

**Joint submission by AGE Platform Europe, HelpAge International, The Law in the Service of the Elderly and the National Association of Community Legal Centres Australia<sup>1</sup>  
Open-Ended Working Group On Ageing, 9<sup>th</sup> Working Session, 23-26 July 2018**

**Autonomy and independence**

**Authors**

1. This joint submission is authored by Robin Allen (Cloisters), Andrew Byrnes (Australian Human Rights Institute, Faculty of Law, University of New South Wales), Israel (Issi) Doron (University of Haifa), Nena Georgantzi (AGE Platform Europe / National University of Ireland Galway), Bill Mitchell (National Association of Community Legal Centres, Australia) and Bridget Sleap (HelpAge International). Our views do not necessarily reflect the broad and consensual positions of the organisations we represent, which will be submitted separately.

**Context of Response**

2. This response addresses the guiding questions from a global perspective. It is an executive summary of a more comprehensive statement which will be provided to the 9<sup>th</sup> working session.

**Guiding Question 1**

3. Autonomy is the ability to make choices and decisions, including with support if necessary, according to one's conscience, values, will and preferences.
4. Independence is the ability to perform actions of daily living and participate in society in accordance with one's will, values and preferences.
5. Whilst the right to equal recognition before the law and the right to a family and private life are enshrined in international human rights law, there are no explicit standards on autonomy and independence in older age in international human rights law.
6. 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**

7. Autonomy is both an underlying principle that governs every human right and a right in and of itself. The principle of autonomy presumes that individuals are able to make choices according to their own will and preferences. In order to make autonomous decisions, and for these decisions to be legally effective, the law requires that the individual has the legal capacity to do so. To enjoy their right to autonomy, therefore, older persons must enjoy legal capacity and equal recognition before the law on an equal basis with others.
8. Independence does not necessarily mean living alone or carrying out all daily activities by or for oneself. Rather independence is having choice and control over decisions about one's own life, including control over decisions which lead to the execution of tasks that someone else carries out. To enjoy their right to independence, older persons must enjoy their right to care and support for independent living.

**Guiding Question 3**

9. Older persons are subjected to ageist attitudes that devalue, discount or ignore their views and choices, or assume they can no longer make, and are thereby denied the opportunity to make, decisions for themselves.
10. Older persons may be denied their autonomy and independence in any aspect of life including decisions about their care and support services; leisure time; property; income; finances; place of residence and living arrangements; personal, family and private life, including sexual and intimate relationships; and political participation.
11. Concerns have also emerged around the denial of older persons' free and informed consent in areas such as medical treatment, restrictive interventions and practices, and end of life care and treatment.
12. A paradigm shift is required away from this and to the presumption that older persons can exercise their autonomy and independence through choice and control over decisions in their lives in line with their will and preferences. The best safeguard for autonomy, independence and legal capacity is respect for will and preferences.
13. This paradigm shift requires us also to change the social construction of human dignity in older age whereby dignity in older age is not centred around protection, intervention and professional care in the 'best interest' of the older person. Rather, dignity in older age means respecting autonomy and ensuring independence in older age. The use of the 'best interests' principle in respect of adults is not a safeguard that complies with international human rights norms.

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**Guiding Question 5**

14. 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.
15. The right should apply to all aspects of life.
16. 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 (More detail on the right to care and support for independent living is included in our submission on long-term care.)
  - 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.
17. 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.
18. The right should apply to all aspects of life.
19. The right should include the right to:
  - Designate one or more trusted persons to assist them to make decisions based on their instructions, will and preferences
  - Make advance directives to express their will and preferences in advance
  - Participate in, and challenge, any decisions that interfere with the exercise of their legal capacity.