

RESEARCH REPORT

GENDER, SEXUALITY AND MASCULINITY

In the context of DISABILITY

SOUL BUDDYZ 3: 2003

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TERMINOLOGY:

DICAG
DPSA

Disabled Children Action Group
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1. BACKGROUND:

The barriers to the sexual expression of disabled people are primarily to do with the society in which we live, not the bodies with which we are endowed. (Shakespeare: 2000)

The birth of a disabled child, especially when the impairment is visible at birth, is a traumatic experience for any family. Issues of guilt, rejection, denial and anguish are emotions that the family has to deal with on a daily basis. These emotions and feelings are underpinned by the manner in which our cultural beliefs about health, sickness and impairments have been shaped over time.

These belief systems place an element of stress and anxiety on the family, which are then mirrored onto the child throughout the child's developmental years. The manner, in which the family respond to the impairment of the child, be it that the response to the child's impairment is positive or negative, also shapes the manner in which society respond to the impairment of the child. Ultimately this response from society will determine how the child views his or her own self worth, depending on how the child's self worth is reflected through the eyes of the parents or society.

Children with disabilities, throughout their development years, have to contend with stigma and prejudice, coupled with assumptions about their disability, which is derived from cultural belief systems.

These assumptions, coupled with isolation is often the cause that prevents disabled children from experiencing opportunities that would allow for the development of social skills and expression of their developing sexuality.

The manner in which the developing sexuality of children with disabilities is suppressed, places the child in a vulnerable state. It ultimately leads to the violation of their person, and has much to do with the manner in which the general society responds to their impairment. The South African society in particular views disabled people as a homogenous grouping of people. This implies that all disabled people, irrespective of their impairment and difference in relation to class, gender, race and culture are all the same, and all have the same needs and requirements. There is also the assumption by society that all disabled people are a-sexual.

Soul City, within their programme Soul Buddyz, is in the process of developing a new series that looks at issues of Gender, Sexuality and Masculinity. One of the important aspects in the development of this series, is

that Soul City wants to bring across to their readers and viewers information on the experiences of persons with disabilities, and in particular children with disabilities, within this context.

Soul City's interest in the experiences of disabled children within this context centres on the challenges that children with disabilities experience throughout their development years. Particular focus areas are the ones that deal with their developing sexuality, their experiences in forming relationships, and the manner in which they rise to the occasion to meet the challenges experienced.

In pursuing the answers to these questions, a total of four participatory workshops were held within the provinces of Western Cape, and Mpumalanga. The target groups included children with disabilities, parents of children with disabilities and disabled rehabilitation consultants.

This report provides the findings of these participatory workshops. It also contains messages about disability that the target groups have provided for Soul City. It also contains recommendations for the portrayal and conveyance of messages on disability matters and issues.

2. TARGET GROUPS:

Children:

The children who participated within this small study, represented various disabilities that included the following:

- Blindness
- Deafness
- Physical Disabilities
- Mental and Neurological disabilities

The children within the Western Cape were from urban areas, mainly from poor socio-economic communities on the Cape Flats and their language was the typical Cape Flats Afrikaans. Most of the children were from the coloured and Asian communities, and the majority of them were physically disabled and wheelchair users. Only two children were intellectually disabled. The majority of the children within this group attended special school, with one child attending mainstream school. The average age of the group was thirteen, the youngest were ten, and the eldest one was eighteen years old.

The children within Mpumalanga were mainly from very poor rural communities, and they communicated in Swati, with the exception of two Afrikaner boys that participated as well. The children represented a mixture of disabilities, including Deaf children, blind children, mentally disabled, hyperactive children and children with Down syndrome. Most of the children attended an integrated special school that caters for the needs of Deaf, Blind and physically disabled children. Three of the children did not attend school, and the two Afrikaner boys attended a newly developed, very private special

school. The average age of the group were fifteen; the youngest were 11 years and the eldest one were 18 years old. Within this group, a child with intellectual disability was raped at the age of nine years.

Parents:

The parent's group held in Mpumalanga was attended by mothers and one father represented his son. There were eleven parents in total. Half of the parents were single parents and on average had between 2 to 6 children within their families. Three other families indicated extended families living with them. One parent has two children with disabilities, both boys. One family was also indicated to be an all female household. Grandchildren also formed part of most of the households. The parents were all above and over the age of forty.

The parents within this group mainly came from the rural areas, with the exception of the Afrikaner mothers that came from the urban areas. The parents mainly spoke in Swati, and the Afrikaner mothers used a mixture of Afrikaans and English as their medium of communication.

Disabled Rehabilitation Consultants

The rehabilitation consultants were an initiative that was implemented by Disabled People South Africa, the Office on the Status of Disabled Persons within the Premier Office of Mpumalanga and the provincial department of Health. Their main form of service delivery is the identification of persons with disabilities in rural communities, providing information on the rights of persons with disabilities and supporting persons with disabilities through referrals to the correct service providers.

The consultants are all disabled people, representing various physical disabilities, blindness and deafness. The majority of the consultants are African with a few coloured consultants. A disabled person coordinates their activities.

The consultants work within three districts of Mpumalanga Province, namely Ehlanzeni District, Gert Sibande District, and the Nkangala District. A total of thirty consultants participated within the workshop, representing 12 women 18 men. Though most of them had a good command of the English Language, the communication was mostly done with a mixture of Swati and English.

4. RESEARCH APPROACH:

The research approach was a qualitative approach that included active participation from the children, parents and rehabilitation workers within a workshop format. Within these workshops, extensive use was made of language translators to translate from English to Swati and back to English, and also from English to Afrikaans and back to English; sign language interpreters for the deaf, and attendant carers for the intellectually disabled to assist disabled children within the activities.

Within the use of materials, specific care was taken to use descriptive language to accommodate blind persons. Aroma dough was used with the children of Mpumalanga as an introductory tool to gather background information about the children. This exercise and use of the activity tool was specifically to accommodate the various disability specific categories within this grouping of children.

A collage of picture cuttings from media and magazines, as well as photos from our personal collection, of able-bodied and disabled persons were developed as a tool to engage the children in discussions on positive images and valuing of the self.

The Western Cape children were engaged in drawings to share their experiences of friendships, development and growth path experiences. The children also engaged within small intimate group discussions to gather information of each other.

A video was shown to the children of Mpumalanga to share the experiences of children with disabilities and young disabled people that speak to issues of rights and inclusion, and the coping skills of parents from various cultural contexts.

A specific set of questions, accompanied by activities was developed for each of the three groups.

For the children's participation the activities were in accordance with the following research activity outline:

ACTIVITY	Materials and time	ACTIONS	OBJECTIVE
1. Introduction Ice breaker: Observations and Perceptions	No materials 20 minutes for observation and feedback.	Each Participant is provided with a partner. They observe their partners for a few minutes. Each partner will then be given the opportunity to provide feedback of their observations and perceptions of their partner. Feedback must	To determine their perceptions and observations of each other, and how others perceive them to be as individuals through first impressions. Understanding how they are seen through

		include within their assumptions where they think the person comes from, their family, schooling and likes and dislikes. The other partner is provided with an opportunity to validate whether the observation and perception is correct.	someone else's eyes. Getting to know each other as a group.
2. Development Experiences: Mapping our growth path	Materials: Crayons, and Flipchart paper. Aroma dough Time: 30 Minutes	Each participant will draw pictures of their friends at various age levels such as at age 6 years, 10 years, and to date. They will respond to questions such as who did you play with? What did you like best about your friends at that particular age? What did you not like? Who are your friends now? Is there a difference now that you are older? What is different? How is it different?	To determine whether any challenges have been experienced whilst growing up, and what those challenges were or whether it still exists. Whether in forming relationships with others whilst growing up they had experience any difficulties, how they dealt with it and whether such challenges still exists.
3. Introducing Gender and Sexuality.	Materials: Flipchart paper, Coki pens. Time: 45 minutes	Girls and boys are grouped separately. Each group will discuss what they think Gender and Sexuality means. Researchers will observe the activity, and record the discussions. Researches will encourage the discussions with probes such as: Is it better to be a boy or a girl? Why do they think so? Are you treated any different than your siblings if any? How are you treated different, and why? Amongst your friends, are you accepted and treated equally or different, how and why?	To determine the level of understanding and exposure the participants has with the subject. To find out how they are valued within the family and amongst their peers, and whether they value themselves. To determine whether they have opportunity for socialisation. To determine whether non-disabled persons are uncomfortable in their presence. To determine whether they are comfortable to be in the presence of their non-disabled peers.
4. Positive and Negative images, valuing ourselves. Media images and clippings of women and men will be used to prompt discussions on acceptance.	Materials: Overheads, Media clippings, Pictures from personal Photo album.	In a plenary discussion, groups will be asked to respond to the visuals presented. Probes for this session will be: Do you believe what the media portrays of body image and how we ought	To determine whether they are comfortable with and have accepted their disability and appearances. To determine whether

<p>Pictures of disabled people who are married and disabled women with children will be used as prompts for the discussions.</p>	<p>Time: 60 Minutes</p>	<p>to be? If not, why?</p> <p>Are there really differences between disabled boys/girls and non-disabled boys/girls? What are those differences?</p> <p>Do you think that disabled men and women can be parents? If no, why not and if yes, is it easier for disabled people to get married than non-disabled women?</p> <p>Do you wish to be married some day and have your own family?</p> <p>Did you ever find yourself liking someone of the opposite gender, and what did you do about it?</p>	<p>they have opportunities to dating and forming relationships with the opposite gender.</p> <p>To determine how they perceive their non-disabled peers.</p> <p>To determine how they deal with their feelings for the opposite gender.</p>
<p>5. Providing positive images and messages about disability.</p> <p>This activity will be a free flowing interactive activity where the participants can either respond through drawings, clay model expressions, or verbal presentations.</p>	<p>Materials: Flipchart paper, Coki Pens, Crayons,</p> <p>Time: 45 minutes</p>	<p>Researchers will prompt this activity with questions such as:</p> <p>How do you want Soul Buddyz to present disabled boys and girls on television?</p> <p>Is there something special that you want Soul Buddyz to convey about disabled boys and girls?</p> <p>What do you want Soul Buddyz to convey to your parents through television?</p>	<p>To get the views of the participants on how disability needs to be presented within the Media.</p> <p>To determine how they want their relationship with their parents and family to be.</p>

Parents:

The activities with the parents were done in accordance to the research activities outline:

ACTIVITY	Materials and time	ACTIONS	OBJECTIVE
<p>2. Introduction Ice breaker: Observations and</p>	<p>No materials</p> <p>10 minutes</p>	<p>Participants will be partnered with someone that they do not know</p>	<p>To determine their reaction to the instruction.</p>

Perceptions	for observation and feedback.	and will be asked to share a very personal sexual experience that they had recently.	To gauge the level of comfort ability that they have with their own sexuality. To demonstrate the complexity of the topic and the situation of children with disabilities in dealing with issues of sexuality.
2. Introducing Gender and Sexuality	Materials: Flipchart, Coki Pens Time: 30 Minutes	Plenary discussion: Specific probes for this activity will be: What is your understanding of gender and sexuality? Do you believe that children with disabilities develop a sexual identity? If no, why? Is there a difference between children with disabilities and non-disabled children in sexual developments? If no, why do you say so, and if yes, what is the difference and how is it different?	To determine the level of understanding and participants has with the subject. To determine how participants value their children with disabilities.
3. Adolescents and transforming bodies.	Materials: Flipchart paper, Coki pens. Time: 45 minutes	Participants are grouped in two. Each group will discuss the following questions: What are the challenges that you face with your growing disabled child especially in relation to body changes? How do you deal with these changes given your child's specific gender and disability? What specific fears do you have regarding your child's developing	To determine whether the challenges of adolescent children with disabilities are a different experience to parents than that of their able-bodied children. To determine how they deal with the challenges of adolescents, especially in young children with disabilities. To determine whether they have any specific prejudices towards their

		<p>sexuality?</p> <p>Would you allow your child to enter into a dating relationship?</p> <p>Do you think that your child could get married and have children someday?</p>	<p>children with disabilities, and whether the fears experienced are general fears towards every adolescent child.</p> <p>To determine whether they allow their children with disabilities opportunity for socialisation and exploration.</p> <p>To determine whether parents equally harbour the same aspirations for the future of their children with disabilities as they would for their non-disabled children.</p> <p>To determine whether they have come to accept and live with their child's disability.</p>
<p>4. Providing positive images and messages about disability.</p> <p>This activity will be a free flowing interactive activity where the participants can either respond through drawings, clay model expressions, or verbal presentations.</p>	<p>Materials: Flipchart, Coki Pens.</p> <p>Time: 45 minutes</p>	<p>Researchers will prompt this activity with questions such as:</p> <p>How do you want Soul Buddyz to present the issues of sexuality in terms of children with disabilities?</p> <p>Is there something special that you want Soul Buddyz to convey about disabled boys and girls?</p> <p>What do you want Soul Buddyz to convey to other parents through television?</p>	<p>To get the views of the participants on how disability and sexuality needs to be presented within the Media.</p> <p>To determine whether parents have specific ideas and advice about the issue for the series and to other parents of children with disabilities.</p>

Disabled Rehabilitation consultants:

A specific set of questions relating to the service delivery was developed for the consultants. The lead to these questions was derived from the Un 22 Standard Rules on the Equalization of Opportunities for Persons with

Disabilities. These Un Standard Rules form the basis for the South African White Paper on an Integrated National Disability Strategy. The questions were dealt with in the following manner:

- Working group sessions
- Plenary discussion
- Question and answer sessions.

The questions were presented to the group:

<u>GROUP 1</u>	<u>GROUP 2</u>	<u>GROUP 3</u>
<p>Un Standard Rules: Pre-conditions for Equal Participation: <u>Rule 3</u></p> <p>States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning</p>	<p>Un Standard Rules: Target areas for Equal Participation: <u>Rule 9</u></p> <p>States should promote the full participation of persons with disabilities in family life. They should promote their rights and personal integrity and ensure that laws do not discriminate against persons with disability with respect to sexual relationships, marriage and parenthood.</p>	<p>Un Standard Rules: Implementation Measures: <u>Rule 13</u></p> <p>States assumes the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all aspects, including the obstacles that affect the lives of persons with disabilities.</p>
<p><u>Questions</u></p> <p>Are these issues raised relevant in the lives of children with disabilities? If not, why not. And if yes, how does it apply.</p> <p>What will you recommend as an improved service delivery strategy.</p>	<p><u>Questions</u></p> <p>Does your service delivery strategies include issues that deal with sexual relationships, marriage and parenthood? If not, why not? How would you change this? If yes, what are your key strategies?</p>	<p><u>Questions</u></p> <p>Within the context of disability and in relation to children with disabilities, does your service delivery include all aspects of the growing disabled child's living conditions? What are the barriers that you experience within your service delivery to children in terms of:</p> <ul style="list-style-type: none"> • Developing sexuality • Abuse • Vulnerability within HIV/Aids

The recordings of the information obtained were translations of the communication captured on tape, and flipchart. The tapes and flipchart information was then transcribed.

5. FINDINGS:

Children:

Within the children's groups, we developed four key areas from which we obtained our information. These specific areas were developed from the broad base question that was posed by Soul Buddyz:

- Perceptions and valuing of the self.
- Development experiences and challenges encountered
- Level of exposure to information on sexuality issues
- Positive and negative images, valuing ourselves
- Providing positive images and messages about disability

These broad areas provide the insight into the children's experiences in their ongoing development within a framework of adversity that they face on a daily basis.

Perceptions and valuing of the self:

Within the Western Cape, we engaged the children within an activity that requires the participants to observe and perceive each other from first impressions. Girls were partnered with boys and one of the facilitators partnered the youngest participant. Each one of the participants then needed to validate the observations and perceptions that were made. From this activity we observed the following:

Within this group, we found that the girls were far more confident than the boys. Feedback from the small groups included:

Boy's perception "She likes to play outside and go around by her friends" The girl was validating "I don't have friends at home. I don't do those things I choose to be alone"

From this exercise and after validating each other's perceptions, the group understood that they could be wrong in their perceptions of others on meeting the person for the first time.

It was evident that such experiences contributed to the high level of poor self-image that was evident within both groups of children. Children with severe physical disabilities and intellectual disabilities were far more conscious about themselves and far more reluctant to speak about themselves than the children who are Deaf, and the children who are Blind. These children were far more outspoken and willing to engage. Most of the boys within the Western Cape group were very hesitant to engage with the girls in such a small and intimate grouping. They needed much more coaxing and when they did comment on their observations of the girls, it was more as if they were hesitant to reveal their true thoughts and observations of the girls.

Within the Mpumalanga group, the activity was revised to accommodate the visually impaired, Deaf and Down syndrome participants. The participants were given Aroma dough to provide information on their background, where they came from, their family and their surroundings.

Within this group, the girls were very reluctant to speak about themselves, whilst the boys were much more vocal, and they all participated actively.

The situation within this province could be understood in that the cultural experiences are more profound in relation to disability and disabled girls. Disabled girls have far less opportunity to social exposure than boys. Boys would have far more opportunities than girls with disabilities to enter and receive education. Within the Western Cape, and particularly within urban settings, the opportunities for social exposure and education are more or less balanced between boys and girls.

Development experiences and challenges encountered

Within this activity, the participants were asked to share their experiences of their friends starting at age 6 through to their present age. It was clear from the information received that the school was the first and only place where children with disabilities had opportunity for social inter-action and to develop their social skills.

The children within both groups experienced minimal challenges in forming friendships at the age of six years. They experienced no discrimination against them due to the fact that they were not yet exposed to the awareness of their disability. One boy in Mpumalanga expressed his feelings for his young friend at the time:

“ I loved him so much, we were playing with each other and socialising and doing all the good things.”

The girls expressed the same feelings about their friends at that age, and shared that they inter-acted with their able-bodied friends very naturally. One of the girls shared her experiences with her friends at that time as:

“I liked my friends because we could do running and drawing together”

It was also evident that some of the children’s social and emotional development was slower than others. Most of these children’s friends were younger by two to three years.

Some of the children’s experiences of disability also impacted on their ability and opportunity to develop their socialising skills at a very young age. One such boy related his experiences through the interpreter as follows:

“ He did not have any friends when he was six years old. He was late to walk. The family tried to make him walk and took him to the traditional healers. That’s where he lived his life.”

All the children indicated that they started to experience challenges in the formulations of friendships and maintaining their friends, as they got older. They had fewer friends than what they had at the age of 6 years. This can be attributed to the fact that at a young age, most of the children are not really aware that they are viewed “different” from other children who do not have disabilities. As they grow up they become more aware. Often it was the friends at home who made them aware that they are “different.” Boys in particular described their experiences of abuse and ridicule when they were amongst friends:

“ The boys they go out, and ... I don’t talk to them much...they say nasty things and are just plain rude.... They call me names, make fun of me I just ignore them ”

When asked how he dealt with such rudeness, he said, ***“Nothing,,,, I am being rude back at them. If they mess with me then I get other friends to get at them, I get people to attack them.”***

While the children were reluctant to speak of such experiences, their parents volunteered much more information. One mother indicated that her son who has a visual impairment, experienced abuse at school.

“They would tease him, because his eyes is crossed over, you know, crossed eyed.”

His mother explained that her son is now much more withdrawn, and more attached to the family. He prefers to play with his sister and cousin who are much younger than him. He very rarely plays outside and has no friends at home.

The father of the physically disabled child explained his son’s experiences as:

“They would push him to see how he falls.”

The father, with the assistance of the disability rights movement in Mpumalanga talked to the principal, who in turn spoke to the children about the son’s disability. The son also mobilized other children to take care of the children that tease him on his behalf. With these mechanisms in place, he was able to continue his schooling.

These are some of the reasons most of the children had friends that were far younger than themselves. The impression that was conveyed here was that it was almost much safer to be with younger children. They were also very careful at selecting their friends, and most would end up playing with the extended family’s children, or would prefer not to have friends at all.

When we probed further to establish how friendships are governed, we found that most of the children indicated that they waited for their friends to come to them, and that they never went to the homes of their friends. It indicates the

dependence syndrome within the friendship and the power imbalances implied by the limitations that the children experience in being viewed as equal partners within the friendship. It also highlighted the limitations that the children experienced in the continuation of their social skills development, should the friendship be ended. They have less opportunity to experience and develop their social skills, because they have less opportunity for exposure to make new friends.

Most of the children did not speak about their disability to their friends. When asked by their friends what was “wrong” with them, they avoided a response. Only one boy, who wanted the assurance of acceptance by his friends, asked whether his friends were ever curious about his disability. He has a physical disability known as Thalidomide.

Interestingly was the fact that most of the children had able-bodied friends. The boys in particular chose to have able-bodied or hearing friends. In some instances, these friends were much older. We found that as their friends become older, and much more independent, the interests of their friends differed from theirs. This is mainly attributed to the difference in the development and maturity level of the children that also plays a role in the continuation of friendships. One of the girls with an intellectual disability describe her experiences as:

“Last year I met Tasneem and Natalie. They were just over boys and I don’t agree with that. They just talk about boys, how they look ... so I stopped seeing them.”

As a result, the children tend to become more isolated and lonely. It was evident that this was the most difficult part of the children’s experience and some of the most difficult challenges that they face in forming relationships.

One of the girls, became disabled at the age of sixteen years when she was shot on her way to the local community shop. Since she has become disabled, she has lost all her friends and her extended family ignores her. She is now viewed as being “bad luck” to the family. Her mother is currently caring for her. It has been two years since she was last at school. She expressed her loneliness, and indicated that:

“I don’t have any friends at home, I would like to mix with my friends again. My family and friends ignores me now”

Some of the disabled children seemed to have developed more confidently than their peers who participated with them within the workshops. This could be attributed to the specific disability category that the children experience and the opportunities to engage in early intervention programmes at an early age. Children who engage in early intervention services are often much more confident within their disposition than those who do not. In contrast to girls and boys with severe physical disabilities, mental disabilities or intellectual disabilities who often experiences more challenges in the formulation and maintenance of their friendships than deaf or mildly physically disabled

children. One such girl with Spina Bifida, who is a wheelchair user and who was accompanied by her friend/attendant for the past seven years, described her experience:

“ I have a lot of friends at home (and she names them). They are all able-bodied. We go to my house, sit in my house and talk about stuff.”

Presently this child is only 13 years old, but the challenge increases as the children get older. The children indicated that they feel good when they are amongst their “own” but found it very difficult within the “normal” society. One of the girls who has an intellectual disability stated this very clearly:

“When I find myself in a crowd they would stare at me and say that I am stupid and they mock me.”

Level of exposure to information on sexuality issues:

It was clear from the onset that most of the children were not familiar with the word gender, and that the children between the age groups of 11 and 12 had very little information and understanding on what gender and sexuality meant. The older ones understood it to mean sex. One boy ventured his understanding of sexuality by asking in Cape Flats Afrikaans:

“Is daai nie miskien iemand wat ge-force word om seks te he nie, of soe iets vannie aard.”

(Is it not someone who has been forced to have sex?)

Most of them however indicated that they understood gender to be the difference between male and female. One of the girls, in demonstrating her understanding of gender, equated herself with her mother and said:

“I like the things that my Mom does.”

We then explained that sexuality was more than sex. The question was then revised to allow the children to express their feelings around the issues of sexuality and gender. When we posed the question, “Is it better to be a boy or a girl,” there were much more responses, especially from the boys.

The boys indicated that they preferred to be boys because it is much better to be a man. The boys within the Western Cape made their position clear in Cape Flats Afrikaans:

“Se maar nou ons is ‘n girl, en ons het sex, dan moet ons die kinders hou, ons moet die kinders groot maak. En die mans weet nie hoe om daai te doen nie, dit is die kwaaieste daai, om ‘n man te wees.”

(If we are a girl, and we have sex, then we have to keep the children, we have to raise the children. Men do not know how to do these things and that is what makes being a man so cool.)

The girls on the other hand indicated that neither one was better than the other, as one of the girls put it:

“I do not find it better to be a boy or a girl, but like being a girl.”

Social problems experienced within the family or community were reflected within the stereotype ideas about girls, and the experiences and their roles within society. On the question of whether girls and boys are treated differently, their responses were:

“They have problems, nou is’ it miskien die lalties, dan se djy vir jousef ja ... daar is nie eens proef nie dan maak sy ‘n saak dan staan hulle nie die man se kant nie, dan vat hulle die vrou se kant. Dan se hulle djy het haar ge-rape, dan is dit nie soe nie.”

(They have problems, maybe it is about children, and then you say to yourself that there is no proof. She then makes a case against you, and then they side with her. Then say you have raped her, and it is not so.)

Positive and negative images, valuing ourselves

We observed that the children, more especially the girls, were struggling with their image and valuing themselves. Most of the children were very self-conscious about their body, especially the children with physical disabilities. The young Afrikaner boys however, were very self-conscious about their stutter.

When asked what does it mean to look sexy, there was a bigger response amongst the boys. The boys agreed that it was important to wear brand name clothing to get the attention of the opposite sex. One of the boys in the Western Cape indicated that it costs money to look sexy:

“Juffrou, djy moet geld het om sexy te kan lyk. ‘n Levy cos’ money and dan moet djy nog ‘n dragon t-shirt daarby het. As djy nie sexy lyk nie, dan sal die girls nie met hulle oe photo’s vat jou nie, hulle sal oek nie naare kom nie.”

(Miss, it takes a lot of money to look sexy and it is very expensive. A levy costs money and you need to have a dragon t-shirt to match the levy. If you do not look sexy, then the girls will not look at you and they would not come closer to you.)

The girls on the other hand found it okay to be sexy. One of the girls who comes from a poverty stricken family added:

“ If I have the nice clothes to put on.”

The parents also shared their experiences of their children's awareness to look and feel good before they appear in public. One of the parents in Mpumalanga shared that his son likes to wear name brand clothing and likes to look good about his appearance. Because he is blind, he always seeks out his mother's approval of his appearance before he ventures outside.

There were far less awareness about sexuality amongst the children of Mpumalanga than there were amongst the children of the Western Cape. The boys were keener to talk about the issues of girls and the issues of marriage. On the issue of dating, the boys all showed keen interest. It was also interesting to note that irrespective of the disability experienced, all the boys had the same stereotype thinking about the type of girls that they wanted to date. One of the Afrikaner boys stated his preference for girls as follows:

“Hulle moet mooi wees. Hulle moet lang bene het. Hulle moet nie vet wees nie. Hulle moet maar wees.”

(They must be beautiful. They must have long legs. They should not be fat. They must be thin.)

The girls on the other hand were far more level headed on the issue of dating. They older ones expressed that they do have opportunity to dating and forming relationships with the opposite sex. One of the girls stated that:

“ I would like to have a boyfriend, and I would kiss him if I like him.”

Because she is Deaf, she also stressed that she would not have a relationship with a hearing person, as she felt that the person would not be able to understand her.

To prompt discussion on marriage, we showed the groups media clippings of disabled people and non-disabled people in relationships and photos of disabled people who were married. On the issue of marriage, most of the boys and girls indicated that they would get married. When asked would they get married to a disabled person, the girls had no problem, but the boys indicated that they would not get married to a girl with a disability. When asked why some of the boys ventured a response. One of the boys who were physically disabled responded:

“ Ons moet met iemand trou wat nie disabled is nie. Se nou die kinnners is stout wie gaan agter hulle hardloop om vir hulle pak te gee?”

(We need to get married to an able-bodied person. What if the children needs discipline, who is going to give them a hiding?)

Another one stated his reasons for choosing an able-bodied girl as:

“Wie gaan my kos gee. Ekke moet my kos optyd kry anners....”(and he smacks his right fist into the palm of his left hand.)

(Who will give me my food? I must always have my food on time.)

The rural boys had different views about why they would not marry or marry a disabled woman. One of the boys who is blind indicated:

“I will not get married because girls cannot work. Girls cannot do washing.”

When we asked him to explain, he related that he has difficulty in finding someone to do his washing, and he has to beg his sister or his neighbour's daughter to do it for him.

Another boy who is physically disabled said:

“I will get married someday. But it must be an able-bodied somebody that can help me.”

When we showed them a pictures of a couple who are both paraplegics and parents of a grown young boy, and of a disabled mother whose disability is Thalidomide, (she has no arms and only one leg and foot that was formed). The boys were very surprised and in awe of her capabilities to have her own child. But despite these positive images, the boys in both groups were adamant that they would not get married to someone who is disabled.

It was clear that the boys had specific stereotype views about girls and their roles. Their understanding of girls and their roles also displayed ingrained cultural practices and experiences within the home environment. We also found that the older children, especially the boys who had relationships, struggled with the management of the relationship, and their expectations of what the relationship should be like. One of the Deaf boys proudly indicated that he does have a girlfriend, and had several others:

“ Before in Barberton, I had a girlfriend, then we separated now. We always happen to argue. My girlfriend was Indian and she is Deaf. Some friends were fighting for me... like why are you going with that girl she looks so and so. She was having too much boyfriends.”

When asked does he have a girlfriend now, he responded:

“Yes, she is beautiful. Her name is Zola. She taught me how to write things, how to do things, actually many things, and she is hearing. I was also having another girlfriend here. But she is too much fast, she is after my money, so I left her and went back to my Zola. She thinks she's a little too good, she thinks that she is too much clever.”

Not all the participants wanted to socialise and form relationships. One of the girls who are intellectually disabled were particularly quiet and did not participate within the discussions. It could be that her traumatic experience about the rape has not been adequately dealt with. Another girl indicated that

though she has a good relationship with her mother, it does get a bit upsetting for her when she is being urged by her mother to socialise and meet boys. She explains that she has difficulty in socialising because of her specific disability:

“ I would not get married, and I do not want children.”

For this reason, she finds being by herself a better option than to face the ridicule of other people who do not understand her. Another of the girls who is Deaf indicated that her opportunities for socialisation happen mostly at school, and that she has no friends to socialise with at home due to the fact that communication is a problem.

When we showed them pictures of role models doing various sporting activities, the children were very surprised and interested. The girls commented that if they could have such an opportunity, they would want to do the same activities.

PARENTS:

Parents were given an introductory activity to ascertain the level of their comfortability with their own sexuality, and to demonstrate the complexity of the issue and the situation of children with disabilities. They were asked to group in partners of the opposite sex and to share an account of a sexual experience.

We observed that some parents were astonished, some were nervous, there were lots of giggling and light laughter, some had their heads bowed, some smiled, others were awkward, and some just showed expressions of disbelief. The exercise reflected that most of the parents felt uncomfortable with the topic at hand and not sure about their own ideas about sexuality. They did however reflect that the topic was sensitive and should not be shared with strangers.

We then explained to the parents what the purpose of the exercise had been, and pointed out that able-bodied children's apprehensions of approaching their parents with the questions on the subject, is much more profound within children with disabilities. They understood that their own discomfort with the subject matter contributes to placing their children within vulnerable situations.

Understanding Gender and Sexuality:

Most of the parents understood gender to be the difference between male and female; however, most of the parents did not understand what sexuality meant. The Afrikaner parents explained their understanding of gender and sexuality as:

“We just said that Gender is male and female and sexuality is basically when they change from girl to woman and boy to man.”

Another parent explained that sexuality to her means that:

“When changes begin to a girl or a boy. The girl starts to menstruate, she became more aware of her body. The boy also starts to be aware of his body.”

This understanding of sexuality reflected the general understanding that it has to do and centres on the physical changes and transformation of the body.

Parents all agreed that children with disabilities do develop a sexual identity:

“ They do have there own sexual identity. There is no difference between the development of an able-bodied and disabled person.”

The father of a blind young man agreed that there is no difference and related his experience with his son:

“ He likes to dress up, and he specifically likes the approval of his mother, and when his mother says to him that he looks nice, and then he smiles which indicates that he feels good.”

However, they disagreed on the question as to whether there is a difference in the sexual development of children with disabilities and non-disabled children. One of the groups presented their argument as follows:

“Yes, there are differences, children with disabilities are less inhibited, and other children are more aware of what is acceptable private, and what is acceptable in public.”

She further explained that her friend who has a mentally disabled child would masturbate when there are visitors at there home and that this is really disturbing to her friend.

Another parent indicated that she does not believe that her child has developed sexually yet, though he was fourteen years old. She explained through the language interpreter:

“She says concerning her child who is 14 years who is blind, there is no sexual development because even now he is not afraid to be naked. And even when the mother try to take off his trousers he does not have any problem yet.”

The parents also expressed the difficulties that the children experience in making friends. The parents attribute these difficulties to the disabilities of the children and their own self-consciousness about it. Often their disabilities cause them to experience abuse from their peers, which takes place in the form of verbal and sexual abuse. The children are often reluctant to tell their parents of their experiences at school, and their silence is often out of fear that they will be removed from school:

“My son did not tell me that he was being physically abused at school, because he was afraid that I would remove him from school as a protection measure.”

Verbal abuse is also experienced and one mother related that her child, in addition to his visual impairment, is also crossed eyed, children at school often teased him about this. As a result, children who experience such abuses, often withdraws into themselves and from inter-action with their peer groups and as such isolates themselves.

Adolescents and transforming bodies:

The parents indicated that their children had become very aware of their changing bodies. One parent relates her experiences with her Deaf son:

“He started to be afraid to wash himself in front of his parents.”

One mother shared her experience of her fifteen-year-old daughter:

“Changes started when she saw the changes... when she started to menstruate and also started to differentiate things.”

The mother of the intellectually disabled young boy shared how she and her son felt when they noted changes in his physical development:

“ My youngster and I was very happy when he started to get pubic hairs and he wanted to show every one what happened.”

Challenges:

Parents related that they experience many challenges, as their children get older. One of the parents who has a daughter of 11 years, and whose disability is hemiplegia explained:

“ I am having a problem of not knowing how she is going to help herself with the menstruation, because she is physically disabled and the right side is not working. There is also the issue of family planning, how will I explain about family planning to her? I have a hearing problem and do not know the correct way of talking to her. She is intellectually disabled as well.”

Another parent expressed her fears through the translator as follows:

“She is afraid that her daughter can become pregnant and that they will not know who the father is, she can also be raped.”

Parents also expressed specific fears that they have for their children's developing sexuality, especially in relation to their disability. An Afrikaner mother of a boy who has Down's syndrome, described her fears:

“ Our biggest fear would be that they are very trusting (children with mental disabilities) so they trust everyone and any one.... They are too trusting. In other words, if you say to them, well I will buy you a cool drink and go with me to Dickson, it could easily lead to some one misusing or abusing them because of that trust in them that they are going to open.”

The fear of unwanted pregnancies, or fathering children is very uppermost in the minds of the mothers. Most of the mothers indicated that they would not want their children to become pregnant, or to father children. They believe that the children would not be able to carry out their responsibility, as parents should this happen. Parents who have physically and mentally disabled children mostly expressed these fears. One of the parents described her fears:

“She fears that the child, if she can have sex with a boy, she can become pregnant.”

Another parent who believes that her child's physical disability will not allow her to be a responsible parent voiced her fear:

“ She is afraid, what if she dies, who is going to take care as a Gogo, she can die and who is going to take care about the Grandchildren?”

The Afrikaner mother explicitly expressed that it would be irresponsible of her as the mother to allow her mentally disabled child to father children:

“So it would not be fair to the child and I though that there is the present responsibility of my child. If I were to let him have a child, I wouldn't mind letting marry, but if I let him have a child, I would be irresponsible myself. It is my responsibility because I know that he could not take care of the child, so that is being irresponsible of me as his mother.”

Dealing with challenges:

Most of the parents indicated that the manner in which they are dealing with the issue of developing sexuality is:

- To teach the children what is right and wrong, and what is acceptable behaviour.
- To make them understand about the changes of their bodies and the implications thereof.
- To make them aware about privacy

- Parents need to support and teach their girls about caring for their bodies during menstruation.

Whilst parents offered that these were the ways in which they had coped with the developing sexuality of their children, they were not entirely truthful. During the breaks I happened to talk to the rehabilitation worker who also interpreted. It was revealed that mothers coped with their fears of unwanted pregnancies by agreeing to sterilisation of their children. Some of their children, especially the physically disabled children, are given the “Depo” injection to prevent pregnancies.

Boys who are mentally disabled, and children who have Down syndrome, are provided with an injection at school to curb their sexual urges. When asked at what age girls are being sterilized, and boys receive these injections, she confided that the ages are very low, 12 and sometimes 14 years.

Relationships:

Despite the fears of unwanted pregnancies that the parents expressed, they nevertheless agreed that they would allow their children to enter into relationships, providing that certain conditions are adhered to. Some parents believed that their children should be married first because:

“She can allow her child, but fears that if they start to be loved without marrying, they can have children.”

Another parent of a mentally disabled child expressed her concerns with the issue of relationships:

“ Because of their mental disability I think to have a relationship you must be able to communicate at a certain level. And if you are mentally disabled, your physical development is that over a Say man or woman, but your mental ability is still that of a nine-year or ten. You won’t have a relationship with a person with a “normal mentality” because you would not have that same relationship. It wouldn’t be a relationship on that type of level. It would be more like a child to an adult because of your mental disability.”

Some of the mothers also expressed their fears of allowing their disabled girls to enter relationships. Their biggest fear is that of sexual exploitation and unwanted pregnancies. For this reason mothers feared the future prospects of allowing their daughters to date, especially girls with physical disabilities, and those who are Blind and Deaf.

On the issue of marriage, a mother of a physically disabled child expressed her fears:

“ She is afraid that if she (daughter) goes to stay with the husband, she can be able to do the house work because the side

is not, the right side is unable to do. It will be difficult for her to do the housework.”

It was evident that the parents had many fears and that they did not always know how to deal with the developing sexuality of their children. It was also clear that many parents came to the participatory workshops looking for answers on how to deal with these issues.

Disabled Rehabilitation Consultants:

The group was provided with a specific set of questions developed specifically to provide information on their experiences within the field. They were also asked to inform on the specific challenges that they encounter within their service delivery to persons with disabilities.

The consultants who participated totalled 30 in all. They were divided into groups of three and each group were provided with a specific set of questions relating to the development of children with disabilities.

Group one were asked to provide information on whether rehabilitation services to persons with disabilities - that is intended to assist disabled people to reach and sustain their optimum level of independence and functioning - are relevant in the lives of children with disabilities. They were asked to provide information if this is not the case, and to explain if it does apply, how it applies.

Group two were asked to provide information on whether their service delivery strategies include issues of sexual relationships, marriage and parenthood to young persons with disabilities. They were also asked to provide explanations if his is not the case, or provide information on key strategies that they use if it was the case.

Group three were asked to provide information on whether their service delivery includes aspects of children with disabilities and their living conditions, especially within the context of their developing sexuality, abuse and vulnerability to HIV/AIDS. They were also asked to expand on the barriers experienced if any.

The relevancy of rehabilitation services in the lives of children with disabilities:

The group reported that in their experience, rehabilitation services are not necessarily designed to assist children with disabilities to reach and sustain their optimum level of independence and functioning. They found that there were a number of “loopholes” in the implementation of services and the design strategies in terms of approach. A particular area of concern was cultural diversity. They explained that as children develop, they would need the support and guidance from their parents, especially where it concerns their developing sexuality. Parents are expected to provide this guidance to

children. But, the culture dictates differently. It is deemed immoral of parents to discuss issues of sexuality, social activities with their children with disabilities, because there are things that parents can and cannot talk about to children. As such parents find it hard to discuss such issues.

This creates other “loopholes” in the upbringing of children, in that children with disabilities especially remain uninformed, which lends them vulnerable to issues of abuse.

They also experienced within their services that there is a lack of information on disability amongst educators, health professionals, HIV counsellors, government departments and society in general. They indicated that despite the fact that there exist good enacted policies and legislations that specify the rights of persons with disabilities, in reality there is no implementation.

The group made examples that related to issues of employment as a key issue that assists children with disabilities in reaching and sustaining their optimum level of independence. Some of the examples made included the Code of Good Practice meant to assist and support the employment of persons with disabilities, which lack s practicality. There are also issues around employment equity that has within it concepts that needs to be interpreted clearly. The group made the example of “inherent requirements” indicated within the Code also needs to be defined to explain what it means within the language used within the concept of disability.

The group further elaborated that within Education are the Education White Paper 6 that looks at the issue of inclusive education that was designed to ensure education to children with disabilities. But, because of negative attitudes, children are still discriminated against from accessing education.

The group explains: ***“In most cases the facilitators or people in charge, in the mainstream education are not even conversant with the policy of Inclusive education. That is why you will find that in mainstream education there are no disabled children that are admitted within our local schools. Even the children with the condition of Albinism, they become the centre of attraction if they are at a mainstream education. That is evidential that yes, there are legislations that seeks to accommodate disability, but there are still laws, gaps that ought to be looked at.”***

On the issue of lack of information about disabilities to professionals in education, health, counselling services, government departments and churches, the group elaborated:

“I should think that these are just areas where the notion of disability should be preached, where we would be saying even to our churches, we should inculcate the spirit of people who are in local churches to have input to participate to issues around disability. As children we would begin to be discriminated to our churches, to our schools, to our respective homes, even to our local clinic. We find that the disabled

teen-ager, it is hard for that particular person to go into a clinic and request for any assistance. Even if the female disabled person, somebody is raped. It is hard for that person to disclose that she is raped. It is even hard to go to the clinic to say that I need 1, 2, 3, and 4 because I have been raped. Because, the environment is not that accommodative to people with disabilities. “

Recommendations:

The group felt that there was a need for awareness campaigns that could raise the sensitive issues relevant to the lives of children with disabilities. Such awareness of disabled children's issues should also encourage disabled people to mobilize themselves through innovative and self-motivated strategies.

Service delivery strategies: issues on sexuality, marriage and parenthood:

The group responded yes to the question that was posed, and went on to explain their service delivery strategy.

They particularly help parents who experience challenges in the management of girls with disabilities who menstruate and boys who inappropriately expresses their sexual urges. Specific actions are taken if it is found that the young girls or boys are mentally disabled, have epilepsy or a mental illness.

The group made examples of their service delivery strategy where there is a mentally disabled girl who has started her menstruation cycle. Together with the parent they would ascertain when in the month the menstruation cycle begins. Once they have determined the cycle, the issues of referral is brought in. Families are counselled, then they refer the family to the clinic. The aim of the referral is **“so that they can see how they can assist with services in terms of medications, so that they can normalise the issue of the behaviour of that person.”**

Whilst the group claim that they do not as consultants take decisions on behalf of disabled people, they nevertheless provide influential counselling. And the group gave an example on the issues of young girls and boys with mental disabilities who became sexually active. They would then advise the family the option of having the womb of the young girl removed. They validate this approach by clarifying that **“after the things have been taken out, we are protecting disabled persons rights, see?”**

They further indicated that they provide support to such families to assist disabled persons to evaluate their responsibility since disabled persons are the only people that can take responsibility for their own disabilities. Whilst the group conceded that they do agree to persons with disabilities being married. But, they are advising through counselling that certain provisions be made. Such provisions for marriage should include that person with disabilities must be able to take responsibility of and for their disability.

On the issue of parenthood, the group indicated that they advise through counselling that persons with disabilities who want to be parents should understand the responsibilities of being a parent and be able to provide for the family.

Collection and dissemination of information on living conditions of children with disabilities:

This groups indicated that the living conditions of disabled children are very poor. They attributed this to the following issues:

Service delivery:

Most of the services do not reach disabled people on farms and in rural communities, and as a result “children with disabilities are suffering.”

Lack of information:

The group indicated that parents of children born with disabilities and living within rural areas are often not educated. They also have very little access to information. Because of a lack of information on how to raise children with disabilities, the children are often discriminated against. More importantly, the children are often send to the traditional healers to right the disability “disabled child must follow the culture.”

Poor parenting

The group made strong allegations of poor parenting against parents of disabled children. The group believes that once the child’s disability has been identified, or is visible at birth, parents then hide their children. The children then would grow up in a very bad environment. They also alleged that parents do not believe that their disabled children are human beings “They just think for an example it is an animal.”

Lack of resources:

This group also pointed out that resources to assist the management of childhood disability are lacking more in rural communities than in the urban communities. Issues like assistive devices such as hearing aids, wheelchairs etc. the issue of inaccessible transport was also a major barrier in obtaining resources.

Negative attitudes:

The fact that parents in rural communities are not educated on raising children with disabilities, has also a profound impact on the parents’ confidence level. As such, the parents are unable to protect the child’s rights when the child experiences negative attitudes.

Lack of Education:

The group indicated that because of the disability experienced, many children with disabilities in rural communities do not go to school. They also believe that because children with disabilities are not aware of their rights to go to school, rights violations of such a manner occurs without any objection from the children.

Barriers encountered:

The group explained that the lack of transport for the rehabilitation workers impacted greatly on their service delivery potential, especially if their clients have emergency needs to attend hospitals, or in the event of abuse taking place.

The group indicated that parents of children with disabilities contribute to the abuse of their children. Often it was found that they are the first offenders in terms of abusing the care dependency grant of the child. Because of the poor socio-economic conditions the grant is used to sustain entire families at the expense of the disabled child.

Discrimination:

The group found that high levels of discrimination exist within the community. This is very visible when children with disabilities want to participate in sports. They felt that despite protective measures such as within the Bill of Rights, discrimination are still very rife in rural communities “people are saying, ha! You are disabled ” you can’t play soccer, or you are blind or deaf you can’t be involved. You cant be a referee issues like this. Ha, you are using a wheelchair but you want to play basketball.”

Opportunists:

One of their greatest concerns was the issue of abuse, violence and sexual abuse that children with disabilities are experiencing. Within the rural communities, opportunists take advantage of situations where parents leave their children to go to work. Knowing that a mentally disabled child is residing within that home, they would then enter and rape the child.

“It is like a disadvantage because they know that they won’t take the issue forward because the child is mentally retarded. “

HIV/AIDS

This group were also concerned about the need for protection against HIV infection of children with disabilities. However, they indicated that young disabled people are not getting information because they do not get the education. There is also the issue of negative attitude towards young disabled men and women from health services practitioners. Often when these young

people seek health services, such as prevention or pre-natal services the **“nurses they say, oh you are pregnant now, you were raped, and who raped you.”** And things like that. **“You have got Aids”** it is just like that.

Perspectives:

The group recommended that it would be a good idea that persons with disabilities can become HIV counsellors. In so doing, they would bring various perspectives and experiences forward. This is especially when **“maybe you say Dumisani is an Albino than he’ll advise you; hey this guy is using a wheelchair I trust him. Then maybe he can help me. I think it is important for government to help disabled people to have the skills about aids then maybe we as disabled people we trust each other and can help disabled people with HIV.”**

6. PROVIDING RECOMMENDATIONS, POSITIVE MESSAGES ABOUT DISABILITY, AND RAISING CONCERNS:

Service provision:

Within the Western Cape, the participants in the children's group were very concerned with the issue of services. Their main concerns were that they do not get "proper" wheelchairs. Not all the disabilities are the same and physical disabilities have specific needs and requirements where mobility was concerned. The specific request to Soul Buddyz was to bring across to service providers the need to provide the correct wheelchairs. They further elaborated that because of lack of appropriate wheelchairs, they cannot go out and socialize and make new friends.

The boy, who raised this issue, has a severe physical disability that affects his limbs. Known as Thalidomide. He has out grown his "baby Buggy " and is quite huge for his age. His mother is a single parent and they struggle to get support for a motorised wheelchair.

Education:

Some of the children indicated that there are not enough schools available or willing to teach children with intellectual disabilities, or slow learners. They requested that Soul Buddyz raise the awareness of such children's need to be educated.

The children also talked about the issue of preparation for employment. Most of the children felt that they have fewer opportunities because they are not prepared for employment. They requested that Soul Buddyz raised the awareness on the issue on the need for vocational training and preparation within the series.

Discrimination:

The children felt that their the loneliness that they experiences are because of prejudices that exists within the communities. They requested that Soul Buddyz highlight these issues and talk about the negative attitudes that they experiences within the community, ***"to prevent discrimination against us."***

Parents requested that Soul Buddyz make a concerted effort not to use derogatory names that will cause further discrimination of disabled persons: ***"they must make away with issues such as naming disabled people in a way that will feel much worse than they are already experiencing, such as calling names that are hurtful."***

Awareness

The children felt that there is a need to raise awareness about the issue of disability, so that able-bodied persons can become more are and ***"more tolerant of us as disabled people."***

Another child requested that Soul Buddyz ***"teach able-bodied children about children with disabilities, so that they can be aware about children with disabilities."***

One of the boys raised the issue of community participation and involvement through assistance of disabled persons, ***“on the road (in rural areas) able bodied people must assist disabled people and others who do not see the traffic so that they cannot get hurt.”*** And requested that Soul Buddyz raised awareness on this issue.

Parents requested that Soul Buddyz raise the awareness of other parents and parents of disabled children ***“that it is quite “normal” to have a disabled child. They need to talk about it.”***

Another parent added that it is important for disabled children to see on television that their parents love them: ***“even disabled children can be pleased if they see others loving their disabled children.”***

In addition to this, parents requested that awareness be raised on disabled people’s need to for ***“a sense of belonging and acceptance in society.”*** And to place: ***“emphasis on the achievements of disabled people through sport and more.”***

Inclusion:

The children requested that Soul Buddyz include different disabilities within the series and other disabled children as well. They felt that if this is done, then ***“children and people can learn from each other’s disabilities and should not laugh at each other.”***

One of the boys requested Soul Buddyz promotes the issue of inclusion: ***“we as disabled children we don’t ... able-bodied children must not ignore us, but they have to play with us, soccer, swimming, in everything we do they have to socialize with us.”***

One of the girls requested that Soul Buddyz also include Deaf children within the series, to bring across and raise awareness about their issues.

Some of the parents requested that Soul Buddyz include children with mental disabilities within their series, because ***“there is this stigma still attached to mental disability.”***

Concerns:

Parents also raised concerns on the issue of difference between disability and the need for Soul Buddyz to be aware of the differences, especially between mentally disabled and physically disabled children: ***“there is a difference and I think that they should recognize that and also find and not pull it all together because there is a difference between the two.”***

The same parent later explained: ***“when we talk about disability, we just lump all together and then the physically disabled tend to get more attention, if I can put it that way, and the mentally disabled actually get,***

still even in the way we try to integrate the disabled into society, the mentally disabled are often unlucky.”

The parents also raised their concerns on the lack of positive role models of persons with disabilities that their children can emulate and aspire towards. They also requested that there be role models that is representative of the various disability specific categories.

7. CONCLUSION

Children with disabilities, look towards their parents as their protectors and providers. One of the most invaluable lessons that came from this research experience was the fact that the fears that the parents have, are imposed upon their children. This fear governs how information is presented about children with disabilities to service providers and relevant people that play a role in the development of the child. This fear also governs how information is being provided to children with disabilities, which is of utmost importance for the developing sexuality of the child, and a healthy well-balanced sense of self.

Yet, our inter-actions with the children and our findings contradicted most the fears that the parents held for their children. Children with disabilities too have dreams and aspirations. But the realisation of these dreams and aspirations are thwarted from an early age, by the circumstances in which they find themselves. Their opportunities for socialisation and the development of their potential are to a great extent reliant on the conduciveness of their environment and their surroundings. And an unwelcoming environment does have a profound impact on disabled children’s sense of self and self-worth.

Children with disabilities need education to socialise, be informed and to develop their social skills. If they are skilled to access information, and if they are informed persons, they are able to better project their self-image, which is an essential component within developing sexualities.

We acknowledge the important role that parents play in the development of children with disabilities, and some of the well-grounded fears for their children with disabilities that they have. While parents have the power of decision-making, the children are the ones that experience disability, and are the recipients of the outcome of the parent’s decisions. But, given some of the experiences with parents that the rehabilitation consultants conveyed, how and when do we know that the parent makes decisions that are in the best interest of the child, if the child’s voice is silenced by the consultation process?

The information provided by the rehabilitation workers calls for measures that will not only inform and empower parents, but children with disabilities too. If the fears that parents have can be turned into positive attitude, then the children will develop a sense of belonging, and a confident sense of identity.

Within the Human Scale Development framework, Max-Neef argues that one of the ways in which to meet fundamental development needs is:

Through the way we feel or regard ourselves (BEING) e.g.: being healthy and feeling good about oneself can meet the need for identity, and help meet the need for affection or participation. (Max-Neef: 2001)

However, the experiences of exclusion; discrimination; the sense of being a burden unto the family; their helplessness that is being preyed upon and their bodies that are being violated; the rejection that they experience because of their difference; and the fact that they are made to feel inadequate because of their impairment; are all issues that prevent children with disabilities from meeting this most important need. For, these are the issues that undermine opportunities for social growth and development.

The resilience that the children display within such a negative and disempowering environment is commendable. However, much more than admiration is needed if we are to strive for the improvement of the status and quality of life of children with disabilities.

One of the most important helping mechanisms is to raise awareness on issues of disability. The media, with its strong influences and potential to reach and educate millions of people, is one of the most powerful tools that can bring about change and transformation to the lives of children with disabilities.

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