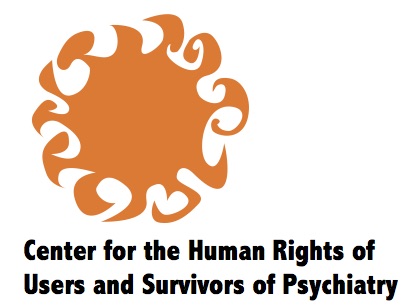


**Violence, neglect and abuse – Normative requirements – Submission to 9th Session Open Ended Working Group on Ageing[[1]](#endnote-1)\***

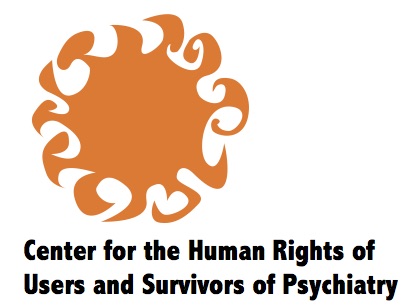
Issues relating to respect for physical and mental integrity, privacy and dignity[[2]](#endnote-2)

1. Older persons have a right to maintain their alertness and full range of emotion to the extent they desire, and not to be controlled with drugs.[[3]](#endnote-3)
2. Neuroleptics and other psychotropic drugs are often used on older people as a form of chemical restraint, for example to quell ‘agitation.’ It is a serious and widespread problem in psychiatric institutions, in nursing homes, in facilities designated to serve older persons, and in some palliative care facilities. Chemical restraint and forced drugging for any reason must be prohibited as torture and ill-treatment.
3. Psychotropic drugs can be used only with the free and informed consent of the person concerned, in the absence of any coercion or incentive and ensuring that alternatives are adequately explored, along with individuals’ values and inclinations regarding different classes of psychotropic drugs.[[4]](#endnote-4) The resulting course of action must adhere to the individual’s will and preferences.
4. Older women have been disproportionately subjected to electroshock, which impairs the memory and causes other cognitive impairment, as a psychiatric intervention. This practice should be banned, in light of the increased vulnerability of older persons.[[5]](#endnote-5)
5. Service providers must respect the bodily privacy of older persons, for example by conducting physical examinations in private and not in common rooms of a facility.
6. When a person is experiencing pain or distress or discomfort, service providers as well as friends or family attending them need to respond in a timely manner to acknowledge the person’s suffering and offer any available relief.
7. Older persons who require assistance with mobility or other bodily needs must be treated with care and dignity. Service providers and friends and family attending them must deal with any negative emotions or reactions they may have to the older person they are caring for, in ways that do not cause harm to that person.
8. Exploitation of the older person can occur when family members or service providers call into question the older person’s decision-making so as to implement a decision contrary to that person’s will and preferences. This can result in financial exploitation, dispossession of the person from their home and surroundings, placement in an institution, drugging, and other restriction of the person’s autonomy and participation. Even when it does not result in such abuses, depriving an older person of the right to make decisions violates obligations under the CRPD to respect the legal capacity of all adults, including older persons, to make decisions and not have others make substituted decisions for them against their will.[[6]](#endnote-6)
9. Training and support should be provided to service providers and friends and family caring for older persons to prevent neglect, violence, exploitation, and abuse of any kind.



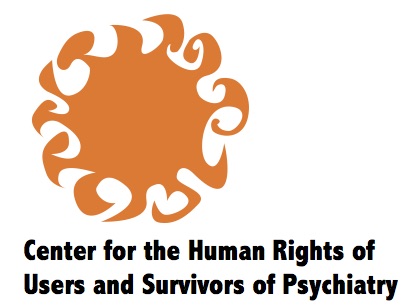
**Long term and palliative care – Submission to 9th Session Open Ended Working Group on Ageing[[7]](#endnote-7)\***

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.[[8]](#endnote-8) 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.[[9]](#endnote-9) 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.[[10]](#endnote-10) 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.



**Equality and non-discrimination – Normative requirements – Submission to 9th Session Open Ended Working Group on Ageing[[11]](#endnote-11)\***

1. A convention on the rights of older persons should address multiple and intersectional discrimination.[[12]](#endnote-12) Disability is in no way synonymous with aging or being an older person, but older disabled persons must be taken into account as a subset of older persons experiencing multiple and intersectional discrimination based on age and disability.
2. As older disabled persons represent a substantial constituency, the convention must look to the CRPD and its jurisprudence as a guide to understanding disability within the human rights framework, so that older disabled persons can have benefit of this standard. A social model of disability does not permit segregation or marginalization of disabled persons based on a view that they cannot be accommodated in mainstream settings. Older disabled persons are not objects of care but rights holders on a basis of full equality with other older persons, younger persons with disabilities, and younger persons without disabilities. Older disabled persons should be taken into account transversally by considering how any provision of text relates to their situation. Their experiences and concerns need to be addressed within the social model and human rights framework of disability, with guarantees of equal legal capacity, liberty and security of the person, and the right to live independently and be included in the community.[[13]](#endnote-13)
3. The convention should specify that community services for the general population, as well as both age-related and disability-related supports and services, must include older disabled persons on an equal basis and take account of their particular situations and intersectional discrimination. They must adhere to human rights principles including respect for individual autonomy and freedom to make one’s own choices, and full and effective participation and inclusion in society.[[14]](#endnote-14)
4. Multiple and intersectional discrimination against older women, including older disabled women, based on sex, should be particularly acknowledged, and taken into account transversally.[[15]](#endnote-15)
5. The term ‘special measures’ has a negative connotation in the disability community. It is preferable to say ‘specific measures’ to refer to states’ positive obligations towards a group that confronts discrimination.[[16]](#endnote-16)



**Autonomy and Independence – Submission to 9th Session Open Ended Working Group on Ageing[[17]](#endnote-17)\***

I. Principles

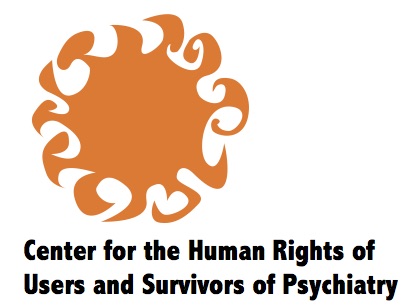
1. Older people are protagonists of their own lives and advocacy. They possess inherent human agency and moral personhood, respond to their environment, make choices and relate to other persons.
   1. ‘Autonomy’ is not a characteristic of individuals but a human right – legal capacity, or the right to decide for oneself and to prevent others from making decisions contrary to one’s wishes.[[18]](#endnote-18) Older persons with and without disabilities have this right equally with other adults.[[19]](#endnote-19)
   2. 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.[[20]](#endnote-20)
2. High support needs cannot justify placing the person under coercion.[[21]](#endnote-21) 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

1. 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.[[22]](#endnote-22)
2. 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.[[23]](#endnote-23)
3. 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

1. 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.
2. Substitute decision-making, including capacity assessments to place individuals in restrictive care or housing, must be eliminated.
3. Support must be provided based on respect for the older person’s autonomy, will and preferences.
4. Community spaces must welcome older persons and respond to their needs.



**Statement on Autonomy and Independence, 9th Session of the Open Ended Working Group on Ageing**

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

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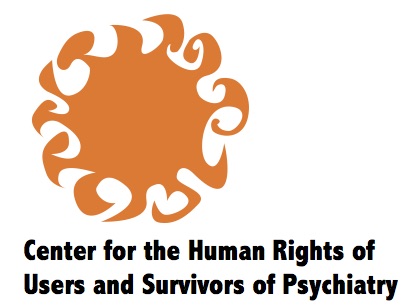
The rights of older persons with disabilities need to be made explicit in normative standards on autonomy and independence.

The independent living model applies to the situation of older persons with disabilities equally as to younger persons. However, due to ageism, policies for older persons with disabilities remain focused on institutionalization, under the concept of long-term care. This is unacceptable.

The prospective convention should ensure that a range of community living options are made available to all older persons along with support and accessibility measures related to any disabilities they may have. It should guarantee the right to freely choose or invent their living arrangement and support services according to the person’s own will and preferences. Deprivation of liberty in any service facility must be abolished by law, and forced drugging with antipsychotics is never justified whether for medical reasons or overt purpose of control. States must eliminate institutional forms of care for older persons with disabilities and instead provide supports and services to people where they choose to live, whether that be individual housing, shared housing or housing with family members. The right to respect for intimate relationships, friendships and support networks, for personal habits and choice of surroundings, and for personal dimensions of life such as sexual orientation, must be guaranteed. Older persons with disabilities have a right to human assistance as well as that of service animals and assistive devices; complex human support cannot be replaced by robotics.

The right to legal capacity is indispensable for older persons with disabilities to enjoy autonomy and independence. The prospective convention should incorporate key elements of the framework for universal legal capacity established in General Comment No. 1 of the Committee on the Rights of Persons with Disabilities. In particular, it should provide that all older persons have a right to enjoy and exercise legal capacity at all times in all aspects of life. Neither disability nor the concept of mental capacity can justify restriction of the legal capacity to make one’s own decisions. It should specify the obligation of states to eliminate substitute decision-making regimes and to guarantee that support and accommodations are made available to those who need them in exercising their legal capacity, without obligating anyone to accept unwanted support. Support measures are defined by making the effort to determine and follow the person’s will and preferences in all matters, making a best interpretation of will and preferences if it is not feasible to determine with certainty. Advance planning for support arrangements should begin at an early stage, to evolve with the person’s needs and in accordance with their will and preferences. States should inform older persons about their right to maintain their autonomy and have needed support, and provide effective remedies against any limitation of their autonomy by public or private actors.

A legally binding convention can enhance and clarify the rights of older persons with disabilities, and ensure that arrangements for independent living and the exercise of legal capacity are tailored to their needs as older persons. Older persons with disabilities need to be included as experts in the development of binding norms. Thank you.



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

**Normative Standards on Equality and Non-discrimination, and on Violence, Neglect and Abuse, 9th Session of the Open Ended Working Group on Ageing**

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Normative standards for the rights of older persons need to transversally include all older persons. This means both a provision protecting against multiple and intersectional discrimination, and ensuring that nothing in the standards will exclude any subsector of older persons from equal enjoyment of human rights. Norms should be stated unequivocally with no exceptions, for example the rights to legal capacity and independent living in the community need to be articulated inclusively without the possibility of institutionalization or substitute decision-making to be used as a last resort, which would exclude a sector of older persons from those rights.

Normative standards should incorporate the concept of substantive equality along with formal equality.

One dimension of substantive equality relevant to older persons is equal and equitable claim on the resources of society, family and community.

Another dimension is the elimination of discriminatory barriers to enjoyment of a fulfilling life. For example, mandatory retirement as well as unimaginative and managerial approaches to a person’s care and support needs constitute such barriers.

A third relevant dimension of equality is that we should not accept the imposition of conditions of life on older persons that we reject as inhumane for younger persons; again thinking about institutionalization in particular.

These dimensions of equality should be incorporated as both rights and principles in binding normative standards. In this meeting, we have extensively discussed autonomy and independence, which should likewise be incorporated as a right and a principle.

With regard to violence, neglect and abuse:

We need to include all forms of exploitation in this category, including financial exploitation and theft of resources, as well as the exploitation of older persons as unpaid and underpaid workers.

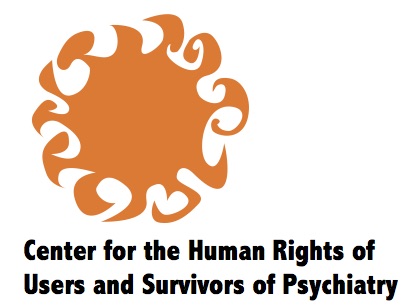
We need to conceptualize guardianship and institutionalization as forms of abuse.

There must be no chemical restraints used on older persons, and no use of neuroleptic drugs or electroshock whether for sedation or to treat psychosocial distress or disturbance. These destructive treatment modalities are widely used on older people experiencing such distress, who are given varying diagnoses including psychosis and depression, in addition to dementia. Electroshock is widely used on older women in particular. The Special Rapporteur on Health has recommended a shift from medical to psychosocial interventions in mental health; there is no reason to accept destructive treatments for any subsector of older people or to medicalize diagnoses that result in psychosocial disabilities or cognitive disabilities. All older persons need caring human support at all stages, and instances of aggression and conflict need to be managed socially rather than resorting to chemical sedation.

As people with psychosocial disabilities age, they are vulnerable to discrimination in both the mental health system and services for older persons. Unless they are extraordinarily resilient and resourceful, they will be written off as needing only to be held in custodial institutions and drugged until they die. This relates to the question of resource equity as well as the lifelong discrimination and abuses they have confronted in the mental health system. Human rights must leave no one behind.

The binding norms of a new convention should incorporate obligations of action as well as obligations of result to ensure that older people with psychosocial disabilities are given the support they need and the freedom from unwanted interventions.

We reiterate our support for a binding convention on the rights of older persons, who are ourselves and the future of all human beings. Thank you.



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**

* Check against delivery –

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 facilities where staff exercise control over the person’s daily life and make decisions about the person’s care, which may include 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 a disability issue as much as one 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 supports in the community provided by persons other than family members, for all persons with disabilities who need such supports. There are no individuals, irrespective of the nature or degree of their disability – and irrespective of their age – who can be deemed to require segregation and confinement. Yet in our experience, older persons with disabilities have not benefited significantly from de-institutionalization initiatives, due to gaps in the responsibilities of government agencies and due to ageism.

All older persons have a right to live independently and be included in the community, irrespective of any disability they may have, including persons with psychosocial disabilities and persons with cognitive disabilities caused by dementia. This right needs to be enshrined in the prospective convention, and it includes the provision of long-term supports and services to the person where they choose to live. As pointed out by Independent Expert, non-coercive 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 mental health services or other disability-related services. Older persons with psychosocial disabilities have the right to live in freedom and dignity without threat of forced hospitalization and forced drugging, and to be provided with desired supports and services according to an independent living model.

I turn now to palliative care. Palliative care is often a good practice that can serve as a model for the provision of support that aims to discover and facilitate the person’s will and preferences. However, it is crucial to guard against the improper conceptualization of palliative care as sedation with psychotropic drugs, whether pain-relieving drugs or neuroleptics (erroneously called antipsychotics), which reduce the person’s capability to be present in their own life. The right to palliative care should be framed with reference to the values of comfort and choice; it includes pain relief but is focused on supporting the person’s well-being in the circumstances of life-threatening illness and the process of dying.

Thank you.

1. \* 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](mailto:info@chrusp.org); website [www.chrusp.org](http://www.chrusp.org). [↑](#endnote-ref-1)
2. CRPD Arts 15 and 16

   Freedom from torture or cruel, inhuman or degrading treatment or punishment

   1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.

   2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

   Freedom from exploitation, violence and abuse

   1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

   2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.

   3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.

   4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

   5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

   African Disability Protocol Arts 5 and 6

   Right to Liberty, Security of Person and Freedom from Torture or Cruel, Inhuman or Degrading Treatment or Punishment

   1. Every person with a disability has the right to liberty and security of person and the right to be free from torture or cruel, inhuman or degrading treatment or punishment.
   2. States Parties shall take appropriate and effective measures to ensure that persons with disabilities, on an equal basis with others:
      1. Enjoy the right to liberty and security of person and are not deprived of their liberty unlawfully or arbitrarily;
      2. Are not forcibly confined or otherwise concealed by any person or institution;
      3. Are not subjected to torture or cruel, inhuman or degrading treatment or punishment;
      4. Are not subjected without their free, prior and informed consent to medical or scientific experimentation or intervention;
      5. Are not subjected to sterilisation or any other invasive procedure without their free, prior and informed consent;
      6. Are protected, both within and outside the home, from all forms of exploitation, violence and abuse.
   3. 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.
   4. 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.

   Harmful Practices

   1. States Parties shall take all appropriate measures, including legal sanctions, educational and advocacy campaigns, to eliminate harmful practices perpetrated on persons with disabilities, including witchcraft, abandonment, concealment, ritual killings or the association of disability with omens.

   2. States Parties shall take measures to discourage stereotyped views on the capabilities, appearance or behaviour of persons with disabilities, and they shall prohibit the use of derogatory language against persons with disabilities.

   3. States Parties shall offer appropriate support and assistance to victims of harmful practices.

   CRPD General Comment 3, para 55

   … Age and impairment, separately or jointly, can increase the risk of institutionalization of older persons with disabilities. In addition, it has been widely documented that institutionalization may expose persons with disabilities to violence and abuse, with women with disabilities being particularly exposed. [↑](#endnote-ref-2)
3. Inter-American Convention to Prevent and Punish Torture, Article 2

   Torture shall also be understood to be the use of methods upon a person intended to obliterate the personality of the victim or to diminish his physical or mental capacities, even if they do not cause physical pain or mental anguish. [↑](#endnote-ref-3)
4. CRPD General Comment 1 para 42

   As has been stated by the Committee in several concluding observations, forced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law and an infringement of the rights to personal integrity (art. 17); freedom from torture (art. 15); and freedom from violence, exploitation and abuse (art. 16). This practice denies the legal capacity of a person to choose medical treatment and is therefore a violation of article 12 of the Convention. States parties must, instead, respect the legal capacity of persons with disabilities to make decisions at all times, including in crisis situations; must ensure that accurate and accessible information is provided about service options and that non-medical approaches are made available; and must provide access to independent support. States parties have an obligation to provide access to support for decisions regarding psychiatric and other medical treatment. Forced treatment is a particular problem for persons with psychosocial, intellectual and other cognitive disabilities. States parties must abolish policies and legislative provisions that allow or perpetrate forced treatment, as it is an ongoing violation found in mental health laws across the globe, despite empirical evidence indicating its lack of effectiveness and the views of people using mental health systems who have experienced deep pain and trauma as a result of forced treatment. The Committee recommends that States parties ensure that decisions relating to a person’s physical or mental integrity can only be taken with the free and informed consent of the person concerned.

   CRPD Guidelines on Article 14, para 12

   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. [internal footnotes omitted] [↑](#endnote-ref-4)
5. Special Rapporteur on Torture Manfred Nowak, A/63/17, para 61

   The use of electroshocks on prisoners has been found to constitute torture or ill-treatment. The use of electroshocks or electroconvulsive therapy (ECT) to induce seizures as a form of treatment for persons with mental and intellectual disabilities began in the 1930s. CPT has documented instances in psychiatric institutions where unmodified ECT (i.e. without anaesthesia, muscle relaxant or oxygenation) is administered to persons to treat their disabilities, and used even as a form of punishment. The Special Rapporteur notes that unmodified ECT may inflict severe pain and suffering and often leads to medical consequences, including bone, ligament and spinal fractures, cognitive deficits and possible loss of memory. It cannot be considered as an acceptable medical practice, and may constitute torture or ill-treatment. In its modified form, it is of vital importance that ECT be administered only with the free and informed consent of the person concerned, including on the basis of information on the secondary effects and related risks such as heart complications, confusion, loss of memory and even death. [↑](#endnote-ref-5)
6. See CRPD references on legal capacity in endnotes to submission on Autonomy and Independence, as well as Arts 15 and 16 cited above. Further reference:

   Special Rapporteur on Torture Manfred Nowak, A/63/175 para 50

   Torture, as the most serious violation of the human right to personal integrity and dignity, presupposes a situation of powerlessness, whereby the victim is under the total control of another person. Persons with disabilities often find themselves in such situations, for instance when they are deprived of their liberty in prisons or other places, or when they are under the control of their caregivers or legal guardians. In a given context, the particular disability of an individual may render him or her more likely to be in a dependant situation and make him or her an easier target of abuse. However, it is often circumstances external to the individual that render them “powerless”, such as when one’s exercise of decision-making and legal capacity is taken away by discriminatory laws or practices and given to others. [↑](#endnote-ref-6)
7. \* 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](mailto:info@chrusp.org); website [www.chrusp.org](http://www.chrusp.org). [↑](#endnote-ref-7)
8. 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. [↑](#endnote-ref-8)
9. 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. [↑](#endnote-ref-9)
10. 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. [↑](#endnote-ref-10)
11. \* 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](mailto:info@chrusp.org); website [www.chrusp.org](http://www.chrusp.org). [↑](#endnote-ref-11)
12. CRPD Art 5

    1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

    2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

    3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

    4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

    See also generally CRPD General Comment 6, CRPD/C/GC/6 (2017). [↑](#endnote-ref-12)
13. CRPD Articles 12, 14, 19, see references in endnotes for submission on Autonomy and Independence. [↑](#endnote-ref-13)
14. CRPD Article 3

    The principles of the present Convention shall be:

    (a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;

    (b) Non-discrimination;

    (c) Full and effective participation and inclusion in society;

    (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

    (e) Equality of opportunity;

    (f) Accessibility;

    (g) Equality between men and women;

    (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities. [↑](#endnote-ref-14)
15. CRPD Art 6

    Article 6 Women with disabilities

    1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.

    2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

    CRPD General Comment 3 paras 55 and 59

    The right of women with disabilities to choose their place of residence may be adversely affected by cultural norms and patriarchal family values that limit autonomy and oblige them to live in a particular living arrangement. Thus, multiple discrimination can prevent the full and equal enjoyment of the right to live independently and to be included in the community. Age and impairment, separately or jointly, can increase the risk of institutionalization of older persons with disabilities. In addition, it has been widely documented that institutionalization may expose persons with disabilities to violence and abuse, with women with disabilities being particularly exposed.

    As a consequence of discrimination, women represent a disproportionate percentage of the world’s poor, which leads to a lack of choice and opportunities, especially in terms of formal employment income. Poverty is both a compounding factor and the result of multiple discrimination. Older women with disabilities especially face many difficulties in accessing adequate housing, are more likely to be institutionalized and do not have equal access to social protection and poverty reduction programmes. [↑](#endnote-ref-15)
16. See CRPD Art 5.4 cited above. [↑](#endnote-ref-16)
17. \* 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](mailto:info@chrusp.org); website [www.chrusp.org](http://www.chrusp.org). [↑](#endnote-ref-17)
18. 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. [↑](#endnote-ref-18)
19. 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. [↑](#endnote-ref-19)
20. 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. [↑](#endnote-ref-20)
21. 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. [↑](#endnote-ref-21)
22. 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:

    * 1. a) Enjoy the right to liberty and security of person and are not deprived of their liberty unlawfully or arbitrarily;
      2. b) Are not forcibly confined or otherwise concealed by any person or institution;
      3. c) Are not subjected to torture or cruel, inhuman or degrading treatment or punishment;
      4. d) Are not subjected without their free, prior and informed consent to medical or scientific experimentation or intervention;
      5. e) Are not subjected to sterilisation or any other invasive procedure without their free, prior and informed consent;
      6. f) Are protected, both within and outside the home, from all forms of exploitation, violence and abuse.
    1. 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.
    2. 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.

    1. 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:
    2. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live;
    3. 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;

    1. Persons with disabilities have personal mobility with the greatest possible independence;
    2. Community-based rehabilitation services are provided in ways that enhance the participation and inclusion of persons with disabilities in the community;
    3. 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;
    4. 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. [↑](#endnote-ref-22)
23. CRPD GuidelinesArt14 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. [↑](#endnote-ref-23)