

WHO's response to UN request for input on VIV Session of UN Open-ended Working Group on Ageing

Autonomy and Independence

Older age is characterized by great diversity. While WHO works to reduce “care dependency” we promote “interdependency” in preference to “independence”. A strong focus on independence risks marginalising those people experiencing significant loss of physical or mental capacities for which independence is not a possibility. As such, much of the following discussion focus on autonomy - the ability to having choices and control over one's actions (but not necessarily execute them) and independence where relevant.

Autonomy has been repeatedly identified by older adults as a core component of their well-being and powerful influences on their dignity, integrity, freedom and independence. Older adults have the right to make choices and take control over a range of issues including where they live, the relationships they have, what they wear, how they spend their time, and whether they embark on a treatment or not. Nevertheless, many older people – particularly women - do not yet enjoy these opportunities across the life course. These fundamental rights and freedoms must exist regardless of age, sex or level of intrinsic capacity, including in emergency situations and need to be enshrined in law.

Autonomy and independence are shaped by many factors including the capacity of the older person; the environments they inhabit; the personal (such as relationships with children and other family members, friends, neighbours and broader social networks) and financial resources they can draw on; and the opportunities available to them. Autonomy and independence are heavily dependent both on an older person's basic needs being met, and on access to a range of services – such as transport, appropriate housing, accessible urban environments and lifelong learning. Older people's autonomy and independence can be particularly comprised in emergency situations if appropriate action is not taken.

Enhancing autonomy regardless of an older person's level of capacity can be achieved through a range of person centred mechanisms including advanced care planning, shared or supported decision making and access to appropriate social support or/and assistive devices. When appropriately adapted to the person and their environments, which may both change over time, these can enable older people to retain the maximum level of control over their lives. Other actions which impact directly on older peoples' autonomy, include protecting and ensuring their human rights through awareness raising, legislation and mechanisms to address breaches in rights. For example one key threat to autonomy is elder abuse, which currently affects 15.7% of older people living in the community and an even higher proportion living in institutions. Specific actions are therefore required to protect older people rights' to freedom from violence and abuse.

Enhancing independence can be achieved by providing integrated care for older persons, creating supportive physical and social environments that help to maintain physical, mental, psychosocial and spiritual capacity across the life course and into older age and compensate when these may decline.

The Global strategy and action plan on ageing and health, developed through broad consultation with WHO's 194 Member States, organization of the United Nations and international and national partners, highlights the need to foster older people's autonomy

and independence (see Strategic objective 2). It provides a framework for coordinated action until 2030 to align with the sustainable development goals. Actions under the strategy including

- Developing age-friendly environments at the local, regional and national levels through multisectoral action including areas such as of housing, transport, health, long-term care and palliative care, urban planning and development, information and communication etc.;
- Implementing evidence based elder abuse prevention and response programmes;
- Raising awareness about the rights of older persons and create mechanisms to address breaches of these rights including in long-term care and palliative care and emergency situations;
- Providing mechanisms for advanced care planning (including in long-term care and palliative care provision), appropriate social support and assistive technologies and supported decision-making that enable older people to retain the maximum level of control over their lives despite significant loss of capacity

Actions already taken or underway by the World Health Organization include:

1. Development and expansion of the *WHO Global Network for age-friendly cities and communities* to support the implementation of the Sustainable development goals notable Goal 11 as well as the New Urban Agenda. The network currently covers over 550 cities and communities in 37 countries supporting over 180 million people. Two new initiatives released so far this year include:

- A new database of age-friendly practices to support cities and communities identify innovative examples that may be relevant to their context.
<https://extranet.who.int/agefriendlyworld/afp/>
- A new Mentorship programme to build community leaders capacity to create age-friendly environments.

2. The release of a Priority assistive products list to support countries to identify those devices that may be needed for older adults to maintain autonomy and independence
http://www.who.int/phi/implementation/assistive_technology/EMP_PHI_2016.01/en/

3. A range of activities to better understand and respond to elder abuse as previous outlined to the OEWG such as new systematic reviews on prevalence of elder abuse; a new database of available evidence on prevalence, risk factors, consequences and interventions in elder abuse which is under development.

Long-term and Palliative Care

Worldwide, the need for Long-Term Care (LTC), including Palliative Care (PC), is great among older people, due to significant ongoing losses in physical or mental capacities. . The World Health Organization defines LTC as: 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 (WHO, 2015). PC is part of LTC, focusing on older people and their families who are facing life-threatening illness, with the goal to prevent and relieve their

suffering, whether physical, psychosocial or spiritual. These definitions take a person-centred approach, defining the goal of care, rather than specific services needed.

LTC-systems integrate paid and unpaid social care, palliative care, health care, rehabilitation, and training, counselling and support for caregivers. To ensure optimal co-ordination and efficiencies, contributions of other sectors, such as education, should be integrated. LTC is most effective and efficient when it is matched to a person's unique needs and goals at the time and over time. Importantly, long-term care should enable the person's autonomy to do as much as possible themselves, rather than replace their existing or potential ability with a service that may ultimately decrease function and increase care dependency. LTC, including PC, should also enable ageing in place. For example, older people should be empowered to stay and die at home in dignity surrounded by their friends and families.

In many countries, the provision of LTC and PC is left entirely to families. They 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, suffering or in pain or in some instances experiencing flagrant abuses of their fundamental rights. It also places an unnecessary burden on caregivers, who are overwhelmingly female, and it drives inequities. Caregivers may experience a loss of, or a cut back in, paid work, a loss of education and/or health problems, like depression and physical problems.

Family care without supporting, complementing or supplementing services is unsustainable, even more so as the need for LTC and PC increases and family structures change (having less children, migration of children to urban areas).

WHO's Global strategy and action plan on ageing and health calls upon all countries to establish an effective, sustainable and equitable system of LTC. This strategy was adopted by the World Health Assembly in 2016. Specific underlying principles are: LTC must be affordable and accessible, with special attention for poor and marginalized people; it should uphold the rights of older people, and be provided in a way that enhances people's dignity; it should be oriented around their needs, and enable their ability to make choices. **WHO's resolution on palliative care** adopted by the World Health Assembly in 2014, calls upon all countries to improve access to palliative care, especially in primary health care and community/home-based care.

Based on the evidence described in **WHO's World Report on Ageing and Health** (2015), three action areas are distinguished to establish effective, sustainable and equitable LTC-systems: 1. Development and continually improvement of the LTC-system infrastructure, for which stakeholders need to work together in concert involving active community participation, under the stewardship of governments; 2. Capacity building of the workforce (training, career opportunities), support of families and other unpaid caregivers, and adequate supply and equitable balance between the paid workforce, families and other unpaid caregivers. Training and support are also important to improve the quality of care and prevent abuse, violations and the use of restraints; 3. Improvement of the quality of LTC, including PC, with the provision of person-centred and integrated services and through the establishment of minimum standards and accreditation for care providers.

Actions by the World Health Organization already taken or underway:

- Building understanding and commitment to develop LTC-systems and improve integrated care, including palliative care, through global, regional and local policy dialogues and educational resources to catalyse change;
- A tool to map the current situation of LTC-provision in countries and monitor improvements over time, and the global atlas on palliative care, both to inform country action;
- Provision of tools and technical assistance for countries to establish effective, sustainable and equitable LTC-systems and improve their palliative care services.

Constructing long-term care systems should not be viewed as a financial burden, but rather as a prerequisite for Universal Health Coverage and an investment in human capital that is necessary to achieve the Sustainable Development Goals.