A Look into the Current State of Autism in Morocco

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To Benefit Autism Speaks
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Abstract

Autism affects an estimated half a million people, but only 20% are diagnosed and even fewer receive treatment or services. This project surveyed caregivers of autistic children to gauge the level of awareness of autism spectrum disorder, as well as the scope of services and treatments offered in Morocco. We interviewed families and professionals and gathered information from autism centers. With this information, we compiled a database and report for Autism Speaks that can identify areas of improvement for care.

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Executive Summary

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التوحد، مرض نفسي، يصيب الأطفال، ويحد من قدرتهم على الارتباط بالمجتمع الخارجي، ومن التواصل بشكل سليم مع الآخر. معظم الآباء بإقليم تيزنيت و في المغرب عامة لا يدركون مرض أطفالهم حتى سن بين الرابعة والخامسة، حين

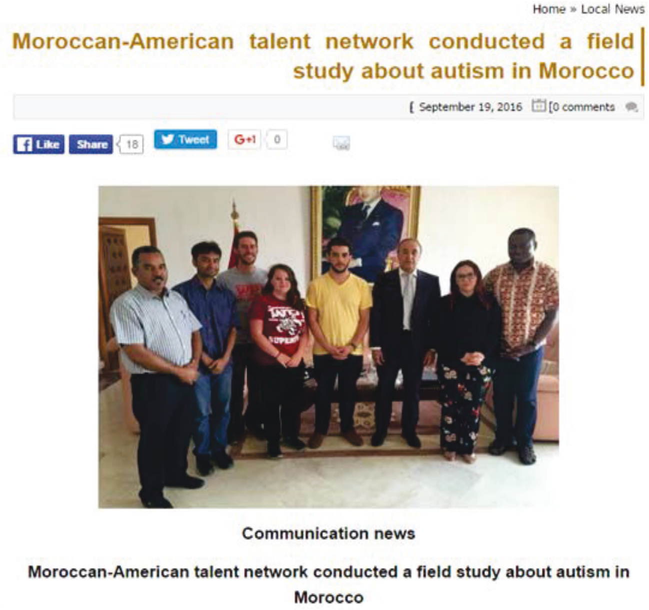
News articles about team's work (in Arabic)

Autism in Morocco

In Morocco, it is not clear if there is consistent diagnosis or even awareness of autism spectrum disorder. Even if a child is accurately diagnosed, treatment can be limited and or even inaccessible to families. It is currently estimated that roughly half a million people between all ages are affected with this condition in Morocco, but only 20% of those affected actually receive special care or treatment. There has not been much previous research done on the state of autism in Morocco, so there is no official statistical data (Mrs.Soumia Amrani, 2014). Therefore, research still needs to be done including: finding out how prevalent autism is throughout the country, what treatment people with autism can get, and the ability of doctors to diagnose all ranges of the spectrum.

Summary

The goal of this project was to start conduct research for Autism Speaks by collecting data about the kind of care and benefits autistic children are receiving in Morocco. We utilized the Caregiver Needs Survey given to us by Autism Speaks to hold in-person interviews in the cities of Tiznit, Agadir, Biougra, Taroudant, Ouarzazate, Skoura, and Casablanca. This survey helped identify what facilities and care autistic children are currently receiving, and, most importantly, what they are lacking. With this infomation, Autism Speaks will be able to propose the required treatment and healthcare plans that the autistic population of Morocco sorely need.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Communication news

Moroccan-American talent network conducted a field study about autism in Morocco

Another news article, including picture with the governor of Tiznit

An Interactive Qualifying Project submitted to the faculty of Worcester Polytechnic Institute in partial fulfillment of the requirements for the Degree of Bachelor Science.

The team with two translators we worked with in the Tiznit region

What is Autism?

Autism, or autism spectrum disorder (ASD), is a group of brain development disorders. The ASD diagnosis is very broad, as there are many different subtypes of autism, each having a wide range of severities. These subtypes are: autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger Syndrome ("Autism Spectrum Disorder," n.d.). Each type of autism used to be its own diagnosis, but they were all grouped into the general diagnosis of ASD in May 2013.

The basic symptoms associated with autism spectrum disorders are difficulties with social interaction and communication, and repetitive behavior. The severity of these symptoms can vary greatly, making every case very different. Certain unusual behaviors, or not showing expected developmental behaviors, can often be the indicators that a child may possibly have autism. Both parents and doctors should be on the lookout for any of these indicators. Evaluations are typically done by multi-person teams, with each person being of a different discipline. This team should include a pediatrician, a psychologist, a speech and language pathologist, and an occupational therapist. Sometimes genetics testing and screening for autism related medical issues is recommended. Extensive testing is required so that parents can understand their child's unique form of autism and his or her specific strengths and needs, and so that they can receive the proper care ("How is Autism Diagnosed," n.d.).

Autism Speaks

The network of care for children with autism extends beyond simple healthcare. Organizations have emerged to help direct families and caregivers to necessary resources, support groups, learning tools, and relevant information. The most prominent organization, founded in 2005, is Autism Speaks. Their mission statement is as follows:

"Autism Speaks aims to bring the autism community together as one strong voice to urge the government and private sector to listen to our concerns and take action to address this urgent global health crisis. It is our firm belief that, working together, we will find the missing pieces of the puzzle" ("Mission", n.d.).

This NGO was founded by Bob and Suzanne Wright in 2005. They were the grandparents of a boy named Christian who was diagnosed with autism. Since its founding it has merged with three different autism organizations and has become the leading organization of autism science and advocacy around the world. The organization is still looking to spread its reach worldwide, especially to regions and countries still lacking in autism care and treatment (Autism Speaks History, n.d.).

Methodology

Our goal was to provide Autism Speaks with a report of statistical and ethnographic data on the needs and resources of families with autistic children in Morocco. We accomplished this goal by meeting the following objectives and deliverables:

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

Deliverables: Database and Report

Autism Speaks provided the team with two surveys to use in Morocco: a professional survey meant for any specialists in the field of autism, and a caregiver survey for families affected by autism. In-person interviews were held in facilities for disabled or autistic children in order to conduct the caregiver surveys. A sample of convenience was used for the surveys. The professional survey provided by Autism Speaks was used to interview teachers and autism professionals including experts and doctors. A sample of convenience and snowball sampling identified our participants. A sample of convenience was used for the surveys and each team member worked with a translator to overcome any language issues, since most families interviewed did not speak English.

Throughout and after the in-person interviews, we collected personal stories that families were willing to share. This generated informal data to add to the report for Autism Speaks for a better overview of the state of autism care in Morocco. The team also interviewed Oum Keltoum Dialmy, author of the book Parole d'Autiste, to learn the story of her experience with an autistic child.

Spenser Martin conducting an interview with a caregiver

Results

A caregiver needs survey, professional survey, and personal stories from families were all used to collect information of the current state of autism care and awareness in Morocco. 183 caregiver surveys and 24 professional surveys were conducted. Within the 183 caregiver surveys there were 123 in which the child was currently diagnosed with autism while the other 60 were undiagnosed or they fell into other categories.

Improper Diagnosis

Major highlights from the data collected showed that children with autism or other disabilities have not been receiving proper diagnosis, as most children remain undiagnosed or have other disabilities that had originally been wrongly diagnosed as autism. Many comments from parents pointed towards the fact that doctors did not know much about disabilities, so they just treat them all the same and lump them under one general diagnosis of "autism." Some examples of this were shown in children that had Down syndrome, mental retardation, and even paralysis, but were told to just treat it as autism. Reasons for the improper diagnosis that came up were that most professionals only had high school degrees (not university degrees) and very little experience, and more specialized doctors are very far away from families. Many families had to travel over two hours to receive a proper diagnosis for their child, and not all families have the ability or means to do that.

Lack of Resources

More findings also further highlighted a lack of resources for autism in Morocco. If children do get properly diagnosed, they have little chance of receiving treatment. Speech therapy was the only type of treatment that a significant amount of children were participating in out of all those listed in the survey. A large majority of families agreed to having difficulties and delays getting services due to services not being available in their area and a lack of information. When children did receive services, most of the time they were provided by teachers in schools for children with disabilities and parents were unsure of the quality of this care or what specifically their children were receiving. From this data we can deduce that the cities we have visited and interviewed in lack the health care and services that families with autistic children are looking for. People do not have easy access to information and the lack of specialists and doctors in the field mean that children with autism are not receiving sufficient care.

Mackenzie Miner conducting an interview with a caregiver

Financial Struggles

Our data has also revealed that there is a huge financial struggle for most families who have a child with autism. Some families mentioned that they either wanted to or had cut down on hours of work to give more attention to their children, many of those same families mentioned that this was a necessity, but also very difficult due to the cost of sending their child to a special school.

It is also interesting to note that when asked about services the child had received in the past and the services the child currently receives, most of the time there would be a huge decrease. One reason for this is that the families wanted to try the services, but then found out they were too expensive. The cost of these services also seems to be gradually increasing not only as the years go by, but also as the age of the child goes up. When asked more about the financial struggles another issue began to arrive: the stigma behind having a child with autism.

Hamza Hachim conducting an interview with a caregiver

Parent and Caregiver Perception

The topic of stigma is especially interesting because it directly correlates with our background research. Most people didn't worry about whether people knew that they had a child with autism because they are proud of their child no matter what, but many did feel like they would be discriminated against. Many times when parents answered yes to this question, they did so very forcefully, indicating that the discrimination is a large problem. Even with this problem, though, we received a very mixed set of answers when we asked if having a child with autism has had a negative impact on their lives instead of the anticipated majority result of yes. One very popular answer that we didn't expect was "it's God's will." Because of this answer and their love for their children, the parents felt as though they could not complain or speak ill of the situation. They then answered no even when we had believed their answer would be a yes based on the rest of the survey. This feeling that they could not answer honestly could have caused skewed the data and caused the surprising results.

Challenges and Priorities

The caregiver survey also provided insight into the challenges and priorities of the families. The top five challenges to caring for a child with autism, in order, were: safety concerns, challenging behaviors, communication difficulties, daily living skills, and social interaction difficulties. The top five challenges caregivers face in getting support for their children, in order, were: making sure the child receives adequate education, making sure the child's basic rights are protected, making sure the child receives adequate health care, making sure the child receives adequate welfare/ social supports, and making sure the family receives adequate respite. The top five greatest priorities for families affected by autism, in order, were: greater rights for individuals with autism, improved education services, improved health care services, greater community awareness, and improved welfare/ social services.

Comparison between Autism Data and Overarching Data

When the data was separated based on the results of those on the autism spectrum we immediately noticed that the data, in most cases, did not change by a significant amount. Many of the percentages only changed by one or two percent. When we discussed this as a team, we came up with a few reasons. The first which is the most plausible is that a significant portion of the undiagnosed population did, in fact, have autism. This becomes interesting because it would point to the slight lack of proper diagnosis based on the amount of professionals available. For many families it is true that finding a professional to medically diagnose their child is extremely difficult, leaving some child undiagnosed for most of their life. Another possibility is that children with disabilities are all going through the same struggles, whether it is autism or not. It is also plausible that the population of undiagnosed children was not statistically significant enough to alter the data in a drastic way. If the population size was bigger, the undiagnosed data would have a bigger impact.

Mohammed Masrur Rahman conducting an interview with a caregiver

It is also important to note that some major differences between the two data sets did appear, however many of these points were unsurprising. One of these differences is the age of first concern, which jumped by about half a year from the overarching set to the autism set. This is not surprising because the age jumped to the expected value of about two years. (The same number we found in our initial literature review).

Another difference is the percentage of children seeing service providers, which decreased in percent for nearly all the types of service providers when comparing the overarching data to the autism data. This difference however is somewhat surprising because we would expect that once a child is diagnosed with autism they would see more professionals, but this is not true according to our data. This trend may hint toward a need for awareness of how to treat autism.

Results vs. Expectations

Overall, the results we found from this study were what we expected after our initial background research. The answers from the survey and stories we heard backed up the fact that most families in Morocco do not have access to proper diagnosis or services for their autistic children, and that there is a negative stigma surrounding autism that the families are very aware of.

Recommendations

From our research, we concluded that the status of autism care in Morocco has the opportunity to improve in several factors, not only in terms of professionals, but also in terms of available treatments and therapies. Due to this, our recommendations are as follows:

- Find opportunities to advance the training for specialists (including medical staff and teachers) in Morocco
- Encourage more doctors to specialize in autism care
- Distribute information about autism and autism care throughout Morocco
- Enhance or reinvigorate the current autism centers, special schools, and facilities in Morocco to better their current services and offer new ones, especially in rural areas
- Set up centers for diagnosis in regions where access to healthcare could be improved
- Set up further programs to help educate families with autistic children
- Lobby the government to subsidize autism related programs and insurance programs to include autism services and treatment

Once these recommendations are put into action, access to knowledge and care regarding autism should slowly increase, allowing a better quality of life for not only the autistic children but their families as well.

Conclusion

Being able to understand and communicate with your own child, it's an ability most parents develop very quickly, without even having to think about it. Some, though, aren't so lucky. Parents of autistic children in Morocco struggle with this task every single day, and see no help in sight. They're desperate to find help for themselves and help for their children, but don't have anywhere to turn. Their requests are simple, for their children that they love so dearly to live normal, happy lives with the same rights and opportunities as everyone else. For their children to have what others so easily take for granted: education, healthcare, and civil liberties. Our research should allow Autism Speaks to set up programs to provide this help to the people of Morocco, relieving some of these struggles and helping to enrich the lives of those affected by autism.

The team training translators in preparation for caregiver interviews

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Each and every family interviewed: for taking time out of their days to help us conduct our research
Our advisors: Professor Ingrid Shockey and Professor Gbetonmasse Somasse

Authorship List

Chapter and Section Number	Primary Author(s)
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2.0 Introduction	Spenser
2.1 What is Autism?	Mackenzie
2.2 Autism Speaks	Masrur
2.3 Diagnosis of Autism	Mackenzie
2.4 The Situation of Autism in Morocco	Hamza, Spenser
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1. Introduction

Autism spectrum disorder and autism are both terms used to describe a group of complex disorders of brain development. These disorders are characterized by difficulties in social interaction, verbal and nonverbal communications, and sometimes can include repetitive behaviors. From what scientists know so far, autism spectrum disorder, or ASD, starts during early brain development, and signs begin to show between two and three years of age. Globally, it currently affects about one percent of the population, or around seven million people, which is a much larger number than previous years. From 2002 to 2010, this statistic has increased by six to fifteen percent each year. ("Facts and Statistics", 2015). The increase is alarming, and means that care for ASD needs to increase as well.

Ideally, with autism being so prevalent throughout the world, every child would receive a timely diagnosis and proper treatment. This would allow families and caregivers to understand the child's specific form of autism and give them a better chance at living a normal, happy life. In reality, however, not every child that has autism is diagnosed at a young age, or even at all. If they are, they may not have access to treatment, especially in less developed countries.

In Morocco, it is not clear if there is consistent diagnosis or even awareness of autism spectrum disorder. Even if a child is accurately diagnosed, treatment can be limited and or even completely inaccessible to families. It is currently estimated that roughly half a million people between all ages are affected with this condition in Morocco, but only 20% of those affected actually receive special care or treatment. There has not been much previous research done on the state of autism in Morocco, so there is no official statistical data, just the estimations (Amrani, 2014). Therefore, research still needs to be done, such as: finding out how prevalent autism is throughout the country, what treatment people with autism can get, and the ability of doctors to diagnose all ranges of the spectrum. The goal of this project was to start some of this research for the company "Autism Speaks" by collecting data about the kind of care and benefits autistic children are receiving in Morocco.

Autism Speaks is an autism advocacy agency founded in the United States. Its efforts are dedicated to sponsoring autism research and conducting awareness and outreach activities aimed at families and governments worldwide. The agencies main goal is: "*to accelerate and fund* *biomedical research into the causes, prevention, treatments and cure for autism spectrum disorders; to increase awareness of the disorder; and to improve the quality of life of affected individuals and their families*" (Autism speaks history, n.d.). Autism Speaks funds its campaigns and researches by raising money through walk programs, retail partners, events and major gifts.

In order to conduct this research, we utilized a "Caregiver Needs Survey" and a "Professional Survey" given to us by Autism Speaks to hold in-person interviews in the cities of Tiznit, Agadir, Biougra, Taroudant, Ouarzazate, and Casablanca. The surveys helped identify what facilities and care autistic children are currently receiving, and, most importantly, what they are lacking. The Caregiver Survey was given to people who were thought to have autistic children or have ties to them, and the Professional Survey was given to professionals who work with disabled children. The information collected was then processed into statistical data that was given to Autism Speaks. With this data, Autism Speaks will be able to propose the required treatment and healthcare plans that the autistic population of Morocco sorely need.

2. Literature Review

In Morocco, autism seems to have little recognition and unreliable diagnosis. When a diagnosis is found, it is very difficult to overcome cultural prejudices surrounding autism and even more difficult to find the proper care or treatment. In this chapter, we define autism spectrum disorder, explain why autism is becoming increasingly important, and then look more specifically at autism in Morocco.

2.1 What is Autism?

Autism, or autism spectrum disorder (ASD), is a group of brain development disorders. The ASD diagnosis is very broad, as there are many different subtypes of autism, each having a wide range of severities. These subtypes include: autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger Syndrome ("Autism Spectrum Disorder," n.d.). Each type of autism used to be its own diagnosis, but they were all grouped into the general diagnosis of ASD in May 2013.

Autism can be caused by a variety of things, usually a combination of rare gene mutations, also known as "autism risk genes," and environmental factors that can influence brain development. Sometimes a mutated gene alone can cause autism, but usually it just causes a predisposition, and then environmental stresses amplify the risk. These risk factors can occur either before or during birth and include: advanced age of the parents at the time of conception, the mother being ill while she is pregnant, and complications during birth (usually involving oxygen deprivation) ("What Is Autism", n.d.). There are more speculative causes of autism, but they have yet to be proven.

Every case of autism is unique and individuals can fall anywhere on the fairly wide spectrum. Many people with autism are also known to have above average visual, music, and academic skills, and about 40 percent have an above average intelligence. Some however, have more severe cases and cannot live independently. For example, 25 percent of people with ASD are nonverbal, so they must learn to communicate through other means ("What Is Autism," n.d.). One way of visualizing the spectrum is depicted below in Figure 1.

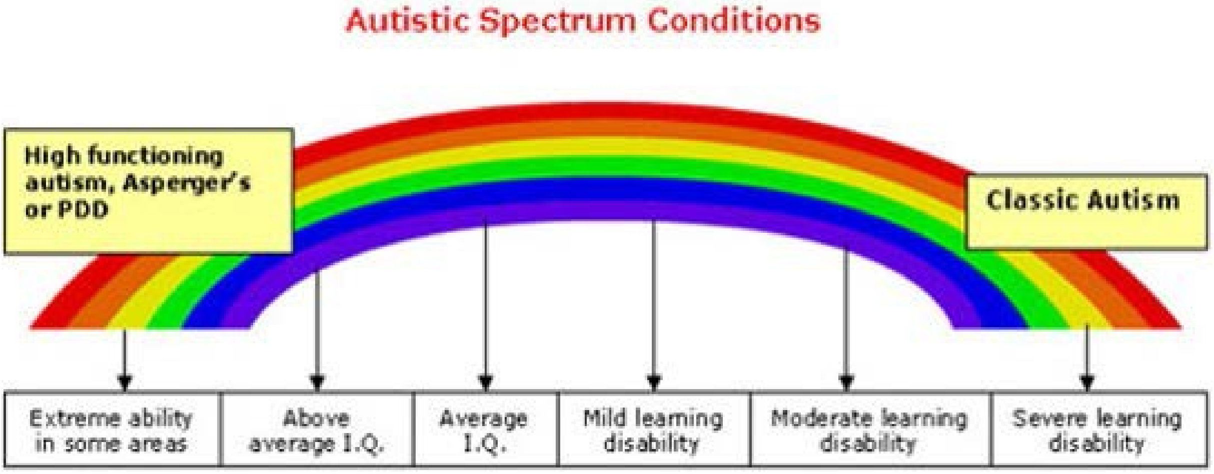


Figure 1: The range, or spectrum, of functionality of people with autism
(Autism Spectrum Conditions [Digital image], 2013)

As shown in Figure 2, the prevalence varies throughout areas of the world, but people are affected by the disorder nearly everywhere. For example, according to the U.S. Centers for Disease Control and Prevention (CDC), about 1 in 68 children in America are somewhere on the autism spectrum. This statistic is differentiated by gender: 1 in 42 boys and 1 in 189 girls, indicating that autism is 4 to 5 times more common in boys than in girls ("Autism Prevalence," n.d.).

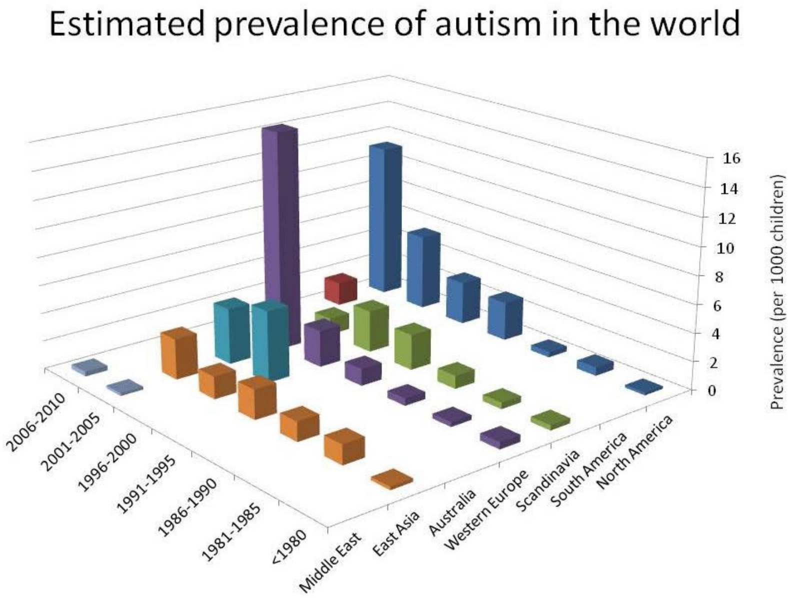


Figure 2: Prevalence of autism in the world
(Estimated prevalence of autism in the world [Digital image], n.d.)

Figure 2 also indicates that the number of people diagnosed with autism globally is steadily rising. In fact, the number of people diagnosed with autism has increased 10 to 17 percent annually in recent years.

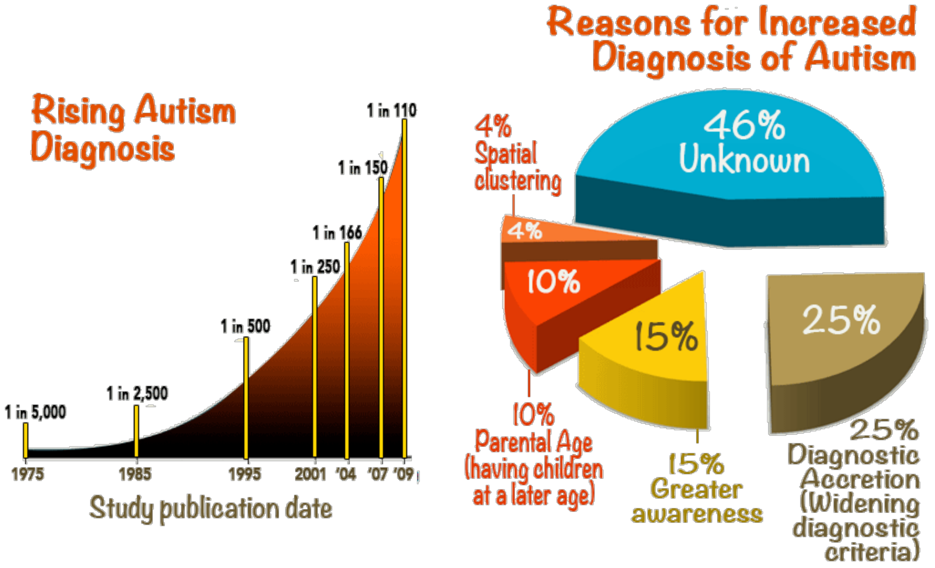


Figure 3: The rise of autism diagnosis and reasons for this rise
(Autism rises. Why? [Digital image], n.d)

The cause for this increase is unknown, but two prevalent factors are thought to be improved diagnosis techniques and environmental causes ("What Is Autism," n.d.). Other possible factors and more data about the rising cases of autism are shown in Figure 3. Though the cause of the increase is unknown, the increase alone should be enough for people to realize that action has to be taken, the first step in taking action is recognizing autism ("Autism rises.Why?" n.d.).

2.2 Symptoms of Autism

The basic symptoms associated with autism spectrum disorders are: difficulties with social interaction and communication, and repetitive behavior. The severity of these symptoms can vary greatly, making every case very different.

Symptoms of autism can be shown as soon as 8 to 10 months of age, when infants do not show the typical interest in people and the world that other infants do. They also tend not to use gestures or sounds to communicate as early as other infants, and some experience significant language delays, often requiring therapy. Later on, as toddlers, autistic children may not be able to play games with other children or imitate actions to learn. In fact, they may not want to be around others at all. Similarly, they may not want comfort, and may not respond to their parent's displays of anger or affection in expected ways ("Symptoms," n.d.).

Autistic individuals often also lack the ability to understand social cues, body language, and the fact that people view the world differently than they do and have different thoughts, goals, and feelings. Some may have difficulty regulating their emotions, and so inappropriate outbursts are common. These outbursts could range from crying to violence and aggressiveness, and could sometimes result in self-harm ("Autism Spectrum Disorder," n.d.).

Unfortunately, because autistic children cannot respond to their parents' displays of affection or go along with normal social cues, they tend to come across as being very disconnected. This may make it may seem like they do not like people, which can be very upsetting to the friends and family that love them. However, studies show that autistic children do feel attachments to people, especially their parents. They just most likely will not show their affection in expected or understood ways ("Symptoms," n.d.).

Another core symptom of autism is unusual, repetitive behavior. One example is that a child may spend hours lining up toys in a specific way instead of playing with them. Adults may show this behavior through making sure every household object is in a specific place ("Symptoms," n.d.). The repetitive behavior also means that autistic people need an extremely consistent routine and environment, and can also manifest in the form of having obsessions for an unusual topic.

Certain medical conditions and challenges are also known to come with autism, including gastrointestinal disorders, seizure disorders, sleep dysfunction, sensory processing problems, and pica (a tendency to eat things that are not food, such as dirt, clay, chalk, or paint chips) ("Physical and Medical Issues Related to Autism Spectrum Disorders," 2015). These, too, will vary in severity.

There is no cure for autism, but therapies can help to reduce the symptoms and increase the skills that individuals are lacking due to their autism. Furthermore, no medical test has been created to diagnose autism, so physicians and psychologists must be trained to give certain behavioral evaluations in order to correctly identify it. Before the evaluations, though, the child must be identified as possibly having autism. Both parents and doctors should be on the lookout for indicators.

Early warning signs include the child not wanting to make eye contact, playing with toys in odd and repetitive ways, and not responding to his or her name. Doctors should also screen every child for developmental milestones from birth to 36 months. Developmental red flags, according to Autism Speaks, include:

- *"No big smiles or other warm, joyful expressions by six months or thereafter*
- *No back-and-forth sharing of sounds, smiles or other facial expressions by nine months*
- *No babbling by 12 months*
- *No back-and-forth gestures such as pointing, showing, reaching or waving by 12 months*
- *No words by 16 months*
- *No meaningful, two-word phrases (not including imitating or repeating) by 24 months*
- *Any loss of speech, babbling or social skills at any age"* (Learn the Signs of Autism, n.d.)

Children exhibiting any of these signs should be referred to a specialist as soon as the concerns come up. The specialists can then conduct hearing and lead-exposure tests, and use specific autism screening tools. Information from parents and teachers is also important ("Diagnosis," n.d.).

Evaluations are typically done by multi-person teams, with each person being of a different discipline. This team should include a pediatrician, a psychologist, a speech and language pathologist, and an occupational therapist. Sometimes genetics testing and screening for autism related medical issues is recommended. Extensive testing is required so that parents can understand their child's unique form of autism and specific strengths and needs, and so that they can receive the proper care ("How is Autism Diagnosed," n.d.).

Autism can be diagnosed at any stage in life. A later diagnosis is usually after noticing learning, social, or emotional difficulties. The diagnosis of adolescents and adults involves an interview by a trained specialist and personal observation, just as with young children. Even late diagnosis is shown to increase the quality of life for those with autism, because it can give them access to needed therapies and assistive technologies, or just even provide them with some piece of mind after struggling for unknown reasons ("How is Autism Diagnosed," n.d.).

2.3 Resources for Treatment: Autism Speaks

The network of care for children with autism extends beyond simple healthcare. Organizations have emerged to help direct families and caregivers to necessary resources, support groups, learning tools, and relevant information. The most prominent organization, founded in 2005, is Autism Speaks. Their mission statement is as follows:

> *"Autism Speaks aims to bring the autism community together as one strong voice to urge the government and private sector to listen to our concerns and take action to address this urgent global health crisis. It is our firm belief that, working together, we will find the missing pieces of the puzzle"* ("Mission", n.d.).

This NGO was founded by Bob and Suzanne Wright in 2005. They were the grandparents of a boy named Christian who was diagnosed with autism. Since its founding it has merged with three different autism organizations and has become the leading organization of autism science and advocacy around the world. The organization is still looking to spread its reach worldwide, especially to regions and countries still lacking in autism care and treatment (Autism Speaks History, n.d.).

2.4 The Situation of Autism in Morocco

It is currently estimated that half a million people in Morocco have autism. Unfortunately, in terms of providing treatment and services for people with autism, the country is considered to be fifty years behind the current treatment in more developed countries, such as the United States. Only an estimated 20% (108,000 autistic) receive treatment or any other special care (Azmani, 2015). This percentage is low and concerning, and is the result of many factors, such as lack of awareness and overpriced treatments.

Being born autistic and living in Morocco is "dreadful", according to "Le Matin" in one of their articles. Families have to fight daily in a society where autism is not yet recognized or accepted. The government has done its best to provide the right treatment and services, but it needs more help to provide better services. The average age when is autism detected or diagnosed is 3 to 4 years old (Hafidi, 2014). Despite the fact that there are only two special centers that host and receive autistic kids for care and treatments, many active organizations, such as Autism Speaks and "Vaincre l'autisme Maroc," are working to provide the right treatments and spread awareness as much as possible in different cities.

As far as data goes in Morocco, there are few sources and studies that reveal statistics on autism, the few that we found paint a lacking picture of autism care and resources (Amrani, 2014). These same sources also point to the fact that any care that exists is also very expensive and because of that the vast majority of the population cannot access it.

As noted in the section above, autism in Morocco is poorly recognized or diagnosed despite the countries best efforts. A look into the culture of Morocco itself may be able to explain this. In general, autism is not only rarely diagnosed, but children who are autistic are treated as outcasts (Hart, 2012). A sizeable portion of the population views autistic kids as "crazy." A dialogue between a school teacher and an interviewer shows just one view of the subject. The teacher is cited saying:

*"'Excuse me, but these children are little crazy people (des petits fous)," Jamila continues. 'Yes or no? I mean – we never called this autism before… Frankly, we would say, he is crazy (fou). She is crazy. But now, when certain parents were affected (touché), they found this word: autism. But it's not true'" (*Hart, 2012).

This quote shows that people still share different ideas of illness, even referring to the disability or mental handicap together under the category "crazy". Because of this view, autism is barely mentioned in the press or mass media networks and the culture, specifically in more rural areas, has retained more traditional views and values, especially when it comes to mental disorders or illnesses (Aitlekhoui, 2016).

That being said, there is a group of people who have a different view, as indicated in this quote from *Moroccan World News*: "In Morocco, autism is still considered a topic best discussed away from the public arena. Some people say that is a handicap, while others claim that is an illness. The fact is that it is neither an illness nor a handicap, but a spectrum." The people that share this view have most likely been informed of autism or have strayed away from the traditional view, but just as the quote states, they still do not see autism as a spectrum. This means that although they do have some idea of what autism is, they still do not know enough to help those with autism.

As a country, Morocco has not yet developed a plan or system for helping children diagnosed with autism or their families. According to a recent article, autistic children face two major obstacles. First, there is no statewide healthcare system. Most of the care given to autistic children comes from a “carer” or another person who acts as a babysitter for the autistic child throughout the day. The lack of knowledge and a consistent health care system also presents the challenge of uniform treatment or care. Many of these “carers” have been trained in different parts of Morocco, and because of that, the care they provide is not always the same and may vary quite drastically (Hart, 2012). In an interview, Mrs. Soumia Amrani, one the biggest disability activists in Morocco and the primary vice-president of Moroccan Collective for Promoting Handicap Rights, mentioned that there is a huge gap in the quality of care that many autistic children receive. When her own 8-year-old daughter was diagnosed with autism, she realized that her daughter, and other autistic children, had potential, but they had no one to help unlock that potential, referring to the lack of professionals who care for autistic children.

The lack of a healthcare system brings upon another challenge: money. For many families in Morocco, caring for an autistic child brings a huge, and sometimes unbearable, financial burden. Sadly, many families forgo this care because of the financial difficulties. In almost all cases, the institutions that do care for autistic children have to be paid out-of-pocket by the family. Monthly fees for these institutions can range from 1000-2000 dirhams, which is equal to about 90-200 US dollars. This amount greatly surpasses the average Moroccan family’s income, so most have no hopes of affording the care (Aitlekhoui, 2016).

A second challenge facing autistic children in Morocco is integrating into the school system. The few schools that have a program for autistic children only have a very small one, usually one classroom. These programs are led by local organizations, which leaves a lot of room for variation in care and education. On top of the small amount of opportunities for care, the number of professionals who are qualified to work with autistic children is even smaller. This is due to the state's lack of interest in the matter: they do not invest in the training and certification of these professionals (Aitlekhoui, 2016). In general, autistic children remain largely marginalized because of the misunderstanding of autism as well as the weakness of technical and educational tools adapted by the teaching staff.

In most cases, schools will not accept students who show obvious signs of autism because they lack the resources to care for autistic children. Those autistic children that do get into schools become alienated. They are left out by not only their peers but also the teachers who cannot afford to cater to one child. This does not help the child at all and in some cases can be very negative for the child. Sadly, this is a reality for many autistic children in Morocco; as a whole, the educational system still needs help before it can provide care and education to autistic children (Hart, 2012).

2.5 A Case Study in Success: Autism Screening in Bangladesh

Before proper care and treatment can be administered to an autistic child, it is important that the people are aware of autism and can easily identify the symptoms of autism. Research has shown that a simple screening test is both practical and effective in identifying autism and other neurodevelopmental disorders ("Advancing Autism Screening in Developing Countries," n.d.). For example, a study (Khan et al., 2014) carried out in the capital of Bangladesh and funded by Autism Speaks, focused on the use of the RNDA, or Rapid Neurodevelopmental Assessment. The study showed that it is not only professionals who can identify autism.

The "Rapid Neurodevelopmental Assessment" is a 53-question checklist that can be used as a screening tool by non-experts. The questions are presented in a yes/no format and focus on developmental milestones. The study (Khan et al., 2014) in Bangladesh showed that, after just a two week training course, therapists without college degrees and special education teachers without experience could "reliably and consistently" administer the RDNA to children aged from 5 to 9 years old and the ones who may benefit from behavioral therapy. Out of the test group of 100 Bangladeshi children, about one third were identified as having neurodevelopmental disabilities.

The researchers were then able to give guidance to the parents on home-therapy activities, provide counseling for the families, and refer the children to specialists for a full evaluation. The study also showed that educating and counseling the parents to reduce their stress is extremely important in improving child development in poorer communities. An earlier study (Khan et al., 2013) showed that the RDNA is also effective on toddlers and preschoolers.

2.6 Summary

Autism is still not fully understood. Methods of education that seem to work for one child may not work at all for another. Generalizing a care plan for autistic children is not easy, as each child has to be given individual attention. Autism can also happen to anyone. Even a child who was born without any medical problems to a family having no history of neurodegenerative diseases could end up suffering from ASD, and there is no cure. Having more people who are aware of autism can help create an environment that allows even an autistic child achieve some sense of normalcy. This is the first and most crucial step in the fight against autism, something we hope to achieve in Morocco.

3. Methodology

Our goal was to provide Autism Speaks with a report of statistical and ethnographic data on the needs and resources of families with autistic children in Morocco. We accomplished this goal by meeting the following objectives:

1. Conduct a quantitative assessment of families with autistic children in Morocco
2. Collect personal stories from families caring for autistic children
3. Evaluate the perspectives of autism experts, NGO's, and centers

The methodological strategies used are outlined in depth below.

3.1 Conduct a Quantitative Assessment

Autism Speaks provided the team with two surveys to use in Morocco. A Caregiver Survey for families affected by autism (shown in Appendix B) was used during in-person interviews. These interviews were held in facilities for disabled or autistic children.

We used a sample of convenience, with most families having been recruited through autism centers and were known to have autistic children, or at least children with a disability, diagnosed or undiagnosed. The surveys were mostly conducted in Darija (a dialect of Arabic), with a few in French. The teams anticipated problems with the language and illiteracy, especially in the rural regions of Morocco. The primary language spoken in Morocco is Darija mixed in with French, and Tamazight in certain regions. One member of the project team was fluent in Darija and French. With Tamazight there was the added problem of having three different dialects, depending on the region. To overcome this, the team worked with translators who were recruited from the local area. All of the interviews were conducted orally in the language spoken by the participant, eliminating both the language barrier and illiteracy issues.

We also converted the surveys provided by Autism Speaks into a digital Arabic format using Google Forms, so that there was the possibility to collect answers from families that could not be interviewed in person. The survey was posted on a website in a format that could be filled out electronically, and that website was distributed to families known to have autistic children through existing autism support programs.

Questions of the Caregiver Survey covered the following topics:

- Commonness of each different type of autism
- Gender distribution
- Age distribution
- Verbal abilities
- Age of first concern
- Issues that raised the concern
- Who first raised concerns (parent, doctor, teacher, other relative)
- Age of diagnosis
- Type of diagnoses
- Distance traveled for diagnosis
- Treatments received
- Care providers availability
- Types of schools attended
- Additional support received at school
- Assistance or training received by parents
- Participation in support or advocacy groups
- Sources parents receive information about autism from
- Availability, eligibility, and cost of services
- Difficulties getting services
- Financial problems and other family stresses
- Stigma against autism
- Quality of life for child and family
- Challenges of raising and getting support for a child with autism
- Greatest priorities for families affected by autism

For the first set of data, the team travelled to Tiznit. In person interviews were carried out in four cities/towns over the course of three days. Forty-three families were interviewed in Tiznit on the first day, forty-two in Agadir on the second, along with eighteen families from Biougra and eight from Taroudant on the third. A map can be viewed in Appendix E.

On a different date, another team travelled to Ouarzazate. Thirty-three families were interviewed there over the course of two days. Following that, the team travelled to Skoura and conducted a further nine interviews with families.

3.2 Collect Personal Stories

Throughout and after the in-person interviews, we collected personal stories that families were willing to share. This generated informal data to add to the report for Autism Speaks for a better overview of the state of autism care in Morocco. The team also interviewed Oum Keltoum

Dialmy, author of the book Parole d'Autiste, to learn the story of her experience with an autistic child. After each interview conducted during the trip to Tiznit and its neighboring towns and cities, ethnographic data was collected in using unstructured interviews and a sample of convenience with families affiliated with the study. This was done by conversing with the families informally after and sometimes even during the interviews, asking about their everyday lives. This gave us a deeper and more humane understanding of their struggles.

In addition, our time spent with families yielded many observations about how the families manage their autistic children, how the children are treated, and how their lives are overall affected by autism.

3.3 Evaluate Perspectives of Experts and Centers

A survey for professionals was provided by Autism Speaks (Appendix C) to interview teachers and autism professionals. These interviews were used to gain perspectives from those who are most likely to have the most information on the current state of autism awareness, diagnosis, and resources in Morocco to fill in the gaps that caregivers may not know. A sample of convenience and snowball sampling identified our participants.

Questions from the Professional Survey covered the following topics:

- Education level of professionals
- Types of professionals and experience
- Types of disabilities professionals treat
- Number of children treated and age range
- Number of children doing treatment that have been officially diagnosed with autism
- Verbal abilities of children
- Types of schools specialized teachers work in, and their positions
- Services/treatments the professionals provide and the training associated with providing these services
- Professionals training needs
- Type of help parents have asked for from the professionals
- Type of facilities doctors work in and their specialties
- Information about diagnostic practices used by the professional
- Types of diagnostic practices are available where the professional works and the training associated with them
- Commonness of at home care
- Courses the professionals take
- Eligibility of patients for treatments
- Availability of treatments for patients
- Waiting lists or backlogs for patients

- Types of services/treatments available for children with autism where the professional works
- Cost of services for families
- Sources professionals get their information from
- Assistance the professionals receive
- Stigma surrounding working with children with autism
- Quality of life of patients
- Challenges facing professionals
- Greatest priorities for professionals

In addition to the interviews, the team planned to travel to Casablanca to visit two autism centers located there: *Aurore and SOS Autisme.* However, this was never accomplished due to the busy schedule of the centers and the teams own schedule.

4. Results and Analysis

In this chapter, we present our preliminary findings from the data analysis. The graphs and tables used were created in excel and were derived from our survey data. We will also present the data for objective one in two separate ways: the data of those specifically diagnosed on the autism spectrum, and the autism data compared to data from children that were undiagnosed or diagnosed with something not on the autism spectrum.

4.1 Quantitative Assessment of Families with Autistic Children in Morocco (Autistic Sample Results)

The results of objective one will be divided into the four sections of the survey in order to organize the data. The results presented do not cover the entirety of the survey, but instead focuses on the major highlights and issues that will be touched upon in our discussion and analysis. The sample used for the analysis is presented in the Table 1 below. In total we surveyed 183 parents across 7 geographical locations, 123 of those parents had children who were diagnosed on the autism spectrum.

Table 1: Sample by Location of Cases with Diagnosed Autism

Location	Sample Size	Format of Interviews	Date of Interviews
Tiznit	30	Paper	8/29/2016
Agadir	28	Paper	8/30/2016
Taroudant	8	Paper	8/31/2016
Biougra	14	Paper	8/31/2016
Casablanca	18	Paper and Online	9/01/2016- 9/24/2016
Ouarzazate	23	Paper	9/21/2016-9/22/2016
Skoura	3	Paper	9/23/2016
Total: 124 Interviews			

Section 1: Family Demographics

In terms of the education, the sample was diverse and pretty evenly split across education level: no schooling, primary school, and high school are represented at about 20% each. 14.6% of the parents attended a secondary school and 17.9% attended high school level. The respondent spouse had a similar education level distribution, but the percentage of high school and secondary school was lower, with 13.8% and 9.8% respectively. In most cases, the respondent was the child’s mother (52% of the time).

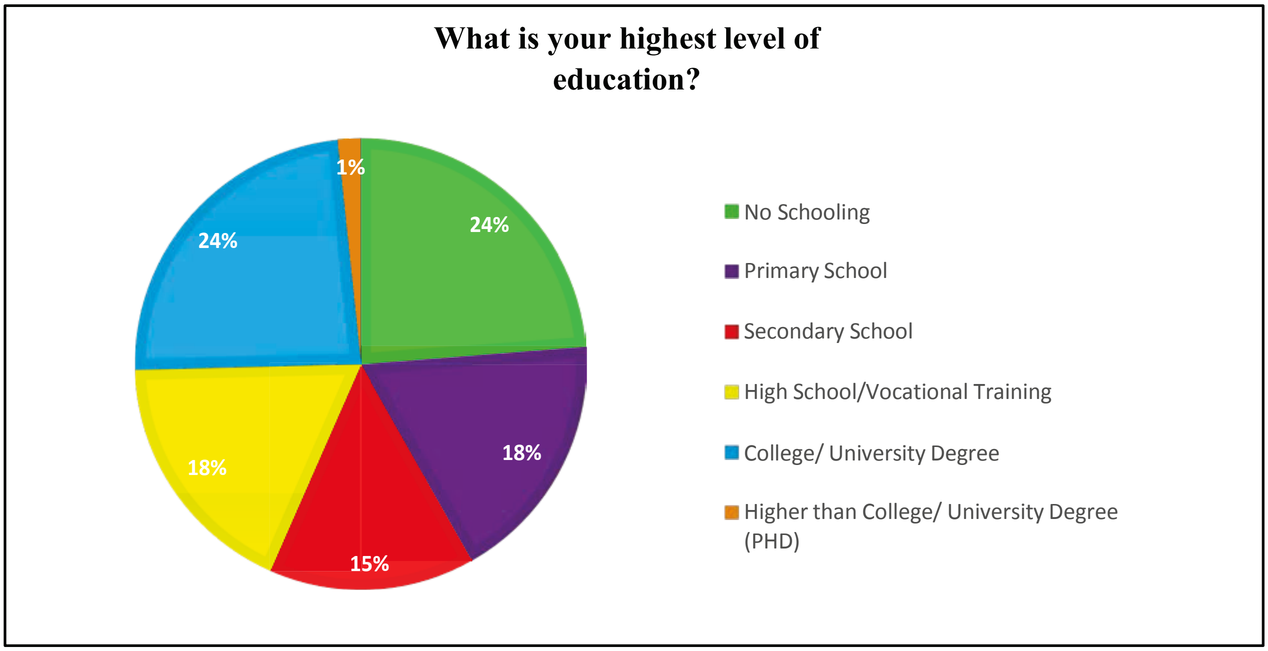


Figure 4: Level of education of parents surveyed

Section 2: Affected Child Characteristics

As shown in Figure 5, most of the children interviewed who were diagnosed were diagnosed with autism/autistic disorder (57.7%), while another 25.3% were diagnosed with autism spectrum disorder. We then asked about the affected child's gender which shows close to a one to three ratio of girls to boys, 25.2% female and 74.8% male. The verbal ability of the child was also asked, in which case the largest population was of children who could use single words around 36.6% but those who could not speak at all made up a similar percentage of 35.8%. Only 9.8% could use complex sentences.

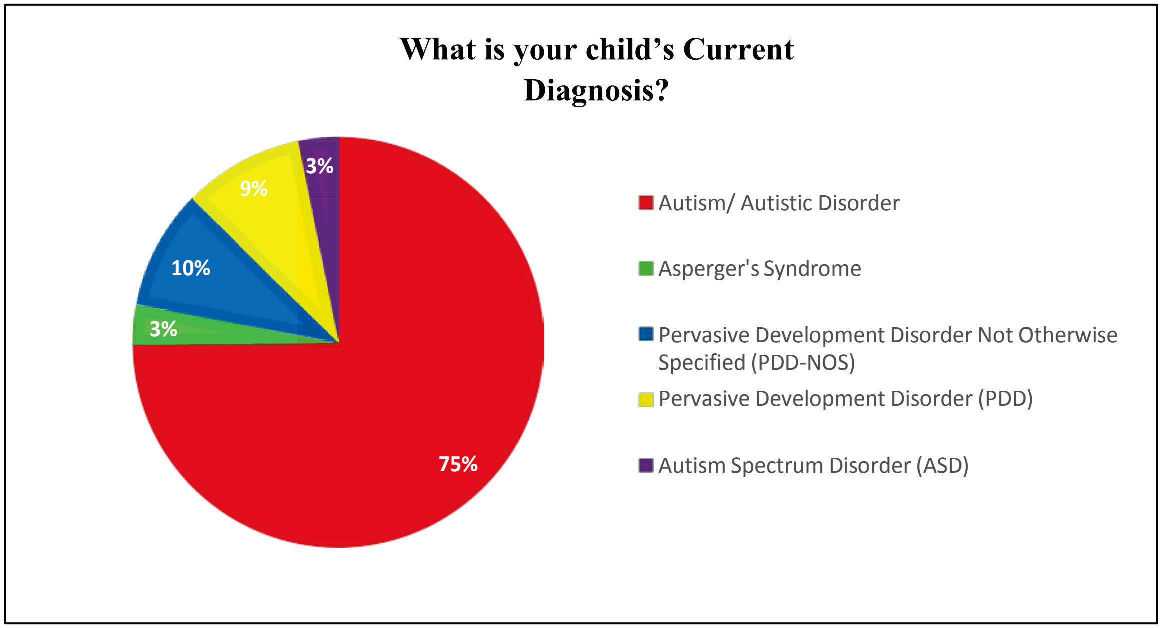


Figure 5: Diagnosis of Affected Children

Section 3: Service Encounters

This section pertained to questions related to the different services that families with an autistic child received for health or education. Most of the data showed that the children do not receive services, with 58.1% not receiving any therapies. However, 45.2% of the surveys had shown that they have received some form of speech or language therapy and 37.1% of families are still currently involved with it. 32.3% received some form of behavioral treatment in the past, such as ABA, and 30.6% of families have tried pharmacotherapy. Other data pertaining to services can be viewed in Table 2.

Table 2: Health care providers worked with in the past and present

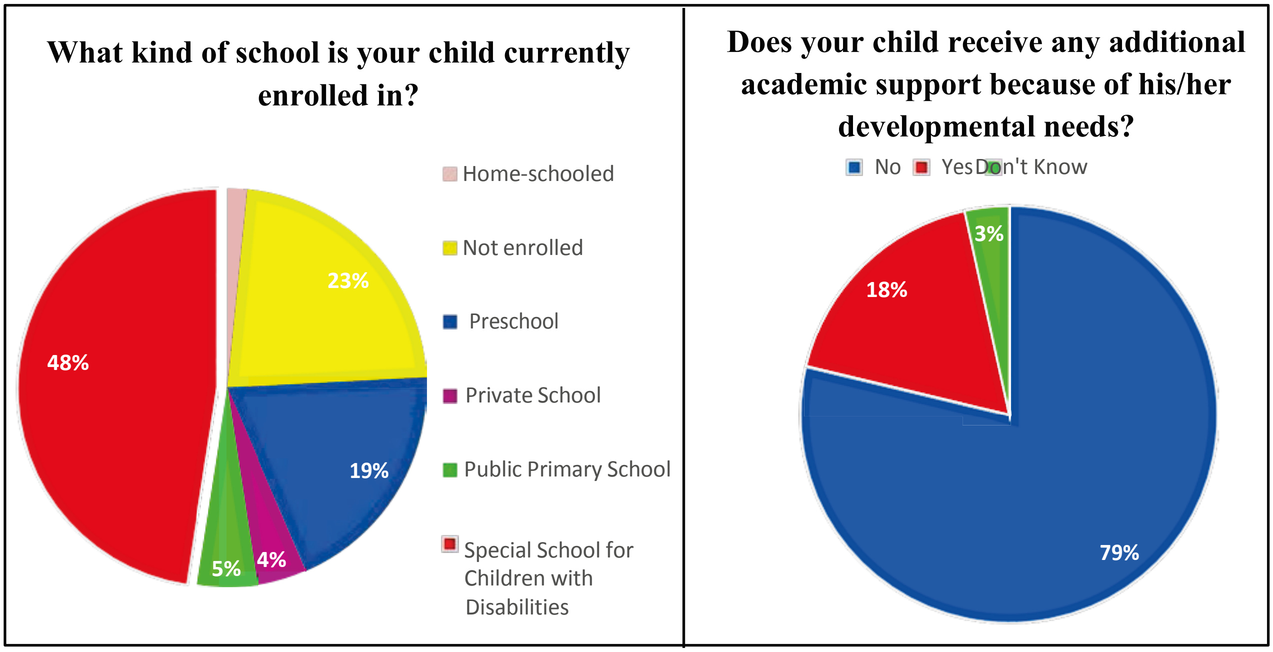
	Past services N. who have used service (%)	**Current services N. who use service (%)**
Behavioral intervention / modification	40 (32.3%)	34 (27.4%)
Sensory integration therapy	24 (19.4%)	19 (15.3%)
Cognitive-based therapy	24 (19.4%)	20 (16.1%)
Occupational therapy	23 (18.5%)	18 (14.5%)
Physical therapy	32 (25.8%)	25 (20.2%)
Social skills training	31 (25%)	25 (20.2%)
Speech and language therapy	56 (45.2%)	46 (37.1%)
Pharmacotherapy / medication	38 (30.6%)	24 (19.4%)
Other	4 (3.2%)	3 (2.4%)

For treatment or advice, the specialist of choice for autism care in Morocco appears to be developmental pediatricians for 39.8% of the respondents having worked with one. At a very close second are psychiatrists with 39%. Each of these percentages goes down drastically when looking at current treatment. Table 3 shows the percentage of families having worked with or are currently working with specialists.

Table 3: Past and present service providers

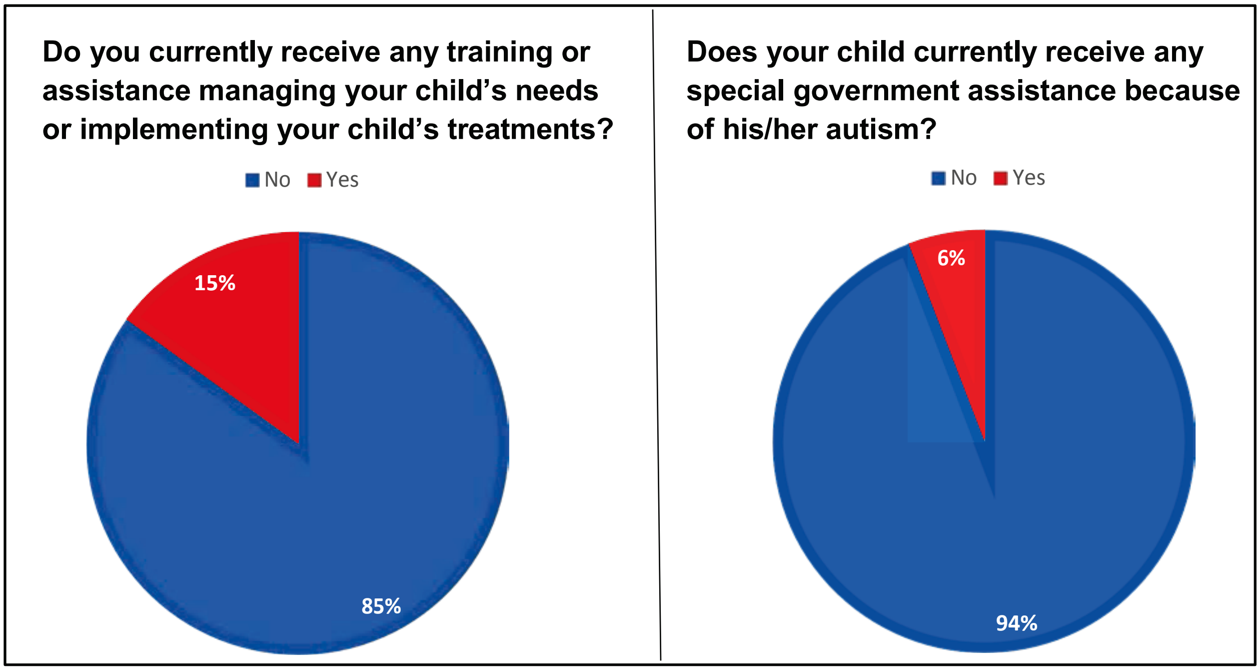
	Past **N. who have seen provider (%)**	**Present** **N. who see provider (%)**
Audiologist	32 (26%)	5 (4.1%)
Behaviorist	29 (23.6%)	15 (12.2%)
Developmental pediatrician	49 (39.8%)	18 (14.6%)
Education specialist	24 (19.5%)	17 (13.8%)
Neurologist	36 (29.3%)	15 (12.2%)
Nutritionist	8 (6.5%)	3 (2.4%)
Psychiatrist	48 (39%)	21 (17.1%)
Psychologist	24 (19.5%)	17 (13.8%)

From the preliminary data we have observed that 47.6% of the children affected with autism attend special schools for children with disabilities. Only two children were homeschooled out of the 123 entries and twenty-two (22.6%) were not receiving any form of education. Also, only 17.9% of families were receiving extra academic support to care for their child with autism. This information can be viewed in Figures 6 and 7.



Figures 6 and 7: Type of school attended by affected children and additional academic support received

Regarding other services or training that families receive to help care for their child, 85% replied that they do not receive any, and only 5.8% receive any form of government assistance. This information can be observed in Figures 8 and 9.



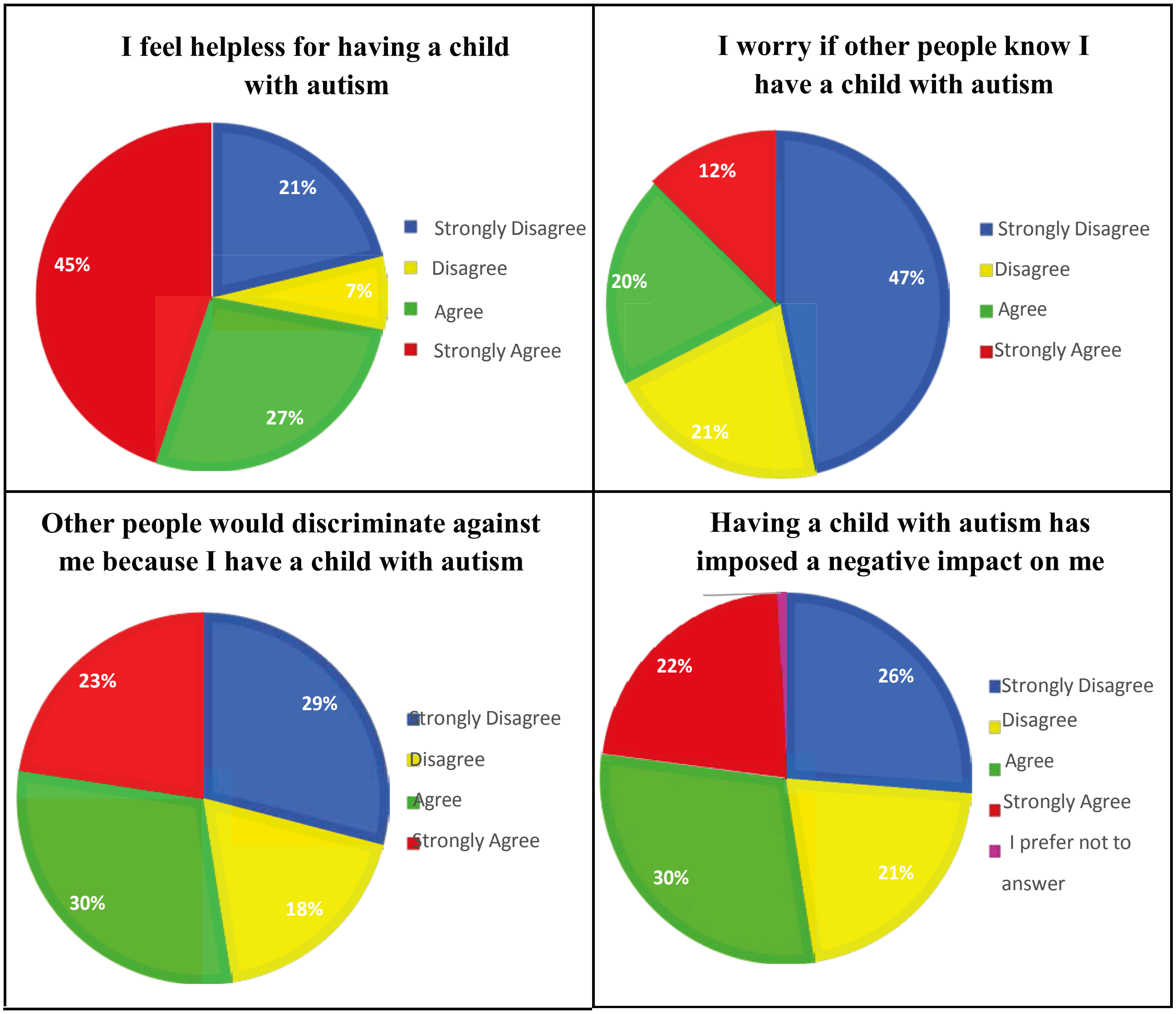
Figures 8 and 9: Additional support

Section 4: Parent/Caregiver Perception

The next set of questions was regarding difficulties related to the availability of medical services. 78% of interviewed families said yes to having difficulties due to services not being available, 77.2% said yes to having difficulties due to cost, and 70.7% said yes to having difficulties due to lack of information. Other difficulties specifically mentioned by parents were that services were too far away to travel to with an autistic child, and that the doctors that were available in the area are not trained specialists so they did not know how to actually help the child. Only 9.7% said that they are never frustrated in their efforts to get services for their children and the rest answered either “don't know” or varying degrees of yes. 55.6% answered always, 22.6% answered sometimes, 7.3% answered usually, and 4.8% answered don't know.

In the question related to finances, 72.4% of the participants answering yes to whether or not autism has caused financial problems for their family. 24.2% of participants said that they had stopped working, and 41.9% said that they had reduced their work hours.

Next, Figure 10 shows how parents felt about the stigma against autism in Morocco, and how it has affected them:


I feel helpless for having a child with autism

I worry if other people know I have a child with autism

Other people would discriminate against me because I have a child with autism

Having a child with autism has imposed a negative impact on me

Figure 10: Information on views of stigma against autism in Morocco

Most parents agreed to feeling helpless for having a child with autism, with 44.9% strongly agreeing, 27.1% agreeing, and only 6.8% disagreeing and 21.2% strongly disagreeing. Most people didn't worry about whether people knew that they had a child with autism (46.7% strongly disagree and 20.8% disagree), a significant number did feel like they would be discriminated against (22.6% strongly agree and 29.8% agree). There was a very mixed set of answers to whether or not having a child with autism imposes a negative impact on the parents, though. 22.1% strongly agreed, 29.5% agreed, 21.3% disagreed, 26.2% strongly disagreed, and 0.8% did not wish to answer. Participants found this question very difficult to answer because they love their child and accept their autism as God's will, so they did not want to complain or speak ill of anything related to their child.

The last thing we learned in this section was the challenges and priorities of the families. Table 4 below shows the highest-ranking answers to the three questions pertaining to the challenges and priorities. The full ranking can be seen in Table 19 of Appendix A.

Table 4: Challenges and priorities

	N. of Participants Who Listed Answer Within their Top 3 (%)
Greatest challenges in caring for a child with autism	
1. Safety concerns (i.e. wandering, climbing)	60 (48.8%)
2. Challenging behaviors (i.e. self-injury, aggression, tantrums)	51 (41.5%)
3. Communication difficulties	51 (41.5%)
Greatest challenges faced in getting support for a child with autism	
1. Making sure the child receives adequate education	97 (78.9%)
2. Making sure the child's basic rights are protected	85 (69.1%)
3. Making sure the child receives adequate health care	82 (66.7%)
Greatest priorities for families affected by autism in Morocco	
1. Greater rights for individuals with autism	78 (63.4%)
2. Improved education services	77 (62.6%)
3. Improved health care services	64 (52%)

4.2 Comparison of Autism Sample with Non-Autism Sample

This part of our results focuses on the differences between the results of the autism data sample and the non-autism data. This section will show graphs and data that presents a difference in comparison to the overarching data. The outline by region and number of cases per region are presented in the table below.

Table 5: Sample by Location of Autism and Non-Autism Cases

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

Section 1: Family Demographics

When comparing the data of only those diagnosed with autism or its subcategories and the non-autistic sample population we found that the data was very similar and in most questions the percentage difference was very small, because of this we will continue onto the next section. The exact percentages and full set of data can be seen in Appendix A.

Section 2: Affected Child Characteristics

Table 6 is a direct comparison of the autistic sample data set, the non-autistic sample data set, and all of the data representing a sample of children with developmental disorders. From this table it is important to note differences such as the ratio of males to females in the non-autistic data set which is 69.5% to 30.5% which is different from the autistic sample set by 5%. The verbal ability of the two data sets is also different. In the two simplest forms of communication, no talking, and single word use, the autistic sample data set contains higher percentages, while for the more complex forms of verbal communication the non-autistic sample data set has the higher percentages. It is also interesting to note that percent difference for "uses complex sentences" is very small: 9.8% to 8.3%.

Table 6: 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	8.93	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%

Section 3: Service Encounters

Table 7 below compare 3 sets of data, autistic, non-Autistic, and all data. From this set of data we can clearly see the drop between past treatments and current treatments for the autistic data set. The difference is more noticeable in the autistic data set, than the non-autistic data set. For example, for the Pharmacotherapy / medication, the autistic data set dropped by 11% from 38% to 24 %, and the non-autistic data increased by 15% from 1.6% to 16.6%.

Table 7: 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 8 below compares the types of assistances and sources of information between the autistic data set, non-autistic data set, and all data (both autistic and non-autistic data). We can see over all the non-autistic set receives more assistance than autistic data set. For example "Receiving training / assistance" the autistic data set has 15%, and on the other hand the non-autistic data set receives 23.4%. For the source of information the internet and other parents of children with autism are the more popular source for autistic data set. The non-autistic data set relies more on professionals such as child's primary care doctor and the child's teacher.

Table 8: 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%	14.0%	16.7%
Type of additional supports, (% who said yes)			
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	10.9%	0%	4.8%

Section 4: Parent/Caregiver Perception

After comparing the unmet needs in the past 12-months, for the autistic and non-autistic data set, we can see that a similar percentage of families had come across difficulties with services and cost related issues as can be seen in Table 9. It should be noted that families who had an autistic child found it more difficult. The cost of the treatments and the unavailability of the services in the area are the most common difficulties that parents in both categories have to face. 77.2% of families with an autistic child and 68.4% of those with child with a different disability had stated that costs were a real concern. Additionally, the level of frustration that both groups have to face is not different from each other.

Table 9: Access and unmet needs 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	51.2%	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	28.2%	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%

The top 5 challenges in caring for a child with a disability appears to be the same for both the autistic and non-autistic data sets, but the ranking is very different. For families with an autistic child, safety concerns and challenging behaviors are the most important concern, whereas for the others, it lies in social interaction difficulties and living skills. In regards to getting support, the number one concern for both groups is that their child receives adequate education. It should also be noted that making sure their child's basic rights is protected is ranked higher in the autistic data set. Both groups seem to view improved education and health service for their children as their greatest priorities. These rankings can be viewed in Table 10.

Table 10: Rankings of greatest challenges and priorities

Autistic	**Non- Autistic**	**All**
Greatest challenges in caring for a child with autism		
1. Safety concerns (i.e. wandering, climbing) 2. Challenging behaviors (i.e. self-injury, aggression, tantrums) 3. Communication difficulties 4. Daily living skills (i.e. toileting, self-feeding) 5. Social interaction difficulties	1. Social interaction difficulties 2. Daily living skills (i.e. toileting, self-feeding) 3. Challenging behaviors (i.e. self-injury, aggression, tantrums) 4. Safety concerns (i.e. wandering, climbing) 5. Communication difficulties	1. Safety concerns (i.e. wandering, climbing) 2. Challenging behaviors (i.e. self-injury, aggression, tantrums) 3. Daily living skills (i.e. toileting, self-feeding) 4. Communication difficulties 5. Social interaction difficulties
Greatest challenges faced in getting support for a child with autism		
1. Making sure the child receives adequate education 2. Making sure the child's basic rights are protected 3. Making sure the child receives adequate health care	1. Making sure the child receives adequate education 2. Making sure the child receives adequate health care 3. Making sure the child receives adequate welfare/ social supports	1. Making sure the child receives adequate education 2. Making sure the child receives adequate health care 3. Making sure the child's basic rights are protected
Greatest priorities for families affected by autism in Morocco		
1. Greater rights for individuals with autism 2. Improved education services 3. Improved health care services	1. Improved education services 2. Improved health care services 3. Greater rights for individuals with autism	1. Improved education services 2. Improved health care services 3. Greater rights for individuals with autism

4.3 Anecdotal Stories from Families with Autistic Children

This objective relies heavily on anecdotal stories provided by the parents interviewed. Our results for this section are small stories collected and presented below.

Stories from Parents:

Throughout the in-person interviews, we also took notes and collected more personal stories that came along with answering the questions. The following are some of the stories that gave us the most information about the state of autism throughout Morocco as a whole:

Families in Tiznit were not satisfied with the schools for children with disabilities in the area. Multiple parents did not think their children were being helped, and some said that they were not even being supervised. One story we were told was an example of the state of the schools. A parent went to pick up his son early for a doctor's appointment and walked into the classroom to find the children sitting around eating paint off the walls with no teacher present to supervise.

One other story shows the lack of information about autism care and centers. A team member was walking to a meeting one morning when she was approached on the street by a seemingly random woman. This woman proceeded to talk about how she had a son with autism and was trying to get medicine for him, but it was only available in the United States. She was looking for an autism center in Rabat that could help her child and get the medicine he needed, but could not find it. She became so desperate that she was walking around and asking anyone who passed her on the street, hoping they would be able to provide her with information.

Another parent recalled their hardships getting information and a correct diagnosis. The family’s involvement on advocacy groups is done through a group chat on whatsapp, so they can’t actually talk to anyone in person and a lot of information may be lost. The child was originally wrongly diagnosed with epilepsy and then received a continual change in the diagnosis. The parents knew things were obviously not right with the children one month after a seizure that "changed him," so they continued to look for the correct diagnosis. Five different professionals said it wasn't autism, but then he was re-diagnosed with autism as his latest diagnosis.

Lastly, some parents talked about how dissatisfied they are with the doctors in the area. In fact, they refuse to work with the hospitals because the quality of the care is so bad. Due to this, they have their child do all of his treatments with teachers, not professionally trained doctors. (Children working with teachers instead of trained doctors actually seemed to be a very common occurrence.) Another family mentioned how they travel to Agadir for better treatment because they are not pleased with the services offered where they live in Tiznit.

Author Oum Keltoum Dialmy

We also had the chance to meet with a wonderful women who is the author of the book "Parole d'autiste" and the founder and president of the two centers in Bouskoura, "*SOS Autism*" and "*Aurore*". She agreed to share her story about her autistic child, Younes, who is now 28 years old.

When Younes was born in 1990, Moroccans were not familiar with autism and usually associated it with other popular syndromes, or in some cases, to old beliefs related to sorcery. At the age of 2, Younes started showing some signs of autism. Oum Keltoum was not familiar with autism at that time, but she was ready to do was what was necessary to help her son. She describes the difficulties and challenges that she had to face in order to get a diagnosis and find out what was wrong with her child. Younes wasn't eligible in any school and had to go to several doctors between Morocco and Europe. After 5 years of multiples diagnosis and consultations, Oum Keltoum finally learned that Younes had autism.

At that time, there were very few specialists or qualified professionals that were able to help her son with autism. Despite several visits to the doctors, Oum Keltoum did not notice any notable results. She decided to contact other families and parents that were in the same situation as her, and founded the first two centers in Casablanca *SOS Autism* and *Aurore*. She worked and directed the associations for 10 years, but decided to leave the Board of Directors due to confrontations with other local associations.

Oum Keltoum also describes how she gave Younes words through her book. She states: *"This book is primarily to give my autistic son a word he never had. Younes was never able to speak, but that does not mean he does not communicate or has nothing to say. Our experience of twenty-eight now is so intense and fusional, it largely allows me to identify its messages and to be his spokesman appropriate. I believe that this experience is rich, and also deserves to be told and brought to the attention of anyone concerned or indirectly by autism. My wish is that this book is a message, a testimony, and a guide."*

4.4 Perspectives of Autism Specialists, NGOs, and Centers

The results of this section are quantified by the Professional Survey given out. With that being said, the sample size of the Professional Survey is not large enough to draw definitive conclusion. Along with the quantitative data, the team was in contact with and tried to visit the two autism centers in Morocco. This will be touched upon later in the discussion section.

From our Professional Surveys we can notice that the majority of educators or professionals interviewed have a degree in high school versus a university degree. Most of the specialists interviewed have experience that does not exceed 3 years, and they are educators in different places such as (high schools or special schools with student who has disabilities). Their responsibilities vary between different sectors from being an ABA trainer to being responsible for a group of special educators. Table 11 below is a synopsis of the demographics of the professionals, while Table 12 is the demographics of their patients.

Table 11: Education and experience level of professionals

Characteristic	
Highest level of education, N. (%)	
No schooling	2 (8%)
Primary school	3 (12%)
Secondary school	4 (16%)
High school / vocational training	10 (41%)
College / university degree	6 (25%)
Higher than college/ University degree PHD	1 (4%)
Years of experience, mean	6.73

Most of the specialists interviewed work with patients who are considered mentally retarded (65.2%), and only 60.9% of the professionals asked actually work with children affected by autism. The median amount of children the professionals see is 11. The popular age range that receive a type of treatment or help are between 6 and 15 years old.

Table 12: Characteristics of patients

Characteristic	
Types of patients worked with, N. (%)	
Autism Spectrum Disorder	14 (60.9%)
Mental retardation	15 (65.2%)
Physical handicaps	7 (30.4%)
Deaf or hearing impaired	2 (8.7%)
Blind or visually impaired	0 (0.0%)
Other psychiatric conditions	9 (39.1%)
Other	1 (4.3%)
I don't know	0 (0.0%)
Not diagnosed	0 (0.0%)
Multi-handicapped	0 (0.0%)
Number of children in classroom/ practice/ case load, median	11
Age range of children worked with, median	6 - 15 years old

In Table 13, some difficulties and challenges faced by the professionals are shown. The focus of this table is on yes or no answers given by the professionals to each question. The difficulties and section part of the Professional Survey also included some more difficult questions such as "Do you feel incapable of teaching a child with autism?" and "Some people discriminate against me because I work with kids with autism".

Table 13: Difficulties and challenges

Characteristic	**N. who responded yes (%)**
Difficulties / delays providing services due to ineligibility	6 (28.6%)
Difficulties / delays because clients were unavailable	6 (28.6%)
Difficulties / delays due to wait lists, backlogs from providers	6 (31.6%)
Difficulties / delays because of issues related to cost	8 (38.1%)
Difficulties / delays because of issues getting the information needed	4 (19%)
Other difficulties or delays	4 (19%)
Level of frustration in efforts to provide services	**N. (%)**
Never	1 (4.8%)
Sometimes	14 (66.7%)
Usually	3 (14.3%)
Always	2 (9.5%)
Don't know	1 (4.8%)
I feel helpless teaching a child with autism	**N. (%)**
Strongly disagree	4 (22.2%)
Disagree	8 (44.4%)
Agree	1 (5.6%)
Strongly agree	5 (27.8%)
Other people would discriminate against me because I work with individuals with autism	**N. (%)**
Strongly disagree	2 (10.5%)
Disagree	5 (26.3%)
Agree	3 (15.8%)
Strongly agree	9 (47.4%)

4.5 Analysis and Discussion

A Caregiver Needs Survey, Professional Survey, and personal stories from families were all used to collect information of the current state of autism care and awareness in Morocco. 183 Caregiver Surveys and 24 Professional Surveys were conducted. Within the 183 Caregiver Surveys there were 124 in which the child was currently diagnosed with autism while the other 59 were undiagnosed or they fell into other categories.

Improper Diagnosis

Major highlights from the data collected showed that children with autism or other disabilities have not been receiving proper diagnosis, as most children remain undiagnosed or have other disabilities that had originally been wrongly diagnosed as autism. Many comments from parents pointed towards the fact that doctors did not know much about disabilities, so they just treat them all the same and lump them under one general diagnosis of "autism." Some examples of this were shown in children that had Down syndrome, mental retardation, and even paralysis, but were told to just treat it as autism. Reasons for the improper diagnosis that came up were that most professionals only had high school degrees (not university degrees) and very little experience, and more specialized doctors are very far away from families. Many families had to travel over two hours to receive a proper diagnosis for their child, and not all families have the ability or means to do that.

Lack of Resources

More findings also further highlighted a lack of resources for autism in Morocco. If children do get properly diagnosed, they have little chance of receiving treatment. Speech therapy was the only type of treatment that a large amount of children were participating in out of all those listed in the survey. A large majority of families agreed to having difficulties and delays getting services due to services not being available in their area and a lack of information. When children did receive services, most of the time they were provided by teachers in schools for children with disabilities and parents were unsure of the quality of this care or what specifically their children were receiving. From this data we can deduce that the cities we have visited and interviewed in lack the health care and services that families with autistic children are looking for. People do not have easy access to information and the lack of specialists and doctors in the field mean that children with autism are not receiving sufficient care.

Financial Struggles

Our data has also revealed that there is a huge financial struggle for most families who have a child with autism. Some families mentioned that they either wanted to or had cut down on hours of work to give more attention to their children, many of those same families mentioned that this was a necessity, but also very difficult due to the cost of sending their child to a special school. It is also interesting to note that when asked about services the child had received in the past and the services the child currently receives, most of the time there would be a huge decrease. One reason for this is that the families wanted to try the services, but then found out they were too expensive. The cost of these services also seems to be gradually increasing not only as the years go by, but also as the age of the child goes up. When asked more about the financial struggles another issue began to arrive: the stigma behind having a child with autism.

Parent and Caregiver Perception

The topic of stigma is especially interesting because it directly correlates with our background research. Most people didn't worry about whether people knew that they had a child with autism because they are proud of their child no matter what, but many did feel like they would be discriminated against. Many times when parents answered yes to this question, they did so very forcefully, indicating that the discrimination is a large problem. Even with this problem, though, we received a very mixed set of answers when we asked if having a child with autism has had a negative impact on their lives instead of the anticipated majority result of yes. One very popular answer that we didn’t expect was “it's God’s will.” Because of this answer and their love for their children, the parents felt as though they could not complain or speak ill of the situation. They then answered no even when we had believed their answer would be a yes based on the rest of the survey. This feeling that they could not answer honestly could have caused skewe d the data and caused the surprising results.

Challenges and Priorities

The Caregiver Survey also provided insight into the challenges and priorities of the families. The top five challenges to caring for a child with autism, in order, were: safety concerns, challenging behaviors, communication difficulties, daily living skills, and social interaction difficulties. The top five challenges caregivers face in getting support for their children, in order, were: making sure the child receives adequate education, making sure the child's basic rights are protected, making sure the child receives adequate health care, making sure the child receives adequate welfare/ social supports, and making sure the family receives adequate respite. The top five greatest priorities for families affected by autism, in order, were: greater rights for individuals with autism, improved education services, improved health care services, greater community awareness, and improved welfare/ social services.

Comparison between Autism Data and Overarching Data

When the data was separated based on the results of those on the autism spectrum we immediately noticed that the data, in most cases, did not change by a significant amount. Many of the percentages only changed by one or two percent. When we discussed this as a team, we came up with a few reasons. The first which is the most plausible is that a large portion of the undiagnosed population did, in fact, have autism. This becomes interesting because it would point to the slight lack of proper diagnosis based on the amount of professionals available. For many families it is true that finding a professional to medically diagnose their child is extremely difficult, leaving some child undiagnosed for most of their life. Another possibility is that children with disabilities are all going through the same struggles, whether it is autism or not. It is also plausible that the population of undiagnosed children was not statistically significant enough to alter the data in a drastic way. If the population size was bigger, the undiagnosed data would have a bigger impact.

It is also important to note that some major differences between the two data sets did appear, however many of these points were unsurprising. One of these differences is the age of first concern, which jumped by about half a year from the overarching set to the autism set. This is not surprising because the age jumped to the expected value of about two years. (The same number we found in our initial literature review).

Another difference is the percentage of children seeing service providers, which decreased in percent for nearly all the types of service providers when comparing the overarching data to the autism data. This difference however is somewhat surprising because we would expect that once a child is diagnosed with autism they would see more professionals, but this is not true according to our data. This trend may hint toward a need for awareness of how to treat autism.

Results vs. Expectations

Overall, the results we found from this study were what we expected after our initial background research. The answers from the survey and stories we heard backed up the fact that most families in Morocco do not have access to proper diagnosis or services for their autistic children, and that there is a negative stigma surrounding autism that the families are very aware of.

Limitations of the Study

We ran into some slight limitations while conducting our research. First, we were unable to gain access to the autism centers in Casablanca that we had planned on visiting, so our sample size of the perspectives of professionals and centers is not very large. Another limitation was the time constraint. Due to the short seven week time frame, our sample size of caregivers was also not as large or as representative as we would have liked, as we had to limit our interviews and they were taken with a sample of convenience in specific areas of the country. One last limitation was caused by the language barrier. Having to use translators made collecting data from caregivers and professionals firsthand very difficult and could have led to an interpreter bias.

5. Recommendations and Conclusions

5.1 Recommendations

From our research, we concluded that the status of autism care in Morocco has the opportunity to improve in several factors, not only in terms of professionals, but also in terms of available treatments and therapies. Due to this, our recommendations are as follows:

- Find opportunities to advance the training for specialists (including medical staff and teachers) in Morocco
- Encourage more doctors to specialize in autism care through scholarships and other incentive programs
- Distribute information about autism and autism care throughout Morocco
- Enhance or reinvigorate the current autism centers, special schools, and facilities in Morocco to better their current services and offer new ones, especially in rural areas
- Set up centers for diagnosis in regions where access to healthcare could be improved
- Set up further programs to help educate families with autistic children
- Lobby the government to subsidize autism related programs and insurance programs to include autism services and treatment

Once these recommendations are put into action, access to knowledge and care regarding autism should slowly increase, allowing a better quality of life for not only the autistic children but their families as well.

5.2 Conclusion

Being able to understand and communicate with your own child. It is an ability most parents develop very quickly, without even having to think about it. Parents of autistic children in Morocco struggle with this task every single day, and see no help in sight. They are desperate to find help for themselves and help for their children, but don’t have anywhere to turn. Their requests are simple: that their children who they love so dearly to live normal, happy lives with the same rights and opportunities as everyone else, and that their children to have what others so easily take for granted, including: education, healthcare, and civil liberties. We hope that this research will build on the excellent work of Autism Speaks to set up programs to provide assistance and additional resources to the people of Morocco, relieving some of these struggles and helping to enrich the lives of those affected by autism.

References

Advancing Autism Screening in Developing Countries. (2014, February 13). Retrieved March 22, 2016, from https://www.autismspeaks.org/science/science-news/advancing-autism-screening-developing-countries

Aitlekhoui, B. (2016, February 16). Autism in Morocco: The Hidden Facts. Retrieved March 21, 2016, from http://www.moroccoworldnews.com/2016/02/180008/autism-morocco-hidden-facts/

Amrani, S. (2014, December 23). Mrs.Soumia Amrani : Autism is pricey! [Interview by O. Hamama]. Retrieved March 21, 2016, from https://www.youtube.com/watch?v=FFcQycHEwJ4

Autism Rises. Why? [Digital image]. (n.d.). Retrieved March 31, 2016, from http://whyfiles.org/2015/danger-life-without-vaccine

Autism speaks history. (n.d.). Retrieved September 20, 2016, from https://www.autismspeaks.org/about-us

Autism Spectrum Conditions [Digital image]. (2013, May 22). Retrieved March 31, 2016, from http://brandchannel.com/2013/05/22/sap-starts-in-on-a-life-changing-plan-to-hire-individuals-on-the-autistic-spectrum/

Azamani, M. (2010, May 31). Autisme: 108.000 enfants touchés au Maroc. Retrieved September 20, 2016, from http://www.maghress.com/fr/leconomiste/100807

Carnaval de l'espoir pour vaincre l'autism au Maroc. Published by 'Vaincre l'autism association' (June 13). Retrieved March 22 from: http://www.vaincrelautisme.org/content/caravane-de-l-espoir-pour-vaincre-l-autisme-au-maroc

Chez, M. (2008). *Autism and its medical management: A guide for parents and professionals*. Jessica Kingsley Publishers.

Daley, T.C., Singhal, N., Krishnamurthy, V. (2013). Ethical Considerations in Conducting Research on Autism Spectrum Disorders in Low and Middle Income Countries. *Journal of Autism and Developmental Disorders, 43(9),* 2002-2014.

Diagnosis. (n.d.). Retrieved September 20, 2016, from http://www.autism-society.org/what-is/diagnosis/

Dialmy, O. (2016). *Parole d'Autiste*. Kalimate Editions

Elhousni, I. *Autism: the contribution of speech therapy in managing autistic children: study at La Passerelle center*.

Estimated prevalence of autism in the world [Digital image]. (n.d.). Retrieved March 31, 2016 from http://readingroom.mindspec.org/?page_id=6523

"Facts and Statistics | Autism Society." *Autism Society Facts and Statistics Comments*. About Autism, 25 Aug. 2015. Web. Retrieved 21 Apr. 2016.

Geoffrey Mohan (Contact reporter), Los Angeles Times "Early treatment may decrease autism signs" (September 9, 2014). Retrieved March 22 from: http://www.latimes.com/science/sciencenow/la-sci-sn-early-treatment-autism-20140908-story.html

Grandin, T. (2002). Teaching Tips for Children and Adults with Autism. Indiana Resource Center for Autism. Retrieved March 28 from: http://www.iidc.indiana.edu/pages/articles

Hamama, O. (2014, December 7). Autism in Morocco. Retrieved April 21, 2016, from http://autisminmorocco.blogspot.com/

Hart, B. (2012, September 17). Notes on Inequalities in Autism Activism and Care in Morocco. Retrieved March 21, 2016, from http://www.jadaliyya.com/pages/index/7388/notes-on-inequalities-in-autism-activism-and-care-

How Is Autism Diagnosed? (n.d.). Retrieved March 21, 2016, from https://www.autismspeaks.org/what-autism/diagnosis

Khan N.Z., Muslima H., Arifeen S.E., McConachie H., Shilpi A.B., Ferdous S., Darmstadt G.L. (2014). Validation of a Rapid Neurodevelopmental Assessment Tool for 5 to 9 Year Old Children in Bangladesh. *The Journal of Pediatrics.* 164(5), 1165-1170.

Khan N.Z., Muslima H.,Shilpi A.B.,Begum D., Parveen M., Akter N.,Ferdous S., Nahar K.,McConachie H., Darmstadt G.L. (2013). *Pediatrics*. 131(2)

Learn the Signs of Autism. (n.d.). Retrieved March 21, 2016, from https://www.autismspeaks.org/what-autism/learn-signs

Luiselli, J. K. (Ed.). (2011). *Teaching and Behavior Support for Children and Adults with Autism Spectrum Disorder: A Practitioners Guide*. Oxford University Press.

Mission. (n.d.). Retrieved September 20, 2016, from https://www.autismspeaks.org/about-us/mission

Mohamed Amine Hafidi, Le Matin “300.000 enfants autistes au Maroc” (Decembre 13, 2014). Retrieved March 22 from: http://lematin.ma/journal/2014/300000-enfants-autistes-au-maroc/213953.html

Mouna Lahrach (March 13, 2012). “Autism au Maroc, Ou on es ?” Statistics of Autistics kids in Morocco. Retrieved March 22 from: http://www.dimabladna.ma/index.php?option=com_flexicontent&view=items&id=3537

Ouardirhi Abdelaziz, Maghress “Lutte contre l’autism” (February 17, 2013) by Albayane. Retrieved March 22 from: http://www.maghress.com/fr/albayane/115901

Physical & Medical Issues Related to Autism Spectrum Disorders. (2015). Retrieved September 20, 2016, from http://delautism.org/about-autism/signs-and-symptoms/physical-medical-issues-related-to-autism-spectrum-disorders/

Practice and Research. *Pediatrics, 136*(Supplement). Retrieved from Early Identification of Autism Spectrum Disorder: Recommendations for Practice and Research.

Symptoms. (n.d.). Retrieved March 21, 2016, from https://www.autismspeaks.org/what-autism/symptoms

Touhami, M., Ouriaghli, F., Manoudi, F., & Asri, F. (2011). P01-360-Autism and violence. *European Psychiatry*, *26*, 362.

Trevarthen, C. (1998). *Children with autism: Diagnosis and interventions to meet their needs*. Jessica Kingsley Publishers.

What Is Autism? (n.d.). Retrieved March 21, 2016, from https://www.autismspeaks.org/what-autism

Zwaigenbaum, L., Bauman, M. L., Stone, W. L., Yirmiya, N., Estes, A., Hansen, R. L. . . . Wetherby, A. (2015). Early Identification of Autism Spectrum Disorder: Recommendations for Practice and Research. Pediatrics, 136(Supplement). doi:10.1542/peds.2014-3667c

Appendices

Appendix A: Caregiver Survey Analytical Data (Tables)

Study Sample

The sample used for the analysis is presented in the Table 1 below. In total we surveyed 183 parents across 7 geographical locations:

Table 1: Sample by Location

Location	Sample Size Autistic	Non-Autistic	All	Format of Interviews	Date of Interviews
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 2: 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 3: 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	8.93	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	2.4%	-	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 4: 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 5: 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	5.8%	17%	10.8%
Pediatrician	36.4%	23.7%	31.7%
Pediatric specialist	9.1%	8.47%	9.6%
Psychologist	12.4%	3.38%	10.2%
Psychiatrist	14.9%	8.47%	14.4%
Neurologist	11.6%	10.17%	12.6%
Nurse	0.8%	0%	0.6%
Team of professionals	2.5%	1.7%	2.4%
Other	6.5%	27.11%	7.8%
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 6: 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%

% = Percentage who have or are currently receiving service

Table 7: Hours per week for current service hours

	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%
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 8: 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 9: 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%

% = Percentage who have or currently see service provider

Table 10: 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%	14.0%	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	10.9%	0%	4.8%

Table 11: 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 12: 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	28.2%	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 13: 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 14: 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 do not wish to 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 do not wish to answer	0.8%	3.9%	1.8%

Table 15: 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%
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%

Table 16: 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 17: 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 18: 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

Table 19 (A): Greatest challenges in caring for a child with autism

Autistic	Non- Autistic	All
1. Safety concerns (i.e. wandering, climbing) 2. Challenging behaviors (i.e. self-injury, aggression, tantrums) 3. Communication difficulties 4. Daily living skills (i.e. toileting, self-feeding) 5. Social interaction difficulties 6. Sleep problems (i.e. trouble falling asleep, trouble staying asleep) 7. Health problems (i.e. co-occurring physical and/or mental health conditions 8. Repetitive behaviors / restrictive interests / insistence on sameness 9. Diet/eating/feeding difficulties 10. Other (independence, job training, education, figuring life out after parents are gone (future), etc.) 11. Sensory issues	1. Social interaction difficulties 2. Daily living skills (i.e. toileting, self- feeding) 3. Challenging behaviors (i.e. self-injury, aggression, tantrums) 4. Safety concerns (i.e. wandering, climbing) 5. Communication difficulties 6. Health problems (i.e. co-occurring physical and/or mental health conditions 7. Sleep problems (i.e. trouble falling asleep, trouble staying asleep) 8. Diet/eating/feeding difficulties 9. Repetitive behaviors/ restrictive interests/ insistence on sameness 10. Sensory issues 11. Other (independence, job training, education, figuring life out after parents are gone (future), etc.)	1. Safety concerns (i.e. wandering, climbing) 2. Challenging behaviors (i.e. self- injury, aggression, tantrums) 3. Daily living skills (i.e. toileting, self- feeding) 4. Communication difficulties 5. Social interaction difficulties 6. Health problems (i.e. co-occurring physical and/or mental health conditions 7. Sleep problems (i.e. trouble falling asleep, trouble staying asleep) 8. Diet/eating/feeding difficulties 9. Repetitive behaviors/ restrictive interests/ insistence on sameness 10. Other (independence, job training, education, figuring life out after parents are gone (future), etc.) 11. Sensory issues

Table 19 (B): Greatest challenges faced in getting support for a child with autism

Autistic	Non- Autistic	All
1. Making sure the child receives adequate education 2. Making sure the child's basic rights are protected 3. Making sure the child receives adequate health care 4. Making sure the child receives adequate welfare/ social supports 5. Making sure the family receives adequate respite 6. Other (having child participate in activities, attention to one child over the other, etc.)	1. Making sure the child receives adequate education 2. Making sure the child receives adequate health care 3. Making sure the child receives adequate welfare/ social supports 4. Other (having child participate in activities, attention to one child over the other, etc.) 5. Making sure the child's basic rights are protected 6. Making sure the family receives adequate respite	1. Making sure the child receives adequate education 2. Making sure the child receives adequate health care 3. Making sure the child's basic rights are protected 4. Making sure the child receives adequate welfare/ social supports 5. Making sure the family receives adequate respite 6. Other (having child participate in activities, attention to one child over the other, etc.)

Table 19 (C): Greatest priorities for families affected by autism in Morocco

Autistic	Non- Autistic	All
1. Greater rights for individuals with autism 2. Improved education services 3. Improved health care services 4. Greater community awareness 5. Improved welfare/ social services 6. More information about autism 7. Greater in-home support 8. Greater opportunities for parent interactions/ networking 9. Other (taking in consideration the children in need of Morocco and provide all necessary services, special schools, special training for parents, etc.)	1. Improved education services 2. Improved health care services 3. Greater rights for individuals with autism 4. Greater community awareness 5. Improved welfare/ social services 6. More information about autism 7. Greater in-home support 8. Greater opportunities for parent interactions/ networking 9. Other (taking in consideration the children in need of Morocco and provide all necessary services, special schools, special training for parents, etc.)	1. Improved education services 2. Improved health care services 3. Greater rights for individuals with autism 4. Greater community awareness 5. Improved welfare/ social services 6. More information about autism 7. Greater in-home support 8. Greater opportunities for parent interactions/ networking 9. Other (taking in consideration the children in need of Morocco and provide all necessary services, special schools, special training for parents, etc.)

Appendix B: Caregiver Survey

Autism Speaks

Caregiver Needs Survey

Developed by Amy Daniels & SEAN National Coordinators

SECTION 0: BASIC SURVEY DATA

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

____

1.2 Delivery method

1. ______In person (interviewer)
2._In-person (self)
3. ______Phone
4. ______Email
5. ______Other (Specify:______________________)

1.3 Format

1. ______Paper
2. ______Electronic

1.4 Setting

1. ______Home
2. ______Facility
3. ______Other (Specify:______________________)

1.5 Facility name (enter name, if applicable)

1. ______NA
2. ________________________________

1.6 Date completed (enter DD/MM/ YYYY)

____

PARTICIPANT CONSENT

Dear Parent / Caregiver,

***Worcester Polytechnic Institute**, in partnership with Autism Speaks (www.autismspeaks.org), is conducting a survey to understand the needs of children with autism and the challenges and difficulties faced by them and their families in seeking and receiving help. While there is no immediate benefit to your participation, the results of this survey will be used for research and planning appropriate measures to improve care and services for children affected by autism and their families. We do not anticipate any risks to your participation other than those encountered in day-to-day life.*

If you agree to participate, the survey should take approximately 30 to 45 minutes to complete. Please read the questions and answers carefully, 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. "TV cartoons")
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. ABA)	1._____Yes 2._____No		1. Yes, totally 2. Yes, in part 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 usually receive per week?	**3.4** Do you have to pay for this 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!

Appendix C: Professional Survey

Autism Speaks Professional Needs Survey

Developed by Amy Daniels & SEAN National Coordinators

Kara A. Reagon

GLOBAL AUTISM
PUBLIC HEALTH
Initiative

SECTION 0: BASIC SURVEY DATA

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

____

1.2 Delivery method

1. ______In person (interviewer)
2.________In-person (self)
3. ______Phone
4. ______Email
5. ______Other (Specify:_______________________)

1.3 Format

1. ______Paper
2. ______Electronic

1.4 Date completed (enter DD/MM/ YYYY)

____

PARTICIPANT CONSENT

Dear Professional,

Worcester Polytechnic Institute]*, 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 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 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 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 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 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 certificate for this instrument	2. I was not trained but learned to use the instrument from the manual/internet/other
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 D: Professional Survey Analytical Data (Tables and Graphs)

Study Sample

Section 1: Demographic Characteristic of Professionals

Table 20: Education and experience level of the professionals

Characteristic	
Highest level of education, N(%)	
No schooling	2 (8%)
Primary school	3 (12%)
Secondary school	4 (16%)
High school / vocational training	10 (41%)
College / university degree	6 (25%)
Higher than college/ University degree PHD	1 (4%)
Years of experience, mean	6.73

Section 2: Characteristics

Table 21: Characteristics of children / patients

Characteristic	
Types of patients worked with, N (%)	
Autism Spectrum Disorder	14 (60.9%)
Mental retardation	15 (65.2%)
Physical handicaps	7 (30.4%)
Deaf or hearing impaired	2 (8.7%)
Blind or visually impaired	0 (0.0%)
Other psychiatric conditions	9 (39.1%)
Other	1 (4.3%)
I don’t know	0 (0.0%)
Not diagnosed	0 (0.0%)
Multi-handicapped	0 (0.0%)
Number of children in classroom/ practice/ case load, median	11
Age range of children worked with, median	6 - 15 years old

Section 3: Service Encounters - For professionals working in the education field

Table 22: Type of school worked in for children with autism

	N(%)
Worked in the education sector	17 (94.4%)
Type of school worked at	
Preschool	1 (5.9%)
Public primary school	1 (5.9%)
Private primary school	1 (5.9%)
Special classroom for children with disabilities	11 (64.7%)
Special classroom for children with autism	6 (35.3%)
Home-schooling teacher	1 (5.9%)
Secondary school	0 (0.0%)
High school / vocational training	0 (0.0%)
College/university	0 (0.0%)
Type of work done at the school	
Classroom/group teacher	1 (6.7%)
Individual teacher	9 (60%)
In-school aide/shadow/tutor	2 (13.3%)
Classroom assistant	0 (0.0%)
Director	1 (6.7%)
Other	2 (13.3%)

Table 23: Training in methods used for children with autism

Characteristic	Trained in the method / has a certificate N(%)	Trained on the job / no certificate N (%)	Not trained / self learnt N (%)
Behavioral intervention or modification	10 (41.6%)	1 (4%)	1 (4%)
TEACCH	3 (12.5%)	6 (25%)	0 (0.0%)
Pivotal response training	5 (20.8%)	0 (0.0%)	0 (0.0%)
Floortime	5 (20.8%)	0 (0.0%)	0 (0.0%)
PECS	5 (20.8%)	2 (8.3%)	0 (0.0%)
Other	0 (0.0%)	2 (8.3%)	0 (0.0%)
No special method	1 (4%)	1 (4%)	0 (0.0%)
Don’t know	0	0	0 (0.0%)

Table 24: Availability of services for children with autism at respective facilities

Characteristic	**Available N(%)**	**Hours per week, mean (SD)**	**Families have to partially/totally pay for it N (%)**
Behavioral intervention or modification	16 (66.6%)	18 (27.6)	12 (50%)
TEACCH	6 (25%)	5 (13.2)	4 (16%)
Pivotal response training	2 (8%)	2 (20)	2 (8%)
Floortime	3 (12%)	2 (20)	2 (8%)
PECS	6 (25%)	2 (20)	3 (12%)
In-school aide/shadow	2 (8%)	2 (20)	1 (4%)
In-school tutor	0 (0%)	0	1 (4%)
Psychomotricien	4 (16%)	3 (14)	3 (12%)
Psychologist	12 (50%)	9 (7.8)	5 (20%)
Speech and language therapist	8 (33.3%)	8 (8.5)	6 (25%)
Social skills training	7 (29%)	5 (11.3)	4 (16%)
Sport	11 (45%)	10 (11.6)	6 (25%)
Musical therapy or music lessons	11 (45%)	8 (11.5)	5 (20%)
Other	2 (8%)	0	0
Don’t know	1 (4%)	0	0

Table 25: Characteristics of the classroom environment, related training and FAQs

Characteristics	
Classroom environment, mean (SD)	
Number of children with autism in the classroom	17 (8)
Number of teachers	18 (4)
Number of classroom assistants	11 (1)
Follows courses / training about autism, N (%)	7 (36.8%)
Source of information regarding autism, N (%)	
The internet	13 (54%)
Doctor / pediatrician	9 (37.5%)
Other teachers	10 (41%)
Parents of children with autism	6 (25%)
Other providers	10 (41%)
Other	1 (4%)
Currently receive assistance in job regarding teaching children with autism, N (%)	12 (63.2%)
Has training needs in regards to autism, N (%)	16 (88.9%)
Receive questions from parents about their child with autism, N (%)	15 (83.3%)
Parents asked about, N (%)	
Health issues	12 (70.6%)
Sleep problems	13 (76.5%)
Diet/eating/feeding difficulties	10 (58.8%)
Daily living skills	12 (70.6%)
Social interaction difficulties	13 (76.5%)
Repetitive behaviors/restrictive interests/insistence on sameness	11 (64.7%)
Language and communication difficulties	12 (70.6%)
Sensory issues	10 (58.8%)
Safety concerns	9 (52.9%)
Challenging behavior	11 (64.7%)
The diagnosis	10 (58.8%)
Treatment	9 (52.9%)
Schooling or problems at school	12 (70.6%)
Schooling or problems at school	7 (41.2%)
Dealing with other family members	0
Other	0

Section 4: Service Encounters - For professionals working in health care or other fields

Table 26: Health care service provided for children with autism

	N(%)
Health care facility worked in	
Hospital	0
Private practice	1 (50%)
General health care center	0
Association for children with handicaps	1 (50%)
Center for sport, music or hobby	0
Other	0
Type of work performed / occupation	
Psychiatrist	1 (50%)
Psychologist	0
General practitioner or Pediatrician	0
Other medical doctor or dentist	0
Speech and language therapist	0
Psychomotricien	0
Trainer or group leader	1 (50%)
Perform diagnostic work for children with autism	
Provide autism screening and refer parents to diagnostic centers	7 (36.8%)
Contribute to the diagnosis with specific assessments	2 (100%)
Uses questionnaires for screening or diagnostic work	1 (50%)

Table 27: Diagnostic instruments and therapies used for children with autism

Characteristic	Trained in the method / has a certificate N(%)	Trained on the job / no certificate N (%)	Not trained / self learnt N (%)
Instruments used at respective centers			
ADI-R	1 (50%)	1 (50%)	0
ADOS	1 (50%)	1 (50%)	0
CARS	1 (50%)	0	0
WISC	1(50%)	0	0
PEP	1 (50%)	0	0
Other	0	0	0
No special instrument used	0	0	0
Don't know	0	0	0
Therapeutic work with children with autism			
Behavioral intervention or modification	1 (50%)	0	0
TEACCH	1 (50%)	0	0
Pivotal response training	1 (50%)	0	0
Floortime	1 (50%)	0	0
PECS	1 (50%)	0	0
Other	0	0	0
No special method	0	0	0
Don't know	0	0	0

Table 28: Services available for the children with autism at respective centers

Characteristic	Available N(%)	Hours per week, mean (SD)	Families have to partially/totally pay for it N (%)
Behavioral intervention or modification	1 (50%)	40	1 (50%)
TEACCH	0	0	1 (50%)
Pivotal response training	0	0	1 (50%)
Floortime	0	0	1 (50%)
PECS	0	0	1 (50%)
Out-school tutor	0	0	1 (50%)
Pharmacotherapy / medication	1 (50%)	0	1 (50%)
Cognitive behavioral therapy	1 (50%)	0	1 (50%)
Psycho motor therapy /sensory integration training	0	0	1 (50%)
Speech and language therapist	0	0	1 (50%)
Occupational therapy	0	0	1 (50%)
Social skills training	0	0	1 (50%)
Training for parents	0	0	1 (50%)
Parents support groups	0	0	1 (50%)
Sport	0	0	1 (50%)
Musical therapy or music lessons	0	0	1 (50%)
Job coaching	0	0	1 (50%)
Other	0	0	1 (50%)
Don’t know or not applicable	0	0	1 (50%)

Table 29: Source of information regarding autism and FAQs

Characteristics	**N (%)**
Provide services for children with autism in their home	1 (50%)
Follow courses / training about autism	2 (100%)
Source of information regarding autism	
The internet	1 (50%)
Doctor / pediatrician	0
Books	0
Parents of children with autism	0
Other providers	1 (50%)
Other	0
Currently receive assistance in regards to children with autism	1 (50%)
Regarding their child with autism, parents asked about	
Health issues	1 (50%)
Sleep problems	2 (100%)
Diet/eating/feeding difficulties	2 (100%)
Daily living skills	2 (100%)
Social interaction difficulties	2 (100%)
Repetitive behaviors/restrictive interests/insistence on sameness	2 (100%)
Language and communication difficulties	2 (100%)
Sensory issues	2 (100%)
Safety concerns	2 (100%)
Challenging behavior	2 (100%)
The diagnosis	1 (50%)
Treatment	2 (100%)
Schooling or problems at school	1 (50%)
Dealing with other family members	1 (50%)
Other	0

Section 5: Professional Perceptions

Table 30: Access and unmet needs in past 12-months

Characteristic	**N (%)**
Difficulties / delays providing services due to ineligibility	6 (28.6%)
Difficulties / delays because clients were unavailable	6 (28.6%)
Difficulties / delays due to wait lists, backlogs from providers	6 (31.6%)
Difficulties / delays because of issues related to cost	8 (38.1%)
Difficulties / delays because of issues getting the information needed	4 (19%)
Other difficulties or delays	4 (19%)
Level of frustration in efforts to provide services	
Never	1 (4.8%)
Sometimes	14 (66.7%)
Usually	3 (14.3%)
Always	2 (9.5%)
Don't know	1 (4.8%)

Table 31: Stigma

	N (%)
I feel helpless teaching a child with autism	
Strongly disagree	4 (22.2%)
Disagree	8 (44.4%)
Agree	1 (5.6%)
Strongly agree	5 (27.8%)
Other people would discriminate against me because I work with individuals with autism	
Strongly disagree	2 (10.5%)
Disagree	5 (26.3%)
Agree	3 (15.8%)
Strongly agree	9 (47.4%)

Table 32: Quality of life

	N (%)
Importance of students having support to make progress in school	
A little important	0
Important	7 (35%)
Very important	13 (65%)
Satisfaction that students have support to make progress in school	
Very dissatisfied	2 (10%)
Neutral	9 (45%)
Very satisfied	9 (45%)
Importance of students having support to make friends	
A little important	0
Important	5 (25%)
Very important	15 (75%)
Satisfaction that students have support to make friends	
Very dissatisfied	2 (10.5%)
Neutral	3 (15.8%)
Very satisfied	14 (73.7%)
Importance of family having a good relationship with services providers who work with their child	
A little important	2 (9.5%)
Important	3 (14.3%)
Very important	16 (76.2%)
Satisfaction with the relationship between the family and I	
Very dissatisfied	2 (10.5%)
Neutral	10 (52.6%)
Very satisfied	7 (36.8%)

Table 33: Challenges and priorities

	N. of Participants Who Listed Answer Within their Top 3 (%)
Greatest challenges faced in getting support for a individuals with autism	
1. Daily living skills (i.e. toileting, self-feeding)	14 (66.7%)
2. Communication difficulties	11 (52.4%)
3. Health problems (i.e. co-occurring physical and/or mental health conditions	7 (33.3%)
4. Social interaction difficulties	4 (19%)
5. Repetitive behaviors/ restrictive interests/ insistence on sameness	5 (23.8%)
6. Diet/eating/feeding difficulties	4 (19%)
7.. Sleep problems (i.e. trouble falling asleep, trouble staying asleep)	6 (28.6%)
8. Challenging behaviors (i.e. self-injury, aggression, tantrums)	5 (23.8%)
9.Dealing with family members (parents, extended family, siblings)	3 (14.3%)
10.Schooling or problems at school (finding a school for the child, learning or behavioral difficulties in the classroom)	6 (28.6%)
11.Treatment (finding treatment for the child, not knowing where to refer a child)	1 (4.8%)
12.The diagnosis (where to refer parents for a diagnosis, did not understand the diagnosis etc)	4 (19%)
13.Safety concerns (i.e. wandering, climbing)	3 (14.3%)
14.Sensory issues (i.e. hypersensitivity to sound, smell, light, touch)	3 (14.3%)
15.Other	0
Greatest challenges faced in getting support for a individuals with autism	
1. Making sure the child receives adequate education	10 (50%)
2. Making sure the child receives adequate health care	17 (85%)
3. Making sure the child's basic rights are protected	10 (50%)
4. Making sure the child receives adequate welfare/ social supports	12 (60%)
5. Making sure the family receives adequate respite	8 (40%)
6. Other (having child participate in activities, attention to one child over the other, etc.)	0
Greatest priorities for families affected by autism in Morocco	
1. Improved education services	15 (75%)
2. Improved health care services	15 (75%)
3. Greater rights for individuals with autism	4 (20%)
4. Greater community awareness	9 (45%)
5. Improved welfare/ social services	12 (60%)
6. More information about autism	8 (40%)
7. Greater in-home support	5 (25%)
8. Greater opportunities for parent interactions/ networking	0
9. Other (taking in consideration the children in need of Morocco and provide all necessary services, special schools, special training for parents, etc.)	

Appendix E: Maps of Survey Locations

Figure A: Map of Morocco

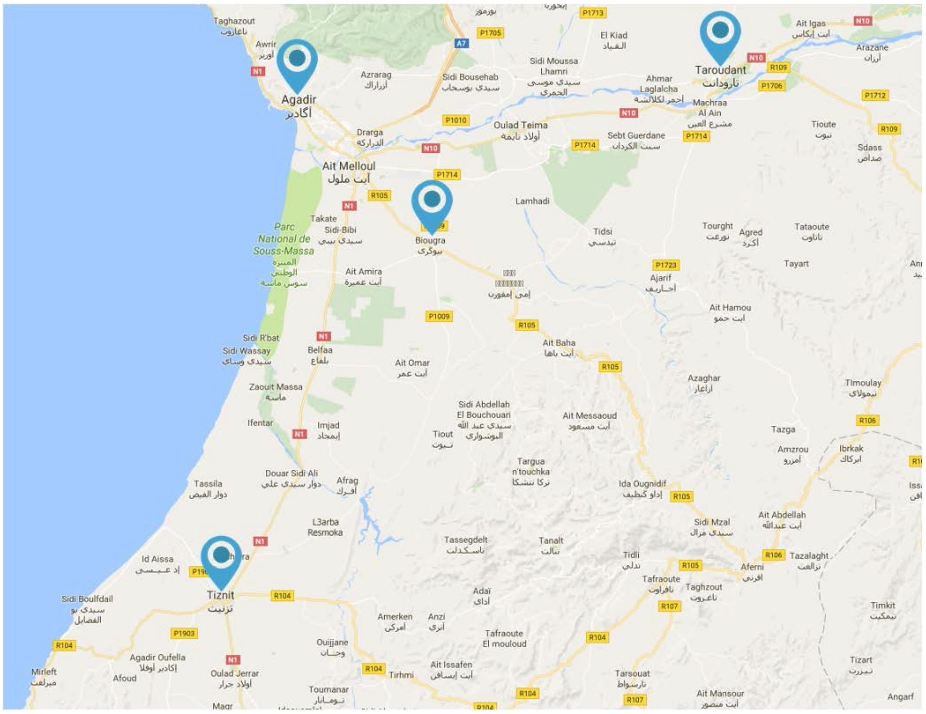


Figure B: Map of Area around Tiznit