Center for the Human Rights of Users and Survivors of Psychiatry

Long term and palliative care – Submission to 9th Session Open Ended Working Group on Ageing*

1. The right to be free from restrictive practices (detention, seclusion, chemical and physical restraint), and from any coercive administration of psychotropic drugs, is immediate and not subject to progressive realization.

2. Palliative care at best pays close attention to the person's expressed needs, their abiding and evolving values and communication style, with the aim of providing support for their well being and comfort.[1] It should not be defined negatively as withholding curative treatment; treatment to delay the progression of a terminal illness may be necessary for well-being even without a cure. Palliative care that adheres to the principle of respect for individual will and preferences should be studied as good practice and replicated, for older and younger persons nearing the end of life.

3. Long-term care should be provided to older persons in settings that respect the right to live independently in the community.[2] This may be the person's own home; family member's home; co-housing; or common living arrangements with services so long as the person has private quarters, retains the right to decide their activities, accept or refuse any services, and remain in their housing so long as they choose, without limitation based on their capabilities or support needs.

4. People utilizing long-term care and palliative care have the right to live in culturally appropriate settings and to have their intimate and familial relationships, including same-sex relationships, honored and respected.[3] No one should be forced to separate from a partner in order to access desired support or housing. All housing must respect individuals' personal identities and life choices, and must accommodate diverse needs and preferences so as to not to disadvantage any person despite conflicting beliefs and values. Women who prefer female service providers and female-only facilities must have their preference respected to safeguard bodily privacy and security. Housing options should be made available for those who want to live in culturally compatible surroundings, e.g. housing designed by and for older

women; older lesbians; older LGBT persons; members of distinct cultural or religious groups.

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[*] The Center for the Human Rights of Users and Survivors of Psychiatry (CHRUSP) works for legal capacity for all, the abolition of committal, forced treatment and substitute decision-making, and creation of supports that respect individual choices and integrity. CHRUSP is a disabled people's organization and holds special consultative status with ECOSOC. Contact Tina Minkowitz, info@chrusp.org; website www.chrusp.org.

[1] See http://judi-lifeasahospicepatient.blogspot.com for account of good quality palliative care. See also normative references in endnotes of CHRUSP submission on Autonomy and Independence for 9th session, particularly for CRPD Articles 12 and 19, and corresponding provisions of the African Disability Protocol.

In addition on respect for the person's will and preferences in all situations:
CRPD General Comment 1 para 29(a)
Supported decision-making must be available to all. A person's level of support needs, especially where these are high, should not be a barrier to obtaining support in decision-making.

CRPD GC1 para 21
Where, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the "best interpretation of will and preferences" must replace the "best interests" determinations. This respects the rights, will and preferences of the individual, in accordance with article 12, paragraph 4. The "best interests" principle is not a safeguard which complies with article 12 in relation to adults. The "will and preferences" paradigm must replace the "best interests" paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others.

[2] CRPD Article 19
States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:
(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
(c) Community services and facilities for the general population are available on an

equal basis to persons with disabilities and are responsive to their needs.

CRPD General Comment 5 para 8
…. The right to live independently and be included in the community refers to all persons with disabilities, irrespective of race, colour, descent, sex, pregnancy and maternity, civil, family or carer situation, gender identity, sexual orientation, language, religion, political or other opinion, national, ethnic, indigenous or social origin, migrant, asylum seeking or refugee status, association with a national minority member, economic status or property, health status, genetic or other predisposition towards illness birth, and age, or any other status.

CRPD GC5 para 16(c) and (d)
(c) **Independent living arrangements:** Both independent living and being included in the community refer to life settings outside residential institutions of all kinds. It is not "just" about living in a particular building or setting, it is, first and foremost, about losing personal choice and autonomy as a result of the imposition of certain life and living arrangements. Neither large-scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals, nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization. Although, institutionalized settings can differ in size, name and setup, there are certain defining elements, such as: obligatory sharing of assistants with others and no or limited influence over by whom one has to accept assistance, isolation and segregation from independent life within the community, lack of control over day-to-day decisions, lack of choice over whom to live with, rigidity of routine irrespective of personal will and preferences, identical activities in the same place for a group of persons under a certain authority, a paternalistic approach in service provision, supervision of living arrangements and usually also a disproportion in the number of persons with disabilities living in the same environment. Institutional settings may offer persons with disabilities a certain degree of choice and control, however, these choices are limited to specific areas of life and do not change the segregating character of institutions. Policies of de-institutionalization therefore require implementation of structural reforms, which go beyond the closure of institutional settings. Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. "Family-like" institutions are still institutions and are no substitute for care by a family.
(d) **Personal assistance:** Personal assistance refers to person-directed/"user"-led human support available to a person with disability and itis a tool for independent living. Although modes of personal assistance may vary, there are certain elements, which distinguish it from other types of personal assistance, namely:
(i) **Funding** for personal assistance must be provided on the basis of personalized criteria and take into account human rights standards for decent employment. The funding is to be controlled by and allocated to the person with

disability with the purpose of paying for any assistance required. It is based on an individual needs assessment and upon the individual life circumstances. Individualised services must not result in reduced budget and/or higher personal payment;

(ii) **The service is controlled by the person with disability**, meaning that he or she can either contract the service from a variety of providers or act as an employer. Persons with disabilities have the option to custom-design his or her own service, i.e. design the service and decide by whom, how, when, where and in what way the service is delivered and to instruct and direct service providers;

(iii) **Personal assistance is a one-to-one relationship.** Personal assistants must be recruited, trained and supervised by the person granted personal assistance. Personal assistants should not be "shared" without full and free consent by the person granted personal assistance. Sharing of personal assistants will potentially limit and hinder the self-determined and spontaneous participation in the community; and

(iv) **Self-management of service delivery.** Persons with disabilities who require personal assistance can freely choose their degree of personal control over service delivery according to their life circumstances and preferences. Even if the responsibilities of "the employer" are contracted out, the person with disability always remains at the center of the decisions concerning the assistance, who must be enquired about and respected upon individual preferences. The control of personal assistance can be through supported decision-making.

17. …. The concept of personal assistance where the person with disabilities does not have full self-determination and self-control are to be considered not compliant with article 19. Persons with complex communication requirements, including those who use informal means of communication (i.e. communication via non-representational means, including facial expression, body position and vocalisation) must be provided with appropriate supports enabling them to develop and convey their directions, decisions, choices and/or preferences, and have these acknowledged and respected.

CRPD GC5 para 20
Article 19 explicitly refers to all persons with disabilities. Neither the full or partial deprivation of any "degree" of legal capacity nor level of support required may be invoked to deny or limit the right to independent and independent living in the community to persons with disabilities.

CRPD GC5 paras 30, 36
While individualized support services may vary in name, type or kind according to the cultural, economic and geographic specifics of the State party, all support services must be designed to be supporting living included within the community preventing isolation and segregation from others within the community and must in actuality be suitable to this purpose. It is important that the aim of these support services is the realization of full inclusion within the community. Therefore, any

institutional form of support services, which segregates and limits personal autonomy, is not permitted by article 19 (b).

Individualised support services, which do not allow for personal choice and self-control are not providing for living independently within the community. Support services provided as combined residential and support service (delivered as a combined “package”) are often offered to persons with disabilities on the premise of cost efficiency. However, while this premise itself can be rebutted economically, aspects of cost efficiency must not override the core of the human right at stake. Personal assistance and assistants should not be “shared” among persons with disabilities by rule, but only whether it is done with full and free consent of the person with disability requiring personal assistance. The possibility to choose is one of the three key elements of the right to live independently within the community.

[3] CRPD General Comment 5 para 60
Disability support services must be available, accessible, affordable, acceptable and adaptable to all persons with disabilities and be sensitive to different living conditions, as e.g. individual or familiar income, and individual circumstances, such as sex, age, national or ethnic origin, linguistic, religious, sexual and/or gender identity. The human rights model of disability does not allow to exclude persons with disabilities upon any reason, including the kind and amount of support services required. Support services, including personal assistance, should not be shared with others unless it is based on a decision through free and informed consent.