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Room S-2979, New York NY 10017

Input of Centenarian Research for Open Ended Working Group on Ageing

Dear Mr. Robert Venne,

As an international group of scientists with research programs focused on the very old, we would like to share some insights and to put forward suggestions to promote the rights of very old individuals. These suggestions are formulated in response to the call for “non-governmental organization input to the open ended working group on ageing”, issued by the UN-DESA, Division for Social Policy and Development, and are based on discussions and findings from studies with very old individuals, especially centenarians, conducted world-wide by a group of researchers supporting this letter.

We strongly support the proposal for an international legal instrument to promote and protect the rights and dignity of older persons, and request to specifically consider very old individuals and centenarians.

Specific consideration of very old individuals and centenarians is important for the following reasons: Very old individuals are the fastest growing segment of the population in most developed countries. For instance, over the past 12 years, the number of centenarians has increased by 300% in Germany. Between 1996 and 2006, the centenarian numbers have increased by 400% in Japan, and doubled in countries such as Austria, Italy, and Spain, and increased by 1.5 times in Nordic and eastern European countries such as Norway, Iceland, Latvia, Lithuania or Bulgaria (Robine et al., 2010). In the UK, the most recent figures estimate that there were 12.640 centenarians in 2010 (Serra et al., 2011). The rise and number of centenarians is, in fact, a particular characteristic of European countries, in which the number has doubled every 10 years since the Second World War. The USA represents the country with the largest number of centenarians; a total number of 53.000 centenarians was documented by the CENSUS in 2010, and population projections estimate between 800.000 and one million centenarians in 2040. Yet, very old individuals and centenarians represent an understudied and underserved group.

From the limited research available today, we know that very old individuals and centenarians are distinct from other groups of older individuals. Although the phenomenon of healthy centenarians exists, the vast majority of the very old is characterized by increased vulnerability and frailty. As a consequence of reaching very old age, almost all of them suffer from multiple and severe health issues



(high co-morbidity) that significantly impair both daily functioning and quality of life. At least 50% experience moderate to severe cognitive impairments, and virtually all experience loss of close social partners, while having to increasingly rely on the support of others. Also, in very old age, the gender disparity is maximized; as a consequence of family roles and work history, many women in this age group have very limited financial resources. Thus, strongly reduced health, cognitive, social and financial resources are major challenges in very advanced age.

Despite health limitations and contrary to common beliefs, many very old individuals and centenarians live in private households, often supported by their families. An important feature of very old age is the extended period of life during which one is in need for support. Whereas even shorter periods of extensive health care needs can pose an enormous strain for family caregivers, the prolonged period of substantial support needs, often spanning 10-20 years, that are typical in very old age, are likely to tax everyone involved to the limits and can therefore lead to an extreme forms of physical, social, psychological, and financial resource depletion. The often long duration of intense care demand adds an additional layer of burden for caregivers of the very old whose other family and work demands are not necessarily different when compared to those caring for younger old individuals in need.

At the same time, there is empirical evidence that many very old individuals and centenarians show great psychological resilience and psychological strengths. Contrasting physical limitations and other age-related loss experiences, the evidence indicates that the very old possess a wide repertoire of coping skills and a strong will to live, and that they experience high levels of meaning and well-being in their lives. Thus, it is clear that societies and cultures could potentially gain important insights from these individuals in terms of learning how to more successfully deal with general life challenges or with specific difficulty related to aging.

Complementarily, most centenarians lived through particularly hard times in terms of social and historical events and periods, and revealed an exceptional capacity to accept life circumstances, difficulties and losses. This ability to move on and handle stress can promote a positive representation of old age, helping to dispel the negative stereotypes that surround aging and older people. Therefore, centenarians' stories and achievements should be disseminated in general society to inspire positive expectations about advanced age and on the other hand reducing ageist thoughts and attitudes.

Consequently, we make the following suggestions:

(a) Purpose

- Creating a comprehensive human rights instrument to protect the human rights of older individuals and adopting nondiscriminatory laws is an important step to ensure rights and dignity of older persons. This instrument will be especially useful when explicitly considering very old individuals and centenarians, given their specific characteristics as outlined above.



(a) Purpose (cont.)

- If explicitly considered, a convention put forth by the UN is likely to draw attention to the unique situation and needs of the very old and to sensitize professionals and the general public, and it is our hope that it will stimulate much needed impulses at the national level and for societies in terms of acknowledgement of very advanced age as a phase of life with specific challenges but also potential.
- It is further our hope that a UN convention specifically considering the very old will encourage nations to recognize and empower the very old and their families, initiate educational efforts that challenge predominant negative views on aging, and facilitate research and the development of support structures considering the needs of the very old and their families.
- The UN convention will provide the basis for advocacy, public awareness and education on the rights of older people.

(b) General Principles

- Very old individuals are in need of specific support given their increased vulnerability, but should also be recognized as valuable resources to society.
- Very old individuals are at risk of physical and cognitive impairment, and therefore in need for specific protection. All nations should understand that it is the duty of governments and all public institutions (hospitals, nursing homes, etc.) to ensure the dignity and development of all individuals, whatever their limitations.
- With increasing numbers of individuals reaching very old age, quality of life will become a central concern. As of now, little is known about factors or mechanisms involved, whether and how these differ from younger old age. Key aspects identified so far include social resources as well as psychological strengths such as meaning in life. Once identified, strengthening these factors is important. For instance, enhancing accessibility to other very old individuals and other network partners, or creating interest groups to increase a sense of purpose, could contribute to improving quality of life.
- With the increase in total numbers, most people are likely to die in very old age. All nations should ensure an end of life in dignity. This includes that governments and public institutions should ensure the protection of the individuals' choices with regards to their end of life (e.g., advanced directives, diversity of religious practices) as well as access to palliative care.
- The families of the very old need to be strengthened. Families need to be supported in their role as caregivers as much as possible, for instance, with flexible family leave policy, life-time work hour accounts, more part-time work options, and the overall goal of allowing parallel (age-integrated) time for education, work, family, and leisure rather than sequentially related to specific ages/ life phases (age-differentiated society). It is also important to recognize and support active family caregivers, for example, by giving them credit in the form of governmental financial support and with respect to their own retirement account.



(b) General Principles (cont.)

- It is important to recognize that the number of very old individuals without family support will increase in the near future, as a consequence of lower birthrate or increased prevalence of childlessness in most developed countries.
- All nations should ensure more training of health and social care personnel, and others involved in the issues concerning very old people, with specific consideration of their particular characteristics.
- All nations should ensure more education on the topic of very old age, as many students to date indicate that they learn about aging and old age only within their families.
- All nations should foster and enable scientific research on challenges and potentials of very old age, given this group represents the fastest growing population around the world; they should furthermore always encourage the collection of age-disaggregated (i.e., separate listing of young-old, old-old, and centenarian) data to best inform policy decisions.

(c) Definition

- Given the specific characteristics of the very old and centenarians, the very old should be considered explicitly in any declaration or legislation developed by the UN.
- Very old age needs to be understood as the endpoint of life-long development. Thus, preparation for a positive old age and successful aging should be facilitated and fostered early on.

(d) Equality and Non-Discrimination

- Old and very old individuals should not be excluded from any activity because of their age.
- All nations should be encouraged to not only protect the human rights of the very old but to create venues for the very old to participate in society (e.g., no age limit on volunteer activities, evaluation of function if in doubt of ability to perform specific task) and to ensure opportunities to contribute in meaningful ways (e.g., to share their knowledge about life with younger generations). Allowing individuals to participate and to contribute to society will foster meaning and contribute to quality of life.
- All nations should be encouraged to allocate all societal resources more fairly and develop programs benefiting older people.
- Given the growing population of the very old individuals who exhibit diversification in health needs but may survive to be centenarians, greater targeting of prevention and health promotion should include people in their 80s and 90s. This group is often excluded under the assumption that health status can no longer positively be influenced, although the evidence to support that notion is unclear.



(e) Specific Human Rights

- All nations need to ensure appropriate living conditions, economic and social security for the very old, as well as protection from violence and discrimination. This should also include protection of property and inheritance rights, as those rights are denied to older women in many countries when their husband is deceased.
- All nations should ensure the development of and access to appropriate care for very old individuals, taking into account the specific vulnerabilities of the very old. This includes access to sufficient medical services and health care, including mental health services. Professional health care services are needed that enable the very old to live in private households for as long as possible. Better formal care options are needed that are flexible to complement what a very old person can do by him/herself, or what the family is able to provide. High quality of life for the very old is the ultimate goal all nations should strive for.
- All nations should take a holistic approach to promote age-sensitive programs and design interventions that integrate health and social care as well as housing and community solutions for very old individuals and centenarians.
- All nations should promote the development and availability of assistive technology for very old individuals and ensure that housing and neighborhoods are better designed and/or adequately adapted in order to enable centenarians to live as long as possibly in the community, with maximum levels of daily functioning and quality of life.

(f) National and International Supervisory Mechanisms

We strongly encourage the enforcement of this UN human rights instrument, for example, by:

- Implementation of human right instrument should be implemented by a separate, to be developed, UN Aging entity.
- Panel of experts should inform policy and make recommendations on a regular basis.
- Governments should ensure considering the rights of the very old within national policies, legislation and programs, encourage advocacy, and create national authorities addressing all aging issues.

We very much appreciate the efforts of UN-DESA to create an international legal instrument to promote and protect the rights and dignity of older persons. Ensuring their human rights and non-discrimination is essential and will not only benefit old and very old individuals but societies as a whole. We hope that the provided information will help the holistic approach taken by UN-DESA.

Respectfully,

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