

“But who can I talk to?”
Psychological Services for the Parents and Children of APDK

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Abstract

This is a study examining the adequacy of the psychological services and support offered by the Association for the Physically Disabled of Kenya, APDK, to the children in its care and the families who utilize the centre. First and foremost this study examined the psychological effect physical disabilities have on children and their families to determine what services are necessary for these individuals. The availability of mental health services was then analyzed in the context of the need for them as expressed by children at APDK and parents of disabled children. It was discovered that very few services are available that address mental health even though all parties, specifically the parents of disabled children, communicated both a strong need and desire for therapy and counseling.

Introduction

Within Kenya, there are 1.6 million people living with some form of a disability; 640,000 of those people have a physical disability.¹ Today, at least 80% of the world's disabled population live in low income countries and the World Health Organization says that in these developing countries, rehabilitative services reach a mere 1-2% of the physically disabled individuals who need them.² This is a shocking assessment of how the majority of people with physical disabilities are living and, when one takes into account how disabilities can have an effect on people financially, emotionally, and even psychologically, it becomes clear how large of a problem this truly is. This research paper will first acquaint the reader with the impact disabilities have on families and the available services by delving into a review of the literature. The research that was undertaken for this project will then be explained.

Introduction: The Impact on Physically Disabled Children

Physical disabilities have been shown to have a psychological effect both on those who live with them and their family members making it necessary to provide these parties with adequate mental health care. The physically disabled are at a much higher risk for depressive symptoms across gender and age.³ Children are especially vulnerable as they have yet to fully develop a sense of self as a physically disabled person or coping mechanisms to deal with the hardships that come with a disability. Children's self-

¹ Association for the Physically Disabled of Kenya. APDK Home, 2009. 25 March 2009. <www.apdk.com>.

² Tinney, M.J.; Chiodo, A.; Haig, A.; and E. Wiredu. "Medical Rehabilitation in Ghana." Disability and Rehabilitation. June 2007; 29(11-12): 921-927.

³ Noh, Samuel and R. Jay Turner. "Physical Disability and Depression: A Longitudinal Analysis." American Sociological Association. 1988.

concepts are linked to the perceptions they have of their own abilities.⁴ This poses a problem for physically disabled children if they have yet to come to terms with what they can and cannot do. Children with a good self-concept tend to have better mental health; those with a poor self-concept are at risk for increased anxiety and depression.⁵

Children are highly influenced by their environment and by the messages they receive from interactions with others. For instance, children with chronic health conditions, including physical and mental disabilities, have been shown to feel less connected to their schools and to also harbor more negative feelings about school in general.⁶ This could stem from how they are treated by their peers. Children who are discriminated against by their peers are at risk for low self-esteem, social isolation, withdrawal, and adjustment difficulties.⁷ Indeed, children with disabilities often show higher levels of social isolation and decreased participation in activities appropriate for their age.⁸

It has been shown that in Western cultures children are more discriminatory towards those with cosmetic disabilities while in labor focused cultures, such as exist in most of the developing world, those with physical disabilities are looked down upon.⁹ In the developing world, the ability to move and perform manual labor are basic necessities for survival meaning that physical disabilities greatly interfere with people's day to day

⁴ Miyahara, M. and J. Piek. "Self-esteem of children and adolescents with physical disabilities: quantitative evidence from meta-analysis." Journal of Development and Physical Disabilities. Sept. 2006; 18(3): 219-234. p. 220.

⁵ Miyahara, M. and J. Piek. p. 219.

⁶ Svavarsdottir, E.K. "Connectedness, belonging and feelings about school among healthy and chronically ill Icelandic schoolchildren." Scandinavian Journal of Caring Science. Sept. 2008; 22(3): 463-71.

⁷ Harper, D. C. "Children's attitudes to physical differences among youth from Western and Non-Western cultures." Cleft Palate-Craniofacial Journal. March 1995; 32(2): 114-119. p. 114.

⁸ Cavallo, S.; Feldman, D.E.; Swaine, B.; and G. Meshefedjian. "Is parental coping associated with the level of function in children with physical disabilities?" Child: care, health and development. 2009; 35(1): 33-40. p. 33.

⁹ Harper, D. C. p. 114-5.

lives.¹⁰ However, children in all Western and Nonwestern studies prefer nondisabled children above all others showing that regardless of location, disabled children are discriminated against.¹¹

Though physically disabled children across the world experience some form of discrimination from their peers, children in the developing world seem to face more extreme forms of discriminatory violence. The belief of virgin cleansing, whereas having sex with a virgin will remove the HIV virus from one's system, has begun to grow across developing countries including numerous ones in sub-Saharan Africa.¹² Even before AIDS and the advent of this belief, the physically disabled were at a three times greater risk of being raped than their nondisabled peers.¹³ The physically disabled, especially children, are physically vulnerable; they often rely on others for simple assistance and are also assumed to be sexually inactive. All of these factors make them easy targets for men looking to be 'cleansed' by a virgin.¹⁴ Those with physical disabilities are already psychologically vulnerable; being raped will only cause further mental disturbance.

Introduction: The Impact on Families of Physically Disabled Children

Caring for a child with a disability is extremely stressful for parents.¹⁵ Stress itself can cause many problems such as frustration, anxiety, and even depression.¹⁶ This is demonstrated by the fact that parents of physically disabled children suffer with poorer

¹⁰ Harper, D. C. p. 115.

¹¹ Harper, D. C. p. 116.

¹² Groce, N. E.; and T. Reshma. "Rape of individuals with disability: AIDS and the folk belief of virgin cleansing." *The Lancet*. May 2004; 363: 1663-1664. p. 1663-4.

¹³ Groce, N. E.; and T. Reshma. p. 1664.

¹⁴ Groce, N. E.; and T. Reshma. p. 1664.

¹⁵ Eddy, L. L. and J. M. Engel. "The impact of child disability type on the family." *Rehabilitation Nursing*. May/June 2008; 33(3): 98-103. p. 98.

¹⁶ Bekry, A. A.; Ndeti, D M.; Mburu, J.; Obondo, A. and D. Kokonya. "Stress and stress management." *The African Textbook of Clinical Psychiatry and Mental Health*. Ed. Prof. David M. Ndeti. Nairobi: AMREF, 2006. 73-79. p. 74.

overall psychological health.¹⁷ Whole families are affected by having a physically disabled member; quality of life is significantly lower in those families as compared to families without a physically disabled child.¹⁸ Even though having a disabled child impacts the whole family, mothers seem to be hit the hardest. For mothers, depression is positively correlated to the level of their child's disability.¹⁹ Mothers who have physically disabled children experience more depression than their husbands or than mothers without physically disabled children.²⁰

Across the world, women shoulder the majority of childcare responsibilities; with disabled children, the duties rest even more heavily on them as they receive less support from their families in caring for the disabled child.²¹ This is due, firstly, to the withdrawal of the father when parenting seems too difficult and, secondly, to the mother's feeling that she is responsible for the child's condition.²² These hardships seem to be amplified in Kenya where traditional beliefs accredit the cause of a disability solely to the mother and often to witchcraft.²³ These attributions mean that a husband is often unreceptive to the child's needs if he has not already abandoned his family altogether.²⁴

Very few studies have been done on physical disabilities in Africa, not to mention Kenya. One study focused on the effect raising a child with cerebral palsy had on the

¹⁷ Ha, J.H.; Hong, J.; Seltzer, M.M.; and J.S. Greenberg. "Age and gender differences in the well-being of midlife and aging parents with children with mental health or developmental problems: report of a national study." Journal of Health and Social Behavior. Sept. 2008; 49(3): 301-16.

¹⁸ "Letter to the editor." p. 354.

¹⁹ Cavallo, S.; Feldman, D.E.; Swaine, B.; and G. Meshefedjian. p. 34.

²⁰ McConnell, A. D.; Furtris, T. G.; and S. Bartholomae. "Mothers of children with physical disabilities: influence of family processes on mothers' depressive symptomatology." Marriage & Family Review. 2009; 45: 68-83. p. 69.

²¹ McConnell, A. D.; Furtris, T. G.; and S. Bartholomae. p. 69.

²² McConnell, A. D.; Furtris, T. G.; and S. Bartholomae. p. 69, 71.

²³ Mwachari, Leia. Administrator. Association for the Physically Disabled of Kenya: Coast. Educational Tour. 3 March 2009.

²⁴ Mwachari, Leia. Administrator. Association for the Physically Disabled of Kenya: Coast. Informal Meeting. 23 March 2009.

health of caregivers in a small community in Nigeria.²⁵ This study found that raising children with cerebral palsy had an overwhelming negative impact on the health of the caregivers.²⁶ Also reinforced by this study was the idea of fathers removing themselves from the care of disabled children. The researchers found that 93% of the participants who brought in their cerebral palsied children were mothers; a mere 2.8% were fathers.²⁷ The fact that 7% of participants in the nondisabled control group were fathers shows that men seem to be more comfortable bringing nondisabled children to health centres.²⁸

The parents in this study emphasized the financial difficulties caused by having a child with cerebral palsy both in terms of basic costs for the child and the money lost by the inability of both parents to work.²⁹ They also discussed the social stigma they face as the community sees disabilities as the result of a curse or punishment by deities. Other impacts include the physical demand, time devoted to the child, and the emotional strain.³⁰ Researchers state that the stigmatization, whether real or perceived, causes mothers to keep their children at home rather than bringing them in for medical attention.³¹ This all adds to the pressure they feel which negatively affects their health.

Introduction: Available Services

Through examining the emotional and psychological effect physical disabilities have on families who live with them it is clear that some form of services are necessary. When examining medical services in developing countries like Kenya, one is confronted

²⁵ Hamzat, T. K. and E. L. Mordi. "Impact of caring for children with cerebral palsy on the general health of their caregivers in an African community." International Journal of Rehabilitation Research. 2007; 30(3): 191-194.

²⁶ Hamzat, T. K. and E. L. Mordi. p. 191.

²⁷ Hamzat, T. K. and E. L. Mordi. p. 193.

²⁸ Hamzat, T. K. and E. L. Mordi. p. 193.

²⁹ Hamzat, T. K. and E. L. Mordi. p. 194.

³⁰ Hamzat, T. K. and E. L. Mordi. p. 193.

³¹ Hamzat, T. K. and E. L. Mordi. p. 194.

with the reality that very little is available to the physically disabled in terms of physical rehabilitation let alone counseling or therapy. The majority of Kenya's physically disabled population live in rural areas which provide them little to no access to rehabilitative services. Beyond that, most of those people are extremely poor and so cannot afford to search for or even utilize available services.³² This is especially discouraging when examining how early admission to rehabilitation for physical and occupational therapy has been shown to help reduce the gravity of a disability.³³ In fact, rehabilitation is thought to most benefit a child when done at a young age.³⁴ In a study done in Canada the average waiting time for occupational therapy was five months and over four months for physical therapy.³⁵ The fact that this much time was lost in a developed country bodes negatively for the situation in a developing country like Kenya.

A study done in Uganda might be more representative of the situation in Kenya. Uganda's disabled population is larger than most which can be attributed to circumstances caused by poverty such as unsanitary conditions, contagious and communicable diseases, malnutrition, and war.³⁶ Poverty both causes an increase in disabilities and prohibits access to and availability of rehabilitative services. In this particular study, forty-nine disabled people were interviewed.³⁷ In this study, the majority of the participants were unable to secure the aids they needed. The primary barrier to medical services in this population was financial; aids are generally very expensive for

³² Association for the Physically Disabled of Kenya. <www.apdk.com>.

³³ Feldman, D. E.; Champagne, F.; Korner-Bitensky, N. and G. Meshefedjian. "Waiting time for rehabilitation services for children with physical disabilities." *Child: Care, Health & Development*. 2002; 28(5): 351-358. p. 351.

³⁴ Feldman, D. E.; Champagne, F.; Korner-Bitensky, N. and G. Meshefedjian. p. 356.

³⁵ Feldman, D. E.; Champagne, F.; Korner-Bitensky, N. and G. Meshefedjian. p. 355-6.

³⁶ May-Teerink, T. "A survey of rehabilitative services and people coping with physical disabilities in Uganda, East Africa." *International Journal of Rehabilitation Research*. 1999; 22: 311-316. p. 312.

³⁷ May-Teerink, T. p. 313.

the population who needs them.³⁸ An inexpensive way to offer aids to the disabled population would be through CBR, or community based rehabilitation which was unavailable to this population.

In other communities, some of which are in Kenya, CBR is a valid option and quite a successful one. Community based rehabilitation programs have many different goals. They teach disabled people skills to carry out their daily activities to help improve mobility and autonomy; they also teach parents how to exercise their disabled child.³⁹ Some provide schooling to children with disabilities by helping with finances and in convincing parents to send their child to school. They often offer socio-economic support such as self-employment opportunities and income generating projects. Additionally, they work to create public awareness about disabilities including causes and prevention.⁴⁰ CBR workers will go to people's homes to help with skills training; this work has been shown to lead to an increase in the learning of new skills, the ability to perform new activities, and increased mobility and autonomy.⁴¹

Along with that, CBR has been shown to improve the quality of life of disabled persons and their families. Evidence shows that it helps to change the perceptions of disabilities that parents of disabled children and other relatives have.⁴² One year after beginning CBR, the majority of participants understood more about the disability, were more confident, and were less worried about their future.⁴³ An important aspect of CBR is how they can discredit myths about disabilities and dispel fears; this reduces the stigma

³⁸ May-Teerink, T. p. 315.

³⁹ Velema, J. P.; Ebenso, B. and P. L. Fuzikawa. "Evidence for the effectiveness of rehabilitation-in-the-community programmes." *Leprosy Review*. 2008; 79: 65-82. p. 67.

⁴⁰ Velema, J. P.; Ebenso, B. and P. L. Fuzikawa. p. 67.

⁴¹ Velema, J. P.; Ebenso, B. and P. L. Fuzikawa. p. 68.

⁴² Velema, J. P.; Ebenso, B. and P. L. Fuzikawa. p. 72.

⁴³ Velema, J. P.; Ebenso, B. and P. L. Fuzikawa. p. 76.

felt by disabled people and allows them greater equality.⁴⁴ CBR can increase knowledge about disabilities which can create hope for the future for disabled people and can improve community members' views of disabilities.⁴⁵

According to one article, CBR's strength lies in the fact that it follows the four principles set down by the World Program of Action Concerning Disabled Persons, a UN initiative ratified in 1982. The principles are: 1) disabled persons should remain within their own communities and share ordinary lifestyles with necessary support; 2) disabled persons should take part in decision-making at all levels, both in general community affairs and in matters that particularly concern them as people with disabilities; 3) disabled persons should receive the assistance they need within the ordinary structures of education, health, social services, etc.; and 4) disabled persons should take an active part in the general social and economic development of society, and their needs should be included in national planning; disabled persons should have adequate opportunity to contribute to national development.⁴⁶ Though access to services is limited, CBR represents an initiative to create real change in the lives of disabled people in the developing world.

Introduction: Current Research

This project will examine the psychological support physically disabled children and their families receive through the Association for the Physically Disabled of Kenya, or APDK. The aim is to determine the adequacy of the psychological health services available through APDK Coast Branch, located in Mombasa. To do so, an assessment

⁴⁴ Velema, J. P.; Ebenso, B. and P. L. Fuzikawa. p. 76.

⁴⁵ Velema, J. P.; Ebenso, B. and P. L. Fuzikawa. p. 78-9.

⁴⁶ Asindua, Shaya. "What is CBR in the African context?" CBR a Participatory Strategy in Africa. 26-36. p. 34.

first must be made of the psychological effects physical disabilities have on those who live with them and their families. Doing so will also help demonstrate what services are necessary for disabled children and their families. As that is a relative question, opinions will be obtained from both psychological professionals and the individuals in question. The next area of focus will be to judge if those necessary services are in fact available through this organization.

To answer these questions, time was spent at the centre observing the children and their behaviors. Interviews were conducted with children at APDK, parents of physically disabled children, APDK staff, and clinical psychiatrists. This was all done to assess the services offered by APDK, how those involved with the centre feel about those services, and what they would like to see added or improved. The goal of this research project was to get an overall idea of how satisfied children of APDK and parents of disabled children are with the psychological services available through APDK Coast.

Physical disabilities undoubtedly cause psychological harm and suffering to those living with them. Sadly, the damage does not stop there; families with disabled children are also strongly affected by the child's disability. These individuals are at risk for mental distress and their needs must be addressed.

Setting

This study was conducted at the Association for the Physically Disabled of Kenya (APDK) Coast Branch which is located in Mombasa, a city on the coast of Kenya. APDK's aim is to provide rehabilitation to persons with disabilities though it offers numerous services to ensure that it can go above and beyond this aim. This is demonstrated with their mission statement which asserts APDK's intent "To enable

people with disability to overcome their physical limitations and empower them socially and economically to become self reliant and fully integrated members of their communities.”⁴⁷

The nine APDK branches across Kenya provide services ranging from medical rehabilitation to vocational and community training to economic empowerment through employment and micro-finance programs.⁴⁸ According to APDK, the majority of people with disabilities live in the slums or rural areas making it difficult for them to access rehabilitation or medical services. Because of this, APDK has mobile clinics which make trips to rural areas to create awareness on the causes of physical disabilities; they also aim to educate those in rural areas about how to prevent and manage numerous disabilities.⁴⁹

APDK Coast works with children between the ages of three and eighteen and helps treat physical disabilities such as clubfeet, bow-legs, spina bifida, and cerebral palsy.⁵⁰ APDK Coast provides medical rehabilitation services to as many children as it can and has room for sixty. Children are admitted via a wait list where more severe cases are given priority. Families are asked to pay a small fee, depending on what they can afford, as the majority of children who are admitted here come from poor families.⁵¹

Besides physical therapy, APDK provides surgery, performed by volunteer doctors, for those who need it. They also have an on-site school with two teachers, one of whom has special education training. The school caters to children of all ages and works at each individual’s level.⁵² The Coast branch also has employees who build walking aids

⁴⁷ Association for the Physically Disabled of Kenya. <www.apdk.com>.

⁴⁸ Association for the Physically Disabled of Kenya. <www.apdk.com>.

⁴⁹ Association for the Physically Disabled of Kenya. <www.apdk.com>.

⁵⁰ Mwachari, Leia. Administrator. 3 March 2009.

⁵¹ Mwachari, Leia. Administrator. 3 March 2009.

⁵² Mwachari, Leia. Administrator. 3 March 2009.

such as leg braces, crutches, special shoes, and artificial limbs. These aids are available to any disabled person who needs them, not just the children staying in APDK. In total, APDK Coast employs 72 people; along with those listed above, these employees include physical therapists, occupational therapists, those working in the field with community based programs, the administration, and a social worker.⁵³

There is only one social worker who comes to APDK, Mary Akumu. Mary is APDK's first social worker; she has been employed there for one year and only comes to the centre on Fridays. She was trained in social work for clubfoot treatment and rehabilitation and, as clubfoot therapy occurs on Friday, she only counsels parents who bring in their children then for clubfoot rehabilitation.⁵⁴ All other parents of both in- and out-patients, not to mention all the children, are not told about Mary's services and so do not have access to them.

Loice Makanga is a social worker affiliated with APDK who works under Salim Bukari, the Community Based Rehabilitation (CBR) Coordinator. Both of these individuals work at Bombolulu, an APDK workshop that offers employment opportunities and housing to adults with physical disabilities. Neither of them works directly with children at APDK but instead do community based work which includes visiting homes of physically disabled children within Mombasa, some of whom have been discharged from APDK.⁵⁵ The CBR staff help educate the public on disability issues. Through home based care they teach parents skills and exercises for their disabled

⁵³ Mwachari, Leia. Administrator. 3 March 2009.

⁵⁴ Akumu, Mary. Social Worker. Association for the Physically Disabled of Kenya: Coast. Interview. 17 April 2009.

⁵⁵ Mwachari, Leia. Administrator. 23 March 2009.

children; this way, the parents are given the ability to better their own and their children's lives without relying on outside therapists.⁵⁶

Having a disabled child has been proven to affect family members' psychological health making it necessary to provide an outlet for their stress. Additionally, it is apparent that a disability can affect a child's mental health and therefore it is equally essential to provide counseling to children with physical disabilities. The psychological stress of the parents might even heighten the mental anxiety experienced by the child. APDK is an amazing centre and offers an incredible range of services to the physically disabled community in and around Mombasa. Unfortunately, the services geared towards psychological health seem inadequate at best.

Methodology

To begin with, time was spent at the centre to observe the daily schedule of the children and how they interacted with both each other and with their caregivers, which includes everyone from physical therapists to teachers. This participant observation allowed both staff and children to become familiar with the researcher's presence so she was viewed as less of an outsider. The first interviews were with APDK's administration. Leia Mwachari, the administrator at APDK, is responsible for the day to day running of the clinic. Jayne Kariuki, the program manager at APDK, was also interviewed. The third staff interview was with Masi Hemed who is the main teacher at APDK. She also acted as the translator for the duration of the author's time at the centre. These three interviews were formal and enabled an understanding of how the centre was run, what they thought of psychological health, and how they thought the children's mental health was affected

⁵⁶ Bukari, Salim. Community Based Rehabilitation Coordinator. Bombolulu. Interview. 20 April 2009.

by physical disabilities. These interviews were necessary because they were with people who knew these children well and have observed their behaviors overtime.

An attempt was first made to interview parents of in-patients though this proved nearly impossible as the majority live in rural areas outside of Mombasa making it difficult for them to visit. An attempt to obtain contact information for the parents who live in Mombasa was unsuccessful. Instead, interviews were conducted with parents of out-patients. These parents would bring their children to the centre in the morning, between ten and twelve-thirty, for physical and occupational therapy.⁵⁷ Twenty-six parents were formally interviewed, the majority of which were mothers, to gather information about their own and their children's mental health needs, what services they would like, and what services they knew about. Often the interviews continued informally after the formal questions were asked.

Nine children at APDK were interviewed to gather information about how they felt about their disability and how it affected them psychologically. These interviews were difficult and little reliable information was acquired. Reasons for this will be discussed in the Limitations section.

In order to collect data on the psychological services offered by APDK, Mary Akumu, the centre's only social worker, was interviewed. Also, Salim Bukari, the CBR Coordinator, was interviewed because he has a lot of interaction with families in the field. Loice Makanga, the CBR social worker, could not be interviewed due to a motorcycle accident. Instead, Samson Makanga, her brother and a CBR occupational therapist, was interviewed. Through these two contacts the author was able to attend a group discussion

⁵⁷ Mwachari, Leia. Administrator. Association for the Physically Disabled of Kenya: Coast. Interview. 14 April 2009.

for parents of disabled children in Likoni. The discussion focused on a new community centre which was both a school for disabled children and an assessment centre. Attending this session granted the researcher the benefit of witnessing a discussion group and seeing how community based rehabilitation actually functioned.

Esther Nyaguthi Khamis was also interviewed formally. Esther started a support group for mothers of children with hydrocephalus and spina bifida, the two disabilities her daughter lives with. Esther was interviewed in order to ascertain the benefits of parental support groups within Mombasa and the wider Coast Province.

Finally, professional psychiatrists were interviewed to better understand how physical disabilities might affect children mentally. Dr. Mahero, a prominent clinical psychiatrist who works in Mombasa, was interviewed. Also, an e-mail interview was conducted with Sheila Devane, a clinical psychologist who runs a mental health centre in Arusha, Tanzania.

APDK was aware of the research aims of this project from the beginning. A consent form was presented for the manager's signature allowing their staff and the children in their care to be spoken to with the intent of using their answers in a written document (see Appendix A). Informed consent was obtained prior to each interview. As the majority of the children are below the age of eighteen, they will remain anonymous in this paper and referred to with numbers in chronological order.

Discussion and Analysis: Effect of Physical Disabilities on Psychological Health

From the literature review, it is clear that there is a psychological impact from physical disabilities and also from raising a child with disabilities. The problem with judging this effect is that every person is different and will be affected differently. According to one clinical psychiatrist, the possible mental distress depends on that person's perception of their disability and how she believes it affects her in a plethora of ways including physically, emotionally, behaviorally, socially, and academically.⁵⁸ The possible effect also depends on one's personal buffers; that is, people's personal strengths and compensatory factors. These factors can include defense mechanisms which are the strategies people use subconsciously to deal with negative feelings. If people cling too strongly to their defense mechanisms, it can delay problem-solving behavior.⁵⁹ Numerous demographic factors also play a role in determining the potential mental effects physical disabilities can have. These factors can include age, gender, religious beliefs, school atmosphere, family system, and level of support from society.⁶⁰ Congenital disabilities and acquired ones can also lead to different results.⁶¹ Dr. Mahero, a clinical psychiatrist in Mombasa, believes that children who are born with a disability are treated worse than those whose disability develops after birth.⁶² Acquired disabilities often are due to an illness; people can understand this type of cause and so the child is accepted. For those with acquired disabilities though, their psychological reaction depends on their perceived sense of loss.⁶³ Yet another factor that might impact a

⁵⁸ Devane, Sheila. "Psychological Effect of Physical Disabilities." E-mail interview to the author. 29 April 2009.

⁵⁹ Bekry, A. A.; Ndeti, D M.; Mburu, J.; Obondo, A. and D. Kokonya. p. 77.

⁶⁰ Devane, Sheila.

⁶¹ Devane, Sheila.

⁶² Mahero, E. H. O. Personal Interview. Aga Khan Plaza, Mombasa. 27 April 2009.

⁶³ Devane, Sheila.

prospective mental reaction is the availability of medical care.⁶⁴ If one is able to access health care services immediately, the impact of the disability might be lessened.

Even though there are numerous factors involved, some hypotheses about mental outcomes can be made. People with disabilities, including children, are often stigmatized and discriminated against by their peers and the general community. Children who are sensitive in general or have yet to accept their disability are more prone to negative reactions because of this treatment.⁶⁵ Additionally, if a child can play and interact with other children then she would not think of herself as unfortunate. If the disability was more serious, then the mental effects could be stronger.⁶⁶ The child needs to have a healthy self-esteem and sense of self to be able to remain strong in the face of criticism.

On top of the factors mentioned above, children are susceptible to an additional impact depending on their primary caregiver, the capacity to care of their families, siblings' reactions, and additional support they receive. One important factor is the type of message the child is receiving from their social environment.⁶⁷ If a child is being talked about as the problem, as the victim of a curse, as being bewitched, or in any other negative way, this will greatly affect how that child feels about herself and her disability. On the other hand, if that child is told that she is special or a gift then she will most likely feel better about herself and the situation. A disabled child might be accepted but not loved or may be loved and be unaware of it. It has been shown that children who are

⁶⁴ Devane, Sheila.

⁶⁵ Mahero, E. H. O.

⁶⁶ Mahero, E. H. O.

⁶⁷ Devane, Sheila.

loved, and are shown that love, are more likely to be stable, confident, and well-behaved. Children who are not loved can be spoiled, unruly, selfish, and irresponsible as adults.⁶⁸

In Kenya there are certain beliefs people hold about physical disabilities that sustain the stigmatization towards disabilities. Typical ideas about the cause of disabilities follow traditional responses including witchcraft because of personal revenge or jealousy, curses within a clan or family, or a general bad omen.⁶⁹ The community puts these beliefs on the whole family causing stress for all; family members are also affected by these beliefs because they do not understand the actual causes.⁷⁰ In general, Dr. Mahero believes that the stigmatization towards mental afflictions is greater than that towards physical disabilities.⁷¹ It is important to keep in mind that the stress of physical disabilities can lead to certain mental conditions meaning that individuals might be discriminated against twofold, once for their or their family's physical disability and later for their mental distress.

Discussion and Analysis: Necessary Services

The risks posed to the mental health of individuals living with physical disabilities and their families are too great to ignore. It is impossible to know how a specific individual with a disability will react but services must be available for those whose disabilities lead to adverse consequences. According to psychiatrists, counseling will be important for those who are more affected by their disabilities and who are not coping well.⁷² As every child is unique, the effect depends on their personal resilience and the

⁶⁸ Musoke, R. and J. Mulimba. "Mental health: from the perspective of a paediatrician and surgeon." The African Textbook of Clinical Psychiatry and Mental Health. Ed. Prof. David M. Ndeti. Nairobi: AMREF, 2006. 24-27. p. 24.

⁶⁹ Mahero, E. H. O.

⁷⁰ Mahero, E. H. O.

⁷¹ Mahero, E. H. O.

⁷² Mahero, E. H. O.

social input they are receiving; be that as it may, there is plenty of evidence that therapy targeting negative issues in a child's life is better than no therapy at all.⁷³ Therapy for a disabled child should focus both on the child as an individual and as a member of their family.⁷⁴ Before deeming it necessary for all the children at APDK to receive counseling, a study should be done to assess the effect of counseling in a group of physically disabled children. A study like this could be unethical as the control group, those not receiving counseling, might contain children who are in desperate need of therapy.

Acceptance by one's family is extremely important in a child's conception of self. Because of this, it could be beneficial to have counseling sessions with the whole family. The two psychiatrists interviewed had conflicting views about the advantages of family therapy. Dr. Devane thought it best to proceed cautiously; having a child present with the parents could be dangerous as the child could become synonymous with the problem or could begin to assume the role of a victim. Counseling is a fairly new concept in East Africa so one would need to be fairly skilled to deal with this type of sensitive issue.⁷⁵ Conversely, Dr. Mahero is an advocate of family therapy. He believes that, as chronic illnesses affect a whole family, it is important for the members to share their personal feelings so that they can understand and support each other. Within this, he feels that parents must have realistic expectations of their child's abilities and state of mind; this lets them appreciate their child for what she can do.⁷⁶

Therapeutic services should also be made available to parents of disabled children. Group therapy can be extremely valuable in enabling parents to see others'

⁷³ Devane, Sheila.

⁷⁴ Devane, Sheila.

⁷⁵ Devane, Sheila.

⁷⁶ Mahero, E. H. O.

problems instead of solely focusing on their own as long as individuals feel comfortable enough to share their own experiences. They will be able to recognize that this has not happened only to their child; discussions help spread ideas about how better to care for one's child both fiscally and emotionally.⁷⁷ If services available to children and their parents are good and sensitive, then this can help the individuals involved to more easily accept the reality of their situation and move forward with their rehabilitation.⁷⁸

Discussion and Analysis: Psychological Services Available through APDK Coast

The Association for the Physically Disabled of Kenya has only had a social worker at their centre for one year. This social worker, Mary Akumu, only works on Fridays with parents who bring in their infants, up to the age of two, for clubfoot rehabilitation.⁷⁹ Mary's goal in her therapy sessions is to teach parents to love and appreciate their child. She believes educating parents about clubfoot and the nature of disabilities will help the parents spread that knowledge to other children and community members. A family must first accept their child; when the disabled are accepted by their families they will accept their disability and themselves. It is only when the family rejects them that they feel abandoned in life. Also, the family's acceptance of their child helps communities to understand that physical disabilities do not necessarily mean rejection for that individual.⁸⁰ Mary wants the parents to see their child as a blessing and spends a lot of time convincing parents that disabilities are neither the cause of witchcraft nor their own fault. Mary finds that some individuals go to traditional healers searching for cures but are unsuccessful. Eventually they turn to prayer and therapy and accept the situation.

⁷⁷ Mahero, E. H. O.

⁷⁸ Devane, Sheila.

⁷⁹ Akumu, Mary.

⁸⁰ Akumu, Mary.

Mary's counseling has strong religious undertones and, somewhat surprisingly, she spends the rest of her weeks attending a theology college in Mombasa. Her counseling revolves around the idea that these children merely have physical disabilities, not spiritual ones. By this she wants the parents to understand that their child is special and has been sent by God. This is difficult for numerous mothers to believe as they are often abandoned by their husbands and find it hard to believe that it was God's will for the child to be disabled. Mary points out how often these mothers have other children who are healthy to help dispel myths of curses and witchcraft. The only logical belief to Mary is that this child is special and that "God has a purpose for giving you this child."⁸¹

Bombolulu, a project started by APDK, houses APDK's community based rehabilitation (CBR) program. CBR has many components the primary one being home based care. CBR staff treat patients in their homes; they teach parents, mainly mothers, skills so that they can care for their own children. They also help with school placement for children and work to raise awareness and sensitize the public about disability issues. With parents, CBR helps train mothers in business and in matters of advocacy to help mainstream disability issues.⁸² The CBR staff employs a social worker but in reality the field workers all speak to the parents about general ways to cope and encourage them to love and stand by their child. According to the CBR coordinator, Salim Bukari, the importance of counseling children needs to be emphasized.⁸³ It is important to speak to the child as an individual and not through a mother as one might not be hearing the whole story. It is an area that has yet to be pursued and it is difficult as resources are tight. Salim

⁸¹ Akumu, Mary.

⁸² Bukari, Salim.

⁸³ Bukari, Salim.

mentioned that someone being a social worker does not necessarily mean that they are trained in psychology; this needs to be addressed.⁸⁴

CBR provides both individual counseling sessions and group discussion options to parents. In his experience, Salim has found that mothers are often depressed making caring for their child a greater burden. While counseling the parents, Salim hopes to get the point across that this is not just rehabilitation for the child but for the whole family; it is necessary to deal with all the challenges that come with having a disability.⁸⁵

Besides the official means of psychological support, there seems to be quite a compassionate community surrounding, at the very least, the children at APDK. According to the administrator, the children need love and attention which requires effort and patience on the part of the staff at the centre. First the child must be befriended by the support staff and nurses; the therapists will then get to know the children and help explain the nature of their disabilities. There is always interaction with the child which creates a supportive environment as all the staff are, in the end, there for the children.⁸⁶ Mary, the social worker, agrees that other members of the APDK staff speak to the children in therapeutic ways.⁸⁷ Masi Hemed, the head teacher of APDK, demonstrates the supportive nature of the APDK staff. Masi says that she often talks to specific children when they seem affected; they talk about how life is more than just their disability, how they are more than a disability.⁸⁸ Even though Masi is an example of APDK's supportive team, she also strongly believes that it is necessary to employ social workers for the children and that not doing so is one of APDK's weaknesses. In her opinion, a social worker

⁸⁴ Bukari, Salim.

⁸⁵ Bukari, Salim.

⁸⁶ Mwachari, Leia. 14 April 2009.

⁸⁷ Akumu, Mary.

⁸⁸ Hemed, Masi. Interview. The Association for the Physically Disabled of Kenya: Coast. 17 April 2009.

should come on certain days to speak to children who seem upset or who are having behavioral issues.⁸⁹

The fact that there are no psychological services offered to children at APDK and very few offered to their families is surprising. The one social worker at APDK, Mary, believes that there should be a social worker specifically for the children as they are internalizing the guilt they feel about being disabled and might begin to feel less worthy because of their disabilities.⁹⁰ In truth, these are only possibilities. To know the adequacy of the services offered by APDK, the situation of the children and disabled children's families must be examined to see the true need and demand for mental health services.

Discussion and Analysis: The Children of APDK Coast

Through time spent at the centre observing the children and speaking to the staff, it seems as if the children of APDK are pretty well adjusted. When first entering the clinic the children can be angry, sad, withdrawn, and even violent. They often do not eat and only want to be alone.⁹¹ They act this way because some were never loved or appreciated at home; over time, though, the love and patience of the staff draws the children out and they become happy and settled. Masi, their teacher, mentioned how some had behavioral problems at first but that these cases were rare.⁹² Through participant observation, these statements were confirmed. The children rarely seemed to act up and when they did staff members were on hand to speak to them. On average the children seemed overwhelmingly happy, at the very least content, with their situations.

⁸⁹ Hemed, Masi.

⁹⁰ Akumu, Mary.

⁹¹ Mwachari, Leia. 14 April 2009.

⁹² Hemed, Masi.

Of the nine children spoken to, only two could be considered articulate informants. The children on average responded very positively to all the questions asked; this became suspicious when one child said she found her disability “enjoyable.”⁹³ It is likely that the children were uncomfortable with the interviewer and responded quickly with answers in the affirmative, which they might have assumed were expected of them, instead of explaining their feelings more thoroughly. For instance, the seven inarticulate informants all said they were not treated differently at home and that they never had issues with their disabilities. The translator, Masi, was also the students’ teacher and wanted the interview to be akin to an English lesson. Because of this, she only translated the question when the child became visibly confused and distressed. Forcing them to speak in English was detrimental to the quality of the answers received.

Nevertheless, of the seven children who understood a question regarding their desire for a professional translator, all answered that they would like one. Child #2 qualified this with saying he would like to speak to someone who understood his situation; he implied that only those with disabilities could really understand.⁹⁴ Some of the children said they currently spoke to their friends when they felt sad or frustrated and that it would be nice to have a counselor. Another child said that she would like a counselor in order to have her disability better explained demonstrating the lack of knowledge the children have about their disabilities.⁹⁵

In fact, it was discovered that very few of the children had information on their disabilities. When asked what their disabilities were, they would answer vaguely saying things like, “my legs” or “I can’t walk.” This is quite worrying when you take into

⁹³ Child #7. Interview. Association for the Physically Disabled of Kenya: Coast. 24 April 2009.

⁹⁴ Child #2. Interview. Association for the Physically Disabled of Kenya: Coast. 16 April 2009.

⁹⁵ Child #8. Interview. Association for the Physically Disabled of Kenya: Coast. 30 April 2009.

account that “one of the most important elements in healing from disease has to be a two-way communication between doctor and patient...”⁹⁶ This was also surprising because Jayne, the program manager, mentioned that dialogue with the child about their disability is not focused on because it never comes up with the children.⁹⁷ It seems somewhat self-explanatory that understanding the nature of one’s disability would be helpful in dealing with it, especially in a culture where causes are attributed to curses and witchcraft. Dr. Mahero touched upon this lack of knowledge explaining that service providers do not see any benefit in explaining the disease they are treating.⁹⁸ They do not seem to understand that sharing information could help raise awareness about treatment and prevention of diseases, including disabilities. It might be that doctors who treat individuals who are poor or from rural areas assume that their patients are not educated and would not understand the nature of their illness. The primary provider should be giving patients this information but currently they do not unless the patient asks many questions.⁹⁹

The two articulate informants provided interesting insights into how they have adapted to their disabilities. Both of these boys are older and have had their disabilities since they were young. For the first boy, having a disability as a child was difficult. He had a hard time dealing with the hardships that came from being disabled, including his feelings about it. When he was young he would watch other children play games that he could not play as he was confined to his wheelchair. He said he was treated differently at home but at APDK they are all treated the same and are comfortable together because

⁹⁶ “The burden of mental illness.” The African Textbook of Clinical Psychiatry and Mental Health. Ed. Prof. David M. Ndeti. Nairobi: AMREF, 2006. 14-17. p. 15.

⁹⁷ Kariuki, Jayne. Program Manager. Association for the Physically Disabled of Kenya: Coast. 17 April 2009.

⁹⁸ Maher, E. H. O.

⁹⁹ Mahero, E. H. O.

“birds of a feather flock together.”¹⁰⁰ His coping mechanisms have improved over the years and he finds it easier to deal with having a physical disability now. There are still difficulties though, such as being unable to hang out and go to parties like other teenagers do but he seems to have accepted his lot in life and to have adjusted well.¹⁰¹

The second child was at first defensive, saying he was never treated differently at home. When asked about his feelings of sadness or frustration over his disability he responded, “everyone has those feelings, why are mine any different?”¹⁰² As the interview continued he admitted that he used to feel very alone because of the way he was treated but that now he felt that he could do and handle anything.

Both of these boys are in their late teens and have had a lot of time to adjust to life with a disability. They were pretty open in talking about their experiences and feelings and have clearly come to terms with having a physical disability and all that it entails. Each of them has come a long way in accepting themselves and seem to have healthy self-concepts which allows them to have higher self-esteem.

As has been shown, supporting and loving children is completely necessary which holds true when it comes to children with physical disabilities. The children all said they liked the staff at APDK and felt loved there. One child believes that they are very careful about choosing staff members as it is a special care institution and has found them to be very nurturing individuals.¹⁰³ From talking to the children, having a social worker seems like an excellent idea. A person in that position would be able to support the children, explain their disabilities, and talk them through negative feelings. This would be

¹⁰⁰ Child #1. Interview. Association for the Physically Disabled of Kenya: Coast. 16 April 2009.

¹⁰¹ Child #1.

¹⁰² Child #2.

¹⁰³ Child #1.

especially helpful for children who were less cared for at home and for those who have little to no understanding of their disability. Overall, from the data gathered and considering all the evidence, a social worker, if correctly trained, would only benefit the children of APDK.

Discussion and Analysis: Parents of Physically Disabled Children

Some of the problems apparent with the children also occurred in interviews with the parents. It seemed as if the twenty-six parents interviewed were not comfortable with the interviewer and this might have influenced the honesty of their answers, especially to questions about their difficulties raising a disabled child. For instance, when asked if they ever felt frustrated the majority of parents said they did not. When asked what was difficult about raising a child with disabilities they said nothing. However, when later asked who they spoke to when they were frustrated they would respond as opposed to denying those feelings. If a question was opened with, “I know it can be hard raising a disabled child...” followed by the question, they seemed to be more comfortable answering. It is completely natural for all parents to feel frustrated and upset at times, let alone parents of children with physical disabilities who require much more time and effort and whose illnesses can cause worry.

Only two parents interviewed did not express an interest in having a professional counselor at APDK. Dora, whose son Victor had cerebral malaria as a child and now cannot walk due to weak legs, is satisfied with the counseling she receives from her pastor and so does not have a need for a professional counselor.¹⁰⁴ Clemence does not care about a counselor for herself because she is only concerned with her son Emanuel

¹⁰⁴ Dora. Interview. Association for the Physically Disabled of Kenya: Coast. 4 May 2009.

receiving proper treatment and recovering.¹⁰⁵ The other twenty-four parents interviewed expressed anything from an affirmative grunt to a fervent yes in response to the question of a possible counselor. One mother, Zakia, said she was not aware that APDK had a social worker and would go to counseling sessions immediately if given the option.¹⁰⁶

It was interesting that two of the parents who talked at length about the need for a counselor both had children with very mild disabilities. Margaret, whose son Sam's legs have recovered to near perfection, lamented that she had searched for a counselor all over, even at APDK, but had been unsuccessful.¹⁰⁷ Franklin, one of the few fathers interviewed, came to the clinic with his whole family. They were there for his son Marshall who started walking late and had a problem with one of his feet; it could not hold his whole weight. Franklin expressed a large need for a professional counselor to give him and other parents more information on disabilities as well as provide therapy sessions.¹⁰⁸

Multiple parents mentioned the fact that a counselor would help raise awareness about disabilities and better explain the cause of their child's disability. When asked what disability their child had, many of them responded in the same ways the children had: with comments like "she can't walk" or "his legs are weak." Some parents knew the names of their children's disabilities such as clubfoot (six cases), cerebral palsy (five), spina bifida (two), and hydrocephalus (one), but even those parents admitted to having little to no information about the disabilities and their causes. And then there were the parents who had the exact opposite information; their children had disabilities without

¹⁰⁵ Clemence. Interview. Association for the Physically Disabled of Kenya: Coast. 15 April 2009.

¹⁰⁶ Zakia. Interview. Association for the Physically Disabled of Kenya: Coast. 15 April 2009.

¹⁰⁷ Margaret. Interview. Association for the Physically Disabled of Kenya: Coast. 30 April 2009.

¹⁰⁸ Franklin. Interview. Association for the Physically Disabled of Kenya: Coast. 28 April 2009.

names but they knew the cause. These were mostly children who were partially paralyzed due to meningitis and children who had weak legs who were unable to walk either because of cerebral malaria or premature birth.

As a professional counselor is unavailable, these parents have found other outlets for their frustrations and sources of comfort and support. Ten of the parents interviewed said they talked to their spouses when they felt upset or frustrated. Others talked to family members such as parents or siblings and some talked to friends and neighbors. A few of the parents stressed how important these individuals' support was; one mother said it was her sisters and brothers who gave her the "morality" to continue caring for her child and bringing him into APDK.¹⁰⁹ Another mother responded to the question sadly saying that she had no one to talk to and prayed for guidance and support; this was especially hard to hear as her husband was sitting nearby.¹¹⁰ Many parents talked about their religion and God as pillars of support as well as explanations for the source of the disability. Numerous mothers said that because they trusted in God they were not worried about their child; their belief gave them hope and faith that their child would be cured.

On the other end of the spectrum are parents who truly have no one to speak to and are in desperate need of help. This was blatantly clear with one woman, Mariam, whose son Abdullah has hydrocephalus and is unable to sit or walk. Her community has completely shunned her and her son. No one goes near them; even her own family will not come see her or her son because they believe the disability is contagious. Mariam is a single mother with two other young children and is unable to work because of the care

¹⁰⁹ Meswale Abdullah. Interview. Association for the Physically Disabled of Kenya: Coast. 24 April 2009.

¹¹⁰ Clemence.

Abdullah requires.¹¹¹ This is a clear example of a mother with no one to turn to who would benefit greatly from the services a social worker has to offer. Even though Mariam has been completely discriminated against by her family and community, she has found some solace in her conversations with other parents where they discuss disabilities, the treatment they receive from their communities, and how to cope with it.¹¹²

The majority of the interviewees had spoken to other parents with disabled children and found their conversations extremely helpful. These conversations revolved around the disabilities their children have, reasons for them, and ideas for helping their children and themselves. The fact that parents find these interactions so helpful might suggest the benefit of group therapy, support groups, or group discussions. One woman, Esther, had this exact idea and decided to start a support group for mothers of children with hydrocephalus and spina bifida. Her daughter, Mercy, was born with these disabilities and both Esther and Mercy were discriminated against by their community.

After realizing how many discouraged mothers she came into contact with, Esther and twenty-six other women decided to start a parental support group in 2005.¹¹³ Their objective is to raise awareness among women about prevention and treatment of hydrocephalus and spina bifida as well as spreading a message of tolerance for disabled individuals. Since 2005, Esther's group has grown to include 104 mothers from all along the Coast Province who meet every three months. In their meetings they encourage one another to stay positive and to continue loving and caring for their child. Esther attempts to counsel the women when she can drawing from her own experiences but, as she

¹¹¹ Mariam. Interview. Association for the Physically Disabled of Kenya: Coast. 30 April 2009.

¹¹² Mariam.

¹¹³ Nyaguthi Khamis, Esther. Interview. Mombasa. 4 May 2009.

explains, it is not enough to rely on her own wisdom.¹¹⁴ Esther hopes to earn a counseling degree so that she can counsel women at APDK and in her group; currently though she does not have the money to pay for this herself and APDK does not have the funds to support this education.

Esther believes that APDK is in strong need of a counselor for the parents of disabled children. She sees numerous stranded and panicked parents who have no information and no one to turn to. The largest need, she believes, is for the parents who have just discovered their child's disability and first come to the centre. There needs to be primary support and counseling for those individuals so they do not become overwhelmed with the situation.¹¹⁵

There are also parental group discussions arranged by APDK's CBR program. One such meeting was held on April 21 in Likoni at the Lengo Community Transition Centre; a new centre that is a school for disabled children and female orphans as well as an assessment centre.¹¹⁶ An assessment centre, in this context, is a place where physically disabled children can be examined by doctors and referred for treatment and schooling. The purpose of this meeting was to share information about this new centre with parents from the area; it is an important location as it is the first assessment centre on the Kenyan mainland meaning that the parents no longer need to cross the ferry.

In general, the meeting seemed like an excellent resource to get parents in contact with each other and to learn about options and resources for themselves and their children. The centre will be a boarding school for those who cannot commute, will provide counseling and guidance, as well as the aforementioned assessment services. The

¹¹⁴ Nyaguthi Khamis, Esther.

¹¹⁵ Nyaguthi Khamis, Esther.

¹¹⁶ Group Discussion. Lengo Community Transition Centre, Likoni. 21 April 2009.

meeting was run by John Mwakuenda, who is both the coordinator of this centre and APDK's educational specialist, and two other CBR workers. They did an excellent job of explaining the centre and its goals. They stressed the fact that fathers should come to future meetings as ten mothers came but only one father did. Also, they spent a lot of time explaining to the parents how they must be patient with their children and, although they understood it can be hard, they must not stop loving and caring for their children.

Considering what has been found through interviews with parents, some suggestions for improving these discussions could include a larger focus on parents' negative feelings to help normalize them and assure these individuals that feeling frustrated does not mean they are bad parents. Also, more time might have been spent allowing the parents to talk and lead the discussion so that their issues were addressed.

All those mentioned above are individuals who do not have access to the APDK's social worker. There are a group of parents who do: those whose children have clubfoot and are young enough to attend the clubfoot rehabilitation on Fridays. These lucky few have the opportunity to be counseled by Mary Akumu and seem to be wholly receptive to and thankful for her services. Three mothers, Ruhema, Mwanajuma, and Anne, have all attended therapy sessions with Mary. In counseling sessions, they discuss the disability and their feelings and expectations. Mary provides advice and helps give them faith and hope for their child's recovery.¹¹⁷

From the research done with parents of physically disabled children, it is clear that there is a large desire of and need for more social workers and counseling services.

¹¹⁷ Anne, Mwanajuma, and Ruhema. Interviews. Association for the Physically Disabled of Kenya: Coast. 24 April 2009.

These parents, mostly mothers, need emotional support and much more information about their child's disability, reasons for it, and advice on how to cope.

Conclusion

From the research done for this project, it is necessary for improved psychological services to be available to both the children at APDK and the parents of disabled children who seek treatment there. For many, this desire is not overt but lurks silently beneath the surface. Children would benefit from these services as they would be able to work through any adjustment difficulties they might be having with their disabilities. While it is not guaranteed that all children would require these services, the fact that absolutely none are available is unacceptable and must be addressed.

It seems, though, that the group that would benefit from counseling services the most would be the parents, specifically the mothers. These women have very few options as it is and are expected to care for their children without any complaints or any stress. This is obviously impossible and they need to be able to share their feelings and receive positive feedback. Currently few group therapy options are available and, though these are beneficial, the services need to be greatly expanded. Parents should not have to search far and wide for therapy opportunities but rather be presented with adequate options to address their health needs.

It needs to be noted that the Association for the Physically Disabled of Kenya is an extremely effective and valuable organization caring for a group of people that have been wildly underrepresented and ignored for a long time. They are stretched thin with their budget as it is and are doing all they can for their children. It is the government of Kenya that needs to take a greater responsibility in caring for the health of its people,

especially in the area of mental health which has been notably overlooked and underfunded.

It was encouraging to speak to different individuals in APDK's administration as almost all of them seem to recognize the need for better mental health services. It is clear that they understand this is an area that needs to be paid more attention to and improved upon. Psychological health is an extremely important area of one's overall well-being but is often ignored. Though APDK is working hard to better the lot of the physically disabled of Kenya, the area of mental health is still being neglected. It is imperative to protect the physically disabled and their families from undue psychological suffering by providing adequate mental health resources.

Limitations

There were numerous limitations to this research project. First and foremost, the entire study had to be planned, implemented, and concluded in the span of four weeks. This was especially difficult because of the sensitive nature of the questions being asked. Parents and children were expected to open up to the researcher after a few minutes of conversation; in the experiences of the CBR coordinator it takes parents between one and three months to share their personal feelings of stress and frustration.¹¹⁸ This caused the information received from the interviews to be somewhat questionable.

The interviews with the children were, on average, wholly unsuccessful. As was already mentioned, the translator was the children's teacher meaning that she expected the interviews to be English lessons. When the children did not understand a question, she would translate the question loudly and somewhat angrily. Because the interviews were conducted in the classroom, other children would hear which meant the interviews

¹¹⁸ Bukari, Salim.

were no longer confidential. It is probable that children were less inclined to divulge personal information to a classroom of their peers. Their teacher's frustration also put them on edge causing them to want the interviews to end as quickly as possible.

An obvious limitation was the language barrier. Using a translator is never foolproof as many things are lost in translation; there was no way to know how certain words or ideas translated into Kiswahili or back into English.

Recommendations

This project provides numerous opportunities both for further research and for practical implementations of the results found. Research can be continued on this topic looking at the effects physical disabilities have on people here in Kenya or more specifically in Mombasa. Also, one could look further into the adequacy of mental health resources by setting up a study that compared the outcome of families who received therapy as opposed to those who did not. There is a lot of room for research in this field as not much has been done concerning mental health and physical disabilities in Kenya.

Based on the conclusions of this project, programs can and should be set up to train social workers and therapists to counsel children with disabilities and their families. Also, programs to raise awareness about psychological services should be created. These programs can discuss the benefits of group and family therapy and perhaps help families improve communication between their members. They could also provide incentive for parents to reach out to each other for additional support.

More research should be done to ensure that the mental health of this vulnerable population is addressed. Projects in this area of research would be extremely beneficial and could have lasting positive repercussions in the lives of numerous individuals.

Appendix A: Interview Questions

Questions for Children:

- Do you feel different from other children?
- How do you think about your disability? Do you consider it a disability?
- Do you ever feel sad because of it and wish to talk about it?
- How do children here at APDK treat you? Do you feel the same or different from them as compared to children at home?
- Did you attend school before APDK? How were you treated at school?
- Do you miss your family/being home (siblings)?
- How do you feel about leaving the centre?
- Are you happy to go home? Or sad? Why do you feel this way?
- How do you think things will be different at home?
- How do you think children at home will treat you? Do you think it will be difficult?
- What do you think of the staff at APDK?

Questions for Parents:

- What is your child's disability?
- Does your child act different from other children, not just physically but mentally or emotionally? Is he/she sadder, quieter, moodier...?
- What do you believe the cause of the disability is?
- Have people in your community treated you or your child differently?
- Who do you talk to when you are feeling frustrated, upset, or worried?
- Do you ever talk to other parents of disabled children? If so, do you find this helpful?
- Do you think having a counselor to talk is necessary for yourself? For the family as a whole?
- What do you think of the services offered by APDK? Do you think there should be more available?
- What are you most worried about for your child's future?
- What is most difficult about raising a child with a disability?

Questions for Social Workers/CBR staff:

- What are the beliefs about disabilities in communities where the children come from?
- How does this affect treatment?
- What is your opinion on the psychological needs of the physically disabled?
- Physically disabled children specifically?
- What psychological/counseling/therapeutic services are necessary for these children?
- What is focused on in current counseling sessions?
- Who is focused on – parents, children, or familial interaction?
- Reintegration – who is it harder on? Are they prepared for it? What kind of follow-up treatment occurs?

Questions for General APDK Staff:

- What are the beliefs about physical disabilities in the children's communities?
- Are many of these children discriminated against at home?
- Do you think physically disabled children have more mental stress? Sadness, depression, withdrawal, moodiness...?
- Can you see children at APDK acting like this? When do you see the most symptoms? When they first arrive, over time
- What kind of treatment/services do you think is necessary?
- Counselor: what's her role? For parents/kids?
- Do the children seem more comfortable together because they all have disabilities?
- How do you think reintegration will be for the children? Will it be hard for them to return to their communities? Will it be hard for their parents? Why?
- Do the children become sad after being at home? Are they treated differently?

Questions for Mental Health Professionals:

- What's the psychological effect or stress that comes from a physical disability?
- How does this present in children?
- Do you think some form of therapy is necessary for all seriously disabled children? Or do you think they should wait and see what symptoms they have, if any?
- What should be focused on in counseling sessions?
- Do you think this therapy is available? Do you think what's available is enough?
- How is the family generally affected by a disabled child?
- What kind of services, if any, should be available to the families?
- Is this highly influenced by the communities' feelings about the source of physical disabilities? How do communities generally feel about physical disabilities?
- Should children and families be counseled together or separately? Pros and cons?
- How difficult is reintegration? Because of family/peer/community feelings? Who is it harder on?
- Should there be follow-up treatment? Counseling, check-ups?

Appendix B: Children of APDK

Total: 39 children currently admitted

Females: 21

Males: 19

Disabilities:

Disability	Number
Cerebral Palsy	II
Amputee	II
Hemiplegia (half paralyzed)	II
Paraplegia (lower half paralyzed)	II
Hydrocephalus	I
Clubfoot	VI
Unhealed fracture; forced joint	II
AMC: joint problems	II
Knock-knees	VIII
Through-knee amputation	I
Bowlegs	VI
Polio	I

Age Breakdown:

Age	Number
3	II
4	I
5	III
6	VII
7	III
8	V
9	-
10	IV
11	I
12	-
13	II
14	I
15	V
16	II
17	III

Works Cited

Written Sources

- Asindua, Shaya. "What is CBR in the African context?" CBR a Participatory Strategy in Africa. 26-36.
- Bekry, A. A.; Ndetei, D M.; Mburu, J.; Obondo, A. and D. Kokonya. "Stress and stress management." The African Textbook of Clinical Psychiatry and Mental Health. Ed. Prof. David M. Ndetei. Nairobi: AMREF, 2006. 73-79.
- "The burden of mental illness." The African Textbook of Clinical Psychiatry and Mental Health. Ed. Prof. David M. Ndetei. Nairobi: AMREF, 2006. 14-17.
- Cavallo, S.; Feldman, D.E.; Swaine, B.; and G. Meshefedjian. "Is parental coping associated with the level of function in children with physical disabilities?" Child: care, health and development. 2009; 35(1): 33-40.
- Eddy, L. L. and J. M. Engel. "The impact of child disability type on the family." Rehabilitation Nursing. May/June 2008; 33(3): 98-103.
- Feldman, D. E.; Champagne, F.; Korner-Bitensky, N. and G. Meshefedjian. "Waiting time for rehabilitation services for children with physical disabilities." Child: Care, Health & Development. 2002; 28(5): 351-358.
- Groce, N. E. and T. Reshma. "Rape of individuals with disability: AIDS and the folk belief of virgin cleansing." The Lancet. May 2004; 363: 1663-1664.
- Ha, J.H.; Hong, J.; Seltzer, M.M.; and J.S. Greenberg. "Age and gender differences in the well-being of midlife and aging parents with children with mental health or developmental problems: report of a national study." Journal of Health and Social Behavior. Sept. 2008; 49(3): 301-16.
- Hamzat, T. K. and E. L. Mordi. "Impact of caring for children with cerebral palsy on the general health of their caregivers in an African community." International Journal of Rehabilitation Research. 2007; 30(3): 191-194.
- Harper, D. C. "Children's attitudes to physical differences among youth from Western and Non-Western cultures." Cleft Palate-Craniofacial Journal. March 1995; 32(2): 114-119.
- "Letter to the editor." Developmental Medicine & Child Neurology. 2000; 42: 354.
- May-Teerink, T. "A survey of rehabilitative services and people coping with physical disabilities in Uganda, East Africa." International Journal of Rehabilitation Research. 1999; 22: 311-316.

- McConnell, A. D.; Furtris, T. G.; and S. Bartholomae. "Mothers of children with physical disabilities: influence of family processes on mothers' depressive symptomatology." Marriage & Family Review. 2009; 45: 68-83.
- Miyahara, M. and J. Piek. "Self-esteem of children and adolescents with physical disabilities: quantitative evidence from meta-analysis." Journal of Development and Physical Disabilities. Sept. 2006; 18(3): 219-234.
- Musoke, R. and J. Mulimba. "Mental health: from the perspective of a paediatrician and surgeon." The African Textbook of Clinical Psychiatry and Mental Health. Ed. Prof. David M. Ndeti. Nairobi: AMREF, 2006. 24-27.
- Noh, Samuel and R. Jay Turner. "Physical Disability and Depression: A Longitudinal Analysis." American Sociological Association. 1988.
- Okasha, T. and D. M. Ndeti. "Mental health, spirituality, and religion." The African Textbook of Clinical Psychiatry and Mental Health. Ed. Prof. David M. Ndeti. Nairobi: AMREF, 2006. 115-122.
- Svavarsdottir, E.K. "Connectedness, belonging and feelings about school among healthy and chronically ill Icelandic schoolchildren." Scandinavian Journal of Caring Science. Sept. 2008; 22(3): 463-71.
- Tinney, M.J.; Chiodo, A.; Haig, A.; and E. Wiredu. "Medical rehabilitation in Ghana." Disability and Rehabilitation. June 2007; 29(11-12): 921-927.
- Velema, J. P.; Ebenso, B. and P. L. Fuzikawa. "Evidence for the effectiveness of rehabilitation-in-the-community programmes." Leprosy Review. 2008; 79: 65-82.

Interviews

- Akumu, Mary. Social Worker. Association for the Physically Disabled of Kenya: Coast. Interview. 17 April 2009.
- Anne, Mwanajuma, and Ruhema. Interviews. Association for the Physically Disabled of Kenya: Coast. 24 April 2009.
- Bukari, Salim. Community Based Rehabilitation Coordinator. Bombolulu. Interview. 20 April 2009.
- Child #1. Interview. Association for the Physically Disabled of Kenya: Coast. 16 April 2009.
- Child #2. Interview. Association for the Physically Disabled of Kenya: Coast. 16 April 2009.

Child #7. Interview. Association for the Physically Disabled of Kenya: Coast. 24 April 2009.

Child #8. Interview. Association for the Physically Disabled of Kenya: Coast. 30 April 2009.

Clemence. Interview. Association for the Physically Disabled of Kenya: Coast. 15 April 2009.

Devane, Sheila. "Psychological Effect of Physical Disabilities." E-mail interview to the author. 29 April 2009.

Dora. Interview. Association for the Physically Disabled of Kenya: Coast. 4 May 2009.

Franklin. Interview. Association for the Physically Disabled of Kenya: Coast. 28 April 2009.

Group Discussion. Lengo Community Transition Centre, Likoni. 21 April 2009.

Hemed, Masi. Interview. The Association for the Physically Disabled of Kenya: Coast. 17 April 2009.

Kariuki, Jayne. Program Manager. Association for the Physically Disabled of Kenya: Coast. 17 April 2009.

Mahero, E. H. O. Interview. Aga Khan Plaza, Mombasa. 27 April 2009.

Margaret. Interview. Association for the Physically Disabled of Kenya: Coast. 30 April 2009.

Mariam. Interview. Association for the Physically Disabled of Kenya: Coast. 30 April 2009.

Meswale Abdullah. Interview. Association for the Physically Disabled of Kenya: Coast. 24 April 2009.

Mwachari, Leia. Administrator. Association for the Physically Disabled of Kenya: Coast. Educational Tour. 3 March 2009.

Mwachari, Leia. Administrator. Association for the Physically Disabled of Kenya: Coast. Informal Meeting. 23 March 2009.

Mwachari, Leia. Administrator. Association for the Physically Disabled of Kenya: Coast. Interview. 14 April 2009.

Nyaguthi Khamis, Esther. Interview. Mombasa. 4 May 2009.

Zakia. Interview. Association for the Physically Disabled of Kenya: Coast. 15 April 2009.

Online Sources

Association for the Physically Disabled of Kenya. APDK Home, 2009. 25 March 2009. <www.apdk.com>.

Narrative Self-Criticism

For this project, I chose to analyze the psychological services that are offered at APDK to both children and parents. I looked at the effect physical disabilities have on children and families first through doing background research and talking to mental health professionals which gave me an idea of what services are necessary. After that I spent time in the field speaking to children and parents about how they felt they were affected by either having physical disabilities or having a child with physical disabilities and about what services they deemed necessary for themselves. This was done in order to determine if these services were in fact available at or through APDK. In the end I concluded that there was an extreme shortage of mental health services available even though these individuals had a clear need for them.

The strengths of this project lie in the fact that this is a wildly under-researched area meaning that my project helps to shed light on the parents and children who wish they had someone to speak to but who do not. This project provides a preliminary assessment of the current situation in the field and paves the way for further research to be done to help improve the lives of these individuals.

The fact that I had to get parents and children to open up to me, an outsider and a stranger, about personal feelings in such a short period of time was the main weakness of this paper. These parents do not want to be perceived as bad parents by talking about negative feelings and the difficulties they face raising their children. Also, my sample was not random; it represented families who had heard about APDK and who had the time and money to come to the centre for assessment and therapy.

In light of the amount of time and effort I put into this project I would give myself an A. I think this is a unique project examining an ignored area of health that was well-planned and successfully implemented. I am very happy with what I have accomplished and only wish that I had more time to spend with the individuals I met and more opportunity to help them receive the services they so badly need.