



**Workshop on the Social Integration  
and Rights of Older Persons in  
the Asia-Pacific region**  
30 September – 2 October 2014, Bangkok



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**Guidance Note:**

**Session on “Long-term Care of Older Persons”**

Many countries in Asia and the Pacific have, until now, treated care of older persons as primarily a family responsibility. However, with changing social and economic realities, in combination with the growing number of older persons, governments are re-examining their approaches. The population of oldest-old, aged 80 years and older - those generally in greatest need of long-term care, increased in the region from 0.88 per cent in 1990 to 1.4 per cent in 2012 and is expected to reach 4.4 per cent in 2050.<sup>1</sup> Due to women’s longer life expectancy the majority of these are women.

Care and support services and the manner in which they are provided are vital to maintaining the health, quality of life and independence of older persons and their participation in their communities and society. Long-term care encompasses a variety of health and social care services for older people who have difficulty caring for themselves for long periods of time. It can include, for example, support in Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) like feeding, dressing, walking, bathing, using the bathroom, taking medication, shopping and coping with household tasks, as well as for example long-term care nursing and palliative care.

In Asia and the Pacific the central pillar of long-term care is home-based care with family members as carers. While children have been, and largely remain the dominant family caregiver, increasingly spouses are the main caregiver and many informal carers are older persons themselves. Community care is often developed as an alternative or complementary to family-based care, with for example community day-care centres and community volunteers providing home-care services. Volunteer services are often organized by community-based organizations, in some cases Older Persons Associations (OPAs), while less frequently by local hospitals or with other government involvement. Institutional care, while less common in the region, is also provided. With changing demographics, internal migration and women’s increasing participation in the labour market, it is however increasingly difficult to rely on the family as the caregiver. Moreover, while many older women are caregivers to spouses, children and grand-children, women themselves often need to rely on formal caregivers or informal carers outside the family, as more older women than older men live alone.<sup>2</sup>

The international human rights system has paid little attention to older persons in long-term care, especially care outside institutions, and there are no provisions in international law specifically focusing on the rights of older persons in long-term care. However, numerous provisions contained in several international instruments are particularly relevant for older persons in long-term care, such as the right to an adequate standard of living; the right to health; freedom from abuse, torture and other cruel, inhuman and degrading treatment; freedom of movement; the right to participate in decision-making; and the right to privacy and personal integrity. The Convention on the Rights of Persons with Disabilities (CRPD) has further contributed to strengthening the protection of older persons with disabilities and introduced principles and concepts which may be relevant for all older persons in long-term care.

Many older persons prefer to remain living at home as far as possible, even when in need of care. The concept “ageing in place” entails the right of everyone to live where they want and with whom they want. Living at home may require additional support such as home care, meal delivery, transport and other support with activities of daily living, as well as modifications of the home. The concepts of “reasonable accommodation” and “universal design” are also important in the context of ageing in

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<sup>1</sup> <http://www.unescapsdd.org/files/documents/SPPS-Factsheet-ageing-v3.pdf>.

<sup>2</sup> DESA, “Profiles of Ageing 2013”: <http://esa.un.org/unpd/popdev/AgingProfiles2013/default.aspx>.

place<sup>3</sup> and are of particular relevance for older persons' ability to benefit from care in family and community settings, as well as in taking an active part in society. The Committee on Economic, Social and Cultural Rights (CESCR) has noted the need for national policies to help older persons to continue to live in their own homes as long as possible, through the restoration and adaptation of homes.<sup>4</sup>

While the needs of older persons in long-term care varies greatly depending on each individual's situation, Alzheimer Disease International estimates that globally around half of all older people in need of long-term care have dementia, with as much as 80% of older people in nursing homes living with dementia.<sup>5</sup> Therefore, increased attention to the care needs of older persons with dementia may be required in the development of policy responses to meet future care needs.

Care in institutional settings poses additional human rights challenges, particularly in relation to due consent, risks for abuse and violence due to poorly trained staff or other vulnerabilities of the older person, such as gender, physical, mental or cognitive impairment. Clear standards and systematic monitoring of institutions is therefore required to protect the rights of older persons in institutional care.

When older persons are not deemed capable of taking care of their own welfare it is important to ensure that older persons are not unnecessarily stripped of their legal capacity or their ability to make decisions about their own lives. The CRPD Article 12 recognizes that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life and stipulates an obligation to provide access by persons with disabilities to the support they may require in exercising their legal capacity; only in last resort should use be made of substitute decision-making. Similar measures could be proposed to ensure support for older persons to exercise their legal capacity.

Another related concern is that older persons need to be provided the time, opportunity and support to give their free, prior and informed consent to their choice of treatment, services and care, particularly in situations of dependency, end-of-life decisions and in the various life situations of long term care.<sup>6</sup> The Special Rapporteur on Health has consequently emphasized the importance of ensuring that older persons are able to make autonomous, informed decisions regarding the quality of health during the process of dying, including choices about pain relief, location of death and other issues related to dying with dignity.<sup>7</sup> A rights-based approach to care at the end of life and palliative care are also of critical concern for older persons, with current great unmet palliative care needs due to lack of national policies, lack of access to essential medicines and lack of training of health care professionals.<sup>8</sup>

Among the issues to be further considered in relation to the rights of older persons in long-term care, are whether informal carers, especially family carers, have a right to be supported<sup>9</sup> and whether there

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<sup>3</sup> Convention on the Rights of Persons with Disabilities, Article 2, "Reasonable accommodation": the necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms; "Universal design": the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.

<sup>4</sup> Committee on Economic, Social and Cultural Rights, General Comment No. 6, 12 August 1995 (E/1996/22(SUPP)), para. 33.

<sup>5</sup> Alzheimer Disease International, "The World Alzheimer Report 2013 *Journey of Caring: An analysis of long-term care for dementia*", <http://www.alz.co.uk/research/WorldAlzheimerReport2013.pdf> (downloaded on 14 July 2014).

<sup>6</sup> UN Human Rights Council, "Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health", 4 July 2011 (A/HRC/18/37), paras. 61-69.

<sup>7</sup> Ibid, para. 59.

<sup>8</sup> Needs are expected to significantly increase due to population ageing according to WHO and WPCA, "Global Atlas of Palliative Care at the End of Life", 2014, <file:///C:/Users/TBjork/Downloads/Global Atlas of Palliative Care.pdf>. See also A/HRC/18/37, paras. 54-60.

<sup>9</sup> The CESCR General Comment No. 6 (E/1996/22(SUPP)), para. 31, recommends that State parties should make all the necessary efforts to support, protect and strengthen the family and help it, in accordance with each society's system of

are sufficient safeguards in international law against forced institutionalization of older persons. Accountability for rights in relation to long-term care can also present challenges, as care often is provided either by informal carers within the family or the community, or by actors in the private sector. When services are provided by the public sector, responsibilities are sometimes diluted as services may be highly decentralized.

### **Guiding Questions**

1. What are the gaps in national frameworks to promote and protect the rights of older persons in long-term care? What are the challenges in the implementation of these frameworks? How can these gaps and challenges be addressed?
2. What are the key priorities with regard to the delivery of long-term care services in order to protect and promote the rights of older persons?
3. Are there particular groups or segments of older persons in long-term care who encounter specific challenges in exercising their rights in your country? How can this be addressed?
4. What should the roles of stakeholders (government, CSOs, national human rights institutions) be in the promotion and protection of the rights of older persons in long-term care?
5. Would the creation of an international instrument on rights of older persons contribute towards the realization of the rights of older persons who depend on long-term care?