**INTERNATIONAL DISABILITY ALLIANCE (IDA)**Member Organisations:Down Syndrome International, International Federation for Spina Bifida and Hydrocephalus, Inclusion International, International Federation of Hard of Hearing People,

World Blind Union, World Federation of the Deaf, World Federation of the DeafBlind,

World Network of Users and Survivors of Psychiatry, Arab Organization of Disabled People, African Disability Forum, European Disability Forum, Pacific Disability Forum,

Red Latinoamericana de Organizaciones no Gubernamentales de Personas con Discapacidad y sus familias (RIADIS)

**IDA submission on the right to live independently**

**& be included in the community**

**Day of General Discussion on Article 19**

**CRPD Committee, 15th session, 19 April 2015**

The International Disability Alliance (IDA) welcomes the initiative of the Committee on the Rights of Persons with Disabilities (*hereinafter* “the CRPD Committee”) to hold a Day of General Discussion on Article 19 of the CRPD, the right to live independently and be included in the community, in the lead up to developing a General Comment. This submission includes essential elements that should be considered in elaborating on the content of Article 19.

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**I. Background**

Throughout history, children and adults with disabilities have been denied choice and independence across all aspects of their lives, not least where and with whom they live. They have been and continue to be hidden away at home or sent to institutions, separated from society. Segregation and isolation of persons with disabilities within their communities over centuries have resulted in exclusion from social, economic and political participation, i.e. denial of inclusion in the life of the community. As both a cause and consequence of the continued marginalisation of persons with disabilities, Article 19 was formulated to address this exclusion and to ensure the provision of necessary supports and services to ensure independent living within the community.

Article 19 requires States to recognise, respect and ensure that persons with disabilities have the opportunity to choose, on an equal basis with others, the way they want to live in and participate in their community. This is not just a matter of living in physical proximity to other members of the community nor the kind of dwelling, but having the legal right to exercise one’s autonomy and having the means and necessary supports to participate meaningfully in community life and development on an equal basis with others, in close connection with Article 12 on equal recognition before the law and legal capacity.

“Living independently” in Article 19 does not necessarily mean living alone. It refers to the preamble of the CRPD, paragraph (n), which sets out that the global community recognise “the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices”, and builds on the principle of “respect for inherent dignity, individual autonomy, including the freedom to make one’s own choices, and independence of persons” (article 3(a) of the CRPD).

In fact, Article 19 conveys the full set of principles of the Convention as set out in Article 3, and as such, holistically reflects implementation of the Convention,[[1]](#footnote-1) i.e. enjoyment and exercise of all rights in accordance with the individual’s will and preferences, with access to a wide range and diversity of support, within a society which is inclusive, accessible and responsive to the needs of persons with disabilities, thus ensuring their full participation.

**II. Elements of Article 19**

 Article 19 articulates three key elements:

* Respect for the individual’s **choice,** on an equal basis with others, for their full inclusion and participation in the community, including about their living arrangement (where and with whom).
* Ensuring access to necessary **support** services as a condition for free choice on an equal basis with others. This implies availability, affordability and quality of a wide range of services.
* Ensuring that *all* community services are **inclusive**, accessible and responsive to the needs of persons with disabilities (including the labour market, housing, transportation, health care, schools etc.) and developed according to universal design.
1. **Choice**

Persons with disabilities must have choices on an equal basis with others for their full inclusion and participation in the community, including the opportunity to choose their place of residence and where and with whom they live and are not obliged to live in a particular living arrangement.

Choice is a key concept which cuts across all facets of Article 19. The exercise of choice concerns not only the place of residence, that persons with disabilities should no longer be denied choice and forced to live in segregation nor isolation- but goes much further, beyond the kind of dwelling or abode in which one resides. Living independently and being included in the community with choices equal to others cannot be fulfilled if the individual’s choice is limited merely to the place of residence. Choice also extends to one’s living arrangement, i.e. one’s routine and schedule, and necessarily encompasses one’s way of life in its full scope covering both the private and public sphere- at home and in the community- and in its daily dimension and longer term projection.

Article 19 is thus intimately and inextricably linked to the recognition and exercise of legal capacity enshrined in Article 12 of the CRPD which upholds the choices, decision-making, will and preferences of persons with disabilities.[[2]](#footnote-2) These provisions are pre-conditions of one another; an individual cannot live independently and be effectively included in the community without having their choices and decisions recognised. Conversely, an individual cannot make choices, express their will and preferences and exercise their legal capacity in a vacuum- these are ineluctably bound to others within the community in which one lives and in which one interacts, where their choices are recognised, and where one can freely pursue their personal development and fulfilment. Both provisions have at their core the provision of support in order to ensure their realisation.

The rights to education, employment and participation in cultural life, among others,[[3]](#footnote-3) are important catalysts for the implementation of Article 19, in particular fostering and upholding choice, which in turn strengthen and facilitate enjoyment of these rights. Inclusive education empowers persons with disabilities providing them with informed decision making, and its deprivation directly hinders the right to live independently and be included in the community. Lack of employment, in particular when combined with lack of State support services, also restricts choice and inclusion in the community due to scarce financial resources. Participation in cultural life contributes to independent living and inclusion, fostering engagement with others, and thereby promotes that persons with disabilities are valued and their choices respected.

***Ensuring choice within the community: need for deinstitutionalisation and choice of housing, services and support within the community***

The obligation to ensure choices equal to others in this context can be violated in several ways. First, laws or practices may prevent persons with disabilities from exercising choice about their living arrangement – for example, when laws permit institutionalisation of a person against their will or by consent of a substitute decision-maker. This may also occur without formal laws or policies where control is exercised by families or caregivers who act as de facto substitute decision-makers compelling individuals to particular living arrangements- whether in an institution, facility or within the family home. Such practices constitute deprivation of liberty on the basis of impairments and are also contrary to Article 14 of the CRPD.[[4]](#footnote-4)

Further, housing options for persons with disabilities may be limited due to financial constraints or inaccessible constructions, or the support needed by an individual is not available nor accessible within the community. Such scenarios offer restricted choice and as a result individuals may be forced into living arrangements such as in social care institutions, rehabilitation centres, orphanages, prayer camps, psychiatric hospitals, nursing homes, group homes, assisted living facilities, etc.

The Committee has been very systematic in recommending to **phase out institutions**. It has requested to reform laws,[[5]](#footnote-5) adopt a deinstitutionalisation policy, plan or strategy with proper timeframe, benchmarks and indicators,[[6]](#footnote-6) and including those in psychiatric hospitals, and incorporating a comprehensive, human rights-centred mental health strategy.[[7]](#footnote-7) Stressing this CRPD compliant path, it has explicitly requested to end the use of State-guaranteed loans to build institution-like residences for persons with disabilities.[[8]](#footnote-8)In line with the second element of Article 19 (support), the CRPD Committee has requested that strategies for deinstitutionalisation include the development of personal assistance services.[[9]](#footnote-9)

In addition, it has explicitly expressed its concern that “despite the policy to close large residential centres, new initiatives replicate institutional living arrangements, and many persons with disabilities are still compelled to live in residential institutions.”[[10]](#footnote-10) In this same line of preventing new forms of “smaller scale” institutionalisation, it has requested to “review the structure and functioning of the small community living centres.”[[11]](#footnote-11)

***Ensuring choice within the family : need for support directed at families***

As noted, **the family itself frequently serves as a support for individuals** regardless of whether they are a child or adult, to foster their inclusion and participation within the family and wider community, and to inhibit isolation and segregation. Commonly, the lack of community based support and services by the State, and related loss of income generation when a parent assumes the role of caregiver (usually the mother), creates pressures and constraints for families. These critical situations may force families to opt for institutionalisation as no other alternatives for support in the community exist, or support services may be conditioned to institutionalisation. Further the lack of accessibility and inclusiveness of general community services, such as education and social support, are pivotal factors which restrict choice for active participation and inclusion in the family and community. Furthermore, the pervasive stigma and negative stereotypes which continue to exist across most societies and cultures toward persons with disabilities may also impact upon families. And combined with a general lack of awareness of the rights of persons with disabilities, this may lead to situations in which families feel they must keep persons with disabilities at the home, or send them to an institution, often intended as a measure for the individual’s protection. Dissemination of information and awareness raising should be strengthened in line with Article 19 and support services for families made available. The Committee has called for the necessary measures to prevent isolation or segregation of persons with disabilities from the community hidden in the family,[[12]](#footnote-12) including granting their families the necessary support”.[[13]](#footnote-13)

Hence, Article 19 is intimately linked with Article 23 of the CRPD to ensure that supports are in place to uphold the right to family, both for children with disabilities and parents with disabilities. Article 23 guarantees support services and financial aid to parents of children with disabilities, especially those facing severe financial constraints due to disability related costs and/or in poverty situation, and thus also to prevent children being taken away from them. It also promotes supports to families to ensure prevent removal of children with disabilities and their institutionalisation, and the development of policies on adoption of children with disabilities to guarantee to all individuals a “family environment within the community.”[[14]](#footnote-14) In this line, the CRPD Committee has recommended to urgently remove children with disabilities from residential institutions and develop family and community based alternatives,[[15]](#footnote-15) and to abolish the placement of children under three years old in institutionalised care as soon as possible.[[16]](#footnote-16) UNICEF has called to end the institutionalisation of children and adolescents with disabilities by starting with a **moratorium on new admissions** and more attention and resource allocation invested in the promotion of and increased support for family based care.[[17]](#footnote-17)

In particular, families should receive information, guidance and support to uphold their child’s rights and promote their participation and inclusion, for example the right of deaf children to learn sign language from birth and to be included in the deaf community, as well as families learning sign language themselves. Often due to a lack of information or misinformation, deaf children are not taught sign language from early on and due to the lack of communication and language skills, they may find themselves isolated- not participating in the community nor fully within their own family. Families should receive information on the cultural and linguistic identity of deaf persons to enable supporting deaf children to embrace their identity and to foster their participation and inclusion within the community.

1. **Provision of support** *-* Range of support services to meet the needs of the diversity of persons with disabilities across all aspects of life

To enable all persons with disabilities to live independently, the State is required to provide a range of in-home, residential and community support services that may include community support and personal assistance services, communication support and sign language interpreters, specific support services for families with parents with disabilities or children with disabilities, sexual assistance services, as well as support services directed in the workplace, schools or home such as those among others.[[18]](#footnote-18) Those services should be made available and affordable to support living and inclusion in the community and participation in decision making, and to prevent isolation and segregation from the community.

Article 28 on adequate standard of living and social protection is another provision of the CRPD which is intrinsically bound to Article 19. Covering both disability specific and mainstream schemes, Article 28 ensures access to basic income support, social services and adequate housing, all of which are key components to ensuring living independently and inclusion in the community. As highlighted by the Special Rapporteur on the rights of persons with disabilities, “Social protection can also constitute a powerful strategy for developing human capacity and promoting full and effective participation. By facilitating access to food, health care and education, as well as support services, social protection can enhance the independence, inclusion and active participation of persons with disabilities, as it liberates them from a day-to-day struggle for survival.”[[19]](#footnote-19) Social protection policies and schemes to be adopted under Article 28, both general to all persons and specific to persons with disabilities, must be consistent with and contribute to ensuring independent living and inclusion in the community.

***Choice in support***

Access to support services, housing options, social protection schemes etc, is a pre-condition to exercising free choice in determining where one lives and how one lives (Article 19(a)), and information about these must be disseminated and available in Braille, sign language, easy to read formats, and alternative modes of communication.

At the same time, access to those supports must not be compromised by bundling them with measures which effectively restrict choice. For example, an individual should be able to access housing without having to accept case management, medication or day treatment services, nor should they be obliged to accept any of these services while rejecting another. Schemes involving financial support, such as disability allowances or benefits, must not be made conditional upon measures which undermine choice, such as compelling an individual to undergo treatment or be subjected to a particular living arrangement.

In addition, the person concerned must have the choice and control over the support services, which should also “be culturally appropriate, enable beneficiaries to choose their lifestyle and place of residence and express their preferences and needs, and contain a gender and age perspective.”[[20]](#footnote-20) Consequently, support and support persons must never be imposed nor withheld when requested.

**Choice in support must also be extended to children with disabilities to ensure their effective inclusion and participation in the community and to foster their independence and autonomy.** In many countries, the support and services available and offered to children with disabilities commonly target rehabilitation and therapies rather than inclusion in community activities, and consultation with children with disabilities is limited.

For example, Australia’s new National Disability Insurance Scheme (NDIS) is a $22billion dollar scheme established to provide individualised services and support to people with disabilities, including “children with developmental delay or disability”. Choice and control are important concepts in the legislation underpinning the NDIS. According to legislation and program guidelines, people with disabilities can set their own goals, plan their care and coordinate their support services. However, children entering the scheme fall under separate Early Intervention Access Requirements and Operational Guidelines enshrined in the Act and its related Rules.  For example, the early Intervention part of the scheme has a strong focus on functional capacity rather than inclusion in education, family and community.[[21]](#footnote-21) For autistic children, this focus on improving functioning is essentially framed in a medical model requiring treatment and leads to plans for children having purely functional goals rather than supports for increased access and inclusion and improving quality of life.  Further, it focuses on normalisation through behavior modification and intensive early intervention which has been documented to be harmful.[[22]](#footnote-22)

Schemes for support such as NDIS must equally ensure choice and control for children, including through direct consultation with them, which is respectful of their identity, refraining from harmful interventions which deny identity, autonomy and independence, with the ultimate objective of promoting their participation and inclusion in society.

***Diversity of forms of support to meet the needs of the diversity of persons with disabilities***

Needless to say, there is a vast diversity of needs for support among persons with disabilities. It is important to recognise that persons with disabilities have different requirements for support and inclusion and that policies and practices need to address this diversity while always respecting the principle of personal autonomy, including freedom to make one’s own choices.[[23]](#footnote-23)

In particular, there is a close relationship between Article 19 and Article 9 on accessibility, specifically when referring to access to community based services including the need for accessible public transport to ensure that persons with disabilities can benefit from and make use of the services available within one’s own community.[[24]](#footnote-24)

For many persons with disabilities, support to live in the community is not only about overcoming inaccessible barriers, but also about being supported in managing interactions in specific situations or getting support to make informed decisions, for example through different support networks. Community support networks can take many different forms. The main idea is to have key people in the community- family, friends, peers- to whom the individual can turn and depend on in managing daily life activities, making important decisions, or for example overcoming a crisis moment. It is crucial that the individual’s autonomy and choices are fully respected. A particular individual may want certain family members to be involved or not, or to include certain service providers or not, including sign language interpreters and communication support person; support and support persons should never be imposed.

Diverse forms of support should be acknowledged and accepted, including informal support arrangements such as “circles of support”. However, spontaneous forms of support must not be the sole base of supports available; the Committee has expressed its concern that often families are the sole base of support for persons with disabilities due to the lack of registered personal assistance services.[[25]](#footnote-25) Formal systems of personal assistance must be made available, affordable and accessible.[[26]](#footnote-26) The Committee has recommended the adoption of a legal framework providing for an **entitlement to personal assistance services** in the community,[[27]](#footnote-27) which is key to enforce Article 19 and ensure its effectiveness. It is essential that such criteria goes beyond what could be a restrictive understanding of personal assistance services to embrace all support services, of any kind and extent, as required by the individual.

**Eligibility and provision criteria** must not restrict access to support services to live independently and be included in the community. Throughout its jurisprudence, the CRPD Committee has elaborated on eligibility and provision criteria for support, and rejected that which is not consistent with the Convention. It is important to reiterate those criteria to include them explicitly in the general comment:

* Support systems, including personal assistance services, must not exclude persons with disabilities on account of the **type of disability**, as is commonly the case for persons with intellectual and psychosocial disabilities.[[28]](#footnote-28)
* Support must not be limited on account of the **“degree” of disability or the “multiplicity of disability.”**[[29]](#footnote-29)
* Support must not be limited to a **number of pre-established activities.**[[30]](#footnote-30)
* Personal assistance services must be provided to persons with disabilities, **regardless of whether they have a family or not**.[[31]](#footnote-31)
* Support must be provided on the basis of the free and informed consent of the individual concerned, notably in the case of persons with intellectual and psychosocial disabilities.[[32]](#footnote-32)
* The amount of payment for the personal assistance services must be based on the characteristics, circumstances and needs of individual, rather than on the “degree of impairment”.[[33]](#footnote-33)
* The amount of payment for personal assistance services must be based on the income of the person with disabilities concerned, rather than on the income of their family.[[34]](#footnote-34)
* Programmes and benefits to support living in the community must cover disability-related costs.[[35]](#footnote-35)
* The person with disabilities must retain the control over the support system, including when provided through vouchers and cash transfers.[[36]](#footnote-36)
* All measures presuppose access to information, including through sign language, Braille and alternative modes of communication, in line with Articles 2, 9 and 21).
* Migrants with disabilities or disabled children of migrants should have equal access to social protection.[[37]](#footnote-37)

Concerning migrants with disabilities, it must be recognised that this category of persons with disabilities which is commonly subjected to long waiting periods or altogether denied access to support services and social protection schemes- whether they are disability specific or not- are migrants with disabilities, including asylum seekers, refugees, immigrants or others. For example, in Australia all migrants that come to Australia (except for those immigrating on humanitarian grounds) have to wait two years before they can access general income support. However, migrants with disabilities have to wait ten years as specified by the *Social Security Act 1991* (Cth)[[38]](#footnote-38) in order to access the Disability Support Pension. The ten year qualifying period creates financial difficulties for the estimated 5,000 affected migrants with disabilities, particularly if they are unable to achieve financial security through employment.[[39]](#footnote-39)

In particular, migrant children with disabilities and their families often face more difficulties in accessing services and support as well as disability benefits.[[40]](#footnote-40) In Argentina, Decree 432/97, which regulates article 9 of Law no 13478 for the assignment of allowances for the elderly and persons with disabilities, deprives equal access to benefits for children with disabilities due to a prerequisite of 20 years residence before being permitted to access disability benefits. The Supreme Court of Argentina has found the policy to be unconstitutional,[[41]](#footnote-41) but the State has yet to reform the law. In relation to these practices, the CRPD Committee called on the Argentinean government to review social security legislation and reformulate provisions “that prevent persons with disabilities, including migrant workers and **disabled children** of migrant workers, from having equal access to social protection in accordance with Article 28 of the Convention.”[[42]](#footnote-42)

1. **Accessibility and availability of all services**

It is not just incumbent on the State to ensure the provision of disability specific services; in order to ensure full inclusion and participation in the community, services available for the general population must also be accessible to and inclusive of persons with disabilities. This includes a wide range of services as well as accessibility of related information through Braille, sign language, easy to read formats, and alternative modes of communication, including in the context of education, health care, housing, labour market, transportation, recreation and leisure, etc. For example, US Senate bill, the Disability Integration Act of 2015 (DIA), calls for expanded access to affordable housing for people with disabilities and engages State and local authorities in conjunction with State and local housing agencies to ensure the “sufficient availability of affordable accessible and integrated housing in a setting that is not a disability-specific residential setting” as well as ensuring that funds and programs implemented or overseen by the public entity are targeted toward individuals with disabilities who have the lowest income levels in the jurisdiction as a priority over any other development.[[43]](#footnote-43)

Obligations under Article 9 (Accessibility) are extremely important in this respect. The sooner accessibility becomes widespread in all its dimensions across all general programmes and services, the sooner greater inclusion will be achieved. In recognition of the importance of access to information, the DIA also requires state governments to provide adequate information about home and community-based services to populations that require those services.[[44]](#footnote-44) The CRPD Committee’s general comment no 2 on accessibility should be explicitly mentioned and strengthened in the draft general comment on Article 19. In connection to that, ensuring personal mobility, under Article 20, is crucial to allow for living independently and inclusion in the community persons with disabilities. Therefore, States must foster accessibility of transportation and public spaces, including sidewalks, to ensure persons with disabilities can independently go to facilities where services are provided as well in an accessible and inclusive manner.

**III. Considerations for implementation**

**Consultation**

The **close consultation and active involvement of persons with disabilities**, through their representative organisations, is crucial for the adoption of all plans or strategies[[45]](#footnote-45) as well as for its implementation and follow up. In line with **Article 4(3)**, States Parties must consult with organisations of persons with disabilities on the design, implementation and evaluation of support measures, systems[[46]](#footnote-46) and developing strategies.[[47]](#footnote-47)

Furthermore, in line with Articles 8, 19 and 21, States must systematically **provide information in accessible formats and means of communication to persons with disabilities and their families on how to claim support services and assistance** that would enable them to live independently in accordance with their own choice and as part of the community.[[48]](#footnote-48)

**State obligations at all levels**

All levels of government have their role to fulfil for the implementation of Article 19, according to their respective competencies in States Parties. In particular, the local and community authorities, being the governmental level closer to the residence of the individual and the organisation of daily life, must be competent, proactive and sufficiently resourced for the development of policies and measures related to Article 19. Signaling this point should never entail a withdrawal of obligations from other levels of government. This Committee has stressed the significant role of local and community levels of authority.[[49]](#footnote-49) Further, it has indicated the need for developing support services at the community level[[50]](#footnote-50) and for making local communities and mainstream services accessible to persons with disabilities.[[51]](#footnote-51)

**Resources**

In terms of resources, the Committee has stressed the need for an **adequate and sufficient level of funding**[[52]](#footnote-52) **of support systems**, for re-examining the allocation of resources, particularly where competing with the funding of large institutions,[[53]](#footnote-53) and for access to sufficient financial resources for persons with disabilities.[[54]](#footnote-54) Action plans on the implementation of support services should be aimed at not generating waiting lists of persons with disabilities that do not receive support services and/or financial assistance.[[55]](#footnote-55) “Specific budgetary allocations […] including cash transfer schemes for personal assistance services” can be a technical way to ensure availability of resources.[[56]](#footnote-56)

*Austerity measures as retrogressive measures regarding Article 19*

In the last years, austerity measures have had a negative impact on the budgets allocated for policies to support persons with disabilities. On occasions, budget reductions have targeted disability related social protection schemes and policies, entailing structural discrimination through the public budget.[[57]](#footnote-57) This contradicts international human rights standards on non-retrogression and non-discrimination. In particular, the CESCR Committee has advised that in times of economic crisis, any proposed policy change must not be “discriminatory and comprise all possible measures to support social transfers to mitigate inequalities that can grow in times of crisis and to ensure that the rights of the disadvantaged and marginalized individuals and groups are not disproportionately affected.”[[58]](#footnote-58)

For example, due to the economic crisis, last year the central and local governments of Mongolia started to make cuts from budget related to community based disability welfare services and this year they have suspended those services. These cuts targeted solely disability specific services and benefits whose reduction disproportionately impacts upon persons with disabilities, particularly women with disabilities who have less access to employment and income generating activities, and who are dependent on these services in order to conduct their daily activities and participate within the community. Recently, the CEDAW Committee have addressed this issue.”[[59]](#footnote-59)

Austerity measures have also resulted in trends of re-institutionalisation of persons with disabilities as well as dependent persons such as older persons. In Italy,[[60]](#footnote-60) the re-institutionalisation process started in the Marche region with the Regional Council resolution no 1260/2013[[61]](#footnote-61), which establishes that residential units for any person depending on others’ support, on account of disability, psychosocial disability or old age, must not have less than 20 beds, and recommends the merging of 20-beds units in residential facilities accommodating not less than 40-60 residents. This resolution has the same effect as compulsory placement of all dependent persons lacking support of families as there are no alternatives or provision of other forms of support in the community. This is indeed leading to retrogression and return to institutionalisation as a policy supported by public budget.[[62]](#footnote-62)

In the United Kingdom, austerity measures targeting social protection benefits have resulted in extensive reduction of support to persons with disabilities, seriously compromising their livelihood and access to basic needs -such as housing and food- and leading to extreme situations such as a rise in suicides.[[63]](#footnote-63) Administrative delays often leave persons with disabilities without support for long periods, sometimes more than year.[[64]](#footnote-64) In Scotland, five claimants with disabilities challenged the “bedroom tax”, which reduces the housing benefit when having a spare room and impacts disproportionately on persons with disabilities who need personal assistance services, thus restricting their right to adequate housing. The case has reached the Supreme Court.[[65]](#footnote-65)

In response to these negative developments, the House of Lords decided to suspend the application of a new “Welfare reform and work bill” until the government presents an impact assessment of the measures on the physical and mental health, financial situation and ability to return to work of the persons concerned.[[66]](#footnote-66) In this context, the State obligation under Article 4(3) of the CRPD to consult with persons with disabilities and their representative organisations is essential to prevent more violations to Article 19 from current and foreseen policies related to support and inclusion in the community.[[67]](#footnote-67)

The CRPD Committee addressed “austerity measures” in the case of Sweden, where “State-funded personal assistance ha[d] been withdrawn for a number of people since 2010 due to a revised interpretation of ‘basic needs’ and ‘other personal needs’, and [where] persons who still receive[d] assistance ha[d] experienced sharp cutbacks.”[[68]](#footnote-68) While corroborating the existence of a “number of positive decisions under the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments […] not executed,” the Committee recommended to ensure sufficient and fair financial assistance to ensure that a person can live independently in the community.[[69]](#footnote-69)

**Legal enforcement & justiciability**

The right to living independently and being included in the community must not only be recognised in the law, but it must also be justiciable before courts with available and effective remedies for individuals who have seen their right infringed.

A current US Senate Bill, the Disability Integration Act of 2015 (DIA), if passed, would require states and health insurers to provide services to people with disabilities in community settings rather than in institutions whenever possible, and gives grounds to sue if the requirement is not met.[[70]](#footnote-70) The DIA will make it illegal for states and other insurers to deny community-based long-term services and supports to all eligible individuals with disabilities without restrictions.  It requires states to develop a plan to implement these community based programs, and opens states up to federal lawsuits if they fail to offer full integration for people with disabilities.[[71]](#footnote-71)

Courts have a pivotal role to play in monitoring the effective implementation of Article 19. Awareness-raising and continuous training and education of judges on the Convention, with the active participation of representative organisations of persons with disabilities, will determine whether the right to living independently and being included in the community exists in practice and can be invoked, remedied and upheld. Or, on the contrary, whether courts act to entrench segregated services and practices, thereby perpetuating the exclusion of persons with disabilities.

The US Supreme Court case *Olmstead*[[72]](#footnote-72) is a landmark case for Article 19. The case concerned two women with mental health problems who were confined in a psychiatric unit who successfully invoked their right to live in the community and to benefit from community-based services. In *Olmstead*, the US Supreme Court ruled that “isolation […] is properly regarded as discrimination based on disability”, observing that “institutional placements of persons who can … benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life”. More recently, post-Olmstead litigation led to a District Court ruling requiring New York-state level governmental agencies to immediately begin transferring thousands of people with mental illnesses previously housed in large ‘adult homes’ into supported housing within the community.[[73]](#footnote-73)

In other jurisdictions, courts have been actively upholding rights which constitute important components of the right to live in the community. In Argentina, the 3rd Chamber of the Federal Civil and Commercial High Court recently adopted a precautionary measure ordering a private medical insurance company, obliged by national legislation on persons with disabilities to cover and administer support services, to provide a monthly allowance of approximately 1000USD to the mother of a boy with disabilities to cover the rent of an accessible and adequate apartment for her son’s needs.[[74]](#footnote-74)

Recently, the European Court of Human Rights found a violation against Croatia for failing to consider the accessibility needs of a child with disabilities, a wheelchair user, concerning a **request for a tax exemption[[75]](#footnote-75) related to the purchase of a house to replace an inaccessible flat.** The Court was unambiguous that the applicant’s flat situated on the third floor of a building without a lift did not meet the family’s housing needs. The Court made the connection between adequate and accessible property and inclusion in the community by recognising that **inaccessible housing “severely impaired his son’s mobility and consequently threatened his personal development and the ability to reach his maximum potential, making it extremely difficult for him to fully participate in the community and children’s educative, cultural and social activities.** The absence of a lift must have impeded the quality of living of the applicant’s family and in particular his son…”[[76]](#footnote-76) The European Court found a violation related to the right to property and discrimination on the basis of disability- **the applicant had been excluded from benefitting from the tax exemption because the authorities had not taken into account the housing needs of his child with disabilities in violation of his right to property, and that this constituted discriminatory treatment of the applicant on account of the disability of his child.** **For the first time, the Court recognised that discrimination by association- that the applicant, the father, had been subjected to discriminatory treatment on account of the disability of his child.** This reflects the Committee’s own jurisprudence, and was put forward very strongly by IDA together with EDF and Croatian DPOs in a joint amicus brief to the Court. [[77]](#footnote-77)

In another European Court case decided in March 2016, the Court found a **violation against Russia of the right to family and private life for denying parental rights to a man with intellectual disabilities whose child had been removed from him and placed since birth in a children’s institution.** While the father had moved from an institution into the community and had prepared a home for his child and family and was earning a living, his child continued to be detained in an institution **denying their right to family as well as the right to live independently and be included in the community**. IDA together with EDF and inclusion International raised CRPD standards in a joint third party intervention, in particular the obligation to provide supports to families of parents with disabilities to ensure their right to family on an equal basis with others.[[78]](#footnote-78)

**International cooperation**

Article 32 of the CRPD on international cooperation can play a pivotal role in developing policies under Article 19, notably in recipient countries where there are no support systems. The CRPD Committee has encouraged States to devise international cooperation programmes respectful of Article 19 and that involve organisations of persons with disabilities, in line with Articles 4(3) and 32.[[79]](#footnote-79)

Vigilance is needed to ensure that international cooperation efforts do not contribute to perpetuating projects and practices that contradict the CRPD, such as the use of EU Structural Funds to re-develop or expand institutions for persons with disabilities.[[80]](#footnote-80)

**IV. Proposed actions for States**

The full implementation of Article 19 cannot solely be secured through laws and services provisions. It is ultimately about community transformation. CRPD compliant laws, provision of support services and enforcement of non-discrimination and accessibility are essential elements that can contribute to the creation of a virtuous cycle in which higher levels of participation of persons with disabilities through the provision of support services and greater accessibility generates more awareness and openness from communities, which in turn contribute to increased removal of barriers and greater inclusion which in turn facilitate participation of persons with disabilities…

The following actions are proposed to set in motion this virtuous cycle toward upholding Article 19:

* Closely consult with and actively involve a diverse range of persons with disabilities, and their representative organisations, across disability constituencies, including women, children, older persons, indigenous persons, persons from ethnic minorities, migrants, LGBTI persons, among others, on all aspects of living independently within the community, in particular the development of, and investment of resources in support services within the community – both with respect to disability specific services and programmes and mainstream services.
* Modify existing legal frameworks to repeal discriminatory laws and policies contrary to Article 19 which restrict choice of persons with disabilities on where and with whom to live on an equal basis with others, including repeal of laws which permit substituted decision-making also contrary to Article 12 and forced institutionalisation or hospitalisation also contrary to Article 14.
* Ensure a cross government, coordinated approach to develop the necessary range of reforms and innovation needed from different sectors and ministries, as well as coordination, planning monitoring and evaluation of the delivery of community services including under at local authority levels. Clear institutionalised mechanisms in accordance with Article 33 are essential.
* Develop systems and provide adequate resources for development, and provision of affordable support services for all persons with disabilities including children with disabilities, parents with disabilities and their families, as well as all migrants with disabilities. These supports should be wide-ranging and include community based early intervention supports, including personal assistance, sign language education, income support and financial support for disability-related costs, affordable and accessible housing, in-home support and adaptations, sexual assistance, accessible transportation, support in workplaces and schools, etc; and must not constitute harmful practices, should be consensual and never be conditioned on the acceptance of a specific treatment or living arrangement.
* Provide and disseminate timely, accurate and up to date information, in accessible formats, including Braille, sign language, easy to read formats and alternative modes of communication, essential for informed decision-making on choices for independent living and choices about supports and services in the community.
* Ensure awareness raising and support to families so that they are in better position to contribute to the independent living and inclusion in the community of persons with disabilities according to the Convention principles, in particular, personal autonomy and freedom to make one’s own choice.
* Ensure availability of accessible and affordable housing in all communities and that access to housing is not made conditional in any way upon requirements that reduce individual autonomy, choice and control over one’s life.
* As a part of promoting deinstitutionalisation, provide appropriate training to professionals and current staff of community living homes, retirement villages and general aged care facilities, etc., to allow people with disabilities access to a wide choice of living arrangements which maximise their participation, as opposed to contributing to their isolation.
* Cease investments in the creation of new institutions, renovation of existing institutions for people with disabilities, and adopt a moratorium of new admission of persons with disabilities in those existing institutions, starting with children with disabilities. This includes congregate living situations in which personal autonomy and choice are restricted and caregivers exercise control whether by formal or de facto substitute decision-making. Progressively close all segregated residential institutions and redirect funds into the development of community support services and affordable and accessible housing. Ensure that people leaving institutions have the freedom of choice with respect to services of any kind, and that services are not bundled or made conditional upon living arrangements.
* Develop, implement and monitor policies ensuring that mainstream community services are equally inclusive, accessible and responsive to persons with disabilities.
* Abstain from retrogressive measures which target cutting or suppressing benefits, services and programmes for persons with disabilities, as well as services and programmes for the general population whose restriction disproportionately impact on persons with disabilities; in consultation with representative organisations of persons with disabilities, systematically carry out disability and gender impact studies before the application of austerity measures with specific focus on non-discrimination and full inclusion and participation in the community.
* Ensure that international cooperation efforts, including projects and investment, do not contribute to perpetuating projects and practices that create barriers to living independently and being included in the community; international cooperation actors must engage in close consultation with representative organisations of persons with disabilities in the design, implementation, monitoring and evaluation of projects and investment.
* Ensure the provision of available and effective legal remedies to enforce the right to live independently and be included in the community. States should actively disseminate and provide in local languages and accessible and alternative formats jurisprudence of the CRPD Committee and ensure education and professional development for judges, judicial staff and the legal profession on the rights of persons with disabilities, including the enforceable right to living independently and being included in the community and all its components- non-discrimination, exercise of choice equal to others to live and be included in the community, access to support services, accessible and inclusive mainstream services, etc- for effective CRPD compliant monitoring by courts.

The International Disability Alliance (IDA) is a network of nine global and four regional organisations of persons with disabilities and their families (DPOs), representing the estimated one billion persons with disabilities worldwide. Founded in 1999, as a network of international disability rights organisations, a unique composition, that allows IDA to act as an authoritative and representative voice of persons with disabilities in the United Nations (UN) system in New York, Geneva and worldwide. IDA’s Advocacy seeks to advance Human Rights utilising the UNCRPD and other Conventions, harnessing the strengthened united voice of its members, forging working relationships with partners to achieve common goals inclusive of persons with disabilities worldwide.

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**ANNEX - Link to other CRPD provisions**

Article 19 is interconnected with all articles of the Convention. Article 19 is more than the sum of all those rights as it affirms that all rights should be exercised and enjoyed in the community where a person chooses freely to live in and to participate in.

* Article 3, principles: in particular considering the respect for individual autonomy including the freedom to make one’s own choices and independence of persons. Choice and control over one’s life is key for Article 19.
* Article 4, general obligations: in particular to modify or abolish existing laws, regulations and practices that constitute discrimination against persons with disabilities, such as forced institutionalisation; to take ensure Article 19 within all mainstream policies and programmes; to provide accessible information on all forms aids, assistance and support services; to train professionals; to undertake and promote research for universally design goods, services, equipment and facilities and on new technologies; to closely consult with and actively involve persons with disabilities and their representative organisations in the drafting of laws and policies; to refrain from retrogressive measures; to ensure that these obligations extend to all levels of government, including within federal states.
* Article 5, non-discrimination: including the provision of reasonable accommodation is paramount to living independently and being included in the community.
* Article 6, women with disabilities: particular attention should be paid to gender equality, in many instances women and girls with disabilities have their choices with respect to where and with whom they live, and how they live, subjected to more restrictions than men and boys with disabilities.
* Article 7, children with disabilities: respecting the evolving capacities of children with disabilities and supporting them having a say on choices that impact them is critical. Support, information and guidance to families to prevent institutionalisation of children with disabilities and inclusive policies on adoption are key to ensure equal opportunities to children with disabilities.
* Article 8, awareness raising: is essential to create open, enabling and inclusive community. Negative stereotypes that prevent persons with disabilities from living independently must be eradicated and their positive image and contributions to society promoted.
* Article 9, accessibility: implies general accessibility of all public places, transport, information, communications, facilities and services open to public in the community.
* Article 11, situations of risk and humanitarian emergencies: in particular, services and facilities available during emergency situations and reconstruction must be inclusive of and accessible to persons with disabilities so that they may enjoy their rights during these periods on an equal basis with others.
* Article 12, equal recognition before the law: which ensures that all people with disabilities have the right to exercise their full legal capacity and therefore have the equal right to decide and have control over their own life, for instance by choosing where they want to live, with whom they would like to live and how, in an arrangement that responds to their will and preferences.
* Article 13, on access to justice: is essential to ensure the enforceable character of the right to live independently and being included in the community, by being able to challenge institutionalisation or restriction of choice by lodging complaints to claim support measures and by seeking compensation and redress when rights are violated under Article 19.
* Article 14, right to liberty and security of person: which prohibits deprivation of liberty on the basis of disability including forced institutionalisation, as well as forced hospitalisation and any short- or long-term detention in mental health facilities. Article 14 is also a key precondition for the full implementation of Article 19. The right to liberty in the community and not to be subject to discriminatory or otherwise arbitrary detention is essential for the participation and inclusion in the community on an equal basis with others.
* Articles 15, 16, 17: prohibit compulsory medical treatment including compulsory psychiatric interventions. People with psychosocial disabilities have the right to live and to be included in the community and should not have their freedom conditional upon being subjected to forced interventions.
* Article 18, liberty of movement and nationality: it is key to ensure to its full extent the right to choose where and with whom to live and the living arrangement, by ensuring a nationality and prohibiting restrictions, including in immigration procedures, on the basis of disability.
* Article 20: personal mobility, without support to personal mobility, barriers remain to living independently for many persons with disabilities
* Article 21: Freedom of expression and opinion, and access to information: persons with disabilities have the right to access all public information in accessible formats and have the right to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, including Braille, sign language, easy to read formats, etc., in particular about support services and social protection (including disability related schemes) from a diversity of sources to make fully informed choices about choosing services to help them live independently in the community.
* Article 22, right to privacy: Forced and institutionalised living arrangements interfere with privacy. Independent living serves as a safeguard against arbitrary interferences in the life of individual.
* Article 23, right to home and family: support should be provided to parents with disabilities as well as children with disabilities and their families so that they can live independently in their community.
* Articles 24, 25, 26, 27: supports and services under Article 19 aim to ensure participation and inclusion in community living including in education, the workplace, access to healthcare, etc. and these provisions also contribute to creating enabling conditions for living independently and being including in the community, for instance, through an inclusive education system that also ensures the qualifications for employment and income generation.
* Article 28, adequate standard of living and social protection: which stipulates that the State is required to take steps to ensure an adequate standard of living for people with disabilities – including affordable housing, basic income support as well as assistance in accessing disability related services and facing disability-related costs.
* Article 29, participation in political and public life: in order to influence and to take part in decisions impacting the development of their community, all persons with disabilities should enjoy and exercise their rights to participation in political and public life on equal basis with others.
* Article 30, on participation on cultural life, recreation, leisure and sport, which are dimensions of social and community life in which inclusion can be pursued and achieved, including by ensuring that events, activities and facilities are accessible and inclusive.
* Article 31, data collection: data and information should be disaggregated systematically by disability across all sectors including with respect to housing, living arrangements, social protection schemes, access to community supports and services.
* Article 32, international cooperation: has a significant role to play to ensure the development of support systems in countries where there is little implementation of Article 19(b) due to lack of resources or expertise.
* Article 33, national implementation and monitoring: Article 19 requires horizontal and vertical coordination across different government departments and levels, and requires oversight by an independent body with the participation of persons with disabilities and their representative organisations.
1. For a detailed linkage of Article 19 with other CRPD Articles, see Annex [↑](#footnote-ref-1)
2. General Comment no 1 on Article 12 [↑](#footnote-ref-2)
3. For a detailed linkage of Article 19 with other CRPD Articles, see Annex [↑](#footnote-ref-3)
4. The CRPD Committee has explained that persons with disabilities can only be deprived of their liberty when found guilty of a crime after following a criminal procedure with all due safeguards and guarantees and respectful of Article 13 of the CRPD, CRPD/C/NZL/CO/1, para 33 [↑](#footnote-ref-4)
5. [CRPD/C/DEU/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fDEU%2fCO%2f1&Lang=en), para 42(a) [↑](#footnote-ref-5)
6. [CRPD/C/CHN/CO/1](http://www.ohchr.org/Documents/HRBodies/CRPD/8thSession/CRPD-C-CHN-CO-1_en.doc), para 32; [CRPD/C/PRY/CO/1](http://www.ohchr.org/Documents/HRBodies/CRPD/9thSession/CRPD.C.PRY.CO.1-ENG.doc), para 48; [CRPD/C/SLV/CO/1](http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/SLV/CRPD_C_SLV_CO_1_15177_E.doc), para 42; [CRPD/C/AUT/CO/1](http://www.ohchr.org/Documents/HRBodies/CRPD/10thSession/CRPD-C-AUT-CO-1_en.doc), para 37; [CRPD/C/MEX/CO/1](http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhskE4iNFvKWCCGr4TiTUdbhp1hRBVKZKZHlLwRNlRdjmM5HXlP6Xo1vIipxOztb9bY7YaCPATa6I3Og%2fSZcx%2bDeRsTabqXSgSqMmz%2fHMR02Oi), para 44(b); [CRPD/C/KEN/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fKEN%2fCO%2f1&Lang=en), para 38(a)[CRPD/C/BEL/CO/1](http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsjjHe7ia4QapdfXcn9RXjWGUnLq7lBzf6jZqm5v8d04CHmp7F4CYraPSGkq8DobTcdMA5AUGYfwBkUk1KR%2bYgxpUpELLRKGqpAXglC81HePB), para 33; [CRPD/C/CZE/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fCZE%2fCO%2f1&Lang=en), para 39 [↑](#footnote-ref-6)
7. [CRPD/C/CRI/CO/1](http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhskFKDgKhXLo%2bcnplYu%2fg7eKtH%2fPFr0c6p3UKHvXqyC%2bD%2biG%2fPfRxuBYRkPQQe2%2bgS6rONDGgS7taA%2bg0xGQ%2f4GzkIy2jidsNngVxItHEY8u6), para 40 [↑](#footnote-ref-7)
8. [CRPD/C/DEN/CO/1](http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsrxgrMqyLrvLrl%2f6hod6mnZ5w6Or5OgmaXjKC%2bkJbNwXf58Tuqzhdo7nnm2ksXJYLVUELVMje6X74w4dYLO91T3MF2yjjZ3dOHZcQMi%2f4SKe), para 43 [↑](#footnote-ref-8)
9. [CRPD/C/KOR/CO/1](http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsoxt94eoN8sNkD3vNzr%2bPXZtiTUZC2xkNs96PtQyIfVry6P%2b8CiWN9mJ%2fPvpi4kybwosx%2fNqU54wUxrhhxCOpHHjzBAqDiPeX63%2f00rhLm28), para 38; [CRPD/C/TKM/CO/1](http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/TKM/CRPD_C_TKM_CO_1_20188_E.doc), para 35; [CRPD/C/KEN/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fKEN%2fCO%2f1&Lang=en), para 38(a) [↑](#footnote-ref-9)
10. [CRPD/C/AUS/CO/1](http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnzSGolKOaUX8SsM2PfxU7tjZ6g%2fxLBVYsYEv6iDyTXyNk%2bsAB%2fHgrVpAKHcEYTB%2b1t%2fH3HX1F%2f%2bo%2bk3O4KhxfiKAJSqUxhKQWsZDFEBoxAb), para 41 [↑](#footnote-ref-10)
11. [CRPD/C/HUN/CO/1](http://www.ohchr.org/Documents/HRBodies/CRPD/8thSession/CRPD-C-HUN-CO-1_en.doc), para 34; other human rights bodies have also aligned their approach; for example the CESCR Committee concerned with the continued institutionalisation of persons with psychosocial and intellectual disabilities, recommended that housing plans and policies take into account the needs of persons with disabilities and to increase the availability of affordable and social housing units as well as community based services for persons with psychosocial and intellectual disabilities (CESCR Committee Concluding Observations on Canada, March 2016, E/C.12/CAN/CO/6 paras 45-46) [↑](#footnote-ref-11)
12. [CRPD/C/GAB/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fGAB%2fCO%2f1&Lang=en), para 45 [↑](#footnote-ref-12)
13. [CRPD/C/SLV/CO/1](http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/SLV/CRPD_C_SLV_CO_1_15177_E.doc), para 42 [↑](#footnote-ref-13)
14. Consistently, the CRC Committee’s approach places emphasis on supporting the strengths and resources of the child him/herself and the family and community to which they belong and is reflected in its guidance to States to develop child protection services in such a way as to ensure that as many children as possible are able to live in families and not in institutions. Articles 7, 9, 18, 19, 27 of the CRC highlight the crucial role of the family and support to the family to uphold protection and the rights of the child. See also UN Office of the High Commissioner for Human Rights, The rights of vulnerable children under the age of three: ending their placement in institutional care, 2011, p 9 [↑](#footnote-ref-14)
15. [CRPD/C/MUS/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fMUS%2fCO%2f1&Lang=en), para 32 [↑](#footnote-ref-15)
16. [CRPD/C/CZE/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fCZE%2fCO%2f1&Lang=en), para 39 [↑](#footnote-ref-16)
17. UNICEF, State of the World’s Children, 2013, p 80 [↑](#footnote-ref-17)
18. In this regard, connections with other Articles such as Articles 23, 24 and 27 are crucial. [↑](#footnote-ref-18)
19. Report of the Special Rapporteur on the rights of persons with disabilities, **A/70/297,** para 9 [↑](#footnote-ref-19)
20. [CRPD/C/MEX/CO/1](http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhskE4iNFvKWCCGr4TiTUdbhp1hRBVKZKZHlLwRNlRdjmM5HXlP6Xo1vIipxOztb9bY7YaCPATa6I3Og%2fSZcx%2bDeRsTabqXSgSqMmz%2fHMR02Oi), para 44(a) [↑](#footnote-ref-20)
21. Section 25(1) NDIS Act sets out:

 "the CEO is satisfied that provision of early intervention supports for the person is likely to benefit the person by:

(i)  mitigating or alleviating the impact of the person's impairment upon the functional capacity of the person to undertake communication, social interaction, learning, mobility, self-care or self-management; or

(ii) preventing the deterioration of such functional capacity; or

(iii) improving such functional capacity; or

(iv) strengthening the sustainability of informal supports available to the person, including through building the capacity of the person’s carer”   [↑](#footnote-ref-21)
22. <http://autisticfamilycollective.org.au/therapy/> ; <http://autisticfamilycollective.org.au/2016/02/26/expert-panel/> [↑](#footnote-ref-22)
23. For example, blind persons may require training in mobility, specific daily living related skills, access to assistive devices and personal assistance, and accessibility, including information in most accessible formats such as braille, large print, audio, electronic text, of community services and places, including transportation. Deaf persons need to receive community services in sign language and to be able to express themselves freely in sign language when interacting with those services. Deaf blind persons may require training in mobility, specific daily living related skills, access to assistive devices, personal assistance and interpreters, and accessibility of community services and places, including transportation. Persons who are hard of hearing may require access to hearing aids, assistive devices, and captioning as well as accessibility of public places and accommodation. Persons with intellectual disabilities may require training and counselling in daily living skills, personal assistance or community support network. It implies also significant awareness and shift of attitudes within community to understand the different abilities and support needs that person with intellectual disabilities might have. Persons with physical disabilities may require assistive devices, adaptation of their home, as well as personal assistance support and counselling for performing their activities of daily living depending of their level of support needs. It is important to note that while accessibility of housing, transport and other community services and facilities will progressively decrease the need for support for many of them, the provision of personal assistance according to person’s choice will always be a key element for those with higher support needs. Persons with psychosocial disabilities may choose to access personal assistance, peer support or community support networks, crisis planning, peer crisis respite, and a wide range of practices that meet the person on their own terms to provide meaningful support as an alternative to the medical model of mental health. Such practices include, for example, family group conferencing for supported self-decision in a crisis situation, personal advocacy (Personal Ombud/PO), and support groups for people who hear voices or who have unusual beliefs or fears (labelled as delusions or paranoia). They also include mental health services that are based in community organising work and promotion of mental well-being as opposed to the medicalisation of life problems and experiences of severe distress and altered reality. This implies significant awareness and a shift of attitudes within communities to understand the support needs that persons with psychosocial disabilities may have. [↑](#footnote-ref-23)
24. See General Comment no 2 (2014) on accessibility, CRPD/C/GC/2, para 23 which highlights the connection between Articles 9 and 19. [↑](#footnote-ref-24)
25. [CRPD/C/COK/CO/1](http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/COK/INT_CRPD_COC_COK_20208_E.doc), para 39 [↑](#footnote-ref-25)
26. Personal assistance service in the framework of article 19 refers to human support delivered to an individual with respect to his/her own choice. There is not one definition of personal assistance. The independent living movement describes it as follows: “The term personal assistance user refers to a disabled person choosing a personal assistant of their choice to aid them in everyday tasks and in negotiating environmental, transport and other social barriers. However, not all disabled people want or require personal assistance, but all disabled people including those that use or wish to use personal assistance want to exercise choice, control and self-determination over their own lives.” See Dr Adolf Ratzka (ed.). 2004-10. "Model National Personal Assistance Policy." A project of the European Center for Excellence in Personal Assistance (ECEPA) which sets key principles in place:

- The funding of [personal assistance] services follows the person and not the service provider

- Personal assistance users are free to choose their preferred degree of personal control over service delivery according to their needs, capabilities, current life circumstances, preferences and aspirations.

- Their range of options includes the right to custom-design their own services, which requires that the user decides who is to work, with which tasks, at which times, where and how.

Therefore, a policy for “personal assistance”, among other solutions, enables the individual to contract the service of their choice from a variety of providers or to hire, train, schedule, supervise, and, if necessary, fire their assistants. Simply put, "personal assistance" means the user is customer or boss.

Available at <http://www.independentliving.org/docs6/ratzka200410a.html> [↑](#footnote-ref-26)
27. CRPD/C/HRV/CO/1, para 30; [CRPD/C/BRA/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fBRA%2fCO%2f1&Lang=en), para 37 [↑](#footnote-ref-27)
28. [CRPD/C/AUT/CO/1](http://www.ohchr.org/Documents/HRBodies/CRPD/10thSession/CRPD-C-AUT-CO-1_en.doc), para 39. See also [CRPD/C/UKR/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fUKR%2fCO%2f1&Lang=en), para 36; [CRPD/C/EU/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fEU%2fCO%2f1&Lang=en), para 50. See also, A/HRC/28/37, para 34 [↑](#footnote-ref-28)
29. [CRPD/C/ESP/CO/1](http://www.ohchr.org/Documents/HRBodies/CRPD/6thsession/CRPD.C.ESP.CO.1_en.doc), para 39, 41-42 [↑](#footnote-ref-29)
30. “The Committee is concerned that the law for the promotion of autonomy limits the resources to hire personal assistants only to those persons who have level 3 disabilities and only for education and work. **The Committee encourages the State party to expand resources for personal assistants to all persons with disabilities in accordance with their requirements.”**  [CRPD/C/ESP/CO/1](http://www.ohchr.org/Documents/HRBodies/CRPD/6thsession/CRPD.C.ESP.CO.1_en.doc), paras 39, 41-42 [↑](#footnote-ref-30)
31. [CRPD/C/MNG/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fMNG%2fCO%2f1&Lang=en), para 32 [↑](#footnote-ref-31)
32. [CRPD/C/DEU/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fDEU%2fCO%2f1&Lang=en), para 42(b) [↑](#footnote-ref-32)
33. [CRPD/C/KOR/CO/1](http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsoxt94eoN8sNkD3vNzr%2bPXZtiTUZC2xkNs96PtQyIfVry6P%2b8CiWN9mJ%2fPvpi4kybwosx%2fNqU54wUxrhhxCOpHHjzBAqDiPeX63%2f00rhLm28), para 40 [↑](#footnote-ref-33)
34. [CRPD/C/KOR/CO/1](http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsoxt94eoN8sNkD3vNzr%2bPXZtiTUZC2xkNs96PtQyIfVry6P%2b8CiWN9mJ%2fPvpi4kybwosx%2fNqU54wUxrhhxCOpHHjzBAqDiPeX63%2f00rhLm28), para 40 [↑](#footnote-ref-34)
35. [CRPD/C/DEU/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fDEU%2fCO%2f1&Lang=en), paras 41, 42(c) [↑](#footnote-ref-35)
36. CRPD/C/ECU/CO/1, paras 34-35 [↑](#footnote-ref-36)
37. [CRPD/C/ARG/CO/1](http://www.ohchr.org/Documents/HRBodies/CRPD/8thSession/CRPD-C-ARG-CO-1_en.doc), 2012, para 45-46 [↑](#footnote-ref-37)
38. *Social Security Act 1991*(Cth) s 94. [↑](#footnote-ref-38)
39. National Ethnic Disability Alliance, ‘Migrants with Disability and the 10 Year Qualifying Period for Disability Support Pension’ (Report, May 2009) <[www.neda.org.au/page/migrants\_with\_disability\_and\_
social\_security.html](http://www.neda.org.au/page/migrants_with_disability_and_social_security.html)>. [↑](#footnote-ref-39)
40. The Special Rapporteur on the Human Rights of Migrants raised this issue with respect to Japan; “The Special Rapporteur was also informed that migrant children with disabilities or in need of psychological assistance do not receive adequate support. Migrant parents have difficulties in obtaining the financial support to which they are entitled for their disabled children, and children who require urgent psychological attention must wait eight months to one year in order to receive it.” [A/HRC/17/33/Add.3](http://uhri.ohchr.org/Document/File/d1652c85-fa7a-4db5-b0bf-77ac3f88fbac/2de85fca-abc7-403f-ba5a-969fa3387816), 2011, para 69

“With respect to the human rights of migrant children: …(d) Migrant children with disabilities or in need of psychological assistance should receive adequate and timely support, in order not to compromise their development, education and health. Their parents should also receive adequate support, as provided by the law, including financial support at least at the same level as provided for Japanese children;” [A/HRC/17/33/Add.3](http://uhri.ohchr.org/Document/File/d1652c85-fa7a-4db5-b0bf-77ac3f88fbac/2de85fca-abc7-403f-ba5a-969fa3387816), 2011, para 81. [↑](#footnote-ref-40)
41. The Supreme Court decision *Reyes Aguilera, D v National Government* of 7 September 2007. In this decision, the Supreme Court of Argentina ruled on the case of a Bolivian girl with disabilities, born in 1989 and legally resident in the State since 1999, who applied for a disability allowance. The State denied the benefit because she did not fulfil the 20-year residence requirement set out in the Decree. The Supreme Court considered the requirement established in article 1, section (e) of the Annex to Decree no 432/97 to be unconstitutional and ordered the granting of the disability allowance to the claimant on the grounds of article 16 of the American Declaration of the Rights and Duties of Man, article 25(1) of the Universal Declaration of Human Rights, and article 9 of the International Covenant on Economic, Social and Cultural Rights, General Observation no 5 (HRI/GEN/1/Rev.6, pages 34/35, paragraph 28). The Ombudsman’s Office of Buenos Aires has repeatedly sent letters to the President to abolish this unconstitutional requirement of the Decree, however to date no action has been taken to implement the Supreme Court’s decision. [↑](#footnote-ref-41)
42. CRPD Committee Concluding Observations on Argentina, [CRPD/C/ARG/CO/1](http://www.ohchr.org/Documents/HRBodies/CRPD/8thSession/CRPD-C-ARG-CO-1_en.doc), 2012, para 45-46. Other treaty bodies have also made recommendations in this direction: in 2011, the Committee on the Protection of the Rights of All Migrant Workers and Members of Their Families (CMW Committee) recommended that Argentina review the required length of residence for non-contributory social benefits, [CMW/C/ARG/CO/1](http://www2.ohchr.org/english/bodies/cmw/docs/CMW.C.ARG.CO.1_en.pdf), Para 4; and the CESCR Committee recommended that Argentina ensure unrestricted coverage of the universal allowance for children, E/C.12/ARG/CO/3, 2011, para 20 [↑](#footnote-ref-42)
43. Disability Integration Act of 2015 (DIA), section 6(b)(6)(A) & (E). According to section 6(b)(6), public entities should “review and improve community capacity, in all communities throughout the entirety of that jurisdiction, in providing affordable, accessible and integrated housing including an evaluation of available units, unmet need and other identifiable barriers to the provision of that housing.” The full text of the bill is available here https://www.congress.gov/114/bills/s2427/BILLS-114s2427is.pdf [↑](#footnote-ref-43)
44. http://specialneedsanswers.com/senate-bill-would-strengthen-mandate-that-people-with-disabilities-be-integrated-in-the-community--15441 [↑](#footnote-ref-44)
45. [CRPD/C/TKM/CO/1](http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/TKM/CRPD_C_TKM_CO_1_20188_E.doc), para 35; [CRPD/C/MNG/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fMNG%2fCO%2f1&Lang=en), para 32; [CRPD/C/BRA/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fBRA%2fCO%2f1&Lang=en), para 37 [↑](#footnote-ref-45)
46. [CRPD/C/CHN/CO/1](http://www.ohchr.org/Documents/HRBodies/CRPD/8thSession/CRPD-C-CHN-CO-1_en.doc), para 32; [CRPD/C/COK/CO/1](http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/COK/INT_CRPD_COC_COK_20208_E.doc), para 40 [↑](#footnote-ref-46)
47. [CRPD/C/KEN/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fKEN%2fCO%2f1&Lang=en), para 38(b); [CRPD/C/BRA/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fBRA%2fCO%2f1&Lang=en), para 37 [↑](#footnote-ref-47)
48. [CRPD/C/QAT/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fQAT%2fCO%2f1&Lang=en), para 38 [↑](#footnote-ref-48)
49. [CRPD/C/PRY/CO/1](http://www.ohchr.org/Documents/HRBodies/CRPD/9thSession/CRPD.C.PRY.CO.1-ENG.doc), para 50 [↑](#footnote-ref-49)
50. CRPD/C/CZE/CO/1, para 39; CRPD/C/UKR/CO/1, para 37 [↑](#footnote-ref-50)
51. CRPD/C/HRV/CO/1, para 30; [CRPD/C/BRA/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fBRA%2fCO%2f1&Lang=en), para 37 [↑](#footnote-ref-51)
52. [CRPD/C/ESP/CO/1](http://www.ohchr.org/Documents/HRBodies/CRPD/6thsession/CRPD.C.ESP.CO.1_en.doc), para 40; [CRPD/C/DEU/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fDEU%2fCO%2f1&Lang=en), para 42(b); [CRPD/C/COK/CO/1](http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/COK/INT_CRPD_COC_COK_20208_E.doc), para 40; [CRPD/C/UKR/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fUKR%2fCO%2f1&Lang=en), para 37 [↑](#footnote-ref-52)
53. [CRPD/C/HUN/CO/1](http://www.ohchr.org/Documents/HRBodies/CRPD/8thSession/CRPD-C-HUN-CO-1_en.doc), para 35 [↑](#footnote-ref-53)
54. [CRPD/C/BEL/CO/1](http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsjjHe7ia4QapdfXcn9RXjWGUnLq7lBzf6jZqm5v8d04CHmp7F4CYraPSGkq8DobTcdMA5AUGYfwBkUk1KR%2bYgxpUpELLRKGqpAXglC81HePB), para 33; [CRPD/C/AZE/CO/1](http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnkKJq%2bDPfPrSem4tEJ9xFPXG%2fyKOQhvwXO1wP1F6%2btz4ndr%2b2t4brr4jSlFhd1TpHz40faHRZyPnB0El3iv8%2bqSrwjQreFOEzPt8vVR968M), para 33 [↑](#footnote-ref-54)
55. [CRPD/C/BEL/CO/1](http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsjjHe7ia4QapdfXcn9RXjWGUnLq7lBzf6jZqm5v8d04CHmp7F4CYraPSGkq8DobTcdMA5AUGYfwBkUk1KR%2bYgxpUpELLRKGqpAXglC81HePB), para 33 [↑](#footnote-ref-55)
56. [CRPD/C/KEN/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fKEN%2fCO%2f1&Lang=en), para 38(c) [↑](#footnote-ref-56)
57. See Report of the Independent Expert on the effects of foreign debt and other related international financial obligations of States on the full enjoyment of all human rights, particularly economic, social and cultural rights on his mission to Greece, February 2016, which reveals that “spending to support sick persons and **persons with disabilities decreased also disproportionately**”. [↑](#footnote-ref-57)
58. CESCR Committee letter to States Parties of the International Covenant on Economic, Social and Cultural Rights, 16 May 2012 [↑](#footnote-ref-58)
59. In response to these austerity measures raised, recommendations were made concerning women and girls with disabilities “to adopt comprehensive policies and programmes ensuring their access to education, employment, housing, health care and other basic services, social protection and … access to community services" (CEDAW/C/MNG/CO/8-9, para 35). [↑](#footnote-ref-59)
60. See submissions of the Italian Disability Forum to the CESCR Committee, July 2015, and to the CRPD Committee, January 2016 [↑](#footnote-ref-60)
61. <http://www.grusol.it/informazioni/18-09-13.PDF> [↑](#footnote-ref-61)
62. In Tuscany, two big institutions for persons with intellectual and developmental disabilities are under construction in Empoli and Pisa, the first one providing 20 places in a residential service plus 60 places in a day service, the second one providing 100 places in a residential service and 400 places in a daily service. At national level, the municipality’s expenditure for support at home to persons with disabilities (211,201,622 euros) is lower than the funds allocated to residential facilities (256,926,187 euros, net of the user’s participation quota). The average expense for disability varies noticeably according to the type of service, ranging from 3,469 euros/year/user in Social assistance services (RSA) to 12,201 euros in residential healthcare facilities for persons with disabilities (RSD) (net of the user’s participation quota). [↑](#footnote-ref-62)
63. See for example, <http://www.mirror.co.uk/news/uk-news/more-80-suicide-cases-directly-5634404> and

<https://welfaretales.wordpress.com/2014/03/26/benefits-assessment-led-to-womans-suicide-says-watchdog/> (“The MWC said a survey of psychiatrists conducted as part of its investigation found that 13% reported that at least one of their patients had attempted suicide as a result of the assessment process” relating to eligibility foot benefits.) [↑](#footnote-ref-63)
64. See <http://www.theguardian.com/politics/2015/jun/05/disabled-payment-delay-unlawful-judge-rules-iain-duncan-smith> [↑](#footnote-ref-64)
65. See <http://www.theguardian.com/society/2016/feb/29/disabled-people-challenge-bedroom-tax-at-supreme-court?CMP=share_btn_fb> [↑](#footnote-ref-65)
66. See [www.parliament.uk/business/publications/business-papers/lords/lords-divisions/?date=2016-Feb-29&itemId=1&session=2015-May-18](http://www.parliament.uk/business/publications/business-papers/lords/lords-divisions/?date=2016-Feb-29&itemId=1&session=2015-May-18) [↑](#footnote-ref-66)
67. For instance, the Disability Benefits Consortium warned that the Employment and Support Allowance cuts make in fact harder for persons with disabilities to find an employment. [↑](#footnote-ref-67)
68. CRPD/C/SWE/CO/1, para 43 [↑](#footnote-ref-68)
69. CRPD/C/SWE/CO/1, para 44 [↑](#footnote-ref-69)
70. While the Supreme Court has upheld the “integration mandate” of the Americans with Disabilities Act, state Medicaid programs have ignored this mandate and have continued to discriminate against people with disabilities, denying their right to live in the community by creating lengthy waiting lists for community-based Medicaid services and by capping the services provided, forcing many people with disabilities into institutional settings because the state will not pay for sufficient care at home.  The full text of the bill is available here https://www.congress.gov/114/bills/s2427/BILLS-114s2427is.pdf [↑](#footnote-ref-70)
71. See section 8, Disability Integration Act of 2015 (DIA) on enforcement which includes actual and punitive damages, and immediate injunctive relief to prevent institutionalisation. The full text of the bill is available here https://www.congress.gov/114/bills/s2427/BILLS-114s2427is.pdf [↑](#footnote-ref-71)
72. *Olmstead v. LC* (98-536) 527 U.S. 581 (1999) [↑](#footnote-ref-72)
73. *Disability Advocates, Inc. v. Paterson*, No. 03-CV-3209 [↑](#footnote-ref-73)
74. Argentina Federal, Civil and Commercial High Court, Chamber III, LAF c/ Sociedad Española de Beneficiencia Hospital Español s/ amparo de salud, Case 4189/2015/CA1, Buenos Aires, 8 March 2016 [↑](#footnote-ref-74)
75. The tax exemption’s purpose was to ensure solving the housing needs of the applicant and family. [↑](#footnote-ref-75)
76. *Guberina v Croatia*, European Court of Human Rights, Application no [23682/13](http://hudoc.echr.coe.int/eng%22%20%5Cl%20%22%7B%22appno%22%3A%5B%2223682/13%22%5D%7D%22%20%5Ct%20%22_blank), 22 March 2016 [↑](#footnote-ref-76)
77. This is the first time that the European Court makes a finding of discrimination by association, see *Guberina v Croatia*, European Court of Human Rights, Application no [23682/13](http://hudoc.echr.coe.int/eng%22%20%5Cl%20%22%7B%22appno%22%3A%5B%2223682/13%22%5D%7D%22%20%5Ct%20%22_blank), 22 March 2016, para 79. IDA, EDF and the Croatian Union of Associations of Persons with Disabilities (SOIH) submitted a third party intervention in this case raising CRPD standards concerning accessible housing, reasonable accommodation, discrimination by association and the right to live in the community; the amicus brief is referred to in the Court’s judgment at paras 63-65 and the full amicus brief is available [here](http://www.internationaldisabilityalliance.org/sites/disalliance.e-presentaciones.net/files/public/files/Guberina%20v%20Croatia.SOIH%2C%20EDF%2C%20IDA.Final.doc). [↑](#footnote-ref-77)
78. The third party intervention can be read [here](http://www.internationaldisabilityalliance.org/sites/disalliance.e-presentaciones.net/files/public/files/Kocherov%20and%20Sergeyeva.EDF%2C%20IE%2C%20II%20%26%20IDA%20third%20party%20intervention.final.doc). While the Court found a violation of the right to family, it did not examine the claim under disability based discrimination- which is typical in many discrimination on different grounds before the Court. However, there is a promise of further and imminent evolution as put forward by a strong dissenting opinion by the Swiss judge, a former member of the Human Rights Committee, which raised the operation of negative stereotypes concerning disabled parents and hence recognised the inherent discrimination on the basis of disability in this case. [↑](#footnote-ref-78)
79. [CRPD/C/BEL/CO/1](http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsjjHe7ia4QapdfXcn9RXjWGUnLq7lBzf6jZqm5v8d04CHmp7F4CYraPSGkq8DobTcdMA5AUGYfwBkUk1KR%2bYgxpUpELLRKGqpAXglC81HePB), para 33 [↑](#footnote-ref-79)
80. [CRPD/C/EU/CO/1](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fEU%2fCO%2f1&Lang=en), para 50-51 [↑](#footnote-ref-80)