

A FATHER'S GRIEF IN HAVING DISABLED CHILDREN: "LIVING WITH A CURSE"

The following is an interview conducted by SignHealth Uganda with a man who had come to them in search of assistance for his deaf child.

"I am a Ugandan man aged 42 and my entire life is so full of stressed that's why I'm looking for help. I got married to my dear wife who gave birth to four children. The first child she gave me was an 'omugogo', which means he could only lie on his back. He would sleep all day long and could not do anything on his own his whole entire life. He later died aged 18 years.

Later on my wife gave birth to two 'normal' baby girls, but then she gave me a 'kasiru' (a deaf child, literally translated as 'stupid') as the fourth born. The whole family thought I was a cursed, poor man. They would throw insults towards me and my wife. I became so disillusioned and thought of how our marriage could come to this. I was psychologically taunted as with this child I had to bear the burden of my family's pressure to marry another wife because they said that the one I had married had brought bad omens to the family.

Do you know how it feels to have such children madam? (said to the SignHealth Uganda staff member). I lost meaning for life and felt so cheated by God. My two girls are in school and this 'kasiru', aged 10 now, years has not been to school yet.

Owing to the many hardships I was going through, my wife and I separated after she developed a mental disorder. She went back to her parent's home in the company of my fourth born the 'kasiru'. Later I heard that the condition of Michael (deaf child) had worsened,



as a neighbour told my mother-in-law that the boy had developed a mental problem. The old lady (mother-in-law) got fed up and called me to retake possession of my child. I brought the child to my own mother in Mpererwe, but the condition of the child had deteriorated. I then took him to hospital and was told that he was suffering from a mental problem, but the treatment was too expensive so we did not buy it.

For the last four months my mother has been tying him up with a rope to avoid car accidents, because her house is near the main road and we do not understand what he is trying to say and he does not understand us. So this is where he has been up-to-date.

My mother is an old woman in poor health and is tired of looking after this boy, yet I cannot take him to my home as my new wife would not accept him into the house as she believes he is cursed. I am fed up too and may end up fighting or picking an argument with my mother over

this child. That's why today I decided to look for a place to get rid of him. My friends directed me to Katalemwa Cherish Home, who often take 'kasiru', but on reaching there I discovered that the maintenance costs were too high, at around 300,000 Ugandan Shillings (*approx £80*) each month and I would also have to bring food stuffs. I sat down and calculated all the costs and it was too much for me to afford, but then my neighbour told me to go to the Uganda School for the Deaf, in Ntinda, where I met a teacher, discussed a number of issues relating to my problems and he advised me to come to go and SignHealth Uganda for assistance and that is why I am here today."

As SignHealth Uganda is working closely with the Mental Health Unit at Mulago hospital, in Kampala, we referred Michael for a full assessment and recommendations for possible intervention. The father also received initial counselling and awareness training about deafness and was advised to first focus on the mental and social challenges which Michael faces. After this Michael received a full hearing assessment and is now receiving an education.

When SignHealth Uganda staff made a follow-up call to the father, he promised good care for his son, who is now living with him. Michael is receiving on-going mental health treatment medication. The father says that there have been some other improvements in his condition and more so, they no longer tie him on the tree as before. The family is however alarmed at the boy's new rate of eating, as he easily eats the amount of food meant for 3 people if he is given half the chance!

NB: There are many such cases of deaf children stranded with limited support and unable to get proper assessment and reach school. To be followed up.