

Independent Living Institute, Sweden

Identification of paragraphs

15 a

... make all decisions that concern their lives. **Self-determination is fundamental to independent living.** This includes, but is not...

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... Although institutionalized settings can differ in size, name and setup, there are certain defining elements, such as: **forced dependence on assistants who are shared by other residents and no or limited influence over one has to accept assistance from,** isolation and segregation from community life,...

15 d

... It is based on an individual needs assessment and a person/user's life circumstances. *Methods of assessing individual needs may be incompatible article 17. The rates allocated to persons with disabilities for personal assistance need to be in line with the current salary rates in each country. Enough resources need to be allocated to cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance.* The service is led by the person with disability, meaning...

15 d

... Independent and community living can also not be counted as personal assistance if the assistance is only provided within certain arrangements, such as a group home.

The individual's dependence on and the individual's lack of control over the shared staff are the decisive criteria in the operational definition of a residential institution, not the number of persons with disabilities in the particular living arrangement – one, two or more persons. This is in contrast to personal assistance with a one-on-one relationship between one assistance user and an assistant where the assistant is recruited, trained, and supervised by the service user.

Institutionalized settings are not compliant with the concepts of independent and community living.

....

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... Whereas the right to independent living refers to an individual dimension, i.e., the place of residence, lifestyle, *everyday life activities* and most importantly, the living arrangements...

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...They are not restricted to services inside the home, but must also be able to extend to the spheres of employment, education, **assistance with raising one's small children, attending to aging relatives, participation in political and cultural life, one's interests, travel as well as recreation.**

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... Accessible housing, providing accommodation to persons with disabilities, who live as singles or as a part of a family, must be available in sufficient number *throughout the community, to ensure-the same degree of choice in the housing market that the non-disabled population enjoys.* To this end, barrier-free

residential new construction and the barrier-free retrofitting of existing residential structures are required. In addition, housing must be *made* affordable to persons with disabilities,.....

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... Accessible housing, providing accommodation to persons with disabilities, who live as singles or as a part of a family, must be available in sufficient number *throughout the community, to ensure-the same degree of choice in the housing market that the non-disabled population enjoys. To this end, barrier-free residential new construction and the barrier-free retrofitting of existing residential structures are required.* In addition, housing must be *made* affordable to persons with disabilities...

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... However, as article 19 of the Convention is about being included in the community, the right to choose a residential, institutional setting does not correspond with a states' party duty to maintain institutions or to ensure the availability of residential support services. *States parties must not allocate resources into living arrangements that do not respect the freedom of choice and autonomy of persons with disabilities. As long as a person who lives in such an arrangement is not free and able to do what she or he wants, to live with his or her partner or other persons who she or he wants to live with, that living arrangement will be an example of an institution.*

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... Examples include guardianship and mental health laws which force persons with disabilities to live in institutions as well as laws on social protection or building law which prioritize residential or institutional services.

As "particular living arrangements" are phased out progressively, individual support services in the community, such as personal assistance or other forms of user-led-support, and barrier-free housing in existing housing stock and new residential construction are to be phased in instead. To this end, State Parties are to issue comprehensive plans with specific targets, timetable, budget and monitoring mechanisms including sanctions for non-compliance. Phasing out means no new construction of residential institutions, no additions to nor renovation of existing residential institutions beyond the most urgent measures necessary to safeguard residents' physical safety. No new persons are to be placed in a residential institution. As previously institutionalized residents move into the community, the vacant places they leave behind are to remain vacant. State parties are to closely monitor this particular requirement without compensating residential institutions' owners and operators for any resulting increased costs.

Residents of existing institutions are to be offered information and advice as well as trial periods with support and training of several different community-based alternatives. Residents who still are not prepared to move out to the community, shall not be forced to leave institutional settings. The individual

informed choice, with supported decision-making, if wanted and needed, free from any undue influence, must be decisive on the choice of living arrangements.

Persons with disabilities have the right to choose to live by themselves or together with other persons without or with disabilities. Regardless of whether an individual lives alone or together with other persons, State parties are responsible for providing the individual with a disability with the quantity and quality of individualized support services, such as personal assistance, that enable the individual to live independently and in self-determination in the community pursuing one's interests, exercising one's rights and fulfilling one's duties as citizen.

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... It is also important that resources are allocated to community support services and that the creation of new institutions or **the enlargement or** structural refurbishment of existing institutions is ended....

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... conditional upon requirements that reduce autonomy and independence of persons with disabilities **or reduce their geographical mobility**. Public buildings and spaces and all forms of transport must be designed in a way to accommodate the requirements of all persons with disabilities. ...

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... must be provided irrespective of persons with disabilities having a family or the income **or property** of the individual or family and should be delivered on the grounds of free and informed consent....

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... The assessment should be based on a human rights approach to disability, focus on the requirements of the person because of barriers within society rather than the impairment; take into account a person's will, **interests, and individual** preferences; **respect the individual's dignity and uniqueness as a human being rather than associating him or her with a group**; and ensure the participation of persons with disabilities...

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... States parties should ensure access to justice and provide appropriate legal advice, remedies, **legal aid** and support, including through..

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... to prevent institutionalization of children with disabilities and to have inclusive policies on adoption to ensure equal opportunities to children with disabilities **and to adoptive parents with disabilities**. **Moreover, parents with disabilities may need support services, such as personal assistance to facilitate their child-rearing responsibilities.**

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... order to exercise their legal capacity on an equal basis with others. To achieve this, they have to be a part of the community *and have to be ensured access to mainstream as well as personalized community-based services*. Accordingly, support in the exercise of legal capacity should be provided by using a community-based approach which respects the will and preferences of individuals with disabilities.

Access to justice is fundamental to ensure full enjoyment of the right to independent and community living. States parties must ensure that all persons with disabilities have legal capacity and standing in courts. States parties must furthermore ensure that all decisions concerning independent and community living may be subject to appeal. Support to enable independent and community living shall be justiciable as rights and entitlements. To ensure equal and effective access to justice substantial rights to legal aid, support and reasonable accommodation are essential

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...It is of paramount significance to ensure that support services leave no space for potential abuse, exploitation of persons with disabilities or any violence against them (art. 16). *Since potential for abuse increases with lack of power in hierarchically structured systems where persons with disabilities typically are at the hierarchy's bottom, support services, such as personal assistance, that empower service users through self-determination and freedom of choice can be an antidote to abuse*. Disability, gender and age-sensitive monitoring, legal remedies and relief must be available for all persons with disabilities who use services prescribed in article 19....

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... assistive technologies and forms of live assistance and intermediaries as enshrined in article 20 is a pre-condition for the full inclusion and participation of persons with disabilities in ~~their respective~~ the community.

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... from being taken away from their families and being institutionalized as well as to support families in community living. *These rights are equally important to ensure that children are not taken away from their parents due to the latter's disability*. States parties should provide information, guidance and support to families in upholding *the rights of disabled children and the rights of disabled parents to their families through measures such as personal assistance* and promote inclusion and participation in the community...

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...independent and community living are inherently linked to inclusive education (art. 24), health care (art. 25), *habilitation and* rehabilitation (art. 26) and work...

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... General health facilities and services (art. 25) should be accessible for persons with disabilities in their respective communities on an equal basis with others. **Examples are diagnostic equipment and processes such as mammography, osteoporosis, gynecology, dental treatment.** It is also important to distinguish support services as envisaged in article 19...

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... Data and information should be disaggregated systematically (art. 31) by disability across all sectors including with respect to housing, **transportation**, living arrangements, **parenthood, education, employment**, social protection schemes as well as access to community...

93 a

Repeal all laws that prevent persons with disabilities, **directly or indirectly**, to choose where and with whom and how to live....

93 c

Provide persons with disabilities with substantive and procedural rights to independent living and community living; *, including providing effective remedies that the individual can use for redress if the rights under article 19 are violated;*

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..with an adequate time frame for their implementation and sanctions *which are effective, deterrent and proportionate* for violations by public or private...

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Monitoring and implementation envisaged under article 19 should be carried out in full consultation and participation of persons with disabilities through their representative organizations.

Strengthen civil society organizations' capacity for raising awareness among public and private entities regarding the rights of persons with disabilities according to article 19, in developing legal expertise for the purpose of monitoring compliance with article 19 and for using the law as a tool for implementing article 19.