



## *Turning the tide of HIV and AIDS in Africa*

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### **Contribution for UN Independent Expert: Rights of Older Women**

#### **Introduction**

Grandmothers in sub-Saharan Africa have had a unique experience navigating the impacts of the AIDS pandemic. The challenges they have faced, including income insecurity, violence and inequitable healthcare have been driven by gender inequality and ageism. However, in the face of these challenges, these grandmothers have been on an extraordinary journey, working with community-based organizations to reclaim their rights. African grandmothers have joined forces with other grandmothers around the world through the Grandmothers to Grandmothers Campaign as a way to reclaim their voices while coming together and using tribunals and international gatherings as tools to advance their advocacy. The work of community-based organizations together with grandmothers in sub-Saharan Africa and the stories and voices of grandmothers themselves are inspiring examples of how older women are overcoming barriers and becoming powerful agents of change in their communities.

#### **Background**

Sub-Saharan Africa, particularly Southern Africa, remains the region most heavily affected by the HIV and AIDS pandemic. In 2019, sub-Saharan Africa accounted for approximately 68 per cent of people of all ages living with HIV and 88 percent of children and adolescents living with HIV worldwide. Since 2006, older women have been dealing with the pain of losing their adult children to AIDS. They have been emotionally and financially overwhelmed by the need to care for those who are suffering from AIDS-related illnesses, as well as children who have been orphaned by the pandemic. They have used their savings and assets to care for their dying children and to house, educate and feed the grandchildren who have been left behind. The death of their own children as a result of AIDS has robbed them of their loved ones. This has all put an immense emotional, physical and social burden on these older women.

Gender equality is core to the fulfilment of human rights, yet inequitable gender norms and relations continue to compound the challenges and issues faced by grandmothers across sub-Saharan Africa. Despite existing legal frameworks, the realities of systemic structural inequality are ever-present for grandmothers, including gender inequality.

## **Gender Inequality**

There are a number of international conventions and national legal frameworks that protect the rights of older people in Africa and around the world, these include:

- The 1948 Universal Declaration of Human Rights which affirms the right of everyone to equality before the law and full participation as citizens as well as other rights, including the right to social security and an adequate standard of living (Articles 22 and 25).
- The 1981 African Charter on Human and People's Rights which protects every African citizen regardless of age. Its optional protocol on the rights of women specifically protects the rights of older women and widows.
- Other international human rights treaties protect the rights of older people.<sup>1</sup> The majority of African countries have ratified various additional conventions, such as the 1966 Convention on Economic, Social and Cultural Rights and the 1979 Convention on the Elimination of All Forms of Discrimination Against Women.

The intersectionality of women's identities means that grandmothers continue to disproportionately carry the domestic care burden. Additionally, while women are less likely to be employed in the formal sector and earn lower wages than men, older women experience this disparity to a much greater degree.

Ageism and gender inequality also translate into limited access to the national policy dialogues that shape grandmothers' futures. Government failure to protect and fulfill the rights of older women has resulted in systemic discrimination where not only do grandmothers lack access to land and property entitlements, but also they do not have the power to realize their rights. Further, there exists a lack of investment in grandmothers, which includes a failure to consider their specific needs and unique circumstances, posing social and economic costs to society as a whole, with implications for future generations. According to Dr. Monique Nsanzabaganwa, the African Union's First Female Deputy Chairperson, "Women are responsible for 60% of work done globally yet earn just 10% income and 1% of property. In Africa, 70% of women are excluded financially. The continent has a US\$42-billion financing gap between men and women."<sup>2</sup>

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<sup>1</sup> Protecting the Rights of Older People in Africa, HelpAge International, p.2, <https://www.helpage.org/silo/files/protecting-the-rights-of-older-people-in-africa.pdf>

<sup>2</sup> Global Partnership for Education, One of the Greatest Threats to Africa's Future: Gender Inequality, December 16, 2019, <https://www.globalpartnership.org/blog/one-greatest-threats-africas-future-gender-inequality>

## **Expressed Challenges Faced by Grandmothers**

SLF partner organizations have asserted that the rights of grandmothers must be respected and fulfilled, and their work, achievements and contributions to their communities must be recognized. Older women must be supported by and have representation in programs and services provided at the community level and by all levels of government. In solidarity, the SLF continues to amplify the voices of our partners by articulating and sharing the challenges faced by grandmothers as they build a human rights movement.

### **Income Security**

Grandmothers are suffering from an extreme depletion of their resources in every sense – economic, emotional and physical – because of the challenges they face to support orphaned children as well as themselves. They have been emptying their small savings, begging, farming small plots of land while holding off ‘property grabbers’, studying new skills to earn paltry income, and exhausting themselves with piecework and day labour. Only a few countries with high HIV and AIDS prevalence provide pensions, or even lesser forms of financial support, to older women.

Driven by concern and necessity, many grandmothers have become community health workers, and form the backbone of the home-based care programs that are the primary entry points for medical assistance for people living with HIV and AIDS in rural areas. However, the vast majority are working with no compensation at all, as unpaid volunteers. While these women are giving everything they can to help heal their communities, their own lives are extremely precarious, and one bad turn can lead to hunger, the end of the children’s schooling, the termination of HIV treatment, or homelessness.

### **Housing, Land and Property**

The AIDS pandemic brought a crisis of mass eviction into the grandmothers’ lives. In regions where women do not have equal rights to own and inherit land, grandmothers are vulnerable when their husbands die, or when they are faced with divorce or abandonment because of their HIV status. At alarming rates, relatives are claiming ownership of grandmothers’ land—a practice known as land grabbing—and grandmothers have little recourse. While some countries in sub-Saharan Africa have recently enacted progressive property law reforms, many continue to enforce laws and customs that can prevent women from owning, inheriting and protecting land. The additional challenge that grandmothers are confronting is that too often, even the rights they do have are not being recognized and enforced in their communities.

## **Violence Against Women**

Older women living with HIV and AIDS are especially vulnerable to violence. Women are often blamed for bringing HIV into the family, and may be abused as a result. Husbands and family members may become aggressive and violent towards the women, who they want to drive from their homes. The stigma linked to both HIV and age create barriers to reporting violence against them, especially sexual violence. Perhaps most difficult for grandmothers who are caring for children orphaned by AIDS is to report incidents of violent behavior from their own traumatized grandchildren.

## **Healthcare**

In recent years there has been a dramatic increase in the number of people receiving lifesaving and life-extending antiretroviral (ARV) treatment for HIV and AIDS. Unfortunately, grandmothers are not equal beneficiaries of this development, and they continue to experience limited access to healthcare. Gender-based and age-based discrimination continue to severely disadvantage them within healthcare programs. The obstacles and challenges they face are mainly ignored: isolation, lack of information about the virus and AIDS-related illnesses, inability to travel long distances, high costs of drugs, and vulnerability to violence. The blatant marginalization of older women runs right through the healthcare response—from the failure to collect national statistics on rates of HIV transmission, or remotely consider their needs in national HIV programs, to the resistance of local hospital workers to serving (or accommodating) older women. The grandmothers of sub-Saharan Africa are facing a triple threat of discrimination, based on gender, age and HIV status. Their situation is not accidental or a matter of simple misfortune. The intersection of age discrimination and HIV and AIDS has not only made it easier for the virus to permeate African communities, it has given rise to a wide range of human rights violations that have centred and settled on women, particularly on older women.

## **The Grandmothers Movement**

### **The Grandmothers to Grandmothers Campaign**

In the face of the above challenges, grandmothers are becoming a force for change. The SLF launched the Grandmothers to Grandmothers Campaign in 2006, in response to the emerging crisis faced by African grandmothers. Grandmothers and grandmothers in Canada, Australia, the United Kingdom and the United States have rallied in response, creating a powerful movement. They raise funds in their communities to support the life-enhancing programs run by African grandmothers and the community-based organizations who support them.

The grandmothers movement amplifies the voices and expertise of grandmothers from across sub-Saharan Africa, and shows the world that leadership by older women is critical in reclaiming hope and rebuilding resilience for communities. The SLF has participated in

the development of the grandmothers movement through long-term partnerships with many community-based organizations that work to support grandmothers through service delivery, and support and advocacy for rights. We support the movement by bringing our partners together, co-creating spaces in which they can share their experiences and expertise, and strategize for the future. As grandmothers have come together over the years, there has been a clear trajectory from dealing with grief and stigma, to coming together in support groups, to restoring lives through income generation and access to healthcare and funds for school fees for grandchildren, to mobilizing for human rights.

## **Organizing for Justice**

Through the efforts of grassroots community organizations, grandmothers across sub-Saharan Africa have continued to step in to care for millions of children orphaned by AIDS, many of whom are also living with HIV and AIDS. These organizations provide resilience-building support, often led by grandmothers, including healthcare, grief counselling, parenting assistance, leadership training, and income generation. Over time, grandmothers have been developing networks. They are organizing to claim their human rights and collectively advocate for secure futures at local, national and international levels.

Grandmothers, and their community-based organizations, are beginning to work with their local and national governments to demand change. They are reaching agreements with health departments to collaborate on the delivery of home-based care to grandmothers and their families. They are joining watchdog committees to oversee the implementation of national budget allocations for the elderly. Grandmothers are joining local councils for older persons, land rights and child protection, and running for election. They are demanding that the laws and procedures around land ownership be changed to protect grandmothers from losing their homes and farms to property grabbing. Community-based organizations are networking and leading campaigns to convince their governments of the urgent need to provide pensions and other social benefits to the grandmothers who have worked for so long, without any recognition of their efforts, to care for another generation of children.

Grandmothers groups—there are now over 800 of them in 15 African countries—have thrived and expanded beyond survival initiatives in a remarkable way. What is particularly interesting about these groups is how the grandmothers are organizing.

## **Grandmothers Gatherings and Tribunals**

Over the past 15 years, as a result of five national and international grandmothers gatherings and one ground-breaking tribunal, grandmothers have identified and seized opportunities to advance the realization of their rights. Supported by community-based organizations across sub-Saharan Africa, they are mobilizing and challenging the politics of exclusion. These gatherings have provided spaces for them to come together and identify

issues, galvanize and strategize to achieve recognition and protection of their human rights, and articulate their demands. Their voices are being heard.

In 2006, the SLF hosted the first Grandmothers Gathering in Toronto, Canada, immediately preceding the 16th International AIDS Conference also held in Toronto. The Gathering brought together 100 grandmothers and staff from community-based organizations, and 200 Canadian grandmothers. At that time, the conversations focussed on the ravages AIDS—grief, isolation, fear and stigma, struggling to parent once again, psychosocial support and counselling, and the desperate search for resources to support the orphans.

In 2010, together with a community-based partner organization, the SLF co-hosted a second Grandmothers Gathering in Manzini, Eswatini, attended by 500 grandmothers from 11 countries. The discussion had shifted significantly. With enough support to create at least minimal, basic security for their families, the grandmothers were starting to address larger challenges. They developed a common agenda that began to articulate the need for systemic change and support.

The next step at a global level was a People's Tribunal in 2013 in Vancouver, Canada, which made a public case for the greater protection of grandmothers' human rights. Grandmothers from Kenya, Eswatini, South Africa, Uganda and Zimbabwe presented their personal testimonies. The Executive Directors of several community-based organizations served as expert witnesses on the human rights challenges grandmothers face, and the Tribunal's judges (Gloria Steinem, Joy Phumaphi, Theo Sowa, and Mary Ellen Turpel-Lafond), spoke to the responses that must be enacted. The Tribunal concluded with grandmothers issuing their call to action:

*It is time to recognize that grandmothers at the forefront of the HIV and AIDS crisis must have our human rights respected and protected. We will not let the AIDS pandemic defeat us nor destroy our communities, but we cannot prevail alone. Africa cannot survive without us. We call on you to act with urgency and purpose to support our efforts to secure justice.*

The Ugandan Grandmothers Gathering (2015), followed by the South African Grandmothers Gathering (2016) and the Tanzanian Grandmothers Gathering (2018) signaled an historic moment—a grandmothers movement is moving from the local to the national, and to the highest echelons of power, where up until now, decisions about their rights and their lives were being made without them.

These national-level gatherings provided a space for grandmothers to come together and identify the issues, gain strength from one another, strategize around mobilizing for the realization and protection of their human rights, and articulate their demands. The impact has been transformative. Older women raising a generation of orphaned children are demanding their human rights. They are not requesting kindness or

generosity from their governments, but the recognition and fulfillment of their human rights.

Grandmothers gatherings from 2015, 2016 and 2018 have led to powerful outcomes.

In Uganda, a Grandmothers' Consortium was established to:

- Coordinate grandmothers' advocacy, to push for action on pensions, elder abuse, access to healthcare for older women;
- Lobby for a new bill, which successfully passed, that reserves seats at all levels of government for older persons;
- Work with key stakeholders to draft a new law on the Rights of Older Persons with specific protections and budget allocations for grandmothers.
- Create an advocacy and lobbying-training program to mobilize Grandmother Advocacy Champions in districts across the country. The champions recently met with the current Ugandan Prime Minister to address grandmothers' priorities, including discrimination in healthcare.

In South Africa, a National Grandmothers Movement Organizing Committee formed to continue to mobilize support for grandmothers across the country to:

- Meet with the Minister of Social Development to discuss reforms to pensions, child support grants, access to medication and other critical issues. As a direct result, increases have already been made to grandmothers' pensions in some regions of the country.
- Lobby for a more humane childcare grant policy, action to prevent elder abuse and violence, and a healthcare system that is more responsive to their particular needs.

In Tanzania, the momentum is building in exciting ways:

- Grandmothers are convening to build advocacy skills and strategize on follow-up activities that will contribute to a more visible grandmothers movement in Tanzania.
- A National Grandmothers Council has been formed to ensure that the voices and expertise of grandmothers is heard, amplified, and given due support country-wide, at local and national levels.
- Grandmothers are leading meetings and advocacy activities to hold local and national governments accountable, pressing for the resources they need for their own physical and mental well-being as well as the support that is necessary to raise the children in their care.

## **Partner Voices**

For their part, together with grandmothers, community-based SLF partners are dedicated to providing holistic support to grandmothers to foster real change in their lives and the lives of those in their care. They are not simply delivering packages of services in areas such as

health, education, or economic security. They are responding to the whole person, and are aiming to restore the long-term well-being and dignity of people in their communities. This means that emotional and psychological needs are addressed alongside material needs. It also means that gender equality and respect for human rights are central and past injustices are acknowledged to help create and shape opportunities for meaningful engagement.

## Children in Distress Network (CINDI), Zambia

Children in Distress Network (CINDI) is a community-based organization in Kitwe, Zambia, working to reduce HIV and STI transmissions among children, youth and women. CINDI's approach is holistic and while grounded in work to support children's well-being, it recognizes the crucial need for caregivers and grandparents to be engaged and supported as well.

### *The story of Prisca Muma<sup>3</sup>*

With support from the team at CINDI, Prisca, a grandmother who had lost her own children to the AIDS pandemic, participated in a training in small-business management. She received a grant to start a small business so that she could earn money to support the ten orphaned children in her care. Running the business from her home, Prisca is able to save some money, which she uses to pay school fees and feed all of the children, and also buy farming supplies to support her activities at a women's club where she grows crops alongside other women. Prisca now owns the title deeds for six hectares of land.



**Prisca Muma at business site**

*'I am what I am now because of the grandmothers' network and the support I received from CINDI. I am amazed that there are people out there who are concerned about people who are vulnerable.'*

CINDI's thoughts on its work with grandmothers:

*For CINDI, one of the most significant parts of its work is the great levels of transformation in grandmothers' livelihoods from being mere recipients and dependants of aid to robust, self-reliant, dignified, carers of their own lives and their grandchildren.*

<sup>3</sup> Extracted from CINDI's report to the SLF (1 February 2021)



## Reach One Touch One Ministries (ROTOM), Uganda

Reach One Touch One Ministries (ROTOM) is a non-profit organization established in 2003 in Uganda, with a focus on supporting the needs of older persons. ROTOM's programs reaching older persons and their dependents has provided healthcare, psychosocial support, spiritual support, food and income support, which has lessened the burden of dependents on older persons.

### *The story of Edridah<sup>4</sup>*

Edridah is a grandmother who registered with ROTOM in 2007 when she was very ill and had no medical support or access to information that could support her health and well-being. She was married and had had 11 children. One of her children died and others had moved away. but one daughter had separated from her husband and came back home with her two children, which increased the burden on Edridah's household.. One of her grandsons, Laban, was in school and it was Edridah who was struggling to pay for his school fees. She was having a hard time keeping him in school and his chances of dropping out were very high.



After joining ROTOM, Edridah received medical treatment and was empowered to improve her health through hygiene and sanitation awareness that also helped the family to reduce their risk of getting sick. She learnt how to save for her future and to fruitfully harvest from her gardens. She further learnt how to improve access to good nutrition by growing vegetables and received a water drum from ROTOM that

helped her harvest clean rain water.

Her grandson Laban also received education support. ROTOM registered him when he was in primary one and he is currently in secondary five. With the food and income support from ROTOM, Edridah is able to earn some income that she uses to contribute to Laban's education.

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<sup>4</sup> Extracted from ROTOM's report to the SLF (8 January 2021)

Edridah shared: *'I am now able to access medical treatment from ROTOM facilities and ROTOM has helped meet most of my basic needs. I am aware of what to do even during this terror of COVID -19 and my grandson has been supported to acquire an education.*

*I hope that my grandson will finish his education, get a job and earn income to support me and other family members. I am now more hopeful and I believe that I am living a dignified and fulfilled life.'*

ROTOM, on working with grandmothers:

*'With the support of ROTOM, in partnership with the Stephen Lewis Foundation (SLF), through mobilization into social support groups, health care, livelihood support, and education for the orphans among other initiatives, the grandmothers came together, re-energized each other and started pushing back against the pandemic, turning the tide of HIV and AIDS.*

*Now the children have grown, the grannies are empowered and they are a strong voice in holding their communities together. They have joined with grandmothers across Uganda, the African continent and Canada to advocate for social justice and issues affecting older persons. They are now leaders in their immediate communities and in the local and national councils. We see a growing movement of grandmothers coming together to support and empower each other, and also becoming agents of change in Uganda and the African continent. These grannies are now heroes of our communities.'*

### **Grandmothers Consortium (GMC), Uganda**

The Grandmothers' Consortium is 'a collaborative of six Uganda grassroots organizations working with grandmothers to create a platform for grandmothers to advocate and lobby for their rights. The Consortium is one of the outcomes of the grandmothers gathering held in Entebbe, Uganda, in October 2015, at which over 500 grandmothers met for three days to share their experiences, learn from each other and air their concerns. Its role is to continue furthering the agenda of grandmothers in Uganda with a focus on advocacy and resource development for grassroots organizations working with grandmothers.'<sup>5</sup>

The two examples provided below are demonstrative of the grandmothers' strength and resilience in taking forward their rights as an underserved population that needs to be given due recognition and support.

#### *Grandmother advocates in action<sup>6</sup>*

A virtual meeting by Zoom was held between 11 grandmother advocates and the head of department for Disability and Elderly in the Ministry of Health in September 2020. The purpose was to follow up on the process of approving the healthcare strategy for older

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<sup>5</sup> Grandmothers Consortium Agency Agreement, August 2020

<sup>6</sup> Extracted from GMC's narrative report to the SLF (Agency Agreement 5, Narrative Report 1, December 2020)

persons. The grandmother advocates had two representatives who participated in the drafting of the strategy. The Minister informed the grandmothers that though the COVID pandemic was a set back in the process, the Ministry would pick up from the stage reached which was presentation to the committee. The grandmother advocates also took up the need for the Ministry of Health to have COVID prevention messages that target the elderly, which the Minister promised to submit to relevant committees.

Prior to COVID-19, two grandmother advocacy champions participated in the stakeholder engagement process called by the National Council for Older Persons and the Ministry of Gender, Labour and Social Development in September 2019. This engagement aimed at taking stock of the services delivered to benefit older persons in Uganda. The grandmothers joined voices with other participants to ask for better representation and service delivery for older persons. They further advocated for lowering the age of benefits in the Senior Citizens Grant from the present 80 years to at least 70 years. The participants also sought to end discrimination based on age in many spheres of service delivery. The National Council for Older Persons (OP) and Ministry of Gender committed to following through with their asks and to fast-track the final passing of the OP bill for the protection of the rights of older people.

The above is a clear demonstration of the path towards resilience by grandmothers. Facing deep injustices and challenges, they have spearheaded a movement enabling them to realize their inner strength and writ. Through support groups, grandmothers are recovering from some of the worst losses they have suffered, and are regaining the resilience they must have to cope with the challenges they continue to face in raising the next generation. Grandmothers are making their voices heard and mobilizing to claim their human rights.

## **The Stephen Lewis Foundation**

The Stephen Lewis Foundation (SLF) is a progressive, feminist organization rooted in the principles of social justice, international solidarity, and substantive equality. The SLF was created with the express purpose of supporting community-based organizations working on the frontlines of the AIDS pandemic in sub-Saharan Africa.

Since 2003, the SLF has partnered with 325 community-based organizations on more than 1,800 initiatives in the 15 countries (Ethiopia, Uganda, Kenya, Democratic Republic of Congo, Rwanda, Tanzania, Zambia, Zimbabwe, Mozambique, Malawi, Namibia, Botswana, South Africa, Lesotho and Eswatini) that have been hardest hit by the AIDS pandemic in Africa.