



STUDY INTO SUCCESSION PLANNING AND IDENTIFICATION AND PREPARATION OF STAND-BY GUARDIANS BY PARENTS OF CHILDREN WITH DISABILITIES

ROKPA Support Network
34 Quendon Road
Monavale
Harare
Tel: 04/304 202
Email:ROKPA@zol.co.zw

STRIVE Project
CRS ZIMBABWE

June 2007

Acknowledgments

The study was conceived and funded by STRIVE Zimbabwe, and carried out by a research team from the ROKPA Support Network, consisting of:

- ❖ Winnie Mtapure
- ❖ Melusi Nkomo
- ❖ Alison Nyoni
- ❖ Debra Chimuka
- ❖ Mia Goos (Co-director)
- ❖ Jane Nineham (Co-director, writer)

Special thanks also go to the following people:

Agnes Mupangami, who facilitated the research in Mhondoro, hosted our team there and set up the Talk Time with such alacrity; **Sister Igna Powell**, for support in Mhondoro – and for long-term and unstinting support to so many vulnerable families; **Michael Triest**, for technical help with the creation of the questionnaire and compilation of the answers; **Beauty Gova**, **Keresencia Mangoya**, and **Joyce Mutunda**, who took part in the case-study roleplays to train the research team; and other ROKPA staff who held the fort for colleagues on the STRIVE study team.

We are especially grateful to the mothers and grandmothers and other caregivers who so willingly took part and shared their challenges and hopes and dreams, and to the children whose lives and struggles are what this research was all about. We hope that this small study will be complemented by their own views and voices, and will lead to action on their behalf and with their participation.

CONTENTS

- 1.0 Executive Summary
- 2.0 Introduction: Children with disabilities in Zimbabwe
 - 2.1 The scope of the study
 - 2.2 The ROKPA background
- 3.0 Aims and Objectives
- 4.0 The study process
 - 4.1 The respondents: a profile
 - 4.2 Limitations of the study
- 5.0 Findings: The Children
 - 5.1 Birth Certificates
 - 5.2 Education and training
 - 5.3 Orphans with disability
 - 5.4 Cases of abuse
- 6.0 Findings: The Parents and Caregivers
 - 6.1 Succession Planning
 - 6.2 Sources of support
 - 6.3 What mothers (and grandmothers) want - and what they need to plan
 - 6.4 How mothers can plan
 - 6.4 Findings on HIV Awareness: Statistics and Attitudes
- 7.0 Case Studies: an Introduction
 - 7.1 Case Studies: Urban
 - 7.2 Case Studies: Rural
- 8.0 Conclusions and Recommendations
 - 8.1 Revisiting the objectives
 - 8.2 Recommendations
 - 8.3 The Way Forward

APPENDICES

- APPENDIX 1: Questionnaire in English
- APPENDIX 2: Questionnaire in Shona
- APPENDIX 3: Questionnaire answers on succession planning
- APPENDIX 4: Questionnaire answers on orphans with disabilities
- APPENDIX 5: Questionnaire answers on abuse of disabled children
- APPENDIX 6: Questionnaire answers on parents' HIV testing
- APPENDIX 7: Kubatana listing of orphan- and child-focused organisations
- APPENDIX 8: Kubatana listing of disability organisations

LIST OF ACRONYMS

RSN	Rokpa Support Network
CRU	Central Rehabilitation Unit, Harare Hospital
CRS	Catholic Relief Services
ZPCDA	Zimbabwe Parents of children with Disabilities Association (formerly ZPHCA)
PDC	Parents of Disabled Children
PLWH	People living with HIV
STRIVE	
ARV	Anti-retrovirals
FGD	Focus group discussion
NPA	National Plan of Action
OVC	Orphans and Vulnerable Children

NOTE: ROKPA is not an acronym; it is a Tibetan word meaning **to help** or **to serve**.

1.0 EXECUTIVE SUMMARY

Succession planning is a process in which parents take action to ensure a better future for their dependent children in the event of their illness and death. It particularly involves identifying the most suitable and willing people to be standby guardians, discussing this with them and legalising their appointment. This preparedness is especially important in the context of HIV and AIDS in Zimbabwe, and doubly so for children with disabilities who have special and often long-term care needs.

The aim of this small study was to assess the current state of succession planning in four communities (3 in Harare, one in rural Mhondoro) by parents of children with disabilities, and identify areas and strategies of support which can strengthen this and make it more sustainable. The study's objectives were framed in a number of questions focusing primarily on succession planning initiatives by parents, families, community bodies, and NGOs, but also on birth registration of children with disabilities, levels of school attendance and the impact of the AIDS pandemic on their care. The study was also intended to point the way forward to creating a package of support which will ensure proper and sustainable care and education for children with disabilities in the event of a parent's death or chronic illness.

The study was carried out between March and May 2007 by ROKPA Support Network (RSN), a faith-based organisation which focuses on providing assistance to children with disabilities in Harare and Chitungwiza, and to their families, as well as to other vulnerable groups. The study was requested and funded by the STRIVE Project of Catholic Relief Services/Zimbabwe, who are seeking to mobilise the NGO community to more effectively assist children with disabilities, and especially disabled orphans, who are among the most vulnerable, disadvantaged and neglected populations in the community.

In the three urban areas selected, a total of 58 mothers and grandmothers took part in the study, completing a questionnaire, participating in focus group discussions and responding to feedback about the general result. Six of these urban families also agreed to be the subject of detailed case studies, as did five families in Mhondoro, where there were logistical challenges in using the other research tools. The use of so small a sample obviously means that the study makes no claims to be comprehensive, especially not of the rural situation. Moreover, the fact that the urban respondents were all members of self-help support groups for mothers and grandmothers of children with disabilities meant that they were more likely to have benefited from support and awareness-building programmes than those outside such groups.

The central finding of the study is that although 83% of caregiving mothers and grandmothers could, when asked, name someone they might wish to be a stand-by guardian of the child in the event of their serious illness or death, most of these being family members, **no-one** had done any solid succession planning or made any legal or traditional preparation for the appointment of stand-by guardians. Only one primary caregiver had discussed the matter with the person involved, less than half (all female, almost all mothers and grandmothers) felt they would even be able to discuss the issue with their partners, and there was no legal knowledge of how to make wills and protect inheritances, though this knowledge was seen as desirable.

At support group level, the issue of planning for the children's future had sometimes been raised; nothing had actually been done by any of the groups, but this may be an entry point for initiatives where such groups exist. There was also no evidence of community, NGO or local-authority initiatives around succession planning; though these may exist but not have been publicised.

Other findings were that 78% of children with disabilities covered in the urban areas of the study have had their births registered, but that only 40 % of children with disabilities in urban areas covered in the study are currently going to school: of three school-age children in the

Mhondoro case studies, none is currently going to school. Stigma against children with disabilities is widespread though by no means universal, and half the reports of orphaned children with disabilities recounted instances of neglect, abandonment, stealing of inheritance, physical and sexual abuse and extreme material deprivation. Even those fortunate enough to be taken in by grandmothers or other relatives suffered materially.

Deaths from AIDS have created a rising number of orphans, with and without disabilities, many mothers gave evidence of the stress it causes to those who fear themselves at risk but also fear being tested and more than half felt that a positive result was like a death sentence. Interestingly, however, we found no evidence that it was motivating parents to make more sustainable and effective plans for their children's future, and two mothers stated clearly that learning their status in no way affected their plans for their children's future. What was evident was that programmes encouraging mothers to go for testing had had some effect – and some who had tested did so because they wanted to prolong their own lives and look after their children better. This may serve as a point of intervention in the future.

Overall, parents greatly appreciated the fact that the study had highlighted the issue of planning for their children's future, and were well able to suggest strategies which would enable them to put better succession planning in place and to provide effective and sustainable care and support for their children with disabilities, both now and in the future.

Their suggestions make up the key recommendations of the study, given below, and show clearly that working to make succession planning effective and sustainable means looking at the wider situation of the children and families involved, and addressing all of these issues involved.

- Material assistance: food, clothing, medication and other medical care – parents often know what is needed but are unable to afford it.
- Training for caregivers and relatives and siblings – in planning for the future, life skills and how to care for their disabled child, HIV counselling and training. Special effort needed to target men.
- Training and education for the children – life skills, vocational and 'normal' education – and all the assistance needed surrounding this - for special and also 'normal' schools.
- Starting projects which can be joined by family members, especially the stand-by guardian, either now or on the mother's death, so that the benefits will still go to the child – a key request.
- Secure and decent accommodation while the parents are still alive, that the child can stay in when the parents die.
- Someone to take care of the child in the future –relatives, organisation, government, 'even' homes. While grandparents are the key choice they or other relatives vitally need material assistance.
- More networking through support groups - a huge source of strength – many mothers feel that other mothers with disabled children will know best how to look after their own children. Families to be involved in these too, and other community groups.

- Health care for their children **and for themselves**. (Note: Rehabilitation units and services especially need strengthening.) HIV information and treatment are not specifically mentioned – though this appears to be a key area of health care)
- Campaigns to fight stigma in the community.
- Building a home and/or centre in their area where fellow mothers can take care of orphaned children – also a relief and respite centre, where parents can sometimes leave the child and do other social or economic activity and be supported by other mothers. *If this exists, even when parents die, the child can carry on meeting with others and receiving the same benefits as before. Children can be taught at this centre.* (It is not clear whether this would also work in rural areas, and organisations establishing these centres may need support and capacity-building)
- Teaching life-skills and income-generating skills to other children in the family so that they will have something to sustain themselves and the disabled child
- Writing wills and including a person who loves the child - other legal information and assistance too, especially about guardians, birth certificates and making sure the child gets the inheritance parents leave.
- Involving men and other relatives in sensitisation and other activities : a variety of strategies was suggested for this.
- Opening a savings account for the child.
- Avoid sending urban children to rural areas when parents die.

A prioritising activity at feedback meetings gave the top ranking to the issues below, in order – indicating that immediate material needs are of great concern, but discussions also made clear that lower-ranked support needs are also important.

- Food and clothing for children
- A centre for orphans and respite care
- Money to support grandparents and other relatives
- Teaching families and communities about disability
- Legal advice on birth certificates, wills and inheritance
- Training in caring for mothers and relatives

The package of support detailed is somewhat daunting, and it would be premature to map out a holistic strategy without investigation and consultation with major governmental and non-governmental players and without some participation of the children themselves. What is clear, however, is the urgent need for attention to the whole situation of children with disabilities, and their families, and especially to those already orphaned.

One possible way forward would be to set up an interim Task Force to look at the findings of this study, widen the scope of the investigation, collaborate with ministries and major organisations to plot the next steps and create an interim action plan. The work of this Task Force could include mapping out the scale of the problem, as there are no consistent figures of children with disabilities or orphaned children with disabilities. It would also be useful to create a district-level map or directory of organisations already involved with children with disabilities, what each is doing and where. This could be set against the package of support needed, so that there would be a clearer picture of where existing initiatives can be strengthened, where gaps need to be filled and where new initiatives need to be established.

Tasks could then be prioritised and assigned. A wider consultative workshop could be held at some point to establish working teams for specific areas of action and to consolidate the central task force to unify the programme.

At the same time, existing materials could be combined and adapted to produce a community-friendly training package for children with disabilities and their families – on succession planning, guardians, birth certificates, wills and inheritance – and link this to HIV risk reduction and testing- promotion programmes (but first review what is already in existence, possibly in collaboration with NASCOH, Progressio and the organisations using findings of its report on HIV and people with disabilities. Note that much material is also available through the \Legal Resources Foundation, SAfAIDS, SAT etc

Consult on possible rollout strategies for this and other campaigns.

Hold Consider as models past campaigns concerning child sexual abuse, HIV testing promotion, anti-stigma HIV campaigns – and the use of the media to bring selected issues to national attention.

2

In addition, the resilience and determination shown by their mothers and grandmothers in giving the children as fulfilled a life as possible despite the dearth of services and support systems cannot be stressed enough, and forms a solid base for any initiative to build on.

In conclusion, let us hope that this small study will spur readers into further research and networking – and most of all, into action - to build on and support the enormous resilience, creativity and hope of the mothers and grandmothers of children with disabilities, and to take steps to fulfil the untapped potential of the thousands of children who have been so sidelined for so long.

2.0 INTRODUCTION: CHILDREN WITH DISABILITY IN ZIMBABWE

There are no up-to-date and consistent figures of the number of disabled children (or adults) in Zimbabwe. The 2002 Census notes 348,861 disabled people, of whom 31% are under 15; 19% live in urban areas, 81% in rural. A ZPDCA estimate in 2004 is much higher but very vague, putting the figure for disabled adults and children somewhere between one and three million. Ministry of Education figures only apply to children enrolled in schools, while the majority of disabled children are kept at home. Some figures are available from Rehabilitation Units of government hospitals, especially the CRU of the Harare Children's Hospital; these do provide a breakdown on age, gender and type of disability, but are far from comprehensive.

What is well-known, however, is that families with children with disabilities are frequently among the most marginalized and economically vulnerable in Zimbabwe, and that services for the disabled, social networks and special education, transport and health care facilities are extremely limited; where they exist, they are heavily overburdened. There are insufficient places in 'special' schools, and fees and transport costs put them beyond the reach of most families. Integration into 'normal' schools is hampered by lack of facilities, of staff trained in special needs, and by the attitude of overburdened school heads. This creates a vicious circle, as carers (usually mothers) have to look after the child and cannot work, and their financial problems are exacerbated by additional expenses for the child's special needs. Especially in rural areas, lack of money is a constant explanation for parents' inability to access medical treatment and assistive devices and appropriate education for their children, or even to get information about the options available.

Agencies working with disabled people state that there is a good deal of stigma and discrimination against families with a disabled child. This causes a number of problems; one that particularly affects urban families without their own accommodation is the difficulty of finding somewhere to rent. Because of this stigma, the child may be hidden away, increasing challenges to their development and limiting the contact and stimulation needed for healthy development.

While agencies and rehabilitation units are making an effort, there is little education available for carers on their children's special needs and what they can do to help in home and community. Once flourishing Rehabilitation Units in most provincial hospitals have virtually closed down because of lack of funds; in any case, transport costs have become prohibitive.

Poverty exacerbates mothers' vulnerability to HIV infection; lack of time limits access to prevention and treatment information. Disabled children also form one of the most at-risk populations for HIV. Myths about disability, sexuality and HIV 'cures' add to the vulnerability that goes with a number of disabilities, and little information about HIV risk reduction has been made accessible for different-ability children (or adults), though some efforts are being made in this direction.

A mass of anecdotal evidence suggests that the death or serious illness of one or both parents causes extreme suffering to disabled child; neglect, abuse, abandonment and early death are not uncommon. Like other orphans, even when there is someone to care for them – often a grandmother – there is significant deterioration in their material and emotional condition. For orphans with disabilities, this deterioration is often extreme.

There are, however, some positive developments concerning children with disabilities: the formation of many self-help groups in recent years, the establishment of the NPA programme for OVCs, and a growing (if still inadequate) awareness of the need of children and their families.

2.1 THE SCOPE OF THE STUDY

The study was done in three urban and one rural district of Zimbabwe. The urban investigations, all in Harare's high-density suburbs, were done with established groups of parents of disabled children with whom ROKPA already has a strong connection. The rural investigation was carried out in Mhondoro, a rural area where there is no formal group of parents of disabled children, but where ROKPA has connections through the Dominican Sisters and one of our beneficiaries who moved there to care for a group of orphans.

2.2 THE ROKPA BACKGROUND

ROKPA Support Network (RSN) is the humanitarian wing of the faith-based ROKPA Buddhist Centre, which was established in 1992 and is registered as ROKPA Trust of Zimbabwe; its motto is 'Helping where help is needed'. The RSN has grown organically from a volunteer project to a registered organisation with nine full-time staff, as well as a number of volunteers and part-time workers, mostly selected from the people we assist. The RSN is affiliated to ROKPA International, which has 18 branches - in Tibet, Nepal and southern Africa, as well as throughout Europe and North America.

Since the RSN's inception in 2000, one of its key target groups has been the self-help groups of mothers of children with disability established by the Zimbabwe Parents of Children with Disability Association (ZPCDA). There are 18 groups in Harare and Chitungwiza, with at least 630 member parents. The support offered includes training and follow-up in food security (low-input and herbal gardening) and income-generating projects, as well as food and medicine assistance, counselling, child massage and reflexology, and programmes in HIV prevention, positive living, and relaxation and stress-management therapies.

ROKPA offers similar holistic assistance to the chronically ill, orphans and vulnerable children (OVC) and their caregivers, PLWH and homeless, destitute and other vulnerable people. It also provides a Drop-in and Referral Centre and has a strong network of organisational linkages within Zimbabwe. In 2007 it has also begun programmes, specifically for children with disability, in two rural wards as part of the National Plan of Action (NPA) for OVCs.

In January 2007 ROKPA held a meeting with representatives of parents of children with disabilities, to investigate the level of HIV awareness, action and skills among the PDC groups, with a view to developing a suitable HIV/ AIDS awareness programme to complement what already existed. Among the key issues discussed was: *What happens to disabled children when their parents die?* The mothers' response was unequivocal: Most children go into the custody of relatives, where few are cared for adequately and most live in very difficult situations, often dying not long after their parent.

The representatives also reported that most parents in their groups are unwilling to go for HIV testing, for a number of reasons:

- ❖ Many are in denial and unable to accept that they could be infected
- ❖ There is a widespread belief that the main results of an HIV-positive test are stigma, rejection and an early death
- ❖ Most mothers of disabled children concentrate on caring for their handicapped children and have no time or energy to deal with HIV and AIDS issues.

Few mothers, they said, had been moved to action by the widespread media and public health campaigns on HIV and AIDS issues, and encouragement by Harare Hospital representatives for the mothers to go for testing had had no effect. However, when members of some groups had started doing the CDC Talk Time programme through ROKPA and had introduced it to

their colleagues in the self-help groups, mothers did accept the programme and some had gone for testing as a result.

STRIVE's growing awareness of the neglected plight of children with disability in OVC programmes led to their request for a small pilot study, specifically on succession planning but potentially with wider implications, which linked in with ROKPA's desire to make its existing programmes more relevant to mothers and other relatives of children with disabilities.

3.0 AIMS AND OBJECTIVES

The overall aim of the study was to investigate the current state of succession planning by parents of children with disabilities, and identify areas and strategies of support which can strengthen this and make it more sustainable.

The objectives were framed as questions to be answered, namely:

- What percentage of children with disabilities covered in the study have had their births registered?
- What percentage of children with disabilities covered in the study are currently going to school?
- What succession planning currently exists by parents of children with disabilities?
- Are parents identifying or hoping to identify stand-by guardians?
- How effective and sustainable are these planning strategies, and where do they need support?
- Are there any family or community-based group initiatives already in place to provide care and support for orphaned children with disabilities?
- Are there any family or community-based initiatives being developed to provide care and support for orphaned children with disabilities?
- What support is required to strengthen these initiatives so that they become sustainable?
- Are there any NGO or other initiatives already in place to provide care and support for orphaned children with disabilities?
- Are there any NGO or other initiatives being developed to provide care and support for orphaned children with disabilities?
- What support is required to strengthen these initiatives so that they become sustainable?
- How has the AIDS pandemic impacted on the care of children with disabilities?
- What package of support is required to ensure proper and sustainable care and education for children with disabilities in the event of a parent's death or chronic illness?

4.0 THE STUDY PROCESS

Four investigative tools were used with the urban groups in the study: questionnaires, focus group discussions, case studies and feedback meetings. All research, except for the individual case studies, was carried out at the places and on the days where the PCD groups from each area meet.

Questionnaires: These were completed in small groups with a research worker available to clarify where necessary. English and Shona versions of the questionnaires can be seen in Appendix 1 and 2. The key areas covered in the questionnaire were: the personal details of the respondent, the social and economic profile of the household, a profile of the child with disability, the state of planning for the child's future and identification of stand-by guardians, and the parent's awareness of HIV and attitudes to testing.

Focus group discussions: These explored in more detail the sources of support for mothers and grandmothers, and any education and training the children had experienced and found beneficial. Groups also discussed the current state of their succession planning and identification of stand-by guardians, made suggestions for how to make this more effective and sustainable, and outlined the support they needed to put these suggestions into action. Some also looked at how to encourage the involvement of men in the care of children with disabilities, and the comparative advantages of 'special' schools versus integration into 'regular' schools for children with disabilities.

Case studies: Caregivers and/or their spouses gave detailed profiles of the family's circumstances, the child's condition, educational and medical history, community and family response, the parents' attitudes to HIV and testing, and any plans for the child's future. Two studies were done in each of the urban areas covered, totalling six; five were done in Mhondoro.

Feedback meetings: These were done after compiling the results of the questionnaire and FGDs, and presented the findings in the form of: problems identified, strengths to build on, and the state of succession planning. They focussed primarily, however, on presenting the combined package of support suggested by the three groups, and carried out a participatory activity in which mothers prioritised the long list of recommendations and discussed its results.

RURAL AREA, MHONDORO: The procedure here was different because of research logistics, especially because there was no group in the area through whom we could work and long distances between homesteads make it difficult for people to meet. However, a volunteer in the area, who looks after a number of orphans, contacted families with a disabled child and had gained permission for a visiting team to do four case studies.

In the event, word had spread that there was a project targeting families with children with disabilities, and a total of 15 families came to meet the research team and see if any assistance was being offered – an interesting event in itself, as it shows both the level of need for support, and the commitment of the parents to improving the lot of their children.

Some of the parents have since formed a group and started Talk Time, an HIV prevention and risk reduction programme. They had held three meetings by mid- July 2007, and are asking for ROKPA's assistance with the programme, as well as with other types of help for both children and the families. ROKPA is currently in the process of establishing a small NASCOH/UNICEF-funded project in the ward, which is likely to focus on funding formal education for a number of children, and informal education to their families.

4.1 THE RESPONDENTS : A PROFILE

The figures below were compiled from the personal details section of the questionnaires. Percentages have been rounded off to the nearest whole figure.

58 people answered the questionnaire; all were women caregivers living in Hatcliff, Mabvuku or Epworth. 51 were mothers of the disabled child; 7 were grandmothers. All are members of active ZPCDA groups, who meet regularly and have contact with various organisations through their groups. Three of the respondents were mothers whose children had died while still with them: in all these cases, the mothers remain members of the support group.

The Mabvuku group is well-established, having started in 1986, and has their own small two-roomed house and covered outside verandah, given by a private donor. They organise respite care for members four days a week. The group in Hatcliff, founded in 2001, lost their centre in the removal of informal buildings in 2005 but meet once a week in a pole and pTendaic shelter loaned them by an aunt of one of the members. Some of the group moved away after the destruction of their dwellings in 2005, but the group seeks others to join them and even welcomes parents of 'normal' children. Epworth, the third study area, has a very disadvantaged and shifting population, but the group, founded in 1996, has a spacious purpose-built centre funded by Plan International.

69% of the respondents (from the three groups together) are living with a husband or partner; 7% are single, and 22% divorced.

The women have between 3 and 8 children of their own, and most of them care for two other children as well.

98 percent are Zimbabwean citizens, (81% Shona, 4 % Ndebele), though 15% described themselves as neither Shona, Ndebele or Tonga.

Exactly half own their accommodation; the other half are renting. Most have one or two rooms; the largest house size mentioned was 5 rooms. 69% have a vegetable garden.

Only 10 per cent have an income through a husband with a job (though this may not be adequate to survive on). Two –thirds describe themselves or their partner as self-employed (usually meaning informal employment), and 22 per cent describe themselves as having no source of income at all.

The women belong to the following religious groups, in order: Vapostori 40 %; Catholic 31%; Methodist 14%; Other 14 %. Nobody described themselves as 'traditionalist'.

4.2 LIMITATIONS OF THE STUDY

Although the study gives an indication of certain key facts and ways to go forward, it makes no claims to be definitive or fully representative of the situation in Zimbabwe, for a number of reasons:

- ❖ The study was carried out with a very small sample of mothers and grandmothers of children with disabilities, and the research was done only in three urban districts (all in Harare) and one rural ward of Mhondoro. In the latter, for logistical reasons, it was possible to do only informal discussion and case studies, making it especially limited in its picture of the situation in rural areas – though by no means irrelevant.
- ❖ In addition, in looking at parents' plans for the future of their children, no attempt was made to distinguish between the many different types of disability, and the

- ❖ Similarly, children were not divided by gender or by their place in the family (as first or Tendai-born, etc).
- ❖ All the urban respondents are members of support groups set up by ZPCDA; they meet regularly and are assisted by other organisations, which makes them unrepresentative of those outside support groups and less likely to be targeted by various support programmes.
- ❖ Because the topic was succession planning by caregivers, research was done with the mothers and grandmothers and not with the children themselves. Further research **must** also access the views and wishes of children and youth themselves about their future.

5.0 FINDINGS: THE CHILDREN

The children of the respondents vary in age from very young to over 20, reminding us that when talking about children with disabilities it is important to ask caregivers and the children themselves where they would draw the lines for 'child' and 'youth'. The average age was just under ten years.

The children have a range of disabilities, and these are often multiple; some parents can name the disability, others not. Of the 58 urban children:

- ❖ 50% cannot walk.
- ❖ 47 % cannot speak.
- ❖ 7% of the children are blind or visually impaired..
- ❖ 13 % are deaf or hearing impaired.
- ❖ 50% cannot use the toilet, even with help.
- ❖ 42% cannot eat without help.

5.1 BIRTH CERTIFICATES

Of the urban children, 78 per cent have a birth certificate; 22 percent do not.

The reasons given for not getting birth certificates vary: the mother or father not having an ID; the mother not having citizenship; the mother dying and the death certificate not being available; the parents being divorced; not knowing where the father is; disputes between parents or – in the case of one orphaned child – between two sides of the family. One woman states simply: *I do not have money for bus fare and I do not know what to do*. Full responses can be seen in Appendix 3.

In fact, all of these challenges could be overcome, if information and support were available.

5.2 EDUCATION AND TRAINING

In the urban areas, only 40 per cent of the children are currently going to school – but all the mothers want some education for their children.

Of the three out of five school-age rural children in the case studies, none are currently in school. Two had started in local schools but been unable to continue because of disability (and one 'beat up other kids'). One girl who is blind had done very well at pre-school, and the community recognises that she is clever, but the family had no money for her to continue at a special school despite wanting this badly. Two of the five children were below school age; one mother planned to send her deaf and dumb son to the local school, but seemed unaware of any challenges he might face.

In focus group discussions, most mothers had mixed feelings about whether or not children with disabilities should be integrated into regular schools or be educated in special schools. Some felt that the children will learn faster and better in regular schools, and – a major advantage - the teachers and other children will also learn to accept these children in their societies faster, and learn to love them from the beginning. Others noted that integration is good, but felt that it depends on the disability of the child.

There were strong arguments against integration as well, some feeling that children will learn faster and better in special schools, because of their small intake and small classes. One mother argued that the special schools teach children much more than the special classes in

normal schools, so it is better for children to learn to stay in special schools until they are mature. Thereafter they will cope better in mixed schools.

Key questions, of course, are the conditions of the regular schools in general, and the way in which integration is carried out.

Case studies also revealed that, whether children are in school or not, family members teach children with disabilities informally – lifeskills and counting, sports and games, even lip-reading. This is equally true in urban and rural areas. Some parents try and teach livelihood skills but capital is often a problem.

A number of organisations, and especially the Harare Hospital CRU, have helped with various kinds of training, and these have been much appreciated. However, these services are erratic and have been adversely affected by the economic challenges and lack of fuel in recent years. St Giles and Jairos Jiri were mentioned by all the groups; people also knew of Manzinde School in Mutare and Naran school for the Handicapped in Gweru. Skills taught include toilet training, teaching children to cook, take tablets on their own, computer literacy, walking, standing on their own, reading and good socialising skills – all these give the children some independence, but fees and transport costs limit the people who can access them.

In one discussion, mothers mentioned that leaving children at the relief care centre, which they organise and take turns to staff, has made them more responsive and has improved their social skills so that they can get on better with their other children. However, mothers expressed a wish for much more comprehensive and ongoing education – both formal and informal – to fulfil the untapped potential of children with disabilities and allow them to make a better life.

5.3 ORPHANS WITH DISABILITIES

22 of the 58 of all mothers participating answered positively that they knew about disabled children whose parents had died or about children abandoned/rejected by the parents. 11 of these gave a negative picture – and several were talking about more than one child.

Of the 22 cases known, three reported children being looked after by grandmothers, one by other relatives, but noted that this was usually with great financial difficulty. In addition (and not included in the 22 answers) seven of the respondents were themselves grandmothers looking after grandchildren with disabilities.

Caring institutions were involved in only two cases: Jairos Jiri took in one girl, and the Red Cross built a two-roomed house for another and her siblings; one child was sent to a home.

11 examples were given of abandonment or abuse: disabled orphaned children are left alone to look after themselves, they risk rape and other abuse, their property taken by relatives, Some were sent to the rural area, where they are reportedly likely to be abused and mistreated by relatives; and often die soon after the parents.

A selection of quotes gives a stark picture:

- ❖ *The child could not get any relatives to help so the child is staying alone and looking after himself.*
- ❖ *I know a boy who lives in Shamva (Musana area). His mother and father died five years ago. Now he does not go to school, he does all household chores. His father's wealth was taken away by his father's brother and relatives.*
- ❖ *Some passed away and some run away from home.*

- ❖ *The parents passed away and are now subject to sexual abuse because they do not have anyone looking after them*
- ❖ *The father rejected him because of disability.*
- ❖ *The child was left alone.*

5.4 CASES OF ABUSE

Respondents were asked in the questionnaire if they were aware of any abuse their child had suffered. There was some misunderstanding of the term 'abuse': although sexual abuse was specified, people also noted physical and emotional abuse.

16 of the 58 caregivers noted that their children had been abused in some way – sexually or physically abused, attacked, teased, stigmatised or left without food. Figures may well be higher than reported.

Three cases of sexual abuse were mentioned and one gang rape by 'street kids' described in detail. The mother asked for the details to remain confidential as she had not disclosed the incident to anyone. The child had been treated at a psychiatric centre, and although the police said they apprehended one of the perpetrators, the mother did not follow up the case.

Focus group discussions also emphasised that sexual abuse is common when orphaned children are sent from urban to rural areas. It must be noted that this is a perception that ignores the fact that there is also a high occurrence of abuse in urban areas. The key issue may be not so much rural versus urban levels of abuse, but that moving a child with disabilities away from her primary caregiver and support system makes her more vulnerable to abuse of all kinds. This is compounded by the fact that there is also a lack of medical and welfare facilities in many rural areas, and those that exist are difficult for families to access, as distances are longer, transport less available and more expensive and income levels generally lower than in urban areas.

Further details of answers on abuse can be seen in Appendix 5.

6.0 FINDINGS: PARENTS AND CAREGIVERS

A profile of the 58 urban respondents to the questionnaire is given in Section 4.1. As noted earlier, the fact that all the respondents belong to self-help groups does give them more access to information and material support than those in areas where these do not exist.

A vital point to stress – implicit in every aspect of the study - is the constant evidence of the mothers' and grandmothers' great love for their children with disabilities, and the tireless care and immense effort they show in hugely difficult economic, social and emotional circumstances. Their resilience and determination cannot be stressed strongly enough, and form a major resource on which any intervention can build.

6.1 SUCCESSION PLANNING

The findings here were very clear. Everyone was deeply concerned about the future of their children and expressed deep gratitude that the issue had been raised and asked for advice and training about what to do, some mentioning the issue of wills and inheritance. However, only **one** respondent had discussed with the identified relative, her sister, and had agreed that she would take over her child's care when the mother died. Of the remaining 57 respondents, 47 could identify someone they would like to be a stand-by guardian, but none had made clear plans with the person, let alone any legal or practical preparations. (Those who mentioned Rokpa have been included in those who knew nobody to take over the child).

The table below shows the breakdown of answers to the question of who people would like to take over the care of their children in the event of their death: results are self-evident.

Who I would like to care for my (grand)child with disabilities	Number
❖ Family member	45
❖ Support group	3
❖ Someone in the community	0
❖ An organisation (all mentioned Rokpa)	3
❖ I do not know anybody	7
TOTAL	58

While people can therefore identify someone when the question is raised, and it is clear that family members are the most popular people chosen (usually a grandmother or aunt or the disabled child, sometimes a married brother or sister), this is only a first step – but one that can be built on. Because the desired guardian is usually a family member, it is theoretically sustainable, but there are - as they themselves noted - numerous challenges that would need to be solved to transform a vague wish into effective and sustainable care and support for children with disabilities. Briefly, these include: basic survival for the extended family, especially grandmothers, who are already burdened with other orphans and in any case are likely to need a guardian to replace them when they grow too old to care; difficulties of talking to partners; issues of wills and guardianship; and the involvement of the named guardian in current care, and training them in necessary skills.

Other points arising in the findings should be noted:

- ❖ This was often the first time that parents had openly discussed the subject of what would happen to their children in the future, either in groups or in their families.

- ❖ One challenge was that less than half (46 %) feel able to talk to their partner about the future of the disabled child and identifying a stand-by guardian - and of those who feel able, very few have done so. Over half don't feel they can even discuss the question with their partner.
- ❖ Parents of children with minor and only physical disabilities were often trying to educate the child so that she could be independent in future, but even this was a struggle financially. Others did have plans to educate siblings so they can look after the disabled child in future – and hope to encourage their willingness to do so.
- ❖ Groups were aware that making wills was useful, but none knew how to do this, and none mentioned issues of guardianship and custody. In general comments about future planning, several mothers mentioned the possibility of leaving goats or a house to the child, but are worried that this would be taken by others in the family, and had no plans or information about how to prevent this happening.
- ❖ Insurance was mentioned only in one case study, and then only as a benefit given by a job the father had now left.
- ❖ Concern with immediate needs and the struggle to survive often took precedence over planning for the future – not only for the disabled child, but for the whole family.
- ❖ Very few thought that the community was currently able to look after the child if the mother or caregiver gets sick; 62% strongly disagreed that this was possible. Around 25% thought they could help to prepare the family and community to do this, but 37% felt this would not be possible at all.
- ❖ In the final 'other comments' question on the future of the child, respondents talked about their children's future in vague terms – reinforcing the evidence that this had not been considered before. There are frequent but vague mentions of 'welfare organisations' as someone to take care of the child, and a telling reference to 'even' homes.
- ❖ In focus group discussions, a good deal of emphasis was placed on the idea of having other mothers in the self-help group look after their child when they die (*because fellow mothers are the ones who understand and know how these children should be looked after*) – possibly with the assistance of a centre or home in their area which could also offer respite care and serve as a general meeting place.

6.2 SOURCES OF SUPPORT

A number of **close family members** do often give support of various kinds. A quote: *Close relatives such as a sister (help us) because they see our children as their own and some of them just feel pity for us as we are widows* In some cases, relatives offer to take the child but the mother feels they are better off near to her. Some fathers play football or teach the child other skills, and play with them; this was also the case with rural fathers who worked away from home. Financial support is also welcomed, and is sometimes also seen as a sign of love for the child: *Older children may give financial support because they will be wanting to reduce the burden on me*. There are also, unfortunately, a few examples cited of family members being ashamed of having a disabled child, but these were definitely in the minority. In case studies, almost everybody said, in different expressions: *We look after the child like*

all the others; she is just our child like them. The main problems with family support are that it is inconsistent, and families do not have spare resources – if a relative does not live nearby, then even bus-fare is an issue. In addition, people often asked for family members to be included in any programmes aiming to improve the care and support of the child – livelihood, health-care trainings, and anything else.

Many organisations are cited as supporting, and work especially through the self-help support groups. They include : **PLAN International (School fees, building one centre), ROKPA (food and medicine, HIV training), IPA, ZPCDA, Faith and Light.** Again, **this help may not be long-term.**

Organisations that provide **training for the children (lifeskills, recreation, informal education)** are especially appreciated, as are those that recognise the mothers' own need for care.

One organisation often mentioned is the **Zimbabwe Parents of Children with Disabilities Association (ZPCDA)** ; they provide various types of support, especially workshops *on how to take care of our children because they saw the need to enlighten us.* One mother explains the key role they and others have played in helping the mothers come to terms with their child's condition. It might sometimes come as a shock and you may be ashamed of having that child in your home at first. ZPCDA noted this gap between us and the children. We did not have enough knowledge on how to take care of the children and just did it because we had no real choice, but they have taught us to have love towards our children.

The **CRU at Harare Hospital** is constantly mentioned as the body that provides medical care and exercises for the children as well as counselling for parents .They used to have a mobile clinic, but this has since stopped because of fuel and transport difficulties, and busfare for parents to go there is often prohibitive. (In provincial and other hospitals, the Rehabilitation Units, once excellent and with skilled and committed staff, are now largely non-functional; children are all referred to the CRU: testimony from Irene Mhlanga, CRU)

Support groups are described as a major source of strength and sometimes respite care, and as having the potential as a focus for income-generating activities, the joining of housing co-operatives.

Churches do give some support, but are not cited often.

Neighbours similarly may help with respite care but this is not common: stigma and rejection, or simply not getting involved, are equally common, and not seen as something to build on – though mothers would like a campaign to make them appreciate their child with disabilities.

6.3 WHAT MOTHERS (AND GRANDMOTHERS) WANT – AND WHAT THEY NEED TO PLAN

Findings show that what mothers want in the present is inextricably linked to their and their families' ability to provide viable care for the child both now and in the future. The list below gives a composite of ideas from the focus group discussions, and all the recommendations were 'approved' in the feedback meetings. It is also this list, long as it is, that can be used as a basis for creating a 'package of support' to ensure effective and sustainable care for children with disabilities.

- Someone to take care of the child – organisation, relatives, government, 'even' homes. Grandparents are important guardians, but they need support in terms of food, school fees, medication, general upkeep and preparation for the future of the child – as well as someone to help them.

- Training for caregivers and families – in planning for the future, life skills and how to care for their disabled child, HIV counselling and training. Relatives and siblings (especially) should be involved too, and a special effort made to target men.
- Training and education for the children – life skills, vocational and ‘normal’ education – and all the assistance needed surrounding this. Many have ‘untapped potential’. This should involve special schools and also ‘normal’ schools, so that wherever possible, children can stay near the mothers who care for them- and also have other children in their community get to know and love them.
- Material assistance: food, clothing, medication and other medical care – parents often know what is needed but are unable to afford it. Some of the needs could be quite easily met – a one-off operation, special shoes – others are longer term.
 - ❖ Starting projects which can be joined by family members, especially the stand-by guardian, either now or on the mother’s death, so that the benefits will still go to the child – a key request.
- Secure and decent and permanent accommodation while parents are still alive, that the child can stay in when parents die.
- More networking through support groups - a huge source of strength – many mothers feel that other mothers with disabled children will know best how to look after their own children. Families to be involved too, and other community groups.
- Health care for their children **and for themselves** (HIV information and treatment are not specifically mentioned – interesting in itself, though some have tested after group programmes with e.g. Mopane Junction)
- An end to stigma in the community – campaigns to fight this.
- Building a home and/or centre in their area where fellow mothers can take care of orphaned children – also a relief and respite centre, where parents can sometimes leave the child and do other social or economic activity and be supported by other mothers. *If this exists, even when parents die, the child can carry on meeting with others and receiving the same benefits as before. Children can be taught at this centre.*
- Encouraging relatives to attend sensitization workshops so they will understand the different situations faced by children with disability, and where to get help. Building a strong relationship with other parents who have children with disabilities as well.
- Teaching lifeskills and income-generating skills to other children in the family so that they will have something to sustain themselves and the disabled child
- Writing wills and looking for someone who has love for the child and including a person who loves the child - other legal information and assistance too, especially about guardians and birth certificates. Making sure the child gets the inheritance parents leave.
- Involving men and other relatives by sharing information with them; formally inviting them to workshops and other activities for parents; holding drama sessions to

increase their awareness; using community leaders (pastors etc) who have children with disabilities, to talk publicly about how their family situation and how they cope

- Opening a savings account for the child.
- Avoid sending urban children to rural areas when parents die.

At feedback meetings, recommendations were summarised into a list of twelve, and groups ‘voted with stones’ to choose those they felt were most important for the future care of their children. The results are shown in the two tables below.

Ranking number	Epworth	Mabvuku	Hatcliff Extension
1	Food and clothing for children	Money to support grandparents and other family caregivers	Food and clothing for children
2	A centre for orphans and respite care	Teaching families and communities about disability	A centre for orphans and respite care
3	Legal advice on birth certificates, wills and inheritance	Food and clothing for children	Training in caring for mothers and relatives

OVERALL RANKING OF TOP 3 PRIORITIES	
What we want	Number of points
○ Food and clothing for children	7
○ A centre for orphans and respite care	4
○ Money to support grandparents and other relatives	3
○ Teaching families and communities about disability	2
○ Legal advice on birth certificates, wills and inheritance	1
○ Training in caring for mothers and relatives	1

6.5 FINDINGS ON HIV AWARENESS: STATISTICS AND ATTITUDES

A key concern of the study was to look at the links between the HIV pandemic and people’s planning for the future of their children, testing the assumption that the pandemic might increase concern about what happened in the event of serious illness and/or death. A majority of respondents agreed that HIV and AIDS have greatly influenced their pattern of life, with 53 % agreeing strongly.

58 % of the caregivers in the urban areas studied know their HIV status; 42 % don't, though all know of VCT availability. Although this is far below the ideal, it is in fact a high level of status-awareness, especially in a country where treatment options and ARV access are very limited, and probably results from interventions such as the Mopani Junction programme introduced to the support groups.

Other findings show that despite the relatively high level of people having tested, 50% strongly believed that *Being HIV positive is like having a death sentence*, and many others agreed with the statement to some extent. This level of fear suggests either that messages about the effects of positive living and the possibility of life-prolonging treatment are not even widespread even in the capital, and/or that the deterioration of health services and the erosion of standards of living has taken undermined such messages.

In addition, while 77 % believe that the individual is the one responsible for avoiding HIV infection, only 58 % say that they can take any action to protect themselves from getting HIV a telling figure which is likely to relate to their being women.

Various reasons were given for not testing; the most common was fear, followed by the husband's or partner's refusal to test, and forbidding their wives to do so. Other women fully trusted their one husband, some did not have time, or simply had not thought about it because they were healthy (claims that sometimes hide other reasons) and if true, show lack of awareness of several key risk factors.

The reasons people gave for having tested, were, in order of frequency: their own deteriorating health, the death or ill-health of their husband or children, being pregnant, and wanting to look after themselves and their children well, and plan for the future. Full responses can be seen in Appendix 6.

Rural case studies revealed only one out of five respondents had been tested, and that long ago in 1992; also, easy opportunities for testing were limited to very infrequent visits of mobile VCT units. One mother lived in 'perpetual fear' for herself and her children, but felt testing positive would be too stressful. Other reasons for not testing or re-testing were: that they hadn't thought about it, that the children were all healthy so they saw no reason, and that they had planned to go but were away when VCT unit came to the village (and had not made any effort to go elsewhere).

In the case studies, interestingly, several people mentioned that while learning their status has been very important for their lives in general, it has had no impact of their planning for the future of their child. This needs further research, as the number of people involved is tiny, and the item was not foregrounded in any of the research tools. Another area which was not specifically raised in the study, but would benefit from more comprehensive research, is the number of children with disabilities who are HIV positive, and how they have become positive.

7.0 CASE STUDIES: AN INTRODUCTION (inc name changes)

Two case studies were done in each of the urban areas covered in the study, totalling six. A further five were done in the rural ward, giving substance and flesh to the statistics and comments gleaned from the questionnaire, FGDs and feedback meetings.

Names have been changed to protect identities.

7.1 CASE STUDIES: URBAN

Urban Study 1: Stella Gumbura, aged 5.

Stella, aged 5, was born with a disabled left leg. Her father has a similar disability, though it is less severe, and the grandfather suffered from the same problem, so the parents found it easy to accept. The parents could not afford the special operation to correct the deformity on her legs; nor were they able to buy the special shoes that were prescribed by the physiotherapist. They treat her just like her sister; and do not do her anything different because of her disability.

The parents have another daughter, two years older than Stella. Their mother is a member of the local women's support group of parents of children with special needs, and also belongs to another women's project in Tafara. In the latter the women make jam and sweets which they sell to get money to support their children.

Stella's father used to work as a general hand at Parirenyatwa Hospital but left the job and is now a student nurse at Parirenyatwa Hospital School of Nursing. When he was working he had insurance cover for his wife and two daughters, but when he left his job that stopped. The house the family stays in used to belong to Mr. Gumbura's parents.

At the moment Stella does not have a birth certificate. The reason is that her mother is of Zambian descent and does not have Zimbabwean identity particulars. This has made it very difficult for them to obtain a birth certificate from the Registrar General's office.

Stella has not yet enrolled for primary school, but the parents are planning to send her next year.

At present the parents have no concrete plans for Stella, except for her education, because all their money is currently going into the father's education. There are things they would like to do, but they have not yet been able to take any steps towards achieving them. The father said that the only other people he could trust to take care of Stella were her grandparents, especially the grandmother; they accept her as she is because of the history of disability in the family. The neighbours do not do anything to help the family support their child.

The father, Mr. Gumbura, is the only one in the family who has had an HIV test, and he did this because it was one of the entry requirements at the School of Nursing. Mrs Gumbura does not know her HIV status and has never specifically thought about getting tested.

Urban study 2: Barbara Moyo, age 14

Although Barbara does not have many health problems, she often experiences serious spasms all over her body which makes it hard for her to study, though she does not have other health problems. The problem started when she was around 4 years of age but the family could not afford to take her for medical attention, though her grandmother performs some exercises on Barbara which she learnt from the Children's Rehabilitation Unit (CRU).

Barbara's biological parents are not together and Barbara lives with her grandparents, Mr. and Mrs Moyo. A lot of other grandchildren stay with them too. Mr. Moyo is a tailor who works at home and his wife is a peasant farmer. They are both over 50 years of age.

Barbara's father was a teacher who disappeared soon after the mother got pregnant and never came back. Her mother is now married to another man; they stay somewhere else and the stepfather is not in a position to look after her.

Barbara does not have a birth certificate because they could not afford to go to the Registrar General's office in Goromonzi, which they needed to do to get her the birth certificate. Despite this, she is a pupil at Tinokwirira School, which she greatly enjoys, and her school experience has helped her a lot, especially in how she responds to other children at home or in the community. The grandparents hope she can finish her schooling and become independent in the future but they are currently finding it very expensive to send her to school.

In their community only one neighbour sometimes helps them to take care of Barbara, especially when they have to go out. No one else in the neighborhood is giving any other help.

Mr. Moyo said that they have not yet planned anything for their grandchild's future, except to educate her.

Neither Mr nor Mrs. Moyo has yet had an HIV test, as they trust each other deeply and see no reason to be worried.

Urban Study 3: Elbert Marope, age seven.

Elbert has cerebral palsy and cannot speak, walk or eat properly. He has been getting some exercises at Harare Hospital, which have helped him to be able to eat on his own and develop some form of speech.

His father Tinashe Marope is a security guard at Harare International Airport. As a way to supplement his income and do some plans for the child with a disability, Mr. Marope is looking forward to get involved in some income generating projects with other men in Epworth. Elbert has got one sister, and Mr. Marope's two younger brothers also live with the family.

Elbert does not have a birth certificate because his mother does not have any identity particulars. Nor does he go to school, because the family saw no reason to send him because of his disability.

Mr Marope feels there is a lot of stigma in the community, both against the child, whom they see as inferior to others, and against the family in general. Elbert's mother is a member of the support group for mothers of children with special needs at Kuwirirana Centre. The group provides some psychosocial support to the mothers and their children, but has not yet

Mr. Marope's younger brothers whom he looked after are the only other people that he can trust to look after the child with disability in the event that he is no longer there or can no longer continue to look after his child.

At the moment the parents have not planned anything for Elbert's future, nor has the support group done any planning for the future of their children with special needs.

Neither of Elbert's parents has ever gone for HIV tests, because they trust each other a lot and therefore see no reason to be worried. Mr. Marope also feels that knowing or not knowing his

HIV status does not change anything about his plans for Elbert; the only problem he faces is that he does not earn enough to allow him to plan anything.

Urban Study 4: Chipo Mushonge, age eight.

Chipo is eight years old and has a deformed leg. Chipo's parents are both dead and she lives with her aunt, Chipo Tembo. Chipo is a widow who looks after her own four daughters as well as her two young brothers and Chipo. Her only source of income is a vegetable stall. She is also a member of the Epworth support group for parents of children with disabilities.

Chipo does not have a birth certificate, because her parents died before getting one for her. She goes to Simukai School and is currently in Grade Two, her school fees being paid by ROKPA Support Network. She is doing well there, and is not hampered by her disability.

Chipo's mother sometimes looks after Chipo when Chipo is not around and sometimes gives basics like food and soap to help the child.

Chipo herself was tested for HIV and says that knowing her status has helped her take better care of herself, but has had very little bearing on planning for Chipo. Neither she nor any of Chipo's other relatives have thought about making plans for the child's future, but are glad that she has the chance to go to school.

Chipo would like her mother to take care of Chipo in the event that she can no longer afford to do so or when she is no longer there to look after the child, because of the support she already gives them.

Urban Study 5: Farai Mtetwa, age twenty-two

Farai is epileptic and also cannot walk; his parents died two years ago and since then he has been staying with his aunt and uncle and their children.

Farai has no birth certificate because his late parents never bothered to get him one, and he has never been to school his whole life. His parents lived in the rural areas and the school was far away, so he could not go there. His mother took really good care of him, but had little support from the rest of the family and community and died without putting in place any plans to make his life easier.

Farai's aunt (Mrs. Mtetwa) just treats him like any other member of her family, her husband fully accepts him and his school-going cousins have been teaching him how to read and write, so that now he can write his own name. The community also treats him normally and neighbours will come and help if he has a fit when his aunt is not at home. However, he gets no material support from anyone else, and other parts of the family show no interest in his plight. Nothing has been planned for Farai's future.

Farai is able to use his hands to do some knitting and crocheting, but has no capital to buy wool and other inputs that would allow him to start up his own small business.

The aunt is a member of the support group for parents/caregivers of children with disability at Rutendo Centre. Some of the other women in the group have joined a housing cooperative to as a strategy to give their children something for the future, and Farai's aunt is thinking of joining too. The only reason she has not yet gone ahead with this plan is that she fears her nephew might not be mentally stable enough to be responsible for a house. She also feels that even if she joins the cooperative, it may not help him, because he would still need assistance from others in the family, and this is unlikely to happen.

Farai's aunt has never been tested for HIV because she is from the Vapostori religious sect and they do not believe in HIV testing.

Urban Study 6: Memory Chuma, age twenty-five

Memory has cerebral palsy and at the same time is deaf and dumb. Her mother earns her living as a peasant farmer and a vendor, supplemented by food handouts from Rokpa and clothes from some Catholic nuns. The father does not provide any form of support for his daughter although the mother has tried to get him to discuss their child and her future. The Chuma family has four other children, three boys and a girl. The mother has always treated Memory like any other child in the family, without any discrimination.

Memory completed her primary education but could not go on to secondary school (in Bulawayo) because the school head in Bulawayo said her low mental capacity would create problems with other students. Her mother feels that the loneliness resulting from her stopping school may have made her more unstable mentally. Memory's mother said that she had sent her daughter to school in the hope of giving her a better future but that this was all ended when her daughter could not proceed with her education. The family have so far made no other plans for the young woman's future.

Memory's mother went for an HIV test, which she says has changed her attitudes and view of life but has not had any impact on her planning for her daughter.

The neighbours and the community never come to help the Chuma family but Mrs. Chuma is an active member of the Rutendo Centre for mothers of disabled children. The group has not made any solid preparations for the future of their children with special needs. They did have a building for their group until it was destroyed in Operation Murambatsvina in 2005, which dealt a severe blow to the group and, she feels, any hopes they had of giving a decent future to their children with special needs.

Urban Study 7: Tinashe Makasa age ten.

Tinashe Makasa is 10 years old, has cerebral palsy and lives with his grandmother and grandfather. His grandmother, Mrs Giwa, is his primary caregiver, but was not at home when researchers visited. His grandfather said that he did not want to have anything to do with the study because he did not know anything about caring for the child and was not in a position to answer any questions.

7.1 CASE STUDIES: RURAL

Rural Study 1: Tinashe Sango, 15 years.

Tinashe Sango is 15 years old and epileptic; he also has learning difficulties. Tinashe was born healthy but his mother believes that his brain is now damaged by the disability. Besides being epileptic, Tinashe is mentally challenged in other ways but his mother is teaching him to chop firewood. He also had difficulties understanding things at school and his performance was very poor.

Tinashe's mother is forty years old and a farmer; his father is fifty-seven, works as a mechanic in Harare, and helps to support the family. The parents have six children in total, two boys and four girls. Tinashe is the only child with a disability.

Tinashe used to attend school, although he had great difficulty understanding things, but dropped out when he was in grade three. This was because he started having fits while he was in class, so his mother had to go to school with him every day. This was an impossible situation, so they withdrew Tinashe from school. At one point he was taken to hospital and was given some medication but he the family cannot afford it any more.

Most of the time, the family takes care of Tinashe as they do their other children but when he is attacked by fits, the family seeks help from their church, the Johanne Masowe sect, which blames evil spirits for Tinashe's condition. Mrs. Sango admits that the church has not helped Tinashe in any way, but does allow her to share her problems with others and lessen the burden. None of the family relatives cares about Tinashe, but see him as a burden. One neighbour takes care of him when the mother is away but most other people see the epilepsy as a problem which the family should deal with themselves. They say that the disability is a punishment on the family because one of the ancestors sinned.

Tinashe does have a birth certificate, but his mother has found it very difficult to make plans for his future. She once thought of buying him some livestock of his own but she fears that his siblings will take them away from him if she dies. She has however managed to keep some goats for him. She would also like him to be taught to do practical work like gardening as he has the strength but needs training and practice. She had not identified anyone who might take care of Tinashe when she died, only suggesting Rokpa (who do not in fact do this).

Mrs. Sango has never gone for an HIV test because all her children are healthy so she sees no reason to go for the test. She did think, however, that plans should be made for children with disabilities in the light of the HIV/AIDS pandemic, and suggested the building of a school or home, where the children could be taught different skills and taken care of in the event that their parents pass on.

Rural Study 2: Tendai Munemo, age fourteen.

Tendai is the youngest of a family of eight children, five boys and three girls; he is the only child with a disability and he is the Tendai-born. His parents are Titus Munemo and Mrs. Esther Munemo (40). Mr. Munemo is a Zimbabwean citizen who was born and bred in Nyanga but relocated to Mhondoro where he now stays with his family. He is 59 years old. As well as his own children, he also looks after a grandchild from a daughter whose husband passed away.

Tendai's problem began soon after his birth. At first he was healthy but then developed yellow fever. He was taken to the clinic and was transferred first to Chegutu Hospital, where he stayed for six months, and later to Harare. He stayed in hospital for a year altogether and lost weight drastically; there was no improvement in his health. At one stage his body became very swollen and the doctors wanted to operate but the father was too scared, feeling it was better for Tendai to die at home than at the hospital. When he came home neighbours said that he had probably been bewitched by someone who keeps seashells as charms and it was now too late to cure the problem. However, the family did obtain one shell and used it in the child's bathwater, after which, they say, he did begin to improve and regained his basic physical health – but never returned to normal, cannot talk properly and is only partly toilet trained – he can use the toilet on his own, but often wets his pants when playing. His parents say they manage to take care of him by themselves, and help each other so that they can share both the household chores and taking care of him. His siblings, however, find it hard to look after him when the parents are away because he also has stomach problems.

Tendai has been to the local school three times, but beat up other children when he was there, behaviour which the parents attributed simply to his mental disability. His father wishes he

could go to a special school for children with similar needs, as this would be better for him. Mrs Munemo's family have offered to take him to a school in Mutare, but his mother has refused, as she does not want to be separated from her son.

They also have problems of getting the nutritious food that Tendai especially needs; it is difficult enough to get enough food for the family as a whole. Medical care is also far from adequate, as rural clinics sometimes have insufficient medicine supplies for children with disabilities.

However, the community where they live do not mistreat or abuse him: people have accepted him as he is and enjoy playing with him like that.. The parents also have strong support from other family members, especially a married daughter who lives nearby and often takes Tendai to her house, where he can play with her children and is known and accepted by the people around them, who take care of him well and without discrimination, and have managed to teach him some skills such as counting.

Although the family have made no legal arrangements for someone to look after Tendai if the parents die, Mr. Munemo was confident that his daughter would be able to do it; the only problem she might face was being able to send him to school.

Asked about HIV testing, the parents said they had agreed to go for an HIV test but had not yet done so. There was a time when some people came to their village and did voluntary testing, but they were away at the time so did not have the chance to get tested.

Rural Study 3: Joyce Gondo, age two.

Joyce is a 2-year-old girl who has cerebral palsy. She was born prematurely at 34 weeks, since her mother, Primrose Chinyani, was suffering from high blood pressure. The family has four children, three girls and a boy. Joyce's father works at a supermarket in Marondera as a general hand and only comes home every two months. The mother sometimes goes to Marondera and begs for food and clothes as a way to earn a living.

Joyce's mother used to take her to Marondera for physiotherapy every month, but since her eldest daughter got pregnant at the age of 15 and was recently ill, she is too worried about her and her other twelve-year old daughter to leave them alone. No-one else from the husband's family offers to help her take care of the children and there is no organised group for parents of disabled children.

Joyce can only eat porridge, pumpkins and milk and also gets a stomach upset whenever she drinks. The mother sometimes does some of the exercises that the physiotherapist taught her and this helps her to relax a bit.

The father seems ashamed of his child's disability and shuns Primrose and Joyce whenever his friends are around. The wife often tries to discuss the future of their child with her husband, suggesting that she goes and stays in Marondera, where she could be a vendor and have easy access to medical facilities for Joyce, as well as water and electricity which will make her own chores easier. The husband has shown very little enthusiasm for this, even though Joyce has suffered from sores more or less since she was born, but has not seen a doctor or had medication for a long time, so that her health has seriously deteriorated.

Some relatives and community members say that Joyce's disability results from her father refusing to pay traditional customary compensation (chiredzwa) to some people who looked after him. Other people say that the child is a reincarnation of a family member who died in the 1970s and used to be badly treated. The family used to dig a pit and place him in there, or tie him onto the roof support and leave him because they had no time to take care of him.

Joyce's mother said that no-one in the family had ever thought about having an HIV test.

Rural study 4: Tabitha Kunaka, age twelve.

Tabitha Kunaka is twelve years old girl and blind. Her father is a farmer and does share cropping to support the family. When she was younger they At first they went to Mubaira to visit the clinic there and were advised to go to Jairos Jiri, where Tabitha could get some education. They went once and the cause of her blindness was discovered, but he did not know it and had not gone back because they had no money to take her there again.

Tabitha did attend pre-school, where she proved to be very intelligent, and was recognized as clever by the community. Her father expressed his wish that she would one day attend a good school, and said that neighbours sometimes advised him and the mother to send her to a special school. However, they had not tried to do this because of lack of money.

Tabitha's grandmother helps them to care for her, and sometimes takes Tabitha to stay with her. Mr Kunaka's sister also takes her sometimes but as parents they feel that it is not good for a child with Tabitha's disability to stay away from her parents for long periods of time. The community has accepted Tabitha as she is; she has never had problems with them and none of the community members treat her badly. There is no formal group in which they can discuss the lives of their children with disabilities, but people do give them advice about educating her.

Mr Kunaka felt that Tabitha's grandmother is the only person who could take good care of her if her parents died or were sick. They have no plans for her own education, but as parents had discussed and agreed to send the other siblings to school so that in the future they will be able to take care of Tabitha. This they are already doing.

Mr. Kunaka said he had had an HIV test in 1992 when a group of people came to his village testing people on voluntary basis. That was the first and Tendai time that he got tested; he has been thinking of going for another test, but has not yet done so.

Rural Study 5: Lovemore Chuma, age five.

Lovemore's mother, Rudo Hatendi, is 26 years old, has two children and survives on ploughing other people's fields in exchange for food or money. Lovemore's father is working in Chegutu as a gold panner and has been away for the past eight months. The house where they live was left to them by Alice's mother in law.

Lovemore is deaf and dumb. When he was born some people said that his disability might be because his tongue was stuck to the bottom of his mouth so his mother sought help from sangomas, but to no avail. She then went to local clinic, where they referred her to Chegutu Hospital, but she did not have the money to go there so just stayed at home with her son. Some people also said that his disability was due to his mother being malnourished or working too hard while she was pregnant.

Now that Lovemore will soon be old enough start school, Rudo plans to send him so he can be educated and become independent. She has not questioned how he will fit in at school, but is currently trying to teach him to speak by making him follow her lips.

Other children often assault Lovemore, but since he cannot speak, he does not say anything; when he comes home, however, his mother can tell that something is wrong with him. She always has to keep an eye on him to make sure he is safe, although she also has to work hard

in people's fields to be able to fend for the family. When Rudo is away, a neighbour often takes care of Lovemore but relatives rarely offer any help. Rudo's husband, who comes home after a long period of time does exercises with Lovemore and also teaches him to play soccer. Lovemore's father does not bring anything for the family when he comes around so the mother has to do everything for the family.

Rudo has not gone for an HIV test yet because she fears that if she tests positive, she will become stressed, so she feels it better to remain ignorant. However, she lives in perpetual fear that she is HIV positive as her husband is away for long periods of time. Her husband is also afraid to get tested. At one point in the past Rudo did want to get tested, but he refused. Her children often suffer from rashes and sores and she fears that they may also be positive. She said her sister in law has tuberculosis, but did not link it to being HIV positive.

Although Rudo said it is easy to talk to her husband, who has accepted the condition of the boy, about the future of their son, she also said that they have never talked about it. In the event that she passes on, the only person that she thinks will be able to take care of her son well is the maternal grandmother who has shown a great deal of care and concern for him. Other members of the community sometimes give her advice about taking him to school but do not really show concern about him, and she cannot identify anyone in the community who could look after her child if she dies.

When asked whether looking at past problems helps her prepare for the future, Rudo said she has so many current problems that this kind of thing does not help her at all.

8.0 CONCLUSIONS AND RECOMMENDATIONS

The central finding is that, 83% of caregiving mothers and grandmothers of children with disabilities are, when asked, able to name someone they might wish to be a stand-by guardian of the child in the event of their serious illness or death; 94% of those named are family members, usually grandmothers or aunts of the child, and 6% would like a member of their support group to be the child's guardian. However, only one person out of fifty-eight has made even an informal arrangement with the person involved and **no-one** had done any solid succession planning or made any legal or traditional preparation for the appointment of stand-by guardians.

While there were references to the importance of wills and inheritance issues, and two people in case-studies mentioned leaving their child a house or livestock – and their concerns about this - there was no evidence that people had even basic information about how to go about dealing with these issues. Some people also had ideas about safeguarding the future of the child through education and training of the child or siblings.

Evidence given about respondents' knowledge of previously orphaned children with disabilities bore this out. Apart from those orphans who were being cared for by the seven grandmothers taking part in the research, and two who had been helped by Jairos Jiri and Zimbabwe Red Cross respectively, the stories were all negative, presenting a variety of examples of abuse and abandonment.

Also of note is the fact that only 46% of caregivers (all female, almost all mothers and grandmothers) felt they would even be able to discuss the issue with their partners, and those who felt it would be possible had not in fact done so. Case- study evidence bears this out: several mothers mentioned that they had been unable to convince their husbands or partners to talk about even immediate issues concerning their child's welfare.

At support group level, the issue of planning for the children's future had sometimes been raised; nothing had actually been done, but this does suggest a fertile field for the introduction of the issue, at least where these ZPCDA groups exist.

There was also no evidence of community or NGO or local-authority initiatives around succession planning, but the small scope of this study means that some may exist elsewhere in the country, probably in the fields of HIV and AIDS (for example in the use of the John Snow International/ SAfAIDS publication *Planning Our Future: A Booklet for Families and Communities*) and through campaigns promoting the writing of wills, the acquisition of birth certificates and the accessing of support from the network of Legal Projects Centres and Legal Advice Centres throughout the country.

However, parents consistently welcomed the simple fact that the study had highlighted the issue, which all acknowledged as a cause of great concern. Moreover, they were able to identify many sources of past and present support for parents of children with disabilities – at family, support group, governmental and NGO levels – and to suggest strategies showing how some of these could be strengthened and made more sustainable. They emphasised too that any attempt to support them in planning for the future of their children must also focus on the amelioration of the present circumstances of their immediate families, and must involve the relatives, especially the current or potential stand-by guardians, and also the men in the family whose involvement in decision-making is important.

There was also evidence of widespread – though by no means universal- stigma against children with disabilities, as well as an even more pervasive lack of community and national awareness of the challenges they and their carers face, and the resilience and effort shown by

their carers in giving the children as fulfilled a life as possible despite the dearth of services and support systems, and the inadequacy of those that do exist.

Another unavoidable conclusion is that improving the plight of children with disabilities and those who care for them requires far more than training and support in succession planning and identification and preparation of stand-by guardians; or, rather, that working to make succession planning effective and sustainable means looking at the wider situation of the children and families involved, and addressing these wider issues.

8.1 Revisiting the Objectives

Some of the questions raised in the objectives have been addressed above; others are answered, or summarised below:

78% of children with disabilities covered in the urban areas of the study have had their births registered.

Only 40 % of children with disabilities covered in the study are currently going to school in urban areas: of three school-age children in Mhondoro, none is currently going to school. Key reasons are the insufficiency of educational facilities for children with mental, behavioural or severe physical disabilities, and the cost of those that do exist, as well as lack of a sufficiently effective programme to integrate children with special needs into 'normal' schools. Informal education and rehabilitation are limitedly available in Harare and bigger towns, but accessing it is costly.

There was no evidence of any family or community-based initiatives in place to provide care and support for orphaned children with disabilities, nor any systematic NGO or other initiatives, but existing ZPCDA self-help groups appeared to provide a ready-made network through which such initiatives could be rolled out. In addition, Jairos Jiri and Zimbabwe Red Cross were both mentioned as having helped particular individual orphans, and one child had been taken into a home but no more details were available about this. Further research is needed to investigate other child-and-orphan focused organisations, as well as disability organisations, churches and governmental structures. (lists of these are given in Appendix 7 and 8)

Interestingly, mothers did not themselves link the AIDS pandemic to the care of children with disabilities, and two mothers specifically stated that learning their status in no way affected their plans for their children's future. However, a majority felt that HIV and AIDS had had a major effect on their lives in general, and it is evident that if one in four children in Zimbabwe is now an orphan (figures cited in an Al Jazeera report July 2007), the numbers of orphaned children with disabilities will have risen accordingly. Anecdotal reports of orphaned children with disabilities reinforced the existing portrayal; half of those who knew of such cases recounted instances of neglect, abandonment, stealing of inheritance, physical and sexual abuse and extreme material deprivation. Even those who were fortunate enough to be taken in by grandmothers or other relatives suffered materially; such grandmothers are usually already overburdened and have little if any means of support.

While the pandemic is definitely creating more orphans, with and without disabilities, and causing a great deal of stress in those who fear themselves at risk, we found no evidence that it was motivating parents to make more sustainable and effective plans for their children's future, even though many were still afraid of learning their status and more than half felt that a positive result was like a death sentence. What was evident was that programmes aimed at supporting mothers to go for testing had had some effect – and some who had tested did so because they wanted to prolong their own lives and look after their children better. This may serve as a point of intervention in the future.

8.2 RECOMMENDATIONS

What we are looking at here is far more than the issue of succession planning and identification and preparation of stand-by guardians, but a whole package of support, the areas suggested in Section 6.4 above, **What mothers and Grandmothers want – and what they need to plan**. So much needs to be done that a study of this limited nature can only point to areas and to a possible way forward; it would be premature to map out a holistic strategy without investigation and consultation with major governmental and non-governmental players.

At this stage it is wiser to limit recommendations to four:

- ❖ An invitation to revisit the package of support suggested by the mothers and grandmothers in this study
- ❖ An emphasis on the need to involve the children themselves, to whatever level this is possible
- ❖ The consideration of a list of levels on which intervention is needed: children, primary carers, immediate families, extended families, support groups, wider communities (local authorities, schools and clinics and welfare services, religious and other groups) and national level.
- ❖ The consideration of a list of areas where action is needed, namely:
 - Material support – food and clothing
 - Accommodation (present and future) – possibility of urban housing co-operatives??
 - Formal education: special schools and facilities for integrating children with disabilities into ‘normal’ schools, and anti-stigma and other measures to make this viable
 - Life skills training for children with Disabilities
 - Livelihood training and projects – for older children, immediate families, and identified stand-by guardians
 - Rehabilitation care – Rehabilitation Units, mobile clinics, provision for rural areas
 - Medical care and medicine provision – for children and their families
 - Training in caring – for parents, siblings, wider family, men
 - Succession planning and identification and preparation of stand-by guardian – legal and practical matters: other legal information and assistance
 - Self-help support groups and organisations that sustain these – what support do they need? Are they viable in non-urban areas, or is something else needed?
 - Network of centres for support groups – should they also provide residential facilities for special-case orphans??
 - Wider advocacy campaign against stigma and advocating support of people with disability –to target especially schools, churches, authorities, HIV and other NGOs.

One issue which mothers did not note is the need to raise awareness of preventable causes of disability in children, and to provide the services and facilities to reduce the risk.

8.3: THE WAY FORWARD

What is clear above all is the urgent need for attention to the whole situation of children with disabilities, and their families, and especially to those already orphaned. One possible way

forward has been charted below for consideration, even if it turns out to be simply a starting point for something completely different:

1. Set up an interim Task Force to look at the findings of this study, widen the scope of the investigation, collaborate with ministries and major organisations to plot the next steps and create an action plan that may choose to assess the following suggestions:

- ❖ Map out - at least roughly - the scale of the problem – possibly along the lines of the UNICEF/Government of Zimbabwe 2004 report on Orphans and Vulnerable Children, which incidentally excluded children with disabilities as outside its range).
 - ❖ Create a map/directory of organisations already involved in the field of children with disability and what they are doing in each district – possibly modelled on the ZAN (Zimbabwe AIDS Network)’s Directory in the field of HIV and AIDS, or UNICEF’s Nutrition Atlas. Be sure to include relevant ministries, umbrella church organisations such as (ZACH and ZINDERELLA and ZCC and ones specific to major bodies, not forgetting Vapostori and other less ‘mainline’ religious groupings) and work with organisations Levels – areas.
 - ❖ Look in more detail at the package of support needed, where existing initiatives can be strengthened , where gaps need to be filled and where new initiatives need to be established. Either now or later, work out priorities, and set up teams to oversee each one.
- 3 Create, or begin to plan for, a community-friendly training package for children with disabilities and their families – on succession planning, guardians, birth certificates, wills and inheritance – and link this to HIV risk reduction and testing- promotion programmes (but first review what is already in existence, possibly in collaboration with NASCOH, Progressio and the organisations using findings of its report on HIV and people with disabilities. Note that much material is also available through the \Legal Resources Foundation, SAfAIDS, SAT etc Consult on possible rollout strategies for this and other campaigns.
- 4 Hold wiser consultative workshops at national level to establish working teams for specific areas of action and consolidate the central task force that will oversee and unify the programme. Consider as models past campaigns concerning child sexual abuse, HIV testing promotion, anti-stigma HIV campaigns – and the use of the media to bring selected issues to national attention.

In conclusion, let us hope that this small study will spur readers into further research and networking – and most of all, into action - to build on and support the enormous resilience, creativity and hope of the mothers and grandmothers of children with disabilities, and to take steps to fulfil the untapped potential of the thousands of children who have been so sidelined for so long.

APPENDICES

APPENDIX 1: Questionnaire in English

APPENDIX 2: Questionnaire in Shona

APPENDIX 3: Questionnaire answers on succession planning

APPENDIX 4: Questionnaire answers on orphans with disabilities

APPENDIX 5: Questionnaire answers on abuse of disabled children

APPENDIX 6: Questionnaire answers on parents' HIV testing

APPENDIX 7: Kubatana listing of orphan- and child-focused organisations

APPENDIX 8: Kubatana listing of disability organisations

APPENDIX 1: Questionnaire in English

ROKPA/STRIVE STUDY

Please DO NOT put your name
ROKPA identity number

Part A. Personal Details

Are you: [tick only one box per line]

- 1. Male Female
- 2. Single Married Divorced Widow/Widower
- 3. 24 or younger years 25-34 years 35-44 years 45-54 years
 55 or older
- 4. Shona Ndebele Tonga Other
- 5. Do you live in: Harare Chitungwiza Other:.....?
- 6. Are you Catholic Pentecostal
 Methodist/Anglican/Presbyterian
 Vapostori Traditionalist Other (say what)
- 7. Your living quarters: renting owning
 7.a. Number of rooms incl. kitchen and bathroom:.....
 7.b. Do you have a vegetable garden: Yes No
- 8. Family situation & Income: Salaried employment
 informal income please specify:..... self employment no income

Citizenship: Zimbabwean ID? : : Yes No:

Part B. Present Status [Tick only one box per line or write the answer]

- 9. Are you: a single parent with a partner
- 10. How many children do you call your own?.....
- 11. How many children (dependants) are living with you in your house?.....
- 12. How old is your handicapped child?
- 13. Do you have a birth certificate for your child? No Yes
 If not, why did you not get one?

- 14. Info about your child's disability
 - a) Can your child walk? Yes No
 - b) Can your child speak? Yes No
 - c) Can your child see? Yes No

- d) Can your child hear? Yes No
- e) Is your child toilet-trained? Yes No
- f) Can your child eat and drink without help? Yes No
- g) Does your child go to school? Yes No

If YES, what school and grade/form is she/he attending?

.....

If NO, why

not?.....

15. Do you know your HIV status? Yes No

16. If you answered YES, when did you get tested? Year:Month:

.....

17. Where did you get tested?

18. What were your **three** most important reasons for getting tested:

.....

.....

.....

IF you answered NO, give **three** reasons why you do **not** want to know your HIV status:

.....

.....

.....

Part C. Knowledge, Behaviour and Attitudes

<i>[Put a tick in the column you agree with most, only one tick per line]</i>	Individuals like myself	The government	Churches, schools	Health workers
19. Who is PRIMARILY responsible for stopping the spread of AIDS?				

<i>[Put a tick in the column you agree with most, only one tick per line]</i>	Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree
20. How strongly do you agree with the statement "I am able to take actions to protect myself from getting HIV"				

Can one transmit HIV through <i>[Put a tick in the column you agree with most, only one tick per line]</i>	Not at all possible	Possible but not likely	Likely	Very likely
21. sharing needles/syringes?				
22. kissing on the mouth?				
23. shaking hands with the infected?				
24. having sex with the infected?				
25. mosquito bites?				
26. as an infected mother to baby (during				

pregnancy/birth/breastfeeding)?				
27. sharing cups/spoons with infected?				
28. using public bathrooms?				
29. living with or near infected?				

Can one reduce risk by..	Completely eliminates risk	Greatly lowers risk	Somewhat lowers risk	Does not lower risk
30. no sex?				
31. no sex except for masturbation?				
32. having only one partner?				
33. applying dry sex?				
34. having fewer partners?				
35. always and correctly using condoms?				
36. urinating after sex?				
37. getting treated for STIs?				
38. taking a shower after sex				
39. being circumcised?				

<i>[Put a tick in the column you agree with most, only one tick per line]</i>	Yes	No	Don't know
40. Is it possible for an HIV positive person to appear healthy?			
41. Is it possible for an HIV positive person to appear healthy and still pass on HIV to another person?			
42. When someone passes the HIV virus to another person, does it lower the amount of virus in the first person's body, or even cure it?			
43. Is there a cure for AIDS?			
44. Is there a difference between HIV and AIDS?			
45. Is there an effective vaccine against AIDS?			

Can you delay the onset of AIDS by... <i>[Tick in the column you agree with most, 1 tick per line]:</i>	Yes	No	Don't know
46. eating healthy food?			
47. avoiding stress?			
48. having safer sex?			
49. seeking care when ill?			
50. taking ARVs correctly?			
51. getting treatment from a n'anga?			

Part D. Effects of HIV-AIDS on disabled children

<p align="center">Please read the following statements and show what you think [[Put a tick in the column you agree with most, only one tick per line]</p>	Strongly Disagree	Somewhat Disagree	I'm in the middle	Somewhat Agree	Strongly Agree
52. Looking into the difficult moments of my past helps prepare me to face the challenges of the future					
53. HIV and AIDS have greatly influenced my pattern of life					
54. If I have HIV it is like a death sentence for my child as well as for me, because nobody wants to care for a disabled child					
55. It is possible to talk with my partner and immediate family about taking over the care of my disabled child if/when I get sick.					
56. The community can/will help in looking after my disabled child					
57. There are things I can do to help to prepare my family, and members of the community, so they can take good care of my child when I am not there any more					

58. To your knowledge, has your disabled child ever been subjected to any form of sexual abuse?

(If the answer is YES, please explain what kind of abuse)

.....

.....

.....

.....

59. Do you know of any disabled children in your community whose mother or father died? What happened to the child or children?

.....

.....

.....

.....

.....

.....

60. Who would you like to look after your child if you get very sick or die:

- a) a family member: who?
- b) a support group: name of the group?
- c) the community: who in the community?
- d) an organisation: which one do you think of?

61. Is there anything you would like to add concerning your health, and the future of your disabled child? Please feel free to write anything you feel:

.....

.....

.....

Thank you very much for your cooperation.

APPENDIX 2: Questionnaire in Shona

ROKPA/STRIVE STUDY Please DO NOT put your name

Musanyore zita renyu.

ROKPA identity number

Chikamu A.Mamiriro emunhu.

Uri...?; [Nyora kamwe chete muchikamu chimwe nechimwe]

19. Murume Mukadzi
20. Haasati aroora Akarooro Akasiyana nemurume/mukadzi Chirikadzi
21. 24 Zvichidzika 25-34 years 35-44 years 45-54 years 55
zvichikwidza
22. Shona Ndebele Tonga Mamwewo marudzi
23. Vanogaramu Harare Chitungwiza Imwewo
nzvimbo:.....
24. Catholic Pentecostal Methodist/Anglican Vapostori
 Zvechinyake Zvimwewo zvitendero.....

7. Pamba pamunogara: Munoroja Ndepenyu

7.a.Zvikamu zvemba kusanganisira pokugezera nepokubikira:.....

7.b.Mune bindu remuriwo here? Hongu Kwete

8.Mamiriro emhuri nechouviri: Munosevenza muchihora

Zvemaoko/Zvekuzviitira,taura zvaunoita..... munozvishandira

hamuwani Mari

Muri chizvarwa: Chine chitupa cheZimbabwe:: Hongu

kwete:Munobvepi?.....

Chikamu B. Zvauri parizvino.[Nyora muchikamu chimwe chete pindura mubvunzo]

9. Parizvino: Munoriritira vana mega here? Mune mukadzi/murume here?

10.Vana vamungati venyu vangani?.....

11.Vamwewo vana vamunoriritira mumba menyu vangani?.....

12.Mwana wenyu akaremara ane makore mangani?.....

13.Mwana wenyu uyu ane tsamba yekuzvarwa kwake here? Kwete

Hongu Kana asina sei asina kutoreswa?

.....
.....

14. Maremariro akaita mwana

- Anofamba here? Hongu Kwete
 Anotaura here? Hongu Kwete
 Anooka here? Hongu Kwete
 Anonzwa here? Hongu Kwete
 Anoenda kuchimbudzi ega here? Hongu Kwete
 Anodya nokunwa ega here? Hongu Kwete
 Anodzidza here? Hongu Kwete

Kana mati hongu, anodzidza kupi? Mugwaro rechingani?

.....

Kana mati kwete, nemhaka yeyi?

15. Makaongororwa ropa renyu here kuti muone kuti hamuna utachiona hwe HIV here?

- Hongu Kwete

16. Kana makaongororwa, makaongororwa rini? Gore:..... Mwedzi:.....

17. Makaongororwa kupi?.....

18. Ndezvipi zvinhu zvitatu zvakaita kuti mude kuongororwa ropa?:

.....

Kana mati kwete: Ipai zvikonzero zvitatu?

.....

Chikamu C.Ruzivo,Maitiro neMaonero

<i>[Nyorai kamwechete pamunobvumirana napo]:</i>	Vanhuwo zvavo sewe neni	Hurumende	Vezvitende ro,zvikoro	Vanoona nezveutsanana, noutano
19. Mungati AIDS inofanira kupedzwa nani?				

<i>[Nyorai kamwechete pamunobvumirana napo]</i>	Havakwani se zvachose kuzvidzivirira	Vangagone kutadza kuzvidzivirira	Vangagone kuzvidzivirira	Vanokwanisa chaizvo kuzvidzivirira.
20. Munobvuma here kuti pane zvamunokwanisa kuita kuzvidzivirira paHIV?				

Munhu angatapurire here utachiona ne...? <i>[Nyorai kamwe chete pamunobvumirana napo]:</i>	Hazvigoneki.	Zvingagone ke asi kwete nguva dzose	Zvingagone ke	Zvinotogoneka.
21. Nokushandisa tsono, reza imwe nevamwe ?				
22. Nokutsvodana pamuromo?				
23. Nokumhoesana neanorwara?				
24. Kuita bonde neanorwara?				
25. Kurumwa neutunga?				
26. Kubva pamubereki kuenda pamwana <i>[nokuzvara, kuyamwisa, munhumbu?]</i>				
27. Kushandisa ndiro, zvipunu nevanorwara?				
28. Kushandisa zvimbudzi zveveruzhinji?				
29. Kugara pedyo nevanorwara?				

Tingadzivirire dambudziko here ne...? <i>[Nyorai kamwechete pamunobvumirana napo]</i>	Zvinotopedza dambudziko.	Zvinodzora dambudziko.	Zvingangodzora dambudziko.	Hazvitobatsiri padambudziko.
30. Kuregedza bonde?				
31. Kungobonyora chete?				
32. Kuva nemumwe waunovimba naye?				
33. Bonde rokungobatana chete?				
34. Kuita vaunodanana navo vashoma?				
35. Kugona uye kusevenzesa kondomu nguva dzose?				
36. Kuita weti wapedza bonde?				
37. Kurapwa zvirwere zvebonde?				
38. Kugeza wapedza bonde?				
39. Kuchekwa rukanda rwepanhengo?				

<i>[Nyora kamwe chete pamunobvumirana napo]:</i>	Hongu.	Kwete.	Handizive.
40. Munhu ane HIV anogona kuratidzika somutano here?			
41. Munhu ane HIV anogona here kuratidzika somutano asi achikwanisa kutapurira vamwe utachiona?			

42. Kutapurira vamwe utachiona kunodzisa here kana kupedza HIV mumuviri?			
43. Denda reAIDS rinorapika here?			
44. Pane musiyano here pakati peHIV neAIDS?			
45. Pane mushonga here unodzivirira AIDS?			

Unokwanisa here kunonoka kuita Aids kana.....? [Nyora kamwe chete paunobvumirana napo]	Hongu	Kwete	Handizive
46. Ukadya zvine utano?			
47. Ukasazvidya moyo?			
48. Kuzvidzivirira pabonde?			
49. Kurapwa warwara?			
50. Kunwa maARV nenzira chaiyo?			
51. Kurapwa nen'anga?			

Chikamu D. Matambudziko eHIV-AIDS pavana vakaremara.

Verenga mitsara inotevera utaridze zvaunobvumirana nazvo [Nyora kamwe chete panoratidza pfungwa dzako]	Handibume	Zvachose Zvimwewo	handibvumi Ndiripakati	nepakati Zvimwewo	ndinobvuma Ndinobvuma	zvachose
52. Kutarisa matambudziko angu akadarika kunoita kuti ndigadzirire matambudziko epamberi						
53. HIV/AIDS zvashandura mararamiro angu						
54. Kuva neHIV kunenge kutongerwa rufu nokuti hapana anoda kundibatsira uye mwana akaremara.						
55. Ndinokwanisa kutaura nemumwe wanu nezvekuchengetwa kwemwana akaremara kana ndarwara						
56. Vavakidzani vanogona kubatsira kuriritira mwana akaremara						
57. Pane matanho andinogona kutora kuti vemumhuri nevavakidzani vagozochengeta mwana akaremara ndisisipo.						

58. Sekuziva kwenyu kana zvamakamboona mwana wenyu akaremara akamboshungurudzwa-kungave kubhinywa kana kubatwa zvisina kukodzera Kana mati hongu tsanangurai kuti akashungurudzwa sei?

.....

59. Pane vana vakaremara vasisina vabereki vamunoziva here?Chii chakaitika kwavari?

.....

.....
.....
.....

60. Wamugade kuti asare achiritira mwana wenyu imi marwara kana kuti musisipo ndiani?

- a) Hama yenyu: ani wenyu:
- b) Boka rinobatsira : zita reboka:
- c) Vomunharaunda : ani wacho munharaunda:
- d) Sangano: nderipi zángano ramunofunga:

61. Ndezvipi zvamugade kutaura kana kutizivisa pamusoro peutano hwenyu, uye remangwana remwana akaremara. Sunungukai kunyora zvese

zvamunonzwa:.....
.....
.....
.....
.....

Tatenda chaizvo

APPENDIX 3: Questionnaire answers on succession planning

APPENDIX 4: Questionnaire answers on orphans with disabilities

59. Do you know of any disabled children in your community whose mother or father died? What happened to the child or children?

M	6	I know a boy who lives in Shamva (Musana area). His mother and father died five years ago. Now he does not go to school, he does all household chores. His father's wealth was taken away by his father's brother and relatives.
M	12	Yes. They are just at home, not going to school.
M	16	I know of a girl called Jina. She is taken care by Jairos Jiri association.
M	21	No, but I have a disabled child and my husband is late.
M	22	No, but I am looking after my grandchild
M	23	Yes, but some passed away.
M	26	Yes they are being looked after by their grandparents, but with many difficulties.
M	27	I know of some. They were eventually taken to a care home because there was no-one directly responsible for them.
M	36	No, but I am looking after my grandchild. The mother died.
M	37	No, but I am also looking after my disabled grandchild.
M	40	Yes, but they are being looked after by relatives.
E	7	Yes, some passed away and some run away from home.
E	16	Yes, the parents died and the children are staying with their grandmother.
E	22	No, but I also have a child who is disabled.
E	24	Yes, The children are being looked after by their grandmother.
E	26	The parents passed away and are now subject to sexual abuse because they do not have anyone looking after them.
E	30	Yes, the parents died.
E	39	Yes, The father rejected him because of disability.

E	40	Yes, it is difficult to look after a disabled child when the parents are dead.
H	4	Yes, the parents are dead.
H	5	Yes, The disabled children were raped.
H	7	Yes, abandoned by parents.
H	15	Yes, the orphan was sent to a rural area in Nyanyadzi.
H	16	Yes, The children eventually got help from Red Cross who built them a two roomed house.
H	17	Yes, the parents passed away.
H	21	Yes, the child was left alone.
H	24	Yes, the child could not get any relatives to help so the child is staying alone and looking after himself.

Summary:

Half of all mothers participating answered positively knowing about disabled children whose parents were deceased or about children abandoned/rejected by the parents.

- Seven of the parents answering are grandmothers/-parents looking after their disabled grandchild.
- Only two 'caring' institutions are mentioned by name: Jairos Jiri and the Red Cross.
- Orphaned disabled children die soon after the parents. Others are left alone to look after themselves, sent to the rural area, being raped, disowned and abused by relatives.

Recommendation:

APPENDIX 5: Questionnaire answers on abuse of disabled children

APPENDIX 6: Questionnaire answers on parents' HIV testing

M	2	Just to know my status My deteriorating health
M	3	I know my HIV status I went as requested by the Doctor To enable me to watch my health and diet
M	4	I had stomach problems and frequent headaches
M	14	My husband diagnosed TB To know my HIV status To use it to inform me on how to look after myself
M	16	The disability of my child pushed me The health condition of my child My health condition was deteriorating
M	21	I was always sick Just to know my HIV status To use it to inform my diet
M	24	I wanted to know my HIV status

M	26	My husband died of meningitis I was losing weight I suffered from herpe
M	31	I was pregnant I wanted my husband to know his HIV status To protect the unborn child
M	34	I was pregnant I wanted to know my HIV status I did not trust my husband
E	7	I was always sick. To know my status. To plan for the future.
E	8	To know my HIV status
E	22	To know my HIV status
E	29	I was pregnant
E	36	I was told being HIV will make you having a disabled child
E	37	I wanted to know my status. I was sick. My husband died.
H	4	I was always sick. People in the family were sick. I wanted to know my status.
H	7	To see if I was negative. I was sick.
H	14	I wanted to know my status after my husband's dead so that I could properly look after my children.
H	15	My husband had passed away. My back had a problem.
H	16	I was always sick. My husband had passed away. I wanted to know my status.
H	23	I wanted to know my status. My body was changing and was painful.
H	25	My child was sick.
H	27	I wanted to know my status and the status of my boyfriend.

Summary:

Most important reasons that made the mothers taking the decision to get HIV tested were:

- Their own deteriorating health
- The death/health condition of the husband and disabled/other children
- Being pregnant
- Wanting to know their status in order to look after themselves and their children well
- Health and disability of the child
- Planning for the future of the children
- Mistrust of husband

Recommendation:

- *Experiencing deteriorating health as care-giver makes a strong motivation to get tested. Counselling and mutual support in parents groups looks to be very important.*
- *Workshops to motivate and assist parents to plan for the future of their disabled children could be very beneficial*

18/ NO ANSWERS Question on HIV testing – whether been tested and why.

If you answered NO, give **three** reasons why you do **not** want to know your HIV status:

M	1	I am not yet ready to go
M	6	My husband says he is not ready yet. He thinks he is fit so that he does not have it.
M	7	My husband refuses My health is fine

M	12	I am afraid
M	13	I am afraid
M	15	I am afraid I also do not have time
M	18	I am not yet prepared but I am determined
M	22	I do not have time
M	23	I am afraid
M	27	Never thought about being tested
M	28	My husband refused
M	29	I haven't come to terms with the idea but I will go
M	30	I do not have enough knowledge about it I trust my husband
M	35	I am afraid
M	36	I have no husband I am not sexually active
M	37	I was afraid I have one husband
M	40	I am afraid
M	41	I was afraid and I did not have enough knowledge about it
M	42	My health is fine I trust my husband.
E	15	I haven't any reason I think my health is fine and I am strong
E	16	I am afraid
E	24	I am just postponing it.
E	26	I am afraid of death once I know.
E	30	I have a problem. I have high blood pressure.
E	34	It never came to my mind.
E	39	Because I separated from my husband
E	40	I have plans to be tested.
H	3	I do not know
H	5	I am lazy to go and get tested
H	6	I am afraid
H	9	I was afraid
H	17	I do not know where to go. I was not concerned about it. I was afraid
H	21	I was afraid My husband did not allow me to get tested.
H	24	I was afraid I was not concerned about getting tested.

APPENDIX 7: KUBATANA LISTING OF ORPHAN and CHILD-FOCUSED ORGANISATIONS

ADD:

Jonathan Brakarsh, Journey of Life director, independent: Tel (04) 304829
AIDS Counselling Trust in Rowland Square, Milton Park
UNICEF

<u>Africare Zimbabwe</u>	(0)4-443198-201 schikowero@africare.co.zw ; general@africare.co.zw
<u>Alternative Business Association (ABA)</u>	(0)4-589625, (0)912-924151 alternative_bus@yahoo.com
<u>Batsiranai</u>	(0)248-2324, 2423 batsiranai@zol.co.zw
<u>Catholic Health Care Commission (CHCC)</u>	(0)67-24450, 22320 diochcc@zol.co.zw
<u>Catholic Relief Services (CRS)</u>	(0)4-736715, 736728, 736740, 726555 general@crszim.org.zw
<u>Chiedza Child Care Centre</u>	(0)4-660811/2/4/5, (0)912-437690 marko@chiedza.org.zw
<u>Child Protection Society</u>	0)4-708829 cps@cps.org.zw ; hcp@mweb.co.zw
<u>Community Foundation for the Western Region of Zimbabwe</u>	(0)9-200078, 209617 westfund@mweb.co.zw
<u>Dananai Child Care Organisation</u>	(0)21-264, 2274/5 murambinda.home.care@healthnet.zw
<u>Farm Orphan Support Trust of Zimbabwe (FOST)</u>	(0)4-309800/67 ext 228, 309869 ext 257/251/282 fost@cfu.co.zw ; fostad@cfu.co.zw ; fostkm@cfu.co.zw
<u>Helpage Zimbabwe</u>	(0)4-747696/7, 747236 helpage@africaonline.co.zw
<u>Hospice Association of Zimbabwe (HOSPAZ)</u>	(0)4-705771/2 info@hospaz.co.zw ; renias@hospaz.co.zw
<u>IFRC: International Federation of Red Cross and Red Crescent Societies - Regional Delegation For Southern Africa</u>	(0)4-705166/7, 702405, 793449 ifrczw01@ifrc.org
<u>Island Hospice and Bereavement Service</u>	(0)4-701674-7
<u>J.F. Kapnek Trust</u>	(0)4-792152, 723375/723377/722250 jfkapnek@mweb.co.zw ; gpowell@ctazim.co.zw ; gpowell@healthnet.zw
<u>Jesuit AIDS Project</u>	(0)4-300811 jesuitaids@mango.zw
<u>Just Children Foundation</u>	(0)4-781890; 211727; 211731; (0)912-240168 justkids@mango.zw ; justchildren@mweb.co.zw ; justkids@mweb.co.zw
<u>Kapnek Trust – SEE JF Kapnek</u>	

<u>Loving Hand</u>	(0)9-887844, 61967 lovinghand@zol.co.zw
<u>Mashambanzou Care Trust</u>	(0)4-610937,610079 mashamba@icon.co.zw
<u>Matabeleland AIDS Council (MAC)</u>	(0)9-62370,61540 linmac@mweb.co.zw; danmac@mweb.co.zw
<u>Midlands AIDS Service Organisation (MASO)</u>	(0)54-250356, 250377, 252647 maso@adtech.co.zw
<u>MntWANA Child to Child Support Project</u>	(0)4-300925,309730 aede@chipawo.co.zw
<u>Mother of Peace Orphanage Community</u>	(0)72-2345, 2708, 2704 MutokoMotherPeace@africaonline.co.zw
<u>MS-Zimbabwe</u>	(0)4-253145-9
<u>Danish Association for International Cooperation)</u>	mszim@mszim.co.zw; msdw@mweb.co.zw
<u>Murambinda Mission Hospital</u>	(0)21-2274/5 murambinda.hosp@healthnet.zw ; glenshaw@mweb.co.zw
<u>National Federation of Women's Institutes of Zimbabwe NFWIZ</u>	(0)61-2728 debby@zambezi.net
<u>New Hope Zimbabwe</u>	(04)-743332, 743329 nhz@zol.co.zw
<u>Plan International Zimbabwe</u>	(0)4-791601-4, 737067, 737070 zimbabwe.co@plan-international.org
<u>Rural Unity for Development Organisation (RUDO)</u>	(0)39-263903, 262374 rudo1@mweb.co.zw
<u>SOS Children's Village Association of Zimbabwe</u>	(0)4-746451/3 soszim@soszim.co.zw
<u>terre des hommes, Germany</u>	(0)4-747397,747307, Dir Line: 747505 tdh@ecoweb.co.zw
<u>Tsungirirai</u>	(0)62-2996,2080 tsungi@mweb.co.zw
<u>Umkhathi Theatre Works</u>	(09)-403386 umkhathi@email.com
<u>World Vision International (Zimbabwe)</u>	(0)4-301715,301709,369027/8,301178, 301192, stewart_muchapera@wvi.org
<u>Young Women Christian Association (YWCA)</u>	(0)4-487491/486142 ywcass@ywca.co.zw
<u>Zimbabwe AHEAD</u>	(0)25-2735, (0)11-638413 juliet@africaahead.com
<u>Zimbabwe AIDS Network (ZAN)</u>	(0)4-700832, 795337, 775520 info@zan.co.zw
<u>Zimbabwe National Association for Mental Health (ZIMNAMH)</u>	(0)4-731272,792946,728538 zimnamh@africaonline.co.zw ; zimnamh@mweb.co.zw
<u>Zimbabwe Network for Informal Settlement Action (ZINISA)</u>	(0)4-746175,776304 effie@ipa.co.zw
<u>Zimbabwe Red Cross Society</u>	zrcs@ecoweb.co.zw

KUBATANA LISTING OF CHILDREN'S ORGANISATIONS

(duplications with orphan listing omitted)

Organisation Fact Sheet – children's orgs

**Action (magazine)

Africa Community Publishing and
Development Trust (ACPDT)

African Networks for Health Research and
Development (AFRO-NETS)

AIMED (Accessible Instructional Methods

Telephone

263-(0)4-747213, 747213/74

action@action.co.zw

(0)4-253608/9

management@bookteam.co.zw;

admin@bookteam.co.zw

(0)4-496723

neuvians@mweb.co.za; gtz-

hsr@mweb.co.zw

(0)4-496796, (0)912-263315,

<u>for Education & Development)</u>	(0)912-355834 mpacey@mango.zw
<u>Association of Women's Clubs (AWC)</u>	(0)4-571903 awc@mango.zw
** <u>CamFed Association - Campaign for Female Education</u>	(0)4-737435 camfedzimbabwe@camfed.org.zw, angie@camfed.org.zw
<u>Centre for Peace Initiatives in Africa (CPIA)</u>	(0)4-443442/3, (0)11-411653 cpia@africaonline.co.zw, chitombo@cpia.org.zw
** <u>Centre, The</u>	(0)4-790096, 251429, 724494 directors@centre2.co.zw; lyndefrancis@africaonline.co.zw; infor@centre2.co.zw
** <u>Childline</u>	(0)4-734252, 796741, 793715 childl@africaonline.co.zw
** <u>CHIPAWO</u>	(0)4-300925, 309730 info@chipawo.co.zw; programmes@chipawo.co.zw; zimartsed@mango.zw; chipawocmc@mango.zw
<u>Discovery Channel Global Education Partnership</u>	(0)81-30239 ndo.mbambo@gmail.com
** <u>Dorothy Duncan Centre for the Blind and Physically Handicapped</u>	(0)4-496667, 495116, 251116, 251117 chiedza@mweb.co.zw; ddc@zol.co.zw
<u>Educators Association For Human Rights (EAHR)</u>	(0)20-30684,64623 (0)11- 424683,700314 eahr@myway.com
<u>Ensemble for Performing Arts Zimbabwe</u>	(0)59-2886 oniasmatumbu@yahoo.com
<u>Environment Africa (EA)</u>	(0)4-492143, 492147, 492148, 492152 eafrika@utande.co.zw
** <u>Family Support Trust (FST)</u>	(0)4-668056/57 fstadmin@mweb.co.zw
** <u>Girl Child Network Trust</u>	(0)70-31132/21509
<u>Harare Inner City Partnership</u>	(0)4-250404, 736953/54 hicp@zol.co.zw; pp@anthill.co.zw; theog@anthill.co.zw
<u>Human Rights Trust of Southern Africa (SAHRIT)</u>	(0)4-339819,333882,332179 sahrit@sahrit.org.zw
** <u>Jairos Jiri Association : Southerton Centre</u>	(0)4-662545/6/8 jairosj@ecoweb.co.zw
** <u>Justice for Children Trust</u>	(04)-797723, 796795 admin@jctrust.co.zw; nenjerama@jctrust.co.zw; mutandwa@jctrust.co.zw
<u>Kadoma Writers Association</u>	(0)912-355390 info@kwa.kabissa.org; morren.chivange@kwa.kabissa.org
<u>Kunzwana Trust</u>	(0)15-573 kunzwana@mweb.co.zw
<u>Kunzwana Women's Association</u>	(0)4-747190,747519 kwa@africaonline.co.zw
<u>Media for Development Trust</u>	(0)4-701323/4 info@mfd.co.zw

**Midlands AIDS Service Organisation (MASO) (0)54-250356, 250377, 252647

Mutare Vocational Training Centre (0)20-68797

National Federation of Women's Institutes of Zimbabwe (NFWIZ) (0)61-2728

National Youth Development Trust (0)9-63330
nydt@justice.com;
youthtrustzim@gmail.com

**Padare/Enkundleni/Men's Forum on Gender padare@mweb.co.zw,
kmgt@mweb.co.zw,
hbc@mweb.co.zw

Population Services Zimbabwe pszim@africaonline.co.zw

Radio Dialogue (0)9-881009, 881020, 884858
radio@radiodialogue.co.zw;
njohnson@mweb.co.zw

**Regional Psychosocial Support Initiative (REPSSI) (0)9-883678, 883273
info@repssi.org;
brighton@repssi.org

Rodwel Foundation Women's Co-operative SAHRIT - Human Rights Trust of Southern Africa (0)55-40263 rodwel@telco.co.zw

**Salvation Army Masiye Camp, The (0)9-60727, 880834, 883586
info@byo.masiye.com

**Shape Zimbabwe Trust (0)4-303211 Ext 1361
mushingam@yahoo.com

Southern Africa AIDS Information Dissemination Service (SAfAIDS) (0)4-336193/4, 307898
info@saf aids.org.zw

**Southern African Federation of the Disabled (SAFOD) (0)9-69356
safod@netconnect.co.zw

***Streets Ahead (0)4-705074, (0)23-280648
streetsahead@zol.co.zw

**Student Partnership Worldwide Zimbabwe (SPWZ) (0)4-722579
spwzim@mweb.co.zw

Students Aids Action Forum (SAAF) (0)4-708043, 708070, 334050
aidsactionforum@yahoo.com

**Students And Youths Working on reproductive Health Action Team (SAYWHAT) (0)912-819786, 788099/100
saywhat@cwgh.co.zw;
saywhatpublicity@yahoo.co.uk

Students Christian Movement of Zimbabwe (ZSCM) (0)4-738920,703474

Students Solidarity Trust (SST) (0)912-251384, (0)912-974435,
(0)912-973294
sst@africaonline.co.zw

Training and Research Support Centre (TARSC) (0)4-708835,705108
tarsc@mweb.co.zw;
admin@tarsc.org

Women and AIDS Support Network (WASN) (0)4-791401/2/4
director@mweb.co.zw

Women in Politics Support Unit (WiPSU) (0)4-744969, 744847, 744283
wipsu@wipsu.co.zw

**Young Africa (0)70-23659, 30076
office@youngafrica.co.zw;
yvette@youngafrica.co.zw

Young Women Christian Association (YWCA) (0)4-487491/486142
ywcass@ywca.co.zw

<u>Youth Affirmative Foundation</u>	(0)4-620131-4 itayi@wilson.co.zw; itayitawona@yahoo.com; youthaffirmatives@yahoo.com
<u>Youth Alive Zimbabwe (Mutare)</u>	(0)20-62530 yazim@zol.co.zw
<u>Zimbabwe Aids Prevention Services Organisation (ZAPSO)</u>	(0)4-332882,307847/8, 302571, 307847 zapso@mweb.co.zw
<u>Zimbabwe Human Rights Association (ZimRights)</u>	(0)4-707278,705898 dmachingura@zimrights.co.zw
<u>**Zimbabwe Integrated Youth Survival Alternative Programme (ZIYSAP)</u>	(0)4-573182 chiysap@comone.co.zw; chiysap@mango.zw
<u>Zimbabwe National Council for the Welfare of Children (ZNCWC)</u>	(0)4-738429,793966 zncwc@africaonline.co.zw
<u>Zimbabwe National Family Planning Council (ZNFPC)</u>	(0)4- 620281/5,661962/4,661748,668770 zmfpc@ecoweb.co.zw
<u>Zimbabwe National Students Union (ZINASU)</u>	(0)4-788135 zinasu@gmail.com
<u>**Zimbabwe Parents of Children with Disabilities Association (ZPCDA)</u>	(0)4-576521/2 messages, (0)912- 357936 zphcabyo@netconnect.co.zw; theresamakwara@yahoo.com
<u>Zimbabwe Students Christian Movement (ZSCM)</u>	zscm@mango.zw; masimba_zw2001@hotmail.com; innocentkasiyano@yahoo.com
<u>Zimbabwe Women Lawyers Association (ZWLA)</u>	(0)4-706676,703766,708491 zwla@zwla.co.zw, byo@zwla.co.zw
<u>Zimbabwe Women's Bureau (ZWB)</u>	(0)4-747905,747809,747433

APPENDIX 8: KUBATANA LISTING OF DISABILITY ORGANISATIONS

<u>Alzheimer's Society - Harare: see ZARDA</u>	
<u>Bulawayo Society for the Adult Blind - Barbara Burrell Centre</u>	(0)9-242540 osborne@mweb.co.zw
<u>Council for the Blind</u>	(0)9-64940, 69081 cfb@telconet.co.zw; council@mweb.co.zw
<u>Danhiko Project</u>	(0)4-492087,492367,492382 danhiko@mango.zw
<u>(ICD) (CIIR) – see Progressio</u>	
<u>National Association of Societies for the Care of the Handicapped (NASCOH)</u>	(0)4-4-746967, (0)11- 862072, (0)912-385417 nascoh@zol.co.zw
<u>National Federation of Women's Institutes of Zimbabwe (NFWIZ)</u>	(0)61-2728 debby@zambezi.net
<u>Post Independence Survivors' Trust (PIST)</u>	(0)9-65701 postindependencesurvivorstrust@yahoo.com (0)4-791959, 791972 progressiocr@zol.co.zw; progressioadmin@zol.co.zw
<u>Progressio (formerly CIIR)</u>	(0)4-304202 rokpa@zol.co.zw;
<u>Rokpa Support Network</u>	(0)912-339670; (0)4-860166 coxsu@renniestravel.co.zw
<u>Zimbabwe Alzheimers and Related Disorders Association (ZARDA)</u>	(0)4-731272,792946,728538 zimnamh@africaonline.co.zw; zimnamh@mweb.co.zw
<u>Zimbabwe National Association for Mental Health (ZIMNAMH)</u>	
<u>Zimbabwe Parents of Children with Disabilities Association (ZPCDA)</u>	(0)4-576521/2 messages, (0)912-357936

Other disability organisations are listed, with contact details, in Children and Orphan Listings, as follows:

- ❖ Dorothy Duncan Centre for the Blind and Physically Handicapped
- ❖ Helpage Zimbabwe
- ❖ Jairos Jiri Association : Southerton Centre
- ❖ J.F. Kapnek Trust
- ❖ Matabeleland AIDS Council (MAC)
- ❖ Mother of Peace Orphanage Community
- ❖ Murambinda Mission Hospital
- ❖ Plan International Zimbabwe
- ❖ Southern African Federation of the Disabled (SAFOD)
- ❖ Umkhathi Theatre Works
- ❖ Zimbabwe AHEAD
- ❖ Zimbabwe Parents of Children with Disabilities Association (ZPCDA)