

PSYCHOSOCIAL WELLBEING SERIES

Supporting Young Carers

PROGRAMME GUIDELINES FOR
HOUSEHOLDS IN WHICH
YOUNG PEOPLE ARE
CARING FOR OTHER
HOUSEHOLD MEMBERS





Psychosocial Wellbeing For All Children

REPSSI (the Regional Psychosocial Support Initiative) is a non-profit organisation working to lessen the devastating social and emotional (psychosocial) impact of poverty, conflict, HIV and AIDS among children and youth. Our aim is to ensure that all children have access to stable care and protection through quality psychosocial support. We work at the international, regional and national level in East and Southern Africa.

We believe that the best way to support vulnerable children and youth is within a healthy family and community environment. We partner with governments, development partners, international organisations and NGOs to provide programmes that strengthen communities' and families' competencies to better promote the psychosocial wellbeing of their children and youth.

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Foreword

REPSSI is a regional non-governmental organization working with partners to promote psychosocial support (PSS) and care for children affected by HIV and AIDS, poverty and conflict in East and Southern Africa.

With more than 22 million people in sub-Saharan Africa infected with HIV, many of whom are parents and caregivers, some 70 million children in this region alone are likely to be directly HIV affected as individuals living with people who are sick as a result of AIDS.¹

For many years there has been a call by its partners for REPSSI to develop programmatic guidelines for households in which young people are performing significant caring for other unwell or elderly or frail household members, and where this caring goes beyond what is locally expected of the young carers and is having or likely to have negative health and psychosocial outcomes for the young person.

The process of developing these guidelines has been highly participatory, involving not only young carers but also unwell household members, teachers, academics and NGOs. It is hoped that these guidelines will result in increased and strengthened knowledge, skills and empowerment for young carers and their various support systems.



Noreen Masiwa Huni

Executive Director

REPSSI

We define a young carer as any young person under the age of 18 years who is caring for other household members who are unwell or elderly or disabled. This care is beyond what is normally expected of a young person.

¹ I. Cluver (2011), NATURE, 474, 27

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Contents

Foreword	i	Theme 2: Young Carers' Wellbeing	22	Theme 4: Livelihood Strengthening	55
Acknowledgements	ii	Wellbeing of Young Carers	23	Types of Livelihood Strengthening Activities	56
Aims of the Guidelines	5	Young Carers' Rights	23	Young Carers Leading Economic	
How to Use the Guidelines	6	Rights and Responsibilities	25	Strengthening Activities	60
Introduction	8	Child Safety	26	Thinking Long Term	60
Theme 1: Support for Young Carers	9	Psychosocial Wellbeing	27	Let's Check Ourselves	61
Cumulative Burden of Care	11	Psychosocial Support Tools	28	Theme 5: HCT and Disclosure	62
Risks for Young Carers	12	Communication in the Family	29	The Importance of Testing	64
Positive Outcomes of Young Caring	12	Supporting the Role of Unwell Caregivers	31	Disclosure	64
Gender Equality	12	Caring for Younger Siblings	33	Disclosure to Young Carers	67
Where to Invest our Energy	14	Let's Check Ourselves	36	Young Carers Own Health	68
Let's Get Specific	15	Theme 3: Connecting Young Carers	37	Let's Check Ourselves	69
Who Can Support Young Carers?	17	The Benefits of Young Carers Support Groups	38		
Connecting Young Carers	19	Topics to Cover When Starting a Young			
Let's Check Ourselves	20	Carers Support Group	39		
		Types of Activities Covered in Young			
		Carers Support Groups	48		
		Let's Check Ourselves	54		

Contents

Theme 6: Treatment Literacy and Support	70	Theme 8: Grief and Loss	87	References for Further Reading	103
Understanding HIV and AIDS Terminology	70	Understanding Grief	88	Appendices	105
Symptoms of HIV and AIDS	72	Supporting a Young Carer Who is Grieving	90	Appendix 1: The Caring Jobs I Do	105
Side Effects of ART	73	Remembering	91	Appendix 2: Windows	107
When to Get Emergency Help	73	Strengthening Community Support for		Appendix 3: Family Tree Exercise	109
Keeping Bedridden Household Members Healthy	74	Young Carers Experiencing Loss	94	Appendix 4: Disclosure to Different Aged Children	110
Let's Check Ourselves	78	Let's Check Ourselves	95	Appendix 5: Proposed Workshop Programme	113
 Theme 7: Future Planning and Preparation for Death	 79	 Theme 9: From Awareness to Action	 96		
Celebrating a Life	79	Overall Aims of the Guidelines	96		
Taking Care of the People Who are Left Behind	81	Summary of Thematic Outcomes	98		
Making a Will	83	Celebrating Success	101		
Opening Discussions About Death and Dying	85				
Let's Check Ourselves	86				

Aims of the Guidelines

The overall aims of the guidelines are to help young carers:

1. To feel more empowered (by the acquisition of new knowledge and skills) and less vulnerable in their role as young carers
2. To feel more supported (by other individuals and groups) in their role as a young carer.

The guidelines make special reference to the following types of programmes, which are ideally placed to support households where there is a young carer:

- Schools (in which case the guideline is aimed at teachers, school principals and education officials)
- Home based care community programmes (in which case the guidelines are aimed at home based carers, home and community based carers, and individuals or organizations who programme in the area of home and community based care)
- Programmes with young people supporting other young people (in which case the guidelines are aimed at youth

leaders or “behind-the-scenes adults” who support such programmes, for example a youth leader of a kids club or a youth leader of a young carer support group, or an adult who supports such a programme. This adult might be even be a community and home based carer or a teacher.)

Thus it must be emphasized that these guidelines are not aimed for use directly with young carers but will inform and empower anyone who works with households in which there are young carers and unwell household members. The guidelines however can be adapted for use directly with young carers, for example a teacher might use some of the content into a school lesson. Or a community and home based carer might use some of the content to counsel a child who is grieving.



Those activities that we think may be adapted for use directly with young carers have been marked with the symbol YC. In order for the activity to be meaningful and understandable

for young carers, the facilitator will however have to explain some of the information that came before in language that the young carers can understand. This does not mean that those activities marked Practical Activities cannot be used directly by young carers however those marked with the symbol YC were thought to be the most obvious ones.

These guidelines aim to increase support to young carers whose responsibilities extend beyond what is normally and traditionally expected of children.

How to use the Guidelines

The guidelines are for anyone working with young carers and their households. We hope that you will draw on your own experience with children and young carers and apply the guidelines in a way that fits best with your context.

You may use these guidelines for self-study or they may be used as a learner handbook for training courses. A suggested training programme is provided in Appendix 5 which may be adapted to your purpose.

The guidelines provide the following learning opportunities:

- Characterisation of the themes through stories of a young carer called Noko, her mother Emma, and various people supporting her wellbeing
- Case examples
- Reflection exercises for individual reflection or group discussion with other colleagues supporting young carers
- Theoretical input
- Practical activities which may be facilitated with young carers or communities supporting young carers

Meet the characters you will encounter in this guide!

They represent some of the key roleplayers who are relevant to working with young carers.



Noko:
a young carer



Emma:
Noko's mother



Mr Hlaphi:
Noko's teacher



Jennifer:
a community home
based carer



Busi:
Noko's good friend,
also a young carer



Babalwa:
The leader of the Kind
Lions support group for
young carers

Introduction

Within many African cultural traditions, young people are given responsibility for important household tasks like cooking, cleaning, taking care of younger children, herding animals and working in the fields in rural areas. Even young children participate and develop skills in everyday household tasks. Being involved in household tasks and caring for others can have many positive benefits for young people.

Due to the HIV and AIDS pandemic in Africa, as well as the effects of poverty, there are many households in which at least one person is ill. Many of these unwell individuals need special care and much of this support comes from young people. Chimwazi and Watkins (2004) found that in addition to practical support, young carers in rural areas of Malawi were also providing emotional and moral support to sick relatives who were too ill to be left alone.

Sometimes where a community faces extreme difficulties, like in the times of HIV and AIDS and where there is severe poverty, the task which falls to young carers exceeds what is

normally and traditionally expected of children. This is when the burden of caregiving has reached a point where there may be negative outcomes for the young carer placing them at greater risk than their peers.

There has been a call to design programmatic interventions that address the risks associated with child caring and that seek to maximize the positive opportunities associated with the role of young caring. The belief is that if the young carer is not sufficiently supported, negative outcomes can be expected. However, with support, the young carer role can build resilience and mental health amongst children and youth who are in caregiving roles.

An extensive peer review process, which included the participation of young carers, home based carers, teachers, NGO workers and researchers, helped us to identify the following themes in regard to households in which there are young carers.

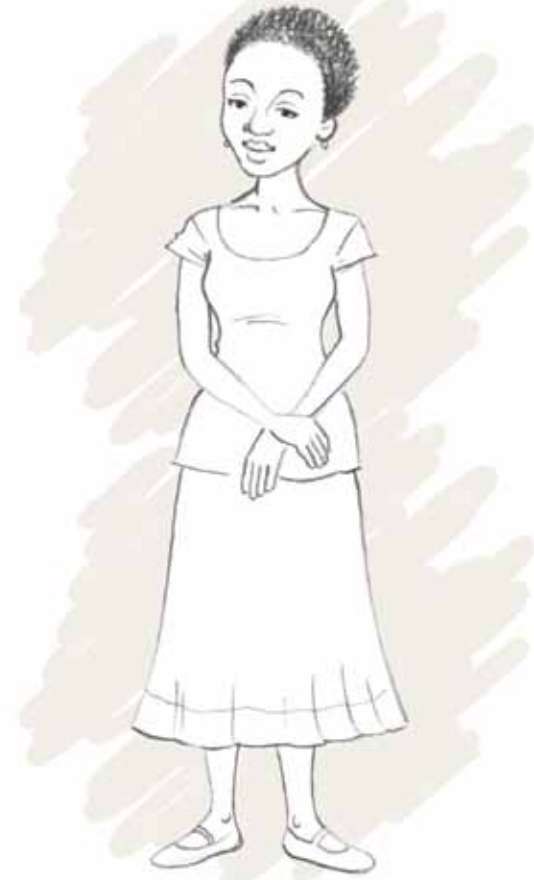
Themes

1. Support for Young Carers
2. Young Carers Wellbeing
3. Connecting Young Carers
4. Livelihood Strengthening
5. HCT and Disclosure
6. Treatment Literacy and Support
7. Future Planning and Preparation for Death
8. Grief and Loss
9. From Awareness to Action



Support for Young Carers

Noko is a young carer who is 14 years old. She lives in a rural area. Noko's mother Emma is very sick. Noko spends a lot of time feeding, cleaning, and nursing her mother. Noko worries a lot about her mother. She often misses school. And even when she does go to school she cannot concentrate, both because she is often hungry and also because she is worrying about her mother. Although looking after her mother is difficult, it also has its good sides. Noko and her mother have become very close. Noko's mother worries a lot about Noko and wishes she had more energy to help Noko with the household chores. At least she has the energy to help Noko with her homework and to listen to Noko's many stories as Noko is quite the story teller!



Here is a list of everyday tasks.

Noko ticked most of these boxes!

HOUSEHOLD CHORES	✓
Preparing meals and cooking	✓
Cleaning and tidying	✓
Laundry	✓
Washing dishes	✓
Making tea / drinks	✓
Fetching water	✓
Shopping / buying food	✓
Tending livestock	
Cultivating crops and vegetables	✓
Heating water for baths	✓
Carrying / lifting items	✓
Fetching firewood	
HEALTHCARE RESPONSIBILITIES	✓
Reminding assisting to take medication	✓
Seeking help to transport parent to hospital	
Preparing special diet for parent	✓
Caring for an ill person overnight	✓

Accompanying parent to clinic / hospital	✓
Overnight care for parent in clinic / hospital	
Caring in emergencies	✓
Assisting with mobility	✓
Cooking food for parent in hospital	
Washing sores and treating minor illnesses	✓
Collecting medication	✓
PERSONAL CARE TASKS	✓
Encouraging and helping parent to eat	
Washing / bathing parent	✓
Assisting parent to use toilet / washing soiled laundry	✓
Assisting with dressing	✓
Tucking parent in bed	✓
CHILD CARE RESPONSIBILITIES	✓
Getting younger children ready for school	✓
Bathing young children	✓
Supervising younger children	✓

Helping younger children with homework	✓
Accompanying younger children to and from school	
Preparing food for younger children	✓
Caring for younger children during the night	✓
INCOME GENERATION ACTIVITIES	✓
Taking on wage earning casual work	✓
Subsistence farming	✓
Begging	✓
Transactional sex	
Sewing and tailoring	
Selling produce or goods at the market	✓
EMOTIONAL AND PRACTICAL SUPPORT	✓
Talking and comforting	✓
Being there	✓
Running errands e.g. going to the post office or bank	✓

Table 1: Evans and Becker (2009)
Tasks of Young Carers



For discussion or reflection:

- Where do we draw the line between what is too much for a young carer and what is culturally and traditionally expected of a young person?
- What do you think - is Noko doing too much?
- Which tasks would you consider particularly unhealthy for a young carer?
- What are the possible negative effects of doing these tasks?
- What are the good things that might come from Noko doing some of the above tasks?
- How much are young carers doing in your community? Fill in this checklist for a young carer in your area.

It is easy to see that for many children for whom we can tick the box for most (if not all) of the responsibilities on page 10, the burden of care that has fallen upon them may be too much to bear. In this case they are clearly in need of support.

Cumulative Burden of Care

Evans and Becker (2009) have used a continuum which shows a cumulative burden of care. They show how on one end of the continuum children may be appropriately involved in participating in household activities. And on the other end of the continuum, children may be burdened by too much work and responsibility for their age. Additional support may be needed for young carers at this latter end of the continuum.

Those children who need additional support are children who not only provide substantial care but:

1. where this care is more like “full time care” and which is considered age and culturally inappropriate within and by the culture in which the household are located, and
2. where the burden of care is resulting in significant negative outcomes for the young carer, and
3. where young carers engage in inappropriate activities relative to their age and situation, such as transactional sex or begging

Understanding Childhood

In most cultures, childhood is seen mainly as a time for:

- fun and play
- learning (attending school and doing homework)
- learning to take on some family or social responsibility beginning with small household tasks

Appendix I has a user-friendly assessment tool on the positive and negative outcomes of young people involved in caring. This is from the Manual for Measures of Caring Activities and Outcomes for Children and Young People (Joseph, Becker and Becker, 2009), which you can download free of charge from www.youngcarers.net.au.

Risks for Young Carers

Cluver et al (2011) have found that children who are carers are at higher risk for the following negative outcomes:

- TB infections due to exposure to coughing and closeness to the sick person in the nursing role
- problems attending school and concentrating at school
- anxiety and depression
- abuse in the home due to stress and depression of adult caregivers
- likelihood for girls to engage in transactional sex, due to increased poverty

"I have not been to secondary school, but I would very much like to. When I was in primary school I was very clever but when mum became ill I was so worried about her and didn't think much about school."

(Grace, aged 15, Tanzania, from Evans and Becker, 2009)

Positive Outcomes of Young Caring

There are of course also potential positive outcomes associated with young caring. Some of these include:

- children gaining new skills and knowledge, such as a better understanding of HIV, nursing skills, patience, listening and support skills greater maturity, emotional strength and independence, perhaps gained through developing a strong, loving bond with the care recipient
 - children in caring roles might develop a social and personal identity if their role in, and their tremendous contribution to, the household is recognized and affirmed (Skovdal, 2011)
- Reflection Exercise: Positive Outcomes for Young Carers**

"I would like to become an AIDS educator. I would teach people about proper behavior, to live with their families and not to use things like razors and syringes carelessly."

(Magdalena, aged 15, Tanzania, from Evans and Becker, 2009)

Reflection Exercise: Positive Outcomes for Young Carers

See if you can add to this list of potential positive outcomes for children who are involved in caring, and who are well supported in their caring role.

Gender Equality

Gender equality means that males and females are treated the same and have access to the same opportunities in life. Evans (2011) has found that amongst young carers in Eastern Africa, girls tend to take on more caring responsibilities than boys.

Reflection Exercise: Gender Equality in Young Carers' Roles and Responsibilities

Compare your assessment of young carers' tasks (that you did in the previous exercise) between the tasks carried out by boys and girls. Here are some questions for reflection or discussion:

- In your context, who is taking on more of the caring responsibilities – boys or girls?
- How can we encourage a sharing of responsibilities without undermining our local culture?
- How can we strengthen men's involvement in caring without undermining their masculinity and rather strengthening their social identity?

While boys and girls might have different responsibilities, each should feel that they are treated fairly and that all their rights as a child are respected.

In Tanzania, the Kwa Wazee project found that often the work done by young carers went across the culturally defined gender barriers (for example boys cooking and girls chopping firewood). However they found that this can increase the children's isolation as this kind of work is stigmatized in the community. Therefore care needs to be taken to empower boys and girls to share responsibilities in a way that does not stigmatize them. This also shows the value in raising awareness in the community about gender roles and the involvement of men in caring roles, especially in the time of HIV and AIDS.

Here is an exercise that may be facilitated with men and women (or boys and girls) about sharing responsibilities of caring. It is adapted from the manual "Engaging Men and Boys in Gender Equality and Health" by Instituto Promundo (2010).

For other practical activities on how to promote men's involvement in caring, you can download the manual "Engaging Men and Boys in Gender Equality and Health" free of charge from the Brazilian organization Instituto Promundo (www.institutopromundo.org.br/en).



Practical Activity: Division of Labor in the Home

Make a list of typical household activities. Next to each activity, make a note about whether the activity is done by a man or a woman or both. Add up the number of activities done by men and women.

Here are some questions for reflection or discussion:

- How many activities are done by men and how many activities are done by women?
- Did the results surprise you, or not?
- How has HIV changed the burden of care in many households?
- What prevents men from being involved in caring activities?
- What are the benefits for men to be involved in caring activities?
- What can be done to promote men's involvement in caring activities?
- Can any of these ideas be applied to your own situation at home?

One way of helping to divide tasks fairly between boys and girls is to help young carers to organize a schedule of their tasks. This schedule may then be negotiated amongst every household member, so that the load of work is shared fairly amongst everyone.

Many young carers have already developed good organizing and planning skills. This is how William, aged 16, from Tanzania, organizes his day (from Evans and Becker, 2009):

Case Example:
Organizing Household Chores

"On school days I wake up at 5am and I milk the goat. At 6am I make tea. At 6.30am I put on my school uniform. I don't wash the dishes or cut the grass for the livestock because I did that the previous evening. At 7am I remind grandma to take her medicine and I go to school. At 4pm when I come back I cut grass for the livestock and prepare the evening meal. I study when I've finished the work, maybe by 8pm."

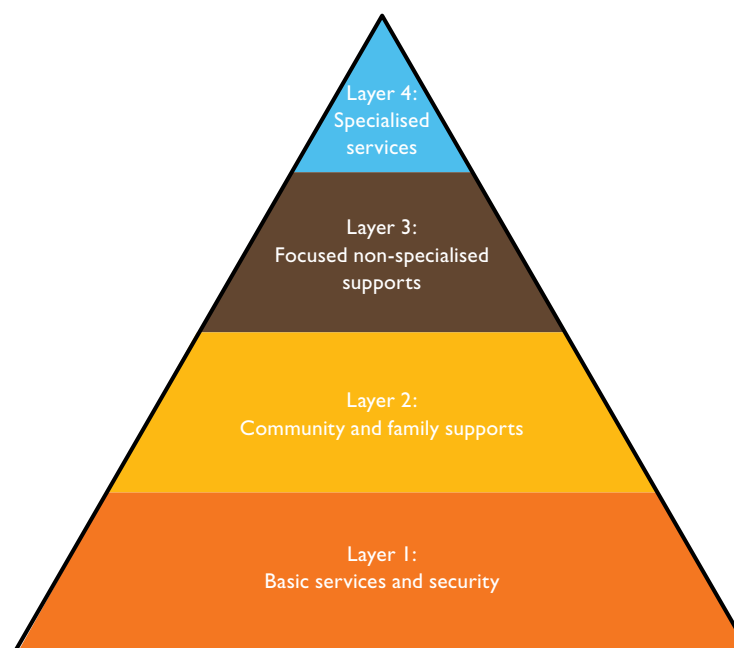
We can support young carers by understanding what tasks are acceptable for them to be doing, how to balance these tasks between males and females in the household, and how to organize these tasks in a way that allows them enough time to play and learn.

Where to Invest our Energy

Given the numbers of young people caring for unwell household members, there is a need to think carefully about where to invest our energy. We should also be careful of not disturbing local systems of support that are working well, and rather to strengthen these local systems in their role of supporting young carers.

The IASC Pyramid of Mental Health and Psychosocial Interventions provides a logical and coherent framework within which to locate and stagger different types of support. The framework REPSSI works within when planning programmatic interventions is presented below.

Diagram 1: REPSSI Adapted IASC pyramid of Multi-layered and Integrated Psychosocial and Mental Health Interventions for Children



Layer 4. Psychological and psychiatric support and specialized traditional healer services for those who experience significant difficulties in basic daily functioning.

Layer 3. Children, youth, family and group interventions by trained and supervised workers. This includes children and youth who have special coping needs, such as survivors of gender-based violence and those who have experienced complicated forms of grief.

Layer 2. Strengthening family and community care and support; activating social networks (support groups); providing information on constructive coping methods, available resources and community mental health education.

Layer 1. Includes advocacy for basic services, documenting impact of services on PSS wellbeing and/or mental health.

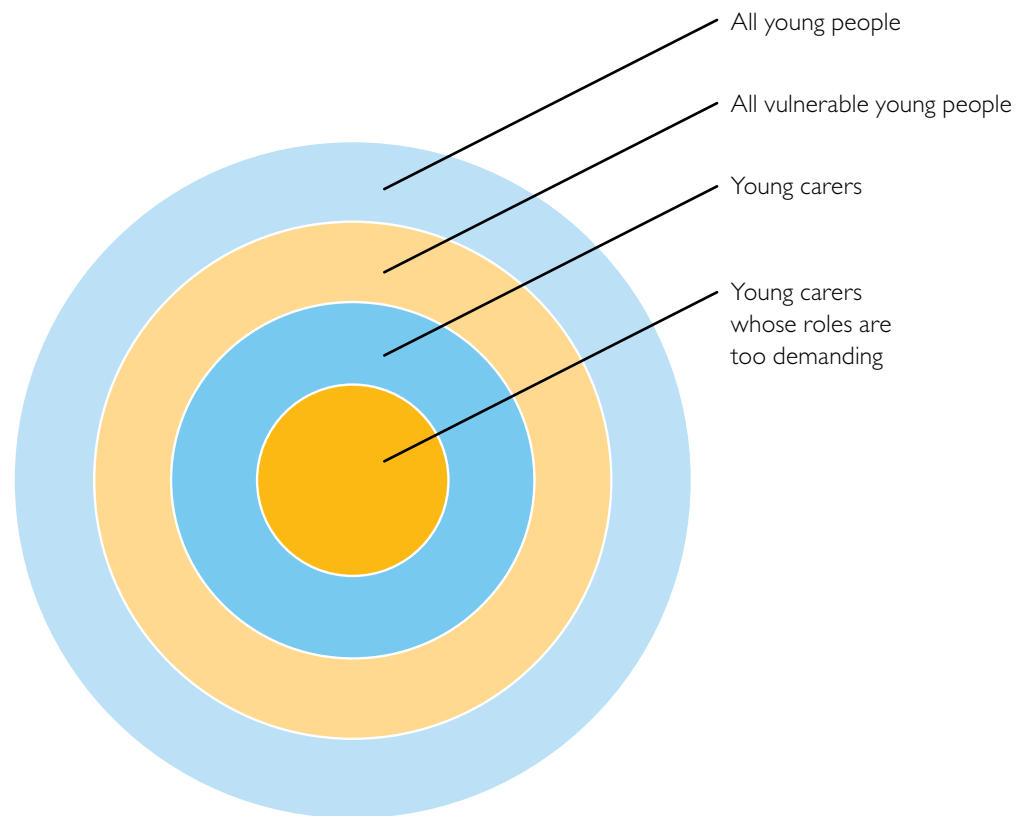
At the bottom of the pyramid, all children are targeted. As one moves higher up the pyramid, interventions become more specialized reaching less children. At the top of the pyramid, it is only the most affected children that are receiving more specialized interventions.

Children who require additional support may be identified at the bottom of the pyramid, and might then be referred to or targeted for the next level of intervention. The interventions at different levels of the pyramid may be complementary (work together for the good of all children).

Let's Get Specific

With regard to young carers, we may wish to focus more energy on the sub category of “children who perform caring roles beyond what is normally expected of them as children” (Cluver et al, 2011, Evans and Becker, 2009). This group of children may be selected from within the broader category of vulnerable children, and from within the even broader category of “all children”. This is shown in Diagram 2:

Diagram 2: Selection of Young Carers for Further Support



The kinds of support that the group “young carers who may require additional more specialized support” might be around:

- engaging the assistance of other family and community members to reduce the burden of care
- minimizing the risk of TB infection and the risk of HIV infection via nursing and attending to open wounds of the person they are caring for
- school attendance and performance
- their vulnerability to anxiety or depression
- a possible increased risk to engage in transactional sex.

There is no single quick fix to address these challenges and each risk and context has to be considered separately.

Bearing all of this mind, let us consider how the challenges and opportunities of young carers can be addressed at all levels.

Sometimes we can provide specialized support ourselves through our programmes. Other times we can call on other organizations or departments to provide specialized services (referral).

Table 2: Summary of multi layered integrated interventions to support households in which there are young carers

Multilayered Integrated Support	Possible Intervention
Level 5 – Specialized Mental Health Services: Psychiatric, clinical psychological, and specialized traditional healer services, for children with clinical mental health diagnoses (potential to benefit only small numbers of the most severely affected children at any time)	Disseminate these guidelines to psychologists and social workers likely to receive referrals of young carers who are in severe or acute psychological distress. Develop community members' skills to identify and refer children needing specialized care.
Level 4 Focused Non-Specialist Support For special needs of children who are not coping, and who are exhibiting symptoms of distress (potential to affect and benefit hundreds but probably not thousands of more severely affected children at any time)	An intervention that squarely targets a young carer in the household and that minimizes potential negative outcomes of the young carer role and that maximizes positive outcomes of young carer role. Examples could be doing memory work with young carers or starting young carer support groups.
Level 3 – Family And Community Support: Everyday care and support provided by caregivers, friends, community members (potential to affect and benefit thousands of children at any time, the most powerful and sustainable form of support)	Integrate issues of young carer into community and family mobilization strengthening approaches.
Level 2 – Provision of Basic Services: Food, shelter, education, housing, health etc into which support needs to be mainstreamed (potential to affect and benefit millions of children at any time)	Identify key issues of young carers and mainstream support for young carers and their households through systematic interventions aimed at community home based care and Schools.
Level 1 – Advocacy: Influence policy and direct change to the social conditions that directly affect wellbeing (potential to affect and benefit millions of children)	Advocate for fundamental support for all young carers.

Case Example:

Targeted Intervention Following Consultation

The KwaWazee Project in Tanzania consulted grandchildren who were looking after ageing grandparents. They call these households “skipped generation” families. Their consultation revealed the following results, summarized into suggested recommendations for intervention (Madoerin, 2011):

- Interventions should contribute to a more structured and predictable future. This might include secure education, increased security about the assets through will writing, promoting discussions and planning with grandparents and grandchildren about possible emergency situations.
- Interventions should increase the income security of the households.
- Interventions should contribute to decrease the work load through labour-saving investments (e.g. improved stoves, water tanks) and through promoting mutual support groups. Further interventions should promote income generation which is profitable and less time-consuming.
- Interventions should promote networking among the grandchildren in order to decrease isolation and stigma. Among five proposed possible motivations for forming groups, most children selected the motivation “similar experiences with illness and death of the parents” as their leading motivation.



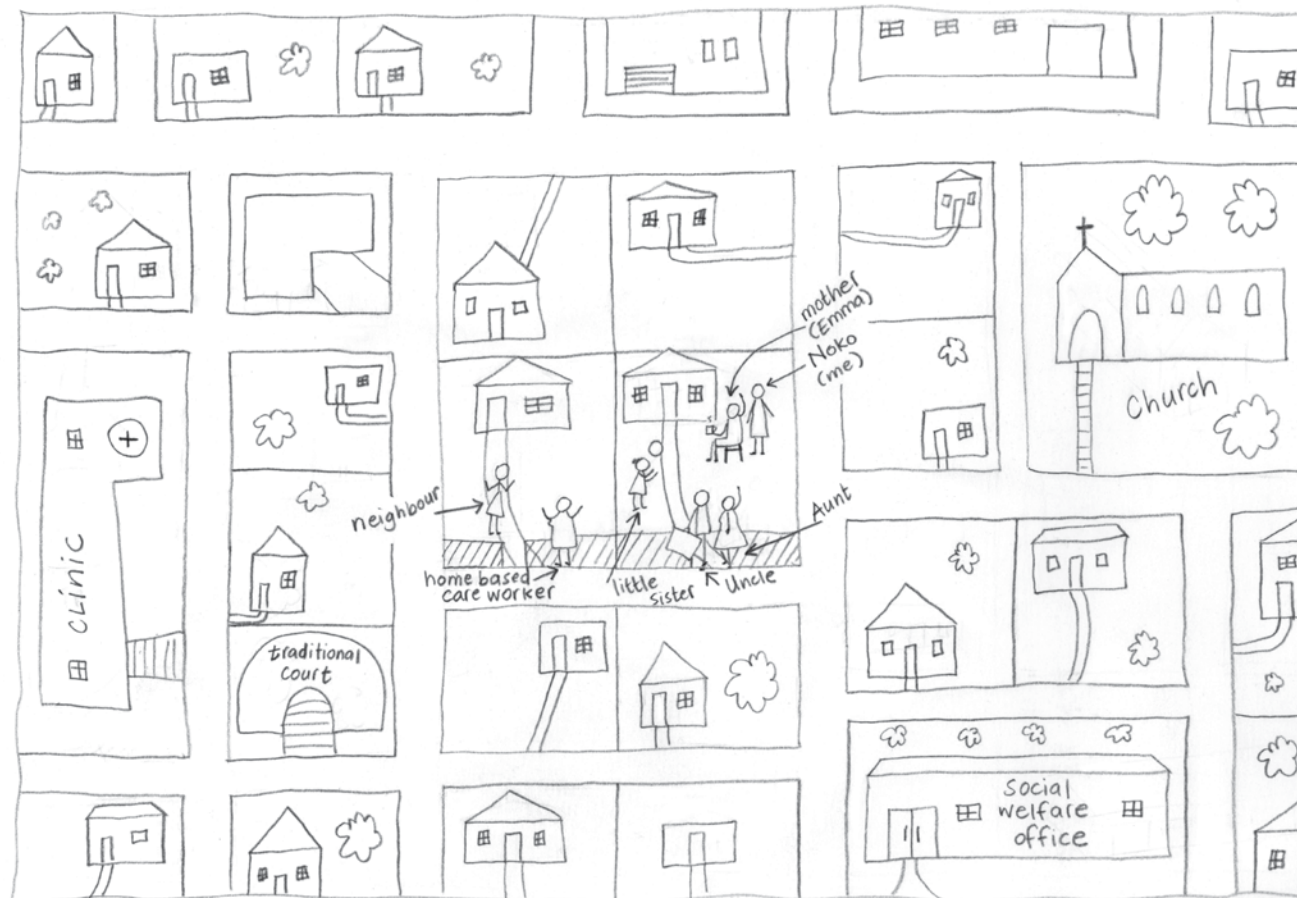
Practical Activity: Consulting Young Carers

The needs of young carers in your context may be similar or different to the needs expressed by the above-mentioned young carers. You may wish to facilitate a similar consultation activity with young carers in your area by asking young carers about their needs for support and which of these needs they prioritise.

Who Can Support Young Carers?

This leads us onto our next topic – strengthening the support for young carers so that their caring role builds them up as people and does not place them at risk for the negative effects of taking on too much responsibility.

Here is a map
that I drew of
my community



Around the theme of young carers, the following key stakeholders have been identified:

- Young carers themselves
- Unwell household members
- Other household members
- Teachers and school principals
- Community home based carers
- Community leaders
- Other community members including the extended family

Use the following exercise to think more specifically about which stakeholders may be relevant to providing support for young carers in your community:

Practical Activity: Social Network Mapping

On a large piece of paper, draw a map of your community. Start in the middle of the map and draw the house of a young carer. Draw into your picture all the people within that household who are linked to the young carer. Now draw the neighborhood around the house, and again fill in all the people, places and structures which could be involved in supporting the young carer at the centre of your map. Think about schools, traditional structures, government services, places of worship and community projects.

Questions for reflection or discussion:

- Which people or structures are already supporting young carers?
- Which could be strengthened?
- How well connected young carers in your community are amongst one another?
- Where can these connections between young carers be strengthened?

Connecting Young Carers

One of the best ways of supporting young carers is to connect them up with one another. This helps them to feel less isolated. Young carers may also share good ideas and strategies about their strengths and solutions to local issues. Theme 3 of this guide focuses on this topic.

Connecting young carers to extended family support is a very important way of expanding their network of care and safety.

"When I met other girls and boys who were also caring for young children I found out that they have similar problems to mine. It has made me to know that I am not the only one with problems. This made me feel stronger."

(Girl, aged 16, Zambia, from Clacherty, 2010)

Let's Check Ourselves

Theme 1 focused on supporting young carers so that we strengthen the positive impact of caring and reduce the risks for carers whose caring roles are too demanding. Use the following questions to measure how well you are doing in reaching these aims through your programme.

Some of the questions ask you to respond with:

- ✓ tick if you feel you have achieved this objective
- ✗ a cross if you have not achieved this objective
- an open circle if you would like to do more towards achieving this objective.

There are also spaces provided for you to fill in key points that apply to your context.

Supporting Young Carers	✓ / ✗ / ○
I am aware of the number of households in my area where children are performing caring roles	
I can identify the following strengths and resources of the young carers in my area:	
I am building on the strengths and resources of young carers in my area in the following way:	

Supporting Young Carers	✓ / ✗ / ○
I can see which young carers' responsibilities extend beyond what is traditionally expected of children	
I can see where caring is likely to be having negative impacts on the health and the mental health of these young carers	
The negative impacts I have identified on young carers in my area are:	
I can see where there are areas of danger or risk to the young carers in my area	
I can see how well connected or how isolated the young carers in my area are to different types of support	
I have identified the following people, places and structures whose support of young carers could be strengthened:	
I have been able to connect young carers with one another using child and youth participation approaches	
I have been able to connect young carers to their relatives so that they have the support of extended family members	
I have worked out where to invest my energy so that I help as many young carers as possible in my area	
I have worked out which young carers are most in need of specialized support and how to strengthen this support	
People in the households I support are all treated fairly and each have their fair share of responsibility	
Boys and girls share the responsibilities fairly	

THEME 2

Young Carers' Wellbeing

Meet Noko's mother Emma. Emma is very sick and she is grateful for the help that she gets from Noko. Emma worries a lot about Noko. Like most mothers she would like Noko to live a happy and healthy life.



Reflection Exercise: Children's Wellbeing

What does a child need to live a happy and healthy life? Find or draw a picture of a child. You could cut out a picture of a child from a magazine or use a photograph of a child who is important to you.

Around this picture of a child, write or draw or cut out and glue pictures which show all the different aspects of the child and his or her life that contribute towards their wellbeing. Think about the things that contribute towards the child's:

- physical wellbeing
- mental wellbeing
- feelings of happiness and security
- identity and self image (thoughts and feelings about him or herself)
- relationships (with family, friends and others in the community)
- and achievements

Add to your picture anything you consider important for the wellbeing of a child in your context. Please also think about whether there are any differences between what a girl and what a boy need to live a happy and healthy life.



You can use this same exercise as a practical activity with young carers, to consult them about things that are important to them or missing in their lives.

Wellbeing of Young Carers

When the role of caring becomes too demanding for a young person it can mean that they are at risk of not living a full, happy and healthy life. In this theme we will focus on the following important aspects of wellbeing which may be at risk of not being met in young carers who carry too much responsibility without good support:

- safety and access to basic rights
- psychosocial wellbeing

Young Carers' Rights

Meet Noko's teacher, Mr Hlaphi. He knows a lot about children's rights.

Here are some of the basic rights, listed in the United Nations Charter on the Rights of the Child:

All children have a right to:

- safety and protection from harm
- good nutrition to help them grow strong and healthy
- a safe and warm home
- health care
- education
- belong and be part of a community
- respect and privacy



Many of the things that you put on your picture of a child who is happy and healthy are probably basic children's rights. Rights are legal entitlements which our countries agree that all children should have. These agreements of children's rights are meant to ensure children are protected and supported to reach their full potential.

For example, an important right of all children is to access education, or to be in school. We should make sure that all young carers are able to stay in school. This protects them from harm, provides emotional and social support and helps them to develop. Being in school means that teachers can assess the wellbeing of the young carer and can call in other authorities to assist if they notice that any of the child's other rights are not being met.



Practical Activity: Children's Rights

Photocopy and cut up this table into a card game for matching the terms or statements on the left with the statements on the right.

If you have a group you can divide participants into teams. When you have put together all the cards, discuss what you read or learned amongst yourselves and how this fits with your life.

Term	Matching Statements
A right	What you are entitled to as a member of a society – for example the right to clean water and the right to safety.
Children's rights	What every person under 18 is entitled to according to the United Nations Convention on the Rights of the Child (UNCRC).
Do boys and girls have equal rights?	Yes – Boys and girls might have different responsibilities but each should feel that they are treated fairly and that all their rights as a child are respected.
Child labor	Work that deprives children of their childhood, their potential and their dignity, and that is harmful to their physical, social and mental development (www.ilo.org)
Where should children's voices be heard?	Children need to share in the life of, and have a voice in, their family, school, community and nation
If a child does not do what we or their parent or caregiver tells them to, can we take away their rights?	No, Children's rights should be accompanied by children's responsibilities but are not dependent on them.

The rights of young carers may be affected in the following way:

Table 3: Rights of Young Carers (adapted from the Children's Rights Trust)

Right	Description of right	Young Carers Rights
Survival	Children have a right to life: to have their basic physical needs met for food, shelter, safety and health care	Because there may be no adult to provide for them, young carers' right to food and shelter is at risk.
Protection from harm	Children need to be protected from injury and harm, both physical and emotional	There may be no one to protect young carers so their safety is at risk. They may be at risk of infection. In addition to these physical risks for harm, it is emotionally very difficult looking after someone who is sick.
Development	Children need all the things that will help them to grow and develop. They need care from an adult. They need friends and family, love and laughter. They need fresh air and safe places to play. They need stories and music, schools and libraries and all that stimulates the mind.	Young carers sometimes stop attending school. They may have less time to play, do homework, and study for tests.
Belonging	It is important for children to have a sense of belonging (and identity). Children have a right to legal identity and also the cultural and social identity of their family, clan, tribe, religion or faith.	Sometimes young carers are not invited to family functions and community events and do not always have an adult who can teach them about their family history, culture, religion or faith.



Reflection Exercise: Young Carers' Rights

Think about the young carers in your context. Describe or role-play which of their rights are most neglected. Now describe or role-play how you could intervene constructively in situations where young carers' rights are being neglected. Try to come up with creative solutions where you strengthen relationships and support for young carers in the community, rather than breaking down relationships or making people react negatively.

Rights and Responsibilities

To "lecture" the household members, especially chronically ill household members, around child rights is unlikely to have much effect. In cases where children have been informed about their rights without taking into account culture and circumstances, this can lead to tension in the household and have negative outcomes for the child. However an awareness of child rights both on the part of the household members and young carers is still considered to be important. Using the framework of "rights and responsibilities" may be a helpful way of encouraging positive engagement. This means that while we each have rights, we also have responsibilities towards others.

In instances where abuse or neglect is taking place, the level of intervention needs to be around protection and the strengthening of circles of support that lie beyond the household itself.

Child Safety

In situations where young carers are being neglected, the root cause may be poverty and lack of support for the household. Thus care has to be taken not to blame any particular person. Having said this, where there is abuse and severe neglect, the child has to be protected immediately.

Here are some tips for how to handle situations of abuse or severe neglect:

- Stay calm and do not create unnecessary “drama” which may upset and stigmatize the child and family
- Tell the child that it is not their fault
- Listen respectfully to the child and always believe what she or he is saying. Remember it is not your job to decide what is true and what must happen. Call for the assistance of local authorities in a calm and organized way which protects the privacy of the family and child
- NGOs and government services specializing in child abuse often know how to handle situations constructively so try to involve them from the start in case management
- Try not to separate or remove children from their home, their family and siblings unless there is no other option to

keep the child safe. Rather bring in extra support, or in cases of abuse, remove the perpetrator

- Follow up on the situation to see how the case is being managed

We have a legal obligation (duty) to report any suspected cases of child abuse and neglect.



Reflection Exercise: Child Abuse Intervention

Imagine that you are a teacher, or a community home based carer, or a young person. You suspect that a young carer or any child in your community is being abused.

Write out or role-play:

- how you would speak to the child
- what you would report to the authorities



Psychosocial Wellbeing

Children's wellbeing is not only about their physical health and safety. Their wellbeing is also about their feelings, thoughts and relationships.

Reflection Exercise: Children's Psychosocial Wellbeing

Think of your own children or children that you know well:

- What are they good at (what are their strengths)?
- What do you enjoy about them (what do you like about them)?
- What are their hopes and dreams for their lives?
- When do they speak most easily about their feelings about life and themselves?
- When are they best able to talk about their relationships with others?

Psychosocial wellbeing is said to exist when an individual, family and community has emotional, spiritual, and psychological strength, as well as positive social relations which enables them to understand their environment, engage with it, and make choices, with hope for the future.

I am part of a group called the Kind Lions. It is a support group made up of other young carers. We share ideas about how to deal with our everyday problems. We find that there are also matters of the heart that need attention. That is how we feel, how we make each other feel, how we communicate, how we support, how we respect each other, how we share responsibilities – a big word for all of this is psychosocial wellbeing but I think you know what I mean.



For more information about psychosocial wellbeing see www.repssi.org.

Reflection Exercise: Traditional Forms of Psychosocial Support

Traditionally within your culture or religion, what ways did you use to support people emotionally and socially during times of difficulty? What has been helpful with regard to ways that people have supported you during difficult times? What has not been helpful?

Psychosocial Support Tools

The next section gives some practical tools and ideas about how to strengthen psychosocial wellbeing within the households of young carers. You can use these sections to choose which tools would work best to support the young carers in your context.

Memory Work

Sometimes what builds family unity and family wellbeing, as well as family communication, is doing things together - things that need to be done like cleaning and cooking, but also fun or meaningful things. Memory work is something that has been shown to improve family communication and strengthen children's psychosocial wellbeing. One suggestion is to make a family box or a memory box. This is a box that the family can make together that has meaning for individuals and for the family as a whole.

Memory boxes and books are used for people to record and tell their own life stories in a new and fresh way. Individuals can retell their stories in ways that make the teller feel better and stronger, and as hopeful and as proud of their life as they possibly can be. In the retellings, we try and make sure to note things like courage, survival skills, hopes, important values, and how a bad situation can be turned around for good by learning coping mechanisms to help deal with it.

The boxes can be made out of anything (wood, tin, grass) but cardboard boxes are most often used. The books can be made out of cardboard, string and paper or an existing book with blank pages.

For detailed instructions and help about how to do memory work, you can order the REPSSI memory work manual (www.repssi.org)





There might be many families or households who don't want to do memory work so it's a good idea to ask any household you are working with whether or not this is something they want to do. In the Appendices 2 and 3 there are some more ideas along these lines.

Communication in the Family

The most valuable psychosocial support may come from one's own family. Strengthening communication, respect and care in young carer households will contribute towards their psychosocial wellbeing.



Reflection Exercise: Strengthening Communication in the Family

Think about your own household. When do you tend to communicate well? What activities work well for your own family to connect with each other and communicate well? Prepare a role play to show healthy communication in a family.

Describe or discuss how you can strengthen communication in a young carer's households so that there is an atmosphere of listening respectfully to one another.

Try this in your own family!



One simple way of strengthening communication and support in a family is to develop a culture of asking each other “How was your day?” Other questions that family members can ask each other are:

- What was your best moment?
- What are you worrying about?
- It is important to listen to one another and acknowledge (appreciate) what has been said.

Windows

The practical tool called “Windows” is a type of memory work that helps young carers to re-tell the story of their lives in a hopeful way. The exercise helps one to explore and re-author one’s life story to find a new and fresh story (a story that is not only about pain and suffering but that also notes courage, survival skills, values and hope). It is suitable for older children and adults. Facilitating the Windows exercise needs some experience in psychosocial support, facilitation and counseling, as some of the feelings which come out during this exercise may cause people to cry or feel bad.

“There are many of us at home but we make sure that we share equally and we discuss about things that cause problems like conflict. We counsel each other and discuss discipline”

(Boy, aged 15, Zambia, from Clacherty, 2010)

Sometimes I feel helpless in my role as a parent to Noko. I wish I could do more for her.





It is important that we do not undermine the role of unwell caregivers in the household. There are many things that an unwell caregiver can contribute to the wellbeing of a young carer

Supporting the Role of Unwell Caregivers

As we said earlier, it is more helpful when psychosocial care comes from one's own family (especially one's caregiver or parents), than when it comes from outsiders or experts. Therefore when supporting young carers we should be careful not to take over the role of parenting, and rather strengthen the role of the caregivers of children, providing support where needed. It may be helpful to support unwell caregivers to redefine their role. Even if there are physical limitations, they may be involved in parenting of their children, such as offering psychosocial support, strengthening communication in the family, passing on their experiences and wisdom, being involved in discipline and expressing their appreciation for what their children are doing to assist the household.

Here is a discussion exercise which may be used with unwell household members who are redefining their role as caregivers.

Practical Activity: My Role as a Caregiver

Use the following questions to open discussions with unwell household members who are redefining their role as caregivers:

- What are you most proud of about the way that you raised your child?
- What do you feel frustrated about in your role as a parent, or what do you wish you could still do for your child?
- What do you feel that you can still do well?
- How can you stay strong as a parent of your child, even if you are unwell?
- What would you like to say to your children to express your care and appreciation of them?



Here are some things that we can do as teachers, community home based carers or development facilitators, to strengthen the role of unwell caregivers of young carers:

- Acknowledge and affirm what caregivers have already done for their children
- Consult caregivers about anything involving the wellbeing of their children
- Discuss future plans of the children with caregivers
- Encourage caregivers to take the lead in dealing with issues such as disclosure of health status and future planning
- Respect the values and practices of caregivers and try to uphold these when dealing with the children
- Make it clear that the authority of the household still rests with caregivers and that your role is to support them in their role

Caring for Younger Siblings

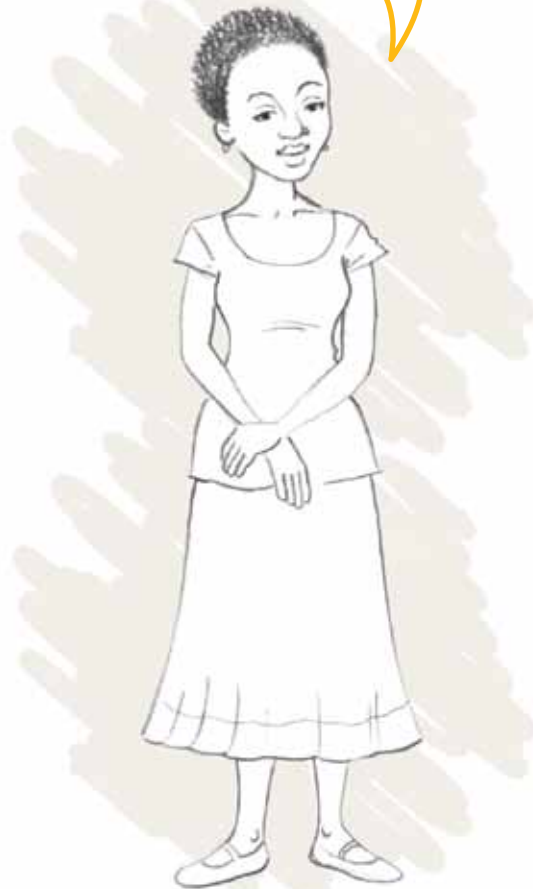
Many young carers are also involved in taking care of their younger brothers and sisters. They can benefit from specialized training on physical care, health care and parenting skills.

Reflection Exercise: Caring for Young Children

Here are some questions for self-reflection or discussion:

- What are the most valuable things I have learnt, that I wish I knew when I started caring for younger children?
- What are the essential skills for a young carer to know about caring for younger siblings?

It is a good idea to start by consulting young carers about the types of skills and topics they could like to cover in learning more about how to care for younger children. You can use the exercise below to consult young carers about their needs around caring for younger children:



Practical Activity: Caring for Young Children

This activity is from the manual "We Care for Young Children: Helping Adolescent Caregivers Look After Young Children" by Glynis Clacherty, in association with Project Concern International.

Discuss and then role play these two different aspects of caring for young children:

- What is good about caring for young children?
- What is difficult about caring for young children?

The role plays may be used to affirm young carers role in caring for younger children, and to consult them about the topics they would like further training on.



Here are some of the things we have found that young carers wish to know more about when caring for younger siblings:

- How to help children to learn well (educational support)
- How to raise children well (basic parenting skills)
- How to help children when they are upset (emotional support)

Here are some comments from young carers who are taking care of younger siblings: (Clarcherty, 2010)

"I am the one that looks after my little brother and sister. Even though it is difficult but I try to do my best for them. I am like the father and mother that they don't have."

(Boy, aged 15)

"Small ones are hard work. As soon as you wash them they get dirty again."

(Girl, 16)

"At least those who are above seven can do some things for themselves and we can even work together."

(Girl, 14)

"I don't want the children to regret, I try to keep them at the standard of other children. I give them money for porridge at school so that they enjoy school life like others."

(Boy, aged 17)

"When the little ones get sad and look like they are going to cry I give them a ride on the bicycle and give them something to play with."

(Boy, aged 17)

"We all work together, even the small ones. I fetch water with my brothers and we also dig in the neighbour's garden together as a small team to get money to buy clothes."

(Girl, aged 15)



Here are our top tips for caring for younger siblings!



"When I met other girls and boys who were also caring for young children I found out that they have similar problems like mine. It has made me to know that I am not the only one with problems." (Girl, aged 16, from Clacherty, 2010)

- Children need a lot of love – this can be shown to them physically (by holding children and hugging them) and by telling them that you love them
- Children need a lot of praise and encouragement to grow a strong sense of self – give them lots of compliments and positive feedback when you see them doing things well
- Children need routine and structure in their lives – try to keep to the same daily times for eating, sleeping, playing and homework
- Children need some boundaries and rules to feel safe, and these can be put in place in a caring way
- All discipline should come from a relationship of love and care
- Using positive feedback and compliments for good behavior often works better than punishing bad behavior
- Children need to talk and play about things that bother them – you can help children to process their feelings and experiences by listening to them
- Children need a lot of time to play and their minds grow strong when they play because they are learning all the time
- Children love to learn and you can help to grow their minds by showing and naming things (like colors, textures, names of things and animals), counting things, and helping them to read

For more information about caring for younger siblings, see "We Care for Young Children: Helping Adolescent Caregivers Look After Young Children" by Glynis Clacherty, in association with Project Concern International. You can download this manual free of charge from www.coregroup.org.

Let's Check Ourselves

Theme 2 focused on the wellbeing of young carers, including their rights and psychosocial wellbeing. Use the following checklist to measure how well you are doing in supporting young carers through your programme. Remember that the symbols used in the right hand column mean:

- ✓ tick if you feel you have achieved this objective
- ✗ a cross if you have not achieved this objective
- an open circle if you would like to do more towards achieving this objective.

These checklists can be revisited for example first you complete it now at the time of reading or being trained in these guidelines, then again 3 months later, then again one year later etc.

Strengthening the Wellbeing of Young Carers	✓ / ✗ / ○
The basic rights of the young carers I work with are all met and they:	
• Are safe from abuse and harm	
• Live in a comfortable home	
• Have clean water	
• Have good health care	
• Attend school regularly and have time for learning	
• Have fun and have time to play	
• Have friends with whom they regularly meet to play and talk	
• Attend family and community functions and have a sense of belonging	
The young carers in my area have a positive sense of themselves	
The young carers in my area have been assisted with memory work to strengthen their psychosocial wellbeing	
The young carers in my area have good relationships with others	
We have found practical ways to support young carers emotionally and socially during times of difficulty. These are:	
People in the young carer households support each other to have hope for the future	
They listen to one another respectfully	
In the young carer households, authority is respected, without this authority being too controlling or harsh	
The young carer has basic skills in how to care for younger siblings and feels confident in their role	

THEME 3

Connecting Young Carers



This whole section is directed at any person working directly with young carers (for example a community worker, a home based carer or teacher who mobilizes a young carer support group or young carer support group leader). It is for people with high levels of literacy and facilitation and counseling skills.

Before we started the Kind Lions support group I felt very lonely and unsupported. Now I have many friends like Babalwa and Busi and we are able to give each other good ideas. We get training in important skills which help with our everyday lives.



You can also do things in your support group which are fun. You will be more help to your sick parent or old grandparent if you take good care of yourself and are happier in yourself.



*Yes, with support and knowledge
you can be much happier and an
agent of change in your family!*



The Benefits of Young Carers Support Groups

While it is true that young carers need support from community home based carers, teachers, other community members, etc, there is also a lot they can do for themselves if they stand together and further develop their caring skills.

This section of the guidelines encourages you to mobilize children and youth who are performing young caring responsibilities into their own support groups.

In the context of these groups, all of the themes covered in this guideline may be explored. This theme gives you some ideas about the process of setting up a young carer support group or club. Once the young carer support club is established, the different themes covered in this guideline can be tackled one by one.

Case Example: Humuliza Project (REPSSI, 2010)

The Humuliza Project in Tanzania brought together seventeen children who had lost their parents. At the workshop the children spent time identifying their existing strengths, i.e. what they had learnt and could do well **because** they were orphaned children. They also talked about where support from others would be helpful. They identified areas in which they could support each other, which ranged from practical support such as helping each other with agricultural activities, to emotional support such as consoling each other.

Subsequent to this the “Vijana Simama Imara – VSI” (Youth standing upright firmly) organization was formed. VSI is run by the young people themselves through elected committees. Humuliza provides training and monitoring.

Topics to Cover When Starting a Young Carers Support Group

Here are some ideas of the process and topics that could be covered when first starting a young carers support group:

- Selection and invitation of group members
- Identifying a suitable location
- Introductions and relationship building
- Consultation of group needs and setting the agenda of the group
- Organizing the structure of the group
- Strengthening relationships in the group
- Mobilizing support from adults

We will give some hints and tips for each of these topics.

Selection and Invitation of Group Members

Once you have identified an initial group of young carers, the young carers themselves may be the best people to work out who else should join the group. They can take responsibility for inviting other members to the group. The young carers can discuss who to approach to join the group, and then practice what they will say to invite others to join. Practicing in role plays can be fun.



Teachers and community home based carers are often in an ideal position to be able to identify young carers and other vulnerable children. This may be a good starting point for your support group.

If you are worried that people will say “those are the kids with AIDS in their houses” make sure your club is open to all children, including young children in the household and children who are looking after older people like their grannies and grandpas.

Here is a practical game and exercise to help young carers to decide who to invite to join their support group:



Practical Activity: Inviting Young Carers to Join a Support Group

Play a catching game where two people start catching other people, and those who are caught join the group who is catching others, until everyone is “caught” and part of the same team.

In groups of 2 or 3, design a role play which shows:

- What type of person we would like to approach to join our group
- How we will invite that person to join our group

On the basis of what came out of the role plays, discuss these questions together with young carers:

- What type of people would we like to have joining our group?
- Is there any type of person we don't want or is our group open to everyone?
- What are the advantages and disadvantages of a closed or limited membership group?
- What are the advantages and disadvantages of an open membership group?
- How will we invite people to join our group?
- How will we make sure that we develop a positive group image and that we don't become labeled as a group for needy children?

Identifying a Suitable Location

The location and venue of a support group meeting makes a huge difference to the attendance of its members.

Practical Activity: Finding a Safe Location to Meet

Here are some ideas for discussion with young carers about a suitable location:

- What is the most centrally accessible place for the support group meetings to take place?
- Will we rotate the location or keep the meetings at the same place each week?
- What about the transport costs for young people who live far away from the location?
- Is there a place that is safe and where we may talk and play with freedom?
- Is it possible to get a place that is free of charge, or do we need to contribute towards the costs of things like water and electricity?

For more ideas about participatory approaches to working with children and young people, you can download the manual **Mainstreaming Psychosocial Support Through Child and Youth Participation** from www.repssi.org.

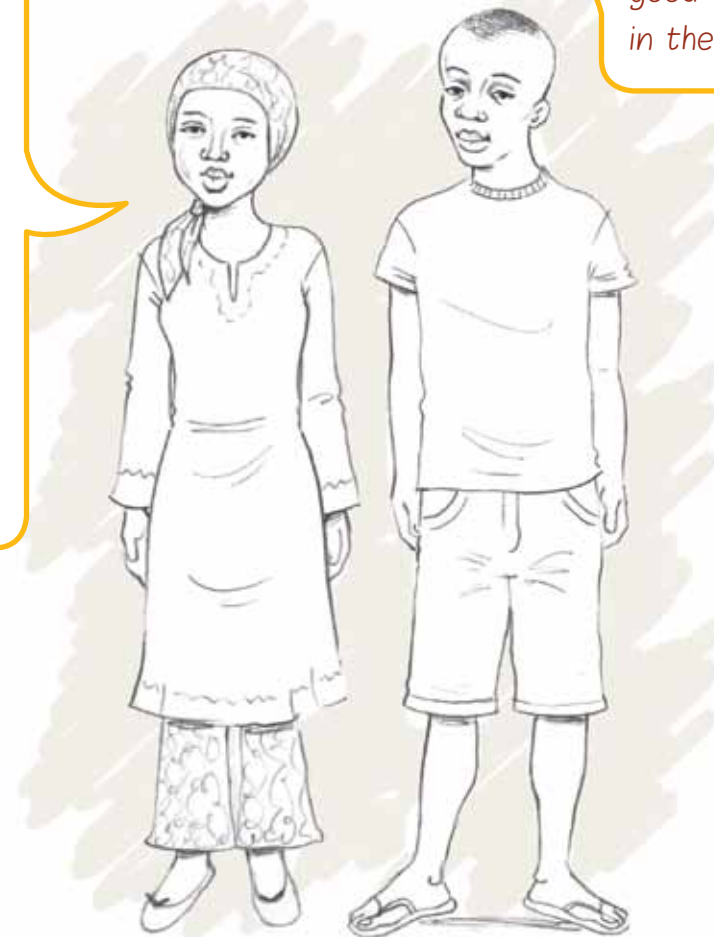
Introductions and Relationship Building

Here are some ideas of activities to facilitate introductions and build relationships in the group:

- Think of fun ways to get each person to introduce themselves which bring out commonalities amongst people. For example you could ask people to answer “What is your favorite food?” or “Who is your favorite musician?”
- Play plenty of games which include everyone
- Talk about how communication will happen in the group by discussing group norms or ground rules
- Have a “talking stick” which is passed around the group to make sure that everyone has a chance to say something
- Develop a group name together
- Make badges or a flag or poster with the group name, a picture and a slogan which represents the attitude or purpose of the group
- Encourage group members to visit one another at home
- Encourage group members to walk together to and from the group
- Give the group members specific tasks about information to find out from one another
- Each week the group members may be asked to share about their “highs” and “lows” of the previous week

It is very important that a young carers support group is a place of safety and trust. Young carers should enjoy coming to the group and they should feel that they are welcome and appreciated in the group.

It is important to build a good atmosphere and good relationships in the group.



Here is a game that may be played with young carers in a support group. It helps to connect young carers by showing them how much they have in common with one another.

YC Practical Activity: Game of Favorites

A leader will call out a type of favorite thing. Then everyone in the group must find others who share their same favorites. Those who share the same favourites must cluster together in a small group. For example, the leader can call out:

- Find everyone who has the same favorite color as you
- Find everyone who has the same favorite food as you
- Find everyone who has the same favorite musician as you
- Find everyone who has the same favorite song as you
- Find everyone who has the same favorite month of the year as you
- Find everyone who has the same favorite type of animal as you

Establishing group norms is a good practice, especially if the young carers come up with the principles for constructive collaboration themselves. Here are some questions from the REPSSI Child and Youth Participation guide to help the young carers to develop their own guidelines about how to work together effectively:

YC Practical Activity: How We Will Behave Towards Each Other:

Here are some questions for discussion amongst young carers in a support group:

- How can we make sure that everyone who joins this group feels welcome?
- How do we make sure that everyone has an equal chance to say what they think in this group?
- How do we build each other up, rather than breaking each other down when we speak to one another?
- If you were a very shy creature, like a very small mouse, how could other mice help you to be braver? (This question can be adapted to other creatures and group dynamics – like an angry lion that has hurt his foot)

YC Practical Activity: Caring for One Another:

Here are some questions for discussion amongst young carers in a support group:

- If you were someone who had a bad week at home, what would you like others to do for you?
- If you knew someone who was struggling with something, how could you help that person to feel better?
- If we notice that someone is missing from our group meetings, what should we do?
- How do friends show each other that they are friends?

It is good to make a mission statement – that is to decide and to write down what the purpose of the group is – and to give the group a name. We called our group “the Kind Lions” because we think we are very brave and very kind.



*Our mission (main purpose):
The Kind Lions exist to give children and youth who are caring for old or sick people support and to teach each other the skills we need to do this caring.*

Consultation of Group Needs

This is about prioritizing the programme of the group (topics to be covered) and it is about developing the meeting structure (or schedule) of each group session.



Practical Activity: Our Priorities

Here are some questions for discussion with young carers in the support group:

- What do you think is the most important thing that we should be working on together?
- What would need to happen here for you to say that it was worthwhile for you to be part of this group?

For a group to be successful, the topics that are covered should be interesting and relevant to the group members.



Here is a democratic way of prioritizing which topics should be addressed in the coming weeks:



Practical Activity: Prioritizing Topics

Put up the list of topics that were identified as needs by the group. Or if the group members struggle to read, use objects (like stones and sticks) to represent each topic. Tell each group member that they have 3 votes. These votes are for them to use to say which topic is most important for them. They can use up all 3 of their votes on the same topic if it is very important to them. Give each person a chance to cast their 3 votes on the topics that are important to them. They can cast their votes by making a mark (e.g., on flipchart or in the sand) next to their topics of choice.

Once again, developing the structure of the meeting should be a consultative process. In the early stages of the group the facilitator may suggest the structure, but as group members become more confident they can develop their own structure according to what works well.

The Kind Lions group meets every week on the same day of every week. Here is an example of our group meeting structure:

- *Greetings and welcome*
- *Introductions and welcome of new members*
- *Game*
- *Sharing of each person's "highs" and "lows" of the past week*
- *Sharing of ideas and solutions to difficulties*
- *Game*
- *Feedback on any action that was taken after last week's meeting*
- *Decisions about any new action that needs to be taken*



Organizing the Structure of the Group

As a group grows in size and maturity, the members may decide that they would like a structure to the group. For example they may decide that they would like to have one person to take responsibility for leading the group for 6 months. Or they may choose to have someone taking notes on the group decisions. Let the group decide what structure would work best for them. Here are some hints that have been found helpful in the past in relation to young carer support group internal structures:

- Try to encourage the principles of democracy. It is better not to make the group too hierarchical. In other words, the power of the group should rest with the majority, not with any individuals.
- Change the group roles regularly so that people do not become stuck in one role, or become too dominant. Changing roles also gives different people a chance to develop new skills.
- Encourage the group to give unlikely members a chance at different roles. For example, they shouldn't always choose the oldest loudest male to be the group leader! Think about gender balance and giving the quieter more thoughtful group members a chance to develop their skills.
- Make sure that the people chosen understand what is expected of them. It can even be a good idea to write down a shared understanding of their role, like a job description.
- Regularly review the structure of the group (without embarrassing any individual members) to make sure that it stays fresh and relevant

Strengthening Relationships in the Group

Here are some ways to strengthen relationships in a group:

- Give one another a lot of positive feedback and affirmation
- Have structured times when each group member is given positive feedback
- Talk openly about how each person is feeling in a group
- Try to resolve conflicts in the group. If needed, call in someone the group trusts to help manage the conflict
- Try not to resolve conflicts between people by behaving as a go-between. This can create triangles of conflict and may increase confusion. Rather bring people together to talk about what is happening
- Visit members who do not attend the group after each session, so that you can support them with any difficulties and pick up if there are any problems. Share this responsibility amongst group members, for example by having the person who lives closest to that person, or someone that person trusts and gets on well with to visit them
- Facilitate team-building games and activities, rather than games which are competitive and divide people
- If there is a split decision about something, try to resolve it by compromising on both sides. Think “both and” rather than “either or”.
- If this is not possible, take a vote on the matter, but be sure to check how the person who lost the vote is feeling (their dignity may be hurt). Make sure that people understand that the vote is for an issue, not for a person. Do something immediately afterwards to bring the person who lost

straight back into the action, like giving him or her a special responsibility or giving a compliment to that person.

Reflection questions are a useful way of giving constructive feedback. This can strengthen the relationships in the group.

Building good relationships amongst group members is something that should happen throughout the life of a group.

Yes – conflicts, misunderstandings or feelings of being left out are common in the life of a group.

For example, when our group collected some money to start a business, there was a lot more conflict in our group. We needed to spend a lot of time on team-building to make sure that the group didn't break up.



Mobilizing Support from Adults

It is helpful for young carers to think about how to mobilize more support from adults for their support group. This may involve young carers raising the awareness of household members, other community members, leadership and local organizations about their needs and the benefits of being involved in a support group. It can also mean that youth leaders go to adults with counseling and leadership experience for supervision.



Practical Activity: Reflection Questions

Here are some ideas about reflection questions which may be used with young carer support groups (from the Humuliza project in Tanzania):

- What I liked most about today was ...
- I felt most excited when we were ...
- I felt most disconnected (cut off from what was happening) when we were
- What I wish we could do more of is ...
- What I noticed someone else doing well today was ...
- What I like about you is ...

Case Example:

Humuliza Project (REPSSI, 2010)

The group members of the youth-led VSI said that these activities had helped them to overcome their stresses (Clacherty and Donald, 2005):

- The group activities (meetings, training sessions, playing and singing together, etc.) gave a sense of acceptance and confidence, a common identity and a sense of purpose
- The friendships and the strong social co-operation gave a sense of self-respect and social acceptance
- The practical and income generating skills reduced worries about coping and the future and gave a sense of competence, confidence and purpose
- The resources that became available through the organization and its income earning activities, (meeting school costs, buying new clothes, repairing a house, etc.) gave a sense of security and dignity

Types of Activities Covered in Young Carer Support Groups

Young carer support groups may cover the following types of activities:

- Skills training around needs identified by the young carers themselves
- Sharing of experiences and feelings about their life experiences
- Fun activities which involve taking their mind off their worries
- Social connecting activities which strengthen the relationships between the young carers
- Sharing strategies and finding solutions for everyday common problems experienced by young carers
- Household management
- Economic strengthening
- Joint advocacy and lobbying activities to address common problems

We will keep saying it: The best people to identify the skills that are needed for everyday life are the young carers themselves!



Skills Training

Here is an exercise that you may use with young carers to start identifying the skills needed for them to feel confident and competent in their roles. It comes from Solution Focused Approaches, developed by Steve de Shazer and Insoo Kim Berg (1995).

Sometimes young carers will surprise you with the skills that they want to develop. For example, one group of young carers who lived near the sea requested swimming lessons, so that they could enjoy being at the beach while being safe.



Practical Activity: The Miracle Question

Imagine that one night you go to sleep, and while you are sleeping a miracle takes place. Overnight you become confident and competent at dealing with your life. You have the knowledge and skills to handle any situation that comes your way. As you wake up you can feel a difference but you are not sure what has happened. You start going about your day. Describe what you are doing as you go about your day, the new confident, competent you. How do you start realizing that this change has taken place? What are you doing differently?

The participants may share their experience in small groups or pairs, and from this discussion may begin to identify some of the skills that they would like to develop.

Some of the common skills requested by other young carers include:

- Home based care including nursing skills
- Basic cooking
- Vegetable gardening
- How to fill out application forms
- Basic business management
- Selling and marketing your products
- Peer counseling

As a school you could consider building some of these skills into your everyday teaching, as many children may benefit from this learning. Sometimes local NGOs will come and do specialized training free of charge.



Fun Activities

We have a lot of fun in the Kind Lions group. Our favorite activity is to play sport.

Go for team activities and make it clear that it is more about having fun and connecting with each other than winning!

Here are some ideas of fun activities that your group may enjoy:

- Team sports
- Games
- Drama and role plays
- Pretending to be on game shows
- Music, songs and dance
- Poetry and story telling
- Fun walks

Make sure that everyone is included in all games and sports. Boys and girls can have a lot of fun playing all types of sports.

Remind everyone that it is more important that we have fun than it is to win a game



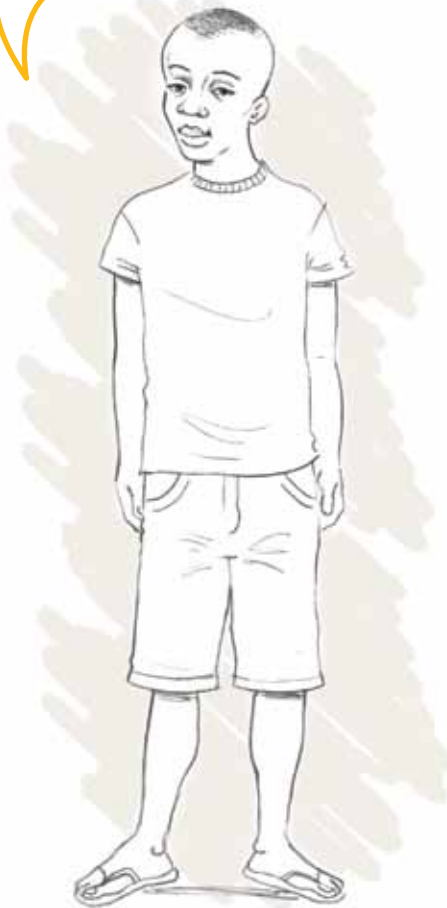
Social Connecting Activities

One of the most helpful things about young carers groups is that they connect people to one another. This helps people to feel less lonely and more supported.

Here are some ideas of ways to connect people:

- Work in pairs or small groups
- Emphasize things that people have in common
- Give a lot of compliments and focus on every person's strengths
- Facilitate activities involving caring and empathy
- Have group norms about making everyone feel included and welcome
- Encourage home visits and time together outside the group
- Find ways of supporting each other outside of the group (for example visiting someone when a person in their household passes away)
- Have time for playing and socializing, rather than working too hard all the time

*Notice what works well in your group
– when do people have most fun and
when are they most connected?
Then do more of this!*



Sharing Practical Strategies and Solutions

Young carers have a lot of wisdom to share with one another. They may also listen better to ideas coming from one another than ideas coming from outsiders or so-called experts.

Here are some solution-focused questions and compliments that may be used to encourage young carers to share good ideas with one another:

- What do others find works well in dealing with that issue?
- What is working well that we can do more of?
- What is not working well that we can do less of?
- What I have noticed that you have done well is ...
- I was impressed by the way that you handled that situation because you ...

Household Management

It may be helpful for young carers to share ideas about how to manage their households. They may find ways of supporting one another by sharing their duties in a way that benefits everyone.

Case Example:

Tatu Tano

The Tatu Tano (which means “Three Five”) are support groups for children living with grandparents. The groups run as part of the broader Kwa Wazee Project in Tanzania. It is an example of connecting young carers by organizing households into smaller units that are geographically close to each other and which have matching needs and skills.

For example: household one has a very ill bedridden mother, no male adult in the house, and three children aged 5, 10 and 15 years.

About half a km away is household two who has a chronically ill bedridden father, a frail grandmother and two children aged 10 and 12 years

The two households form a relationship where:

- the 15 year old from household one helps the two 10 year olds with their homework twice a week
- while this happens the 12 year old from household two sits with the 5 year old and helps feed the unwell household member from household one
- once a week the 15 and 12 year olds take turns to go to the market together to sell dried fish – they share the profits amongst the two households
- the 12 and 15 year olds carry messages of support from the frail and unwell household members between the two homes



There is great power in young people finding a collective voice! People tend to really listen when young people speak out about their good ideas.

Joint Advocacy and Lobbying Activities

If a young carers support group has good ideas about things that can change the lives of many young people, it is helpful to organize some joint advocacy and lobbying activities. These activities need not be aggressive, but can be done positively in a way that builds people up. At the same time this can build up the reputation of young people in the community.

Here are some ideas about advocacy activities which can be done by young people:

- Giving positive feedback or compliments about things that are working well (for example to government service providers or schools or clinics)
- Writing letters which give both positive feedback and suggest changes
- Having meetings with leaders
- A community walk or fun march which highlights an issue or idea
- Talking on the radio or writing an article for the newspaper
- Designing songs, dance or drama to communicate messages about positive changes

- Designing slogans for banners, T-shirts or caps which communicate positive messages
- Organizing young people to lead a community project (e.g., a clean-up campaign or vegetable gardening campaign)

These activities can also be used to change negative attitudes and stigma towards young carers or households affected by HIV and AIDS.

The people who will know best what types of activities to cover in these support groups are of course the young carers themselves!



Let's Check Ourselves

Theme 3 focused on connecting young carers so that they provide practical and psychosocial support to one another. Use the following checklist to measure how well you are doing in reaching these aims through your programme:

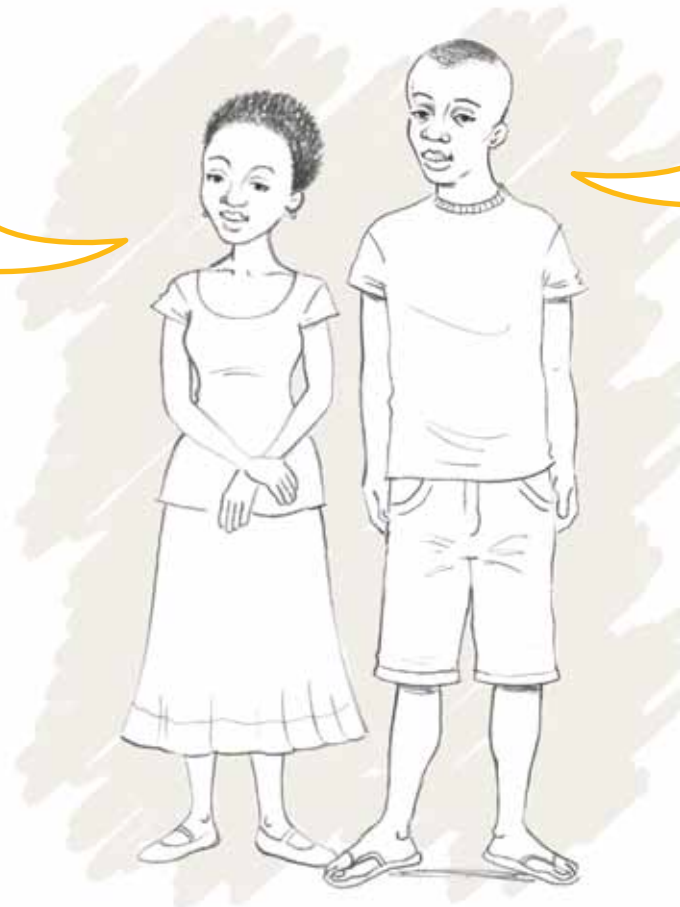
- ✓ tick if you feel you have achieved this objective
- ✗ a cross if you have not achieved this objective
- an open circle if you would like to do more towards achieving this objective.

Connecting Young Carers	✓ / ✗ / ○
The young carers in my area meet regularly in a support group	
They work together on issues identified by themselves	
There is a caring atmosphere in the group	
Young carers have a positive image in the community (no stigma)	
The young carers visit each other to provide practical and psychosocial support outside of the group	
The young carers living near each other have made practical arrangements to help each other and improve their situation	
The young carers work together to change the situation for all young people in their community (advocacy)	

THEME 4

Livelihood Strengthening

Now that my mother is ill, one of my main worries is money. I decided to talk to the other members of my youth club, the Kind Lions, about my worries.

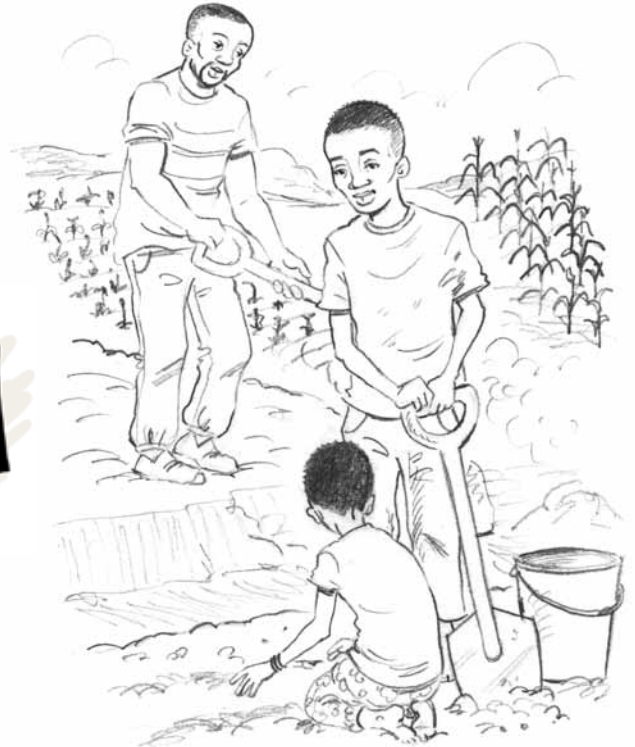
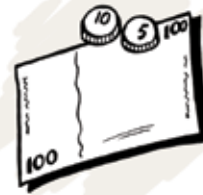


These guidelines cannot solve everything, however the following case studies might help young carers who are worrying about money matters.

Types of Livelihood Strengthening Activities

These are some of the ideas that we came up with in our youth club for helping one another:

- We started a savings club where we each pay a small monthly amount. It means that we can give each other loans for emergencies.
- We used our savings club to give each other small business loans.
- We helped each other to start vegetable gardens at home.
- We helped each other to start income generating projects like brick-making, poultry and goat farming.
- We found out what government grants we can apply for and got our community home based carers to help us to apply for grants.



"I have a neighbor who is kind to me. He lets me know when anyone needs some help to build or wash their car and I get the work. He advises me to work hard too." (Boy, aged 15, Zambia, from Clacherty, 2010)

See how the solutions that the Young Lions Youth Club came up with compare with recommended economic strengthening activities proposed by USAID and Save the Children:

Table 4: Categories of economic strengthening interventions (USAID and Save the Children, 2008)

Social Assistance	Asset Growth & Protection	Income growth
<ul style="list-style-type: none"> • Asset transfers • Food aid • Social grants and pensions • Public works programmes (developed by governments to encourage greater employment opportunities) • Social grants (for the elderly and disabled) 	<ul style="list-style-type: none"> • Savings • Insurance (life, disability, health, loan and agriculture) • Legal services for asset protection 	<ul style="list-style-type: none"> • Skills training and access to tertiary education • Income generating activities (IGAs) • Job creation and vocational training • Market linkages (create links between individuals and markets so that they are able to sell their products) • Business loans

Case Example:

Income Generating Activities

Happy (aged 12) from Tanzania grows vegetables and sells them at the market every weekend. She usually earns about 1,000 – 1,500 TZS per day. John (aged 11) from Tanzania usually gets home at about 2pm every day. Then he works for the neighbors. He says “I wash people’s clothes, dishes and I clean their houses. I earn about 1,500 TZS per day.”

From Evans and Becker, 2009.

These are good ideas. At the same time, a young person should not be solely responsible for the income of their family.



Reflection Questions: Limits to Economic Strengthening

Here are some questions for self-reflection of discussion:

- In your context, how can you help young carers to balance their time between attending to their ill caregivers (especially those who are bedridden) and their economic strengthening projects and their own needs for development as a child?
- Where do we draw the line between child labor and economic strengthening activities?
- How can young carers be protected from exploitation?



As community members we should all try to help young carers in our area by:

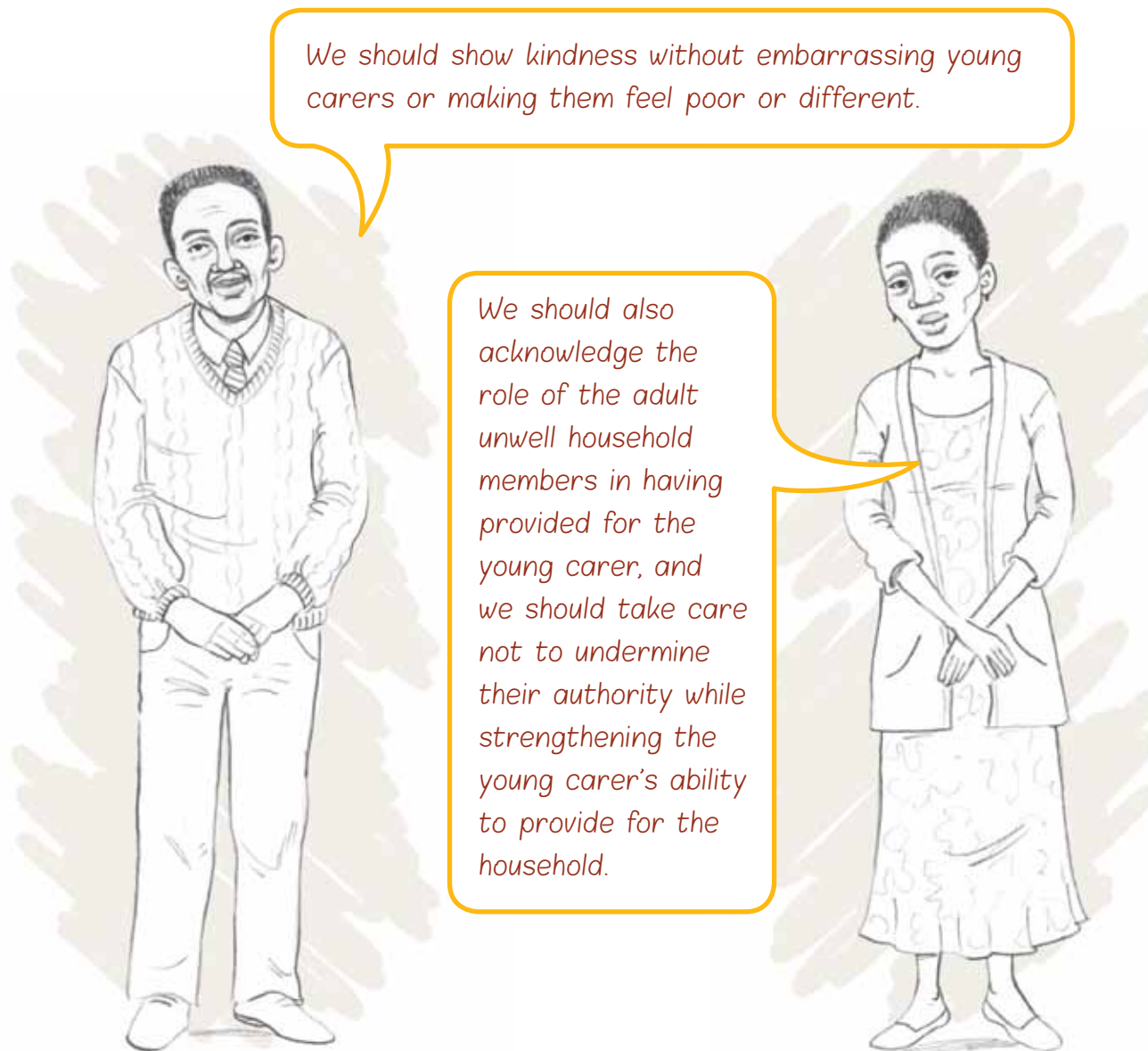
- *Acknowledging the burden of responsibility that the young carer is carrying*
- *Supporting their own economic strengthening initiatives*
- *Helping them to get time off in their role in caring to engage in economic strengthening activities*
- *Making sure that they are not taking on too much work (child labour)*
- *Making sure that they get government grants where these are available*
- *Giving them school fee exemption which means not having to pay for education*
- *Helping them by donating practical things like school uniforms, clothes, school books and food*
- *Protecting their inheritance rights*

Case Example:

Economic Strengthening Activities

There are a number of ongoing economic strengthening activities facilitated by the Kwa Wazee community project in Tanzania (Madoerin, 2011). These include:

- **Educational support:** Financial support for education is seen as critical for children living with their grandmothers. It reduces the stigma at schools and in the community and it allows the children who passed the examination to pursue their studies in Secondary School. The project provide grants for essential items such as school fees, a study desk and school uniforms.
- **Income generation:** Kwa Wazee supports the children in their income generating activities through training and loans.
- **Savings:** Kwa Wazee trains the groups in how to run savings schemes, in order to strengthen the transparency and accountability.



Young Carers Leading Economic Strengthening Activities

Young carers may be empowered to participate actively in designing their own economic strengthening programmes. This can shift our perspective from simply giving them donations to building their skills. This idea is captured in the table below which shows the range of participation which is possible, from basic consultation to participation to self-advocacy.

Thinking Long Term

The young carers in your area may be encouraged to think about economic strengthening activities both for the short term (immediate future) and the long term. For example, shorter term activities may include asking for help from neighbors. Longer term activities may include attending school and studying to develop skills for a particular career. Long term activities can break the cycle of poverty in some families. In order to reach long term goals, one may need to make sacrifices in the short term, and save and plan ahead. This takes a lot of strength and determination, and it is helpful to have other people who believe in your vision and support your dream for the future.

Case Example: Humuliza Project (REPSSI, 2010)

The Humuliza Project in Tanzania's youth led organization VSI also focuses on a number of economic strengthening activities, which include:

- Slip payment: a child is assigned to a pensioner to help with tasks, the pensioner records and signs off on this and the child then receives a stipend from Humuliza.
- VSI bank: set up by VSI to support young people to save and expanded to providing small interest free loans.
- Income Generating Activities: which include raising chickens for eggs, selling fish or running a small kiosk.
- Auctions: VSI members auction foodstuff once a month. Money raised is used to set up a fund available for emergencies.

Case Example: Studying

From a young age, Busi, from an informal settlement in South Africa, took care of her parents who were alcoholic. She felt that she was falling into the same life that her mother had led, getting pregnant while young and drinking. She decided to change her situation. She went to a local college and asked the head of the college to let her study. He asked her "What would make me give you a bursary and not someone else?" She convinced him that she was serious and finally he said he would let her study for the first year and see how her results were at the end of the year. "It was very tough" said Busi. "I worked two days a week as a domestic worker to get enough money for books and transport. I used to hide my books in the trees or my family used them as trays. I used to see other girls my age with nice hairstyles and clothes and I was tempted to quit." But finally after many years of sacrifice Busi became a chemical engineer. She now gives motivational talks to other young people to encourage them to study. From Sinani, www.survivors.org.za.

Use the following questions from Humuliza to identify opportunities for economic strengthening with the young carers in your area:

YC Practical Activity: Economic Strengthening for Young Carers

You can ask young carers:

- What type of work or career would we each like to have one day? (Our personal vision)
- What strengths do we have because of having been young carers?
- What resources and skills do we have in relation to providing for our households?
- What laws and programmes already exist from which we could be accessing support?
- What ideas do we have for strengthening our income? (Think of both short term and long term ideas)
- What additional support would we like?

For more information about participatory economic strengthening activities for young people, you can download the manual *Mainstreaming Psychosocial Care and Support into Economic Strengthening Programmes* from www.repssi.org.

Let's Check Ourselves

Theme 4 focused on economic strengthening of young carers through participatory approaches and additional support. Use the following checklist to measure how well you are doing in reaching these aims of supporting young carers in your programme:

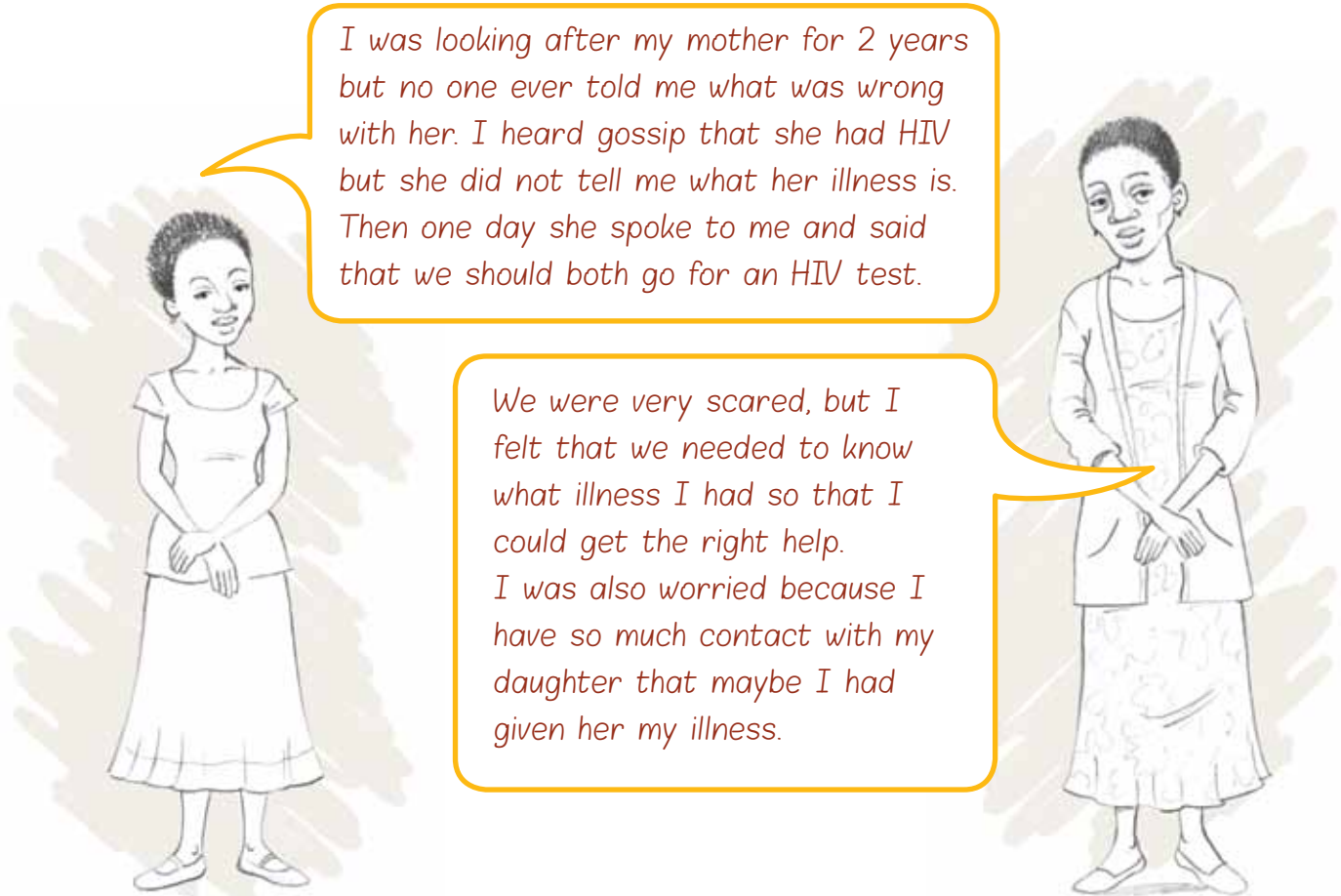
- ✓ tick if you feel you have achieved this objective
- ✗ a cross if you have not achieved this objective
- an open circle if you would like to do more towards achieving this objective.

Economic Strengthening	✓ / ✗ / ○
I have acknowledged the burden of responsibility carried by the young carers in my area to them	
I have found out the existing policies, programmes and resources that are available in my country for supporting young carers	
I have assisted the young carers in my area to access the resources which are available to them in my country	
I have facilitated a participatory process to engage them in economic strengthening activities	
Young carers are supporting one another to strengthen their household income	
My programme and school supports the income generating activities of young carers in our area	
My programme and school supports the further education of young carers in our area	

THEME 5

HCT (HIV Counseling and Testing) and Disclosure

Another way to support young carers is to encourage all members of their households, including themselves, to become aware of their health status. This is because many young carers worry about the health of unwell household members, and it can be a relief to understand what illness they are dealing with. In the time of HIV and AIDS, this may mean encouraging each household member to go for HIV Counseling and Testing (HCT). The term HCT in more recent times, in some circles, come to replace the term Voluntary Counseling and Testing (VCT) however in many countries and circles it is still referred to as VCT. You may use either term, depending on usage in your context.



Meet Jennifer. She is a community home based carer for our area. She helped us with our fears about HIV.

No matter what illness someone has, for correct treatment we need to know what it is. This also helps us to take the right precautions to help those who are looking after the person to protect themselves and to protect a sick person from re-infecting herself.

HCT means HIV Counseling and Testing. It means taking a test so that you know whether or not you are HIV positive. Some people call it "knowing your status."



Reflection Exercise: HCT

Here are some questions for reflection or discussion:

- Have you been tested yourself? Without revealing your status, discuss or describe whether or not you have been for an HIV test yourself.
- What stops people from going for testing?
- What helps people to go for testing?
- Describe or role play a situation where you introduce the idea of going for HCT with a young carer and their family in a helpful way.
- Think about other approaches which could be used in your area to encourage people to go for testing.

The exercise above may also be facilitated with community groups.

The Importance of Testing

It is very difficult to suggest that someone goes for testing. We need to use the greatest respect and care when speaking to someone about going for testing. Try to think of ways that you would like to be spoken to yourself, about this sensitive topic.

It is important to go for all household members to go for testing because:

- In order to provide the right kind of care we need to know what illness we are dealing with
- The sooner we know what an illness is, usually the easier it is to treat it well and develop a treatment plan
- It is important to know the risks of infection for other household members and to minimize these risks

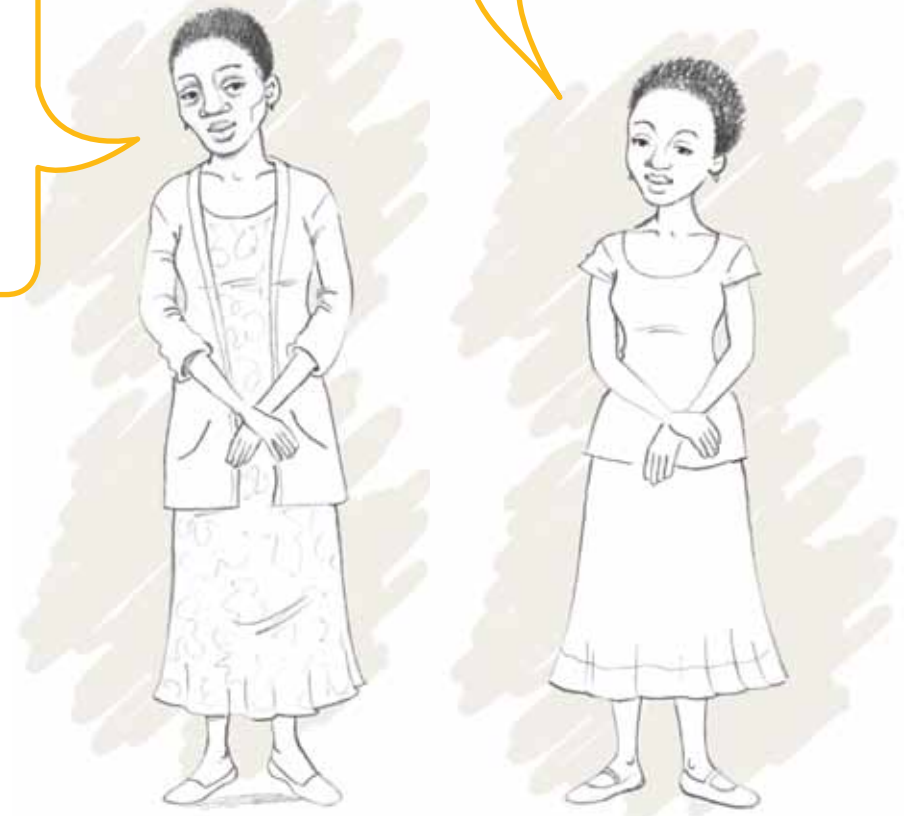
"Because I have given birth I know that this illness can visit my house too some day."

(Rural woman in South Africa, from CINDI, 2007)

Disclosure

After I went for testing I found out that I am HIV positive. Now that I know I have HIV, I know I must disclose to Noko but I am afraid.

I have always suspected that mom has HIV but if she actually told me it would be a relief...to know what we are dealing with and get her onto treatment.





Disclosure means opening up to someone. In this case it means telling someone that you are HIV positive. Here are some ideas to help you with this difficult process of disclosing your HIV status to other people. Remember that you do not need to disclose your status to everybody. Rather start with people you trust and who are easier to talk to.

"When I'm ill I have some HIV friends, my friends who are also the same. I call them and ask them this is this, what can I do, and they give me advice."

(Lucy, East Africa, from Evans and Becker, 2009)

Memory Work with Disclosure

Memory Boxes and Memory Books can be made for many reasons. In Uganda, where memory work first took place in Africa, HIV positive women began making boxes with their children as a way to begin to talk about their HIV status. They recognized that disclosing one's HIV status, particularly to one's own child, is a very difficult thing for to do.

Here is an exercise to help community and home based carers to support HIV positive household members to plan their disclosure to young carers. We recommend that you start with self-reflection so that you may experience this exercise personally before facilitating it with others.

Practical Activity: Helping HIV Positive Household Members to Plan Their Disclosure to Young Carers

We think it is important to think about disclosure in a focused way.

To do this, we will now practice disclosing.

Start by dividing a page into 4 parts, and filling in a table like the example below.

Choose the name of a real person for each block, and then fill in how you might disclose to that person.

Table 5: Planning Disclosure

An adult who it is easier to disclose to	A child who it is easier to disclose to
Name of adult: Simon	Name of child: Mary
Age of adult: 42	Age of child: 6
Relationship to you: friend	Relationship to you: daughter
Exact words you might or did use to disclose: "Simon, I have something to tell you..."	Exact words you might or did use to disclose: "Mary, have you heard about HIV? Well... " Or: "Mary, now-days people are opening up about HIV, and..."
An adult who it is easier to disclose to	A child who it is easier to disclose to
Name of adult: Sarah	Name of child: Benny
Age of adult: 23	Age of child: 4
Relationship to you: boss	Relationship to you: son
Exact words you might or did use to disclose: "Excuse me, Sarah...I have something I would like to discuss with you..." Or: "Hello Sarah, I wish to find out whether our organization has an HIV and AIDS policy..."	Exact words you might or did use to disclose: "Benny, umm... I have a long illness I need to live with but you don't have to worry, I have medicines that can keep me well."

Compare your answers to the ideas in Appendix 4 which has more information about disclosure, especially to different aged children.

Disclosure to Young Carers

Telling others, especially ones own children, about one's own HIV status can be very difficult. Sometimes when we face a difficult decision it is helpful to make lists comparing the different choices. In the following tables, you will see lists of things that others have said about why they should or shouldn't disclose their HIV status. These may help HIV positive household members start to ask these questions for themselves.

"I was helped by my aunt who gave me good advice. We sat down together and started talking about this illness."

(Rural child in South Africa, from CINDI, 2007)

Practical Activity: Disclosing to Children

Looking at the first table below, decide if you agree or disagree with each reason. Tick the ones that you agree with, and cross out those that you don't. Add in some of your own reasons in the blank parts of the table, if you want to just talk and not write that is fine.

Table 6: Disclosing to Children

Why I should disclose to my children	Why it is difficult for me to disclose to my children
I would rather the child hears it from me I can decide what to say	I have not told others and I'm worried that my child will tell others
The child may need to prepare for tasks ahead and protect themselves from becoming infected (sickness, painful procedures, discrimination and death)	I do not want to worry my child
I want my children to know from me the modes of transmission of HIV so that they do not contract HIV as I did	I do not know the impact this would have on the child
We as adults need to help children talk about fears and feelings	I think I should begin to talk about this but I just avoid it – it is very difficult
Maybe the child has already picked up some signals or someone else has said something, and I think I can reassure him or her	I think it will harm the child
I often feel guilty but I need to keep telling myself that this thing is not my fault	I think my child might reject me
Research has shown that disclosure to children helps both parents and children psychologically	I feel it is my business and a private issue
My children could help me with adherence to my medicines if they know about why I need to take these	



Although it is important to discuss HIV with children, we recommend that you first have a series of sessions with the adults in the family before opening this topic with children. It may be easier for children to have this discussion with the adults in their family rather than with someone outside of the family.

Case Example:
Telling People About My Illness

Mary, from Tanzania, was open about her HIV status, saying: "I have told a lot of people about my illness. So when I am ill, a lot of people came to see me, because they know about my problem. I go to see them and so they are close to me. If they hear that the children are ill, they come to help me." From Evans and Becker, 2009

It is especially important to encourage unwell household members to disclose their HIV status to young carers who are looking after them. This may protect them from harm. Care should be taken to help them to process the fears and worries so that they may understand how to deal with this information constructively.

For more information about Disclosure and health related information, see:

- "Weaving Hope for Our Children, Home Based Care as an Entry Point for Enhancing Psychosocial Care and Support for Children Affected by HIV and AIDS", REPSSI (2007)
- The Talking Book - Safe disclosure to children with HIV and AIDS, REPSSI (2008)

Young Carers' Own Health

The information on HIV and AIDS is also relevant to the young carers, in terms of their own health behavior. Opening discussions about sex and sexuality and safe practices in relation to HIV can help to give young carers an opportunity to ask questions and learn more about their own health and safety. Where possible this may be done with their caregivers, or together with other young people in a group. There are many good materials about working with young people on HIV prevention, identity, sex and sexuality. Find out about materials which are available and relevant to your context.

The Soul City Buddyz project has user-friendly materials which may be used with young people to open discussions about their health. These can be downloaded free of charge at www.soulcity.org.za.

Let's Check Ourselves

Theme 5 focused on HIV Counseling and Testing (HCT) and Disclosure. Use the following checklist to measure how well you are doing in reaching these aims through your programme:

- ✓ tick if you feel you have achieved this objective
- ✗ a cross if you have not achieved this objective
- an open circle if you would like to do more towards achieving this objective.

HIV Counseling and Testing (HCT) and Disclosure	✓ / ✗ / ○
I have been for an HIV test myself and I know my status	
The members of the unwell households I support know what illness they have and have been for an HIV test	
They have spoken to young carers about their HIV status	
They have shown support to any other household members who are HIV positive	
Young carers have an opportunity to learn more about their own health and safety	

THEME 6

Treatment Literacy and Support

Since many young carers are dealing with the practical realities of illness and health care, support may be given to them to improve their knowledge and skills in this regard. This can help young carers to feel more empowered in their role, and to feel more secure about asking for additional help for health matters beyond their ability.



Understanding HIV and AIDS Terminology

Now that I know my mother has HIV and that she is on medication, I need to know more about her treatment. I need to know about the symptoms of the illness and the side effects of the medicine. I also need to know when to worry and when not to worry, when to ask for additional emergency support, how to care for an ill person. I will ask Jennifer, the community home based carer. She will know the answers to my questions





From Jennifer, Noko learnt the following:

What is HIV?

HIV is a virus which weakens the immune system. The immune system is your body's way of fighting off illnesses. So HIV makes your body less powerful in fighting off diseases. If you have HIV you need to give your body lots of extra help in fighting off illnesses.



What is ART?

ART means Anti Retroviral Therapy. It is treatment (medicine) for HIV. Even though HIV stays in your body forever, ART can help people to live a long and healthy life.

Here are some important things to know about ART:

- *ART cannot cure HIV but it slows HIV down*
- *You must take the medicine you are given exactly as the doctor tells you to*
- *It helps to have food before taking your medicine*





Here are some words that are often used when people talk about HIV:

These are illnesses that take the opportunity of your immune system when it is low, for example rashes like Thrush, colds and flu, and more serious illnesses like TB.

TB:

TB stands for Tuberculosis. It is an illness that affects your lungs. Usually people with TB cough a lot. Drug resistant TB is a very strong type of TB that is difficult to cure.

CD4 Count:

The CD4 cells are part of your immune system - the ones that fight illnesses. So if your CD4 count is low, your body needs help fighting off illnesses. Anti-Retroviral Therapy (ART) can improve your CD4 count.

AIDS:

This is when your immune system becomes very weak as a result of HIV and you struggle to fight off illnesses. It is important to go for regular medical check-ups to monitor one's health.

Symptoms of HIV and AIDS

HIV is an invisible illness and you cannot easily see when someone is HIV positive. But if their immune system starts becoming very weak you may see the following signs:

- Tiredness and weakness
- Taking a long time to heal from illnesses like colds and flu
- A cough that won't go away (which could be TB)
- Weight loss (getting thinner)
- Running stomach
- Sores and infections on the lips and skin that don't go away easily
- Grey or dull skin color
- Night sweats

When a person becomes very sick you may also see changes in their behavior, like becoming confused, talking about strange beliefs, and becoming aggressive (like fighting off people who are trying to help).



Side Effects of ART

The medicine itself can cause side effects (symptoms), such as:

- Running stomach
- Stomach pains
- Bloating
- Nausea (feeling sick)
- Muscle pain and weakness
- Confusion

It is best to ask a doctor, nurse or community home based carer about these symptoms and if the medicine needs to be changed or if they can be treated.

When to get Emergency Help

It is best for a young carer to ask their doctor, nurse or community home based carer about what to look out for when an unwell person needs emergency help. But in general, we usually call for emergency help when:

- A person has a very high temperature that does not come down within a few hours. You can recognize this by feeling a person's forehead (it will feel hot), or if a person is sweating, or if a person is shaking (shivering) and says they feel cold when their body feels hot).
- A person has a running stomach for more than 1 or 2 days
- A person is vomiting for more than 1 or 2 days

- A person is not drinking water (they can easily become dehydrated)

Here is a practical exercise that may be facilitated with young carers about accessing emergency help.

For more information about HIV, AIDS and ART, you can visit the website of the Treatment Action Campaign: www.tac.org.za.

Practical Activity: Who Will We Call?

Together with young carers, make a poster of an emergency call list.

- Let them think of a specific situation where they might need help (eg if the person they are caring for gets very sick. They should write down the steps that they will follow in an emergency. For example:
- Stay calm
- Make sure that my younger sister is safe
- Walk to my neighbor's house to ask for help
- Collect the things that we may need to take with us (help the young carer to make a list)

They should write down the list of names of the people they can ask to help them in an emergency (in order of priority).

They should choose the order of their list (prioritize) according to criteria like who lives closest to them, who is trustworthy and likely to be helpful in an emergency, who has a telephone or a car.

The young carers may like to decorate their poster so that it helps them to feel calm and to stay positive in an emergency.

They may put this poster on a wall in their house when they can easily see it and read it if there is an emergency.



This next section covers some practical information which may be shared with young carers to help them feel more empowered to take care of unwell household members.

Keeping Bedridden Household Members Healthy

Noko's mother Emma is bedridden. She is too weak to get out of bed herself. Noko has learnt to take good care of her mother thanks to help she gets from a community home based carer called Jennifer who visits her house three times a week.

Jennifer and Noko say that these things are helpful when caring for a bedridden person:



- *Keeping someone clean and dry helps them to stay healthy! Wet and dirty means that there is danger for infection.*
- *All wounds should be kept clean.*
- *Apply clean dressings to open wounds every day. Reusable dressings like bandages should be very clean, washed in clean water and disinfectant, then properly dried so that they do not cause infection. Remember, wet and dirty things cause infection!*
- *Use disinfectant (like Dettol or Savlon) in clean water to clean wounds*
- *Use a disinfectant cream on dressings if wounds look swollen or are leaking (showing puss or bleeding).*



- The bedridden person should be washed thoroughly every day and kept clean and dry.
- Clean soiled (dirty) linen, underwear, nappies and private parts to avoid sores and infection.
- Turn people over every few hours so that they lie on a different side of their body or on their back. This stops bedsores from happening, where someone has been lying in the same position for too long.
- If a person's skin or lips are dry and cracked, first clean and dry them, and then apply moisturizing cream like Vaseline.



- Always wear clean gloves when working with a sick person, so that you do not bring germs near their wounds. If you do not have gloves find a clean and strong plastic packet that you can put your hands in and tie around it.
- Always wear gloves or plastic bags when cleaning up any body fluids like blood, so that you do not spread germs and so that you do not pass germs onto yourself.
- Wash your own hands after caring for or nursing the sick person
- Cover up your mouth and open a window if the sick person is coughing to prevent TB infection
- If you have someone to help you, or if the ill person feels stronger, help them to get out of bed and sit in a warm comfortable place. If it is a warm clear day and not too hot or windy, wash the person so that they are clean and dry and then help the person to sit outside in the sun. You will soon see how much better they feel!
- Keep the person's mind active by doing things that the person enjoys, like singing together, talking to him or her, playing games, organizing visitors, reading to the person, organizing church visits or praying together. Ask the person what he or she finds helpful.
- Don't overdo any activities. It is better to do things for a short time before the person gets over tired.



Case Example: Caring for My Mother

Good Luck (aged 18) cared for his mother until she passed away. He says this:

"Her health started deteriorating slowly. She would be poorly one day and would be better the next day and would resume doing her usual chores at home. She also ran a small business. Later she became very poorly and couldn't get out of bed. So that is when I started caring for her full time... I used to bathe her, she didn't mind that I was a boy. When it was time to go to hospital I would take her there. When she was very poorly and couldn't walk, I used to carry her. Sometimes she wasn't able to eat on her own, so I would feed her. When she vomited I used to wash the soiled clothing. Later ... the doctors gave me gloves for washing soiled clothing and some for using when bathing her and tending her sores. So that is how I cared for her until she died." From Evans and Becker, 2009.

A tracing book may be used by young carers to help explain to a doctor or nurse or community home based carer how an unwell person's body is feeling. It can help the doctors and nurses to know what medicine is needed or how someone's body is reacting to the medicine.



Practical Activity: Tracing Book

A tracing book is a tool which helps a person track how they feel when they are ill and well. It can be done with adults or children. Try it out for yourself by following these steps:

- Draw a small outline of your body shape on a piece of paper (you may wish to provide an example)
- Choose a color to outline your body shape. It could be your favorite color, or a color which means something to you. It could be a color which describes how you are feeling now.
- Now it is time to listen carefully to what your body is telling you. We will try to draw what our body is telling us on our picture. Remember that you are the person who knows your body best, so there are no wrong marks!
- Listen carefully to your body. Where in your body you are feeling strong and healthy? Make a mark on your picture to show this – it could be a symbol that you draw.
- Now listen to your body again for where you are feeling unwell. Where is your body telling you that it is struggling? Use different pictures, words or symbols for different types of feelings (different types of pain, stiffness, itching, places which are swollen, tiredness or weakness).
- Are you taking any treatment or medicine? These may be modern or traditional medicines or approaches. Show how you are taking treatment and how often you have been taking it on your picture.
- Now think about how your body is fighting off illnesses. Draw this into your picture.
- Now listen to what your body is saying it needs to make it even stronger to fight illnesses. Does it need water, or healthy food, or rest or exercise? Draw this on your picture.

A tracing book can be used regularly (e.g., every day or every week or every month) with people who are unwell to strengthen the immune system, like planning nutritious meals. It can be used for visualization – where you imagine your body fighting off illnesses and becoming stronger.

For a more detailed handbook on using Tracing Books see “Tracking Your Health: A Guide to Using Tracing Books”, which may be ordered through the REPSSI website (www.repssi.org).

Let's Check Ourselves

Theme 6 focused on treatment literacy and treatment support for young carers supporting people living with HIV and AIDS. Use the following checklist to measure how well you are doing in supporting young carers by reaching these aims through your programme:

- ✓ tick if you feel you have achieved this objective
- ✗ a cross if you have not achieved this objective
- an open circle if you would like to do more towards achieving this objective.

Treatment Literacy and Treatment Support	✓ / ✗ / ○
The young carers I support understand what it means to have HIV	
They know the symptoms of advanced HIV and AIDS	
They understand the behavior changes that might take place when a person becomes very ill (and they know that it is not their fault or the person's fault if they behave differently)	
They know when someone needs emergency help	
They have a clear plan of action for emergency help	
They have basic skills of how to care for a bedridden person	
The unwell person being cared for is kept comfortable and as healthy as possible	
The young carer always uses clean gloves or clean plastic bags when caring for an unwell person and cleaning up any body fluids	
My own programme or school models and normalizes using gloves to care for any unwell or injured person	
The young carer has regular support from professionals and community members to assist with health care of an unwell person	



Future Planning and Preparation for Death




In our support group, there are children whose grandparents or parents have died. I know that any one of us can die anytime – you can get run over by a car or die from a disease. The important thing is as a family to be prepared for death where possible, and to be kind to one another during such difficult times.

Celebrating a Life

Elizabeth Kubler-Ross is someone who has worked with many unwell and dying people. She says that almost all people are very peaceful at the actual time of their death. She says that the few people who seemed upset when they passed away said that they had unresolved things that they wanted to talk about. These were mostly things that they felt guilty about, for example times that they had said hurtful things to their family members. It is a good idea to open up spaces where people who are facing death can say what they need in order to help them pass away peacefully.

It is a good idea to ask people if there is anything they would still like to do in their lives before one day passing away.





I need to talk to my sister before I pass away. We had a fight many years ago and I would like to heal our relationship before it becomes too late. I will ask my neighbours to help Noko to invite my sister to visit me at home.

We are not suggesting that everyone will find these things easy to do or even useful but here are some ideas about what other people have found useful in preparing for passing away.

- Invite close family members to visit them
- Have a family function where everyone is together
- Pay their respects to other family members who have passed away (eg visiting a grave site)
- Write letters to each person that they care about
- Heal a broken relationship with someone
- Talk about a difficult experience that they have had
- Talk about something that they feel guilty about
- Give specific instructions for how they would like their life to be celebrated once they have passed away
- Give instructions about who should get which of their possessions once they have passed away
- Give instructions about what to do during and after the funeral (rituals)

Here is an exercise to try yourself, in order to experience what it is like to face these questions and to come up with your own ideas about how the households you support may be assisted to celebrate their life and prepare for their death:

Reflection Exercise: Celebrating Your Life

Think about yourself and answer these questions:

- What would I like to do before I pass away?
- What practical matters do I need to sort out before I pass away?
- How can I have these discussions with my family members in a way that is encouraging and hopeful?
- How would I like my life to be celebrated when I pass away?
- What would I like to be done with my remains when I pass away?
- What is the legacy (main memory or message) that I would like to leave people with in celebrating my life?

Talking about passing away is something that we should all be doing, not just when someone is really sick. Try to find culturally appropriate and hopeful ways of talking about these things in your own family, while supporting households where there is an unwell person to do the same.



When it comes to young carers who are looking after someone who is dying, it is a good idea to open discussions about what will happen to them after someone has passed away.



Taking Care of the People Who are Left Behind

Here is some important information to keep in mind:

- It is important for young people to stay with someone they really trust and like – someone who cares about their wellbeing.
- It is better for families to stay together (eg brothers and sisters)
- It is easier for young people to stay near friends and in the same school when they are going through a difficult time
- It is better if young carers are connected to family members and future guardians well before a caregiver passes away

YC Practical Activity: My New Home

Try to find the best place for young people to be secure and well cared for if their main caregiver in their household passes away. This exercise can be done together with household members and young people themselves. It could be facilitated as a discussion or a drama.

Here are some of the things young carers might want to think about and talk about in their family or support group:

- Is it a good idea to find time to talk openly with your household members about death and the possibility that someone might die?
- What is a polite and sensitive way to do this?
- Who outside of your household cares about you and your family the most?
- Who outside of your household do you trust to be able to help you?
- Where would your mother / father / grandparent of the young carers like you to live?
- Where would you like to live?
- How will we keep our family together (eg brothers and sisters)?
- How can we make sure that all young people in the family stay in school?

It helps to take care of the practical things before someone passes away. Here are some of the things that we encourage our group members and their households to work out.


- *Property ownership and rights: Who owns your house and land? What will happen if the owner passes away?*
- *Will: Does everyone in your household have a written and signed Will? We call this a Last Will and Testament. It explains who should get your things when you pass away. It explains who should take care of your children if you pass away.*

As a community home based carer I have found it helpful to know about some of the property laws so that I can protect the young carers in my area from land and property grabbing when someone passes away.

Beatrice Were from NACWOLA, the National Association of Women living with HIV and AIDS in Uganda, once wrote:

"One of the ways some HIV positive women are dealing with the possibility of death is by concentrating on practical plans. We've sorted out our wills, we've planned our own funeral and where necessary the funeral of our partner. We've made arrangements for our children to be looked after by relatives or friends."





When I first heard about a Will I thought it was something very complicated. But now we have made a simple form that can be filled in by anyone who wants to make their own Will.

Making a will

The laws about Wills vary from country to country, so please check that the guidelines below meet the legal requirements in your country. Here are some instructions for how you can explain to someone the need to write a Will:

“Written Wills might or might not be part of your culture. Remember culture is always changing, and it is people who change it. You should decide if you want a Will or not. Most people will tell you that it is a good idea for everyone, no matter how healthy or sick or old or young, to have a Will.”

A Will is a written document, which makes clear what you wish to happen after your death. A Will can do the following:

- Ensure that your property, land and valuables are passed on to the people that you want to receive them
- Make clear who will look after your property, land or valuables until your children are old enough to do so themselves
- Make clear who will look after your children in future
- Appoint a guardian to look after your children

In order for a Will to be legal you need to:

- Write the date on which you wrote the Will on every page
- Sign or make your mark on every page in the presence of a witness
- The witness must also sign the Will on every page, in your presence

- Appoint an executor who is the person who will make sure that your intentions and wishes are carried out after you die
- The witness must be a person who is not getting anything in the Will
- The Will must be written when you are in sound mind and you are not forced to write the Will by anyone else
- Appointing a guardian for your children
- It is important for all of us to choose a guardian for our children when we think about dying and when we think about the future of our children without us.
- Talk to the person you have chosen and make sure that they are willing to look after your children.
- Wherever possible, the child should participate in discussions and decisions about his/her future
- Consider starting the process of handing over guardianship of the children while you are still alive so that the children and the new guardian can get used to each other - arrange visits between the guardian and the children
- How you explain to your children about the future and appointing a guardian, will depend on you and your situation

Below you can see a format of a sample Will. In addition to making a will, it might be useful to store copies or originals of certain documents like birth certificates, ID books, title deeds, etc. A memory box, especially one that can be locked, is a good place for these. An even safer place is a community leader's or a lawyer's office.

Format of a Sample Will

This is the last Will of (put your name and place of residence here)

I want (put the name of the Executor - the person who carries out your wishes here and his/her place of residence) to be the Executor of this Will.

I leave: (Put the property / land / or valuables here),

To: (Put the names of the people you wish to receive them after your death here)

.....,

I appoint (put the name and address of the person who you want to look after your children here) as the guardian for my children.

Signed at Place where you have made the will) on (day, month, year)

..... (Sign here)

Witness:

Name Signature

Address (physical address) Date Place

Opening Discussions about Death and Dying

Reflection Exercise: Future Planning

Describe or role play of one of the following situations, showing how you would deal with this difficult issue constructively:

- You are a community home based carer who talks to an unwell household member about preparing for passing away, especially about planning that good care is taken of her children
- You are a grandmother who talks to her grandchildren to tell them that she is passing away
- You are a father who makes plans for his children to continue their schooling after he passes away
- You are a mother who is making plans for her funeral. One of the things that she is struggling with is whether or not to recommend that children be included in the funeral
- You are a community leader who feels that people in the community should know more about succession planning in terms of property rights and Wills

Here are some helpful ways of saying difficult things about death and planning for death.

You can use some of these questions when talking to an unwell household member:

- I would assume this is a very difficult thing to think and talk about but I suspect it is something you worry about a lot. Would it help if we think and talk about this together?
- I would guess that you worry about your health. Perhaps you are even thinking and worrying about what will happen if you die. I don't want you to carry all that worry by yourself. Would you like to talk about it? I would think that this is difficult to talk about but I think it is important.
- I would like to suggest that we ask all of the children who they would like to look after them if something happens to you.
- Maybe I or someone else can help you approach some relatives or friends to ask if they would be willing to look after the children?

You can use some of these questions when talking to young carers:

- How do you feel about us talking and listening to each other talk about what might happen if the person we are caring for dies? For some of us this has already happened and you might want to share your experiences with us.
- For those of you who have agreed to talk about these things, I am now going to invite you to go a little deeper.

Have you thought about who you and your siblings will stay with?

- I think it is important to try to keep all of us together as a family and not separate the siblings, do you think this might be possible?

Let's Check Ourselves

Theme 7 focused on future planning and preparation for loss. Use the following checklist to measure how well you are doing in reaching these aims through your programme:

Future Planning and Preparation for Death	✓ / ✕ / ○
The households in my area have spoken openly to one another about death and dying	
Unwell household members have said how they would like their life to be celebrated	
People's property rights are protected	
Adult household members have made a Will	
Plans have been made for the care of younger people in the event that their main caregiver passes away	
Arrangements have been made that siblings stay together if their main caregiver passes away	
Young people have been consulted about whom they would like to live with in future	
Their anxieties about what will happen to them have been addressed	
Arrangements have been made that young people are able to continue their schooling if their main caregiver passes away	
Young people have developed a good relationship with their future guardian	

- ✓ tick if you feel you have achieved this objective
- ✕ a cross if you have not achieved this objective
- an open circle if you would like to do more towards achieving this objective.

THEME 8

Grief and Loss



My mother died when I was 5 years old. I had a very kind teacher who explained to me what happened. She answered a lot of my questions about my mother's death.

We are all affected by loss.

My mother is very sick and she told me that she will also pass away. I feel very sad about this and I have a lot of questions about what is happening. I am glad to have you as a friend to help me through this time Busi.



Understanding Grief

People react differently to loss. The feelings, thoughts and bodily sensations that are experienced as a response to loss is what is called grief.

Definition of Grief:

Grief describes the thoughts and feelings that are associated with the loss of someone or something significant.



Here are some things that we learnt at school about when someone we love passes away:

- Grief is a personal experience
- People grieve in different ways
- We should not judge or label a particular grief reaction or what we think is a lack of a grief reaction





- It is important to understand that children of different ages experience grief differently
- Grief is usually experienced as a painful time of personal suffering and thus people who are grieving need support
- When people grieve, it affects the way they feel, think and behave Therefore, children can be bewildered by the reaction of their caregivers to loss
- Children also grieve, although there is general lack of insight and understanding about their experience of grief. This often leads to children who have experienced loss not being given the support that they need

Never push someone to “move on from their loss” or to grieve in the way that you think is best for them. Grief is a very personal process. The only way for a person to move on to the next stage of grief is to do the stage that they are currently in thoroughly.



Supporting a Young Carer Who is Grieving



We cannot take away the feelings of sadness from someone who is grieving. We can only be there patiently to support people to grieve in their own way.

You should never try to rush a person into accepting a loss. The person knows what is best and will grieve when he or she is ready. Sometimes denial and guilt are a defense against the pain of grief. In other words, grieving is so painful we may try to avoid going through such a process of suffering until we are ready. Always be patient and help the person to cope and feel safe until he or she is ready to grieve.

What if someone seems very stuck – for example they are refusing to accept what happened?

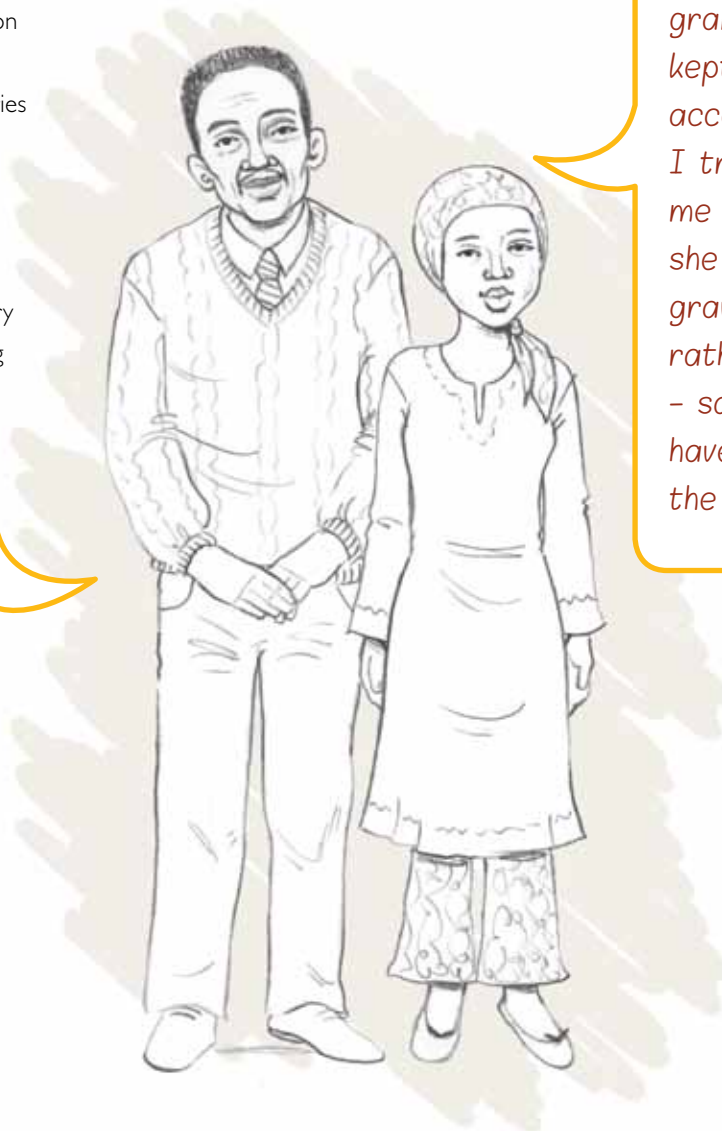


Remembering

One thing that you can do to support someone who is grieving is to help them honour their memories of the person who has passed away. Help someone who is grieving to remember their loved one – for example listen to their stories about that person. You can ask about what they liked most about that person, or what made them unique. You can ask what their favourite memories are of that person.

You can help someone to make a memory box or a memory book of the person who passed away, as a way of treasuring their memory of that person.

It is helpful to ask someone what they feel that they need to do in order to honour the memory of someone who has passed away. This is unique and personal so don't impose what you think would be helpful onto that person – rather find out their ideas of how to honor the memory of that person.



This is true - I remember when I lost my grandmother who I was very close to and I kept on crying. Everyone told me I need to accept that she is gone and to say goodbye. I tried this but it never worked. What helped me was to keep talking to her even though she is gone from this world. I kept visiting her grave and I still do. I kept on saying hello rather than goodbye. That is what helped me - saying hello again and again. This is how I have come to accept what happened, keeping the memory of her alive.

The psychosocial effects of loss on children are not always obvious and visible, and thus can be overlooked.

Children often act or play out their emotions as they find it difficult to verbalize how they are feeling. Children often experience loss before the actual event of death. This is called anticipatory loss.

Mr Hlaphi: Here are some ways that you can help young carers or their caregivers in a time of loss:

- Find ways to normalise death by explaining to young carers that:
- Death is a natural part of life
- Death needs to be openly and honestly discussed – untrue explanations such as “your mother has gone to sleep” or “your mother has gone away” will cause child to expect mother to wake up again or return and lead to disappointment and do more harm than good
- Avoid the situation where child learns of this death by someone else – for example a school bully
- Tell them that everyone dies but that we don't know when a person is going to die, some die when they are young and some when they are old but that once we are dead we cannot come back to life
- It is normal to worry about death and to feel sad when someone dies
- Encourage them to talk to you or to someone else when they feel this way
- Tell them that they will always remember the person who has died in their hearts and minds
- Use age appropriate language to talk about death to children of different ages
- The child must understand that the death was not his or her fault



Remember – never push a child or young person to talk about loss. It is better if they start asking questions when they feel safe enough to talk about the loss.

Maintain an ongoing loving relationship with the young carer:

- Having a close and affectionate relationship with the remaining caregiver or new caregiver will help a child cope more easily with the changes in his or her life
- Physical contact (hugging and holding) may give the child a sense of safety and security. If a child does not like to be hugged it is important to respect this
- Ask each child what helps him or her to cope

Maintain a routine for the young carer:

- Where possible the child should remain in his or her home environment, remain in the same school and follow the same routines he or she followed before the loss. This might be more important than offering the child “bereavement counseling”
- Siblings should not be separated wherever possible
- Encourage the child to play with other children and carry on with his or her day to day activities
- Help the child to know that it is normal to feel very sad sometimes and still to feel very happy at other times. This does not mean that you do not care about the person's loss

Observe changes in the young carer:

- Notice any signs of distress or regression (child acting younger than he or she did before the death eg bedwetting, temper tantrums)
- Make time to be with the child and accept his or her behaviour
- Seek help if the behaviour carries on for a long time (longer than 6 months) or the behaviour worsens

Keep a link with the deceased person. Young carers need to remember and protect their relationships with their deceased parents or caregivers:

- Talk about the deceased person in a natural way
- Let the child ask questions about that person
- Encourage him or her to share good memories of that person
- Allow the child to share bad memories as well if he or she needs to
- Keep some of the things that will remind the child about the deceased person. These things will help to build a bridge between the deceased person and the child
- You can encourage the child to make sense of their experience by making a memory book or memory box which can become a source of comfort and a store of meaningful memories
- Visit the grave with the child (if it is culturally and age appropriate)

Keep communication open:

- Be ready to answer many questions about death
- The questions may come at unexpected times, and children often ask something, then want to stop talking about it. Be prepared for this “stop-start” type of discussion
- Repetitive questioning about a parent's death may result from the child's fear that you as the remaining caregiver may die too
- It is important to reassure the child (if this is the case) that their caregiver is not going to die or go away. You may need to reassure the child about this again and again
- If the caregiver is not well, tell the child that they are doing all they can to stay healthy (eg taking medicines, eating as healthily as you can etc) but that if something had to happen to them, there will always be someone to look after the child

Reflection Exercise: Answering Children's Questions About Death

Think about or discuss helpful ways of answering these typical questions that children ask about death:

- How does a person die?
- Why did this person die?
- What happens when a person dies?
- Did the person die because I did something wrong?
- Will it happen to me?
- Does dying hurt?
- What happens to a person's body once it is buried?
- Where do people go when they die?

Sometimes it is fine to say “I don't know the answer to that question”. This is better than making up information that you are unsure about.

For more ideas about psychosocial care and support read: “Building Resilience in Children affected by HIV and AIDS” Catholic Aids Action in Namibia

“Psychosocial Care and Support: Facilitator's Manual”, REPSSI, (2011).

Strengthening Support for Young Carers Experiencing Loss

Communities have their own resources and ways for dealing with loss. For this reason they should be actively involved in the care and support of young carers affected by loss.

Reflection Exercise: Community Support for Children Experiencing Loss

Think about or debate the following statement “Children are too young to understand death hence they should not be told of their loss or be involved in the funeral or other ritual ceremonies”. List some of the ways people in your community support children affected by loss.

Here are some examples of what communities can do to support young carers affected by loss:

- Help set up children's clubs or support groups
- Establish play centers (where the young carer can drop off her / his siblings and have time to her / his self)
- Arrange church visits
- People can give support with practical things such as food for the funeral, ensuring the deceased property is protected etc
- Community members can teach children life skills, such as cooking or traditional music or dance

Children, like adults, grieve although their understanding of loss and death varies depending on their age. We have an important role to play in supporting children through the grief process.

Open communication, honesty, and reassurance, are very important in supporting children who have been bereaved.



Reflection Exercise: Your Family's Rituals

Different cultures, religions and even different families within one culture or religion usually have their own specific ways of honoring the memory of someone they have lost. What are the rituals followed by your family to honor the memory of someone who has passed away?

Draw on cultural beliefs and values:

- If concepts like heaven or reincarnation are part of someone's culture, explaining these to the young carer might be comforting and help them give meaning to the loss
- Praying with the young carer might also be comforting, especially if this was something that formed part of their routine before the loss
- The principle of child participation may also be applied to funerals. Involve the young carers in funeral arrangements. You might additionally want to ask them to plan and take part in a child friendly funeral ceremony separate from the main funeral
- Allow the children to take part in religious and cultural rituals after the death. Attending the funeral is likely to help them understand what has happened and to help them cope. Ensure that the funeral is safe and supportive (for example family conflict can be difficult for children

to witness). Things like viewing the body also need to be clearly thought through because if the person looks very different to their usual self this can affect children negatively. Funeral participation needs to be age and stage appropriate.

For more ideas about psychosocial care and support, read “Providing Psychosocial care and support to Orphans and Vulnerable Children” produced by the Government of Botswana in 2008.

Let's Check Ourselves

Theme 8 focused on supporting children and adults in times of loss and grief. Use the following checklist to measure how well you are doing in supporting young carers affected by loss through your programme:

Grief and Loss	✓ / ✕ / ○
When there is a loss in the households in my area, each person is given time to grieve in their own personal way	
Young carers are given opportunities to talk about the person who has passed away	
Young carers are consulted about what they would find helpful in grieving for their loved ones	
Young carers are given opportunities to honor the memory of their lost loved ones	
People are aware that children also experience loss	
Children are included appropriately in grieving	
Children's questions about death are answered	
Children's routines are kept stable during times of loss	
The memories of children's departed loved ones are kept alive	

- ✓ tick if you feel you have achieved this objective
- ✕ a cross if you have not achieved this objective
- an open circle if you would like to do more towards achieving this objective.

THEME 9

From Awareness to Action



Wow this has been a lot of information!

Yes it has. This section is to help you to remember the main ideas covered and to turn these ideas into action.



The purpose of this module is to review what we have done so far and for each person to leave with an action plan, adapting what they have learned to what is possible and appropriate for their situation.

Overall Aims of the Guidelines

Remember that the overall aims of the guidelines are to help young carers:

1. To feel more empowered (by the acquisition of new knowledge and skills) and less vulnerable in their role
2. To feel more supported (by other individuals and groups) in their role as a young carer.

We wanted to help people working with young carers to achieve the above. The guidelines were especially focusing on community home based carers, teachers and schools, community development facilitators and young carers who are helping other young carers.

When we are helping young carers, we should not forget about empowering the unwell household members. We should be careful not to undermine their authority and role in the house, and rather to strengthen their role in supporting the young carers who are looking after them.

And so the guidelines also remind us to help unwell household members to strengthen a positive self identity in the household as someone with special needs but also as someone who is respected and cared for, and not to feel undermined or supplanted in the role they have played thus far in the household

Here is a case example of a focused but holistic community intervention with young carers in Tanzania:

Case Example:

Holistic Intervention for Young Carers

Since 2007, the Kwa Wazee Project in Tanzania has developed different tools of intervention (Madoerin, 2011).

The main objectives are to:

- keep the parents alive as caregivers for their children
- strengthen the relationship between the (sick) parents and caregivers and the children and promote the acknowledgment of the care given by the children
- decrease isolation and stigma by forming mutual support groups

For the adults being on ARV and having revealed their status to the children, the intervention consisted of:

- Cash transfers according to their health status
- Introduction of microfinance
- Monthly training on various topics including their relationship with their children
- Forming of mutual support groups

For the children the intervention consisted of:

- Life skill training (mainly during the school holidays).
Training sessions were done with 8 groups of children on the topics
“What do we share in common?”, “HIV/AIDS, prevention and reproductive health”,
“Gender awareness”, “Group formation”, “Income generation” and “Violence”.
- Building of mutual support groups. The support groups were integrated into the groups of children living with grandparents – called “TatuTano”.
- Educational support
- Income generation activities
- Self-defense training for the girls (a corresponding training in prevention of violence for boys is in preparation)

Summary of Thematic Outcomes

Here is a summary of the themes covered in these guidelines to help you to plan your own intervention to support young carers.

The table below shows the outcomes (changes) we hope to see for the young carers' household.

Mark the third column with either:

- ✓ a tick if you feel you have achieved this objective
- ✗ a cross if you have not achieved this objective
- an open circle if you would like to do more towards achieving this objective.

In the fourth column we have left space for your notes about your own plans.

Table 10: Summary of Thematic Outcomes

Theme	Outcome for the household	✓ / ✗ / ○	Notes for action plan
Support for Young Carers	Young carers feel less isolated and receive more support		
	Households where young carers are taking on too much responsibility are identified		
	Fair workloads are shared amongst males and females		
	Neighbours, community members and government services provide more support to young carers to reduce the risks of caring		

Theme	Outcome for the household	✓ / ✕ / ○	Notes for action plan
Connecting Young Carers	Young carers join a support group and feel less isolated. They share skills and strategies which improve their situation at home.		
	Young carers are appreciated for what they do and not labeled or stigmatized		
	Young carers are mobilized to raise their needs with government and community leaders		
Livelihood Strengthening	Young carers are supported with their income generating activities such that household income increases		
	Young carers are assisted to further their education		
Young Carers Wellbeing	Young carers' access their basic rights, including the rights to safety, good nutrition, health care, education and care		
	Young carers' psychosocial needs are addressed with community support and psychosocial tools such as memory work		

Theme	Outcome for the household	✓ / ✗ / O	Notes for action plan
	Family members ask each other how they are doing, and they discuss their hopes for the future, all of which contributes to a healthy communication style and atmosphere in the home		
HCT and Disclosure	Households go for health testing and know their HIV status		
	Household members talk to one another, including young carers, about their illness and HIV status		
Treatment Literacy and Support	Young carers feel confident about their role		
	Unwell household members are as healthy as possible		
Future Planning and Preparation for Death	Young carers' anxieties and practical needs are taken care of for the future, especially in the event of a possible loss of a caregiver		
Grief and Loss	Young carers affected by loss are supported to grieve and remember their caregivers		

Our school had a ceremony to thank young carers for what they were doing to help others.

Celebrating Success!

A ceremony to appreciate the role of young carers is helpful in affirming them socially. This can also raise the awareness of the community about the need to support young carers. If a young carer's role is socially acknowledged, he or she may feel supported, empowered and appreciated. This may also help to reduce any negative stigma associated with their caring role.

Case Example: Award Ceremony

One community had a "Day of Appreciation" in which various community members' roles in caring for one another was appreciated. The people who were publically thanked in the ceremony included community home based carers, teachers who had helped children, active community members and young carers. Each person was called to the stage and thanked for their contribution to the wellbeing of others. They were each given a certificate of appreciation. The event was attended by the Mayor, staff from the clinic and other important people in the community. It included local music and dance groups, and the day ended with lunch and drinks for everyone.

You can use this certificate template to acknowledge the learning and achievement and dedication of the young carers in your community!



Certificate of Achievement

This certificate is awarded to

.....

*who is hereby recognized as a true hero
for the following reasons:*

- ✓ *During his or her life s/he has provided the highest quality leadership and guidance in her / his household*
- ✓ *Has succeeded in raising other children*
- ✓ *Is well respected in the community*

*Some of the skills and knowledge he or she has
mastered in her / his lifetime include:*

.....

.....

.....

.....

Signed by:

Community and Home Based Carer / Youth Care Support Group Facilitator /Teacher or Principal

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www.caregivingchildren.org

Appendices

Appendix I: The Caring Jobs I Do

On the following page is a user-friendly assessment tool on the positive and negative outcomes of young people involved in caring. This is from the Manual for Measures of Caring Activities and Outcomes for Children and Young People (Joseph, Becker and Becker, 2009), which you can download free of charge from www.youngcarers.net.au.

The caring jobs I do

MACA-YC18

Below are some jobs that young carers do to help. Think about the help you have provided **over the last month**. Please read each one and put a tick in the box to show how often you have done each of the jobs in the last month. **Thank you.**

	Never	Some of the time	A lot of the time
1 Clean your own bedroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 Clean other rooms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 Wash up dishes or put dishes in a dishwasher	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4 Decorate rooms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5 Take responsibility for shopping for food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 Help with lifting or carrying heavy things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7 Help with financial matters such as dealing with bills, banking money, collecting benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8 Work part time to bring money in	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9 Interpret, sign or use another communication system for the person you care for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10 Help the person you care for to dress or undress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11 Help the person you care for to have a wash	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12 Help the person you care for to have a bath or shower	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13 Keep the person you care for company e.g. sitting with them, reading to them, talking to them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14 Keep an eye on the person you care for to make sure they are alright	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15 Take the person you care for out e.g. for a walk or to see friends or relatives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16 Take brothers or sisters to school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17 Look after brothers or sisters whilst another adult is near by	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18 Look after brothers or sisters on your own	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Interpretation of scores on the MACA-YC18

Higher scores indicate greater levels of caring activity. The following categories are useful:

0	No caring activity recorded
1-9	Low amount of caring activity
10-13	Moderate amount
14-17	High amount
18 and above	Very high amount of caring activity

Appendix 2: Windows



The practical tool called “Windows” is a type of memory work that helps young carers to re-tell the story of their lives in a hopeful way. The exercise helps one to explore and re-author one’s life story to find a new and fresh story (a story that is not only about pain and suffering but that also notes courage, survival skills, values and hope). It is suitable for older children and adults.

Here are the instructions for explaining this exercise: “Your life is big but your book or your box is small. You cannot fit your whole story into it. These windows can help you decide which stories and parts of your life you want to draw and write about. Each window is a story about you or a part of your life. Maybe you want to begin with now or maybe you want to look at your history. You can write a heading, or draw a small picture in each of the six windows.”

Here is an example of Noko’s friend Busi’s Windows drawing:



For window 1, I drew when I was 8 years old, as you can see the person looks sad, it was when my troubles started when my mother became very ill.



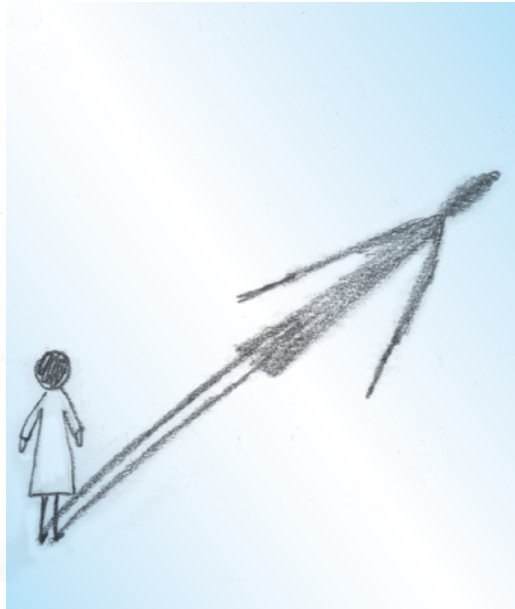
For window 2, I drew a book, it symbolizes when I was given free schooling. I was so excited, the school even gave me a uniform. I was good at school and in grade 9 I started to come first in class.



For window 3, this is a step ladder with the arrows going up, the person is me, I was starting to have a good progress at school, I thought I would get to the top of the ladder, even if I had a difficult time at home I would have an education.



For window 4, the arrows are going down because my mother became even more ill and I was very sad.



For window 5, I have drawn a shadow, I got diagnosed with HIV. I was confused - I was learning for a better life then this HIV thing came in.



For window 6, when I joined Treatment Action Campaign (TAC), my life changed, I became a hopeful person, that's why my arms are like that, the confusion and the shadow went away.

Some people prefer to use words rather than drawings to fill in their windows.

Once each person has had a chance to work on their windows, help them with the telling of their story. This can be done in pairs. Introduce the telling of the story by saying: "Get into partners of two, and invite each other to share your windows and story. Allow about 10 minutes per person for this initial sharing. The person who tells the story is called "the teller." The listener is going to tell the same story back to the teller after they have heard it and when they do this they are called "the re-teller." The person who is listening needs to take notes on the following:

1. What parts of the story you are listening to touched or moved you the most?
2. What idea can you think of that runs through this story that is about courage, survival skills, values and hope?
3. What do you think is a suitable name for the person who is sharing e.g. 'He or she who never gives up' or the 'One with Great Courage'".

Now the listener should use these notes and tell the story they have just heard, and the answers to the questions above, to retell the same story they just heard back to the teller. It is likely that the first time the teller told the story, they focused on lots of problems. In the re-telling the re-teller should focus on the special qualities of the teller; e.g., courage, survival skills, their positive values and hope.

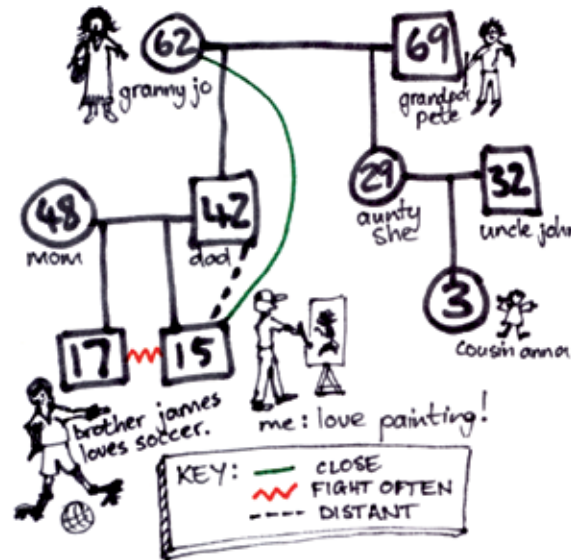
Appendix 3: Family Tree Exercise



Family trees help children to know how they are connected to other people, and they increase a sense of social belonging to an extended family structure.

You can introduce the activity by saying:

"A family tree is a list of all the members of a family showing how they are related to each other. You can use for a man and for a woman and a line joining them to show they had a relationship. Here is an example where grandfather A married grandmother B, and they had 2 children C and D. Then C married E and D married F. C and E had 3 daughters, G, H and I. D and F had one son J.



- Now you can make your own family trees starting with a basic outline like this.
- Then you can fill in the names of all the people in your family, as well as their dates of birth and death, and their ages.
- You can also make small drawings of each family member if you like.
- You might want to show with different colored lines what the relationship between two people is like. For example, you could draw a red dotted line between two sisters who fight a lot, or a green straight line between a mother and son who are very close. You can then add in any other information about your family.

Appendix 4: Disclosure to Different Aged Children

Here are some points about disclosure to both adults and children:

- Disclosure is a process and not an event. Particularly when dealing with younger children, they will need more preparation time.
- You can't just say "I'm HIV positive." The disclosure process should be ongoing and should rest on good general communication around a range of issues.
- People need time to process the information. Do not expect an immediate supportive response from the person you are disclosing to. They will have their own emotional reaction – sadness, shock, anger, confusion, denial. Usually people will have a strong reaction to the news that you are HIV positive, and they may need some time before they become supportive.
- Disclosure does not automatically mean you tell everyone about your HIV status.
- The person who is thinking about disclosing might be worried about confidentiality and might be worried that the child might tell others who she is not ready to share this kind of information with. Does this mean one should not disclose to children?
- For young children, a lot can be said without using the words HIV and AIDS. HIV and AIDS can be very scary words. You might explain to them in ways that are appropriate to the

child's age that make HIV and AIDS sound less scary, for example, "a long illness I need to live with".

Here are some guidelines about how to disclose appropriately to children of different ages:

Age Group	Suggestions for Disclosure
– 4 years	<p>These children do not understand difficult ideas or adult behavior.</p> <p>They are learning about the world through play so you can use play to explain things to them.</p> <p>Parents should start creating a climate in which children feel free to ask questions.</p> <p>Children at this age usually interpret events according to how they see the adults respond. For example if they see you crying and upset they will think it is something very bad that is happening. Try to normalize things and behave in a calm and organized way.</p> <p>With all the age groups always remember to use age appropriate language.</p>
5 - 8 years	<p>Children at this age are able to understand more complicated issues.</p> <p>They understand the world through everyday life experiences, and you can use real examples from their lives when talking to them.</p> <p>For example: Do you remember yesterday when I was not feeling well?</p> <p>They tend to respond well to routine and structure, so it may help to give a clear plan and structure about what will happen. Their own routines should be kept as normal as possible.</p> <p>Children at this age are quite self centered and tend to blame themselves for things that go wrong. It is important to give clear explanations that show that they are not at fault. Deal openly and gently with any guilt feelings.</p> <p>Children at this age have "magical thinking". For example they may believe that if they are very good they can make their parent well. Let them talk openly about any beliefs that they have about the illness and gently correct any misperceptions.</p>

Age Group	Suggestions for Disclosure
9 - 12 years	<p>They are able to understand more complicated information and they need preparation for things that will happen to them.</p> <p>They need to know practical information.</p> <p>They need to be reassured that the illness was not their fault.</p> <p>They should be consulted about what they would find helpful in dealing with this situation.</p> <p>Children at this age have a strong need to be seen as “normal” or like other children. It may be helpful to say that all families have problems which they are dealing with. They may need help planning how to respond to any negative comments or stigma in a way that is normalizing</p>
13 – 19 years	<p>Young people of this age can be told the truth about the situation and should be assisted with planning for the future.</p> <p>They should be consulted about what they would find helpful in dealing with this situation.</p> <p>Peer support becomes very important at this age, and it may be helpful to discuss who could support them in this matter.</p> <p>Idols are also important at this age and it could be helpful to talk about how famous people (perhaps with HIV) whom they like would have handled such a situation.</p> <p>Young people of this age can be quite dramatic. Music and dance is usually very important to young people of this age, and they may be encouraged to write their own words to a song or create a dance about what is happening.</p> <p>Young people have a strong need to spend time alone at this age, and they should be assisted to find a private space where they can reflect about what is happening.</p>

These points may be helpful for household members to consider about disclosing their health status to children:

- Think carefully about the personality of the child. What is the best time to speak to him or her? What are the times when he or she listens well and is calm? What strengths does the child have that you can draw on or affirm?
- Most children and young people can only handle a few minutes of intense conversation about serious things. Don't push them too hard and rather arrange for several shorter times when you can talk. Listen out for signs which might tell you that the child wants to talk more and talk at these times which can be less artificial than a formal speech in which you disclose your health status.
- Sometimes children talk more easily while doing something together – like while drawing, or playing a game, or tidying a room, or gardening, or going for a walk. They may find it intimidating to be sat down and spoken to very directly.
- Many children believe that another person's sickness is their own fault – as a result of something they said or did. They need reassurance that the parent's illness is not a punishment.
- They need to be told you will do everything within your means to help them.
- Children need to hear that HIV is not contagious through the air or everyday contact.
- Check out their level of understanding in relation to HIV and AIDS.
- Try not to alarm or frighten them unnecessarily.

- Do not give unnecessary details. Keep explanations simple. Do not give graphic (horrible) details.
- Normalize behaviors like wearing gloves or plastic bags, taking medicine, rather than creating unnecessary “drama”
- Be as simple, clear and honest as you can.
- Disclosure is not just one conversation – it is a process.
- You might want to discuss possible scenarios with people you trust, that may come up before you tell your child.

What are the most important things that a household member may want children to know? For example, they might want children to know:

- that they are ill but that they love them
- that they will do everything they can to make sure that the children are safe and well looked after

Depending on the age of the child, you or household members can give them information on HIV and AIDS, modes of transmission, treatment, how to avoid risky behaviour and how to handle peer pressure.

When to Disclose

Household members may be asking themselves: “When is the right time to disclose to my children?” Here are some suggestions:

- Each family must decide this according to their particular needs and circumstances.
- It is important that the person disclosing feels ready to

disclose. This can be at a point when they are coping and understand their status.

- Household members may look for clues from their children that might suggest signs of distress. Sometimes these can be signs that it is time to disclose to them.
- If children are asking direct or indirect questions about health, this is a good indication that they are ready or needing to know more.
- Household members may check out a child's readiness by asking them indirect questions, such as “I haven't been feeling well lately, have you noticed?”, and their answers can be a guide about their readiness to talk.
- There is no “rule” about age: information should be adapted to the child's personality, maturity and age.

Appendix 5: Proposed Workshop Programme

The following shows how the themes covered in this guideline may be structured into a workshop for people working with young carers. The various sections of each theme, along with the reflection exercises and practical activities have been used to construct a learning process. It may be used to raise awareness about the needs of young carers with teachers, community home based carers, community development facilitators, or anyone working with young carers.

This programme should be adapted to the needs of the participants and context in which it is being applied, and it may also be used in parts. It is assumed that participants already have basic skills of listening and facilitating community projects.

You will find the sessions below use the same titles as the topic headings and reflection exercises and practical exercises in the guide.

PSYCHO SOCIAL AND PRACTICAL SUPPORT FOR HOUSEHOLDS WITH YOUNG CARERS	
Time	Topic
Day 1	Theme 1: Supporting Young Carers
09h00 – 09h30	Welcome, orientation and administration Introductions
09h30 – 10h30	Workshop aims and overview Expectations Norms
10h30 – 11h00	Tea Break
11h00 – 11h30	Reflection Exercise: Young Carer Tasks
11h30 – 12h00	Input: Cumulative Burden of Care Reflection Exercise: Positive Outcomes for Young Carers
12h00 – 13h00	Reflection Exercise: Gender Equality in Young Carers' Roles and Responsibilities Practical Activity: Division of Labor in the Home
13h00 – 14h00	Lunch Break
14h00 – 15h00	Input: Where to Invest our Energy and Let's Get Specific Case Example: Targeted Intervention Following Consultation
15h00 – 15h30	Practical Activity: Social Network Mapping
15h30 – 16h30	Let's Check Ourselves: Theme 1 Time for personal planning and discussion

Day 2	Theme 2: Young Carers' Wellbeing
09h00 – 09h30	Daily way of starting (eg prayers, song and asking each participant how they are today)
09h30 – 10h00	Reflection Exercise: Children's Wellbeing Input: Wellbeing of Young Carers
10h00 – 10h30	Input: Young Carers' Rights Practical Activity: Children's Rights
10h30 – 11h00	Tea Break
11h00 – 11h30	Reflection Exercise: Young Carers' Rights
11h30 – 12h00	Reflection Exercise: Child Abuse Intervention
12h00 – 13h00	Reflection Exercise: Children's Psychosocial Wellbeing
13h00 – 14h00	Lunch
14h00 – 14h30	Reflection Exercise: Traditional Forms of Psychosocial Support
14h00 – 14h30	Input: Practical Forms of Psychosocial Support Memory work, Windows, Family Trees
15h00 – 15h30	Input and discussion: Supporting the Role of Unwell Household Members
15h30 – 16h30	Let's Check Ourselves: Theme 2 Time for personal planning and discussion

Day 3	Connecting Young Carers
09h00 – 09h30	Daily way of starting (eg prayers, song and asking each participant how they are today)
09h30 – 10h30	Input: Benefits of Connecting Young Carers Case Example: Humuliza Project in Tanzania
10h30 – 11h00	Tea Break
11h00 – 11h30	Input: Topics to Cover When Starting a Young Carers Support Group Practical Activity: Game of Favorites
11h30 – 12h00	Input: Types of Activities Covered in Young Carer Support Groups Case Example: Tatu Tano
12h00 – 13h00	Let's Check Ourselves: Theme 3 Time for personal planning and discussion
13h00 – 14h00	Lunch
	Theme 4: Livelihood Strengthening
14h00 – 14h30	Input: Economic Strengthening Activities Case Examples: Income Generating and Economic Strengthening Activities
14h30 – 15h30	Reflection Questions: Limits to Economic Strengthening
15h30 – 16h30	Let's Check Ourselves: Theme 4 Time for personal planning and discussion

Day 4	Theme 5: HCT and Disclosure
09h00 – 09h30	Daily way of starting (eg prayers, song and asking each participant how they are today)
09h30 – 10h30	Reflection Exercise: HCT Input: The Importance of Testing, Disclosure and Memory Work with Disclosure
10h30 – 11h00	Tea Break
11h00 – 12h00	Practical Activity: Disclosing to Children
12h00 – 13h00	Let's Check Ourselves: Theme 5 Time for personal planning and discussion
13h00 – 14h00	Lunch
	Theme 6: Treatment Literacy and Support
14h00 – 14h30	Input: Treatment Literacy Explain the Practical Activity: Who Will We Call
14h30 – 15h30	Practical Activity: Tracing Book
15h30 – 16h30	Let's Check Ourselves: Theme 6 Time for personal planning and discussion

Day 5	Theme 7: Future Planning and Preparation for Death
09h00 – 09h30	Daily way of starting (eg prayers, song and asking each participant how they are today)
09h30 – 10h30	Reflection Exercise: Celebrating Your Life Input: Celebrating a Life
10h30 – 11h00	Tea Break
11h00 – 11h30	Explain Practical Activity: My New Home Input: Writing a Will (which can be done as a practical or homework activity)
11h30 – 12h00	Reflection Exercise: Future Planning
12h00 – 13h00	Let's Check Ourselves: Theme 7 Time for personal planning and discussion
13h00 – 14h00	Lunch
	Theme 8: Grief and Loss
14h00 – 15h00	Input: Supporting Young Carers Who Are Grieving Reflection Exercise: Answering Children's Questions About Death
15h00 – 15h30	Reflection Exercise: Community Support for Young Carers Experiencing Loss
15h30 – 16h30	Let's Check Ourselves: Theme 7 Time for personal planning and discussion

Follow Up	Theme 9: From Awareness to Action
09h00 – 09h30	Daily way of starting (eg prayers, song and asking each participant how they are today)
09h30 – 10h30	Summary of Themes Covered Previously Case Example: Holistic Intervention for Young Carers
10h30 – 11h00	Tea Break
11h00 – 12h00	Planning: Table of Summary of Thematic Outcomes
12h00 – 13h00	Presentation of Certificates Evaluation and Closure
13h00 – 14h00	Lunch



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