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“The Invisible Disability:” Perceptions and Potential of Children with Autism in Kisumu, Kenya

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“The Invisible Disability:”
Perceptions and Potential of Children with Autism in Kisumu, Kenya

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Spring 2012

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ABSTRACT

Awareness and prevalence of autism around the world is on the rise; however, much remains unknown about this developmental disability. This study is a survey of perceptions of individuals with autism in Kisumu and the services available to facilitate their development. Two areas of interest arose during this study. First, many children do not receive intervention services until a very late age, seriously hindering the success of the intervention. Many special schools do not accept children until they are well into vital stages of development, and the Educational Assessment and Resource Center (EARC) lacks the personal and funding to provide adequate services for young children. Second, most parents do not have sufficient knowledge of autism or how to help their children, limiting the success of intervention services due to lack of follow up. This paper analyzes the trends mentioned above and provides recommendations for future research and interventions for autistic persons in Kisumu, Kenya.

INTRODUCTION

Autism in Kenya presents many challenges. Identification of autism is difficult, and interventions are costly. Doctors often simply treat the symptoms of autism, failing to recognize the root of the problem. It is now widely accepted that early diagnoses and intervention is extremely important for children with autism; however, most children do not see specialists that have the knowledge to diagnose autism until they are older, if at all.¹ Parents are essential actors in ensuring the healthy development of their children; however, many parents with children with disabilities are unable to access vital services for their children due to stigma, poverty, and lack of knowledge of available services. This study will outline the available resources for children with autism in Kisumu, Kenya, analyzing the factors that limit access to and success of vital interventions for this marginalized population. Several barriers to successful interventions for children with autism in Kisumu were identified by speaking to parents, teachers, and other professionals, and by conducting observations at schools and households with children with autism. These barriers include inadequate accessibility and quality of assessments and interventions, as well as lack of parental knowledge and involvement. This paper culminates in recommendations for future steps that should be taken to improve interventions for children with autism in Kisumu.

Overview of Autism

Autism is extremely difficult to define due to its various manifestations in different individuals. The Oxford English Dictionary defines autism as “a condition which has its onset in childhood and is marked by severely limited responsiveness to other persons, restricted behaviour patterns, difficulty with abstract concepts, and usually abnormal speech

¹ H. Darrat and Adel M. Zeglam, “Autism – What Is It? Are We Up to it in Africa?,” *African Journal of Neurological Sciences* 27, no. 1 (2008): 142-145.

² *Oxford English Dictionary*, 2nd., s.v. "autism, n.," last modified March 2011.

development.”² All disorders “in which the subject displays autistic characteristics”³ are known as autism spectrum disorders (ASD). Autistic characteristics differ greatly among individuals with ASD, and therefore it is considered a spectrum. The main disabilities included under the umbrella of ASD are autistic disorder, Asperger syndrome, and pervasive developmental disorder (PDD). In addition, there are many other disorders thought to have autism-like characteristics. Due to the different ways in which these characteristics manifest themselves, autism is a very complicated disorder.

It has been said that individuals with ASD “handle information in their brain differently than other people.”⁴ These spectrum disorders affect each person differently, and can range from mild to severe. Autistic disorders typically cause language delay, social and communication challenges, unusual behaviors and interests, and intellectual disability. With Asperger syndrome we see milder symptoms of autistic disorder.⁵ Individuals with Asperger syndrome are typically very literal thinkers, obsess over certain topics, have excellent memories, and are often considered “eccentric.”⁶ PDD is the diagnosis for individuals who meet some of the criteria for autistic disorder or Asperger syndrome, but not all. PDD has mild symptoms, usually including social and communication challenges.⁷

Symptoms of ASD typically start appearing between the ages of 18 months and three years. Many children develop normally until these symptoms begin to appear; this is known as regressive autism. In others there are indicators that can be identified much earlier. Characteristics of ASD include slow development of communication, social skills, and cognition, self-stimulatory behaviors, self-injury, sleeping and eating problems, poor eye

² *Oxford English Dictionary*, 2nd., s.v. "autism, n.," last modified March 2011.

³ *Ibid.*

⁴ "Facts, Autism Spectrum Disorders," Centers for Disease Control and Prevention, accessed April 1, 2011, last modified December 29, 2010, <http://cdc.gov/ncbddd/autism/facts.html>.

⁵ *Ibid.*

⁶ Stephen M. Edelson Ph.D., "Overview of Autism," *Center for the Study of Autism* (1999): 2, <http://www.winningconnection.com.au/data/OverviewOfAutism.pdf>.

⁷ "Facts, Autism Spectrum Disorders," Centers for Disease Control and Prevention, accessed April 1, 2011, last modified December 29, 2010, <http://cdc.gov/ncbddd/autism/facts.html>.

contact, insensitivity to pain, hyperactivity or hypoactivity, attention deficits, and insistence on routines.⁸ These symptoms will last throughout the individual's life; however, various therapies and interventions can be utilized to help the individual manage these symptoms. The diagnosis of ASD is based on what has been referred to as a "triad of impairments." These impairment categories include communication, social interaction, and imagination. A diagnosis is made based on consistent patterns of behaviors in these three categories.⁹

Autism in Kenya

The Autism Society of Kenya (ASK) refers to autism as "an invisible disability." "ASK was formed by a group of parents who were experiencing problems finding information, help and services for their children due to the lack of awareness of autism, even amongst health and education professionals."¹⁰ This lack of awareness and access to information on autism is thematic in Kenya. The research on autism in Kenya, or even in Africa more generally, is very sparse. Prevalence rates in Africa are unknown, but it is clear that autism does exist.¹¹

It is important to consider cultural perceptions of disabilities in Kenya. While cultural differences in the onset age of autism have been observed, the core characteristics are consistent globally. Culture does become an important factor, however, in the way children with autism are treated by their family and society as a whole, affecting capacity to achieve their full potential. In "Autism Spectrum Disorder: A Global Perspective," Alisha Richmond discusses the impact of social stigma on help-seeking behaviors. "Families may wait to seek

⁸ Stephen M. Edelson Ph.D., "Overview of Autism," *Center for the Study of Autism* (1999): 1, <http://www.winningconnection.com.au/data/OverviewOfAutism.pdf>.

⁹ L. V. Pelios and S. K. Lund, "A Selective Overview of Issues on Classification, Causation, and Early Intensive Behavioral Intervention for Autism," *Behavior Modification*, 25, no. 5 (October 2001): 680-681.

¹⁰ Autism Society of Kenya, *Autism Society of Kenya*, accessed March 12, 2012, <http://www.autismsocietyofkenya.org>.

¹¹ Ametepee K Lawrence and Morgan Chitiyo, "What We Know about Autism in Africa: A Brief Research Synthesis," *Journal of the International Association of Special Education* 10, no. 1 (2009): 11-13.

assistance if there is a social stigma attached to an ASD diagnosis,”¹² writes Richmond. Due to cultural perceptions of disability in Kenya, and lack of knowledge of available services, parents choose to wait many years before bringing their children to be evaluated and diagnosed. This is extremely problematic as late diagnoses and interventions significantly reduce effectiveness of said interventions. In addition, “Children with ASD also may not be able to abide by all of the local customs because of the symptoms of the disorder.”¹³ This has the potential to cause great difficulties for families of children with autism. Finally, culture affects parents’ opinions on how best to treat autism.

An article published in *The Standard* on April 22, 2011 discusses the perception of witchcraft that surround children with autism. The article, entitled “What many don't understand is often dismissed as witchcraft” writes, “The only plausible explanation people think of [for autism] is supernatural forces, which underscores the level of awareness of autism in Kenya, and Africa in general.”¹⁴ ASK also mentions the discourse of witchcraft on their website, stating “Children with autism do not fit into any known category of disability and therefore they are often classified as victims of witchcraft. The effect of this is that they are often robbed of their rights as human beings in society. We often find that such children are often hidden in homes, even locked behind doors.”¹⁵ In order to access appropriate interventions, autism awareness must be improved so that parents may seek treatment from doctors and other professionals, rather than attributing autism to witchcraft and keeping their children secluded in the home.

In recent years the Kenyan government has taken a few important steps to protect the rights of its disabled population. On March 30, 2007 Kenya ratified the UN Convention on

¹² Alisha S. Richmond, “Autism Spectrum Disorder: A Global Perspective,” *Perspectives on Global Issues in Communication Sciences and Related Disorders* 1 (September 2011): 40.

¹³ Ibid.

¹⁴ Michelle Ayuma, “What Many Don't Understand is Often Dismissed as Witchcraft,” *The Standard* (Nairobi, Kenya), April 22, 2011.

¹⁵ Autism Society of Kenya, *Autism Society of Kenya*, accessed March 12, 2012, <http://www.autismsocietyofkenya.org>.

the Rights of Persons with Disabilities.¹⁶ Additionally, in 2010, Kenya passed a new constitution which, in chapter 4, part 3, section 54, stipulates the rights of individuals with disabilities. It outlines the following rights:

1. "A person with any disability is entitled—
 - a. to be treated with dignity and respect and to be addressed and referred to in a manner that is not demeaning;
 - b. to access educational institutions and facilities for persons with disabilities that are integrated into society to the extent compatible with the interests of the person;
 - c. to reasonable access to all places, public transport and information;
 - d. to use Sign language, Braille or other appropriate means of communication; and
 - e. to access materials and devices to overcome constraints arising from the person's disability."¹⁷

Unfortunately, these documents have not been translated into mandatory laws in regards to services for individuals with disabilities. There seems to remain a lack of political will to provide the resources and services needed in order to achieve successful special education programming.¹⁸ A document published by the Ministry of Education, Science, and Technology on the development of education in Kenya discusses "the need to provide learning opportunities to the vulnerable groups and to discard prohibitive cultural practices that keep children away from school;"¹⁹ however, children with disabilities, continue to struggle to access the appropriate resources to facilitate their development.

The Kenya Society for the Mentally Handicapped (KSMH) is working to secure the rights of individuals with disabilities in Kenya. On their website they identify some of the barriers the face in improving the lives of the disabled. These barriers include, but are not limited to "lack of early identification and assessment services for children with intellectual

¹⁶ "UN Enable - Promoting the Rights of Persons with Disabilities." Welcome to the United Nations: It's Your World. Web. 15 Sept. 2010. <<http://www.un.org/disabilities/index.asp>>.

¹⁷ "The Constitution of Kenya," August 27, 2010, Kenya Law Reports, National Council for Law Reporting, <http://www.unhcr.org/refworld/docid/4c8508822.html>.

¹⁸ Sakui W. G. Malakpa, "Planning and Implementing Policies for Special Education and Rehabilitation Services in Sub-Saharan Africa: Problems and Suggestion,," *Journal of the International Association of Special Education* 10, no. 1 (2009): 65-70.

¹⁹ Ministry of Education, Science, and Technology, "Development of Education in Kenya," August 2004, <http://www.ibe.unesco.org/International/ICE47/English/Natreps/reports/kenya.pdf>: 16-17.

disabilities,” “high poverty levels that has increased the incidence of intellectual disabilities in the country and affected its management,” and “deeply entrenched social, cultural and religious stigma associated with intellectual disability.”²⁰ This study will illustrate several obstacles that children with autism face in Kisumu, Kenya in accessing the successful intervention services that they so desperately need.

²⁰ Kenya Society for the Mentally Handicapped (KSMH), accessed March 6, 2012, <http://www.ksmh.org/>.

SETTING

This study was conducted in and around Kisumu, Kenya. Kisumu was chosen as very little research on autism has been done in this location previously, despite increased prevalence. Kisumu is home to an Educational Assessment and Resource Center (EARC) that serves a large population of families with children with disabilities providing assessment and referral services. In addition, in the greater Kisumu area there are two schools, the Lutheran Church Special School for the Mentally Handicapped and Disciples of Mercy Academy, that have units specifically for children with autism. Despite these resources, families continue to struggle to access successful interventions for their children with autism.

Kisumu is located in the Nyanza Province of Kenya, on the shores of Lake Victoria. It is the third largest city in Kenya, “and the poorest of the major towns.”²¹ In 2006, the UN Human Settlements Program found that 48% of the urban population in Kisumu “live within the absolute poverty bracket,” and 53.4% of the population lives below the food poverty line. Furthermore, Kisumu has an unemployment rate of 30%, and 52% of the working population make just 3,000-4,000 KSH/month in the informal sector.²² The poverty rates in Kisumu are pertinent for the present study as people living in poverty are at a greater risk of developing a disability, and have a limited capacity to manage the disability.²³

An article identifying children at risk for developmental delay comments, “An estimated 200 million children in developing countries fail to achieve their developmental and cognitive potential due to exposure to chronic poverty and its co-factors.”²⁴ The co-factors of poverty discussed in the article include “stunting, being underweight, little maternal schooling and a child’s history of ill-health,” all of which increase the risk of developmental

²¹United Nations Human Settlements Programme, "Kisumu, Kenya," 2006, http://www.unhabitat.org/downloads/docs/4058_85367_Kisumu.pdf.

²²Ibid.

²³ Amina Abubakar et al., "Children at Risk for Developmental Delay Can be Recognised by Stunting, Being Underweight, Ill Health, Little Maternal Schooling or High Gravidity," *Journal of Child Psychology and Psychiatry* 51, no. 6 (2010).

²⁴ Ibid., p. 652.

delay in children.²⁵ The locale of Kisumu provided an interesting amalgamation of factors that have the potential to confound a family's ability to identify and properly manage their child's autism.

²⁵ Ibid., p. 658.

METHODS

The majority of information for this qualitative study was collected through informal interviews and observations. Parents of seven children in the autism unit at Lutheran Church Special School for the Mentally Handicapped were interviewed to ascertain their experiences in raising a child diagnosed with autism. A series of questions were asked with the intent of uncovering perceptions of autism as well as utilization and knowledge of intervention services. Home-based observations were also conducted as a method of gathering information. Two schools, Lutheran Church Special School and Disciples of Mercy Academy, were observed to analyze educational interventions, and three teachers and two head teachers were interviewed to gather information on other available services as well as teacher knowledge of autism. Finally, the Educational Assessment and Resource Center (EARC) coordinator, Sam Atieno was interviewed to learn about the assessment process and other services provided by the EARC. He also provided valuable information on local perceptions of autism and disability in general. The names of all informants for this study have been changed in order to protect their identities. (For a complete list of interview questions see Appendices A-C.)

DISCUSSION AND ANALYSIS

Autism Resources in Kisumu

Lutheran Church Special School for the Mentally Handicapped

The Lutheran Church Special School for the Mentally Handicapped is a public school for children with mental handicaps with a private boarding option. The classes at the school are funded by the government, but if parents choose to have the child board they must pay fees. There are 114 students, 72 girls and 42 boys, currently enrolled in the Lutheran school, with 104 of the students boarding. There are only three “house parents,” or staff members that live in the dormitory and take care of the students after school hours.²⁶ Parents are free to visit their children on weekends, but one teacher informed me that often they just send house girls in their place, or no one comes at all. It has also happened that parents give false information when they drop their kids off, never intending to pick them up again. To avoid this problem, the school is very thorough in gathering and checking the parents’ information before they accept the child.²⁷

The school’s moto is “training develops the mind,” and their mission is “to encourage the Mentally Handicapped pupils to be as less dependent as possible in the society.”²⁸ The school’s aims are:

1. To provide basic academic achievement to enable pupils to communicate effectively
2. To develop pupils ability to use their manipulative skills without much assistance
3. To provide vocational skills to enable pupils to fit in the world of work
4. To encourage pupils to respect and preserve their environment
5. To give equal learning opportunities to boys and girls²⁹

²⁶ Monica Onyango, interview by author, Lutheran Church Special School, Kisumu, Kenya, March 19, 2012.

²⁷ John Ochieng, interview by author, Lutheran Church Special School, Kisumu, Kenya, April 4, 2012.

²⁸ Visit to Lutheran Church Special School for the Mentally Handicapped, Kisumu, Kenya, April 4, 2012.

²⁹ Ibid.

The school puts a much greater emphasis on vocational and life skills than academic achievement for the pupils, as will be discussed in greater detail below.

The school is made up of a variety of separate building including the office, dining hall, dormitory, and block of classrooms. All of these buildings surround a courtyard with four trees, some grass and several benches. The students spend a significant amount of time hanging out in the courtyard before, after, and in between classes. The children at the school all wear blue and white uniforms. The girls wear white and blue checkered dresses with blue sweaters and grey socks, while the boys wear blue shorts, white and blue checkered button down shirts, blue sweaters, and grey socks.³⁰

Lutheran Special School has ten separate classrooms, including a pre-primary class, primary classes one through three, a pre-vocational class, vocational classes one through four, called workshops, and a class specifically for students with autism. The autism classroom is a large, mostly empty room with some chairs and benches, a table, a few posters, and a sink that is used to practice self-care skills such as brushing teeth and washing. The other classrooms have desks for the teachers and students and many colorful posters that display academic lessons including body parts, numbers, and letters.³¹

In 2007 the Lutheran School opened the class specifically for learners with autism as a result of the initiative of John Ochieng, one of the teachers. After obtaining a diploma in Special Education from Kyambogo University in Kampala, Uganda, Mr. Ochieng returned to Kenya determined to establish a class specifically for children with autism. He wanted to replicate the classes in Uganda, which he said are better defined with a more established syllabus. Furthermore, Mr. Ochieng stated,

This school is for children with mental retardation, so their teaching program is a bit different from the teaching program of learners with autism. So I realized that we were giving these

³⁰ Visit to Lutheran Church Special School for the Mentally Handicapped, Kisumu, Kenya, April 11, 2012.

³¹ Visit to Lutheran Church Special School for the Mentally Handicapped, Kisumu, Kenya, March 19, 2012.

children what is beyond them. So I said, let us have a special class for them. Like you want to take them to the workshop, some of them would only hold the materials there, and some would cry when they touch them. It means they are hypersensitive. And so I said, why do we push them to what they can't do?³²

While Mr. Ochieng is correct that learners with autism should utilize unique and specific teaching programs, what is slightly problematic is his statement, “why do we push them to what they can't do?” Perhaps it is due to the late age at which intervention begins that Mr. Ochieng's students struggle to make meaningful progress; however, autism in and of itself should not prevent the child from being successful in school. As will continue to be illustrated throughout this paper, many individuals in Kisumu underestimate the potential of children with autism, and people with disabilities more generally. With the proper interventions and services children with autism should be able to become productive members of society.

After establishing the class, Mr. Ochieng went back to school, obtaining a Bachelors of Education from Kampala International University. He then went on to obtain a certificate for management of children with autism from the Kenya Institute for Special Education (KISE).³³ Mr. Ochieng is one of the few individuals in the Kisumu area that specializes in autism, further illustrating the need for increased provisions for individuals with autism in Kisumu as well as throughout Kenya.

When the autism unit first began, there were three teachers and ten students. Now, there are fourteen students and three teachers. In the morning, from about 9:00 AM until 12:30 PM, the children in the autism unit rotate between working on self care tasks (brushing teeth, washing face, applying lotion) and working on communication skills through semi-structured play. They also sometimes do “environmental activities” where they get to know the school compound and work on following a schedule and moving from one activity to the

³² John Ochieng, interview by author, Lutheran Church Special School, Kisumu, Kenya, April 11, 2012.

³³ John Ochieng, interview by author, Lutheran Church Special School, Kisumu, Kenya, March 19, 2012.

next independently. From 12:30 PM until 2:00 there is a lunch break, and the students all gather in the dining hall to eat. The dining hall is very hectic, with many children requiring assistance and not enough staff to provide the required help. After lunch, from 2:00 PM until 2:30 is rest time. Mr. Ochieng has constructed a sensory room, a useful tool for children with autism, out of the limited supplies available. The students may either rest in the sensory room, a quiet room in the dormitory with mattresses on the floor, or play in an adjacent room where the chairs have been pushed aside for free play. After rest time there is an hour of games, followed by afternoon chores such as cleaning and washing.³⁴

The limited curricular aims of the autism unit at Lutheran Special School, with no academic subjects included in the curriculum, exemplifies societal perceptions of individuals with autism, and individuals with severe developmental disabilities more generally. In 2002 Jacqueline Muuya found that special education teachers were focusing on personal care and problematic behaviors, and not on the development of skills to prepare these children for a life as part of the community. This is due to the assumptions that have long existed within Kenya that individuals with special needs will spend their lives in the home, unable to meaningfully contribute to society.³⁵ The potential of children with autism in Kisumu is restricted due to limited curricular aims. Additionally, Lutheran Special School does not admit children until they are nine years old. As discussed in the introduction, early intervention is extremely important for children with autism, and this late entrance age has the potential to seriously hinder developmental potential.

Disciples of Mercy Academy

Disciples of Mercy Academy is a private primary school located in Mamboleo, Kisumu. It is a regular primary school with six units for students with special needs, in

³⁴ Visit to Lutheran Church Special School for the Mentally Handicapped, Kisumu, Kenya, April 4, 2012.

³⁵ Jacqueline Muuya, "The Aims of Special Education Schools and Units in Kenya: A Survey of Headteachers," *European Journal of Special Needs Education* 17, no. 3 (2002), doi:10.1080/08856250210162130.

addition to the typical primary school classes. The school is housed within a grassy compound with a playground equipped with two swing sets, a slide, monkey bars, and a teeter totter. As a private school, about half of the students pay school fees, with the other half relying on private sponsors. The school does not have a boarding facility, and some student come to school from as far as one hour away.³⁶ The Disciples of Mercy head teacher stated that many of the children in the special units come to school after many years of being hidden away at home. Only after being compelled by a neighbor will the parents bring the child to school. Most of these children rely on private donors to cover their school fees.³⁷

Disciples of Mercy has six units for approximately 70 children with special needs. Two of the special units are for children with mild disabilities, called progressive classes. If the children in these classes show improvement they are moved to the mainstreaming class, another special unit, which attempts to prepare the children for integration into a regular primary school classroom. The school also has a pre-vocational class for older children, a class for children with cerebral palsy, and finally, a class specifically for children with autism.

The children at Disciples of Mercy are categorized in classes in order to individualize their education. The school uses Individualized Education Plans (IEPs) to tailor each child's education to his or her needs. The IEPs are developed by the class teacher, a social worker, and an occupational therapist, with input from the parents. In addition to a teacher and an assistant teacher in each class, Disciples of Mercy employs a part time occupational therapist as well as a social worker. Each student is able to see the occupational therapist once a week.³⁸ It is important to note that this information was simply conveyed during an informal interview. No observation of the provision of these services was able to be made.

³⁶ Dolores Adhiambo, interview by author, Disciples of Mercy Academy, Mamboleo, Kenya, April 10, 2012.

³⁷ Mary Akeyo, interview by author, Disciples of Mercy Academy, Mamboleo, Kenya, April 10, 2012.

³⁸ Dolores Adhiambo, interview by author, Disciples of Mercy Academy, Mamboleo, Kenya, April 10, 2012.

The autism unit at Disciples of Mercy has seven students between the ages of five and ten. While at first glance Disciples of Mercy appears to be a great option for children with autism that are able to afford school fees or find a sponsor, the teacher of the autism unit, Sylvia, brought up several significant challenges that they face at the school. First, no one at the school has any training specifically in autism. Sylvia received her diploma in special education in Nairobi and this is only her second year working at Disciples of Mercy. Furthermore, the children are all at different developmental levels, so Sylvia feels she needs to work one on one with the students. Although the student to teacher ratio at Disciples of Mercy is quite low, with a teacher and an assistant teacher and only seven students, it is not low enough to support one to one teaching at all times. Finally, the attitudes of her students' parents pose a great challenge for Sylvia. According to her, many parents are in denial about their child's condition. They want their child to be in a typical primary class, believing they have only a slight problem. The goals set for students are hard to reach and therefore take time. They also require parental participation outside of school, and while some parents will work on skills with their children at home, many leave it up to the school. The impatience of parents and lack of involvement hinders the schools ability to assist the students.³⁹

Disciples of Mercy begins every Monday through Saturday with a school wide assembly. After the assembly the students with autism return to class for a lesson on brushing their teeth, followed by free time until nine o'clock. At nine, they begin their formal lessons covering topics such as fine motor skills, perceptual training, communication, pre-academics ("scribbling, coloring, number recognition"), and activities of daily living. On Fridays they begin with an assembly as per usual, but following the assembly they have guidance and counseling, where they are divided by age and gender (older girls, younger girls, older boys,

³⁹ Sylvia Awour, interview by author, Disciples of Mercy Academy, Mamboleo, Kenya, April 10, 2012.

younger boys) with all of the other special units. They then have physical education, a break at ten, and then devotion (prayers).⁴⁰

As a private school, Disciples of Mercy has many more resources than the Lutheran Special School, including the onsite social worker and occupational therapist, yet they still struggle to include parents which hinders the school's ability to enact meaningful interventions to promote the development of their students. In addition, the lack of an autism specialist is cause for concern. Due to the timing of this study, prolonged observations of Disciples of Mercy was not possible as the school was closed for much of the month of April. Future investigation should be done to evaluate the approach of this school and its success in fostering the development of students with autism.

Educational Assessment and Resource Center (EARC)

The EARC in Kisumu, located at Joyland School for the Physically Handicapped, has the difficult task of identifying children with disabilities and referring them to the appropriate places for treatment. Every Wednesday parents may bring their children to the center for assessment. The EARC also conducts mobile assessments where they travel outside of the city to provide evaluations of children in rural areas. The Kisumu EARC serves the districts of Kisumu East, Kisumu municipality, and Kisumu West.⁴¹

Ideally, the EARC should have specialists on staff in each of the four major categories of disability: visual impairment, intellectually challenged, physical impairment, and hearing impairment. The assessment team should include an ENT (ears, nose, and throat) specialist, an occupational therapist, a physiotherapist, an ophthalmologist, and a social worker; however, there is a shortage of specialists in these areas in Kenya, even the hospitals are understaffed, so the EARC operates on a referral basis. The EARC in Kisumu currently

⁴⁰ Ibid.

⁴¹ Sam Atieno, interview by author, Educational Assessment and Resource Center, Kisumu, Kenya, April 19, 2012.

employs three full time staff members including a visual impairment specialist, a hearing impairment specialist, and a specialist in intellectual disabilities. They are missing a specialist in the area of physical disabilities. The teachers at the center assess the children, and then send them to the proper offices for follow up. This is sometimes problematic as the clients may not be able to afford the transport costs, so even after being assessed the child may be unable to access treatment.⁴²

The assessment process consists of collecting information from the parents in the form of a questionnaire to learn the child's history, in addition to having the child perform a variety of tasks to assess the child's capabilities in a several areas. The EARC coordinator, Sam Atieno remarked, "we do not only assess the mental capabilities, we also assess the auditory. Does the child hear the instruction properly, the hand eye coordination, comprehension, can the child hold the object properly? So as we are instructing the child we assess how the other modalities work and how the modalities integrate."⁴³ (For a complete list of questions parents are asked about the child's history, see Appendix D.)

Following an a assessment, if the child is of school-going age he or she will be referred to the appropriate school. The child may be referred for inclusion within a typical classroom, perhaps recommended to attend a typical school with a special need education unit, such as Disciples of Mercy, or finally they may be referred to a special school, such as Lutheran Special School. The child may also be referred for medical intervention, if necessary. If the child is not of school-going age, Mr. Atieno stated that they will be put in a home-based program, providing the following description of home-based programs.

The home-based program [is] geared toward supporting parents and children with disability in the home environment... We try to stress [that]... the responsibility of taking care of this child is not one person, we stress to them that it is important that other members of the family be involved in supporting the child's

⁴² Ibid.

⁴³ Ibid.

disability, and we specify areas where they should be given support. This I think is important because, in our society, in most of our society, once the child has a problem, then it remains the work of the mother, and we try to tell them no, she is a human being, she can get tired. . . . We try to involve the father. Actually, convincing him that the wellbeing of this child is the wellbeing of the rest of the family. We also train the parents to make locally assistive devices maybe using locally available materials, like when the child is physically challenged. . . . Also, we encourage them that the child should not be seated there. If he can hold, make things, and washing dishes. They should be involved in family activities as much as possible, should not just be left to sit there.⁴⁴

There are a couple of problems that arise from this description of home-based programs. First, there does not seem to be a set curriculum to teach parents how to work with their children to facilitate development. While it is important to provide counseling and talk to parents about involving the child with a disability in the life of the family, and sharing the responsibility of caring for such a child, this will not be sufficient in empowering the family to foster the growth of the child prior to reaching school-going age. What is even more troubling is that none of the families interviewed for this study had ever heard of home-based programs, let alone benefited from them. Mr. Atieno explained that the home-based programs are supposed to be run by community-based rehabilitation workers (CBRs), “though they are not very active” as they are volunteers.⁴⁵ There is a great need to improve the home-based programs both in structure and in its capabilities to reach all children in need.

The EARC does place an emphasis on early intervention, understanding how important it is to start working with children when they are young to maximize their future potential. As Mr. Atieno remarked, “I think when we identify this problem and start intervention early enough, then dealing with such a child that grows up is very simple, it is easier to even socially integrate, the child integrates socially well.”⁴⁶ While the importance of early intervention is recognized, the center lacks the resources and personnel to ensure that

⁴⁴ Ibid.

⁴⁵ Ibid.

⁴⁶ Ibid.

children in Kisumu access early intervention services. The staff at EARC do their best to assist children with disabilities in the Kisumu area; however, there simply are not enough trained professionals, resources, or funding for the center to be able to reach all children in need.

Mr. Atieno stressed the importance of follow up, stating “follow up is very important and the assessment process is not over until proper follow ups are made and pieces of advice, guidelines on how to deal with certain cases [are given].”⁴⁷ Unfortunately, the center sees so many clients that they hardly have any time for follow up with the parents. As will be explored in greater detail below, most parents interviewed for this study had very limited knowledge on the specifics of their child’s condition. Lack of knowledge limits parental participation in interventions, hindering their success. While Mr. Atieno, along with many other teachers, stressed the importance of involving parents and keeping them informed, very few steps are taken to ensure that parental involvement is a reality.⁴⁸

Diagnosing children with autism presents a unique challenge to the staff at the EARC. As Mr. Atieno commented, “autism is one area which is quite challenging. In fact, that is one of the areas where we have to be very very cautious.”⁴⁹ One major problem is that the center does not have an autism specialist on staff. Mr. Atieno described the center’s approach to autism intervention, with an emphasis on dietary intervention. There is little empirical evidence to support dietary interventions for children with autism, especially when it is the sole intervention utilized. A brochure from the ASK also stressed the importance of dietary interventions,⁵⁰ as did several news segments from Citizen TV on autism,^{51 52} illustrating a misguided focus when it comes to interventions for children with autism in Kenya.

⁴⁷ Ibid.

⁴⁸ Ibid.

⁴⁹ Ibid.

⁵⁰ Autism Society of Kenya, *A Brighter Future for People Living with Autism in Kenya* (Nairobi, Kenya: Amkeni Wakenya, n.d.),

Mr. Atieno seemed to underestimate the potential of children with autism who receive successful interventions, perhaps because very few children in Kisumu are able to access successful interventions. He stated, “one area which I have realized there is a lot of difficulty is to orient this child on strict academics. We find it quite difficult because of their, some of them actually are very hypersensitive and they get a lot of sensory information at one time, and because of this they fail to actually concentrate on the issues.”⁵³ Dietary interventions are used to calm children with autism down by removing gluten and casein. Misguided ideas about the potential of children with autism and proper intervention methods hinder the developmental potential of children with autism in Kisumu.

The number of autism cases found by the center has increased significantly in recent years. Mr. Atieno believes it may be due to increased awareness rather than an increase in prevalence. The center used to diagnose approximately two children a year with autism, but recently they have seen approximately ten children per term⁵⁴ who show autistic characteristics. EARC, in partnership with ASK has conducted several awareness workshops for parents, government officials, and teachers to educate them on autism.⁵⁵ Two of the parents interviewed had been able to attend an awareness workshop, however, as will be discussed in the following section, when asked to describe autism they were still unsure of the specific characteristics, limiting their ability to assist their children.^{56 57}

According to Mr. Atieno, there are some that still attribute autism and other developmental disabilities to witchcraft, though that number seems to be decreasing as awareness increases. “Some actually think of witchcraft,” commented Atieno, “but that one is

⁵¹ *Citizen News*, "Autism Awareness Month," Kenya Citizen TV, April 8, 2012, <http://www.youtube.com/watch?v=b1TK3yKumu0&feature=plcp>.

⁵² *Citizen News*, "Understanding Autism," Kenya Citizen TV, February 14, 2010, <http://www.youtube.com/watch?v=xhwhnATFqh0&feature=plcp>

⁵³ Sam Atieno, interview by author, Educational Assessment and Resource Center, Kisumu, Kenya, April 19, 2012.

⁵⁴ A term in Kenya is a period of three months.

⁵⁵ *Ibid.*

⁵⁶ Lauren Adongo, interview by author, Kisumu, Kenya, April 5, 2012.

⁵⁷ Jane Odhiambo, interview by author, Lutheran Church Special School, Kisumu, Kenya, April 11, 2012.

actually dying out because we've been sensitizing the public on causes, signs, symptoms, and prevention, and management of disability."⁵⁸ The parental interviews conducted for this study supported Atieno's beliefs, with all parents saying that although there was still stigma surrounding disability, few continue to attribute disability to witchcraft. While many parents continue to struggle with the lack of acceptance of their child, what is more concerning to them is the lack of information they receive on how to provide proper care. The following section will outline the barriers parents face in caring for their children with autism, namely lack of access to information and early intervention services. Only by improving parents knowledge and ability to access important resources will children with autism in Kisumu be able to reach their full potential.

⁵⁸ Sam Atieno, interview by author, Educational Assessment and Resource Center, Kisumu, Kenya, April 19, 2012.

Raising a Child with Autism in Kisumu: The Parents' Perspective

The resources to support children with autism are not nearly accessible enough for the many families in Kisumu that are in desperate need of assistance for their children. Take Greg and Emma Achieng and their daughter Florence for example. Greg and Emma are both Luos living in Nyamasaria with their three children. Their oldest child, Florence, attends the Lutheran Special School as a day student in the autism unit. Florence is nine years old. She just began to attend the school this past term. When Florence was three her parents realized she was not developing typically. When she was five, a neighbor of theirs who works as a teacher at Lutheran Special School advised them to take Florence to be evaluated at the EARC. At the EARC Florence was given a referral letter to the Lutheran Special School, but when her parents brought her to the school, the head teacher informed them that they only take children nine years and older. Since Florence was only five, they simply took her home and waited for her to turn nine. When she turned nine, less than a year ago, her parents brought her back to the school. The Lutheran Special School assessed Florence when she started attending, however her parents were never informed of the results of her assessment.⁵⁹

Greg and Emma said that they find it very difficult to raise a child like Florence. They try to train her in activities of daily living at home, in addition to the work that she does at school to learn to be more independent. Florence's mother stated that she has no idea why her child is the way she is. Many of the Achieng's neighbors think Florence is mad, and her parents stated that she is "abused by the society."⁶⁰ When questioned about their daughter's future, the parents came up blank. They do not know what life will be like for Florence when she grows up.⁶¹

When asked specifically of autism, the mother had heard of it, but she did not know anything about it. She said that she knows her child has it, but did not seem to have an

⁵⁹ Greg Achieng and Emma Achieng, interviewed by author, Nyamasaria, Kisumu, Kenya, April 5, 2012.

⁶⁰ Ibid.

⁶¹ Ibid.

understanding of the disability, may not have even known that autism is a disability. This exemplifies the little knowledge that the family has of autism in general and their daughter's condition more specifically. The few times that Florence was assessed, first at the EARC when she was five, and then later at the Lutheran Special School when she was nine, no one ever explained Florence's disability to her parents.⁶²

This story, and many others like it, represents the inaccessibility of early intervention services, and the need for parental empowerment and inclusion in their child's treatment process. Mr. Atieno from Kisumu's EARC stressed the importance of parents in the assessment process in providing prenatal, perinatal, and postnatal history. As he said, "The parents, especially the mother, they are very important in telling us the history. How the whole thing started...So the mother, the parents are very, very important in the process of assessment, in fact indispensable. We talked of assessment team, one important member of that team I did not mention of course is the parents. They are very important."⁶³ While the importance of parents is recognized, not nearly enough is done to include them in the process of assessment and in determining the best possible intervention.

All of the parents included in this study had their child assessed at the EARC and subsequently referred to the Lutheran Church Special School. When asked about the assessment process, one parent, Harriet said, "They just tell you, you leave the child. They don't ask anything." Following the assessment, Harriet was informed that her son exhibited some autistic tendencies, in her words "there is a bit of it [autism];" however, the EARC staff did not explain to Harriet what that meant or provide her with any information about autism.⁶⁴

⁶² Ibid.

⁶³ Sam Atieno, interview by author, Educational Assessment and Resource Center, Kisumu, Kenya, April 19, 2012.

⁶⁴ Harriet Amondi, interview by author, Lutheran Church Special School, Kisumu, Kenya, April 11, 2012.

Another mother, Jane, took her son to the EARC for the sole purpose of finding a school placement for him. Jane stated that she “never paid much attention at Joyland [EARC],” because her sole interest was obtaining a school referral for her son.⁶⁵ Her usage of the EARC supports the findings of a study conducted in Bondo, Kenya on the efficacy of the EARC assessment process, which found “that the parents usually seek this screen only when it is already known that the child has a problem and needs to be placed in a special school.”⁶⁶ Efforts should be made to compel parents to bring their children to be assessed well before they reach school-going age, when early intervention can be utilized. The study recommends the “ten questions screen” that can be conducted by community health workers and others with limited training to identify children at an early age that should go to the EARC for a more intensive assessment. “The ‘ten questions’ can be used to screen out potentially disabled children and then the EARC be used to diagnose the type and degree of the disability and refer the ill children for treatment.”⁶⁷ The hope is that this will enable children with disabilities to access early intervention services rather than waiting until they are of school-going age to seek assessment and referral.

At the end of each interview, parents were asked what they knew about autism. A couple of the parents, including Florence’s parents, didn’t know anything about autism and had only heard the word being used in relation to their child.⁶⁸ One parent stated, “I think it is a brain condition, and I was told it is not treatable.”⁶⁹ Some parents had limited knowledge of the specifics of autism, like Antonius who spoke of perseveration, a common autistic trait. “The child may be adapted to a certain thing, and once is accustomed to something is just...

⁶⁵ Jane Odhiambo, interview by author, Kisumu, Kenya, April 11, 2012.

⁶⁶ Emily Muga, "Screening for Disability in a Community: The 'Ten Questions' Screen for Children, in Bondo, Kenya," *African Health Sciences* 3, no. 1 (April 2003): p. 37.

⁶⁷ *Ibid.*: p. 39.

⁶⁸ Greg Achieng and Emma Achieng, interviewed by author, Nyamasaria, Kisumu, Kenya, April 5, 2012.

⁶⁹ Harriet Amondi, interview by author, Lutheran Church Special School, Kisumu, Kenya, April 11, 2012.

so we are trying to divert them so that they will become acquainted to the environment. Make them to learn to do this and this and this.”⁷⁰

Even parents who has attended seminars on autism run by ASK and the EARC, like Lauren and Jane, had limited, misguided beliefs about the specifics of this developmental disability. Lauren spoke of delayed developmental milestones, commenting that autism “is a condition whereby a child which has reached maybe an age of walking, can’t walk. Or maybe the one who is supposed to speak, can’t speak. And she can’t even grow taller. You will always see her remaining maybe at a very funny height. And when you look at her, she is looking like a grown up.”⁷¹ While delayed milestones and speech and language difficulties are commonly found in individuals with autism, autism has no affect on physical growth. Jane was unable to articulate much about the specifics of autism, stating “When I came here [to Lutheran] is when I heard that word...when I came here is when I’ve been taken to some workshop. We have been sharing with the teacher, the class teacher, and others. So it’s like I’ve gained some interest. I want to know more. The development, the daily development.”⁷²

Almost every parent expressed a deep desire to learn more in order to better assist their child. Alice, a mother of five whose youngest, Benjamin, attends Lutheran Church Special School as a student in the autism unit, is unsure of any specifics of autism. Alice just knows that children with autism are children with a mental disability. She stated that neither the Lutheran school nor the EARC has done anything to teach her about her child’s disability. “They don’t tell you anything. They just tell you that your child has a mental disability.”⁷³ In 2010, J.K. Gona et al. studied the experiences of people caring for children with disabilities in Kilifi, Kenya. The study found that “most carers expected the medical staff to give information about the child’s condition that they could easily understand. However,

⁷⁰ Antonius Ouma, interview by author, Kisumu, Kenya, April 11, 2012.

⁷¹ Lauren Adongo, interview by author, Kisumu, Kenya, April 5, 2012.

⁷² Jane Odhiambo, interview by author, Kisumu, Kenya, April 11, 2012.

⁷³ Alice Okeyo, interview by author, Kisumu, Kenya, April 10, 2012.

information given was scanty or sometimes none at all.”⁷⁴ There is a great need to empower parents to enable them to be active participants in their child’s intervention. Educating parents on the specifics of autism will not only ease their anxiety in caring for their children, but it will also increase the success of interventions.

⁷⁴ J. K. Gona et al., "Caring for Children with Disabilities in Kilifi, Kenya: What is the Carer's Experience?" *Child: care, health and development* 37, no. 2 (2010): p. 179, doi:10.1111/j.1365-2214.2010.01124.x.

CONCLUSION

It is unclear what the future holds for children with autism in Kisumu. Every parent interviewed was asked what they expected their child's future to look like, and time and again they were at a loss. Many parents are desperate for advice on how to better care for and support their children; unfortunately, they do not know where to go to get information and services to enable them to foster their child's development in a positive manner.

Kenya's Special Needs Education Policy identifies the "lack of appropriate tools and skills for early identification and assessment" and "inadequate skilled manpower and inappropriate placement of children with special needs and disabilities" as two major challenges faced by the government in providing essential services for children with special needs.⁷⁵ For children with autism, these challenges are exacerbated since there are so few individuals with training specifically in autism. As a complicated disability that has only recently gained recognition in Kenya, children with autism experience significant barriers in accessing the necessary intervention services at a sufficiently early age, if at all. While awareness and knowledge of autism in Kenya is on the rise, the potential of children with autism remains inhibited due to inaccessibility and poor quality of intervention services.

Several steps should be taken to improve the future prospects of children with autism in Kisumu. First, parents must be compelled to take their children to the EARC for assessment before they reach school-going age. By utilizing community health workers and raising awareness of autism and the importance of early intervention, this can be achieved. Second, a greater emphasis must be placed on the EARC's home-based programs to improve early intervention services. By devoting more funding and personnel for this project and by establishing a curriculum more children will benefit from early intervention.

⁷⁵ Ministry of Education, "The National Special Needs Education Policy Framework," July 2009, Republic of Kenya.

In addition, parents must be educated on how to best work with their child.

Empowering parents will enable them to work with teachers and other professions, increasing the chances that the child will achieve his or her full potential. Finally, efforts should be made to disseminate information about autism to teachers and medical professionals. With the proper interventions children with autism have unbounded potential. By expanding curricular aims and increasing the number of trained autism professionals, children with autism in Kisumu will have a much greater chance at successful development.

As this study has illustrated, families and children with autism face many barriers in accessing necessary services in Kisumu. The complicated nature of autism makes identification difficult. Furthermore, knowledge of autism in Kenya remains limited, despite important advances that have recently been achieved. Early intervention is extremely important for children with autism, but these services remain inaccessible and impractical. The importance of parental involvement cannot be overstated. Unfortunately, parents remain marginalized by professionals, unable to access the knowledge that would facilitate their involvement in their child's intervention. By following the recommendations outlined in this paper, the potential of children with autism in Kisumu would increase exponentially, due to improved access to, and quality of, vital intervention services.

RECOMMENDATIONS

Due to the limited one month period in which this study was conducted, there are several areas which would be interesting to pursue further. With more time it would have been valuable to conduct observations of assessments at the EARC, as well as attend autism awareness workshops run by the EARC and ASK. Furthermore, it would have been valuable to conduct prolonged observations at Disciples of Mercy Academy, but due to the timing of the research and the school holiday, this was not a possibility for the present study. Parents of students in the autism unit at Disciples of Mercy could also be interviewed for a more diverse group of participants.

Additionally, in five out of seven cases in the present study, parents attributed their child's onset of autism to a severe case of malaria that resulted in seizures and hospitalization. A study conducted in Tanzania in 2006 found a correlation between severe malaria and autism.⁷⁶ Kisumu would serve as an interesting location to conduct further research on this correlation due to the high rate of malaria, with a prevalence of around 40% for children.⁷⁷ Malaria specialist as well as autism specialist should be consulted, and a broader pool of children should be identified to find out how common it is for autistic symptoms to appear following a case of severe malaria in young children.

⁷⁶ Raymond E. Mankoski et al., "Etiologies of Autism in a Case-series from Tanzania," *Journal of Autism and Developmental Disorders* 36, no. 8 (2006): 1039-1051, doi:10.1007/s10803-006-0143-9.

⁷⁷ Division of Malaria Control, Ministry of Public Health and Sanitation, "2010 Kenya Malaria Indicator Survey," July 2011, Kenya National Bureau of Statistics.

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Organizations

Disciples of Mercy Academy
 P.O. Box 20-40100
 Kisumu, Kenya

Educational Assessment and Resource Center, Kisumu
 Located at Joyland School for the Physically Handicapped
 P.O. Box 1790
 Kisumu, Kenya

Lutheran Church Special School for the Mentally Handicapped
 P.O. Box 1203
 Kisumu, Kenya

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Appendix A: Interview Questions for Parents of Lutheran Special School Students

1. Name and gender of interviewee
2. How many children do you have?
3. Name, age, and gender of child with Autism
4. Marital status
5. When did you realize that your child wasn't developing typically?
 - a. What were the signs?
 - b. What did you do when you realized your child was different? (Bring to doctor, EARC, etc.)
6. Does your child have a specific diagnosis?
 - a. If yes, what is it?
 - b. what was it like for you when he/she was diagnosed?
7. When and why did you decide to send your child to the Lutheran School?
8. How independent is your child in regards to self care?
9. Do you have any ideas or beliefs as to why your child is the way he/she is?
10. How have your friends, family, and community treated your child?
11. What level of education do you expect your child to complete?
12. Do you do anything else, outside of school, to help your child with his/her development?
13. Are you happy with the services available to you in Kisumu to support your child?
14. What do you expect your child's future to look like? Where will he/she live? Will he/she have a job? Etc.
15. Do you know of parents that don't address their child's disability the same way you do?
16. How do you feel about having a child with a disability?
17. Have you heard of Autism?
 - a. If yes, what do you know about it?

Appendix B: Interview Questions for Teachers

1. What is your degree in and where did you go to school?
2. When did you begin working at this school?
3. How many children are in your class?
4. What are the ages of your students?
5. What are the minimum and maximum ages for students?
6. What types of disabilities do your students have?
7. Do you know about autism?
 - a. If yes, what are the major characteristics of autism?
 - b. Why do children have autism?
 - i. What does the public think?
 - c. Where does autism come from?
 - i. What does the public think?
8. What is a typical day like for your class?
9. What subjects are included in your curriculum?
10. What do you find is your greatest challenge in teaching children with special needs?
11. Are parents involved in their child's education?
 - a. If yes, how?
12. Are parents knowledgeable regarding the specifics of their child's diagnosis and condition?
13. What are some of the perceptions of disabilities in the community?
14. Do you know any families that choose to keep their child at home rather than sending him or her to school?
15. Have you heard non-medical explanations for Autism or other disabilities? Do parents have ideas as to why their child has a disability?

Appendix C: Interview Questions for EARC Staff

16. What is your job title?
17. What does your job entail?
18. What is your degree in?
19. When did you begin working at the EARC?
20. What brought you to the EARC center?
21. What services does the center provide?
22. When a child is first brought to the center, what is the typical protocol?
23. What are the specific steps of the assessment process?
24. What is the purpose of assessments? How are they used?
25. How are the parents involved in their child's assessment?
26. After the child is assessed and referred, is there any follow up with the family?
27. Are there any services available to educate or counsel parents and family members of children with disabilities?

Autism specific questions

1. Does the center diagnose children with autism?
2. What are the major characteristics of autism?
3. Why do children have autism?
 - a. What does the public think?
4. Where does autism come from?
 - a. What does the public think?
5. What are the criteria for diagnosis of autism?
6. How often are children diagnosed with autism?
7. What is the prevalence of autism in Kenya?
8. At what age is autism usually noticed?
9. What is the main barrier to diagnosis?
10. How could diagnostics be improved in Kenya?
11. When a child is diagnosed, what happens next?
 - a. When does treatment start?
12. What do you know about early intervention treatment? What are your thoughts about it?
13. What does autism treatment consist of?
14. What services are available/recommended for children with Autism in the Kisumu area?
 - a. Government services
 - b. Therapists
 - c. Special Schools
15. Are there Autism specialists in the Kisumu area?
 - a. What training do they have?
16. What school are children with Autism referred to?
17. Does the center provide any educational information on Autism for parents? Teachers? The community?

18. Can Autism be cured?

Perceptions

1. What are some of the perceptions of disabilities in the community?
2. Are parents knowledgeable regarding the specifics of their child's diagnosis and condition?
3. What work is done to reduce the stigma surrounding disability?
4. How can disability awareness be improved in Kenya?
5. Do you know any families that choose to keep their child at home rather than sending him or her to school?
6. Have you heard non-medical explanations for Autism or other disabilities? Do parents have ideas as to why their child has a disability?

Appendix D: EARC Questionnaire for Obtaining Background Information

MINISTRY OF EDUCATION
INSPECTORATE SPECIAL EDUCATION UNIT
EDUCATIONAL ASSESSMENT AND RESOURCE SERVICES

QUESTIONNAIRE FOR OBTAINING BACKGROUND INFORMATION

Name of Child _____ No. _____

Name child is called at home _____ Sex _____ Age _____ Date of Birth _____

Father's Name _____ Age _____ Father's occupation _____

Permanent address _____

Mother's name _____ Age _____ Permanent address _____

Child's residential address _____ Child's school and address _____

Class/Form _____ District _____ Location _____ Sub-Location _____ Village _____

Name of chief _____ Tribe _____ (nationality if not Kenyan) _____

Language spoken in family _____ At school _____ Child's position in family _____

Number of children in family (still living) _____ Number of children in family (deceased) _____

At what age did child/ren die? _____ What was the cause of death? _____

Is anyone in the family handicapped? _____ If yes, what kind of handicapped? _____

HISTORY OF BIRTH AND PREGNANCY

Was the child born at home or in a health institution? _____

Was the birth of the child normal or not? _____

If it was complicated, give details _____

Has the mother had any previous or later miscarriages or abortions _____

Did the mother suffer from any bleeding, illness or receive any immunisations during pregnancy? If yes, give details _____

What was the birth weight? _____ Did the child cry immediately at birth? _____

HISTORY OF THE CHILD

What is the problem with the child? _____

When did the parents first observe difficulties with the child? _____

What were the symptoms? _____

Has the child suffered from any disease? _____

Did the child suffer from an accident? _____ Give details? _____

Was the child vaccinated against whooping cough? _____ Polio 1,2, and 3 _____

Tuberculosis _____ Tetanus _____ Measles _____

How old was the child when he/she could Stand? _____ Walk? _____

say first word? _____ How does the child express its needs? _____

Does the child attend school? _____ If yes, at which education level? _____

What is the child's attitude towards parents, siblings and other children? _____

For children 4 years and above, is the child toilet trained (day/night)? _____

Does the child play normally with the other children? _____

HAS THE CHILD HAD ANY SERIOUS ILLNESS/OPERATIONS?

If yes, give details _____

IS THE CHILD EPILEPTIC?

If yes, describe the fits and the frequency of the fits _____

At what age did these fits start? _____

Previous or ongoing treatment _____

HAS THE CHILD VISUAL DIFFICULTIES

If yes, give details _____

At what age did the parents first observe the visual problem? _____

Previous or ongoing treatment _____

HAD THE CHILD HEARING DIFFICULTIES?

If yes, give details _____

At what age did the parents first observe the hearing problem? _____

Previous or ongoing treatment _____

HAS THE CHILD MOTOR DIFFICULTIES?

If yes, give details _____

At what age did the parents first observe the motor problem? _____

Previous or ongoing treatment _____

HAS THE CHILD SPEECH OR LANGUAGE DIFFICULTIES?

If yes, give details _____

At what age did the parents first observe speech and language problems? _____

Previous or ongoing training _____

HAS THE CHILD READING OR MATHS DIFFICULTIES?

If yes, give details _____

At what age did the parents first observe reading and maths difficulties/problems? _____

Previous or ongoing training _____

Any other relevant information _____

The information was given by:_____

NOTES. _____

Name of assessor:_____

Date:_____Assessment centre._____