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SCHOOL ACCESS:

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UGANDA SOCIETY FOR DISABLED CHILDREN, UGANDA

KATALEMWA CHESHIRE HOME, KAMPALA, UGANDA

UNIVERSITY OF VICTORIA, B.C., CANADA

CHRISTIAN BLIND MISSION, GERMANY, CANADA, E. AFRICA

THE CANADIAN GOVERNMENT: CIDA/CBIE...

***... And my husband, Dr. J. Norgrove Penny,
whose love for God and children with disabilities
brought me to Uganda.***

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REPORT PART ONE : RECOMMENDATIONS

1. **Continued and increased community-level sensitization of parents, *particularly the maternal caregiver***, as to the importance of education for their children with motor disabilities. *Illiterate or less-educated parents* should be specific targets. *Male heads of households* should be encouraged to see the long-term benefits from releasing finances to put such children through school.
2. **Community sensitization** must also **target the children with the disability** themselves—if *at an early age* they can catch a vision for their future to see their own worth and potential, they will be more willing to make the increased sacrifices required for regular school attendance.
3. **Donations and subsidies** should focus on *relieving children with mobility disabilities from pain* as they move distances. This includes providing: wheelchairs, bicycles, properly-fitting crutches, braces and supports, surgery and physiotherapy.
4. **Parents** of children with motor disabilities can play a key role in sustaining their children's school attendance by doing the following:
 - a. Communicate supportively and regularly with their child's teacher.
 - b. Request that their child sit at the front of the class.
 - c. Report cruel behaviours of classmates.
 - d. Require another child to travel slowly to school alongside the child with disabilities, as protection.In addition, parents can help other similar children by word of mouth testimonies of how they have accessed help for their own child.
5. **Teachers'** special awareness regarding the needs of children with motor disabilities can greatly assist:
 - a. During rainy days, be lenient with lateness or absence.
 - b. If during the rainy season several days are missed, send work home so the child doesn't miss too much academic work.
 - c. Make an effort to supervise all children during breaktimes, so cruel behaviour doesn't occur towards such children (particularly the young children).
 - d. Be strict in the punishment if cruelty occurs.
 - e. Place the child at the front of the classroom so that he/she doesn't miss out on the actual teaching (particularly the young children).
 - f. Make sure he/she gets all the assignments that other children do.
 - g. Provide alternate physical exercises for the child during physical education class, find equipment that this child can play with.
 - h. Encourage the other pupils to be friendly towards the child:
eg. help carry the child's books or lunch, assist in moving the child, or play games with the child.
6. **School buildings** should be constructed with children with locomotor disabilities in mind:
 - a. Eliminate or minimize the doorsills/thresholds
 - b. Doorways should be wide enough for wheelchairs
 - c. If stairs are required, have a ramp alternative
 - d. Have at least one raised-seat pit latrine

REPORT PART TWO: QUALITATIVE ANALYSIS

Ugandan Children With Motor Disabilities

INTRODUCTION

Overcoming Isolation: Stepping Stones Towards Educating Rural Ugandan Children With Motor Disabilities

REVIEW OF THE LITERATURE AND COUNTRY BACKGROUND

Uganda is a land of many challenges, particularly in the area of education. The country has a high population growth rate, and a large proportion of the population lives in rural areas. This has led to a significant number of children, particularly in rural areas, who are not enrolled in school. This is due to a number of factors, including poverty, lack of access to schools, and a lack of awareness of the importance of education. In addition, there is a significant number of children with motor disabilities who are not enrolled in school. This is due to a number of factors, including a lack of awareness of the importance of education for children with disabilities, a lack of access to schools, and a lack of resources to support children with disabilities in school. The purpose of this study is to explore the challenges faced by rural Ugandan children with motor disabilities in accessing education, and to identify strategies to overcome these challenges.

Overcoming Isolation: Stepping Stones Towards Educating Rural Ugandan Children With Motor Disabilities

INTRODUCTION

In this grounded theory study I examine the various situations that mothers and their children with motor disabilities face, while seeking primary education in rural Uganda. The perspective of the data comes from the mother of the child, but is on behalf of the child and the environment in which he dwells. (For simplicity the male gender is used for the child throughout this paper, but represents both male and female). While the focus was on the child obtaining an education, as the study progressed it became clear that the major context of the child with motor disabilities was that of isolation; this paper proposes a substantive theory for the child in this circumstance. The quest for education is a journey, one major path that is travelled to overcome the isolation that the child with motor disabilities in Uganda faces.

REVIEW OF THE LITERATURE and COUNTRY BACKGROUND

Uganda is a data-poor country due to the lack of resources and continued civil strife in certain areas. There are no recent studies of which I am aware that focus exclusively on motor disabilities and school attendance. The estimation of children under eighteen in Uganda who have motor disabilities is 190,000 (EARS, 1997). This category is largely comprised of children who have succumbed to poliomyelitis or osteomyelitis (bone infection), or were born with clubfeet (Atria, 1994). The prevalence of polio in

Uganda is unusually high for Sub-Saharan Africa, because the years of civil strife Uganda faced during the 70's and early 80's made it difficult to continue the vaccination programs. In 1992 one percent of the children attending school were disabled in some form (MoES, 1992); this must be compared with the statistic that 10% of Uganda's children have a disability (Barton, 1994). It is clear that the majority of children with some form of disabilities were not getting education at the time of research.

In 1996 the Government of Uganda declared a Universal Primary Education (UPE) program providing four children from each paternal family with free primary schooling (EARS, 1997). The average family size per mother is seven children (Bellamy, 1999). While UPE does not cover every child in the family, its constitution declares prioritization of children between the ages of 6 and 18 who are girls, disabled, or orphans, recognizing their vulnerability. With the implementation of UPE, government schools became flooded with children, and primary classrooms of over 100 children became common. Within this milieu, the rural child with motor disabilities seeks education.

The benefits of primary schooling in developing nations are considerable, even when school quality is low (Colclough, 1980). Maternal education in Africa is one key to the enrollment factor (Lavy, 1992), but economics is the major factor in the decision to send children to school (Honig, 1995). The backdrop to school-going decisions in rural Uganda is one of poverty and subsistence farming. Although the financial returns on creating schools and sending children to primary schools in Africa are worthwhile, some parents cannot afford to invest now and be rewarded later.

Since UPE has been implemented, field workers testify that enrollment numbers of children with disabilities have increased to some extent, although no studies have

yet documented the details (S. Kisitu and F. Byansi, personal communication, June 19th, 1999). With the current favourable government, the continued under-enrollment of children with motor disabilities in primary school merits further investigation. My analysis presents conclusions based on a small purposive sample of rural mothers and grandmothers in a children's treatment centre. I do not attempt to explain all the complex and highly interactive processes affecting the decisions made by caregivers to send children to school. However, the indicated phases of the journey towards primary education for these children need to be defined and addressed by concerned citizens and organizations at the national, district, sub-county, village, school, and family level. To this end, I asked the mothers this research question: "How does a child with motor disabilities achieve education in rural Uganda?"

METHOD

Grounded theory as developed by Glaser and Strauss (1967) was chosen because of its usefulness in investigations of relatively uncharted waters (Stern, 1980). Variables of race, gender and social class must earn their way into the theory through the data analysis process. The group of nine female respondents were interviewed and analysed within the Ugandan culture by myself, a female North American researcher. Seven women were involved in the focus group, two of whom were further interviewed individually. Two new caregiver participants were also interviewed individually. The women's educational backgrounds varied from being illiterate with no schooling at all, to having a 'O' levels (equivalent to North American grade 10) and a teacher's college degree.

Data collection took place in a short-term rehabilitation hostel in Kampala, Uganda. All of the caregivers were from rural village or rural town settings within Lugandan-speaking districts, and had children with motor disabilities who were unable to walk unassisted (e.g. needed the use of crutches, braces, club, or had to crawl). Luganda is one of forty languages spoken within Uganda, and it is used by the Bugandan tribe. Nine children's lives were being queried in the study: six of the children were polio patients, one of whom also had a congenital hand deformity; two children were disabled due to osteomyelitis (bone infection); another had a congenital spinal deformity. The children's ages ranged from 6 to 15 years of age.

All respondents were solicited prior to the researcher's arrival through a Ugandan resident teacher in the short-term hostel; he later worked as a translator for the focus group and two of the interviews that were conducted in the Lugandan language with non-English speaking participants. The translator's familiarity with the mothers due to daily contact was a favourable element in the study, as was the female gender of the primary researcher. Before commencing the group discussion and the translated interview sessions, the translator and another fluent assistant cross-checked the translation of the questions into the Lugandan language and back to English again with the primary researcher. The questions were then fine-tuned in an attempt to minimize potential errors in translation. The Lugandan language is composed of a basic working vocabulary, and is not given to the psychological nuances of the English language. In-depth sharing of one's feelings about a situation is not a familiar part of cultural interaction, therefore responses had built-in linguistic limitations.

Ethical measures for permission, confidentiality and protection were taken. The written consent form included an explanation that the medical treatment the child received at the hostel would not be any different due to participation of the caregiver in the study. The translator and the respondents confirmed through their signatures or fingerprints that they understood the purpose, means and procedures of the study.

Data collection began with an hour-long focus group of seven women (six mothers and a grandmother). Five individual interviews lasting from 45-60 minutes followed: two consecutive interviews with an English-speaking teacher/mother who had extensive experience in primary schools; one interview with an English-speaking mother, who had worked out a detailed plan of cooperation with the private school her child attended; one interview with an unschooled illiterate mother whose child had never been to school; and one interview with a grandmother whose disabled granddaughter did not attend school. Finally, the translator, who is himself disabled, also had many insightful comments about disability, the school system and the Ugandan culture. After assisting in the interview process, he voluntarily gave his perspective on the issues being researched. His input was valuable as a caregiver and teacher of hundreds of children with motor disabilities who have been short-term patients in the rehabilitation home over the past ten years. Interviews were audio-taped and transcribed.

The focus group data was transcribed and analysed immediately, and the resulting categories were brought back to the participants during the individual interviews. The two English-speaking respondents were also part of the Lugandan focus group, and

they confirmed as well as added to the categories that had been formulated. Through later analysis of subsequent interviews, further categories were created, and existing ones revised. Using the translator, the researcher was able to re-question and clarify various uncertainties with respondents on the spot. The technique of rephrasing and repeating back to the respondent through the interpreter was helpful in light of the language barrier.

Hypotheses based on previous data and resultant categories were continually compared against incoming data. Existing data was re-mined, and memos were written recording further hypotheses, general thoughts, and future areas to expand on or clarify during interviews to come. Visual representations of the hypotheses were shared at several interviews, and their accuracy confirmed. However, it is of note that rural Ugandan women might be unlikely to contradict an 'educated Westerner'. Therefore this method of ensuring rigour in the developed world may not always be as accurate in the developing world where there is a more pronounced cultural, educational and power discrepancy between researcher and respondent. Perceived roles and expectations of assistance from the 'white person' became evident at one point during the focus group, when the researcher was asked for financial assistance to purchase a bicycle for a child with disabilities. At that time the purpose for the study and the consent information was reviewed, and the group continued in their discussion quite peaceably.

I have now lived within the culture of the respondents for the past three years, and have regularly volunteered with people who are similar to this sample group

throughout that time, although not at the rural setting. My experiences within the social, cultural and political context of Uganda colour the lens from which I view this study. I have spent several years being a part of a medical assistance program for children with motor disabilities. The shift of focus in this study towards education maintains my former advocacy perspective.

At the end of the study, a simplified diagram was given to the translator of the project at the hostel, who put it up for the mothers/caregivers staying there to view (See Appendix A). A copy of this paper in its entirety is left at the rehabilitation home for anyone to access. The main national newspaper also received an edited version of suggestions given by the respondents that would assist their children in crossing the stepping stones they face on the path to education. An insert article based on these suggestions was written for publication in late September 1999. This monthly newsprint article called "Straight Talk" is sent free of charge to every school district in Uganda (12,000 primary schools), and has national dissemination. I also purchased 1000 copies to be distributed amongst the work of Uganda Society for Disabled Children, and Katalemwa Cheshire Home children (See Appendix B).

Due to time limitation and the small sample, saturation was not reached; new issues continued to be revealed with every interview. However, the emergent theory's core category was evident in every respondent's interviews, as they shared their stories of watching their child 'being left behind' and 'unable to be with the others'.

RESULTS

The pursuit of education by the women in this study for their children with disabilities was seen as a series of many challenges (the Lugandan translation is 'problems'), or stepping stones used to journey away from the isolation that the children faced. The traditional calm, accepting front of the Ugandan women was probed as they shared their struggles and wishes for their children with disabilities. Education was not perceived by the women as an end unto itself, but as a means of bringing their children with disabilities out isolated positions in their small households. The ultimate goal of education was obtained when the children with disabilities had meaningful participation, becoming productive members of society who are self-supporting and socially interacting within their community.

Each step of the challenging path towards education is deeply intertwined with isolation issues for the child with disabilities; integration and participation become more possible with each progressive stride towards education. Physical environmental factors merge with the attitudinal persuasions of various actors within this process to influence the level of isolation that the child suffers, or is blocked at. The unanimous will of mother and child to pursue this course of overcoming barriers, in spite of the immense sacrifices, energy and pain, is a testimony to the amazing courage of these vulnerable women and children.

Overcoming Isolation consists of six sequential and interactive stepping stones along the journey towards education: 'Attaining Household Consensus', 'Securing the Funds', 'Crossing the Distance', 'Coping with Cruelty', 'Managing at School', and

'Achieving Learning'. A seventh category was formed to display the positive emotional supports from others that the child receives: these serve as 'Helping Hands' to assist him in his precarious journey, lending encouragement and stability at any place during his passage.

THE LIFE OF ISOLATION

The child with a motor disability in rural Uganda without an education is destined to remain at home without purpose and use. His world is not much larger than his hut, and the mat outside it. The lifestyle is physical: digging, collecting firewood, and carrying water. The definition of motor disabilities for this study was that the child must not be able to walk unassisted. Mobility would require the use of the child's hands, thus rendering the child's usefulness for physical labour very limited. The child with a disability is a burden on his family. Not only is his present scope limited, but his future is bleak. Without education, the child's life is bound to future poverty and dependency. The loneliness of isolation is also compounded by the fearful need for protection from those who choose to persecute others weaker than themselves. Isolation means not only being alone but, for a child with disabilities in this setting, it means being left behind; the child with disabilities watches the daily mass exodus of the village children to school, and is often unable to follow. Those children who are able to find the means and transport to get to school are still excluded to some extent by a school environment suited only for those who are able-bodied. Attitudes from peers and

teachers can sometimes force them to remain on the fringe as well. Education is not an easy escape route from isolation, and requires perseverance and fortitude.

ATTAINING HOUSEHOLD CONSENSUS

The first stepping stone to education for these children is attaining agreement in the family that the child with disabilities should attend school. The UPE government ruling that children with disabilities ought to be in school has favourably set the scene for parents to enroll these children. Parents are compelled to consider schooling as an option and not remain with the child hidden in their hut. The knowledge of causes of illnesses is increasing, removing some of the stigma and superstitions previously associated with disabilities. The translator explained, "Ten years ago the attitude towards disabled children was worse.... these children bear less shame now, but it is still there." If the child's disability was caused by an illness, a preliminary assumption before consensus can be achieved is that the child's health is now stabilized and he is otherwise physically well.

Within the Ugandan culture it is the 'woman's concern' to care for children in all aspects. In fact, there was laughter when the researcher questioned if the father was to play a role in securing an education for his children. At best the father was emotionally supportive of the child with disabilities, assisting financially with school costs. In a dual parent household, in order for consensus to be reached with the husband, a vision for the future of the child and the purpose of education had to be

realized. The child needed to be seen as a valued investment. Some husbands viewed school attendance as 'wasting money on a useless child', thus blocking progress to education at the beginning. In this patriarchal society the husband's will prevails; the mothers were not able to find alternate solutions for their children, particularly because the man is the financial controller. Half of the mothers in this study were raising their children on their own. Some fathers had so few coping mechanisms to deal with a newly disabled child, that they abandoned their families after realizing the child's disability was permanent.

Polygamy is common in rural Uganda; in households where there is a co-wife, it is possible for the child's educational chances to be hindered due to a jealous co-wife's influence on her husband to withhold funds. One mother in such a setting describes with sad acceptance: "It is my problem... I can do nothing." Consensus must be achieved in the household before the child's educational journey can progress any further than this first stepping stone.

SECURING THE FUNDS

Poverty is the overriding factor that deeply affects the lives of rural children in Uganda; the issue of money arises repeatedly during progress towards education. The rural economy is driven by subsistence farming, and it is still fairly dependent upon the barter system--actual cash is scarce: "My main problem is poverty...because I want to look after my family, but because of poverty I might fail". In addition to an average of seven children, many households take care of aging parents and orphans from relatives who have passed away due to HIV. The level of poverty severely

restricts the choices that families are able to make regarding schools. In addition, the more severe the child's disability is, the more expensive his journey towards education is going to be, due to the environmental and medical supports he will require.

Even the poorest parents who are determined to get their children into school need hard cash. Hidden school costs within the 'free' UPE program still involve the parent paying for books, pencils and uniforms. Additionally, there may be requests each term from government schools for funds to upgrade the buildings.

The UPE program may have begun with the best of political intentions, but the preparation to receive the influx of children has not been adequate. If a child is put into a UPE program, he may pay no official school fees, but a 'price' that the parents do pay is an immensely large class size, often well over 100 in the earliest grades. All of the mothers recognized that the standard of education in this situation is low even for the able-bodied children, and that teachers are ill equipped to cope with the vast numbers of children. One grandmother refused to make her child with disabilities suffer the journey to school, because she knew that under the UPE program her child "would not be taught anything anyway".

Private day schools are expensive, but offer a class size of about 40 instead of 120. Only one mother was "a little bit lucky as she has her son in a private school". She came from a two-parent household, where both she and the father brought in incomes. Single parents have a more difficult time 'Securing the Funds'.

Private boarding schools are more expensive yet, but they solve the difficult daily transportation issue that these children face. None of the parents interviewed could afford this option, although they mentioned their desire for it.

A varying amount of funds must be secured before the child with disabilities can progress on his journey towards education, and the amount of available funds correlates directly with the quality of the education the child receives. Fathers in households must agree to release the funds. Mothers on their own sacrifice to secure the means for whatever level of education they can afford, within a context where the means for survival is still a struggle.

CROSSING THE DISTANCE

The mothers all believed that the physical act of getting to school was the most difficult part of making sure that their child received an education. "The children stay home because of transport problems from home to school. It is an even bigger problem than the attitude of teachers and children."

In the developed world, disability rights advocates have stressed that coping with the physical aspects of a disability is far easier than the discrimination and oppression encountered by people with disabilities (Asch & Fine, 1988). But in this study within the context of Uganda, the families interviewed reported the opposite to be their case.

Some of the children were able to walk to school, using a club, stick, or crutches and braces. Another crawled to school in the dirt and mud, without knee protection. One was daily given a lift to school and back on a bicycle, and another hired a motorcycle to and from his private school. Three were not able to make it to school at all, one because it was too far to crawl, and two because their mode of locomotion was too slow (not able to crawl, they could only slowly inch forward on their behind). These

three could not afford any transport alternatives such as wheelchair, bicycle or motorcycle.

Single mothers or grandmothers had the hardest time in coming up with the funds required for bicycle or motorcycle transport. The schools varied in distance between 1/2 kilometer to 4 kilometers from the children's homes. It took the children from five minutes (motorcycle) to two hours to cross the distance.

Due to the weather, slowness, fatigue and pain, the child makes the journey alone most of the time. Even siblings instructed to remain with the child usually go on ahead. Every mother confirmed that this daily trek is a heavy burden on the child physically and emotionally. Even the child lucky enough to ride the motorcycle to school told his mother that "he wishes he could just walk with his friends". The hunger to belong, to be a part of the group with the others is very strong. The child can often cry from fatigue, cry from the pain, and cry from the shame at not being able to keep up.

Uganda is a tropical country with a high annual rainfall. There are two seasons that come every few months throughout the year: the wet season and the dry season. The rain comes down torrentially, churning up the red soil, making locomotion to school extremely difficult. The children who use crutches, clubs, sticks and leg braces find that the mud does not support them as they move, and they often fall in the mud on their way, arriving at school very dirty. There can be many days of school that the child may be absent due to the rain.

The child's slowness of mobility means that he not only makes the journey alone, but it is a longer process; he must get up earlier and start earlier than the others. They

pass him on the way. At times he will reach school late. Caning is still the most common form of punishment in school for misdemeanors, including lateness.

Fatigue is also an issue as the child with disabilities needs much more effort to get to school than the able-bodied child whose muscles and limbs are all working in good order. Fatigue alone can cause the child to lose speed, forcing him to take rest stops along the way, even hindering his progress altogether. Only one child's mother came along with him on the journey to school, as she taught at the same school. She recalls, "at times I would lift my seven year old son with his braces and crutches and carry him on my back, moving slowly by slowly until we reach there".

Often the child with disabilities will encounter pain in his efforts to move to school. The pain can come both from the disabled limb itself, as well as the body parts that are making extraordinary efforts in order to move him along (e.g. bruised and blistered hands from using a club to walk two miles). Children who had received medical intervention (physiotherapy, surgery, and/or braces and crutches) had less pain than those who were still putting body weight on deformed limbs (e.g. knees) rather than the soles of their feet. However, the price and effort of obtaining medical treatment created a whole new array of burdens for the family. None of the children had wheelchairs due to the cost.

The physical effort and time required in crossing the distance to school meant that none of the children, except those who came by motorcycle or bicycle, went home for lunch. Those who remained went without lunch, as it is not yet a custom to send a 'packed lunch' (there was laughter when packed lunches were inquired about). Some schools provided lunch at a cost, but not everybody could afford the lunch. This is not

just a disability issue; it is still customary in many rural areas to have only one large meal at night, and allow the children to forage in the trees for fruits throughout the day. However, the child with disabilities who crosses a distance has a higher energy expenditure and requires more calories than the able-bodied child. When food is scarce, malnutrition is a greater risk for him.

Children from P4 to P7 (North American Grade 4 to Grade 7) are required to carry their books to school daily. This is yet another challenge that must be dealt with by children whose arms are not free while crossing the distance. One mother suggested a knapsack as a solution, but once again cost was a prohibiting factor.

The dirt road to school in a rural village is a lonely place for the child with disabilities; he moves along slowly, others passing him, laughing, chatting and playing. To be alone on this walk is not only a sad time, but also a fearful time due to lack of protection from the unkindness he might encounter along the way.

COPING WITH CRUELTY

Children are known in all cultures for their ability to be cruel to the underdog, particularly when they are in a group setting. Cruelty is an issue for the child with disabilities throughout each phase of the quest for education, but there are certain factors that increase the likelihood of cruelty.

The women interviewed confirmed the post-analysis suggestion that the closeness of relationship the child with disabilities had with other children directly correlated with the kindness with which the child was treated. Therefore, the more intimate village setting seemed more conducive to positive emotional support than the very large

school setting. A village can be made up of 50 people, whereas a primary school can often hold 1500 children, most of whom do not personally know the child with the disability.

Cruelty in the form of nicknames, punching, slapping, beating, stoning and throwing away crutches is most common when children are without adult supervision. While this can occur in the village setting at times when caregivers are out digging or doing other chores, it is a more frequent occurrence during the travel to and from school when children are unaccompanied. Some teachers control the class behaviour even if they were not present at the time of the cruelty, and other teachers choose not to. One mother describes:

Some disabled children find problems at school, some are given nicknames, and others go to the extent of beating them and run away because they know the disabled child cannot run after them to get revenge...the able-bodied children have a bad attitude towards the disabled...at times they grab the crutches or stick of the children and throw it away. Even if the teachers know, they don't always help... The worst time can be if they are on their way to school and on their way home.

There was a difference of opinion among the mothers about the ability to change the negative attitude of other children towards their child with disabilities. Most mothers believed that attitudes could not be changed: "I don't think some of those ones can ever change their attitudes towards the lame ones. They are born naturally stubborn, and cannot change that stubbornness. They stay cruel and mean. That's

why a separate school [just for disabilities] would be best. These stubborn children are brought up this way...it is the attitude of the parents as well."

One mother was adamant that attitudes could change, and had gone through an involved process to ensure that her child was treated with respect in his school setting. She kept close communication with the teacher and the Head Master; the teacher threatened, and subsequently caned children who exhibited cruel behaviour towards the child. With the protection of a vigilant mother and teacher, this child now has a very positive school environment, where his friends treat him well, and care for him with little acts of kindness throughout the day. He attends a private school, and has the protection of a motorcycle ride for his transport. The driver serves as a guardian for him.

Some mothers, who could not afford private schools, felt uncomfortable with the idea of networking with the teacher in the government school. They believed that their communications would be seen as interference, and that their suggestions would be seen as criticisms. The massive class sizes and the more lax work ethic of teachers who 'dodge classes' in the government schools are also factors against securing the teacher's support in combating cruelty. The mother who had been a teacher in both private and public schools, felt that communication with the class teacher would be helpful, but she herself feared to do it with her own colleagues in the public school, in case of repercussions on her child:

I don't say anything. That's how children behave at school...I just keep quiet. When children beat my child, the teacher was never watching this.

He will come crying and tell me. I say nothing to the teacher, she was not

here, ...I just say I am very very sorry to my son. It makes my heart feel very bad. I feel pity. I know that most children even if they are not lame can be stubborn...they do these things. I do not want the teacher to punish my child because I complain. Sometimes teachers look at disabled children another way....some teachers are naturally good and kind...others are naturally unkind.

The mothers appeared to respond quite passively to these attacks of cruelty, without the 'mother-bear' defense often exhibited by Western mothers. Mothers were careful to comfort their weeping child for only a little while, before pushing him out the door once again to face the world of school. They feared giving in to the sorrow would cause him to remain at home. But there was a unanimous desire to see their child in a specialized school for children with disabilities, "because it is so difficult to put these children in with the other ones". While they hope for this end, it is not a feasible financial possibility in the developing world (Kustaa, 1990).

Cruelty can also happen in the home in the form of beatings from a parent figure. If drinking of alcohol is involved, beatings are more likely. The co-wife can be a regular source of cruelty towards the child: "Even at times my co-wife also sends the other child, the son, to come and beat my disabled child for no reason..."

While the stepping stone of 'Coping With Cruelty' is painful, it is the phase least likely to hinder a child's progress towards education. Children who excelled academically were treated with more respect. The children who had few external coping supports to face cruelty gathered the internal fortitude to continue their school attendance in spite of it. Not one of the children would quit school merely because of

cruelty encountered. They had practice in dealing with this kind of pain in the village already. And, they were willing to suffer in order to reach their goal of education.

MANAGING AT SCHOOL

The physical school environment is a constant challenge for the child with motor disabilities. The more physically challenged a child is, the less likely a teacher would be willing to have him in the classroom. The child had to have a means of managing the environment independently in a regular school. Assistants are an option, but were too expensive to hire for those in this study. Special boarding schools set up for children with disabilities are also a viable option for the severely disabled child, but again require a greater financial commitment than participants could afford, and there are only a few such schools in Uganda.

Sometimes there are several children with a motor disability in one government class, but often there is only one, if any at all. The class size is a very threatening physical issue; with over one hundred children in one room, the child with a disability has a good chance of being trampled. Competition from other children can force him to be edged out. Several mothers addressed this challenge by requesting the teacher to put their child at the front of the class where the teacher could keep an eye on him.

Stairs are not easy to negotiate for a crawling child, or even one using crutches; ramps are much easier, but are rarely in place. The thresholds at the door are also difficult for the child with disabilities, and mothers requested that they be kept to a minimum. Wider doors were suggested in hopes that wheelchair access might one day be available for the children with limited mobility. The children manage with these

awkward physical structures by going more slowly, but they are at risk of being crushed if they remain too long 'in the way'.

Of particular concern to the child who is in braces and crutches is the pit latrine toilet. Ordinarily these toilets are just rectangular holes in the ground, but it is difficult for these children to bend and squat. A raised toilet with a seat would mean less soiling of the toilet area, less soiling of clothes, and less shame.

Physical education is another time of separation for the child with disabilities. Most of the P.E. activities are focused on speed which require lower limb function, and the child with disabilities is left alone in the classroom while the others go to the field and play. "It would be helpful to have some things for the lame children to play with in the field. Even the lame child needs things to do to exercise his muscles. Most of them cannot do P.E., but they do need to wake up their minds..." None of the schools attended had exercise equipment set apart for the child with disabilities.

The child with disabilities is desperate enough to learn, that he makes his way in an overcrowded school that has been built with able-bodied children in mind. Other children can play a positive role in carrying for him, and assisting him in the physical tasks that he is unable to perform. The child with disabilities deals with the issues of "Managing at School" within his own limited means, slowly, and in spite of teasing and trampling. He manages the physical challenges while concurrently setting his goal on 'Achieving Learning'.

ACHIEVING LEARNING

The simple act of being in the classroom does not ensure that the child with disabilities is learning:

I found at the end of the year my kid was learning nothing from school-- only what I have taught him. I was disappointed, because I felt that my kid had suffered through school for nothing. If I had the money for a private school I would put him there...sometimes people think that a lame mind goes with a lame body.

Some children with disabilities were overtly ignored by the teachers, who "didn't take any notice of the disabled child, just carrying on with the other children". Parents who felt their child was learning had been assertive enough to speak to the teacher. "Sometimes the parent must speak to the class teacher to care for the child, and say 'my child is disabled, and cannot do something, don't just leave him neglected, make him learn with the others, make him learn because his mind is O.K.'" Requesting a front-row position for their child not only assisted him with the physical space for protection, but ensured access to the teacher as well.

Parents were fearful of asking special favours and disturbing the teachers. Contact with the Head Master was agreed to be a good way of ensuring goodwill and attention towards the child with disabilities. This was most effective in the private school where the Head controls the salary of the teacher. The low standard of the public school was discouraging for these mothers, but they were well aware that this was not solely a disability issue, but affected able-bodied children as well.

The teachers who were thoughtful towards the child with disabilities showed their acceptance of him in the class by their actions towards him: "They are kind to the child, they talk to him and tell him what work to do. They do not want to leave the child behind. They like him to study and take extra care of him." The child under these teachers achieves learning, but the child in a less supportive classroom may not.

Parents were also quick to comment that their child had a responsibility to "behave well in school" for the teacher, and "not to be stubborn and quarrel with the others".

When learning is achieved, literacy bursts in to open a new world of possible occupations. The child with disabilities can fix his sights on jobs that relieve him of the physical lifestyle, and use his mental skills. He can go on to further academics if the means, desire and skill is present, or he can pursue more technical vocations.

HELPING HANDS

Helping hands along the path of the child with disabilities purpose to balance him on his journey, assisting him to reach his goals. These are defined by the attitudes and acts of goodwill towards the child at every level of his circles of environment. Empathy does not play a large role in the Lugandan culture, nor does the Lugandan vocabulary lend itself to empathetic roles. But, throughout the child's progress to education, small acts of kindness make a great difference to his world.

Positive support begins with the child himself. In keeping with traditional African expectations, a child's willingness to do something is not mandatory, he could be forced to do something for his own good. However, the nine children in the study

unequivocally longed for the chance to go to school, and this longing served their inner fortitude to hang in there in the tough times.

The child's will itself is not enough to make the journey; in order to escape isolation, the child in his powerless position must have an advocate...a champion...a supporter. The main caregiver often becomes this, usually at a great cost to herself and her household, because of the tremendous demands on her limited time and energy. The emotional and physical resources she is able to give to the child dictate the level of her ability to assist him on this journey; the wellbeing of a child is directly linked to the wellbeing of the mother (Knutsson, 1997).

A father who is reluctant to assist his child with disabilities can sometimes be persuaded by another supportive male in the community to show more consideration towards his child regarding his education and treatment. More than just the immediate household members can play a role in being 'Helping Hands'; thoughtful neighbours or relatives can influence decisions made for 'Attaining Household Consensus'.

Emotional support from the father is a helpful asset in some homes, but the key ingredient in his support is the release of school funds. If there is a father in the home, 'Securing the Funds' is pivotal upon his decision. Where there is a co-wife, the father has potential to help protect the child from her jealous tactics of withholding financial support or beatings.

Community members have sometimes given the struggling child an occasional lift on the way home from school on motorcycles or bicycles. The mothers acknowledge this support to 'Crossing the Distance' gratefully with surprise in their voice: "When they find such a child on their way they can even give the child a lift." Concerned

people also pass word of mouth information about programs of subsidized medical help to families of children with disabilities. Eventually this can lead to physical assistance such as physiotherapy, appliances or surgery that enhance the child's ability to 'Cross the Distance' to school.

'Coping with Cruelty' involves the assistance of the mothers, the teachers and the friends of the child. Cruelty is not commonly revenged by the child with disabilities, as the child cannot 'run away' or 'chase them' and 'hit back'. Except in the case of the teacher who punishes those who are unkind, coping is assisted through vigilant protection by others of the child. The child's own inner strength to withstand attacks, and the soothing words of comfort from the mother figure to her child are supports as well. Through awareness education, friends of the child can learn to stand up and support him during attacks of cruelty.

External 'Helping Hands' greatly assist children with disabilities. Uganda Society for Disabled Children is one productive organization that has linked with other services both in the government and in the private sector to assist these children in the villages in which they live. Katalemwa Cheshire Home is a temporary-stay rehabilitation home in which children receive assistance when they must remain in the city. Christian Blind Mission partners with local organizations within Uganda to fund and assist children who suffer with disabilities of all kinds. Organizations such as these make efforts towards sensitization of attitudes, awareness and education, material assistance with locomotor helps, rehabilitation, surgery, and physiotherapy. However, the need is tremendous, and while many children are helped, thousands of others remain unassisted due to lack of funding and resources.

Children with disabilities will be assisted with 'Managing at School' when the school environment is adapted to their needs. There are efforts beginning from advocacy groups to petition the government with special requests on behalf of children with disabilities as the new and much needed classrooms are built. The medical treatment of the children to make them more mobile or equip them with wheelchairs is an NGO effort that affects their progress to education particularly in 'Crossing the Distance', and 'Managing at School'.

'Achieving Learning' is largely dependent upon the attention that teachers bestow upon the child. One mother also assisted her child by teaching him the alphabet and basic numbers at home before he attended school. Fathers who take great pride in their child's scholastic ability, spur their child with disabilities on to greater achievements with their support. There is no doubt that parental involvement enhances the child's potential for 'Achieving Learning'. Siblings who are kind and thoughtful have the potential to be of particular comfort and assistance to the child, not only during 'Crossing the Distance', 'Coping With Cruelty', 'Managing at School' but also at the 'Achieving Learning' phase of the journey. Because caregivers' lifestyles are so busy, this area of sibling assistance could be explored and encouraged further.

Kindness can be trained and developed both in the children at school and at home:

I believe that other children need to be told to be friendly to disabled children. They need to be happy to see them. They can show love by bringing small presents and giving them things. They must take the time to talk to the disabled one...get to know the disabled one, and try to help

them....our community was sorry for my son, they were friendly and helped us.

The larger circle of the child's sphere extends to his village community. Thoughtfulness shown by other children towards the child with disabilities nurtures his sense of worth and also counters the cruelty of physical or emotional abuse that is inevitable in his life:

At times, it might be raining or drizzling when the mother or someone concerned is away, then the other child comes, and maybe lifts the child and puts him in the shade, or shelter where there is not rain. Or maybe the child is feeling hungry, and one of the children goes to the mango tree, gets the mangoes and brings to him....because he is unable to get to the mango tree. At times they can include him in their games.

Local awareness campaigns, radio advertisements and newsprint educational materials all serve to reach out and 'help' the child with disabilities, broadening the awareness of others towards him.

CONCLUSIONS

The circumstance of motor disability in a third world rural setting destines children with disabilities for a life of isolation, unless planned measures to overcome it are taken. *Overcoming Isolation* via the stepping stones of education is a process in which the caregiver and the child with disabilities join their energies together. At any stone along the way the mother and child's progress can be blocked by external circumstances out of their control, or by the attitudes of key players who hold the

power in their environments to push them off their stepping stone. Conversely, at every step along the journey, helping hands of many forms may reach out to assist their efforts.

Future research to refine and direct theory in this area would start with expanding the data collection of the education process until saturation. In addition, other avenues than education could be explored for the purposes of overcoming isolation (e.g. learning a handcraft, receiving better medical treatment and equipment). But literacy enhances participation in every sphere of society. Children with disabilities who grow up to beg on the streets of the larger cities have a means of income, but would still suffer a real form of isolation. The escape from isolation includes having meaningful participation in society.

It would be useful to pursue the educational background and the socioeconomic status of the caregiver to review its correlation with motivation and ability to achieve education for the child with disabilities. Gender issues have not been explored in this study, but it is a well-known fact that girls in Uganda are particularly susceptible to discrimination. The data collection could be expanded to include the perspective of more parents, other family members, the children with disabilities themselves, the children's friends at school, teachers, headmasters, local council members (leaders) of the community, and disability rehabilitation workers. It would be interesting to explore whether the advent of medical intervention and rehabilitation for the child raises his worth in the eyes of those who presently see him as worthless. Practical assistance needs to be obtained for families who could use bicycles, wheelchairs, knapsacks, and other equipment or medical treatment for their children. School environments should

be petitioned to become less 'disabling' in layout. In-service teacher training would be a logical outcome for further development and study.

This study assists caregivers and their children with motor disabilities to develop a better understanding of the passage from isolation to meaningful participation through the means of education. It has also served to give them a voice via the newsprint media, enlisting support, assistance and understanding from others in their world. As awareness grows, both at government and community levels, the plight of the child with disabilities will improve. With the attainment of education, these children's valuable contributions to their society will serve to make less visible the disabilities that once isolated and defined them.

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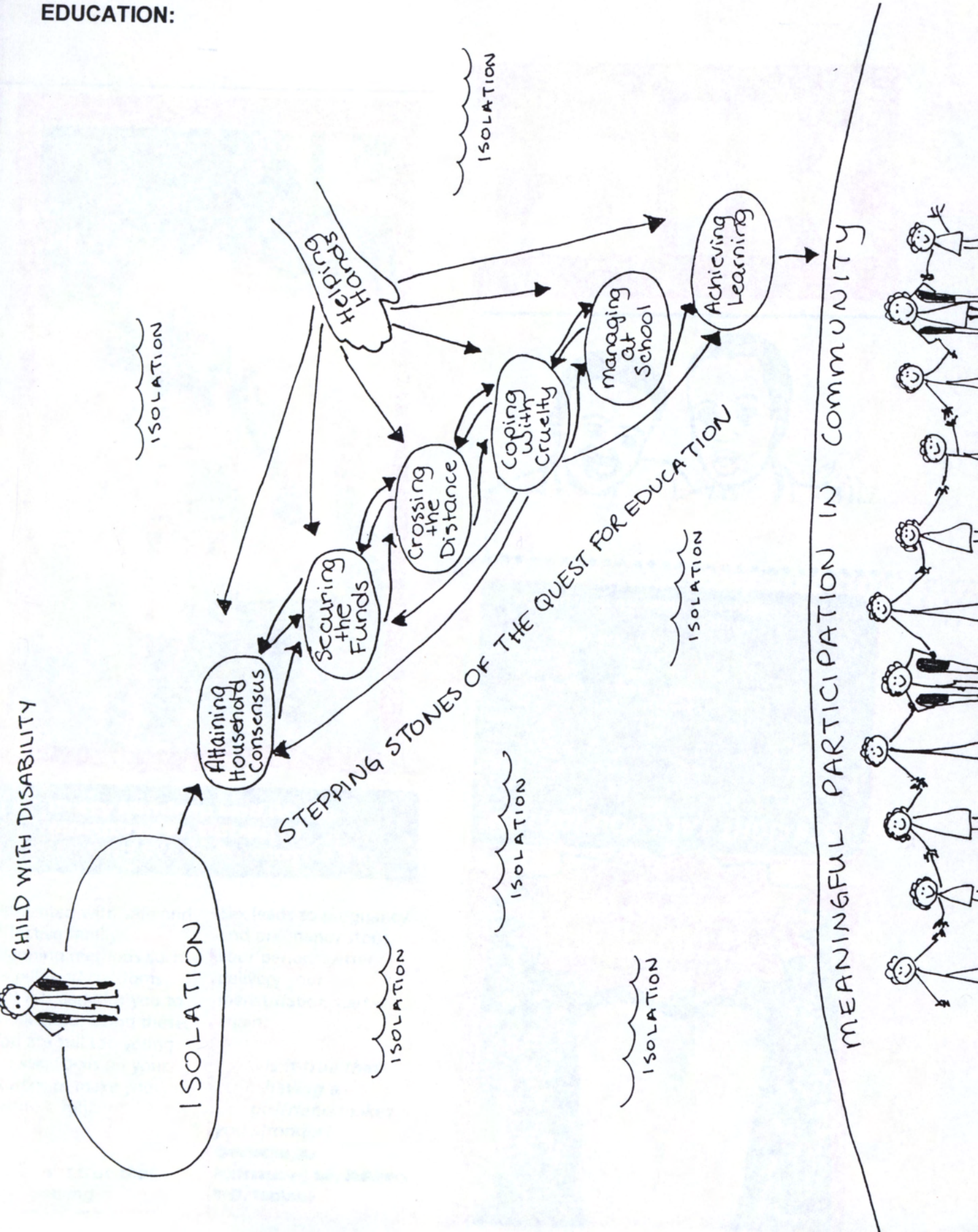
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APPENDIX A

DIAGRAM DEPICTING THE VARIOUS STEPPING STONES OF THE QUEST FOR EDUCATION:



APPENDIX B NEWSPRINT ARTICLE FROM SEPTEMBER 1999 SENT NATIONWIDE TO ALL 12,000 UGANDAN PRIMARY SCHOOLS :

(See Section: 'Children with disabilities have rights!' 'Key messages' and overleaf 'For Teachers')



**Betty Mindraa and Abiria
Margaret Fr. Bilbao of
Memorial P/S Moyo are Young Talk fans**

prevented with safe and
effective family
planning methods such
as pills and condoms.
But it is early for you to
think about using these.
You are still too young
for sex. Focus on your
studies to make your
future bright.

Sex leads to pregnancy,
and pregnancy stops
your periods. After
delivery your
menstruation starts
again.

 **Is it true that
having a
girlfriend makes
you stronger?**

**Owachgiu
Kamure, 14, Afere
PS, Nebbi**

 **Is it true that
having**

talk



STRAIGHT TALK FOUNDATION
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SIDA, Save the Children Alliance, Unicef, DANIDA, DFI

**Murungi Sylvia
Star, 14, Jinja
Thanks for the
sticker**



REPORT PART THREE: QUANTITATIVE ANALYSIS

INTRODUCTION

**QUANTITATIVE SCHOOL ATTENDANCE FACTORS:
CHILDREN WITH MOBILITY DISABILITIES IN RURAL UGANDA**

QUANTITATIVE SCHOOL ATTENDANCE FACTORS:

CHILDREN WITH MOBILITY DISABILITIES IN RURAL UGANDA

INTRODUCTION

In most countries of the world, children's needs in general and children with disabilities in particular are not a high priority. In much of Africa, only about 1% of children with disabilities attend any form of school (Mittler, 1992).

In 1992, an estimated one percent of the children attending school in Uganda were disabled in some form (MoSES, 1992); this must be compared with the statistic that 10% of Uganda's children have a disability (Barton, 1994). It is clear that the majority of children with disabilities were not receiving education at that time.

The estimation of children under eighteen in Uganda who have motor disabilities is 190,000 (EARS, 1997). This group of children is largely comprised of those who have succumbed to poliomyelitis or osteomyelitis (bone infection), or were born with clubfeet (Atria, 1994). This prevalence of polio in Uganda is unusually high for Sub-Saharan Africa, because the years of civil strife Uganda faced during the 70's and early 80's made it difficult to continue the vaccination programs.

In Uganda, subsistence farming sustains the rural population, and a physical disability can be an insurmountable challenge to this lifestyle, both for the child with the disability and for the family who must sustain his/her life. The chance to pursue education offers children with mobility disabilities (CWMD) an opportunity to realize independence for their futures, and have alternative occupations to the peasant farming lifestyle.

In late 1996 the Government of Uganda declared the Universal Primary Education (UPE) program providing four children from each family free primary schooling (EARS, 1997). The average family size per mother is seven children (Bellamy, 1999). While UPE does not cover every child in the family, its constitution declares prioritization of children between the ages of 6 and 18 who are girls, disabled, or orphans, recognizing their vulnerability.

Informal conversations with Uganda Society for Disabled Children (USDC) field coordinators (S. Kisitu & F. Byansi, June 19th, 1999) indicate that increased numbers of CWMD have now entered the public school system since community awareness programs have been initiated, and also due to the support of UPE. In this study I seek to uncover what are the major factors that continue to affect CWMD's school attendance, particularly in light of the new UPE program.

METHOD

Instrument Development & Description

The participants in the study included caregivers, and their children between the ages 6 to 18 who had physical disabilities that effected their mobility. The participating children had no other impairments, mentally, visually or auditory. A questionnaire was designed using qualitative information gleaned from focus group sessions with caregivers of CWMD that I held in June, 1999 at Katalemwa Cheshire Home for Children with Disabilities.

Basil Kandyomunda, a researcher from an organization called Uganda Society for Disabled Children (USDC), screened the questionnaire. His input regarding English

usage for direct translations to some of the local languages was invaluable, as were his suggestions regarding cross-checking responses through alternate questioning. Six questionnaires went to the districts of Masaka and Luweero for field testing by two USDC field co-ordinators. Further amendments were made following the field-testing.

The purpose of the study was explained to participants, and they were given the freedom to avoid any questions, or quit the interview at any point. Caregiver, child and interviewer signed or fingerprinted the consent form. The interviewers spoke both English and the local language of the district. This enabled them to translate the written English questions to the respondents, and again translate the answers that were given in the local language back into English. This way, many illiterate respondents could take part verbally in the survey. Some of the questions were directed to the caregiver, and others were asked solely of the child.

The Interviewers

The interviewers consisted of two groups of special education teachers and local USDC appointed community facilitators. They participated in training sessions on how to fill in the questionnaires on the field. In Kampala, one group of five interviewers representing the districts of Luweero, Masaka, and Masindi were trained; another group of four interviewers representing the districts of Arua and Nebbi were trained in Arua town. The nine interviewers spent four hours with me examining consent issues, each specific question to be asked from the questionnaire, practicing the novel approach of the bead on the string for an interval response, and reviewing appropriate questioning techniques. Each of the five districts received 40 questionnaires. USDC allowed the

interviewers access to their files so that they could ascertain in which villages such children might be found.

The Sample

To get the large purposive sample of CWMD in this study was an enormous task, involving a great deal of time and transport expense to search deep into village areas. In order to find the caregiver with the child, these families were interviewed in their home village during school holiday time. In the end, 135 of the 200 questionnaires were completed appropriately. Due to the scattered distribution of CWMD throughout the districts, this sample was obtained by visiting 114 villages to find 123 participant pairs, and 5 towns to find 12 participant pairs.

The number of CWMD who attended school was 78 (58%), and those who were not attending school numbered 57 (42%). Although interviewers were asked to get an even numbers of girls and boys, in the end twice as many boys as girls were involved in the study. The greatest number of girls involved came from the sample group who was not receiving education.

The expected age for entrance for an able-bodied child into P1 (Grade 1) is 6 years, and increases an extra year of age per added grade. However, the mean age of the CWMD in the study entering P1 was 9.5 years. The mean age for the CWMD remained consistently three of four years above the expected age of able-bodied children in the same grade. Most of the children interviewed (85%) attended local government dayschools, and a smaller percentage (15%) attended the more expensive private day schools.

The largest percentage (66.7%) of children interviewed had their natural mothers as the main caregiver. Other situations included caregiving by grandparents, aunts, fathers, fosterparents or siblings. Education was highly valued by the adult respondents, with 98.6% of the caregivers in the study desiring education for their child, even those whose CWMD were not in school at this time. The CWMD showed a great desire to attend school through the statistic that 98% of them wanted to go to school, in spite of the physical difficulties they must face in order to be present.

Measuring the Variables

The variables in this study include:

1. How many **days per week** that the CWMD attended school. Because school attendance was rated from 0-5, this number included the CWMD who are not in school, as well as those who attended less than fulltime, and those who were involved fulltime. (DAYS/WEEK)
2. How many **kilometers** from home that the **school** was located, ranging from 0-7 kilometers. (KM/SCHOOL)
3. The years of **education that the main caregiver** had completed (1=Grade one equivalent, 5=Grade five equivalent, 12=Grade 12 equivalent, 15=Three years of university). (EDUC/CARE)
4. The **number of children in the family**, ranging from 1-19. (#CHILDREN)
5. The amount of **pain** the CWMD were in as they moved a distance equivalent to school from home (CWMD were specifically asked). This ranged from 1-5. 1=never

in pain, 2=most of the time in pain, 3=sometimes in pain, 4=most of the time in pain, and 5=always in pain. (PAIN)

6. The **age** of the CWMD, ranging from 6 to 18. (AGE)

7. The **gender** of the CWMD ranged from 1-2, with 1=male, and 2=female.

(GENDER)

8. The assessment that the CWMD themselves gave about the **quality of their life** ranged from 0-10. A technique that has been previously used in India was piloted in Uganda for this question (Olweny, 1992). Known as Cantril's Self-Anchoring Striving Scale, this question required the child respondents to choose a number from the scale of 0-10. To assist with visualizing this analogue, a mini-abacus was given to the interviewers so that the respondents could choose where to place a bead on a 10-point string. At the opposite ends of the string are imaginary polar extremes, in this case these were the best life possible (10), versus the worst life possible (0). The number 5 is the exact midpoint. (QUALITY OF LIFE)

RESULTS

Means and standard deviations for all variables included in the study appear in Table

1. Table 2 displays the correlations among the predictor variables used in the regressions in this study. The lack of strong correlation between the predictor variables confirms that there is minimal redundancy amongst these variables. This allows for more confidence in the interpretations of the regressions that follow.

The Analysis of School Attendance

A multiple regression was run using school attendance (days/week) as the dependent variable, with kilometers to school, education of the caregiver, number of children in the family, pain, age and gender as predictors of school attendance. The results (see Table 3) indicate that the education of the caregiver, amount of pain, and age all contribute uniquely to predicting school attendance. The positive regression coefficient for education of the caregiver ($B = 0.27$, $p < 0.002$) shows that the more years of education the caregivers had, the more likely they were to have their CWMD regularly attending school. Also significant is the amount of pain that the CWMD experienced when crossing the distance to school ($p = 0.010$). There was an understandable negative regression coefficient ($B = -0.224$), showing that the more pain that CWMD experienced in travelling the distance to school, the less likely they were to attend. The age of the child comes very close to significance, ($p = 0.052$), the positive regression coefficient ($B = 0.170$) indicates that the older the CWMD were, the more likely they were to attend five days of school per week. Overall, this set of predictors was significantly related to school attendance ($R = .44$, $F(6,119) = 4.83$, $p < .001$).

Table 1. Means and Standard Deviations of All Variables

	Number of Cases	Mean	Standard Dev.
DAYS/WEEK	135	2.607	2.350
KM/SCHOOL	133	2.126	1.488
EDUC/CARE	133	4.248	4.100
#CHILDREN	135	6.274	2.887
PAIN	132	3.174	1.516
AGE	133	12.519	3.661
QUALITY OF LIFE	131	6.008	2.214
GENDER	135	Mode = 1 (male)	90 males (1) 45 females (2)

Table 2. Correlation Matrix: Predictor Variables Used in the Study

N=126	KMSCHOOL	EDUCCARE	#CHILDREN	PAIN	AGE	GENDER
KMSCHOOL	1.000	0.062	-0.143	-0.091	-0.187	-0.059
EDUCCARE	0.062	1.000	0.002	-0.196	-0.115	-0.059
#CHILDREN	-0.143	0.002	1.000	0.113	0.078	-0.122
PAIN	-0.091	-0.196	0.113	1.000	0.194	0.033
AGE	-0.187	-0.115	0.078	0.194	1.000	-0.153
GENDER	-0.059	-0.059	-0.122	0.033	-0.153	1.000

Table 3. Regression on DAYS/WEEK of School Attendance (*p<0.05)

Dep Var: DAYS/WEEK N: 126						
Effect	Coefficient	Std Error	Std Coef	Tolerance	t	P(2 Tail)
CONSTANT	2.725	1.250	0.0	.	2.180	0.031
KM/SCHOOL	0.126	0.133	0.081	0.936	0.949	0.344
EDUC/CARE	0.154	0.048	0.270	0.950	3.201	0.002*
#CHILDREN	-0.058	0.068	-0.072	0.951	-0.850	0.397
PAIN	-0.345	0.132	-0.224	0.917	-2.610	0.010*
AGE	0.111	0.056	0.170	0.898	1.964	0.052 close
GENDER	-0.653	0.415	-0.133	0.945	-1.573	0.118

The Analysis of Quality of Life

A multiple regression was run using quality of life as the dependent variable, with predictors of quality of life being: kilometers to school, education of the caregiver, number of children in the family, pain, age and gender (Table 4). The amount of pain that CWMD experience when moving a distance such as from home to school was found to be uniquely related to the CWMD's rating of their quality of life (p = 0.005). The negative regression coefficient (B = -0.263) indicates that the greater the frequency of pain experienced by CWMD, the lower they rated their quality of life. None of the other predictors in this structure came close to significance. Overall, this set of predictors did not achieve significance in relationship to Quality of Life, but they came very close (R = .31, F(6, 115) = 2.1, p = .058).

The criteria of quality of life and days/week of school attendance were strongly positively correlated with each other in a simple regression ($r = 0.352$ and $p < 0.001$). This indicated that the more days per week that CWMD attended school, the more likely they were to rate themselves as having a better quality of life. To this end, a multiple regression was run (Table 5), using the same variables as Table 4 but also including days/week as another predictor of quality of life.

The Analysis of Quality of Life including School Attendance as a Predictor

This final multiple regression (Table 5) was run to further understand the CWMD's self-defined quality of life, using the predictor of how many days/week that school attendance occurred, in addition to the predictors of kilometers to school, education of caregiver, number of children in the family, pain, age and gender.

School attendance was found to be uniquely related to the CWMD ratings of their quality of life, over and above the effects of the other variables ($p = 0.002$). In this set of predictors explaining quality of life, school attendance resulted in a positive regression coefficient ($B = 0.298$), indicating that the more days the CWMD attended school, the better they rated their quality of life. As found in Table 4, the other predictor that is unique in explaining how the CWMD rated their quality of life was the amount of pain the CWMD coped with ($p = 0.031$). Again, as expected, the negative regression coefficient ($B = -0.199$) indicates that the more frequently CWMD experienced pain as they moved such a distance as from home to school, the lower the quality of life they rated themselves as having. Overall, this set of predictors was significantly related to Quality of Life scores ($R = .41$, $F(7, 114) = 3.37$, $p = .003$).

Table 4. Regression on QUALITY OF LIFE (*p<0.05)

Dep Var: QUALITY OF LIFE N: 122						
Effect	Coefficient	Std Error	Std Coef	Tolerance	t	P(2 Tail)
CONSTANT	7.350	1.268	0.0	.	5.797	0.000
KM/SCHOOL	0.076	0.135	0.052	0.931	0.564	0.574
EDUC/CARE	-0.022	0.050	-0.041	0.951	-0.451	0.653
#CHILDREN	-0.070	0.069	-0.092	0.953	-1.018	0.311
PAIN	-0.381	0.133	-0.263	0.931	-2.863	0.005*
AGE	0.070	0.058	0.113	0.904	1.211	0.228
GENDER	-0.426	0.426	-0.091	0.940	-1.001	0.319

Table 5. Regression on QUALITY OF LIFE including DAYS/WEEK of School Attendance (*p<0.05)

Dep Var: QUALITY OF LIFE N: 122						
Effect	Coefficient	Std Error	Std Coef	Tolerance	t	P(2 Tail)
CONSTANT	6.546	1.247	0.0	.	5.248	0.000
KM/SCHOOL	0.043	0.130	0.029	0.925	0.332	0.741
EDUC/CARE	-0.062	0.049	-0.113	0.890	-1.253	0.213
#CHILDREN	-0.055	0.066	-0.073	0.949	-0.829	0.409
PAIN	-0.288	0.131	-0.199	0.885	-2.191	0.031*
AGE	0.040	0.056	0.064	0.878	0.700	0.485
GENDER	-0.213	0.415	-0.046	0.915	-0.512	0.610
DAYS/WEEK	0.280	0.088	0.298	0.817	3.161	0.002*

DISCUSSION

School Attendance

The major variables in this study that affect CWMD's school attendance are the education of the caregiver, the amount of pain that the CWMD experiences travelling the distance to school and the age of CWMD.

The more years of education that the caregivers had completed, the more likely the caregivers were to make the efforts towards enrolling, and regularly sustaining their CWMD in school. The caregivers who themselves had experienced the value of schooling were naturally more likely to recognize the value of education for their CWMD. Maternal education was the most important factor for enrollment of children in a study in Ghana of able-bodied children (Lavy, 1992). It makes sense that this variable would be of critical importance to both groups of children, those who are able-bodied and those who are disabled. It noteworthy in our study that although 98.6% of the caregivers told the interviewers that they wanted their CWMD in school, the ones that *made the extra financial sacrifices and effort to obtain schooling for their CWMD were those with more education themselves.*

Pain is an issue related to school attendance that is specific to CWMD. While able-bodied children may feel fatigue at travelling the distance to school, CWMD are having to cross the distance to school by weight-bearing on parts of their body that were never designed to take full body-weight. Thus the pain that CWMD's experience on their skin, joints and muscles inhibit their ability to sustain the journey to school regularly, or even make it in the first place.

The CWMD who attend school are already older than the average age of their classmates by three or four years. The fact that the CWMD were more likely to enroll and stay in school as they became older, may be a reflection that the CWMD themselves see the value of literacy in opening their world as well as the need for alternative lifeskills for future occupations. Perhaps as they mature, these children's personal desire and motivation to attain an education increases. Alternatively, this could be a result of the fact that some mothers are reluctant to allow their younger children to attend school for fear of abuse. They purposefully protect their CWMD by withholding their initial school attendance for a few years, in order that the CWMD become more able to combat any negative treatment that might come their way (Katalemwa Focus Group, personal communication, June 14, 1999).

It is noteworthy that the number of kilometers to school from the CWMD's homes was not a factor in explaining school attendance. Studies have shown an inverse correlation between school attendance and kilometers that an able-bodied child must walk to school (Bellamy, 1999). This shows that the CWMD are dealing with are very distinct issues from their able-bodied counterparts. One might imagine that the amount of pain the child is in might increase with the distance to the school. However, while the correlation between pain and distance to school was negative, it did not reach significance ($p=-0.091$). From the qualitative reports in the questionnaires, often the CWMD were in pain just moving about their households.

If the number of children in the family had been a significant factor in school attendance, one might predict that the finances of fees, school uniforms, books and pencils were the largest burden inhibiting the CWMD's access to school. However, the

factors of lower caregiver education and increased pain played a more unique role in explaining the lack of school attendance. This is interesting, because in the qualitative responses from the same questionnaire, lack of funds was listed as the number one reason the CWMD were not attending school. To be fair, sometimes the requested funds were for transport assistance. Transport on bicycles, motorcycles, wheelchairs, or even attaining crutches require cash, which is difficult in the cash-poor economy of subsistence rural farming. CWMD who need external locomotor assistance are an expensive burden on the rural family, requiring much more of the household's limited resources than able-bodied children.

The variable of gender did not reach significance ($p = 0.118$), and yet we know that the girl child is specifically prejudiced against in developing countries (Bellamy, 1999). The purposive sample group that I requested to be interviewed was to be equally balanced in gender. The negative regression coefficient shown in Table 3 ($B = -0.133$) is an indication that the interviewers interviewed more boys attending school, as they were not able to find equal numbers of girls and boys.

Using the results of the regression on school attendance (Table 3), recommendations for the support of CWMD's attendance to school include the following:

1. Continued and increased community-level sensitization of parents, particularly the maternal caregiver, as to the importance of education for their CWMD.
2. More physical supports donated or sold with a subsidy to relieve the CWMD from pain when travelling distances (e.g. properly fitting crutches, wheelchairs and bicycles).

3. Earlier community-level sensitization for the CWMD themselves to catch a vision to prepare for lifeskills for their future.

Quality of Life

A note of caution regarding the quality of life measurement:

In any cross-cultural quality of life work it is crucial that the constructs involved be examined for validity (Hunt, 1998). This was not done in the quality of life portion of the study. The chosen endpoints of 'best possible life' and 'worst possible life' were not formally examined for construct validity or translation in each of the five languages involved. We do not know the extent of rural village children's understanding of these concepts. The measurement error variance of Cantril's Self-Striving Scale needs to be tested with this model. Inter-rater reliability is a concern when there are so many relatively untrained interviewers involved, and when the content matter is so subjective.

We also do not know the effect of having the caregivers present during the responses that the CWMD gave. We have no way of knowing if the whole neighbourhood was present (very likely!) watching the interview take place, or these effects on the results of the whole questionnaire. We do not know if the previous questions about schooling in the questionnaire predisposed the CWMD towards a certain quality of life measurement.

While the statistical significance attained through use of the quality of life question is of great interest, it is submitted with reservation, as much more work in this field must be done before conclusions can be accurately drawn. Having qualified the subsequent

conclusions, here follows a discussion of the statistical information where 'quality of life' was used as a variable.

The quality of life question was one that the CWMD assessed on their own. The most uniquely related variable to the CWMD's quality of life was the number of days of school attendance. The higher the school attendance, the higher the CWMD rated their quality of life. It is interesting that for these children, school had an even more unique relationship with quality of life than pain did. Although pain was an important factor in explaining quality of life, its value of uniqueness dropped when school attendance was also added into the regression model. I believe this is a reflection of the isolation that CWMD experience. Taking part in their local children's community through school attendance gave them an increased sense of social belonging.

The more pain that CWMD experienced, the lower they rated their quality of life. Related to physical pain, is the inability to be mobile due to this pain. For example, we saw that school access is also partly explained by pain. Indeed, the fact that the relationship of pain to quality of life decreased when school attendance was included as a predictor, combined with the fact that school attendance is itself partially determined by pain constitutes a pattern of results consistent with a model of causation in which school attendance mediates the impact of pain on quality of life. That is, the effect of pain on quality of life is particularly acute to the extent it decreases school attendance.

There are other social variables that may be affecting the CWMD's rating of their quality of life linked with pain. Limited mobility restricts CWMD socially; if they cannot move the distance from home to school, then perhaps they cannot move easily to

neighbours and friends either. Thus they are socially isolated. This assumption that greater social isolation reduces QOL through the variables of pain and lowered school attendance bears further investigation.

CONCLUSION

The people of Uganda do value education, but more awareness is required regarding the worthiness of sacrificing in order to obtain education on behalf of CWMD. With consideration of the cautions mentioned above, I do believe this rough study predicts the high value that CWMD place upon school. In addition, we can predict the challenges of lack of parental education, increased pain, and younger age are all continued obstacles to school access for children with mobility disabilities in rural Uganda.

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YES

Consent Form for Participation in the Study Entitled:

A Quantitative Study: Ugandan School Access: Children with Locomotor Disabilities

Purpose of the Study: This research project seeks to discover the priority of the challenges that face caregivers of children with locomotor disabilities as they consider school access in rural Uganda. It is hoped that the findings of this study will result in recommendations to various NGO's and Government Ministries that deal with children with disabilities in Uganda, as well as for lobbying purposes for policy-making in the education system.

Signature or Right Thumb Print of the Participant Acknowledging Understanding of Study's Purpose

Signature of UNISE Teacher/Interviewer Acknowledging Full Translation and Understanding of Study's Purpose

To Participant Caregiver and Child with Disability

Your Involvement in the Study: Your permission is requested to fill out this questionnaire. It should take less than an hour to complete with a field worker. The choice to participate in this study will not affect the current health care that you receive at this time, and is entirely voluntary. You have the right to refuse to answer any questions you do not wish to answer. Your responses will remain anonymous, these consent forms will be kept separately from the questionnaire information, all the questionnaires will remain in a locked cabinet until the information has been noted, and then they will be destroyed. No one but the project field worker currently talking to you, and the Investigator will have access to these forms. If a participant chooses to withdraw at any point in the questionnaire, they may take the information already written and destroy it if they so choose.

Signature or Right Thumb Print of Caregiver Participant Acknowledging 'Understanding of Anonymity' and 'No Change in Status of Current Health Care Will Occur due to Participation'

Signature or Right Thumb Print of Child Participant, Showing Willingness to Participate in the Study

Signature of UNISE Teacher/Interviewer Acknowledging Correct Translation Regarding 'Understanding of Anonymity' and 'No Change in Status of Current Health Care Will Occur' due to Participation

UNISE Teacher/Interviewer's Printed Name and Signature that all of the following information has been verified to the best of their ability, and not falsified in any way.

District _____ Office phone number _____
Investigator: Anne Penny 256-41-222201 Kampala Uganda.

A GIFT OF AN EXERCISE BOOK AND A PEN IS GIVEN EACH CHILD AT THE END OF THE INTERVIEW.

QUESTIONNAIRE (yes)

SCHOOL ACCESS FOR CHILDREN WITH LOCOMOTOR DISABILITIES

Reminder to the Interviewers:

Please find the main guardian of the Child to sign consent and fill out this questionnaire with and on behalf of the Child (ages 6–18). **THIS CHILD MUST BE ATTENDING PRIMARY SCHOOL AND MUST REQUIRE ASSISTANCE IN WALKING** (e.g. stick, crutch, chair, crawl etc) but he/she must not be impaired mentally, exclude hearing and visually impaired. Make sure that the interview takes place after school has been dismissed for the day, or during school holidays so that you can have the input of the child as well. Use the last blank side of the questionnaire to carry over any comments that there is not space for in the lines provided. Do not choose more than 10 Children per subcounty, and no more than one Child with a disability per family. Please try to obtain at least 15/25 responses from villages, and the rest may be from small towns if it is too difficult to move to so many villages. Try to maintain a fair balance between girl students and boy students interviewed. The following categories on this page need to be filled in by yourself as the interviewer, from your knowledge, from the USDC files, and conversation with the caregiver.

1. Disability of Child: (check and circle)

- a. () Neuromuscular Disease: polio, cerebral palsy (with clear talking),
myelomeningocele, spinal paralysis
- b. () Congenital Abnormality: club feet, limb deformity, missing limbs
- c. () Bone and Joint Infection: osteomyelitis, septic arthritis, tuberculosis
- d. () Trauma (describe): _____
- e. () Other (describe): _____

2. District: _____

3. Subcounty: _____

4. Name of Village or Town and describe approximate population:

Village (less than 5,000): _____ population: _____

Town (5,000 or more): _____ population: _____

5. Language Spoken: _____

6. Who is the respondent to the Questionnaire on behalf of the Child? _____

7. Who is the Guardian/Main Caregiver of the Child? _____

8. If respondent is not the Guardian/Main Caregiver, please explain why? _____

9. Level of Education of Mother: _____

10. Level of Education of Father: _____

11. Level of Education of Guardian/Main Caregiver if other than parent: _____

12. What is the main occupation of Mother? _____

13. What is the main occupation of Father? _____

14. What is the main occupation of Guardian/Main Caregiver if other than parent? _____

15. Does this household have:

- a) () a **private** pit latrine () a **shared** pit latrine () **no** pit latrine
- b) a **radio** Yes () No ()
- c) their own **land** Yes () No ()
- d) their own **animals** Yes () No () If Yes, list how many and which animals: _____

QUESTIONS FOR THE PARTICIPANT/CAREGIVER TO RESPOND TO:

1. **Gender** of Child: () Male () Female
2. **Age** of Child (must be between 6 and 18 years): _____ **Year** of Birth: _____
3. **Position of Child** in Family(1=firstborn, 3=thirdborn 7=seventh born etc): _____
4. **Number of Children** in Family: _____
5. Describe the **family grouping this Child lives with** most of the time (e.g. two parent, mother only, father only, grandparent, aunt/uncle, foster parents--describe sibling/cousins/foster siblings in the same dwelling): **Circle Main Caregiver**

6. Locomotion of Child:

- a. () Walks with a stick
- b. () Walks with crutches
- c. () Walks with crutches and braces
- d. () Cannot walk, crawls
- e. () Cannot crawl
- f. () Moves by wheelchair
- g. () Other _____

7. Has the Child been assessed by any professional? (Can check more than one)

- | | |
|-------------------------|-----------------------|
| () Physiotherapist | In what Year(s) _____ |
| () USDC worker | In what Year(s) _____ |
| () EARS worker | In what Year(s) _____ |
| () Orthopaedic Surgeon | In what Year(s) _____ |
| () Other _____ | In what Year(s) _____ |

8. To describe the CHILD'S SOCIAL PARTICIPATION in the VILLAGE/TOWN COMMUNITY USE THE BEAD ON THE STRING TO CHOOSE A NUMBER FROM 0 – 10.

If the top of the string (**#10**) represents the most possible participation (playing and being included with other children) for a child of that age in your community, and the bottom of the string (**#0**) represents the most isolated, segregated life possible where the child is not ever included in the other children's play, **where would you place the bead** to show where you believe your Child's level of social participation lies? _____ (0 – 10) **For what reasons** did you give this number?

9. Regarding the Child's School Attendance:

- a. How many **kilometers** is the school from your home? _____ km
- b. **Days per week attended at school?** () 1 day () 2 days () 3 days () 4 days () 5 days
Explain (if less than five):

- c. **How** does the Child get there? (e.g. walking with crutch/stick, boda boda, bicycle, crawl)

- d. **How long** does that take in hours including restbreaks? _____
- e. Is your Child **in pain** when he travels to school? (ASK THE CHILD)
() Yes, Always () Most of the time () Sometimes () Only once in a while () Never
If any answer other than 'never', **explain where the pain is and when it comes:**

10. a. Does your Child experience the following negative behaviours from other children?

- **verbal teasing and name calling:**
() Yes, Always () Most of the time () Sometimes () Only once in a while () Never
- **hitting or beating:**
() Yes, Always () Most of the time () Sometimes () Only once in a while () Never
- **other children stealing a crutch or appliance and running away:**
(leave blank if Child does not have a crutch or appliance and is crawling only)
() Yes, Always () Most of the time () Sometimes () Only once in a while () Never
- **other cruelty, describe:** _____

b. If any of the above behaviours occur, circle which **times they are most likely to:**

- i) on the way to school
- ii) on the way home from school
- iii) during school time when there is no teacher supervision
- iv) during school time when there is teacher supervision
- v) in the village at home, when Caregiver is absent
- vi) in the village at home, when Caregiver is present
- vii) other _____

c. If negative behaviour occurs towards your Child with disabilities, **how does your Child cope** with the teasing, beating or loss of appliance? (What does the Child do when this happens?)

d. If you answered **never** or **only once in a while** to question 10.a about negative behaviour towards the Child, describe **why** you believe the Child has not suffered in this way: _____

11. Why does the **Caregiver** desire the **Child** to go to School?

12. Does the **Child** desire to go to school? (ASK CHILD)

() Yes () Uncertain () No

Explain Reasons for your Answer:

13. What does the **Child** want to become when he/she is grown? (ASK CHILD)

14. **Who makes the decision** for this Child to go to school or not? (choose main one)

a. () mother

b. () father

c. () foster parent

d. () grandfather

e. () grandmother

f. () aunt

g. () uncle

h. () other _____

15. Do you believe that this **Child** is able to learn as well as an able-bodied child?

() Yes () Uncertain () No

Explain (if not Yes):

16. What **jobs** does this Child assist with in the home?

a. () sweeping

b. () washing the clothes

c. () digging

d. () gathering firewood

e. () food preparation & cooking

f. () fetching water

g. () babysitting of younger children

h. () other (describe below):

17. Are all of the **able-bodied** , **primary school aged siblings** of your Child also **attending** school? Yes () No ()
If **no**, **explain** why not: _____

18. What are the **biggest problems** you faced getting your Child into school?

19. How did you **solve those problems**?

20. What are the **biggest school-related problems**, if any, that you and your Child continue to **have now** while your Child is attending school?

21. How do you think these problems might be **solved**?

22. How does Caregiver get **money for school clothes, shoes, books and fees**?

23. What is the cost of your Child's **School Fees** per term? _____(0=UPE covered)

24. The School that your Child attends is: () **government** () **private**

25. Does the Child miss school due to rain?

- ☐ Yes, Always when it rains ☐ Most of the time when it rains ☐ Sometimes when it rains
☐ Only once in a while when it rains ☐ The Child never misses due to rain

26. What is the class of the Child? P _____

27. In what year did the Child begin to attend school? 19 _____

28. How many children are in your Child's current class? _____

29. Do you know your Child's position in the class?

30. Are you happy with how your Child is doing at school? (Choose main one)

- ☐ Yes ☐ Most of the Time ☐ Sometimes ☐ Not very happy ☐ No, very unhappy

Explain _____

31. Have you spoken to the Head Master about the needs of your Child with disabilities? ☐ Yes ☐ No

32. Have you spoken to the Class Teacher about the needs of your Child with disabilities? ☐ Yes ☐ No

If yes, how many **times per term** do you communicate with the Class Teacher? _____

33. Does your Child play with the other children during break time?

(Choose only one most accurate response--ASK THE CHILD)

- ☐ Yes ☐ Most of the Time ☐ Sometimes ☐ Very little ☐ Not at all

Explain: _____

34. ASK THE CHILD to describe the **CHILD'S SOCIAL PARTICIPATION** in the **SCHOOL SETTING. USE THE BEAD ON THE STRING TO DESCRIBE A NUMBER FROM 0 – 10.**

If the top of the string (**#10**) **represents the most possible participation** (playing and being included with other children) for a child of that age in the school environment, and the bottom of the string (**#0**) **represents the most isolated, segregated life possible** where the child is not ever included in the other children's play, **where would the bead** be placed to show the Child's level of social participation at school? _____ (0 – 10)

For what reasons was this number chosen?

35. ASK THE CHILD'S OPINION to describe the TEACHER'S ATTENTIVENESS at SCHOOL, USING THE BEAD ON THE STRING AND THE NUMBER FROM 0 – 10.

If the top of the string (#10) represents the most possible attention and assistance the teacher can offer a child in the class, and the bottom of the string (#0) represents the least possible assistance...completely ignoring the child's presence in the class--where would the bead be placed to show how attentive the teacher is to the Child in the class? _____ (0 – 10)

For what reasons was this number chosen?

36. Does your Child participate during P.E. class at school? () Yes () Sometimes () No

37. If not yes, does the teacher provide alternative physical activities for the Child to do while the others are exercising? () Yes () Sometimes () No

Describe what happens during P.E. time:

38. Does your Child have any difficulty in dealing with the pit latrines at school?

() Yes, Always () Most of the time () Sometimes () Only once in a while () Never

If Your Child has any difficulty at all, do you believe a raised pit latrine with a seat would be helpful for your child's toilet needs? () Yes () No

39. Do you believe putting your Child in the front of the class would assist the Child's ability to learn? () Yes () No

40. Does your teacher put your Child in the front of the class (ASK THE CHILD if unsure)

() Yes, Always () Most of the time () Sometimes () Only once in a while () Never

41. Does your school have stairs? () Yes () No

If yes, does your child have difficulty with the stairs () Yes () No

If yes, would a ramp be a useful addition to your school entry? () Yes () No

42. USING THE BEAD ON THE STRING TO INDICATE A SCALE OF 0 – 10, ALLOW THE CHILD TO PUT THE BEAD ON THE STRING EXACTLY WHERE HE/SHE BELIEVES IT SHOULD GO TO DESCRIBE HIS/HER LIFE.

The top of the string (#10) represents the best possible life, and the bottom of the string (#0) represents the worst possible life for the Child. _____ (0-10)

Have the Child explain why that place on the string was chosen:

43. LET THE CHILD CHOOSE WHICH FACE BEST REPRESENTS HIS/HER LIFE:

HAPPY



UNSURE



SAD



Let the Child explain why he/she chose that face:

NO

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Investigator: Anne Penny 256-41-222201 Kampala Uganda.

A GIFT OF AN EXERCISE BOOK AND A PEN IS GIVEN EACH CHILD AT THE END OF THE INTERVIEW.

QUESTIONNAIRE (no)

SCHOOL ACCESS FOR CHILDREN WITH LOCOMOTOR DISABILITIES

Reminder to the Interviewers:

Please find the main guardian of the Child to sign consent and fill out this questionnaire with and on behalf of the Child (ages 6 –18). **THIS CHILD MUST NOT BE ATTENDING ANY SCHOOL, AND MUST NOT HAVE COMPLETED HIS/HER PRIMARY SCHOOLING. THE CHILD MUST REQUIRE ASSISTANCE IN WALKING** (e.g. stick, crutch, chair, crawl etc) but he/she must not be impaired mentally, exclude hearing and visually impaired. Make sure that the interview takes place when the Child is available to participate so that you can have the input of the Child as well. Use the blank side of the consent page to carry over any comments that there is not space for in the lines provided, indicating the number of the question that is continued. Do not choose more than 10 Children per subcounty, and no more than one Child with a disability per family. If possible, try to maintain a fair balance between girls and boys interviewed. The following categories on this page need to be filled in by yourself as the interviewer, from your own knowledge, with assistance from the USDC files, and your conversation with the caregiver of the Child in question:

1. Disability of Child: (check and circle)

- a. () Neuromuscular Disease: polio, cerebral palsy (with clear talking), myelomeningocele, spinal paralysis
- b. () Congenital Abnormality: club feet, limb deformity, missing limbs
- c. () Bone and Joint Infection: osteomyelitis, septic arthritis, tuberculosis
- d. () Trauma (describe): _____
- e. () Other (describe): _____

2. District: _____

3. Subcounty: _____

4. Name of Village or Town and describe approximate population:

Village (less than 5,000): _____ population: _____

Town (5,000 or more): _____ population: _____

5. Language spoken: _____

6. Who is the respondent to the Questionnaire on behalf of the Child? _____

7. Who is the Guardian/Main Caregiver of the Child? _____

8. If respondent is not the Guardian/Main Caregiver, please explain why? _____

9. Level of Education of Mother: _____

10. Level of Education of Father: _____

11. Level of Education of Guardian/Main Caregiver if other than parent: _____

12. What is the main occupation of Mother? _____

13. What is the main occupation of Father? _____

14. What is the main occupation of Guardian/Main Caregiver if other than parent? _____

15. Does this household have:

a) () a private pit latrine () a shared pit latrine () no pit latrine

b) a radio Yes () No ()

c) their own land Yes () No ()

d) their own animals Yes () No () If Yes, list how many and which animals: _____

QUESTIONS FOR THE PARTICIPANT/CAREGIVER TO RESPOND TO:

1. **Gender** of Child: () Male () Female
2. **Age** of Child (must be between 6 and 18 years): _____ **Year** of Birth: _____
3. **Position of Child** in Family(1=firstborn, 3=thirdborn 7=seventh born etc): _____
4. **Number of Children** in Family: _____
5. Describe the **family grouping this child lives with most of the time** (e.g. two parent, mother only, father only, grandparent, aunt/uncle, foster parents--describe sibling/cousins/foster siblings in the same dwelling): **Circle Main Caregiver**

6. **Locomotion of Child:**
 - a. () Walks with a stick
 - b. () Walks with crutches
 - c. () Walks with crutches and braces
 - d. () Cannot walk, crawls
 - e. () Cannot crawl
 - f. () Moves by wheelchair
 - g. () Other _____
7. Has the Child been **assessed by any professional?** (Can check more than one)

() Physiotherapist	In what Year(s) _____
() USDC worker	In what Year(s) _____
() EARS worker	In what Year(s) _____
() Orthopaedic Surgeon	In what Year(s) _____
() Other _____	In what Year(s) _____
8. To describe the **CHILD'S SOCIAL PARTICIPATION** in the **VILLAGE/TOWN COMMUNITY** USE THE BEAD ON THE STRING TO CHOOSE A NUMBER FROM 0 – 10.
 If the top of the string (**#10**) represents the most possible participation (playing and being included with other children) for a child of that age in your community, and the bottom of the string (**#0**) represents the most isolated, segregated life possible where the child is not ever included in the other children's play, **where would you place the bead** to show where you believe your Child's level of social participation lies?
 _____ (0 – 10) **For what reasons** did you give this number?

9. Bearing in mind the school you wish your Child to attend:

- a. How many **kilometers** is the school from your home? _____ km
b. How many **days per week** would your Child to attend it? _____ (0-5)
c. **By what means** would it be possible to get your Child to school?
(e.g. walking with crutch/stick, boda boda, bicycle, crawl)

- d. **How long** would that take in hours including restbreaks? _____
e. Does your Child **have pain** when he/she moves his/her body over such a distance as from the school to your home? (ASK THE CHILD)
() Yes, Always () Most of the time () Sometimes () Only once in a while () Never
If any answer other than 'never', **explain where the pain is and when it comes:**

10. a. Does your Child experience the following negative behaviours from other children?

- **verbal teasing and name calling:**
() Yes, Always () Most of the time () Sometimes () Only once in a while () Never
- **hitting or beating:**
() Yes, Always () Most of the time () Sometimes () Only once in a while () Never
- **other children stealing a crutch or appliance and running away:**
(leave blank if Child does not have a crutch or appliance and is crawling only)
() Yes, Always () Most of the time () Sometimes () Only once in a while () Never
- **other cruelty, describe:** _____

b. If any of the above behaviours occur, explain which times they are most likely to:

- i) _____ in the village at home, when Caregiver is absent
ii) _____ in the village at home, when Caregiver is present
iii) other _____

c. If negative behaviour occurs towards your Child with disabilities, how does your Child cope with the teasing, beating or loss of appliance? (What does the Child do when this happens?)

d. If you answered never or only once in a while to question 10. a about negative behaviour towards the Child, describe why you believe the Child has not suffered in this way:

11. Does the Caregiver desire the Child to go to School?()Yes ()Uncertain ()No
Give **reasons** for your answer:

12. Does the Child desire to go to school?

(ASK CHILD) () Yes () Uncertain () No

Explain the Reasons for your Answer:

13. What does the Child want to become when he/she is grown? (ASK CHILD)

14. Who makes the decision for this Child to go to school or not?

(choose main one):

- a. () mother
- b. () father
- c. () foster parent
- d. () grandfather
- e. () grandmother
- f. () aunt
- g. () uncle
- h. () other _____

15. Do you believe that this Child is able to learn as well as an able-bodied child?

() Yes () Uncertain () No

Explain (if not Yes):

16. What jobs does this Child assist with in the Home?

- a. () sweeping
- b. () washing the clothes
- c. () digging
- d. () gathering firewood
- e. () food preparation & cooking
- f. () fetching water
- g. () babysitting of younger children
- h. () other (describe below): _____

17. Are all of the able-bodied , primary school aged siblings of your Child also attending school? Yes () No ()

If no, explain why not: _____

18. What are the reasons that this Child is not in school?

19. Can the Caregiver think of any solutions to these reasons that might assist this Child to get into school?

20. How might the Caregiver obtain money for school clothes, shoes, books and other fees?

21. USING THE BEAD ON THE STRING TO INDICATE A SCALE OF 0 – 10, ALLOW THE CHILD TO PUT THE BEAD ON THE STRING EXACTLY WHERE HE/SHE BELIEVES IT SHOULD GO TO DESCRIBE HIS/HER LIFE: The top of the string (#10) represents the best possible life, and the bottom of the string (#0) represents the worst possible life for the Child. (0-10). Have the Child explain why that place on the string was chosen:

22. LET THE CHILD CHOOSE WHICH FACE BEST REPRESENTS HIS/HER LIFE:

HAPPY



UNSURE



SAD



Let the Child explain why he/she chose that face:

If the Child has never been to school before in his/her life, the questionnaire is now completed.

If the Child has dropped out of school, continue with the following questions:

23. What **year** did the Child **begin** school? _____

24. What **year** did the Child **drop out**? _____

25. What was the **last class** your Child attended? P _____

26. What are the **reasons** that your Child stopped attending school?

27. What does the Caregiver think is **necessary in order to put the Child back into school**?



REPORT PART FOUR: PHOTO JOURNAL

SCHOOL ACCESS: CHILDREN WITH DISABILITIES IN RURAL UGANDA



Arua District: Anne walking in a village to pilot ideas for the questionnaire (August) The courage of many of these children and their families amazed and humbled me. They are special people. I hope the following photos bring to life the situations of the people whom this report seeks to assist.

The rural Ugandan lifestyle is very physical. Men sometimes call women 'their tractors', and the children in turn are called 'little tractors'. It is the children's work to bring the water to the household.



Children's work also includes caring for the livestock, digging in the fields, and taking care of younger siblings. It is not uncommon to find a newborn baby strapped to the back of a four or five year old child, while the mother works elsewhere digging in the field.



In the wheelchair is my very able translator for the individual interviews and focus group. He is a teacher and a resident at Katalemwa Cheshire Home for children with disabilities. Because this young man has muscular dystrophy he strongly empathizes with the children in his care, and has a great understanding of the issues that they face.

The bottom picture shows the translator working with another Ugandan teacher/mother, cross-checking my interview questions through the method of back translation. I would say the question in English without the mother hearing, and the translator would try it out in Luganda to the mother—who, having heard the question only in Luganda would then translate it back to me in English. This way I could cross-check if the questions translated to mean exactly what I wanted to know.



In the top photo, the focus group of caregivers and translator gather for a group photo in June, 1999. Only the British notetaker/assistant smiles for the photo. However, they all burst into joyful laughter the moment after the photo was taken.

Below left is a grandmother who cares for her orphaned granddaughter. The granddaughter suffered from a bone infection (osteomyelitis). This girl used a stick to cross the two miles to school before she came to receive surgical treatment, crutches, and rehabilitation. Her hands were very sore and calloused.

Below right is an illiterate mother whose 14 year old son has received surgery and is in the process of rehabilitation for polio. This boy has never attended school, but he certainly is looking forward to going now. He used to crawl, but now he will walk with the aid of crutches.



The two articulate mothers below were both brilliant at describing their school struggles with their sons. They shared in the focus group and later in individual interviews. Both boys currently attended school. Both mothers had to leave their jobs and other children in order to assist in the rehabilitation of their boys. The boy on the left (8 years old) broke his leg while at school, and then suffered with osteomyelitis and a non-united bone. This mother invented creative ways to assist her son in reintegrating back into his regular school environment after his accident. The boy on the left (6 years old) was afflicted at the age of three with polio, which left him unable to walk. This mother was a teacher, and taught him at home before enrolling him in the school system. She was not shy in describing how many teachers have yet to learn sensitivity to the needs of children like her son. Both boys could not manage to be in the school without the assistance of treatment, and these tenacious mothers who work hard at getting them there each day.



The illiterate mother in the top photo left several ill children at home in order to seek assistance in Kampala for her older daughter below. She participated in the individual interviews, giving the perspective of the parent who still has yet to access school for her child. The smiling girl in the photo below is eight years old, and has a high maintenance disability because she is unable to move at all, except by very slow sliding. She suffers from severe polio, which has left her with scoliosis of the spine and weak arms. This girl loved her stay at Katalemwa, and was especially enthusiastic about the daily school lessons that she received while receiving charity-sponsored medical treatment. When she returned to the village there was no hope of school for her, as her father was unwilling to spend any money on what he labelled 'a useless child'. This girl was part of a polygamous family that shared a small hut; since she was not an offspring of the favoured wife, she suffered abuse from step-brothers and step-mothers.



Below are the nine interviewers for the quantitative survey. The top group of five was trained in Kampala. The lower group of four was trained in Arua-town. Five of the interviewers were special education teachers who fulfilled the questionnaires during their term holiday break. Four of the interviewers were Ugandan Society for Disabled Children community facilitators. In their hands they are holding the string with marks and a bead used for the 'Quality of Life' question (eg. As explained in the Quantitative section of this report, the best life was equal to 10/10, worst life being 0/10---and the mid-point is 5/10).



Here I am in a village in Arua district, sitting with a family and the physiotherapist who is translating for me. We asked the children questions about their disabilities and school access. The family featured here had two step-brothers who were both suffering from 'konzo', a cassava poisoning disease that results in paralysis. One brother had received surgery and was able to get to school two kilometers away using crutches. The other brother was hoping to receive surgery in the future. His wheelchair allowed him to cross the distance to school, but since the school threshold was too high, he had to crawl out of his wheelchair and spend the day crawling on the floor of the classroom.



The boy with the crutches below has had surgery on only one of his knock-knees. He is in P2 (grade 2) and gets to school using his crutches. I found him at the hospital in Arua awaiting surgery for his other knee. The smiling boy in the pink below crawls to school 1 km everyday. His mother gives him thongs for his hands to go in so they don't get too damaged on the dirt roads. When it rains, it is extremely difficult for him in the mud.



This young lady (10 years of age) moves by use of the stool in the top photo. Using the stool she does not have to bend all the way down on all fours to crawl. Many girls who were unable to walk chose to move with only their knees touching the ground, and their backs straight as seen. Although this girl did not attend school, her family would put her on a bicycle sometimes (see photo below) so that she could attend the church 1 km away.



This remarkable 18 year old girl had multiple congenital abnormalities, including webbed fingers, extra toes, and absent tibias. When UPE came into legislation, in 1997 at the age of 16, she crawled to school for the first time, and enrolled herself in P1, Grade One. She has managed to be able to write with a pen, using both webbed hands together (top right). She even showed me how she could crochet yarn (bottom left). I was most impressed and laughingly told her I did not know how, and I had all my fingers separate!

