



# Convention on the Rights of Persons with Disabilities

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## Committee on the Rights of Persons with Disabilities

### **Guidelines on deinstitutionalization, including in emergencies\***

#### **I. Purpose and process**

1. These guidelines complement the Committee's general comment No. 5 (2017) and its guidelines on the right to liberty and security of persons with disabilities (art. 14). They are intended to guide and support States parties, in their efforts to realize the right of persons with disabilities to live independently and be included in the community, and to be the basis for planning deinstitutionalization processes and prevention of institutionalization.
2. The guidelines draw on the experiences of persons with disabilities before and during the coronavirus (COVID-19) pandemic, which uncovered widespread institutionalization, highlighting the harmful impact of institutionalization on the rights and lives of persons with disabilities, and the violence, neglect, abuse, ill-treatment and torture, including chemical, mechanical and physical restraints, that they experience in institutions.
3. The guidelines are the result of a participatory process, which included seven regional consultations organized by the Committee. Over 500 persons with disabilities, including women with disabilities, girls and boys with disabilities, survivors of institutionalization, persons with albinism, grass-roots organizations and other civil society organizations participated.

#### **II. Duty of States parties to end institutionalization**

4. Despite obligations under international law, persons with disabilities worldwide continue to be placed in institutions under life-threatening conditions.
5. The Committee observes that deinstitutionalization processes are either not compliant with the Convention or are overdue.
6. Institutionalization is a discriminatory practice against persons with disabilities, contrary to article 5 of the Convention. It involves de facto denial of the legal capacity of persons with disabilities, in breach of article 12. It constitutes detention and deprivation of liberty based on impairment, contrary to article 14. States parties should recognise institutionalization as a form of violence against persons with disabilities. It exposes persons with disabilities to forced medical intervention with psychotropic medications, such as sedatives, mood stabilizers, electro-convulsive treatment, and conversion therapy, infringing articles 15, 16 and 17. It exposes persons with disabilities to the administration of drugs and other interventions without their free, prior and informed consent, in violation of articles 15 and 25.

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\* Adopted by the Committee at its twenty-seventh session (15 August–9 September 2022).

7. Institutionalization contradicts the right of persons with disabilities to live independently and be included in the community.
8. States parties should abolish all forms of institutionalization, end new placements in institutions and refrain from investing in institutions. Institutionalization must never be considered a form of protection of persons with disabilities, or a “choice”. The exercise of the rights under article 19 of the Convention cannot be suspended in situations of emergency, including in public health emergencies.
9. There is no justification to perpetuate institutionalization. States parties should not use lack of support and services in the community, poverty or stigmas to justify the ongoing maintenance of institutions, or delays to their closure. Inclusive planning, research, pilot projects or the need for law reform should not be used to delay reform or to limit immediate action to support community inclusion.
10. Persons with disabilities experiencing individual crises should never be subjected to institutionalization. Individual crisis should not be treated as a medical problem requiring treatment or as a social problem requiring state intervention, forced medication or forced treatment.
11. Deinstitutionalization processes should aim at ending all forms of institutionalization, isolation and segregation of persons with disabilities, in both private and public spheres.
12. Institutionalization can never be considered as a form of protection of children with disabilities. All forms of institutionalization of children with disabilities, which means placement in any non-family setting, constitute a form of segregation, are harmful and violate the Convention. Children with disabilities – like all children – have the right to family life and a need to live and to grow up with a family in the community.
13. States parties should immediately provide individuals with opportunities to leave institutions, revoke any detention authorized by legislative provisions that are not in compliance with article 14 of the Convention, whether under mental health acts or otherwise, and prohibit involuntary detention based on disability. States parties should immediately halt new placements in institutions, adopt moratoria on new admissions and on the construction of new institutions and wards, and should refrain from refurbishing and renovating existing institutions.

### **III. Understanding and implementing key elements of deinstitutionalization processes**

#### **A. Institutionalization**

14. There are certain defining elements of an institution, such as obligatory sharing of assistants with others and no or limited influence as to who provides the assistance; isolation and segregation from independent life in the community; lack of control over day-to-day decisions; lack of choice for the individuals concerned over with whom they live; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of individuals under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and a disproportionate number of persons with disabilities in the same environment.
15. Institutionalization of persons with disabilities refers to any detention based on disability alone or in conjunction with other grounds such as “care” or “treatment”. Disability-specific detention typically occurs in institutions that include, but are not limited to, social care institutions, psychiatric institutions, long-stay hospitals, nursing homes, secure dementia wards, special boarding schools, rehabilitation centres other than community-based, half-way homes, group homes, family-type homes for children, sheltered or protected living homes, forensic psychiatric settings, transit homes, albinism hostels, leprosy colonies and other congregate settings. Mental health settings where a person can be deprived of their liberty for purposes such as observation, care or treatment and/or preventive detention are a form of institutionalization.

16. All institutions, including those run and controlled by non-State actors, should be included in deinstitutionalization reforms. The absence, reform or removal of one or more institutional elements cannot be used to characterize a setting as community-based. Such is the case, for example, in settings where adults with disabilities continue to be subjected to substituted decision-making or to compulsory treatment, or where they have shared assistants; settings located “in the community” where service providers set a routine and deny autonomy; or “homes” where the same service provider packages housing and support together.

17. States parties should recognize that living independently and being included in the community refer to life settings outside residential institutions of all kinds, in accordance with article 19 of the Convention. Regardless of size, purpose or characteristics, or the duration of any placement or detention, an institution can never be regarded as compliant with the Convention.

18. Persons with disabilities may be overrepresented in other detention settings, such as prisons, refugee camps, migrant shelters, shelters for homeless persons and prayer camps. States should ensure the rights of persons with disabilities detained in other detention settings and eradicate discriminatory practices on the basis of disability to which they are subject.

## **B. Deinstitutionalization processes**

19. Deinstitutionalization comprises interconnected processes that should focus on restoring autonomy, choice and control to persons with disabilities as to how, where and with whom they decide to live.

20. Processes of deinstitutionalization should be led by persons with disabilities, including those affected by institutionalization, and not by those involved in managing or perpetuating institutions. They should avoid practices that violate article 19 of the Convention, including renovation of settings, adding more beds, replacing large institutions with smaller ones, renaming institutions, or applying standards such as the ‘principle of least restriction’ in mental health legislation.

## **C. Respect for the right to choose and for individual will and preferences**

21. Living independently and being included in the community require full legal capacity, access to housing, support and service options that are accessible and enable persons to regain control of their lives. Having choice means that persons with disabilities, including women and older persons, are respected in their decision-making, and that the evolving capacities of children with disabilities are respected. States parties should provide multiple options to those leaving institutions and ensure access to the support persons with disabilities may require to decision-making.

## **D. Community-based support**

22. States parties should prioritize the development of a range of quality, individualized support and inclusive mainstream services in the community, without delay.

23. A core element of living independently and being included in the community is that all persons with disabilities have the support, based on their own choices, that they may require to carry out daily activities and participate in society. Support should be individualized, personalized and offered through a variety of options. Support encompasses a wide range of formal assistance, as well as informal community-based networks.

24. Persons with disabilities should be enabled to exercise their legal capacity in choosing, managing and terminating the provision of community-based support. Support in exercising legal capacity can be provided as a service funded by the State, or through the individual’s informal networks.

25. Support services for living independently should be available, accessible, acceptable, affordable and adaptable.

26. Support services include personal assistance, peer support, supportive caregivers for children in family settings, crisis support, support for communication, support for mobility, provision of assistive technology, support in securing housing and household help, and other community-based services. Support should also be available for persons with disabilities to gain access to and use mainstream services such as education, employment, the justice system and healthcare.

27. Personal assistance services must be individualized, based on individual needs, and controlled by the user. The user should be able to decide the degree to which they manage the service themselves, either acting as employer or engaging the service from a variety of providers. All persons with disabilities should have access to personal assistance, regardless of requirements for support in exercising legal capacity. Persons with disabilities should be connected with personal assistance schemes before leaving institutions, to ensure they can access the service immediately after leaving.

28. Definitions of community-based support services, including in-home, and other support services, and personal assistance, should prevent the emergence of new segregated services, group housing – including ‘small group homes’ – sheltered workshops, institutions for the provision of ‘respite care’, transit homes, day-care centres, or coercive measures such as community treatment orders are not community-based services.

## **E. Allocation of funding and resources**

29. Investments in institutions, including renovation, should be prohibited. Investments should be directed towards the immediate release of residents and the provision of all necessary and appropriate support for living independently. States parties should refrain from suggesting that persons with disabilities “choose” to live in institutions, or using similar arguments to justify the maintenance of institutions.

30. States parties should stop using public funds for the construction and renovation of institutions and should allocate them, including those from international cooperation, to ensure the sustainability of inclusive community support systems and inclusive mainstream services.

31. States parties should provide persons with disabilities, including children with disabilities leaving institutions, with a comprehensive compensatory package comprising goods for daily living, cash, food vouchers, communication devices and information about services available, immediately upon departure. Such packages should provide basic security, support and confidence to persons with disabilities leaving institutions, in order that they can recover, seek support when they require it, and have an adequate standard of living in the community without risk of homelessness or poverty.

## **F. Accessible housing**

32. States parties should ensure safe, accessible and affordable housing in the community, through public housing or rental subsidies, for persons leaving institutions. Aggregating persons leaving institutions into communal housing arrangements or in assigned neighbourhoods, or bundling housing with medical or support packages, are incompatible with articles 19 and 18 (1) of the Convention. Persons leaving institutions should enjoy the right to enter into legally binding rental or ownership agreements. Housing should be neither under the control of the mental health system or other service providers that have managed institutions, nor conditioned on the acceptance of medical treatment or specific support services.

33. The reference to residential services in article 19 of the Convention should not be used to justify the maintenance of institutions. Residential services are community-based support services aimed at ensuring equality and non-discrimination in the exercise by persons with disabilities of their right to adequate housing. Examples of residential services can include social housing, self-managed co-housing, free matching services, and assistance in challenging housing discrimination. For housing to be considered adequate, it must meet

minimum criteria concerning legal security of tenure, availability of services, materials, facilities and infrastructure, affordability, habitability, accessibility, location and cultural adequacy.

### **G. Involvement of persons with disabilities in deinstitutionalization processes**

34. States parties should closely involve persons with disabilities, and their representative organizations – and give priority to the views of persons leaving institutions, survivors of institutionalization, and their representative organizations – in all stages of deinstitutionalization processes, in accordance with articles 4 (3) and 33 of the Convention. Service providers, charities, professional and religious groups, trade unions and those with financial or other interests in keeping institutions open should be prevented from influencing decision-making processes related to deinstitutionalization.

35. Persons with disabilities living in institutions, survivors of institutionalization and those at a higher risk of institutionalization should be provided with support and information in accessible formats to facilitate their full participation in deinstitutionalization processes.

36. States parties should establish open and inclusive planning processes, ensuring the public understands article 19 of the Convention, the harms of institutionalization and exclusion of persons with disabilities from society, and the need for reform. These processes should include dissemination of information and other awareness-raising activities targeting the public, persons with disabilities, family members, policymakers, and service providers.

## **IV. Deinstitutionalization grounded in the dignity and diversity of persons with disabilities**

37. All persons with disabilities have the right to live in the community, and deciding that some people cannot live independently and should stay in institutions is discriminatory. Individuals who have been denied their right to decision-making may not initially feel comfortable with being invited to live independently and being included in the community, even if offered support. For many, the institution may be the only living environment that they know. States parties should be held accountable for limiting the personal development of institutionalized people and should not create new barriers to leaving institutions by attributing “vulnerability” or “weakness” to persons with disabilities. Deinstitutionalization processes should be aimed at restoring the dignity and recognizing the diversity of persons with disabilities. Assessment of capacities for independent living based on impairment are discriminatory and should shift to assessments of individualized requirements and barriers for independent living in the community.

38. The involvement of family members of persons with disabilities in deinstitutionalization processes should be allowed only with the express consent of adult persons with disabilities. Some persons with disabilities may prefer to receive support from a family member, as a complement or alternative to public services. Where a person chooses to receive support from family members, States parties should ensure that the latter have access to adequate financial, social and other assistance to fulfil their support role. State support for family members should be provided only with full respect for the right of persons with disabilities to have choice and control over the kind of support received and the way in which it is used. Support for family members should never include any form of short- or long-term placement of persons with disabilities in an institution, and should enable persons with disabilities to realize their right to live independently and to be included in the community.

### **A. Intersectionality**

39. States parties should adopt an intersectional approach to tackling discrimination, segregation, isolation and other forms of ill-treatment of persons with disabilities living in

and leaving institutions. The personal identities of persons with disabilities are multifaceted, and disability is only one characteristic. Other characteristics including race, sex and gender, gender identity and expression, sexual orientation, sexual characteristics, language, religion, ethnic, indigenous or social origin, migrant or refugee status, age, impairment group, political or other opinion, experience of imprisonment, or other status, intersect to shape a person's individual identity. Intersectionality plays an important role in the lived experiences of all persons with disabilities.

40. Discrimination based on disability may occur whether or not individuals are institutionalized explicitly on the basis of disability. Multiple discrimination, *de jure* or *de facto* discrimination may also occur in the community through a lack of support services, driving persons with disabilities into institutions.

41. States parties should ensure that intersectionality is considered throughout all aspects of deinstitutionalization processes, especially in planning, implementing and monitoring the closure of institutions, in developing inclusive community support systems and inclusive mainstream services, and in ensuring the participation of persons with disabilities throughout these processes, while employing gender-sensitive and age-appropriate approaches. States parties should also tackle structural racism, to prevent discrimination and institutionalization based on race and ethnic origin, in conjunction with disability.

## **B. Women and girls with disabilities**

42. States parties should acknowledge that women and girls with disabilities are subjected to multiple discrimination on the grounds of gender and disability, and that they are not a homogeneous group. Women with disabilities are at a heightened risk of violence, exploitation and abuse compared with other women, and of gender-based violence and harmful practices, such as forced contraception, forced abortion and sterilization, during institutionalization. They are denied the right more often than men with disabilities and more often than other women to exercise their legal capacity, leading to denial of access to justice, choice and autonomy. These risks should be considered when designing and implementing deinstitutionalization plans.

## **C. Children and adolescents with disabilities**

43. For children with disabilities, deinstitutionalization should be directed towards protection of the right to family life, in accordance with their best interests. For children, the core of the right to be included in the community is the right to grow up in a family. An "institution", in the context of children, is any placement that is not family-based. Large or small group homes are especially dangerous for children. International standards that justify or encourage the maintenance of residential care are inconsistent with the Convention and should be updated.

44. States parties should ensure the right to family life for all children with disabilities. A family may include married and unmarried parents, single parents, same-sex parents, adoptive families, kinship care, sibling care, extended family, substitute families or foster care. A healthy living arrangement should allow a child to establish a stable relationship with a committed adult caregiver, and every effort should be made to avoid multiple placements of children who do not live with their family of origin. Children and adolescents with disabilities cannot "choose" to live in an institution. International funding should not support orphanages, residential care, group homes or children's villages.

45. Children placed in institutions based on their actual or perceived impairment, poverty, ethnicity or other social affiliation are likely to develop or exacerbate impairments because of institutional placement. Support for children with disabilities and families, as early as possible, should be included in mainstream support for all children. Peer support for children and adolescents is essential for full community inclusion.

46. Even short-term placement outside a family can cause great suffering, trauma and emotional and physical impairments. Preventing the placement of children in institutions

must be a priority. Opportunities for family-based placements, with financial and other forms of support, should be created for all children with disabilities. Placement within the family of origin should be considered before any alternative family arrangements.

47. Article 23 (4) of the Convention protects against the separation of children from their parents based on a disability of either the child or one or both parents. States parties should provide parents with disabilities support and reasonable accommodation to prevent their children from being placed in institutions and put in place inclusive child protection systems.

48. Children with disabilities, like all children, have the right to be heard on matters that affect them, their views being given due weight in accordance with their age, gender, and maturity, without discrimination on the basis of disability, and to receive age, disability-appropriate and gender-sensitive support. Support and accommodation should be provided to ensure that children and adolescents with disabilities can express their will and preferences and be involved in matters of personal choice and in public policymaking. Parents, relatives and caregivers can play an important role in supporting children with disabilities in expressing their views, and should take the child's views into account.

49. Children and adolescents with disabilities cannot "choose" to live in an institution. Young persons with disabilities should be provided with opportunities to choose where and with whom they live, taking into consideration that independent living arrangements refer to "life settings outside residential institutions of all kinds".

50. States parties should develop and ensure access to support services in the community, including personal assistance and peer support, for children and adolescents with disabilities. Education systems should be inclusive. States parties should include children with disabilities in mainstream schools, and prevent placement in segregated education, which undermines community inclusion and leads to increased pressure to place children in institutional settings.

51. To prevent the institutionalization of children, accessible information should be made available to families and children. It should be presented in multiple user-friendly formats through schools, community centres, doctors' offices, health care facilities, parents' resource centres and religious institutions. Training of professionals, including child protection professionals, on the human rights model of disability is key to preventing situations in which families are advised or encouraged to place their child in an institution.

#### **D. Older persons with disabilities**

52. All deinstitutionalization efforts should include older persons with disabilities, including those with dementia placed in institutions or at risk of institutionalization. Deinstitutionalization should target both disability-specific and other institutional settings for older persons, including "dementia villages". States parties should prevent discrimination against older persons with disabilities in accessing support and services in the community and their own homes.

### **V. Enabling legal and policy frameworks**

53. States parties should repeal laws and regulations, and modify or abolish customs and practices that prevent persons with disabilities from living independently and being included in the community. Legal and policy frameworks should enable the full inclusion of all persons with disabilities and guide deinstitutionalization processes towards the closure of institutions. Such frameworks should enable the development of inclusive community support systems and mainstream services, the creation of a reparations mechanism, and guarantee the availability, accessibility and effectiveness of remedies for survivors of institutionalization. States parties should proceed on the basis that a lack of comprehensive legal reform does not excuse inaction.

## **A. Creating an enabling legal environment**

54. An enabling legal environment for deinstitutionalization includes legislative recognition, for all persons with disabilities, of the right to live independently and to be included in the community, including a right to personal assistance, alongside the following fundamental rights.

### **1. Right to legal capacity**

55. The reform of legislation on legal capacity, in accordance with general comment No. 1, should be carried out immediately, simultaneously with deinstitutionalization. Where persons with disabilities, including those placed in institutions, are subjected to guardianship, forced mental health treatment or other substituted decision-making regimes, such measures should immediately be lifted. To prevent forced mental health treatment, affirmative, free and informed expression of consent by the person concerned is required. The exercise of decision-making by persons with disabilities who are currently placed in institutions should be respected within the deinstitutionalization process. They should be provided with the accommodation and support that they require to exercise their legal capacity, giving full effect to their will and preferences. Support to exercise legal capacity should continue, if required, after persons with disabilities have established themselves in the community.

### **2. Right to access to justice**

56. Access to justice, particularly for women and girls living in or leaving institutions who experience gender-based violence, is key in deinstitutionalization. Environmental, attitudinal, legal, communicational, and procedural barriers to access to justice for persons with disabilities, including those placed in institutions, should be removed across all legal domains. Reasonable and procedural accommodations, including but not limited to Easy Read and plain language, should be made available. Legal standing in courts and tribunals and the provision of free and accessible legal representation should be ensured. States parties must reform penal and procedural law to eliminate declarations of incapacity to participate in proceedings or to be held criminally responsible. States parties should ensure that legislation and judicial procedures are in place to recognize the right of persons with disabilities to provide testimony and stand as witnesses, and ensure that persons in institutions have an effective right to call the police and file criminal charges while in an institution.

57. Where children or adults are in institutions and are unable to file complaints themselves, national human rights institutions and advocacy organizations may be authorized to take legal action. This should only happen based on the person's free and informed consent or, when the person's rights are at stake and it has not been feasible to obtain an expression of will from the person, despite real efforts based on a best interpretation of the will and preferences of the person concerned. Releasing persons with disabilities from disability-based detention and preventing new detentions are immediate obligations, and not subject to discretionary judicial or administrative procedures.

### **3. Right to liberty and security of person**

58. All legislative provisions that authorize the deprivation of liberty or other restrictions on liberty and security of person based on impairment, including involuntary commitment or treatment based on "mental illness or disorder", should be repealed. Security measures applied in criminal proceedings, guardianship and other substituted decision-making regimes, and provisions for psychiatric hospitalization, including that of children, should be repealed. States parties should provide emergency assistance to persons with disabilities to enable them to leave places where they are arbitrarily detained.

### **4. Right to equality and non-discrimination**

59. States parties should recognize in law that institutionalization based on disability, separately or in combination with other grounds, amounts to a prohibited form of discrimination.



## **B. Legal framework and resources**

60. Proper mapping of existing laws, regulatory frameworks, policies, budgets, formal service structures, informal community-based support, new elements of support and the workforce is essential to inform comprehensive reform of laws and policies in support of deinstitutionalization. Mapping processes should be undertaken to accelerate deinstitutionalization, and not to delay closure of institutions.

### **1. Legislation**

61. Primary, secondary, regulatory and other sources of law should be systematically reviewed across all areas to: (a) identify those provisions that facilitate or enable institutionalization based on disability, with a view to their abolition; (b) identify gaps in legal recognition and enforceability of the right to live independently and to be included in the community, and related rights, with a view to initiating legislative proposals to remedy such gaps; and (c) ensure that effective legal remedies are available to persons with disabilities against institutionalization and discrimination on the basis of disability, including the failure to provide reasonable accommodations or support in the community, respectively.

62. Legislation that needs to be harmonized with the Convention includes legal provisions governing legal capacity, disability laws, anti-discrimination laws, family laws, health laws, civil laws, laws governing social care provision for children, adults and older persons, and social protection legislation. Such legislation should be reviewed in accordance with the Convention and Committee's general comments. Provisions in mental health laws allowing for the institutionalization of persons with disabilities should be abolished.

### **2. Institutional settings and the situation of persons living in institutions**

63. Existing institutions should be mapped. States parties should identify funding currently going into institutions and reallocate these to services that respond to the expressed requirements of persons with disabilities. Similarly, the mapping of the networks and important relationships that each individual has, subject to the will and preferences of the individual concerned, can be used when planning the support required by each individual and when developing and/or adapting elements of support services and mainstream community services.

### **3. Community-based services**

64. Existing community-based services should be comprehensively mapped. Services that are segregated, medicalized or not based on the will and preferences of persons with disabilities should be discontinued. Planning should ensure availability, accessibility, acceptability, affordability and adaptability of a range of quality community-based services.

### **4. Identifying new elements of support systems**

65. States parties should, in close consultation with organizations of persons with disabilities:

- (a) Identify gaps in support for persons with disabilities and the need for new service structures to be developed;
- (b) Develop, introduce and evaluate pilot projects;
- (c) Ensure that a wide range of support mechanisms and services exist in the community and that all persons with disabilities can plan and direct their own support, including persons with more intensive support requirements and those that use alternatives to verbal communication, and that children's families are equally supported;
- (d) Ensure support services respond to the will and preferences of persons with disabilities;

- (e) Ensure that persons with disabilities, including those who may require support in choosing and managing their support, have real choice and are not obliged to choose between services that do not comply with the Convention.

## **5. Workforce analysis**

66. States parties should map the workforce, including demographic and employment trends and the impact these may have on deinstitutionalization. States parties should establish priorities for improvement, assessing the feasibility of workforce transformation to ensure the provision of services compliant with the Convention. Services should be provided solely under the direction of the persons with disabilities concerned, or the parents or guardians of children with disabilities, giving due weight to the child's views. Those responsible for human rights violations should not be licensed to provide new services.

## **C. Deinstitutionalization strategies and action plans**

67. States parties should adopt a high-quality and structured plan for deinstitutionalization, which must be comprehensive and contain a detailed action plan with timelines, benchmarks and an overview of the necessary and allocated human, technical and financial resources. States parties should make maximum use of their available resources without delay. Deinstitutionalization strategies require a cross-governmental approach throughout implementation, entailing high-level political leadership and coordination at ministerial or equivalent level, with sufficient authority to initiate and lead law reform processes and to direct policymaking, programming and budgeting. Persons with disabilities, and their representative organizations, including those of children with disabilities and particularly those of survivors of institutionalization, should be involved and consulted at all stages of deinstitutionalization.

68. A clearly stated declaration of what is to be achieved through the deinstitutionalization process, prepared in consultation with persons with disabilities, especially survivors of institutionalization, and their representative organizations, should form the basis for deinstitutionalization strategies and action plans.

## **VI. Inclusive community support services, systems and networks**

### **A. Support systems and networks**

69. Support systems and networks include the relationships that an individual develops with family members, friends, neighbours or other trusted persons who provide the support that a person requires for decision-making or daily activities, in order that the person can exercise the right to live independently and to be included in the community. Support systems are important in enabling persons with disabilities to participate and be fully included in the community. Support systems are key for some persons with disabilities, in particular for persons with intellectual disabilities and persons requiring more intensive support, in navigating and determining the support services that they may require.

70. States parties should invest in peer support, self-advocacy, circles of support and other support networks – including organizations of persons with disabilities, particularly those of survivors of institutionalization – and centres for independent living. States parties should encourage the creation of such support networks, provide financial support and fund access to and design of training in human rights, advocacy and crisis support.

71. States parties should recognize the existence of informal support and ensure communities and families are trained and supported to provide support that is respectful of the choices, will and preferences of persons with disabilities. Persons with disabilities should have access to a wide range of support options, whether or not they wish to be supported by their families or communities.

72. Support persons, circles of support and support networks may be chosen by persons with disabilities only, and not by third parties such as judicial or medical authorities, family

members or service providers. Supporters should respect the will and preferences of persons with disabilities. Support persons should never be appointed against the will of the persons with disabilities.

73. Peer support should be self-directed, independent of institutions and medical professionals, and autonomously organized by persons with disabilities. It is especially important for survivors of institutionalization, and in the interest of consciousness-raising, supported decision-making, crisis support and crisis respite, living independently, empowerment, income generation, political participation, and/or participating in social activities.

74. Where persons with disabilities decide to receive support from their families, adequate support services to family caregivers should be provided, so they can in turn support their relative to live independently in the community. Support arrangements can include a multiplicity of supporters acceptable to the person using support, and to the families of children with disabilities, ensuring continuity and quality of support. States parties should recognise informal supports, such as circles of support and family peer support, and should fund community-based support such as counselling services. Such services should not entail the placement of children or adults with disabilities in institutions, even for short periods of time.

## **B. Support services**

75. Support services should be developed in accordance with a human rights model, respecting the will and preferences of persons with disabilities and ensuring their full participation and their broader support network, if the person so wishes. A person-centred process should be used in identifying the range of support that a person may need to live independently and be included in the community, including by prioritising self-assessment tools. States Parties should not rely exclusively nor mainly on the use medical criteria when developing new needs assessment tools, and medical professionals should not be granted with prevailing or higher status over other professionals involved in assessments nor any decision-making power over persons with disabilities.

76. States parties should ensure that options outside the health-care system, that fully respect the individual's self-knowledge, will and preferences, are made available as primary services without the need for mental health diagnosis or treatment in the individual's own community. Such options should meet requirements for support related to distress or unusual perceptions, including crisis support, decision-making support on a long-term, intermittent or emergent basis, support to heal from trauma, and other support needed to live in the community and to enjoy solidarity and companionship.

77. Disability-related support services, provided in some contexts under the framework of community-based rehabilitation or community-based inclusive development, should link with existing services and networks in the community. They should not be segregating, nor should they strengthen the isolation of persons with disabilities. Day-care centres or sheltered employment do not comply with the Convention.

78. Funding models for support services should be flexible and not limited by "supply". States parties should invest in the creation and development of a wide range of flexible support services to respond to the demands of diverse individuals, respecting their choice and control, including the option of designing new forms of support.

79. State parties should ensure that the choice to return to one's family home after institutionalization does not disqualify a person from eligibility for permanent independent housing.

80. Support should remain subject to the choice and control of persons with disabilities and should not be imposed involuntarily or delivered in a way that infringes upon the person's autonomy, liberty or privacy. States parties should put in place safeguards to that effect, including individualized arrangements that conform with the will and preferences of the person, and accessible and confidential means of reporting abuse. States parties should ensure

that all support services, whether private or public, are based on ethical regulatory frameworks that comply with the Convention.

81. Support for older persons with disabilities should provide the opportunity for persons to stay in their own homes in the community. Persons with disabilities should not lose access to support, such as personal assistance, once they reach old age. Instead, States parties should increase community support over time as needed, and never resort to institutionalization.

82. Children with disabilities may require specific support services. States parties should ensure that support provided to children and their families does not reinforce segregation, exclusion or neglect. Rather, support should enable children with disabilities to realize their full potential.

### **C. Individualized support services**

83. States parties should ensure that all persons with disabilities, including persons leaving institutions, have access to personal assistance if required and that they are informed about how personal assistance works so that they can decide whether to use it.

84. States parties should provide different types of individualized and person-centred support services, such as support persons, support workers, direct support professionals, and personal assistance.

### **D. Assistive technology**

85. States parties should increase and ensure access to affordable assistive technology, including typical and traditional assistive devices, and ensure access to modern information and communication technology and devices. When advanced technologies are available to the general population, persons with disabilities should be provided with equal access, with appropriate adaptations.

### **E. Income support**

86. Persons with disabilities should receive individualized and direct funding that provides for basic income security, coverage of health-care and disability-related costs, including components related to repairing the harm caused by institutionalization, in accordance with their will and preferences. Individual funding should be regularly revised according to the person's requirements and in case of emergencies. Funding should be adapted to changes in costs throughout the lifespan and take into consideration inflation. Administrative support and empowerment, through peer support and self-advocacy, should be available to encourage the take-up of user-led funding options. For persons leaving institutions, income support should be tailored to their new living arrangements.

87. Eligibility for income support that covers disability-related costs should not be tied to an individual's or a household's general income. States parties should ensure that all persons with disabilities benefit from funding that covers the costs of living independently, regardless of job-related income.

88. Budgetary allocations for services for persons with disabilities should be under the direct control of persons with disabilities, or in the case of children their primary caregiver(s), ensuring they have necessary forms of support, reasonable accommodation and a range of choices to enable them to effectively make decisions concerning where and with whom they live and which services, if any, they receive, outside of institutions. States should provide financial incentives and support to persons with disabilities to purchase and manage services in the community. States Parties should provide adequate support to persons with disabilities, including those with intense support requirements, in managing administrative processes related to individual funding management.

89. Poverty among persons with disabilities and their families is a leading driver of institutionalization. States parties should provide general income support to adults with

disabilities that allows them to enjoy an adequate standard of living, as well as their dependents, and relatives who act as their supporters, including families of children with disabilities. Such support should not be considered incompatible with employment. Relatives whose support responsibilities have disadvantaged them in other life paths should be provided with additional support.

## **VII. Access to mainstream services on an equal basis with others**

90. Deinstitutionalization plans should ensure that all persons with disabilities have access to a variety of accessible, affordable, and high-quality mainstream services in areas such as, personal mobility, accessibility, communication, health-care, family life, an adequate standard of living, inclusive education, participation in political and public life, housing, social protection, and participation in cultural and community life, leisure, recreation and sport. States parties should ensure that access to mainstream services is without discrimination and is not conditioned by, withheld or denied on the basis of assessments, family or social support, medication compliance, any determination of “severity” of disability or perceived intensity of support requirements, any finding of a “mental health condition”, or any other disqualifiers.

91. States parties should prevent institutionalization by making mainstream services, such as education and employment, available and accessible to all, ensuring the provision of reasonable accommodation.

92. Access to mainstream services should be planned for and ensured both in preparation for deinstitutionalization and when choosing a place to live in the community, settling down in the community and thereafter. Access to community resources, an adequate standard of living and social protection, should be ensured. States parties should prohibit the use of transitional institutional services as temporary measures or “stepping-stones” to living in the community.

### **A. Preparations for leaving the institution**

93. Deinstitutionalization reverses the unjust practice of institutionalization. It begins while the person is still in the institution and entails planning processes customized to each individual. All persons must have an equal opportunity to be deinstitutionalized and can choose to leave at any time. No person should be left behind in processes of deinstitutionalization, including persons with intense support requirements.

94. States Parties should ensure that institutional staff are trained on a human-rights, reparative and person-centred meaning of deinstitutionalization. Trusted persons, which may include family members, friends and others, should be involved in planning processes in accordance with the will and preferences of the person concerned. Peer support for institutionalized persons and survivors of institutionalization should be facilitated as part of planning and transition to promote full inclusion. Family members of persons who have been institutionalized should be provided with information and guidance, as well as economic and administrative support and dedicated services, to address the harms caused by institutionalization to their relative and prepare to constructively support them when leaving institutions.

95. Persons leaving institutions should:

- (a) Be respected as decision makers, with support if required, in respect of all aspects of leaving the institution;
- (b) Be provided with adequate time and opportunities to prepare physically and emotionally for living in the community. States parties should ensure that all persons have an individualized plan in place according to their will and preferences;
- (c) Be at the core of processes of individualized planning;

(d) Be respected as survivors to whom reparations are due and be provided with information and opportunities to participate fully in the planning and implementation of deinstitutionalization, truth commissions and reparations;

(e) Be offered a wide range of experiences in the community in preparation for leaving the institution, to help build their experience, strengths, social skills and life skills, remove fears and gain positive experiences of living independently;

(f) Receive information about housing options, transport, work and employment, individualized funding and all other measures necessary to ensure an adequate standard of living.

96. States parties should remove all barriers to birth registration and acquisition of citizenship status by persons leaving institutions, and provide official identification documents, including alternative documents for non-citizens and in humanitarian contexts. This applies to all documentation, such as national identity cards, residence permits, voter registration, employment numbers, social security cards, disability cards and passports, as applicable, and includes providing retroactive documentation if necessary. All documentation must be provided by the time of exit. States parties should ensure that no discriminatory or derogatory identification markers or description of the former status of persons leaving institutions exist, and that the highest standards of privacy protection and confidentiality are ensured for all health documentation.

97. Financial institutions, insurance and other financial services should remove all barriers for persons with disabilities to enjoy their right to inclusion in financial matters, on an equal basis with others. Being subjected to inquiry, interrogation or background checks based on their former status constitutes prohibited discrimination.

98. Authorities and personnel responsible for running institutions, and justice and law enforcement personnel, should receive training on the right of persons with disabilities to live in the community and on accessible communication. States parties should prohibit administrative or legal surveillance of persons leaving institutions following their departure. Institutional authorities and personnel should not provide “continuity of care” in the community.

## **B. Living independently in the community**

99. Persons leaving institutions require a wide range of possibilities for daily living, life experiences and opportunities to thrive in the community. States parties must meet their general obligations to uphold the rights of these persons, on an equal basis with others, with respect to accessibility, personal mobility, privacy, physical and mental integrity, legal capacity, liberty, freedom from violence, abuse and exploitation and from torture and other ill-treatment, education, participation in cultural life and recreation and participation in political life.

100. States parties should support awareness-raising activities on the inclusion of persons with disabilities, building the capacity of families, neighbourhoods and communities on the values and practices of inclusion. States should actively seek the participation of persons with disabilities, especially those who live in institutions or are survivors of institutionalization. Community-based organizations, individuals and neighbourhood groups may play a diversified role in the provision of social support, connecting persons to local resources, or provide support as a member of the broader social capital of the community.

101. States parties should ensure that persons leaving institutions have access to transportation, can move freely in the city, rural areas and their neighbourhoods, and can use public spaces on an equal basis with others.

102. States parties should fulfil their obligation to ensure the accessibility of public spaces, taking account of aspects including disability-friendly patrolling, road-related accessibility and the provision of fully accessible information and communication such as Easy Read, and support services, so that persons with disabilities can independently and safely navigate urban areas, including finding their way back safely to their homes and neighbourhoods.

103. States parties should ensure comprehensive healthcare, including primary healthcare, habilitation/rehabilitation and assistive technology, for persons leaving institutions, on an equal basis with others. Healthcare services should respect the choice, will and preferences of persons with disabilities leaving institutions, refrain from embedding the medical model of disability, and provide additional healthcare support as needed. This may include assistance to withdraw from psychiatric medication, access nutritional and fitness programs, always on the basis of free and informed consent and with a view to retrieving overall health and wellbeing.

104. States parties should ensure that persons leaving institutions have access to employment on an equal basis with others, and must prohibit sheltered or segregated employment. States parties should ensure an inclusive legal and policy framework in employment that eliminates barriers faced by persons leaving institutions. A range of choices, allowing time and support for decision-making, should be provided for persons leaving institutions to exercise their right to work and employment.

105. States parties should recognize that the risk of homelessness and poverty is very high for persons leaving institutions. A robust social protection package should be provided to all persons with disabilities leaving institutions to cover immediate and mid-term needs for resettlement. Long-term economic and social support should also be made available across the lifecycle. States parties should ensure that persons with disabilities and families of children with disabilities have access on an equal basis as others to existing social protection measures, such as child support, unemployment benefits, rental subsidies, food stamps, pensions, public health schemes, subsidized public transport and tax credits. Being a recipient of social protection should not be tied to treatment conditions, guardianship or eligibility criteria related to employment. Social protection schemes related to persons with disabilities should include funding for disability-related costs.

106. Persons leaving institutions should have access to inclusive education without discrimination, including opportunities to participate in lifelong learning, complete schooling and access to apprenticeships or higher education, to promote their social and economic empowerment and prevent segregation and institutionalization. States parties should ensure that persons with disabilities leaving institutions, including children, have access to information in accessible formats, are made aware of opportunities to continue or complete their education, and are able to pursue studies pursuant to their will and preferences.

## **VIII. Emergency deinstitutionalization in situations of risk and humanitarian emergencies, including conflicts**

107. During emergency situations, such as pandemics, natural disasters or conflicts, States parties should continue and accelerate efforts to close institutions. States parties should also recognise that climate change disproportionately impacts upon persons with disabilities, particularly those in institutions. During emergencies, immediate efforts are necessary to identify people with disabilities in institutions, and internally displaced persons with disabilities, unaccompanied and separated children with disabilities and refugees with disabilities, to prevent institutionalization. Targeted efforts are needed to ensure inclusion in evacuation, humanitarian relief and recovery measures, ensuring full accessibility in situations of risk and emergency. Emergency, and recovery funding should not support continued institutionalization. Instead, plans for accelerated deinstitutionalization should be included in recovery efforts and in national deinstitutionalization strategies, and implemented immediately in emergencies.

108. While emergencies require additional precautions for persons with disabilities, such precautions should not require changes in immediate action or in long-term plans for deinstitutionalization. Even in emergency contexts, States parties should maintain internationally agreed minimum core standards, preventing isolation, ill-treatment, disability-based discrimination and bias in triage protocols and avoiding preventable injury, illness and death. The prohibition of disability-based detention and the right to legal capacity should be upheld including during emergencies. States parties should ensure that human rights-compliant support services are available to persons with disabilities and apply the Inter-

Agency Standing Committee's Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action. Non-discrimination must be ensured in situations of risk and humanitarian emergencies across all programmes and actions, in line with these standards, ensuring that children with disabilities are included in all family retracing and reunification efforts.

109. States parties' plans to continue and accelerate deinstitutionalization during emergencies should be informed by persons with disabilities, and their representative organizations, particularly those of survivors of institutionalization. States parties and other stakeholders, including humanitarian actors, should ensure that measures aimed at disability-inclusive resilience within the community ensure the active participation of and coordination and meaningful consultation with organizations of persons with disabilities, including those at all levels representing adults and children with disabilities and persons remaining in institutions. These organizations should be involved in the design, implementation, monitoring and evaluation of emergency response, relief and recovery programmes and policies.

110. During emergencies, persons with disabilities with the highest health risks should be prioritized for deinstitutionalization.

111. Women and girls with disabilities in situations of risk and humanitarian emergencies are at a heightened risk of sexual and gender-based violence compared with other women and girls, and are less likely to have access to recovery and rehabilitation services, and access to justice. They are at risk of gender-based, multiple and intersecting forms of discrimination and of institutionalization. States parties should ensure an intersectional approach to disability inclusion is taken in legislation, policies and programmes relating to emergency preparedness, response and recovery. This includes, but is not limited to, prioritized access to disability-inclusive relief programmes, health services, sexual and reproductive health services, habilitation, rehabilitation, assistive devices, personal assistance, housing, employment and community-based services.

112. The principles of the Convention should be integrated into emergency preparedness, response and recovery with clear timeframes, adequate resources, budget allocations, trained staff and clear responsibilities. Deinstitutionalization should be included in national emergency protocols, including, but not limited to, evacuation scenarios and the provision of accessible information and communication helplines. States parties should ensure that humanitarian aid is distributed in an accessible, non-discriminatory manner, and that water, sanitation and hygiene facilities in emergency shelters and camps for refugees, asylum seekers and internally displaced persons are accessible to persons with disabilities. Prevention and protection from sexual exploitation, abuse and harassment and measures to ensure gender equality should be included in national recovery strategies.

113. States parties should ensure that institutions are not rebuilt or repopulated after emergencies. States parties should provide adequate financial and human resources to ensure that persons with disabilities are not left behind in response and recovery processes; measures to do so could include transferring funding from institutions to community support and services. Refugees and internally displaced persons should not be returned to institutions after emergencies or when conflict subsides. State parties should ensure that refugees with disabilities have access to social assistance, mainstream services and reasonable accommodation, as required.

114. In emergency preparedness, and during emergencies, States parties should ensure the use and collection of disaggregated data. Disaster risk reduction requires a multi-hazard approach and inclusive, risk-informed decision-making based on open exchange and dissemination of disaggregated data, including by sex, age and disability, and accessible information on the support persons with disabilities require across the humanitarian programme cycle. The same data and information is required concerning those living in institutions and/or transitioning through deinstitutionalization processes.



## **IX. Remedies, reparations and redress**

115. States parties should recognize institutionalization in all its forms as a multiple violation of the rights enshrined in the Convention. Aggravating factors may include the denial of effective redress, length of stay, infliction of forced medical interventions or other violence or abuse, and inhuman and degrading conditions.

116. States parties should commit to identifying and redressing institutionalization and its consequential harms in accordance with their international obligations, in particular the Convention, the International Principles and Guidelines on Access to Justice for Persons with Disabilities, the Committee's guidelines on the right to liberty and security of persons with disabilities, the United Nations Basic Principles and Guidelines on Remedies and Procedures on the Right of Anyone Deprived of Their Liberty to Bring Proceedings Before a Court, and the Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law.

117. States parties should create a mechanism to identify and raise awareness about the nature and scope of harms caused by all forms of institutionalization and to recommend changes in law and policy. States parties should provide individualized, accessible, effective, prompt and participatory pathways to access to justice for persons with disabilities who wish to seek redress, reparations and restorative justice, and other forms of accountability. Authorities and experts implicated in institutionalization should not have a role in creating or implementing mechanisms for redress and reparations, but should be invited to accept accountability.

118. Mechanisms of redress should acknowledge all forms of human rights violations caused by the institutionalization of persons with disabilities. Redress and reparations should be responsive to the violations suffered and the impact on an individual's life during and after institutionalization, including ongoing, consequential, and intersectional harms.

119. States parties should introduce a mechanism for the provision of formal apologies to survivors of institutionalization, negotiated with all groups representing persons with disabilities having experienced institutionalization and provide for further educational, historical and other cultural measures to raise the status of survivors throughout society. States parties should provide automatic compensation to survivors of institutionalization at levels that redress the pain, suffering and consequential damages experienced as a result of institutionalization. Such financial awards cannot undermine the legal rights of individuals to litigate or access other forms of justice.

120. Reparations should go beyond financial compensation, to include restitution, habilitation and rehabilitation – which may include measures covered in article 26 of the Convention, legal and social services to assist establishment in the community and securing all rights and entitlements, including health services and healing modalities to repair the damage caused by institutionalization – and should be accompanied by guarantees of non-repetition. States parties should legislate to criminalize disability-based detention and institutionalization, and other acts that result in disability-related torture and ill-treatment. Restitution, habilitation and rehabilitation should be tailored to the needs of individuals and to the losses or privations they have experienced, and should respond to their immediate and longer-term desires and aspirations, such as re-establishing relationships with their children or their family of origin, or retrieving any possessions that can be found.

121. Truth commissions should be established to investigate and promote public understanding of all forms of institutionalization, the full scope of harms caused to past and present survivors, and should address the social harms inherent in historic policies that maintained systems of institutionalization of persons with disabilities.

122. All remedies for survivors of institutionalization should be designed and implemented with the consultation and involvement of persons with disabilities, particularly with survivors of institutionalization. States parties should ensure that redress and reparations mechanisms respect the will and preferences of survivors of institutionalization, and that perpetrators do

not hold positions of authority or expert status in such mechanisms or processes and are not called upon to provide habilitation, rehabilitation or other services.

123. None of the above derogates from the obligation of States parties to investigate and prosecute perpetrators of violence and abuse against persons with disabilities under applicable domestic legislation and international human rights law. States parties must prevent reprisals against survivors of institutionalization.

## **X. Disaggregated data**

124. States parties should collect appropriate and ethically disaggregated statistical, research and administrative data, and use these to inform decision-making. Such use of data enhances deinstitutionalization processes, facilitates the design of deinstitutionalization policies, plans and programmes, and enables measurement and tracking of progress in deinstitutionalization's implementation. Statistics and data collected should cover all forms of public, private and faith-based institutions. States parties can refer to the set of questions developed by the Washington Group, and should undertake other efforts to ensure that no groups are excluded. States parties should operationalize the Fundamental Principles of Official Statistics, ensuring that data collection meets established standards of participation, self-identification, disaggregation, privacy, transparency and accountability.

125. States parties should facilitate the participation of persons with disabilities, and their representative organizations, in relevant data collection processes and exercises, such as defining data collection priorities, identifying persons with disabilities and providing information on their circumstances and requirements.

126. Data collected by States parties should be disaggregated according to race, ethnic origin, age, gender, sex, sexual orientation, socioeconomic status, type of impairment, reason for institutionalization, date of admission, expected or actual date of release, and other attributes. This includes collection of reliable, accessible and up-to-date records concerning the numbers and demographics of persons in psychiatric or mental health settings, records of whether the duty to allow persons with disabilities to leave institutions has been fulfilled, the number of persons who have exercised the option of leaving, and other information concerning planning for those who are yet to leave institutions.

127. States parties should ensure access to data collected on deinstitutionalization in various accessible formats by persons with disabilities, civil society, researchers and policymakers, including during emergencies.

128. When collecting data, States parties should apply existing legal safeguards, such as data protection laws, fully respecting the right to privacy of personal data. Existing laws often fail to respect the legal capacity of persons with disabilities, violating their privacy and undermining human rights monitoring and advocacy, and should be amended. Data protection laws should be brought into conformity with international standards on data privacy, subject to their compliance with the Convention.

## **XI. Monitoring deinstitutionalization processes**

129. Monitoring mechanisms should ensure accountability, transparency and the protection and promotion of the human rights of persons with disabilities at all stages of deinstitutionalization processes. Monitoring mechanisms should identify, prevent and remedy human rights violations, offer recommendations on best practices and be mandated to undertake the full range of obligations ascribed under article 33 of the Convention in accordance with the Committee's guidelines on independent monitoring frameworks.

130. Monitoring mechanisms should adhere to established principles of human rights monitoring, including ensuring meaningful participation of persons with disabilities, particularly those who are in institutions or who are survivors, and their representative organizations. National preventive mechanisms, national human rights institutions and other monitoring mechanisms should exclude staff of institutions from deinstitutionalization monitoring activities.

131. States parties should ensure that independent monitoring mechanisms designated under article 33 (2) of the Convention, have sufficient resources and unrestricted access, physical and otherwise, to institutions, documents and information. States parties should also ensure that independent monitoring activities undertaken by civil society and representative organizations of persons with disabilities, including activities under article 33 (3), are facilitated, and that barriers to accessing institutions, documents and information are removed.

132. All monitoring mechanisms should be allowed to freely investigate conditions and human rights violations within public and private institutions. Such access should respect and protect survivors' privacy. Individual privacy goes together with States parties' obligations to refrain from obstructing publication of human rights reports. States parties may not invoke privacy and confidentiality as barriers to independent monitoring. The ability to obtain, store and publish information about the conditions in institutions should be protected. Photographic and video documentation of conditions in institutions are critical to complement and corroborate the factual findings of human rights monitors.

133. States parties should address human rights violations in a timely and effective manner, including those identified through independent monitoring.

134. States parties should honour and facilitate personal data requests from survivors of institutionalization in public and private settings without restriction. States parties should not restrict or deny access to medical records by invoking public health or public order as grounds.

135. Upon release from an institution, the records of persons with disabilities should be handed over to the person concerned and/or expunged, in accordance with the person's will and preferences. Survivors' choices about disclosure should be respected, and legal provisions that permit access to records by States parties, law enforcement agencies, health professionals and others should be immediately repealed.

136. States parties should permit monitoring to continue during emergency situations, ensuring that risks are mitigated to the maximum extent possible. Where in-person monitoring is impossible, States parties should devote available resources to adopting alternatives, such as digital, electronic or other modes of remote communication, to ensure effective independent monitoring.

137. Independent monitoring of residential institutions should continue until all institutions are closed, and should not be suspended in times of emergency. Consistent with articles 16 and 33 (3) of the Convention, persons with disabilities, particularly survivors of institutionalization, including children with disabilities, their representative organizations, and independent civil society organizations should be included in independent monitoring.

## **XII. International cooperation**

138. International cooperation is key to supporting deinstitutionalization reforms. Investments in any form of institutionalization, including emergency response investments and investments in smaller institutions, are not compliant with the Convention, and do not conform with the principle of "progressive realization".

139. Transparent processes for implementing international cooperation and independent accountability mechanisms should be established, to ensure they are not used to maintain or reinforce segregation in institutions or disability-based coercive measures. This includes the collection of disaggregated data, independent monitoring and evaluation of all projects and programmes, and transparency about what is being funded. Complaints mechanisms should be established by States parties and donors.

140. States parties should establish an open and direct consultative process with persons with disabilities, and their representative organizations, on the design and implementation of development projects funded by international cooperation. Persons with disabilities in institutions and survivors of institutionalization should be included in this process. Where civil society organizations lack awareness of the right to live independently and to be included in the community, the consultative process should be supported by international cooperation under the rubric of strengthening civil society.

141. States parties should mainstream the rights of persons with disabilities into all international cooperation efforts and ensure that all measures to implement the 2030 Agenda for Sustainable Development support deinstitutionalization. As international cooperation cannot effectively ensure long-term provision of community-based support and services, States parties should plan to continue running newly created services and complete the process of deinstitutionalization.

142. Regional international organizations can play an important role in promoting deinstitutionalization processes, as part of international cooperation. Disability focal points in national, regional and international organizations should work closely with persons with disabilities, and their representative organizations, and with persons in institutions and survivors of institutionalization. Regional integration organizations have the same responsibilities as States parties to comply with the Convention, and should establish mechanisms for transparency and accountability.

143. International coordination of efforts to support deinstitutionalization are important to prevent the replication of bad practices, such as promoting a medical model approach and coercive mental health laws. States parties should consider establishing an international platform for good practices on deinstitutionalization, in close consultation with persons with disabilities, especially survivors of institutionalization, and their representative organizations. States parties should prevent volunteering by foreign tourists in institutions (known as “voluntourism”), by providing appropriate travel guidance and raising awareness about the Convention and the dangers of institutionalization.

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