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Jordanian Special Needs Children's Access to Services: Parental Perspective

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Jordanian Special Needs Children’s Access to Services:

Parental Perspective

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Selena Rincon

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Abstract

The purpose of this study was to investigate the point of view of parents of special needs children in regards to their access to financial, medical, and educational services in Jordan. The researcher was interested in the question: Do parents of special needs children believe that the government offers adequate educational, financial, and medical services for their special needs children? This study is significant because special needs children are an important part of Jordanian society and must receive proper services in order to develop their abilities as much as possible and become active members of society. Also, it is important to recognize where Jordan needs to improve in its special education and support for families with special needs children. The researcher wants to know about the parents’ opinions because they play an important role in the development of their children as well as in finding services for them. In order to study this, the researcher interviewed five families with children that had different special needs as well as distributed questionnaires at the Time of Learning Academy. Results showed that opinions toward educational services were the least satisfactory compared to financial and medical services as well as that many families who could not find proper educational services chose to keep their children at home. This study plays a role in encouraging improvement within education services for special needs children.

Key words: Special Education, Regional Studies: Middle East, Individual and Family Studies
Introduction

While the United States has a lot of research available on special needs children and the services available to them, this is not the case in other parts of the world. There are also a lot of financial, medical, and educational services available to children with disabilities and their families, either through public or private centers. Whether these resources are effective and satisfactory has been studied in various research papers but generally, they are accepted as more advanced than other countries. This researcher chose to study the parental opinions about financial, medical, and educational services available in Jordan in order to learn more about special needs children in Jordan. The researcher became interested in this topic after spending a summer in Morocco and living with a host family who had a daughter with cerebral palsy. She noticed that the special needs daughter was not a part of the daily life at home and would only leave the house when she went to doctor appointments. It was considered taboo to speak about the daughter with the family. By seeing the way this special needs daughter was treated, the researcher became interested in children with disabilities within the Middle East. Once she returned to the United States, the researcher worked individually with a sixth grade student with Down syndrome and later on, at a special needs public school. In learning about services available within the United States, primarily through the public sector, the researcher’s interest in special needs services increased. This has led to the current research on special needs services in Jordan. In the future, the researcher is interested in studying special needs services within other Arab countries and comparing the standards for special education between the different countries. In addition, she is interested in studying how these services apply to refugees living within the Arab world and in the United States.
Within the last forty years, Jordan has made a stride to improve its services for special needs children yet these efforts are not able to reach everyone as not all families have access to them if they live outside of big cities. Also, since there is not a relatively accurate number of how many children have disabilities, the government is unable to ensure that every child receives proper care. Even then, resources are limited especially because of financial difficulties. This is not only the case in Jordan, but also all over the Middle East. Unlike North America and Europe, the Middle East has been lacking in services for special needs children because of limited resources and the cultural implications behind having a child with disabilities. This research is important because it starts a conversation with families about their children which is something not every family is willing to do. This also offers an insight into how perceptions of special needs children are changing as more families reach out to special centers for help and learn to accept their special needs children. As part of modernization and social change within the Middle East, specifically Jordan, it is important to include the improvement of services for children with disabilities because they are and will continue to be a part of society and their needs cannot be ignored. By offering them improved services, children with disabilities can grow to be active members of Jordanian society. This study is meant for families with special needs children in Jordan, including families who live within and outside of Amman. As part of this study, the researcher visited Time of Learning Academy, a school that offers special education to children from kindergarten until fifth grade.

This research is attempting to answer the question: Do parents of special needs children believe that the government offers adequate educational, financial, and medical services for their special needs children? By interviewing five families and surveying families at the Time of Learning Academy, the researcher will attempt to answer this question.
**Context and Theory**

The conditions presented by the children whose parents were interviewed were autism, cerebral atrophy, Kabuki syndrome, cerebral hypoxia, and cerebral palsy. Of these, autism was the most common among the families surveyed and is considered one of the more common disabilities in Jordan, which has resulted in more research related to it.

In Jordan, although autism is one of the more common disabilities found in children, a large population of Jordanians does not understand the disability. According to Volkmar and Pauls’ (2003) article, “Autism”, the disorder was once considered rare but is now seen as common. In the article, “Autistic Disturbances of Affective Contact”, Kanner (1943) first described the disorder when he studied eleven children. Since then, there have been a lot of studies done to further explain autism and its causes. It is considered a neuropsychiatric disorder, which typically presents itself in a child before the age of three (Volkmar and Pauls, 2003). The disorder affects social interaction, communication, and behavior and was officially recognized in 1980. Volkmar and Pauls (2003) described the genetic factor in autism and the likelihood of reoccurrence within families.

There are three types of cerebral palsy, spastic, dyskinetic, and ataxic, and all three forms affect the motor skills of a child and continue throughout their adult life. In addition the child could suffer from intellectual disabilities and seizures. According to Koman, Smit, and Shilt’s (2004) article, “Cerebral Palsy”, this disorder develops for different reasons depending on what part of the nervous system has been affected. There are different forms of therapy, such as speech, occupational, and physiotherapy, to help treat the disorder and allow the child to lead a healthier life. Diagnosis of cerebral palsy is a long process since it involves physical exams as well as looking into the prenatal history of the mother and child (Koman, Smit, Shilt, 2004). At
the moment, although there is no cure for the disorder, there are many forms of treatment that can improve the quality of life of a child with cerebral palsy.

Kabuki syndrome is not common worldwide and although the specific number of children with this disorder in Jordan is unknown, it can be assumed that the number of cases is very low. The disorder was first described by Niikawa, Matsuura, Fukushima, Ohsawa, and Kajii (1981) in their article, “Kabuki make-up syndrome: A syndrome of mental retardation, unusual facies, large and protruding ears, and postnatal growth deficiency,” in which the researchers initially studied five Japanese children. The researchers found that their parents commonly had mental disabilities, postnatal growth deficiency, facial abnormalities, and frequent ear infections but they were unable to explain why these children had the disorder (Niikawa, Matsuura, Fukushima, Ohsawa, and Kajii, 1981). Since these specific conditions were previously unseen, the researchers decided to name the disorder Kabuki makeup syndrome and later on discovered more children suffering from the disorder. There continues to be research to understand the genetic cause of Kabuki syndrome. Since the disorder was only recognized a few decades ago, the amount of adults who live with it is limited.

**Special education.** Inclusive special education is still in development all over the world, especially in Jordan where teachers, both in public and private sectors, are not prepared to care for special needs children. Although the United Nations Convention on the Rights of the Child declared that all children must be provided with an education (Frankel, 2012), the idea of inclusive special education is difficult to implement. While some countries, such as the United States and Canada, are trying to implement inclusive special education, other countries are still trying to create strong special needs centers that offer adequate services although they separate children based on their needs.
Frankel (2012) states in her article, “Supporting Inclusive Care and Education for Young Children with Special Needs and Their Families: An International Perspective,” that Canada, the United States, and Australia have implemented laws that encourage inclusive education but those laws are applied based on their federal and local powers. For example, in the United States, the American with Disabilities Act encourages inclusive education by prohibiting the discrimination of special needs children from regular childcare. Frankel (2012) noted that some of the difficulties behind inclusive education were government funding, educating staff, and resource support. Each country deals with government funding differently at a national and local level but in the end, they are left with the same problem in not having enough funds to provide proper inclusive education. This situation is complicated by the fact that funding can be based on the disability of a child and that varies within each educational institution. The second barrier to inclusive education was staff training and this is seen all over the world where the requirements to teach in special education vary from state to state. While some institutions, such as in New South Wales, require all teachers to complete a course on special education, that is not the case in other areas of Australia (Frankel, 2012, p.313). The inability to provide proper education to future teachers leads to staff that does not know how to care properly for special needs children. This prohibits special needs children from receiving successful, inclusive education. The third barrier is the support that staff receives while trying to teach special needs children (Frankel, 2012). In order to properly support inclusive special education, institutions need enough funding as well to educate and support their staff. While inclusive education is being developed in these countries through local and federal laws, it is not the common form of special education in Jordan.
**Jordanian special education:** Although special education was not the priority in Jordan at first, it has developed immensely in the past few decades. While there still a lot of progress to be made in the services special needs children receive, there are now special centers throughout the country, both private and public, that offer their services. The number of children with special needs in Jordan is not always accurate but there have been estimates done by the Jordanian government and outside organizations. Regardless, it can be assumed that a large number of special needs children are not receiving educational services. In the 1960s, religious and international organizations began to open institutes for people with disabilities and in the 1970s, the Ministry of Social Affairs opened twelve special education schools (Hadidi, 1998). According to Hadidi (1998), in 1993 the Ministry of Education took control of special needs education and began to encourage inclusive special education. Yet, a similar barrier to that mentioned by Frankel is that the staff is not properly educated to care for special needs children. Not all teachers have received special education training, although there are universities that now offer diplomas in special education (Hadidi, 1998). Although inclusive education is becoming more popular, Jordan does have special centers and residential schools for children with special needs. Hadidi (1998) believes that many children currently enrolled in regular schools are not receiving proper services because they have not been diagnosed correctly and in the end, only a small percentage of children are receiving adequate special education.

A more recent study, “General and Special Education Systems in Jordan: Present and Future Perspectives” by Al-Jabery and Zumberg (2008) states that some limitations in offering proper special education include shortage of funding, limited resources for educators, limited information available, and lack of public awareness. In order to improve services, Al-Jabery and Zumberg (2008) believe that there needs to be more sources of funding for institutions offering
services as well as an effort to increase public awareness through social media. While Jordan has improved its special education, there still needs to be improvement in the services offered to special needs children.

Since inclusive education is in the process of improving, all over the world, there are new theories on how to effectively teach special needs children within mainstream schools. In Garry Hornby’s (2014) book, “Inclusive Special Education”, he discusses methods meant to improve inclusive special education while supporting the teachers who work with special needs children. While it is ideal to offer inclusive special education to children with disabilities, the reality is that some special needs children cannot be educated in mainstream classrooms because they require special care beyond what can be offered in a regular school. This means that when thinking of inclusive special education, Hornby believes it is necessary to look at the policies and philosophies of special education and inclusive education in order to provide all children with a proper education (p.2). According to Hornby, special education and inclusive education stem from different philosophies and were developed for different reasons in an attempt to provide adequate education for children. Hornby’s (2014) theory of inclusive special education is meant to encompass “the philosophy and values of inclusive education with the practices and procedures of special education” (p.5) which will provide effective education for special needs children. While realizing that some children need to be taught at special centers, Hornby believes that the majority of children should be taught at mainstream schools or special classrooms within a regular school. Some of the practices Hornby (2014) believes can be implemented in inclusive special education are creating a feeling of acceptance and diversity, using IEPs for students, and creating a peer tutoring system (p.13). Similarly to Hornby, other researchers are currently trying to find the best methods to include special needs children into mainstream schools and how to
differentiate between children who can and cannot be a part of that environment. In Jordan, special needs centers, especially private ones, continue to be a main focus for children with disabilities. Inclusive special education can become more common once staff is properly trained and social awareness increases.

**Literature Review**

Although Jordan has centers for children with special needs throughout the country, there is not enough research available about the services provided for the children and their families, or other topics related to disabilities. This is the case for the Middle East in general where discussion about special needs children is barely starting. While countries like the United States have a large amount of research being done for different disabilities, in the Middle East research is usually focused on autism, Down syndrome, and other more common disabilities. In addition, Arab and non-Arab researchers are doing some of this research through universities outside of Jordan.

An example of research that focuses on autism is Al-Jabery, Arabiat, Al-Khamra, Betawi, Abdel Jabbar’s(2012) “Parental Perceptions of Services Provided for Children with Autism in Jordan” in which the researchers studied the opinions of parents receiving services for their children with Autism and discovered that the levels of satisfaction vary from low to slight average satisfaction. Al-Jabery, Arabiat, Al-Khamra, Betawi, Abdel Jabbar’s(2012) found that there needed to be improvements which included “the need for unifying the delivered services under one umbrella, to enhance parents-professional partnerships, remove the financial burden caused by the cost of services, and improve the accessibility methods (484).” This study allowed parents the opportunity to decide what their priorities were when thinking of their children and the services they received yet their satisfaction levels are dependent of their specific
circumstances. While this current research will also be focusing on the perceptions of parents it
differs in that the special needs of the children will vary rather than focusing only on autism.
This will affect the results because parental opinions will depend on the services that are
available in Jordan for their children and in what city they live in. While parents with Autistic
children in Amman might have access to services that give them average satisfaction that could
be different with parents whose children have other disabilities or do not live in Amman. The
different services offered by public and private institutions, as well as what disabilities they are
catered towards will affect the opinions of parents.

Similarly, Abu-Hamour and Muhaidat’s (2014) article “Parents’ attitudes towards
inclusion of students with autism in Jordan” chose to focus on autism rather than a wide range of
disabilities. As autistic children have begun attending public schools rather than private special
needs centers, Abu-Hamour and Muhaidat (2014) decided to study the perceptions of parents
with autistic children and their access to public education in Jordan. According to the results,
Abu-Hamour and Muhaidat (2014) found that a slightly higher number of parents were hesitant
to place their autistic child in public school because “According to their opinion, both public-
school personnel and students without disabilities are not ready for inclusion” (p.575) and their
responses were also dependent on the severity of the autism. Not all services offered through the
public school system seem capable of caring for autistic children, especially those with low-
functioning ASD.

Although Al-Jabery, Arabiat, Al-Khamra, Betawi, Abdel Jabbar’s(2012) research was
primarily focused on the relationship between parents and the services they receive for their
autistic child, Abu-Hamour and Muhaidat’s (2014) research focused on the relationship between
autistic children and the public school system. The previous research could be used to improve
the services offered in private special needs centers, which include educational centers, while the later could be used to introduce children with autism into the public school system. Yet, both studies make it clear that services for autistic children and their parents need to be improved, in the private and public sector. This current research is geared towards a greater focus on the parental perspectives about financial, educational, and medical services but it will refer to the necessary improvements within the public and private services offered. Not all staff within public schools, or even private centers, is properly educated to care for special needs children and this research will touch upon this subject when analyzing educational services.

In Hadidi’s article (1998) “Educational Programs for Children with Special Needs in Jordan” the author describes the availability of special needs services for children and their families in Jordan. While Hadidi recognizes that Jordan has made strides towards improving its services for special needs children by creating new centers and educating teachers, the author realizes that there needs to be improvements in family involvement while also recognizing the child’s necessities at an early stage. This current study differs from Hadidi’s research by focusing on parental opinions about the success of educational programs and other services rather than the programs themselves. The goal of this study is to understand what the parents believe about the resources that exist in Jordan regardless of what those programs represent on paper.

In the more recent article “Special Education in Arab Countries: Current challenges”, Hadidi and Al-Khateeb (2015) recognized the improvements in special education in the Arab world but understand that there is still progress to be made. While the Arab world is connected through religion, language, and culture, the special education system varies from country to country and offers integration and segregation for children with special needs. Hadidi and Al-
Khateeb (2015) discovered that the relationship between parents and special needs centers have not improved at the same rate as other services offered. Although the Arab world has been to recognize the needs of children with disabilities, there is still a long road ahead in improving teacher training, inclusive education, and other services. While Hadidi and Al-Khateeb (2015) investigated the status of inclusive education in the Arab world and its need for further development, Abu-Hamour and Muhaidat (2014) discovered that a large number of parents do not believe that their children and the teachers in public schools are currently capable of inclusive education. This current research aims to learn what parents believe needs to be changed in the services their children are receiving and it is likely that many of the improvements mentioned by Hadidi and Al-Khateeb will be repeated by the parents receiving these services in Amman and in surrounding towns.

In Yousef and Hadidi’s (1992) article “Families of Children with Disabilities in Jordan”, the researchers state “Although the past two decades have witnessed an increasing interest in the education of children with disabilities in Jordan, special education services are extended to less than 3% of the target population” (p.127). Although there has been improvement in the services provided to special needs children, this article as well as the previous research mentioned describe the reality of the situation: not enough children are receiving adequate services. Yousef and Hadidi (1992) came to the conclusion that there needs to be more communication between special education staff and families to better fulfill the needs of the parents as well as improve the education of the children. While the communication and education of staff and parents is imperative in improving the lives of special needs children, there needs to be a focus on improving the special centers that offer services to children with disabilities and in the way the government offers its help to families.
A further look at the needs of parents is found in Al-Dababneh, Fayez, and Bataineh’s (2012) article, “Needs of Parents Caring for Children with Physical Disabilities: A Case Study in Jordan” in which the researchers studied parental opinions in Zarqa. They wanted to understand the needs of parents in an attempt to improve the services offered to their children with physical disabilities. Al-Dababneh, Fayez, and Bataineh (2012) concluded that it is necessary for institutions to provide educational and financial support for the parents and for Jordanian universities to properly prepare teachers and specialists (p.12). The researchers believed that for institutions to improve there must be further study about the needs for parents. Similarly, this current study will be researching parental opinions but results will vary depending on the disability of the child and where the family lives. As with previous studies mentioned, the services offered in Jordan depend on the location and the disability. While Yousef and Hadidi’s (1992) study focused on families receiving services in special centers in Amman, Al-Dababneh, Fayez, and Bataineh’s (2012) offered insight in a different part of the country and in more recent years. Yet they both continued to show that there needs to be improvement in the services provided to families.

Abu-Hamour and Al-Hmouz (2014) offer a more recent view at the special education in Jordan in their article “Special Education in Jordan” and believe that integrated education is offered to children with learning disabilities with limited engagement for children with more severe impairments. The researchers focused on the fact that the number of children with special needs is not known (Abu-Hamour and Al-Hmouz, 2014) and that inability to recognize which students need special education leads to students falling through the cracks. Abu-Hamour and Al-Hmouz (2014) believe that “Jordan still faces many problems in management and supervision
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of special education services, lack of valid and reliable assessment tools, as well as insufficient financial resources” (p. 113) similar to the previous research mentioned.

Although this current research is focused on the parental opinions of the educational, medical, and financial services offered for children with special needs, the majority of the research reviewed focused on special education in Jordan. This is the case because research about special needs children in Jordan is limited with a greater focus on the education within public and private sectors. It is expected, overall, that this current research will have similar results in terms of the needs of parents with children with disabilities, especially in relation to their limited financial abilities and the effectiveness of special education services.

**Methodology**

Since special needs children can be a sensitive topic to speak about, some families do not feel comfortable being interviewed about their children. Initially, it was difficult to find families who were willing to be interviewed although the researcher had already met families with special needs children. The researcher was interested in interviewing families both in and outside of Amman to hear about the different experiences families had finding proper services for their children but she was limited by the time constraints and access to transportation. Initially, the researcher was interested in interviewing families that she met outside of special needs centers but when she realized it would be difficult to meet families outside of the centers, she went to the Time of Learning Academy to interview two families. This is also where she chose to drop off twenty questionnaires, although she only received six back. In the end, the researcher was able to interview three families who she met outside of a special needs center and two families that she met at a center, while one of them lived outside of Amman. This means that the type of services the children received changed depending on the families.
The researcher met the five families in different ways. The first family she interviewed in Hawara, a small village near Madaba, was related to a classmate’s host family at SIT and she had previously met them. For this reason, the family was comfortable with being interviewed. Initially, the researcher believed she would be able to interview two more families in Hawara which would have meant the research was more focused on families outside of Amman but these families were not comfortable being interviewed and having access to more families in Hawara was limited by transportation and language barriers. When the researcher realized the difficulty of finding families to interview, she reached out to her advisor, Dr. AmalMalkawi, who connected her with the Time of Learning Academy. The academy offered to help find families and said the researcher could interview four families. When the researcher arrived to interview the four families, only two of them showed up. This meant, that the second and third interviews were through a special needs center but the final two had to be from somewhere else. Dr. AmalMalkawi was able to connect the researcher with another family outside of the special needs center and the fifth family was found through the help of SIT staff. This meant that all the families interviewed had different educational and financial backgrounds as well as the services they had all received were different. Since the researcher met families at the Time of Learning Academy, it was easier to hand out questionnaires there. Initially, the researcher wanted to drop them off at a center outside of Amman but with the time constraints it was too difficult to do that.

From past experiences working with special needs children, the researcher understood the need for clarity and professionalism when speaking to parents. Understanding that this is a sensitive topic, the researcher made it clear to the parents that their identities would be kept private. In addition, they knew that they could stop the interview at any moment or not answer a question if they felt uncomfortable. While conducting interviews, the researcher attempted to
keep the setting private, although that was not always possible. During the first interview, there were children and other adults in the room, entering and exiting often. While the translator and the researcher asked questions to the mother, she was still trying to make sure her daughter was doing well. The second and third interviews were done inside the director’s office but the second interview was in private. During the third interview, there were others in the room because they needed access to the office. The fourth interview was completed at a home where the two parents were a part of the interview. The fifth interview was completed in private as well.

Privacy during interviews was one of the obstacles since the answers could have been affected by the fact that other people were in the room. A second obstacle was that initially, the researcher intended to have twenty questionnaires but was only able to use six. Part of the reason for this was time constraint and the inability for parents to complete the questionnaire in a short amount of time. The researcher had to change her ideal sample of participants and the number of questionnaires used because of the time constraints and difficulty in finding families to participate. The consequence of this is that the data found is mostly based on families who live in Amman and are in a different situation than those who live in small villages and do not have the same access to services as those in a city. In addition, by using data from one special education center, many of the families were more likely to have the same thoughts about educational services since they all received the same one.

**Results**

The results of this research are based on the five interviews that were conducted in Amman and Hawara, as well the six questionnaires that were received from the families at the Time of Learning Academy. The following are summaries of the interviews conducted. During four of the interviews it was necessary to have a translator.
Interview #1:

The mother interviewed spoke about her twenty year old daughter with cerebral atrophy. They live in Hawara, which is about forty-five minutes from Amman. Her daughter was three and a half years old when she got meningitis. Initially, a doctor in Madaba believed the problem was in her lymph nodes but after she became sick there was permanent damage to her brain. When asked what her initial reaction was when she found out her daughter had cerebral atrophy, the mother responded that she was very sad and could not understand what was happening.

Her daughter only received two months of special services at a center but the family found it difficult to pay for educational services and instead chose to focus on her health, especially because she believes that the education for special needs children in Amman is very poor and the teachers are not well trained. Overall, the daughter has not had an education and has stayed home with her family most of her life. Her mother said that it was too financially difficult to travel to Amman for her daughter to receive educational and medical services. Although her daughter is supposed to see a neurologist in Amman once a month, she is not always able to take her daughter because of lack of transportation and money.

In two occasions, her daughter has traveled out of the country to receive medical services. The first time, the Jordanian government covered it but the second time the family paid for it themselves. The mother believes that getting medical services outside of Jordan really helped her daughter improve but once she returned to Jordan and her medicine ran out, she regressed.

Interview #2:

This interview took place in the Time of Learning Academy with the mother of a seven year old with autism. Although the family knew something was wrong when the child was six months old, he was not diagnosed until a year ago when he began attending the academy. When
the mother found out he was autistic, she thanked god. Initially the mother tried to put her son in a regular private school but she had to take him out because the school did not know how to care for his special needs. Although she went through a difficult process finding services for her son, once she was recommended this school, the situation improved.

The mother stated that it was financially difficult for her son to receive medical and educational services because it is very expensive and she does not work. Her mother and brother support her financially. Although there was a government center that supported her with one hundred JD per month that only lasted for three months. She has never had to go outside of Amman to receive services and her son does not need to see doctors regularly. Overall, this mother spoke about the lack of financial support and the very expensive services. Transportation was not difficult since her child receives transportation to the school. She believes that some private centers do not treat children well. She is worried about her son’s future since the academy only offers services until the fifth grade.

**Interview #3:**

The third interview was also conducted in the Time of Learning Academy and it was a mother speaking about her daughter with cerebral palsy. Her daughter had a fever when she was almost two years old and since then she started having difficulties with her muscles. Initially she took her to receive natural treatments but they did not work so she took to a doctor who diagnosed her with cerebral palsy. The mother refused to accept and understand her daughter’s condition until her mother encouraged her to find a solution and get treatment for her daughter. Now, she understands that her daughter needs special services. The mother tried different educational services. First, her daughter attended a public school for kindergarten and was in a resource room. This allowed her daughter to have regular interaction with children but it was not
helping her improve. Then she took her to a private special education school, which was better but still did not help her daughter improve. Two years ago, she brought her daughter to this academy and since then, she had noticed that her daughter has better self-management. Finding the right program for her daughter was a difficult process but once she found this academy, the situation became easier.

Although she does not work, her family is able to manage the services for her daughter. Her daughter will always have to take medicine and every two to three months she needs to get brain scans. In her opinion, there are not a lot of services available for children with cerebral palsy. For example, the games and activities that are meant to be for children her daughter’s age, her daughter cannot always participate in because of her small size. She believes services are acceptable, especially at the academy.

**Interview #4:**

This interview was conducted in the family’s home, initially with just the mother but then the father joined in. The son in this family is fourteen and was diagnosed with Kabuki Makeup syndrome at the age of four months. When the mother noticed that something was wrong with her son, she took him to the Jordanian university hospital. The family tried two different special needs centers for three years but then decided to stop. Their son attended the first center for a year but he was unable to continue attending it because it only cared for him in the morning and the mother had to work. They decided to put him in a different center that could care from him during the hours that the mother worked. When they realized that the centers were not helping him, they chose to stop using them. The child still cannot eat alone and has very limited self-care. The family went through a difficult time finding the centers for the child so they used to have private services go to their home. The family feels that it has been difficult to provide
educational services for their child but not medical services. They have health insurance that allowed the family to take their son to a genetics doctor in Irbid and to have regular wellness visits but they believe it is very expensive to take their son to special needs centers. They think that public centers are not good and cannot offer adequate services for their child. One of their complaints is that the staff at special centers, especially public ones, is not adequately trained to care for their child.

**Interview #5:**

This interview was conducted in a private home in Amman. The mother spoke about her fourteen year old daughter with special needs. Although it is not clear what her daughter’s special need is because of the language barrier, it was understood that she suffered from lack of oxygen at a young age and now lacks recognition of what happens around her. She cannot speak or care for herself. When her daughter was six months old, she could tell something was wrong because she was not acting like her other children so she took her to Al-Bashir hospital. The doctors there told her that her daughter was not receiving enough oxygen so the edges of her brain were not growing properly. Initially, the mother cried a lot when she found out about her daughter’s disability but she accepted it as a test from god. Her daughter received physical therapy at a public center from the age of six months to five years. The government covered the costs for the therapy and she received a wheelchair. The mother believes that physically, her daughter improved and is doing well. Her priority now is for her daughter to receive educational services but those are expensive and do not provide adequate services. The mother is interested in her daughter learning self-care and wants to see her improve. She took her daughter to a private center a couple of times but believed they were only interested in money and not in helping her daughter. Although she received support from her family, the private centers are still
too expensive. Her daughter does not need regular doctor visits but if she does need to go to the
doctor, they have health insurance that covers the fees if they go to a public doctor. When they
went to a private doctor, they had to pay. The mother believes everything is in God’s hands but
she had a positive experience with the physical therapy her daughter received. Her complaints
stem from the lack of educational services for her daughter.

**Interview Analysis**

Although all of the families varied in their need for financial and medical services, it
seems that the biggest concern for parents with special needs children was better access to
special education. The mother in interview #1 was concerned the most with lack of financial
services for transportation and special education, primarily because she did not live in Amman
and did not have access to the same services as parents who live in the city. Both her and the
mother from interview #5 had the least amount of experience with access to special education for
their children. The families most content with the special education their children were receiving
were the two families who had children at the Time of Learning Academy. While most of the
families had assistance from the government so that their children have access to proper medical
services, they do not have adequate financial support for their children to receive special
education. The only family that took their child outside of the country to receive medical services
was the first family interviewed and they believed that the services outside of Jordan were
significantly better. None of the families believe that public institutions offer adequate education
for their children, and even some of the private institutions do not have properly trained staff. If
families were not able to afford private special education or did not find it helpful to their
children, they chose or were forced to keep their children at home. This can be difficult for
families because they must be able to care for their children at all times, while seeing them not being able to improve their self-care and education.

**Questionnaire Results**

The questionnaire results are based on the six questionnaires that were returned from families at the Time of Learning Academy. The families were asked to identify the gender of the person filling out the survey, the education level, monthly income, ethnicity, and religion.

**Family Demographics Table 1.1**

<table>
<thead>
<tr>
<th>Family</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender of Respondent</td>
<td>Male</td>
<td>Male</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Jordanian</td>
<td>Jordanian</td>
<td>Jordanian</td>
<td>Jordanian-Syrian</td>
<td>Jordanian</td>
<td>Jordanian</td>
</tr>
<tr>
<td>Religion</td>
<td>Muslim</td>
<td>Muslim</td>
<td>Muslim</td>
<td>Muslim</td>
<td>Muslim</td>
<td>Muslim</td>
</tr>
<tr>
<td>Income (JD/month)</td>
<td>800</td>
<td>500</td>
<td>3000</td>
<td>700-800</td>
<td>1500</td>
<td>1000</td>
</tr>
<tr>
<td>Education Level</td>
<td>University</td>
<td>University</td>
<td>University</td>
<td>High School</td>
<td>None</td>
<td>University</td>
</tr>
<tr>
<td>Child’s special need</td>
<td>Autism</td>
<td>Not growing well, low learning curve</td>
<td>Autism</td>
<td>ADD</td>
<td>Autism</td>
<td>Autism, speech disability</td>
</tr>
</tbody>
</table>
In order to analyze the questionnaires, the researcher labeled the responses as levels of satisfaction and numbered them. Then she averaged the responses and placed them on the chart above. Unlike the interviews, the majority of questionnaire responders were male and they gave an overall impression that once their children began attending the Time of Learning Academy, they improved significantly. Although most families had a difficult time finding services prior to the academy and struggled to some extent, financially, they were content with the services they were receiving now.

**Conclusion**

The results of the five interviews and six questionnaires demonstrate that Jordanian families generally do not believe that the government is doing enough to provide proper special education for their children. While their opinions regarding access to financial and medical services vary by family, the general consensus is that both public and private institutions are still not providing adequate education.
It is perceived that the teachers at special needs institutions are not prepared to care for the special needs children, especially when their disabilities are less common, such as with the child with Kabuki makeup syndrome. It is important to note that families are commonly choosing to not take their children to special centers because they believe that public centers offer poor services and private centers are too expensive. Since families believe that the private centers are expensive and even then, are not helping their children’s self care improve, they choose to keep them at home. Many children are not getting any educational services because they stay at home with their mother. Families wish to see their children’s abilities improve, even in miniscule ways, so that they can be able to care for themselves more. Yet, this is not happening because of the poor services available in Jordan.

**Study Limitations**

One of the biggest limitations of this study was the limited time to do proper research. There are many special needs centers in Amman and throughout the country. They cater to different special needs and families. In order to do better research there needs to be a deeper analysis of the special needs centers and who is receiving their services. The small amount of time affected the places in which the researcher could interview families and drop off questionnaires. In order to travel outside of Amman to interview families the researcher would need to arrange having transportation and a translator. In order to complete the researcher in a timely manner, it was easier to interview families within Amman. Another reason that it would have been difficult to travel outside of Amman for interviews is that first, the researcher would have had to find families outside of Amman that would be willing to be interviewed.

The research was limited because the families were mostly from Amman, except for one. This means that the research focused primarily on what families within Amman thought about
the services available to them, which could be very different from the opinions of families living outside of Amman. The two families who were currently sending their children to the Time of Learning Academy could also affect the results because they were generally happy with the education services their children were receiving compared to families that were not sending their children to school. One of those interviews could also have been affected by the fact that the school’s director was in the room when the interview was done.

Another way that the study was limited was through the disabilities of the children that were studied. While this study focused on parents with children that had different disabilities, a study that focuses on children with just one disability could offer different results. As well as, studies that focus on a common disability could offer more positive results than a study that focuses on disabilities that are less common.

The sensitivity of the topic was also a limitation because some families do not feel comfortable speaking about their special needs children. This study only involved five interviews and six questionnaires. By the limited number of interviews the results provided do not represent a large pool of people. Although the intended number of questionnaires was supposed to be twenty, it turned out to be only six and that really limited the accuracy of results.

**Future Studies and Recommendations**

For future study, it is recommended to increase the number of families that are studied with a focus on families in Amman. It is important to study how the families in Amman perceive the services offered to their special needs children. Then, it is important to differentiate that with the way families outside of Amman perceive the services offered to their children. Since Jordan has a diverse population, it is important to study different communities in order to fully understand the necessities of special needs children. The results of families living in Amman
could be different from the opinions of families living in other cities, such as Madaba, which could also be different from families living in Badia.

Another recommended study could be how the families of special needs children within refugee camps, of different origins, perceive the services offered to them by international organizations. Since the number of refugees continues to increase in Jordan, the quality of health, educational, and financial services for special needs children needs to be studied.
References


Appendix

Survey

Gender
    Male ______  Female ______

Religion
    Muslim _____ Christian _____

Ethnicity
    Jordanian _____ Other ______

Family Income
    ______________

Education level received
    ______________

1. What is your child’s special need?

2. Has your child received special education from k-12?

3. Did you feel that these special programs helped your child be a more active member of Jordanian society?

4. Did you have a difficult time finding the proper services for your child?

5. Have you felt as if you have lacked financial support throughout this process?

6. Have you traveled outside of Jordan to receive special services? And if so, which type? For example: medical, educational, etc.
استطلاع الرأي

الجنس:
ذكر ______ أثى ______

الديانة:
الإسلام ______ المسيحية ______

الجنسية:
الأردنية ______ أخرى ______

دخل الأسرة: _______________________

مستوى التعليم: _______________________

1 ما هي الحاجة الخاصة لطفلك (مثال: متلازمة داون سندروم, التوحد...الخ)

2 هل حصل طفلك على التعليم الخاص من الروضة حتى التخرج؟

3 هل تشعر بأن هذه البرامج الخاصة ساعدت طفلك أن يكون عضوا أكثر نشاطا من المجتمع الأردني؟

4 هل هناك صعوبة في العثور على الخدمات المناسبة لطفلك؟

5 هل شعرت بأنك تفتقر إلى الدعم المالي طوال هذه العملية؟

6 هل سافرت خارج الأردن لتلقي الخدمات الخاصة؟ وإذا كان كذلك، أي نوع؟ مثل الطبية والتعليمية وغيرها
CONSENT FORM

1. Brief description of the purpose of this study

The purpose of this study is to investigate parental opinions in regards to the services they receive for their special needs child. The researcher is interested in learning about the education, health, and financial services provided by the government to families with special needs children.

2. Rights Notice

In an endeavor to uphold the ethical standards of all SIT ISP proposals, this study has been reviewed and approved by a Local Review Board or SIT Institutional Review Board. If at any time, you feel that you are at risk or exposed to unreasonable harm, you may terminate and stop the interview. Furthermore, you may at any time refuse participation in any aspect of the study. Please take some time to carefully read the statements provided below.

a. Privacy - all information you present in this interview may be recorded and safeguarded. If you do not want the information recorded, you need to let the interviewer know.

b. Anonymity - all names in this study will be kept anonymous unless the participant chooses otherwise.

c. Confidentiality - all names will remain completely confidential and fully protected by the interviewer. By signing below, you give the interviewer full responsibility to uphold this contract and its contents. The interviewer will also sign a copy of this contract and give it to the participant.

d. Future use of data - data and information obtained in this study may be used in future projects done by the researcher. You may at any time request that the information you provide only be utilized in this project.

_________________________                                 _____________
Participant’s name printed                                         Participant’s signature and date

_________________________                                 __________________________
Interviewer’s name printed                                        Interviewer’s signature and date
الغرض من هذه الدراسة هو البحث في آراء الوالدين فيما يتعلق بالخدمات التي يتلقونها لطفلكم من الخدمات الخاصة. الباحث مهتم في دراسة الأفكار المتعلقة بالخدمات التي تخدم الأطفال الذين لديهم احتياجات خاصة.

**المواصفات:**

- **الخصوصية:** جميع المعلومات التي تقدم في هذه المقابلة سيتم تسجيلها وحماية. إذا كنت لا ترغب في تسجيل المعلومات الصوتية، الرجاء إعلام الشخص الذي يقوم بالمقابلة بذلك.

- **عدم الكشف عن الهوية:** سيتم الحفاظ على الكونانة مجهول الاسم. إذا اختار المشاركة خلاف ذلك.

- **السرية:** ستبقى جميع الأسماء مجهولة تامة ومحمية بالكامل. من خلال التوقيع أدناه.

- **حق الرفض:** إذا كان المشارك يشعر بعدم الارتياح اتجاه الدراسة في أي فترة في الوقت، فمن ضمن حقوقه بالكامل رفض الاستمرار في الدراسة. تتم مقابلة أي من المعلومات التي تم جمعها حتى النقطة التي تم التوقف فيها عن اكتساب المشاركين أيضًا. يحق للمشاركين أيضاً الرفض في رفض الإجابة على أي سؤال لا يشعرون بالراحة بشأنه خلال المقابلة.

- **التعويض:** المشاركة في هذا البحث هو طوعي تمامًا وليس هناك أي تعويض.

- **الاستخدام في المستقبل:** يمكن أن يستخدم في دراسات مستقبلية فقط إذا اتصل الباحث بأسماء المشاركين الذين تم التوقيع فيهما.

**التوقيع:**

- **اسم المشارك:** __________________________
- **توقيع المشارك:** __________________________
- **التاريخ:** __________________________

- **اسم الباحث:** __________________________
- **توقيع الباحث:** __________________________
- **التاريخ:** __________________________
(Note: Each AD must complete, sign, and submit this form for every student’s ISP.)

The ISP paper by Ashley Rincon does conform to the Human Subjects Review approval from the Local Review Board, the ethical standards of the local community, and the ethical and academic standards outlined in the SIT student and faculty handbooks.

Completed by: Ashraf F. Alqudah, Ph. D.

Academic Director: __Ashraf F. Alqudah, Ph. D.

Signature:

Program: JOR Fall 2015

Date: Dec 23 2015
## Human Subjects Review

**LRB/IRB ACTION FORM**

| Name of Student: Ashley Selena Rincon | Institution: World Learning Inc. |
| ISP Title: Jordanian children with special needs access to services: Parental Perspective | IRB organization number: IORG0004408 |
| Date Submitted: 10/30/15 | IRB registration number: IRB00005219 |
| Program: SIT Jordan: Modernization and Social Change | Expires: 9 December 2017 |
| Type of review: | LRB members (print names): |
| Exempt | Ashraf F. Alqudah, Ph. D. Chair |
| Expedited | Ismael Abu Aamoud, Ph. D. Member |
| Full | Badr Al Madi, Ph. D. Member |

**LRB REVIEW BOARD ACTION:**

- [X] Approved as submitted
- ____ Approved pending changes
- ____ Requires full IRB review in Vermont
- ____ Disapproved

LRB Chair Signature: [Signature]
Date: Nov. 12 2015

---

**Form below for IRB Vermont use only:**

**Research requiring full IRB review. ACTION TAKEN:**

- [ ] approved as submitted
- [ ] approved pending submission or revisions
- [ ] disapproved

IRB Chairperson’s Signature

Date