

# Psychosocial care and support for older carers of orphaned and vulnerable children: Policy guidelines



## Acknowledgements

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### Uganda

- AMREF, Luwero
- Bukadde Magezi Elderly Association, Luwero
- Butuntumula Elderly Association, Luwero
- Child Fund International
- HelpAge International Uganda
- Ministry of Health, HIV/AIDS Department, Luwero District
- Ministry of Health, Luwero Health Centre IV, Luwero District
- Integrated Community Based Initiatives, Kigombe Health Centre II
- Red Cross Uganda
- Uganda Moslem Supreme Council
- Uganda Reach the Aged Association
- Women Organisation in Luwero District

### Mozambique

- HelpAge International Mozambique

### Kenya

- Nazareth Hospital

### South Africa

- Muthande Society for the Aged

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## Foreword

REPSSI is a regional non-governmental organisation working with partners to promote psychosocial care and support (PSS) for children affected by HIV and AIDS, poverty and conflict in East and Southern Africa. REPSSI advocates that services, programmes and policies designed to support vulnerable communities need to respond holistically to the needs and rights of children and communities. HelpAge's vision is to ensure that the needs and rights of older people in Africa are addressed and met so that they can continue to enhance their capacity in the community. As outlined in our strategy for 2010-2015, we are working towards ensuring a major increase in the delivery of quality health, HIV and AIDS and care services for older people and those they support. The role of older people in our societies is often overlooked. As HelpAge, we are committed to ensuring that older people are valued, not just in terms of their human rights, but for their contributions in society.

Currently, the African continent is burdened by the impact of HIV and AIDS, among other challenges. A major impact of HIV and AIDS on older people is in their role as caregivers to their children living with AIDS and grandchildren who have been left as orphans as a result of AIDS. In many African countries it is mostly the grandmothers who have assumed the parenting/caring role. This has resulted in a drastic change in the traditional family structures in Africa. Older people can no longer rely on their families in their old age for support, partly because they have additional responsibilities as income earners and caregivers for orphaned and vulnerable children.

UNAIDS/WHO (2008) estimated that 12 million children have lost one or both parents to HIV in sub-Saharan Africa, and UNICEF and HelpAge studies indicate that at least 40 – 60 per cent of children orphaned by AIDS are being cared for an older caregiver, mainly older women. As they perform the caring role, older carers encounter a number of problems including lack of knowledge on HIV and AIDS, poverty, stigma, grief and hopelessness. These problems may consequently affect their psychosocial wellbeing.

In recognition of the need to address the psychosocial needs of older caregivers HelpAge collaborated with REPSSI to develop Policy Guidelines and a Training Manual for Psychosocial Care and Support for Older Carers of Orphaned and Vulnerable Children affected by HIV and AIDS. The Policy Guidelines document is intended to offer a concise description of the concept of psychosocial support and how it relates to older caregivers of orphaned and vulnerable children in a time of HIV and AIDS. It offers recommended strategic focus areas which may be used to influence policies which provide support for older carers. Policy makers may find the guidelines helpful in providing ideas to effect changes that will improve the wellbeing of older carers. The Training Manual includes resource materials to enable community caregivers, development facilitators, educators and peer counselors to have relevant information and guidance on strengthening psychosocial care and support to older carers.

We hope that these guidelines will provide the necessary information to offer much-needed psychosocial support to older carers and support older people as they tackle the added roles they now have of caring for the sick, orphans and vulnerable children.

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*The term “older carers” is used in this document to refer to older people caring for orphaned children and people living with HIV and AIDS.*

## Introduction

“But then there emerged – suddenly, almost miraculously, magnificently – one solid wall of protection, a wall so strong that it withstood all the misfortune heaped on the orphans of Africa. It is the wall of grandmothers. You couldn’t penetrate it. You couldn’t destroy it. It stands today as the protective embrace for the orphan children of the continent.”

These words by Stephen Lewis, addressing the African Grandmothers’ gathering in Swaziland on the 6th of May 2010, so movingly describe the role of older carers in bringing hope to the HIV and AIDS pandemic. Older carers are playing an increasingly valuable role in caring for children who have lost their parents due to AIDS and other illnesses. Such older carers include grandmothers, grandfathers, older aunts and uncles, and even neighbours. It is becoming recognised that older carers have become the backbone of support to orphaned and vulnerable children and people living with HIV and AIDS.

*“It is a great privilege to be able to look after my grandchildren. At least I feel that I am able to do something for my own children who have passed on.” Older carer*

HelpAge International (HelpAge) conducted a baseline survey amongst selected regions of 11 Sub-Saharan African countries. They found that older carers are providing on average 55 per cent of the care to children orphaned by AIDS and 44 per cent of the care of family members who are chronically ill or living with AIDS. Older people have taken on the triple roles of carer, homemaker and income earner in many households. In the same baseline survey, HelpAge found that on average each older carer is caring for 3 orphaned children<sup>1</sup>. The number of men becoming involved in this care is also growing. HelpAge studies show that 80 per cent of older carers are female and 20 per cent are male.

*“The children bring a lot of energy and joy into the home. They are keeping me young.” Older carer*

*“Although I would never have invited this disease into my household, I feel that it is a gift to have my children back at home with me, and I am glad that I am able to be there for them at their time of greatest need.” Older carer*

Many older carers describe the joy they experience in caring for grandchildren. Others speak of being grateful to be able to be the ones who care for sick family members in their time of need. At the same time, many have said that they would appreciate more support in managing these challenging roles. In consultation sessions, older carers have spoken of the need for practical support as well as love and care. As one older carer said “As older people we need to be visited and to know that we are loved.” This document describes both the practical and psychosocial needs of older carers, and offers recommendations for priority focus areas in strengthening the support of older carers.

### Aims and intended users of the policy framework

The policy framework is intended to offer a concise description of the concept of psychosocial support and how it relates to older carers of orphaned and vulnerable children in a time of HIV and AIDS. It offers recommended strategic focus areas which may be used to influence policies which provide support for older carers. Decision-makers may find the guidelines helpful in providing ideas to effect changes that will improve the wellbeing of older carers.

*“It is a heavy load because of the age.” Older carer*

<sup>1</sup> *The Burden of Care for Older Women Carers of OVC and PLWA : Key Baseline Indicators for communities in Ethiopia, Kenya, South Africa, Tanzania, Uganda and Zimbabwe, HelpAge, 2006*

## Motivation for psychosocial Support of older carers

### 1.1. Responsibilities of older carers

The responsibilities of older carers are many, and they usually include:

- caring for the sick and for young children (such as feeding children, bathing them, administering treatment, taking them to the clinic)
- meeting costs for medicines, health care, and funerals
- providing food, clothing, and shelter for themselves and for those under their care
- meeting school expenses for children
- socialising children
- providing love, affection and protection to children
- comforting children on the death of their parents.

It is clear that the role played by older carers is very valuable and they contribute significantly to the social capital needed to cope with the impact of HIV and AIDS and other life predicaments on children, families and communities. The reality, however, is that these responsibilities come at a time when older people might be expecting to receive support from their adult children and families, and instead they find themselves confronted with the responsibilities of caring for the sick, orphaned and vulnerable children. This may be overwhelming for the older carers physically, economically, psychologically and socially.

*“I had ideas about how I would like to spend this time of my life. Now I feel like I am starting all over again.” Older carer*

### 1.2. Challenges faced by older carers

Older carers have described some of the challenges that they experience in trying to provide care for the children and sick people in their household:

- lack of regular income to help them with the costs of care

- being neglected by special support programmes, which tend to target mothers of children, rather than older carers
- limited time to engage in income-generating activities due to responsibilities of caring for the sick and young children
- living in dilapidated houses, resulting in poor hygiene, insecurity and limited protection from adverse weather
- difficulties in meeting the educational expenses/needs of their grandchildren
- lack of information and difficulty in accessing their rights and entitlements
- challenges in parenting and imparting skills to children who belong to a different generation
- difficulties in meeting the emotional and psychosocial needs of children due to their own experiences of loss and grief
- challenges in keeping healthy and accessing health services for themselves and those in their care
- lack of information and knowledge about HIV and AIDS, particularly when they find out that they or the children in their care are HIV positive
- difficulty coping with questions of sexuality and reproductive health of the growing grandchildren
- danger of exposure to neglect and violence
- social exclusion and discrimination.

The multiple challenges of older carers may place enormous demands on their psychosocial wellbeing. The fear of the loss of their adult children whom they may be nursing, coupled with worries about what will happen to the

*“Older people want to be visited and to know that they are loved.” Older carer*

children who will remain behind, may be a constant psychological concern for them. They may experience feelings of overload, loss and incompetence. Many older carers are unsupported in their caring responsibilities by family members, the community or government representatives.

Older people need psychosocial support so that

they are able to better cope with the demands of caring, and to enable them to experience personal wellbeing. Ensuring the psychosocial wellbeing of older carers not only ensures their fundamental rights but underpins the very survival of a significant number of children and sick people in their care.



*With a little support*

*older people can make  
a big difference*

## Principles of psychosocial care and support for older carers

The following core concepts about psychosocial care and support of older carers are recommended as foundational principles for all interventions<sup>2</sup>:

### Access to rights

Strive to support the protection of older carers and their access to their rights and entitlements.

### Respect and kindness

Psychosocial support may be provided simply by changing the way we behave towards older carers. This is about showing respect and kindness at all times in a way that builds the dignity of all people.

### Participation

Use a participatory approach where older carers are involved in identifying their needs, planning, facilitating and evaluating interventions.

### Family-based care

Use a family approach which supports the carer within the context of his or her family environment.

### Strengthen existing resources

Start from strengths, by acknowledging the existing knowledge, skills and expertise that the older person brings to each situation.

### Build on locally appropriate practices

Research and strengthen locally appropriate ways of supporting older carers so that one is not encountering resistance to practices which are considered foreign. Older people in particular may appreciate traditional approaches rather than unfamiliar ways of receiving support.

### Consideration of gender

Be gender sensitive, understanding that the needs of older women may be different from those of older men.

### Strategic leverage

and prevention Think about ideas of how you might more broadly influence the lives of older carers, both in the local community, or more or widely, maybe even at a national level. Include a

focus on prevention of suffering in older carers and their families, rather than just the alleviation of suffering. This principle includes consideration of the “do no harm” principles for every intervention with older carers.



*When older people speak*

*we are listening*

<sup>2</sup> REPESSI. 2009. *Psychosocial Care and Support Mainstreaming Guide*. [www.repssi.org](http://www.repssi.org).





*Older people's rights*

*are human rights*

## Strategic focus areas

The following section proposes key focus areas for the provision of psychosocial support of older carers. The recommended focus areas have been selected on the basis of evidence-based practice and research of effective psychosocial support programmes which have been implemented to support older carers in Africa. They provide strategic direction for policy and programme development and they may be used to assist mainstreaming, developing special programmes for older carers, and in determining priorities for policy development and resource allocation. The focus areas are aligned with the broader principles of psychosocial support which have been outlined in the previous sections.

### 3.1. Building social support systems

Being connected to other people is very important to our wellbeing and possibly the most valuable and sustainable psychosocial support may be provided within families and communities, as these are the people who have regular and direct contact with the older community members and those under their care.

- facilitating leisure activities for older carers.

The social support programmes may include a holistic focus on:

- nutritional support programmes
- economic strengthening activities
- training and skills development, educational talks etc
- practical assistance (such as accessing identity documents or social grants)
- counselling, emotional and spiritual support
- HIV testing and treatment assistance
- child care
- psychosocial support of vulnerable children.

### 3.2. Building more supportive relationships between older carers and children in their care

Studies show that children prefer to live with their grandparents after the death of their parents rather than with other relatives.<sup>3</sup> They generally feel that their grandparents provide more love and affection than other relatives. In caring for their orphaned grandchildren, the grandparents are ensuring that they grow up together as a family group, rather than in an institution or separated from each other in different families. As children become older, they may provide their grandparents with economic and emotional security, and care for them when they are ill or in need of special attention<sup>4</sup>

The relationship between a grandparent and grandchildren is often very rewarding. However, as with all parenting relationships, this is not always easy. For a number of reasons, including the large generation gap, older carers may sometimes struggle to bring harmony and understanding into their relationships with their grandchildren and thus may need to be supported.

*“The neighbours said she became increasingly stressed about how she was going to pay for the school uniforms of all the children. Finally she had a heart attack from the stress. I wish she had spoken to us about her worries – we could have done something to help.” Family member of an older carer*

There are various tools and methodologies that can be used to extend the support systems of older carers. These include:

- facilitating social support network maps with older people and their families to assist them in finding connections with others
- establishing support groups for older people;
- developing drop-in centres for older carers or for the children they support
- facilitating community awareness programmes on the needs of older carers

<sup>3</sup> International HIV/AIDS Alliance and HELPAGE, Building Blocks-Africa Wide briefing notes on supporting older carers, 2004

<sup>4</sup> International HIV/AIDS Alliance and HELPAGE, Building Blocks-Africa Wide briefing notes on supporting older carers, 2004

These are critical topics for support in programmes such as parenting skills training. Programmes which build a caring relationship between the older carer and the young people in their care can be the best foundation for addressing such issues. This means that negotiations around behaviour come out of a foundation of care and respect, rather than the young person suddenly being treated like a child or having her freedom taken away.

### 3.3. Supporting older carers through the grief process

Older carers suffer grief, shock and sometimes trauma after the death of their adult children. It is especially difficult for the older carer if he or she has lost several children in a very short space of time. The experiences of grief and the worries about the future make it difficult for the older carers to cope with caring for children left in their care.

Grief is the normal and necessary emotional reaction to the death of a loved one. It is the emotional suffering that people feel when someone that they love is taken away<sup>5</sup>. As a response to loss, people may feel anger, sadness, shock, and guilt. While these feelings can be frightening and sometimes overwhelming, they are normal reactions to loss. Such reactions may last a long time (sometimes many years), and it is important not to rush the grief process.

Providing emotional support to grieving older carers is recommended as a key strategic focus area of any policies and programmes. This may be facilitated through:

- facilitation of support groups
- facilitation of memory work
- facilitation of opportunities to say goodbye
- assistance with succession planning
- provision of individual or family counselling
- pastoral care visits
- facilitation of traditional bereavement rituals.

It is important to consult older carers about what they would consider helpful in honouring the memory of their loved ones.

### 3.4. Protecting against abuse and exploitation

Abuse and exploitation are often a result of extreme stress and poverty, and it is often the most vulnerable members of a society that suffer most under such conditions. Older people, people living with HIV and AIDS, and children all have rights and entitlements that need to be protected. These groups are often not aware of their rights, and even when they are informed they often feel that they can do little to protect or realise their rights.

The following actions may be promoted to prevent carers from being exposed to abuse, or to provide support for carers in situations of abuse:

- provide age-appropriate information about rights and entitlements, including knowledge of laws that provide protection, such as government funds, pensions and child-care grants. Provide assistance with the procedures
- secure correct documentation so that they can access the necessary support
- inform the older carers about protective agencies that they may need to contact for specific assistance
- help older people to protect the property rights of the children in their care by ensuring that they are well informed about their own and the children's rights and how to protect them
- involve legal professionals and community leaders in resolving issues of land security, inheritance, and other disputes. Advocate for paralegal services so that older carers, people living with HIV and orphaned and vulnerable children can access legal support/advice as and when necessary
- report cases of abuse to relevant authorities
- provide counselling and guidance to affected individuals and families

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<sup>5</sup> Thogomelo Psychosocial Support Skills Development Programme Community Caregivers, 2009

- assist by accompanying older carers to health facilities, social welfare offices etc
- lobby for transportation of older carers and those under their care to and from different service points
- help individuals who have experienced abuse to join support groups;
- facilitate community education and awareness on the needs of the older carer, people living with HIV and AIDS, and vulnerable children, discouraging all forms of abuse
- support access to education for vulnerable children, especially where policies for school fees exemptions exist
- visit family members or community members involved in abuse to hear about their needs and to understand the underlying reasons why they may be abusing older carers
- assist organisations working with older carers, people living with HIV and AIDS, or vulnerable children to develop their own policies for dealing with cases of suspected abuse.

### 3.5. Economic strengthening programmes

Older carers may be neglected in economic strengthening programmes, which often tend to focus on men, youth and mothers of young children. The financial stress of caring for people who are sick, or for orphaned children, is often cited by older carers, and is one of their primary sources of stress. Economic strengthening programmes should include older carers, and may include a focus on:

- pensions, child care grants, school fee remission and foster care grants;
- transport, health care and other subsidies for all older people;
- sustainable livelihoods and income generating projects;
- subsistence agriculture;

- encouraging the extended families of older carers to support them financially; and
- donations of material goods, such as school uniforms for orphaned children.

Access to identity documents in order to access resources such as social grants may be a challenge for older carers, and investing in processes to overcome this challenge may make a sustainable difference to the psychosocial wellbeing of many older carers and the children they support.

### 3.6. Working with male older carers

At family level the burden of care for people living with HIV and AIDS and vulnerable children is borne predominantly by older women and girls<sup>6</sup>. Research done by HelpAge indicates that it is the grandmothers rather than the grandfathers who tend to provide care at family level. The ratio is that 80 per cent of grandmothers, as compared to 20 per cent of grandfathers, provide the burden of care at household level. There is evidence to show that in some countries in Africa men are increasingly willing to take an active role in the physical care of sick family members and children. However, the involvement of men is often limited and thus needs to be encouraged.

*“I would like to be more involved in taking care of my sick wife and cleaning the house, but the neighbours keep laughing at me and chasing me away, saying that this is women’s work. It makes me frustrated because I end up just sitting outside and not doing anything.”*  
*Comment by a grandfather*

Many men and women report that there are barriers which prevent the involvement of men in caring. These may include cultural and social perceptions about the role of men in caring. Social programmes challenging such perceptions, and support towards “role models” or “pioneers” involved in caring, may assist in breaking down some of these barriers. Skills development programmes have also been requested by men who are involved in caring.

<sup>6</sup> Reducing the Burden of HIV and AIDS Care on Women and Girls, VSO, 2006

These include capacity building in parenting skills, household management skills, and skills in caring for the sick. Once again social networking may play a significant role in supporting older male carers.

The following strategies have been used effectively by organisations aiming to increase the involvement of men in caring:

- educating community and religious leaders, and traditional leaders about the importance of involving men
- sensitising the community to the involvement of men, and obtaining their buy-in
- providing both mixed-sex and single-sex discussion forums, to allow people to address concerns about involving men
- considering both monetary and non-monetary incentives (such as training, food or food gardens) for men and women
- challenging gender stereotypes
- supporting role-models of men as carers.

### **3.7. Self care for older carers**

Older carers often carry a heavy emotional load. Many carers have been through multiple losses and grief, and this may be exacerbated by other daily stressors, like the struggle to provide food and clothing for the family. Programmes focusing on “care of the caregiver” may be valuable for both older carers and the community caregivers who support them. Such programmes may assist with:

- helping carers to be aware of their limitations and to be honest with others when they cannot give certain types of help
- helping carers to structure their time, including rest periods
- exploring safe local child-care options
- encouraging carers to take time out to do leisure or fun activities and to spend quality time with family and friends

- encouraging carers to ask for help from trusted friends and family members, to invest in relationships with others who can become an ongoing source of strength and support

- when there are problems in the family or in the community, encouraging carers to try to talk these through immediately so that they are not carrying these additional stresses

- encouraging healthy eating as an important part of self-care - older carers can be supported in how to plan and cook healthy meals using locally available and cost-effective food

- encouraging regular exercise in the form of walks in and around the community and engaging in work that they enjoy around their yard, such as gardening - this can provide good exercise for older carers.

Self-care programmes may utilise older carers’ own knowledge about self-care and healthy living, and enable them to identify locally appropriate supportive factors that can be used to strengthen the care of older carers.

A focus on self-care programmes, along with the other recommended strategic focus areas, may be most effectively strengthened with a mainstreaming approach, whereby consideration is given to every aspect of support for older carers, within a wide range of services and organisations. The next section encourages this broader thinking to facilitate psychosocial support even within under-resourced contexts.

## Mainstreaming psychosocial care and support of older carers

Mainstreaming psychosocial support is about looking at every aspect of one's work through the lenses of psychosocial care for older carers.<sup>7</sup> This means "seeing" or acknowledging the presence of older carers where they may have been neglected or invisible in one's everyday actions. Mainstreaming is also about recognising the psychological and social needs of older people, where one may have been primarily focused on other forms of service delivery. It means ensuring that all older carers receive a continuum of care in a way that makes them feel included, valued and supported in all aspects of their lives.

### 4.1. Provision of psychosocially sensitive services

It is important that older carers feel that they are appreciated and integral members of families, communities and the larger society. This requires attention to psychosocial care and support in every interaction with older carers, not just in the development of special programmes for older carers.

*"Older people do not need to be rushed. Treat them with patience and care." Older carer*

Everyday psychosocial support is about showing care and respect in each contact you have with older carers so that it builds their dignity, reduces their stress and brings hope and appreciation even in difficult circumstances.

The following are some ideas about how everyday psychosocial support may be provided to older carers:

- treating all older carers with respect and kindness in ways that build their dignity and hope
- listening respectfully to older carers when they express their concerns, giving them a sense of being taken seriously

- consulting older carers and those under their care about their needs, and finding ways to support them in having their needs met. This may include following up on issues until they are resolved and remembering to refer matters that you cannot deal with to other service providers
- through one's existing work, promoting networks and circles of support around the older carers so as to prevent feelings of loneliness and isolation
- ensuring that your work does not exclude or neglect older carers, and that it takes into account any special needs they may have.

It is recommended that everyday psychosocial care and support of older carers be promoted with the general public, government service providers and civil society organisations who are dealing in any way with older carers through:

- awareness-raising about the value of treating older carers with respect and kindness
- training service-providers in respectful and compassionate ways of interacting with older carers
- encouraging respectful behaviour from all service-providers towards older carers through the establishment of systems of accountability
- consultation processes with older carers about their local challenges regarding access to services and support.

### 4.2. Referral for specialised psychosocial support

Mainstreaming psychosocial care and support of older carers does not mean that each person needs to become an expert in the provision of specialised psychosocial care. Instead, it may be about recognising the psychosocial needs of older carers and linking and referring them to other service providers.

Examples of older carers who may require specialised psychosocial support include:

- older carers who are not well connected socially, and who are struggling to cope with their emotional and social lives because of being disconnected from

<sup>7</sup> REPSSI. 2009. *Psychosocial Care and Support Mainstreaming Guide*. [www.repssi.org](http://www.repssi.org).

their families and community support

- older carers who are struggling with multiple losses, for example the loss of their own children
- older carers who show signs of psychological distress, such as depression and anxiety
- older carers living with chronic illnesses
- older carers living in situations of abuse or potential harm.

The referral of older carers for specialised psychosocial support may become possible through:

- identifying specialised psychosocial needs of older carers or carers who are particularly vulnerable and in need of more intensive psychosocial support, such as the examples listed above
- identifying which types of specialised psychosocial support services and programmes are already operating in the community which might potentially benefit the older carer and those under her or his care
- referring older carers for specialised psychosocial care and following up on this care.

It is recommended that referrals of older carers for specialised psychosocial support be promoted with the general public, government service providers and civil society organisations through:

- awareness-raising about how to identify older carers who may require specialised psychosocial support
- promoting public relations and marketing of existing specialised psychosocial support services and programmes so that people are aware of the local referral resources.

*“The children are in poor health and one is malnourished. I cannot provide the needed care because I have no money and none of my relatives or friends helps me. Sometimes there has been no money and the kids were ill and hungry and I have felt that I just wanted to leave.”*

*The International HIV/AIDS Alliance and HelpAge, Building Blocks- Africa wide briefing notes “Supporting older carers”*

Having outlined the importance of referral of older carers for specialised psychosocial support, it is worth emphasising again that the best form of care is everyday support from a family and community context. This may aid in prevention of severe distress, and may be more effective in alleviating suffering than referrals for expert psychological or social assistance. Therefore, where possible, the family and community support surrounding all older carers should be strengthened.

### 4.3. Maintaining a focus on the holistic wellbeing of older carers

There is more to our overall wellbeing than our emotional and social care. Our overall wellbeing depends on many other things – like the need for food, shelter and clothing. Psychosocial wellbeing is about holistic wellbeing and a sense of feeling complete or satisfied about one’s life. It includes the physical, mental, economic, social, emotional and spiritual parts of our lives – which contribute to our total wellbeing<sup>8</sup>. In terms of mainstreaming, this means looking at each older carer holistically, in terms of the different needs and rights that each person has in order to achieve overall wellbeing.

The CINDI Network ([www.cindi.org.za](http://www.cindi.org.za)) facilitated a participatory survey where they asked older carers what factors they felt created the most stress in their everyday lives. Their comments were clustered in several general categories, with the most difficult areas being:

- health care (for themselves and their families)
- discipline (especially of adolescents)
- material needs (especially providing food for the family)
- school fees and school uniforms
- accessing social grants (like pensions and foster care grants) and documents (such as identity documents and birth certificates of children).

If holistic wellbeing is to be achieved in the lives of the older carers, it is important not just to focus on older carers as individuals, but on their families, social units and the communities that surround them, and to ensure that all their needs are met.

<sup>8</sup> REPSSI, *Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS treatment*, 2008

#### 4.4. Development of psychosocial support programmes for older carers

The circles of support surrounding the older carer may be strengthened through locally appropriate community- and family-based psychosocial support programmes. This is an important aspect of mainstreaming, to ensure that everyday psychosocial support and referrals for specialised care are made possible and enhanced through focused programming.

We can learn from the ideas of other organisations that support older carers have tried and tested.

Comprehensive programmes that address different needs and concerns of older carers have a significant and more sustained impact on the psychosocial wellbeing of older carers and those under their care. It may not be possible for some programmes to offer all the services shown above, however it is essential that organisations and government departments work together and complement each other to improve service delivery to older carers and their families.

Psychosocial support programmes may be strengthened through<sup>9</sup>:

- provision of guidance regarding recommended programmes, practices and tools
- distribution of guidelines and manuals on psychosocial support
- capacity-building on psychosocial support programmes, tools and exercises
- access to resources to develop and implement programmes
- assistance with raising awareness about the services they offer and how such services may be accessed

Recommendations for the strategic development of these intervention programmes are further outlined in section 4 of this guideline.

#### 4.5. Promoting policy development

It has been emphasised that psychosocial wellbeing includes many different aspects of our lives, such as physical and material aspects, and psychological, social, cultural and spiritual aspects. The focus of psychosocial wellbeing is therefore not just on the individual, but on households, families and communities.

To this end, psychosocial support may take place at many different levels:

##### Individual:

Psychosocial care is provided directly to older carers. This may include grief counselling, parenting skills training etc.

##### Family:

Here support is provided to improve the wellbeing of the whole family, like helping older carers to have better relationships with the children in their care, assisting with accessing grants, growing food gardens, gaining access to schools etc.

##### Community:

The focus at this level is on encouraging the community to give support to all older carers in their community. For example, the leadership could encourage positive attitudes and challenge discrimination. Youth groups or churches could organise child care projects to assist older carers to have time to do their shopping and attend church meetings.

##### National and International:

At this level the laws, policies and programmes are challenged to include provision of support to all older carers. This may include policies about pensions for older carers, special grants, school fee exemptions, and priority health care.

Investigation in the development of national policies to support older carers may make a difference to the lives of many people. Such national policies may include a focus on:

- Justification and Rationale: Advocating for the investment of a stronger focus on the support of older carers and how this contributes towards the wellbeing of the country.

<sup>9</sup> Adapted from Department of Social Development in South Africa's "Conceptual Framework for Psychosocial Support for Orphans and Other Children Made Vulnerable by HIV and AIDS", in press



- **Attitudes:** The recommended attitudes and behaviour that government and civil society personnel should show towards older carers.
- **Participation:** An outline of how older carers will be able to contribute their ideas, co-facilitate projects or even lead their own projects with the support of others.
- **Resources:** What resources (for example what percentage of the budget) will be allocated to older carers? What specific resources and materials will be allocated, including social grants?
- **Prioritisation principles:** Will preference be given to older carers, and if so, under what situations?
- **Advocacy:** Will common issues be taken to higher levels to promote change?
- **Monitoring and Evaluation:** How will older carers be involved in assessing the process and impact of the work?

Developing organisational psychosocial support mainstreaming policies for older carers in the various institutions that are involved in development may further assist in addressing the needs of older carers.

Here is a simple example of an organisation's policy around psychosocial care of older carers:

### *Psychosocial care and support of older Carers organisational policy*

*Our organisation recognises the valuable role that older people are playing in caring for orphaned and vulnerable children, and people living with HIV and AIDS.*

*We would like to provide care and support for older carers in the following ways:*

- *treating older carers with respect and appreciation at all times*
- *listening to their ideas, experiences and needs*
- *designing projects together with older carers to reduce their stress and meet their needs*
- *arranging child care so that older carers are able to participate in the activities of our organisation*
- *visiting older carers who have lost family members, offering a donation towards the costs of the funeral expenses, and printing out the funeral programme*
- *setting aside a portion of our annual budget specifically for psychosocial care and support work of older carers*
- *prioritising older carers when it comes to distributing resources that we may have to offer our community partners*
- *involving older carers in evaluating the impact of our work on their psychosocial wellbeing*
- *when common issues are expressed by several older carers and different communities, we will take these suggestions forward to the relevant government departments to promote change.*

## Conclusion

Older carers are contributing significantly to the care of orphaned and vulnerable children and people living with HIV and AIDS. Their contribution to families affected by HIV and AIDS is greatly valued. It is hoped that this guideline will contribute towards the psychosocial care and wellbeing of all older carers who are providing support to others. HelpAge and REPSSI would like to support others in this growing movement of psychosocial support for older carers. Please visit their websites, as shown below, to find out more about regional offices and support programmes.

**HelpAge  
International**

*age helps*

[www.helpage.org](http://www.helpage.org)

  
**REPSSI**  
Psychosocial Wellbeing For All Children

[www.repssi.org](http://www.repssi.org)



*When you give to older*

*they give back*

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*When old people speak*

*we are listening*

**HelpAge  
International**

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