



Center for the Human Rights of  
Users and Survivors of Psychiatry

## 10th Session of the Open-ended Working Group on Ageing Autonomy and Independence: Normative elements

*This submission was prepared by:*

European Network on Independent Living – ENIL  
Center for the Human Rights of Users and Survivors of Psychiatry - CHRUSP

30 January 2019

### 1. Legal framework

Older persons with disabilities are rights holders under the UN Convention on the Rights of Persons with Disabilities (CRPD), which applies to everyone regardless of their age. Whether individuals identify as persons with disabilities or not, they should not be prevented from accessing supports required to live independently in the community and from making decisions about their life.

Pursuant to Article 19 CRPD, persons with disabilities have the right to live independently and be included in the community, with choices equal to others. States must ensure that they can “choose their place of residence and where and with whom they live” and that they are “not obliged to live in a particular living arrangement”. This requires “access to a range or 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.” It also requires access to mainstream services and facilities, which should be available and “responsive to their needs”.

General Comment (GC) No. 5 (2017) on Article 19 CRPD<sup>1</sup> explains that having legal capacity and being able to decide “where, with whom and how to live” is one of the core elements of the right to independent living (§38). The right to enjoy the legal capacity to act has been established through Article 12 CRPD and its jurisprudence (particularly GC No. 1<sup>2</sup>), as a universal right for adults with disabilities.<sup>3</sup> National

---

<sup>1</sup> Committee on the Rights of Persons with Disabilities, General comment No. 5 (2017) on living independently and being included in the community. Available at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en)

<sup>2</sup> Committee on the Rights of Persons with Disabilities, General comment No. 1 (2014) Article 12: Equal recognition before the law. Available at: [https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en)

<sup>3</sup> The right to autonomy and independence is both the underlying value of the normative development of legal capacity to act, as a universal right of adults through Article 15 CEDAW and Article 12 CRPD, and an expansion of the right to legal capacity beyond the narrow concept of the right to perform legally significant acts such as marriage and execution of contracts. CRPD jurisprudence has treated the right to legal capacity as incorporating a substantive right of persons with disabilities to autonomy

implementation that substantially complies with the CRPD has begun to take place, with the 2018 Peruvian Civil Code Reform.<sup>4</sup>

## 2. Normative elements

GC No. 5 sets out the normative content of the right to live independently and to be included in the community. The key elements of the right to independent living are the ability to exercise choice and control over one's life and to make all decisions concerning one's life. This includes all decisions, including those related to intimacy or relationships.<sup>5</sup>

GC No. 5 makes it clear that States must ensure that the support services provided to facilitate independent living are "age sensitive" (§35) and that they "allow for the spontaneous participation of persons with disabilities in the community" (§37), among other. Furthermore, no one should be excluded from accessing support services (§60).

Equal and effective access to justice is also required to live independently, and for that, "age-appropriate accommodations are essential" (§81). Monitoring and legal remedies should be age-sensitive, in order to prevent potential abuse, exploitation or violence against persons with disabilities. Moreover, monitoring should cover all services provided under Article 19, but especially institutions, "since institutions tend to isolate those who reside within them from the rest of the community" (§83).

## 4. Equality and non-discrimination

That discrimination can be based on intersecting characteristics, such as disability and age, is highlighted in GC No. 6 (2018)<sup>6</sup>, on "equality and non-discrimination"<sup>7</sup>. In order

---

and independence in everyday life and in major life decisions, calling on states to take action against informal as well as formal substitute decision-making.

<sup>4</sup> See analysis and link to legislative decree at <https://www.madinamerica.com/2018/10/peruvian-legal-capacity-reform-celebration-and-analysis/>.

<sup>5</sup> Independent Living is defined as follows: "Independent living/living independently means that individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives. Personal autonomy and self-determination are fundamental to independent living, including access to transport, information, communication and personal assistance, place of residence, daily routine, habits, decent employment, personal relationships, clothing, nutrition, hygiene and health care, religious activities, cultural activities and sexual and reproductive rights. These activities are linked to the development of a person's identity and personality: where we live and with whom, what we eat, whether we like to sleep in or go to bed late at night, be inside or outdoors, have a tablecloth and candles on the table, have pets or listen to music. Such actions and decisions constitute who we are. Independent living is an essential part of the individual's autonomy and freedom and does not necessarily mean living alone. It should also not be interpreted solely as the ability to carry out daily activities by oneself. Rather, it should be regarded as the freedom to choose and control, in line with the respect for inherent dignity and individual autonomy as enshrined in article 3 (a) of the Convention. Independence as a form of personal autonomy means that the person with disability is not deprived of the opportunity of choice and control regarding personal lifestyle and daily activities" (§16a)

<sup>6</sup> Committee on the Rights of Persons with Disabilities, General comment No. 6 (2018) on equality and non-discrimination. Available at:

[https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en)

<sup>7</sup> According to the GC, "intersectional discrimination" occurs when a person with a disability or associated to disability suffers discrimination of any form on the basis of disability, combined with, colour, sex, language, religion, ethnic, gender or other status." See:

to be protected from discrimination, “all possible grounds of discrimination and their intersections must be taken into account” (§21). Moreover, States must ensure that eligibility criteria for accessing support are “defined in a non-discriminatory way” and that they “focus on the requirements of the person rather than the impairment, following a human rights-based approach”. In order to prevent discrimination from occurring, the development of support services should be age-sensitive, among other (§59).

Institutionalisation per se is discriminatory, and is a result of the failure to make community-based services available to those who need them. Rather than giving individuals choice and control over their lives, it forces them into a particular living arrangement as their only means of accessing support (§58).

## 5. Participation

GC No. 7 (2018)<sup>8</sup> includes a number of references to the need to ensure that older persons with disabilities participate in decisions that affect them, including through representative organisations. Moreover, it highlights the importance of ensuring that data collected about access to independent living are also disaggregated by age.

## 6. Implementation

Personal autonomy and independence should be recognized as a substantive right for older persons to enjoy on an equal basis with others. A convention on the rights of older persons should also make explicit the expanded substantive right to personal autonomy and independence and its link to the recognition of legal capacity in all aspects of life. It can do so by ensuring that:

- Older persons enjoy the legal capacity to act at all times, and that this right cannot be restricted based on age, actual or perceived impairment, or actual or perceived decision-making skills.
- Older persons have the opportunity to decide where and with whom they live on an equal basis with others, and are not forced into any particular living arrangement due to lack of alternatives.
- Older persons are entitled to receive supports and accommodations in exercising their legal capacity, which are designated by the person concerned and can be modified or terminated by that person.
- Support in exercising legal capacity includes the right to designate future supports and to specify anticipatory will and preferences; such supports and anticipatory directives supplement (and do not replace) the person’s right to exercise legal capacity at all times.
- Older persons have access to safeguards to prevent abuse in support arrangements, which can be designated when designating supports, and are

---

[https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en)

<sup>8</sup> Committee on the Rights of Persons with Disabilities, General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation and monitoring of the Convention. Available at: [https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/7&Lang=en](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/7&Lang=en)

complemented by systemic remedies against any form of exploitation, violence or abuse.

- There exists a mechanism to inform older persons of support options, assist with designation of supports, and provide supports directly, if so desired by the person concerned.
- There exists a mechanism to arrange support for an older person who has not designated supports based on a best interpretation of the person's will and preferences, if real, considerable and pertinent efforts have not succeeded in obtaining an expression of will from the person and designation of support is necessary for the exercise and protection of their rights.

### **About the submitting organisations:**

The [European Network on Independent Living](#) (ENIL) is a Europe-wide network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organizations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalization, democracy, self-representation, cross disability and self-determination. ENIL has been granted special consultative status with ECOSOC in 2017. Contact: Ines Bulic, [ines.bulic@enil.eu](mailto:ines.bulic@enil.eu)

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 the creation of supports that respect individual choices and integrity. CHRUSP is led by users and survivors of psychiatry and people with psychosocial disabilities and holds special consultative status with ECOSOC. Contact: Tina Minkowitz, [tminkowitz@earthlink.net](mailto:tminkowitz@earthlink.net)