



**Center for the Human Rights of
Users and Survivors of Psychiatry**

**Autonomy and Independence – Submission to 9th Session Open Ended
Working Group on Ageing***

I. Principles

1. Older people are protagonists of their own lives and advocacy. They possess inherent human agency and moral personhood, respond to their environment, make choices and relate to other persons.
 - a. ‘Autonomy’ is not a characteristic of individuals but a human right – legal capacity, or the right to decide for oneself and to prevent others from making decisions contrary to one’s wishes.¹ Older persons with and without disabilities have this right equally with other adults.²
 - b. Older people have a right to obtain support in exercising legal capacity, which respects the person’s will and preferences, including their choice whether or not to accept support.³
2. High support needs cannot justify placing the person under coercion.⁴ Supporters should meet people on their own terms, based on the interface between their reality and that of the supporter. Harm reduction strategies that respect personal autonomy should be implemented in offering support to older people in relation to their safety. Such strategies are considered good practice to support victims of domestic violence, people sleeping rough, IV drug users, among others.
3. Loss of autonomy is a social, not natural, process that results from the refusal of family members, service providers, and society to respect older persons’ will and preferences and take time for people to express what they want and need.

II. Concerns

4. Having experienced violent deprivation of autonomy, disabled persons are even more vulnerable to these violations growing older. Potential

questioning of our mental capacity based on age and disability makes it risky to seek health care. People with dementia are locked up, forcibly drugged and restrained alongside younger persons in psychiatric institutions. In order to prevent such abuse, we insist on the protections of CRPD Articles 12, 14, 15 and 19 at all ages.⁵

5. Growing older reduces the responsiveness of service systems to human rights claims. An older person who has been repeatedly institutionalized in mental health settings, cannot afford open-market housing, and risks return to a locked ward if she withdraws from drugs that cause tardive dyskinesia, faces enormous obstacles to re-establishing an independent household and living free from psychotropics.⁶
6. Older disabled people, especially women, often care for spouses or parents. They may lack support for themselves and find it increasingly difficult to manage the support their partner needs. The state's failure to provide in-home personal assistance needed to prevent institutionalization forces people to do without needed care or to enter institutions.

III. Conclusion

7. Rights to legal capacity, liberty and security of person, and independent living in community, must be guaranteed to older persons with and without disabilities equally with other adults, as established in CRPD Article 12 and CRPD General Comment 1.
8. Substitute decision-making, including capacity assessments to place individuals in restrictive care or housing, must be eliminated.
9. Support must be provided based on respect for the older person's autonomy, will and preferences.
10. Community spaces must welcome older persons and respond to their needs.

* 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 Normative references are hereby provided as endnotes.

CRPD General Comment 1, paras 13-14.

Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors. ... Under article 12 of the

Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.

Legal capacity is an inherent right accorded to all people, including persons with disabilities. As noted above, it consists of two strands. The first is legal standing to hold rights and to be recognized as a legal person before the law. This may include, for example, having a birth certificate, seeking medical assistance, registering to be on the electoral role or applying for a passport. The second is legal agency to act on those rights and to have those actions recognized by the law. It is this component that is frequently denied or diminished for persons with disabilities. For example, laws may allow persons with disabilities to own property, but may not always respect the actions taken by them in terms of buying and selling property. Legal capacity means that all people, including persons with disabilities, have legal standing and legal agency simply by virtue of being human. Therefore, both strands of legal capacity must be recognized for the right to legal capacity to be fulfilled; they cannot be separated. The concept of mental capacity is highly controversial in and of itself. Mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity.

² CRPD Art 12.2

States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

ADP Art 8.3.a

States Parties shall take all appropriate and effective measures to ensure that: Persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life, and that State, non-State actors and other individuals do not violate the right to exercise legal capacity by persons with disabilities.

³ CRPD Art 12.3

States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

ADP Art 8.3.b

States Parties shall take all appropriate and effective measures to ensure that: Persons with disabilities are provided with the support they may require in enjoying their legal capacity, and that such support respects the rights, will and preferences of persons with disabilities and does not amount to substituted decision-making.

CRPD GC1 para 27(corrigendum)

Substitute decision-making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these

regimes have certain common characteristics: they can be defined as systems where: (a) legal capacity is removed from a person, even if this is in respect of a single decision; (b) a substitute decision maker can be appointed by someone other than the person concerned, and this can be done against his or her will; or (c) any decision made by a substitute decision maker is based on what is believed to be in the objective “best interests” of the person concerned, as opposed to being based on the person’s own will and preferences.

CRPD GC1 para 29(b)

All forms of support in the exercise of legal capacity, including more intensive forms of support, must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests.

CRPD GC1 para 29(g)

The person must have the right to refuse support and terminate or change the support relationship at any time.

⁴ CRPD GC1 para 18

The type and intensity of support to be provided will vary significantly from one person to another owing to the diversity of persons with disabilities. This is in accordance with article 3 (d), which sets out “respect for difference and acceptance of persons with disabilities as part of human diversity and humanity” as a general principle of the Convention. At all times, including in crisis situations, the individual autonomy and capacity of persons with disabilities to make decisions must be respected.

CRPD GC1 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 29(i)

The provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity.

⁵ CRPD Art 14

States Parties shall ensure (b) that the existence of a disability shall in no case justify a deprivation of liberty.

ADP Art 5.2

States Parties shall take appropriate and effective measures to ensure that persons with disabilities, on an equal basis with others:

a) Enjoy the right to liberty and security of person and are not deprived of their liberty unlawfully or arbitrarily;

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- b) Are not forcibly confined or otherwise concealed by any person or institution;
 - c) Are not subjected to torture or cruel, inhuman or degrading treatment or punishment;
 - d) Are not subjected without their free, prior and informed consent to medical or scientific experimentation or intervention;
 - e) Are not subjected to sterilisation or any other invasive procedure without their free, prior and informed consent;
 - f) Are protected, both within and outside the home, from all forms of exploitation, violence and abuse.
2. States Parties shall take appropriate measures to prevent deprivation of liberty to persons with disabilities, to prosecute perpetrators of such abuse and to provide remedies for the victims.
3. Where persons with disabilities are lawfully deprived of their liberty, States Parties shall ensure that they are on an equal basis with others entitled to guarantees in accordance with international human rights law and the objects and principles of the present Protocol.
5. The existence of a disability or perceived disability shall in no case justify deprivation of liberty.

CRPD Guidelines on Article 14 paras 10, 12, 13

Involuntary commitment of persons with disabilities on health care grounds contradicts the absolute ban on deprivation of liberty on the basis of impairments (article 14(1)(b)) and the principle of free and informed consent of the person concerned for health care (article 25). The Committee has repeatedly stated that States parties should repeal provisions which allow for involuntary commitment of persons with disabilities in mental health institutions based on actual or perceived impairments. Involuntary commitment in mental health facilities carries with it the denial of the person's legal capacity to decide about care, treatment, and admission to a hospital or institution, and therefore violates article 12 in conjunction with article 14.

The Committee has called on States parties to protect the security and personal integrity of persons with disabilities who are deprived of their liberty, including by eliminating the use of forced treatment, seclusion and various methods of restraint in medical facilities, including physical, chemical and mechanic restrains. The Committee has found that these practices are not consistent with the prohibition of torture and other cruel, inhumane or degrading treatment or punishment against persons with disabilities pursuant to article 15 of the Convention.

Throughout all the reviews of State party reports, the Committee has established that it is contrary to article 14 to allow for the detention of persons with disabilities based on the perceived danger of persons to themselves or to others. The involuntary detention of persons with disabilities based on risk or dangerousness, alleged need of care or treatment or other reasons tied to impairment or health

diagnosis is contrary to the right to liberty, and amounts to arbitrary deprivation of liberty.

CRPD Art 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.

ADP Art 10

1. Every person with a disability has the right to live in the community with choices equal to others.

4. States Parties shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of the right to live in the community, on an equal basis with others, including by ensuring that:

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live;
- b. Persons with disabilities who require intensive support and their families have adequate and appropriate facilities and services, including caregivers and respite services;
- c. Persons with disabilities have access to a range of in-home, residential and other community support services necessary to support living and inclusion in the community;
- d. Persons with disabilities have personal mobility with the greatest possible independence;
- e. Community-based rehabilitation services are provided in ways that enhance the participation and inclusion of persons with disabilities in the community;
- f. Community living centres organised or established by persons with disabilities are supported to provide training, peer support, personal assistance services and other services to persons with disabilities;
- g. Community services and facilities for the general population, including health, transportation, housing, social and educational services, are available on an equal basis to persons with disabilities and are responsive to their needs.

CRPD General Comment 5 paras 21, 22

When persons with disabilities are assessed to be requiring high demands for personal service, States parties often consider institutions as the only solution, especially whether personal services are considered to be “too costly” or the person with disabilities as being “unable” to live outside institutionalised settings. Persons with intellectual disabilities, especially those with, complex communication requirements, inter alia, are often assessed as being unable to live outside of institutionalized settings. Such reasoning is contrary to article 19, which extends the right to live independently and be included in the community to all persons with disabilities, regardless of their level of intellectual capacity, self-functioning or support requirement.

All persons with disabilities should be free to choose to be active and belonging to cultures of their own choice, and they must have the same degree of choice and control over their lives as other members of the community. Independent living is not compatible with the promotion of “predefined” individual lifestyle. Young persons with disabilities should not be forced to live in settings designed for elderly persons with disabilities and vice versa.

⁶ CRPD Guidelines Art 14 para 24, internal quotation para 126(d) and (e)
Individuals who are currently detained in a psychiatric hospital or similar institution and/or subjected to forced treatment, or who may be so detained or forcibly treated in the future, must be informed about ways in which they can effectively and promptly secure their release including injunctive relief.

Such relief should consist of an order requiring the facility to release the person immediately and/or to immediately cease any forced treatment, as well as systemic measures such as requiring mental health facilities to unlock their doors and inform persons of their right to leave, and establishing a public authority to provide for access to housing, means of subsistence and other forms of economic and social support in order to facilitate de-institutionalization and the right to live independently and be included in the community. Such assistance programs should not be centred on the provision of mental health services or treatment, but free or affordable community-based services, including alternatives that are free from medical diagnosis and interventions. Access to medications and assistance in withdrawing from medications should be made available for those who so decide.