

## **HelpAge International Submission on Autonomy and Independence**

9<sup>th</sup> Working Session of the Open-ended Working Group on Ageing, 2018

### **Introduction**

Older people must be part of the growing discussion on their human rights. To this end, in November 2017 HelpAge International consulted older people across 24 countries<sup>1</sup> on the rights to be discussed at the 9<sup>th</sup> Session of the UN OEWG. This submission presents the issues they raised and uses their own words. The 450 participants were self-selecting so their responses are not a representative sample of older people.

### **Guiding Question 1: Autonomy and independence in legal and policy frameworks**

Older people in the consultation understood autonomy and independence as making their own decisions without interference from others and being free to enjoy their rights. They also said being able to participate in family and cultural life, acting on their own ideas, doing things for themselves, solving their own problems and achieving their goals were all central to independence.

It was clear from the consultation responses that older people want to lead autonomous and independent lives. They value autonomy and independence highly.

“It’s the most beautiful thing there is, to be able to do what I want because I feel free. A person without independence would be as good as dead.” Costa Rica, 71-year-old woman

There are no explicit standards on autonomy and independence in older age in international human rights law. Everyone’s right to equal recognition before the law and the right to a family and private life, which are both central to autonomy and independence, are enshrined in international human rights law. However, there are no explicit international standards on how these rights apply in older age. Some regional human rights standards recognise the right to autonomy and independence in older age. However, these vary and are inconsistent across regions.

### **Guiding Question 2: Other rights essential for the enjoyment of the right to autonomy and independence**

In the consultation older people said a deterioration in their health or income, the loss of a job or retirement and a change in circumstances, such as going to live with a family member, are events which made them dependent on others, and resulted in them losing their autonomy and independence.

“The moment we have to ask someone to do something for us, our independence vanishes as we depend on their will and mood.” Serbia, 69-year-old woman

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<sup>1</sup> Argentina, Bolivia, Cambodia, Chile, Colombia, Costa Rica, Kenya, Kyrgyzstan, Mauritius, Moldova, Mongolia, Myanmar, Nepal, Nigeria, Peru, Philippines, Russian Federation, Rwanda, Serbia, Slovenia, Sudan, Tanzania, Uganda and Zambia

The enjoyment, therefore, of the rights to social security, to health, to work, to care and support services and to choose where, with whom and how to live their lives are essential for the enjoyment of the right to autonomy and independence.

In addition, to enjoy their right to autonomy and independence older people must have legal capacity at all times and be recognised before the law on an equal basis with others.

Autonomy and independence are also underlying principles that govern every human right. Older people should enjoy autonomy and independence in the exercise of all their rights.

### **Guiding question 3: Key challenges**

Many older people said they are not able to make their own decisions about their finances, employment, management and disposal of their property, who to vote for, where and with whom to live, access to health services, family life and participation in community, voluntary or social activities.

“In health issues we do not have the possibility or the support to choose the type of care we want to have, the type of treatment and appropriate medications.” Colombia, group discussion

Different people are preventing, or interfering with, older people’s autonomy and independence, including government and local authorities, policy makers, local leaders, service providers and family members.

“[I can’t make my own decisions around] attending recreational events and joining organisations because I need to ask for my children’s permission as I am taking care of my grandchildren.” Philippines, group discussion

“We cannot decide the church because we live in a Catholic charitable home. We are obliged to be Catholic.” Rwanda, group discussion

Many older people said the autonomy and independence they enjoyed earlier in their lives is denied them in older age, often because others think they can no longer make their own decisions or disregard them when they do.

“I am seen as if I am finished. This I will not accept.” Nigeria, 78-year-old man

### **Guiding Question 5: Mechanisms necessary**

International human rights standards are needed on older persons’ right to freedom of personal autonomy and legal capacity to make decisions, to determine their life plans and to lead autonomous and independent lives in line with their will and preferences and on an equal basis with others. This includes the right to have those decisions respected.

The right should apply to all aspects of life.

The right should include the right to

- Interact with others and full, effective and meaningful participation in family, social, cultural, economic, public and political life and educational and training activities
- Live independently in the community on an equal basis with others
- Choose where, with whom, and how to live their lives and not to be obliged to live in any particular living arrangement. When older persons choose to live in shared residential settings, their rights to autonomy and independence must be respected
- Access to services to support independent living and inclusion in the community.

Standards are also needed on the right of older persons to legal capacity at all times and the right to equal recognition before the law on an equal basis with others.

The right should apply to all aspects of life.

The right should include the right to:

- Designate one or more trusted persons to support them with making decisions based on their own will and preferences
- Set out their will and preferences in advance
- Participate in, and challenge, any decisions that interfere with the exercise of their legal capacity
- Access to appropriate and effective safeguards to prevent abuse in the exercise of legal capacity.

There should be an obligation on states to ensure trusted persons, support and other service providers receive appropriate training in this area.

A full report of the consultation findings will be submitted to the OEWG in advance of the 9<sup>th</sup> Session and can be found [here](#). For further information contact Bridget Slep, HelpAge International [bslep@helpage.org](mailto:bslep@helpage.org)