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**Annual report of the United Nations High Commissioner
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High Commissioner and the Secretary-General**

**Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development**

Thematic study on the right of persons with disabilities to live independently and be included in the community

**Report of the Office of the United Nations High Commissioner
for Human Rights**

Summary

The present study, developed under Human Rights Council resolution 25/20, is focused on the right to live independently and be included in the community, and the enjoyment, protection and promotion of that right as a substantive means for the realization of other rights, as a condition for avoiding institutionalization and segregation in health and social settings, and as a prerequisite to provide for the full development of the capabilities of persons with disabilities and their meaningful participation in, and contribution to, society.

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I. Introduction

1. In its resolution 25/20, the Human Rights Council requested the Office of the United Nations High Commissioner for Human Rights (OHCHR) to prepare a study on the right of persons with disabilities to live independently and be included in the community (art. 19 of the Convention on the Rights of Persons with Disabilities), in consultation with States and other relevant stakeholders, regional organizations, the Special Rapporteur on disability of the Commission for Social Development, civil society organizations, including organizations of persons with disabilities, and national human rights institutions. The Council requested that the study be made available on the OHCHR website, in an accessible format, prior to the twenty-eighth session of the Council.

2. OHCHR solicited contributions from Member States, regional organizations, civil society organizations and organizations of persons with disabilities, the Special Rapporteur on disability of the Commission for Social Development and national human rights institutions, requesting responses to a set of questions concerning existing legislation and policies enabling persons with disabilities to live independently and be included in the community. OHCHR received 27 responses from States, 12 from national human rights institutions and 16 from civil society organizations and other stakeholders. The full texts of all submissions received are available on the OHCHR website.¹

II. The right to live independently and be included in the community

3. Persons with disabilities are often presumed to be unable to live independently. That presumption is based on misconceptions, including that they lack the ability to make sound decisions for themselves and that, therefore, society needs to protect them. This approach, practised in many countries for a long time, has deprived persons with disabilities of the opportunity to choose where and with whom to live and to determine their own future.

4. In article 19 of the Convention on the Rights of Persons with Disabilities, the States parties to the Convention recognized the equal right of all persons with disabilities to live independently and be included in the community, with choices equal to others. The foundation of that right is the core human rights principle that all humans are born equal in dignity and rights, and that all life is of equal worth. On those grounds, persons with disabilities have claimed the right to participate in all areas of mainstream community living, arguing that the capacity of all individuals to make choices in that regard must be acknowledged and enabled. Knowing their own needs best, persons with disabilities have sought control over options to choose, requesting that community services be made available to them on an equal basis with others. That approach has gradually been introduced in the laws and policies of some countries.

5. Those changes in approach are causes and consequences of the transition from a medical and charity approach to disability, whereby persons with disabilities were seen as passive objects of care, to a human rights-based approach. The latter approach takes the view that it is the society that must accommodate human diversity and enable persons with disabilities, among others, to be an active part of it. An important milestone in the process was the adoption of the Convention on the Rights of Persons with Disabilities in 2006, which established an obligation for States parties to take effective and appropriate measures

¹ www.ohchr.org/EN/Issues/Disability/Pages/LiveIndependently.aspx.

with a view to achieving full inclusion and participation of persons with disabilities in the community.

6. Article 19 reflects the essence of the Convention, in which persons with disabilities are regarded as subjects of rights. The article is aimed at preventing abandonment, institutionalization and segregation in domestic settings through the promotion of enabling and inclusive environments for all, and the abolishment of legal provisions that deprive persons with disabilities of choice by forcing them to live in institutions or other segregated settings. Fulfilment of the obligations under Article 19 also provides the conditions for the full development of the personality and capabilities of persons with disabilities.

7. The foundation of an independent and inclusive life in the community for persons with disabilities is provided for by the general principles of the Convention (art. 3), in particular the principles concerning full and effective participation and inclusion in society, and respect for the individual's inherent dignity, autonomy and independence. Full enjoyment of the right to live independently in the community is both the result of, and a precondition for, the combating of stereotypes and prejudices relating to persons with disabilities and the promotion of awareness of their capabilities and contributions to society (art. 8). Non-discrimination (art. 5) and accessibility (art. 9) are essential to ensure that community services and facilities for the general population are available on an equal basis to persons with disabilities and respond to their needs. Measures to prevent multiple discrimination are required to guarantee women with disabilities the full and equal enjoyment of the right to live independently in the community (art. 6). The specific barriers that children with disabilities face in enjoying this right, including to have their views taken into account on an equal basis with other children, should be duly considered and addressed when determining the best interest of the child on issues related to article 19 (art. 7).

8. The Convention recognizes that persons with disabilities have the right to equal recognition before the law (art. 12). The enjoyment of this right is essential for the effective realization of the right to live independently in the community, to make choices and to have control over their everyday lives, on an equal basis with others.² Similarly, respecting the right to liberty and security of the person (art. 14) includes ending all forms of deprivation of liberty that are based on the existence of an impairment.

9. Ensuring that persons with disabilities enjoy an adequate standard of living (art. 28) entails, *inter alia*, providing for support services that facilitate independence in their daily lives.³ To that end, States parties are obliged to ensure access to appropriate and affordable services, devices and other assistance for impairment-related needs, in particular for those persons with disabilities living in poverty. It also requires that persons with disabilities have access to public housing programmes. Inclusive education systems, accessible general and specific health services, the availability of habilitation and rehabilitation programmes, and equal opportunities in the open labour market are other examples of interconnected rights that contribute significantly to people living independently in the community (arts. 24–27).

10. Article 19 is closely connected to provisions in other human rights treaties, including the International Covenant on Civil and Political Rights,⁴ the International Covenant on Economic, Social and Cultural Rights⁵ and the Convention on the Rights of

² See Committee on the Rights of Persons with Disabilities, general comment No. 1 (2014) on equal recognition before the law, para. 44.

³ See Committee on Economic, Social and Cultural Rights, general comment No. 5 (1994) on persons with disabilities, para. 33.

⁴ For instance, articles 9, 12, 16 and 17.

⁵ For instance, articles 11 and 12.

the Child.⁶ The right to live independently and to be included in the community has also been recognized in regional human rights documents, such as the European Social Charter (art. 15) and the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities (art. 4, para. 2 (b)).

11. Several United Nations human rights treaty bodies and other mechanisms, including the special procedures of the Human Rights Council,⁷ have contributed in developing the various elements of the right of persons with disabilities to live independently and be included in the community. The Committee on Economic, Social and Cultural Rights, for instance, considers this right from a non-discrimination perspective, while the Committee on the Rights of the Child stressed that disability should never be a reason for institutionalization of children.⁸ The Committee on the Rights of Persons with Disabilities has consistently addressed this right in its dialogue with States parties, as well as in individual communications.⁹

III. Elements of article 19: choice, support and availability of community services and facilities

12. Article 19 reflects the diversity of cultural approaches discussed during the negotiations of the Convention on the Rights of Persons with Disabilities, where care was taken to ensure that the right covered under the article was not limited to the provision of services available in developed countries. States parties are given a range of options, with the provision that they respect the principles of control by persons with disabilities over their lives and non-segregation from the community.¹⁰

13. Living independently does not mean living alone or in isolation.¹¹ Rather, it means exercising freedom of choice and control over decisions affecting one's life with the same level of independence and interdependence within society on an equal basis with others. Consequently, article 19 refers to "living independently and being included in the community" as one right, where autonomy and inclusion are mutually reinforcing and jointly avoid segregation.¹²

⁶ For instance, articles 2, 9, 16, 20, 23, 25 and 27.

⁷ For instance, the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment (see A/HRC/22/53), the Working Group on Arbitrary Detention (see A/HRC/27/47) and the Special Rapporteur on violence against women, its causes and consequences (see A/67/227).

⁸ See Committee on Economic, Social and Cultural Rights, general comment No. 5, and Committee on the Rights of the Child, general comment No. 7 (2006) on implementing child rights in early childhood, and general comment No. 9 (2007) on the rights of children with disabilities.

⁹ See Committee on the Rights of Persons with Disabilities, communication No. 3/2011, *H.M. v. Sweden*, Views adopted on 19 April 2012. The Committee determined that the denial of a building permit for an indoor pool for the purpose of rehabilitation was a violation of article 19 (b) and would have the effect of forcing the complainant to enter an institution.

¹⁰ See, for instance, Marianne Schulze, *Understanding the UN Convention on the Rights of Persons with Disabilities* (Handicap International, 2nd ed., 2009).

¹¹ See the contribution of International Disability Alliance.

¹² See, for instance, the daily summaries of discussion at the seventh session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 19 and 20 January, 2006. Available from www.un.org/esa/socdev/enable/rights/ahc7sum19jan.htm and www.un.org/esa/socdev/enable/rights/ahc7sum20jan.htm. See also the report of the third session of the Ad Hoc Committee, footnote 53, available from www.un.org/esa/socdev/enable/rights/ahc3reporte.htm, and the daily summary of discussions related

14. Article 19 provides a road map aimed at achieving the full and effective participation and inclusion in the society of all persons with disabilities (art. 3 (c)). In this approach, general services available and accessible to all, individualized support to enable the inclusion of each person, and choice for the individual in the type and supply of services, are all equally important.

A. Choice

1. Legal capacity and decision-making

15. Article 19 (a) requires States parties to ensure that 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. This entails the possibility to choose from the same range of options as other members of society, or to reject those options.

16. The right to equal recognition before the law of persons with disabilities, who shall enjoy legal capacity on an equal basis with others in all aspects of life (art. 12), underpins the right to live independently in the community. Legal capacity consists of two inseparable elements: to be recognized as a legal person before the law and to exercise rights as a legal person under the law.¹³ The exercise of legal capacity as recognized in the Convention on the Rights of Persons with Disabilities requires that the will and preferences of a person are respected, and allows for the exercise of free and informed consent. That, in turn, applies to, among other matters, the acceptance or rejection of medical treatment, institutionalization or other life-affecting interventions. Several States have recently reformed their legal frameworks in line with article 12. In Peru, for example, full legal capacity of persons with disabilities was recognized by the Government in its General Law on Persons with Disabilities of 2012, in which it also mandated revision of the Civil Code. The submissions received for the present study refer to other proposed or ongoing reforms. It is crucial to note that in their legal reform processes States should actively consult with, and involve, persons with disabilities and their representative organizations.

17. States must replace regimes that provide for substitute decision-making by supported decision-making in order to address discrimination and the denial of legal capacity to persons with disabilities. The new legal regime needs to comply with a number of other defining elements.¹⁴ In the case of children with disabilities, primary consideration needs to be given to the best interest of the child, including the right of children to express their views in determining their best interest.¹⁵

18. Various forms of supported decision-making exist in some countries, while others have forms of supported decision-making under consideration. The recently approved civil code in Argentina includes the possibility of the provision of support in decision-making processes. The Assisted Decision-Making (Capacity) Bill currently under consideration in Ireland would provide a statutory framework that maximizes individual autonomy and establish an “office of the public guardian” to supervise those who provide such support.

to article 15 at the third session of the Ad Hoc Committee, available from www.un.org/esa/socdev/enable/rights/ahc3sum15.htm.

¹³ See Committee on the Rights of Persons with Disabilities, general comment No. 1, paras. 12 and 14.

¹⁴ *Ibid.*, paras. 25–29.

¹⁵ See Committee on the Rights of the Child, general comment No. 14 (2013) on the right of the child to have his or her best interests taken as primary consideration, paras. 52–54.

19. Submissions received for the present report show that, in general, in every region of the world laws or practices deprive persons with disabilities of their legal capacity. Often third parties are given the right to make decisions on their behalf. Common schemes include guardianship, incapacity to appeal against imposed guardianship, and involuntary medical treatment. Substitute decision-making is a violation of article 19, as it shifts the power from the individual to the guardian in decisions related to living arrangements, such as whether and when to move from institution living to community living. While substitute decision-making may affect a wide range of persons with disabilities, in many cases the denial of legal capacity stems from mental health legislation, which results in persons with psychosocial or intellectual disabilities being more likely to be denied the right to choose their living arrangements.

2. Prohibition of forced institutionalization

20. Article 19, in conjunction with articles 12 and 14, prohibits forced institutionalization and deprivation of liberty on the basis of the existence of an impairment. In particular, article 14 does not permit any exceptions on the basis of which persons may be detained on the grounds of their actual or perceived disability, including perceived danger to themselves or others, or lack of fitness to stand trial.¹⁶ However, despite those prohibitions, submissions from all regions indicated that forced institutionalization continues to be widely practised. Mental health legislation is usually the basis for institutionalization without consent (decided by a judicial or administrative authority, or by a guardian) and for compulsory medical measures. In many cases, the presumption of danger to oneself and others is a ground for forced institutionalization.

21. While institutionalization can differ from one context to another, certain common elements define it: isolation and segregation from community life; lack of control over day-to-day decisions; rigidity of routine, irrespective of personal preferences or needs; identical activities in the same place for a group of persons under a central authority; a paternalistic approach in the provision of services; supervision of living arrangements without consent; and disproportion in the number of persons with disabilities living in the same environment. Institutionalization is therefore not just about living in a particular setting; it is, above all, about losing control as a result of the imposition of a certain living arrangement. In that sense, small environments, including group homes, are not necessarily better than large institutions if overall control remains with supervisors.

22. Living arrangements should be assessed taking into account issues such as the choice of housemates, who decides when residents can enter or exit, who is allowed to enter a person's home, who decides the schedule of daily activities, who decides what food is eaten and what is bought and who pays the expenses. Institutions that control those choices, regardless of their size and name, are inconsistent with the Convention on the Rights of Persons with Disabilities and constitute a deprivation of liberty. Lack of thorough understanding of what constitutes institutionalization for persons with disabilities may result in the promotion of newer forms of institutions concealed by superficial changes. For instance, splitting large institutions into smaller ones with the sole purpose of reducing the number of persons living therein only results in the replacement of one type of institution with another.

23. Segregation and institutionalization are often seen as the only available options. However, as the Committee on the Rights of Persons with Disabilities has made clear, institutionalization is incompatible with article 19, and it is an obligation of States parties to

¹⁶ Statement of the Committee on the Rights of Persons with Disabilities on article 14, issued at the twelfth session of the Committee (CRPD/C/12/2, p. 14).

make alternatives available.¹⁷ Other drivers of institutionalization include the lack of adequate knowledge among policymakers, vested interests of institutional care providers, reduction in social and health-care budgets, lack of alternative resources for some persons with disabilities, unavailability of community-based services, and the conditionality of support upon certain living arrangements. In the case of older persons with disabilities, age and impairment, separately or jointly, could increase vulnerability to institutionalization.¹⁸

24. Cutting a person off from family, friends, education and employment through institutionalization results in social exclusion, creates barriers to inclusion in the community and reduces or denies the capacity of persons with disabilities to choose and plan their lives. That inhibits their autonomy by fostering dependency, preventing persons with disabilities from reaching their full potential in terms of independence and social participation. In addition, it has been widely documented that institutionalization may render persons vulnerable to violence and abuse, with women with disabilities particularly exposed to such risk. The risk of abuse is further exacerbated by the absence of public scrutiny, a lack of access to remedies, a fear of reporting violations, and disability-related communication barriers.¹⁹ Instances of abuse are in direct contradiction to the State's obligation to protect persons with disabilities from all forms of exploitation, violence and abuse, including their gender-based aspects (art. 16).

3. Deinstitutionalization

25. The Committee on the Rights of Persons with Disabilities repeatedly urges States parties to adopt adequately funded strategies for deinstitutionalization with clear time frames and benchmarks, in cooperation with organizations of persons with disabilities.²⁰ Deinstitutionalization is a process that provides for a shift in living arrangements for persons with disabilities, from institutional and other segregating settings to a system enabling social participation where services are provided in the community according to individual will and preference. Such a shift entails a reclaiming of control over one's life, and requires that individualized support services (art. 19 (b)) be provided to, and mainstream services and facilities be made available for and accessible to, persons with disabilities (art. 19 (c)). Effective deinstitutionalization requires a systemic approach, in which the transformation of residential institutional services is only one element of a wider change in areas such as health care, rehabilitation, support services, education and employment, as well as in the societal perception of disability. Evidence shows that deinstitutionalization and adequate support enhances the quality of life and improves the personal functioning abilities of persons with disabilities.²¹ The deinstitutionalization process should also cover children with disabilities; in such cases, institutions should be

¹⁷ See, for instance, the Committee's concluding observations on Austria (CRPD/C/AUT/CO/1), China (CRPD/C/CHN/CO/1 and Corr.1) and Spain (CRPD/C/ESP/CO/1).

¹⁸ See the report of the United Nations High Commissioner for Human Rights on the human rights situation of older persons (E/2012/51) submitted to the Economic and Social Council.

¹⁹ For a detailed overview of the consequences of institutionalization, see Council of Europe Commissioner for Human Rights, "The right of people with disabilities to live independently and be included in the community" (Council of Europe, 2012), pp. 37–39. See also the report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment (A/63/175), para. 38.

²⁰ See, for example, the Committee's concluding observations on Australia (CRPD/C/AUS/CO/1), Austria (CRPD/C/AUT/CO/1), El Salvador (CRPD/C/SLV/CO/1), Paraguay (CRPD/C/PRY/CO/1), China (CRPD/C/CHN/CO/1 and Corr.1) and Hungary (CRPD/C/HUN/CO/1).

²¹ See World Health Organization (WHO) and World Bank, *World Report on Disability* (2011), p. 148. The report makes reference to two studies, one in the United Kingdom of Great Britain and Northern Ireland and one in China.

replaced with families, extended families or foster-care systems. Specific steps should be taken to avoid further institutionalization in the transition from care to aftercare.²²

26. Deinstitutionalization should include public and private institutions to avoid transfer from one to the other, and target all persons with disabilities, without exception. Real options need to be made available to persons moving out of an institution: community living arrangements should not be established and monitored by the institution itself. The Government of Finland is currently implementing programmes providing individual housing and community services for persons with intellectual disabilities, with a deadline of 2020 for full deinstitutionalization. Support is particularly important in the transition from institutional to community living and should include individualized assessment, information, counselling, housing and income assistance. Such support should be based on effective coordination among health-care and social-service providers, and the housing sector. The programme “I, just like you” implemented in Croatia has provided persons with intellectual and psychosocial disabilities in institutions with individual planning and skills development as a preparation for life in the community. Continued support is provided even after the project’s beneficiaries move to community-based arrangements. In the Republic of Korea, some local governments provide resettlement benefits to help persons with disabilities discharged from institutions to live independently in local communities.

27. The cost of deinstitutionalization should be addressed by a reallocation of resources, which may require targeted investments, particularly in the initial phase, effective partnerships and prioritization. Adequate resources need to be available to build the new support infrastructure — both accessible mainstream community services and specific support services — prior to altering the balance of service provision. Funding opportunities should be directed to sustaining systemic reforms. For instance, in the new European Union structural funds regulations for 2014–2020, the availability of funding is closely linked to deinstitutionalization through a number of ex ante conditionalities. Community-based services should exist alongside institutions during the transition phase, necessitating double funding. Studies have demonstrated that after the initial phase, community-based services are not necessarily more expensive than institutional services; on the contrary, they are more cost-effective and provide higher quality services.²³ The comparison of the costs of institutional care and those of community-based services should also take into account the long-term impact of deinstitutionalization, including the fiscal implications of a higher number of persons with disabilities being part of the workforce and household income.²⁴

B. Support

1. Community support services

28. Support services are essential for enabling persons with disabilities to live independently and be included in the community; they are also an indispensable element of deinstitutionalization. Article 19 (b) of the Convention on the Rights of Persons with Disabilities requires States parties to ensure that persons with disabilities have access to a

²² See Committee on the Rights of the Child, general comment No. 9, paras. 47–49, and the Guidelines for the Alternative Care of Children, in particular paras. 3, 14, 22, 34 and 132.

²³ See WHO and World Bank, *World Report*, p. 149, and Council of Europe Commissioner for Human Rights, “The right of people with disabilities to live independently”, p. 32.

²⁴ On the impact of employment of persons with disabilities on the gross domestic product, see, for instance, Sebastian Buckup, “The price of exclusion: the economic consequences of excluding people with disabilities from the world of work”, Employment Working Paper No. 43 (International Labour Office, 2009).

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. Support provided in segregated settings to continue institutionalization is therefore not compliant with the Convention.

29. No single option of support fits all contexts. Therefore, article 19 (b) includes a reference to a range of services that can involve different providers. There are, however, certain criteria that need to be met based on the principle that support as intended by article 19 implies a shift from “care” to “rights”. All persons with disabilities should have equal access to, an equal choice of, and control over support services that respect their inherent dignity and individual autonomy and aim to achieve effective participation and inclusion in society. The promotion of participation and self-reliance as a goal of support should also extend to children with disabilities, whose inclusion in society is at the core of both article 23 of the Convention on the Rights of the Child and article 7 of the Convention on the Rights of Persons with Disabilities.²⁵

30. In-home support services include assistance with self-care and housekeeping. In Cuba, for instance, persons with disabilities living independently can have access to the State-funded domestic social assistant service, which provides personal and domestic support. In any case, in-home support must contribute to promoting inclusion and preventing segregation. It should not prevent a person from leaving the home when he or she desires and should be complemented, where needed, by other community-based services.

31. States have established various forms of residential support and accommodation in independent living homes. Residential support must respect the choice of the individual to avoid forms of institutionalization. Day-care centres may also lead to isolation and stigmatization if they are used to keep persons with disabilities separate from the community.²⁶

32. Submissions referred to a wide range of other community support services, often so-called centres for independent living. The support provided in such cases is geared towards information and advice, self and peer support, protection of rights and interests, shelters, housing services, training for independent living, supported decision-making and personal assistance.²⁷ States mentioned transportation and communication support, such as the provision of a sign language interpreter. Community support in the form of professionalized assessments of individual needs or family crisis services, such as mediation and support in cases of violence, has been directed to families. Here, the concept of community should not be necessarily limited to a geographic and physical location: some persons with autism have found that support provided online may be more effective, in certain cases, than support received in person.²⁸

2. Personal assistance

33. Personal assistance fosters inclusion by supporting persons with disabilities to participate fully in community life. Under the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments, for instance, personal assistance can

²⁵ See also Committee on the Rights of the Child, general comment No. 9.

²⁶ Inclusion International, *Inclusive Communities = Stronger Communities: Global Report on Article 19: The Right to Live and Be Included in the Community* (2012), p. 78.

²⁷ See the specific support services for the different constituencies of persons with disabilities referenced in the contribution by International Disability Alliance.

²⁸ See the joint contribution by Autistic Minority International, Alliance Autiste (France) and Enthinderungsselbsthilfe von Autisten für Autisten (und Angehörige) (ESH) (Germany).

include individually designed support for personal hygiene, meals, dressing, mobility and communicating with others. Persons with greater support needs in Thailand can apply for a personal assistant for a maximum period of six hours per day or 180 hours per month. In the Republic of Korea, about 50,000 persons with disabilities had benefited from personal assistance services as at January 2013.

34. Personal assistance should be available to all persons with disabilities. However, in many countries it is available only to persons with certain impairments. The Committee on the Rights of Persons with Disabilities has expressed concern at such limitations in its dialogue with States parties.²⁹ A range of personal assistance approaches, including peer support and advocacy, crisis respite and planning, non-medical support to deal with altered perceptions, assistance to meet practical needs of everyday life, advocates for decision-making support and living support networks to help make connections in the community, have proved particularly beneficial to persons with psychosocial or intellectual disabilities. The provision of access to personal assistants for persons with intellectual and psychosocial disabilities is essential to moving from a medical to a social approach concerning mental health issues with respect to personal autonomy.

3. Naturally occurring community support

35. Alongside the variety of services identified, naturally occurring community support is provided informally to persons with disabilities by family, friends or other members of the community. In some countries policies stipulate that the responsibility to assist persons with disabilities rests with their families. That approach is also sometimes encouraged through incentives such as social security benefits, allowances and pension schemes or eligibility criteria to qualify as service providers.

36. Support provided by family, friends and the broader community is extremely important and should be encouraged in order to promote inclusive and respectful societies; in many situations this is the only support available. Nevertheless, exclusive reliance on informal support can have adverse consequences, including by endorsing gender stereotypes of women as care providers. When women are the principal care providers in families, as mothers they are often exposed to higher levels of stress and fatigue, and as siblings they lose out on opportunities for education. Family support may also affect the choice and control that persons with disabilities exercise over the type of support required, in particular when support is encouraged by State benefits. Women with disabilities may also be exposed to higher risks of segregation, violence and abuse. Provision of informal support may mean that the number of working members in the family is reduced, which will have a direct impact on household income and gross domestic product. Finally, relying on informal support may not be sustainable, as the family members may not be able to provide such support as they age or if they fall ill.³⁰

4. Requisites for adequate support

37. In certain contexts training is essential, in order to ensure that support is in conformity with the standards of the Convention on the Rights of Persons with Disabilities, responds to needs and respects the individual's will. The Personal Assistants Training Programme in Trinidad and Tobago, for instance, comprises classroom and practical training, as well as a 15-month period of on-the-job training. Certification and evaluation are equally important. Specific training should be directed at professionals who currently

²⁹ See, for instance, CRPD/C/AUT/CO/1.

³⁰ See, for instance, WHO and World Bank, *World Report*, p. 142.

work, as well as those who formerly worked, in residential institutions to ensure that they actively contribute to the transformation and complement the deinstitutionalization process.

38. Persons with disabilities must have control over the support provided and be the ones who hire, employ, supervise, evaluate and dismiss their assistants. The possibility to choose between different service providers is a way to make the services more accountable, increase control by the user and provide protection against the risk of abuse. There may be a variety of providers, including the State, as well as providers from the private and non-profit sector, although in practice the choice may be limited by the type of impairment or the available service alternatives. Payment to users rather than providers contributes to ensuring that the support is person-centred and respects the preferences of the person with disabilities. In several countries, direct payments rather than services in kind have been introduced, often in the form of a personal budget payable to the eligible person. In Germany, by 2009 about 10,000 recipients, 31 per cent of whom were persons with intellectual disabilities, had opted to receive vouchers. Independent planning support and facilitation services may be required to assist the person in deciding how to use personal budgets. The National Disability Insurance Scheme currently being piloted in Australia will provide persons with disabilities with individualized planning support to identify suitable and necessary services based on their functional needs rather than on diagnosis.

39. Lack of adequate human resources, poor service coordination, disparities in access between urban and rural settings, and the conditions attached to the provision of support (for example, when dependent on a specific living arrangement) are some of the common barriers to adequate community support services. Lack of information and awareness is often another reason for the exclusion of persons with disabilities. Inappropriate policy and institutional frameworks, as well as the lack of knowledge of policymakers and service providers, often result in low quality support, routinely geared towards medical or charity approaches. There have been instances in which personal assistance has been misused. At the policy level, regulations have failed to establish guarantees for user control over budget and services. At the practical level, service providers have absorbed budgets to cover general expenses, instead of providing individualized services, or personal assistants have imposed decisions or actions on the user. In order to avoid such abuse and ensure that the user has control over the budget and supervision of the personal assistant, a correct understanding of the concept of personal assistance is essential.³¹ This is also needed to enable users to enjoy access to effective redress and remedy.

40. Eligibility criteria for access to support services need to be defined in a non-discriminatory way. In particular, the assessment should shift from a medical to a human rights-based approach to disability, focus on the needs of the person rather than the impairment³² and respect individual choice and preferences by ensuring the participation of persons with disabilities in the decision-making process. In defining criteria, it is also important to ensure that persons with disabilities have equal access to support. Here, adopting an open concept on disability compliant with the Convention on the Rights of Persons with Disabilities (art. 1, second paragraph) is an essential step.

41. There are different options for covering the costs of support services. Some States cover the entire budget for service delivery and provision, while others share costs with beneficiaries. Sometimes services are provided directly by organizations of persons with disabilities, which can receive co-financing by State or local government, or can raise their

³¹ The European Network on Independent Living, for instance, has proposed a definition of personal assistance, available from www.enil.eu/policy/.

³² The Committee on the Rights of Persons with Disability has expressed concern about linking the eligibility of social services to a specific grade of disability. See, for instance, CRPD/C/ESP/CO/1.

own funds. The Committee on the Rights of Persons with Disabilities repeatedly calls on States to allocate adequate resources for support services that enable persons with disabilities to live in their communities.³³

42. Austerity measures have had a significant negative impact on the financing and provision of support in many countries. Measures have included direct budget cuts, closure and merging of services, delivery of more standardized and/or institutional services, cuts in staffing and conditions, cuts in independent-living support, delays in payments from the public to the non-profit sector, postponement of reforms, longer waiting lists and increased privatization of services.³⁴ In some cases, independent-living funds have been closed entirely to new applicants, hence drastically reducing the number of recipients of personal budgets. Austerity measures raise important concerns in relation to the States' obligations of non-retrogression,³⁵ non-discrimination and compliance with minimum core obligations.

C. Availability of community services and facilities

43. Persons with disabilities must be allowed access to mainstream community services and facilities to fully enjoy their right to live independently and be included in the community. Article 19 (c) requires States parties to ensure that community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs. This is to be interpreted broadly to cover all services and facilities provided for in society, and can include, by way of illustration, the rights to attend a community school, to use the general transport system and to have access to work in the open job market depending on individual aspirations and qualifications. In combination with specific support services, the availability of community services and facilities is also essential for successful deinstitutionalization.

44. Article 19 (c) flows from the general principles of article 3, in particular those of full and effective participation and inclusion in society and of respect for difference and acceptance of persons with disabilities as part of human diversity. Building an inclusive community requires (a) the removal of barriers; (b) systemic transformation of mainstream services in society; and (c) an inclusive process in which persons with disabilities are actively involved.

45. Obligations under article 9 of the Convention include taking appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications and to other facilities and services open or provided to the public. Contributions from all regions show advances in the adaptation of public buildings and facilities, roads and transportation, to enhance accessibility. Other measures include the revision of building control acts and urban planning codes, the modification of the information environment, and the inclusion of standards of universal design in a variety of sectors. Measures have also been adopted in the housing sector to ensure that new dwellings are built according to accessibility standards and that persons with disabilities are included in social housing schemes.

³³ See, for instance, the Committee's concluding observations on Australia (CRPD/C/AUS/CO/1), Austria (CRPD/C/AUT/CO/1), Argentina (CRPD/C/ARG/CO/1), China (CRPD/C/CHN/CO/1 and Corr.1), Hungary (CRPD/C/HUN/CO/1), Peru (CRPD/C/PER/CO/1), Spain (CRPD/C/ESP/CO/1) and the Republic of Korea (CRPD/C/KOR/CO/1).

³⁴ See Harald Hauben et al., "Assessing the impact of European governments' austerity plans on the rights of people with disabilities" (European Foundation Centre, 2012).

³⁵ See for instance Committee on Economic, Social and Cultural Rights, general comment No. 19 (2007) on the right to social security, paras. 42 and 64.

Inclusive education systems are promoted in some countries, although persons with disabilities still face various forms of discrimination in education settings. Measures to encourage employment of persons with disabilities are also common, although there is a consistent practice of sheltered work, contrary to article 27 of the Convention on the Rights of Persons with Disabilities. Sheltered work in effect prevents inclusion and interaction with the community.³⁶

46. Community-based rehabilitation can be an effective platform for supporting the inclusion of persons with disabilities in the development of their communities. Over the years, community-based rehabilitation has evolved from a medical-focused, often single-sector approach of service delivery, to a “strategy within general community development for the rehabilitation, equalization of opportunities, and social inclusion of all people with disabilities”.³⁷ The community-based rehabilitation guidelines published in 2010 by the World Health Organization are aimed at promoting access of persons with disabilities to the mainstream health, education, social and employment sectors, while identifying new areas for development with regard to support services, such as personal assistance. The positive impact of community-based rehabilitation was highlighted in the submissions received, in particular those from El Salvador and Nicaragua, where other services for supporting independent life are not yet fully developed.

47. Informal networks play an important role in building an inclusive society. Family group conferencing is a practice found in several countries. In the Netherlands, the Eindhoven Model applies family group conferencing to actual or potential psychosocial crisis situations, using the network of the family, friends, neighbours, peers and other persons to prevent forced psychiatric interventions. “Microboards”, composed of a small group of friends and family, have also been used in some countries to engage community members to provide sustained support structures. Regardless of the nature of informal networks, article 19 requires that persons with disabilities exercise full decision-making abilities, with the network playing a supportive role.³⁸

48. Inadequate or inaccessible infrastructure and remoteness are common reasons for discrimination against persons with disabilities in access to community services. States have an immediate obligation to provide reasonable accommodation in the absence of general accessibility measures in accordance with articles 2 and 5 of the Convention. While ageing cannot be equated with impairment, older persons with disabilities constitute a large section of the population and are particularly vulnerable to exclusion.³⁹ The ongoing development of new standards on older persons should not be regressive and must build on the norms of the Convention on the Rights of Persons with Disabilities.

49. Building inclusive systems requires public investment and may appear costly. However, it is evident that providing for accessibility and inclusion from the outset is more cost-effective than adapting services and facilities at a later stage. Inclusive societies are also more cost-effective in the long term, in that they enable persons with disabilities to fully participate and contribute to economic, social, political and cultural life.

³⁶ In previous reports to the Human Rights Council, OHCHR has addressed inclusion in employment (A/HRC/22/25) and inclusive education (A/HRC/25/29 and Corr.1).

³⁷ As defined in International Labour Office, United Nations Educational, Scientific and Cultural Organization and WHO, *CBR: A Strategy for Rehabilitation, Equalization of Opportunities, Poverty Reduction and Social Inclusion of People with Disabilities*, Joint Position Paper 2004.

³⁸ See further the discussion on choice and control in section III.A of the present study.

³⁹ See E/2012/51, and Committee on Economic, Social and Cultural Rights, general comment No. 6 (1995) on the economic, social and cultural rights of older persons.

IV. National implementation

50. Existing studies and submissions for the present report highlight significant differences, including at the intraregional level, in the availability of community services to persons with disabilities, the provision of individualized support and the opportunities to choose services.⁴⁰ National implementation should be sensitive to local and cultural approaches, including to rural and indigenous practices, placing persons with disability at the center of the control over their life.

51. Persons with disabilities and their representative organizations should be actively involved in the implementation of article 19, including in the development and implementation of legislation, policies and programmes, as stipulated in article 4, paragraph 3, of the Convention on the Rights of Persons with Disabilities.

52. There is a range of legislative and administrative measures that States should consider in order to avoid exclusion of, and discrimination against, persons with disabilities.⁴¹ In most cases, establishing equal recognition before the law and legal capacity for persons with disabilities requires revision of the civil law. The legal framework should recognize the right of persons with disabilities to live independently and be included in the community, and provisions allowing for forced institutionalization should be repealed. In some cases, States have not taken full advantage of reform processes and have made only partial advances. It is important that legislative reviews be aimed at integrating the standards of the Convention on the Rights of Persons with Disabilities in all sectors, not just in one.

53. Deinstitutionalization plans should envisage a systemic transformation and the progressive increase of support and alternative services available in the community, and provide for a realistic time frame. This requires the reallocation of resources from institutions to community support services and an end to the creation of new institutions or structural refurbishment of those that exist. Where residential institutions do not exist, States should not reproduce outdated models but rather implement approaches that promote and protect the rights of persons with disabilities to live independently and be included in the community.

54. States have the responsibility to set relevant non-discriminatory standards for both support services and mainstream community services, and to provide adequate funding. In that sense, it may be effective to include support services in the formulation of a national disability policy and related action plans. Where States do not provide support services directly, they should ensure that, in compliance with article 19, privatization does not negatively affect the availability, accessibility, affordability and quality of services. Support should remain driven by the needs of the individual, not the interests of the provider.

55. Ministries in charge of the implementation of policies on service provision differ from one country to the next. Often ministries with social/welfare portfolios play a major role in providing support services, housing and infrastructure for inclusive environments. In order to guard against an exclusively medical approach to support and services, it is better if all support-related portfolios are not entirely the responsibility of the ministry of health. However, health ministries, together with the ministries of justice, have a particular role in

⁴⁰ See, for instance, Inclusion International, *Inclusive Communities*, chap. 5.

⁴¹ Including the provision of reasonable accommodation in line with articles 2 and 5 of the Convention on the Rights of Persons with Disabilities.

ensuring free and informed consent to prevent forced institutionalization and deprivation of liberty.⁴²

56. Submissions for the study contained descriptions of the variety of mechanisms in place to monitor the implementation of deinstitutionalization policies and the incidence of abuse in current segregated settings, and to ensure access to justice. Such mechanisms include general judicial remedies, national human rights institutions, ombudsmen, specific bodies established by disability laws, insurance bodies and independent monitoring mechanisms established in line with article 33, paragraph 2, of the Convention on the Rights of Persons with Disabilities, which requires that States parties take into account the principles relating to the status and functioning of national institutions for the protection and promotion of human rights. In some States, including Lithuania, specific inter-institutional bodies have been established to oversee the deinstitutionalization process. National preventive mechanisms created in compliance with the Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment have also been mandated, in some cases, to monitor residential institutions. Regardless of the mechanism, its independence must be secured and guided by the standards of the Convention on the Rights of Persons with Disabilities.

V. International cooperation

57. International cooperation has, in some cases, been directed to promote independent and community living. In Serbia, Oxfam, Handicap International, Irish Aid and the United Nations Development Programme funded pilot projects of personal assistance services from 2001 to 2009. In 2013, the Special Rapporteur on disability of the Commission for Social Development worked with the Japanese International Cooperation Agency to establish two independent living centres in Johannesburg, South Africa to build local capacities and replicate the model in other parts of South Africa and the region.⁴³ In the Republic of Moldova, the partnership between OHCHR and the Ministry of Health led to a system-wide decision in 2013 to move, within 18 months, from reliance on large psychiatric hospitals to community-based support. In addition, OHCHR-led United Nations cooperation contributed to the establishment in 2014 of the first non-governmental organization of users and survivors of psychiatry in the Republic of Moldova, and the subsequent opening of the country's first user-managed community center and multiple-service provider.

VI. Conclusions

58. Article 19 of the Convention on the Rights of Persons with Disabilities illustrates the paradigm shift from a medical and charity approach to a social and human rights-based approach to disability. Persons with disabilities, without exception, have the right to live independently and be included in the community. In practice, however, some groups are more likely to be excluded than others.

59. States parties have the obligation to comply with article 19 by putting an end to the segregation of persons with disabilities and enabling them to have control over

⁴² See the thematic report by OHCHR on the structure and role of national mechanisms for the implementation and monitoring of the Convention on the Rights of Persons with Disabilities (A/HRC/13/29).

⁴³ Report of the Special Rapporteur on disability of the Commission for Social Development on monitoring of the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (E/CN.5/2013/10).

their lives, irrespective of whether services to that end are provided by the private sector.

60. Forced institutionalization violates the Convention on the Rights of Persons with Disabilities, as it is a form of deprivation of liberty based on the existence of an impairment, and must be discontinued. States parties must establish full recognition before the law of all persons with disabilities and ensure that they are able to exercise choice and control over their lives on an equal basis with others, with access to supported decision-making when needed.

61. Deinstitutionalization requires a systemic transformation that goes beyond the closure of institutional settings. In order to enable social participation, it should provide for (a) individualized support services and (b) inclusive mainstream services in full respect for the will and preference of persons with disabilities. Newer forms of institutionalization tend to be concealed by superficial changes that do not transfer actual control from service providers to the service users as required by the human rights-based approach to disability.

62. Support for persons with disabilities engages different suppliers and settings. In-home, residential and other community services can offer quality support while reducing adverse consequences for the family and for gender equality.

63. Personal assistance is an effective means to ensure the right to live independently and be included in the community in ways that respect the inherent dignity, individual autonomy and independence of persons with disabilities. Personal assistance should be available to all persons with disabilities, including those with intellectual and psychosocial disabilities.

64. Persons with disabilities are the best experts regarding their needs. Allocating budgets to service users rather than service providers shifts the control and choice to persons with disabilities and ultimately improves the quality of support. Training is also important to ensure that the support provided is of adequate quality and complies with the Convention on the Rights of Persons with Disabilities.

65. High quality individualized support and inclusive mainstream services may require an initial investment. However, inclusive societies, in which persons with disabilities fully participate and contribute to the economic, social, political and cultural life, are more cost-effective in the long term. Resource limitations should not be a reason for inaction; rather, effective partnerships and relevant, rights-based prioritization should be promoted. Austerity measures should not justify retrogressive steps.

66. The Convention on the Rights of Persons with Disabilities contains the most recent norms relating to the right to live independently and be included in the community, which should be considered the minimum standards when developing future human rights instruments at global or regional levels.