**AN EXPLORATORY STUDY OF FAMILIAL AND COMMUNITY**

**INVOLVEMENT OF PEOPLE WITH DEVELOPMENTAL**

**DISABILITIES LIVING IN KIBERA SLUM**

by

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Submitted as partial requirement for

TUL 670 Research Project

School of Liberal Arts and Sciences

Master of Transformational Urban Leadership

July 2013

Nairobi, Kenya

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# ABSTRACT

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Master of Transformational Urban Leadership, 2013

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This exploratory study opens dialogue in Kenya and Sub-Saharan Africa regarding people with developmental disabilities. Approximately 8% of 41 million Kenyans live with developmental disorders, yet there are not enough public policy or community level efforts to involve them in schools, the economy and in their communities. People ages three to nineteen were surveyed to determine the levels of involvement in their communities and families. These people represented three different schools and six different disabilities, with the average participant between the ages of 6-10. Though these individuals are being included, many are not meeting their potential for full authentic inclusion in school, at home and in the community. Females were found to have more skills than male students, those with mental difficulties were found to have the highest home and community involvement of all the disability groups, and parents stated that they felt generally uncomfortable with their children out in the community.

Based on the analysis, recommendations were made for parents and teachers to collaborate in introducing their children to and providing formation to the community. Doctors and health care professionals were encouraged to better communicate with parents and to carefully observe a child’s development so that diagnoses are made early in the child’s life. Schools recommendations included provision of support for fathers and standardization of a skills based learning curriculum. This research has resulted in the formation of relationships between likeminded organizations, and has catalyzed work toward improving services for PWIDD in Kibera and more broadly, in Kenya.

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LIST OF ABBREVIATIONS

AAK Autism Awareness Kenya

ABA Applied Behavioral Analysis

ASD Autism Spectrum Disorders

BCBA Board Certified Behavior Analyst

BT Behavioral Therapy

CBO Church-based organization

CDC Center for Disease Control

DD Developmental Disability

ID Intellectual Difficulties

IDD Intellectual/Developmental Disabilities

KSMH Kenya Society for the Mentally Handicapped

ND Neurological disorders

NGO Non-governmental Organization

MSF Medicins sans Frontiers

OT Occupational Therapist

PWIDD People with Intellectual/Developmental Disabilities

SEP Special Education Professionals

UNICEF United Nations Children’s Funds

WHO World Health Organization

**CHAPTER 1**

**INTRODUCTION**

The current field of study of people with Intellectual or Developmental Disability (PWIDD) has little information pertaining to those living in urban slums. The majority world is severely lacking documentation on PWIDD, as are studies estimating populations with disability in countries more focused on providing basic necessities (United Nations Children’s Fund, 2013, p. 2). Equally unexplored is community involvement for populations outside of the developed world, especially strategies used to increase community involvement. Estimates state that 15% of the Kenyan population is impaired with a physical, mental, visual or auditory condition or a combination of these conditions, and roughly 60% of these individuals are PWIDD (KSMH, 2013).

Using the 5 point scale of Authentic Inclusion (partial inclusion, full inclusion with support, reverse inclusion, skill/behavior based inclusion and authentic inclusion) as developed by Rudy (2010) along with measuring engagement through participation in community activities, this research surveyed families in Kibera, the most well-known informal settlement in Kenya’s capital city, Nairobi, to better understand the levels of community and familial involvement in PWIDD.

Disability, according to the World Health Organization (WHO), in intricately related to a dysfunction of “one or more of these same levels: impairments, activity limitations and participating restrictions,” which will be observed and outlined in this paper (WHO, 2002, p. 10). The research discovered strategies and resources needed to increase involvement, and illuminated issues and successes with Kibera families in involving their family members with PWIDD in the community. Though these, this paper will create a simple framework for further research in the fields of disability studies, slum research and community participation. A goal of the study as participatory action research is also to connect local organizations, providing an opportunity for networking, collaborative ventures and increasing program effectiveness.

Partnering organizations, Tabasamu Watoto and Kaizora Consultants, expressed interest in more contextually appropriate resources to assist them to better understand their target demographic. Through commencing discussions with other organizations, this study endeavors to create linkages, service improvements and ideas that can provide opportunity for further action, as well as opportunities for primary caretakers to connect with local resources for PWIDD.

**DEFINITIONS**

An intellectual disability (ID) refers to a wide range of disabilities that affect the mental capacity of a particular individual. In the Western world the term is commonly used as a synonym for mental retardation. However, according to the Kenya Society for the Mentally Handicapped (KSMH), within the Kenyan context, the following are regarded as intellectual disabilities:

*ADHD, Angelman Syndrome, Asperger Syndrome, autism, Cri Du Chat, Down’s Syndrome, Dysphagia, Dyspraxia, Dyslexia, Epilepsy, Fragile X, Klinefelter Syndrome, Pervasive Developmental Disorder, Prader-Willi Syndrome, Rett’s Syndrome, Trisomy, Soto’s Syndrome, Tourette’s Syndrome, Tuberous Sclerosis, William’s Syndrome.*

(KSMH, 2013).

Comparatively, a developmental disability (DD) isa substantial impairment in mental or physical functioning, with onset before the age of 18 and of indefinite duration. Common examples of developmental disabilities include autism, cerebral palsy, uncontrolled epilepsy, certain other neuropathies, and mental retardation. This research has combined the Kenyan definition of intellectual disability according to KSMH along with the definition of developmental disorders as defined by medical dictionaries.

**OVERVIEW OF KENYA**

Kenya is located on the eastern coast of Sub Saharan Africa bordering Ethiopia to the north, Somalia in the east, the Indian Ocean to the south west, Tanzania to the south, Uganda to the West and South Sudan to the north-west. The country has a population of 41 million people, 60% of who are under the age of 24 according to the Kenyan Census of 2009 (Population Reference Bureau, 2011; CIA World Factbook, n.d.). Kenya also has a high birthrate, an average of 4.7 children per woman. The official languages are English and Kiswahili.

**Demography**

The research evaluated the levels of involvement in people aged three to nineteen living in Kibera slum, Nairobi with IDD. According to the 2009 Kenyan government census, 55% of the Kenyan population is under the age of nineteen (Ministry of Youth Affairs and Sports, 2013). Studies by the Ministry of Health have shown that over 3.6 million Kenyans live with IDD (KSMH, 2013). Therefore, assuming similar demographics in Kibera and a low to moderate estimate of the Kibera population (170,000 – 300,000 people) this exploratory study applies to approximately 8,137 – 14,355 individuals living in Kibera with IDD and their families (Karanja, 2010). This study uses a sample of 43 of these PWIDD.

**Informal Settlements in Kenya**

Kibera is located 5km from Nairobi city center and contains residents representing four of Kenya’s five largest tribes. It is the city’s oldest informal settlement. Though there are toilets, schools and many NGOs, Kibera is documented as having open sewers and no formalized sewage or garbage control systems hence creating a perpetual state of health crisis in communicable diseases. The close proximity between homes facilitates the spread of disease, especially to vulnerable young children, diseases that can lead to brain infections causing neurological disorders (Mung’ala-Odera, Meehan, Njuguna & Mturi, 2006 p. 686). To compound these factors, inadequate healthcare within and outside of the slum lead to unqualified midwives, near-asphyxiation at birth and home deliveries which leave the mother or the child with lasting consequences such as cognitive, neurological or mental difficulties (Mung’ala-Odera, Meehan, Njuguna & Mturi, 2006 p. 687; Muga, 2003 p. 33). Children born in Kibera are at risk for congenital and acquired brain injuries (i.e. infection caused disability) as the cause of an intellectual disorder.

**CHAPTER 2**

**REVIEW OF LITERATURE**

**Family and Community Structure in slums**

Familial structure in Kenyan slums is reflective of trends during the British colonial period. Men would leave the family in search of work in the cities, which created women-led households (Charton-Bigot & Rodriguez, 2006; Sobania, 2003). Consequently, familial structure began to break from the traditional homestead incorporating several generations of sons into single mother household units. Marriage and the birth of the first child are viewed as coming of age events in Kenyan culture, allowing a participant to become a full member of society, so many individuals have their first child at an average age of nineteen (Kenya National Bureau of Statistics & ICF Macro, 2010, p. 54; Buvinic, 1998; Wulf, 2002; Fapohunda & Poukouta, 1997)

Due to early child-bearing, few women bear children at the end of their fertile years (which seems to be one of the causes of the increase of certain genetically linked mental disabilities in the West) (DHS, 1994). During marriage, the burden of activities within the home or within the sphere of caretaking is the responsibility of the woman, though roles are slowly changing in the urban context. A decrease in polygamy and increased female independence has gradually led to an increase in female-headed households in the past 20 years (Lewis, 1966; Sobania, 2003). However, this creates difficulty through the bread-winner/caregiver paradigm, where then one individual, the woman, is required to both financially provide for a household as well as act as the sole caretaker.

Kenyan communities are structured around the system of tribe and the idea of *ubuntu,* an ideology that promotes networks and assistance through the value of “I am because we are”. The kinship system, though disappearing, is still a relational tie that acts as a safety net in difficult circumstances, such as the birth of a child needing additional attention (Van Engen & Tiersma, 1994). Due to the ingrained ideology of *ubuntu*, it is quite difficult for a family to survive without the assistance and support of their community.

**IDD in Kenya**

As awareness surrounding mental disorders and disabilities increases, practitioners worldwide have become interested in mental health. Studies from cross-national surveys in several developing regions have shown that common mental disorders are about twice as frequent among the poor as among the rich (Patel, Araya, de Lima, Ludermir, & Todd, 1999)**.** Poor children in the United States of America, for example, are at increased risk for behavioral disorders and other mental conditions than other American children (WHO 2001). A WHO study showed that mental disorders are found to occur twice as often in those who were of lower socioeconomic categories (2001). Poverty puts individuals at significant risk of having undiagnosed mental disorders, since the poor are often isolated from information or support by either the proximity of affordable housing from quality health care, expensive transport services, or simply a high overall cost of services. The poor are often exposed to more stressors, with fewer resources to manage them and a greater vulnerability (Kaplan, Haan, Syme, Minkler, & Winkleby**,** 1987; Murali & Oyebode, 2004).

According to a statement by WHO, direct governmental participation is crucial, and *“every government should have a mental health policy that is endorsed at the highest level. It is desirable that the policy be the responsibility of the national government,”* in order to create a single, unified policy that works across multiple sectors (2004, p. 13). In response, the Kenyan government began to train mental health personnel as well as front line health workers, many of who were placed in HIV pre and post counseling services (Brandt, 2008). However the government has yet to create services for those with mental disabilities or work towards a better understanding of the nature of IDD. Estimates state that 15% of the Kenyan population is impaired with a physical, mental, visual or auditory condition or a combination of these conditions, and 60% of these individuals are PWIDD (KSMH, 2013).

A ten question questionnaire has been used in several similar contexts in order to determine the percentage of children in a given area who possess neurological disorders. In rural Kenya in particular, it was found that children with neurological disorders (ND) were 6% of the child population, a number expected to increase as child mortality decreases (Mung’ala-Odera, Meehan, Njuguna & Mturi, 2006 p. 685). The number of children with ND in rural Kenya may be higher than this 6% projection, as the survey screens out those with mild disorders in the beginning stages, even those disorders that may create larger problems in the future (Muga, 2003).

Misunderstanding of the causes and interventions for individuals with mental disability, however, abound. In adults, mental disability can be misattributed to the effects of drugs or alcohol; in children and adults alike, community members often misattribute the IDD and various ND to spirit possession (Crabb, Stewart, Kokota, Masson, Chabunya, & Krishnadas, 2012; Hugo, Boshoff, Traut, Zungu-Dirwayi & Stein, 2003). This prevents proper interventions and increases in understanding as to how to manage many of these disorders.

These perceptions of negative causes of IDD and ND can lead to negative responses towards children diagnosed with a mental disability. The Kenyan educational system is characterized by eight years of primary learning and four years of secondary school, and is test based. Children with learning disabilities, autism or mental difficulties tend to struggle in this system (St. Louis Center). These children often attend modified classes, a modified school, or do not attend school at all. In the urban and rural settings alike, there is an emphasis on success in education as a means to escape poverty, consequently placing a significant burden on families of and PWIDD to perform at a certain level academically.

Children with a suspected disability may be recommended by an instructor to be taken for an assessment at the government hospital or obtain a free assessment by Special Education Professionals (SEP). However, according to the United Nations Children’s Fund (UNICEF), “parents may overlook certain signs, or hesitate to report them, because of a lack of acceptance or stigma surrounding disability in their culture” (2013, p. 66). Diagnosis of a disability has significant implications socially and emotionally for the caretaker. Some caretakers will in turn withdraw their child from the school suggesting the child be tested.

When parents discover their child has a disability, they may carry some of these negative attitudes into seeking or choosing to not seek interventions for their child. These thoughts and beliefs may also influence the parent’s perception of their child’s capabilities and limitations. However, what parents say their attitudes are or were previously are not necessarily reflective of the reality within the home and how they interact with the child (Mutua & Dimitrov, 2001; Ingstad, 2003). Interpretations of these parental reactions and attitudes have been thoroughly dissected by practitioners and have had a large influence in creating assumptions amongst field professionals. Practitioners are most interested in how parents are perceived to have adjusted and their emotional responses to the news of a child’s disability. Social scientists and social psychologists have gradually transitioned from blaming the moral character of the parent to citing inner deficiencies, regardless of a positive or negative parental response (Ferguson, 2002). The perceived responses from a practitioner’s perspective tend toward an interpretive bias of the families’ issues. Instead, viewing the child’s disability through the lens of the parents and families’ interpretation of their own needs has proved to be the most effective method of analysis (Muga, 2003).

**Treatment of Disability in Kibera**

People living in Kibera often seek treatment for ailments and diseases from *inter alia* (witch) doctors, churches and finally, hospitals. People visit these traditional healers for everything from illnesses, to curses, marital unfaithfulness and various social issues. Herbalist shops in each neighborhood sell roots, bark, herbs and other natural herbal remedies for maladies ranging from the common cold to HIV (D. Yared, personal communication, September 3, 2012). Though these interventions may not receive acknowledgement in Western society, they are sought after in tandem with certified medical practitioners by locals.

There has been failure in the mainstream Christian community in addressing a holistic perspective of medicine that includes the community and restoration of relationships (D. Yared, personal communication, September 3, 2012). Pentecostal churches in Nairobi are often a source for healing in communities such as Kibera. Faith is viewed as a cure to illness, partly because of the financial inaccessibility of hospital care. People suffering from various maladies are encouraged to attend healing services, where a designated person, will place their hands on the affected individual and pray for their healing or rebuke an evil spirit (Crabb et al., 2012). There is little literature as to the effectiveness of these interventions, though they do provide an opportunity for community involvement in the intervention unlike many medical interventions. Ultimately, the community is the best option for working with a child with a mental disability both contextually and in existing literature (Mutua & Dimitrov, 2001).

**Community Inclusion**

Community inclusion is pivotal in the development and social wellbeing of any person. From the highest levels to the lowest, community inclusion can take various forms. Approximately 3.6 million Kenyans are diagnosed PWIDD and there are further implications for these individuals on the institutional level beyond simply provision of daily care (KSMH 2013). Inclusion, though originally an educational term, has been used in various contexts to refer to the allowance of PWIDD and other physical, visual or auditory impairments to have the same privileges and rights as those without these impairments. For instance, one Kenyan academic contested the idea of a person excluded from voting on the basis of “unsound mind” in an effort to secure the right for functional people with intellectual disabilities in Kenya to vote (Mute, 2010 p. 1). Mute questioned the inherent right of citizens of a country who desire to vote to have the opportunity, as well as the civic duty of voting and if individuals who desire to participate should be excluded from civic engagement. Noting that this is a level of civic engagement, his statements draw into question efforts to involve PWIDD also in lower interactional levels, such as within the community.

Within the Kenyan context, acceptance and inclusion in the community are not exclusively tied to the appearance of “normalcy,” as would be described in a Western context as achieved through behavioral modification therapy or extensive training. Instead, within the rural context, if the individual fulfills their role within their family and their procreative duty of marrying and bearing children, they are more likely to be accepted as a full member of the community (Ogechi & Ruto, 2002). Though much of the literature states otherwise, Ogechi and Ruto suggest individuals are not always discriminated against in the majority world context because of disability (2002).

However, discrimination and exclusion do occur within the school setting, and there is a rising voice against services for the disabled and separation within the school context. Separating students into “special needs” and regular classes often creates an “us versus them” mentality and actually ends in exclusion instead of inclusion (Ogechi & Ruto, 2002; Fennick & Royle, 2003; Ingstad, 2003). For this reason among others, many Kenyan parents will refuse to enroll their disabled children in school (Mutua & Dimitrov, 2001).

The Kenyan educational system is not equipped to handle the needs of children with intellectual disabilities, as compared to the tremendous strides education has made to include children who have auditory, visual or movement impairments. Since the introduction of free primary education, parents feel pressured to include their children in this aspect of the community that will, in turn, label their child incapable and dull, though the children may be capable of learning life skills as well as a trade (Ogechi & Ruto, 2002; Fennick & Royle, 2003; Mutua & Dimitrov, 2001; Ingstad, 2003). In practice, children with mental disabilities are often segregated out of their age mates and left with those who are peers in skill level. Therefore, in this context, participation or lack of participation in the school system may lead to the same end, limitation in the possibilities for community involvement of PWIDD.

One possibility is community inclusion through creation of curricular or extracurricular activities that are mutually appealing to individuals and families with individuals with IDD. Children, for instance, can become involved in the community through interaction with community members, even in a resource poor environment. Community contact and interaction with the child, even in the slum context, create improvements within the community’s views of PWIDD. It also opens further opportunities for the individual with IDD to learn how to interact with others outside of the home (Uy Koe, 2012). Integration through clubs within the school context has also proved effective for teens with IDD and created opportunities for social integration (Bernard-Opitz & Mumm, 2012).

Adults and children can also become involved in organized community activities that connect the impaired with the non-impaired. Prior studies have shown that putting IDD students in the company of others with the addition of an activity coach, allows them to gain skills more quickly and increases their social interaction as compared with those children interacting solely with those of a similar skill level (Fennick & Royle, 2003). This approach is an example of combining several types of inclusion, full inclusion with support in addition to reverse inclusion in order to achieve a particular objective.

In the slum context parents have also proactively involved their children through introducing children to the community and giving them meaningful roles that the community is able to understand (Uy Koe, 2012). One three year study in the slums of Kolkata, India trained members of the community as health workers for families who had children with disabilities including cerebral palsy, multiple disorders as well as intellectual disorders. This proved to be a successful intervention because parents were trained and gained confidence in caring for their children and actively seeking services. Parents also felt better supported by the community, and certain burdens of care were reduced as parental involvement increased as did the child’s skills (Sena & Goldbart, 2005).

Finally, adults with IDD can become quite involved through learning life skills and receiving assistance in identifying suitable and meaningful work to allow them to engage in the community and become fully integrated members (Bureau of Autism Services, 2010). It is crucial to note that individuals living with these disabilities are also capable of leading productive livelihoods and taking care of themselves.

According to UNICEF, more data is needed that discuss, “the barriers to the functioning and community participation of children with disabilities,” and such contextualized data can “help to inform decisions about how to allocate resources, eliminate barriers, design and provide services and meaningfully evaluate such interventions” (2013, p. 67). Due to the gap in knowledge in the current field of study, this study strives to better understand the levels of community and familial involvement in people aged three to nineteen living in Kibera slum with autism spectrum disorders (ASD), Down’s syndrome and mental retardation in particular, as well as other intellectual and neurological disorders that make up IDD.

**CHAPTER 3**

**CURRENT RESOURCES**

The current resources available to families in Kibera are three schools that openly accept and recruit pupils with developmental disorders: Mary Rice School, Tabasamu Watoto and Little Rock School. Outside Kibera, the researcher asked several teachers about resources available for parents who have a child with a developmental disability. Through networking, several organizations working with people with developmental disabilities were found. These organizations included but were not limited to the following: Heshima Children’s Centre (Ngong Rd), Kaizora Consultants (Karen), Kenya Society for the Mentally Handicapped (Westlands), and Autism Awareness Kenya (Parklands). Two of these, Kaizora and Tabasamu, were directly involved in the research process and formation of the study, while Mary Rice, Little Rock and Heshima were involved peripherally i.e. surveyed or interviewed as a practitioner.

Kaizora Consultants is a behavioral therapy center and day school in the Karen suburb of Nairobi, Kenya that enjoys a reputation for being honest, sincere and forthcoming. Kaizora addresses children with autism as well as other developmental disabilities and the organization is the only of its kind in East Africa. Kaizora offers individualized programs that include one-on-one Applied Behavioral Analysis therapy (ABA), various top-of-the-line materials from Montessori and other successful teaching methods, as well as outside activities for the children to participate in.

Kaizora was founded by Director Pooja Pansear who also helped found Autism Awareness Kenya (AAK). One of her organizational objectives as the director of Kaizora is to include as many people as possible in awareness and interventions regarding developmental disabilities. Funds to maintain the program are received through current clients. Though not a non-profit, the organization is managed in a non- profit structure. At this time, Kaizora is only able to matriculate children whose families are able to pay to receive services. However, Dir. Pansear believes strongly in outreach, and therefore provides over-the-phone consultations, half day workshops for teachers and schools, and is willing to do consultations for low income churches and schools *pro bono*. Dir. Pansear is also personally interested in better understanding what happens to adults with autism in the slums, and if there are programs for vocational skills and integration into the communities.

Dir. Pansear will be receiving her degree stating that she is a Board Certified Behavior Analyst (BCBA) which is the certification required to be a supervisor for autism behavioral analysis. This certification also allows for her to train others in ABA. Upon receipt, she will be the only registered BCBA in sub Saharan Africa.

Tabasamu Watoto is a church-based organization (CBO) that operates an informal school in Kibera that serves 30 children, some of who have special needs and learn alongside children without a disability. Most parents bring their children tuition free because they are unable to afford school fees. Other parents, as is the case of many special needs children, do not see a clear benefit to educating their child with a disability, and therefore choose not to invest in education. Tabasamu Watoto encourages these parents to bring their children to attend the school free of charge.

The Tabasamu staff consists of two teachers and the husband and wife team Mr. Dennis and Mrs. Carol Ochieng. Tabasamu began as a daycare center for mothers who worked away from home, but in 2009, the small school began receiving overflow students with developmental disabilities from another school, Little Rock. Mrs. Carol Ochieng also works for an organization, Dignitas Project, which trains schools in various facets of creating an inclusive setting for children with mental or learning disabilities. She has a diploma in special education and Mr. Ochieng a bachelor of primary education.

This husband and wife duo is well known in the community and trusted by parents and other educators. Through them and the teachers that work at Tabasamu, the research was able to connect with parents in the community that have a child with special needs.

Tabasamu has an organizational interest in improving training for their teachers and opening a rehabilitation center for children with disabilities unsuited for traditional schooling.

Through collaboration with Dir. Pansear of Kaizora Consultants, Tabasamu will be able to receive free consultations, teacher training and support services from AAK and Global Autism Project. The research will also help record the experiences of the families, identify the gaps in care provision for families caring for PWIDD.

## CHAPTER 4

## METHODOLOGY

The study consists of five stages. In stage 1, an empirical review of the existing literature examined studies involving PWIDD, community involvement in various contexts and disabilities within resource poor countries. During stage 2, information was gathered through practitioner interviews to construct a framework and background information for the study. The stages yet to be addressed in this paper are 3-5. Stage 3 of the study will discuss practitioner led surveys of local families regarding community involvement. In stage 4, there will be a discussion of data compilation, consistent themes and a categorization of the participants as to their levels of community engagement. Stage 5 was the applicative stage of study, in which families were invited to a group discussion and a closing meeting, both facilitated through Tabasamu. The closing meeting involved collaboration between organizations involved to determine steps forward and encourage and connect families with local resources. All organizations involved in the study will receive a copy of the research and will have an opportunity to create relationships and further collaborative efforts to discuss and implement applicable steps forward to better engage their community.

Research methods for this exploratory study were qualitative in nature, with a large amount of secondary research. Data were analyzed for reoccurring themes and interpreted according to inclusion and community engagement criteria. Data were also analyzed to identify patterns that may have implications beyond the research.

**Population and Sample**

The study took place in Kibera, Nairobi, Kenya. There is no formal health care system within Kibera and most residents are referred to either Mabagathi Hospital or Kenyatta Hospital, both of which are in the vicinity of Kibera. NGOs including the Center for Disease Control (CDC), MSF, the Red Cross and other private entities operate numerous clinics, which mainly consist of primary maternal-child care. There are no referral services within the slum for families suspecting their child has a developmental disability.

One public school in the vicinity, Toi Primary has special education classes offered separate from the mainstream curriculum but the school is understaffed and severely impacted, making further contact difficult. The study area is 700 sq. acres and consists of at minimum approximately 170,070 people according to the Kenyan government census in 2009 up to moderate estimates of 300, 000 people or more (Karanja, 2010).

The research evaluated the levels of involvement in people aged three to nineteen living in Kibera with IDD, focusing on those with communicative, chromosomal, and intellectual disabilities that compose IDD. Involvement was measured with a goal of increasing collaboration between organizations and support of parents of said children.

**CHAPTER 5**

**DATA COLLECTION**

#### Practitioner Interviews

This study collected empirical data through practitioner interviews and a focus group to better understand background information and contextual content. Practitioner information also functions to connect the researcher to resources currently available to slum dwellers for stage 5 of the study. Regarding questionnaire design for children with disabilities, UNICEF recommends the, “choice of questions must be tailored to a child’s age in order to reflect the developmental stages and evolving capacities of children” (2013, p. 66). Questions were created with and reviewed by Tabasamu and were approved as culturally appropriate.

There were four practitioner interviews as well as one focus group consisting of four practitioners representing three different organizations. Interviews were held in English and conducted by the researcher.

#### Family Survey

Family interviews provided broad perspective of family life and a window into common beliefs, ideas and experiences. The limitation to interviews is a tendency on behalf of the interviewee to falsify information in an effort to please the researcher. Similarly, with open-ended questions, interviewees tend to discuss a wide range of subjects in an attempt to eventually arrive at a conclusion that appeases the interviewer. Therefore, questions that are too open-ended (though normatively creating a catalogue of the majority experiences) may lead to many field notes and few conclusions. Assistance was solicited from Tabasamu to adjust questions so that interviewees would more likely to answer according to their own opinions.

There were 41 caretaker interviews surveying 43 children. Interviews were guided by a survey questionnaire and conducted in the language the interviewee was most comfortable. Each interview was led by a Kiswahili native speaker.

## Framework for Data Interpretation

To better understand the data, several criteria were used to analyze it, commencing with definitions of inclusion and community involvement, and finally a categorization of activities that indicate inclusion.

Inclusion is an educational term that means that all students, regardless of mental capacity or special educational needs should learn together with non-disabled students all or most of the time. The research will use the following definitions of the levels of inclusion as described by Rudy (2010):

*"Partial inclusion," wherein a child with autism is included for brief periods of time or in selected settings… "Full inclusion with support," in which the child with autism is physically in a setting with typically developing children, but expectations are modified and supports (such as an aide) are put in place… "Reverse inclusion," wherein typically developing kids are brought into a special needs setting to provide role models and opportunities for building friendships outside the special needs community. [Behavioral] inclusion… wherein children with special needs are allowed to take part in anything they like, provided they can behave like typical children…Authentic Inclusion involves the selection of a typical activity in which the child with autism can fully engage with minimal or no support.*

These criteria for each level of inclusion as created by Rudy were used to gauge community involvement. The scale begins with a complete lack of inclusion indicated by none, and then in increasing in levels of participation, from partial to authentic on the following continuum of inclusion:

None Reverse Inclusion Behavioral Inclusion

Partial inclusion Full Inclusion with Support Authentic Inclusion

*Figure. 1: Inclusion Continuum*

Community involvement and engagement will be used synonymously throughout this paper. According to the CDC, community engagement is defined as,

*The process of working collaboratively with groups of people who are affiliated by geographic proximity, special interests, or similar situations with respect to issues affecting their well-being… Participation by the individuals, community-based organizations, and institutions that will be affected by the effort, investment in the structures, enablement to take action, influence, and make decisions on critical issues* (1997, p 9).

This definition will be simplified by extracting various key elements that apply to PWIDD in the community. The main aspects of this definition that prove applicable are of working collaboratively with those in geographic proximity or special interests and individual participation in community-based organizations and institutions as well as investment in the structures that is accompanied by action. Consequently, the three factors that were used to determine levels of involvement inside as well as outside of the home will incorporate the following:

*Objective: “Working collaboratively with those in geographic proximity”*

**Indicators (within the home)**

* plays/interacts with siblings/other family members
* has household responsibilities
* performs independent tasks (e.g. dresses self, feeds self)

*Objective*: *“Special interests…participation in community based organizations/institutions… investment in structures”*

**Indicators (outside of the home)**

* attends religious services/events with family (church/mosque etc.)
* attends work program/school/day care center/work
* interacts with outsiders (e.g. play, work, assigned activities/errands, short distance travel)

**Variables**

Variables in the study that are less quantifiable are differences between rural and urban populations in discussing community involvement and whether one is a more preferable option for families. It is possible that with the diagnosis a developmental disability that people relocate from one area to another. The research will also include inquires about cultural attitudes and outside relationships and their relation to the child’s IDD to better understand attitudes of families, neighbors and parents toward their children. These come with the assumption that some of these attitudes may be culturally motivated.

**Participatory Action Research**

Practitioners from the interviews were trained in survey methods and dispersed throughout the community with a list of families to survey. One set of interviews took place at the women’s place of employment, Mary Rice School, where interviews were conducted by two practitioners and the researcher to measure participation in common forms of community engagement and levels of inclusion in said activities.

Applied research, or participatory research, involves existing actors in the research with the objective of producing ongoing changes and application of the knowledge. In this study, the practitioners were directly involved in the parent survey process. Practitioners independently chose which parents to survey and split into groups to conduct the surveys. School professionals then collaborated with each other to improve existing services to parents and to reduce redundancy. Families were invited to a group meeting facilitated by partner organizations in order to together determine steps forward.

**Ethics**

This research included a commitment to the following code of ethics in addition to general guidelines for ethical research.

* *Respecting human dignity.* Families are the basic fabric of society and deserve to be treated with respect and dignity. Parents participating in the survey will immediately have the opportunity to discuss with the researcher the meaning of the research and to meet with other parents. At a final ceremony, families will meet again with all the community organizations that provide support and each will receive a copy of the summarized manuscript of the research findings. Full manuscripts were provided to the community organizations, and families were informed that they have the right to access a full copy of the report at their leisure.
* *Rights* *of the informants* were protected by not using names in the manuscripts or during data recording. Instead, data were organized by school and disability.
* *Honesty* *in discourse and communication* will occur through communicating the parameters of the study and its effect and benefit (1) to the parents, (2) to the community organizations. The researcher has made a commitment to not make promises to parents or schools that the research will not be able to deliver e.g. specific services to parents, clients to organizations, funding from the US.
* The researcher has committed to the *impartation of information as power*. The research endeavors to connect families with local organizations to better provide care and better equip parents outside of simply the inclusiveness study. A goal of the study as noted in the introduction is to connect local organizations to provide an opportunity for networking, collaborative ventures and increasing program effectiveness. By receiving more information and learning about resources, organizations and families were better equipped to handle daily challenges.
* *Kindness* and *respect* are other values embraced by this study, which acknowledges that families are imparting information that may have been kept secret or disclosed to only a privileged few confidants in the past. Due to the confidential nature of the information, surveys were distributed by a trusted second party, the instructors, which is a socially acceptable means of collecting information. The research will also respect the parents through distributing the data to the parents in a final ceremony for all the families.

## CHAPTER 6

## DATA

Both qualitative and quantitative data were collected through interviews and surveys respectively. Interviews and one focus group addressed a total of eight professionals who work with children with IDD on a daily basis, from program directors to special needs teachers and an occupational therapist at a school for children with special needs. Interviews ranged from 45 minutes to two hours in length, in which 10 direct questions were asked in respect of the special needs population in Kenya, differences between urban and rural contexts and practical inclusion for PWIDD.

**Cause of Mental Disabilities in Kenya**

Different factors are described as the cause of disability in different settings. After speaking with practitioners, causes surfaced that are quite common in developing countries such as hospital mismanagement (Kristof & WuDunn, Kindle Edition location 1867). One teacher stated that on occasion the doctor will assume the child is dead and won’t provide urgently needed care. Other examples include prolonged labor or when a birth attendant presses the baby while it is in the mother’s womb to give a “massage.”

Early childhood infections such as meningitis were also mentioned, as well as ignorance. One practitioner stated that many children “would have done better if there was the early intervention. No one accepts it and think it’s a bad omen, so they don’t do anything about it. There’s not enough awareness.” Several others agreed that early interventions are crucial. When practitioners stated the cause of disability in Kenya was ignorance; they referred to ignorance as to which disabilities exist, why they exist and what to do about them. Also, several individuals cited lack of parental knowledge such as proper nutrition, how to intellectually stimulate a child and developmental milestones.

**Cultural Attitudes**

There was consistent discussion surrounding witchcraft, curses, bad omens and demons in relation to a child’s disability, mentioned by all participants. Most of the parents, according to one special education instructor, “have gone from witch doctors to prophets to be prayed over thinking [the disability] would go away.” Often girls with mental disabilities are assumed to be virgins and raped to “cleanse” a person with HIV or viewed as an easy target. Only parents who are very well educated or well off financially seem to understand the nature of disabilities. Several respondents also mentioned that when a family is rich and they have a child with a disability, the community believes that they have sacrificed their child for wealth. Epileptic children are often believed to be possessed by demons so they are prayed over, and if the seizures do not stop, people assume that the demons have taken full control of the child. These beliefs seem to be widespread and possibly related to the idea of spiritual causes for the natural world, including in health.

Additionally, several teachers mentioned that parents do not want to bring their disabled child to school because children are viewed as an insurance policy for the future livelihood of the parents. Therefore, some parents will refuse to educate the child since they will not receive anything in return later in the child’s life. Education places a significant burden on poor families, and as it is often marketed as the way out of poverty by creating a chance for children to become competitors in the workplace. Due to the clear correlation between education and future productivity, in efforts to increase school enrolment nationwide, PWIDD are often excluded from learning.

For the parents who do bring their children to school, there may be resistance. Several instructors have reported fellow teachers who threatened to resign from the school if PWIDD were integrated into their classrooms. Sometimes other parents who are in denial will choose to switch their child into a different class if they find that a child in the class has a disability, or they may prevent their children from playing with that child. In more extreme cases, parents who have children with a disability but who do not want to acknowledge it, or those who realize children around their child have a disability may choose to leave the school.

**Parent Reactions and Backlash**

Parents are often confused when their child is diagnosed with a disability because there is a lack of information available to the community about developmental disabilities, especially those that are not readily visible. To add to the confusion, sometimes the doctor will simply prescribe medicine for epilepsy or another condition, but not explain anything about the condition or medication. One practitioner stated that after six months, a doctor may prescribe physical therapy but not tell the parent why the child needs to go to therapy. Early signs are often missed as attached to developmental disability, and in some cases no intervention is performed at all because of inattentive and overworked doctors and nursing staff.

Many practitioners mentioned negative reactions that came from either the husbands or their husband’s family. According to one practitioner from Tabasamu, the common tradition in many communities is that “after marriage, the woman belongs to the man’s family.” Often the husband thinks that the mother did something wrong, making the burden of care and of the child’s disability fall on her. There is also stigma that several individuals described, stating that it comes with having a disability; community members don’t want their child to play with the disabled child and the mothers also are not accepted in the community or in the family. With one woman, her husband’s family refuses to eat anything in her house when they come to visit, even if she cooks, which is a very offensive gesture in Kenyan culture showing that the in-laws do not want to “catch” that child’s disability, with the nuanced thought that it came from the woman, as opposed to their son.

**Disabilities and Urban vs. Rural**

Professionals interviewed in this study agreed that, although people are more educated in the urban areas, PWIDD in rural areas are more likely to be seen as just another member of the family. An occupational therapist stated that, “in the village you can leave your disabled child with your neighbor. Here [in the urban setting] it is me, myself, and I. You can find children who have mental disabilities in the village playing with other kids, but not in Nairobi.” In the village people are closely related, and these kinship ties play a role in the community perception of a child. Therefore, the person with the disability is just a part of either the immediate or extended family, and, accordingly, they deserve to be treated well, as opposed to the urban areas. In the urban areas, people are surrounded by unrelated neighbors making kinship-based cordiality less common.

In the rural areas, being considered a member of the community is defined by how well a person farms, and if they can create an income. If they do these two things, they are eligible for marriage. In the city however, the focus is doing well in school to provide for one’s self, so if a person with a developmental disability has the ability to successfully pursue pastoral activities but struggles with reading, he would fail in Nairobi and his parents would undergo significant criticism. This same individual would be considered a success in the rural context. The urban centers are centered on more mentally intensive employment, so reading and writing are crucial for most jobs. Despite all of this, interviewees stated disability awareness is spreading faster in the urban centers.

**Inclusion: Defining and Illustrating**

Definitions of inclusion varied as much as the interview pool. Some practitioners saw inclusion as getting the child to the same or a similar level as their peers so that the child with disabilities could be involved in mainstream schools. One practitioner described inclusion as not academic per say, but allowing students to be equipped with life skills so that they can live as independently as possible and make decisions for themselves. The director of Tabasamu noted that taking notice of a child’s interests and then encouraging them in what they like is also inclusion, because they are pursuing things stemming from their own desires. Another practitioner provided an example of inclusion, stating that it is not “assuming that the only activity for PWIDD is making beadwork to sell abroad,” but acknowledging that PWIDD have differing interests. Allowing PWIDD to exercise their opinions by pursuing those interests is the best way to include them in the community. A therapist similarly stated that inclusion was the frame of mind of the practitioners and parents through choosing to integrate children and allowing for their opinions to matter. All agreed that full inclusion in all activities was ideal, but inclusion was either impossible or simply an ideal in a culture where the disabled are such a marginalized population.

**Current Efforts on Inclusion**

Dir. Gerald of Mary Rice noted that, in order for children with developmental disabilities to be included in the community and become a viable part, vocational and self-help skills are pivotal with the goal of putting these students into mainstream schools. His school has a vocation training school within the compound and they monitor their former students to evaluate progress. The two schools have formed an agreement so the students stay for two years instead of the usual six months for vocational schools, and the school understands the needs and abilities of the young adults. He also mentioned that, “looking for a good fit for these adults to have a career and something to keep them from being idle” is crucial. This allows for PWIDD to be involved in adult life, which is mainly identified by work, so appropriate work training is a useful method for adult inclusion.

Nelly, a special education teacher, mentioned that often the solution for PWIDD is either people making trinkets to sell to the United States or sitting around, but at Heshima they work to find a place for their growing students, stating, “[We have] been looking at pupils who are capable (i.e. the ones that can walk, communicate etc). There is a [young] girl [who] likes to imitate the teachers, and [we’re] already talking about employing her as an aid. Several boys who are turning 18 are working on their ID cards and will be employed [by] Heshima.” Many groups go to the default of selling and creating jewelry, missing out on the large contribution that PWIDD can make at all different levels of functionality.

**Making it Work in the Community**

When asked about practical steps in making inclusion a possibility, several mentioned possible strategies to be used going forward. The co-director of Tabasamu stated that parents need to be sensitized when they are expecting, and communities need to be sensitized before PWIDD are born. When working with the Dignitas Project, she realized that singling out parents makes them embarrassed, but addressing the entire community reduces the possibility for denial and allows the rest of the community to better understand developmental disabilities. She went on to state that just how there are community meetings surrounding malaria, there should be so with mental difficulties. Talking to parents in the context of the community was a common response, as was training and sensitizing doctors and slum teachers so that they can be better equipped to understand disability.

An instructor mentioned that parents often fixate on what their child cannot do. She stated that, instead of struggling to get the child to talk, parents should be encouraged to teach the child sign language or how to otherwise communicate with the people around them.

Getting parents and children out in the community to interact with others and to involve doctors were also mentioned by a few participants, stating that this would help to reduce stigma, increase participation and promote better care between neighbors. Involvement of doctors would allow parents to seek early interventions instead of receiving a diagnosis at eight or nine years old for a condition that began at three months.

**Caretaker Surveys**

Data was collected on 43 children, and the attitudes and thoughts of 41 caretakers through 16 question multiple choice surveys. Caretaker participants represented three schools, Tabasamu Watoto (four), Mary Rice (ten), Little Rock (25), as well as children who are unaffiliated with any school (two). Children unaffiliated with any school were not included in the school based surveys, though they are included in the disability based analysis if they have a diagnosis. If not, they were included in the final statistics. Surveys were conducted in an interview style on site at Mary Rice by the school occupational therapist and Dennis Ochieng of Tabasamu. Surveys for Tabasamu and Little Rock parents were conducting during home visits with a few interviews conducted outside of the home, all of which were facilitated by Fiona, a reading teacher from Little Rock School and Mr. and Mrs. Ochieng co-directors of Tabasamu Watoto. Ms. Fiona also conducted interviews on site at Little Rock School. Each practitioner-led parent surveys for the parents they were familiar with. In the case where the family was not familiar with the teacher, someone familiar with both parties was asked to join so that the interviewee would feel more comfortable.

The practitioner asked questions from a predesigned survey sheet designed to obtain the attitudes of the caretakers, as well as to gauge the levels of involvement of the children. All families were notified before commencement of the nature of the research, the reporting back process, and were allowed to ask questions before and after the surveys. Questions were asked in either English or Swahili, depending on which language was preferred. Survey length ranged from 15 minutes to over an hour, depending on how much information the family wanted to share.

The surveys taken by community practitioners were in order to determine the levels of community and familial involvement by PWIDD living in Kibera slum. Data was analyzed first by school, and then by disability. Seven study participants had not been formally diagnosed with a specific disability, so they were included in the school analysis but not in the disability specific comparison. During one session of home visit data collection, an instructor was looking for her students and asking parents where various other students lived. During this session, one respondent was found who did not attend school, and data for that respondent is not recorded among school data or among disability specific data (as the child has an unknown disability). However, this data is totaled in the final data tally taking all survey participants into consideration including those with unknown disabilities or without school affiliation.

**Mary Rice School**

At Mary Rice School, eight women were interviewed and ten children were surveyed. The children were equally distributed in gender. Seven women had only one disabled child and one woman had three disabled children. The ten children were mainly between the ages of six to ten (five), while three were between the ages of eleven to 17 and two were between the ages of zero to five years.

The most common disabilities were autism (four) and Epilepsy (four) with some overlap. Two children’s disabilities were unknown, and there was one occurrence each of mental difficulties, ADHD and Cerebral Palsy. All diagnosed children received a diagnosis before the age of five, with four children diagnosed between the ages of three and five, whilst five children diagnosed between birth and two years.

In six of the eight mothers, fathers had either left, been very negative or accused their wives of witchcraft. Half of the mothers have chosen to not disclose their child’s disability to their families, while four mothers told their families and received negative reactions and one family was neutral. With five mothers it was reported that the neighbors reacted very negatively. One mother had indifferent neighbors and two women had very supportive neighbors.

One woman’s neighbors encouraged her to take the boy to the hospital when they suspected the child’s condition. The second woman that stated she had supportive neighbors told how she was chased away by her first set of neighbors, since they believed she was cursed. Fortunately, she fell into the right hands. The woman’s new neighbors welcomed her and her child to stay with them; she built a house next to them and is now very happy.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|   | POSITIVE RX | NEGATIVE RX | NEUTRAL RX | CHANGE? |
| Family | 0 | 4 | 1 | 0 |
| Neighbors | 2 | 5 | 1 | 3 |
| Self | 4 | 3 | 1 | 3 |

**Table 1**: Community reactions (RX) to the news of a disabled child

In terms of personal reactions, three mothers reacted very negatively, four mothers reacted very well/positively valuing that they had a child over the disability, and one mother did not answer as to her initial reaction, but stated that currently she feels positively about her child’s condition. Caretakers were asked if there were any changes in reactions of family, neighbors or themselves over time, and five mothers reported that reactions changed over time, while three mothers reported no change in reactions. Of those who reported changes in reactions, two women reported that their neighbors had become more positive with time, two women reported that her own reaction had improved with time, and one woman reported that both her own and her neighbors reactions have improved.

|  |  |
| --- | --- |
| SKILL | % STUDENTS**Table 2:** Skills at Mary Rice% of students is the number of students out of total number of students (10) that had this particular skill.  |
| Feed self | |||||||||| |
| Walk, sit up | ||||||||| |
| Point, understand directions | |||||||| |
| Use washroom | ||||||| |
| Dress self, speak | |||||| |
| Play with others, help clean | |||| |

Of the ten children surveyed, there were the following skills: 100% (ten) could feed themselves; 90% (nine) could walk, sit up; 80% (eight) could point, understand directions; 70% (seven) could use a washroom; 60% (six) could dress themselves, talk; 40% (four) played with others, can help clean the homestead; 0% could bathe. One child did not talk, but sang instead.

The survey was taken at a school, thus 100% of the respondents attend school four to five days a week. On non-school days, 30% of the children ONLY play at home. 10% sit/sleep and don’t play. Of the remaining six children activities at home are follows; 67% (four) watch television, 83% (five) play at home, and 50% (three) engage in some other activity i.e. running up and down, reading books/dancing, fetching water. Overall, 80% (eight) play at home, 40% (four) watch television, 10% (one) sit/sleep, 30% (three) participate in another activity, and none accompany their caretaker during the day.

The researcher asked parents what responsibilities their child had within the home and found that the school occupational therapist has recommended various parents to give their children household responsibilities. 50% of children have responsibilities within the homestead; of the remaining children without responsibilities, 60% were cited as too young or destructive to help in the house, and lack of capacity was cited for the remaining 40%. Of those with household responsibilities: 100% sweep outside/inside and toss rubbish; 80% wash dishes, wipe surfaces and otherwise clean; 60% serve water for washing hands; 20% wash the floor, wash clothes, put away clothes, clean shoes; none of the respondents cook or assist with cooking.

Parents were asked if the child travels with the family outside of the home. The researcher found that 50% of the children’s only interactions outside of the home are at school. For remaining children: 80% attend religious services with their families; 60% report going to local shops alone or with their families or attend large markets and 40% report going on public transportation. Two survey respondents stated that their children participate in all of the above activities. All respondents stated that activities occurred five times a week or more since most students attend school five times per week.

It was found that 50% of the children at Mary Rice play with others and 40% of these children play exclusively inside, 20% play exclusively outside, and the remaining 40% play both inside and outside the home. All respondents played with neighbors and children from school and 20% played with siblings.

**Figure 3:** How many children play outside?-Mary Rice

In the final section, parents were asked about their comfort levels in the community, with neighbors, and, finally, at school. 50% of parents felt comfortable with their child in the community, and interestingly, 80% of respondents did not feel comfortable with their child being supervised or taken care of by neighbors. 100% of applicants felt comfortable with their children at Mary Rice School. However, it should be noted that the school therapist was interpreting interview questions for 70% of the interviews, so it is possible that parents may have felt pressured to respond yes to the final query.

**Little Rock School**

The largest number of respondents came from Little Rock School, where data was taken on 25 families with one disabled child each. Data from the caretakers showed that 55.6% of the children are male and 44.4% are female. Most of the children were between the ages of six to ten (14) with the second highest age group being eleven to 17 (six) and finally birth to five years (five).

The disabilities had some overlap, though the disabilities ranked by occurrence are as follows: Cerebral Palsy (seven), autism (five), Epilepsy (four), Mental Difficulties (four), Unknown (three), ADHD (one), and Down’s syndrome (one). The vast majority (15) of children were diagnosed between birth and two years, with five children diagnosed between the ages of three to five, two children between the ages of six to eight and three children had never been assessed.

When asked about family reactions, there were 14 negative responses reported from families and ten families were stated to feel neutrally/indifferent of the discovery of a disabled child. One mother has not told her family doesn’t know the response of her family. Families at this school did not discuss the fathers of the children, except one mother remarked that the father still lived there, and another mother remarked specifically that the father said he felt that this must be “a problem with her side of the family.” Caretakers also reported 16 negative responses from neighbors. Eight neighbors responded neutrally/indifferently and one woman stated she did not know about her neighbors thoughts at the time. Notable is that several of the mothers surveyed live in close proximity with another woman who has a child with a developmental disability.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| PERSON | POSITIVE RX | NEGATIVE RX | NEUTRAL RX | CHANGE? |
| Family | 0 | 14 | 10 | 2 |
| Neighbors | 0 | 16 | 8 | 2 |
| Self | 1 | 17 | 7 | 15 |

**Table 3**: Community reactions (RX) to the news of a disabled child-Little Rock

17 women reported negative responses from themselves, while seven reacted neutrally about the news of a child with a developmental disability, and one woman was positive about the news. Comments from the parents were generally about experiencing significant stress and denial regarding their discovery. One parent stated she felt like she had a problem because her child was different than others. A mother who stated that she was okay with the news remarked that she had an obligation to love and accept her child. 16 caretakers reported a change in reaction while nine reported no change in reaction. Of those who reported a change in reactions, two women reported that their neighbors or family had become more positive with time, 15 women reported that their own reactions had improved with time.

When surveying the children’s independent skill capacity, the researcher found that the school has an occupational therapist, but it was unclear as to how many of the children the therapist was able to work with because of large class sizes. Of the 25 children surveyed the following skills were present: 96% (24) could sit up; over 88% (22+/-2) played with others, 88% feed themselves; 76% (19) walk; 64% (16) could understand directions; 60% (15) use washroom; 40% (ten) dress themselves; 36% (nine) talk; 32% (eight) point; 24% (six) bathe/clean up the homestead.

|  |  |
| --- | --- |
| SKILL | # STUDENTS**Table 4:** Skills at Little RockThe total number of students (25) that had a given skill.  |
| Sit up | |||||||||||||||||||||||| |
| Play with others | ||||||||||||||||||||+/-|| |
| Feed self | |||||||||||||||||||||| |
| Walk  | ||||||||||||||||||| |
| Understand directions | |||||||||||||||| |
| Use washroom | ||||||||||||||| |
| Dress self | |||||||||| |
| Talk | ||||||||| |
| Point | |||||||| |
| Bathe/clean homestead | |||||| |

All of the survey respondents attend school five days a week. On non-school days, 92% (23) children play at home, 76% (19) children watch TV/listen to radio and 12% (three) accompany a caretaker. Within the home, 20% (five) of children have responsibilities within the homestead; of the remaining 80% (20) reasons for lack of responsibility were children being incapable, too young, or the mother not wanting the child to participate. Of those with responsibilities: 80% (four) clean up around the homestead; 60% (three) wash dishes, make bed; 40% (two) sweep, serve water, clean shoes; 20% (one) washes clothes, wash floor, toss rubbish or wipe floor.

Most of the children (96%) travel with their families outside of their homes. Of this group 95.8% (23) attend church with their families, use public transportation; 75% (18) go to the shop; 37.5% (nine) go to the market; 29% (seven) of respondents surveyed participate in all of the above activities. All activities occurred five times a week or more (all students attend school five times per week).

Figure 6

At least 88% of children play with others, 86% (19) of who play both inside and outside and with neighbors. 77% (17) children play with siblings and 45% (ten) children play with children from school. All survey respondents played outside seven times or more per week.

When asked about comfort levels and the community, of 25 parents, 36% (nine) felt comfortable with their child in the community. Nearly two-thirds of respondents do not feel comfortable with their child being supervised or taken care of by their neighbors. 44% of respondents stated that they would feel comfortable under a particular condition such as specific neighbors who also care for PWIDD.

All surveyed applicants felt comfortable with their children at Little Rock. However, an instructor from Little Rock School performed the interviews, but parents did not seem to feel pressured to provide a particular response.

**Tabasamu Watoto**

At Tabasamu Watoto six women were interviewed all of whom were primary caretakers for one child with a developmental disability. The children were overwhelmingly female (83%) and were evenly distributed in age with four children under the age of ten, one child between eleven and 17 and one child above 18. Disabilities were also evenly distributed, where an unknown disability and mental difficulties each occurred twice, and Down’s syndrome, Cerebral Palsy and ADHD were each mentioned once with some overlap.

Two-thirds of the participants from Tabasamu Watoto (four) were diagnosed with a developmental disability before the age of five, while one was diagnosed after eight years of age and one person was never assessed.

Most families had negative reactions with one respondent stating their family was indifferent and another stating they were unaware of how their family would react. Half of the neighbors had negative reactions, while the remaining neighbors were indifferent about the realization that the child had a developmental disability.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| PERSON | POSITIVE RX | NEGATIVE RX | NEUTRAL RX | CHANGE? |
| Family | 0 | 4 | 1 | 1 |
| Neighbors | 0 | 3 | 3 | 2 |
| Self | 0 | 6 | 0 | 3 |

**Table 5**: Community reactions (RX) to the news of a disabled child- Tabasamu

All six respondents stated that personally they had very negative initial reactions. Four of these parents stated that these reactions had changed with time and two reported no change in reaction. Of the four who saw a change in reactions, one person reported many change in her neighbors, relatives and self, while two people reported changes in personal reactions becoming more positive with time and one individual stated their neighbors became more positive with time.

**Table 6:** Skills at Tabasamu

% of students is the number of students out of total number of students (10) that had this particular skill.

|  |  |
| --- | --- |
| SKILL | % STUDENTS |
| Understand directions, eat, play with others | |||||| |
| Walk, sit up, use washroom | ||||| |
| Point | |||| |
| Talk, clean homestead, dress, bathe | ||| |

When asked about independent skills, the researcher found that all the children understood directions, could eat independently and played with others. Other skills that were very common were being able to sit up, walk and use the restroom, with five respondents able to do these things independently. Four respondents could point, and three could talk, clean the homestead, dress themselves and bathe themselves. All of the surveyed respondents attend school four to five days a week and watch television on non-school days, while 66% play at home and 33% go with a caretaker. Many (four) also have responsibilities within the homestead, while two children do not; one parent cited not wanting the child to participate within the home. Of those with responsibilities, the most common household participation activities were in sweeping the outside/inside of the home, wiping surfaces, otherwise cleaning the homestead and serving water for washing hands (three). The other activities students did at home included tossing rubbish, washing dishes (two); putting away clothes, making the bed and cook/assist with cooking (one).

All of the children interact outside of the home and attend religious services with their families, while 83% report going to local shops alone or with their families and to school and 16% attend market and use public transportation. The majority of the events occurred five days a week or more.

All respondents played with others both inside and outside of the home of which 66% of children played with neighbors and 50% played with siblings, children from school. 16% played with other children not mentioned.

Half of the parents surveyed felt comfortable with their child in the community. However, one child had been abused by community members and the parent felt helpless, not sure of what to do about it. Despite half of the parents feeling comfortable in the community, 66% of respondents felt uncomfortable with their child being supervised or taken care of by neighbors. 83% of applicants felt comfortable with their children at their current school. For one parent it depended on which teacher was present at the school.

**CHAPTER 7**

**DATA ANALYSIS**

Across all categories of participants evaluated by age, disability and school, high levels of community involvement were observed as determined by inclusion criteria as well as participation in outside activities. Several interesting patterns emerged within schools, the disability specific data as well within the research as a whole. For instance, some children had only a diagnosis of epilepsy but seemed to also have cognitive difficulties.

This may be due to brain damage caused by frequent seizures or by the early brain infections. These individuals were not marked as having mental difficulties, but this should be considered during data analysis. The following themes in the data emerged:

* Autistic children had difficulty in engaging within the community.
* Those with a diagnosis of mental difficulties had the highest levels of participation.
* Females have more skills than male participants.
* Also there is a significant gender divide in skill levels between males and females.
* Students at Mary Rice School who played outside had higher levels of community involvement and had more skills than those who did not play outside.

**Autistic children**

As expected, none of the autistic children (five surveyed) play with other children. Also as expected, three of the children diagnosed with autism do not talk and two do not seem to understand directions at all, while one responds to some directions. Consequently, the element of playing/interacting with others is a difficult aspect of community involvement for these children. It is notable, however that two children attend church with their families regularly and one of these also rides the matatu/bus.

Autistic children surveyed averaged 5.8 skills per child (of the 11 skills surveyed) which is a 52% competency. This is likely to be due to four of the skills having a direct correlation with the communication and interactive competencies that are commonly lacking in the typical autistic individual i.e. play with other children, talk, point, understand directions. When these competencies are removed, the average number of skills per autistic child changes to 4.2 of seven measured skills, or a 60% competency. These children seem to be more incorporated into their community in alternative ways than many autistic children in developed countries.

Families in more individualistic communities tend to keep their child inside and not involve them in as many activities, as opposed to Kibera where interaction with others is nearly unavoidable. It is possible that the parents observed in this study are exceptions; the children are in school, unlike most children with a disability worldwide (United Nations Children’s Fund, 2013). These children may be among the few who are involved in their communities outside of special education classes.

**Gender divide**

Amongst nearly all groups there is a gender divide, where females averaged much higher than males in any group in the number of skills they were able to do independently. Though no conclusive data emerges from comparing involvement outside of the home, in certain groups females had significantly more household responsibility than males of the same disability. There was no discernible difference, however, between males and females in activities outside the home. This is possibly due to cultural expectations for female participation within the home and independence in personal tasks. Females may be expected to do more and perform more chores, and therefore because of an expectation, rise to the occasion by better meeting their capacity than male counterparts. There may be a larger cause of which there is a psychological, neurological or social basis which has allowed for female PWIDD to be more capable than their male counterparts in this particular study.

**Children who play outside: Mary Rice School**

At Mary Rice School there seems to be a difference between the children who play outside and the children who prefer to remain indoors.Children who play outside make up 50% of the sampling pool at Mary Rice and are equally distributed in gender. This group is young, with 80% of these children between the ages of six and ten while the remaining 20% are between the ages of eleven and seventeen. In terms of diagnoses, two children were diagnosed with mental difficulties, two with a main diagnosis of epilepsy (one child has epilepsy and mental difficulties), and one child has cerebral palsy. Four were diagnosed before the age of five while the remaining individual has yet to be diagnosed, and is in the six to eight age bracket.

There was an even distribution of reactions of both family members and neighbors. The differences are indicative in that 80% of the mothers in this group had a positive initial reaction to the news of their child’s disability. This is as compared to the group that did not play outside, in which only 30% of mothers felt positively about their child’s condition from the outset. 60% of these mothers reported no changes in the reactions of neighbors, families or themselves. Additionally, of the women who reported changes over time toward opinions of their children all reported changes in their neighbor’s perceptions rather than their own.

Children who played outside averaged eight skills per child, as opposed to children who did not play outside who averaged 6.5 skills per child. 80% of children who played outside had in home responsibilities as opposed to 20% of children who do not play outside. 80% of children who play outside also go with the family outside the home as opposed to 20% of children who do not play outside. The most interesting statistics was that 80% of parents whose children played outside felt very comfortable with their child in the community as opposed to 20% of parents who did not allow their children outside.

One possible rationale for this trend was that these children may possibly be less severe than their counterparts. However, in this group, there is the same distribution of disabilities as within the other groups, and several parents made remarks regarding the severity of their children’s conditions. When one parent mentioned that their child attended church each Sunday with the family, the Occupational Therapist was surprised, as the child is severely autistic.

Another possibility causing differences between children who play outside and others who do not is that although there is an even distribution of ages, disabilities and age of diagnoses, that the group contains few children with autism. In the interview, children with autism tended to have lower skills overall, and did not play outside because the disability often hinders personal relationships and communication. Stereotypical autism often includes low motivation for play with others let alone playing outside. By beign a category of children who play outside, children with autism were screened out, leaving a group of children with more skills overall, possibly not because of playing outside, but because they are not autistic.

There may be a correlation between how the parents feel toward the community and the children who play outside. If a parent feels more confident that the community will not mistreat their child, they are more likely to allow their child outside. In turn, this provides more opportunities for community interaction, which allows the community to learn about PWIDD (Uy Koe, 2012). It also provides opportunities for learning from non-disabled peers which increases skills and has the positive feedback loop of making the family feel more comfortable going outside the home with the child, therefore creating more opportunities for learning (Fennick & Royle, 2003). This may also be related to the increase in home responsibilities. The child has gained skills through play, thus the parent feels more confident in allowing independence.

**Urban versus Rural**

Something repeated throughout the interviews and surveys from both parents and practitioners was the idea of the rural setting being the ideal place for those with developmental disabilities. Factors mentioned included space, social perception of disability, and life opportunities. Children did not seem to face significantly more abuse in one setting or the other. Interviewees would state a positive aspect of living in the urban centers such as superior care, or better education, but would immediately insert a caveat about how they believed the rural areas to be the best place for PWIDD. Several comments were made about families in the rural that rejected the child with a disability during a short visit. After probing this response further, the researcher found that if the child was born in the rural setting or moved there while very young, the family would view the child without suspicion. Watching a child mature would allow the family members to feel closer to the child, and to dispel some of the pre-existing beliefs about PWIDD in many cases.

Further implications are that either the rural areas are better places for children with disabilities despite suspicion and superstition that often prevail, or that urban Kenyans look fondly upon rural life and livelihoods and consequently are more likely to perceive the rural area to be inherently superior. Another possible interpretation of this trend is that the village is more likely to be composed of close family ties. Therefore, because a village may be composed of family members, people are less likely to view a child born with a disability with suspicion and more likely to see the child as a part of the family.

**Family Involvement**

The definition given for family involvement is *Working collaboratively with those [who are] in geographic proximity,”* as well as the level of inclusion described by Rudy. The three major indicators of involvement within the home were:

* the childplays or interacts with siblings or other family members
* has household responsibilities
* Performs independent tasks (e.g. dresses self, feeds self).

Measurement of the inclusiveness will follow the chart mentioned earlier:

None Reverse Inclusion Behavioral Inclusion

Partial inclusion Full Inclusion with Support Authentic Inclusion

*Fig. 1: Inclusion Continuum*

Using this inclusion continuum most of the children surveyed seemed to be receiving behavioral inclusion, with a few children with higher skill sets or greater autonomy being authentically included in their families. Of the children surveyed in this study, the major indicators resulted in the following data:

Figure 10

Surveyed PWIDD were able to accomplish a variety of tasks depending on the severity of their condition. Time allocated toward teaching skills also seemed to create variety in capability. The most common skills were sitting up and eating and drinking independently, while the least common skills were bathing and cleaning up.

Most PWIDD surveyed were children who went to school and played with others, including their siblings. The least involved in home life (specifically regarding play) were children with cerebral palsy or mental difficulties. In play, children were behaviorally included when interacting with others outside the home.

Figure 11

The majority of children had household responsibilities, and of those who did not, the parents did not allow them to participate out of preference. Whether or not a child was included in household chores seemed to also be a matter of behavioral inclusion rather than authentic inclusion. Variables included whether or not the parent found the child’s behavior appropriate to perform the chores. However one child enjoyed cleaning, and would independently request to clean certain things in the house. This is an excellent example of authentic inclusion.

Many children are doing well within the home, but still do not have many skills. That means that although these individuals are attending school, their further chances at success may be lower because of a lack of self-help instruction in schools. Implications of a child’s involvement in family life may reflect later opportunities to live independently and to acquire new skills. Two of the schools had occupational therapists, and it is possible that while some parents are reinforcing the skills learned at school, other parents are impeding their children’s progress through lack of one-on-one reinforcement at home. The converse is also true, if the parents are teaching their children skills at home but the skills are not reinforced at school, 8-10 hours of learning are lost each day.

**Community Involvement**

Community involvement was defined as *“Special interests…participation in community based organizations/institutions… investment in structures”* indicators included observation outside of the home to determine if the child is involved in the following activities:

* Attends religious services/events with family (church/mosque etc.)
* Attends work program/school/day care center/work
* Interacts with outsiders (e.g. play, work, assigned activities/errands, short distance travel)

83% of surveyed children were taken to religious services with their families. Over 90% of families were Christian, so it was difficult to determine if there were any religious differences in participation levels.

All of the children attended school excepting one individual who was no longer enrolled in school and was not involved in a day program or work program. All children, especially those who had mental difficulties were especially involved in interacting with outsiders through small chores outside, traveling and attending religious services.

When evaluating interaction with outsiders many parents were fearful about unknown outsiders, which is quite common. However, even when discussing neighbors, parents were worried about abuse, and most felt that they could not trust their neighbors to watch their children.

Parents unable to trust the community means a further withdrawal from the people around them. This can perpetuate stigma toward people with disabilities and their families. Many parents, such as the caretaker that mentioned their child has been abused by community members do not have another option and feel powerless in the current state of affairs. The inability to control the behavior of strangers, and fear of rape or abuse largely contribute to caretaker fears.

## CHAPTER 8

## RECOMMENDATIONS

**Working in the community**

Comments from practitioners regarding inclusion suggested that it is crucial to teach productive livelihoods and work skills early on. One practitioner mentioned that there are work options available for adults with IDD and opportunities for vocational training in Raila neighborhood in Kibera. Therefore, preparing students to work and live on their own is important, something that is currently not occurring. Several directors indicated that education should endeavor to teach life skills, self-help skills as well as basic reading, writing and mathematics. Creating a functional adult should be the first priority, and afterwards working to teach as much of the standard curriculum as possible, tailoring it to the needs, learning styles, and desires of the students. In large classrooms this can be challenging, but yet possible through breaking up students into groups that the teacher or the occupational therapist works with while having the students do an alternate activity that works on one particular skill. In order to track this progress will also involve the creation of an individualized educational plan (IEP) which will be explained in the section addressing community learning.

*Educating doctors*

Comments from practitioners suggested that education of doctors is another aspect that needs to be addressed. Nurses, paediatricians and community health workers need to work towards expanding awareness of developmental disabilities just as they spread information regarding malaria and cholera through holding community meetings and asking targeted questions during check-ups. In the time that mothers are attending ante natal appointments, health care professionals need to make mothers aware of the proper milestones that their child should be reaching. Each time the child comes into the clinic for immunizations healthcare personnel and staff should look for these same milestones so that issues can be diagnosed early. Exposing both parents and doctors to the possibility of a developmentally disabled child saves parents later confusion and creates a situation where medical professionals and families work together toward similar goals.

**Playing in the community**

Families did not feel safe in their neighborhoods, and only a few felt safe leaving their children with neighbors. In order to make neighborhoods safer places for children with developmental disabilities to play, there need to be community trainings and creation of awareness among neighbors, even before children are introduced into the community. According to practitioners, training neighbors on disability awareness through community workshops advertised as child safety or children in the community and then addressing disability specifically and the care families need to take to make sure all children are protected. Exposure of mothers with children with disabilities into the mainstream is also important. Mothers of PWIDD tend to self-segregate in a fear of rejection by other women and neighbors. By coming into the community in groups and having their children play as they wash clothes or gather water can assist in sensitizing the community. Also giving the children roles that the community is able to understand will lead to the realization that these are children with a disability rather than disabled children. Holding parent meetings at the school about disability will help parents see PWIDD as fellow human beings with the aim of fostering understanding and a reduction of discrimination.

**Learning in the community**

Educators need to work towards sensitizing others, especially those in the slum and fellow instructors of the importance of investing time and effort in students with developmental disabilities. Teachers need to also allow parents of children without disabilities to realize that PWIDD are capable and normal. One instructor did this by making sure the PWIDD in her reading class were the best readers in the entire school. Consequently, parents who were previously fearful of children with IDD were clamoring to have their child placed in this top performing class. This is an effective strategy to encourage full inclusion in a classroom setting as well as integration of children creating a diverse learning environment.

*“Inclusion goes beyond ‘integration’. The latter implies that children with disabilities are to be brought into a pre-existing framework of prevailing norms and standards. In the context of education, for example, integration might be attempted simply by admitting children with disabilities to ‘regular’ schools. This would fall short of inclusion, which is possible only when schools are designed and administered so that all children can experience quality learning and recreation together. This would entail providing students with disabilities with such needed accommodations as access to Braille, sign language and adapted curricula that allow them equal opportunity to learn and interact.”*

*-State of the World’s Children (2013, p. 3)*

Educators also need to include parents in their plans, and parents need to be proactive in understanding what is happening with their children with IDD inside the classroom. Creation of an individualized education plan is then the next step for many schools. This is a plan that incorporates parents and teachers as to what the child will be learning each month or what skills will be worked on for that child’s individualized objectives for that particular year.

The objectives are small sections that allow a child to meet a particular goal, such as being able to use the restroom independently. Children in classes will be grouped according to similar objectives and indicators. Teachers, parents and occupational therapists need to meet twice a year to review the child’s objectives and what may need to be changed to meet those objectives through steps created at school and at home. The IEP needs to describe the student’s disability, how they learn, how the student shows that they have learned something and things that motivate the student to learn (Kamens, 2004).

**Parental involvement**

There needs to be a particular intervention targeting fathers of children with IDD. In both the United States and in Kenya, fathers who have children with a disability often become disengaged early on, or begin to behave abusively. An outlet needs to be created for fathers to support each other and to be accepted in a group of men who are facing a similar life circumstance and coping well, just as women become endeared to other women who have children with IDD. It would have to be marketed either as a support group for both fathers and mothers or as an informal group of men that do work or other activities together. This would result in creating a sense of worth and social value for fathers who have children generally perceived as incapable by their families and neighbours, restoring a sense of belonging and power.

The last aspect of parental involvement is involving boys in the home. Female participation within the home was overall higher in many groups, and in every group females had higher skills than their male counterparts. It is crucial to invest time in teaching males self-care skills and investing the additional time to ensure skill retention and proficiency. As aforementioned with skills based learning the goal is to reduce the burden of the primary care provider so that they are freed to seek additional employment options.

## CHAPTER 9

## CONCLUSION

One in every eight Kenyans has a developmental disability. That means about 8,137-14,355 people are living in Kibera with IDD. This exploratory study looked at a sample size of 43 people, observing their levels of involvement in their families and within their communities. A larger sample size more representative of the population would be necessary in order to ensure the data integrity as well as the patterns found within each disability.

The individuals represented three different schools and six developmental disabilities. The average participant was between the ages of 6-10, had cerebral palsy and attended Little Rock School, however, many of the students had not been diagnosed with any disability, but their parents knew that something was not along the lines of normative child development. It is important that the parents have their children tested, but also that rates of children who are known to have a disability but have not been tested are surveyed to find the underreported rates in Kibera.

There were several limitations to the study. Participants were found through teachers at schools, so naturally most of the data came from students who are already attending school. Because of this, the likelihood exists that the students surveyed are more involved in their communities because parents have already taken the first step to become involved in their communities by enrolling their children into school. It also indicates that such parents have a high enough opinion of their child or a positive enough outlook on the child’s future with the disability that they felt it was important to enroll the child in school. Therefore, because the majority of the respondents are attending school, the data is in skewed in the direction of a higher likelihood of other sorts of involvement and a higher likelihood of education and positive attitudes on behalf of the parents. Only two participants were not attending school, so there was not enough data to perform a significant analysis between those who attend and those who do not attend school.

Overall, the research illuminated the possible further study of locating adults with developmental disabilities and finding out what they are doing and are involved in, as it was difficult to locate adults for the study. People made remarks that in the city it is often adults who are locked away in the houses since children are viewed as less threatening. Following the study, there was a news report of a woman chaining her twin 25 year old sons with mental difficulties to the bed because she found them bothersome and was tired of caring for them. The bed was reportedly filled with urine and excrement.

A related topic would be the two students who have mental difficulties and are now attending a vocational school. There is no data on the methods being used at that vocational school, how many people are aware of its existence, and if these methods have been useful in vocational training as inclusive and integrated education. This model could be revolutionary in Kenya as well as the East African region.

Another possibility for further research is the reasoning behind females having more skills than males. It was also discovered that there is a difference between males and females in skills, but overall children in particular are very involved inside their homes and in the communities. It was also highlighted that those children who played outside had more skills than those who did not. A suitable explanation for this was not found in the literature and it is a possibility that there is a lengthy answer to this question.

Also unexplored are the activities that children are doing at home and the levels of involvement within the classroom. Though this exploratory study was able to report on some activities, one on one observation would be helpful in determining how closely a parent’s verbal responses and attitudes corresponded with the actual behaviors within the home. This would also lead to more useful interventions overall for families.

Overall, the interventions that emerged for parent action were continuing to feel positively about their child’s disability focusing on what their child can do rather than what the child cannot do, and then sharing this information with neighbors, family and friends in order to increase positive awareness of IDD. Parents were also advised to ask their doctors questions, which is revolutionary in a culture that is at best respectful and at worst fearful of authority. Finally, parents were instructed that it was important that they create plans for their child together with the instructor through creation of an IEP and focusing on one particular skill to teach their child both at home and at school.

Parents responded well to the information and were able to ask questions about the presentation and how to better equip their child for adulthood. More research is needed in the region overall regarding child to adult transitions, specifically for PWIDD as well as various other topics that arose during the research. This research serves as a reminder to the millions of PWIDD across Kenya that they have not been forgotten, and that though there are struggles there are also successes as they strive to raise their families at the intersection of poverty and disability.

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**APPENDIX A**

**GLOSSARY OF TERMS**

***ADHD*** *-* Attention Deficit Hyperactivity Disorder. A disorder characterized by inattention and impulsiveness. It is evidenced by having difficulty organizing and completing tasks correctly, frequent shifting from one activity to another, failure to follow rules. Includes gross motor over-activity, such as excessive running, talking, or manipulation of objects and excessive fidgeting and restlessness.

***Angelman Syndrome*** *-* Genetic condition characterized by mental retardation, seizures, failure/irregular muscle coordination in walking, jerky movements, lack of speech, and frequent smiling or laughing.

***Asperger Syndrome*** *-* A developmental disorder characterized by a lack of social skills, impaired social relationships, poor coordination and poor concentration. Children with Asperger Disorder have average to above average intelligence and adequate language skills in the areas of vocabulary and grammar, but they may not understand the subtleties used in conversation such as irony and humor.

***Autism*** *-* A developmental disorder significantly affecting verbal and nonverbal communication and social relationships. It is generally evident before age three and adversely affects a child's educational performance.

***Behavior Therapy (BT)*** *-* a therapeutic approach that focuses on modifying the patient's observable behavior, rather than on the conflicts and unconscious processes presumed to underlie the behavior.

***Cerebral Palsy*** *-* term used for a group of non-progressive disorders of movement and posture caused by abnormal development of, or damage to, motor control centers of the brain. CP is caused by events before, during, or after birth. The abnormalities of muscle control that define CP are often accompanied by other neurological and physical abnormalities.

***Cri Du Chat*** *-* a hereditary congenital syndrome characterized by abnormally large distance between certain body parts, abnormally small head, severe mental deficiency, and a plaintive catlike cry.

***Developmental disability*** *-* A disability that occurs before the person reaches 22 years of age, substantially impacts the person’s daily life, is caused by mental retardation or related conditions (for example: cerebral palsy, autism, epilepsy, Down syndrome, or other neurological conditions) and impairs the person’s general intellectual functioning. People with developmental disabilities have an IQ of 70 or below, and they experience significantly limited daily living skills in two or more areas

***Disability*** *-* A mental or physical impairment which prevents or interferes with normal mental or physical activities and achievement.

***Disorder*** *-* a derangement or abnormality of function; a morbid physical or mental state.

***Down’s syndrome*** *-* mongoloid features, short fingers, widened space between the first and second toes and fingers, and moderate to severe mental retardation; associated with a chromosomal abnormality, usually trisomy of chromosome 21.

***Dysphagia*** *-* Problems related to swallowing.

***Dyspraxia*** *-* Impairment of the ability to execute purposeful, voluntary movement.

***Dyslexia*** *-* a learning disorder characterized by problems in processing words into meaningful information. This is most strongly reflected in difficulty in learning to read.

***Epilepsy*** *-* Brief, temporary changes in the normal functioning of the brain's electrical system. Also known as seizures.

***Fragile X -***A genetic cause of mental retardation.

***Klinefelter Syndrome*** *-* a condition of gonadal defects appearing in males after puberty, caused by an extra X chromosome in at least one cell line. Characteristics are small firm testes, long legs, female sexual characteristics i.e. hip and breasts, poor social adaptation, subnormal intelligence, chronic pulmonary disease, and varicose veins.

***Inclusion*** *-* educational term. All students, regardless of mental capacity or special educational needs should learn together all/most of the time with non-disabled students.

***Intellectual disability*** *-* The term used to describe cognitive impairment.

***Mental Retardation/Difficulties*** *-* The American Association on Mental Retardation defines mental retardation as referring to substantial limitations in present functioning. It is characterized by significantly below average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental retardation manifests before age eighteen.

***Occupational Therapist (OT)*** *-* Therapist who uses purposeful activities to improve movement and coordination, visual perceptual skills, self-help skills, and reading skills. An OT is also trained to adapt equipment.

***Pervasive Developmental Disorder (PDD-NOS) -*** A broad category of disability that involves problems in social interaction and verbal and nonverbal communication. PDD is not a specific diagnosis but an umbrella term for several disorders and syndromes considered to be mental and/or behavioral disorders. Its major diagnosis is autism. PDD not otherwise specified (PDDNOS) refers to children who have autistic characteristics but do not formally qualify for the diagnosis.

***Prader-Willi Syndrome*** *-* Characteristics of the syndrome include developmental delay, poor muscle tone, short stature, small hands and feet, incomplete sexual development, and unique facial features. Insatiable appetite is a classic feature of PWS. This uncontrollable appetite can lead to health problems and behavior disturbances.

***Rett’s Syndrome*** *-* A progressive brain disorder occurring principally in girls, characterized by autism, dementia, ataxia, and purposeless hand movements, and associated with abnormally high levels of ammonia in the blood.

***Trisomy*** *-* resulting from an extra syndrome causing Down’s syndrome or other irregularities depending on the chromosome affected.

***Soto’s Syndrome*** *-* large head and generalized large muscles in childhood, with mental retardation and defective coordination

***Special needs*** *-* relating to people who have specific needs, as those associated with a disability.

***Tourette’s syndrome*** *-* A neurological disorder characterized by tics - involuntary, rapid, sudden movements or vocalizations that occur repeatedly in the same way.

***Tuberous Sclerosis*** *-* the formation of multi-systemic tumor like growths that produce seizures, mental retardation, and skin lesions on the face.

***William’s Syndrome*** *-* Genetic disorder characterized by distinctive facial appearance with shallow upper border to the eye socket, medial eyebrow flare, star shaped pattern in their eyes, small nose with nostrils going in, and very talkative personality.

**APPENDIX B**

**PRACTITIONER INTERVIEW QUESTIONS**

**What are the levels of familial and community involvement of mentally disabled people in Kibera slum?**

Interview Questions for Teachers/Practitioners

Nelly, Special Education teacher-Heshima Centre

Dir. Pooja- Kaizora Consultants

Gerald, director-Mary Rice School

Esther, OT-Mary Rice School

FOCUS GROUP

Carol Ochieng, co-director-Tabasamu Watoto, Dignitas

Dennis Ochieng, co-director-Tabasamu Watoto

Maureen, teacher-Tabasamu Watoto

Fiona Reading teacher-Little Rock

SECTION 1: GENERAL QUESTIONS

1. What is your position? How long have you been in this position?
2. What are the causes of mental disabilities in Kenya?

SECTION 2: MENTAL DISABILITIES AND THE FAMILY

1. In your opinion, what are the cultural attitudes in Kenya toward mental disabilities? Toward children with mental disabilities?
2. How do parents feel about the discovery that their child was mentally handicapped? What was their reaction and behavior after the discovery?
3. Did it have an effect on any other aspects of their life? If yes, which aspects and how? (How did it affect their marriage, relationship with family and relationship with the community?)
4. Are there differences between the rural and urban perspectives on mental disabilities?

SECTION 3: MENTAL DISABILIES AND PRACTICAL INCLUSION

1. In your opinion, what is inclusion? What is inclusion of people with mental disabilities in day to day activities?
2. How is inclusion of people with intellectual disabilities seen in the rural areas? Is this different than the perspective on inclusion in the urban areas? If so, how?
3. What do you think about current efforts to include adults with mental disabilities? Explain.
4. What do you think can be done so that children and adults with mental disabilities are included in day to day community life?

**APPENDIX C**

**PARENT SURVEY**

**Please circle your answers. If you circle “other” please write in the space to explain your answer. Please read all questions carefully. Thank you!**

1. How many of your children have developmental disabilities? (If you have more than one child, please fill a separate form for each of them.)

1 2 3 or more

2. What is the age of the child with disabilities?

1-5 6-10 11-17 18 or older

3. What disability was your child diagnosed with? CIRCLE ALL THAT APPLY

*ADHD Angelman Syndrome Asperger Syndrome Autism Cri Du Chat, Down’s Syndrome Dysphagia Dyspraxia Dyslexia Epilepsy*

*Fragile X Klinefelter Syndrome Pervasive Developmental Disorder Prader-Willi Syndrome Rett’s Syndrome Trisomy Soto’s Syndrome*

*Tourette’s Syndrome Tuberous Sclerosis William’s Syndrome*

*Cerebral Palsy Mental Retardation OTHER NOT LISTED*

4. At what age was your child diagnosed with a disability?

0-2 3-5 6-8 after 8 years

*The following questions are about different reactions to your child being diagnosed with a disability.* 1-they reacted with negative feelings, 2 -some negative feelings, 3-feeling just okay, 4-feeling more than okay, 5-feeling very good.

5. How did your family up country react?

1 2 3 4 5

6. How did your neighbors react?

1 2 3 4 5

7. How did you react?

1 2 3 4 5

Explain: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**8A.Did any of these reactions change with time? IF NO, PLEASE SKIP TO QUESTION 9**

**a) Yes b) No**

**8B. If marked YES to QUESTION 8A, in what way did they change? EXPLAIN**

**a) neighbors/relatives felt better b) neighbors/relatives felt worse c) I felt better d) I felt worse**

Explain:

*Questions 9-13 are about things your child does at home and outside the home. Please CIRCLE ALL ANSWERS THAT APPLY*

9. What is your child able to do on their own? CIRCLE ALL THAT APPLY

a)get dressed b)eat/drink c)walk d)sit up e)talk f)point

g) bathe h) play with other children i) clean up homestead

j) understand directions k) use washroom l) other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

10. What does your child do during the day?

a) watch television/listen to radio b) go to school/day care centre d) play at home e) sit/sleep at home only (doesn’t play)

f) goes with caretaker (carried on back/sits at shop etc.) g) other \_\_\_\_\_\_\_\_\_\_

**11A. Does the child have responsibilities inside the homestead? IF NO, SKIP TO QUESTION 12**

**a) Yes b) No**

**11B. If marked YES to QUESTION 11A, what responsibilities does he/she have?**

**a) wash dishes b) sweep outside/inside c) wash floor**

**d) cook/light/fan jiko e) clean up things f) clean shoes g) wash clothes**

**h) make bed i) put away clothes j) serve water to wash hands**

**k) toss rubbish l) OTHER\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

*12A. Does your child go with the family outside the home? IF NO, SKIP TO QUESTION 13A*

*a) Yes b) No*

*12B. If marked YES to 12A, what activities does the child do outside the home?*

*a) mosque/church b) school/day care centre c) market d) matatu/bus e) shop*

*12C. How many times in a week is the child in the above activities?*

*1-2 3 4 5 times in a week or more*

**13A. Does the child play with other children? IF NO, SKIP TO QUESTION 14**

**a) Yes b) No**

**13B. If marked YES to above, where do the children play?**

**a) inside the house b) outside c) both inside and outside the home**

**d) at school/day care centre only**

**13C. Who does the child play with?**

**a) brothers/sisters b) neighbors c) children from school d)other\_\_\_\_\_\_\_\_\_\_\_\_\_**

**13D. How many times in a week does the child play with these people?**

**1-2 3-5 7 or more**

*Please choose a number 1-5 to show how comfortable you feel in each situation. 1-not very comfortable at all, 2-a little comfortable, 3- just okay, 4-comfortable, 5-very comfortable, very okay.*

14. Your child outside in the community

1 2 3 4 5

15. Neighbors watching your child?

1 2 3 4 5

16. Teachers at school watching your child?

1 2 3 4 5

Thank you for completing this survey!

**APPENDIX D**

**PRACTITIONER INTERVIEW TRANSCRIPTS**

**Nelly, Heshima Centre**

**SECTION 1: GENERAL QUESTIONS**

1. What is your position? How long have you been in this position?

Special Education Instructor for children with disabilities for the past 5 years when Heshima opened in 2008. Most children at the center have Cerebral palsy, 3 are autistic.

1. What are the causes of mental disabilities in Kenya?

Poverty causing disability; giving birth at home, prolonged labor, mismanagement at the hospital, doctor thought the child was dead, etc.; most from the slum, kids would have done better if there was the early intervention, no one accepts it thinks it a bad omen so they don’t do anything about it. Not enough awareness. Also doctors and nurses that come in contact with the child will often bypass all of the early signs until it is too late for an intervention.

**SECTION 2: MENTAL DISABILITIES AND THE FAMILY**

1. In your opinion, what are the cultural attitudes in Kenya toward mental disabilities? Toward children with mental disabilities?

Community members looked at [disabilities] as a curse, bad omen or witchcraft. Most of the parents have gone from witch doctors to prophets to be prayed over, thinking it would go away by prayers, Now the community [that the children who attend are from] and parents are beginning to be aware that it’s just a disability [and] the kids are just like any other kids and that they’re special in their own way.

1. How do parents feel about the discovery that their child was mentally handicapped? What was their reaction and behavior after the discovery?

Many parents feel confused, because they are given medicine for the child but do not know what is wrong or what it is for.

1. Did it have an effect on any other aspects of their life? If yes, which aspects and how? (How did it affect their marriage, relationship with family and relationship with the community?)

The husband thinks that they (the mother) did something wrong, so the burden falls in the mom. There is stigma that comes with having a disability; community members don’t want their children to play with the child, the moms aren’t accepted in the community or in the family. With one mother, the in laws won’t eat anything in their house when they come to visit; even if she cooks they won’t eat anything.

1. Are there differences between the rural and urban perspectives on mental disabilities?

Her mother said: I saw a child like the ones that you teach. Nelly asked her mother why didn’t she talk to the parent, and her mother responded essentially that she was afraid someone would look at her as if she were trying to get into their affairs. If in Nairobi people are more urban, more learned, and don’t understand disability that means in the village it’s really bad.

**SECTION 3: MENTAL DISABILIES AND PRACTICAL INCLUSION**

1. In your opinion, what is inclusion? What does inclusion of people with mental disabilities look like in day to day activities?

Our goal is not to make them progress in academics because looking at them in their disability they won’t be able to most of them are kind of severe. What we are looking at is kind of helping and training children so that they can fit in the community and to be able to do things and be independent to the maximum i.e. feed themselves, clean themselves, be able to communicate through gestures or pointing or by pictures to communicate with the other person and hygiene and daily skills if they’re able to take care of themselves that is really good.

1. How is inclusion of people with intellectual disabilities seen in the rural areas? Is this different than the perspective on inclusion in the urban areas? If so, how?
2. What do you think about current efforts to include adults with mental disabilities? Explain.

There’s one guy who was at Dagoretti children’s home before coming to Heshima and they had him doing cards and making key chains and necklaces etc. Tracy has been looking at pupils who are capable the ones that can walk, communicate etc. There is a girl who is 11, Celestina, who has been at Heshima for the past 3 years and likes to imitate the teachers, and Tracy is already talking about employing her as an aid. Several boys who are turning 18 are working on their ID cards and will be employed doing light construction for Heshima.

1. What do you think can be done so that children and adults with mental disabilities are included in day to day community life?

**Involvement:** Get them to do something. Bring them out, whether they’re severe or mild. When you bring your child out, you look for advice and insights on how to help them. If the kids were helped and the parents were aware earlier, then they would be different kids right now. Get out there get the information and bring the kids out don’t tie them in a corner, lock them in a room, look for information ad help. Ask questions.

**Practitioners**: Doctors just give the child drugs and don’t tell the parents what the child is suffering from. No one asks. Need to explain to the parents i.e. why my child didn’t cry at birth and inform parents so that they can be enlightened. Mom comes back at 6 months and they say, “Your child needs therapy,” and tells you to take the child to therapy without knowing why or what they are doing. One Mom’s excuse was that it was her first child and she didn’t know the steps to progress. Stays at her house not asking any questions and the child isn’t progressing, and her 2 year old isn’t walking or speaking. Goes every month for vaccinations but no one has told her anything or noticed the disability or that he doesn’t walk. She eventually came to Heshima and they instructed her on how to work with her child and they discovered that the child wasn’t physically disabled but simply had delayed milestones because of autism and her ignorance. *Milestones, child development and what to expect should be taught at Mother and Child Health Centers each time families go to get monthly vaccinations. Everyone has to wake up and help and find people creating awareness all over.*

Overprotective parents can also be a problem, people need to let go and allow their children to be in the community.

Toi primary (a public school) has special needs things: school fees and distance caused them to stop. A class with a lot of kids and the teachers are few. Don’t have facilities.

**Get them out into the community:** When Heshima students go into the slum clean in uniforms and shaking hands with people, the community is beginning to accept them and become friendlier and independently pass by to see how are the kids are doing and congratulate the staff. Starting to accept that the children are only disabled, especially kids who were not walking who started walking.

**Dir. Pooja Pansear, Kaizora Consultants**

**SECTION 1: GENERAL QUESTIONS**

1. What is your position? How long have you been in this position?

Dir. Pooja Pansear of Kaizora Consultants

1. What are the causes of mental disabilities in Kenya?

S**ECTION 2: MENTAL DISABILITIES AND THE FAMILY**

1. In your opinion, what are the cultural attitudes in Kenya toward mental disabilities? Toward children with mental disabilities?

There is a stigma in community involvement. The children are perceived as being possessed, the mother was cursed, magic, and being bad parents because of tantrums. Families then stay away from the spotlight i.e. seeking help/support services and lock the child at home. Girls often get raped if allowed outside and taken advantage of. Especially if the child is not in school they will not go outside because of fear of them running to cars etc.

1. How do parents feel about the discovery that their child was mentally handicapped? What was their reaction and behavior after the discovery?

When given the diagnosis just like in the popular literature parents are often in denial as are the doctors who are insistent that the children will grow out of it, there is a lot of shame and guilt that somehow it was the parents fault. Some begin to look right away for a solution knowing that there has to be a way to help their child.

1. Did it have an effect on any other aspects of their life? If yes, which aspects and how? (How did it affect their marriage, relationship with family and relationship with the community?)

Many families are single parents; the dad can’t deal with the pressure of having a child with autism and walks out. Sometimes there is involvement in the house based on the people who come to her in the first place i.e. sibling involvement trying to be involved doing other things i.e. washing. One mom calls kids from nearby homes in an effort to engage her autistic child and make sure he is involved in the community.

1. Are there differences between the rural and urban perspectives on mental disabilities?

**SECTION 3: MENTAL DISABILIES AND PRACTICAL INCLUSION**

1. In your opinion, what is inclusion? What is inclusion of people with mental disabilities in day to day activities?
2. How is inclusion of people with intellectual disabilities seen in the rural areas? Is this different than the perspective on inclusion in the urban areas? If so, how?

In seeking help: families are also taken advantage of. They are told that the only way to have an intervention for their child is through a particular diet. There is a lot of misinformation and lack of information, i.e. an organization that says it does ABA but they don’t know what ABA is and are not certified to deliver ABA services or behavioral management services. There is currently no government funding and most people have no idea what autism is.

1. What do you think about current efforts to include adults with mental disabilities? Explain.
2. What do you think can be done so that children and adults with mental disabilities are included in day to day community life?

**Gerald Nyalula, Mary Rice School**

**SECTION 1: GENERAL QUESTIONS**

1. What is your position? How long have you been in this position?

Gerald Nyalula director of Mary Rice School, trained teacher; since 2007

1. What are the causes of mental disabilities in Kenya?

Diet, infections when the mom is pregnancy which can affect the baby, poor health, ignorance, alcohol abuse during pregnancy, accidents (falls or is beat) genetics

**SECTION 2: MENTAL DISABILITIES AND THE FAMILY**

1. In your opinion, what are the cultural attitudes in Kenya toward mental disabilities? Toward children with mental disabilities?
2. It is a curse someone did something and it is a punishment form God
3. Witchcraft which leads to stigma
4. How do parents feel about the discovery that their child was mentally handicapped? What was their reaction and behavior after the discovery?

Only 1 parent I know of had a positive attitude toward her child’s disability from when the child was boon she said the child was normal. One lady doesn’t want medications since she says they make her child abnormal and she likes the child the way she is. This is not denial but they have accepted and some feel better after a while and after looking for help. Depends on the neighbors and the approach the neighbors take.

1. Did it have an effect on any other aspects of their life? If yes, which aspects and how? (How did it affect their marriage, relationship with family and relationship with the community?)

Concentration on child with disability leaves other kids out. Unable to work. Concentration diverted some parents also give more attention to the ones without disability looking at their children as investments so they want to put the most time in the one that will be able to give them something.

1. Are there differences between the rural and urban perspectives on mental disabilities?

TANZANIAN DID NOT HAVE ANSWER FOR IN RURAL KENYA

**SECTION 3: MENTAL DISABILIES AND PRACTICAL INCLUSION**

1. In your opinion, what is inclusion? What is inclusion of people with mental disabilities in day to day activities?

Making sure children are a part of everything. Getting students Involved and encouraging skills training as well as self-help. The school also has children go to a non-disabled class every Wednesday to socialize, build self-esteem and self-confidence.

1. How is inclusion of people with intellectual disabilities seen in the rural areas? Is this different than the perspective on inclusion in the urban areas? If so, how?

TANZANIAN DID NOT HAVE ANSWER FOR IN RURAL KENYA

1. What do you think about current efforts to include adults with mental disabilities? Explain.

It’s not enough, we need to do more.

1. What do you think can be done so that children and adults with mental disabilities are included in day to day community life?

Skills training, self-help skills with the goal of putting them into mainstream schools. Vocation training school within compound and they monitor their former student to see how they are doing. Two students there one doing carpentry and the other is doing catering. They are having them stay for 2 years instead of the 6 months. The school understands the needs and abilities of the kids. Looking for a good fit for these adults to have a career and something to keep them from being idle.

**Esther, Mary Rice School**

**SECTION 1: GENERAL QUESTIONS**

1. What is your position? How long have you been in this position?

Esther, Occupational Therapist at Mary Rice, 2 years

1. What are the causes of mental disabilities in Kenya?

genetics

**SECTION 2: MENTAL DISABILITIES AND THE FAMILY**

1. In your opinion, what are the cultural attitudes in Kenya toward mental disabilities? Toward children with mental disabilities?

Believe it is a curse/witchcraft. Only trained parents have positive ideas like ones who are rich and have education or those who understand the nature of these disabilities.

1. How do parents feel about the discovery that their child was mentally handicapped? What was their reaction and behavior after the discovery?

Tend to feel bad. I.e. stigmatized finger pointing, saying it’s your side that caused it, it’s a curse, or witchcraft. If the family is rich others will say that they donated their child for wealth. Kambas believe in bewitching a child to get wealth. Epileptic children are believed to be demons so they are prayed over, if it doesn’t go away the demons must have taken full control of the child. In other cases, some people even refuse to pray over them in fear that you will get the demons.

1. Did it have an effect on any other aspects of their life? If yes, which aspects and how? (How did it affect their marriage, relationship with family and relationship with the community?)

Most parents are breadwinners and are very affected by the discrimination their child is experiencing. They can’t go out looking for money because they need to stay at home and care for the child.

1. Are there differences between the rural and urban perspectives on mental disabilities?

In village you can leave your disabled child with your neighbor. Here [in the urban setting] it is me, myself, and I. You can find children who have mental disabilities in the village playing with other kids, but not in Nairobi.

**SECTION 3: MENTAL DISABILIES AND PRACTICAL INCLUSION**

1. In your opinion, what is inclusion? What is inclusion of people with mental disabilities in day to day activities?

Inclusion is integrating with other children and being a part of something i.e. their opinion matters. Never feels that children are included because no one want sot include or touch the children and they are easily segregated from other children.

1. How is inclusion of people with intellectual disabilities seen in the rural areas? Is this different than the perspective on inclusion in the urban areas? If so, how?

**SEE NO.6**

1. What do you think about current efforts to include adults with mental disabilities? Explain.

Children are easy and people are more understanding. But adults are the ones tied up somewhere in the house. There is nothing for them except for the 1 mental hospital in the Nairobi area that is already overflowing with people who dump their relatives there. There needs to be a facility that allows them to be productive and not just in the house.

1. What do you think can be done so that children and adults with mental disabilities are included in day to day community life?

Sensitization and community trainings that explain disabilities to community members. Also children need to be allowed to be empowered through skills trainings and self-help skills. They need to be encouraged and striving for more social interaction and independence. She wants them to see that these children are just like any other children.

**FOCUS GROUP**

Carol Owala Ochieng (Tabasamu Watoto/Dignitas)

Dennis Ochieng (Tabasamu Watoto)

Maureen (Tabasamu Watoto)

Fiona (Little Rock Ayany)

**SECTION 1: GENERAL QUESTIONS**

1. What is your position? How long have you been in this position?

Caroline: Director at Tabasamu Watoto. Works at Dignitas Project as a special needs teacher leader and trains other teachers on how to make schools more effective in including children with special needs in the classes.

Maureen: special education teacher for 2 years at Tabasamu Watoto & current student

Fiona: teacher at Little Rock since 2007. Works in the reading department 1- 1 with disabled and non-disabled students.

Dennis: Began working at Tabasamu Watoto as a music education teacher and co-director. Recently graduated from Africa Nazarene for BA of primary education

1. What are the causes of mental disabilities in Kenya?

Carol: from experience the main causes of the children that I’ve seen is as a result of meningitis. Some children are born normally but because the homes in Kibera/slums are very small diseases pass quickly. There is often a lack of early stimulation after working with a child they become better. Parents hide the children even regular children at home.

Maureen: when mother is pregnant using too many medicines

Dennis: hereditary with some, not sure. Stress in the mother/child?

Fiona: biological and environmental causes. Hereditary factors, drugs and substances, family planning drugs, accidents or chemicals.

**SECTION 2: MENTAL DISABILITIES AND THE FAMILY**

1. In your opinion, what are the cultural attitudes in Kenya toward mental disabilities? Toward children with mental disabilities?

Carol: There is so much stigma surrounding mental disability. In Nairobi we have Mathare Mental hospital people view it as the crazy house. Even mental disability is the most challenging disability because not many people would like to associate with those people. A parent who has such a child does not allow them to even play outside because other parents believe they will pass a disease to their children and the child will “catch” the developmental disability. Within the school setting, parents of non-disabled children threatened to remove their children from Little Rock. People are okay with a child with physical disability but not of mental disabilities.

There’s also a lot of superstition. Parents also say it’s because of witchcraft and they often go to witchdoctors to try and see who did this to their child. One lady went to all the witch doctors until she became the witch doctor herself. It’s hard to get people to take their child for assessment [to see if the child has a developmental disability] etc. when they have this mindset.

To them [many parents think] “why should I pay school fees for a child who won’t help me in the future?” there is also the belief that if someone is rich and they have one child with a disability that they sacrificed their child for riches.

Maureen: Parents don’t want the child to leave them, and often can’t pay school fees for the child because the child won’t help them. All of their dreams are on the child and they’re all gone once they find the child has a disability.

Dennis: depends on the location of the children, such as if it’s an urban or a rural area. People have different perceptions of people with mental disabilities. In towns here we are being educated, in the communities like here in Kibera we are being educated about people with mental disabilities such as how to deal with and accept them and you find people who have accepted them and that it is a disability. There are others who think it might be something cultural or superstitious or God is angry with the family or they did something wrong. Education in the rural areas hasn’t fully infiltrated. There are actually so many beliefs about people with mental disabilities, some think it is witchcraft or people did something wrong or something about the goats. Most people in the communities don’t know that there can be treatment and training.

At Little Rock not many teachers would allow children with mental disabilities in their classes. One teacher refused completely and even said she would resign. Some think that if other children play with them they might wear that mental disability.

Fiona: children are bad omen or their parents were cursed that why they give birth with those children with mental disabilities.

1. How do parents feel about the discovery that their child was mentally handicapped? What was their reaction and behavior after the discovery?

Carol: It’s normally very shocking to them. The child will not go through the developmental milestones; maybe the child takes long to talk or walk or self-care skills. So the parents are worrying “what might be wrong with my child.” Most of the time parents don’t go to a specialist or the hospital, but first they talk to their neighbors who know very little about special needs. They follow the feedback from the neighbors who may advise them to keep the children in the house or might ask “what did you do” or “why is your child like this.” So parents begin to deny anything is wrong and begin keeping their children in the house without leaving.

With meningitis caused disability the doctors will talk to them. Sometimes as a teacher if you ask a parent to take their child for educational assessment they become angry and remove the child from the school. For those that go, sometimes teachers are also not ready to support the parents.

There are many single moms in Kibera as a result of this. The mothers are always there for the children no matter what. Now when they realized they’ve given birth to such a child the blame game begins and the husband says, “This has never happened from our side of the family.”

Often ask for boarding schools so they can dump their children. Some of the children are really abused and have a lot of scars on their body because the parents are not accepted and they put it on the child.

Maureen: Many feel “I won’t get a child again.” They fear they may give birth to another child with the same problem

Dennis: Some are in denial they don’t want to accept it. They get angry and begin blaming each other.

Fiona: Many live in denial and never accept it. It is hard taking them through so they can understand or accept that “I have a child and that child has disability.”

1. Did it have an effect on any other aspects of their life? If yes, which aspects and how? (How did it affect their marriage, relationship with family and relationship with the community?)

Carol: This really affects mothers who have such children they are very close to other mothers with the same children rather than mothers with non-disabled children. They feel like they belong together. Also neighbors talk about the woman or don’t want their children interacting with a special needs child and the mothers feel it. Socially they are not interacting with other neighbors except those neighbors who are very kind/patient. Sometimes they have to walk with their children everywhere and sometimes the children are disruptive and the neighbors beat them so she can’t leave her child with anyone.

With family up country not so sure: tend to take the child back to the village to the mother’s parents. Well to do families become closer when the child has mental disabilities. One child came with both parents [and that was unusual]. Otherwise you usually see only the mothers you don’t see families coming together.

Maureen: so many are being chased away by their husbands

Dennis: Especially on the woman there is a large burden. In most of the communities here, after marriage the woman belongs to the husband’s family. The woman will get a lot of complaints from others and the in-laws will say things like, “why did you come to this family,” and “why did you bring us this child.” It creates a lot of disharmony. NGOS are the only things that bring the parents together in the community.

Apart from daily stress there is a lot of pressure put on the husbands, who may then come back in the evening and start beating their wives and blaming them for the disability of the child and relatives also putting a lot of pressure on the family.

Fiona: The parent tends to see the child as a burden and may want to go outside and earn a living but because of the child it is hard for the parent to do everything. They want to leave the house but they can’t leave the child alone. A parent will sometimes come and dump the child [at Little Rock School] and will not want to come for the child. i.e. the father of the children is in denial and doesn’t want the child so he is telling the mother to take the child away.

1. Are there differences between the rural and urban perspectives on mental disabilities?

Carol: In urban centers its worse. In urban you have to do activities that involve the brain i.e. school, write if you want to get a job you have to know how to read but not the case always with those in mental disabilities. Had an uncle who would just milk cows etc and it wasn’t really a big deal like it is in the urban centers. In rural a person like that would just be sent to do things but not really asked of their opinion on things.

 Fiona: Disability awareness has really helped. People know that these people are here and will stay with us. Some people see it still as that person is mad and they aren’t aware of what is happening with the people with disability so they don’t understand it and see the person as a mad person and it’s a bad omen to the community.

**SECTION 3: MENTAL DISABILIES AND PRACTICAL INCLUSION**

1. In your opinion, what is inclusion? What is inclusion of people with mental disabilities in day to day activities?

Carol: Inclusion is giving equal opportunities. I don’t know if it’s *really* equal but looking at what someone really needs. Like in a school the child is given equal opportunity like the regular learner. If I have learning disabilities and I’m in a class I might be slower at getting a concept so the teacher should see how to modify my tasks so I get something even if I don’t get everything. With children with disabilities that are physical they build ramps etc. to include and the same should be for children with mental disabilities. Having a mental disability does not mean that I do not have an opinion or that people should make decisions for me, I should be the one to decide if I should do beadwork or if I should do anything else. I.e. Right now there are holes being dug in Kibera and roads being built we should use people with special needs doing physical labor and contributing their ideas. Inclusion needs the whole community for it to work and should be sensitive of how children should be included.

Maureen: Should be with them. Put them together and be as one teacher to them [as opposed to having them in separate classes and treating pupils differently].

Dennis: It just means including everyone in the class regardless of if they have a disability or not. There is the expectations of the parents, teachers and then in an interest that the child has. In most cases they will expect certain things by the end of the term but you find that it’s not the interest of the child so she doesn’t develop interest. As a teacher you need to find out what the child is really interested in doing. And try and encourage the child in what they are interested in. This is also part of inclusion.

Fiona: inclusion should be there in this country and people should be sensitized about people with disability and everyone everywhere should be positive about disability. And every place so they can be comfortable and well updated like any other human being. At school children with disability should be able to interact with normal children so they can see that all of the children are loved by the community and they can have that positive attitude.

1. How is inclusion of people with intellectual disabilities seen in the rural areas? Is this different than the perspective on inclusion in the urban areas? If so, how?

Carol: urban people more enlightened on special disabilities because of TV and magazines but they are limited by resources, space and activities. When you compare Kibera, in the rural the houses are bigger and there are more activities. Activities in the urban areas are ones that are intellectually challenging; mainly school, reading and writing, and answering questions. They are limited on inclusion with resources in performance. While there is stigma in the rural areas, just by being born you are reducing physical burden for the family. You go to the garden and you are given their piece of land. People with mental difficulties in the rural areas find their way, they are married, and they are happy and families are happy as long as you are a successful farmer and have figured out how to have money. People with intellectual challenges in the village are better off because they have more opportunities to do better than in the urban places. Unless you had many vocational skills it’s hard for them to make it here. Inclusion should start early and have schools with vocational trainings. They should also have some skills that they are learning. Then they don’t know what to do with themselves.

 Also in the rural setting everything is family so even if someone is born with mental challenge they are seen as a part of the family. But here you’re staying with different people… it’s hard to involve them.

Maureen: same

Dennis: in the rural areas they are privileged to have the bigger spaces. The only space that people have is places like in school and when they are taught vocational skills in the different centers. That’s the only place they get spaces. In the village they have wider space boys can herd cattle and play together without having issues.

Fiona: in the urban settings the children are being hidden they don’t want people to know that there is a special child in that house. People may laugh at you or tell you that it’s a bad omen. But in the rural they have that time to interact with people in the community

1. What do you think about current efforts to include adults with mental disabilities? Explain.

Carol: people don’t know where to start. There is Jacaranda special school and you go in and nothing is happening there, children are just sitting down and they are given toys and it’s a government school and they just sit. They don’t know how to help these people. In Kenya they just have a system where it’s just working hard and studying in school but mentally they can’t prove themselves.

Maureen: No comment.

Dennis: major challenge by Kenya. Teacher with intellectual disabilities teaching a college course.

Fiona: People aren’t doing enough to include adults. There is only the mental hospital.

1. What do you think can be done so that children and adults with mental disabilities are included in day to day community life?

Carol: Training the parents on how to deal with it through taking precautions and asking what-if. Before the child is born the community should be sensitized. Initially she would go to a school and show teachers how to identify children who needed an assessment and then they would call the parents and request a meeting. This was a problem. People asked “why should 5 parents in the school be called?” and felt singled out and embarrassed. Some would come but others wouldn’t. Now we do it differently in that we call the entire school for a meeting about disability and the causes. Then parents come to you. The same thing should happen in the community. Now there are meetings in the community where people are taught and the health workers do it with malaria and then they should do the same with mental difficulties. People hide their children is because they are worried about the community responses.

Dennis & Carol: on TABASAMU’s role

Talk to parents during parents meeting and issues of disability. They have realized that inclusion is good for every child: patience and helpfulness are important skills. Continue with door to door talking about disability. More education is needed. Yes. I had tried to have an integrated class but when we bought special needs students in all the parents of the regular children withdrew their children from my class. So I made sure my class of special needs students were the best readers in the entire school. Then parents who had earlier said they did not want their children learning alongside special needs children changed their minds and were trying to join my class. Setting an example/pace as teachers is important and can change parent’s minds. Learning difficulties, special needs are everywhere. Attitudes need to be changed in school administrators and teachers. And creating awareness. If a child has not performed well and you’ve had him repeat 4 times they should not repeat a 5th. Many teachers in the slums have never gone through any training and they are overwhelmed. When they are trained and sensitized they give better services.

Fiona: sign language for teachers and parents they are taught in school so the parents can communicate with any child who has hearing impairment or that doesn’t speak.

**APPENDIX E**

**DATA, COMPILED BY DISABILITY**

ADHD

2 children were diagnosed with ADHD, 1 male, 1 female. Both are between the ages of 1-5. One was diagnosed between 0-2 and may have another disorder as she is the result of a failed abortion that killed her mother. The other was diagnosed between the ages of 3-5. Both sets of neighbors reacted well while the child who was nearly aborted elicited a strong reaction from her family, as they felt she was responsible for the death of her mother. With this child, people have changed their attitudes over time as they have seen the child going to school and growing up. In the other family, the family and mother had felt okay about him and these reactions have not changed. The children average 7.5 skills each (68% competency) and both struggle with talking, bathing and cleaning the homestead.

Both children watch TV/listen to the radio, attend school and play at home. One child also accompanies the caretaker. Both children have responsibilities within the homestead. Both clean up things/wipe table after eating, while the girl sweeps outside/inside and serves water to wash hands. Both children accompany their families outside the home attending religious services, school/day care, market and shops. The girl does these things 3 times per week and the boy does them 5 times per week or more.

The two children play both inside and outside the home with neighbors and children from the school. The boy also has siblings to play with. Both children play outside 7 times per week or more.

The two families feel positively about having their children interacting with the community at large, the neighbors and at school.

AUTISM (AND JOINT DIAGNOSIS AUTISM/EPILIPESY)

9 children diagnosed with autism or with a joint diagnosis of autism were included in the survey, 5 male and 4 female. Three are between the ages of 1-5, five are between the age of 6-10 and one child is between the ages of 11-17. 6 were diagnosed between 0-2 and 3 were diagnosed between the ages of 3-5. 77.7% (7) families reacted negatively, 66.7% (6) of neighbors also reacted negatively, with one family unaware of how their neighbors felt about their child. Another 66.7% (6) of parents reacted negatively, with one having a very positive outlook. Two husbands have left specifically blaming the wife for witchcraft, and three women mentioned feeling stressed and very sad, possibly depressed. In 4 families, reactions have not changed with time. In the remaining 54% of families, 4 caretakers saw positive changes in themselves, and 1 caretaker saw positive changes in their own as well as the perspective of family/neighbors.

The children average 6.2 skills each (56% competency) and struggle with speaking, bathing and cleaning the homestead (2 children speak); though children that play with others averaged slightly higher (6.75). Females averaged 6.25 skills and males averaged 6.2 skills.

All of the children attend school full time, and after school hours or during weekends, 77.7% play at home and 66.6% watch television or listen to the radio. In this group one child does not have the attention span to watch television and does not enjoy playing. Instead, she spends her time running back and forth within the house, possibly as a self-stimulatory activity. Another child also spends time reading and dancing in addition to the other activities listed. Only 1 (11%) child had responsibilities within the homestead, and it is to make his bed when he wakes up in the morning. Though only marginally active in home life, 66% of children go with the family outside of the home, a number made up of all 4 of the female respondents and only 2 of the males. All 6(100%) of these children attend religious services with their families and school/day care. 5 (83%) use public transportation, 3 (50%) children go to the local shops, and 1 child goes to the market. Activity outside the home within the genders was equal.

Four children play with others, and of these respondents 3 were female and 1 was male. They play both inside and outside the home and have a higher average of activities outside the home (an average of 4 per child as opposed to the overall average of 3.5). 100% of those who play with others are playing with siblings and neighbors, and 1 respondent also played with children from school on play dates. All children play outside 7 times per week or more.

The families overall felt negatively about the community and their neighbors, stating that they were overall a little comfortable (a score of 1.8 for the community and 2.0 for the neighbors). However, the families whose children play with others ranked the community .2 points higher than the average and .4 points higher than the group whose children did not play with others. There was a more significant difference in the feelings towards neighbors watching a child which was .5 points higher than the average and nearly 1 full point higher than the group whose children did not play with others. All parents felt positively about having their children interacting with the teachers at school.

CEREBRAL PALSY

9 children are diagnosed with cerebral palsy, 3 males and 6 females. Seven are between the age of 6-10 and two children are between the ages of 11-17. 8 respondents (88.9%) were diagnosed between the age of 0-2 and 1 was diagnosed between the age of 3-5. Following the diagnosis, 44% (4) families responded indifferently, 22% (2) families were unaware of how their family would react, and 33% (3) reacted negatively. 44% (4) of neighbors also reacted indifferently, 44% (4) reacted negatively and 1 family had neighbors that reacted very positively. 77% (7) people reacted negatively, with 1 parent having an okay/indifferent reaction, and 1 parent having a very positive reaction. Two parents mentioned being stressed about the news, while others mentioned sadness and fear about their child’s condition. One parent felt as if when the child was born she had a huge problem since her child was different from others. One mother particularly stated that the child’s father blamed her side of the family for producing a child with cerebral palsy. The only father in the entire study is in this group, and stated his child was “God’s creature.”

In 3 families, reactions have not changed with time. In the remaining 66% of families, all caretakers saw positive changes in themselves. The children average 4.5 skills each (41% competency) and struggle with dressing themselves, independently using the using the washroom, pointing and walking. Females averaged 4.8 skills and males averaged 4 skills. All of the respondents attend school full time and watch television/listen to the radio. 88% (8) play at home, and 2 children go with their caretaker.

Only 1 (11%) child had responsibilities within the homestead, and they are to wash dishes/utensils, clean up things, sweep outside/inside, clean the shoes, wash floor and make the bed. Though only marginally active in home life, 88% of children go with the family outside of the home. All 8 (100%) of these children attend religious services with their families and school/day care. 7 (87.5%) use public transportation, 4 (50%) children go to the local shops, and 1 child goes to the market. Activity outside the home within the genders was equal.

8 children play with others, 5 were female and 3 were male. 6 children play both inside and outside, and one child plays inside the home and at school/day care center. 7 (87.5%) children play with both neighbors and children from school, 5 (62.5%) children play with their sibling and one respondent did not answer. 87% of children play outside 7 times per week, and 1 child plays outside 3-5 times in a week.

 The families overall felt negatively about the community and their neighbors, stating that they were overall a little comfortable (a score of 2.4 for the community and 2.5 for the neighbors). All parents felt positively about having their children interacting with the teachers at school.

DOWN’S SYNDROME

2 children are diagnosed with Down’s syndrome, one male and one female. Both are between the ages of 6-10 and were diagnosed between the ages of 0-2. The families had similarly negative reactions. In the girl’s family, the close family was supportive but the extended relatives didn’t like the child. Her mother also felt negatively and in a lot of emotional pain, but decided to accept the situation, and their neighbors were generally indifferent. The boy’s family, neighbors and parents all reacted negatively overall. The boy’s caretakers’ reaction changed and she felt better after some time had passed.

The children average 7 skills each (77% competency) and struggle with dressing themselves, cleaning up and pointing. The female had 8 skills and the male had 6. Both children attend school/day care and play at home, and the female respondent also watches TV/listens to the radio.

The female respondent also has responsibilities inside the home, including washing dishes, cleaning up things, putting away clothes, sweeping outside/inside, serving water to wash hands and tossing rubbish while the boy does not. Both children go with the family outside of the home and attend religious services, school, use public transportation and go to the local shops. The male respondent also attends the market and participates in these activities 5 times in a week, while the female respondent is involved in activities outside the home 1-2 times in a week.

Both children play with others both inside and outside of the home with siblings 7 times or more per week. The female respondent also plays with neighbors and children from school. The families overall felt negatively about the community and their neighbors, stating that they were overall a little comfortable with the community and not very comfortable at all with leaving their children with the neighbors (a score of 2.5 for the community and 1 for the neighbors). All parents felt positively about having their children interacting with the teachers at school.

ANALYSIS

There are only two respondents for this category. However, the gender roles strongly reflect traditional Kenyan culture in this disability. Are females overall pushed to be more involved in chores in the home?

EPILEPSY

6 children are diagnosed with epilepsy, and 1 child had a joint diagnosis of epilepsy and mental difficulties. This group was overwhelmingly male, with 5 males and 1 female. One child is between the ages of 1-5, three were between the ages of 6-10, and two are between the ages of 11-17. Four respondents were diagnosed between the ages of 3-5, while two were diagnosed between the ages of 0-2. Following the diagnosis, 50% (3) families responded indifferently, 33% (2) families reacted negatively and 1 family did not introduce the child to the rest of the family. 83% (5) of neighbors reacted negatively and 1 family had neighbors that reacted very positively and encouraged the mother to take the child to the hospital for an assessment. Four parents reacted negatively and 2 reacted positively about their child’s condition. For those who reacted negatively shock, stress and denial were mentioned, and 50% of caretakers have noticed changes in reactions over time, specifically of themselves becoming more positive about their child.

The children average 8.3 skills each (75% competency) and struggle with bathing and cleaning up the homestead. The sole female participant had 9 skills while the males averaged 8.2 skills. All of the respondents attend school full time and play at home. 33% also watch TV/listen to the radio.

Two children have responsibilities within the home. Both sweep outside/inside, serve water to wash hands and toss rubbish. The second child also washes dishes, cleans up things and fetches water for the family. This second child is in a family where his other two siblings also have developmental disabilities and has been recognized as one of the most capable of the three. Though marginally active in home life, 100% (6) of children go with the family outside of the home. All of these children attend school/day care. 83% (5) attend religious services and go to the local shops. 66% (4) use public transportation, and go to the market. All of these activities occurred 5 times per week or more.

All of the children play with others, 5 children play both inside and outside of the home and one child is allowed to play outside and at the school/day care center. All children played with neighbors, 4 children played with children from school, and 4 children played with siblings. All respondents played with these people 7 times or more each week.

The families overall felt negatively about the community and their neighbors, stating that they were overall a little comfortable (a score of 2.3 for the community and 2.6 for the neighbors). All parents felt positively about having their children interacting with the teachers at school.

MENTAL DIFFICULTIES/RETARDATION

8 children are diagnosed with mental difficulties. Although several children have a cross diagnosis of epilepsy or autism with mental difficulties, this category is reserved for those with a sole diagnosis of mental difficulties. This category includes 3 males and 5 females. Three are between the age of 6-10 and four are between the ages of 11-17 and 1 is 18 or older, making this the oldest group overall. 3 respondents (37.5%) were diagnosed between the age of 0-2, 1 was diagnosed between the age of 3-5, 2 were diagnosed between the ages of 6-8 and 1 was diagnosed after 8 years of age. Following the diagnosis, 75% (6) families responded negatively, with one husband divorcing his wife after learning of the child’s condition. 1 family reacted indifferently the remaining family positively. 62% (5) of neighbors reacted negatively, and the remaining neighbors reacted indifferently to the news. This group had the most positive parents overall, with 3 (37.5%) parents reacting very positively initially, 2 (25%) parents reacting indifferently or feeling okay about the news and 3 (37.5%) parents reacting negatively.

75% (6) of families reported that reactions have changed with time. 66% of parents saw their own reactions become more positive or improvement in their relatives or neighbor’s perspectives. One parent noted that some relatives felt worse with time. The children average 8.5 skills each (77% competency) and struggle with talking. Females averaged 9 skills and males averaged 8.3 skills. All of the respondents attend school full time, 50% watch television/listen to the radio, 62.5% play at home, and 1 child sits at home or sleeps outside of school.

75% of children had responsibilities within the homestead. One child was only allowed to serve water to wash hands as the mother did not allow her to do other things around the house. The most common responsibilities were to wash dishes/utensils, clean up things, sweep outside/inside, and to toss rubbish. One child also cooks/assists with cooking, and another child fetches water. One mother remarked that the child used to sit and now they have realized the importance of involvement due to the school’s intervention in the situation. Females with responsibilities within the home accounted for an average of 4.75 chores, while males accounted for an average of 6.5 chores.

87.5% of children accompany their families outside of the home. All of the children who accompany their families outside the home attend religious services with their families and school/day care. 6 (85%) go to the local shops, with one child going independently, 5 (71%) use public transportation and 3 (42%) go to the market. Females who accompany their families averaged 3.75 activities outside of the home and males averaged 4.3 activities.

87.5% (7) of children play with others, 4 females and 3 males. 5 children play both inside and outside, one child plays inside the home and another plays outside the home. 5 children play with neighbors, 3 children play with siblings or children from school and one child plays with those younger than her. One parent did not respond. All children play outside 7 times per week.

 The families overall felt okay about the community, giving an overall score of 3, although one parent stated that her child had been abused several times within the community and didn’t know what to do about it. Neighbors were also given an overall score of 3 with one parent remarking that they felt very good and don’t worry at all about leaving their child with a neighbor. All parents felt positively about having their children interacting with the teachers at school giving a score of 4.8 overall.