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| **Article 19 - List of illustrative indicators on Living independently and being included in the community** | | | |
| **Living independently and being included in the community** | | | |
| **Attributes/**  **Indicators** | **Choice of independent living arrangements**[[1]](#endnote-1) | **Support services[[2]](#endnote-2)** | **Accessibility and responsiveness of mainstream services[[3]](#endnote-3)** |
| **Structure** | 19.1 Legislation enacted recognizing the right to live independently and be included in the community as an enforceable right of all persons with disabilities ensuring their individual autonomy and control over their life, regardless of impairment and required level of support.[[4]](#endnote-4)  19.2 Existence of comprehensive national strategy and/or plan with timeframes and measurable goals to implement this right, developed with the active involvement of representative organizations of persons with disabilities, including the availability of housing options and support services.[[5]](#endnote-5)  19.2.1 Existence of a national strategy and/or plan to achieve deinstitutionalization of all persons with disabilities with benchmarks, timeframes and measurable goals, developed with the active involvement of representative organizations of persons with disabilities.[[6]](#endnote-6)  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  19.3 Legal provisions protecting persons with disabilities against forced evictions 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 notably those leaving institutions into community life, and accessing 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 access support services for living independently.[[7]](#endnote-7) | | 19.11 Existence of uniform national accessibility standards respected and ensured by all mainstream services,[[8]](#endnote-8) including all public administration and private facilities providing services to the public.  19.12 Existence of a strategy or plan(s) to ensure accessibility and responsiveness of mainstream services to persons with disabilities, including provision of reasonable accommodation to persons with disabilities.[[9]](#endnote-9) |
| 19.6. No legal provision restricting directly or indirectly the right of persons with disabilities to choose where and with whom to live on equal basis with others.[[10]](#endnote-10)  19.7 Existence of mandatory accessibility standards for housing accessible to all persons with disabilities.  19.8 Existence of a national strategy and/or plan to ensure the availability and affordability of accessible and adaptable housing options for persons with disabilities, within all areas of the community.[[11]](#endnote-11) | 19.9 Existence 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[[12]](#endnote-12) and provision of assistive products.  19.10 Existence of support measures, including counselling and financial support or allowance for persons with disabilities and those relatives and/or others with whom the person decides to live.19.11 Existence of a national policy to ensure support to families of children with disabilities, including appropriate and adequate social services for alternative care within a family setting, to ensure their right to a family life and inclusion in the community.[[13]](#endnote-13) |
| **Process** | 19.13 Number and percentage of persons with disabilities granted social housing within the community, disaggregated by sex, age, disability, geographical location | | 19.21 Training of staff of mainstream services 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.[[14]](#endnote-14)  19.22 Budget allocated to accessibility and provision of reasonable accommodation within mainstream services.  19.23 Proportion of mainstream service providers that fully comply with national accessibility standards. |
|  | 19.14 Number and proportion of all public staff and private actors involved in the housing policy and market undergoing training on the rights of persons with disabilities, and on relevant aspects of this right.[[15]](#endnote-15) | 19.15 Number of persons, including professionals, certified to provide support services in-home, residential and other community support services, including personal assistance to support living and inclusion in the community, per 1000 persons with disabilities, disaggregated by type of certification and/or profession. |
| 19.16 Number and proportion of persons with disabilities living in institutions accessing support and programs to facilitate transitioning from institutional care to living in the community.  19.17 Number and proportion of staff undergoing training or continuous training to support the transition from institutional care to people with disabilities living independently and being included in community.  19.18 Public awareness campaign to promote the right of persons with disabilities to live independently and live in the community, targeting the general public and notably persons with disabilities and their relatives,[[16]](#endnote-16) including dissemination of information on the range of entitlements, services and housing available.  19.19 Budget allocated to measures aimed at ensuring the right of persons with disabilities to choose their living arrangements and access support services for living independently, and average amount spent per person as compared to amount spent per institutionalized person with disabilities.  19.20 Number of complaints on the right of persons with disabilities to live independently and be included in the community, investigated and adjudicated and the proportion of these complied with by the Government. | |
| **Outcome** | 19.24 Number and percentage of adult persons with disabilities head of household disaggregated by age, sex, disability and kind of entitlement (owner, tenant, etc), as compared to other persons.[[17]](#endnote-17)  19.25 Number of persons living in social housing, disaggregated by sex, age and disability.  19.26 Number and proportion of adults with disabilities reporting satisfaction with their level of independence in their living arrangement.[[18]](#endnote-18)  19.27 Number of persons with disabilities who are homeless and proportion they represent out of the total of the homeless population, disaggregated by age, sex and disability. | 19.28 Number and proportion of persons with disabilities accessing community based support services, including personal assistance, out of the total number of requests made, disaggregated by age, sex and disability and support service provided.  19.29 Number and proportion of persons with disabilities provided with assistive products for independent living, out of the total number of requests made, disaggregated by age, sex, disability and support service provided. | 19.33 Number of persons with disabilities using mainstream services, and proportion out of the total of service users, disaggregated by age, sex, disability, and kind of service, as compared to other persons.[[19]](#endnote-19)  19.34 Number and proportion of requests for reasonable accommodation granted to persons with disabilities in using mainstream services.  19.35 Level of satisfaction of persons with disabilities with mainstream services disaggregated by type of service, age, sex and disability. |
| 19.30 Number and proportion of persons with disabilities who left institutions (e.g. psychiatric institutions, residences for persons with intellectual disabilities) and entered into independent living arrangements, out of the total of persons with disabilities still institutionalized, disaggregated by age, sex and disability, in a given period.  19.31 Number and proportion of persons with disabilities released from institutions provided with community based support services, including personal assistance, to the extent requested by the person, disaggregated by age, sex and disability and support service provided.  19.32 Number and proportion of institutions, including group homes, closed down per year, disaggregated by type of institution and geographical location.[[20]](#endnote-20) | |

**ANNEX**

1. See CRPD Committee, General Comment no 5 on Article 19, para 16: “(c) Independent living arrangements. Both independent living and being included in the community refer to life settings outside residential institutions of all kinds. It is not “just” about living in a particular building or setting; it is, first and foremost, about 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; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities living in the same environment. Institutional settings may offer persons with disabilities a certain degree of choice and control; however, these choices are limited to specific areas of life and do not change the segregating character of institutions. Policies of deinstitutionalization therefore require implementation of structural reforms which go beyond the closure of institutional settings. Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. “Family-like” institutions are still institutions and are no substitute for care by a family”. [↑](#endnote-ref-1)
2. “Support services” constitute a broad term that encompasses different kind of services whose purpose, design and/or outcome is to facilitate persons with disabilities their life in the community, preventing isolation and segregation from others. Personal assistance for daily life is a clear example. Support services:

   - are not restricted to services inside the home;

   - extended to the spheres of employment, education and political and cultural participation; etc.

   - may vary in name, type or kind according to the cultural, economic and geographic specifics each State.

   - must comply a set of criteria (see below endnote vii). [↑](#endnote-ref-2)
3. The concept of “mainstream services” refers to a wide variety of services available to the community and are as well referred to by the CRPD Committee as “community services and facilities” and/or “general services”. As such, they include “accessible information and communications technologies, websites, social media, cinemas, public parks, theatres and sports facilities” (general comment 5, on Article 19 of the CRPD), but also education, health, administrative services by governments, etc. In this sense, when utilizing indicators under this attribute for reporting and 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. [↑](#endnote-ref-3)
4. 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. [↑](#endnote-ref-4)
5. Such a plan should foresee:

   - Sufficient availability of housing, delinked from any obligation to accept services, that meets accessibility and affordability needs of diverse population 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) [↑](#endnote-ref-5)
6. 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 what types of services; and the provision of social and economic assistance designed to meet transitional needs, including supporti in finding employment. Social assistance and support must be designed and delivered in a manner sensitive to individual with recognition of the harm caused by institutionalization; it should offer services adaptable to the individual’s needs according to their will and preferences.

   A plan for deinstitutionalization should explicitly include:

   The release 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 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. [↑](#endnote-ref-6)
7. This should include for example, spending of housing programs benefitting persons with disabilities; the development and provision of support services; and costs of deinstitutionalization processes. [↑](#endnote-ref-7)
8. “Mainstream services” include, among others, public administration (e.g. municipalities, civil registry, etc.), health and education, banks, etc., and “accessibility standards” must addressed different dimensions of accessibility (built environment, transportation, information and communication). [↑](#endnote-ref-8)
9. Such a strategy or plan should consider and include:

   accessibility to the build environment, and to related transportation, information and communication, when accessing the services, and includes, among others, ramps, signage in Braille, and easy to read language, sign language interpretation, captioning, alternative and augmentative modes of communications, tactile communication, among others.

   Measures to identify barriers faced by persons with diverse types of disabilities in using mainstream services or finding them responsive, in order to remove them. [↑](#endnote-ref-9)
10. E.g. restriction or denial of legal capacity contrary to Article 12 of the CRPD, laws allowing deprivation of liberty based on mental health condition or other impairment, laws or regulations conditioning access to social housing on acceptance of a particular treatment, etc.. [↑](#endnote-ref-10)
11. Measures in this regard may include:

    Direct attribution of social housing units;

    Promotion and facilitation of affordable loans to access ownership for persons with disabilities

    Tax or other exemptions to compensate private costs for accessibility features (ex. renovation of restrooms) [↑](#endnote-ref-11)
12. Provision of support services, notably personal assistance services, must respect the following criteria:

    *Funding allocation / allowance*

    Funding allocation for hiring personal assistance must follow personalized criteria, be based on based on an individual needs assessment and upon the individual life circumstances, and respect human rights standards, as well as national legislations 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 transfers schemes must distinguish clearly income support due to lack of income or poverty from coverage of disability related costs

    *Service control*

    The support service must be controlled by the person with disability (contract the service from a variety of providers or act as an employer; custom design their own service, instruct and direct service providers)

    Personal assistants must be recruited, trained and supervised by the person granted personal assistance. ;

    Personal assistants should not be “shared” without the full and free consent of the person 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; and

    The control of personal assistance can be exercised through supported decision-making.

    *Decentralisation of service provision and transferability*

    Decentralisation of service provision should not undermine quality and the criteria enumerated.

    Support allowances and services should be transferable, within the different regions of the State and regional organisation. [↑](#endnote-ref-12)
13. See indicators on Article 23. [↑](#endnote-ref-13)
14. The training should include:

    - Awareness on disability and on the rights of persons with disabilities;

    - Use of appropriate augmentative and alternative modes, means and formats of communication;

    - Entitlement to and provision of reasonable accommodation.

    - Related administrative procedure and/or protocols. [↑](#endnote-ref-14)
15. This includes:

    Social housing public policy makers;

    Chambers, confederations or Associations representing real estate agents and brokers;

    Tenants associations implicated in public policy development;

    Notaries Associations, inasmuch as they might be involved in housing related commerce. [↑](#endnote-ref-15)
16. In particular, persons with intellectual disabilities and persons with psychosocial disabilities, and their families. [↑](#endnote-ref-16)
17. Given the complexity of assessing the subjective element of choice, especially 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 and living independently. [↑](#endnote-ref-17)
18. Self report assessment strategies, within disability and/or quality of life surveys or studies, might prove very useful to capture the level of satisfaction of persons with disabilities with their living arrangement and level of independence, as a means to provide a proxy indication on the extent on the exercise of choice. [↑](#endnote-ref-18)
19. This indicator seeks to gather information across different mainstream services (e.g. governmental administrative services, education, health, etc.) and contributes to give 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 operation of the specific service; e.g. enrollment rate of persons with disabilities in regular education gives an indication of an inclusive education system. However, this should not been taken categorically, many other factors come into play including the particular purpose or characteristic of the service (e.g. it might be the case that persons with disabilities represent a higher proportion of users of rehabilitation services). [↑](#endnote-ref-19)
20. In order to assess whether or not an institution (of any kind) has effectively been closed down, the focus should simultaneously be on verifying the current use of the facilities in practice and on whether the persons with disabilities who were institutionalized there have moved into the community , in order to prevent “renaming” or “recycling” of institutions (e.g. a residential institution for children with disabilities becoming a boarding school for special education). [↑](#endnote-ref-20)