CINDI & SINANI STIGMA RESEARCH
SIMPLIFIED SUMMARY REPORT

1. INTRODUCTION

The research was commissioned by the CINDI Network through funding by Irish Aid. This research topic was identified by CINDI members in a workshop process. It was considered valuable for enhancing their future practice.

This research project looks at stigma towards children affected by HIV and AIDS. It tries to see:

- What are the different types of stigma that children are facing
- Why are people showing this stigma towards children
- What can be done to stop stigma towards children

2. LITERATURE REVIEW

This section summarises what other research projects have found about stigma.

What is stigma?

Stigma is any form of negative labelling or categorising of people. HIV and AIDS-related stigma is about prejudice and discrimination towards people who are thought to have HIV or AIDS. Stigma involves making judgements about a person because you think they are HIV positive or living with AIDS. This can be subtle (like passing comments about someone) or extreme (like rejecting someone). Stigma may be felt - for example if a person living with HIV or AIDS believes people have negative attitudes towards him or her. Or it may be enacted - like if a person makes a judgement about someone on the basis of having HIV or AIDS.

How do we see stigmatisation?

Stigma towards children affected by HIV and AIDS may be seen in:

- Social rejection or isolation (eg not letting other children play with a child, making bad comments about a child, making the child eat or sleep in a different place from the other children)
- Not giving children access to basic services and rights (eg not giving the child good treatment, neglecting a child in terms of food, clothing, education)

This may happen to children who are HIV positive or who have lost a parent to AIDS.

Children who have lost their parents (orphaned children) and who are affected by HIV and AIDS are said to have double stigma. Children living in poverty may also be stigmatised for being poor.

How are children affected by stigma?

Children who suffer from stigma:

- may be neglected and even have their basic rights not met

- may be excluded from social activities
- may not feel a sense of belonging
- may have low self esteem
- may not feel able to talk about other problems linked to HIV (like the grief of having lost a parent)

If there is a lot of stigma, people may hide their HIV status. This may mean that they do not get good treatment and support. Where there is a lot of stigma people may also be afraid to practice safe sex. This means that stigma affects both prevention of HIV transmission and support to people living with HIV and AIDS.

If there is a lot of stigma, parents who are dying of AIDS-related illnesses may not want to disclose (be open about) their HIV status. This may block plans for the child's future, like making arrangements for the child to live with someone else or handing over social grants and documents.

Why do people show stigma towards others?
Here are some of the reasons suggested about why people may behave negatively to children affected by HIV and AIDS:

- Fear based on wrong information about how HIV can be transmitted
- Moral judgements (believing that people who have HIV have behaved badly and therefore deserve the illness)
- Avoidance or denial, meaning that you believe HIV and so you treat others like they are a different type of person

Ideas about how to change stigma
Here are some ideas that people have suggested to try to stop stigma towards people affected by HIV and AIDS:

- Educate people to lower their fears of transmission through:
    - Media
    - home visits
    - community workshops
    - messages by traditional healers
    - messages in sports campaigns
    - school awareness campaigns
- Show positive role modelling about care of people affected by HIV and AIDS
- Challenge moral judgements about HIV
- Challenge gender-based judgements (about women and sex)
- Change stereotypes (the type of people we imagine to have HIV) by giving other examples of people who are HIV positive
- Find ways of discussing fears and stigma in non-threatening ways
- Start anti-bullying and anti-stigma campaigns in schools
- Help people who are HIV positive to see that their fears of stigma are higher than actual (enacted) stigma

It has also been recommended that we stop singling out children as “orphans” or children affected by HIV and AIDS. Programmes which build social integration, self esteem and a sense of fun amongst children are also recommended.

(References have been left out of this literature review to make it easier to read. Please see the full research report for detailed references)

3. METHODS OF THE RESEARCH

Participants (or sample)

The research was done in 3 communities:

- Rural (Richmond)
- Semi-rural (Sweetwaters)
- Urban (Edendale)

The specific areas in each of these communities is not mentioned, to protect the people who participated. This table shows who the participants where and the types of interviews done.

Participants	Communities	Groups & Interviews
Children (ages 8-14)	Richmond, Sweetwaters, Edendale	4 groups of 5/6 8 individual interviews
Caregivers of the children (grannies, mothers, aunts)	Richmond, Sweetwaters, Edendale	3 groups of 5/6 8 individual interviews
CBO members (mostly home based care volunteers and youth from HIV support groups)	Richmond, Sweetwaters, Edendale	2 groups of 3-4 8 individual interviews
Teachers	Richmond, Sweetwaters, Edendale	2 individual interviews
Leadership	Richmond, Sweetwaters, Edendale	4 individual interviews

Who did the research

The research was done by members from 3 community based organisations (CBOs) linked to CINDI and it was supervised by SINANI. It was done in isiZulu and then translated into English. People participated voluntarily, were told what the research would be used for, were paid for their time and signed forms to show that they were willing to be involved in the project.

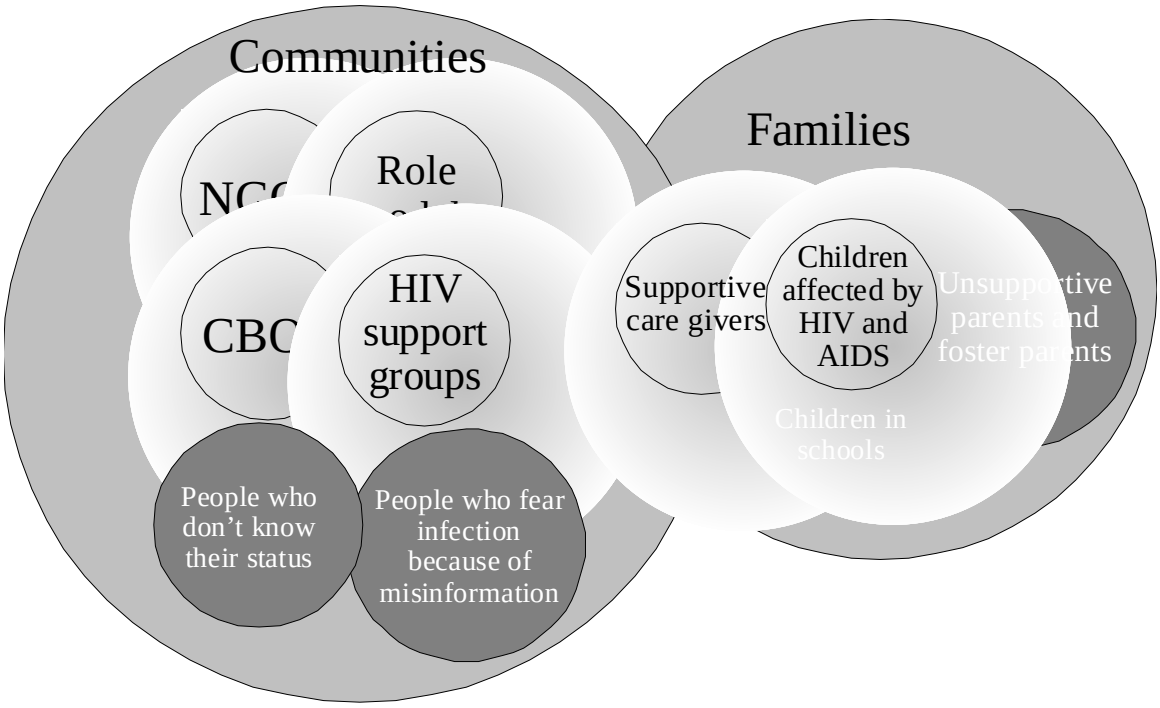
Understanding the findings (data analysis)

The form of research was asking people questions about what they believed and had experienced around stigma (phenomenological approach). The data was analysed by going through the data and finding common themes or codes. These codes were then grouped and linked together (simple form of grounded theory).

The researchers then tried to put all of these ideas together in a simple theory or model to explain what people were saying.

Challenges (limitations)
Most of the participants were linked to CBOs and HIV support groups. This means that they were already exposed to HIV work and so might have more positive attitudes towards people affected by HIV and AIDS. But it also means that they might have real experiences of stigma, especially since many of the participants (adults and children) were open about being HIV positive. The research was also based on believing what people were saying, and did not try to prove that what people were saying was true.

4. FINDINGS AND DISCUSSION
The researched showed pockets of support towards children affected by HIV and AIDS, and clear groups showing stigma towards these children. This is summarised in the diagram below.



Stigma towards children
It was found that children affected by HIV and AIDS are experiencing high levels of stigma, including teasing, name calling, negative comments, abuse and neglect. Stigma was directed at children who have lost their parents (where people presume the loss was due to AIDS) and children who are showing physical signs of illness or taking regular treatment. The most serious stigma was found in the rural area of Richmond. The most change in people's attitudes were

found in Edendale where people are showing more support to those affected by HIV and AIDS.

Who is Showing the Stigma
There were four groups were identified by participants as showing stigma towards children:

- Those who lack correct information about HIV
- Those who have not been tested and who may even themselves be HIV positive
- Some children in schools
- Family members (especially foster parents)

Possible Causes of Stigma
It was found that the causes of stigma may be related to:

- Fears about transmission (based on incorrect information)
- Fears about one's own HIV status
- Children adopting the attitudes of parents and educators
- Unresolved family conflicts being taken out on the child

Support Towards Children
There were also pockets of strong support towards children affected by HIV and AIDS. These included particular caring family members (both male and female), educators, CBOs, NGOs and HIV positive support groups. The support included emotional and social support, assistance with treatment and material support (food, clothing etc).

Reasons for Support
It was said that the most support is shown by people who have been personally affected by HIV and AIDS. For example, if they are HIV positive and have accepted their status, or if they have a child who is HIV positive. The others showing support are those who believe that "this illness can visit my home too."

5. SUGGESTIONS ON HOW TO CHANGE STIGMA
To change stigma it was suggested that we:

- grow the pockets of support
- address the deeper fears and other needs of people showing stigma

Growing pockets of support
Children and families affected by HIV and AIDS may be empowered to withstand stigma by giving them specific messages. It was also found that wherever children were able to talk about their illness (and the stigma they experienced) with a trusted caregiver, they were better able to ignore or challenge stigma. It was suggested that caregivers may be trained to talk to their children about such issues.

Support projects for children should not isolate children affected by HIV and AIDS. They should be more general and may help children with different types of problems. This may help to bring more people into the pockets of support and to reduce the stigma associated with such support.

Addressing fears and needs

People said that we should make specific messages about wrong information about transmission. We should target people who are showing the worst stigma, not just the usual people who come to community meetings and workshops. People's fears about their own status may also be addressed by giving messages of hope. This can be done by explaining that there is treatment available and that one may live a long healthy life with HIV.

Treating the illness like a normal illness should be balanced with giving specialised support (for example in Richmond people say there are not specialised doctors and facilities for people who are sick).

Schools should have policies about how to help all injured children, not treating those who they think have HIV differently. Educators should role model support to children who are sick.

Families showing serious stigma and even abuse may be identified by home based care workers and CBOs. Relationships might be built with them to understand the deeper reasons behind their bad treatment of children. The children may be helped to find someone who does give them support. Specialised support might be given by social workers and CINDI members (eg trauma counselling, grief counselling).

6. THE RESEARCH PROCESS

Working with CBOs was a good way of getting honest information. This was because the CBOs already knew the children and adults they were interviewing. It meant that they could give follow up support where needed.

It is suggested that the CINDI clusters look at the suggestions coming out of the research. They could encourage members to take on the ideas that link with their work.

7. CONCLUSION

The research results tied in well with the literature on stigma towards children affected by HIV and AIDS. It also gave some very specific ideas on how to change stigma. Sinani is grateful for having been involved in this project. We thank the CINDI Network, the CBO partners and the members for supporting this project.

There is a more detailed report on the project if people would like to read more.

CINDI & SINANI STIGMA RESEARCH
DISCUSSION WITH MEMBERS

The discussion group explore priority focus points for future intervention:

Rural areas:
The fact that stigma is higher in the rural area of the study may be due to many factors, for example:

- there have been less awareness workshops in rural areas
- lack of economic opportunities in rural areas means that people move to cities for work. When they come back sick there may already be broken relationships with families left behind.

The group felt there was a need to focus more on development and education in rural areas.

Education / Awareness Raising
The usual mass meetings are not so effective and are usually attended by the same people. But there is a need to inform people accurately about transmission. Some suggestions were made about awareness raising / education around HIV transmission:

- We should explain the difference between TB transmission and HIV transmission because people are confusing the information they get from the doctors.
- Spread the message that there is Life with HIV!
- Use interesting topics that people want to talk about
- Respect and work with cultural traditions that encourage openness

Encouraging Testing
Here are some suggestions about encouraging people to go for VCT:

- It must be voluntary not forced
- There must be good information so that the person is ready
- There must be someone to support the person before, during and after the testing
- If you see someone is sick, don't assume its HIV, but encourage the person to get a medical assessment and treatment

Work with Men
Men were identified as priority partners in the fight against HIV. Some suggestions were made:

- Change the socialisation of men around health matters
- Make it clear that HIV is a male and female thing – it affects both
- Change the socialisation of men around talking about issues and discussing feelings (communication)
- Encourage men who are HIV positive to become a hero against HIV

Balancing Support and Avoiding Stigmatising People

The difficulty of giving the most affected people support without stigmatising them was debated. Some ideas were presented:

- Find ways of bringing support (like vegetables) to people that does not label them (eg unmarked cars)
- You might use a central home of a recognised and respected person, like of an Induna or church leader to offer support
- Give different types of support so that it is not just linked to HIV – eg vegetable gardening support to all who are interested in starting gardens
- Ask people what works for them – for example some people don't mind sending children to fetch food parcels
- Have general policies that focus on hygiene at home and at school (eg using gloves in all situations. Promote normal hygiene.
- Focus on family support because this is the most important thing for people
- Start more support groups so that people even have choices about which group they want to attend