Children with visual impairment talk about their lives

“I love to sing. I can sing! When we practise our concert I sing loud! I like the song about the Hippopotamus. It is funny, funny!” (Girl, 4)

A pilot study using a modified non-verbal methodology for ORBIS Southern Africa

February 2013
Summary of findings

What emerges from this pilot is that it is possible to create a process for children with visual impairments to talk about their lives. They can talk about both the challenges they face and how they overcome them.

What is striking is that schooling is important in the children’s lives as it teaches them independence and it allows them to make friends and build up their confidence. At school older and younger children can move around freely, can make friends and can learn how to swim and run and play as well as to read and write.

Home is not always an easy place for them to be largely because of the ignorance of parents and guardians about their visual impairment and how they could build their confidence and lifeskills. Parents often attributed their children’s disability to metaphysical sources such as ancestors and witchcraft and seemed to have little understanding of the medical reasons for their child’s disability.

Children with visual impairment have reduced mobility at home, many have few friends within or outside of the family and though family members often love them they limit them (often through their wish to protect them). They also experience significant levels of discrimination within the community and there is a sense that family members are often ashamed of their disability, sometimes hiding them away. This points to the need to educate parents of children with visual disability about why their children are visually disabled and how they can create an enabling environment for them at home.

Though we did not get too far below the surface in terms of emotions, partly because of the time we had available and because of not wanting to cause distress in the children, it is clear that children with visual impairments often feel very sad about their disability (even very small children). It seems that, on the whole, no one talks to them about these feelings and about their disability.
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1. Background

ORBIS Southern Africa is the local branch of an international NGO that works for the early detection and treatment of eye disease. As part of their advocacy work in southern Africa they wish to make the point that visual impairment has an impact on children’s development, their family life, relationships and future lives. In order to do this they wish to collect and record the voices and lived experience of visually impaired children about their lives. This material will be used in advocacy reports and presentations alongside the quantitative data ORBIS uses on the prevalence and impact of eye disease on children in southern Africa.

ORBIS works throughout Africa and over time they would like to collect information from children with visual impairment in all of the areas where they work. But because very little research work (Ward, 1997a and 1997b; Butler 1998; Ferell, 2011) has been done directly with visually impaired children ORBIS requested a small pilot study that would allow them to test out methods of working with visually impaired children and also provide the beginnings of a collection of voices that could be used in advocacy work. The decision was made to conduct this work in South Africa because of ease of access given the timeframe and budget available for the work.

2. Ethical issues

Since the adoption of the social model of disability there has been much debate about non-disabled researchers doing research on disability. Sullivan 2009 describes how most research did not benefit those living with disabilities but benefited the academics that did the research. Correa-Torres (2011) in an article on the ethics of research with children with disabilities suggests that researchers adopt a new model of disability research,

“According to Sullivan (2009), a new model on disability research developed as a result of the “Emancipatory Paradigm,” which not only examines the world, but also suggests making changes to it. This new paradigm also changed the relationship between researcher and research participant, and gave people with a disability a more active voice during the research process (Sullivan, 2009).” (P. 35 and 36).

This debate informed the approach we chose to use in this research. We chose an approach that allowed us to do research with the children. It is important to note that internationally, there is a move to doing research with rather than on children. Rather than viewing children as ‘objects’ of study, researchers are seeing the importance of involving children as active participants in research which concerns them and their lives (Grover, 2004). This change has come about, partly as a response to the growing awareness of the Convention on the Rights of the Child (CRC) which enshrines children’s participation (Article 12), but also because of the realisation that without hearing from children themselves about the problems and issues that concern them, “we cannot hope to devise strategies or solutions that will address their concerns, and will constantly be struggling to make sense of the world without
some of the vital information we need.” (Ivan-Smith & Johnson, 1998, P. 299).

In participatory research with children (including children with disabilities), ethical issues are of critical importance. An overriding factor in all such ethical issues is the relative marginality and powerlessness of children in relation to adults in society (Morrow & Richards, 1996; Thomas and O’Kane, 1998) and the need therefore to consider this power disparity with especially close attention for its implications in every ethical decision (Save the Children, 2004). Methodologically, for instance, it is crucial to penetrate beyond children’s token participation to their authentic engagement, and to generate data gathering processes that are appropriate to children’s developmental capacities (Grover, 2004; Hart, 1997; Boyden & Ennew, 1997).

Much work has been done on ethics amongst those researchers who work with children. Ethical issues that pertain specifically to work with children are now extensively represented in the current literature (Corlyon, van der Merwe, Katz, & Ghate, 2006; CP MERG, 2012). In addition organisations that commission research work with children have developed ethical codes specific to participatory research with children. Save the Children Sweden have been leaders in this field with the production of a number of publications that deal directly with ethics in practice (Boyden and Ennew, 1997; Save the Children 2004).

The children who participated in this ORBIS research study were additionally vulnerable because of their disability. As Boyden and Ennew (1997) state,

> It is not ethical to expose a child already vulnerable to any additional risk through an investigation that carries no benefit for the child. Interviews about painful subjects should be performed with the principle of ‘least harm’ (Boyden and Ennew, 1997, P. 43).

A number of practical strategies were applied during the research to minimise harm. The theoretical frame (see discussion in the first paragraph of this section) with which we approached the issue of disability informed the first strategy. We collected children’s experiences of visual impairment not through a “problem-saturated” approach that focused on “the problems in my life” but on a solution-focused approach that rather looked at “how I overcome things that get in my way”. This approach is drawn from the narrative therapy approach of White (2005) and adapted for research with children. Using this approach reduces the likelihood of causing distress and a feeling of powerlessness as it allows the child to talk about their challenges in the context of overcoming them.

In addition to this we tried to reduce the possibility of children feeling distress and if it is expressed we have strategies for dealing with it. Firstly, we use a participatory research approach that has the explicit aim of transferring control

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Note that this outline of approaches is partly informed by a UNICEF review of literature on the ethical principles, dilemmas and risks in collecting data on violence against children conducted in 2012 by Statistics and Monitoring Section/Division of Policy and Strategy, UNICEF, New York. (CP MERG, 2012)
of the research process to the children. This means that the process proceeds at the child’s pace and under the child's control (Mudaly & Goddard, 2009). Children can choose if they want to talk about a particular topic or do any activity. Central to this strategy is the creation of a relaxed child-friendly environment in which children feel free to say they do not want to answer a question or talk about a particular topic. At the beginning of the research interaction we teach younger children how to express dissent explicitly (Gorin et al., 2008) by saying “I don’t feel comfortable talking about that.” We practice this phrase together. If a child does express dissent of any sort we affirm this action by saying something like, “Well done. It is your right to choose what you answer or talk about” then we move on (Clacherty & Donald, 2007).

Additionally, we move at the child’s pace, we do not probe if the child chooses to tell a sad or distressing story but allow the child always to choose how much he or she wishes to say. Our experience in working with vulnerable children allows us to be vigilant in attending to children’s visual, verbal and non-verbal cues to recognise unspoken expressions of unease or dissent (Ahsan, 2009; Cree et al., 2002). We also structure the research workshops so that any activity that may cause distress is followed by one that focuses on capabilities and agency. In both of the research sites we had experienced counselling services where we could refer the children if they needed follow-up help.

The research protocol was approved by the Medical Research Ethics Committee of the University of the Witwatersrand (Clearance certificate: M121056).

3. Description of research

3.1 Research objectives

Most research with visually impaired children asks for the perspectives and experiences of caregivers, especially in the case of young children (Ward, 1997a). There are few examples, therefore, to inform a study with children themselves. The aim of this study was twofold:

- to develop and refine an approach to doing qualitative work with children who are visually impaired to find a method for gathering information
- to begin a collection of children’s voices and perspectives on being visually impaired that could be used in ORBIS’s advocacy work.

3.2 Methodology

In recent years a non-verbal and child-friendly approach to child research has been more and more widely used (for example, Boyden and Ennew, 1997; Mann and Tolfree, 2003; Grover, 2004). These approaches are built on the idea that it is not always easy for children to talk about their perceptions and opinions of the very particular issue of concern to the researchers. This is why the approach needs to be a process oriented one in which boys and girls are asked about their lives and within this context they are able to articulate their ideas and experiences of a particular topic. The research becomes “a process by which children are empowered to construct a representation of their social
world” (Woodhead, 1998, P. 22). Mann and Tolfree (2003) point out that this approach is greatly facilitated

… if the researcher is able to provide a range of media which are culturally- and age- appropriate through which children can express themselves, without the process being dominated by the researchers’ own constructions, ideas and opinions. It is important for researchers to be aware of the local “currency of communication” and to use an appropriate variety of activities such as drama, mapping, drawings, ranking etc. that suit the context of children's daily lives. (Mann and Tolfree, 2003, P. 14)

The challenge in the context of this research is that many of the approaches Mann and Tolfree describe involve visual ability. One of the specific aims of this pilot study was, therefore, to test if these approaches could be adapted to work with visually impaired children.

We also made use of the few studies (Beresford, 1997; Nair, 1996; Murphy, 1998; Ward, 1997; Worth, 2009) we could find on research with children with visual impairment borrowing some research activities from these studies. Worth’s 2009 work where she used audio diaries with young people with visual impairment was particularly useful as it draws on the participatory child research tradition that the present researchers were familiar with.

The outline of the activities we did with the children, our reflections on how well they worked and our recommendations for work in future projects are given in 3.4 and 3.5 below.

3.3 Participants in the research
We worked with two groups of visually impaired children in two different areas. Seven children aged between 13 and 16 in Katlehong (a large formal and informal housing area outside Johannesburg) in Gauteng Province and 10 children aged between three and seven years in Durban who came from different areas (both urban and rural) of KwaZulu-Natal Province. The children in Katlehong were accessed through a local government boarding school for the blind but we worked with them in the school holidays when they were living at home. The children in Durban attended the KwaZulu-Natal Society for the Blind, Bauman Early Childhood Development Centre. We worked with them at school.

3.4 Research activities – proposed
One of the important principles of research with children is that the approach used is developmentally appropriate (Boyden and Ennew, 1997). We were working with different age groups of children so we made the decision to develop two sets of research activities, one for younger children (three to seven) and another for older children (over 10).

Research with the younger group
Our initial plan was to work with the children in a day-long workshop. The activities as we planned to do them are outlined in the box below. One of the
aims of the activities was to allow the children to do research with us rather than for us to do research on them. This is in line with the emancipatory paradigm described in the section on ethical issues above. Notes about how we adapted the activities and why are given in 3.5. Note that the research discussion was held in a mixture of English and the children’s home language.

**Sound stories about our lives**

**Activity 1**
Introduce the digital voice recorders to the children and show them how to operate them. Tell them they are going to make a story about their school. They can record sounds – let them listen to the sounds around them. They can also do interviews.
Talk about what they do at school and who is there – choose one thing to record that will tell someone about their school – it could be a sound recording or they could interview their teacher. Explain that they will have to introduce their teacher and say what she does in their school and for them. Then they can ask her to say something into the recorder about them or their school. Let them do this recording.

Let them listen to some of what they have recorded.

**Activity 2**
Discuss what they could say about the hostel on their recorders. Let them record interviews or sounds that tell about this part of their lives.

**Thinking about good and bad and feelings**

**Activity 3**
Have a bag of stones ready. Ask them to put their hand in the bag and feel the stones. Stones are bad things that happen to children.
“How does the stone feel? Hard and horrible – bad. It makes us feel sad and worried and frightened and angry.” “How do we look when we are sad?” “How do we look when we are worried?” “How do we look when we are frightened?” “How do we look when we are angry?”

Now take out a stone and say if there is a place or person or event that makes you feel like the stone.

Go around and let each do this and say what they feel and why. E.g.”I feel angry when there is no food for lunch when I get home from school”. Record this.

If they are not getting jumpy you could go around the circle again with another stone.

**Activity 4**
Now have a bag with marshmallows. Pass it round and let them put their hands in. “It feels happy and sweet and relaxed?” How do you look when you are happy, sweet and relaxed?”. They take out a marshmallow and tell about a place or person or event that makes them feel happy, relaxed or sweet.
Each in turn and they say what and why they feel this way. Record this. You can go around the circle again with another marshmallow. Eat the marshmallows up!

**Research with the older group**

Our initial plan was to spend a full day working with the group in a child-friendly venue (for notes on how we adjusted this and why see section 3.5). The research activities were designed to allow visually impaired children to participate fully and to do research *with* us as adult researchers. They included work with clay and tactile sensory games that we hoped would allow the children to represent their social, emotional and physical context and how they live in this context. The discussion was to be conducted in the children’s home language and taped, transcribed and translated to form the data we would use.

The aim was then after the research workshop to visit two children whose parents had volunteered to allow us to visit their home. With the children themselves we hoped to find out about the significant adults in their lives, their friends and the place where they live. We aimed to record the interviews and physical environment through audio recorders.

**Outline of proposed one-day workshop with older children**

**Focus activity**

A large timeline made up of clay ‘sculptures’ on the floor will be used as the focus for many of the activities. Alongside this we will also use a set of cloths with different textures as a concrete symbol of feelings (e.g. velvet for ‘safe’, bubble wrap for ‘happy’, rough hessian for ‘sad’ and spiky cloth for ‘angry’ and ball of elastic for ‘frustrated’). These will be used to facilitate the discussions about how children feel about the activities they do and relationships they have.

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<td><strong>Introductory games</strong></td>
<td>To create a relaxed and trusting environment</td>
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### Activity one: My Day
Place a marker to show the beginning and end of the day on the floor and between this they create small sculptures to show what they do at the different times of the day. The clay will create a concrete focus for looking at their daily experiences and their feelings about them. “Using clay make small models of your day from the time you wake up to the time you go to sleep at night. Each activity has a different piece of clay.” Look at weekends and how these are different from weekdays. Discuss what they have made.

### Activity two: The work I do
Use clay to show the work they do. “Show the work you do at home and outside the home.” “Put a coin on your time line if you do work that earns money.” Discuss what they have made.

### Activity three: The problems I face
“Place a rough stone at a place in your day when you have a problem.” Discuss the stones. Probe worries about their future, access to schooling, access to basic needs, social networks vs isolation. Discuss what they have made.

### Activity four: Important people
Using small, smooth pebbles tell us about people who help you in your day. How do they help you? Discuss what they have made.

### Activity five: Happy times
Place a marshmallow at a place where good things happen in your day. Discuss what they have made. Eat the marshmallows.

### 3.5 Reflecting on our research approach and activities

The first reflection is that we found observation of the children’s home (in the case of the older children) and school (in the case of the younger children) situation very useful. The field notes we made to record this observation gave us much more information about the children’s lives than we had anticipated. Observation allowed us to find out something about the children’s social networks, their relationship with their family members and peers. It also allowed us to see how the presence (or not in the case of the younger children in the early learning centre) of negative attitudes to disability affected
the children’s development and their everyday lives. The observation of context should play an important role in any future research.

**Research with younger children**

Eleven young children aged three to seven attend the Bauman Early Learning Development Centre. All but three are resident there. During the day the children attend the centre where they do a mixture of lifeskills, learning and play. Three teachers work with them there. When the centre was approached to help us with the research the children were very busy preparing for their end of year concert so the teachers suggested that we integrate the work we wanted to do with them into a number of days.

On the first day the researcher was introduced to the children and merely joined in the lessons and activities so that the children could get to know her. The second and third day she did a number of age-appropriate activities that allowed them to explore their lives.

This approach was mostly successful. Firstly, we realised how important it was for the children to work in a familiar environment where they felt safe and could move around easily. Spending time getting to know them was also an important part of the process. It took the first day for the children to get used to an outsider and to invite the researcher into their life at school. It also took some time for the researcher to adjust to the particular needs of visually impaired children. This mostly consisted of understanding how they moved around their physical space and some of the details of interaction such as taking their hand when they wanted me to accompany them somewhere and allowing them to find out about me through touch. Most of the children’s behaviour and level of understanding, concentration spans, their interactions with their teachers and with each other were little different from children that age who had no physical disability.

Most of the children were fluent in English but where needed we encouraged them to speak in *isizulu* and the teacher translated for the English-speaking researcher.

What was perhaps the greatest challenge was the age range of three to seven years and the fact that one of the children (aged 6) was newly arrived in the school and could not communicate or move around alone. This meant that working with the whole group was sometimes difficult but with the three year old on the researcher’s lap and the new boy left to move around the room as he wanted to we soon worked out how to get the activities done happily.

The recording activities worked well with the older children (six and sevens) but not with the younger ones as they were too interested in the workings of the recorders and could not understand that they needed to think of a question they could ask. But, the activity was done towards the end of a busy day and we are sure that if we had worked in small groups and at the beginning of the day when the children could concentrate for longer that the activity would have worked better even with the younger ones.
The data we collected from the audio story recording activity does show us the important parts of the children’s lives at school. It also highlights both the challenge and the adjustment of the children to their visual impairment (see Section 3.1).

The activity with the stones and the marshmallows worked very well, though we did substitute a velvety cloth for the marshmallows after everyone told us about the food that made them happy and not the events and people. The quality of information we gained from this activity points to the fact that even very young children can reflect on their lives (see Section 3.2). Centre staff were dubious about the children’s ability to reflect on the challenges they face but were amazed at the children’s ability to talk about their lives.

_I really didn’t think they would tell you anything when you said you wanted to do the activity about stones (challenges) in their lives. But they talked and a lot of it was about their disability even though you didn’t ask about that. It made me think that we need to do much more talking about living with blindness – we never talk about it with them – we just don’t raise it – but they raised it so we need to help them cope more._ (Teacher, early learning centre)

It is important to point out that the Baumann Centre works closely with parents to educate them about their child’s disability. This was obvious in the interactions that we had with the parents of two of the children who live at home and come into the school everyday (see Section 4.1 xx). We did not interview any of the parents whose children were living in the boarding house.

**Research with older children**

The research with the older children posed many more challenges. These challenges tell us much about the hard reality of disability in South Africa, where children who are disabled are deeply vulnerable because of their marginalisation and isolation from services and because of the many levels of stigma attached to disability at home and in the community. Setting up this research pilot is described below in detail because it gives us important information about the reality of ‘being visually impaired’.

Our first barrier was accessing children to participate in the research. Children with visual impairment are a small population that are geographically dispersed. Apart from schools for children with disabilities there is no organisation that can help with access of children who are visually impaired. It is also extremely difficult to get permission to work in government schools. Ferrell (2011) describes exactly this problem in a paper looking at research with children with visual impairment in the USA.

_Educational research on students with visual impairments is difficult to conduct. The population is geographically dispersed, making it difficult to identify an adequate group of study participants without considerable expense. Participants who are identified are often extremely heterogeneous and exhibit a range of visual disorders … [and] local_
school districts are reluctant to consent to research because it takes away from other instruction. (P. 17 and 18)

We were unable to work in a school for children with visual impairment but one principal was happy to give us the contact details for parents and guardians of children attending her school who lived in the Katlehong area. She suggested we work with them during the school holidays when they were home. Though this made the logistics of the research work much more complex it did allow us important information about the reality of being visually impaired within the home and the community that we would not have had if we had conducted the research in a school setting.

Our initial idea was to run a one-day group workshop at a local community-based psychological support centre, which was easily accessible by public transport for all of the parents. The Ekupholeni Centre based at the Natalspruit government hospital in Thokoza had agreed to allow us to use their group room and also to provide any follow-up support the children may need. On contacting parents we soon realised that this would not be possible. All of the (10) parents we contacted indicated that it would be impossible for them to bring the children to the centre as they were working (or busy) and could not come with the children, who could of course not come to the centre alone. This issue of individual mobility is discussed in detail under 3.2 below.

Two fieldworkers conducted the research – a male and a female. They spoke the children’s home languages and came from a nearby area. This gave them an understanding of the children’s cultural contexts.

4. Findings
The findings are presented in two sections, one about the younger and the other about the older children. The information under each section is organised into themes.

A note about quotations from the children:
- R: indicates the researcher
- A new child speaking is shown by a new line.

4.1 Young children tell us about their lives

We can do things for ourselves
The sound stories made by the younger children were built very much around their pride in being able to move around their space and to do things for themselves. Apiwe chose to make a sound story about the house next to the learning centre where the children board during the week – they and staff call the house “Chestnut” after the street in which it stands.

R: What do you want to show me about your life here, Apiwe?
Apiwe: Chestnut! (He takes me by the one hand, holding the recorder in the other and walks confidently outside, across the playground, up

2 All names changed and photographs have been chosen so they do not reveal the children’s identities.
the ramp and into the dining room of the house. We meet one of the staff and he interviews her as we have practised.)

 Apiwe: Hello Aunty Lerato.
 Lerato: Hello Apiwe.
 Apiwe: What do you do at my school?
 Lerato: I am looking after you all. I make your breakfast and supper. I help you wash and look after you all.
 Apiwe: Thank you. The bedroom! (He runs ahead of me). Here’s my bedroom. This bed is for me. This one is for Lihle, come, come I will show you. Lihle sleeps here. Xolani sleeps here. This is the clothes. 
(He crosses to a chest of drawers and holds a printed label up close to his eyes)
 Apiwe: Lihle. Mine. The girls. (He crosses the passage, checking to make sure I am following him into the girl’s room). It (the room) smells of the girls. Lindi here and Mphumi here. (He rushes out of the room leaving me to follow). I can go to the toilet at night. (He says this proudly and walks confidently to the bathroom.) Wash hands and flush! 
(Said with great pride). (Boy, 6)

“I can tie my own shoelaces! Look look.” (Boy, 6)

This same confidence of movement was also obvious in the playground and with those who were partially sighted as well as those who were blind. They all moved confidently around the playground even though there were a number of obstacles they could have walked into.
Staff explained that they encourage independence and leave the children to explore the space on their own (supervised) when they arrive so they can orientate themselves. It was obvious that this was what the one boy who had arrived only a few weeks ago was doing. He spent any free play-time slowly wandering around the playground feeling his way around learning the borders and objects in his space.
This extract from Phumlani’s sound story highlights how the teachers emphasise lifeskills.

Phumlani: Shadow is my teacher. Hello to my teacher Shadow. Tell me what you do at my school Teacher Shadow? 
Shadow: I am here to teach you so you can become a confident and a good student. 
(He runs across to the researcher with the recorder to report what she has told him) 
Phumlani: She is teaching me considens (sic)! 
(Phumlani arrived at the school a few months ago speaking only isiZulu. He needed to be able to speak English before he could be accepted at the Open Air School for children with disabilities. He enthusiastically repeats words, not always knowing what they mean. But his English has improved enough for him to attend the school from January 2013).

Staff said that they saw lifeskills as an essential part of the learning. They began by teaching the children basic practical skills like washing hands and going to the toilet, taking shoes on and off, putting toys away, eating with a spoon and communication skills such as asking for what you need. Then moved on to more complex skills such as communication, assertiveness and conflict resolution. Apiwe recorded a meal-time for his audio story. The extract below illustrates one of the teacher’s encouraging assertiveness (as well as the children’s enjoyment of their beans and rice).
Apiwe, introducing the sound story: We eat lunch at school. We say grace first.  
(They all sing) “Thank you father thank you father for our food, for our food. For our many blessings, for our many blessings. Ahahmen, ahahmen.” (Discussion follows)  
We are eating rice and boontjies.  
I like boontjies.  
I like rice.  
Mmm.  
Ngaaa! (Colloquial expression for “very nice!”)  
I am eating with my spoon. Apiwe is eating with a spoon. Boontjies.  
(Apiwe finishes and takes his plate to his teacher)  
Teacher: Do you want more?  
Silence.  
Teacher: Now tell me if you want more. If you don’t tell me I can’t help you.  
Apiwe: I want more.  
Teacher: Good, you need to tell me. Let’s get some more for you.

The children were practising for their end of term concert during the research period. This is an extract from the researcher’s notes describing the rehearsal.

Everyone lined up to practise singing for the concert. Nadina had to be reminded to look at the front but the others all work it out for themselves. The children call “Suguma (stand) Olwethu!” to remind the new boy to stand up and face the “audience”. The tape begins and everyone sings enthusiastically, Mdu adds in the “pom, pom, pom” at the top of his voice between the verses as the piano plays. They all sway and swing their arms doing the actions they have been taught. It is clear that they enjoy the repetition of each chorus and they all know almost all of the words of the six or so songs.
The extract below from Mdu’s audio story about his school includes information about the end of term concert. It also illustrates how confidently the children move around their school and use their hands to gain information.

(Mdu leads me around his school playground where the children are all playing – he has the recorder in his hand)
Mdu: This is Phumlani my friend. How old you Phumlani?
Phumlani: I am six years.
Mdu: What school you go to Phumlani?
Phumani: Umbilo. Society for the Blind (said very quickly with all of the words running together – the school is in Umbilo Road).
Mdu: How you get here? (This is a question he has added himself, not one we discussed before)
Phumlani: I am walking to this school every day. I go on the taxi and walk here, with my aunty.
(Shadow, the teacher is sitting in the shade watching the children while they play. Mdu goes straight up to her, knowing where she will be).
Mdu: Aunty Shadow. What do you do at school Aunty Shadow?
Shadow: I am here to teach you to read and introduce Braille to you with the doll and I teach lifeskills.
Mdu: Thank you.
(Mdu marches off into the school house, I follow)
Mdu: This is my classroom. The animals (for the concert) are here. We are singing. I sing about the rhinoceros. I am the elephant. I want to see the elephant, where is it?
R: Here it is.
(Nadina joins us)
Nadina: What is this?
R: The lion. He has wool for hair.
Nadina: Where is the moo cow, moooooo! What is this? (She and M are feeling the animals gently with her hands, working out which is which)
R: The lion.
Nadina: What is this?
R: His nose.
Nadina: What is this?
R: His mane.
Mdu: What is this?
R: The elephant.
Mdu: That is me! Here is his trunk. (Extract from Mdu’s audio story)

Another important lifeskill observed was supporting each other. The children spontaneously helped the new boy who could not move around confidently yet, taking his hand as they went outside to play, reminding him to stand up at certain times, leading him to the bathroom to wash his hands.
Nadina’s story

Nadina is three years old, a diminutive, always moving, always talking, little girl with long black hair. She has been blind since birth because of retinopathy of prematurity (caused by an excess of oxygen given to premature babies). She has been at the school for a year now. She lives at home with her mother and father, two older brothers and a severely disabled older sister who cannot walk or talk. When we discussed “things that make us angry” she told us this story, which gives insight into some of the dynamics of living with her severely disabled sister and Nadina’s feelings about this.

My sister (makes me angry) – she can’t do nothing - that makes me cross then I pinch her and my mother shouts at me. I get cross with her every day. Her name is M. Two months she is making me cross. She hit me. I pinched her and she hit me – she hit me two times (she flails her arms around wildly). Then I say don’t hit me I will pinch you. If they hit me (adults at home) I pinch her.

Nadina’s father brings her to school every day at 7.30am and picks her up after work at 5.30pm. This is a long day for a young child (and Nadina has to be constantly alert processing extra information to work out what is going on around her) but she sleeps in the middle of the day in a cot in her classroom, which she loves because she showed it to me a few times, “This is my cot where I sleep, see Glynis?”

She has developed numerous strategies for coping with her blindness. She asks questions constantly to orientate herself to her space, to identify what she is feeling with her hands and to find out where people are. She uses her good verbal ability to charm those around her. The older children, some of who are partially sighted often spontaneously take her hand and lead her outside to the playground or to the toilet. She is a clear favourite with everybody.

Her teacher said she struggled to get her to sit still and to do focussed work but she thought this was largely because she was only three years old. Next year the staff will focus on helping her to concentrate and to develop her fine motor skills, essential if she is to learn to read Braille.

She made an audio story about her school but could not quite understand that the recorder recorded sound – she used it as a cell phone (because that is what it felt like to her). She did, however understand the idea of taking me for a tour around her school so I held the recorder while she showed me around. The following extract from our guided tour illustrates how she
copes confidently with her disability.

This is my classroom. We are going to my class to see. Where you are, Glynis*?
R: I am here.
Here is my classroom. Come see my train. Where is it now? Here it is. And come see the piano (she plays a few keys). Piano. This is Emelda. She is my teacher! Come see my cot. I sleep in here. And this is my desk where I sit and do work, puzzles. Come stand here, Glynis*. Oh I have too much teddy bears. (She feels them on the shelf). This is the piano (she is feeling all of the things on the shelf). This is a shaker (she shakes it). Put it in the basket, right now (she puts it back). This is my cot - I sleep here every day. Glynis* where you are? R: I am here right next to you. Where are we going?
Come see my classroom for next year, I want to take you here.
R: Oh, here is Aunty Emelda. What did you want to ask her, Nadina?
Emelda, what you teaching me?
Emelda: All your shapes, your body parts, we are doing counting.
She says body parts and counting and beads and threading and all my shapes. She is teaching me.
(We continue on our way to her new classroom which is across the playground – Nadina leads the way confidently)

Nadina will stay at the Early Learning Centre until she has the concentration and coordination to learn Braille and then she will probably move to the Open Air School (a nearby school for children with disabilities) where she will be able to continue her schooling to Matric level.

*Note that the Glynis mentioned above refers to the researcher Glynis Clacherty.

The discussion about challenges in their lives gave important information about the children’s lived experience of visual impairment.

Teasing from other children
During the activity with the stones a few children talked about being teased by peers. Lindi and Phumlani told the following stories
I get very angry.
R: When?
The neighbour’s children come up and hit me and run away. Then when I tell their mother they just say, “we did not tease her, she cannot see – it was not us.” They know I cannot see so they say this. I get very angry. Then I just sit by myself. (Girl, 6)

When I walk to the shop they shout, “Check your eyes, check your eyes!” (Boy, 6)

This same boy (who has albinism and whose eyes do not see well outside in the sunlight) told a story about his cousin/brother just did not understand that he could not see easily outside.

My one eye is not working outside and my brother does not understand and he wants to go outside and I can’t and he does not understand and goes outside but I cannot see outside. I feel very angry. It is not nice to be angry – it feels yoooghhghghh! (said very softly) (Boy, 6)

Moving around easily
When discussing what makes them feel angry one boy of 6 raised the issue of mobility.

When I go to the farm in the holidays, to granny’s house. My mother is not there and they leave me. There is no one to take me to the toilet. (His voice is very soft now). That makes me angry. (Boy, 5)
The staff confirmed that he often returns from holidays with bumps and scratches were he has fallen suggesting that he has had to find his way around the unfamiliar environment alone.

*Feeling sad about our visual disability*

Two of the younger children talked about how being visually impaired made them feel angry.

*This one not open and this one open (pointing to each of his eyes). It makes me feel cross. This one is open in house but outside it is not open and this makes me to feel cross! (Boy, 6)*

He also talked about how he felt angry when he went to the doctor and the doctor just shone a torch in his eye without talking to him.

*The doctor. He puts a torch and shine in eyes. Just shine. It feels like the stone (referring to the stone in his hand). Shine in eyes. He does not talk me, just shine! (He says the last indignantly) (Boy, 6)*

### 4.3 Older children tell us about their lives

*Lack of mobility*

The fact that the older children could not come to the centre at the hospital to participate in a research workshop points to one of the biggest challenges faced by children with visual impairments - they are dependent on others for movement. The children we spoke to confirmed this reality.

*R: Can you tell me about the places you go to?*
*R: In the holidays?*
*I go to school.*
*R: Do you go to the shops, to a friend’s house, to play soccer?*
*Nowhere. I just stay home in the holidays. Sometimes I go to church with my mother. This is boring.*
*R: What do you do in the holidays?*
*I watch TV here in the house.*
*R: And …?*
*I watch TV and sit.*
*R: Can you see the TV?*
*No, I can listen to the story. (Girl, 9, blind)*

Another girl of 12 who was also blind described how her parents restricted her movement around the area partly because of their fear for her. She told us, however, that she can move around on her own at school so she found the restrictions frustrating.
My sister goes to swim (at the local public swimming pool) but my mother won't let me go. She says I will not be ok. But at school I swim, I can walk to the pool. I can walk anywhere at school because there are bars to hold on and because I know the place. I can walk in the street with my sister but she does not like to take me. She feels shame. I try to tell my mother I can go around but she is afraid. So I stay inside and watch TV in the holidays. It is boring. (Girl, 15)

The shame of disability
Another reason for the parent’s reluctance to allow the children to attend a workshop outside the home was because they did not want to move around their community with the children. Field researchers felt that there was a definite sense of shame linked to having a child with a disability.

I think there were a number of reasons why the families were so suspicious. I have not had this experience before when doing home visits to families with children who are not disabled. So I can only think that it has to do with their disability. It seemed like the child was a secret. It felt like the families were ashamed of the children and by my visiting I drew attention to the fact that they had a disabled child. Most of the families first asked, when I explained that I had got their phone number from the school, “What has she/he done wrong at school?” most then went on to explain that the child was “not right in the head,” or “not normal”. It was as if they immediately thought of justifying the child’s behaviour or blaming the child. They could not believe that I wanted to just come and chat to the child, many said, “but she/he will not be able to tell you anything!” Sometimes you do get this from parents of ordinary children as they cannot believe that children can tell us anything but with this work it was just exaggerated more.

(Researcher’s field notes)

This shame was clearly linked to a lack of knowledge about disability. None of the caregivers knew exactly what their child’s condition was and how it had come about. When asked, most attributed their child’s visual impairment to a cause other than medical.

She is blind because … I don’t know. I think that it was in my husband’s family (blindness) or bewitching. You just don’t know these things. (Mother)

This same parent described how her nine-year-old child (who was blind) got very angry and aggressive.

She can get sooo angry. Then she just hits. She threw her glasses away once. Once she got so angry because she lost R2. R2 that is all. She could not find it and she started hitting everyone. The only one who can control her is the grandmother. She took a stick and beat her and then she stops. I cannot understand how she can get so angry about R2. I am suspecting something wrong in her mind because of the anger. (Mother)
Caregiver’s lack of knowledge about disability and the impact this ignorance had on the children is confirmed by Siphiwe’s story.

**Siphiwe’s story**

Siphiwe is 15 and lives with his grandmother. He has no sight in one eye and partial sight in the other. Neither Siphiwe nor his grandmother know any details about his disability but his grandmother is convinced that he was visually impaired because of the physical abuse his mother received from his father when she was pregnant with him. Siphiwe is a quiet boy who spends a lot of his time at home. He helps his grandmother with housework. He likes to cook.

*R: What else do you do when you are at home?*
*I clean, sweep the yard everything. When I want to I cook for myself.*

*R: Do you know how to cook?*
*Yes.*

*R: Who teaches you how to cook?*
*I learn myself. (He laughs softly, proud of himself).*

*R: Boy there are kids that don’t know how to cook - but you can cook. Cooking is easy you boil the water put salt and mealie mealie, stir 3 times then your pap is ready. I like Sundays, good time is on Sundays. I cook for my grandmother I eat what I want salad, ice cream all the nice food we eat on Sunday, I cook.*

He also goes shopping for his grandmother. He described how most people in the community do not trouble him, it seems that this is partly because they are afraid of his disability.

*I go to the shop for Gogo. They do not try to rob me because they are afraid of me. The gangsters. They are afraid because of my eyes. They go to the other side of the street.*

He did have spectacles to help him to see but he told us he no longer used his glasses, mostly because he was teased.

*I was carrying my glasses at school.*

*R: So you have glasses?*
*No they broke up when I was young.*

*R: So never go for another pair?*
*My grandmother will buy again for me.*

*R: Did you go to the doctor?*
*The doctor doesn’t want to give me.*

*R: Why they don’t want to give you?*
*The doctors give me the big ones that I don’t like.*

*R: Why? Is it because they are not in fashion?*
*No. It is not because they are not on fashion I do wear them but when I go out they laugh at me on the street.*

*R: What do they say?*
*You wearing so big glasses!*

Siphiwe has one special friend who lives nearby. He met him at his school. This boy was involved in an accident and lost his sight. Siphiwe described how he supports his friend.

*We met at school - we hanged together. He calls me and I go to him - he is living near here. He calls me or sends me ‘please call’ (message). If he tells me that he is not okay I go to him. I stay with him and ask why is saying he is not right. He feels bad about not seeing. We talk about that. I also help him to get on the train to go to school.*

Siphiwe told us that he liked to work on the computer at school and he sometimes went to his uncle’s house to use his computer. He did things slowly but seemed to us to cope well with everyday life. His grandmother, however, insisted that he had “only half a mind” or a “small mind”. This was a phrase she used repeatedly even when he was in the room. Siphiwe interviewed his grandmother for his audio story and even here she repeated this idea.
Siphiwe: How do you think of me Gogo?
I know what kind of a child you are. You don’t give me a hard time - you don’t, you only give me a hard time because of your small mind and I understand that your mind is small – it is not the same as your age I understand, it is the only thing you give hard time with because we fight because of your small mind that is all, nothing more than that I don’t see you giving me any hard time. Are you happy staying with me as a grandmother?
Siphiwe: Yes
Gogo: How do I treat you?
Siphiwe: You treat me well.
Gogo: Okay

In spite of telling him he had a “small mind” his grandmother did love him, she told the researchers.
I love, love him. I always correct him every day. He wouldn’t be like he is if I don’t shout at him. I took him to live with me because I knew he would be street kid if he lived with his mother.

But her continual comments about his small mind had an impact on Siphiwe. He lacks confidence.

I would like to do something when I finish school. To work on computers maybe. But I cannot go places. I may not be able to do work. I worry about what will happen when my grandmother is not here. I think I cannot do things like other boys maybe. I worry about me and what I can do. I think about my eyes and wish they were all right.

One of the main areas of ignorance (see theme below) amongst parents was related to the children’s capabilities. They assumed that they could do little for themselves. Bongega described how her mother dressed and washed her every morning when she was home.

My mother washes me. She dresses me.
R: Can you dress yourself?
Yes, at school we do it ourself. I can do it myself. (Girl, 9)

Parent’s lack of awareness of their children’s capabilities and the difference that some education of parents would make to the children’s lives is illustrated in the interaction below which comes from one of the children’s audio stories. Lebo is completely blind but the researcher encouraged her to draw like the other children he had interviewed by asking her to draw around her hand with a crayon.
In her audio story she proudly shows her grandmother what she has drawn.

Gogo: You made a nice drawing there, have you seen that?
Lebo: Yes.
Gogo: Who taught you how to draw that much?
Lebo: It’s the talent of my hand!
Gogo: I am going to give you a big piece of paper so that you can draw for me and crayons. Wasn’t he (the researcher) guiding your hand?
Lebo: No.
Gogo: Were you doing it for yourself?
Lebo: Yes, this is what I did; I put a hand and then started drawing around my hand like this. I can do things Gogo. (Girl, 12)

Spatial isolation at home
Once we realised we could not work with the older children at the centre we decided to visit each child in their home, having made arrangements with parents and guardians by phone to do this. The visits to the children’s homes tell us much about the lives of children with visual impairments. Eight children in seven homes (two boys were from the same family) participated in the research. We developed an adapted form of the participatory workshops we had planned. We decided that using clay and drawing (in some cases) would be suitable for an interaction in a home environment. The researchers also made a set of field notes after each home visit was over.

In most of the homes the researchers (a man and a woman, both isiZulu-speaking) began by introducing themselves and explaining the purpose of the
research to parents/guardians and getting their consent for the child to participate.

In some instances the child was in the room (either the kitchen or sitting room or in the case of an informal house under the tree outside) but in most homes the child was in a back room and the family indicated that they would bring the child to the researcher. Observation of this points to another reality of the lives of children with visual impairment – many of them spend most of their lives inside and often in one room.

Bongega and the researcher working on the clay sculptures about her day. This is where she spends most of her day when home during the school holidays.

Most of the eight children we worked with could not move easily around their own home, either because there was so much furniture squashed into the small house or because the child had not been helped to find their way around the house. The children we spoke to confirmed this reality.

At school it is easy to move there are spaces. Also you can go anywhere outside. There are bars by the corridors so you can walk. Here it is hard to move. I have to call my sister to go to the toilet outside. Sometimes she is not there. (Girl, 12)

Three of the eight children spent most of their day in a back room (usually a bedroom with a large bed and little floor space) and had to rely on a family member to lead them to the toilet (which was sometimes outside) or to the kitchen. These three children seldom went outside to sit or play and did not spend time interacting with the family in the kitchen space or outside as other children in the family did.
What stuck out for me was that many of the children were kept away in a back room, or in the case where a family lived in two one-roomed shacks, in the sleeping room. The one little girl who was completely blind she just sat on a blanket in a small space next to a big double bed in the back room. She had a few toys to play with but mostly she just sat. Then the family told me that she got very angry sometimes and they could not control her. The only one who could control her was the granny who beat her with a stick. (Researcher’s field notes)

But, as with all relationships, the picture was more complex than just isolation, many of the mothers and grannies clearly loved the children. The same granny who beat the little girl also cared for her and was much loved by the little girl as this extract from her audio story about her granny shows.

*Bonge: Hello Gogo.
Gogo: Hello.
Bonge: How are you?
Gogo: I am fine.
Bonge: How is your fever?
Gogo: It’s getting better.
Bonge: Did you go to the clinic?
Gogo: Yes, I have been.
Bonge: Have you taken your tablets?
Gogo: Yes.
Bonge: What about your headache tablets?
Gogo: I have also drunk the headache tablets.
Bonge: Granny you must sleep, you are going to get better.
Gogo: I am going to be fine.
Bonge: Please drink your porridge.
Gogo: Yes, I am going to drink it.
Bonge: Stay well.
Gogo: Okay.
Bonge: Bye Gogo.
Gogo: Bye. (Extract from B’s audio story about her granny, 9 years old)*

The grandmother who told us repeatedly that her grandson had only “half a mind” clearly loved him. What is clear though is that this love needs to be coupled with information if caregivers are to stop stigmatising the child’s disability.

*Isolated from siblings at home*

Another observation made by the field researchers was the fact that most of the eight children (5 of them) did not interact with siblings (younger or older).

*I tried to make everyone relax and feel at ease so I asked if the other siblings in the house could join us in the activities we were doing. I thought if we had a small group it would be more fun. What I noticed was that in three of the houses they were not used to interacting with the child with the visual disability. They did not naturally sit down and*
play or draw or do the clay sculpture together. The younger siblings did not interact with the child who was visually disabled. They did not talk to them, or interact physically – like they did with each other. I think they did not do things together much ever. One girl did call her sister to help her to find a letter on her cell phone when she was showing us how she could send an sms but the little sister just treated her like she was a bit stupid – she wasn’t she just could not see the difference between the 6 and the 9 but she had typed out the sms holding the phone up close to her eyes. She said they taught her this at school. (Researcher’s field notes)

When we asked the children we were working with to interview an adult in their house it was also clear that there was very little interaction between adults and the child too. Only in one house did it seem that the mother talked to her two boys who both had a visual disability and in another home a small boy with albinism seemed to have a fairly normal interactive relationship with his granny. In the other homes the child was completely tongue-tied even when the researcher left them to interact with the adult on their own. In most of the homes the child with visual impairment merely stood with the recorder and the adult spoke.

**Isolated from peers in the community**

The children’s descriptions of their days show that they were also isolated from peers in the community – many did not interact with any friends their own age. One boy had another disabled boy in the community that he interacted with (see Siphiwe’s story above). The boy with albinism had two friends that he spent time with in the yard and in the streets. But most of the children had no friends at home.

*R*: What else have you drawn, what is this?
*It’s a person.*

*R*: Who is this person?
*I don’t know.*

*R*: What is this person doing?
*Doing nothing. Just sitting.*

*R*: Okay. Who are your friends?
*I don’t have friends. I am just sitting here at home.* (Girl, 9)

**Discrimination in the community**

Many of the children also described how they were teased by other children and adults. Siphiwe describes how people cross to the other side of the street when he walks past (see Siphiwe’s story) because they are afraid of him.

*R*: Now Siphiwe tell us in your day what do you do when you wake up in the morning?
*I wash my face then my grandmother sends me to spar to buy some things*

*R*: What kind of things you buy?
*Like milk, cold drink, bread, airtime and cheese things like that*

*R*: They don’t try to rob you on the way
The boy with albinism describes how people call out rude names to him and how they tease him about not being able to see, “Check your eyes, check you eyes!” He also described how when he first moved to the area he was afraid of going out.

R: Before they got used to you what where they saying?
They would call names like how I am? Am I an Umhlungu? They laugh because I cannot see and my eyes make tears all the time.
R: What would you do then?
I would just sit indoors. I was thinking how I can make them understand me. Then my mother asked two boys to come and I made friends. Now I have many friends and they are all used to me. (Boy, 11)

Feeling sad about being visually disabled
Another theme that emerged was the way the children and young people felt about their disability. Not all of them spoke about it but three children described their feelings about their disability. One girl of 12 made a small clay sculpture of a heart with a hole in it.

R: Why is there a hole in your heart?
Not being able to see. My heart is broken.
R: Do you ever talk to anyone about this?
No.
R: At school?
No, at school we just work and lay. Sometimes we talk with friends but it makes us sad to think about our future so we don’t say much.
R: To teachers?
No.
R: To your mother?
It makes her sad so I don’t talk to her. (Girl, 12)

Another boy spoke about how he feels sad when he cannot get help.

I like bright colours because I am able to see the brighter colours.
R: When you can’t see clearly what do you do?
I call a friend to help.
R: When you can’t get help?
I stop. Let it go. Then my heart becomes sore. (Boy, 11)

The issue of wearing spectacles was also brought up by three of the children. Simphiwe did not wear his as he thought they were ugly. One girl had thrown hers away in a fit of anger and Lebo and her sister talk about the fact that she does not wear her spectacles with the researcher.

R: What about watching TV at night, doesn’t it bother your eyes?
Sister: She doesn’t see clearly, she uses spectacles.
Lebo: No you speaking lies.
R: How do your spectacles look like?
[She goes out to look for her glasses]
R: Lebo has just returned. Can I see them on you?
[She puts them on]
R: How do you see now?
Lebo: Better.
R: Which eye is seeing?
Lebo: This one.
R: What about the other one?
Lebo: It does not see.
R: What does the doctor say about this one?
Lebo: I don’t know.
R: Were you ever taken to the doctor?
Lebo: No.
R: Do you like your glasses?
Lebo: No.
R: Why?
Silence
R: What do other children say about your spectacles?
Lebo: Nothing
R: When you go out with your spectacles what do other people in the community say?
Silent.
Sister: She doesn’t go out with spectacles
R: What about other children at school?
Sister: She doesn’t take them to school. (Girl, 12)

Being proud of myself
Another theme that emerged from the discussions with the children was their sense of pride in their achievements, including overcoming their daily difficulties. One of the boys we visited had recently returned from competing as a representative of South Africa in an athletics competition in Zambia. He wore his official uniform for the interview and made a model of his medal out of clay.

I feel very good when I compete because I meet a lot of new people and we get to know each other better. I run all distances, 100, 200, 400 and 800 metres. 100 meters I do it in 2 minutes 48 seconds. My medals are at school. I have five gold medals. Year before last I got two, I got one in last year and this year I got three in Durban and then I got one bronze in Zambia. I don’t think there is anything that can stop me now. I forget about my eyes when I am running. (Boy, 14)

Though other children did not have these kinds of achievements they were just as proud of what they could do.

I read well and I will be a teacher. To teach children Braille. (Boy, 12)
When I am writing it makes me feel happy. I also like spelling. We play a game with spelling and I am good. Sometimes you spell a word like invite, you say i-n-v-i-t-e
R: That is a difficult word, do you know that there older people who cannot spell that word, some don’t even know what that word means. Serious yho yho yho! I want to do teaching when I grow up. (Girl, 12)

I can dress myself. (Girl, 9)

I like cars. I am learning to work with cars. That is why I drew a car. (Boy, 11)

5. Conclusion

What emerges from this pilot is that it is possible to create a process for children with visual impairments to talk about their lives. They can talk about both the challenges they face and how they overcome them.

What is striking is that schooling is important in the children’s lives as it teaches them independence and it allows them to make friends and build up their confidence. At school older and younger children can move around freely, can make friends and can learn how to swim and run and play as well as to read and write.
Home is not always an easy place for them to be largely because of the ignorance of parents and guardians about their visual impairment and how they could build their confidence and lifeskills. Parents often attributed their children’s disability to metaphysical sources such as ancestors and witchcraft and seemed to have little understanding of the medical reasons for their child’s disability.

Children with visual impairment have reduced mobility at home, many have few friends within or outside of the family and though family members often love them they limit them (often through their wish to protect them). They also experience significant levels of discrimination within the community and there is a sense that family members are often ashamed of their disability, sometimes hiding them away. This points to the need to educate parents of children with visual disability about why their children are visually disabled and how they can create an enabling environment for them at home.

Though we did not get too far below the surface in terms of emotions, partly because of the time we had available and because of not wanting to cause distress in the children, it is clear that children with visual impairments often feel very sad about their disability (even very small children). It seems that, on the whole, no one talks to them about these feelings and about their disability.
6. References


