CENTRE FOR INTERNATIONAL
HEALTH AND DEVELOPMENT

UCL - INSTITUTE OF CHILD HEALTH

“Out of the Shadows”:

A Qualitative study of Parents’ and Professionals’ attitudes and beliefs about children with Communication Disability in Uganda and how best to help them.

An MSc Thesis by Julia McGeown.

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Photographs outside the Centres where the Research took place:

Outside Dawn Children's Centre

Outside Mukisa (Charitable) Foundation

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1.Abbreviations

ICH= Institute of Child Health
IRB= Institutional Review Board
DPOs= Disabled Persons Organisations
MDGs= Millennium Development Goals
TASO (U) = The Aids Support Organisation , Uganda
UCL= University College London
UNCRPD= United Nations Convention for the Rights of Persons with Disabilities
UNCST= Uganda National Council for Science of Technology
WHO= World Health Organisation

Glossary of Terms

AAC =Alternative and Augmentative Communication

Alternative and Augmentative Communication are communication methods used instead of speech, or alongside speech, for people with impairments in the production or comprehension of spoken language. This includes Cerebral Palsy, Autism and Learning Difficulties/ Intellectual Impairment. This can include “low tech” methods such as communication boards, eye gaze systems where the individual eye points to a word or picture on a board, visual symbol systems, unaided systems such as sign language, and “high tech” systems including speech generating devices with artificial voices activated by buttons or switches. Only “low tech” methods were used by participants in this study.

ASD= Autistic Spectrum Disorder

There is a triad of impairments in Autism; in communication, in social skills and in restricted and repetitive behaviour. It is a disorder of neural development, due to altered connections between nerve cells and their synapses leading to disordered processing of information within the brain. Children are usually diagnosed within the first three years, and it cannot be cured although it can be treated with therapy to reduce the effects. There are strong genetic links.

CBR= Community Based Rehabilitation

This began in the 1980s, designed to help people with disabilities access rehabilitation in rural settings in the developing world. It has become a wider ranging approach, so in addition to addressing rehabilitative service needs, CBR also includes empowerment, advocacy and addressing stigma by trying to change negative attitudes towards people with disabilities. It is run by a mixture of government and Non-governmental organisations (NGOS), and combines a range of health, educational, work based and social services.

Gestures

Sometimes the terms “gestures” and “signs” are used interchangeably but gestures are a non-formal system of communication, and signs are a formal system. This is because gestures usually vary between individuals and are family or context specific. They are often not used consistently and are not part of a language, unlike formal signs as part of a recognised sign language. They are also unlikely to represent higher level concepts like signs do, such as prepositions, adjectives and adverbs. They tend to be more basic ideas, such as “no”, “yes”, “more” and “stop”.

Hand Leading

This is mainly used by children with Autism/ASD as a functional means of communication but it is not usually found in typically developing children. The child uses the adult’s hand as an instrument to get what they want, by physically placing the adult’s hand on the item they need or the door they want to open for example. A typically developing toddler would try to engage in a conversation by pointing and attempting to verbalise, and does not normally go through this stage.

Objects of reference

Objects of Reference systems are usually set up to try to help explain what activity is coming next to a child with severe communication and cognitive impairments. The key with objects of reference is to present the child with a familiar item connected with that activity before it occurs, and they should remain with the object during the activity. Over time, the child learns to choose what activity they want by using objects such as “towel” for swimming or “cup” for drinks time. The centres in this study often used objects of reference to help request items they needed although they did not call this “objects of reference” necessarily.

PECS = Picture Exchange Communication System

This is a system that teaches children to a make request by exchanging pictures with items that they want. There are six distinct stages and it is a very structured teaching process, based on behavioural psychology approaches. It uses prompting and reinforcement strategies. In the final stage, they learn to make comments and full sentences using pictures and sentence strips. This teaches children how to have a conversation and initiate communication rather than just pointing to pictures (Bondy and Frost 2001).

PMLD= Profound and Multiple Learning Difficulties

People with profound and multiple learning difficulties need care and support from other people throughout their lives. Most people with PMLD will also have physical disabilities and will be unable to walk, and some have additional hearing / sight problems. The majority are non-verbal and communicate using signs, symbols, facial expressions or noises. They have difficulties learning literacy and numeracy skills, and also basic self-help, reasoning and communication skills. PMLD is often linked to severe developmental delay and epilepsy.

Signs

Signs refer to the use of a formal sign language system, such as British Sign Language or Ugandan Sign Language. For people with additional cognitive difficulties, simpler systems such as “Makaton” may be used, which is based on British Sign language, but it not as grammatically complex (Walker 1976). Only key words are signed and words such as “the” and word endings such as “ing” are omitted. Makaton was used at “Mukissa”, a centre in the study.

Symbols

Symbols are similar to pictures, in that they represent objects in a visual way. However, a symbol represents a single concept and can be put together into phrases or sentences to build more precise information. Also, a symbol can represent something that it is difficult to draw a picture or take a photograph of, such as “more” or “want”.

2.List of Figures and Tables

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3.Abstract

This was a qualitative study to explore how parents, teachers and classroom assistants in Uganda view children with communication impairments, the reasons they give for their difficulties, and how they currently help them. This included an exploration of any Alternative and Augmentative Communication (AAC) methods used. AAC allows people to communicate without using speech, for example by signing or using pictures.The overall aim was to generate solutions and recommendations to remove any barriers preventing these children from communicating effectively and potentially to improve their quality of life. Data was collected through 18 semi-structured interviews (with parents, classroom assistants and teachers), and one focus group discussion with teachers, across three sites in Entebbe and Kampala.

The findings showed that traditional beliefs about disability are still common and explanations for a child's communication impairment included witchcraft, taboos, Gods, incorrect diet, woman's fault, use of family planning pills and the child's upbringing. Western or biomedical views were also present but less common. Most participants combined their beliefs, emphasizing the need for traditional and bio-medical professionals to work together. The results highlighted that both disability sensitisation within society and more specific AAC training programmes for parents and teachers are needed. Interventions should emphasise how this training can reduce the burden of care, increase long term prosperity, improve child protection measures (regarding the ability to report abuse), and improve quality of life. The data was analysed using a combination of models and approaches; ecological theory (Bronfenbrenner 1997) and complexity theory (De Bortoli et al 2010) as a way of looking at "stigma" and views on "inclusion", and the "Coping Strategy model" (Lazarus and Folkman 1984) analysing how parents cope. This was an action-based research project, looking for solutions to any problems identified by the participants.

Recommendations are that at district level, there should be more support for parent groups and training sessions for parents and teachers, and inclusive education should be enforced to allow all disabled children access to education. At national level, the government should support media campaigns to raise awareness of communication disabilities as an important issue impacting on the wellbeing of disabled children and their families.

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4.Introduction

Communication forms the basis of human life and the complex ways with which humans can communicate and interact with each other sets us apart from all other species. However, not all humans are able to communicate effectively due to a range of communication impairments. This can have a knock on effect on their ability to access education or employment and to be able to enjoy a reasonable standard of living, particularly if they reside in low income countries. An estimated 190.5 million people in low income countries are expected to have communication disabilities by 2025, which is why it is so important to do research in this area (Hartley 1998).

Uganda is one such low income country located in East Africa, with a population of 32.7 million, and a life expectancy of 53 years (World Bank 2012).It has a poverty ratio of 31.1% highlighting real inequalities within the country. The 1980s saw a period of liberalisation and pro market policies, leading to private sector reforms in the 1990s, and a more stable economy, with the growth rate shifting from 6.3 to 7% (World Bank 2012).

Yet 25% of people still live in poverty, and a disproportionate number of those are disabled. In their disability scoping study, Lang et al (2009) highlighted the discrepancy between the 2005 Uganda National Household Survey disability prevalence figure (7.1%) and the 2002 Population and Housing Census figure (3.5%).This is misleading because of the way the categories are used. Between 15-20% of disabled people in Uganda are reported to have hearing impairments, which often affect communication abilities but deafness does not account for all the causes of communication disability. Many people with physical impairments may also have communication disabilities which are not their primary impairment. Therefore, the true numbers of people requiring help for communication impairments in Uganda is likely to be over half a million, based on the above figures (24% of disabled population). Indeed, between 38 - 49% of disabled people requiring help from Community Based rehabilitation schemes had communication disabilities (Hartley 1998).

This is more than just a human rights issue. It is particularly timely to focus on developing disability services in low income countries. Groce (2011) comments on the rise of the political profile of disability and development issues, culminating in the 2008 United Nations convention for the Rights of Persons with Disabilities, the UNCRPD, ratified by Uganda in 2008. She highlights that the 2010 review of the Millennium Development Goals (MDGS) revealed that they would not be met in many countries, if disability issues were not specifically addressed.

There is a sound economic reason to improve the lives of people with communication disabilities within Uganda. Poverty is often the root cause of disabilities and can also be a consequence of disability, and the cost of disabled people not being economically active will affect the growth of the whole country (Coleridge 2007). Being able to communicate to others using augmentative systems may mean the difference between being employable or not, whatever the profession.

Incredibly, 87% of the world's disabled children live in a developing country, but only 1-2 % of them receive any formal schooling. Uganda is at the forefront of inclusive education in developing countries, having adopted an inclusive education policy in 1997 (Coleridge 2007). However, in one study, only 35% of the primary school aged children with disabilities in a Southern Ugandan district went to school (Afako et al 2001) so implementation is clearly a problem.

5 Literature Review

5.1.Models and beliefs about disability in Africa

Assistive technology is commonplace in high income countries, and refers to any rehabilitative devices for people with disabilities; e.g. wheelchairs, braille and hearing aids. Aids for people who have little or no speech are called Augmentative and Alternative Communication (AAC) and therefore are forms of assistive technology (see glossary).These range from “low tech” methods such as communication boards with pictures to ‘high tech’ systems including computer aided devices which produce an “electronic voice”.

Before introducing any form of assistive technology into a culture, it is important to study the explanation given to the cause of disability, within that cultural context (Ripat et al 2010). Local explanations for communication impairments could be at an individual level based on the biomedical model, at a social world level where disability is the result of somebody wronging another person in the community, or there could be a supernatural explanation involving witchcraft (Ripat et al 2010).

The explanation of the causes of impairment determines how disabling it is in that context. This links to the social model of disability which distinguishes between impairment, which is the actual “deficit” or difficulty that the person has, and the disability, which is how society responds to people with impairments (Shakespeare 2012). In its purest form, this model states that people with disabilities face difficulties because of discrimination and lack of services .Society should change and remove these barriers, rather than the people with impairments, who should just be seen as being part of natural human diversity.

However, in Africa, rehabilitation and the use of AAC may only be adopted if it fits in with the families’ explanation of the impairment. So whilst it fits well if the explanation is biomedical, meaning that the child requires help to become independent, if the impairment is seen as shameful, then it may be more difficult to introduce rehabilitation aids aiming to give the child a voice (Ripat et al 2010).

There is only limited research looking at communication disabilities and the role of traditional healers and traditional beliefs in Africa. In South Africa, Dagher et al (2004) looked at cleft palate and Andrade et al (2005) focused on hearing impairment. Both cite examples of healers attributing the impairment to ancestors causing curses or failure to take part in rituals or to adhere to taboos. However in both studies the traditional healers expressed a wish to collaborate more with western doctors. Andrade et al (2005) found that 12 out of 15 healers referred to modern doctors when their treatment did not work.

This is not always the case. Many families of disabled children who have had interactions with traditional healers may be skeptical of Western medicine. However, a belief in God's will or a curse on the family as a cause of disability is not necessarily negative. Ingstad (1990) cites a survey which found that mothers' felt more guilt after giving birth to a disabled baby in Norway than in Botswana, as they attributed individual factors as the cause, whereas the Botswana mothers felt that it was out of their control, and due to witchcraft.

Cultural beliefs are often mistakenly believed to be the cause of a disabled child's neglect or abuse, when actually socio-economic factors may be the root cause. It is often a question of priorities: in a situation of hunger, disease and extreme poverty, the disabled child is often weaker and less of a priority to send to school, and it can be difficult to take them to appointments with a large family to look after (Ingstad 1990).

5.2.Multicultural Issues in AAC research

As the study of AAC has grown as a discipline, recognition of the need to gather information from multi-cultural settings has increased, but challenges remain. Matsumo (1994) describes the three main challenges: allowing our own culture to affect how we see the others’ behaviour, creating representations of how we think others should behave rather than how they actually behave, and creating cultural stereotypes. Reflexivity is therefore crucial in this type of research (Bridges 2004).

The overall culture of the family is particularly important. Hetzroni et al (1996) created guidelines for cultural assessment intervention, to find out what aspects of the language and culture lend themselves to AAC. Parette et al (2004) highlighted further cultural considerations when working with children with communication disabilities and their use of AAC. It is imperative that the child’s AAC device is matched to their natural environment, in terms of everyday activities. Furthermore, it may be preferable for a child to learn a sense of duty and collective support, rather than learning to be independent (Parette et al 2004). A final point regarding multi-cultural issues is that it is important to adapt training programmes for local populations, to suit the cultural context (Kent Walsh 2003).

5.3.Disability issues and AAC use in East Africa

A literature review was conducted to investigate disability issues within East Africa and specifically Uganda, particularly in relation to communication disabilities and AAC. In a survey of rehabilitation services and how people cope with disability in Uganda, May-teerink (1999) interviewed 49 mobility impaired Ugandans and found access to assistive devices was a major indicator of the participants’ quality of life, and the main barrier to this was financial. Those without assistive devices for mobility had to beg, whereas those with assistive devices were able to gain access to education and employment.

Hartley et al (2005) looked at how carers of disabled Ugandan children coped. They looked at the traditional views and issues associated with child disability in three Ugandan districts. Challenges faced by families included the time needed to look after the child, the lack of funds for food, treatment and transport costs, parental stress and resulting health problems. Communication problems emerged as a major challenge, with several carers complaining that their children showed challenging behaviour because they had no way to communicate. Many respondents mentioned that negative attitudes towards children with disabilities were rife in their communities. Observational data confirmed this, as many children in the study were observed hidden in back rooms. As with other parts of Africa, parents often believed that the cause of their child's disability was God's will, or due to spirits and witchcraft (Hartley et al 2005). Most families in the study accepted their children in the family setting and attempted to seek cures both from modern doctors and traditional healers, showing their desire to try to help their children (Hartley et al 2005). The overall conclusion from this study was the need for a holistic approach and full collaboration between all stakeholders.

In a survey of AAC use in East Africa, Swann (1987) found that extreme poverty meant that AAC tended to be given a lower priority on the health and family agenda. Also, families would often assume that rehabilitation was irrelevant as their child's cure was in the hands of fate. Alternatively, they would expect an immediate cure after intervention.

Alant (1996) looked at AAC use in developing countries and how to implement effective change, highlighting the fact that people with communication disabilities are often one of the most neglected amongst disabled groups. Alant (1999) also conducted a prevalence study of students with little or no functional speech in special needs settings in Pretoria, South Africa. Only 1% of the children in this category had been exposed to AAC methods.

More recently, Mukhopadhyay et al (2009) looked at AAC use in Botswana, focusing on teachers' perceptions regarding AAC use in their classes and their knowledge, skills and attitude towards using AAC for their non-speaking learners. Child related challenges included the difficulty of understanding children with limited speech, knowing how to discipline them, and also knowing what developmental level they were functioning at. Additional challenges included the stigma of working in a special needs school, the amount of work involved, and the lack of time and resources available for implementation (Mukhopadhyay et al 2009). The recommendations were for more support staff in special needs classrooms, more culturally appropriate resources and more of a focus on teamwork within schools through training (Mukhopadhyay et al 2009).

5.4. **Global Findings – Barriers and Facilitators to AAC use**

The majority of global findings regarding AAC originate from research in high income countries, although only those including low tech AAC are discussed below. In a review, Baxter et al (2012) found that barriers included the parents not being involved enough during the decision making process (McNaughton et al 2008) and negative family attitudes towards the AAC system (Johnson 2006) .The implications are that attitudes and input of the people surrounding the child using AAC are crucial to its successful implementation.

The issue of insufficient time was highlighted as a barrier throughout the literature: to make and create resources, for training, and for the child. Indeed lack of time and lack of flexibility from teachers and other professionals can prevent AAC from working at all (Feiler et al 2010). There also needs to be an individual approach to developing AAC for each child, requiring a close relationship with teaching assistants, under supervision from professionals. The final barrier to highlight is insufficient resources to fund teaching assistants, and insufficient training to deliver an individual approach to AAC. Therefore, a key factor to help disabled children use AAC more effectively is training for staff and parents. Schlosser et al (2000) evaluated a training package for staff working with a child using an AAC system, and described positive outcomes from the training. The need for more training for both parents and professionals was also found in studies by Lund and Light (2007) and Goldbart and Marshall (2004).

Teachers also need to be multi-talented with sufficient creativity, patience, flexibility, and practical AAC knowledge and skills (Soto et al 2001). Without this, it is unlikely that their students who need AAC will develop appropriately. Teachers' attitudes were noted to be particularly important. Often when teachers realise the value of AAC for improving the students’ behaviour in addition to their communication skills, this improves their attitude towards its use. Theoretical training should therefore be combined with attitudinal change. De Bortoli et al (2010) cite a number of studies where teachers showed no significant improvement in their observed interaction skills after training but a more important positive correlation was between teachers' attitudes and the amount of interaction they had with their students. A recommendation in the study was for hands on training to take place with the students with communication disabilities based on interactional skills, rather than giving theory based training alone.

Attitudes of parents, teachers or assistants are often part of a bigger picture, and not just their individual viewpoints. De Bortoli et al (2010) discussed "complexity theory" meaning that systems are built in layers, with different contextual factors taking place on each level:

the school level is in turn embedded at district level, and then at institutional and national levels. These levels are not isolated, but are inter-connected in many complex ways. This is similar to Bronfemmer's (1997) ecological theory, with five embedded systems.

5.5 Summary

This review has discussed the real need for qualitative research about children with communication disabilities in Uganda, and why this is a timely piece of research. To set the scene and the context for this research, traditional beliefs regarding disability in Africa were summarized. Alternative and Augmentative Communication (AAC) has been discussed, particularly by looking at multicultural issues regarding its use. Whilst there is a plethora of studies looking at the facilitators and barriers towards the use of AAC in developed countries, there is a real dearth of such literature in East Africa. Hartley's (2005) study focused on how Ugandan families cope with disabled children, and their attitudes and beliefs about disability. This study would add to this body of knowledge by contributing a specific focus on communication disabilities and attitudes towards using different methods of communication.

This is an optimum time for this research as the first cohort of Ugandan Speech and Language therapists graduated in 2011, so there are professionals available with the clinical skills needed to implement change once more is known. The recent upsurge in technology in Africa means that there is likely to be a growing market for high tech communication aids in the future and an increased use of low tech methods. It is important to look at any current cultural, practical and attitudinal barriers preventing children from accessing AAC to make the best use of this new technology.

5.6 Research Questions

1. **What are the attitudes, beliefs and explanations of parents and professionals regarding communication disability in children, and how do they feel these children are viewed by society?**

2. **How do the participants currently help the children with communication disabilities to communicate? What are the perceived barriers to or facilitators helping them to do this effectively?**

The overall aim is to generate solutions and recommendations for the removal of any barriers to helping these children from communicating effectively and potentially improve their quality of life.

6. Methodology

This study consisted of primary research in Entebbe and Kampala, Uganda.

6.1 Design

A qualitative interview methodology was chosen as there has been no previous research looking at school staff and parents' attitudes and beliefs regarding children using AAC in Uganda so this was a preliminary investigation to explore the issues. This methodology gave the participants opportunity to provide rich descriptions of their own specific contexts, which gave a more in-depth level of analysis. It also adds to previous qualitative research looking at beliefs of parents regarding causation of disability, and attitudes towards disability (Hartley 1995).

6.2 Target and Study Population

The target population for this study was children with communication disability, and the study population were parents, teachers and classroom assistants of such children. The recruitment of the participants in this study was achieved initially by direct e-mail contact with the directors of three centres in Kampala and Entebbe and subsequent face to face meetings. A purposive sampling method was used to select 6 teachers, assistants and parents, with guidance from the directors of the centres who ensured that there was as much diversity in the socio-economic and educational backgrounds of the participants as possible. Purposive sampling improves the chance of research generating meaningful results (Green et al 2009).

The main inclusion criteria for teachers and assistants, was that they had daily contact with at least one child with a severe communication disability. All participants were given an information sheet in English. The use of a translator was offered but not necessary, as all the participants chose to converse in English. It was emphasised that they would be free to leave the study at any time and were under no obligation to take part, and that it would not affect any services they receive if they did not wish to take part. The participants were also asked to sign a consent form acknowledging their consent to take part in the study. A separate written consent form was also gained from all the participants consenting to the audio-recordings.

6.3 Materials

An Olympus WS-321M digital voice recorder was used for the recordings, with an inbuilt USB stick. This was compatible with the Compaq laptop used for the analysis of the recordings, using basic Microsoft word software.

Table 1: Participants' Details

Participant Group and Quote Code	Centre Name and Quote Code	Initial + Age, Sex	Level of experience / occupation	Education level	Communication Impairment (s) described
Teachers (T)	Mukissa (M) (charitable)	H, 34 yrs, female	6 months at this school, 8 years in inclusive school.	Diploma in Special Education	Autism, Hearing Impairment
		J, 29 yrs, female	3 months at this school, 3 years in mainstream school.	BA(Hons) in Special Education	Autism
	Dawn (D) (fees/ urban)	D, 38 yrs, female	5 months special needs, 12 years in mainstream school.	Diploma in Primary teaching.	Learning Difficulties, Cerebral Palsy
		M, 27 yrs, female	18 months special needs, 4 years in nursery schools	Diploma in Primary teaching.	Cerebral Palsy, Autism
	Komo (K) (fees/ peri-urban)	D, 31 yrs, female	4 years special needs teaching	Diploma in Special Ed.	Autism
		J, 42 years, female	15 years teaching mainstream infants	Diploma in primary teaching	Autism
Parents (P)	Mukissa (M) (charitable)	G, 28 yrs, female	Informally fostering the child.	Secondary Certificate	Autism
		J, 28 yrs, female	Mother to 5 children.	Primary Certificate	Cerebral Palsy due to Cerebral malaria
	Dawn (D) (fees/ urban)	A, 29 yrs, male	Caregiver and worker within family for 3 years	Unknown	Profound and Multiple Learning Difficulties
		G, 23 yrs,	Mother and	Primary	Hemiplegia

		female	housewife	Certificate	
	Komo (K) (fees/ peri-urban)	G, 51 yrs, female	Used to be a teacher, but took early retirement to set up candle making business	BA in Education	Autistic features following Cerebral Malaria
		J, 33 yrs, female	Works as an administrator, has a house girl.	Diploma in Admin.	Autism
Assistants (A)	Mukissa M) (charitable)	F, 27 yrs, male	3 years at an Occupational Therapist (OT)	BA (Hons) in OT	Cerebral Palsy
		J, 44 yrs, female	4 years as a classroom assistant	Secondary Certificate	Autism, and Cerebral Palsy
	Dawn (D) (fees/ urban)	F, 24 years, male	2 ½ years as an occupational therapist (OT)	BA (Hons) in OT.	Cerebral Palsy, Learning Difficulties
		A, 28 yrs, female	4 years as a physiotherapist	BA (Hons) in Physio.	Cerebral Palsy
	Komo (K) (fees/ peri-urban)	G, 23 years, female	Assistant to Teacher C, for 2 years	Secondary Certificate	Autism
		J, 25 years	Special needs Assistant for 3 years	Secondary Certificate	Autism

6.4 Procedures

Prior to the primary data collection, a thorough literature review was undertaken, using pub-med, SCOPUS, JSTOR and other online journal databases .Search terms such as “ AAC”, “Communication Impairments”, “Africa”, “Traditional beliefs”, “parents”, “teachers” and “attitudes” were used.

The initial data collection involved semi-structured interviews as described by Kvale (1996). The interviews were conducted in as quiet a room as possible in the school/ home/centre, depending on the choice or availability of the participant, and ranged from 25 minutes to 1 hour in length. A flexible topic guide (see appendix i) was developed for use in these interviews, which consisted of a series of 8 overall themes for discussion. A pilot interview took place initially with two Ugandans known to the researcher, who consented to take part and the wording in the topic guides was slightly altered as a result. However, the exact wording used and the sequence of questions asked varied depending on responses. At the beginning of each interview, the investigator explained that she was interested in finding out all of their thoughts and experiences regarding communication disability and how these children communicate, even if they were not covered by the questions asked. The private nature of these interviews meant that the participants were free to discuss sensitive issues without being influenced by others.

A focus group discussion was carried out with one homogenous group, the teachers, previously interviewed. The purpose of the focus group discussions was to generate and spark further discussions that may not have come to light during the individual interviews and to allow participants to air views that they may only be comfortable with discussing once they knew others were in agreement.

As this is an action research project, another aim was to create a suitable forum for generating ideas for improving the current situation if any problems were identified by participants. Participatory methods were used to generate initial discussion, involving free-listing and brain storming (Green et al 2009) A separate topic guide was used to enable the facilitator to guide the focus group discussion (appendix ii).

6.5 Methods of Analysis

The digitally recorded interviews and focus group discussion were transcribed using broad transcription by the investigator. Observational notes were also taken concurrently, which were corroborated with the transcripts to ensure accuracy. The researcher then reviewed the transcripts using thematic content analysis (Green et al 2009). This was a comparative process whereby the researcher reviewed the transcript with increasing amounts of detail, initially highlighting key points using memos, using codes to organize the data into types and finally analysing recurring themes and sub themes within the data set. Manual “cut and paste” and “long table analysis” techniques were used in order to sort and collate the data into themes (Krueger and Casey 2000). This was an inductive process, which was continually revisited as more data was analysed. Although there were initially 37 themes, this was finally grouped together as 7 major themes, in 2 overall categories. The final interpretation of the transcripts was then checked verbally with a sub set of 8 participants to ensure accuracy and to enhance internal validity. This was particularly important as this is an action research project, aiming to identify problems and generate solutions through the participants themselves (Green et al 2009).

6.6 Ethics Procedures

This study was approved by the UCL Ethics Committee prior to the research being carried out, and was also approved by TASO Institutional Review Committee, one of the accredited ethical review boards in Uganda. This process also required clearance from UNCST. All participants signed consent forms for both taking part in the study and to allow audio recordings. No names appeared on any of the transcripts or results tables, to preserve anonymity. The participants were not given any monitory reimbursement as they did not need to make any special journeys, but they were offered small gifts for their children, or for the school as a gesture of thanks.

6.7 Adaptations

Initially, the intention was to carry out three focus group discussions. However, due to time and logistical constraints it was only possible to carry out one focus group discussion with teachers. Only four teachers were able to attend. It was decided to include this data in with the rest, as it generated some interesting discussion that had not been present during the individual interviews, and it also corroborated previous points made during the interviews, so provided a degree of triangulation (Green et al 2009).

Two of the parents interviewed were primary care-givers, but not the biological parents of the children. Due to a limited number of teaching assistants, two of the assistants interviewed functioned as assistants at the centres, but had additional qualifications, in physiotherapy and occupational therapy.

6.8 Reflexivity

All researchers should be aware of their own biases and preconceptions before entering into field study, and need to eliminate these as much as possible when asking questions analysing results. As a Speech and Language Therapist, and having worked previously in

Uganda, it was important for me to interview participants completely impartially, and not take on a teaching role, as I had been previously. As a Caucasian female, I was aware of my own differences in a Ugandan setting when interviewing the participants, and how this may affect the results. For example, I believe in the rights of the child, and the universal right to education and healthcare. However, having spent three years in East and West Africa, including a year in Uganda, I was able to show enough familiarity with local customs and culture to make the participants feel at ease with my presence. Many authors conclude that primary data loses some of its quality if initial data collection is in a foreign language (Kenny 1994). Because I conducted the research in urban / peri-urban settings near the capital, the respondents all spoke English, which allowed me a closer understanding of the data, as there was no third party or language barrier.

7. Results, Analysis and Discussion

Model 1 demonstrates how all the themes are interlinked. The two major themes, "Attitudes and beliefs" and "Developing AAC" relate to the two research questions.

7.1 Attitudes ,Beliefs and Explanations

An individual's attitude and belief towards a child with communication disability can directly impact on whether that child receives help or treatment. This direct impact was highlighted in the focus group held with the teachers:

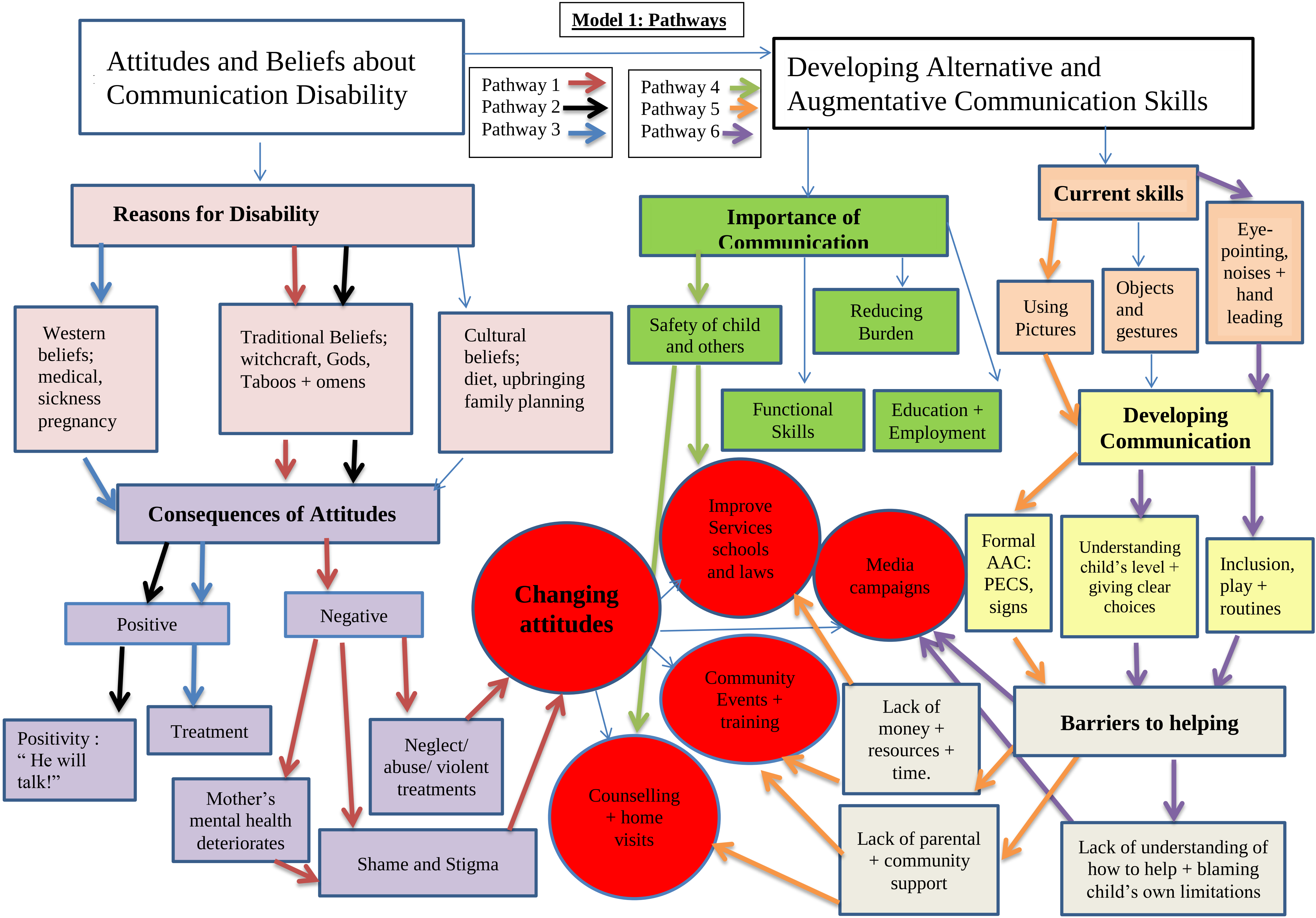
> *"And some people, because they think it is a curse, and they would not endeavour to take the child anywhere." (FGD, D: 132)*

Model 1 demonstrates this situation through **Pathway 1.** Traditional and cultural beliefs for the causation of the communication disability were common in the data set, backing up Hartley's (2005) findings that many rural Ugandan parents believe witchcraft as an explanation. Interestingly though, the parents here were all from urban/ peri-urban settings, yet the same views were common. The negative consequences of these beliefs have led some participants to suggest "changing attitudes". This is in turn linked to "barriers to helping" a child to develop communication skills. For example, a major barrier to helping develop AAC is that there is a lack of parental and community support, which is embedded in beliefs around curses and witchcraft. Such beliefs are what Ripat el al (2010) terms supernatural explanations, or social world level explanations, where disability is the result of somebody wronging another. Staff and parents have suggested that "changing attitudes" can be done through media campaigns to raise awareness about causes and treatment:

> *"Maybe sensitisation of the public…The radio, TV you know. So people get to know that it is actually a problem out there. Like the Oprah show...how I got to know. I think that is the best option."(KP;191-194)*

This mother learnt that her child has Autism through watching the Oprah show and explained that it really helped her to understand the problem and that she wasn't to blame. These same barriers can also be tackled though counselling and home visits to families, helping to alleviate the negative consequences of attitudes, as happens at some centres:
"So what usually happens here. We do home visits." (KA 275)

Model 1: Pathways



Attitudes and Beliefs about Communication Disability

Pathway 1 →
Pathway 2 →
Pathway 3 →

Pathway 4 →
Pathway 5 →
Pathway 6 →

Developing Alternative and Augmentative Communication Skills

Reasons for Disability

Western beliefs; medical, sickness pregnancy

Traditional Beliefs; witchcraft, Gods, Taboos + omens

Cultural beliefs; diet, upbringing family planning

Consequences of Attitudes

Positive

Negative

Positivity : " He will talk!"

Treatment

Mother's mental health deteriorates

Neglect/ abuse/ violent treatments

Shame and Stigma

Changing attitudes

Importance of Communication

Safety of child and others

Reducing Burden

Functional Skills

Education + Employment

Improve Services schools and laws

Media campaigns

Community Events + training

Counselling + home visits

Current skills

Using Pictures

Objects and gestures

Eye-pointing, noises + hand leading

Developing Communication

Formal AAC: PECS, signs

Understanding child's level + giving clear choices

Inclusion, play + routines

Barriers to helping

Lack of money + resources + time.

Lack of parental + community support

Lack of understanding of how to help + blaming child's own limitations

Teachers agreed that home visits would be a good idea:

> *"It would be better if you also went to homes with kids with disabilities and explained to them."(DT: 206)*

One of the negative consequences in **Pathway 1** is neglect, a subject that the teachers in the focus group discussion all agreed on:

> *" J: Sometimes they just lock them inside the house. They don't even go out.*
> *D: Yeah*
> *M: Hmmm*
> *J: Some even fall sick and this parent doesn't even take them to the hospital*
> *D: And the parent has kind of neglected or even is not willing to*
> *H:They are ignore*
> *J: Some are like, I just wish God took this child away.*
> *D and H: Hmmm*
> *D: Such parents they normally lock them in the room. They don't even want visitors to know…"*
> *(FGD: 243-261 edited)*

A problem – tree analysis was conducted to investigate the root causes and effects of this issue but space limitations prevent it being displayed here. In summary, the root causes are poverty, lack of education, cultural beliefs regarding shame and blame, lack of time for the child, and fear for the child's safety outside the home.

> *"If they don't know that this is a problem, a sickness kind of, they will shun, they will torture, they will make that child suffer." (DT: 401-2)*

> *" They do try to keep them indoors because they fear for these children to be harmed. (MT: 108)*

These causes lead to low prioritisation for the child to go to school, stigmatisation and community level abuse, and parental mental health problems (**pathway 1**). The major effects are that the child may have stunted/unusual development, meaning that they are less likely to become independent, and more likely to remain a burden.

> *"I just heard of a scenario of a child who was just locked indoors. The cat was always the one that was just next…So this kid just got the characters of a puss cat. The sounds. "(KT: 276-281)*

7.2 Positive Consequences of Attitudes

Pathways **2** and **3** (see model 1) demonstrate some positive consequences of attitudes, both traditional and western biomedical views. In **pathway 2**, a strong belief in God can give rise to positivity which can be beneficial to the child, as the family has faith that the child will improve.

> *"I know God is there. I know he will talk however much...I know he will talk." (MP: 153)*

This links to Instad's (1990) survey where Botswanan mothers believing in supernatural causes such felt less guilty than Norwegian mothers believing in bio-medical causes. Hope and spiritual beliefs are ways that parents of disabled children can help protect themselves against emotional trauma (Poston and Turnbull 2004).

Pathway 3 demonstrates how medical beliefs lead to parents seeking medicine and therapy for their child:

> *"There is some medicine which can help…But even there are trying. They are also bringing him here.(ie special needs centre) " (DP: 108-112)*

However, it is too simplistic to state that those parents who give medical reasons for their child's disability are likely to take them for therapy/schooling whilst those with cultural beliefs use more traditional treatments. In many cases there is a combined approach, even though the first step is often more traditional:

> *"When I talk to the mothers around they tell you they have gone to witch doctors and they have gone to so many places but I wish I had come here first." (MA 277-278)*

> *"Most of the mothers here…they first take the children to the witchcraft….That's why the children takes long to come and learn. The time they spend down." (MP: 141,147)*

Dagher et al (2004) and Andrade et al (2005) reported that traditional healers attributed cleft palate and hearing impairment (respectively) to be caused by angry ancestors, omitted rituals, or curses. Crucially though, Andrade et al (2005) stated that most healers referred on to biomedical doctors if their treatment was not successful, highlighting the need for a syncretic approach between the traditional and the modern healers. This was also called for by Hartley (2005) in rural Uganda.

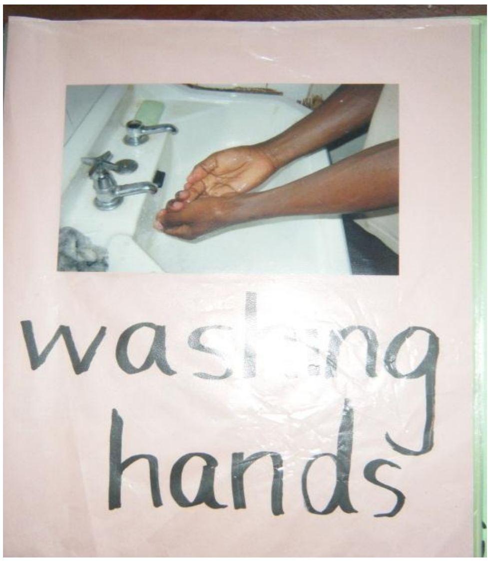
7.3 How do Parents and Professionals help children to develop communication skills?

The following table shows the AAC approaches currently being used in the centres.

Table 2: Low Tech AAC Techniques

Low tech AAC method	Example	Place
Objects of reference	"If he wants food, he will go pick a plate, present it, and you know that he wants food" (KP; 54)	Home
Picture pointing	"We did the picture print out. What the child would like to do. What would run into their life the whole day. " (DT: 265-266)	Dawn
Picture exchange	" Most of the time he use picture exchange to communicate." (MA:138) "That's when I can come down to teaching them how to ask using pictures." (KT: 352)	Mukissa, Komo,
Communication books	" At home we encourage them to have communication books." (MT: 215)	Home
Sign Language	" Because in my class they can sign for you red, blue, orange, black." (MT:159-161) " they use signs" (KT: 56)	Mukissa. Komo
Writing	" If you do not understand, he can just get a pen and a paper…(and write something)" (KA: 290)	Komo

Komo Centre: Visual Timetable



Mukissa: Communication Book

The “current skills” theme is linked “Developing communication” in the future (model 1). These themes overlap, but in some cases the child’s full potential is not being met, and so the participants have identified ways of improving the skills further. However, they also identified “barriers to helping” this to be achieved successfully.

The “importance of communication” is a separate theme concerning explanations about why it is crucial to focus on this, which is linked “changing attitudes”. Explaining the “importance of communication” can help to change how people see this issue.

Pathway 4 (model 1) shows why it is important for children to be able to communicate in some way, for the safety of others:

> *“ Because he can get your arm. You don’t take care of him, you say “leave me” and he gets angry. He can do something bad.” (MP: 201-203)*

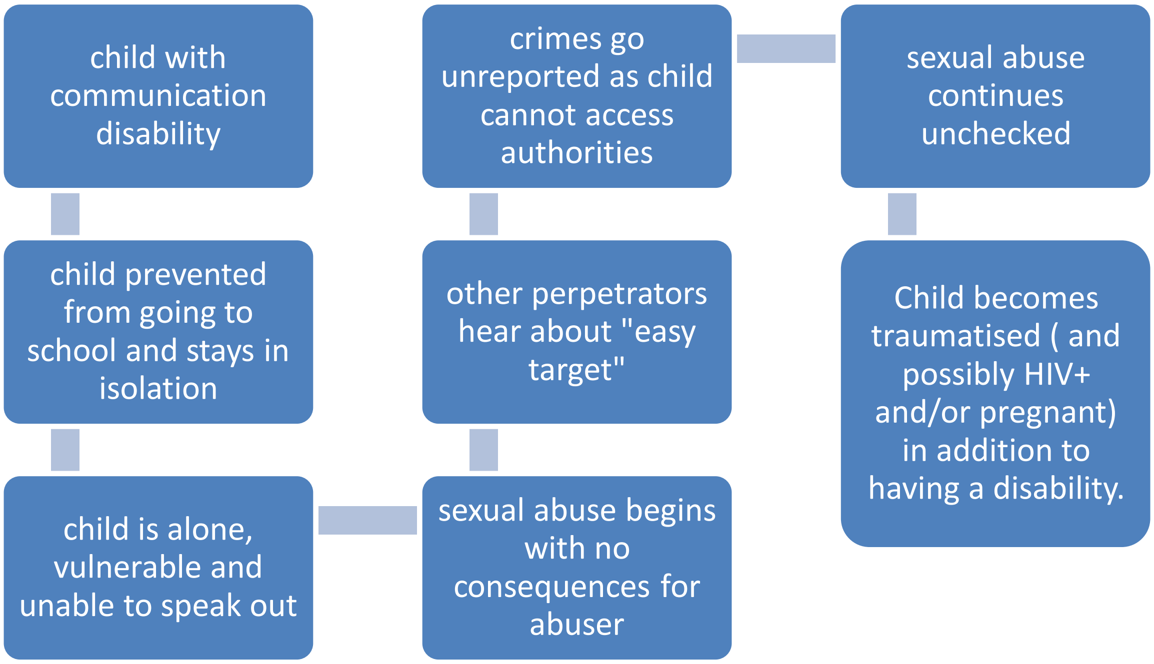
This parent of a child with Autism found that her son would “do something bad” like hit her or others if he couldn’t make his needs known, or if he felt that he was being ignored. Such anger is often brought on through the child’s inability to communicate effectively. If “Community events” were held to help explain how best to handle this, and how to give children alternative ways of communicating what they need, this should reduce the threat of violence and aggression in these children.

The safety of the child is often also under threat, which is why communication skills are so vital:

> *“She was raped and got HIV and then later she was raped by her own dad…She couldn’t tell people. They just caught people in action.” (DT: 158-165)*

If children were given an alternative means of communication, they have more chance of being able to report such atrocious crimes. This feeds into the idea of improving services and laws, both to protect vulnerable youngsters and in terms of reporting crimes, and also services to improve the communication skills of disabled children.

Figure 2 : The link between sexual abuse and children with communication impairment



This model is based on the data from the current study. Ellery et al (2011) also found similar findings in four East African countries:

> "Children with disabilities are especially vulnerable as a result of entrenched social and structural discrimination against them" and they are "at disproportionate risk from physical and sexual violence". (Ellery et al 2011, pg 7)

There is also a remarkable resilience in children with disabilities. In a study looking at quality of life, children with disabilities in South Africa reported that they had functional difficulties, but did not show any significantly lower quality of life than children without disabilities (Jelsma et al 2010). The impairment itself was rarely seen as an important factor contributing to the child's perceived quality of life. The implications are that the impairment itself is not necessarily the disabling factor, but the environment around the person, linking back to the social model of disability.

7.4 Barriers to helping

The previous section highlights one of the many reasons why it is so crucial that children are able to communicate. Pathways **5** and **6** show how this can happen, but also highlight some potential barriers (see Model 1).

Pathway 5 shows how a child may be able to follow pictures to understand currently, but that this may be developed in a more complex and formal communication system:

> *"Now he is communicating using pictures. Using picture communication."(MP: 7-9)*

-Lack of Time and Parental Support

However, time and parental support were major barriers:

> *"Then what makes it hard is that we do it here, but sometimes at home they fail to do it" (KA: 231)*

> *"But the problem with the parents, they don't have time. They leave this to maids who have no idea." (DT: 270-271)*

-Lack of Resources and money

Only one participant was aware of the existence of high tech AAC, such as electronic voice output communication aids. He emphasised the lack of money and resources for such equipment:

> *"They make sound on a computer or some other thing. They would really get it! But these are things that are really not accessible. But we would love them to be integrated in what…in our systems of working with them." (MA: 414-420)*

These themes mirror previous research findings, such as Mukhopadhyay et al (2009) who found that shortage of time and resources available to staff to implement AAC in Botswana were major issues. McNaughton (2008) looked at major barriers for parents using more high tech approaches in the USA, and despite the differences, a major barrier was also the negative attitude towards these children in society echoing the current findings. Feiler et al (2010) found that insufficient time for training and to make resources were key barriers in the USA, highlighting the commonalities across cultural boundaries and contexts.

Further evidence that lack of money and accessibility to resources is prevalent in Uganda came from the May-teerink (1999) study into rehabilitation services in Uganda. Access to assistive devices was found to be the major indicator into the quality of life of the participants, and although this was a study about mobility rather than communication problems, the current study reflects similar findings. Hartley et al (2005) also found that a major challenge for Ugandan families with disabled children was lack of funds for treatment, transport to appointments, equipment and schooling.

-Lack of Understanding and Training

Pathway 6 (model 1) demonstrates how a child's current skills should be enhanced in order for them to develop functional communication. It can be easy for a child to only communicate at a basic level such as hand-leading (see glossary), but if sufficient training is given to parents, that child could be taught to understand choices and might later begin to speak. Teachers in this study suggested this:

> *"For some parents who have been with us for some time, at least they try to draw choices for their child." (KT: 338*-339*)*

Professionals and parents may believe that the child's own limitations are the major barrier to progression. However, the difficulty lies with the adults working with the child and with appropriate training, the children may be able to progress further:

> *"There should be… workshops in schools, so that a professional can know how to assess a child who has a speech problem and what that child needs." (DT: 421-423)*

Others recognise their limited knowledge about how to develop these skills, a finding which was also prevalent in Mukhopadhyay et al's (2009) study, who found that child related challenges including the difficulty of understanding non-verbal children:

> *"Now these days you cannot know exactly what he wants because he doesn't talk." (DP: 57)*
>
> *"I don't know that runs in her mind when she sees it. I don't know if she can tell that this picture is of this." (DT: 70*-71)

Consequently, as **pathway 6** (model 1) indicates, such children are prevented from progressing due to a lack of understanding about their skills. The implications are that if home visits incorporated training on communication skills, this should help to remove this barrier. Without this, parents can feel lost:

> *"We used to just keep him in the house, we didn't know where to go, we didn't have the skills, the techniques to use to change him." (KP: 200-202)*

Kent Walsh (2003) cautions that training programmes should always be adapted to suit local populations, and Parette (2004) adds that the AAC method used should match the child. This example from the data shows how problems emerge when the AAC method is not appropriate to the child's environment:

> *" I don't think home looks like the centre…The pictures that are used could be different…. At home there is no swing. He wants to play with a swing at home. So he will bring "swing" (symbol) and then it won't be there for him." (MA: 180-189)*

7.5 Cross-Cutting Themes

A range of interesting themes have emerged from the data, which can be analysed using a variety of analytical approaches. Time and space constraints limit the level of analysis in this context, so the following sections present an overview of two possible conceptual models and theories that could be used to fit the data.

7.5.1 Coping Strategies

A recurrent theme throughout is how well parents and school staff cope with the child with communication disability. Their attitudes and beliefs impact on how they view the child, and in turn, how they are able to help that child to progress. The sub themes that are directly associated with coping strategies , are the consequences of attitudes (mental health, abuse and neglect) , changing attitudes (home visits, counselling and community events) and barriers to helping (lack of understanding, time and money) .

In Figures 3 and 4 below, two contrasting examples from the current data have been used to map onto the "Coping Strategy Model" developed by Lazarus and Folkman (1984). This has been adapted to included Kishore (2011)'s distinction of "problem focussed" versus "emotion focussed" coping strategies. This dichotomy was also used by Gona et al (2010) who identified that "problem-focused" parents were able to learn new skills in order to cope, and seek out external support. Whilst both "emotion" and "problem focussed" parents tended to move from healer to healer looking for a cure, the "emotion focussed" parents were less likely to focus on improving their own skills to help their child, relying more on their spirituality and sharing their emotions with others (Gona et al 2010).

Figure 3: Model to show how a parent uses an emotion focused coping strategy

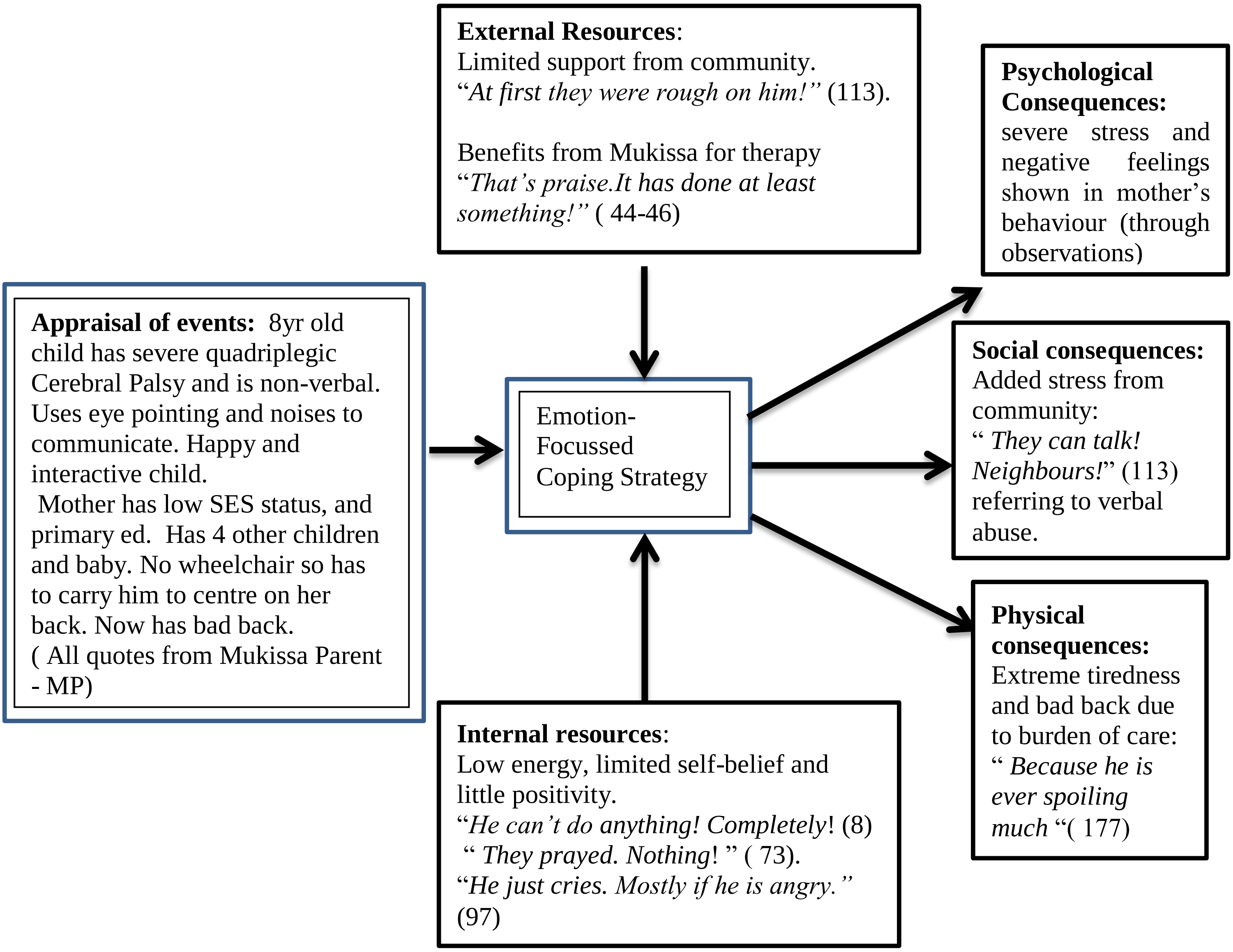
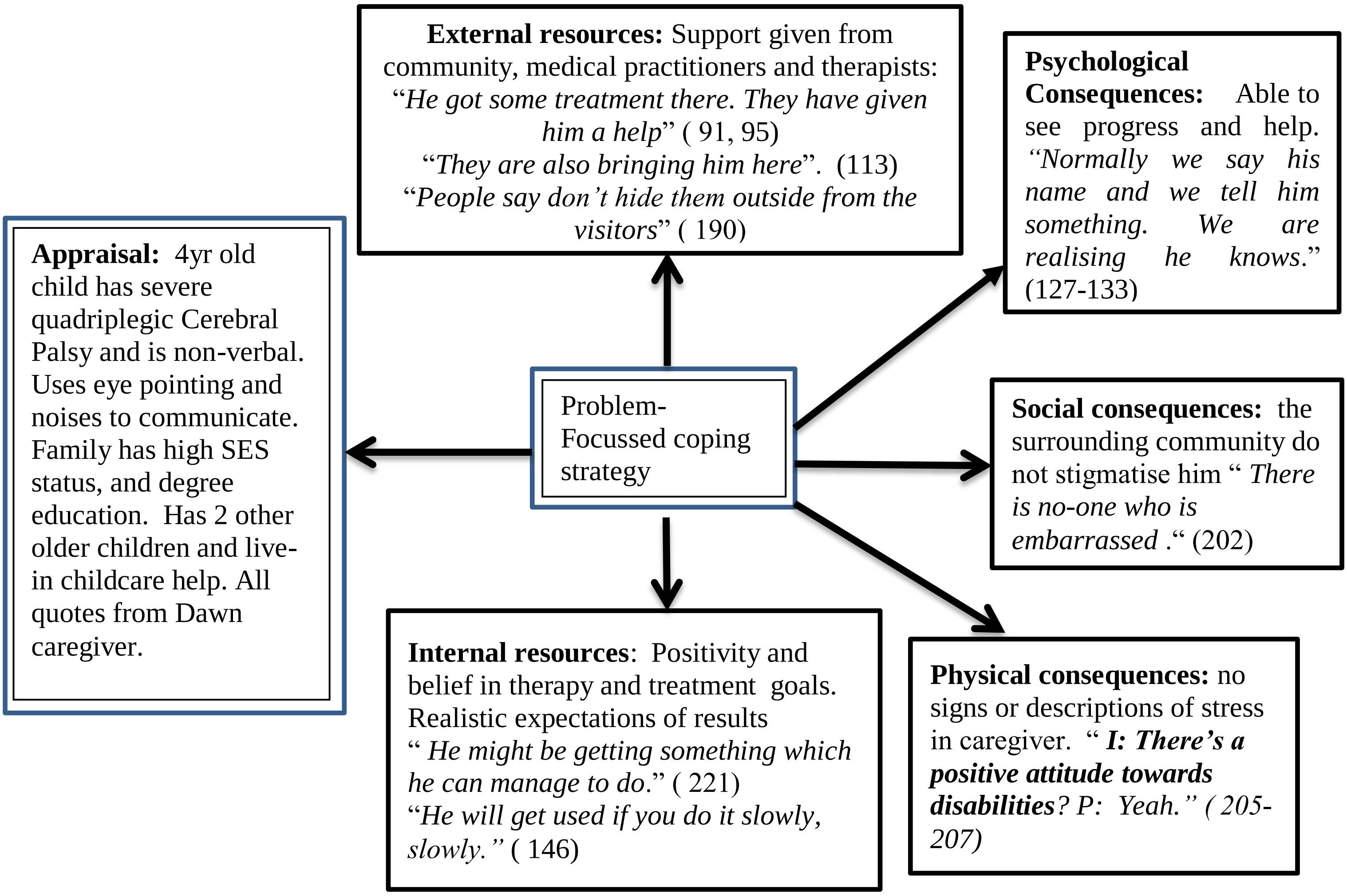


Figure 4 : Model to show how a parent uses the problem focused coping strategy



Problem-Focussed coping strategy

External resources: Support given from community, medical practitioners and therapists: "*He got some treatment there. They have given him a help*" (91, 95) "*They are also bringing him here*". (113) "*People say don't hide them outside from the visitors*" (190)

Appraisal: 4yr old child has severe quadriplegic Cerebral Palsy and is non-verbal. Uses eye pointing and noises to communicate. Family has high SES status, and degree education. Has 2 other older children and live-in childcare help. All quotes from Dawn caregiver.

Internal resources: Positivity and belief in therapy and treatment goals. Realistic expectations of results " *He might be getting something which he can manage to do*." (221) "*He will get used if you do it slowly, slowly.*" (146)

Psychological Consequences: Able to see progress and help. *"Normally we say his name and we tell him something. We are realising he knows*." (127-133)

Social consequences: the surrounding community do not stigmatise him " *There is no-one who is embarrassed* ." (202)

Physical consequences: no signs or descriptions of stress in caregiver. " ***I: There's a positive attitude towards disabilities****? P: Yeah." (205-207)*

[Figures 3 and 4 adapted from the "coping strategy model" by Lazarus and Folkman (1984)]

The two contrasting examples in figures 3 and 4 have been chosen to highlight how the appraisal of events is not just based on the characteristics of the disability and the treatment, but also the demographic characteristics of the caregiver (Maes et al 1996 cited in Hartley 2005).The child described in Figure 4 has the same type and degree of impairment as in Figure 3, but the circumstances are very different, and hence the coping strategy alters. Therefore, the original coping mechanism (Lazarus and Folkman 1984) works in this context too, echoing Hartley (2005).

The difference in external and internal resources in the two examples, coupled with the demographic differences contributing towards the appraisal of events explains why the coping mechanisms are so different for caregivers despite the similar disabilities, and why the resulting psychological, social and physical consequences are divergent.

7.5.2 Services

As shown on Model 1, traditional and cultural beliefs can give rise to negative consequences for the child, in the form of shame and stigma, parental blame, and subsequent neglect or abuse **(pathway 1**). In order to change attitudes, counselling, community events and media can all help but unless services are provided that can demonstrate how a different attitude may lead to a positive outcome, it will be difficult to alter peoples' minds. Training on attitudinal change is fruitless unless there is some tangible gain for the parents and children involved.

> *" Because it's just like only information. What am I going to do with that? I am going to have this child….So I think helping them would be important." (DT: 209-212)*

Conversely, De Bortoli et al (2010) cite studies demonstrating how crucial it is to combine practical training on communication skills with training on attitudinal change. For example, teachers were found to have no improvement in their interaction skills after training sessions, yet they improved their attitudes towards the students after increased actual interaction and communication with their students. The implication from the data is that combining theory with practical hands on training sessions is crucial.

Equally it is important that media campaigns combine attitudinal change with practical advice as to how to help, and why it is important to believe in therapeutic techniques:

> *"Films showing children. Those films should show them how they have been helped…That's what everyone would like to see so that they can be convinced and tell other parents. And it gives them hope. " (KP: 325-29)*

Newspaper articles have directly impacted on a number of the participants so a combined approach is the best method to change attitudes and improve understanding:

> *"That's how I got to know, from "New vision" (KP: 196-7) (This refers to a local paper, giving information about a local centre for Autism).*

Staff in the study suggested that educating the community is very important if negative attitudes are to change:

> *"We have a walk around with them, we move with our vouchers, our flyers. We go talk to them. We move with our children. The children talk to them." (MA: 99-100)*

However the data showed that people often wonder "Why should we bother?", "Why should these attitudes be changed?" In line with this, Gona et al (2010) found that many carers of children with disabilities in Kenya had shattered future dreams , and if their disabled child's " positive outcome is not realised, they wonder if it was worth the effort." (Gona et al 2010, pg 180):

> *"Teacher M: People wonder why? Why you are giving the time to him. He can't get anything so they think, however much you put in your effort, your effort will not be seen/*
>
> *Teacher H: You are wasting your time!" (FGD: 96-98)*

Such beliefs often go along with the idea that the child's cure is in the hands of fate, and that rehabilitation is irrelevant, as highlighted by Hartley (1998). It is therefore important to link the "improving services " issue back to reducing the burden for the family, and increasing their economic prospects. Time and money are valuable to most families. Indeed both are key themes in "barriers to change". If both can be saved, it can be a strong influence on changing attitudes. If maids come to understand that when a child in their care is helped to communicate effectively, they will develop functional skills such as explaining when they need to go to the toilet, rather than soiling themselves, they may see the benefits to their own time and effort. An assistant explained what she would say:

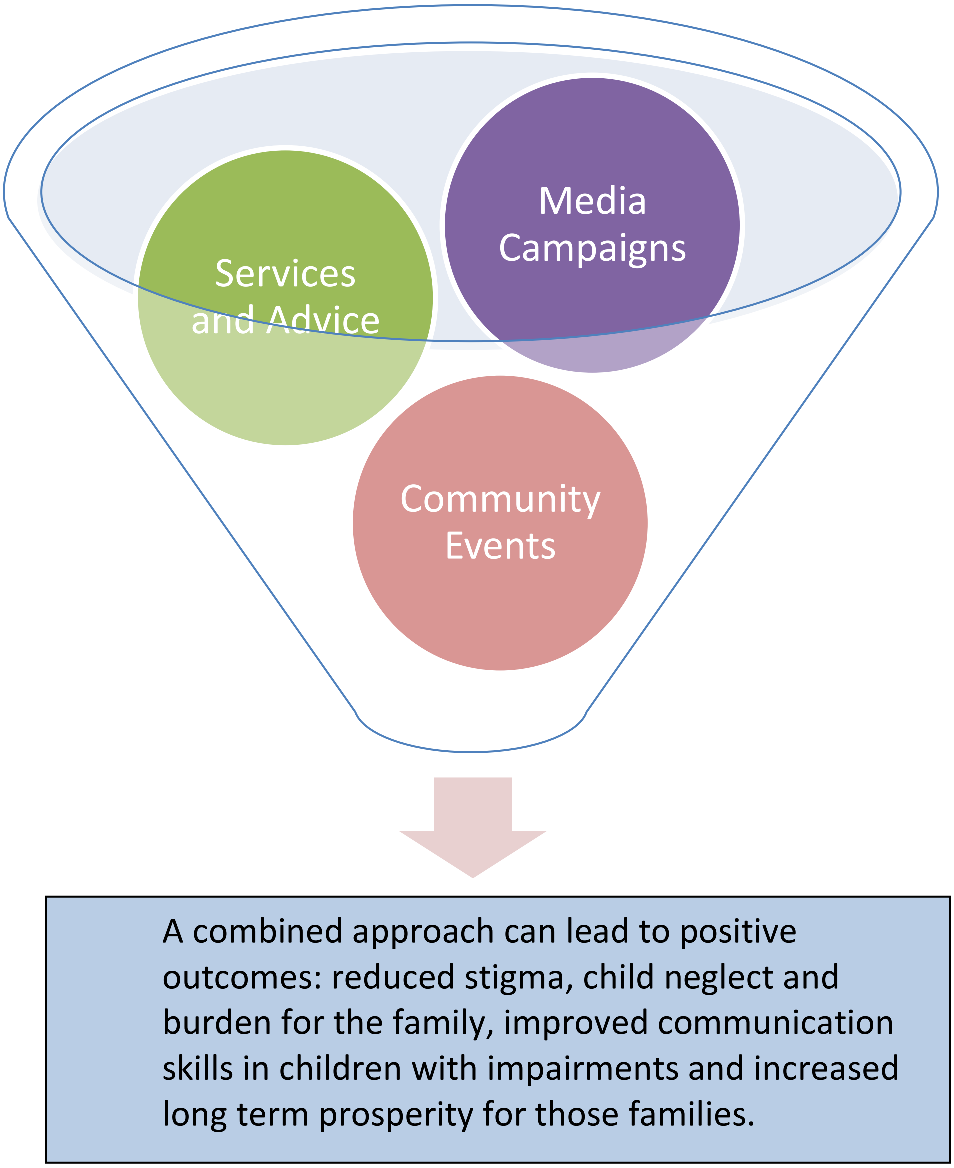
> *"Yes, you won't have to wash. You won't have to do any more washing, you won't have the sitting room littered with susu (urine)." (KA: 307-308)*

If a parent can understand that if they help their child to communicate functionally, that child may go on to develop skills that enable them to earn a living:

> *"Somehow it is not a burden. And if you are to employ such a person you know that he will do…what they are supposed to do." (MT: 262-263)*

In summary, the argument for delivering effective services and practical support to help families develop their children's communication skills is strong. Not only may this help them to reduce their feelings of shame and blame (often caused by traditional and cultural beliefs), but it may also convince them of how developing their child's communication skills can help reduce their own economic and social burden in the long term.

Figure 5: Model to show how a combination of approaches is required to help improve outcomes for children with communication disabilities



A combined approach can lead to positive outcomes: reduced stigma, child neglect and burden for the family, improved communication skills in children with impairments and increased long term prosperity for those families.

7.5.3 Complexity Theory and Ecological Systems

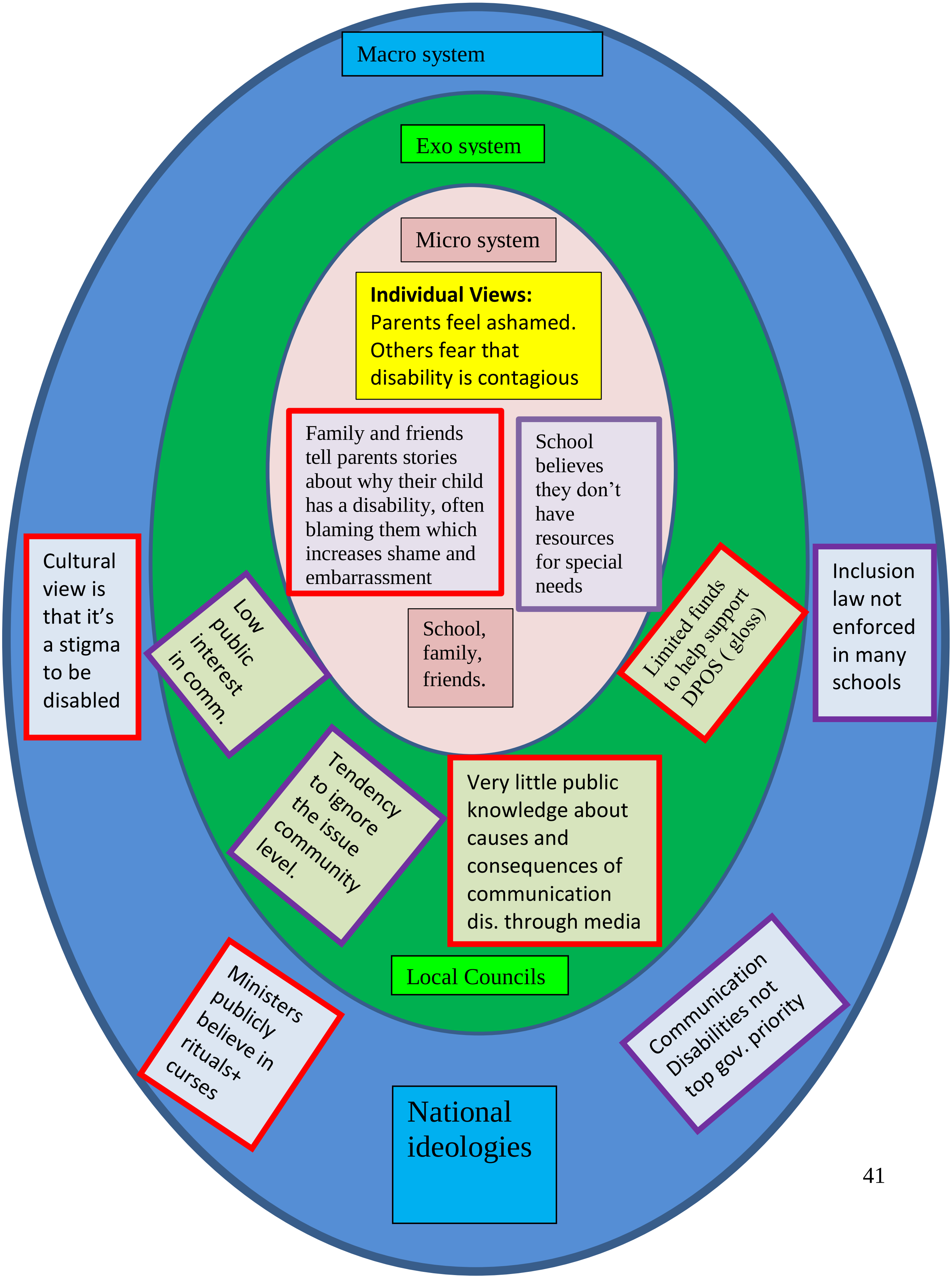
The attitudes and beliefs of parents, teachers and assistants should be seen as part of a more complex mechanism, rather than just individual viewpoints. De Bortoli et al (2010) referred to "complexity theory" where systems are built in layers with interacting forces between each one. This is similar to Bronfenbrenner (1997) who suggested that child development , and indeed the development of humans over a life course, is shaped by different environmental systems; the microsystem (such as family and school), the mesosystem (the interactions between the groups in the microsystem),the exosystem (friends of family, neighbours, media, social services) and the macro system (national attitudes and the cultural ideologies.) Bronfenbrenner (1997) also refers to the chronosystem, adding the time element incorporating the fact that socio-historical conditions over time will change individual's viewpoints. We can see the influence of these theories, looking at two examples from the data.

Table 3 : Information for Complexity / Ecological theory : "Stigma" and "Inclusion"

SYSTEM /LEVEL	Example 1: The stigma of disability	Example 2: Inclusive Education.
National Ideologies and laws/ Macrosystem	"All these are rich families. So the attitude is like, how will they see me with such a child?...One of them was even a minister for education who doesn't want the public to know that I have such a child. So how are we now going to convince them to also get to others? (KT: 442-444,471-476)	"They could be meant to be inclusive but they are not." (DT: 148) "If we can really get support from the government…That is what we are lacking." (MP: 23—235) "Even if there is a law. In Uganda, laws don't work." (DT: 371)
Local Gov./District and community level Exosystem	"The local councillors were not interested. So we had nowhere to appeal to. We had nowhere to tell. Even the government, it was as if they were not interested in it." (*the parent support group*) (KP: 196-197)	" And the community around us. They don't sympathise with us…they think these ones are crazy so they don't want their kids to mingle with these ones." (KA 151-154)
Family, friends, School - Micro System	"Some of the peoples tell me the cause is the father's kind or me." (108 DP) "They keep on blaming the parents...Even if you went to a party and the child disorganised the things…they say "Your mother brought you up in a very bad way!" (KA 166-167) ."They tell you that…these children…it seems there is a curse. It might be the mother offended somebody. (MT 149-150)	" Some schools will not allow your child to be in the school because they give you explanation we don't have special needs teacher…" (DT: 151) "We want to do inclusive education…every normal child to come to the day care, but the response that I have been getting is " I can't mix my child" (DT 82-91)
Individual	"Even the mothers, they are embarrassed so they don't move with them." (KA: 124-125)	"If I get my child in that school with children with special needs my child will also become one of those." (KA 78)

Figure 6: A Diagram to show how an individual's viewpoint is embedded in a series of systems, using two examples from the data (based on Complexity theory and Ecological Theory) adapted from Bronfenbrenner (1997) De Bortoli et al (2010)

1. The Stigma of disability
2. Inclusive Education



The Stigma of disability

“Shame and stigma” emerged as a specific sub- theme, within “Consequence of Attitudes”. It has been chosen as an example here, as it clearly demonstrates how beliefs at different levels can influence the individual. At the national level, e.g. within senior positions such as ministers, there is a strong belief that it is a stigma to have a disabled child. If families suddenly become rich, some people believe that this is due to rituals and sacrifices that have taken place, including sacrificing their own children. The consequence of such rituals could be that such children become disabled, which is why rich families do not want to be seen with a disabled child. It may be seen as evidence that they have been doing rituals and sacrifices:

> *“ Others maybe think they have done rituals and that’s why they are rich.“(KT: 492-493)*
> *“Someone tried to sell a child to become rich. Like give a child to witchcraft.” (DT: 98-100)*

This belief at national level then filters down to community levels, and other associated beliefs become prominent, where community members inform parents that they are to blame for a child’s disability due to a curse or breaking a taboo (see table 2).

Inclusive Education

A side theme, within the “Inclusion and play” sub-theme, was attitudes towards inclusive education. Although many recognised the benefits of inclusion, especially in relation to peer interaction and play, they noted that many other community members were not as keen to have disabled children in mainstream schools, often fearing that communication impairments were in some way contagious. This attitude may well be embedded in common local and national attitudes. With limited media campaigns or local support groups to explain the causes and consequences, it is difficult to change stigmatisation at family level.

7.6 Solutions

This section summarises the key solutions to emerge from the data:

Solution	Example from Data
1.**Use media to raise awareness about communication disabilities and what practical steps / approaches to help these children.**	“*Now the internet is there it’s really something that will give information*”.(KT 246) “*I have seen adverts on TV about disability about how they should make buildings more accessible…. I think we should go all out and mention about all the disabilities*” (DA: 251-252) “ *Those films should show them how they have been helped. The process*.” (KP: 325-6)
2.Increase parental support and training through home visits, counselling and parent groups.	“*I would just maybe give them social support, emotional support. Whatever.”* (KT: 227) “ *They really need to be counselled. Those parents*.” (KP: 349) “ *Even one time we started to make a group of people so that we can be helped.* ” (KP 188-190)
3.Improve services, schools and laws,(including promoting the enforcement of inclusion law)	“ *I think it would be better if there is a group of people who comes in. If you can set up a centre in that place or if you can help do something*” (DT: 218-9) “*You go with a service. That’s when people will come over*.” (KP: 311)
4.Increase community events to raise awareness about the causes of children with communication disabilities and how to help.	“ *There has to be a campaign to announce this problem*.” (DT: 386) “*I think we need more advocacy right now, here in Uganda. We need to talk about it with others who are not aware, to understand what is on the ground.*” (KT: 406-407)
5. Increase staff and parental practical training on how to help these children, particularly focussing on low tech AAC such as sign and using communication books.	“ *I wish there was a way of sign language*.” (DT: 225) “ *Pointing?* (communication book) I *have never tried it. But I think it would work.* “ (DA: 153-157) *“Like right now, I cannot try to show him… I don’t know when he can do that.” (DP: 155-159)* (discussing how to introduce picture communication)
6. Increase government support for this cause, and lobby them for more help for these children.	“ *What I would like government to do for us it’s a home for such children.”* (MP: 363-4) “*Because disability movements have come up and people are pushing for it*.” (DA: 465) “*We would like the government to come in and help us*.” (KP: 203)

8. Conclusion

Being able to communicate is a fundamental human right. It is only through communication that a person's basic needs can be met. In addition to the very real link with improving educational performance and economic prospects (Coleridge 2007), improving communication skills can also be linked to child protection through improving a child's ability to report abuse (Ellery et al 2011). Therefore it is crucial to understand the context in which children with communication disabilities live in low income countries.

Research Question 1 : What are the attitudes, beliefs and explanations of parents and professionals regarding communication disability in children, and how do they feel these children are viewed by society?

The data showed that traditional beliefs are still common in the urban/ peri-urban settings of Kampala and Entebbe, replicating findings in rural settings seen in Hartley's (2005) study. Explanations for a child's communication disability included witchcraft, taboos, Gods, incorrect diet, woman's fault, use of family planning pills and upbringing of the child. Western or biomedical views were also prevalent in the data, but these views were less common .The data also showed that most parents and professionals feel that these children are viewed negatively in society (appendix v). Traditional views did not necessarily give rise to negative consequences, as it sometimes led to positivity. However the embarrassment of having a child with a communication disability may still lead parents to hide that child away even if they understand the cause as being bio-medical. The most common finding was that families tried a combination of treatments, often starting with traditional cures and then later adopting western treatments (appendix v). Therefore, if traditional healers were able to refer families onto therapy and schools as early as possible when families first come to them, and give basic advice to parents, it may help that child to reach his/ her communicative potential. It is well documented that early intervention is best (Ljubesic 2012).

Research Question 2: How do the participants currently help the children with communication disabilities to communicate? What are the perceived barriers or facilitators to help them to do this effectively?

The formal AAC methods used were objects of reference, picture pointing, picture exchange, communication books, sign language, and writing (see glossary) . Other non-formal methods included hand-leading, eye pointing, behaviours, noises, and whole body movements. Formal methods have more potential for helping the children to develop their functional communication skills. Teachers described using formal methods double the number of times that parents or assistants did (appendix v). Parents themselves acknowledged their own need to understand more about what to do, describing a lack of knowledge about how to help as a key problem. All three respondent groups agreed that lack of time, and the child's own limitations were barriers to helping, and teachers and parents in particular agreed that lack of money and resources was a key problem.

The "Changing Attitudes" section highlights some of the facilitators to help children with communication disabilities to use AAC more effectively (see model 1 and table 3). The findings have highlighted that it is important not to separate tackling disability awareness-raising in society, from more specific training programmes to help these children to use low tech AAC more effectively. By using "complexity" and "ecological theory" we have seen how national views are embedded across society. It is important to run campaigns at a national rather than a local level, and to involve national ministries in the implementation of the policies. Also, by looking at how parental coping strategies can impact on a child's outcome, and potentially their ability to communicate, the findings suggest that there should be a larger focus on mental health services, counselling and parent support groups. Finally, by highlighting the issue of abuse in these children and their inability to report such crimes this becomes a child protection issue. This is another way the communication disability issue can make it onto the mainstream agenda, rather than being side-lined as an issue of little importance.

9. Recommendations for Action in the light of the data

- For Local District Councillors (LDCs) to support parents training seminars and sessions, and the adoption of parent groups for children with communication disabilities.

- For Local Education Councils to implement inclusive education in their districts, and increase training on communication disabilities for both special needs and mainstream teachers.

- For the National Government to back a nation-wide media campaign to raise awareness of communication disabilities and the impact on society.

10. Dissemination of Study Findings

It is a requirement of both the IRB in Uganda (TASO) and UNCST to be sent a summary report of this study. The full report will be available at the ICH, UCL library.

11.Limitations

Because there was only a 6 week data collection period, the main limitation was time constraints. Data saturation was almost reached by the last interview, so doing additional interviews may not have yielded much new information. However, other benefits would have been to further substantiate previous data, and to allow further focus group discussions to have taken place in order to help triangulate the data. With more time, it would have been interesting to include more detailed observations of what happens within the home or school environment, for additional triangulation. Due to the word limit, it has also only been possible to analyse the main themes to emerge, rather than the differences between the individual respondents' attitudes and views, and their demographics.

12. Ideas for future research

It would be interesting to do a large scale mixed methods study to see if there is a significant pattern to the attitudes and beliefs and behaviours in the three different groups, and in different socio-economic classes. It would also be beneficial to include observations in this study to substantiate interview findings. This study could also include the attitudes and beliefs of different groups such as older children with communication disabilities, grandparents and village chiefs or other key community members such as pastors.

It is hoped that such a project would endorse the findings of this preliminary study, and a more detailed analysis of the theoretical frameworks used here could be undertaken.

Word count = 10,997

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APPENDIX

Appendix i

Topic Guide for Semi-Structured Interviews

1. **What do you know about ________’s communication difficulty?**

- Do you know the name of difficulty?

- Can you describe what it is like?

- Have you seen a child with similar difficulties?

- Can you think what the reasons for ______’s communication difficulty?

2. What do you feel about ___________ and his/her disability?

- What are your own feelings about _____’s communication difficulties?

- How you feel that this affects his/her life?

(after the pilot this was modified to the following:)

(2. What did you used to feel about communication disabilities before you came here?)

3. How do you think other people view ______?

- How would you compare him/ her to other children?

- Do they think he/ she is able to join in with other children?

- When he/ she meets new people, how do they react?

- Do people ever talk to you about why ____has a communication disability?

4. How does ____communicate?

- If he/she cannot speak, how else does he/ she explain what he/she wants or feels?

- Do other people understand what he/ she is trying to say?

- How do you know when ___ is hungry/ thirsty/ tired/ happy etc?

5. How do you help _____to communicate?

- How does he/she show you what he/ she wants or feels?

- Do you give him/her choices? What kind?

- How can you tell that _____has understood what you are saying?

6. Is there anything that ______'s communication disability prevent him/ her from doing?

- Is there anywhere that ____can't go to because of his/her communication difficulty?

- Are there aspects of his/her life that are affected because of this difficulty?

- Do you think this may affect him/ her in the future? If yes, in what ways?

7. Is it easy or it difficult for you to help _____to use a communication aid or pointing board?

- Are you restricted by anything at all?

- Do you think you know what to do to help?

- What have you tried that has worked well? Why did it work well?

- Have you tried anything so far which hasn't worked?

8. Can you think of any ways to make it easier for you to help _______to communicate?

- How could you find out what parents/school staff (from other areas) do?

- How could you find out more about what to do to help him/her?

- Can you think of how you could find out more about his/ her difficulties?

- Can you think of anything else you want to mention that we haven't covered? For example, what you would like to see in the future for these children? How can we change any negative attitudes?

"Thank you for taking part in this interview. I will let you know what the overall findings are".

Appendix ii.

Topic Guide for Focus Group Discussions

1. What do you think is meant by the term "communication disabilities" or people with communication difficulties? Can you list as many different types of communication disabilities as possible? *(brain storming)*

2. What are all the different ways that the children you work with communicate, apart from using speech? Which are easiest and which are hardest do you think? Which methods work well and which don't?

3. How do you think children with communication difficulties are viewed by other people? Do other people ever suggest why they think the child has the disability? If yes, then what are the reasons?

   - People at the market/ shops / church
   - Relatives and friends
   - Older people in the community
   - Experts in hospitals or schools.

4. What is the impact that this has on that child's ability to access services such as school and therapy?

5. Problems and Solutions: brainstorm any problems or issues and possible ways to solve them.

Appendix iii

Information Sheet for ……………………………………………in Research Studies

Title: Exploring attitudes and beliefs regarding disabled children with communication difficulties and their use of augmentative communication systems in Uganda

This study has been approved by the UCL
Research Ethics Committee [Project ID
Number]: 3680/001

Name, Address and Contact Details of
Investigators:

Julia McGeown, UCL, London
Department of International Child
Health.

Insert Details of Study:

My name is Julia McGeown and I am a research student at UCL in London. I have also worked in Uganda as a Speech and Language therapist. I am doing this study to find out what parents, teachers and assistants in Uganda think and know about communication disabilities in children. I also want to find out what you think about how to help those children who cannot speak, but use other ways to communicate.

The main aim is to find out why it can be difficult to help these children, and to come up with some practical solutions to change this. I want to get the views of parents, teachers and assistants. This should help the children in their daily lives, and make it easier for adults to communicate with them. Hopefully parents, teachers and assistants will all be able to share their own experiences and ideas.

If you agree to take part, I will ask you to come to a thirty to forty minute interview to ask you some questions about this topic. I will also invite you to take part in a group discussion with other parents/ teachers/ assistants who are in the study. This will be on a different day and will take an hour.

It is up to you to decide whether you want to take part in either the individual interview or the group discussion or both. If you do decide to be part of the study, and then you want to pull out at a later time, you do not have to say why. You will be free to leave and this will not affect your child if you are a parent or your work if you are a teacher or assistant.
If you decide to take part you will be given this information sheet to keep and be asked to

sign a consent form.

When the research is written up, your name and the children's names will be shown with initials, so everyone stays completely anonymous as far as possible. It will not be known to anyone else that you have been involved.

I will be writing a report about the study for the university and this will be available from the university library. I will also write a short summary of the study findings, which I will send to you afterwards if you are interested.

All data will be collected and stored in accordance with the Data Protection Act 1998.

Appendix iv: Chart of Sub-themes with extracts from data

Overall Theme 1 = Attitudes and Beliefs

Subtheme	**Example from Data**
Medical	"The causes could be environmental or genetical. That's what I know." (KP)
Sickness	" Some say it might be due to the sicknesses, the illnesses like this cerebral malaria." (KT)
Pregnancy / Birth/ woman's fault	" Actually they will think it is more of a woman who brought it into a family. The woman …is responsible for how that child is." (DT)
Taboos,omens, Gods sacrifice	"Others believe certain things that are not done…that some others don't do…it could be an effect." (DA)
Witchcraft and curses	"The biggest percentage of people around here think it is witchcraft." (MA)
Family Planning	"One of the family members told me that maybe it's because you used family planning before you got married. That I used pills. " (KP)
Diet and upbringing	"So you will find that child will get difficulties in speaking. Because he or she is not associating with the others." (KT) "Others believe certain foods that children feed on when they are tender"(DA)
Treatment - traditional and western/ medical	"So they get to say like " Where you came from, it's a curse on a woman, so they will try and get herbs…give the child, they will tie things around the joints."(DT) "We came here and consulted a good doctor who told us that with medication he would improve." (KP)
Neglect of child	" She was over- left in the house. She used to stay in one room all the time." (KA)
Abuse of Child	"if they don't know that this is a problem, a sickness kind of, they will shun, they will torture, they will make that child suffer." (DT)
Mental health for mothers	"Someone has a disability and they think…What did I do to God to deserve this? They are thinking they are alone." (MA)
Positivity	" At least there are some good reactions. Because they are seeing the changes the children have." (MT)
Shame/Stigma / Contagious	"Especially if it is high profile or what family. They end up not want to be embarrassed or something." (DT) "They think this disease could definitely get to these ones who are okay." (KA)
Media	"Maybe sensitisation of the public.. The radio, tv, you know. So people get to know that it is actually a problem out there. Like the Oprah, how I got to know. I think that is the best option." (KP)
Home visits and counselling	" It would be better if you also went to homes with kids with disabilities and explained to them." (DT)

	"I would just give them social support, emotional support ". (KT)
Improve Services, schools and Laws	"Yes, you go with a service. That's when people will come over. Once you go there without anything they just go there and will not go back. That's what they believe. Something to help." (KP)
Community events	"I think we need more advocacy right now here in Uganda. We need to talk about it with like the others who are not aware, to understand what is on the ground." (KT)

Overall theme 2 = Developing Augmentative and Alternative forms of Communication (AAC)

Sub-themes	**Examples**
Objects or words	"He just does actions. So it he wants food, he will go pick a plate, present it and you know he wants food." (KP) "If you do not understand he can just get a pen and a paper." (KA)
Picture pointing or Exchange	"We have some pictures of a toilet. So they know that this direction takes me to the toilet." (KT) " Most of the time he use picture exchange to communicate" (MA)
Gestures/ points	"And he could just point. Whenever he would see a cup he would point to the cup and I would know that he would want a drink "(KP)
Hand leading	"They can come and pull your hand towards what they wants. " (DA)
Eye pointing	"H most of the time uses the eyes." (MA)
Behaviours/ noises	"When he doesn't like something he makes funny noises. " (MA)
Approp. Speech + giving Choices (S)	"For some parents who have been with use for some time, at least they try to draw choices for their child. " (KA)
Formal AAC (AAC)	"You use total communication. And even sign language." (MT)
Routines (R)	"He is using some kind of routine." (FGD)
Inclusion and play (I)	"So I try to make them play with him. He learns that I have to play with others. It has make him to concentrate to others." (MP)
Understanding the child's level(U)	" He has words that he speaks but you don't get to understand them. You have to think in his area, what he wants." (DT)
Safety of child and others	" She was raped and got HIV and then later she was raped by her own dad. She couldn't tell people. They just caught people in action. " (DT)
Reducing burden on family	"When you don't have to take them to the toilet, show them where food is…Life is easier when they know. Somehow it is not a burden" (MT)
Increasing functional skills	"The teaching should be around really emphasising the basics of their living." (DT)

Education and employment	“ However much as they are disabled they can do something. We introduced vocational skills. I want them ..somewhere where they can earn” (KA)
Lack of Parental /comm. support	“Yes the local councillors were not interested. So we had nowhere to appeal to. We had nowhere to tell." (KP)
Lack of Money and Resources	“It’s very expensive for parents to afford therapy.” (FGD)
Lack of Understanding	“Here in Uganda it’s not easy for a person to know that this is Autism, this is cerebral Palsy.” (MP) “ You just see a condition and you really don’t know what it is exactly.” (MA)
Lack of Time	“ At home. No, so busy. He needs too much time.” (MP) “Some of them have maids who try but you know the maid has so many things. She has to work, she has to cook, she has to do the laundry and she cannot find the time…to sit with your child.” (KA)
Child’s own Limitations	“And you are trying to figure out what he is saying. He points at something and you are wondering is it what he wants? “ (MT) “The barrier comes in that point of understanding a picture.” (DA)

Key

M= Mukissa, k= Komo School, D=Dawn Childrens’ Centre P= Parent, T= Teacher, A= Assistant

🟫 Reasons for Disability
🟧 Current Skills
⬜ Barriers to helping
🟪 Consequences of Attitudes
🟨 Developing Communication
🟥 Changing Attitudes
🟩 Importance of Communication

Appendix v : Table of the number of quotes for each theme, per group

	Teachers (+ FGD)	Parents	Assistants
	No of Quotes	No of quotes	No of quotes in theme
Reasons for disability	Total = 6 western : 8 traditional	Total = 5 western : 8 traditional	Total = 6 western : 8 traditional
Medical	3	1	3
Sickness	1	3	1
Pregnancy	2	1	2
Taboos	3	2	3
Witchcraft	3	3	3
Family planning		2	
Diet and upbringing	2	1	2
Consequence of attitudes	Total = 15 negative, 8 positive	Total = 8 negative, 8 positive	Total = 13 negative, 2 positive
Treatment	4	4	
Neglect	7	2	4
Abuse	4	3	3
Mental health issues	3	3	4
Positivity	4	4	2
Shame and stigma	4		2
Changing attitudes	Total = 16 ideas	Total = 6 ideas	Total = 13 ideas
Media	4	3	4
Home visits /couns.	6	1	3
Improves services schools and laws	2	1	2
Community events	4	1	4
Current skills	Total = 11 formal , 9 non-formal	Total = 6 formal, 7 non-formal	Total = 5 formal, 12 non-formal
Objects and words (F)	1	2	3
Picture pointing /ex. (F)	4	1	2
Gestures /points (F)	6	3	
Hand leading (NF)	4	2	3
Eye pointing (NF)	2	2	4
Behaviours/ noises (NF)	3	3	5
Development of Comm.	Total =15 ideas	Total = 8 ideas	Total = 12 ideas
Formal AAC	6	2	4
Routines	4	2	3
Inclusion and play	3	4	2
Understanding child's level	2		3
Importance of comm.	Total = 10 ideas	Total = 10 ideas	Total = 9 ideas
Safety of child /others	4	3	2
Reduce burden	1	2	1

Functional skills	**3**	**2**	**2**
Education and employment	**2**	**3**	**4**
Barriers to helping	**Total = 14 barriers**	**Total = 16 barriers**	**Total = 16 barriers**
Lack of parental support	**2**	**1**	**5**
Lack of money /resources	**4**	**4**	**1**
Lack of understanding	**3**	**6**	**4**
Lack of time	**2**	**2**	**3**
Child's own limitations	**3**	**3**	**3**

Appendix vi

vi: Informed Consent Form for ………………………………… in Research Studies
(*define target group i.e. Parent/ Teacher/Assistant*)

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project:	**An exploration of attitudes and beliefs of parents and school staff regarding disabled children with communication difficulties and their use of augmentative communication systems in Uganda.**

This study has been approved by the UCL Research Ethics
Committee [Project ID Number]: 3680/001

- I understand that my participation will be taped recorded and I am aware of and consent to, any use you intend to make of the recordings for the purposes of this study alone.
- I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Participant's Statement

I ……………………………………………………………………………

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed: Date:

Researcher's Statement

I ……………………………………………………………………..

confirm that I have carefully explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits (where applicable).

Signed: Date:

Appendix vii

: Informed Consent Form for ………………………………. in Research Studies
(*Teacher/ Parent/ Assistant*)

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project:	**An exploration of attitudes and beliefs of parents and school staff regarding disabled children with communication difficulties and their use of augmentative communication systems in Uganda.**

This study has been approved by the UCL Research Ethics Committee [Project ID Number]: 3680/001

- Thank you for considering to take part in this research. The person organising the research must explain the project to you before you agree to take part.
- If you have any questions after reading the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form.
- I understand that if I decide at any other time during the research that I don't want to take part, I can tell the researchers involved and be withdrawn from it immediately. I understand that this will not affect any services that *my child receives/ children in the school receive.*
- I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Participant's Statement

I ……………………………………………………………………………

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed: Date:

Researcher's Statement

I ……………………………………………………………………………..

confirm that I have carefully explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits (where applicable)

Signed: Date: