AUTISM SPEAKS, MOROCCO LISTENS

Documenting, Analyzing, and Presenting the State of Autism in Morocco

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Chapter 1: Introduction

Autism Spectrum Disorder (ASD) is a neurological developmental disorder with symptoms typically first observed between the ages of one and two years (Elder, 2012). In most cases, these symptoms are treatable but incurable, and they continue throughout an individual's lifetime. Patients diagnosed with ASD fall on a spectrum which people commonly identify under the umbrella term "autism." As a result, patients diagnosed with autism often show a range of signs and symptoms which, in turn, present different kinds of challenges that each individual must overcome. Commonly cited complications include difficulty concentrating, difficulty with traditional school settings, and difficulty controlling impulses and interactions.

Unfortunately, ASD research has been conducted in the United States. This dedication to understanding and accommodating people with the disorder on a comprehensive level is not reflected equally in other areas of the world, such as Morocco. As a result, teachers, parents, and families of individuals with Autism have had to establish start-up organizations with the intent of providing caregivers and teachers with resources to help care for children with autism.

International and start-up organizations are working together to enhance understanding and support of individuals with autism in Morocco. Association AMAL Enfants Aux Besions Specifiques Mentaux (AMAL), founded by advocates for those with mental disabilities, is an organization centered in Casablanca. Their mission statement focuses on supporting people affected by ASD by educating families and children as well as improving the public perception of ASD. In addition to smaller, locally run organizations set out to tackle the needs of the autistic community, there exist larger, international groups with similar objectives. Autism Speaks is an international organization that is dedicated to providing treatments and resources to individuals and families living with ASD. They have worked to increase understanding and acceptance of people with autism around the world by spreading awareness and advancing research around the topic.

Together, Autism Speaks recently began an initiative to provide effective solutions to Moroccans with ASD. However, there are incomplete assessments of the resources available for those with ASD throughout the country, preventing the advancement of this initiative. Therefore, the next step toward advancement means analyzing data that already exists and presenting the data to stakeholders. Additionally, more detailed information regarding the state of autism awareness and resources in Morocco is needed to build a more complete understanding of the current situation.

The goal of our project is to collect and analyze data regarding the current treatments and education available to the autistic children in Rabat, Morocco; as well as to share information on autism with parents and teachers of affected children. To accomplish our goal, we have identified three essential objectives that we will complete on site. First, we will analyze and present the existing qualitative and quantitative data gathered in 2016. Second, we will assess the current available resources for families of children with autism as well as the challenges those families face in the Rabat region. Lastly, based on our findings from objectives one and two, we will conduct targeted evaluations of resources and experiences in Rabat. We will forward our findings from these objectives to our sponsoring organizations to contribute to the understanding of autism in Morocco.

Chapter 2: Literature Review

This chapter addresses the components of our project that are necessary to understand before we complete our goal of raising autism awareness of parents and teachers; and gaining knowledge of resources for autism in Morocco. We provide a working definition for Autism Spectrum Disorder and explain the common conditions associated with it. We evaluate the social implications that people afflicted with autism face in Moroccan society. Our overview examines a cross cultural comparison of legislations pertaining to the rights and resources of the disabled. Finally, we profile the stakeholders that this project will work with in Morocco.

2.1 Autism Spectrum Disorder and its Complexity

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

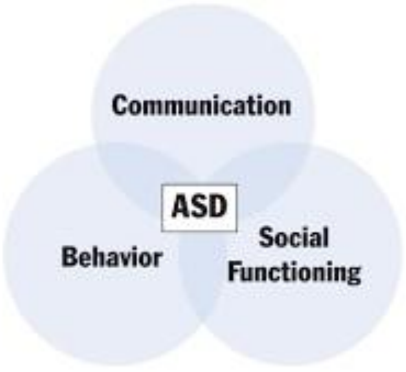

Figure 2.1 Aspects of life impacted by autism (RDH, 2014).

The diagram above represents the overlap potential of the areas of life affected by ASD. Children with ASD can be affected in a single area, two areas, or all three areas of daily functioning simultaneously. Additionally, the severity of each inhibition children with autism experience varies from child to child. Being that the disorder exists as a spectrum, children diagnosed with autism can have any combination of hindrances or abilities in their affected areas of life (What is Autism, 2012). The resultant variety in symptoms requires thoughtful individualization of care and treatments for each child.

As the severity of autistic behaviors and conditions increases in an individual, the impairment of their normal daily functioning increases as well. Similarly, autism research has linked intellectual disabilities to Autism Spectrum Disorder, existing in one third of the population (What is Autism, 2012). Unfortunately, combinations of these same characteristics frequently lead to social isolation of people with autism. Lack of proper understanding of the specifics and complexity of the disorder has led to widespread stigma around ASD.

2.1.1 Physical Ailments Associated with Autism

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

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

Autism and Epilepsy

The most common condition seen in children with autism is epilepsy, affecting one fifth to one third of the autistic population. Health experts characterize epilepsy by "unexplained staring spells, stiffening of muscles, involuntary limb-jerking, sleepiness, marked or unexplained irritability or aggressiveness, and regression in normal development" (Autism and Health, 2017). Unfortunately, the severity of epilepsy can cause death in some cases. This condition is most prevalent during children's preschool and adolescent stages of development. Epilepsy is consistently seen in tandem with regular sleep disturbances. Resultant sleep disturbances can lead to an increase in the prevalence of daytime behaviors such as repetitive actions and withdrawal from social interaction. Both autism and epilepsy, when occurring independently, respond to the same gene mutations.

Autism and Gastrointestinal Issues

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

Autism and Eating/Feeding Issues

United States government-funded research makes evident that “seventy percent of autistic children have feeding issues; thirty-six percent of these cases are severe” (Autism and Health, 2017). Health care professionals characterize feeding issues by pickiness in eating, insufficient consumption, and disruptive behavior while eating. Some causes for these behaviors include sensory aversions, anxiety, and resistance to change. Chronic overeating, another problem commonly seen in the autistic community, has been linked to behavioral medications which affect metabolism and appetite. Pica, or the condition of eating nonfood items, is also associated with autism and can lead to severe health issues or death.

2.1.2 Cognitive Ailments Associated with Autism

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

Autism and ADHD

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

Autism, Anxiety and Depression

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

2.2 Social Implications of Autism in Morocco

The symptoms and other ailments that tend to accompany autism, detailed above, are often easily identified in individuals affected by autism. Thus, children with autism typically exhibit multiple characteristics that set them distinctly apart from their peers. As a result, social stigma can often develop around individuals who exhibit these traits.

When autistic individuals act in a manner considered inappropriate to the norms of Moroccan society, other Moroccans may stigmatize them due to their general lack of awareness of mental disabilities in general, and autism in particular. Various testimonies from current and past residents support this claim; many families struggle to raise children with these disabilities (Galindo, Grant, Languet, & Sirry, 2016; Hachim, Martin, Miner, & Rahman, 2016). One testimony accounts how schoolmates labeled a child as "the funny kid" due to an unidentified mental illness. They made fun of, avoided, and criticized him. Another indication of the harsh stigma in Morocco is the testimonial book described in Morocco World News: *My name is Momo. I am autistic*. This book explains the hardships of finding qualified personnel to help children with autism and the fight for rights of the autistic community (Morocco World News, 2016). Unfortunately, the stigma associated with autism in Morocco is undeniable and impedes the social development of the individuals it affects.

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

2.3 Advocacy in the Context of Site Specific Concerns: Rabat

Although advocacy and support groups raise awareness of ASD in Morocco, they have not yet made a significant change in the policies toward and resources available to those with the disorder. Many factors contribute to the lack of resources available to the population, and here we consider these factors relative to the design and integrity of this investigation.

2.3.1 Trend Towards Urbanization

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

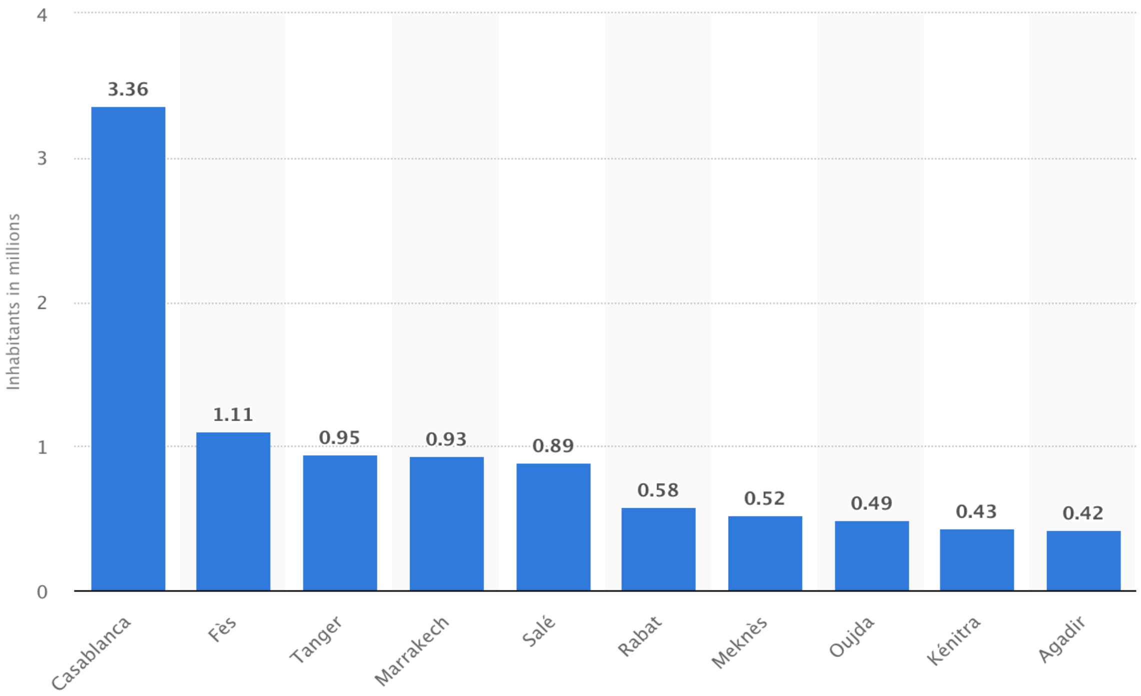

Figure 2.2 Graph of populations in millions of cities in Morocco (Morocco-Largest Cities, 2014)

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

2.3.2 Literacy and Language

The overall literacy rate of Morocco is 68.5%, with a gender distribution of 78.6% for men and 58.8% for women (World Factbook). More specifically with regard to the Rabat region, Salé's overall literacy rate is 63% while Rabat's is 74% (Francoise, 2003). This may have caused barriers to arise in the past concerning attempts to spread awareness among the Moroccan population. For example, brochures and pamphlets may not have been equally accessible to every domain of Moroccan society. Information must be shared in multiple languages in order to be received by a majority of the Moroccan population.

Moroccans speak many languages and the most prevalent languages vary between regions. Arabic is considered the national language of Morocco. However, those who live in the Rabat region most commonly speak the local Darija dialect. Additionally, Moroccans speak French as the language of diplomatic and government business (World Factbook). Darija and French are the two most widely spoken languages in Rabat and its surrounding cities. This data is important to consider while determining an effective method to spread awareness about autism to citizens in the Rabat region.

2.4 Limitations with Governmental Support

The Moroccan government has begun to develop and implement legislation to protect the rights of individuals with disabilities (Morocco: Flawed Draft, 2017) However, these laws are not implemented in the manner intended due to factors such as limited access to necessary resources and the stigmatization of mental disabilities. An assessment of recent policies and actions revealed that Morocco can contribute much more for its citizens.

2.4.1 Recent Legislative Efforts

In October of 2015, the Moroccan parliament adopted an initiative to protect the rights of the disabled under the Draft Framework Law. Also known as Draft Law 97.13, this law is the first law in Morocco to address the rights of people with disabilities. However, Morocco recently signed an International Human Rights Treaty that set the rights outlined in the Draft Framework Law as below the international standard (Letter to Moroccan Parliament, 2015). Although Morocco was one of the first countries to adhere to the United Nations' Convention on the Rights of Persons with Disabilities, the Draft Framework Law does not follow the legislation of the international treaty (Letter to Moroccan Parliament, 2015). Human Rights Watch, an international nongovernmental organization that advocates for human rights, addressed the flaws presented in the Draft Framework Law in a letter to the Moroccan parliament. Flawed elements include the lack of an established right to education and a rights based approach to disability (Letter to Moroccan Parliament, 2015). The Draft Framework Law states the right to education under article 24. In their letter to parliament, the Human Rights Watch writes of the separation of special needs children from regular classrooms. This lack of proper accommodations for the disabled in an educational setting denies children with disabilities the right to education. (Letter to Moroccan Parliament, 2015). There are aspects of Moroccan legislature that could be ameliorated to better suit the needs of the disabled Moroccan population.

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

2.4.2 Regional Comparisons of Legislation for the Disabled

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

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

2.5 Stakeholders

To compensate for limited governmental efforts to improve the quality of life for the disabled in Morocco, organizations in the form of local, family-run corporations have developed with the intention of providing awareness and resources for ASD.

Founded in 2010, the AAEBSM (Association AMAL Enfants Aux Besions Specifiques Mentaux) organization, otherwise known as AMAL, specializes in medical and psychological care of people with various levels of mental disabilities. AAEBSM's involvement focuses, but is not limited; to children from disadvantaged backgrounds. Their mission is to support the needs of families and children affected by Autism Spectrum Disorder. They accomplish this mission by educating parents on the needs of their special needs child, as well as helping children flourish in modern society. Their goal for children includes providing proper education and support regarding social integration. Additionally, AMAL aims to alter public perception of mental disabilities to promote mutual respect and dignity for each member of society (AAEBSM, 2017).

The primary stakeholders for this project will feature families of children with autism and members of AMAL. These families are a primary source of statistical and qualitative information regarding experiences the autistic community encounters in the Rabat region. Professional caregivers, including doctors and teachers, can provide technical insight to the current system of diagnosing and treating children with autism. AMAL can facilitate interviews and contact with the families and professional caregivers affiliated with their organization. Table 2.1, shown below, outlines the interests, perspectives, and assets of these key stakeholders.

Figure 2.5 AMAL's logo (AAESM, 2017)

Stakeholders	**Interests**	**Perspectives**	**Assets**
Families	- Children’s well-being - Gaining resources and knowledge to help best care for their children	- Helping their children personally develop, thrive, and socially integrate	- Knowledge of local resources - Experience with social implications associated with autism in Morocco -Knowledge of specific children’s difficulties
Professional caregivers	- Improving the ability to accurately diagnosis autism - Improving quality of treatment for individuals with autism	- Experiencing the advantages and disadvantages of current diagnosis and treatment methods	- Insight to the current methods of diagnosis and treatment for autism in Morocco
AMAL	- Advancing resources and awareness of autism in Morocco	- Treating autistic children - Spreading awareness of autistic information and resources	- On site offices - Connections with autistic families and association in the area

Table 2.1 Primary stakeholders involved in our project

The stakeholders outlined in Table 2.1 include those we will interact with over the course of our project. We hope that these stakeholders’ experiences and expertise will provide us with insight to the current state of autism in Morocco.

2.6 Relevant Case Study: Autism Assessment in Morocco, 2016

We evaluated the methods that two student teams used in 2016 to conduct a project similar to ours. This case study depicts their interview methodologies as well as the obstacles they experienced throughout their project.

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

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

The logistical planning and communication between participants and agencies faced challenges as well. This resulted in parents who brought their children to interview sites with the expectation of receiving a medical diagnosis. In another situation, the teams encountered problems with the surveys Autism Speaks provided for them. Through their interviews with families, the team found that a few of the questions on the survey were culturally insensitive to the interviewed families. As a result, the team suggested avoiding asking questions related to religion and the stigma around autism. Additionally, they noted that language barriers led to inaccurate responses to survey questions by physicians and other professionals.

2.7 Summary

There is currently insufficient data to fully understand the current resources available to children with autism in Morocco. Individuals with autism are seen as unfit to care for themselves in Moroccan society, which is supplemented by the fact that the Moroccan government does not guarantee the rights of these individuals. The Moroccan government has attempted to guarantee more rights for individuals with autism through recent legislative efforts. However, these laws have not been enforced properly yet. Knowing this information, we will develop methodologies that help us collect and analyze data regarding the resources and education available to children with autism in Morocco; as well as share our findings with parents and teachers of affected individuals.

Chapter 3: Methodology

The goal of this project is to collect and analyze data regarding the current treatments and education available to children with autism in Morocco; as well as share information on autism with parents and teachers of affected children. We will complete the following three objectives while in Morocco in order to effectively reach our goal:

1. Analyze and present qualitative and quantitative data from 2016
2. Assess resources and challenges for families of children with autism in the Rabat region
3. Conduct targeted evaluations of resources and experiences in Rabat

Figure 3.1, shown below, represents the order in which we will complete our three objectives and the methodologies we will use to complete each one. Our plans to implement each of these methodologies are described in detail below.

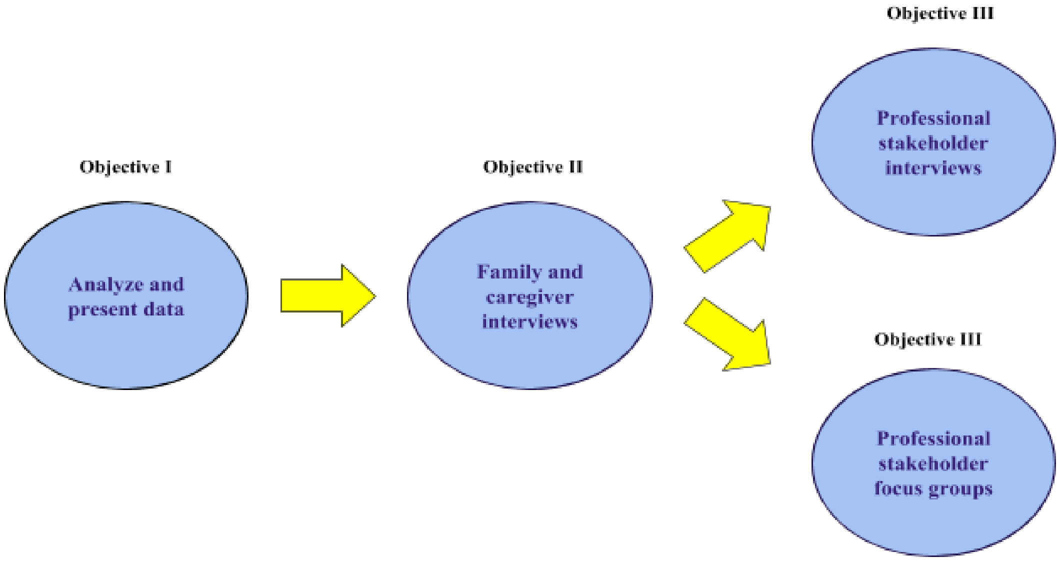

Figure 3.1 Flow chart depicting our three objectives

3.1 Analyze and present raw data from 2016

In 2016, two teams of students collected a set of data regarding the current state of autism awareness and resource availability in Morocco. The teams used a survey that Autism Speaks provided to conduct in-person interviews of families and caregivers affected by autism. These interviews provided both qualitative and quantitative data. We will analyze this data by performing content analysis on the statistical data and personal stories found in this collection. We will organize personal responses to each open ended question into categories depending on the types of responses present in the data (Berg, 2012). These organization techniques will include standard methods of coding in order to find aspects of qualitative data that a computer can analyze. We will analyze quantitative data by performing statistical analyses that we feel are appropriate for coherently representing the data set. Over the course of this process, we will identify areas of information that are crucial to understanding the overall autistic condition in Morocco. Additionally, we will identify any questions from the survey tool used by the teams in 2016 which would benefit from revision.

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Figure 3.2 Autism Speaks logo (Autism Speaks, 2017)

Construct Infographic

Our team will use our analysis of data from 2016 to construct an infographic depicting the current understanding of autism in Morocco. An infographic is simply a visual representation of a data set or collection of information. We will gain access to the data collected in 2016 from Dr. Maretha de Jonge, a cognitive behavioral psychologist in the Netherlands. Dr. de Jonge worked with the 2016 student groups to gather this data. The purpose of this infographic is to synthesize the existing information about autism in Morocco and use the findings to increase awareness of the needs and resources of the autistic community.

Refine Survey Tool

Our team will reword questions on the survey after analyzing the data collected in 2016.With assistance from Dr. de Jonge, we will also design streamlined questions that will shed light on previously unexplored topics that may be useful in understanding the complexity of the autistic services in Morocco. While we design our questions, we will focus on phrasing questions in an unbiased and culturally appropriate manner. Our questions will be simple and direct while avoiding questions that contain two parts separated by a conjunction (Berg, 2012). We will keep a close correspondence with Dr. de Jonge while designing these questions so that she can professionally approve them. Finally, we will submit any additional questions to the Institutional Review Board (IRB) to be approved by our university.

3.2 Assess resources and challenges for families in Rabat

Using our refined survey tool, we will conduct interviews with families and caregivers of children with autism in Rabat and surrounding cities including Casablanca, Sale, and Kenitra. AMAL, an autism awareness group located in Casablanca, will provide our stakeholder sample through their contacts of around one hundred and sixty families of children with autism.

Family and Caregiver Interviews

We will present the survey Autism Speaks provides us in the form of an interview due to limitations with language compatibility and internet access in Morocco. Some of the questions that our team will ask in these interviews are contingent on the data analysis our team will conduct in objective one.

We will use convenience sampling to determine the families we interview. AMAL will reach out to the families associated with their organization to ask them to take part in our study. We will interview the families who attend. Our team will conduct two interviews simultaneously, with each interview consisting of one respondent, one translator, and two team members. In each interview, one team member will record the responses of the respondent while the other monitors the physical demeanor, body language, and tone of the respondent(s). Interviews will begin with team members working in conjunction with translators to explain that our team is conducting a survey in order to gain insight on the state of available resources and services for families of children with autism in Morocco. The team member recording responses in each interview will take electronic notes in addition to audio recording the session. We aim to conduct between eight and ten interviews a day, each lasting between thirty minutes to an hour in length depending on translation requirements.

A calibration session will take place between interviewers and translators in order to discuss specific wording for each question and unify conceptual understanding of each question across translators. We will perform simultaneous mock interviews with our translators where each team member acts as a stakeholder and answers the survey questions as asked by the translators (Ward, 2014). Afterwards, each group will come together to compare and correct the different ways each translator interpreted and conveyed each question. These actions will be completed before the first official interview with a respondent.

3.3 Targeted evaluations of resources in Rabat

The purpose of targeted evaluations is to pinpoint insight on aspects of the state of autism in Morocco that we did not learn from analyzing family interviews from 2016 or 2018. The outcome of objectives one and two will determine the exact methods that we will use to complete objective 3. Table 3.1, shown below, describes the stakeholders that we anticipate we will speak to as well as the methodologies we feel are applicable to this objective. Additionally, the table below describes why we would choose each of these stakeholders and methodologies.

	Focus Group	**Interviews**
Physicians/Clinicians	- Use to gather information on the technicalities of treating and diagnosis autism in Morocco. - Most relevant if we want to hear differing opinions on a particular topic regarding autism	- Use to gather private and personal stories of medical professionals on treatment and diagnosis of autism in Morocco - Most relevant to hear accounts of how the medical system affects children and families living with autism
Teachers	- Use to gather technical information regarding the current resources that provide children access to education - Most relevant to understand the current state of education for children with autism and hear teachers' input on future progress	- Use to gather private and personal stories of teachers for children with Autism in Morocco - Most relevant to hear accounts of how teachers have seen the schooling systems in Morocco positively or negatively affect families and children affected with autism

Table 3.1 Factors to be considered in choosing the methodology for Objective 3.

We anticipate that we will organize and conduct either one focus group or a small set of individual interviews during this stage of our project. Both of these methodologies are detailed below; however, we will chose the method that suits our needs while we are on site.

Professional Interviews

We will use AMAL’s contacts, which include teachers and physicians, to set up in-person interviews with professionals. We will write the questions for these interviews based on our results from family interviews in objectives one and two. The questions we design for these interviews will provide a more detailed account of particular information regarding the autistic experience we are interested in further investigating.

Professional Focus Group

We will use AMAL’s contacts to connect with stakeholders for this method. Our team will ask these stakeholders, likely teachers or medical professionals, if they know other professionals in their field who could provide information relating to our questions. We will use a sample of convenience to gather participants for this focus group that can each offer a differing perspective on the topic. We will use translators for this focus group if one or more of our stakeholders does not speak English. We will determine the question(s) for this focus group after reviewing the data collected from caregiver interviews in objectives one and two. We will designate one team member to facilitate the discussion while three team members take minutes on the focus group. Additionally, we will audio record the focus group in case we miss important information. However, if not all members of the focus group speak English, we will use a translator to facilitate the discussion in French or Arabic. We will also use our additional translators to translate for the focus group participants. In this case, team members will still record the meeting minutes as well as a video.

3.4 Logistics and Data Management

While developing our methodological designs, we collaborated with the students and advisors who were involved with the Autism Speaks IQP projects in 2016. From our discussions, we gained insight on key factors to consider while developing our methodologies. These logistical factors include:

Clarity in Study Parameters

We will personally communicate the purpose and potential outcomes of our interviews to the interviewees before each session begins. Additionally, our sponsor will clearly articulate the purpose of our project to the families when they are invited to interviews. This will help avoid miscommunications regarding the purpose of our study to stakeholders.

Calibrated Translators

Avoiding conflict of interest between the interviewer, translator, and interviewee is essential for obtaining the data we require to complete objective two. Therefore, WPI will hire translators prior to conducting interviews and our team will train these translators in order to mitigate unintended biases during the interviews. A calibration session will take place between interviewers and translators in order to discuss specific wording for each question and unify conceptual understanding of each question across translators. We anticipate needing two translators for five days. Dr. Tahar El-Korchi, the co-director of our project site, is in the process of organizing these translators.

Accommodations for Privacy and Child Care

Our team will work with our collaborators to stagger the arrival times for the family interviews. Staggered arrival times will mitigate families waiting all day to be interviewed, a problem that occurred in 2016 when many families arrived simultaneously in the morning. Additionally, we will collaborate with our sponsor to convey to families that they may be asked to wait and encourage them to bring any necessary accommodations. It is also essential that restroom facilities and snacks are available for those who must wait for their interview.

3.5 Tentative Timeline

Timeline	**Week 1**	**Week 2**	**Week 3**	**Week 4**	**Week 5**	**Week 6**	**Week 7**
	1/10 - 1/16	**1/17-1/23**	**1/24-1/30**	**1/31-2/6**	**2/7-2/13**	**2/14-2/20**	**2/21-2/27**
Analyze Existing Data	🟪	🟪					
Develop Infographic	🟨	🟨	🟨				
Interviews & Surveying		🟦		🟦	🟦		
Compile New & Existing Data			🟥	🟥	🟥	🟥	
Final Analysis & Conclusion					🟩	🟩	🟩

Table 3.2: Tentative timeline for the progression of our project.

Chapter 4: Conclusion

It is our hope that this project will advance the understanding of autism in Morocco. Our team will accomplish this by synthesizing and distributing data collected in 2016 regarding autistic experiences and resources in Morocco to families affected by autism. Additionally, our team will expand this database of information by interviewing additional stakeholders about their experiences pertaining to autism in the Rabat region.

There is a lot of work to be done in terms of spreading awareness on autism and mental illnesses in general in Morocco. A lack of adequate governmental support for autism research negatively compounds with insufficient information about the complexities and needs of those with mental illnesses. As a result, children and families affected by autism often struggle with obtaining the resources and support they need. The goal of autism advocacy organizations such as Autism Speaks and AMAL is to provide this support. Our project will assist in accomplishing this goal by expanding the documentation of autistic experiences in Morocco and distributing applicable information to the families and caregivers of children with autism through the AMAL organization.

Overall, we hope that the information we gather and analyze in conjunction with Autism Speaks and AMAL will deepen the current understanding of autism in Morocco. We are open to the discussion of possible refinements to our project proposal upon our arrival on site in January. We are enthusiastically looking forward to working with Autism Speaks and AMAL to spread awareness of autism in Morocco.

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Appendices

Appendix A-Family and Caregiver Survey

Our team will use the appendix tool that the Institutional Review Board (IRB) and World Health Organization (WHO) approved in 2016. The appendix includes a lengthy survey tool targeted toward caregivers of children with autism in Morocco. We have attached the link to the final paper written by one of the 2016 teams. This survey can be found on pages 59-73. Our revised survey tool will be submitted to the IRB from Morocco for expedited review in C-term.

https://web.wpi.edu/Pubs/E-project/Available/E-project-101216-082715/restricted/ALookintotheCurrentStateofAutisminMoroccoFinal.pdf

Appendix B-Statement of Purpose

Hello, we are a team of university students from the United States. We are here to interview you because we want to understand the resources and educational opportunities that are available to your child. We are unable to diagnose or treat your child; however, we would love to hear about you and your families' experiences with your child's condition.