Center for the Human Rights of
Users and Survivors of Psychiatry

Tina Minkowitz, Center for the Human Rights of Users and Survivors of Psychiatry

Statement on Long-Term Care and Palliative Care, in the 9th Session of the Open Ended Working Group on Ageing

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We need a human rights-based approach to long term supports and services for older persons, and to avoid medicalization of either old age or disability.

Long-term care is too often used as a euphemism for institutionalization of older persons in segregated residential facilities where staff exercise control over daily life and make decisions about the person's care, which can include restrictions of autonomy such as placement in locked wards, administration of psychotropic drugs, or use of restraints. The vast majority of older persons in such facilities are older persons with disabilities, including those with cognitive disabilities caused by dementia, who find that needed services and supports are not made available to them outside institutions, or who are placed there against their will by family members or abusive guardians. The conceptualization of long-term care for older persons is very much a disability issue as well as an issue of ageing.

The Committee on the Rights of Persons with Disabilities interprets Article 19 of the CRPD to require states to progressively eliminate institutionalization and replace it with formal supports in the community (i.e. not provided by family members) for all persons with disabilities. There are no individuals, irrespective of the nature or degree of their disability, who can be deemed to require segregation and confinement. Yet older persons with disabilities have not benefited to the same extent as younger persons from de-institutionalization initiatives, due to separate government agencies having responsibility and due to ageism.

All older persons, irrespective of whether the person has a disability, including persons with cognitive disabilities caused by dementia, have a right to live independently and be included in the community. This right needs to be enshrined in the prospective convention, and long-term supports and services must be provided to the person where they choose to live as part of this right. As the Independent Expert acknowledged in her report, non-restrictive supports are possible for older persons with cognitive disabilities, for example, multi-sensory environments, augmented reality and support escorts.

The CRPD Committee also interprets Article 19 to contain an immediate obligation to release all persons with disabilities confined against their will in any service facility, including mental health facilities. Older persons with psychosocial disabilities have the same rights as other older persons, including the right to autonomy and independence without infringements of any kind, and the right to supports and services provided according to an independent living model.

Palliative care is a necessity and can be an experience of superlative nurturance and comfort in the final stages of life. However, it is crucial to guard against improper conceptualization of palliative care as sedation with psychotropic drugs. This is a managerial approach rather than a human rights-based approach. The right of older persons to palliative care needs to be framed with reference to the values of comfort and choice, with access to pain-relieving medications according to the person's will and preferences. Neuroleptic drugs, erroneously called antipsychotics, should be avoided as they more often amount to chemical restraint. The values of comfort and choice are best promoted when palliative care is offered in a range of settings for the person to choose according to their evolving needs, from their own home to community centers, hospitals and hospice centers. Chosen family and support networks need to be taken into account and involved according to the person's wishes.

Thank you.