

## **LISILOJULIKANA (THE UNKNOWN) – Notes for a talk before and after showing film**

### **The initial inspiration**

The story behind the making of The Unknown really goes right back to 2008. Whilst researching for a film about disability in Bangladesh, I went, with a physiotherapist friend to visit a boy who had cerebral palsy living in Dhaka. Ali Hosein was about 12 years old at the time, and I shall never forget him. We found him lying on his bed, the lower half of his body completely twisted and so tight that it was difficult for his mother to move him or care for him. He had very little control of his arms, which were shooting out in all directions, and difficulty in framing the simplest of words. And yet there he was working on a laptop typing words he could barely speak but which he could spell in both English and Bangla, studying for his English O Levels - and displaying an incredible sense of humour.

At the pleading of his parents, my physiotherapist friend examined Ali, and she later explained to me that there was nothing at all that she could do to help him – but that had he had the opportunity of physiotherapy when he was a baby, he would almost certainly be sitting up now, enjoying a certain amount of movement and free from the terrible pain which we had witnessed. His whole life could have been so very different.

My desire to do anything I could to help children with cerebral palsy receive early treatment stemmed from that day.

**Later** as we worked in Africa on films aimed at improving services for children with CP **in Ghana & Kenya** we became horribly aware – not only of the lack of services available, but also of the terrible stigma with which they and their families were surrounded. Parents were considered cursed. They were blamed, isolated and cut off from their families – and because of this tried to hide or disown their children. The children themselves were often called vultures, and parents encouraged to do away with them – many were abandoned altogether or left in psychiatric hospitals. We heard terrible stories of highly intelligent, normal children just left lying on the floor uncared for and in terrible condition in such hospitals.

And nearly always, fathers, on discovering that their child was disabled, deserted the mother and she was left in the almost impossible position of providing 24 hour care for the child with CP and earning sufficient to care and provide for her other children. Inevitably the disabled child often had to be shut away while she went out in search of work. The stories we heard were horrendous.

**The first two films** we made with CPA were **designed to get better treatment for the children** – one **The Time is Now** was a campaigning film - appealing to the Government for more services – and the other a specialist teaching film for physiotherapists in Africa. **That was good – but if we were really going to attack this awful stigma we had to reach out to the**

**general public in quite a different way – something that would help them to understand what CP really is and see the potential ability of these children –something to get them on their side – a trigger to discussion of the issues – something memorable that would cause people to go away and think about and talk about the problem for a long time – something that would really change behaviour.**

The first question was **WHERE to make it**

Such a film was needed all over Africa but we settled on Kenya for a number of reasons –

1. Swahili is the second most commonly spoken language in the continent – and and we would be able to take it later to other countries without the need to dub
2. here too we found a very sympathetic community, essential to enabling us to work on such a stigmatized subject in the village setting –
3. and also we found a wonderful story to weave into our plot

### **Making the film**

All the actors were local people – amateurs who had never acted before – and they were wonderful.

Nearly everyone who sees the film over here tells me that they think **the Priest** really is a priest – but not at all. He is the very kindly man who owns the houses and land which we chose as our location and almost literally turned his life upside down to fit in with us. I shall always remember when I was looking at the houses for the first time – pondering – he came up and asked me what I was thinking – and I explained. Well he replied – that’s easy, I could turn one of them round for you !

And then there was **Vanessa herself – our star** – and if anyone ever was a star, it is her.

Vanessa, who appears as Grace in the film, has cerebral palsy, and has struggled with disability since birth. Her father has left her mother to bring up the two children on her own and Vanessa and her mother have had to cope with all the problems of living without a male wage earner in a poor country that has no welfare state - to struggle alone with all the problems of pain and severe disability. But she is bright and determined and has managed to get into mainstream school. On joining the cast, the one of our crew members – **“The only thing that worries me is the bit where I have to cry – I’ve never done that.”**

And throughout the shooting, although we had tried to arrange scenes so that she could have a day off, I don’t think she ever did. She wanted to follow it – to see what was going on.

The most difficult scene for her was one with a fire in it – but she was determined to get it right. At one point, her mother said “its really hurting her to do it again and the Director said “Then we won’t we will settle for what we have got.” **But Vanessa was not happy with this – she was going to get it right – what ever it took and she was the one that insisted we went on.**

I am to say that we were able to do the first screening of this film at Vanessa’s film so that she could show it to her friends before it went out to anybody else.

But now – it is your chance to see it – SHOW FILM

## **DISTRIBUTION & IMPACT**

### **Method of Screening**

We have showm *Lisilojulikana* across Kenya throughout 2016 - 2017.

It was shown on K24, a major Kenyan TV channel in its prime slot on Christmas Day afternoon to an estimated audience of 300,000 people.

However, the film’s major impact has been in rural communities where the need is the greatest - where access to information is limited and therefore fear and superstition most persistent.

In order to reach these areas, we have designed and produced an easy to carry backpack cinema kit powered by solar energy for situations where no mains electricity is available.

The kit is important – invaluable - but most important of all to the success of this project are the people

We needed to find a Local Distribution Manager who could travel around – someone who knew the country and the people and spoke the language , someone who had a knowledge of the health issues, could set up the necessary contacts - but above all someone who really cared

Our hunt for the right person took some time, but finally, in the offices of APDK (Association for the Physically Disabled of Kenya) in Nairobi, our representative, George, met Salome Jordano.

Salome is a fully qualified health worker who works part time for both ADPK and EARC .

The **Education Assessment and Resource Centre** is a government wide programme with a Centre in each district reporting to the Ministry of Education – their purpose is to identify disabled children and to arrange for their educational needs to be met – although shortage of funding and hence personnel means that the service is limited.

Other factors make it very difficult for those involved to provide the support required.

Salome carried out this role in an area of Nairobi and she cared desperately and passionately about it – but she found carrying it out was difficult. The parents of

disabled children were so ashamed frightened and stigmatized that they did not want to admit to the existence of their children. Salome had to work hard , trying to interact with communities who just did not want to engage and she knew that because of this many children were left abandoned, locked up, alone.

With such a background she was immediately interested in our film and suggested doing a screening in Kangemi slum, which was part of her work area. So a few days later, on a Friday evening, she and George set up a film show. It went down very well. Afterwards, Salome addressed the audience, saying a few words about the Lisilojulikana, disability in general and where to find her at APDK if anyone wanted to talk. And then a father addressed the audience to explain that he had a child with cerebral palsy and that it was a wonderful thing to receive support for the child and yourself. He urged others to do the same.

On the following Monday morning, an amazing thing happened. Salome found three women with children waiting on the bench outside her office. She could hardly believe it. They were all mothers of disabled children who had been at the screening on Friday evening, seen the film and had now come, of their own volition to seek treatment and advice – and later even returned with a fourth mother. Salome could hardly believe it. It was normally so difficult to get people to even talk about these things, but now four mothers had actually come to her of their own initiative, asked for help. Salome has become committed to the film and has remained so ever since.

She has recruited her nephew, plans her own tours – two weeks at a time -and two or them set off - carrying the cinema kit on their backs, traveling for the most part by public transport, and putting up the screen anywhere they can.

By this means, they have achieved an amazing amount on a very low budget of only about £70-80 per screening. ( £800- £1500 per tour depending on length and distance) They have also reached some fairly isolated communities, and have never shied from areas where fear and superstition run high.

In this way they have now undertaken some 200 screenings in the rural areas –

**Figures mid November still rising were - 193 community screenings to date reaching an estimated total audience of approx 22,017**

## **STIGMA & SUPERSTITION**

Everywhere they go, our team was confronted with evidence of the stigma and superstition surrounding cerebral palsy, and with the terrible consequences for those concerned.

## **EXAMPLES OF STIGMA & SUPERSTITION**

**1. In Samburu**, a father spoke to Salome after one of the screenings and it transpired he had a daughter with CP. They went to visit and Salome wrote afterwards to tell us that she had met the girl, Ruth, who was 16 years of age, but had never gone to school and was normally locked in the house because the family believed she had a curse from her grandmother. They had been able to persuade the family that this was not the case and had advised the father to take his daughter for therapy and assessment for school placement. They were going back the next week with someone who could follow this up.

**2. In Meru**, Salome met a man who confessed that he had divorced his wife after she conceived a child with cerebral palsy because he thought it was a curse. Salome spoke with him for quite some time and by the end of their discussion he was ready to ask for forgiveness and bring his wife back.

**3. In Lodwar** disability is termed as a Curse and is associated with witchcraft. ...Some parents would even run away from their kids after giving birth to a disabled child claiming its a bad omen... The locals believe that children with disability have been bewitched by enemies and are often taken to witchdoctors (juju men) and you will find the children with a lot of body cuts in believe that the blood in the child will be driven and forced out and that the children be normal again!! .. Most of the parents and guardians openly despise children with disability saying they are a burden. There is one parent that went to say that its better for her child to die.

We heard of these sort of stories again and again.

## **2. POST SCREENING DISCUSSIONS.**

These discussions we have after the screening are of enormous importance in dispelling these fears and superstitions.

Some of the things that came up in discussion were these –

1. People wanted to know the real cause of cerebral palsy. It is not enough just to say it is not a curse – you have to fill that gap and give a reason that can be explained and understood – at the same time doing away with fears that anyone is to blame – or that CP is infectious and other myths surrounding it. Parents wanted to talk about how the stigma affected them – and how to deal with it.

Misinformation is discussed. Some people actually say that they have been misguided by Learned Doctors and self-proclaimed Pastors that eventually their children would walk and/or talk normally so they kept their children locked in wait for the day the misguided advice and prophecy would come to pass.

2. There is often discussion around the words of Mama Lydia made with regard to the fact that she deemed it better for Lydia to die than suffer with the disability and stigmatization. Many members of the audience confess that they have also reached the same conclusion and some were still considering it. Some said they had even prayed for such horrendous thing to happen to their disabled children – and in one instance the parents actually admitted that they had starved their child in the hope that he or she would die that way. However, after watching the film another parent said she now had hoped that her son would have a meaningful and better life beyond her comprehension.

3. Most Parents with disabled children in the audience changed their entire outlook, attitude and views towards their disabled children and those of other parents or neighbours. They felt moved by the change of stance in the experience of Christine in the film from being harsh and indifferent towards Grace to a more soft spot at heart for her (Grace)

The entire audience was of the unanimous view and stand that it was important to spread word and share their experience with other people in the society who were not

present at the screening to help fight for, stand with and show support to people and especially children with disabilities.

## TWO QUOTES

**“I was very young when I got pregnant: just when finishing high school. My baby turned out to be disabled, and this broke my heart, especially since it was my firstborn. My boyfriend left me too, and I was depressed about all this.... Later, I found the hope that I needed to raise my kid, and appreciate him just as he was. I love that kid so much. I feel that a lot of women need that kind of hope. This film gives them that.”**

**A lady in the audience said, “The people who hide kids like Grace are many in our community. These kids are wonderful, and I want to urge these people to bring the kids out, we’re ready to accept them”**

## OUTCOMES

There is no doubt, too, that the film is having an enormously beneficial effect on the morale of families affected by CP. From our very first screenings in Western Kenya, people were telling us that they felt that the film had a powerful voice that they could finally believe in: They had previously been told that disability was not a curse, but only now that they saw this reinforced within a film and story that was so real and true could they actually believe it. It was empowering.

In addition, we see it as important to make sure that we put the families we meet in touch with those who can give them practical help.

For example, many people are amazed by the fact that a child with cerebral palsy like Grace can learn not only at home but in school. This surprise is registered by both the general public - and my parents. One of the things Salome does afterwards is go round and visit families and help to get the children registered for school – either a mainstream or special as appropriate.

As an EARC\* worker, Salome has an opposite number in each district – someone dedicated to the support of disabled children and their families - with she can put people in touch.

The morning after each screening she goes round and visits all the families who have had the bravery to come forward and admit to having a disabled child. She finds out about their needs and puts them in touch with those who can help. She doesn’t move on until she has done this.

**1. In Meru, for example,** a mother brought her son disabled with cerebral palsy. Salome was able to talk with her in relation to her problems and offer her advice to enable her to place her son in a special school. Salome then went with the mother to visit the EARC (Educational Assessment and Resource Centre) offices where parents can seek the assistance of EARC staff.

**In another place,** a member of the audience told Salome about **her neighbor** and took me her to the house where she met the mother with her disabled child. Salome wrote **“I was able to assist them and left her with my contacts to use when her young child became of age and needed more help from us. I received many calls**

**from parents with children with Cerebral palsy asking for advice on care, placements into schools and other assistance which advice and or assistance was rendered accordingly.”**

**We receive many such reports from her**

**2. At Archer’s Post**, an elderly lady got very emotional during one of the screenings. Salome discovered that she was caring for her disabled grandson after the mother had run away. Salome took her to the National Council and insisted that they register the grandson, and a few days later the Council called Salome to confirm that they registered the boy along with several other children and adults. Registration means the child gets a disability ID card, can go to school, and has access to a free wheelchair. Yet we have discovered that many people don’t know about registering disabled children with the National council, or that they are eligible for free education and other forms of assistance. This is something else that the screening had given Salome the opportunity to explain.

**3. At one screening in Maralal** a man drunkenly explained that he had a disabled child at his house and asked Salome to come and see her. Salome asked him to contact her in the morning, which he did. So that day Salome went to his house and met his daughter who has cerebral palsy and has been locked in the house for all her 16 years, receiving no therapy and little interaction with others. So they took her to the hospital in Maralal that day and she was given therapy and at last put on the medication which she needed for epilepsy. The father was fond of his daughter and said he loved her, but just hadn’t known what to do.

After they had seen the film in the **Naivasha** area, somebody told Salome of a lady that was drinking the local brew and had an unattended child with CP. Salome went to visit the lady and wrote to us “Luckily she was sober and I will take her case in January 2017 – (I am) looking for a children home to place the beautiful girl.

## **CONCLUSION**

It has been a highly successful first year. The impact of Lisilojulikana has outstripped anything we could have imagined – but there is still much to do. The people we have reached with this film have been greatly affected, and the lives not just of the children with cerebral palsy, but of whole families have been changed for the better – but although we have worked hard, we have to date only reached about 323,000 of the 48 million people in Kenya.

Salome wrote to us recently asking us to find more money for further screenings – this is what she said – and it expresses exactly how we also feel – and why we ask now for your support –

**to have a real impact or change which is far reaching and helpful there is need to sustain and continue with as much help as we can offer, I feel that i cannot rest with the knowledge that even one child with Cerebral Palsy is out their locked in a dark room scared and deprived of their dignity as a human being.”**

