



Living in the Community

Position Paper

Draft Position Paper of Inclusion Europe

- For adoption at the 2010 Annual General Assembly of Inclusion Europe -

The United Nations Convention on the Rights of Persons with Disabilities, hereinafter CRPD, is the first legally binding Human Rights Treaty recognizing explicitly the right to live in the community in its Article 19. While this represents in itself an achievement and a recognition of the fight for de-institutionalisation as well as the movement for independent living, many efforts at international, European, national and local levels are still needed to make this right a reality for all people with disabilities. Indeed, in the past years, Inclusion Europe and other organisations have been denouncing the everlasting high number of people with intellectual disabilities, including children, living in residential care and the lack of community-based alternatives to long-stay residential institutions.

Whenever the word “institutions” is used in this Position Paper, we refer to the definition proposed by the Canadian Association for Community Living (CACL) that was endorsed by many European associations and public bodies:

"An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size."

Inclusion Europe contributed in 2009 to the focus report of the European Coalition for Community Living on Article 19 of the CRPD and actively participated in the Ad-Hoc Expert Group on the Transition from Institutional to Community-based Care set up by the Špidla cabinet, where a report on this specific topic has been written. Inclusion Europe would like to acknowledge the contributions of these two documents to the production of this Position Paper.

The meaning of Article 19

Article 19 CRPD sets out the “right to **all** persons with disabilities to live in the community with equal choices to others”. This key article is based on the general principles underpinning the Convention: inclusion and full and effective participation in the community.

Article 19 clearly describes what the right to live in the community includes:

- People with disabilities have the right to choose their place of residence
- People with disabilities have the right to choose where they want to live and with whom
- People with disabilities have access to a range of community support services, based on the needs of the person
- Mainstream services, available to the general population, must be available and adapted to the needs of people with disabilities.

Article 19 also explicitly says that “persons with disabilities cannot be obliged to live in a particular living arrangement”. Services provided to people with disabilities should prevent isolation and segregation from the community.

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This is a clear message to State Parties to stop the placement of people with intellectual disabilities in long term residential care or large residential institutions. States Parties have not only to protect people with disabilities from segregation but they have to actively ensure the existence of the necessary community-based services to make living in the community possible.

The interpretation of Article 19 is also informed by other Articles of the Convention focusing on independent living, such as Article 12 on Legal Capacity, Article 9 on Accessibility, and Article 28 on Adequate Living Standard and Social Protection¹. Without the right to take decisions or the right to live in an accessible environment or to earn money for a decent life, the scope of Article 19 is reduced.

The right to live in the community is an essential component of international, European and national policies. Actions to implement the right to live in the community are needed at all levels to create real and sustainable change.

Recommendations to States Parties in Europe

A strong policy framework for community living

While the ratification process is taking place, States Parties must undertake a legislative review to establish which provisions are in compliance or not with the CRPD. The exercise is of utmost importance to identify the barriers to implement the right to live in the community.

All States Parties in Europe should have a clear **strategy and action plan** for the promotion and implementation of supported living in the community which must be accompanied by a clear timeframe and budget for the development of services in the community and the closure of long-stay residential institutions. These plans should include a proper monitoring, including indicators to measure the implementation.

All States Parties as well as the EU statistical office Eurostat should make sure that **data** about children in institutions are collected and **disaggregated by type of disability and by age**. The same information should be available for adults with intellectual disabilities. Data and information collection are also enshrined in Article 31 CRPD.

As it has been claimed already in the past, a '**no new admissions policy**' should be put in place: no new persons with disabilities should be admitted in long-stay residential institutions.

A strong collaboration with users and their representatives: “nothing about us, without us”

NGOs of persons with intellectual disabilities and their families should be actively involved in the mapping of services and the identification of shortcomings in terms of community-based services, as stipulated by the CRPD.

User-led services, i.e. services where users are involved in decision-making positions at all stages from the design and the delivery to the evaluation of services, are an important development to ensure that these services really meet the needs and wishes of their users². Good practices of user-led services by persons with intellectual disabilities exist and they should be promoted and further developed. All States Parties in Europe should start to develop legislation that ensures participation of users in decision-making positions in disability services.

Personal budgets or direct payment schemes are an important step into the direction of more user influence. If users can decide which support services they want to purchase from which provider they can exercise their power as consumers of support services. Governments should implement personal budgets to allow autonomy and choices by persons with intellectual disabilities. The system of personal budgets should be well controlled to avoid misusing of the funds.

1. For the positions of Inclusion Europe on some of these topics, please consult our website at www.inclusion-europe.org
2. See also the Position Paper on “User Councils in Special Services for People with Intellectual Disabilities”

The evaluation of the quality of support services must be based on the **quality of life of the users as defined by them**. User-defined quality-of-life indicators may differ significantly from theoretical constructs and give a real picture of the output of a support service in terms of enhancing quality of life and well-being of its users. The creation of new services for people with intellectual disabilities should be strictly controlled, checked according to specific terms of reference and evaluated by persons with intellectual disabilities themselves.

A strong focus on the quality of life of users and their families

Professional staff should be well trained, not only in care practices, but also in issues related to protecting the Human Rights, personal dignity and freedoms of people with disabilities. They need to respect the values of inclusion and autonomy, but also the promotion of user-defined quality of life.

All services should be **person-centred**, also for people with severe disabilities. States Parties in Europe should extend the knowledge about person-centred planning to all European countries to make it a common approach in working with people with intellectual disabilities.

Families of persons with severe disabilities or complex needs should be able to obtain the **necessary support** (counselling) to find the best services for their dependent member, at every stage of their life. States Parties should provide the necessary **at home services and respite care services** to allow families with a dependent member to have the same opportunities as other families.

Member States should pay specific attention to the sufficient and quality provision of community-based services for **older people with intellectual disabilities**. Policy measures towards the ageing population should take into account the needs of older people with intellectual disabilities. The risks of isolation and segregation exist for the general ageing population and is therefore even higher for this group at risk of double discrimination.

Bringing the 'invisible citizens' to the society

Member States should **raise awareness** among policy-makers but also professionals about the meaning of "community living" for people with intellectual disabilities – use personal success stories to explain and promote "community living". In addition, several scientific reports have shown the **persistence of institutionalisation** in Europe, mainly - but not exclusively - in Central and Eastern Europe. The results are often restrained to a small circle of people – more powerful and less academic information should be developed for a wider public.

Recommendations to the European Commission

Inclusion Europe and its members call upon the **European Union to ratify the CRPD and its Optional Protocol without any delay** and to encourage the Member States and other European countries to ratify the CRPD in the shortest period possible.

Inclusion Europe and its members call upon the European Commission and the Member States **to stop using the Structural Funds to build new segregating residential institutions or to improve the infrastructure of existing ones**. As described in the Ad-hoc Report³, the Structural Funds should be used to support the development of community-based services: "The European Social Fund can provide funding for the training (and re-training) of staff while the European Regional Development Fund (ERDF) can simultaneously be used for developing social infrastructure which will support the new community-based services."

Inclusion Europe and its members call upon the European Commission **to train the staff in the relevant DGs and geographical units** on the rights of persons with intellectual disabilities and the other groups concerned on the practices of segregation of persons with intellectual disabilities in long-stay residential care.

3. Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care, p. 20.

Inclusion Europe and its members call upon the European Commission to provide to the managing authorities in all the Member States clear **guidelines on the use of the Structural Funds and other EU funding instruments for deinstitutionalisation**. The guidelines should contain straightforward provisions that it is not allowed to use the Structural Funds to build new segregating residential institutions or to improve the infrastructure of existing ones. This should be closely **monitored** by the European Commission and penalties should be foreseen to make sure that the practices really change.

Inclusion Europe and its members call upon the European Commission to include the issue of transition from institutional to community-based services into the **Open Method of Coordination on Social Protection and Social Inclusion** and to set **objectives to reduce the number of children and adults with intellectual disabilities living in long-term residential care**. Peer pressure between Member States and towards other European countries should be used to implement the right to live in the community.

Inclusion Europe and its members call upon the Commission to collect a minimum of **data and statistics** to be available on residential services which would allow for the monitoring of progress in the closure of large residential institutions and the development of services in the community in Europe.

Inclusion Europe and its members call upon the Commission to further support and encourage **exchange of good practices and models of user-led evaluation** by people with intellectual disabilities and of **models of excellence** on the transition from residential care to community services.

Inclusion Europe and its members call upon the European Union to include in the **EU 2020 Strategy** as well as in the new **EU Disability Strategy beyond 2010** a strong **commitment to the objective of deinstitutionalisation** of children and adults with intellectual disabilities – to end this violation of the most basic Human Rights in Europe.

Recommendations at international level

Inclusion Europe and its members call upon the development agencies and international financial institutions such as the World Bank to adopt policies **stop the use of funds for the building new long-stay residential institutions** and to develop strategies on the inclusion of people with disabilities in **mainstream policies**.

Inclusion Europe and its members call upon the relevant international organisations to address the **problem of institutionalisation in the fight against poverty and social exclusion**.

Position Paper
Living in the Community
Easy-to read version

The United Nations is a meeting of all states in the world.
It has agreed on a new law on the Rights of Persons with Disabilities.
This new law is called a “Convention”.
All States must follow this new law.

One part of this law deals with living in the community like everybody else.
This is very important for people with intellectual disabilities and their families.
The Convention supports their fight for the necessary support to be able to live like other people.

However, the real situation is not very good.
There is very little support for community living available.
Many people with disabilities are still forced to live in large institutions.
Only few living facilities offer real possibilities for living included in society.

In this Position Paper, we use the word “institution” quite a lot.
But this word can mean different things for different people.
Therefore, we want to be clear what an institution is for us:

An institution is a place where people with disabilities
are living without contact to the society,
do not have a choice with whom they want to live,
are not allowed decide about their lives, and
are not allowed to take decisions by themselves.
An institution is not just a big living facility.
There can be also quite small places which are in fact institutions.

Inclusion Europe worked quite a lot for the possibility to live included in the community.
We have found also many friends who share these goals.
Together we have written many papers about this topic.

1. What does the Convention say about living in the community?

The Convention is divided into different articles.

Article 19 says that **all** persons with disabilities have the right to live in the community.

It also says what this right includes:

People with disabilities have the right to choose their home

People with disabilities can choose where they want to live and with whom

People with disabilities must have support when they need it

All public services must be available to people with disabilities and be adapted to their needs.

This Article also says that people with disabilities cannot be forced to live in a particular place, for example in an institution.

Following this Article, States must stop putting people into institutions.

They must make sure that they get support to live in the community.

This new right is therefore very important.

We all must make sure that people with intellectual disabilities and their families can benefit from it.

2. What we want States in Europe to do

Making good policies for community living

States should check if all their laws are following the UN Convention.

If the laws are not good enough, they must be changed.

States should have a plan about how to provide community living for all.

They should say what they want to do and when.

They should say when they want to close large institutions.

They also should give money for this.

We also need figures about what is happening.

How many children and adults are still in institutions?

What kind of disability do they have?

How old are they?

The European Union should collect this information.

It is also very important that no new people are getting into institutions.

Nothing about us, without us!

People with disabilities should say which services they need.

People with disabilities should also be involved in making all important decisions in services:

Where new services are created.

How the services are organised.

When the quality of the service is checked.

States should make laws that allow people with disabilities to do this.

Some countries give money to people with disabilities to buy their own services.

This gives them much more power.

Users with disabilities can decide which services they want.

All countries should make this possible.

People with disabilities themselves have to say what a good life is.

They have to say if they have a good life in the service or not.

New services should only be planned together with people with disabilities.

A better quality of life

Staff in services must be well trained.

They must understand how to respect and support people with intellectual disabilities.

They must respect values like inclusion.

All services must be there for the persons.

The planning of services must follow the needs of each person.

Families of persons with disabilities should also get support.

They need help to find the best services.

States should make sure that families are supported at home.

Services for older people with disabilities are also important.

They should be included in general services for older people.

No more “invisible citizens”

Many people and politicians do not know any person with a disability.

They do not have an idea what they can do to support them.

Many people with disabilities are hidden in institutions.

Everyone should be better informed about the needs and abilities of people with intellectual disabilities.

3. What we want the European Commission to do

Inclusion Europe asks the Commission to agree to the UN Convention as soon as possible.

It should also ask all members of the European Union to do the same.

At present, the Commission pays for new large institutions.

They also pay for renovating old large institutions.

This must stop!

European money should only be spent for community-based services.

The European Commission should make sure that Member States follow these policies.

Member States should work together to learn from good examples.

All the staff of the European Commission should also be trained in disability rights.

They need to understand about exclusion of people with intellectual disabilities in large institutions.

When the Commission plans what to do until 2020, it should include community living for people with intellectual disabilities.

In the next 10 years the Commission must make sure that the right of all persons with disabilities are fully respected.

4. What can be done around the world

Nobody should finance any large residential institutions any more.

All countries must make sure that their people with disabilities can live included in society.

They should include people with disabilities whenever new policies are being developed.

Especially all countries should work against poverty and social exclusion of people with disabilities.