



Hearing the Voices of Children and Caregivers

*Situation Analysis of Children with Disabilities
in South Africa*

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May 2011

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This report reflects the voices of children with disabilities and forms part of a more comprehensive situational analysis of children with disabilities in South Africa. The situation analysis was undertaken by the Department of Social Development; Department of Women, Children and People with Disabilities; and UNICEF South Africa.

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 - Lungi Radebe co-ordinated the group with the caregivers, with support of the organization Community Based Education and Training for Empowerment (CREATE).

It is hoped that listening to the experiences documented here – both in words and in pictures – will enable us all to gain strength and energy as we continue in our struggle to build a "Society for All".

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Cover photograph: Urban children building model of community resources

Photograph on page 3: Rural children building model of community resources

All illustrations used with the permission of children who participated in the groups

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1. Background to the situation analysis

Children with physical, sensory, intellectual or mental health disabilities are among the most excluded of all the world's children and face serious barriers to the full enjoyment of their human rights. They are less likely than other children to be in school, they often have trouble using the health services they need, and are particularly vulnerable to violence, abuse and exploitation. They are also more likely to be denied the right to grow up in a family environment than their able-bodied peers. The barrier is frequently not the impairment itself, but rather a combination of social, cultural, attitudinal and physical obstacles, which children with disabilities encounter in their daily lives. Many of the factors contributing to the high levels of impairment are potentially preventable, and include congenital defects, malnutrition, childhood illnesses, lack of sanitation and clean water and accidents.

The past two decades have witnessed a new global focus on the rights of persons with disabilities in general and children in particular. These include:

- The Convention on the Rights of the Child, which was the first human rights treaty that contained a specific reference to disability (article 2 on non-discrimination) and a separate article (23) exclusively dedicated to the rights and needs of children with disabilities.
- The African Charter on the Rights and Welfare of the Child has a number of particular articles on rights of children with disabilities.
- The Convention on the Rights of Persons with Disabilities points the way towards overcoming discrimination and recognizing the right to full participation of children with disabilities – in the home and community, in school, health services, recreation activities and in all other aspects of life.

Despite opportunities for prevention of disability, the number of children with disabilities is very high. Globally, an estimated 200 million children – 10% of the world's young people – are born with a disability or become disabled before the age of 19. Around 80 percent of them live in developing countries (UN, 2006).

South Africa has some of the most comprehensive legislation and policies protecting and promoting the rights of children with disabilities. The constitutional principles of human dignity, the achievement of equality and the advancement of human rights and freedoms, although applicable to everyone, are especially important for children with disabilities. The Integrated National Disability Strategy was developed in 1997 and the Office on the Status of Disabled Persons was established to monitor its implementation. Other key pieces of legislation and policies include, among others: the admission Policy for Ordinary Public Schools; White Paper on Special Needs Education; free health care for persons with disabilities; the Mental Health Act; the Social Assistance Act; and the Disability Framework for Local Government 2009-2014. In 2009, the Inter-Departmental Technical Task Team developed a Strategy for the Integration of Services to Children with Disabilities. The Children's Act, which came into effect in April 2010, places particular emphasis on the recognition of a child's disability and on the creation of an enabling environment to respond to the special needs of that child.

Despite the achievements in terms of policy and legislation, there has been limited impact on the lives of children with disabilities. While there is political will to address the needs of people with disabilities, knowledge on disability is very fragmented, and many gaps in service delivery remain due to inadequate budgetary allocations, weak capacity, patchy implementation and procedural bottlenecks.

This publication forms part of a broader assignment, the purpose of which is to conduct a detailed *situation analysis* of children with disabilities in South Africa. The study is undertaken using a human rights-based approach, providing an understanding of the current status of children with disabilities in the country and improving national knowledge gaps. The report will be used to strengthen advocacy for a more effective programme response to the situation of children with disabilities in the country. It will also contribute to implementation of the Strategy for the Integration of Services to Children with Disabilities by addressing the problem of coherent data and information available for effective planning and implementation.

In addition to review of existing research, international obligations of the state and current policy and legislation, this study contains a qualitative element: it provides for two focus groups (one urban and one rural) to be conducted with children with disabilities as well as one focus group with parents or caregivers. The purpose of the focus groups is to *document the experiences of children with disabilities and caregivers with regard to service delivery, as well as stigma and discrimination that they encounter in their everyday lives.*

2. How this information was collected

In order to hear about the experiences and opinions of children with disabilities, two focus group discussions were held. The first was organized through the community based rehabilitation facilitator at KwaZamokuhle Special School near Estcourt, and it was with children living in rural areas of the KwaZulu Natal midlands. Of the eleven children who participated in the group, five are attending a special school, five are at a mainstream school and one is not at school.

The second group was organized through the Disabled Children's Action Group (DICAG), together with the Deaf Federation of South Africa (Gauteng Branch) and was held with children living in urban areas of Gauteng. There were nine children in the group – two of whom attend care centres, four are at special schools and three are in mainstream schools.

The same format was used for each of the groups:

- We began by introducing each other, saying what we like and what we don't like.
- The children were then asked to work individually and either draw or use modeling clay to show what activities they had been involved in on the previous day. This led to a discussion about how they spend their time during the week and over weekends. *These are the pictures which are used in this report.*
- Then the children worked as a group, using scrap materials to make a 'model' of resources within their community. Once this was complete, they spoke about how easy (or difficult) it is to make use of resources such as schools, clinics and water tanks.
- In the last activity, a bag of marshmallows and stones was passed around the group. Each child was asked to choose one or the other – a marshmallow to indicate something sweet or nice in their lives, or a stone to represent something which is difficult or hard. The children also had an opportunity to make suggestions or recommendations for things that would make a difference in their lives.

The group discussion with caregivers was organized through the Community-based Rehabilitation Education and Training for Empowerment (CREATE). It was held in Impendle, a rural area of KwaZulu Natal. The caregivers were each given an opportunity to tell other group members about their child. Thereafter they spoke about the roles that they play with respect to their child, the support that they receive in fulfilling these roles, and the difficulties and challenges that they experience. They also had an opportunity to make recommendations regarding improving the lives of children with disabilities.

3. Findings

3.1 What rural children said

Likes and dislikes

Children said they *like* sports and playing. Some specific games were mentioned such as hide and seek.

Some of the things they *don't like* relate to how they are treated.

- Children don't like being teased about their disabilities
- A child in a wheelchair said she didn't like being pushed in her wheelchair without being asked.

One girl said she didn't like people smoking and drinking.

Activities

The children drew pictures of what they did the previous day; this was used for a general discussion on how they spend their time.

Several of the children are in the hostel at the special school. All of them spoke about relaxing after school, but also helping out with chores at the hostel and/or at home:

When I came back from school yesterday, N and I went to the dining hall to watch TV. We then went to study and after that, we played outside.

Yesterday I swept the veranda at the dormitory, watched TV, and then went to sleep.

After school I went home, washed my clothes, ate, and then went to study. After that I went to bed.

I came back from school; washed my socks... ate and then went to bed.

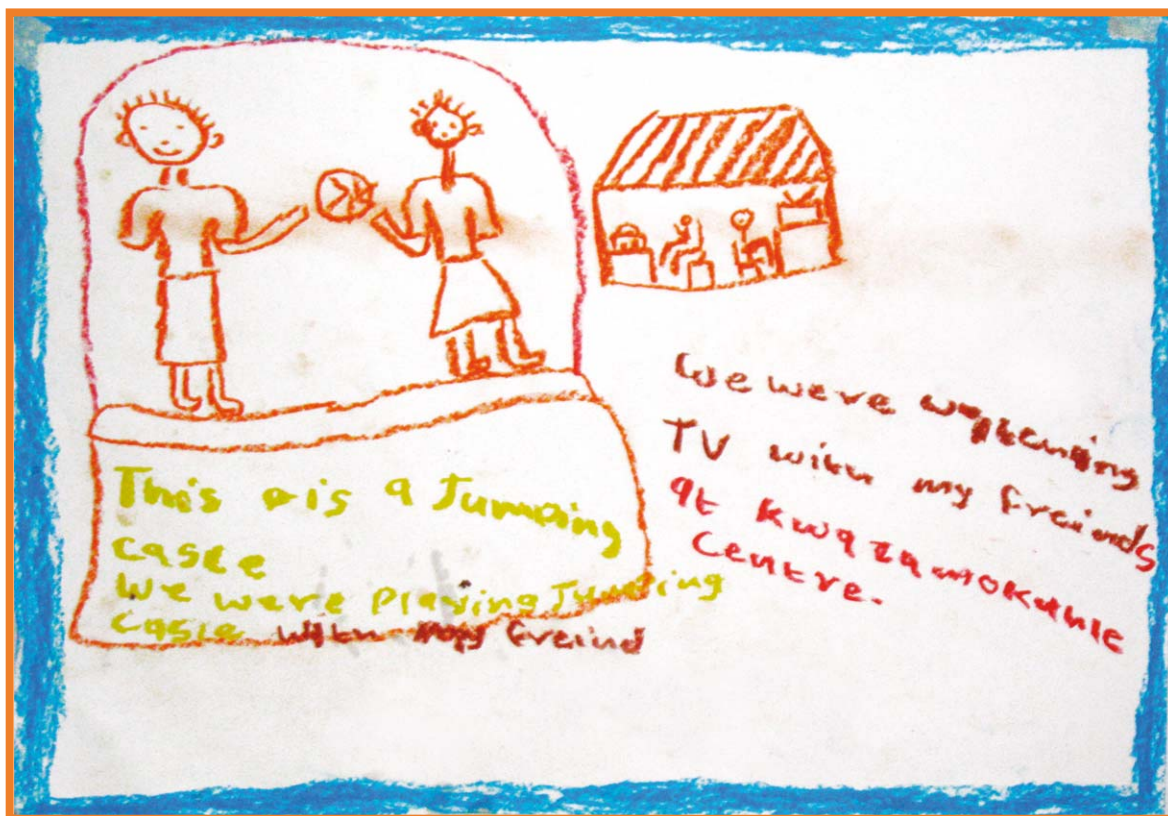
I came back from school and washed the dishes.

I watched DVDs then went outside to water the garden.

I clean, wash pots and cook when it's my turn.



Activities at home – rural child, age 13



Activities at the hostel – rural child, age 16

Most of the children referred to interaction with others during the afternoons after school:

I spent the day playing with my friend Z, and we went to the jumping castle. We made some drawings and then watched TV.

Yesterday I came back from school and did all my house chores. Then my friend came to visit. We played cards and soccer.

I came back from school and washed my clothes, cooked and went outside to play soccer. I came back...and then went to bed.

I went to school, came back, and then went to play basket ball. I showered after that and went to watch TV.

I wash the dishes and then play.

I cook and clean, sweep the yard and then go visit my friends.

How do the children perceive their responsibilities?

Facilitator: *Some of you come home and do things like washing the dishes. Why is it that some of you come home and play and not you do any house chores?*

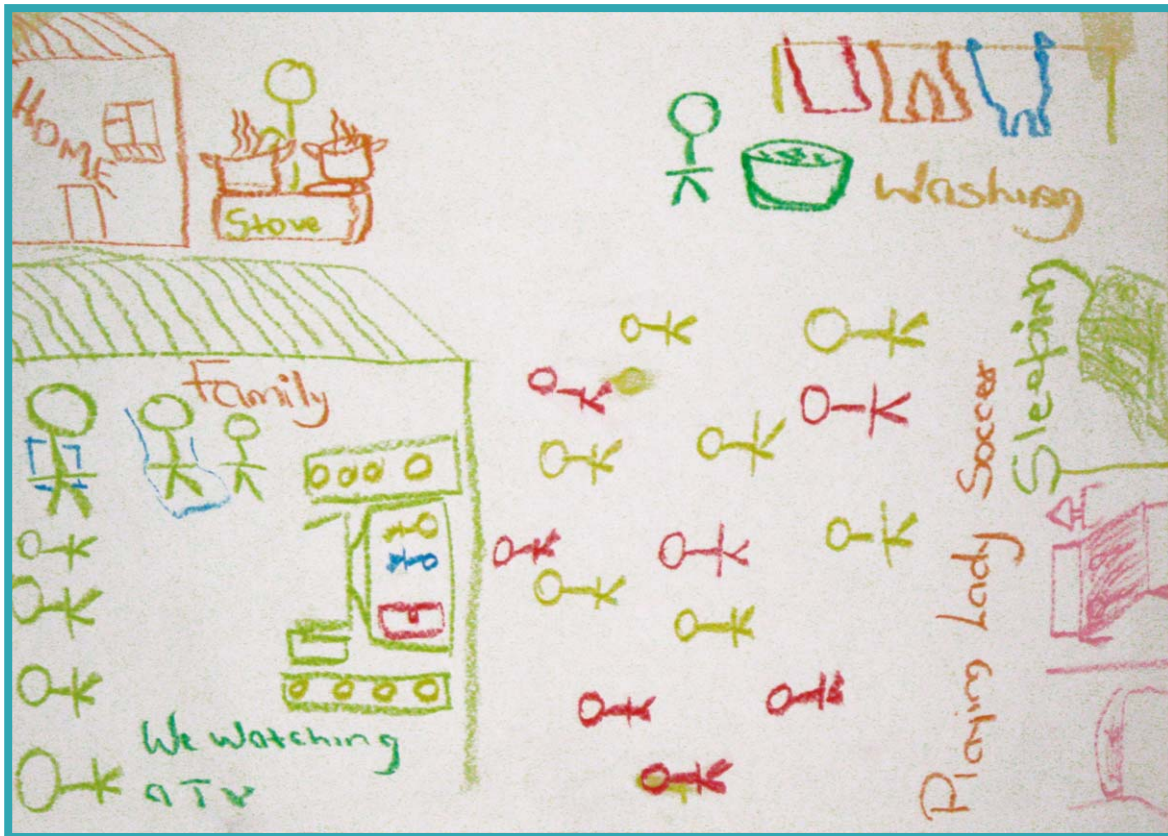
Child 1: *It's because we have people who help out and do all those things at home.*

Child 2: I have a sister who is in grade 3. She does the dishes and I clean and fetch water.

Facilitator: Aren't you bothered by the fact that you have a disability and yet you have to fetch water?

Child 2: No, I'm used to it. I don't think they are giving me too much work.

It takes this boy about 25 minutes to fetch water in a wheelbarrow for his family every day.



Activities at home – rural child, age 16

Within the hostel, responsibilities are shared, with children helping out as they are able. For example a girl with a right-sided hemiplegia is unable to help with cooking or chopping vegetables, but she is able to sweep the dormitory.

The children discussed going to different social events – playing with other children as well as going to parties, weddings and to church.

Child: I don't go to parties.

Facilitator: Why not?

Child: I don't want to.

Facilitator: Why is that? Everyone likes to go to places where there's fun and people. There must be something that makes you not want to go.

Child: It's because of people who drink alcohol.

Facilitator: Aside from those who drink, you know not everyone drinks at parties, is there anything else that makes you not want to go? Let me put it this way; if there are events concerning the community, like certain politicians coming, do you not go? No? Why is that?

Child: Because of people.

Facilitator: What about the people? What will they do?

Child: I'm afraid they will look and laugh at me.

The facilitator asked the children how they feel about attending church:

Child 1: I feel happy when I'm in church.

Facilitator: What makes you feel happy in church?

Child 1: Everyone doesn't look at me funny.

Facilitator: You said you enjoy being in church. Do you experience any problems getting in there, any difficulties?

Child 2: No, I use crutches.

Child 3: There are no steps in our church, so I don't have a problem going in.

Resources in the community

The children worked together, using scrap materials to build a "model" of services in their community.

The children named different resources as being of value to them – a community hall, shop, clinic, taps (water tanks), gardens, and a school. The facilitator asked if they were able to use them:

Facilitator: Are you able to use them; are they easily accessible to you? Do you have to send someone to access them for you? Can you get to them yourself?

Child 1: Yes and no.

Facilitator: Which can you not access properly?

Child 1: The school, because there are steps.

Child 2: It's also too far and it's difficult to get there.

One child in the group related that she has to hire a car to get to school. Sometimes the car comes so late, that she has to start walking to school and it picks her up along the way, or else her teachers give her a lift.

The children also indicated that they have difficulty fetching water because the water tanks are far from their homes and it is difficult to get to them. Gravel roads are particularly difficult for wheelchairs to move on.

One child reported that the clinic in her community has steps that she can't climb and therefore she needs to have someone help her get up them. Another indicated that she had difficulties getting access to the clinic, because it is far away from the public transport system. Particularly when it is muddy, she finds it difficult to get from the taxi stop to the clinic. One of the girls in the group related how she waited a long time at the clinic without getting help. She was unable to say if this was due to the busyness of the nurses, or because they were purposely ignoring her as a disabled child.

Generally, long distances to community resources in rural areas creates barriers to access for the disabled children.

Challenges and supports

A bag containing marshmallows and stones was passed around the group; the children were asked to choose one or other and say what was difficult/hard or what was good in their lives.

The children started by identifying things that are positive in their lives. These included getting a social security [disability] grant.

Child 1: The good thing that happened was that the road was rough and they put tar on the road.

Child 2: I would thank God for the fact that my community doesn't discriminate against me.

Child 3: The fact that I managed to get into school.

Child 4: The good thing that happened to me is that I have a family. Both my parents don't work, yet my mother is still able to get money by selling on pensioner's pay day.

Child 5: My family loves me and people don't discriminate against me.

Child 6: I'm happy that no one looks down on me and no one looks at me differently and that I'm in a school where I can play like other kids...

Difficulties included the challenge of covering long distances when the child has a physical disability and tires easily. For a number of the children, this was the reason that they could not attend schools in their local areas

The school was too far and it was difficult to walk all the way there.

One of the girls reported that she is not able to use public transport and cannot go to town on her own.

I'd like to have a person who will help me so that people won't push me around They should talk to the drivers and tell them to wait for us to cross and not hit us...

One of the other difficulties named by the children was the delay in finding a suitable school:

Child: I couldn't find a school for a long time because schools in my community couldn't accommodate me.

Facilitator: How long were you out of school?

Child: 6 years

One child in the group was in hospital for long periods of time and only started school at the age of 9 and another started at the age of 15.

The issue of inaccessibility was also named as a challenge:

Child: When I'm sick I can't get into the clinic because of the steps and need someone to lift me up.



Activities at home – rural child, age 17

There was discussion about attitudes of community members towards the children and one of the boys related his experience:

Child: This granny used to call me 'stshikwane' [someone whose body is crooked]

Facilitator: How did that make you feel?

Child: It would upset me.

Facilitator: Did she stop or is she still doing it?

Child: She stopped

Facilitator: What made her stop?

Child: My uncles warned her to stop.

Recommendations

The following recommendations were made by the children

- The gravel roads should be tarred
- Children with disabilities should be able to attend schools which are closer to their homes
- Transport should be provided to assist disabled children to get to school
- Taxi drivers need to be more sensitive to needs of disabled people
- Clinics must be accessible, especially for wheelchair-users
- There should be community awareness programmes so that people do not tease or call disabled children derogatory names.

3.2 What urban children said

Likes and dislikes

The likes of the children from urban areas around Gauteng included many things that one would expect from teenagers – sports, socializing, watching TV and DVDs. *Generations* is a favourite programme!

I like sports, cooking and to socialise.

*At school I participate in drama ...
I like to be around deaf people.*

I like to communicate in a friendly way with people and not to argue or fight.

Their dislikes (mostly) focused on issues relating to relationships with people:

I don't like people when they think that I can't do certain things, 'cause I'm disabled.

I don't like people to look at me and feel pity because I was created like this.

I don't like fights and gossips.

A child with a physical disability said that she didn't like walking long distances.

I don't want to walk for long, going anywhere...

Activities

The children said that they spend time visiting friends and socializing; watching TV and going to school. There were two Deaf girls in the group, and both had positive experiences of mainstream schooling:

My school is a mainstream school, I enjoy being there, we learn different things from other cultures. I have some friends who are physically disabled and those with hearing, we teach each other things. I help where I can. There are no problems. Our teacher is hearing, and the assistant teacher helps us. The principal is hearing but she can sign. [This refers to being able to use Sign Language]



Children draw pictures of what they did the previous day

Around my home there are other people who are Deaf and I go and socialize with them after school. I travel to school with the school transport, I am happy that at home they can sign, we can communicate with each other.

However, another child had recently started attending a special school [having been at a mainstream school] and related his experiences:

Child: We used to learn at school. Now we are not learning anymore. I do not know why. It's a special school for children who are using wheelchairs.

Facilitator: Are there teachers there?

Child: Yes, [but] we just sit....we get bored

Facilitator: Do you have grades?

Child: No. [There are] no grades

Most of the children indicated that they socialize with other children (both able-bodied and disabled) through sports and other activities. [Note that in comparison with children from rural areas, little was said about time spent doing chores – only one child referred to helping with the cooking]. However, for the Deaf children, communication at home is not always easy:

At home I haven't got anyone who can sign. So there is ... a communication barrier at home.

Resources in the community

The children worked together, using scrap materials to build a "model" of services in their community.

(a) School

All of the children attend either a care centre, mainstream school or special school. The main focus of the "modeling" activity was the school. In fact, on the model there were two schools constructed – one by the two Deaf girls and one by three of the other children who were working together.

The schools were described in detail, especially the one made by the Deaf girls. It had a swimming pool – they even made miniature people swimming! It also had its own clinic, with a doctor and school nurse.

(b) Health services

When probed, the children indicated that clinics and hospitals are not easily accessible, they need taxis to get to them. Communication for Deaf people is difficult in public health facilities – they need to communicate using writing. This is because there are no sign language interpreters available.



"This is a road I walk on with my friends. It has flowers next to it." – urban child, age 15

(c) Religious life

The children indicated that they are able to attend different religious ceremonies, and it was clear that this was significant to them, giving them a strong sense of value and purpose for their lives. One of the Deaf girls is accompanied to church by her mother, who signs for her.

(d) Commercial activity

Most of the children indicated that things are "fine" when they go into town, but one girl with a physical disability (she has muscle wasting on one leg) said:

I get tired easily and the more I say I am tired, people say they also have been there [in the queue] for a long time in the meantime the taxi is filling up, and the people are pushing. Other people do not feel for you. They do not care. People are just pushing. They do not care about you. Some people do not care about you.

(e) Transport

In terms of using public transport, most of the comments were positive. One of the participants who is a wheelchair-user indicated that she usually travels by train.

I wait at a place where the train driver will see me and see the wheelchair, not in the crowd.

There was no police station or social worker office on the model made by the children. When asked about this, they said they had never been to a police station.

During the discussion, the children acknowledged that disability can be caused by violence, and one boy described how a friend of his was injured during a shootout by gangsters in his community. He is now paraplegic. Asked whether in their experience adults and children with disabilities are targeted for attack the response was:

No. There is that sympathy. They don't usually [attack].

Challenges and supports

A bag of marshmallows and stones was passed around the group; the children were asked to choose one or other and say what was difficult/hard or what was good in their lives.

(a) Challenges

In comparison with the group of rural children, most of the urban children cited difficulties. They all relate to the way that they are treated as children with disabilities:

I take a stone, because disability is hard; people laugh at me. It is hard to be a disabled person. People talk badly about me.

I have a stone, because when I go outside to other people, who do not know me, you find that they look at you pointing at you, talking about you. This pains me.

I have chosen a stone because I struggle in my daily life; people tease me and call me names because I can't hear. They laugh at me and it hurts a lot.

One participant reported physical abuse at home:

At home, they always want to send me to the shop. When I do not want to go, they beat me. I did tell my sister about this, but I am scared to talk about it because they will beat me.

[This is being followed up by the organization that she is involved with].

(b) Supports

Children spoke about things that give them strength in their lives. One is a deep spirituality – having a sense of meaning and purpose in their disability:

I picked out a sweet because I understand that I am disabled. I was created by God to be like this.

I am satisfied with the way I am, whatever the next person thinks of me. It's OK. God created me like this. So whatever they say it does not concern me much.

The support of family members is also very important:

Whenever I ask my mom for anything, she just gives it to me.

My mother [helps me] – whenever I feel down and sad, she says sharp! It's alright! Mother comes back [from work] and I am happy ...she brings me sweets.

Several of the children spoke about the importance of finding avenues through which they can achieve such as academics and sports, and key to this is their own self-confidence and appreciation of what they have:

I picked out a marshmallow because, although many children go hungry, I am so fortunate unlike other children. Some people laugh at me because I am short and they come to me at the mall, wanting to have my photo with their young children to show how small I am. But I don't show people that I am upset ...

Recommendations

The children made the following recommendations

- There need to be adaptations to the physical environment e.g. separate express check-out points for disabled people (not just for wheelchairs, but for people with different disabilities who might tire easily and are not able to wait in long queues)
- Resources such as libraries, clinics and hospitals should be closer to communities so that disabled children can use them more easily
- Disabled children need to have accessible transport to school.

3.3 What caregivers said

Role of caregivers

The focus group began with each caregiver telling other participants about their disabled family member. Those that they care for have many different types of disabilities; these include physical, intellectual and communication (speech and hearing) disabilities.

Z. is okay mentally, but she can't walk and she can't talk properly. You have to listen to her carefully to understand her. But she can hear everything you say and she can crawl around.

My child is physically disabled. He can't talk and can't sit up.

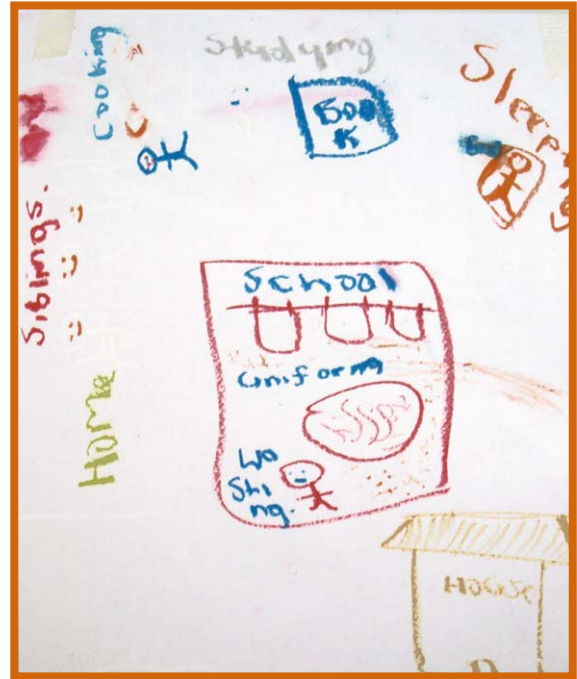


Activities at home – rural child, age 14

B. is physically disabled. She can't walk. Most of the time she can only sit on one side. She has a wheelchair but we normally [only] use it when she is going somewhere. At home she sits on the floor. She crawls to the toilet.

Although caregivers were aware of their child's limitations, they tended to focus on their abilities:

D. can't talk. He can do other things, there's little he can't for himself! My family loves him. We're comfortable. I'm the one who looks after him. He doesn't have a big problem, really. He doesn't have enough strength to work, though. He gets tired very easily. His brain is a little bit slow, but his main problem is that he can't speak. He can do many things.



Helping with chores at home – rural child, age 14

An instance was cited of a caregiver teaching her child mobility:

N. is my daughter's child... She could stand after she turned 6 years old. She learnt to stand but couldn't move her leg. Her one side can't function properly. You tell her to stand, she will stand, but tell her to walk; she moves only one leg the other side can't move.... I gave her a stick and taught her to move around with it. She walked around like a granny. She dragged her right leg. She finally stopped using the stick and started to hop around very slowly. She got used to it though.

The caregivers described a number of different roles that they play in relation to their children:

(a) Tracking developmental milestones

The caregivers play an important role in watching the development of the disabled child on a day-to-day level, and noticing when he or she does not develop at the same rate as other children of the same age.

Facilitator: How old was he when you started looking for a school for him?

Caregiver: He was 4. The fact that he couldn't talk at that age scared me. He was supposed to be speaking at that age. I took him to the social workers, who said they know a school for the deaf and the speech impaired. [But] they said if I take him there, it might do more damage, I should just wait. They said I

should keep taking him to the doctors. Even now, he talks very little. You can barely understand what he says. He can answer the phone and tell me who called but he speaks very slowly. His brain is slow, so it affects his speech.

(b) Provision of care

Participants described the tasks that are required of them in caring for the children on a daily basis:

Caregiver 1: I do treat him differently because he can't speak. He can't wash his clothes or bath himself. I do all of that. The others can't do this for him, they shout at him. He then gets angry and they fight. What he can do is fetch water. He does that by himself and he enjoys it.

Facilitator: Do you do all this for him because he can't do for himself, or do you feel you have to do it because he's disabled? Do you teach him to do it like you do the others?

Caregiver 1: I do teach him but he just can't do it. I don't do it because of his disability. I pour water for him to wash up, but he doesn't do it properly. So I have to wash him again and he gets angry. You have to promise him something before he calms down. He can sweep and wash some of his stuff.

Caregiver 2: I bathe her, feed her, and wash her clothes. You can see when she's tired of sleeping, so I then put her on her wheelchair. Normally after bathing her, I do some physical exercises with her. She is able to indicate what she doesn't like; she can hear. We tried to give her what she needs and what she likes, most especially since she receives a [care dependency] grant. We use it for her needs.

Some children require purchase and preparation of food that is easy to chew and swallow:

B [who is 7] ... only eats soft food. He can't swallow. He uses his tongue to push food that doesn't go down by itself.

(c) Teaching independence

Caregivers also described the emphasis they place on teaching their child to be independent:

I teach her how to wash herself, comb her etc.

I show her what to do and how to do it. But she's short tempered, she can even hit you.

Yes she is very slow but I teach her how to get water and wash herself. She likes doing the washing. I also teach her how to cook. She knows how to do house chores like washing dishes and sweeping etc.

We get along very well with Z, but she's also very short tempered. When I realized that she is growing up, I decided to teach her how to do house chores. She likes looking after herself. She's good at doing the washing.



Activities at home – urban child, age 15

Some caregivers reported acceptance of the disabled children within the family, but there was an instance cited revealing that the demands of care requirements of a disabled child can result in strained family relationships:

B. is very short tempered. She can't bathe herself. You have to get everything ready for her. She can't do things for herself, she often needs help. Because she's a person with a short temper, my kids complain about her and don't want to help her out.

Overall, caregivers reported that the attitudes of community members towards their children is positive:

Facilitator: Do you receive support from the community?

Caregiver: Yes, they love them very much. They are always happy to see them [disabled children].

Experiences of services

a) Health

Throughout the discussions it was evident that the health sector has a major role in terms of children with disabilities. Unfortunately, many of these were experienced by caregivers as being negative. Experiences of health services by caregivers have been grouped under key themes:

► *False reassurances and lack of information*

The doctor discharged us the next day [after the baby was born] and said there was nothing wrong with him. When we got home, I realized that he wasn't well. We took him to traditional healers. I also took him to the doctor but he said he was fine. So I kept taking him to the doctor every now and then. He appeared to be okay but I wasn't satisfied with his health. He couldn't sit on his own. He took a while to crawl and I took him to the doctor but he said there's nothing wrong with. When he finally started to crawl, he did so for a little while, then stood and walked. When I was looking for a school for him, I talked to social workers in Ashdown. He was slow mentally.

My granddaughter doesn't talk, she was born that way ... We took her to the doctor, who said she's going to be fine, that there was no sign of a disability and she will eventually talk, which she never did.

Facilitator: *Has her mother ever mentioned why she turned out this way?*

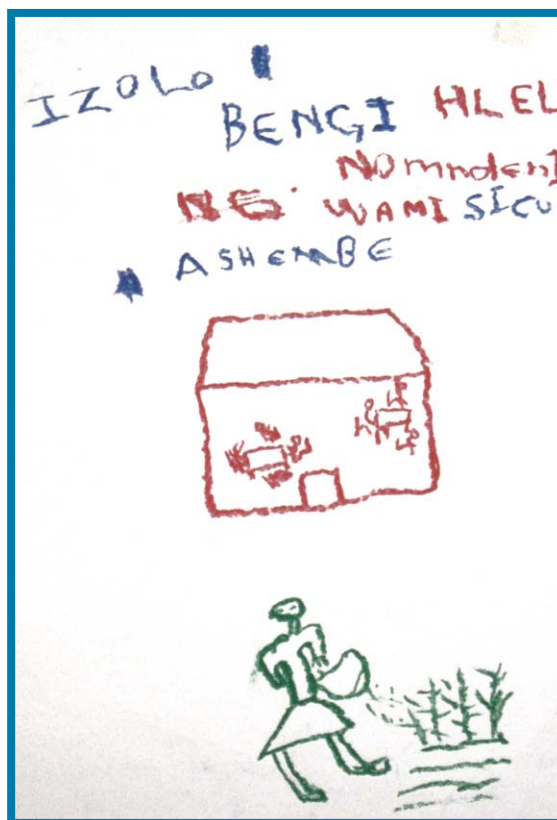
Caregiver: *No, she never mentioned anything. I never asked her. What she did say though, was that a doctor once said the problem was with her teeth.*

Facilitator: *What does her disability have to do with her teeth?*

Caregiver: *I don't know. But when you look at her molars, you notice that they are abnormal and unusual.*

False reassurances result in caregivers losing faith in the health system and also means that the children concerned do not get the necessary early intervention. The following account illustrates the long-term damage that this can cause:

I fell pregnant with Z and gave birth in Edendale [Hospital]. They said she doesn't have much strength. After that she couldn't sit when she tried to. When I tried to support her, she would just fall. For years she couldn't sit For about two years. She would just fall over when I tried to support her with a blanket. I took her to Edendale hospital and they said she will walk. I took her to doctors and they said she will walk. When she tried walking, she had already developed contractures She tried walking with her toes. I tried sending her to the hospital, hoping they would help, but her right side wasn't working. She sits leaning toward the right side, even when she sleeps. She has a wheelchair but can't use it. When her right hand



Watering the garden at home – rural child, age 15

contracts she tries to 'untie' or straighten it with her other hand. Even her legs have gone small.

► *Allegations of malpractice*

One caregiver blames the health system for her child's disability because he was delivered by forceps. Lack of explanation and support has resulted in bitterness and anger towards staff at a provincial hospital:

I was very ill when I was pregnant ... I had terrible headaches. On the ninth month, I went into labor for about three days. I went to the hospital when my water had broken ... When I got to Edendale hospital, they didn't pay much attention to me ... it took a while for them to deliver the baby ... When I got there, they took me to the labor ward and laid me down and I stayed there a while. It was a weekend and there weren't that many doctors. I sat there till evening. Doctors would come in to check on me, saying the baby is still too far.

I fell asleep and woke up when the doctor came in. He said they were going to perform caesarian section, only to find that the baby was already showing, all I had to do was push I could feel it but they had injected me twice. They took the baby out with forceps. When they did that, they must have mishandled the baby's head, because the baby was hurt. By the time they took him out, he was blue. They washed him, but he didn't even cry or move. He was in hospital for three months, didn't cry, or move, he just lay there. They asked me if I wanted to keep him on life support. They said the machine is doing the breathing, there's no life. They took him off life support. He got better, [but] he was still in a coma and kept having seizures. He came out of the coma, but wore an oxygen mask. [When] they discharged me, they knew it was their fault, so they didn't tell me what was wrong with my baby.

After being home, I went back and forth to clinics. The baby was so sick...

I went to clinics and hospitals but they never told me [the diagnosis]. They only told me after 11 months that he won't be able to do anything ... He also had pneumonia. He would stay in hospital for months; he's still very weak and frail. He can't sit or do anything, he just sleeps [stays lying]. But he turns when I speak and he makes small noises. He doesn't gain any weight though ...

► *Need for assistive devices*

Many of the caregivers cited the need for assistive devices, but found it difficult to access them:

I wish he'd get some things that will help him sit up, like a buggy for example. I try to support him when he sits.

I was wondering if she could get something to cover her knees because she gets blisters and they catch dirt. We can't put her on the wheelchair because she can only sit there for a while. She doesn't like it because she normally sits on her side. She crawls without anything covering her knees.

She uses a wheelchair but it's bigger than her. Before she had one, I used to carry her on my back. Someone gave me a wheelchair but she can't push it on her own. When she tries, she just falls to the ground.

When I tried to support her, she would fall over. They put calipers on her legs. When they took them off and gave her crutches, her legs became spastic. They put them on and took them off a number of times. They realized that they were hurting her and she ended up not wanting to put them on. They took her to Hlengabantu hospital where she stayed for a while. Her grandma took her out of the hospital because it was no use. She also sleeps on one side. Her right side doesn't function properly. She eats with her left hand while lying on her stomach and leaning on her right elbow. She sometimes sleeps on her back with her legs drawn up. She can't stretch them. She can speak but can't do a lot of things herself. We don't use a wheelchair unless we have to go somewhere. She can't even push it herself. She also can't get onto the wheelchair by herself. You have to pick her up. She's never walked in her life.

► Information

Some caregivers reported that they had received some advice from therapists at the provincial hospital, but it was not always felt to be useful or appropriate:

Facilitator: After being discharged from the hospital, even when you went to hospitals and clinics, were you ever taught how to feed him, how to position him and how to help him swallow?

Caregiver: I know how to do it. They taught me but their way doesn't work. The food doesn't go down.

► Attitudes of health personnel

When asked about the attitude of clinic and hospital staff, most of the caregivers were positive. However, the following negative experience was cited:

Caregiver: I tried to get a buggy for him at Edendale, but they said it's not suitable for people who use public transport.

Facilitator: They didn't give you because of that?

Caregiver: Yes, but they made me fill in some form. It depends on who you find there. If you don't get along with the nurse that's in that day, then you won't get any help.

Facilitator: So you ended up not getting the buggy?

Caregiver: Yes. They said it's not suitable for taxis.

Facilitator: So you're not happy with the way they treat you?

Caregiver: Yes. They refused to give me food parcels they were giving me before because I refused to put something on the baby that they suggested. I refused because it wasn't helpful to me. But now, they are using it against me.

Although the caregivers acknowledged that they have had some contact with community workers, it was evident that their input was not seen to be beneficial to children with disabilities or to take cognizance of their everyday situation:

Caregiver: They only come when they want to announce something that's taking place in the community. They never come to check on how the kids live.



"I played on my computer" – urban child, age 18

b) Education

The caregivers saw great benefit of their disabled children having access to education, but many of them had not been able to do so. For example, one caregiver attributed her daughter's knowledge of sexuality to the input that she had had at school:

Yes, she knows how to look after herself during her periods. She knows what's going on. She said her teacher taught them at school. She knows that she has to use pads during her period.

However, while the caregivers long for their disabled children to be in school, many of them have not been able to access education.

Facilitator: Has anyone ever tried to find her a school?

Caregiver: No, I don't think so. There are people who came around taking names of children. Saying they are going to build a special school, so we wrote her name down.

Facilitator: But it never happened?

Caregiver: No, nothing was continued.

Some caregivers indicated that they had tried to enroll their children in local schools, but they soon dropped out:

Caregiver: M doesn't go to school. He tried but it didn't work out.

Facilitator: What is M's disability?

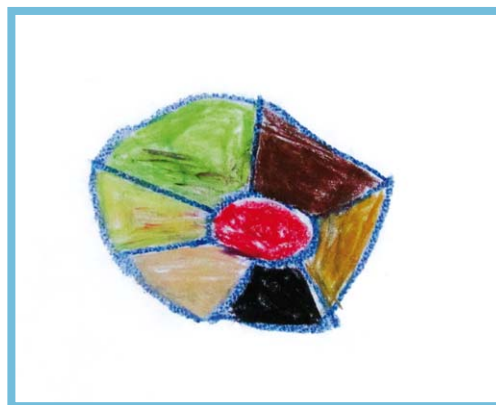
Caregiver: He is mentally disabled. He can see and speak.

Facilitator: Can he walk and hear?

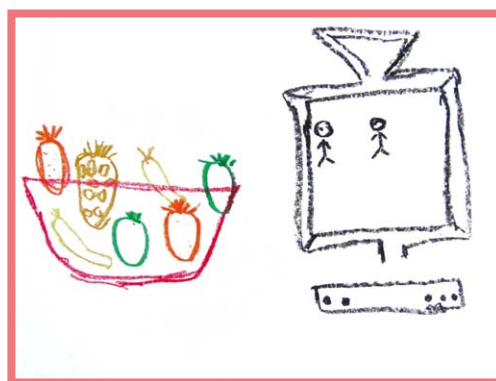
Caregiver: Yes, but he's very stubborn. He doesn't listen. He does what you tell him not to do. He likes wandering off too much. I sometimes get worried, thinking someone had killed him and then he shows up out of nowhere. He tried going to school but he struggled to learn.

Even where caregivers did find suitable placement, problems were experienced. Of the eleven caregivers in the group, only one was able to report that the child is currently at school:

My granddaughter doesn't talk... We took her to the doctor, who said she's going to be fine, that there was no sign of a disability and she will eventually talk, which she never did. We took her to a school in Bulwer ... where she went for two years. But it was closed down because of mishandlings of the kids. About two or three kids died and she would have died had we not taken her out. We took her back [home] and stayed with her. There was a man called V. who opened a school for children with disabilities and they were treated well there. But it was later realized that it's not safe, it's next to the road, and thieves could come in at any time because there were no police around. The school was also not registered. So they relocated to town and they stayed there. But V. didn't have the money to pay them, so the workers' left. They hired people nearby but they weren't as good as the previous workers. They didn't treat the kids well. One of the children who could talk said they were given one slice of bread the whole day. So we took the kids back [home].



"A beautiful flower we have at home."
– urban child, age 18



"I enjoy watching TV." – urban child, age 16

It must be acknowledged that the 'school' referred to above is run by an NGO and could more appropriately be referred to as a 'care centre'. However, it raises a concern regarding the regulation and sustainability of such centres in terms of children with disabilities.

Even with regard to accessing a special school within the same municipality, barriers were encountered:

N. can walk; it's just that he can't speak. He's 15. I noticed when he was younger that he can't speak. So I took him to a doctor in Edendale. They made him practice speech. He can hear properly. They organized a care dependency grant for him. There was a social worker called Z. who helped me find a school; it is called Ekukhanyeni. I went there to fill in some forms and they said they will take him at the age of 14 only if he can wash his socks and bathe himself. That was my problem. I never saw Z. again ... so he doesn't go to school, he's at home. If you give him a piece of paper to go to the shop, he comes back with that stuff. He points at what he wants and doesn't want.

c) Social development

Caregivers acknowledged that social security is a great support to them.

Caregiver: The social [care dependency] grant.... It's not much, but it helps.

Facilitator: Do you have problems accessing the social grant?

Caregiver: No, it's the schools that are a problem.

Recommendations

The recommendations made by caregivers were:

- Children with disabilities should be able to attend schools which are close to where their families live
- Children with disabilities need to be included in programmes targeting other vulnerable children
- Caregivers and disabled young people should be included in local skills development and economic activities
- There need to be improved outreach services that support disabled children in their homes
- Disabled children should have positive opportunities and exposure to new experiences (such as visits to the beach).



Caregivers who participated in the focus group discussion

4. Summary and conclusion

Both the groups of children – rural and urban – expressed their enjoyment of sports and of playing and socializing with other children. The urban group spoke more about watching TV and DVDs – with one boy who said he spent most of a recent public holiday on his computer! However, the things that they don't like relate to *the way that they are treated and the attitudes of people towards them*, as children with disabilities. In particular, children with disabilities don't like being teased, being judged about their (in)abilities or other people making decisions about them. The prejudicial attitudes of people towards them were identified as being amongst the hardest things that the children face in their lives, and they expressed some of the deep pain that they feel in response.

In the context of such hostile and discriminatory attitudes, it was evident that some of the children derive great comfort and solace from their religious beliefs. This was about finding a reason for their disability, and a purpose for their lives as young people with disability. It also helped to build a sense of self-acceptance, as expressed by one of the children: "I am satisfied with the way I am... God created me like this." Although religious buildings and events are not always easy to access, a number of the children indicated that they draw strength and encouragement from their participation as part of these communities.

The children from rural areas spoke a lot about the chores that they do at home and at the school hostel, and many of the illustrations included in this report show their involvement in household activities. When asked about what they like, some of this group of children expressed their appreciation of the fact that they are not discriminated against within their community. One boy who was called a derogatory name by a granny, reported that an uncle had challenged her not to use such terms. The accounts by these children (of some extent) of social inclusion in the rural areas nearby KwaZamokuhle Special School, may be explained by a number of factors.

- ▶ Firstly, the school is based on an Evangelical Lutheran Church Farm (Ephangweni) where the Swedish Mission founded the KwaZamokuhle Centre in 1965. This centre has provided opportunities for children with disabilities in many different ways. The boarding accommodation opened in 1984 for physically disabled children to be able to go to local mainstream primary and secondary schools; and the KwaZamokuhle Special School was established in 1990. Through this work, people in the area have become familiar with disability and have been able to see and experience integration.
- ▶ As part of the rollout of inclusive education in KwaZulu Natal, the KwaZamokuhle Special School was designated a "resource centre" and has received support from the Dept of Education in the form of educator and support staff training. There have also been disability awareness programmes run for parents and community members.
- ▶ In addition, the outreach work conducted through the community-based rehabilitation (CBR) programme of the school is likely to have contributed to increased awareness of disability within the community.

- Finally, the relationship between this special school and a local mainstream high school, has helped to ensure that learners with disabilities have the opportunity to continue with their education up to high school level.

Most of the children expressed appreciation for their schools. Only one child (who has recently moved to a special school) felt that he was not benefiting from his school. However, it was clear that accessing an appropriate learning environment is fraught with many difficulties. These include the fact that most local schools are not accessible for children with physical disabilities, and do not cater for those with intellectual and hearing disabilities; there are transport difficulties in getting to school; and some children with disabilities only enter school long past the age of most other children.

The caregivers also related the difficulties in accessing schooling for their children. Special schools are in the nearest city (about 100km away), but even then the children have to comply with certain criteria and levels of independence before they are accepted. Many of the caregivers reported that after unsuccessfully pursuing a long search for a suitable school – special school or privately run day care centre – they simply give up and keep their children at home.

Apart from those provided at school, health services are difficult for children with disabilities to access – both in terms of information, distance and physical access. Caregivers in particular, struggle with health services because of mis-information and attitudes of health workers. As a result they are not able to benefit from appropriate assistive devices, or rehabilitation programmes that are beneficial to their children.

Most of the children and caregivers who participated in the focus groups have been able to benefit from social security. Indeed, for many families, this is the only source of income in the household. (In the group of caregivers, a number of the families are receiving both Old Age Pensions and Care Dependency Grants or Disability Grants.)

The recommendations that the children and caregivers made relate to issues that most other people take for granted. Tar roads so that wheelchairs can travel freely. Local schools that cater for a diversity of needs, so that disabled children can live with their families while receiving the benefits of education. Transport that is user-friendly for all children. Clinics and hospitals that they can get into, with personnel who are respectful and supportive, and who have the necessary knowledge and information. The call of children with disabilities and of caregivers who participated in these focus groups is not so much for 'special services,' but to be respected, to be given opportunities to participate and learn, and to have use of facilities within their communities. It is a call to be valued and to belong.

5. Appendices

5.1 Ethical principles

The ethical principles considered in this participatory research with children were as follows:

- ▶ Informed consent i.e. children clearly understand what the study is all about and what is being asked of them
- ▶ They are assured of confidentiality
- ▶ There is respect for their opinions and opportunity given for their meaningful participation
- ▶ They are part of an ongoing support group, with people who can build on and/or respond to what emerges from the discussion
- ▶ There is facilitation of a positive process that recognizes and affirms the child's own coping strategies and strengths
- ▶ There is feedback about the outcomes and findings of the study in a way that is meaningful to the children involved.

5.2. Schedule

The schedule for focus group discussions with the children was as follows:

Activity	Procedure	Aims
Introduction	Children introduce themselves and name something that they like and don't like	• Enable children to get to know one another
Activity 1: My day	Children draw pictures of (or model with clay) what they did yesterday. This is used to as the basis to ask questions about what they do on other days e.g. weekends and holidays.	• Find out what children do & how they spend their time • Find out what services and facilities they have access to
Activity 2: My place	Children draw/make a "map" of their area, showing people that they interact with every day and services that they use.	• Find out the extent to which the children are integrated into their communities • Identify which services they use and the extent of accessibility
Activity 3: My strengths and needs	A packet of marshmallows and stones is passed around the group. Children talk about the good things in their lives (internal and external) – represented by the marshmallows. They also talk about the difficult things in their lives (internal and external), represented by the stones. There is discussion on how the difficulties could be addressed.	• Identify existing coping strategies of the children • Find out what services they think government could provide for them • Find out how they think these should be provided.

5.3 Participants of the different groups

(a) Rural children

Children from rural areas of KwaZulu-Natal midlands					
Area & description: This group was organized through the community based rehabilitation worker at Kwazamokuhle Special School. It comprised of some children from the school, some attending a nearby (mainstream) high school and one child who is currently not in school. The children come from surrounding rural areas – Loskop, Bergville, Bhekuzulu, Wembezi and Ntabamhlophe					
Gender and age	Disability	Attending school	Family make-up	Adults working	Social grants
Female 19	Physical & epilepsy	No	Mother and 4 brothers	None	Yes
Female 17	Physical	Mainstream	Grandmother and 2 siblings	None	Yes
Female 17	Physical	Special school	Father and 7 siblings	None	No
Female 14	Physical	Special school	Mother, grandmother and 4 siblings	None	Yes
Female 16	Physical	Mainstream	Grandmother, aunt and siblings	Yes	No
Male 15	Physical	Mainstream	Mother, father and 3 siblings	None	Yes
Female 14	Physical, (wheelchair user)	Special school	Grandmother, aunt and 3 siblings	Brother	Yes
Female 13	Physical	Mainstream	Mother, grandmother and 1 sibling	None	No
Female 16	Physical	Mainstream	Grandmother, uncle and 1 sibling	None	Yes
Female 17	Physical, (wheelchair user)	Special school	Father, mother and 4 siblings	Father	Yes
Female 14	Physical, (wheelchair user)	Special school	Aunt, uncle, grandmother and 3 siblings	None	Yes

(b) Urban children

Children from urban areas around Gauteng

Area & description:

This group was organized through a parent's organization (DICAG) and Deafsa. Children came from township areas around the Vaal – including Orange Farm, Sharpville, Tshepiso and Lakeside

Gender and age	Disability	Attending school	Family make-up	Adults working	Social grants
Female 18	Paraplegic (wheelchair user)	Care centre	Mother, father, 2 siblings	None	Yes
Female 17	Cerebral palsy (wheelchair user)	Special school	Grandmother, 3 siblings	Part-time (domestic worker)	Yes
Female 18	Down Syndrome	Special school	Mother, father, two siblings	2	Yes
Female 17	Tetraplegic (wheelchair user)	Special school	Mother, sister	None	Yes
Male 18	Osteogenesis imperfecta	Special school	Father, mother, sister	Father and mother	Yes
Female 16	Polio	Mainstream	Mother, father and 3 siblings	None	Yes
Female 15	Deaf	Mainstream	Mother, father and 2 siblings	Mother	Yes
Male 18	Paraplegic (wheelchair user)	Care centre	Mother and 2 siblings	None	Yes
Female 15	Deaf	Mainstream	Mother	None	Yes

(c) Caregivers

This group comprised of caregivers of children with disabilities from the rural area of Impendle. This group was organized through a community-based rehabilitation facilitator who is based at CREATE

Gender and age	Relationship to child	Disability of child	Attending school	Family make-up	Adults working	Social grants
Female 25	Mother	Cerebral palsy	No	Grandmother, mother, uncle, brother, sister	Yes	CDG & OAP
Female 65	Mother	Intellectual	No	Mother and brother	Yes	OAP & DG
Female 42	Aunt	Hemiplegia	No	Aunt and 4 children	No	CDG
Female 69	Mother	Intellectual	No	Father, mother, brother, sister	No	OAP (2) & DG
Female 58	Mother	Intellectual	No	Mother, brother and 3 children	No	OAP (2) & DG
Female 43	Mother	Speech	No	Mother, father, sister and brother	No	OAP & CDG
Female 53	Mother	Speech	No	Mother and brother	No	DG
Female 57	Grandmother	Physical and speech	No	Grandmother, mother, sister, brother, aunt and uncle	No	CDG & OAP
Female 17	Sister	Physical (wheelchair user)	No	Grandmother, mother, sister and brother	No	CDG & OAP
Female 48	Aunt	Physical	No	Grandmother, brother, aunt, grandchildren	No	DG, CSG, OAP
Female 69	Mother	Physical	No	Mother and brother	No	OAP & CDG
Female 56	Grandmother	Hemiplegia	Yes	Grandmother, grandfather and 2 children	No	CDG

This report reflects the voices of children with disabilities and their caregivers, and forms part of a more comprehensive situational analysis of children with disabilities in South Africa.

The situation analysis was undertaken by the Department of Social Development; Department of Women, Children and People with Disabilities; and UNICEF South Africa.