common challenge for the overall population.

The next observations that we made were regarding the first time that the families had noticed something concerning about their child. The median of the range of when they had first recognized that there was an issue with their child was 24 months. Although this seems somewhat delayed, it is actually quite common for children with autism to get diagnosed at this age.

The age of diagnosis ranged from 0 to 19 years (228 months). Here, we found the median to be 36 months, with the first quartile being 18 and the third being 48. This shows us that most parents were able to get their children diagnosed within the first four years of their lives. Their diagnosis appeared to be given about an entire year after the parents had first something wrong though. There were more outliers in this data set as well; using the upper fence rule, we were able to determine the 10 outliers.

When families were able to receive a comprehensive diagnosis, it was typically from a pediatrician (32%). Some parents felt that the diagnosis from a pediatrician could have been incorrect, while some parents reported that pediatricians seem to simply diagnose most mental disabilities as autism. The question that addressed this allowed multiple responses; with that said, some parents reported having sought out other doctors in order to receive a better diagnosis for their child. Even though, the results still show that a pediatrician is the most common doctor visited for diagnosing purposes.

First diagnosis and schooling

As education plays a pivotal role in any mentally disabled child, we asked families about the schooling status of their children. The family's responses demonstrated the struggle of enrolling their children in a public primary school, since only 8% of the overall population and 4.8% of the autistic population is enrolled in a public school. Most children are enrolled in a special school for children with disabilities (42.3% Overall and 48% Autistic). The percentage of un-enrolled children in the overall population is higher than that of the autistic population. This indicates that children with other mental disabilities have greater chances of not attending school. The overall percentage those un-enrolled in school is 27.7%; the percentage of autistic children un-enrolled in school is 22.6%. This can be seen in Figure 8 and Figure 8.1. After that, we asked those enrolled in school if they receive any additional academic help. The responses of the overall population were, for the most part, negative. 81% claimed that they are not receiving any additional academic help; additionally, 82% of the autistic population claims that they do not receive any academic help. This can be seen in Figure 10 and Figure 11.

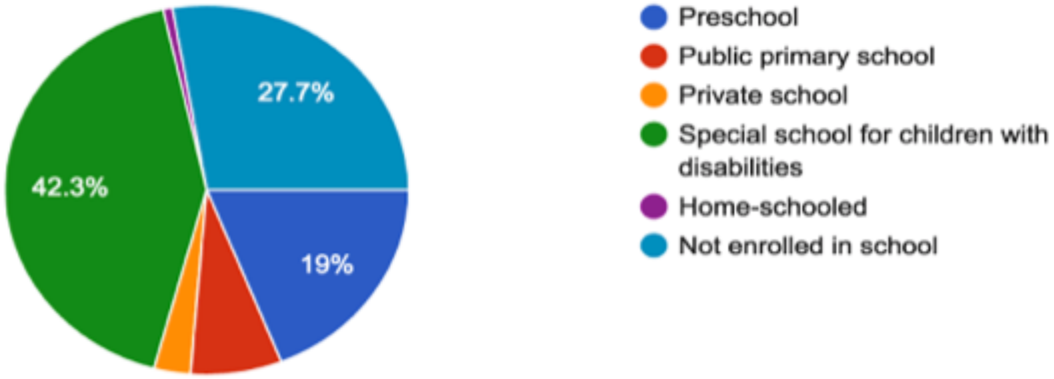

Figure 10: Current schooling for children of interviewed sample

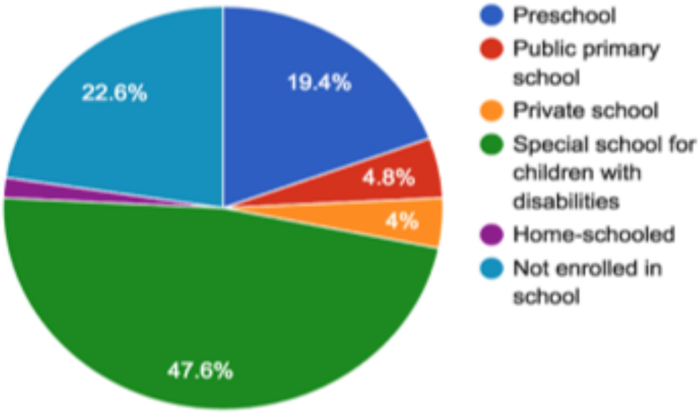

Figure 11: Current schooling for autistic children of interviewed sample

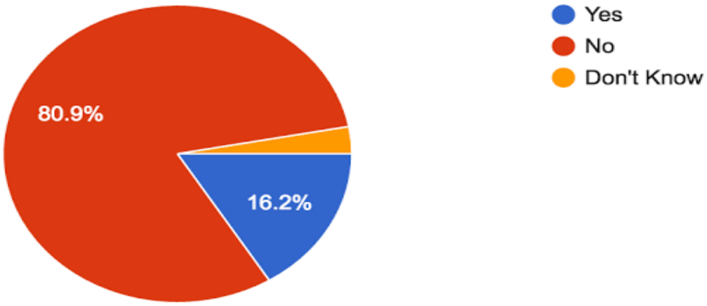

Figure 12: Percentage of overall children receiving additional academic support

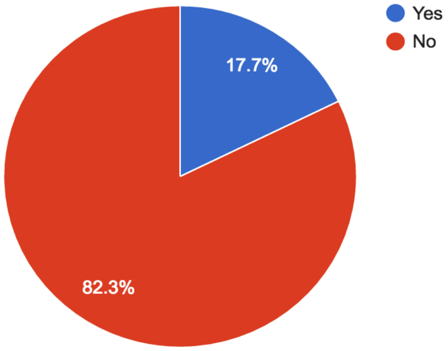

Figure 13: Percentage of autistic children receiving additional academic support

Services and treatment

In terms of services and treatments that were given to families, we asked how long families traveled to seek help for their children. 33.5% of families had to travel more than 2 hours to seek help for their children. As the data shows, there are not a lot of professionals spread throughout the country for diagnosing autism (see Table 2 below).

Table 2: Amount of time traveled by interviewed sample to obtain diagnosis

	Percentage		
Time	Overall Sample	Autistic Sample	Other Disabilities
Less than 30 minutes traveling	21.4%	24%	15.3%
Between 30 minutes to 1 hour	16%	16%	17%
Between 1-2 hours	18.7%	20.8%	13.6%
More than 2 hours	33.5%	36%	27.11%
I traveled outside the country	1.6%	1.6%	1.7%
Not Applicable	8.8%	1.6%	25.4%

Out of the ten most common treatments for autism, most families reported that their autistic children do not receive any of the following services: Behavioral intervention or modification (e.g. ABA), sensory integration therapy, cognitive based therapy, occupational therapy, physical therapy, social skills training, speech or language therapy, pharmacotherapy/medication. The figure below shows that most parents do not have access to any services or treatments for their children:

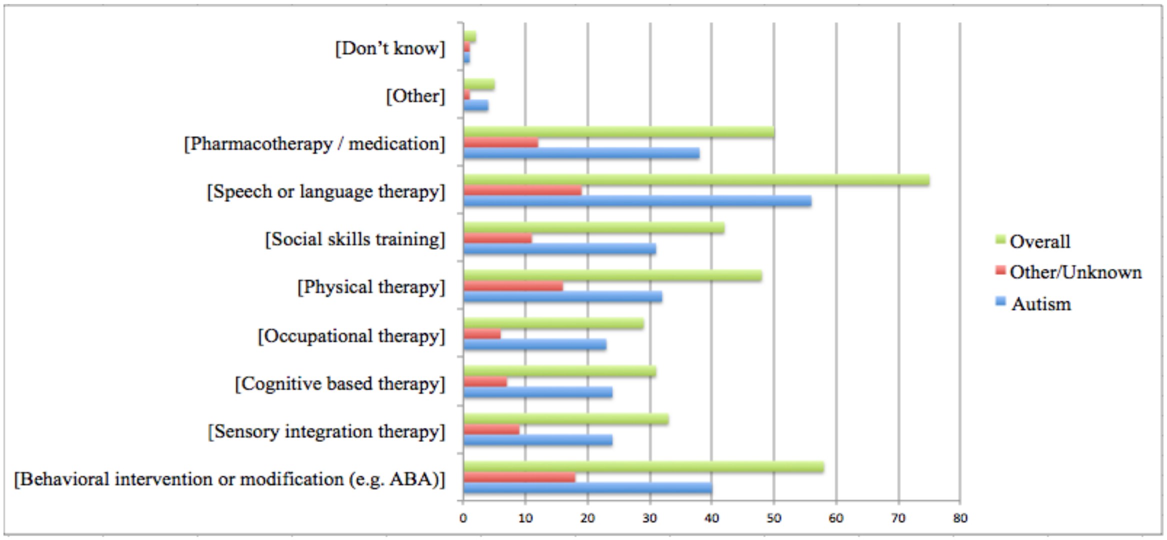

Figure 14: Ten most commonly used treatments for three sample populations

The survey also asked families to provide us with a list of specialists or doctors that are currently working with their children. The overall access to specialists is still very low (about 40% of the overall population currently does not see a doctor in any specialization). The table below provides the reported specialists currently working with the interviewed sample of autistic children:

Table 3: Reported specialists working with the interviewed sample's children (percentages based on total number of respondents)

Sample	Overall Sample		Autistic Sample		Other and Unknown Sample	
Professional	Number of Patients	Percentage	Number of Patients	Percentage	Number of Patients	Percentage
Psychiatrist	62	46.2%	49	17.5%	14	15.2%
Developmental pediatrician	66	49.2%	50	17.8%	12	13.04%
None	53	40.2%	24	8.5%	26	28.4%
Neurologist	45	33.3%	36	12.8%	7	7.6%
Audiologist	39	29.8%	32	11.4%	7	7.6%
Behaviorist	39	28.8%	30	10.7%	7	7.6%
Education Specialist	35	25.8%	24	8.57%	10	11%
Psychologist	28	21.2%	24	8.57%	5	5.5%
Other	16	11.4%	2	0.71%	1	1.1%
Nutritionist	12	8.3%	9	3.2%	3	3.3%

Family training and governmental help

The survey asked whether the families receive any training in order to help care for children with autism. 82% of families do not receive any additional training to address their child's needs. Additionally, they do not receive any help or discounts from the government. Some families pay additional fees for public transportation services if their children are handicapped and need accommodations. For these reasons, most families do not participate in any family support or autism advocacy groups because they cannot afford the time, the money, and the effort.

Source of information

With regards to obtaining information about their children's health, only 34% of the participants reported that they have direct contact with a specialist, while 62% rely on the internet, 17.7% rely on recommendations from their children's teachers, and most others use recommendations from parents that they trust. We also interviewed many families who never received any kind of advice from a specialist, teacher, recommender, or even the internet. These families rely on their own experience, based on their children's behavior in similar previous situations. The table below shows these different sources of information that families rely on.

Table 4: Primary sources of information for parents of the overall sample

Source of information	Number of participant	Percentage (%)
Internet	93	59.6%
Doctors	86	55.1%
Other parents	58	37.2%
Teachers	38	24.4%
Health specialist	36	23.1%
Other	32	20.5%
None or their own experience	30	19.3%

Life skills and activities

When it comes to daily life skills and activities, 44% of autistic children in this study do participate in daily family activities, such as washing dishes and food preparation. This percentage drops to 39% when it comes to outdoor activities, such as using public transportation, going to the nearest religious center, or visiting families. Families reported that they would not allow their children to go outside, even if they could. Thus, it is more a matter of security rather than the ability of the child that limits these outdoors activities. On the other hand, 90% of interviewed sample does not participate in any social activities, such as swimming lessons or soccer clubs. This is mainly because parents reported that they weren't able to afford these extracurricular activities. However, we interviewed one parent whose child was able to win a gold medal in a national 100-meter dash. The other 10% who practice sports outside of school usually practice soccer (known as football in Morocco) due to its popularity in this region of the globe.

Access and unmet needs

As discussed in the methodology chapter, one of the main objectives asked by our sponsor was to identify the family's priorities that need to be focused on when cooperating with the Moroccan government and other Moroccan organizations. For these reasons, in section four of the survey, we asked families about the difficulties encountered over the past years. These difficulties included financial problems, accessing services and information, and being wait-listed for specialists working in the field of autism. It turned out that 20% of those interviewed did not have any delays accessing services for their children, including access to medications, doctor appointments, or specialists working in that field within a short travelling distance. However, 74% of families with autistic children reported difficulties accessing information, due to the lack of specialists and valuable online resources, in addition to long waitlists on doctor's schedules. However, the biggest challenges encountered by most families with autistic children are cost-related problems. Out of the interviewed sample, 85% agreed that they could not fulfill their children's needs because they could not afford these services. One mother reported in an open discussion after the interview:

> My husband died and he was the only financial support of the family. Now, I do a morning job only 9 months per year while my son is at school. I had no qualification so I had to work as a servant to clean people's house. I get 600 Dirhams monthly so I cannot afford any of the medication that he needs, and even when I can, I get waitlisted sometimes up to six months to see a doctor. Services in my country are really awful. (Casablanca, 28 Aug. 2016).

Figure 15 below summarizes the responses we received when we asked families if they experienced difficulties as a result of not being eligible for services, a lack of services in their area, problems getting appointments or accessing information, or cost:

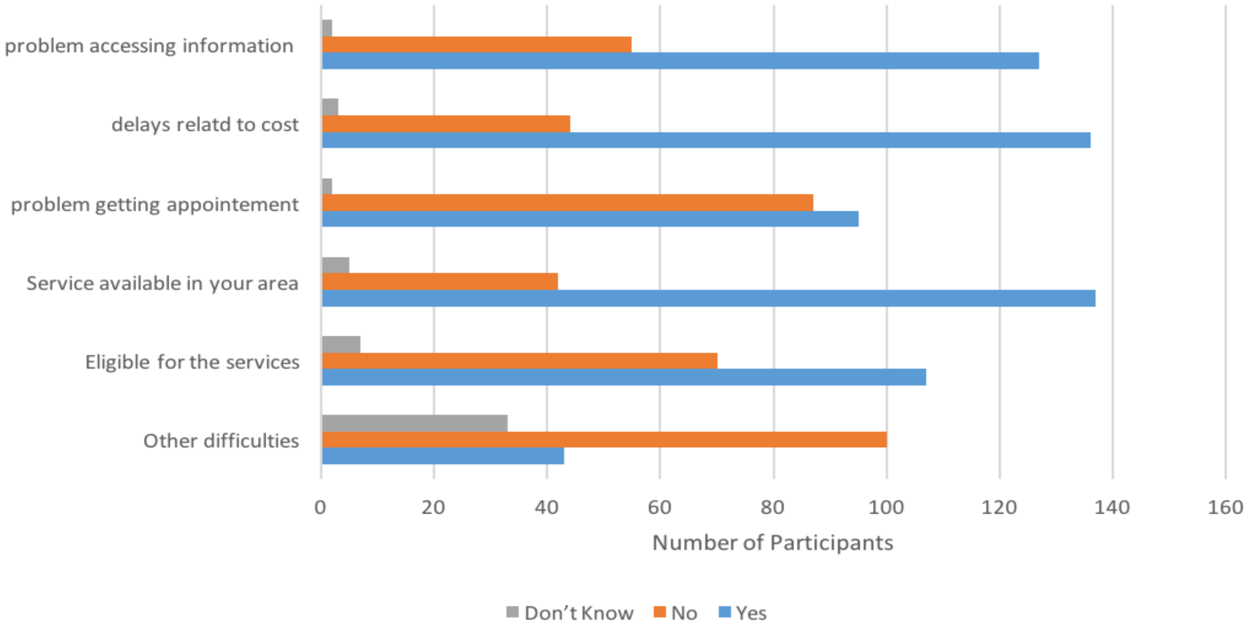

Figure 15: Difficulties experienced by all families

Throughout the interviews, we asked about the different difficulties experienced. In order to get an overall estimation of the number of families experiencing difficulties related to any of the above reasons, we asked the following question: In general, do you experience daily difficulties as a result of your autistic child? The results are shown in the figure below:

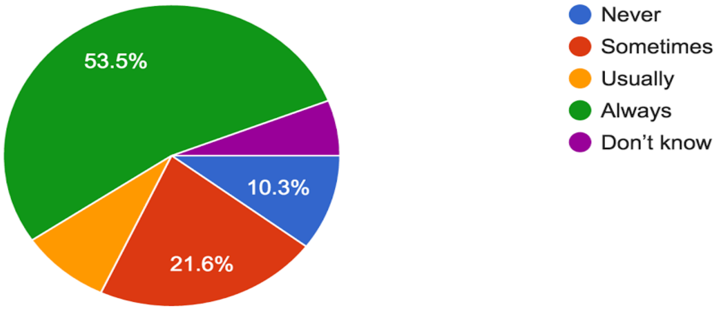

Figure 16: Efforts to get services for all families

Caregiver/Family impact

This portion of the survey was developed to understand the impacts of having an autistic child in a family. About 71% of our sample experienced financial problems because of their disabled child. In fact, 23% stopped working in order to spend time trying to improve their child's current diagnosis (See Appendix A, table 14). In our post-survey interview in Casablanca, one parent reported that he lost his engineering job due to the number of days off that he had to take in order to drive his son to the doctor, travel to diagnose his son, or even spend some time trying to work on improving his son's social interaction skills. He also reported that he is not getting any help from the government, including any discounts or services for children with disabilities.

We also asked if families have had to cut back on work hours because of their children, but most parents said that they did not simply because their employer would not allow it. They were forced to decide either to work full-time or to leave their jobs, and most of them decided to quit.

Stigma

Through our surveying, it has been made clear to us that there is a stigma of autistic people. We were able to determine this after taking note of the discontent of the families, the general public's lack of awareness on the subject matter, and others' disinterest in presenting services to autistic individuals by cooperating with effective partners. Participants expressed their frustration towards how their autistic relatives are deemed unfit for society in many cases and are quickly dismissed by others. Families worry deeply about the manner in which their children are acknowledged, getting furious when they are not treated as functioning humans who deserve proper treatment and understanding. Autistic people face challenges everyday and are being denied what is necessary in order for them to have better lives, directly impacting society's perceptions of the autistic population. A climate of more compassion for families and caregivers of individuals with various disabilities should be generated to generate an impact on this stigma.

The survey prompted parents about their experiences as the parent of an autistic child in a country where awareness of the problem is low. From the family's responses, 47% of parents said that they felt helpless, while half of this group was asked if they worry if other people know that they have an autistic child. Some caregivers said that they fought with other people because of their attitude towards their autistic child, usually while using public transportation. Additionally, 57% of families reported that they were, at least once, discriminated against because they have an autistic child. This discrimination was mainly in regards to job positions for the autistic child's parent. More than 90% of families reported that they are happy with the school that their child is enrolled in. However, when we asked the families to explain, none mentioned the improvement of their child; in contrast, they explained that it is a free school that takes care of the children and provides them with the chance to interact with other autistic children and adults. Thus, the reason for satisfaction is not really the quality of the school, nor their children's improvement, but rather the free education and social interaction that their children receive in school.

Challenges

At the end of the survey, we asked families about the challenges that they encounter and the main priorities for their children. We asked them three different questions, which all required them to choose their top three responses among a list of options. The questions, followed by the results, can be seen in Table 5, Table 6, and Table 7:

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.

Table 5: Challenges faced by families with mentally disabled children (care)

Population	Overall Population		Autistic Population	
Challenges	Number of Participant	Percentage (%)	Number of Participant	Percentage (%)
Safety concerns (i.e. wandering, climbing)	79	45.1%	61	16.5%
Challenging behaviors (i.e. self-injury, aggression, tantrums)	73	41.7%	51	13.95%
Daily living skills (i.e. toileting, self-feeding)	71	40.6%	47	12.8%
Communication difficulties	71	40.6%	52	14.2%
Social interaction difficulties	70	40%	43	11.7%
Health problems (i.e. co-occurring physical and/or mental health conditions)	37	21.1%	25	6.8%
Sleep problems (i.e. trouble falling asleep, trouble staying asleep)	36	20.6%	28	7.6%
Diet/eating/feeding difficulties	27	15.4%	20	5.4%
Repetitive behaviors/restrictive interests/insistence on sameness	26	14.9%	22	6.0%
Other	12	6.9%	14	3.8%
Sensory issues	4	0.3%	4	1.1%

What are the greatest challenges you face in getting support for your child?

Table 6: Challenges faced by families with mentally disabled children (support)

Population	Overall Population		Autistic Population	
Challenges in getting support	Number of Participant	Percentage (%)	Number of Participant	Percentage (%)
Making sure my child receives adequate education	133	76.4%	97	78.9%
Making sure my child receives adequate health care	112	64.4%	82	66.7%
Making sure my child's basic rights are protected	104	61%	85	69.1%
Making sure my child receives adequate welfare / social supports	88	50.6%	62	50.4%
Making sure my family and I receive adequate respite	48	27.6%	41	33.3%
Other	15	8.6%	3	2.4%

What you consider to be the greatest priorities for families affected by autism in your country?

Table 7: Top priorities for families with mentally disabled children

Population	Overall Population		Autistic Population	
Priorities	Number of Participant	Percentage (%)	Number of Participant	Percentage (%)
Improved education services	102	57.6%	74	20.8
Improved health care services	89	50.3%	61	17.1
Greater rights for individuals with autism	87	49.2%	74	20.8
Greater community awareness	66	37.3%	51	14.3
Improved welfare / social services	62	35%	38	10.7
More information about autism	36	20.3%	22	6.2
Greater in-home support	30	16.9%	17	4.8
Greater opportunities for parent interactions / networking	20	11.3%	14	3.9
Other	16	9%	5	1.4

Objective 2: The survey for medical professionals, experts, teachers, and assistants

The first set of professional surveys was done on September 5th, 2016 in Casablanca at the first school we visited (Amal School for Disabled Children). We had the professionals complete the paper surveys on their own. We believe that allowing the professionals to complete the surveys alone was an error on our part. We should have taken the time to go through the survey with each professional because there were some questions on the survey where the professionals got confused and, sometimes, simply did not answer. Consequently, we cannot draw any final conclusions based on the professional survey. The findings below are on a much lower confidence level than those of the family survey.

Demographics of participants

From our small sample of professionals, we were able to see that most of those interviewed had attended a vocational school to earn a degree (7 professionals). Only one person had a high school level degree, and the remaining professionals (5) had gotten their degree from a university. All of the professionals at the school were educators with varying titles, primarily ABA. The professionals at the school have experience of about 7.5 years on average, with two outliers having 21 years of experience in the field.

Expertise of participants

In order to obtain a good understanding of treatments being used for autistic children in Morocco, we have to know the qualifications and experience of the professionals, as well as the number of students that are supervised by each professional. Our interviewed sample of professionals was really small, and we believe that no conclusions or interpretations should be drawn on this sample population. However, we still want to give an estimation on what the data could indicate. We first asked professionals about the kind of disability that they are qualified to work with. 62% of the interviewed sample is qualified to work with mentally retarded children, a syndrome professionally known as trisomy 21. Only 43.8% are qualified to work with autistic children or children with Asperger syndrome. Only a small percentage is qualified to work with those who are physically handicapped, while 50% of the professionals chose “other” as their response without specifying what other qualifications they have. Their class sizes vary depending on the levels of professionals working with them.

Most of the interviewed professionals reported having ten students in classes involving sports, music, and drawing. The classes involving numbers and letters are generally smaller, since these require more attention for every child. Overall, the average class size varies between 2-10 students per class. At the school where the survey took place, the ages of students varies a great deal. The age varies between 3 and 25 years old. While talking to Khadija Bariki, the vice president of the Amal school, we learned that professionals tend to focus on children between the ages of 6 and 15 so that later on they can be enrolled in a normal public school. While the success of this enrollment is difficult, Khadija reported that the school had been successful in doing so for two autistic children. Adults (ages 15 and older) usually get more attention for the developing of social, drawing, sports, and musical skills since their chances of enrolling into a public school are so extremely low.

We also asked the professionals about the speaking abilities of students. Generally, 60% of students at the Amal school do not speak at all, while another 30-35% speak one or two words maximum (for example, “Bottle water” or “Dad shoes”). The other 5% use complex words and are able to get their point across. According to the vice president of the school, these 5% usually spend more time in the classroom in order to be able to enroll in public school; but again, the success percentage is very low.

Professional affiliation

This portion of the professional survey focused on the type of environment that the professionals work in and how they interact with both parents and autistic children. A full percentage of our professional sample interviewed reported that they work in the education sector. A majority of them (61.5%) work at a special school for disabled children. Of the professionals interviewed, 81.8% are employed as individual educators, working with only 1 or 2 students at a time. We asked the professionals if they used any of the following methods when working with autistic children, and to what extent they had been educated on them: behavioral intervention (ABA), TEACCH, Response Processing Pivot, Floortime, PECS. A larger percentage said that they were trained in and used ABA, which was also available to autistic children at the schools where they worked. Most families have to pay for this treatment completely on their own. Most of the professionals agreed that their main source of information about autism was simply the internet, rather than a more reliable source, such as doctors, other teachers, other professionals, etc. 85.7% of this sample indicated that they strongly needed training in the field of autism. The majority of these professionals reported communication and TEACCH trainings as their highest need. Professionals receive questions from parents primarily about health problems, sleep disorders, social interaction difficulties, and school/problems at school.

Professional perceptions

The last part of the professional survey pertained to the issues that professionals face when working with autistic children. When surveying our professionals, we found that the only high percentage of difficulties that they experienced with obtaining services for autistic children were related to costs. 40% reported that they experienced difficulties or delays due to cost-related problems. 87.6% of the professionals interviewed said that they sometimes experience frustration in view of their efforts to provide services for autistic children. Also, 53.8% of the sample interviewed said that other people tend to discriminate against them because they work with people with autism. A majority of the professionals agreed that autistic children need support in order to make progress at school (57.1%), in order to make friends (78.6%), and that families should have a good relationship with the service providers who work with their children (73.3%). We asked the professionals what they saw as the biggest challenges in regards to the education of children with autism. Most said autonomy of daily living (64.3%), health problems (50%), and language/communication difficulties (42.9%). We also wanted to know what the professionals considered to be the top priorities for families affected by autism. We discovered the top three priorities to be improved healthcare services (84.6%), improved education services (61.5%), and improved welfare/social services (77%).

Objective 3. Personal stories from the field

The survey provided us with information about diagnoses, doctors, accessibility, and sources of information. In order to learn more about the day-to-day struggles, we asked the interviewed families to share some of their stories with us at the end of each survey. We interacted with dozens of families and listened to their personal stories of heartbreak or, in some cases, sheer willpower to find a way to help. Many families reported their frustration with the disregard they felt from medical professionals. Many families chose to be anonymous, but for those who did not, their names and profession will be indicated. Below are the highlights of the stories that we heard:

- **President of the Ibtisama Center**

Fatima El Zahra has a mentally retarded child, named Ahmed. As a doctor diagnosed him very early in his life, Fatima started to look for an organization, center, or a school for mentally disabled children in order to obtain education for her kid, gather information, and expose Ahmed to other children. Unfortunately, the nearest children's disability center was in Marrakesh, 300 kilometers away. Fatima added, "I was lucky to figure out my son's disability at an early age. When he reached the age of 9, I was ready with a plan". Fatima did not rely on services offered in her city, Ouarzazate, but rather she started thinking of initiating a new organization to educate children with all kinds of mental disabilities. She reached out too many international and local organizations in order to help her get in touch with professionals that could supervise her center. She proposed petitions to the Moroccan government, explaining how important the center would be for the city of Ouarzazate. Fatima did not only rely on federal and international aids; however, she compromised half of her actual house to be the campus for her newborn organization, "Ibtisama", which means "smile" in Arabic. After being open for five years, Ibtisama Center hosts 55 students with various mental disabilities. It offers services at a very low price to families that can afford it. If any family is unable to afford it, the center will offer the services for free. Ibtisama Center also offers free courses and trainings for parents of autistic children.

- **Extremely rare physical condition**

T.M. is the mother of two children who lives in Skoura, a small city next to Ouarzazate. Her daughter is 32 and her son is 22. The two siblings have an extremely rare condition, according to their mother. Neither of them have seen a doctor or specialist. They rely on medication that their parents can afford. Both siblings presented physiological deformities, with the son in particular suffering from spinal and neck problems. In addition, he only has 4 fingers on each foot. This extremely rare situation has nothing to do with autism, or at least, none of his physical condition is linked autism. An interesting point is that the mother did not see a doctor not because she doesn't want to, but because she said her son's situation is extremely hopeless and that she didn't want to travel a long distance and spend a lot of money that she can hardly afford. She and her husband agreed upon accepting what they call "God's will".

- **Memory problem**

M.B. lives in Ouarzazate and is the father of an autistic 9 years old boy. This case is incredibly rare since the boy can learn everything really fast, but has the capability of forgetting it right away. His father reported, it is "as if he has the memory of a fish". His father was the one who first noticed his child's symptoms. He said they were going down the mountain and the child did not see any obstacles on the way (for example, he would walk into a huge rock or a wall). He did not seem to understand the danger in what he was doing. On that day, he was hardly injured and later they found out that he was autistic. The boy learned how to read, however, he cannot read anymore. He used to be good in soccer, but he stopped playing it. His dad reported that he even used to talk and say simple words, such as "dad, mom, play or water", but also stopped. The father talked to a lot of specialists throughout Morocco. They proposed a lot of medications for his son. The mother is joining a training class to know how to deal with her son, however, nothing has changed. He keeps forgetting every talent that he once learned. His father said that they are travelling to Paris, France next month because they found a specialist who has experience in dealing this rare syndrome.

- **High cost of diagnosis**

F.K. is the mother of an autistic boy who is 6 years old. The story she shared with us is related to the extreme high cost and travel she has to do in order to see a doctor or a specialist working with autistic children. Her son, who doesn't talk at all, needs to see many specialists such as an audiologist, behaviorist, education specialist, psychiatrist and psychologist. She expects to spend about 20,000 MAD on doctors and travels per year, which is equivalent to $2000. She is always waitlisted for a long time in order to to get onto most doctors' schedules. She reported that sometimes she can be waitlisted for up to 1 year, with the visit to the doctor costing around 6,000 MAD and lasting for about 10-15 minutes. F.K. is thankful to the Ibstisama Association in Ouarzazate for the effort they make to educate her child; however, she needs a medical assistant in Ouarzazate which will, at least, save her the cost and the effort of travelling each time to Marrakesh, Casablanca, or Rabat in order to see a specialist. F.K. also reported: “I always think about people who cannot afford to make these travels and visits to doctors; in Ouarzazate, there are no specialist that works with these type of mental disabilities.”

- **Syndrome Hémolytique Urémique**

A.L. is the mother of an extremely rare case. Her son, who’s aged 3 years old was not born with any mental disabilities. However, at an early age, he had a virus called SHU, or Syndrome Hémolytique Urémique. This rare disease attacks kidneys and requires an immediate blood change. After many unsuccessful surgeries, the virus ended up in her son’s brain, which slowed his development and his ability to communicate. The women travelled to Paris, France with her husband. They have seen a doctor who performed another surgery on her son. The virus is not completely cured; however, there are a lot of signs of improvement. Her son still cannot communicate; but he recognizes his name and can walk a little. A.L. finds it hard to trust any recommendations from specialists in Morocco. Most specialists do not have experience with her son’s syndrome. She always has difficulty getting access to the medications she needs for her child. She reported that she relies on her friends and relatives who live in Europe to provide her with the necessary medications.

- **President of Al Tahady Organization**

M. El Hassan is an Arabic professor at a public high school in the city of Ouarzazate. He is the father of an autistic child who is 5 years old. He is also the cofounder of the most recent center specialized in autism in Ouarzazate. After realizing that all centers in Ouarzazate do not have any specialization in any mental disability, M. El Hassan thought of opening the first specialized center for autistic children in Ouarzazate, which would be the 23rd center specialized in autism in the Kingdom of Morocco. The center named “Challenge” or Tahady, is in its debut. After getting approved by the Cooperation of Autistic Organizations in Morocco, M. El Hassan requires all kinds of assistance in order to open his center. He reported that he requires financial help, but more importantly, professional volunteers that can help him begin operating the center at a low cost.

- **A disaster for the family**

X.T. is a mother who lives an extremely difficult life as a result of her son's disability. Her son is ten years old, with an unknown diagnosis. She first realized something different in her son at birth. Her son is unable to walk. She shared an extraordinary story with us during the interviewing process. She informed us that the child's father felt hopeless for the son and refused to pay one bit for the son's improvement. The father's family took their-14-year old daughter, preventing the mother from seeing her ever again. The father told her that she can keep her son because he does not want him. He is very rich and sends money to his own mother and sister, but none to her. The mother now lives in one, very small room. It floods in there when it rains outside and there are snakes and scorpions. There is no light in the room because she has been kicked out, while she has nowhere else to go. Once she went to her husband's house and he fought with her and said that she wasn't his wife. This woman also recounted having to carry her son up the mountain where she lived (in his wheelchair). This has resulted in back pains for the mother, since he is so heavy at this point. The mother reported having to work at houses in order to make money, while medication for autistic people can very expensive. However, she sees these houses as risky places to work in (bad things usually happen on the job at these places). She was working in a house once and her son broke all the dishes. The owners said she had to pay for it all. Her doctor told her that her son needs a $2 million operation, making her feel extremely hopeless for her son because she is unable to pay. She feels that it is all her fault that she can't help her son. She has also had some back luck when attempting to get treatments for her son. A woman had been working with her son on his feet and hands. But this professional has left the area since then, and the mother has been waiting for four months now for her to return to start receiving further treatments. The mother shared that her son passes out sometimes when she leaves him alone (once he passed out for an entire week). The mother reported that no one is ever nice to her son. One time, she even asked her neighbor to help lift her son up in the chair, only to see him hitting her son.

- **Behavioral problem**

M.D. is the aunt of a brain-late 32-year-old. He uses sentences with four or more words, some of them being words that no one can understand. This autistic female has never been to school. When she was six years old, she was sent home from school on her very first day once the teacher noticed a concern. This individual was never diagnosed, but she provides an interesting example of people with disabilities. She is able to complete household activities, is very organized, and understands emotions. The aunt shared stories of her niece washing clothes, and hiding the ones that remained dirty around the house. However, she does cry and break things when she does not get what she wants. If she knows that something makes you happy, she will keep it from you just to make you angry. She feels very comfortable at her best friend's house, who treats her like a normal human. She is friends with everyone and makes jokes. The aunt said that she is only doing everything that she does at home to support her niece because she is not in school. But she would much rather prefer her to be in school.

- **A birth injury or a genetic problem?**

C.Z. is the mother of a five-year-old girl with Asperger's syndrome, in addition to another unknown condition. A concern was raised fifteen days after birth, but after two months the girl was diagnosed with a genetic disease that causes her to experience difficulty with breathing. The mother says that the doctor was wrong in his diagnosis because she was not expected to live as long as she has. The mother had to repeatedly visit the doctor when her daughter was born because he did not believe that there was anything wrong with her. The interesting part is that the girl has a twin who is completely normal. The mother has a theory that the nurse who delivered her twins could have caused an injury that impacted her brain. One doctor told the mother that her daughter might never walk. The mother then went to see another doctor and he was able to help her walk after two years of therapy everyday. The daughter has been improving in her symptoms over time. For example, she was scared to use the toilet for a long time. But a doctor recommended that the mother leave her to go when she really needed to and she did. The mother and her daughter went to a center for autism and they ended up sending her far away (she actually lives in France, but now she has to stay in Morocco). She reported having been to a lot of doctors in France because she either went to free centers that provided all of them in one location, or went to doctors who referred her to other doctors. She said that she was not finding any doctors in Morocco. The centers in France provided different therapies on different days of the week for her child. Unfortunately, now she plans to live in Ouarzazate and travel to see doctors in Casablanca only once a month. At the school where he child used to attend in France, she studied for only one hour a day with her own private teacher and completed treatments and therapies with doctors for the remainder of the time. She was able to pay for all of this with a card provided to her called “100 percent” that paid for any treatments, supports, etc. for children with disabilities. It would even pay for any food that her daughter consumed. In France, her daughter was treated as equal to the rest of society. But in Morocco, it is much more difficult because her daughter is not accepted by society. In order to deal with this, the mother says that she will stop all communication with people who speak badly about her daughter.

- **A tragic case of abuse**

A.V. is the father of a female autistic child, who shares his personal story of the struggles that his family has gone through to help his fifteen years old daughter. This girl, besides suffering from a mental disability, has always had severe problems with her motor skills. Rarely standing up from her bed and solely receiving attention from her family for any basic needs sums up the story of this teenager’s life. Moreover, the girl was sometimes “tied up” to the window in her room, by having her arms tied when she suddenly experienced overactive behavior and what the family referred to as “the animal inside of her”. The family strongly believes in the idea of homeschooling, especially in the small town which they chose to live in because it is near Skoura.

Being home schooled by hopeless parents who have not received any training is just the beginning of their problems. Their solution to the lack of mobility of her daughter was to remain having her locked within four walls, her bedroom being the definition of life and the only picture of the outer world. Besides the pediatrician regularly seen by the family, since the age of two the girl never visited or received a visit from any other doctor. After dealing with the death of their other three children who were also born with the same condition (described by parents), the family felt hopeless when thinking about the girl's future. The parents’ denial of any problem explains why the daughter has not been seen by the eyes of a doctor. The mother of the child stopped communicating with her daughter, 10 years ago, even though she never really talked anyways. The mother was only able to determine how her daughter was feeling through certain sounds and mumbled words. The father shared how frustrating it has been for his wife, saying how unfortunate it is to be a mother of four children which she could “never enjoy or see grow up in life”. Unfortunately, the girl’s life has been decided by the choices made by her parents. She lives life without receiving any assistance from her family, let alone anyone else.

- **Safety concerns**

A.G. is a preoccupied mother of a twelve years old boy who suffers from autistic spectrum disorder and has attempted to escape the house several times. Many factors can cause any caring parent to lose sight of their child, especially when they don’t respond or, even more so, when the child has no way of returning home because he does not know his own name or how to speak. Luckily, the community that this family decided to live in is small enough to know their neighbors, who could then bring their child safely home (this has happened three times already).

The mother began realizing strange behaviors in her child beginning at the age of two. Her concerns about her child's development arose after experiencing sudden aggressiveness when her child attacked other children. Moreover, the child unexpectedly fainted many times without being exposed to any extreme climate conditions, physical exhaustion, or bad alimentation. This lead the mother to start searching for a doctor who could provide answers for all of her questions, which could then explain many of the behaviors that are common in autistic people. Her first visit to a doctor was in Marrakesh, where she was first made aware that services were too expensive for her pocket. The grandfather of the child planned to pay for the first doctor visit by sending money overseas to the mother's brother, who then stole the money and kept it for himself.

This mother still has many questions to be answered, after hearing many different opinions of many doctors throughout the country. Why does he have this unusual hand movement that involves knocking his nose? Why is he always hungry? Why does he sleep so much sometimes? Why did he stop saying the words he could say before? Many questions remained unanswered to a point where the frustration of this mother led her to buy unprescribed medicines without understanding the effects of each of them. After consulting with a doctor, she still hopes that one of these medicines will work. The mother has to do exactly what many parents who do not receive the best explanations from experts in Morocco do: hope and wait for the best.

Lastly, the brother of the autistic child has been in jail for the last two years for being involved in the drug selling business. A.G., a mother who already had a lot to deal with on her mind, had to accept that her son in jail would not want her help in getting out of prison to return back to what he called “a poor house with a retarded kid to take care of”. The truth for this family, is that the child’s condition ripped this family apart. It caused the older brother to search for easier money on the streets, which would get him out of what he called “the misery the family has to live through economically to fulfill only one member, my stupid brother”.

Discussion

Demographics

When looking back at the demographics, we start to think about what types of people that came to us to complete this survey. We had a large variety of participants with many different backgrounds. Going to the locations that we did allowed us to get a better understanding of how well autism is understood in Morocco because they were in very distinct areas of the country. Women were typically the primary caretakers of the children. This assumption comes from the fact that a lot more women had come in to see us, compared to the men.

Education was another topic that varied from place to place. Education in the less modernized areas was fairly low, which is understandable because, in the more remote areas, most families came from a farming background. In cities, education rates were higher. Even though the women we surveyed in these locations had lower education levels, their husbands achieved higher levels of education. In cities there are more job opportunities, which sometimes require some form of higher education.

Characteristics of the children

When we were doing the interviews, we received a wide range of mental disabilities. On the survey, we listed disorders that were similar to autism as options. We ran into cases where the children did not have autism. There were also cases of kids who were undiagnosed. The reason we ran into some of these issues is because some of the places we went, like the school in Casablanca and the association in Ouarzazate, were places where they took care of kids with all sorts mental disabilities. The Ibtisama Association in Ouarzazate was actually started as a place for those with down syndrome, due to the president's son having the disorder. The findings show that males tended to be afflicted with a mental disability over a female by almost a 1:3 ratio. According to the Autism Speaks website, this is a fairly accurate compared to the studies that they have done globally, saying that boys are five times more likely to develop autism than girls (Autism Speaks).

By taking the age of the children we were able to determine what age range was coming to us through basic descriptive statistics. Interpreting this data, we can see that most of the families that came to see us had younger children and were seeking early on for help with them. The outliers in the analysis can be seen as children/adults who may have never gotten diagnosed before, had trouble getting to places where they could see a doctor and have come to see us hoping that we would be able to give the first diagnose to their child.

When looking at the verbal ability of the children we see that the large percentage of children did not speak or only used single words. This is typical of a child who is on the spectrum. This can vary from case to case because some of the children, according to the parents, were able to use phrases or complex sentence structure.

First diagnosis and schooling

Most children were diagnosed by their pediatrician (31.7%). There was no other large percentage of specialists that diagnosed the participant's children first. It can be concluded that, if the primary care doctor or pediatrician could not diagnose the disorder specifically, other specialists were often able to. The translators experienced slight confusion at times, while parents could have given the wrong answer or been unsure.

The school where the interviews took place in Casablanca, the Al Amal School for Autistic Children, generally provides a lot of services for children with different kinds of mental disabilities. Touria Mabrok is a Moroccan woman whose financial status permitted her to travel abroad multiple times in order to diagnose her autistic daughter. This is unlike many other Moroccan families, who are unable to find the right specialist throughout the entire Kingdom in Morocco. When she returned to Morocco, Touria established the first free public school for autistic children in Casablanca, where families could register their kids in school. The school provides specialists experienced with autistic children, as well as playing areas and various other activities for autistic children. Most of our sample population in Casablanca are enrolled in this special school for children with disabilities. Others went to public primary school, due to their amazing performance at the autism school.

Services and treatment

Traveling is a major part of what families do to help their autistic child. From looking at the data, we can see that a small portion of families (see Table 1: Travel to obtain diagnosis) only had to travel about 30 minutes to get a diagnosis. There is a whole 76.3% that would have to go even further than 30 minutes to receive a diagnosis. This data shows us that there is a lack of professionals scattered throughout the area and that most people are traveling long distances to try and get to professionals who can diagnose their child.

When looking back at all the different types of therapies, it was clear that most children were not receiving these. This also points to lack of professionals present to help. During the survey, we were surprised that some parents did not even know that their children were in need of these treatments. Autistic families reported that the most commonly used service or treatment for autistic children is the behavioral intervention (ABA). This method is commonly used in special schools for autism in Morocco and it teaches the autistic child the principles of learning and motivation through behavioral analysis. We also learned that the second most used treatment for autistic children is pharmacotherapy and medication, which is the least effective for autism, based on an article published by Autism Speaks (Medicines). Instead, medication is generally used in conjunction with other treatments for autistic people.

Looking back at our table of specialists that work with children in Morocco (see Table 3: Family report specialists working with their children), we can see that half the participants do not have a specialist currently working with their child. It was good to see that most of those who were seeing a specialist were seeing a developmental pediatrician. It is apparent here that families do not have the adequate resources within reach to help their child.

Family training and governmental help

We have asked families about whether or not they received any additional training or assistance in managing or addressing their child's needs. The answer to this question always depended on whether the center where the interview was taking place was offering such a service. In Casablanca, we conducted interviews at two different centers, one of which offered training and courses for parents; consequently, most families there receive a training to address their child's needs. In Ouarzazate, most families said that they are trained to deal with their child's needs because the center offers these free training classes, with the help of Dr. Maretha De Jonge from Autism Speaks. In Skoura, Tiznit, and Agadir, families reported that they do not receive any trainings because the school or center where their children go do not offer this service.

Source of information

The source of information depended on the region where the interview took place. For the interviews that took place in Casablanca, Agadir, and Ouarzazate, most families reported that they have a good reliable source of information. This could be the internet, direct contact with a specialist, or recommendations from other families. However, in cities such as Skoura or Tiznit, responses were a lot different. We met family with two children that had never been diagnosed before. They have never seen a doctor, nor taken any medication. This family lives in Skoura, which is an extremely poor city next to Ouarzazate. In these cases, our solution was to reach out to our sponsor and ask about conducting the interview, while we were already expecting some responses regarding source of information, diagnoses, and child improvement. In this case, we had a child with an unknown diagnosis. This child is 22 years old and still cannot talk, walk, or have any social interaction. With the help of Dr. De Jonge, we sent a picture of his face and body to Autism Speaks in Holland to see if they can do a scientific diagnosis of his disorder. In other words, we have realized that the responses of our samples depended on the region the interview took place; the more developed the city was, the bigger the chances of families gaining access to a convenient and reliable source of information.

Parents/Caregiver perceptions

Preoccupied parents of autistic children commented poorly in many aspects regarding the current state of the medical care, education, and specialized treatment children receive throughout Morocco. The vast majority expressed discontent with the few existing possibilities for accessing resources. Children are being deprived of basic medical services, schooling opportunities, and other service providers. Of the many concerns that we have had the chance to hear about from parents so far, the most popular ones are the following:

- Lack of understanding of this mental disability by the public health sector
- Issues related to the costs of such needed treatments
- Limited amount of viable information provided about the subject matter
- The amount of progress children make through schooling and other services (some feel there is no improvement and that different strategies should be considered)
- The need for more specialists at centers in order to provide more individualized attention for each child throughout the school day
- Both preschools and elementary schools rejecting/denying the entrance of autistic children, preventing them from receiving a proper education

Parents often remain hopeless after having exhausted all available resources. Also the lack of well-prepared centers and professionals throughout the entire country makes it more difficult for families to receive weekly treatment as needed. Most families are satisfied with the current school system their children are enrolled in. This satisfaction is a result of the low cost education offered. A lot of families reported that they need immediate assistance from the government in the following fields: education, healthcare, and human rights for disabled children.

Challenges

1. What you consider to be the greatest challenges to caring for a child with autism?

First choice: Safety concerns (45.1%).

Second choice: Challenging behaviors (41.7%).

Third choice: Communication difficulties/Daily Living skills (40.6%).

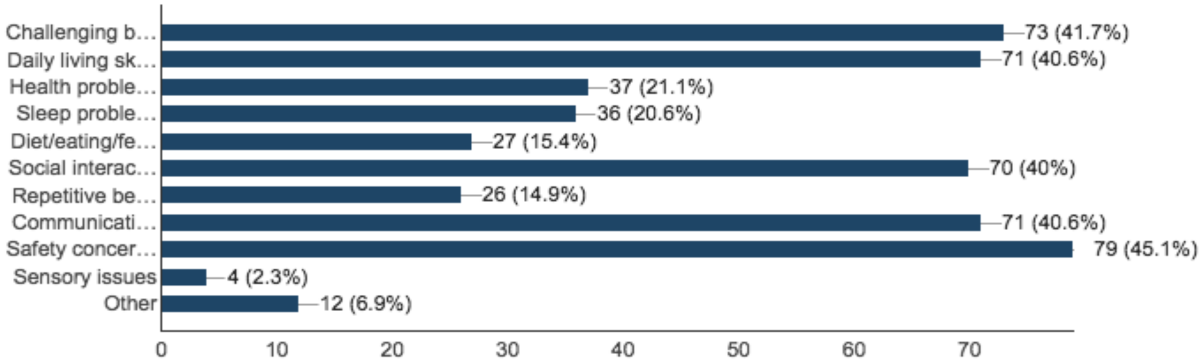

Figure 17: Challenges in caring for mentally disabled children (From top to bottom: Challenging behaviors, Daily living skills, Health problems, Sleep problems, Diet/eating/feeding difficulties, Social interaction difficulties, Repetitive behaviors/restrictive interests/insistence on sameness, Communication difficulties, Safety concerns, Sensory issues and Other)

Safety concern was always the greatest challenge to caring for a child with autism. Most families could not control their children when going to the mosque, the garden, or walking in the streets. People in Morocco often live in crowded locations such as the medina, full of small shops and restaurants. It is really hard for them to find their children once he/she goes out alone. We talked to a lot of family members who said that they are unable to control this. Social interaction and communication difficulties are the second and third concern for the families. As discussed in Section 2, most autistic children speak one word or cannot say a complete complex sentence, which explains why families chose these to be the second and third most important challenges.

2. What are the greatest challenges you face in getting support for your child?

First choice: Making sure my child receives adequate education (76.4%)

Second choice: Making sure my child receives adequate health care (64.4%)
Third choice: Making sure my child's basic rights are protected (59.8%)

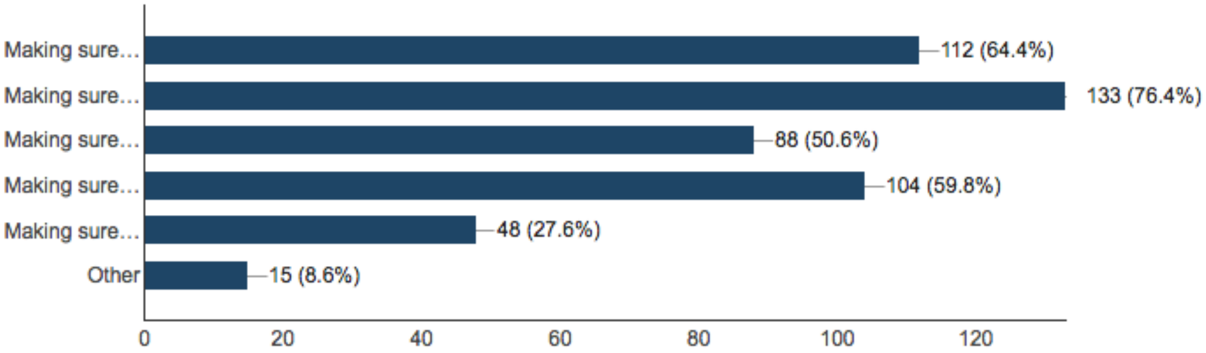

Figure 18: Challenges with getting support for mentally disabled children (From top to bottom: Making sure my child receives adequate health care, making sure my child receives adequate education, making sure my child receives adequate welfare/social supports, making sure my child's basic rights are protected, making sure my family and I receive adequate respite, other)

Education, basic rights, and healthcare are the three greatest challenges in getting support for autistic children. They require a better quality of education, despite that most of the parents interviewed are happy with services provided by the school that their children are currently enrolled in. But as discussed before, their happiness is due to the fact that the education is free, and not because they are receiving the right education that will improve their child's social skills. Autistic children need more social rights, such as laws that help prevent discrimination and provide discounts for public services, such as trams or busses. Lastly, they need to be provided more specialists that are trained and experienced. Most Moroccan families will have to drive long distances, as well as be waitlisted, before seeing a doctor that is specialized in working with autistic children.

The data generated by our study presents a dire situation for families and caregivers living with autistic children in Morocco. The trends clearly point to deficiencies in resources and networks, a lack of available trained medical professionals, virtually no consistent educational strategies, and poor basic services for these families. Moreover, in-depth discussions and interactions with our respondents reveal the extent to which families suffer profoundly in their daily lives as they struggle to make ends meet and simply provide a safe environment for their children. We were struck by dismal ratings in certain domains that could be addressed with modern intervention and programming that is available for autistic people elsewhere in the world.

We were also struck by the extraordinary efforts of individuals that have sacrificed their own resources to help individuals with autism. This includes a family who started a center for children with disabilities in Ouarzazate, to which they donated the bottom of their house, as well as a couple of sisters in Casablanca that opened a school for autistic children. This also includes the parents who traveled long distances to meet us and share their stories with us. Another great example is Autism Speaks, which works to make the lives of autistic people better every day through research and other tools that it provides.

Overall, we believe that our research has given us insight into what the needs to be implemented in Morocco in order to improve the lives of autistic people, as well as their families, their caregivers, and their teachers. We know that diagnostic services, treatments, and education for autistic children are most definitely the most difficult to achieve. However, we hope that our recommendations can be implemented in order to help the situation for autistic people.

Chapter 5: Project Outcomes

Recommendations

After analyzing all of the data collected in our database system, we were able to determine what we though was needed to be implemented in Morocco in order to address the biggest issues that families of autistic children face on a daily basis. We recommend the following:

- Connect sister associations in different cities by sharing information and benefits
- Through the internet and conventions, create a network that connects people to services and resources for autistic people
- Organize autism awareness and fundraising campaigns for teachers
- Organize autism awareness campaigns for the general public
- Organize campaigns for autistic people to make public transportation services accessible to autistic people
- Initiate Co-Ops or similar projects for psychology students to collaborate with organizations for school credit in this area of expertise
- Arrange annual conferences where professionals can interact and discuss the subject matter

We believe that connecting sister associations and creating a network in the Kingdom of Morocco would allow them to collaborate as one strong force with one same purpose, fighting for the cause of autism and hopefully create better specialized schools for children with disabilities. If this were to be facilitated, the different organizations could combine to share their resources and create a greater presence advocating for those with this mental disability. In the end, the different associations collaborating in this way would also ultimately provide more resources for families of children with disabilities looking to educate their child. Moreover, inviting all interested specialists working in the field of autism to an annual convention would promote education on the subject matter and developing professional connections. Additionally, campaigns organized for teachers could inform them of new teaching methods, while campaigns for the general public would reduce both ignorance and stigma. Lastly, initiating Co-Ops and projects for students in psychology or related departments from around the world would incentivize the student community and offer them a variety of possibilities to collaborate with associations, the public health sector, the private health sector, research agencies, or specialized schools. This would encourage research to be continued in this area.

We believe that implementing the above recommendations would greatly improve the conditions for autistic people and their families in Morocco. Although there are already a number of successful schools, centers, and associations for children with disabilities established in Morocco, we believe that the above recommendations are important steps that will aid in the autistic population achieving decent living standards that are in accordance with the law.

Conclusions

Given the current lack of research, our project was important because it allowed us to contribute by collecting data about the autistic population in Morocco, making us more familiar with the problem, while assisting future studies with data that we were unable to find. Through our project, were also able to extend understanding of the issues that autistic people struggle with every day in Morocco. Lastly, our research also allowed us to determine improvements that could be made to treatments for children in need. We also determined the qualifications of doctors in the public health sector diagnosing children with this disorder, as well as what treatments are required for autistic children. Our research enabled us to raise awareness about autism spectrum disorder in Morocco and draw the attention of the Moroccan authorities to the issues that need to be addressed.

Over the past 8 weeks, we have been working with multiple organization that are specified in working with children with disabilities. Although our target was to interview families with autistic children; however, we have conducted interviews covering many disabilities such as: mentally retard, trisomy 21, SHU, Asperger's syndromes and Pervasive Development. Over our study, we were able to create an online database in order to study the response collected from the families. We were also able to survey professional in order to provide these data to Autism Speaks, which will make them evaluate the level of professionals working with children disability in Morocco. In order to be more aware of the problem and go beyond the survey provided by Autism Speaks, we were having interviews with every family that takes to survey and ask them to share a story that reflects their day-to-day life. We have concluded that the main problems to be the lack of professionals, especially in rural cities such as Skoora and Tiznit. Families with children having a rare syndrome such as SHU or the unknown syndrome discussed in the finding chapter 4 (check Syndrome Hémolytique Urémique), have problems getting diagnosed in Morocco. In the cases that we have seen, they are either not diagnosed or travel outside of the country to see foreign professionals. Government help only exist towards center, school and organization specialized with children disabilities. Fatima al Zahra and M.El Hassan, presidents of Ibtisama center and Al Tahady center, both agreed that receive partial financial help for their center, but none of these as well as other interviewed families said they were getting any governmental help for their children.

At the end of our project, we left a strong and reliable database that can be the background of any future research related to Autism in Morocco. Our team has developed two online surveys: a professional survey and family survey. The family survey can be found in English or Arabic. These survey will always be accessible through Google Forms and the result can be reviewed through the permission of Autism Speaks. This data will guarantee a better understanding of the situation in Morocco before studying the situation in the field. As we began to research autism in Morocco prior to our arrival, our biggest obstacle was getting information about Autism in Morocco. We will be glad to offer future researchers the information that we needed at the start of our project.

Since our project mainly consisted of addressing the absence of resources, we strongly encourage the next researchers to focus more on the actual needs and priorities of the autistic population. All throughout our interviewing process, we received families that hoped that we were able to portray to either concerned organizations or government representatives about how poor the services were that they were receiving. In cities such as Skoura and Tiznit, some families showed up and asked us to diagnose their children even after they were told that we weren't doctors. These families shared their stories hoping that their voices will be heard. Consequently, we recommend for future researches to deliver these stories and the condition these families live in to concerned organizations or a government representative.

Ultimately, we aspire for our project to be a contribution to the community. We hope that our data and personal stories will be used in order to provide future researchers with information on the subject matter, and ultimately improve the lives of autistic people and their families. We also believe that the families who participated in our surveying and interviewing will be pleased to have their experiences shared. We expect that it will mean a lot for their struggles to be recounted and brought to the attention of the government. Overall, this project held great meaning for our group. It was extremely difficult to hear about the many trials that autistic people and their families face in Morocco. It was all that we could do to collect data and pass it along to our sponsor to be used to better the lives of people developing countries with limited resources for helping children with disabilities.

Appendices

Appendix A: Survey Data for Autistic population

Caregiver Survey

Study Sample

The sample used for the analysis is presented in the Table 8 below. In total we surveyed 183 parents across 7 geographical locations:

Table 8: Sample by Location

Location	Sample Size			Format of Interviews	Date of Interviews
	Autistic	Non-Autistic	All		
Tiznit	30	13	43	Paper	8/29/2016
Agadir	28	14	42	Paper	8/30/2016
Taroudant	8	1	9	Paper	8/31/2016
Biougra	14	4	18	Paper	8/31/2016
Casablanca	18	8	26	Paper and Online	9/01/2016 - 9/24/2016
Ouarzazate	23	13	36	Paper	9/21/2016 - 9/22/2016
Skoura	3	6	9	Paper	9/23/2016
Total	124	59	183		

Section 1: Family Demographic Characteristics

Table 9: Family demographic characteristics

Characteristic	**%**		
	Autistic	**Non-Autistic**	**All**
Respondent relationship to child			
Mother	52%	69%	55.9%
Father	42.3%	27.5%	39.2%
Grandparent	0.8%	3.5%	1.1%
Other	4.9%	0%	4.8%
Respondent highest level of education			
No Schooling	23.6%	22.5%	23.8%
Primary school	17.9%	19%	18.9%
Secondary School	14.6%	13.8%	14.1%
High school/ vocational training	17.9%	20.7%	18.4%
College/ University degree	23.6%	22.5%	23.2%
Higher than College/ University degree PHD	1.6%	1.7%	1.6%
Spouse's highest level of education			
No Schooling	25.2%	27.1%	25.7%
Primary school	22.8%	17%	21.3%
Secondary School	9.8%	15.25%	11.5%
High school/ vocational training	13.8%	13.55%	14.2%
College/ University degree	17.1%	20.3%	18.6%
Higher than College/ University degree PHD	6.5%	6.77%	7.1%
Not Applicable	4.8%	0%	1.6%

Section 2: Affected Child Characteristics

Table 10: Basic child characteristics

Characteristic			
	Autistic	**Non-Autistic**	**All**
Gender, (%)			
Male	74.8%	69.5%	73.7%
Female	25.2%	30.5%	26.3%
Age in years, mean	9.3	11.5	9.18
Current diagnosis, (%)			
Autism / Autistic disorder	57.7%	-	39.2%
Asperger's syndrome	2.4%	-	2.2%
PDD-NOS	7.3%	-	4.8%
PDD	7.3%	-	4.8%
ASD	25.3%	-	17.2%
No Diagnosis	-	55%	17.2%
Other	-	45%	14.5%
Verbal ability, (%)			
Does not talk	35.8%	28.3%	33.7%
Uses single words only	36.6%	31.6%	34.8%
Uses two- or three-word phrases	11.4%	15%	12.5%
Uses sentences with four or more words	5.7%	16.67%	9.8%
Uses complex sentences	9.8%	8.3%	9.2%

Table 11: First concern

Characteristic			
	Autistic	**Non-Autistic**	**All**
Age of child at first concern in months, mean	26.06	12.49	21.67
Nature of first concern, (% that answered yes)			
Medical problems, i.e. seizures	35%	45.7%	38.7%
Didn't make any eye contact	51.2	49.15%	48.9%
Didn't respond to name when called	33.3%	37.2%	34.9%
Didn't seem to understand non-verbal communication	38.2%	33.8%	37.1%
Had behavioral difficulties, i.e. tantrums	66.7%	66.1%	65.6%
Had problems with coordination / gross motor	30.9%	39%	33.9%
Talked later than usual for most children	66.7%	74.5%	69.4%
Was not talking at all	60.2%	64.4%	61.8%
Did not talk as well as other children of same age	82.1%	72.88%	79.6%
Some speech / skills were lost	47.2%	45.76%	46.8%
Didn't seem to understand what adults said to him/her	58.5%	59.3%	58.6%
Had problems with fine motor skills, i.e. drawing with crayons	66.7%	61.01%	66.1%
Had difficulty play or interacting with others	55.3%	61.01%	56.5%
Insisted on sameness / had difficulty with change	45.5%	50.84%	46.8%
Had difficulty learning new skills, i.e. toilet training	64.2%	66.1%	64%
Had difficulty learning new things, i.e. the alphabet	68.3%	72.88%	69.9%
Had unusual gestures of movements, i.e. hand-flapping	64.2%	60%	60.8%
First person who identified concern, (%)			
I was	47.2%	59.3%	52.2%

My spouse	23.6%	18.6%	23.1%
Other family member / relative	19.5%	8.47%	14%
Doctor or other health care professional	4.9%	0%	6.5%
Teacher	1.6%	11.8%	2.7%
Other	3.2%	1.7%	4.8%

Table 12: Diagnosis

Characteristic			
	Autistic	**Non-Autistic**	**All**
Age at diagnosis in months, mean	30.8	36.6	34.40
Clinician assigning initial diagnosis, (%)			
Primary care doctor	6.0%	16%	9.2%
Pediatrician	41.8%	25%	38.0%
Pediatric specialist	8.2%	9%	8.7%
Psychologist	10.4%	9%	10.3%
Psychiatrist	14.2%	9%	13.0%
Neurologist	10.4%	11%	10.9%
Nurse	1.5%	0%	0.5%
Team of professionals	2.2%	2%	2.2%
Other	3.7%	5%	1.6%
No Diagnosis	1.5%	14%	5.4%
Distance traveled for diagnosis, (%)			
Less than 30 minutes travelling	24.4%	13.55%	23.7%
Between 30 minutes and 1 hour	14.6%	17%	17.2%
Between 1-2 hours	21.1%	0%	20.1%
More than 2 hours	36.6%	27.11%	37.3%
I traveled outside the country	1.6%	1.7%	1.8%

Section 3: Service Encounters

Table 13: Past and Current health service encounters

	Autistic		Non-Autistic		All	
	Past (%)	**Current (%)**	**Past (%)**	**Current (%)**	**Past (%)**	**Current (%)**
Behavioral intervention / modification	32.3%	27.4%	16.67%	30%	31.2%	28%
Sensory integration therapy	19.4%	15.3%	13.34%	16.67%	17.2%	15.1%
Cognitive-based therapy	19.4%	16.1%	10%	8.3%	16.1%	12.9%
Occupational therapy	18.5%	14.5%	26.66%	6.67%	15.1%	11.8%
Physical therapy	25.8%	20.2%	18.3%	15%	25.3%	17.7%
Social skills training	25.0%	20.2%	31.67%	16.67%	23.1%	18.8%
Speech and language therapy	45.2%	37.1%	20%	21.6%	40.3%	31.7%
Pharmacotherapy / medication	30.6%	19.4%	1.67%	16.67%	26%	17.7%
Other	3.20%	2.40%	1.67%	0%	2.69%	1.6%
Does not receive any therapy	58.1%	64%	49.2%	56%	79%	68%

% = Percentage who have or are currently receiving service

Table 14: Hours per week for current service

	Hours/week (%)	**Autistic**	**Non-Autistic**	**All**
Behavioral intervention / modification	Not Applicable	75.8%	76.3%	76.0%
	0-2 hrs	11.3%	5.1%	9.3%
	3-5 hrs	3.2%	6.8%	4.4%
	6-8 hrs	2.4%	3.4%	2.7%
	8-10 hrs	1.6%	5.1%	2.7%
	11+ hrs	5.6%	3.4%	4.9%
Sensory integration therapy	Not Applicable	87.1%	89.8%	88.0%
	0-2 hrs	7.3%	5.1%	6.6%
	3-5 hrs	1.6%	0%	1.1%
	6-8 hrs	1.6%	1.7%	1.6%
	8-10 hrs	0%	1.7%	0.5%
	11+ hrs	2.4%	1.7%	2.2%
Cognitive-based therapy	Not Applicable	87.9%	89.8%	88.5%
	0-2 hrs	7.3%	3.4%	6.0%
	3-5 hrs	1.6%	3.4%	2.2%
	6-8 hrs	1.6%	1.7%	1.6%
	8-10 hrs	0	1.7%	0.5%
	11+ hrs	1.6%	0%	1.1%
Occupational therapy	Not Applicable	86.3%	91.5%	88.0%
	0-2 hrs	8.1%	3.4%	6.6%
	3-5 hrs	1.6%	1.7%	1.6%
	6-8 hrs	1.6%	1.7%	1.6%
	8-10 hrs	0.8%	1.7%	1.1%

	11+ hrs	1.6%	0%	1.1%
Physical therapy	Not Applicable	79.8%	83.1%	80.9%
	0-2 hrs	15.3%	10.2%	13.7%
	3-5 hrs	4.0%	3.4%	3.8%
	6-8 hrs	0.8%	1.7%	1.1%
	8-10 hrs	0%	0%	0%
	11+ hrs	0%	1.7%	0.5%
Social skills training	Not Applicable	82.3%	0%	55.8%
	0-2 hrs	9.7%	89.8%	35.5%
	3-5 hrs	1.6%	1.7%	1.6%
	6-8 hrs	0.8%	0%	0.5%
	8-10 hrs	0.8%	3.4%	1.6%
	11+ hrs	4.8%	1.7%	3.8%
Speech and language therapy	Not Applicable	68.5%	84.8%	73.8%
	0-2 hrs	22.6%	5.1%	17.0%
	3-5 hrs	3.2%	3.4%	3.3%
	6-8 hrs	1.6%	1.7%	1.6%
	8-10 hrs	0.8%	1.7%	1.1%
	11+ hrs	3.2%	3.4%	3.3%
Pharmacotherapy / medication	Not Applicable	-	-	-
	0-2 hrs	-	-	-
	3-5 hrs	-	-	-
	6-8 hrs	-	-	-
	8-10 hrs	-	-	-
	11+ hrs	-	-	-
Other	Not Applicable	96.8%	98.3%	97.3%

	0-2 hrs	1.6%	0%	1.1%
	3-5 hrs	0%	1.7%	0.5%
	6-8 hrs	0%	0%	0%
	8-10 hrs	0%	0%	0%
	11+ hrs	1.6%	0%	1.1%

Table 15: Payment for current service hours

	Partial/Whole Payment (%)	**Autistic**	**Non-Autistic**	**All**
Behavioral intervention / modification	Yes	18.5%	16.9%	18%
	No	8.9%	13.6%	10.4%
	Not Applicable	72.6%	69.5%	71.6%
Sensory integration therapy	Yes	8.1%	8.5%	8.2%
	No	7.3%	5.1%	6.6%
	Not Applicable	84.7%	86.4%	85.2%
Cognitive-based therapy	Yes	8.1%	5.1%	7.1%
	No	6.5%	8.5%	7.1%
	Not Applicable	85.5%	86.4%	85.8%
Occupational therapy	Yes	8.1%	5.1%	7.1%
	No	8.9%	6.8%	8.2%
	Not Applicable	83.1%	88.1%	84.7%
Physical therapy	Yes	13.7%	10.2%	12.6%
	No	8.9%	8.5%	8.8%
	Not Applicable	77.4%	81.4%	78.7%
Social skills training	Yes	15.3%	6.8%	12.6%
	No	6.5%	6.8%	6.6%

	Not Applicable	78.2%	86.4%	80.8%
Speech and language therapy	Yes	27.4%	11.9%	22.4%
	No	8.1%	8.5%	8.2%
	Not Applicable	64.5%	79.7%	69.4%
Pharmacotherapy / medication	Yes	16.9%	10.2%	14.7
	No	4.8%	6.8%	5.4
	Not Applicable	78.2%	83.1%	79.8
Other	Yes	3.2%	0%	2.2
	No	4.0%	3.4%	3.8
	Not Applicable	92.7%	96.6%	94

Table 16: Past and present service providers

	Autistic		**Non-Autistic**		**All**	
	Past (%)	**Current (%)**	**Past (%)**	**Current (%)**	**Past (%)**	**Current (%)**
Audiologist	26%	4.1%	10%	2.32%	29.3%	7%
Behaviorist	23.6%	12.2%	11.42%	14%	29.3%	24.4%
Developmental pediatrician	39.8%	14.6%	20%	23.2%	49.6%	32.6%
Education specialist	19.5%	13.8%	17.14%	18.6%	26.3%	27.9%
Neurologist	29.3%	12.2%	11.42%	21%	33.8%	26.7%
Nutritionist	6.5%	2.4%	4.28%	2.32%	9%	4.7%
Psychiatrist	39%	17.1%	15.71%	9.30%	45.9%	27.9%
Psychologist	19.5%	13.8%	10%	9.30%	21.1%	23.3%
Other	8.13%	3.3%	0%	0%	12%	8.1%
Does not see any service provider	21%	40.4%	41%	59%	29.3%	52.7%

% = Percentage who have or currently see service provider

Table 17: Education services

Characteristic			
	Autistic	**Non-Autistic**	**All**
Type of school, (%)			
Preschool	19.4%	6.55%	15.8%
Public primary school	4.8%	9.83%	6.6%
Private school	4%	1.64%	3.3%
Special school for children with disabilities	47.6%	23%	40.4%
Home-schooled	1.6%	3.27%	1.6%
Not enrolled in school	22.6%	55.7%	32.2%
Received additional supports	17.9%	14%	16.7%
Type of additional supports, (%)			
Special classroom for children with autism	8.9%	8.17%	19%
Special classroom for children with disabilities	12.9%	22.5%	25.2%
In-school tutor	3%	2%	8.2%
In-school aide / shadow	1%	0%	5.4%
Tutor outside of school	6.9%	2.04%	6.8%
Other		0%	4.8%

Table 18: Other services/assistance

Characteristic	**(%)**		
	Autistic	**Non-Autistic**	**All**
Receiving training / assistance	15%	23.4%	17.1%
Receiving government assistance	5.8%	1.7%	5.5%
Participation in advocacy groups	20.2%	29.3%	22.7%
Sources of information about autism			
The Internet	26.9%	53.1%	59.6%
My child's primary care doctor / pediatrician	15.1%	44.9%	37.2%
My child's teacher	11.4%	20.4%	24.4%
Other parents of children with autism	25.3%	46.9%	55.1%
Other providers	10.6%	24.5%	23.1%
Other	10.6%	16.3%	20.5%

% = Percentage who answered yes

Section 4: Caregiver Perspectives

Table 19: Access and unmet need in past 12-months

Characteristic			
	(% who answered yes)		
	Autistic	**Non-Autistic**	**All**
Difficulties / delays receiving services due to ineligibility	61%	51.7%	58.2%
Difficulties / delays because needed services were unavailable	78%	67.2%	74.5%
Difficulties / delays due to wait lists, backlogs, appointments	1.2%	51.7%	51.6%
Difficulties / delays because of issues related to cost	77.2%	68.4%	74.3%
Difficulties / delays because of issues getting the information needed	70.7%	63.8%	69%
Other difficulties or delays		16.4%	24.4%
Level of frustration in efforts to get services, (%)			
Never	9.7%	8.6%	10.3%
Sometimes	22.6%	22.4%	21.6%
Usually	7.3%	10.3%	8.6%
Always	55.6%	50%	53.5%
Don’t know	4.8%	8.6%	5.9%

Table 20: Caregiver / family impact

	(% who said yes)		
	Autistic	**Non-Autistic**	**All**
Child's autism has caused financial problems for family	72.4%	64.3%	71%
Family members have stopped working because of child's autism	24.2%	19.3%	22.8%
Family members have cut down on work hours because of child's autism	41.9%	30.4%	39.3%

Table 21: Stigma

	(%)		
	Autistic	**Non-Autistic**	**All**
I feel helpless for having a child with autism			
Strongly disagree	19.7%	13.7%	19.1%
Disagree	7.1%	18.6%	6.6%
Agree	24.1%	29.5%	37.2%
Strongly agree	34.1%	18%	26.2%
I prefer to not answer	15%	2.7%	11%
I worry if other people would know I have a child with autism			
Strongly disagree	46.7%	44.4%	46.4%
Disagree	20.8%	15.6%	19%
Agree	20%	26.7%	22%

Strongly agree	12.5%	13.3%	12.5%
Other people would discriminate against me because I have a child with autism			
Strongly disagree	29%	21.6%	26.4%
Disagree	18.5%	25.5%	21.3%
Agree	29.8%	31.4%	30.3%
Strongly agree	22.6%	21.6%	21.9%
Having a child with autism imposes a negative impact on me			
Strongly disagree	26.2%	33.3%	28.4%
Disagree	21.3%	9.8%	18.2%
Agree	29.5%	41.2%	33%
Strongly agree	22.1%	11.8%	18.8%
I prefer to not answer	0.8%	3.9%	1.8%

Table 22: Quality of life

	(%)		
	Autistic	**Non-Autistic**	**All**
Importance of child having support to make progress in school			
A little important	1.7%	2.3%	1.8%
Important	7.6%	4.7%	7.3%
Very important	90.8%	93%	90.9%
Satisfaction that child has support to make progress in school			
Very dissatisfied	36.4%	39%	37%
Neutral	25.4%	19.5%	24.1%

Very satisfied	38.1%	41.5%	38.9%
Importance of child having support to make progress at home			
A little important	1.6%	14%	5.1%
Important	12.2%	6%	10.8%
Very important	86.2%	80%	84.1%
Satisfaction that child has support to make progress at home			
Very dissatisfied	37.9%	36.2%	37.4%
Neutral	31.5%	31.9%	32.8%
Very satisfied	30.6%	31.9%	29.9%
Importance of child having support to make friends			
A little important	10.7%	19.6%	13.1%
Important	14.8%	7.8%	13.1%
Very important	74.6%	72.5%	73.9%
Satisfaction that child has support to make friends			
Very dissatisfied	41.7%	52%	44.5%
Neutral	30.8%	14%	26.6%
Very satisfied	27.5%	34%	28.9%
Importance of family having a good relationship with services providers			
A little important	4.9%	10.9%	6.4%
Important	13.1%	8.5%	11.7%
Very important	82%	82.6%	81.9%
Not applicable			
Satisfaction with family's relationship with			

service providers			
Very dissatisfied	30.6%	25%	29.6%
Neutral	27.3%	25%	26.2%
Very satisfied	42.1%	50%	44%
Not applicable			

Table 23: Top 3 challenges and priorities for autism data set only

	(%)
Greatest challenges in caring for a child with autism	
1. Safety concerns (i.e. wandering, climbing)	48.8%
2. Challenging behaviors (i.e. self-injury, aggression, tantrums)	41.5%
3. Communication difficulties	41.5%
4. Daily living skills (i.e. toileting, self-feeding)	38.2%
5. Social interaction difficulties	35%
6. Sleep problems (i.e. trouble falling asleep, trouble staying asleep)	22.8%
7. Health problems (i.e. co-occurring physical and/or mental health conditions	20.3%
8. Repetitive behaviors/ restrictive interests/ insistence on sameness	15.4%
9. Diet/eating/feeding difficulties	12.2%
10. Other (independence, job training, education, figuring life out after parents are gone (future), etc.)	4.9%
11. Sensory issues	2.4%
Greatest challenges faced in getting support for a child with autism	
1. Making sure the child receives adequate education	78.9%
2. Making sure the child's basic rights are protected	69.1%
3. Making sure the child receives adequate health care	66.7%
4. Making sure the child receives adequate welfare/ social supports	50.4%

5. Making sure the family receives adequate respite	33.3%
6. Other (having child participate in activities, attention to one child over the other, etc.)	2.4%
Greatest priorities for families affected by autism in Morocco	
1. Greater rights for individuals with autism	63.4%
2. Improved education services	62.6%
3. Improved health care services	52%
4. Greater community awareness	44.7%
5. Improved welfare/ social services	34.1%
6. More information about autism	21.2%
7. Greater in-home support	16.3%
8. Greater opportunities for parent interactions/ networking	14.6%
9. Other (taking in consideration the children in need of Morocco and provide all necessary services, special schools, special training for parents, etc.)	4%

% = Percentage of Participants Who Listed Answer within their Top 3

Table 24: Top 3 challenges and priorities for non-autism data only

	(%)
Greatest challenges in caring for a child with autism	
1. Social interaction difficulties	18.1%
2. Daily living skills (i.e. toileting, self-feeding)	17.5%
3. Challenging behaviors (i.e. self-injury, aggression, tantrums)	15.4%
4. Safety concerns (i.e. wandering, climbing)	13.2%
5. Communication difficulties	11.9%
6. Health problems (i.e. co-occurring physical and/or mental health conditions	7.7%
7. Sleep problems (i.e. trouble falling asleep, trouble staying asleep)	5.6%
8. Diet/eating/feeding difficulties	5.6%
9. Repetitive behaviors/ restrictive interests/ insistence on sameness	4.2%

10. Sensory issues	0.7%
11. Other (independence, job training, education, figuring life out after parents are gone (future), etc.)	0%
Greatest challenges faced in getting support for a child with autism	
1. Making sure the child receives adequate education	29.2%
2. Making sure the child receives adequate health care	24.9%
3. Making sure the child receives adequate welfare/ social supports	21.9%
4. Other (having child participate in activities, attention to one child over the other, etc.)	20.3%
5. Making sure the child's basic rights are protected	16.0%
6. Making sure the family receives adequate respite	8%
Greatest priorities for families affected by autism in Morocco	
1. Improved education services	62.7%
2. Improved health care services	60.8%
3. Greater rights for individuals with autism	43.1%
4. Greater community awareness	35.3%
5. Improved welfare/ social services	31.4%
6. More information about autism	31.4%
7. Greater in-home support	29.4%
8. Greater opportunities for parent interactions/ networking	15.7%
9. Other (taking in consideration the children in need of Morocco and provide all necessary services, special schools, special training for parents, etc.)	1.96%

% = Percentage of Participants Who Listed Answer within their Top 3

Table 25: Top 3 challenges and priorities for the entire data set

	(%)
Greatest challenges in caring for a child with autism	
1. Safety concerns (i.e. wandering, climbing)	45.1%
2. Challenging behaviors (i.e. self-injury, aggression, tantrums)	41.7%
3. Daily living skills (i.e. toileting, self-feeding)	40.6%
4. Communication difficulties	40.6%
5. Social interaction difficulties	40%
6. Health problems (i.e. co-occurring physical and/or mental health conditions	21.2%
7. Sleep problems (i.e. trouble falling asleep, trouble staying asleep)	20.6%
8. Diet/eating/feeding difficulties	15.4%
9. Repetitive behaviors/ restrictive interests/ insistence on sameness	14.9%
10. Other (independence, job training, education, figuring life out after parents are gone (future), etc.)	6.9%
11. Sensory issues	2.3%
Greatest challenges faced in getting support for a child with autism	
1. Making sure the child receives adequate education	76.4%
2. Making sure the child receives adequate health care	64.4%
3. Making sure the child's basic rights are protected	59.8%
4. Making sure the child receives adequate welfare/ social supports	50.6%
5. Making sure the family receives adequate respite	27.6%
6. Other (having child participate in activities, attention to one child over the other, etc.)	8.6%
Greatest priorities for families affected by autism in Morocco	
1. Improved education services	57.6%

2. Improved health care services	50.3%
3. Greater rights for individuals with autism	49.2%
4. Greater community awareness	37.3%
5. Improved welfare/ social services	35%
6. More information about autism	20.3%
7. Greater in-home support	16.9%
8. Greater opportunities for parent interactions/ networking	11.3%
9. Other (taking in consideration the children in need of Morocco and provide all necessary services, special schools, special training for parents, etc.)	9%

% = Percent of Participants Who Listed Answer within their Top 3

Appendix B: English Professional Survey

Autism Speaks

Professional Needs Survey

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

SECTION 0: BASIC SURVEY DATA

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

____

0.2 Delivery method
1. _____ In person (interviewer)
2.______ _In-person (self)
3. _____Phone
4. _____Email
5. _____Other (Specify:____________________)

0.3 Format
1. _____Paper
2. _____Electronic

0.4 Date completed (enter DD/MM/ YYYY)

____

PARTICIPANT CONSENT

Dear Professional,

[NAME OF UNIVERSITY/ENTITY]*, in partnership with Autism Speaks (www.autismspeaks.org), is conducting a survey to understand the needs of professionals, 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, and indicate clearly with an "X" the answer you chose. 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! If you have any questions please do not hesitate to contact [NAME] at [PHONE AND/OR EMAIL] at any time.

****

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

__________ *Participant initials*

Thank you!

SECTION 1: PROFESSIONAL DEMOGRAPHIC CHARACTERISTICS

1.1 What is your highest level of education?
0.______ No schooling
1.______ Primary school with degree / without degree
2.______ Secondary school with degree / without degree
3. _____ High school / vocational training with degree / without degree
4.______ College/university degree with degree / without degree
5.______ Higher than college/university degree PhD

1.2 Profession: ______________________________
Title: ______________________________
Years of experience: ______________________________
Brief job description: ______________________________

SECTION 2: CHARACTERISTICS

These questions pertain to characteristics of the children with whom you work.

2.1 Specify the individuals with whom you work. Check all that apply.
1.______ Autism Spectrum Disorder (including: TED, PDD, Autism, Asperger's Syndrome)
2.______ Mental retardation (including Down syndrome)
3.______ Physical handicaps (motor disabilities)________
4.______ Deaf or hearing impaired
5.______ Blind or visually impaired
6.______ Other psychiatric conditions (including ADHD, OCD, anxiety disorders, etc)
7.______ Other (Specify: ____________________)
7._____ I don't know
8._____Not diagnosed
9._____Multi-handicapped

2.2 How many children do you have in your classroom/practice/case load?
give the exact number if possible _____
or give an estimation _____

2.3 What is the age-range of the individuals you work with?
_____ to _____

2.4 How many of your clients/patients/students are diagnosed with an autism spectrum disorders?
give the exact number if possible _____
or give an estimation _____

2.5 Can you make an estimation of the percentage of children in your classroom/practice that has the following verbal abilities.
1.______% Does not talk
2.______% Uses single words only (e.g. "water")
3.______% Uses two- or three-word phrases (e.g. "Daddy shoe")
4.______% Uses sentences with four or more words (e.g. "I want more juice")
5.______% Uses complex sentences (e.g. "I am tired and I want to sleep")

SECTION 3: SERVICE ENCOUNTERS: For professionals working in the education field

3.1 Do you work in the education field?
1.______ No please go to section 4
2.______ Yes

3.2 What kind of school do you work? Check all that apply
1.______ Preschool
2.______ Public primary school
3.______ Private primary school
4.______ Special classroom for children with disabilities (Classe intégrée/CLIS)
5.______ Special school for children with disabilities
6. Special classroom for children with autism
5.______ Home-schooling teacher
6.______ Secondary school
7. _____High school / vocational training
8.______ College/university

3.3 What kind of work do you? Check all that apply
1.______ Classroom/group teacher
2.______ Individual teacher (max. 1 or 2 children at the same time)
3.______ In-school aide/shadow/tutor
4. _____Classroom assistant
5. _____Director
6. _____Other (Specify: _____________________)

3.4 Do you use any specific methods for children with autism? Check all that apply
Please indicate what kind of training you received.

	Services/treatments	1. I was trained in the method and I have a certificate for this method	2. I was trained on the job by colleagues and/or I don't have a certificate for this method	2. I was not trained but learned this method from a book/internet/other
a.	Behavioral intervention or modification (e.g. ABA)			
b.	TEACCH			
c.	Pivotal response training			
d.	Floortime			
e.	PECS			

f.	Other (Specify: _____________________)			
g.	No special method			
h.	Don’t know			

3.4 Are any of the following services are available for children with autism in the school you work in? Check all that apply

	Services	Not Available	Available	How many hours per week is this service available for a student?	Do families have to pay for this service?
a.	Behavioral intervention or modification (e.g. ABA)				1._____ Yes, totally 2._____ Yes, in part 3._____ No
b.	TEACCH				1._____ Yes, totally 2._____ Yes, in part 3._____ No
c.	Pivotal response training				1._____ Yes, totally 2._____ Yes, in part 3._____ No
d.	Floortime				1._____ Yes, totally 2._____ Yes, in part 3._____ No
e.	PECS				1._____ Yes, totally 2._____ Yes, in part 3._____ No

f.	In-school aide/shadow				1._____ Yes, totally 2._____ Yes, in part 3._____ No
G	In-school tutor				1._____ Yes, totally 2._____ Yes, in part 3._____ No
H	Psychomotricien				1._____ Yes, totally 2._____ Yes, in part 3._____ No
I	Psychologist				1._____ Yes, totally 2._____ Yes, in part 3._____ No
J	Speech and language therapist				1._____ Yes, totally 2._____ Yes, in part 3._____ No
K	Social skills training				1._____ Yes, totally 2._____ Yes, in part 3._____ No
L	Sport				1._____ Yes, totally 2._____ Yes, in part 3._____ No
M	Musical therapy or music lessons				1._____ Yes, totally 2._____ Yes, in part 3._____ No

N	Other (Specify: _____________________)				1._____ Yes, totally 2._____ Yes, in part 3._____ No
o	Don't know or not applicable				

3.5 How many teachers are there in your classroom for the children with autism?

Number of children with autism in the classroom _____________
Number of teachers _____________
Number of classroom assistants _____________

3.6 Did you follow any courses/training about autism?
1. No
2. Yes. Please specify:
____
____

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

	Information sources	1. Yes	2. No
a.	The Internet		
b.	Doctor/pediatrician		
c.	Other teachers		
d.	Parents of children with autism		
e.	Other providers (i.e. health specialists, therapists)		
f.	Other (Specify:_____________________)		

3.8 Do you ***currently*** receive any assistance in your job with regard to teaching children with autism?
1.______ No
2.______ Yes
If yes: by whom? ____

What kind of assistance? ____
How many hours a month? ____

3.9 Do you have any training needs with regard to autism? If yes, what are your training needs?

1. No
2. Yes.
3. If yes - Please indicate the first 3 training needs you have?

1. ____________________

2. ____________________

3. ____________________

3.11 Do you ever get questions from parents about their child with autism?

1. No, parents did not ask me questions or asked me for help
2. Yes

If yes: What kind of questions did they ask you or what kind of help did they need? Select the top three:

Parents asked about:

a. Health issues (e.g. physical problems, medication, bowel problems etc)
b. Sleep problems (i.e. trouble falling asleep, trouble staying asleep)
c. Diet/eating/feeding difficulties
d. Daily living skills (i.e. toileting, self-feeding, getting dressed)
e. Social interaction difficulties
f. Repetitive behaviors/restrictive interests/insistence on sameness
g. Language and communication difficulties
h. Sensory issues (i.e. hypersensitivity to sound, smell, light, touch)
i. Safety concerns (i.e. wandering, climbing)
j. Challenging behavior (aggression, tantrums, self-injury, anxiety, rigidity, etc)
k. The diagnosis (where to get a diagnosis, did not understand the diagnosis etc)
l. Treatment
m. Schooling or problems at school
n. Dealing with other family members (husband, extended family, siblings)
o. Other. Please specify: ____
____

SECTION 4: SERVICE ENCOUNTERS: For professionals working in health care or other fields

If you work in the educational field and filled out section 3, please skip section 4 and go to section 5.

4.1 What kind of setting do you work in? Check all that apply
1.______ Hospital
2.______ Private practice
3.______ General health care center (i.e. GP, well baby clinic)
4.______ Association for children with handicaps
5.______ Center for sport, music or hobby (i.e. scouting, sportclub, youth music club)
5. _____Other (Specify: _____________________)

4.2 What kind of work do you? Check all that apply
1.______ Psychiatrist
2.______ Psychologist
3.______ General practitioner or Pediatrician
4.______ Other medical doctor or dentist
5.______ Speech and language therapist
6. _____ Psychomotricien
7. _____ Trainer or group leader (i.e. sport trainer, scouts leader)
8. _____Other (Specify: _____________________)

4.3 Do you do diagnostic work for children with autism?
1.______ I do autism screening and refer parents to a diagnostic center/practice
2.______ I contribute to the diagnosis with specific assessments (speech and language test, psychological assessment, psychiatric assessment)
Please Specify: _____________________

4.4 Do you use any questionnaires for your screening or diagnostic work?
1.______ No
2.______ Yes. Please specify which questionnaires:
____

4.5 Are the following diagnostic instruments used in your center/practice?

		1. I was trained in the method and I have a certificate for this instrument	2. I was trained on the job by colleagues and/or I don't have a	2. I was not trained but learned to use the instrument from the manual/internet/oth

			certificate for this instrument	er
a.	ADI-R			
b.	ADOS			
c.	CARS			
d.	WISC			
e.	PEP			
g.	Other (Specify: _____________________)			
h.	No special instrument used			
i	Don't know			

4.6 Do you do therapeutic work with children with autism? Do you use any specific methods? Check all that apply. Please indicate what kind of training you received.

	Services/treatments	1. I was trained in the method and I have a certificate for this method	2. I was trained on the job by colleagues and/or I don't have a certificate for this method	2. I was not trained but learned this method from a book/internet/other
a.	Behavioral intervention or modification (e.g. ABA)			
b.	TEACCH			
c.	Pivotal response training			
d.	Floortime			
e.	PECS			
f.	Other (Specify: _____________________)			
g.	No special method			

h.	Don’t know			

4.7 Are any of the following services are available for children with autism in the center you work in? Check all that apply

	Services	Not Available	Available	How many hours per week is this service available for a child?	Do families have to pay for this service?
a.	Behavioral intervention or modification (e.g. ABA)				1._____ Yes, totally 2._____ Yes, in part 3._____ No
b.	TEACCH				1._____ Yes, totally 2._____ Yes, in part 3._____ No
c.	Pivotal response training				1._____ Yes, totally 2._____ Yes, in part 3._____ No
d.	Floortime				1._____ Yes, totally 2._____ Yes, in part 3._____ No
e.	PECS				1._____ Yes, totally 2._____ Yes, in part 3._____ No
f.	Out-school tutor				1._____ Yes, totally 2._____ Yes, in part

					3._____ No
G	Pharmacotherapy / medication				1._____ Yes, totally 2._____ Yes, in part 3._____ No
H	Cognitive behavioral therapy				1._____ Yes, totally 2._____ Yes, in part 3._____ No
I	Psycho motor therapy /sensory integration training				1._____ Yes, totally 2._____ Yes, in part 3._____ No
J	Speech and language therapy				1._____ Yes, totally 2._____ Yes, in part 3._____ No
K	Occupational therapy				1._____ Yes, totally 2._____ Yes, in part 3._____ No
L	Social skills training				1._____ Yes, totally 2._____ Yes, in part 3._____ No
M	Training for parents				1._____ Yes, totally 2._____ Yes, in part 3._____ No
N	Parents support groups				1._____ Yes, totally 2._____ Yes, in

					part 3._____ No
O	Sport				1._____ Yes, totally 2._____ Yes, in part 3._____ No
P	Musical therapy or music lessons				1._____ Yes, totally 2._____ Yes, in part 3._____ No
Q	Job coaching				1._____ Yes, totally 2._____ Yes, in part 3._____ No
R	Other (Specify: ______________________)				1._____ Yes, totally 2._____ Yes, in part 3._____ No
S	Don’t know or not applicable				

4.8 Do you provide any services for children with autism or their parents in their home?
1.______ Yes (Specify: ______________________)
2.______ No

4.9 Did you follow any courses/training about autism?
3. No
4. Yes. Please specify:
____
____

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

	Information sources	1. Yes	2. No
a.	The Internet		
b.	Doctor/pediatrician		
c.	Books		
d.	Parents of children with autism		
e.	Other providers (i.e. health specialists, therapists)		
f.	Other (Specify:____________________)		

4.11 Do you ***currently*** receive any assistance in your job with regard to working with children with autism?
1.______ No
2.______ Yes
If yes: by whom? ____
What kind of assistance? ____
How many hours a month? ____

4.12 Do you have any training needs with regard to autism? If yes, what are your training needs?
1. No
2. Yes.
If yes - Please indicate the first 3 training needs you have?

1. ___________________

2. ___________________

3. ___________________

4.13 What kind of questions parents asked you about their child with autism?
Select the top three:

Parents asked about:
a. Health issues (e.g. physical problems, medication, bowel problems etc)
b. Sleep problems (i.e. trouble falling asleep, trouble staying asleep)
c. Diet/eating/feeding difficulties

d. Daily living skills (i.e. toileting, self-feeding, getting dressed)
e. Social interaction difficulties
f. Repetitive behaviors/restrictive interests/insistence on sameness
g. Language and communication difficulties
h. Sensory issues (i.e. hypersensitivity to sound, smell, light, touch)
i. Safety concerns (i.e. wandering, climbing)
j. Challenging behavior (aggression, tantrums, self-injury, anxiety, rigidity, etc)
k. The diagnosis (where to get a diagnosis, did not understand the diagnosis etc)
l. Treatment
m. Schooling or problems at school
n. Dealing with other family members (husband, extended family, siblings)
o. Other. Please specify: ____
____

:

SECTION 5: PROFESSIONAL PERCEPTIONS

ACCESS & UNMET NEEDS

These questions are about all the types of services children with autism 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.

5.1 During the past 12 months, did you have any difficulties or delays in getting services for your students/clients/patients because he/she was ***not eligible*** for the services?
1.______ Yes
2.______ No
3.______ Don't know

5.2 During the past 12 months, did you have any difficulties or delays because services students/clients/patients needed were ***not available*** in your area?
1.______ Yes
2.______ No
3.______ Don't know

5.3 During the past 12 months, did you have any difficulties or delays because there were waiting lists, backlogs, or other problems getting assistance from providers?
1.______ Yes
2.______ No
3.______ Don't know

5.4 During the past 12 months, did you have any difficulties or delays to arrange services your students/clients/patients needed because of issues related to cost?
1.______ Yes
2.______ No
3.______ Don't know

5.5 During the past 12 months, did you have any difficulties or delays to arrange services your students/clients/patients needed because you had trouble getting the information you needed?
1.______ Yes
2.______ No
3.______ Don't know

5.6 During the past 12 months, did you have any difficulties or delays to arrange services your students/clients/patients needed for any other reason?
1.______ Yes (Specify: ____________________)
2.______ No
3.______ Don't know

5.7 During the past 12 months, how often have you been frustrated in your efforts to provide services for children with autism?
1.______ Never
2.______ Sometimes
3.______ Usually
4.______ Always
5.______ Don't know

STIGMA

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

5.11 I feel helpless teaching a child with autism.
1.______ Strongly disagree
2.______ Disagree
3.______ Agree
4.______ Strongly agree

5.13 Other people would discriminate against me because I work with individuals with autism.
1.______ Strongly disagree
2.______ Disagree
3.______ Agree
4.______ Strongly agree

QUALITY OF LIFE
For these next questions, we want to learn how you feel about your students' quality of life.

5.15 How important is it that my students with autism have support to make progress in school?
1.______ A little important
2.______ Important
3.______ Very important

5.16 How satisfied am I with the support for my students with autism to make progress in school?
1.______ Very dissatisfied
2.______ Neutral
3.______ Very satisfied

5.19 How important is it that students with autism have the support to make friends?
1.______ A little important
2.______ Important
3.______ Very important

5.20 How satisfied am I with the support to make friends for my students with autism?
1.______ Very dissatisfied
2.______ Neutral
3.______ Very satisfied

5.21 How important is it that families have a good relationship with the services providers or teachers who work with their child?
1.______ A little important
2.______ Important
3.______ Very important

5.22 How satisfied am I with the relationship that I have with the families with whom I work?
1.______ Very dissatisfied
2.______ Neutral
3.______ Very satisfied

CHALLENGES & PRIORITIES

5.23 We are now interested in learning what you consider to be the greatest challenges to working with/educating children with autism.
*Please select the **top 3** challenges from the list below.*

a. Health issues (e.g. physical problems, medication, bowel problems etc)
b. Sleep problems (i.e. trouble falling asleep, trouble staying asleep)
c. Diet/eating/feeding difficulties
d. Daily living skills (i.e. toileting, self-feeding, getting dressed)
e. Social interaction difficulties
f. Repetitive behaviors/restrictive interests/insistence on sameness
g. Language and communication difficulties
h. Sensory issues (i.e. hypersensitivity to sound, smell, light, touch)
i. Safety concerns (i.e. wandering, climbing)
j. Challenging behavior (aggression, tantrums, self-injury, anxiety, rigidity, etc)
k. The diagnosis (where to refer parents for a diagnosis, did not understand the diagnosis etc)
l. Treatment (finding treatment for the child, not knowing where to refer a child)
m. Schooling or problems at school (finding a school for the child, learning or behavioral difficulties in the classroom)
n. Dealing with family members (parents, extended family, siblings)
o. Other. Please specify: ____
____

5.24 What are the greatest challenges you face in getting support for individuals with autism. *Please select the **top 3** challenges from the list below.*

1.______ Making sure individuals with autism are adequately diagnosed
2.______ Making sure individuals with autism receive adequate health care
3.______ Making sure individuals with autism receive adequate education
4.______ Making sure individuals with autism receive adequate welfare / social supports
5.______ Making sure individuals with autism basic rights are protected
6.______ Making sure families with individuals with autism receive adequate respite
7.______ Other (Specify:______________________)

5.25 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.*

1.______ Improved health care services
2.______ Improved education services
3.______ Improved welfare / social services
4.______ Greater rights for individuals with autism
5.______ Greater protection of existing rights for individuals with autism
6.______ More information about autism
7.______ Greater in-home support
8.______ Greater community awareness
9.______ Greater opportunities for parent interactions / networking
10.____ Other (Specify:______________________)

Thank you for your time

Appendix C: English Family Survey

Autism Speaks

Caregiver Needs Survey

Developed by Amy Daniels & SEAN National Coordinators

SECTION 0: BASIC SURVEY DATA

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

____

0.2 Delivery method

1. _____ In person (interviewer)
2._____ _In-person (self)
3. _____Phone
4. _____Email
5. _____Other (Specify:_____________________)

0.3 Format

1. _____Paper
2. _____Electronic

0.4 Setting

1. _____Home
2. _____Facility
3. _____Other (Specify: _____________________)

0.5 Facility name (enter name, if applicable)

1. _____NA
2. ________________________________

0.6 Date completed (enter DD/MM/ YYYY)

____

PARTICIPANT CONSENT

Dear Parent / Caregiver,

***[NAME OF UNIVERSITY/ENTITY]**, 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, and indicate clearly with an "X" the answer you chose. 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! If you have any questions please do not hesitate to contact [NAME] at [PHONE AND/OR EMAIL] at any time.

****

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

___________ *Participant initials*

Thank you!

SECTION 1: FAMILY DEMOGRAPHIC CHARACTERISTICS

1.1 What is your highest level of education?

0.______ No schooling
1.______ Primary school with degree / without degree
2.______ Secondary school with degree / without degree
3. _____ High school / vocational training with degree / without degree
4.______ College/university degree with degree / without degree
5.______ Higher than college/university degree PhD

1.2 What is your husband/wife's highest level of education?

0.______ No schooling
1.______ Primary school with degree / without degree
2.______ Secondary school with degree / without degree
3. _____ High school / vocational training with degree / without degree
4.______ College/university degree with degree / without degree

5.______ Higher than college/university degree PhD
6.______ Not applicable

1.3. What is your relationship to the child*?
1.______ Mother
2.______ Father
3.______ Grandfather / grandmother
4.______ Other (Specify: ____________________)

** Henceforth referred to as "your child"*

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.

2.1 What is your child's *current* diagnosis?
1.______ Autism or Autistic disorder
2.______ Asperger's Syndrome
3.______ Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)
4.______ Pervasive Developmental Disorder (PDD)
5.______ Autism Spectrum Disorder (ASD)
6.______ Other (Specify: ____________________)
7.______ Unknown / No diagnosis (yet)

2.2 What is your child's gender?

1.______ Male
2.______ Female

2.3 What is your child's *current* age?
1.______ Years and ______ Months

2.4 What is the verbal ability of your child?
1.______ Does not talk
2.______ Uses single words only (e.g. "bread")
3.______ Uses two- or three-word phrases (e.g. "Daddy shoes")
4.______ Uses sentences with four or more words (e.g. "I want more juice")
5.______ Uses complex sentences (e.g. "I am tired and I want to sleep")

FIRST CONCERN

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

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	1.Yes	2.No
a.	Had medical problems such as seizures, lack of physical growth, or stomach problems		
b.	Didn't make eye contact when talking or playing with others		
c.	Didn't respond when called or didn't respond to sound		
d.	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.		
e.	Had behavioral difficulties such as sleeping or eating problems, high activity level, wandering, tantrums, aggressive or destructive behavior		
f.	Had problems with coordination or gross motor skills such walking		
g.	Talked later than usual for most children		
h.	Was not talking at all		
i.	Did not talk as well as other children that were the same age		
j.	Some speech skills that he/she had already developed were lost		
k.	Didn't seem to understand what you or other adults said to him/her		
l.	Had problems with fine motor skills such as using scissors or drawing with crayons		
m	Had difficulty playing or interacting with others, or played alone "in her/her		

.	own world”		
n.	Insisted on sameness or had difficulties with change		
o.	Had difficulty learning new skills such as toilet training or getting dressed		
p.	Had difficulty learning new things such as the alphabet or numbers		
q.	Had unusual gestures or movements such as hand-flapping, toe-walking, or self-spinning		

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

1.______ I was
2.______ My husband / my wife
3.______ Other family member/relative
4.______ Doctor or other health care provider
5.______ Teacher
6.______ Other (Specify:_____________________)

DIAGNOSIS

2.8 How old was your child when he/she was first diagnosed with autism?

________ Months

2.9 Who gave your child this ***initial*** diagnosis?

1.______ Primary care doctor
2.______ Pediatrician
3.______ Pediatric specialist (i.e. developmental pediatrician)
4.______ Psychologist
5.______ Psychiatrist
6.______ Neurologist
7.______ Nurse
8.______ Team of professionals
9.______ Other (Specify:______________________)

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

________ Less than 30 minutes traveling
________ Between 30 minutes and 1 hour
________ Between 1 – 2 hours
________ More than 2 hours

________ I traveled outside the country

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.

HEALTH SERVICE ENCOUNTERS

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	1. Yes	2. No
a.	Behavioral intervention or modification (e.g. ABA)		
b.	Sensory integration therapy		
c.	Cognitive based therapy		
d.	Occupational therapy		
e.	Physical therapy		
f.	Social skills training		
g.	Speech or language therapy		
h.	Pharmacotherapy / medication		
i.	Other (Specify: _____________________)		
j.	Don't know		

3.2 Is your child ***currently*** receiving any of the following services to meet his/her needs?			**3.3** How many hours of does your child usually receive per week?	**3.4** Do you have to pay for this service?
a.	Behavioral intervention or modification (e.g.	1.______ Yes 2.______ No		1._____ Yes, totally 2._____ Yes, in part

	ABA)			3._____ No
b.	Sensory integration therapy	1._____ Yes 2._____ No		1._____ Yes, totally 2._____ Yes, in part 3._____ No
c.	Cognitive based therapy	1._____ Yes 2._____ No		1._____ Yes, totally 2._____ Yes, in part 3._____ No
d.	Occupational therapy	1._____ Yes 2._____ No		1._____ Yes, totally 2._____ Yes, in part 3._____ No
e.	Physical therapy	1._____ Yes 2._____ No		1._____ Yes, totally 2._____ Yes, in part 3._____ No
f.	Social skills training	1._____ Yes 2._____ No		1._____ Yes, totally 2._____ Yes, in part 3._____ No
g.	Speech or language therapy	1._____ Yes 2._____ No		1._____ Yes, totally 2._____ Yes, in part 3._____ No
h.	Pharmacotherapy / medication	1._____ Yes 2._____ No		1._____ Yes, totally 2._____ Yes, in part 3._____ No
3.2 Is your child ***currently*** receiving any of the following services to meet his/her needs? Continued)			**3.3** How many hours of does your child	**3.4** Do you have to pay for this

			usually receive per week?	service?
i.	Other	1._____ Yes 2._____ No		1._____ Yes, totally 2._____ Yes, in part 3._____ No
j.	Don't know			

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

	Provider	1. Yes	2. No
a.	Audiologist		
b.	Behaviorist		
c.	Developmental pediatrician		
d.	Education specialist		
e.	Neurologist		
f.	Nutritionist		
g.	Psychiatrist		
h.	Psychologist		
i.	Other (Specify:_____________________)		

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

	Provider	1. Yes	2. No
a.	Audiologist		
b.	Behaviorist		
c.	Developmental pediatrician		

d.	Education specialist		
e.	Neurologist		
f.	Nutritionist		
g.	Psychiatrist		
h.	Psychologist		
i.	Other (Specify:_____________________)		

EDUCATION SERVICES

3.7 What kind of school is your child ***currently*** enrolled in?
1.______ Preschool
2.______ Public primary school
3.______ Private school
4.______ Special school for children with disabilities
5.______ Home-schooled
6.______ Not enrolled in school

3.8 Does your child receive any ***additional*** academic support because of his/her developmental needs?
1.______ Yes
2.______ No
3.______ Don't know

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

	Education supports	1. Yes	2. No
a.	Special classroom for children with autism		
b.	Special classroom for children with disabilities (Classe intégrée/CLIS)		
c.	In-school tutor		
d.	In-school aide/shadow		
e.	Tutor outside of school		
f.	Other (Specify:_____________________)		
g.	Not applicable		

OTHER SERVICES/ASSISTANCE

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

1.______ Yes (Specify: ______________________)
2.______ No

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

1.______ Yes (Specify: _____________________)
2.______ No

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

1.______ Yes
2.______ No
3.______ Don't know

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

	Information sources	1. Yes	2. No
a.	The Internet		
b.	My child's primary care doctor/pediatrician		
c.	My child's teacher		
d.	Other parents of children with autism		
e.	Other providers (i.e. health specialists, therapists) who work with my child		
f.	Other (Specify:_____________________)		

3.14 - Please indicate the first 3 training needs you have?

1. ____________________

2. ____________________

3. ____________________

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

1. ______ Yes
2. ______ No
3. (specify: ____________________).

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

1. ______ Yes
2. ______ No
3. (specify: ____________________).

3.17 - Does your child currently take part in any organized social activities (such as swimming lessons, soccer, clubs)?
1. ______ Yes
2. ______ No
3. (specify: ____________________).

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.

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?
1.______ Yes
2.______ No
3.______ Don’t know

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?
1.______ Yes
2.______ No
3.______ Don’t know

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?

1.______ Yes
2.______ No
3.______ Don't know

4.4 During the past 12 months, did you have any difficulties or delays because of issues related to cost?
1.______ Yes
2.______ No
3.______ Don't know

4.5 During the past 12 months, did you have any difficulties or delays because you had trouble getting the information you needed?
1.______ Yes
2.______ No
3.______ Don't know

4.6 During the past 12 months, did you have any difficulties or delays for any other reason?
1.______ Yes (Specify: ______________________)
2.______ No
3.______ Don't know

4.7 During the past 12 months, how often have you been frustrated in your efforts to get services for your child?
1.______ Never
2.______ Sometimes
3.______ Usually
4.______ Always
5.______ 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.

4.8 Has your child's autism caused financial problems for your family?
1.______ Yes
2.______ No
3.______ Don't know

4.9 Have you or other family members stopped working because of your child's autism?
1.______ Yes
2.______ No
3.______ Don't know

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

1.______ Yes
2.______ No
3.______ Don’t know

STIGMA

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

4.11 I feel helpless for having a child with autism.
1.______ Strongly disagree
2.______ Disagree
3.______ Agree
4.______ Strongly agree

4.12 I worry if other people would know I have a child with autism.
1.______ Strongly disagree
2.______ Disagree
3.______ Agree
4.______ Strongly agree

4.13 Other people would discriminate against me because I have a child with autism.
1.______ Strongly disagree
2.______ Disagree
3.______ Agree
4.______ Strongly agree

4.14 Having a child with autism imposes a negative impact on me.
1.______ Strongly disagree
2.______ Disagree
3.______ Agree
4.______ Strongly agree

QUALITY OF LIFE

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

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?
1.______ A little important
2.______ Important
3.______ Very important

4.16 How satisfied am I with the support my child with autism gets to make progress in school?
1.______ Very dissatisfied
2.______ Neutral

3.______ Very satisfied

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?
1.______ A little important
2.______ Important
3.______ Very important

4.18 How satisfied am I with the support my child with autism gets to make progress at home?
1.______ Very dissatisfied
2.______ Neutral
3.______ Very satisfied

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?
1.______ A little important
2.______ Important
3.______ Very important

4.20 How satisfied am I with the support my child with autism gets to make friends?
1.______ Very dissatisfied
2.______ Neutral
3.______ Very satisfied

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?
1.______ A little important
2.______ Important
3.______ Very important

4.22 How satisfied am I with the relationship with the service providers who work with my child?
1.______ Very dissatisfied
2.______ Neutral
3.______ Very satisfied

CHALLENGES & PRIORITIES

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.*
1.______ Challenging behaviors (i.e. self-injury, aggression, tantrums)
2.______ Daily living skills (i.e. toileting, self-feeding)
3.______ Health problems (i.e. co-occurring physical and/or mental health conditions)
4.______ Sleep problems (i.e. trouble falling asleep, trouble staying asleep)
5.______ Diet/eating/feeding difficulties
6.______ Social interaction difficulties

7.______ Repetitive behaviors/restrictive interests/insistence on sameness
8.______ Communication difficulties
9.______ Safety concerns (i.e. wandering, climbing)
10._____ Sensory issues
11._____ Other (Specify:______________________)

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.*
1.______ Making sure my child receives adequate health care
2.______ Making sure my child receives adequate education
3.______ Making sure my child receives adequate welfare / social supports
4.______ Making sure my child's basic rights are protected
5.______ Making sure my family and I receive adequate respite
6.______ Other (Specify:_______________________)

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.*
1.______ Improved health care services
2.______ Improved education services
3.______ Improved welfare / social services
4.______ Greater rights for individuals with autism
5.______ More information about autism
6.______ Greater in-home support
7.______ Greater community awareness
8.______ Greater opportunities for parent interactions / networking
9.______ Other (Specify:_______________________)

Thank you for your time!

References

Anonymous (12 Aug. 2015). Autism Spectrum Disorder. *CDC.* Retrieved from http://www.cdc.gov/ncbddd/autism/treatment.html

Anonymous (15 Sept. 2016). Medicines for Treating Autism's Core Symptoms. *Autism Speaks*. Retrieved from https://www.autismspeaks.org/what-autism/treatment/medicines-treating-core-symptoms

Anonymous (2016). About. *ASAN.* Retrieved from http://autisticadvocacy.org/home/about-asan/

Anonymous (2016). About NAC. *NAC.* Retrieved from http://www.nationalautismcenter.org/

Anonymous (2016). A History of Autism. *WebMD.* Retrieved from http://www.webmd.com/brain/autism/history-of-autism?page=3

Anonymous (2016). Mission. *Autism Speaks*. Retrieved from https://www.autismspeaks.org/about-us/mission

Anonymous (2016). Top 8 Autism Therapies. *Autism Speaks.* Retrieved from https://www.autismspeaks.org/blog/2012/09/25/top-8-autism-therapies-%E2%80%93-reported-parents

Anonymous (2016). Treatments. *Autism Speaks.* Retrieved from https://www.autismspeaks.org/family-services/tool-kits/100-day-kit/treatments-therapies

(2016). "Websites For Families." *Autism Speaks.* Retrieved from https://www.autismspeaks.org/family-services/resource-library/websites-families

Anonymous (2016). Where Autism Professionals Connect. *Network Autism.* Retrieved from http://network.autism.org.uk/

Anonymous (23 Feb. 2016). 10 Years of Progress: What We've Learned About Autism. *Autism Speaks.* Retrieved from https://www.autismspeaks.org/news/news-item/10-years-progress-what-we039ve-learned-about-autism

Anonymous (3 Oct. 2016). Autism Spectrum Disorder. *CDC.* Retrieved from http://www.cdc.gov/ncbddd/autism/index.html

Braus, P. (2014). Autism. *The Gale Encyclopedia of Science*. Retrieved from http://ic.galegroup.com.ezproxy.wpi.edu/ic/scic/ReferenceDetailsPage/ReferenceDetailsWindow?disableHighlighting=&displayGroupName=Reference&currPage=&dviSelectedPage=&scanId=&query=&source=&prodId=&search_within_results=&p=SCIC&mode=view&catId=&u=mlin_

c_worpoly&limiter=&displayquery=&displayGroups=&contentModules=&action=e&sortBy=&documentId=GALE%7CCV2644030211&windowstate=normal&activityType=&failOverType=&commentary=

Morocco World News (2014). Autism: Experts Say The Syndrome Is Better Understood Now Than Ever Before. *Morocco World News.* Retrieved from https://www.moroccoworldnews.com/2014/12/147048/autism-experts-say-the-syndrome-is-better-understood-now-than-ever-before/

Morocco World News (2016). Autism in Morocco: The Hidden Facts. *Morocco World News.* Retrieved from https://www.moroccoworldnews.com/2016/02/180008/autism-morocco-hidden-facts/

Mostafa, E. (29 Aug. 2016). NGO Law Monitor: Morocco. *ICNL.* Retrieved from http://www.icnl.org/research/monitor/morocco.html

Purdy, E. (2008). Autism. *Encyclopedia of Global Health, 4, 187-192*. doi: 10.4135/9781412963855.n132

Sabir, B., Dr. (3 July 2015). A Cross Sectional Descriptive Research on Prevalence of Communication Disorders in Morocco through Speech-Language Therapist Survey. *E-Science Central.* Retrieved from http://www.esciencecentral.org/journals/a-cross-sectional-descriptive-research-on-prevalence-of-communicationdisorders-in-morocco-through-speechlanguage-therapist-survey-2375-4427-1000138.pdf

Shabib, A.G. (1 Jan. 2006). الخصائص ما بالتوحد المصابين للأطفال والعقلية والاجتماعية النفسية الخصائص الآباء نظر وجهة من بالتوحد المصابين للأطفال والعقليـــة والاجتماعيـة النفسيـة. *Virtual Academy Open Learning Britain.* Retrieved from http://www.abahe.co.uk/Research-Papers/Autism.pdf

Sirry, A. *Map of autism centers in Morocco* [map]. (scale not given.) 2016.

Touhami, M., Ouriaghli, F., Manoudi, F., & Asri, F. (4 May 2011). P01-360 - Autism and violence. *European Psychiatry, 26*, *362*. doi:10.1016/s0924-9338(11)72071-5