WHO series on long-term care

Towards long-term care systems in sub-Saharan Africa

World Health Organization

WHO series on long-term care

Towards long-term care systems in sub-Saharan Africa

World Health Organization

Towards long-term care systems in sub-Saharan Africa

(WHO series on long-term care)

ISBN 978-92-4-151338-8

Suggested citation. Towards long-term care systems in sub-Saharan Africa: WHO series on long-term care. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO.

Cataloguing-in-Publication (CIP) data. CIP data are available at http://apps.who.int/iris.

Sales, rights and licensing. To purchase WHO publications, see http://apps.who.int/bookorders. To submit requests for commercial use and queries on rights and licensing, see http://www.who.int/about/licensing.

Cover: The painting in flowing watercolors, on the front cover, is by 85 year old Jock Meijer. Jock has painted for many years taking inspiration from famous Dutch artists such as Armando. Jock currently lives on a care farm for people with dementia in the Netherlands. She continues to find peace in painting and can be found each week in the art studio. Copyright by Jock Meijer. All rights reserved.

Design and layout: L'IV Com Sàrl, Villars-sous-Yens, Switzerland.

Printed by the WHO Document Production Services, Geneva, Switzerland.

Content

Contributors . . . iv
Executive summary . . . v
Preface . . . vi
1. Introduction . . . 1
1.1 Scope . . . 1
1.2 Approach . . . 1
1.3 Definitions . . . 2
2. Long-term care in sub-Saharan Africa . . . 5
2.1 Principles and policy frameworks for long-term care systems . . . 5
2.2 Family care in sub-Saharan Africa . . . 7
2.2.1 Implications for building long-term care systems in sub-Saharan Africa . . . 8
2.3 Organized care in sub-Saharan Africa . . . 9
2.3.1 Innovative approaches for delivering organized care . . . 9
2.3.2 Ghana: Care for Aged Foundation . . . 11
2.3.3 Kenya: Private nursing agency . . . 12
2.3.4 South Africa: Rand Aid . . . 13
2.3.5 United Republic of Tanzania: Better Health for Older People in Africa . . . 14
2.3.6 Implications for building long-term care systems in sub-Saharan Africa . . . 14
2.4 Towards systems of long-term care: national efforts in sub-Saharan Africa . . . 16
2.4.1 Mauritius . . . 16
2.4.2 Seychelles . . . 17
2.4.3 South Africa . . . 18
2.4.4 Implications for building long-term care systems in sub-Saharan Africa . . . 19
3. Practical next steps . . . 20
3.1 Build understanding and commitment for long-term care systems . . . 21
3.2 Establish national coordination mechanisms . . . 22
3.3 Develop indicators and map long-term care . . . 24
3.4 Foster cross-national learning and exchange . . . 24
4. Conclusion . . . 27
Annex 1. Topics covered at 2nd IAGG Africa Region Conference on Gerontology and Geriatrics . . . 28
Annex 2. Process for establishing the regional evidence base . . . 29
References . . . 30

Contributors

Key contributors

Isabella ABODERIN
African Population and Health Research Center
Nairobi, Kenya

JoAnne EPPING-JORDAN
Global health consultant
Seattle, United States of America

Editors WHO series on long-term care

Anne Margriet POT
World Health Organization
Geneva, Switzerland

John BEARD
World Health Organization
Geneva, Switzerland

Executive summary

Sub-Saharan Africa's need for long-term care is large and growing. Already, 46 million older people live in the region; and this number is expected to more than triple (to 165 million) by 2050. A significant proportion of these people will require long-term care: the activities undertaken by others in order to ensure that people with, or at risk of, a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity.

This report provides an overview of long-term care across sub-Saharan Africa and points to practical next steps that countries can take to establish systems that support older people who need care and support, while ensuring the burden of caregiving is equitably shared. It finds that, in almost all settings, provision of care is left to families who lack support and guidance on what care might be appropriate or how this might be provided. This results in millions of vulnerable older people not having their basic needs met, or in some instances experiencing flagrant abuses of their fundamental rights. It also places an unnecessary burden on caregivers, who are overwhelmingly female.

The report contains three main sections.

Section 1 introduces the report, outlines its scope and the approach that was used in order to assemble the information and evidence concerning long-term care in sub-Saharan Africa. This section also defines key terms used within the report, particularly "long-term care systems", the infrastructure required to ensure that long-term care is available in a sustainable, equitable and integrated manner.

Section 2 describes long-term care as it currently exists in sub-Saharan Africa.

The report presents **general principles of long-term care systems** and identifies **global and regional policy frameworks** to inform action. Despite some progress in the region, focused work on long-term care has been largely absent, reflecting the low policy and political priority accorded to the issue.

Next, the report explores **family care** in sub-Saharan Africa. Currently, families provide most long-term care in sub-Saharan Africa, and generally do so without any training or support. Care quality is often poor, and in some cases incapacitated older people are ostracized, tortured, or even killed. Reliance on families also places a heavy burden on female relatives who are called upon to forego education, employment or other economic engagement in order to care for older relatives. This practice perpetuates and sometimes deepens household poverty and – more broadly – hinders efforts to expand education, employment and economic opportunities to sub-Saharan Africa's women and girls.

Provision of organized long-term care is patchy in sub-Saharan Africa but the report shares what is known overall and presents illustrative emerging models from different parts of the region. Most organized care is clustered in urban settings and two major service models appear to dominate: charitable care for the most destitute older people (typically operated with few resources by faith-based-, civil society- or public welfare bodies); and private for-profit services, mostly in the form of residential homes for those who are able to pay. There appear to be few, if any, organized services for the majority of older people who lie between these extremes of the spectrum.

Within sub-Saharan Africa, **national efforts to develop long-term care systems** exist only in Mauritius, Seychelles and South Africa. The report presents brief case descriptions of each experience, outlining progress to date and the major challenges and gaps still faced. Action has been grounded in a relatively well-developed, rights-based legal architecture.

Section 3 contains practical next steps that can be considered in order to establish systems of long-term care. These steps take into account sub-Saharan Africa's unique cultural and economic context.

Build understanding and commitment for long-term care systems. Long-term care must be recognized both societally and politically as a public good. The enormous social and economic costs of neglecting this challenge also need to be acknowledged and better studied. In particular, more attention needs to be paid to a potential "care economy" and the positive influence it might have on socioeconomic development.

Establish national coordination mechanisms. Governments have an essential coordination role in building and implementing systems of long-term care. This does not mean that governments must fund or provide all services. Combinations of "who does what" will vary but in all cases, effective and integrated partnerships between government, families, volunteers, nongovernmental organizations, professionals and the private sector are essential. Governments should take overall responsibility for ensuring that the system works.

Develop indicators and map long-term care. Countries introducing long-term care systems will need to map what already exists in the country in order to build on it. A prerequisite of this mapping process is the development of a set of indicators that can capture and predict national needs for long-term care and services. Mapping can offer a baseline measure and a basis for comparison and evaluation.

Foster cross-national learning and exchange. Cross-national learning and exchange can catalyse change across sub-Saharan Africa and provide a mechanism to coordinate action between international agencies and other key stakeholders, including nongovernmental organizations and professional bodies. This type of information-sharing can occur via Internet-based platforms and/or face-to-face discussions.

All countries in sub-Saharan Africa need a fully integrated long-term care system. For the vast majority, this implies building an entirely new system. While only governments can establish and govern long-term care systems as a whole, a range of partners can work together to decide together what needs to be done and who will be responsible for what. Readers of this report are encouraged to consider what they can contribute to such efforts.

Preface

This report is part of a WHO series on long-term care. The series aims to increase understanding of the importance of long-term care systems and to provide guidance on how to establish such systems in different regions of the world. Both thematic and region-specific reports will be included in the series.

The region-specific reports will describe the outcomes of regional discussions on long-term care systems, including gaps and challenges, and models that already exist in the region. Each region-specific report will include practical next steps that countries can consider in order to establish or improve their long-term care systems, based on prevailing regional norms and contexts.

The thematic reports will provide cross-cutting information and evidence on those key issues that shape the development of sustainable and equitable long-term care systems. Financing, human resources development, monitoring and evaluation are examples of topics that will be covered. These reports will take into consideration the fact that sustainable and equitable long-term care systems will necessarily differ between regions and countries.

WHO is committed to providing technical support to countries as they grapple with ways in which to provide good-quality long-term care to increasing numbers of older people in need and to do so in a way that is affordable, accessible and fair to older people, their families, the long-term care workforce and society at large.

46

million older people are living in sub-Saharan Africa. This number will triple to 165 million by 2050.

1. Introduction

Populations around the world are ageing rapidly and this demographic transition is placing new demands on societies to provide comprehensive systems for long-term care at home, in communities or in institutions. In sub-Saharan Africa, 46 million older people live in the region and this number is expected to more than triple (to 165 million[1]) by 2050. A significant proportion of these people will require long-term care at some point in their lives.

Long-term care can be provided in a range of settings – including people's homes – and by a range of people. Currently, families provide most long-term care in sub-Saharan Africa and do so without any organized training or support. Reliance on families alone to provide this care results in inconsistent care quality and places a particularly heavy burden on women and girls. Moreover, it may be unsustainable given the rapidly increasing number of older people.

The WHO *Global strategy and action plan on ageing and health (1)* highlights the challenges faced by countries around the world in responding to the long-term care needs of their ageing populations. Adopted by the Sixty-ninth World Health Assembly in May 2016[2], the Strategy calls for every country to develop a system of long-term care. The form this system takes will vary, depending on each country's context, available resources and societal choices about the distribution of the overall costs of care. However, any long-term care system should be based on the key principles outlined in Section 2.1 of this document.

1.1 Scope

This document provides an overview of long-term care across sub-Saharan Africa. It describes overall patterns of care provision, key challenges and innovative long-term care service approaches. As part of the first action area outlined above, this document aims to provide the background and evidence necessary for the development of long-term care systems in sub-Saharan Africa.

1.2 Approach

The information contained in this document was compiled as part of the preparations for a regional conference, held in December 2016, on setting agendas for the development of long-term

[1] http://esa.un.org/unpd/wpp/Download/Probabilistic/Population, accessed 2 November 2017.

[2] Resolution WHA69.3.

care systems with special focus on sub-Saharan Africa. The conference was organized by the Africa Region of the International Association of Gerontology and Geriatrics in cooperation with the African Union Commission and the World Health Organization. The meeting was hosted locally by the African Population and Health Research Center and the Kenya Association of Gerontology and Geriatrics. The conference brought together some 110 researchers, service providers, advocates, private sector and government stakeholders from sub-Saharan Africa and beyond (see Annex 1 for conference topics).

A longer resource document upon which this document is based *(2)* provided the background evidence for conference attendees. It was developed by identifying and compiling information on long-term care in sub-Saharan Africa. This included assessing relevant regional and national policies and legal frameworks; reviewing scientific evidence and grey literature on realities of long-term care in the region; developing and piloting a tool for mapping the landscape of existing long-term care services; profiling a number of promising new practice models in the region; and describing existing national long-term care systems in Mauritius, Seychelles and South Africa. Annex 2 describes in greater detail the process that was used to develop the evidence base.

1.3 Definitions

The following terms are used in this document and serve as a framework for describing long-term care.

Functional ability and intrinsic capacity

Functional ability refers to the attributes that enable people to be and to do what they have reason to value. It is determined by individuals' intrinsic capacity (the combination of all their physical and mental – including psychosocial – capacities), the environments they inhabit and the interaction between the individual and these environments.

Long-term care

Long-term care covers those activities undertaken by others to ensure that people with, or at risk of, a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity.

Long-term care systems

Long-term care systems are national systems that ensure integrated long-term care that is appropriate, affordable, accessible and upholds the rights of older people and caregivers alike. Depending on the national context, funding and care may be provided by some combination of families, civil society, the private sector and/or the public sector. Governments do not need to do everything but should take overall responsibility for ensuring the system's functioning.

Organized versus unorganized care

Organized care is coordinated by agencies, institutions or governments. Unorganized care is provided by family or other unpaid caregivers and is not coordinated beyond the level of individuals or families.

Paid versus unpaid care

Caregivers can be grouped into two broad categories: those who are paid for their work and those who are not. Paid caregivers may include professionals and paraprofessionals or family members who receive compensation for the long-term care services they provide to relatives.

In sub-Saharan Africa, long-term care rests overwhelmingly with

families

2. Long-term care in sub-Saharan Africa

The need for long-term care is great. Already, large numbers of older people in sub-Saharan Africa are unable to perform essential tasks of daily life without the assistance of others *(3-8)*. For people older than 65 years living in sub-Saharan Africa, care needs are far higher than for people of similar ages in more developed settings. WHO has estimated that in Ghana, more than 50% of people between the ages of 65 years and 75 years require some assistance with daily activities. For those 75 years and older, the percentage jumps to more than 65%. In South Africa, more than 35% and 45%, respectively, of those at similar ages require assistance, while in Switzerland the proportion is less than 5% and 20%, respectively *(8)*.

Responding to long-term care needs is a cross-cutting development issue for sub-Saharan Africa. It is relevant to broader African development agendas on health, including universal health coverage; on social protection, gender equality, and the advancement of human rights; and on economic development through expanded opportunities for education, employment, and entrepreneurship in long-term care service provision. Recognizing this, the Executive Council of the African Union recently adopted a Common African Position on Long-Term Care Systems for Africa *(9)*. The directions for action encompassed in the position statement build directly on the evidence-based perspectives and insights generated at the regional conference referred to in Section 2.1 above.

Despite this progress, few regional or national frameworks exist to guide more specific action. Focused debate has been largely absent, reflecting the low policy and political priority accorded to long-term care, combined with a belief that the issue has little impact on economic development. With the exception of a few countries, little organized service capacity or national coordination exists *(8, 10)*. Rather, the provision of long-term care rests overwhelmingly with family members, in line with customary sub-Saharan African norms of family solidarity and obligation *(11–14)*. This is fuelled by a belief among some that western models of organized long-term care pose a threat to African values *(15)*.

2.1 Principles and policy frameworks for long-term care systems

WHO's *Global strategy and action plan on ageing and health (1)* calls upon all countries to develop a system of long-term care. The Strategy emphasizes that no single system of long-term care can be applied in every setting, even in countries with similar resource constraints. Governments need to take into account the number of older people and their need for long-term care, existing models of service delivery, the availability and skills of unpaid caregivers

and paid care workers, information and data systems, infrastructure and assistive technology, finances, and care policies.

Despite this diversity, WHO has identified general principles that apply in all contexts *(8)*.

- Long-term care must be affordable and accessible. Special attention should be given to ensuring that poor and marginalized people are able to access services.
- Long-term care must uphold the human rights of care-dependent older people. Care must be provided in a manner that enables older people to maintain their dignity and respects their right to self-expression and, where possible, choice and growth.
- When possible, long-term care should enhance and maintain older people's intrinsic capacity, as well as help them to compensate for losses of capacity.
- Long-term care should be person-centred and oriented around the needs of the older person, rather than the service structure.
- The long-term care workforce, both paid and unpaid, should be treated fairly and receive the social status and recognition it deserves.
- National governments must take overall responsibility for the provision and functioning of long-term care systems.

These principles are consistent with a number of broader global policy instruments, including the United Nations' Sustainable Development Goals *(16)*. Establishing systems of long-term care would contribute to sustainable development through poverty alleviation (Goal 1); universal health coverage (Goal 3); gender and age equality (Goals 5 and 10); and promoting economic growth and employment (Goal 8).

The African Union has drafted several policy frameworks relevant to long-term care. These include the AU Policy Framework and Plan of Action on Ageing *(17)*; the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa *(18)*; and the Common African Position on Long-term Care Systems for Africa *(9)*. At the national level, several countries including Ethiopia, Ghana, Kenya, Mauritius, Uganda and the United Republic of Tanzania have adopted consistent overarching ageing policies or national legislation relevant to older people, such as the Older Persons Acts of South Africa and Zimbabwe.

However, with few exceptions, national policies and legislation overlook significant aspects of sustainable systems of long-term care. In general, they do not provide a framework or roadmap for integrating long-term care across a range of settings and often do not examine the cultural norms and expectations inherent in substantial family involvement in long-term care provision. In addition, they do not specify mechanisms for preparing and supporting caregivers and rarely specify how to ensure a sustainable financing mechanism and workforce supply as sub-Saharan Africa's older population grows. Few of the frameworks address how to improve access and affordability for poor and marginalized groups.

2.2 Family care in sub-Saharan Africa

Published studies and reports of the long-term care provided by families in sub-Saharan Africa are limited and skewed overwhelmingly to southern, western and eastern parts of the region, particularly to Ghana, Kenya, Nigeria, and South Africa. Almost no information is available for other countries, or for central parts of the region. Notwithstanding these limitations, available evidence raises a number of key themes concerning the provision and receipt of family-based care *(2)*.

Because organized systems of long-term care are generally lacking, families constitute the major source of care for older people who are no longer able to live independently *(8, 10, 19, 20)*. However, evidence also reveals that a substantial group of older people receive no family care whatsoever *(3)*.

The majority of family care is provided by female relatives, ranging in age from children to older adults *(11, 21–26)* although some studies document significant involvement of men in caregiving *(11, 22, 26)*. Some further evidence points to a role played by unorganized and unregulated domestic workers in long-term care provision *(25, 27)*. Care is provided either in older people's homes or in the home of caregiving relatives *(23)*.

Numerous concerns about quality of care have been documented. These range from general neglect of older people to exclusion, marginalization and abuse *(19, 28–34)*. Care inadequacies may result in older people being unable to maintain their functional ability, or lead to depression or early death *(3, 19, 35)*.

Inadequacies in family care arise particularly in contexts of poverty and vulnerable employment. In these cases, the family members who provide long-term care lack the resources to give better care and are faced with a choice between neglecting their work, training or other economic activities or neglecting their dependent older relative *(29–31, 36)*.

In addition to material resource constraints, some studies point to a general absence of caregiving knowledge and skills *(29, 30, 32, 37, 38)*. Most family caregivers are left to provide support with little or no guidance on how to address complex issues that sometimes arise. Dementia is a key example: few caregivers understand the nature of the condition, the ways it can influence behaviour and what responses can ease the burden and enhance the lives of care recipients. Situations such as these increase the risk of elder abuse, either as a stress response from overwhelmed caregivers or as a means of unscrupulously accessing older people's assets *(39)*.

In some circumstances, older people's kin accuse them of witchcraft. These older people – often women – can be ostracized, tortured or even killed as a result. Although it is not yet fully understood what drives such accusations, they are rooted in beliefs of sorcery as a cause of ills or misfortunes befalling families or communities and tend to occur when older people show a noticeable decline in their mental or physical capacities *(40)*.

Unpaid family caregivers also pay a price in terms of foregone education and/or income-earning opportunities *(21, 22, 26, 37, 41)*. Study findings further highlight adverse effects on caregivers' physical health, including fewer opportunities for self care, and their mental health, including depression *(23, 24, 30, 41–44)*. Some evidence documents the considerable financial costs of caregiving borne by families, particularly in households with dependent children *(26, 42, 45)*.

Many researchers and some policy-makers in sub-Saharan Africa have concluded that it is no longer feasible to rely on kin as the mainstay of long-term care provision, given a perceived weakening of extended family support systems *(19, 23, 33, 34, 37, 44, 46–49)*. Key factors assumed to underly this shift include increased rural to urban migration and labour force participation, especially among young women; increasingly monetized economies; the impact of the HIV/AIDS epidemic (increased deaths among younger adults) and loosening norms and structures for extended family solidarity *(11, 35, 44, 46, 48, 50–52)*.

Although perhaps intuitive, it is important to note that presumed declines in family care provision have not yet been studied formally and considerable debate continues about the ways in which social trends are shaping the experiences of families and later life in sub-Saharan Africa *(14)*.

2.2.1 Implications for building long-term care systems in sub-Saharan Africa

Available evidence on the current state of unpaid and unorganized family care in sub-Saharan Africa points to a number of principles and directions that should be considered as countries develop their long-term care systems.

Family-based care, in its present configuration, is unable to deliver good-quality and integrated long-term care for the many older people who need it. The poor and those suffering from dementia or other complex conditions are particularly affected.

As it currently stands, family care also creates substantial and inequitably distributed burdens for caregivers. These include the direct costs associated with providing care, as well as opportunity costs for missed education, employment or other economic engagement. These latter costs of caregiving are borne disproportionately by females, thereby hindering core development efforts to expand education, employment and economic opportunities to sub-Saharan Africa's young women and girls. The implications of these opportunity costs on socioeconomic development need to be better studied and understood. Moreover, evidence from high-income countries suggests that at any given age, the need for care is greater among the poor, who generally have the least access to resources and for whom the opportunity cost of providing care is the greatest.

Organized and paid long-term care services are therefore needed in order to supplement and strengthen family care, including for poorer families. In addition, skills training and – where needed – social protection mechanisms for family caregivers are important policy issues to be considered.

More information and evidence on family care for older people from a wider range of sub-Saharan African countries would help the development of broader and more effective systems of long-term care.

2.3 Organized care in sub-Saharan Africa

Published studies and reports of organized long-term care in sub-Saharan Africa are even more limited than the evidence base on family care cited in the previous section. Most research comes from South Africa and concerns a particular sub-setting: residential facilities. Although the organized provision of long-term care remains largely undocumented for most countries, it is highly likely that only a small fraction of those older people who need it receive any form of organized care and support *(10)*.

The expansion of organized long-term care has been organic and uneven in terms of geographical spread, populations served and services offered. Most organized care is clustered in urban metropolitan settings *(41, 53, 54)*. Two major service models appear to dominate: charitable care for the most destitute older people (usually operated with few resources by faith-based, civil society or public welfare bodies) and private for-profit services, mostly in the form of residential homes for those who are able to pay *(54)*. There appear to be few, if any, organized services for the majority of older people who fall between these extremes of the spectrum *(53, 54)*.

Moreover, the quality of care provided is uncertain and organized long-term care workers lack adequate training and are largely unprepared for the demands placed upon them *(53–56)*. Employment conditions are often unfavourable in relation to workload, remuneration and professional development *(53, 54, 57)*, while guidelines and quality assurance processes are typically lacking *(53, 54)*.

Operational deficiencies compound these problems. Typical challenges include care settings that are unhygienic, cramped, or without reliable access to electricity or water *(53)*.

The net result is that many older people receive care that is grossly inadequate. Outdated ideas and ways of working, which concentrate on keeping older people alive rather than supporting dignified living and functional ability, are all too common. At best, care is focused on meeting people's basic needs such as help with bathing or dressing, at the expense of broader objectives such as well-being and maintenance of dignity personal choice and respect *(54, 58, 59)*. Fragmentation of long-term care services from mainstream health care further exacerbates the problem *(53)*.

2.3.1 Innovative approaches for delivering organized care

New approaches to organized care services – not yet captured in the scientific literature – have begun to emerge in various settings. These efforts are being led by nongovernmental, community-based and private sector actors, seeking to respond to unmet long-term care needs. The full spectrum of these services across sub-Saharan Africa remains poorly understood but information available on innovative approaches offers potential for redressing existing shortcomings.

Case studies from urban Kenya and South Africa, semi-urban Ghana and rural United Republic of Tanzania were examined. A number of common features emerged, as well as unique elements. Together, these offer examples that countries can consider as they develop systems of long-term care.

Key elements include:

- **family involvement.** Relatives were actively involved in the development of care plans, including their own roles and contributions. In some cases, families overviewed the implementation of the care plan, including the performance of paid caregivers;

- **person-centred care.** Older people were involved in the development of their care plans. This helped ensure that their unique needs and preferences were considered;

- **caregiver training.** Caregivers were provided with training and skill development opportunities, although curricula and approaches varied across settings;

- **integration with health care services.** Local formal or informal arrangements with heath care providers or facilities helped ensure in-house or external medical care for older people;

- **access equity.** In South Africa, an innovative within-service, cross-subsidization scheme offered a possible pathway to reducing access inequities. All settings welcomed older people with dementia or other cognitive impairment;

- **workforce conditions.** The South Africa case study featured an open work culture that viewed caregivers as partners and explicitly valued the lowest cadres;

- **sustainability.** The case studies revealed a variety of ways to ensure financial sustainability: well-established donors (Ghana); willingness to pay out-of-pocket (Kenya and South Africa); and likely underwriting by the public sector (United Republic of Tanzania). With the exception of the United Republic of Tanzania, all services envisage growth in the scale of their operations, given an already considerable unmet demand for their services, as well as an inevitable rise in the number of older people requiring long-term care. However, it is uncertain that these expansions can be sustained, in terms of both financial resources and availability of trained caregivers. The ambiguities about expansion are underpinned by the current "niche" position of emerging service models and their limited connections to broader public or private services, insurance, training or regulatory systems.

2.3.2 Ghana: Care for Aged Foundation

The Care for Aged Foundation (formerly known as Akrowa Aged Life Foundation) was formed in 2006 to address the needs of frail older people who do not have traditional family support. It operates mainly within Ga East municipality where a disproportionately high number of neglected older people live.

The organization provides a range of services. Individualized care plans, based on initial assessments, are developed in collaboration with the older people/clients and, when involved, their families. Young people living in the same community then pay home-care visits to clients to fulfil the care plan. They assist with tasks such as bathing, personal grooming, dressing wounds, cooking, light housework, shopping, accompanying older people to hospital appointments and providing companionship. Although these young people are not paid, they benefit from free health care at specific partner facilities. In addition, a volunteer physiotherapist is intermittently available to clients and the organization has an ambulance service that it can call upon when necessary.

Initially, many families were resistant to enrolling their older relatives and some were suspicious of the idea of strangers coming into their homes. However, seeing the positive impact on neighbouring families, many soon realized that the organization could ease the burden of caregiving. Slowly, the area's openness to organized long-term care grew. Currently, the organization provides regular home visits to approximately 160 older people and medical care – if required – to 400 older people.

The organization's operations are reliant on a number of partners. Services are resourced through cash and in-kind donations such as geriatric training, medical supplies and supervisory support. Well-established donors provide the bulk of direct monetary support. The organization also has formed alliances with educational and health care facilities, relevant government authorities (Ministry of Health and Department of Social Welfare) and chiefs and traditional authorities in its geographic area of operation.

Expansion of services beyond the immediate geographic area and existing clientele would require an infusion of additional resources. Currently, around 3000 older people are on a waiting list, and the organization is struggling to attract and retain volunteers because it is unable to offer any financial compensation. Nonetheless, this example illustrates how organized home-care services can be provided in a manner that is culturally acceptable and integrated with health care services.

2.3.3 Kenya: Private nursing agency

This nursing agency (name withheld in accordance with WHO policy) is an example of how private companies are being formed to provide organized long-term care services to those who can afford to pay for them or who have medical insurance that covers home-based care. The agency was formed in 2012 and is geared to provide professional services in clients' homes. It offers personal care, specialized home health care, nutritional advice, psychosocial support and disease management services. Its diverse staff consists of approximately 140 people. Almost half are health professionals (nurses; physical, occupational and speech therapists; counsellors; and an agency physician); the others are patient attendants who assist clients with activities of daily living. All employees are screened and subject to background checks prior to employment. Services can be of short or long duration and on a part-time, full-time or live-in basis.

Care managers conduct initial assessments and develop individualized care plans according to clients' and families' needs, preferences and available resources. Care plans are highly personalized and adapted over time, according to changing needs. Clients and their families participate in the selection of specific caregivers and provide structured feedback to the agency on caregivers' performance. Other quality assurance practices include clearly articulated standards of care, supervision and regular personalized contacts with the client and family by a site supervisor.

This agency is illustrative of the type of good-quality, multidisciplinary, integrated and personalized long-term care that can be provided to those who have the resources to pay for it. Some medical insurance companies are realizing the advantages of including home-based services in their policies. However, because most older people do not have medical insurance, they or their families generally pay out-of-pocket for care. This substantially limits the number of people who benefit from the services offered by this agency.

2.3.4 South Africa: Rand Aid

Rand Aid is a registered non-profit-making organization in Johannesburg, South Africa that serves a dual purpose: it provides a range of upscale retirement accommodation and long-term care to older people who can afford it. This generates a source of income that is used to assist other older people in need. Currently, around 1800 older people reside in Rand Aid properties, including approximately 360 who live in long-term care ("frail care") facilities.

Units in these retirement villages are sold on the life rights concept. Residents buy the right to live in the village and they (or their estate) receive 80% of the initial purchase price when they depart. In addition, residents pay a monthly fee for services that are available to them, regardless of whether or not they use them. Villages offer housing, 24-hour security, nursing care, garden and domestic services, physiotherapy and podiatry. Every effort is made to ensure that residents' needs are met.

At one of Rand Aid's two long-term facilities, residents pay for their board and lodge in full. The other facility receives a small government subsidy but is funded mainly by the organization through a cross-subsidy of a portion of the 20% of the life rights purchase price.

Long-term care facilities offer multidisciplinary and personalized care to those who need help in order to maintain their functional ability. The facilities have adopted the Eden Alternative philosophy, which aims to transform traditional, institutionalized long-term care facilities into "human habitats". Based on the principles of person-centred care, the facilities emphasize freedom of choice for all residents. Older people and their families are involved in care planning and residents are encouraged and enabled to exercise autonomy in their day-to-day lives to the maximum extent possible. Integrated care teams of nurses, nursing assistants, social workers, occupational therapists, medical doctors (on call), recreation officers and volunteers provide a range of services to residents in these facilities.

The full-pay long-term care facility is located within one of the retirement villages, thus enabling ageing in place, if residents' care needs increase over time. This facility also features a specialized dementia unit. The subsidized long-term care facility, which is also situated in spacious grounds, accommodates 180 older people in particular need of 24-hour nursing care.

Rand Aid is more than 100 years old and has demonstrated financial sustainability. The cross-subsidization model requires financial balance between income-generating activities (its retirement villages) and its charity work (its subsidized long-term care facility and other outreach services to those in need). Any further expansion of its charity work would need to be balanced with commensurate increased revenue.

2.3.5 United Republic of Tanzania: Better Health for Older People in Africa

HelpAge International working in Tanzania is implementing the Better Health for Older People in Africa programme in the country. The project, funded by the Department for International Development of the United Kingdom, runs from 2014 to 2017 and aims to improve access to home-based services for poor older people, thereby reducing their vulnerability to illness and worsening poverty.

The programme supports approximately 4500 older people in four districts across three of the country's regions. Care is provided by 425 trained volunteers who, either directly or through linkages with other services, ensure that clients' physical, emotional, social and spiritual needs are addressed. Coordinators (typically registered nurses or clinical officers) provide supervision and monitor the volunteers. Volunteers are selected in consultation with older people's fora and local community and health leaders. They usually live near the people they serve and are assigned no more than 15 households at a time.

Individualized care plans are developed in consultation with clients and families and may include assistance with activities of daily living such as eating, dressing and bathing; bed sore management; medication assistance; companionship and support; and escorts to medical appointments. Clients are visited in their homes two or three times per week and provided with care services as necessary. All care activities are documented on patient cards. Monitoring forms are submitted monthly to the coordinator at the nearby health facility, who reports to national health authorities. Screening, health services, and medications are free of charge to those older people participating in the programme. Faith-based organizations, community-based organizations and village governments sometimes offer loans or access to gardens or fishing ponds. Clients are also enrolled in psychosocial support networks and engaged in programmes that enable them to socialize, prepare and eat meals together, discuss their health needs and learn from health workers about important topics such as nutrition and exercise.

This care model relies primarily on volunteers. However, training, supervision and day-to-day support are co-financed by donors and local governments.

2.3.6 Implications for building long-term care systems in sub-Saharan Africa

Available evidence and examples of organized care in sub-Saharan Africa suggest several directions that might be considered by countries as they lay the foundations for their long-term care systems.

There is a growing need for organized care in sub-Saharan Africa. As the number of older people (including those with cognitive impairment) will rise rapidly in coming decades, families will be unable to continue providing the bulk of services in an unpaid and unorganized way. Contrary to assumptions that organized care services are incompatible with cultural values and norms of family obligation, evidence shows that organized care services can operate in a way that retains family involvement while supporting, complementing or, in some cases, substituting for family care.

As organized care expands across sub-Saharan Africa, there is an opportunity to extend service provision beyond institutional or residential settings. Organized long-term care need not be conceptualized as an "all or nothing" dichotomy between no care on one hand and institutional care on the other. In reality, organized long-term care can be provided in older people's own homes, in friends' or family members' homes that are safer and more adapted to their needs and/or in community-based settings, as well as in residential settings.

Quality of care also needs to be improved. Current organized long-term care generally suffers from substantive shortcomings in quality and integration with other services. These shortcomings reflect poorly developed workforce skills; limited human, material and infrastructure resources; and an absence of regulatory structures and oversight. Government coordination is needed in order to ensure service access for underserved groups and to address quality deficits. Areas for action may include training and skills development for long-term care workers, development of standards and systems of regulation, including integration with mainstream health services and development of long-term care models which are community-based and promote ageing in place.

2.4 Towards systems of long-term care: national efforts in sub-Saharan Africa

Within sub-Saharan Africa, national efforts to develop long-term care systems exist only in Mauritius, Seychelles, and South Africa. Perhaps not by coincidence, all three countries – in contrast to many others in the region – are more or less established middle-income economies *(60)*. The brief case descriptions below outline progress to date and describe major challenges and gaps still facing each country.

2.4.1 Mauritius

The small island nation of Mauritius has been in the vanguard of policy and legislation specific to older people. It was the first country to adopt a national policy on the elderly (in 2001). It also has a Protection of Elderly Persons Act 2005, which is aimed at protecting older people from all forms of neglect and abuse. Older people are afforded further rights and protections in the more general National Human Rights Action Plan (2012–2020). The Government of Mauritius oversees and funds many aspects of health and social care for older people. All older people in Mauritius receive a basic pension and have access to free public transport and free health care. Day care centres offer recreational and educational programmes throughout the country. Those with demonstrated need receive free assistive devices and home health visits.

Long-term care is typically viewed as a family responsibility, although this is being challenged as society undergoes change. The government acknowledges that family caregivers require support and allocates a monthly allowance to caregivers of older people experiencing significant declines in capacity. Some efforts have been made to provide practical training to family caregivers.

A number of residential facilities also exist. Currently, approximately 25 charitable homes are operated by nongovernmental organizations and funded by the government. Nursing and medical care is provided on site. Access to these homes is first-come, first-served and based on means testing. Overall, the demand for admission into these homes far outweighs their bed capacity. The number of private retirement homes, for those who can afford them, has increased in recent years.

The Residential Care Homes Act 2003 was enacted in order to establish standards and codes of practice and to monitor the quality of care delivered in private homes. Regular inspections of both public and private homes help to ensure that residents receive adequate care.

In the future, Mauritius expects to face even greater demands for long-term care. Its Observatory on Ageing (established in 2013) provides data to help inform policy and service development. The Government of Mauritius foresees rising rates of dementia and disability and increased overall demand for long-term care. It is planning for a 52% increase in publicly funded residential bed capacity by 2030.

2.4.2 Seychelles

The right to health care and social protection for all citizens is enshrined in the Seychelles' Constitution of 1993. All citizens receive free health care and people over the age of 63 are entitled to a monthly retirement pension. In addition, a number of government-funded long-term care services are available, including both home care and residential services. Long-term care provision remains mainly in the public sector, with some involvement of civil society and limited participation of the private sector.

The country's home care scheme was established in 1987. This programme makes it possible for people to remain at home rather than using residential or institution-based care. Caregivers are chosen by the beneficiary, usually a family member of the older person. The care is focused on assisting and enabling older people with activities of daily living in their homes in order to maximize their functional capacity. Nurses and allied health professionals provide complementary home health care.

Public residential facilities take the form of regional homes for older people and one 136-bed long-term care nursing facility. The regional homes usually consist of ten single-occupancy independent living units. They are designed to provide a supportive environment for older people to help them stay independent while benefiting from some support and security. Residents do not pay rent but are responsible for living costs. The country's sole long-term nursing facility is in high demand: the waiting list is long.

Notwithstanding its achievements, shortfalls also exist in the Seychelles' long-term care system. Long-term care needs have not been formally assessed across the country. A clearly articulated long-term care strategy is needed. The home care scheme is funded solely by the government with open-ended benefits and few or no contributions from users. Consequently, the scheme's financial sustainability has been called into question. Quality of care is another issue: the government pays home-based caregivers (typically family members) but does not provide training, credentials or monitor quality of care. Furthermore, regional homes are minimally staffed and generally lack access to nursing or social care.

The Government of the Seychelles has recently unified health and social care in a Ministry of Health and Social Affairs. This new Ministry has an opportunity to strengthen long-term care governance and to develop plans to ensure the quality and financial sustainability of long-term care in years to come.

2.4.3 South Africa

South Africa's Older Persons Act (2006), as well as more general legal and policy instruments, guides national action on long-term care. Coordination and implementation of national policy fall mainly to the Department of Social Development and to the Department of Health. The former administers old-age pensions and finances and oversees residential, community and home-based care, while the latter addresses older people's health care needs. The Department of Human Settlements plays a lesser role, in that it regulates retirement villages. Overall coordination of long-term care across these Departments is lacking and clinical-level integration of health and social care is limited.

Old-age pensions are means-tested and distributed to people determined to be in financial need. All older people can access primary health care services free of charge but hospital care is free only to those who are indigent. Traditionally, long-term care has been seen as a family responsibility yet few schemes are in place to support family caregivers.

Private retirement villages cater mainly to older people with financial means. The villages operated by Rand Aid (see section 2.3.4) are an example of the multidisciplinary and stepped care that is generally available to residents.

Publicly funded long-term care is available to only a small fraction of the older population. The majority of this type of care is provided in residential facilities which tend to be clustered in urban settings. Applicants are subject to a comprehensive assessment of their current living situation, family support, financial means and care needs. Only those who meet the criteria are eligible for admission. Individual care homes usually have their own admission policies and procedures, in addition to the formal criteria for obtaining public financial support. Availability of beds is another hurdle: most facilities have waiting lists for admission.

South Africa has National Norms and Standards (2008) that outline acceptable levels of service to be provided to older people. Recent audits have found many facilities in partial non-compliance. In addition, informal racially discriminatory practices were observed in some facilities, both in terms of admissions and quality of care.

Opportunity exists for national authorities to strengthen coordination across the different government departments involved in long-term care. Organized long-term care could be expanded to include a broader range of service approaches and settings. Improving equitable access, quality and financial sustainability also need to be addressed.

2.4.4 Implications for building long-term care systems in sub-Saharan Africa

The experiences of Mauritius, Seychelles, and South Africa highlight common themes and challenges in developing national systems for long-term care.

Legal architecture. Mauritius, Seychelles and South Africa all have a relatively well-developed, rights-based legal architecture within which their care system has been built. Provisions in their constitutions enshrine (older) citizens' basic entitlements to care or protection.

Direct service provision. In all three countries, the government engages in the direct delivery of long-term care to older people. All either operate or subsidize "charitable" care institutions, principally for older people who are unable to afford private-for-fee services.

Standards and monitoring. A further aspect common to the three countries is some element of oversight of organized long-term care services. Typically based on legal provisions and regulations, such oversight takes the form of accreditation of long-term care facilities, as well as regular (although not necessarily frequent) monitoring of care standards and operations. Mechanisms for enforcing standards and norms appear to be less well developed.

Health care access. A final common area is that the government facilitates access to health care for care-dependent older adults. In all three countries, interventions in this regard include the provision of free or subsidized assistive devices, facility-based health care and regular outreach health care to older people in their homes.

Challenges also exist. In all three countries, long-term care provision already falls short of demand. This is especially true for those population groups unable to afford out-of-pocket care. It is anticipated that this unmet need will expand further as the number of older people in Mauritius, Seychelles and South Africa continues to increase. This raises the crucial challenge of how to sustain an expansion of such services, in terms of both financing and workforce.

Long-term care must be recognized as a

public good

A long-term care system can help meet older people's needs, protect families from inequitable burdens, and create a care economy.

3. Practical next steps

Many areas for action have been identified that would help countries to establish systems of long-term care *(1, 8)*, but sub-Saharan Africa's context requires special consideration. Most long-term care is currently provided by families and is largely unorganized and unpaid. Organized care exists in select settings, but is not accessible to a vast majority of care-dependent older people. This presents both a challenge and an opportunity for countries. The challenge is to build understanding, commitment and the capacity to establish and continually strengthen long-term care systems; the opportunity is to create systems of long-term care which are relevant and tailored to each country's unique needs. If managed appropriately, these systems have the potential to provide employment and reinforce economic development.

The most important next steps for sub-Saharan Africa are summarized below. Many of these steps build on recommendations made in the African Union Common African Position on Long-term Care Systems for Africa *(9)*.

3.1 Build understanding and commitment for long-term care systems

In sub-Saharan Africa and elsewhere, long-term care is poorly understood and often invisible. An important first step is therefore to build an understanding of the issues facing sub-Saharan African countries as the number of care-dependent older people continues to grow.

Long-term care must be recognized both societally and politically as a public good. The enormous social and economic costs of neglecting this challenge also need to be acknowledged and better studied. Rather than considering long-term care as a minimal, basic safety net for frail older people, perceptions must shift radically towards a more positive and proactive agenda. Long-term care should be oriented towards optimizing capacity or compensating for lack of capacity so that functional ability is maintained and well-being ensured. More broadly, long-term care should ensure an acceptable level of well-being, not only for dependent older people but also for those who care for them.

In order to achieve this, more attention needs to be paid to a potential "care economy" that can develop and the positive influence it may have on socioeconomic development. Often, long-term care is perceived as a drain on government finances with little economic dividend, leading to an emphasis on cost savings. However, properly managed, a long-term care system can create employment for relatively untrained workers. This can be financed by families,

insurance systems or through the transfer of assets accumulated by older people throughout their lives. The forging of long-term-care systems should be considered as an area of focus in sub-Saharan Africa's attempts to foster employment and entrepreneurship opportunities for its large population of young people – towards reaping a demographic dividend. Moreover, even a basic system can save costs by reducing inappropriate use of acute health services, reduce the stress and health consequences experienced by caregivers and free women to participate in the workforce.

The African Union Commission could play an important role in engaging Member States and partners on this agenda. It could provide fora for its member states in order to raise awareness and increase understanding of, and stimulate discussion and action on, long-term care; and engage with partners to build support for initiatives on long-term care in sub-Saharan Africa. The Commission could also promote constructive regional debate by disseminating information about the current long-term care situation and addressing misconceptions about it.

At the national level, multisectoral dialogue can be encouraged in order to take stock of the status of long-term care provision and receipt, and to identify emerging challenges and opportunities for policy and action. Awareness-raising initiatives can be implemented in order to stimulate and inform public debate on long-term care.

The WHO Regional Office for Africa and WHO country offices can provide leadership and technical support and catalyse the development of sustainable and equitable systems of long-term care. This will entail building understanding and galvanizing commitments through Regional and local policy dialogue, as well as creating partnerships with relevant stakeholders in order to catalyse change.

International development partners can support active consideration of long-term care issues, goals and options as part of regional or global debates. This could include support to the implementation and testing of innovative approaches; conferences on ageing, health and universal health coverage; on social protection, gender equality and advancement of human rights; and education, employment and entrepreneurship opportunities for youth.

3.2 Establish national coordination mechanisms

Governments have an essential coordination role to play in building and implementing systems of long-term care. This does not mean that governments must fund or provide all services. Combinations of "who does what" will vary across countries. In all cases, however, effective and integrated partnerships between governments, families, volunteers, nongovernmental organizations, professionals and the private sector are essential. National authorities should take overall responsibility for ensuring that the system functions well.

In some countries, an essential first step will be to identify the people and/or departments within government who will spearhead these efforts. In some countries, this responsibility will fall within the ministry of health while others may decide that primary responsibility for coordination lies


© WHO /Fid Thompson

within a different government sector. Regardless of the arrangement, primary responsibility for coordination must be clearly designated.

Once primary responsibility for spearheading the effort has been determined, a multisectoral coordinating body or mechanism needs to be established and – importantly – adequately resourced. It may include a range of government departments and/or sectors (for example, health, social welfare, housing, education) as well as local/municipal levels of government. Depending on the country context, it may also encompass civil society, community-based, faith-based and private sector stakeholders actively involved in the provision or receipt of long-term care. All these stakeholders should be engaged in constructive debate on long-term care in order to consolidate the national policy architecture on long-term care, and to pursue and monitor its implementation. It is imperative to include the input of older people themselves in this process.

Elements of a new system will require resources, some of which may be available through in-kind contributions, appropriate training for care workers and ongoing minimal support for unpaid caregivers. For example, many community groups – in particular older people's self-help groups – may be able to provide different elements of the system if adequately prepared and supported to do so.

The WHO Regional Office for Africa and WHO country offices can offer technical support for building capacity and establishing national coordination mechanisms. They can also support countries in setting norms and standards, monitoring provision of long-term care, developing evidence-based policy options, setting investment priorities, shaping the research agenda and stimulating the generation, translation and dissemination of valuable knowledge.

3.3 Develop indicators and map long-term care

Any government that plans to introduce or enhance a system of long-term care will need to map what already exists in the country, in order to build upon it. An essential prerequisite of this mapping process is the development of a set of indicators that will capture and predict long-term care needs and services across the country. Mapping offers a baseline measure and a basis for comparison and evaluation.

At the global level, metrics and monitoring methods used in the field of long-term care are limited. WHO has prioritized work in building consensus on common terminology, indicators and those data collection approaches that are most appropriate for mapping long-term care needs and services.

The African Union also has recently recommended the development and use of an action framework to help its member states measure and track progress in long-term care *(9)*. Such a framework would form part of a broader regional effort to monitor and evaluate the implementation of the AU Policy Framework and Plan of Action on Ageing, and its Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa.

3.4 Foster cross-national learning and exchange

As sub-Saharan African countries develop their systems of long-term care, the sharing of local experiences and innovations can catalyse change across the region. This cross-national learning and exchange could occur via Internet-based platforms and face-to-face discussions. It would also provide a mechanism for coordinating action between international agencies and other key stakeholders including nongovernmental organizations and professional bodies.

Synthesized information on long-term care experiences and evidence would capture the range of diversity in a manner that is easily accessible and useful to those who wish to implement systems of long-term care in their own settings. Such information might include, for example, details of an on-line clearinghouse of measures, policies, care models, implementation tools and financing approaches.

The African Union has recently recommended the development of an Internet-based platform for the sharing of resources and knowledge on long-term care policy and legal agendas, interventions, care models and systems approaches for its member states and stakeholders. It has also committed to facilitating and providing fora for its member states to engage in cross-country exchange and learning on long-term care policy agendas, interventions, care models and systems approaches *(9)*.

Governments have an essential role to play as

stewards

of long-term care systems.

4. Conclusion

In many sub-Saharan African countries, organized long-term care services are essentially non-existent. The task of supporting care-dependent older people typically falls to female relatives who are unpaid and untrained for this work. The quality of this care often falls short, focusing at best on meeting older people's basic needs while overlooking ways to maximize their autonomy, dignity and functional ability.

All countries need a fully integrated long-term care system. For the vast majority of countries, this implies building an entirely new system. Governments can convene stakeholders in order to discuss and decide what needs to be done, and who will be responsible for what. In all countries, it is likely that a wide range of stakeholders will be involved in the process, although only governments can establish and govern long-term care systems as a whole. This needs to be considered as a core component of universal health coverage.

Families, who currently provide the bulk of long-term care in sub-Saharan Africa, merit special attention. Cultural norms concerning the centrality of family care must be acknowledged and accommodated. As long-term care systems develop, special efforts will be needed to ensure that family caregivers have access to the resources, information and training they need in order to perform their roles. This will ensure that older people receive the best possible care and that family caregivers are relieved of unnecessary stress that arises from being insufficiently informed and skilled in how to deal with challenging situations. Other mechanisms that can ease the load on caregivers include respite care (which could be provided, for example, by community-based groups) and stipends for the services they provide. In the longer term, the development of services provided by others will help ease the burden on family caregivers and ensure that care-dependent older people have access to the full complement of services needed to maximize their functional ability and well-being.

Annex 1

Topics covered at 2nd IAGG Africa Region Conference on Gerontology and Geriatrics

2nd IAGG Africa Region Conference on Gerontology and Geriatrics
Long-term care systems for Africa: setting agendas
6–8 December 2016 | Nairobi, Kenya

Day 1: Tuesday 6 December

16.30 – 17.00	Opening ceremony
17.00 – 18.30	Opening plenary: Toward long-term care systems in Africa – the stakes

Day 2: Wednesday 7 December

08.30 – 10.00	Panel I: Toward long-term care systems in Africa: Policy architecture and gaps
10.00 – 10.20	Tea/coffee
10.20 – 11.45	Panel II: Realities of long-term care: Family systems
11.45 – 13.00	Structured small group work and plenary feedback
13.00 – 14.00	Lunch
14.00 – 15.15	Panel III: Realities of long-term care: Formal services and systems
15:15 – 15.30	Tea/coffee
15.30 – 16.30	Structured small group work and plenary feedback
18.30 – 20.30	Conference dinner

Day 3: Thursday 8 December

08.30 – 10.15	Panel IV: Toward formal long-term care service models
10:15 – 10.45	Tea/coffee
10.45 – 12.00	Structured small group work and plenary feedback
12.00 – 13.00	Panel V: Toward long-term care system approaches (Part 1)
13.00 – 14.00	Lunch
14.00 – 15.15	Panel V: Toward long-term care system approaches (Part 2)
15.15 – 16.00	Closing plenary
16.00 – 16.30	Farewell tea/coffee

Annex 2

Process for establishing the regional evidence base

In order to establish the evidence base for long-term care in sub-Saharan Africa, conceptual analyses and a synthesis and generation of evidence was undertaken. This involved:

1. Analysis of existing regional and national policy or legal long-term care frameworks in order to determine their responsiveness to both the ultimate goals of long-term care implied by global frames and commitments and the realities of long-term care in the region.

2. Conduct of a full review of the scope of existing scientific and grey literature on long-term care in the region. The review was used to pinpoint key themes and to identify major gaps.

3. Development of conceptual perspectives on potential implications of current long-term care realities for important 'population and development' agendas in sub-Saharan Africa – specifically the quest to achieve a demographic dividend in the region through the expansion of education, health, employment and entrepreneurial opportunities for its young.

4. Development of a classification framework to guide exploration and profiling of the nature and operation of existing long-term care services in the region.

5. Application of the framework to:
   - conduct a mapping study in three counties of Kenya, to (i) develop a "typology" of dominant service forms; (ii) identify emerging service models; and (iii) identify aggregate-level patterns and gaps in long-term care;
   - use in the development of detailed profiles of emerging long-term care service models across a range of settings.

6. Development of case studies of national experiences of long-term care provision.

References

1. World Health Organization (2016). Multisectoral action for a life course approach to healthy ageing: global strategy and plan of action on ageing and health. Geneva: World Health Organization; 2016

2. Aboderin I (2017). Towards long-term care systems for Africa: setting agendas. A resource document. Geneva: World Health Organization.

3. Gureje O, Ogunniyi A, Kola L, Afolabi E (2006). Functional disability in elderly Nigerians: results from the Ibadan Study of Aging. J Am Geriatr Soc.54(11):1784-9. doi:10.1111/j.1532-5415.2006.00944.x.

4. Debpuur C, Welaga P, Wak G, Hodgson A (2010). Self-reported health and functional limitations among older people in the Kassena-Nankana District, Ghana. Glob Health Action.3. doi:10.3402/gha.v3i0.2151.

5. Payne CF, Mkandawire J, Kohler HP (2013). Disability transitions and health expectancies among adults 45 years and older in Malawi: a cohort-based model. PLoS Med.10(5):e1001435. doi:10.1371/journal.pmed.1001435.

6. Wandera SO, Ntozi J, Kwagala B (2014). Prevalence and correlates of disability among older Ugandans: evidence from the Uganda National Household Survey. Glob Health Action.7:25686. doi:10.3402/gha.v7.25686.

7. Aboderin IA, Beard JR (2015). Older people's health in sub-Saharan Africa. Lancet.385(9968):e9-e11. doi:10.1016/S0140-6736(14)61602-0.

8. World Health Organization (2015). World report on ageing and health. Geneva: World Health Organization; 2015.

9. African Union (2017). Draft common position on long-term care systems for Africa. Addis Ababa: African Union.

10. Scheil-Adlung X (2015). Long term care protection for older persons: a review of coverage deficits in 46 countries. Geneva: International Labour Organization; 2015.

11. van Der Geest S (2002). Respect and reciprocity: care of elderly people in rural Ghana. J Cross Cult Gerontol.17(1):3-31.

12. van der Geest, S (2016). Will families in Ghana continue to care for older people? Logic and contradiction in policy. In: Hoffman J and Pype K, editors. Ageing in sub-Saharan Africa: spaces and practices of care. Bristol: Policy Press; 2016.

13. Bohman DM, Van Wyk NC, Ekman SL (2009). Tradition in transition - intergenerational relations with focus on the aged and their family members in a South African context. Scand J Caring Sci.23:446-55. doi:10.1111/j.1471-6712.2008.00640.x.

14. Aboderin I, Hoffman J (2015). Families, intergenerational bonds, and aging in sub-Saharan Africa. Can J Aging.34(3):282-9. doi:10.1017/S0714980815000239.

15. Aboderin I, Hoffman J (2017). Research debate on 'older carers and work' in sub-Saharan Africa? Current gaps and future frames. J Cross Cult Gerontol. doi:10.1007/s10823-017-9331-7.

16. United Nations (2015). Transforming our world: the 2030 agenda for sustainable development. New York: United Nations.

17. African Union, HelpAge International (2003). Policy framework and plan of action on aging. Nairobi: HAI Africa Regional Development Centre.

18. African Union (2016). Protocol to the African charter on human and peoples' rights on the rights of older persons in Africa. Addis Ababa: African Union.

19. Clausen T, Wilson AO, Molebatsi RM, Holmboe-Ottesen G (2007). Diminished mental and physical function and lack of social support are associated with shorter survival in community dwelling older persons of Botswana. BMC Public Health.7:144. doi:10.1111/j.1471-6712.2008.00640.x.

20. Berthé A, Berthé-Sanou L, Somda S, Konaté B, Hien H, Tou F et al. (2014b). The key actors maintaining elders in functional autonomy in Bobo-Dioulasso (Burkina Faso). BMC Public Health.14:689. doi:10.1186/1471-2458-14-689.

21. Skovdal M, Ogutu VO, Aoro C, Campbell C (2009). Young carers as social actors: coping strategies of children caring for ailing or ageing guardians in Western Kenya. Soc Sci Med.69(4):587-95. doi:10.1016/j.socscimed.2009.06.016.

22. Uwakwe R, Ibeh CC, Modebe AI, Bo E, Ezeama N, Njelita I et al. (2009). The epidemiology of dependence in older people in Nigeria: prevalence, determinants, informal care, and health service utilization. A 10/66 dementia research group cross-sectional survey. J Am Geriatr Soc.57(9):1620-7. doi:10.1111/j.1532-5415.2009.02397.x.

23. Obrist B (2012). Who cares for frail older people? A rural-urban comparison from Tanzania. Paper presented at the 1st IAGG Africa Region Conference on Gerontology and Geriatrics, Cape Town, South Africa, 2012.

24. van Eeuwijk P (2014). The elderly providing care for the elderly in Tanzania and Indonesia: making 'elder to elder' care visible. Sociologus.64:29-5. doi:10.3790/soc.64.1.29.

25. Aboagye E, Agyemang OS, Tjerbo T (2013). Elderly demand for family-based care and support: evidence from a social intervention strategy. Glob J Health Sci.6(2):94-104. doi:10.5539/gjhs.v6n2p94.

26. Nortey ST, Aryeetey GC, Aikins M, Amendah D, Nonvignon J (2017). Economic burden of family caregiving for elderly population in southern Ghana: the case of a peri-urban district. Int J Equity Health.16(1):16. doi:10.1186/s12939-016-0511-9.

27. van der Geest S, Mul A, Vermeulen H (2004). Linkages between migration and the care of frail older people: observations from Greece, Ghana and the Netherlands. Ageing Soc.24:431-50. doi:10.1017/S0144686X04002302.

28. Ferreira M (2004). Elder abuse in sub-Saharan Africa: what policy and legal provisions are there to address the violence? J Elder Abuse Negl.16(2):17-32. doi:10.1300/J084v16n02_02.

29. Ananias J (2012). The relationship between informal caregiving, elder abuse and neglect in urban and rural areas of the Khomas Region in Namibia. Paper presented at the 1st IAGG Africa Region Conference on Gerontology and Geriatrics, Cape Town, South Africa, 2012.

30. Aboderin I, Hoffman J (2011). Caregiving in contexts of poverty in sub-Saharan Africa: critical perspectives on debates and realities. Keynote paper presented at the Festival of International Conferences on Caregiving, Disability, Aging and Technology, Toronto, Canada, 2011.

31. Yussuf AJ, Baiyewu O (2014). Elder abuse and neglect in Zaria northern Nigeria. Niger Postgrad Med J.21(2):171-6.

32. Berthé A, Berthé-Sanou L, Konaté B, Hien H, Tou F, Somda S et al.(2013). The unmet needs of the elderly living with functional disabilities in Bobo-Dioulasso (Burkina Faso). Rev Epidemiol Sante Publique.6:531-37.

33. Tam WJ, Yap P (2015). Lessons to exchange: a comparison of long-term care between two cultures: Uganda and Singapore. J Am Med Dir Assoc.16(12):1104.e15-9. doi:10.1016/j.jamda.2015.09.009.

34. Pype K (2016). Caring for people with and without value: Kinshasa's retirement homes between the family, the state and the church. In: Hoffman J, Pype K, editors. Ageing in sub-Saharan Africa: spaces and practices of care. Bristol: Policy Press; 2016.

35. Berthé A, Berthé-Sanou L, Konaté B, Hien H, Tou F, Somda S et al. (2014a). Motivations, gains and losses of actors supporting the elderly with functional disabilities and living at home in Bobo-Dioulasso (Burkina Faso). Revue Geriatr.39:91-8.

36. Mudiare, PEU (2013). Abuse of the aged in Nigeria: elders also cry. Am Int J Contemp Res.3:79-87.

37. van de Keere L (2010). Aging in an era of change: contextualizing the upcoming demographic shift in Marich Pass, North Western Kenya [thesis]. Halifax: Dalhouse University; 2010.

38. van der Westhuizen M (2012). The service centre as a supportive structure in the community. Paper presented at the 1st IAGG Africa Region Conference on Gerontology and Geriatrics, Cape Town, South Africa, 2012.

39. Pillemer K, Burnes D, Riffin C, Lachs MS (2016). Elder abuse: global situation, risk factors, and prevention strategies. Gerontologist.56 Suppl 2:S194-205. doi:10.1093/geront/gnw004.

40. Aboderin I, Hatendi N (2013). Elder abuse in sub-Saharan Africa. Nairobi: African Population Health and Research Center.

41. Schatz E, Seeley J (2015). Gender, ageing and carework in East and Southern Africa: A review. Glob Public Health.10(10):1185-200. doi:10.1080/17441692.2015.1035664.

42. Marais S, Conradie G, Kritzinger A (2006). Risk factors for elder abuse and neglect: brief descriptions of different scenarios in South Africa. Int J Older People Nurs.1(3):186-9. doi:10.1111/j.1748-3743.2006.00025.x.

43. Okoye UO, Asa SS (2011). Caregiving and stress: experience of people taking care of elderly relations in south-eastern Nigeria. Arts Social Sci J.29.

44. Govender T, Barnes JM (2014). The health status and unmet health needs of old-age pensioners living in selected urban poor communities in Cape Town, South Africa. J Community Health.39(6):1063-70. doi:10.1007/s10900-014-9851-9.

45. du Rand P, Engelbrecht K (2001). Needs of frail elderly people in informal settlements. Curationis.24(4):10-6.

46. Apt NA (1993). Care of the elderly in Ghana: an emerging issue. J Cross Cult Gerontol.8:301-12.

47. Apt NA (1995). International models. Health care of the elderly in Africa: focus on Ghana. Caring: National Association for Home Care Magazine.4:42-45, 47.

48. Apt N (1997). Aging in Ghana. Caring: National Association for Home Care Magazine.16:32-34, 36.

49. Dokpesi, AO (2015). The future of elderly care in Nigeria: borrowing a leaf from a foreign land. Ageing International. 40: 81-97.

50. Khasiani SA (1987). The role of the family in meeting the social and economic needs of the aging population in Kenya. Genus.43:103-20.

51. Kautz T, Bendavid E, Bhattacharya J, Miller G (2010). AIDS and declining support for dependent elderly people in Africa: retrospective analysis using demographic and health surveys. BMJ.16;340:c2841. doi:10.1136/bmj.c2841.

52. Dotchin CL, Paddick SM, Longdon AR, Kisoli A, Gray WK, Dewhurst F et al. (2014). A comparison of caregiver burden in older persons and persons with Parkinson's disease or dementia in sub-Saharan Africa. Int Psychogeriatr.26(4):687-92. doi:10.1017/S104161021300255X.

53. Department of Social Development, South Africa (2010). Final report: audit of residential facilities. Pretoria: Department of Social Development.

54. Aboderin I, Owii H (2016). Mapping extant formal long-term care service provision for older adults in Kenya. Developing a locally relevant typology and identifying emerging practice. Technical report submitted to the United Nations Department for Economic and Social Affairs.

55. Perold A, Muller M (2000). The composition of old age homes in South Africa in relation to the residents and nursing personnel. Curationis.23(1):87-94.

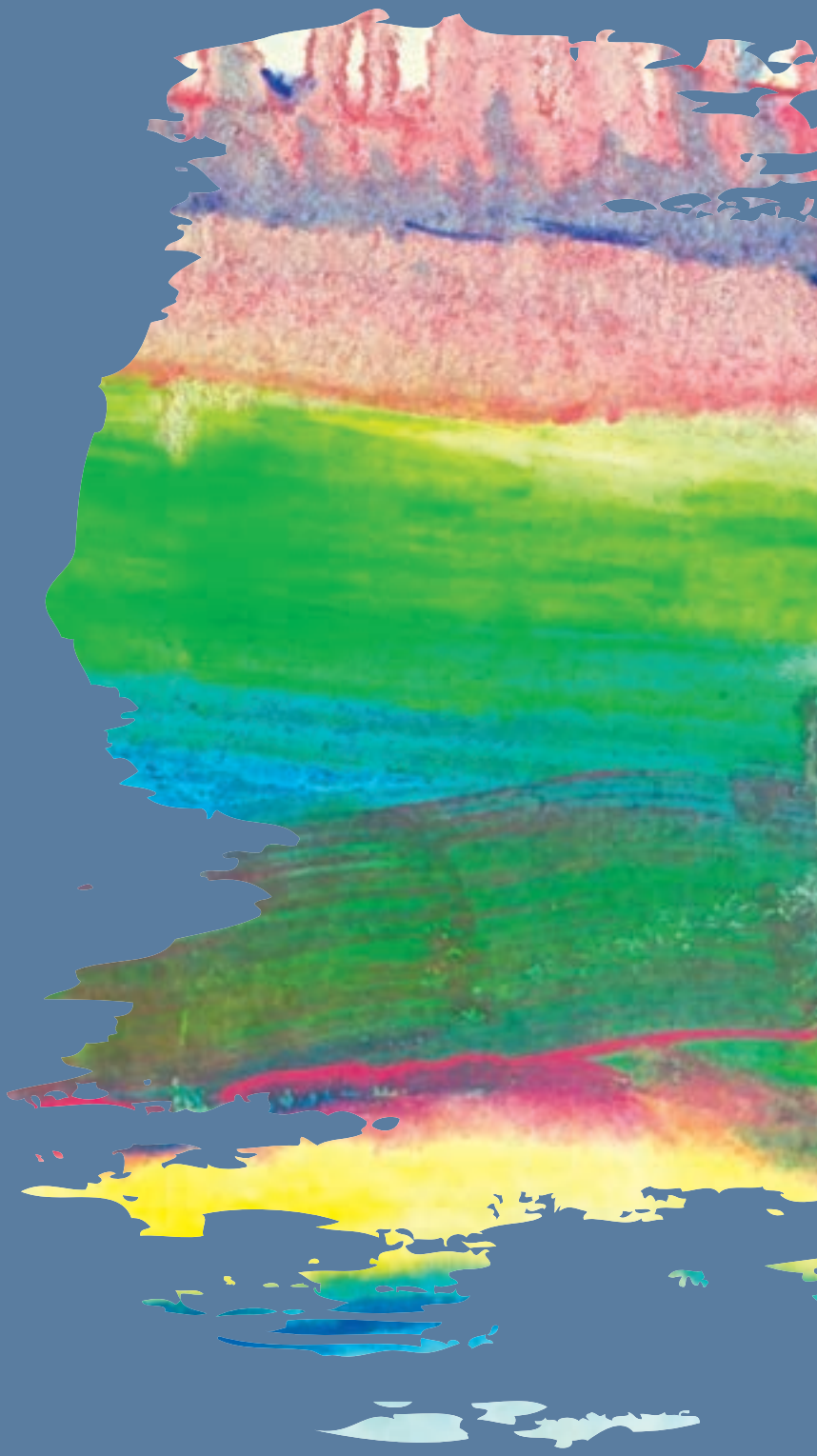
56. Olojede OI, Rispel LC (2015). Exploring the characteristics of nursing agencies in South Africa. Glob Health Action.8:27878. doi:10.3402/gha.v8.27878.

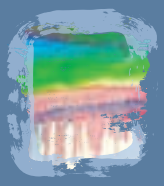
57. Hunt NB, Uys LR (1990). The quality of nursing care of the frail aged in selected institutions in eastern Cape and Natal. Curationis.13:21-3.

58. Shabangu TR (2011). An exploration of the experiences of older persons in an economically deprived residential care facility [thesis]. Potchefstroom: North-West University; 2011.

59. Teka A, Adamek ME (2014). "We prefer greeting rather than eating:" life in an elder care center in Ethiopia. J Cross Cult Gerontol.29(4):389-404. doi:10.1007/s10823-014-9244-7.

60. World Bank country and lending groups [website]. Washington: The World Bank; 2017 (https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups, accessed 1 October 2017).





For more information
Department of Ageing and Life-Course
World Health Organization
Avenue Appia 20
1211 Geneva 27
Switzerland

Email: ageing@who.int
Website: www.who.int/ageing

ISBN 978 92 4 151338 8