Article 19: Illustrative indicators on living independently and being included in the community

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Attribute/type of indicator	**Choice of independent living arrangements[a]**	**Support services[b]**	**Accessibility and responsiveness of mainstream services[c]**
Structure	19.1: Legislation enacted recognizing the right to live independently and to be included in the community as an enforceable right of all persons with disabilities, ensuring their individual autonomy and control over their lives, regardless of impairment and required level of support[d] 19.2: Adoption of a comprehensive national strategy and/or plan with time frames and measurable goals to implement this right, including the availability of a range of housing options and support services[e] 19.2.1: Adoption of a national strategy and/or plan to achieve deinstitutionalization of all children and adults with disabilities with benchmarks, time frames and measurable goals[f] 19.2.2: Adoption of a moratorium on new admissions through forced institutionalization of persons with disabilities 19.2.3: Adoption of a moratorium on new admissions to institutions of children with disabilities (see also indicator 23.8 on the Convention on the Rights of Persons with Disabilities) 19.3: Legal provisions protecting persons with disabilities against forced evictions on an equal basis with others in all forms of housing tenure (ownership, formal rental agreements, informal settlements, etc.) and ensuring continuous provision of housing and necessary support 19.4: Legal requirement to collect data on the number and proportion of persons with disabilities exercising the right to choose their living arrangements, including those leaving institutions for community life, and gaining access to support services for living independently 19.5: Legal requirement to establish a marker on all spending related to the exercise by persons with disabilities of the right to choose their living arrangements and to have access to support services for living independently[g]		19.12: Adoption of uniform national accessibility standards respected and ensured by all mainstream services,[h] including all public administration and private facilities providing services to the public 19.13: Adoption of a strategy or plan to ensure the universal design, accessibility, cultural appropriateness and responsiveness of mainstream services for persons with disabilities, including the provision of reasonable accommodation for persons with disabilities[i]
	19.6: No legal provision restricting directly or indirectly the right of persons with disabilities to choose where and with whom to live on an equal basis with others[j] 19.7: Adoption of mandatory accessibility standards for housing accessible to all persons with disabilities 19.8: Adoption of a national strategy and/or plan to ensure the availability and affordability of housing options, including	19.9: Adoption of a national strategy and/or plan to develop and increase the access, availability and diversity of support allowances and services for persons with disabilities, including person-directed/user-led human support,[l] support tailored to situations of mental distress, psychosocial crisis and other intermittent or emergent needs, and the provision of assistive devices and technologies[m]	

<table>
<tr><td></td><td>accessible and adaptable units, for persons with disabilities, across all areas of the community[k]</td><td>19.10: Availability of support measures, including home support, peer counselling and financial support or allowance, for persons with disabilities and the relatives and/or others with whom the person decides to live
19.11: Adoption of a national policy to ensure support to families of children with disabilities to prevent family separation, including the provision of appropriate and adequate social services for quality family-based alternative care options, to ensure the right of children with disabilities to a family life and inclusion in the community[n]</td><td></td></tr>
<tr><td rowspan="4">Process</td><td colspan="2">19.14: Number and proportion of persons with disabilities granted public/social housing within the community, disaggregated by sex, age, disability and geographical location</td><td rowspan="4">19.24: Number and proportion of staff of mainstream services trained on the rights of persons with disabilities, in particular on non-discrimination and the provision of reasonable accommodation, to increase responsiveness to the individual's needs[o]
19.25: Budget allocated to and spent on accessibility and provision of reasonable accommodation within mainstream services
19.26: Proportion of mainstream service providers that fully comply with national accessibility standards
19.27: Number and proportion of requests for reasonable accommodation granted to persons</td></tr>
<tr><td>19.15: Number and proportion of all public sector staff and private actors involved in housing policy and the housing market trained on the rights of persons with disabilities and on relevant aspects of that right[p]
19.16: Number and proportion of facilities of disability-specific deprivation of liberty (such as institutions, including group homes and residences for persons with intellectual disabilities) closed down per year, disaggregated by type of institution and geographical location[q]</td><td>19.17: Number of persons, including professionals, certified to provide support services at home, residential and other community support services, including personal assistance to support living and inclusion in the community, and non-coercive forms of support tailored to situations of mental distress or psychosocial crisis, per 1,000 persons with disabilities, disaggregated by type of certification and/or profession</td></tr>
<tr><td colspan="2">19.18: Number and proportion of persons with disabilities living in institutions who gained access to support and programmes, including economic assistance, to facilitate transitioning from institutional care to living in the community
19.19: Number and proportion of staff trained to support transition from institutional care to people with disabilities living independently and being included in the community
19.20: Number of awareness-raising campaigns and activities to promote the right of persons with disabilities to live independently and to live in the community, targeting the general public and the diversity of persons with disabilities and their relatives, including dissemination of information</td></tr>
</table>

	on the range of entitlements, services and housing available; and proportion of population who gained access to those campaigns and activities, disaggregated by age, sex, disability and geographical location 19.21: Budget allocated to measures aimed at ensuring the right of persons with disabilities to choose their living arrangements and to gain access to support services for living independently, and average amount spent per person as compared to amount spent per institutionalized person with disabilities 19.22: Number of consultation processes undertaken on the design, implementation and monitoring of laws, regulations, policies and programmes to ensure the right to live independently and to be included in the community, and proportion of persons with disabilities who participated in those processes, disaggregated by age, sex, disability and geographical location[r] 19.23: Proportion of complaints received on the right of persons with disabilities to live independently and to be included in the community that have been investigated and adjudicated; proportion of those found in favour of the complainant; and proportion of the latter that have been complied with by the Government and/or duty bearer; each disaggregated by type of mechanism		with disabilities to use mainstream services
Outcome	19.28: Number and proportion of adults with disabilities who are heads of households, disaggregated by sex, age, disability and type of entitlement (owner, tenant, etc.), as compared to other persons[s] 19.29: Number and proportion of adults with disabilities reporting satisfaction with their level of independence in their living arrangements, disaggregated by sex, age and disability[t]	19.30: Number and proportion of persons with disabilities gaining access to community-based support services, including personal assistance, out of the total number of requests made, disaggregated by sex, age, disability and support service provided 19.31: Number and proportion of persons with disabilities provided with assistive devices and technologies for independent living, out of the total number of requests made, disaggregated by sex, age, disability and assistive product provided	19.35: Number of persons with disabilities using mainstream services and their proportion of the total number of service users, disaggregated by sex, age, disability and type of service, as compared to other persons[u] 19.36: Level of satisfaction of persons with disabilities with mainstream services, disaggregated by type of service, sex, age and disability
	19.32: Number and proportion of persons with disabilities currently residing in institutions (e.g. psychiatric inpatient settings, residences for persons with intellectual disabilities – from large scale facilities to group homes), disaggregated by sex, age, disability and type of institution or facility 19.33: Number and proportion of persons with disabilities who have left institutions (e.g. psychiatric inpatient settings and residences for persons with intellectual disabilities) and entered into independent living arrangements, out of the total number of persons with disabilities institutionalized, disaggregated by sex, age and disability		

	19.34: Number and proportion of persons with disabilities released from institutions and provided with community-based support services, including personal assistance, to the extent requested by the person, disaggregated by sex, age, disability and support service provided	

[a] Independent living arrangements: Both independent living and being included in the community refer to life settings outside residential institutions of all kinds. It is not "just" about living in a particular building or setting; it is, first and foremost, about not losing personal choice and autonomy as a result of the imposition of certain life and living arrangements. Neither large-scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization. Although institutionalized settings can differ in size, name and set-up, there are certain defining elements, such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; a lack of control over day-to-day decisions; a lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities living in the same environment. Institutional settings may offer persons with disabilities a certain degree of choice and control; however, these choices are limited to specific areas of life and do not change the segregating character of institutions. Policies of deinstitutionalization therefore require implementation of structural reforms that go beyond the closure of institutional settings. Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. "Family-like" institutions are still institutions and are no substitute for care by a family (Committee on the Rights of Persons with Disabilities, general comment No. 5 (2017), para. 16 (c)).

[b] "Support services" is a broad term that encompasses different types of services whose purpose, design and/or outcome is to facilitate the inclusion and participation of persons with disabilities in the community, preventing isolation and segregation from others, such as personal assistance for daily living. Support services:

- Include services both within and outside the home
- May extend into the spheres of employment, education, and political and cultural participation
- Include supports specifically tailored to psychosocial crisis ("mental health crisis") situations that have the aim of facilitating the person's ability to continue to meet their needs in the community and to prevent isolation and segregation
- May vary in name or type according to the cultural, economic and geographic specificities of each State
- Must comply with a set of criteria (see endnote l, below)

See also report of the Special Rapporteur on the rights of persons with disabilities (A/HRC/34/58).

[c] The concept of "mainstream services" refers to a wide variety of services available in the community and is also referred to by the Committee on the Rights of Persons with Disabilities as "community services and facilities" or "general services". As such, they include accessible information and communications technology, websites, social media, cinemas, public parks, theatres and sports facilities (Committee on the Rights of Persons with Disabilities, general comment No. 5 (2017), para. 39), as well as education, health and administrative services of Governments and others. In this sense, when utilizing indicators under this attribute for reporting or monitoring, the focus should be on the existence and implementation of plans and measures across general services to adopt and comply with accessibility standards and the provision of reasonable accommodation when required in particular cases.

[d] The diversity of cultural approaches to human living and family life and models must not prevent persons with disabilities from exercising autonomy and control over their lives.

[e] Such a plan should foresee:

- Availability of housing, delinked from any obligation to accept services, that meets accessibility and affordability needs of the diverse population of persons with disabilities. Housing options may include ownership, rental, co-housing, family housing and any other form of housing customary for the general population in a particular community that meets the requirements of respecting the individual autonomy of persons with disabilities (see indicator 19.8)
- Availability, without financial barriers, of support services, including personal assistance, to be provided in the context in which the person requests such support (at home, participating in activities, etc.), designed by the individual or freely accepted and readily adaptable to the individual's needs (see indicator 19.9)

[f] Deinstitutionalization requires supporting individuals to explore and assert their will and preferences concerning where and with whom to live; whether to receive support services and which types of services; and the provision of social and economic assistance designed to meet transitional needs, including support in finding employment. Social assistance and support must be designed and delivered in a culturally appropriate manner sensitive to the individual, recognizing the harm caused by institutionalization; it should offer services tailored to the individual's needs according to their will and preferences.

A plan for deinstitutionalization should explicitly include:

- The immediate cessation of detention of all individuals who are confined against their will in mental health services or other disability-specific forms of deprivation of liberty
- Measures to provide social and economic assistance designed to meet the transitional needs of persons with disabilities who leave institutions
- The absolute prohibition of building, developing or investing in new institutions for persons with disabilities, either by the State or by private entities
- Prohibition of the renovation of existing institutions, with the exception of the most urgent measures necessary to safeguard residents' physical safety
- Appropriate and adequate resource allocation to develop community-based support services, with increasing reallocation of budgetary resources from institutional care to community-based care

[g] This should include, for example, resources allocated to housing programmes benefiting persons with disabilities; the development and delivery of support services; and costs of deinstitutionalization processes.

[h] Mainstream services include, among others, public administration (e.g. municipalities and civil registry), health and education, and banks. Accessibility standards should address the different dimensions of accessibility (built environment, transportation, information and communications).

[i] Such a strategy or plan should consider and include:

- Accessibility of the built environment, transportation, information and communications when gaining access to services, and include, among others, ramps, signage in Braille, Easy Read language, sign language interpretation, captioning, alternative and augmentative modes of communications, and tactile communication
- Measures to identify barriers faced by persons with diverse types of disabilities in using mainstream services in order to remove them and improve access

[j] For example, the restriction or denial of legal capacity contrary to article 12 of the Convention on the Rights of Persons with Disabilities, laws allowing deprivation of liberty based on mental health condition or impairment, and laws or regulations conditioning access to social housing upon compliance with a particular treatment.

[k] Measures in this regard may include:

- Direct attribution of social housing units
- Promotion and facilitation of affordable loans for persons with disabilities to become homeowners
- Tax or other exemptions to compensate for private spending to ensure accessibility (e.g. renovation of entryways, corridors, living spaces and bathrooms)

[l] Provision of support services, notably personal assistance services, must respect the criteria listed below.

Service control

- The support service must be controlled by the person with disability (e.g. by having the option to choose from a variety of providers and directly contracting the provider, or by acting as an employer, custom designing their own service, and instructing and directing service providers).
- Personal assistants must be recruited, trained and supervised by the individual who is granted personal assistance.
- Personal assistants should not be "shared" without the full and free consent of the individual who is granted personal assistance.
- Persons with disabilities requiring personal assistance can freely choose the degree of personal control over service delivery according to their life circumstances and preferences.
- The control of personal assistance can be exercised through supported decision-making.

Funding allocation/allowance

- Funding allocation for hiring a personal assistant must follow personalized criteria, be based on an individual needs assessment with regard to individual life circumstances and respect for human rights standards, as well as national legislation and regulations, for decent employment.
- Eligibility criteria must not be limited to medical criteria.
- Individualized services must not result in a reduced budget and/or higher personal payment.
- Funding is to be controlled by, and allocated to, the person with disability with the purpose of paying for any assistance required.
- Programmes and entitlements to support living independently in the community must cover disability-related costs.
- Allowances and cash transfer schemes must clearly distinguish income support due to a lack of income from coverage of disability-related costs.

Decentralization of service provision and transferability

- Decentralization of service provision should not undermine the quality or compliance with the criteria enumerated above.
- Support allowances and services should be transferable within the different regions of the State.

[m] See report of the Special Rapporteur on the rights of persons with disabilities (A/HRC/34/58, para. 14); and World Health Organization and United Nations Children's Fund (UNICEF), *Global Report on Assistive Technology* (2022).

[n] Policies should explicitly call for ending the institutionalization of children and prioritizing investments in social services to support families and communities to prioritize family preservation. If the immediate family is unable to care for the child, alternative care within the wider family should be prioritized, then quality family-based alternative care options, including kinship and foster care within family-based settings.

[o] The training should include:

- The human rights-based approach to disability
- Communication with persons with disabilities, including alternative means and modes of communication
- The obligation to provide reasonable accommodation

[p] This includes:

- Social housing policymakers
- Chambers, confederations or associations representing real estate agents and brokers
- Tenants associations
- Notaries associations

[q] In order to assess whether or not an institution (of any kind) has effectively been closed down, the focus should be on simultaneously verifying the use of the facilities in practice and on whether persons with disabilities who were institutionalized there have moved into the community, in order to gauge an effective closure and identify any "renaming" or "recycling" of institutions (e.g. a residential institution for children with disabilities being relabelled as a boarding school for special education).

[r] This indicator requires verifying concrete activities undertaken by public authorities to involve persons with disabilities in decision-making processes related to issues that directly or indirectly affect them in line with article 4 (3) of the Convention on the Rights of Persons with Disabilities and general comment No. 7 (2018) of the Committee on the Rights of Persons with Disabilities, including consultation meetings, technical briefings, online consultation surveys, and calls for comments on draft legislation and policies, among other methods and mechanisms of participation. In this regard, States must:

- Ensure that consultation processes are transparent and accessible
- Ensure the provision of appropriate and accessible information
- Not withhold information or condition or prevent representatives of persons with disabilities from freely expressing their opinions
- Include both registered and unregistered organizations

- Ensure early and continuous involvement of persons with disabilities
- Cover related expenses of participants

[s] Given the complexity of assessing the subjective element of choice, particularly where options and resources are limited, the concept of head of household may be considered as a proxy indicator that may illustrate, to some extent, that persons with disabilities are exercising choice of living arrangements and living independently.

[t] Self-reporting assessments within disability and/or quality of life surveys or studies may prove useful to capture the level of satisfaction of persons with disabilities with their living arrangements and level of independence as a means to provide a proxy indication on the extent of the exercise of choice.

[u] This indicator seeks to gather information across different mainstream services (e.g. governmental administrative, education and health services) and contributes to providing an overall picture of their inclusiveness and responsiveness to persons with disabilities. A result in which the proportion of users with disabilities is similar to the proportion of persons with disabilities in the total population (considering age, geographical coverage, etc.) could indicate inclusive delivery of the specific service (e.g. enrolment rate of persons with disabilities in regular education gives an indication of an inclusive education system). However, this should not be taken categorically, as several other factors come into play, including the particular purpose or characteristic of the service (e.g. it may be the case that persons with disabilities represent a higher proportion of users of rehabilitation services).