

WORKING TOWARDS STRONG PARENT INVOLVEMENT IN UGANDA, WHAT NEEDS TO CHANGE

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ABSTRACT

Introduction: The involvement of parents is crucial in achieving timely (early) intervention. Especially in a situation where the formal infrastructure is weak and social security exists through strong communal ties. As is the case in Uganda where people are faced with social exclusion through stigmatisation, economic exclusion through poverty and lack of government provided health and education, and political exclusion through both lack of awareness and representation. This research examines the factors that inhibit parents from being included and advocate for the rights of their children.

Method: Participatory workshops with 25 parents assessing their stress factors throughout the life of their deaf child, followed by a focus group discussion and interviews all in Kampala Uganda.

Results: Qualitative analyses of the workshop and interviews shows that parents fear social exclusion which compromises their social security. A lack of communication skills is a direct threat to the safety of the child as it shows parents fear sexual abuse of their child from infant to adulthood. Poverty and living in remote rural areas decreases the awareness and increases the risk of sexual, physical, and/or emotional abuse.

Conclusions: Parents can be strong actors of change if they are aware of the rights and abilities of their child and have the opportunities to be their advocates. Schools often perceive parents as uninterested and current interventions to protect and educate deaf children often do not involve parents as stakeholders. Culturally appropriate programmes that involve, teach and empower parents are urgently needed.

INTRODUCTION

Deaf children in Uganda who are in school are estimated to belong to a privileged 2% of deaf children in Uganda (Miles, Wapling and Beard 2011), The enrolment rate among deaf children is in sharp contrast with Uganda's net enrolment rate of 94% in 2012 (Unicef, 2012). This indicates severe exclusion of deaf children in education. This paper focusses on parents as potential agents of change in eradicating this exclusion. Furthermore it discusses the need for culturally relevant models of intervention that take into account the specific regional factors including poverty, lack of healthcare and lack of appropriate education.

There is an international focus on universal primary education, however there are hardly any specific policies implemented that focus on children with disabilities, and even fewer policies that take the specific communication and education needs of deaf children into account. In 1997 Uganda enforced UPE (Universal Primary Education) that made primary education free and open to everyone. However parents believe that the quality of these free schools are often poor due to very low teacher to student ratio (some reported 1/200) and lack of motivated teachers. Since the government of Uganda acknowledges the fact that free public schools are too few to educate all children, private schools are often government aided, in which case the

government pays a basic salary to a minimum amount of teachers per school. Many parents in Uganda, are willing to invest in the education of their children by sending them to private schools. With financial resources being scarce to the vast majority of Ugandans, parents will choose schools based on what they can afford. Besides school fees parents are also required to pay for supplies such as uniforms, sitting exams, or books.

Legally, parents are entitled to be informed about the rights of their child (UN, 2006). This empowers parents to demand good services for their child and advocate for their rights. However when parents are faced with the challenges of having a deaf child, their abilities to advocate are often hindered by a lack of confidence in their own abilities to raise this child. Studies carried out in developed countries show that parents experience variable degrees of stress related to their child being deaf or hard of hearing (Hintermair, 2006). Factors that have an effect on the stress experienced by parents are (among others) whether the child has additional disabilities, whether the parents feel they have the necessary competences to raise their deaf or hard of hearing child, and if parents have resources such as personal confidence and strength but also a strong social network (ibid, 4 & 8). Financial resources have not shown to influence the stress as experienced by parents per se (ibid.). However in many developed countries healthcare and education are free, at least to a large degree which poses the question in how far this particular research result is applicable to the Ugandan context. Hintermair (2006,8) also shows that the communicative competence is a determining factor.

PURPOSE

The purpose of this research was to determine the stress factors for parents of deaf children in Uganda, as exemplary for the East African context. Furthermore this study looked at solutions that could lower the impact of these factors by considering parents as the prime stakeholders and agents of change, looking at what parents themselves felt were solutions to their problems, specifically related to having a deaf child.

Although research has been done on, stress factors for parents of deaf children in developed countries, no study has been done specifically looking at parents of deaf children in Africa as a developing region, and Uganda specifically. This research sets out to make a start with looking at their specific situation and potential, taking cultural and regional factors into account.

METHODOLOGY

This research was conducted at two boarding schools for the deaf in Kampala, Uganda. Kampala is the capital city of Uganda with a population of 1.72 million (UBOS, 2012). Both schools have between 190-250 children from pre-primary to primary 7.

This research is qualitative and participatory in nature. Parents were selected on the basis of at random presence at the schools, no further selection criteria was used. At the time of this research only one of the schools offered free sign language classes on a weekly basis for parents and other family members of deaf children. Subsequent to one of these classes parents were invited to participate in this workshop.

A participatory workshop was organised for which 25 parents joined. All parents were hearing, 23 were female 2 were male. The participants made and analysed an adaptation of the Participatory Rural Appraisal tool: a seasonal calendar. This is "a visual method of showing the distribution of seasonal varying phenomena" (World

Bank, web). For this study the seasonal calendar was adapted to show the varying factors of stress and worries of parents of deaf children throughout the child's life. Instead of indicating different months on the x-axis, five different stages in the child's life were indicated. These five stages were: a) before school, b) primary school, c) secondary school / vocational training, d) after school, and e) adulthood.

Parents who participated in the workshop were divided into two groups and each group was asked to discuss their worries and fill in the calendar accordingly. Discussions took place in their local language (mostly Luganda) and the calendar was filled in in English. Hereafter, they joined in a plenary discussion with the researcher to discuss the similarities between the two calendars and discuss what possible solutions could be found for each factor. Separate from this workshop 10 parents were interviewed at two different schools to verify the data gathered.

RESULTS

Parents' most important worries are related to: a) early diagnostics & intervention, awareness within the community and communication, b) availability and costs of , medical care and education, c) social exclusion of the child, d) sexual abuse.

A) Early diagnostics & intervention, awareness within the community and communication:

These issues are reported by all parents and throughout the life of the child but are most pressing in the early stages of the child's life.

It often takes time for parents to find out their child might not be hearing well or is deaf. Diagnostics are scarcely available and expensive. Once they find out their child is deaf they experience a severe lack of awareness and information on a variety of issues. Many parents do not know their child is capable of learning. All parents report problems with communication, especially before sending their child to school due to a lack of awareness about, and opportunities to learn Sign Language. Parents experience exclusion from their extended families and local community. Marriages often end in divorce. As one of the parents said: "*Do you see all these parents here, most of them are single, their spouse has abandoned them and their child, because they blame these ones*".

Community life is important in Uganda, due to government's failure in providing social security. It is the community that functions as a support network. Parents of deaf children are often blamed for the deafness of their child and shunned by their community. With no provisions through (local) government parents rely on their social network for financial support, child care, work, and transportation. Being excluded from the community means being excluded from social security.

B) Availability and costs of medical care and education:

As most cases of deafness are causally linked to delay or lack of treatment of diseases such as meningitis, or drugs to treat malaria, availability and/or de facto access to medical care is seen as one of the primary stress factors. A timely and qualitatively good diagnostics, again is a financial burden, thereby often delayed or neglected. The fact that parents are not aware of options in diagnostics, in care and support, combined with competing demands on family finance result in not attending to the deafness of the child at an early age.

In parents' decision making on education, a similar dynamics is occurring: pressure on family economy and lack of awareness of opportunities and capabilities for educational careers of a deaf child go hand in hand.

As said, education for deaf children is not free, and mainly available in private schools. School fees for deaf children at the schools involved in this research are around \$350 US annually excluding supplies (which for boarding schools also include investments such as a mattress, a mosquito net, a trunk, and supplies such as soap).¹ Lincove (2012, 803) showed that on average parent of children in private schools pay \$27 US a year for tuition and supplies combined. For government-owned schools this is only \$11 US, and parents of children in community-owned schools pay \$5 US a year.

Parents fear the costs of education throughout the educational career of their child and whether the child can continue with their education or sit exams at the end of the year is determined by whether parents were able to pay the required fees. Many children in the schools are sponsored by NGOs or by individuals, a situation that makes parents depended on the goodwill of others. Not being able to meet school fees is often associated by the school and teachers as a lack of interest in the child, and although this is certainly a factor in some cases, many parents simply cannot afford to pay the fees.

C) Social exclusion of the child:

Parents do not only face their own exclusion from the community but also the exclusion of their child. Parents report that children are treated differently within society. When children are younger parents report that their unawareness of appropriate behaviour results in exclusion in the community. At a later age their desired spouses' family is unlikely to accept them as an appropriate candidate for their child. Once they have children they are at risk of getting their child taken away from them since the community might believe that the new-born will not learn to speak from deaf parents. Parents also fear that their child will not be able to find a job and be able to provide for their own basic needs. This is linked by parents not only to social exclusion but also communication. Interpreters are few and expensive and society has little knowledge of sign language.

D) Sexual abuse.

Parents consistently, at all stages of their child's life fear that their child will be sexually abused. Due to the fact that their child will be seen as an easy target, and because they will not be believed by the police. Parents report fearing for their girls more than for boys, although they state that both are at risk. Parents also say that although they recognise that all children are at risk of (sexual) abuse, they feel like they can protect their hearing children better because of better communication. The lack of good communication between parents and their deaf children hence puts deaf children at greater risk of sexual abuse.

When we look at the various solutions parent propose they show a lack of trust in , government officials as stakeholders and agents of change. Although some parents are aware that this is the government's responsibility they feel advocating at this level will not pay off.

¹ Recently many schools have received different government support. The schools involved in this research have received more financial support through city-government. However the tuition fees have gone up since.

Parents feel that government will not change their policy and provide adequate healthcare, education, protection, and availability of Sign Language.

The research shows, that instead, parents themselves are advocating and educating at community level, in the public-private sphere that they can influence. Many speak to members of their community and they report that this is affecting the attitude towards deaf children for the better. School records show that the vast majority of children is referred to the school by other parents of deaf children. Parents bring forward that the solution of their problems lies in more schools, more awareness and more donors who can sponsor individual children.

Parents of deaf children are the most important stakeholders in their child's lives. They are the ones directly affected by a lack of provision by the government due to extreme school fees, medical bills and lack of social exclusion in their community. And they find each others as peers in this process.

IMPLICATIONS

The results show that the specific characteristics of Uganda as a developing country with a high poverty rate and a government that does not prioritise education mean that parents do not only worry about these factors but that they have serious consequences for the basic rights of deaf children in the areas of protection, provision, and participation. There is a big gap between, on the one hand, de jure entitlement and, on the other hand, de facto enjoyment of those rights. The study also revealed that parents are the most important agents of change, in particular in the context of local community life.

Once they have sufficient information many parents are highly motivated to send their children to school and are trying in many ways to fulfil the financial requirements necessary. The specific situation in Uganda with regards to community life demands an inclusive approach to involving parents where all members of the community are informed and educated on deaf children, their capabilities and their rights. Without including the local community, parents and children will continue to experience social exclusion.

A lack of (a possibility to acquire) appropriate means for communication between parents and their children further excludes deaf children from their community, from learning within the community and increases the risk of being exploited, or otherwise abused, sexually, emotionally and physically. Appropriate communication is now often treated as a means to an education. Teachers list Sign Language as a teaching method and acquisition of Sign Language often starts in school. However, communication is essential for all other aspects of the life of deaf children.

In order to empower parents in developing countries a high emphasis needs to be placed on taking away financial barriers. Parents are unable to focus on many aspects of their child's care due to a constant financial strain that is disproportionate compared to the financial strain of education for hearing children. Hintermair (2006) concluded that having financial resources was not related to stress experienced by parents in all studies. However for developing countries the financial implications of having a deaf child can be expected to be bigger due to a lack of free or affordable healthcare and education and because the poverty rate in developing countries is higher than that in developed countries.

NEED FOR FURTHER RESEARCH

The qualitative nature of this study prevents statistical comparison with data from developed countries. , Furthermore this research was conducted in a highly urbanised area, at schools. As one of the fathers said: *“We are grateful that you are here, [...] but you need to go to the villages. In the village the challenges are much greater.”* Hence further research providing quantitative data and that includes parents from both rural and urban areas, with parents of deaf children who are in school, and those who do not attend school is needed. A comparative study on ' parents as agents of change' , might reveal that - independent from the developmental situation in a country - still parents can be considered the most important stakeholders in the social, economic, health and educational well-being of a deaf child.

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