THE SITUATIONAL ANALYSIS OF OLDER PERSONS IN UGANDA: STUDY FINDINGS

Kampala, September 2018
CONTENTS OF THIS PRESENTATION

• Study background
• Overview: Situation of older persons
• Context: Ageing in Uganda
• Accessibility of services
• Key takeaways
In early 2018, the study was commissioned by the Ministry of Gender, Labour and Social Development to:

- Understand the situation of older persons in Uganda
- Highlight priority areas for the formulation of Older Persons’ Act
- Produce glossy publication to be released on October 1, 2018, on Older Persons’ Day
<table>
<thead>
<tr>
<th>Overarching questions</th>
<th>Study objectives</th>
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</table>
| **What is the current situation of older populations (60+ and above) in Uganda?** | a) Understand the socio-economic, cultural, health and disability situation of persons in Uganda  
  b) Provide an overview of differences by  
      - Gender  
      - Disability  
      - Living arrangements  
      - Location  
      - Other relevant disaggregators |
| **What are the priority actions that need to be taken at the policy level to improve the lives of older persons in Uganda?** | a) Provide an overview of challenges and achievements of services provision to older persons  
  b) Identify actionable priorities to inform policy level strategies for older persons |
# OVERVIEW OF METHODOLOGY

**Literature Review**
- **Objective**: Identifying literature gaps, study questions and themes
- **Review** of existing policy and legal frameworks
- **Source**: Academic and grey literature

**Qualitative Research**
- **Objective**: Understanding key risks, vulnerabilities, contributions of older persons, and successes and challenges of existing services for older persons
- **Source**: Primary research
  - Focus group discussions and interviews with older persons and caregivers,
  - Key informant interviews

**Quantitative Research**
- **Objective**: Developing demographic and socio-economic profiles, determining health and well-being status and access to services of older persons across regions, gender, socio-economic status
- **Source**: Analysis of existing national level data sets

**LIMITATIONS**
- Budget constraints for primary data collection
- Reliance on small sample size
- Limited disaggregation beyond 75 years
- Underestimation of disability
- Absence of UNDHS data for persons beyond 49 years
QUALITATIVE METHODS: COLLECTING PRIMARY DATA

WHY?
1. Bring forth older persons’ voices on their experiences of ageing in Uganda
2. Develop a contextualised picture of their
   • Role and relevance
   • Risks and vulnerabilities
   • Care systems
   • Knowledge of and access to services

WHO?
• Older persons
• Caregivers
• Community and clan leaders
• Government and non-government stakeholders at sub-county, district and national level

HOW?
• Semi-structured individual interviews (SSIs)
• Focus group discussions (FGDs)
• Participatory tools
• Key informant interviews (KII)

WHERE?
• West: Rukungiri
• Central: Mubende and Kampala
• East: Sironko and Tororo
• North: Arua and Pader
WHY?

Present national level disaggregated data on older persons:
  • Key demographics
  • Livelihoods
  • Poverty and living conditions
  • Ageing and health
  • Ageing and disability
  • Access to services

HOW?

• National Population and Housing Census (2016);
• Uganda Demographic and Health Survey (2016);
• Uganda National Household Survey (2016/17)
• Uganda National Panel Survey (2009/10)

DISAGGREGATORS

• Sex
• Location
  • Urban/rural
  • 15 sub-regions
• Living arrangements
• Disability
• Consumption quintiles
CAPABILITIES FRAMEWORK

Enables us to:
- Incorporate historical perspective
- Understand active ageing
- Address the myth of sickness and frailty

- Sen and Nussbaum

HUMAN RIGHTS FRAMEWORK

Enables us to:
- Understand the role of the state in present day
- Analyse service provision using the Availability, Accessibility, Acceptability and Quality framework (AAAQ)

CONCEPTUAL FRAMEWORK

Individual
- Freedoms & Functionings
- Household
- Community

Civil and Political Rights
Economic, Social and Cultural Rights (ESCR)

State
OVERVIEW: SITUATION OF OLDER PERSONS
• 2.9 per cent of population is above 60 years
• 17 per cent of households have an older person
• 55 per cent of older persons are women
• Highest share of older persons in Kigezi
• Lowest share of older persons in Kampala
At present, Uganda is not a rapidly ageing population.

Between 2050 and 2070, the number of older persons will increase by more than 2 times.
• Average life expectancy at 60 years is more than 15 years
• Average healthy life expectancy is 13 years
• Women have a higher life expectancy at 60 years

The graph shows life expectancy of older persons at five-year age group, by sex and calculation year.
Average number of reported sick days increases significantly with age

Age-related issues for older persons in Uganda include

- Arthritis
- Stroke
- Dementia
- Hypertension
- Diabetes
- Ulcers
- Cancer
- Respiratory problems
- Orthopaedic problems
- Vision and hearing loss

‘It’s common for people at that age not to be able to see. This is taken as something that comes with age and so they don’t take him to the hospital about it’
Disability prevalence increases significantly with age

6 out of 10 older persons has some difficulty one of the four areas of functional limitations (walking, seeing, hearing, remembering)

1 out of 8 older persons have a lot of difficulty in at least one of functional areas
**AGEING AND DISABILITY**

**Percentage of older persons with a severe functional limitation, by sex and five-year age group**

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**Ageing-related disability:**

- Mobility and movement functions
- Vision and hearing

Disability strongly related to socio-economic conditions and health

More older women have a disability in comparison to older men

Order of prevalence of various types of disability remains unchanged across all regions

Prevalence rates of disability are much higher in Acholi, a post-conflict region
Size and composition of the population in poverty significantly influenced by the choice of equivalence scales employed.

Equivalence rates used by the Uganda Bureau of Statistics (UBOS) may underestimate poverty rates among older people.
• **2 out of 5** older persons live below the international extreme poverty line (UGX 2700 per person per day)

• **Only 2 out of 50** older persons live on more than UGX 13,700 per person per day
CONTEXT: AGEING IN UGANDA
**WHO IS CONSIDERED AN OLDER PERSON IN UGANDA?**

**Social perceptions**
- Someone above 60-70 years (responses vary)
- Prone to frailty, disability and illness
- Grandparent and head of household
- Behaves ‘well’
- Lower levels of engagement in economic activities
- Physically dependent on others

**In contrast: Lived experiences of an older person**
- Older persons are socio-economically active unless severely disabled or chronically ill
- Older persons play a key role in the care of young children
- Financial demands in old age have increased
- The culture of reciprocal care of ageing family members has eroded over time
- Age-based discrimination embedded in service provision
<table>
<thead>
<tr>
<th>Type of major events/disruptors</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Civil conflict and displacement</td>
<td>Experience of long term poverty</td>
</tr>
<tr>
<td>Urbanisation</td>
<td>Change in community and family structures</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>Change in role and value of older persons</td>
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<tr>
<td>Land conflict and sub-division</td>
<td></td>
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<tr>
<td>Drought and weather related shocks</td>
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</tbody>
</table>

**TYPICAL LIFE-COURSE OF AN OLDER PERSON**

**ABSENCE OF THE STATE and APPROPRIATE SERVICES**
****HISTORICAL RELEVANCE****

Older persons as socio-cultural leaders

- Transmitting cultural traditions and gender norms over generations
- Guardians of indigenous knowledge, for example, art and history and healthcare
- Guide and conflict mediator within communities
- Protectors of ancestral and communal land
- Oral historians

****ROLE AND RELEVANCE OF OLDER PERSONS****

Relevance in the present day

Relevant in their families and communities by striving to adhere to traditional gender roles

- Older women remain relevant by caring of children within the household
- Older men remain relevant by heading families and being cared for by their spouses and younger members

Striving to maintain their dignity and autonomy through work and income

- An important aspect of dignity is having their own home and being able to cover their basic needs
- Older persons continue as farmers to retain a fundamental part of their identity
- SCG bestows dignity and restores autonomy to an older person, thus perceived to ‘stay younger for longer’
Kinship is defined by both biological and social relations.

Wealth in the kinship circle determines to a large extent their socio-economic vulnerability.

Kinship circles determine the family structures and informal care.

Multi-generational households most prevalent followed by skipped generation households.
Older women are more likely to live alone than older men when they have a severe disability.
1 out of 6 older persons live only with children under 18.

77 per cent of the children have both parents living.

Older women twice more likely than men to live only with children.

Distribution of orphanage status of children in skipped generation households and other households that include an older person.
Women take on a disproportionate share of unpaid care work across their lifetime.

At 60 years, 65 percent of women are still doing care work.
CASE STUDY OF FAMILY CARE

Peace is a 55-year old woman who is HIV positive and a caregiver of her older mother who is above the age of 80 years and of her niece whose parents died of HIV/AIDS in the 1980s.

She received anti-retroviral treatment on time and now lives what she considers a healthy life.

She often worries about her ability to care for her mother, given her chronic medical condition which may deteriorate at any time, especially as she advances into old age.

Eventually the next woman relative, her niece will become the only source of support.

‘The sick are caring for the sick’
Children in skipped generation households are 28 per cent more likely to have a care burden.

Percentage of children taking on care responsibilities, by living arrangement.
• 2 out of 3 older persons in *skipped generation households* engage in care work

• The *financial burden of care* forces many to continue working as agricultural workers but at lower pay
• 30 per cent of all children under the age of 5 years are stunted.

• Nearly one in two children in a skipped generation household is stunted.

“Some of the children who died left very tiny babies and as an older person it became a challenge to find ways to take care of these babies’
The majority still reliant on agriculture which is physically strenuous

- **60 per cent** rely on subsistence agriculture as main source of income
- Followed by remittances at **12 per cent**
- **11 per cent** rely on wage employment, concentrated in Kampala

**Older women**: subsistence farming, handicrafts, petty trade, agriculture labour, brewery

**Older men**: cash crops - banana and coffee plantations, maize, selling livestock

<table>
<thead>
<tr>
<th>Sex of household head</th>
<th>Main income source for households headed by older persons, by sex, location and consumption quintile</th>
</tr>
</thead>
<tbody>
<tr>
<td>Females</td>
<td>Subsistence farming: 54, Wage employment: 10, Non-agricultural enterprise: 8, Remittances: 21, Others: 6</td>
</tr>
<tr>
<td>Males</td>
<td>Subsistence farming: 64, Wage employment: 12, Non-agricultural enterprise: 10, Remittances: 5, Others: 9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Consumption Quintile</th>
<th>Subsistence farming</th>
<th>Wage employment</th>
<th>Non-agricultural enterprise</th>
<th>Remittances</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Richest</td>
<td>45</td>
<td>13</td>
<td>11</td>
<td>16</td>
<td>15</td>
</tr>
<tr>
<td>4</td>
<td>55</td>
<td>7</td>
<td>15</td>
<td>13</td>
<td>10</td>
</tr>
<tr>
<td>3</td>
<td>60</td>
<td>15</td>
<td>8</td>
<td>12</td>
<td>5</td>
</tr>
<tr>
<td>2</td>
<td>70</td>
<td>7</td>
<td>7</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Poorest</td>
<td>69</td>
<td>13</td>
<td>4</td>
<td>10</td>
<td>3</td>
</tr>
</tbody>
</table>
Older persons rely heavily on remittances as one key source of income in comparison to other households.

Older women rely more heavily on remittances in comparison to older men.

### Percentage of households headed by older persons receiving remittances as major income source, by sex and living arrangements

<table>
<thead>
<tr>
<th>Living Arrangement</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skipped generation household</td>
<td>62%</td>
</tr>
<tr>
<td>Only older persons</td>
<td>64%</td>
</tr>
<tr>
<td>Older person and working age</td>
<td>47%</td>
</tr>
<tr>
<td>Multigenerational households</td>
<td>41%</td>
</tr>
<tr>
<td>Male</td>
<td>40%</td>
</tr>
<tr>
<td>Female</td>
<td>65%</td>
</tr>
</tbody>
</table>

Older persons living alone
A majority report ‘too old to work’ which indicates ageing-related functional limitations (disabilities)

- **32 per cent** of all older persons also reported not working and not looking for work
- **31 per cent** of these respondents cited disability or injury as the main reason
Approximately **two-thirds** of households headed by older persons rely on an irregular source of income.

Nearly **3 out of 4** of these households is headed by an older person **that is 80 years or older**.
Food insecurity and poor nutrition increases the likelihood of ageing-related illness and disability

- Food consumption scores (FCS) worsens with age
- Older persons living alone have the poorest FCS, followed by skipped generation households

Risks

- Unable to survive on subsistence farming and forced to purchase expensive foods
- Food availability and storage affected by drought and flooding
- Lack of storage facilities forces older persons to sell food instead of consuming
- Older persons go hungry if unable to cook or there is no one to cook for them
• Over 1 in 4 older persons live in a household without a permanent roof

• 3 in 4 older persons do not have an improved toilet in their house

When put in context..

• Improved housing: Older persons without male family members or financial resources are unable to improve housing

• Improved drinking water:
  • Older persons have access when there are young children to fetch water
  • Boreholes and community taps often have long waiting times and associated costs

• Improved toilet: Older persons’ struggle to squat even in improved pit latrines
NEGLECT AND ABUSE OF OLDER PERSONS

**Economic violence:** land grabbing and conflict
- Widows at risk of land eviction by family
- Central Uganda: squatters at risk on private Mailo land
- Land grabbing by private investors
- Lack of land title puts older persons at risk

**Other types of violence and neglect**
- At risk of theft and physical violence by young men
- Emotional torture and harassment
- Coerced by sons into selling land for boda bodas

**Psycho-social abuse**
- Verbal abuse
- Accusations of witchcraft
- Social exclusion and discrimination by service providers

**Gender based violence**
- Older women living with spouse at risk of intimate partner violence
- Older women living alone at risk of rape by strangers
ACCESSIBILITY OF SERVICES
Rights of older persons:

• The right of everyone to the enjoyment of the highest attainable standard of physical and mental health
• The right to life
• The right not to be subjected to torture or to cruel, inhuman or degrading treatment
• The right to privacy, family and home
• The right to adequate standard of living

Challenges

• Overwhelming focus on maternal and child health in the health sector
• NCD health interventions focusing on youth in urban areas with certain lifestyles
• Lack of training of community based VHTs on providing care to older persons
• Neglect and negative attitudes of health workers and staff
• NCDs and ageing-related illness only treatable at HC4s
• Understocking of medicines for high pressure and diabetes
• No equipment to diagnose or treat ageing-related illnesses and NCDs
LONG-TERM CARE

Rights of older persons:

- The right of everyone to the enjoyment of the highest attainable standard of physical and mental health
- The right to life
- The right not to be subjected to torture or to cruel, inhuman or degrading treatment
- The right to privacy, family and home
- The right to adequate standard of living

Challenges

- **Overwhelming focus on family** as the central care unit, with burden falling on women
- **Family care structures ill-equipped** to address specific the long-term care needs, including palliative care
- **Lack of affordable and high quality residential care** for older persons that do not receive sufficient care at home
- **Absence of community care systems** that include outreach services offered by volunteers or paid government workers
HEALTH AND WELL-BEING: BEST PRACTICE EXAMPLES

**Who:** ROTOM and CARITAS  
**How:** Training, sensitising and incentivizing community health extension workers to prioritise older persons

**Who:** Sightsavers and Queen Elizabeth Diamond Jubilee Trust’s Trachoma Initiative  
**How:** Using a SCG pay points as a service location for free cataract and trachoma diagnosis and treatment

**Who:** Health Centre IV, Rukungiri  
**How:** Older persons co-operative model to fund treatment of diabetes through adequate provision of equipment and medicines
**Rights of older persons:**
- The right to equal recognition before the law
- The right to access to Justice
- The right to privacy, family and home
- The right not to be subjected to torture or to cruel, inhuman or degrading treatment
- The right to life
- The right to liberty and security of the person
- The right to property

**Challenges**
- **Local Council courts** at the parish level have weakened over time
- **Discrepancy** between customary ‘unwritten law’ and statutory ‘written’ law
- **Limited access to full information** on their legal rights
- **Poor physical access** to law and order authorities
POLITICAL REPRESENTATION

Political structures

• District and sub-county level councils of older persons institutionalised and recognised by law

• Male and female councillors of older persons appointed at district and sub-county level

• Key facilitators for ensuring the rights of older persons

• Older persons need and demand a political voice in the government

Challenges

• Budget constraints in facilitation of their activities

• District level government often unaware of the role and importance of the councils

• Older persons often unaware of the presence of council of older persons

• Main activities include occasional meetings
Challenges

Less than 50% of the total population of Ugandans access any form of credit

Access to credit reduces with age

Why?

• Denied access to formal loans, savings and debt insurance
• Older persons considered a credit risk
• Stereotyped as frail and not economically active
Challenges for retirees from the formal sector, especially public services

• Retirement age set at 60 years
• Inadequate post-retirement orientation
• Challenges in getting approved for public service pension
• Government retirees unable to access Senior Citizen’s Grant

INCOME SECURITY FOR NON-SCG RECIPIENTS

Percentage of people living in households receiving any form of pensions

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage of People Receiving any Form of Pension</th>
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<tbody>
<tr>
<td>Youth (15 – 24 years)</td>
<td>1.6%</td>
</tr>
<tr>
<td>Working age (25 – 59 years)</td>
<td>2.2%</td>
</tr>
<tr>
<td>60 - 64 years</td>
<td>0.9%</td>
</tr>
<tr>
<td>65 - 69 years</td>
<td>0.4%</td>
</tr>
<tr>
<td>70 - 74 years</td>
<td>0.9%</td>
</tr>
<tr>
<td>75+ years</td>
<td>1.8%</td>
</tr>
<tr>
<td>Total</td>
<td>1.8%</td>
</tr>
</tbody>
</table>
The SCG is documented to improve children’s schooling and nutrition, boost local economies and provide additional income to entire households.

For SCG recipients, the likelihood of being in poverty dropped by almost 18 percentage points.

The poverty rate among recipient households would fall by 21% if everyone over 65 years were to receive the SCG.

The poverty rate among recipient households would fall by 33%, if the SCG were raised to UGX 40,000 per month.

Illustration of difference-in-difference of poverty rates between SCG beneficiaries and comparison group.
THE SENIOR CITIZENS’ GRANT: CHALLENGES

PILOT DISTRICTS
Over 60% of older persons across pilot districts are receiving the pension
Over 80% of older persons targeted in 10 of the pilot districts

ROLL OUT DISTRICTS
Less than 40% of older persons being targeted in roll out districts
RECOMMENDATIONS

- Support active ageing: integrated service provision
- Addressing age-based discrimination in services
- Implementing a universal old age pension
- Life cycle approach to social protection
- Improving health care for older persons
- Establishing long-term care systems
- Access to justice systems
- Strengthening political influence
EXAMPLE: HOW CAN THE STATE PROVIDE BETTER HEALTH CARE?

**Availability**
- Bringing the health services used by older people closer to their communities
- Providing early diagnosis for prevention and onset of non-communicable diseases and disability
- Providing rehabilitation and palliative care services
- Improving availability of assistive devices
- Addressing treatable impairments such as cataracts

**Accessibility**
- Ensuring affordability of treatment
- Improving physical accessibility
- Creating access to information

**Acceptability**
- Changing attitudes of community health workers
- Establishing a gender and age-sensitive health care system

**Quality**
- Training of health professionals on ageing related issues
- Provision of appropriate diagnostic equipment and medication
OLDER PERSONS’ ACT: CREATING A THEORY OF CHANGE

The state of Uganda
- Social protection throughout the lifecycle to prepare for old age
- Integrated service provision for older persons

Shift in institutional approach to enable ageing with dignity
- Distinction between ageing as a medical condition and older persons as human beings with rights
- Distinction between older persons that are active and older persons with long-term care needs

Shift in policy discourse
- Promotion and protection of freedom and rights

Shift in social perceptions
- Economic empowerment

Improved health and wellbeing

Ageing with dignity
- Ability to contribute
- Decision making power
- Ability to cover needs
- Relevance and respect
The second phase of the Expanding Social Protection Programme (ESP II) is implemented by the Ministry of Gender, Labour and Social Development, funded by the UK Department for International Development and Irish Aid, and managed by Maxwell Stamp in association with Development Pathways.