

Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities



ECCL
European Coalition
for Community Living

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on the Rights of Persons with Disabilities
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Introduction

Ines Bulić

Coordinator of the European Coalition for Community Living

This Focus Report has been prepared by the European Coalition for Community Living (ECCL) as part of its work to promote the right of disabled people to live in the community as equal citizens. It focuses on Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD), which provides that all disabled people have the right to live and participate in the community. This report seeks to provide a clear explanation of the scope and purpose of Article 19 and makes a series of recommendations designed to facilitate the effective implementation of this right.

The CRPD is the first legally binding instrument to give explicit recognition to the right to live and participate in the community. While the recognition of this right is an important step, much more needs to be done to make it a reality for all disabled people. In Europe, although many Governments' policies, strategies and political statements purport to promote the social inclusion of disabled people, progress towards this goal is still very slow. In many countries people with disabilities continue to be segregated in residential institutions, often for life. Many of those disabled people who live with their families are also excluded from society because of the lack of the necessary support to enable them to participate in the community.

ECCL's Position Paper on Article 19, on pages 5–15 of this report, sets out the key steps that national, regional and local governments, the European Commission and the Council of Europe should take to give effect to the right to live and participate in the community. In addition, the Focus Report includes articles that provide more detailed commentary on Article 19 and the CRPD, including its huge potential to bring about real change to the lives of disabled people and highlighting some possible challenges in achieving such positive change.

This report aims to be of assistance to individuals and organisations involved in promoting, implementing and monitoring the CRPD, such as policy makers, organisations of disabled people and service providers. It can be used to identify actions that should be taken to realise the right to live and participate in the community, as well as to monitor progress towards implementation of the CRPD.

Article 19 of the CRPD provides a clear vision for the future – that disabled people can live in the community as equal citizens. Its effective implementation requires a partnership between many different actors – from disabled people and their representative organisations, governments, service providers to local communities and individuals. By highlighting the importance of Article 19 and setting out recommendations on the steps that should be taken to realise this vision, ECCL seeks to ensure that focused action is taken now to reach the goal of community living for ALL.

The Right to Live in the Community: ECCL Briefing on Article 19 of the UN Convention on the Rights of Persons with Disabilities

Introduction

With the advent of the United Nations Convention on the Rights of Persons with Disabilities ('CRPD') much welcome attention has been given to the responsibilities of States to take action to protect and promote the rights of disabled people. However, such a significant development will have little meaning for those disabled people who are segregated in institutions, often for life, unless governments take concrete action to end this practice.

Prevalence of institutionalisation across Europe

Reports over the last decade have raised serious concerns about the situation of disabled people in Central and Eastern Europe (CEE).¹ They point to the high numbers of disabled people placed in institutions, the neglect of residents and their isolation from their families, communities and the wider society, as well as the severe lack of community-based alternatives to institutionalisation. Moreover, many of these reports highlight the appalling living conditions in some institutions and widespread human rights abuses such as the use of physical restraints, sexual and physical abuse by the staff and other residents, inadequate food, heating and clothing.

The institutionalisation of disabled people in residential institutions is by no means exclusive to CEE. The report of a study of the European Union Member States and Turkey, 'De-institutionalisation and community living: outcomes and costs' found that nearly 1.2 million disabled people lived in institutions. This is likely to be an underestimate because most countries keep only partial data about the number of people in institutions, and others (such as Austria, Germany and Greece) provided no data to the researchers. The

study found that in 16 out of 25 countries for which information was available, state funds (local or regional) were being used, at least in part, to support institutions of more than 100 places. In 21 countries across Europe state funds were being used to support institutions of more than 30 places.²

The Right to Community Living and Article 19

Article 19 of the CRPD sets out the right of all disabled people³ to ‘live in the community, with choices equal to others’, requiring States to enable disabled people to be fully included and participate in society (see Box).

Community living refers to people with disabilities being able to live in their local communities as equal citizens, with the support that they need to participate in every-day life. This includes living in their own homes or with their families, going to work, going to school and taking part in community activities. To ensure that disabled people have the same choice, control and freedom as any other citizen, any practical assistance provided to them should be based on their own choices and aspirations.

BOX

Article 19 – Living independently and being included in the community

States Parties to the present Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

This briefing sets out the key steps that need to be taken by national, regional and local Governments, the European Commission and the Council of Europe in order to make the right to live independently and be included in the community a reality.

Key steps for implementing Article 19 of the UN Convention on the Rights of Persons with Disabilities

By recognising ‘the equal right of all persons with disabilities to live in the community, with choices equal to others’, Article 19 of the CRPD sends a clear message to States that the practice of isolating and segregating disabled people in long-stay residential institutions⁴ is a violation of disabled people’s human rights.

States that continue to rely on institutions as the preferred model of care are failing to comply with Article 19, which explicitly requires that services for disabled people should ‘support living and inclusion in the community’ and aim to ‘prevent isolation or segregation from the community’. The kind of relationships with family, friends and the wider community that people develop if provided with appropriate support to live in their own homes cannot be achieved in institutions, which are often placed in isolated locations, far removed from the residents’ original communities.

Enjoyment of the right to live in the community is central to the implementation of many other rights in the CRPD. For example, the right to habilitation and rehabilitation (Article 26), which requires States to enable disabled people to attain and maintain maximum independence, and the right to work on an equal basis with others (Article 27) cannot be achieved if disabled people are not supported to live in the community.

Article 19 of the CRPD provides a clear vision for the future – that disabled people can live in the community as equal citizens. The work to realise this vision requires a partnership between governments and disabled people, in addition to a range of other individuals and organisations such as family members, service providers, schools and employers.

The following recommendations set out a range of actions that are intended to facilitate the effective implementation of Article 19.⁵

Recognise the right of all disabled people to participate in the community

As a first step, States should make a commitment to realising the right of all disabled people to live in the community.⁶

Although States will not be expected to realise all aspects of Article 19 immediately, they will be required to take concrete measures towards realising this right, using the maximum of their available resources to do so. This is because while acknowledging that it often takes time to achieve economic, social and cultural rights, such as Article 19, the CRPD requires States to take measures with a view 'to achieving progressively the full realisation of these rights'.⁷ A lack of resources does not justify inaction. States should therefore plan what action they will need to take to meet their obligations under Article 19. For many, this will include the planning and development of community-based services as alternatives to institutionalisation.

Research into the cost of institutional care and services in the community has shown that community-based models of care are not inherently more costly than institutions, once the comparison is made on the basis of comparable needs of residents and comparable quality of care. There is therefore no sound basis for the argument that community-based services are too expensive for some countries.

Ensuring that there is no delay in implementing Article 19 is of great importance because of the link between Article 19 and other CRPD articles which require immediate application. This includes, for example, Article 12 (Equal recognition before the law), Article 14 (Liberty and security of person) and Article 23 (Respect for home and the family). The implementation of these articles is dependent on countries' progress in ensuring the right of disabled people to choose where and with whom to live, and to participate in the community.

Recommendation 1

Governments and the European Community should ratify the CRPD and its Optional Protocol as a matter of priority, and without reservations to any of the CRPD articles.

Recommendation 2

Governments should undertake a review of existing legislation to establish the level of compliance with the CRPD and to make recommendations in areas where reform is needed. Appropriate legislative, administrative and other measures which make clear that all disabled people have the equal right 'to live in the community, with choices equal to others' should be adopted in order to facilitate the implementation of Article 19.

Develop services to support participation in the community

Article 19 of the CRPD requires States to ensure that disabled people have access to a range of community services to support them to participate in the community. In addition, community services and facilities for the general population must be 'available on an equal basis to persons with disabilities' and 'responsive to their needs'.

Good community-based services are organised on the basis of the following key principles:

- They are person-centred, which means that they are tailored to the individual's needs, wishes and aspirations, and can change as required over time;
- They support family and community life, ensuring that additional help is given to the person, their family and friends, to enable them to live and participate in the community;
- They adopt a social model of disability (this identifies the failure of society to accommodate disabled people, such as the inaccessibility of buildings and discriminatory attitudes, as the barrier to their inclusion in society rather than their particular impairment);
- They are user-led, which means that people with disabilities are closely consulted with and actively involved in the design, delivery and evaluation of services;
- They address all of people's lives, ensuring that they provide whatever help is needed to enable the person to have a good quality of life, regardless of the effects of their impairment and disability; and
- They ensure that these principles are expressed in the day-to-day assistance provided to the individuals they support.

Sustaining a system of special institutions, such as special kindergartens, special schools and sheltered workshops cannot lead to the full and effective participation and inclusion of disabled people in society. The development of community-based services must therefore be accompanied by actions to ensure that services for the general population are accessible to disabled people. This will require the involvement of a number of different agencies or sectors, including health, social care, housing, education, employment, transport, leisure, criminal justice and social security. At the European Union level, the European Commission should promote quality standards in the provision of social services for the general population which are in line with the CRPD.

Recommendation 3

Governments should develop and implement national strategies to transfer the provision of care from institutions to the community. Such strategies should specify the overall timetable, plan and budget for this transition and how this work will be co-ordinated between the relevant Government Ministries (e.g. social welfare, health and education). The process of transition to community-based services should be underpinned by the general principles of the CRPD (Article 3). These include: 'respect for inherent dignity, the freedom to make one's own choices, independence and full and effective participation and inclusion in society'.

Recommendation 4

Governments should adopt a holistic approach to implementation of Article 19, addressing all the barriers to the right to live in the community that have been identified in cooperation with disabled people and other individuals and organisations working to promote community living.

Ensure that the involvement of disabled people is central to policy development

Disabled people must be involved in all stages of the process to ensure the effective implementation of Article 19.

The CRPD requires that State Parties 'closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations' in the development and implementation of legislation and policies to implement the CRPD (Article 4). This is particularly important in the transition from institutional to community-based services. While it is relatively easy to close an institution, it is much more difficult to replace it with a system of services in the community that will offer the kind of support and opportunities that people with disabilities need and want. Without listening to disabled people and understanding their wishes and needs, there is a danger that institutional practices will be replicated in the community.

ECCL uses the following definition of an institution: '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. It 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.'

The transition from institutional care to community-based services is much more than changing the location of care. Article 19 requires that support services are designed to

facilitate disabled people's inclusion and participation in society. This can only be achieved if disabled people are equal partners in the planning, provision, monitoring and evaluation of such services.

Recommendation 5

In line with Article 4(3) of the CRPD, disabled people and their representative organisations should be actively involved in the preparation for the ratification of the CRPD. For example, they should be consulted in the process of translating the CRPD, in identifying what needs to be done to implement the CRPD and in raising awareness about it. Equally, Governments and the European Community should ensure that disabled people and their representative organisations are adequately represented in the monitoring bodies set up under Article 33 of the CRPD.⁸ It is important that no particular group of disabled people is excluded from this process (for example, people with mental health problems).

Recommendation 6

Governments should actively involve disabled people, their families and representative organisations in the process of planning, developing and evaluating services in the community. Furthermore, Governments should work with disabled people to consider all relevant policy areas, such as employment, education, health, housing, social policy and transport and identify how to make mainstream services in these areas available and accessible to disabled people.

Remove barriers to participation in the community

An important area of work to be undertaken is to identify the obstacles to implementing Article 19. These might include the need to revise the legal and financial mechanisms to allow for services to be delivered in the community by non-governmental organisations rather than in an institution run by a State agency. Furthermore, ECCL is concerned that European and international funds are being used to renovate existing institutions, or build new institutions, rather than to help develop community-based alternatives.

Another area of concern is the use of guardianship in many countries, particularly CEE. Under this system, a person who has been deemed to lack capacity to make decisions for themselves is placed under guardianship. Individuals placed under plenary (full) guardianship are not permitted to make any decisions of a legal nature, such as entering into employment, getting married or opening a bank account.

The system of guardianship gives rise to a series of violations of rights under the CRPD. For example, it contravenes one of the guiding principles of the CRPD, which is the ‘freedom to make one’s own choices, and independence of persons’ (Article 3) and Article 12, which requires that State Parties ‘recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.’ Furthermore, it undermines a significant right under Article 19 which requires that disabled people are able to choose where and with whom to live and are not obliged to live in a particular living arrangement. In many countries it is common practice for individuals subject to plenary guardianship to be placed in a residential institution by their guardian without their consent, for life and without the right of appeal.

Recommendation 7

Governments should abolish outdated guardianship systems and replace them with a framework which will support disabled people to make decisions to the maximum of their capacity, and promote choice and control of disabled people over their lives.

Recommendation 8

Governments and the European Commission should ensure that public funds are not used to redevelop or build new institutions. Investments in, and support to, existing institutions for disabled people must be limited to targeted interventions – actions that are necessary to address risks to residents’ health or safety – and should be accompanied with a plan to develop alternative services in the community and close the institution.

Raise awareness on disabled people’s right to participate in the community

The CRPD requires that States raise awareness about the rights of people with disabilities and promote the positive contribution of disabled people to society (Article 8).

To facilitate the transition to community-based services, disabled people and their families, policy makers, service providers, the media and the wider public should be familiar with the right of disabled people to live in the community and participate in society. A key factor in this work will be to combat stereotypes and prejudice against people with disabilities. In particular, staff and professionals working with disabled people should receive training on the rights set out under the CRPD so that they are better able to provide the assistance and services guaranteed by these rights (Article 4(i)). This should be done in cooperation with disabled people and their representative organisations.

Examples of good practice in social inclusion of disabled people through the provision of community-based services should be promoted through awareness raising campaigns and other activities to facilitate exchange of knowledge and skills. Countries with few community-based services can benefit from good practice developed in countries that have made substantial progress in the development of alternatives to institutional care. This can help to prevent the development of poor quality services.

Recommendation 9

Governments, the European Commission and the Council of Europe should raise awareness about the right of disabled people to live in the community among all the stakeholders. They include disabled people, national, regional and local governments, service providers, media and the wider public, the European Union institutions (the European Commission and the European Parliament), the Council of Europe and funding institutions (such as the World Bank and the Council of Europe Development Bank).

Recommendation 10

The European Commission and the Council of Europe should facilitate exchange of best practice in developing community-based services between the countries. A pool of experts on de-institutionalisation should be established at the European level in order to provide governments with technical assistance and support the implementation of Article 19 of the CRPD.

Monitoring progress in implementing Article 19

Governments should collect data about the number and quality of services in the community and people using them, and the number of disabled people in institutional care, in order to allow for the monitoring of progress towards implementation of Article 19. Such information should also be collected at European level, to permit the review of countries' progress in the closure of institutions and the growth of independent living and services in the community. The European Commission should regularly publish statistics demonstrating progress in each country.

Recommendation 11

Governments should set up a compulsory quality assurance and monitoring system for all services for disabled people to ensure that the rights of disabled people, as set out in the CRPD, are respected. Institutions and other services for disabled people should be the subject of regular monitoring, involving disabled people and their representative organisations.

Ensure that children with disabilities can grow up in a family environment

Article 7 of the CRPD requires State parties to ensure 'the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children'. Research has shown that institutionalisation has a severe negative impact on children's happiness, their development and future.⁹ It affects children's emotional and physical development, results in additional disabilities and can jeopardise their physical health. It is therefore crucial that all children with disabilities are able to grow up in a family environment and that no child is placed in residential care.

The first step to the closure of institutions for children with disabilities is preventing any new admissions to institutions. While many disabled children will need a range of professional support services throughout their lives, there is no justification for providing such services in an isolated or segregated environment, whatever the nature of the child's disability. All of the services that they need can be provided in the family home or through foster care in small community homes.

Families (including foster families) must be adequately supported to care for their disabled child. Furthermore, rather than maintaining a system of special institutions, States should mainstream support and policies for disabled children into all general children's, educational, family and health policies. Only by ensuring that children with disabilities are able to grow up in a family environment, play and learn with their non-disabled peers, can States build inclusive societies in which disabled people are equal to other citizens.

Recommendation 12

Governments should close all institutions for disabled children by preventing any new admissions to institutions. Any available resources should be used to establish a range of community-based services for all children with disabilities.

Endnotes

- 1 See, for example, Handicap International Disability Monitor Initiative South East Europe (2008), *The Right to Live in the Community: Making it happen for people with intellectual disabilities in Bosnia and Herzegovina, Montenegro, Serbia and Kosovo*; UNICEF/Centre for Legal Resources Romania (2007), *Monitoring the Rights of Mentally Disabled Children and Young People in Public Institutions*, Mental Disability Advocacy Centre (2006–08), *Human Rights and Guardianship reports*; Amnesty International (2002), *Bulgaria: Far from the Eyes of Society*.
- 2 Mansell J, Knapp M, Beadle-Brown J and Beecham, J (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report*. Canterbury: Tizard Centre, University of Kent, available at: http://www.kent.ac.uk/tizard/research/research_projects/DECLOC%20Volume%202%20Report%20for%20Web%20.pdf. This report (the DECLOC report) aimed to identify successful strategies for replacing institutions for people with disabilities with community-based services, paying particular attention to economic issues in the transition. Research was carried out in the 27 European Union Member States and Turkey, making it the most wide-ranging study of its kind undertaken to date. The report will be a valuable resource for governments planning the transition from long-stay residential institutions to community-based services. Many of the points in this briefing have been drawn from the DECLOC report.
- 3 The UN CRPD applies to all disabled people, including people with mental health problems. See Article 1 of the CRPD: ‘persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’.
- 4 See page 10 for ECCL’s definition of an institution.
- 5 Recommendations 3, 8, 10 and 11 have been taken from the DECLOC report.
- 6 United Nations (2007), *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities, Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol*.
- 7 *Ibid*, pages 18–19.
- 8 Article 33 requires that State Parties develop mechanisms within the government, including one or more focal points, and a framework, including one or more independent mechanisms, to coordinate promotion, implementation and monitoring of the CRPD.
- 9 See, for example UNICEF/Innocenti Research Centre (2005), *Children and Disability in Transition in CEE/CIS and Baltic States*, page 15.

It Has Been a Long Time Coming

John D. Evans¹

The 3rd May 2008 was a historic day for the international disability movement as it was the day on which the UN Disability Rights Convention came into force. This was the day when enough countries ratified the Convention to make it legal and binding. For many disability rights campaigners and activists it has been a long time coming! This significant event is a testimony to two decades of hard and consistent campaigning by disabled people and their supporters worldwide. We have every reason to be proud of what has now been achieved. It is a time of celebration that we finally have an international legal instrument which can be used throughout the world in our struggle to combat discrimination, in order to protect the rights of 650 million people in the world.

However, we know it is not the golden elixir which will solve all our problems in eradicating unlawful discrimination. It is a beginning though, and for many of us who have been travelling down this long road of oppression, exploitation and discrimination, it is a welcoming relief. We salute our colleagues from all over the world who for many years worked tirelessly with dedicated commitment with the UN AdHoc Committee, debating, negotiating and creating this important Convention in the meeting rooms and corridors of the UN in New York.

It is indeed 'the dawn of a new era for disabled people' as Kofi Annan said when he announced the adoption of the Convention on 13th December 2007.

This has been a great achievement but we know that we still have to be politically astute and active in continuing to engage ourselves in the next stages of this long process. We cannot be complacent as this is a crucial time. We know we have a struggle on our hands and everything will not necessarily be straight forward. It now means that countries will have to ensure that there is a process, whereby international law can be merged into national laws in order to ensure that the Convention can be used in practice in countries to combat discrimination.

Our work right now is to make sure that our Governments ratify the Convention and the Optional Protocol. We need to follow this up diligently with the appropriate government representatives who are responsible for this and to lobby them to do it.

The international independent living movement is extremely pleased that there is now a specific Article 19 on independent living and personal assistance. This is very significant

because never before have we had an international legal instrument, which 'recognises the equal right of all persons with disabilities to live in the community, with choices equal to others'. The article goes further in highlighting other basic independent living principles and says:

'Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.'

This clause is very important for the independent living movement as it stresses that disabled people should not be obliged to live in an institution or residential facility. The independent living philosophy has always emphasized that disabled people should have the right to live in the community with everybody else, and to have the same choices and rights as others.

Article 19 provides us with legal and practical support to assist us in the development of community based services with the control, choice and participation of disabled people. We need to remind Governments of their obligation and responsibility to ensure this.

What pleases the independent living movement is that independent living and personal assistance are now enshrined in an international legal instrument. This is particularly significant for those countries in the world that have no laws governing the need for personal assistance and independent living. This means that the opportunity for personal assistance can now be made available to many more people, especially if their countries have ratified the Convention and the Optional Protocol.

For many years now the independent living movement in Europe has campaigned and lobbied for the equality of opportunity for all European disabled citizens to have the right to personal assistance. Every two years since 2003, the European Network on Independent Living (ENIL) has taken this issue to the European Parliament in Strasbourg through its 'Freedom Drives' and lobbied the European Commission at the same time about the importance of personal assistance for empowering disabled people in Europe. Until now, they have argued that it is the competence of the Member State to do this, but we feel now that with the Convention, the European Commission and Parliament also have an obligation to do something about the right to personal assistance.

An issue that does concern disability activists is that many of the countries that have ratified the Convention do not have a particularly good track record in providing good services and respecting the rights of disabled people. We hope that as time goes by, other countries with better traditions in providing good models of independent living and personal assistance will also ratify the Convention, which would help to improve the situation for those countries lacking in good practice.

We know that Article 19 will not change things overnight, and that it will take time. The main thing is that it does provide the opportunity and possibilities for personal assistance

and independent living to be made available to disabled people throughout the world who have until now been denied this option. If this happens, we have the possibility of freeing millions of disabled people from institutions and liberating their lives into a more participative and inclusive existence.

This is where the work for all of us involved in promoting the aims and objectives of the European Coalition for Community Living in establishing community based services can be mobilised to promote our work more effectively throughout Europe.

Endnote

- 1 John D. Evans OBE is a Board Member of the European Network on Independent Living and one of the founders of the European Coalition for Community Living. He has been a life-long advocate for the rights of people with disabilities in the United Kingdom and Europe-wide.



Key Steps for Implementing Article 19 of the UN Convention on the Rights of Persons with Disabilities

Recommendation 1

Governments and the European Community should ratify the CRPD and its Optional Protocol as a matter of priority, and without reservations to any of the CRPD articles.

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Governments should develop and implement national strategies to transfer the provision of care from institutions to the community. Such strategies should specify the overall timetable, plan and budget for this transition and how this work will be co-ordinated between the relevant Government Ministries (e.g. social welfare, health and education). The process of transition to community-based services should be underpinned by the general principles of the CRPD (Article 3). These include: 'respect for inherent dignity, the freedom to make one's own choices, independence and full and effective participation and inclusion in society'.

Recommendation 4

Governments should adopt a holistic approach to implementation of Article 19, addressing all the barriers to the right to live in the community that have been identified in cooperation with disabled people and other individuals and organisations working to promote community living.

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In line with Article 4(3) of the CRPD, disabled people and their representative organisations should be actively involved in the preparation for the ratification of the CRPD. For example, they should be consulted in the process of translating the CRPD, in identifying what needs to be done to implement the CRPD and in raising awareness about it. Equally, Governments and the European Community should ensure that disabled people and their representative organisations are adequately represented in the monitoring bodies set up under Article 33 of the CRPD. It is important that no particular group of disabled people is excluded from this process (for example, people with mental health problems).

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Governments should actively involve disabled people, their families and representative organisations in the process of planning, developing and evaluating services in the community. Furthermore, Governments should work with disabled people to consider all relevant policy areas, such as employment, education, health, housing, social policy and transport and identify how to make mainstream services in these areas available and accessible to disabled people.

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Governments and the European Commission should ensure that public funds are not used to redevelop or build new institutions. Investments in, and support to, existing institutions for disabled people must be limited to targeted interventions – actions that are necessary to address risks to residents' health or safety – and should be accompanied with a plan to develop alternative services in the community and close the institution.

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Governments, the European Commission and the Council of Europe should raise awareness about the right of disabled people to live in the community among all the stakeholders. They include disabled people, national, regional and local governments, service providers, media and the wider public, the European Union institutions (the European Commission and the European Parliament), the Council of Europe and funding institutions (such as the World Bank and the Council of Europe Development Bank).

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The European Commission and the Council of Europe should facilitate exchange of best practice in developing community-based services between the countries. A pool of experts on de-institutionalisation should be established at the European level in order to provide governments with technical assistance and support the implementation of Article 19 of the CRPD.

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Governments should set up a compulsory quality assurance and monitoring system for all services for disabled people to ensure that the rights of disabled people, as set out in the CRPD, are respected. Institutions and other services for disabled people should be the subject of regular monitoring, involving disabled people and their representative organisations.

Recommendation 12

Governments should close all institutions for disabled children by preventing any new admissions to institutions. Any available resources should be used to establish a range of community-based services for all children with disabilities.

An Overview of Article 19 of the UN Convention on the Rights of Persons with Disabilities

Camilla Parker¹

The United Nations Convention on the Rights of Persons with Disabilities ('the CRPD') came into force on 3rd May 2008. It includes a range of rights such as the promotion of equality and protection from discrimination, the right to privacy, freedom from torture or cruel or degrading treatment, access to justice; participation in political and public life; education and employment.

Importantly, the CRPD is the first international human rights treaty to expressly recognise the right of all disabled people² to live in the community as equal citizens. Article 19 of the CRPD recognises 'the equal rights of all persons with disabilities to live in the community, with choices equal to others'.

This article provides an overview of Article 19 and explains why this is such a crucial right for disabled people, and other individuals and organisations, seeking to promote 'community living'.

Community living and independent living

The term 'community living' (also known as 'independent living') refers to:

'...people with disabilities being able to live in their communities as equal citizens, with the support that they need to participate in everyday life, such as living in their own homes with their families, going to work, going to school and taking part in community activities.'³

The right to community living/independent living has strong connections with the social model of disability which stresses that people who have physical, mental, intellectual or sensory impairments are disabled by the physical and attitudinal barriers within today's society. Those promoting the right to community living seek to address the long-standing and pervasive negative attitudes towards (which often lead to discrimination against) disabled people.

Community Living: a core principle of the CRPD

The emphasis of community living is to ensure that disabled people receive the support that they need so that they can achieve their aspirations and engage in community life.⁴ This approach is fundamental not just to Article 19 but also the CRPD as a whole.

Article 19 (see Box on page 6 for the full text) requires governments to take action to facilitate disabled people's 'full enjoyment' of the right to live in the community and their 'full inclusion and participation in the community'. They must ensure that disabled people:

- Have the opportunity to choose their place of residence and where and with whom to live, on an equal basis with others;
- Are not obliged to live in a particular living arrangement;
- Have access to a range of community support services – 'to support community living and inclusion in the community, and to prevent isolation or segregation from the community';
- Have equal access to community services and facilities for the general population (and these services to be responsive to their needs).

Although Article 19 focuses on the right to 'full inclusion and participation in the community', this is a theme that runs throughout the CRPD. For example:

- Article 3 (General principles) includes 'the freedom to make one's own choices and independence of persons', 'full and effective participation of persons' and 'equality of opportunity';
- Article 9 (Accessibility) requires States to take action to make a range of areas accessible to disabled people (such as the physical environment, public services and information) so that disabled people can 'live independently and participate fully in all aspects of life';
- Article 26 (Habilitation and rehabilitation) seeks to enable disabled people 'to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life'.

Institutionalisation is a violation of Article 19

The continued institutionalisation of disabled people in long stay institutions (often for life), that is common practice in many parts of Europe, represents a serious violation of rights under the CRPD, in particular Article 19.

There have been many reports outlining human rights abuses in institutional settings over the last decade. Many have focused on the situation of disabled people in long stay institutions in Central and Eastern Europe, highlighting a range of substantial human rights abuses such as the involuntary placements subject to no independent review, appalling living conditions, the lack of privacy and the absence of rehabilitative or therapeutic activities.⁵ Human rights abuses in institutional settings are not, however, confined to Central and Eastern Europe. In 2006, an investigation into the care and treatment of people with learning disabilities in the UK found that the residents had been subject to years of abusive practice, with the report concluding that 'institutional abuse was widespread'.⁶

However, improving the conditions within institutions is not the answer. Article 19 makes clear that the unjustified segregation of disabled people in institutions is in itself a human rights violation. The CRPD shows that if disabled people are to truly achieve full and equal enjoyment of their human rights and freedoms, governments must take concrete action to ensure that disabled people can live and participate in the community.

Towards community living

That there is an urgent need for governments to commence work to promote community living is highlighted by the findings of a study published in 2007. 'Deinstitutionalisation and community living – outcomes and costs: report of a European Study' found that across 25 of the European countries included in the study nearly 1.2 million disabled people were living in long stay residential establishments.⁷ It made a series of recommendations aimed at assisting governments shift the provision of care and support from institutional settings to the community, including that governments should ratify the CRPD. The report also recommended that governments should:

'Set out the goal that all disabled people should be included in society and that the help they receive should be based on the principles of respect for all individuals, choice and control over how they live their lives, full participation in society and support to maximise independence.'

Such a goal reflects the core values of the CRPD. The promotion of community living and participation are also policy objectives of both the European Union and the Council of Europe. For example, in 2006 the Council of Europe published its disability action plan which identified independent living as a key goal. The plan states:

'People with disabilities should be able to live as independently as possible, including being able to choose where and how to live. Opportunities for independent living and social inclusion are first and foremost created by living in the community.'⁸

In its recent resolution, 'Access to rights for people with disabilities and their full and active participation in society' the Council of Europe's Parliamentary Assembly stressed:

'...in order to enable the active participation of persons with disabilities in society it is imperative that the right to live in the community be upheld.'⁹

The European Union (EU) was active in supporting the development of the CRPD and is now a signatory. Article 13 of the Treaty of Amsterdam authorising the EU to take action to combat discrimination based on a range of grounds, including disability, has led to the introduction of an EU Strategy on Disability and action plan, which aims to 'develop concrete actions in crucial areas to enhance the integration of people with disabilities'.¹⁰

Furthermore, Article 26 of the European Union's Charter of Fundamental Rights (2000) provides:

'The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.'

Article 4 of the CRPD requires governments 'to take measures to the maximum of their available resources ... with a view to achieving progressively the full realisation of these rights'. While this acknowledges that governments may not be able to achieve compliance with all CRPD rights immediately, they should take concrete steps towards achieving these rights.¹¹ Furthermore, some obligations take effect immediately, such as the guarantee that rights will be exercised without discrimination.¹² Thus, governments should show what steps they are taking to eliminate discrimination against disabled people and promote the social inclusion of disabled people.

Conclusion

The CRPD reflects the vision and principles that organisations such as the European Coalition for Community Living (ECCL) and its network members seek to promote: a society in which disabled people can live as equal citizens. However such a vision cannot be realised if the practice of institutionalisation of disabled people continues. Governments must take action to develop community based services that are responsive to the individual needs of disabled people. This is a vital step towards achieving social inclusion and ensuring respect for the human rights of disabled people.

Endnotes

- 1 Camilla Parker is a Consultant at the Open Society Mental Health Initiative. This paper is based on 'The Right to Community Living and the UN Convention on the Rights of Persons with Disabilities', published in the European Coalition for Community Living Newsletter Issue No. 6, April 2008, p.2
- 2 This paper refers to 'disabled people' rather than 'persons with disabilities'. The UNCRPD provides a broad definition of disability: '...includes those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'.
- 3 ECCL, *Creating Successful Campaigns for Community Living: An advocacy manual for disability organisations and service providers*, November 2008.
- 4 See also a discussion on 'independent living' in Jim Elder-Woodward, 'From the Rolling Quads to Direct Payments', published in the European Coalition for Community Living Newsletter Issue No. 2, November 2006, p.3, http://www.community-living.info/documents/Newsletter_no_2_06.pdf.
- 5 See for example, Amnesty International (2003) *Bulgaria, Far from the Eyes of Society: Systematic Discrimination against People with Mental Disabilities*, London, Amnesty International and Mental Disability Advocacy Center (MDAC) (2003) *Cage Beds, Inhuman and Degrading Treatment in Four Accession Countries*, Budapest, MDAC.
- 6 Commission for Social Care and Inspection and Healthcare Commission, *Joint Investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust*, July 2006.
- 7 Mansell J, Knapp M, Beadle-Brown J and Beecham J (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report*. Canterbury: Tizard Centre, University of Kent, p.25. The study included all 27 European Union Members and Turkey. The relevant information was not available for Austria, Germany and Greece.
- 8 Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006–2015, Recommendation Rec(2006)5.
- 9 Resolution 1642 (2009), paragraph 8.
- 10 Equal opportunities for people with disabilities: A European Action Plan COM (2003) 650 Final.
- 11 This argument is based on the approach taken by the Committee on Economic, Social and Cultural Rights, see the Committee's General Comment 3, 14/12/90.
- 12 See Article 4(2).

Challenges in Realising the Right to Live in the Community

Gerard Quinn & Michael Ashley Stein¹

One of the central motivations for passage of the Convention on the Rights of Persons with Disabilities (CRPD) was the invisibility of persons with disabilities, both from international law and, most importantly, from their communities. Independent living is therefore critically important to the intellectual and political structure of the CRPD and forms a crucible through which to judge what effect the treaty has on the daily lives of persons with disabilities.

When observing European engagement with disability law and policy it becomes clear that having contributed to the CRPD negotiations, in both substance and process, Europe is now benefiting from the framework established by the CRPD. Recent examples include the ruling by the European Committee on Social Rights against Bulgaria on the rights of children with intellectual disabilities in institutions to receive appropriate education,² and the ruling by the Court of Human Rights against Russia for involuntary institutionalisation.³ Although these and other juridical decisions do not specifically reference the CRPD, they are harmonious with its principles. It also is worth noting that pending and future cases (such as the one against Lithuania) explicitly invoke the CRPD as the standard against which European-based social justice for persons with disabilities must be measured.⁴

Nevertheless, despite evidence of promising pre-CRPD progress towards independent living in Europe, many challenges remain. In what follows, we touch on some central issues.

The core challenge is how to affect real change. Advocates often are tempted to use new texts that explicitly refer to disability, whether the CRPD or a domestic parallel, to challenge the outputs of the political process. These can include bad laws, bad policies, bad financial systems, and bad service delivery design, among others. Yet the true added value of the CRPD goes beyond such narrow legalistic approaches that challenge the outcomes, and instead seeks to change the process itself. To create a new dynamic of disability politics in which the default setting moves away from viewing disability simply as cost, towards viewing disability as an issue inherent to the rule of law and justice and human rights. In other words, to transform the entrenched and exclusionary default setting.

In practical terms, one simple and very powerful message of the CRPD is that people with disabilities are subjects capable of controlling their own personal destinies, not objects to be managed by others. This notion is reflected in the desire to restore autonomy to people with disabilities as conceptualised in Article 12 on legal capacity. This right acknowledges that people with disabilities have an innate capacity to decide their destinies for themselves – where to live, who to live with, what education or employment to pursue – and to have those choices respected. And if there is to be an intervention on the part of the State, the primary impulse should be to support a residuum of capacity, and to intervene to support people to make decisions for themselves, with appropriate safeguards.

Article 12 encapsulates the revolution of ideas behind the CRPD by moving persons with disabilities from object to subject. It requires States to break down the walls between ‘us’ and ‘them’, to recognise the equal dignity and worth of persons formerly shunted aside, and in doing so, is meeting with resistance and reservations from certain States. Yet, because legal capacity is at the heart of the CRPD, reservations to Article 12, in our opinion, ought to be declared incompatible with the object and purpose of the CRPD.

Article 19 likewise is the result of the CRPD’s revolution of ideas, and provides the alternative vision and positive counterpoint to the devastating and unacceptable circumstance of institutionalisation. The ‘equal right of all persons with disabilities to live in the community’ is the equal right to fully enjoy one’s human rights and fundamental freedoms, or what political scientist and disability rights advocate Jacobus tenBroek called ‘the right to live in the world’. States parties are tasked with creating the means through which persons with disabilities are able to become integral parts of their societies so that they can flourish through collective activities. This is a direct remedy to the historical treatment of disabled persons through programming that isolated and exploited them, and denied entire segments of society the ability to explore and exercise their talents.

Among the notable things about Article 19 is the necessity of reengineering services. This will not be easy because it will meet with resistance from traditional service providers who fear change. Thus, one of the large challenges that looms ahead for disability rights advocates is to educate those in power about the practicable models to bring about change. (Parenthetically, the same may also be said regarding Article 26 on habilitation and rehabilitation.) This signals a distinct break with prior practices.

Ultimately, the fiercest and most deeply entrenched resistance – whether in Europe or beyond its borders – will likely arise in the context of freeing people from being housed in institutional settings and towards being housed, independently, in their own communities. In this context, recent experience from the United States is illuminating. Many disability rights advocates took the Supreme Court’s 1999 decision in *Olmstead v L.C.* that people with disabilities are entitled to live and to receive treatment in “the most integrated setting” as a great victory.⁵ And in many ways it was. Yet, at the same time the Court made clear that the right is not absolute and must take into account the economic impact of moving individuals to community-based homes. For example, American states can consider

whether deploying the resources necessary for community-based living for some individuals with disabilities will deprive other similar individuals from adequate institutional-based care. Not surprisingly, American states used this rather large loophole to argue against deinstitutionalisation suits; fortunately, the courts have upheld the rights of persons with disabilities.

But there is a lesson to be learned here about the temptation for States to try and resist their duties by citing to the progressive nature of economic and social and cultural rights. Certainly, there is a fluid dimension to the general obligations of States. Not everything will be achieved immediately. Some things are going to take time and greater resource allocation. However, the right to live independently under the CRPD need not genuflect before resource scarcity. The dynamic of progressive realisation is not an excuse for failing to put into place plans that move in the right direction. Nor is it an excuse for avoiding the creation of measurable goals that make States accountable. As the European Committee of Social Rights stated in *International Association of Autisme Europe v France*:

When the achievement of one of the rights in question is exceptionally complex and particularly expensive to resolve, a State Party must take measures that allows it to achieve the objectives of the Charter within a reasonable time, with measurable progress and to an extent consistent with the maximum use of available resources. States Parties must be particularly mindful of the impact that their [allocational] choices will have for groups with heightened vulnerabilities as well as for other persons affected including, especially, their families on whom falls the heaviest burden in the event of institutional shortcomings.⁶

Finally, those measurable goals should be that societies catch up to civilised standards regarding the right to live independently in two or five or even seven years, but not in some unknown and unidentified time frame.

Endnotes

- 1 Professor Gerard Quinn is a Director of the Centre for Disability Law and Policy at the National University of Ireland, Galway. Professor Michael Stein is a Director of the Harvard Law School Project on Disability.
- 2 *Mental Disability Advocacy Center (MDAC) v. Bulgaria*, European Committee on Social Rights, Complaint No. 41/2007 (3 June 2008).
- 3 *Case of Shtukurov v. Russia*, European Court of Human Rights (First Section), Application no. 44009/05 (27 March 2008).
- 4 *Case of D.D. v. Lithuania*, European Court of Human Rights (Second Section), Application no. 13469/06 (pending). The CRPD was featured in Amicus briefs filed,

respectively, by the European National Human Rights Institutions and the Harvard Project on Disability.

5 527 US 581 (1999).

6 Collective Complaint 13, Decision dated 4 November 2003. The Decision is available at: http://www.coe.int/t/dghl/monitoring/socialcharter/Complaints/CC13Merits_en.pdf.

We Want Equal, Not Special Treatment!

Interview with Elena Pečarič, the Chair of YHD
– Association for the Theory and Culture of Handicap, Slovenia

Ratification

To date 50 countries have ratified the UN Convention on the Rights of Persons with Disabilities (the Convention).¹ Slovenia ratified the Convention on 24 April 2008 and was one of the first countries in Europe to do so. The process leading up to the ratification differs from one country to another. While some countries seek to ensure that they can comply with their obligations before ratification, by checking if there will be any obstacles to implementation, for others such debates and reviews only take place after ratification.

Q. What was the process leading to ratification like in Slovenia? Was there any debate or publicity about the Convention? How was your organisation involved in this process?

There was no public debate about the Convention in preparation for the ratification. There was also very little information in the mainstream media. Soon after the ratification, the Convention was presented and discussed at a disability conference organised on the occasion of Slovenian Presidency of the European Union, in May 2008. As for consultation with organisations of disabled people, so far as we are aware, there was none. However, the Office for People with Disabilities at the Ministry of Labour favours older and bigger disability organisations. Smaller organisations like ours have to work very hard to be heard.

In the process of ratification, the Convention was translated into Slovenian, but we were not consulted. Consequently, we are not happy with the result. Our organisation has been working on independent living issues for 12 years now, and we think that concepts such as 'personal assistance' and 'independent living', in their Slovenian translation, are not in line with the independent living philosophy.²

I believe that the main reason why Slovenia ratified the Convention was to make a good impression in front of the international community. I find it surprising that a number of Eastern European countries (such as Croatia, Slovenia and Hungary) ratified the Convention

before Western European countries, many of which are much further ahead in protecting the rights of disabled people. I suspect that some countries ratify the Convention without being fully aware of the responsibility it brings.

One thing we have managed to achieve since ratification is the Government's commitment to pass a Law on Personal Assistance during the time they are in power. Before the parliamentary elections last year, we invited MPs to spend a day working as personal assistants to disabled people, in order to get a better understanding of what personal assistance means to us. We also prepared a draft law on personal assistance and presented it to MPs, the Prime Minister and the President. Our draft proposal suggests the way in which personal assistance can be provided for the people who need it, in order to allow them to live independently in their own homes. Our organisation has been promoting the rights of people with disabilities for a long time before the Convention was adopted, and we will keep doing so in the future. The difference between now and then is that we have an additional tool we can use to demand change.

Implementation

One of the preconditions for the implementation of any international human rights treaty is that individuals know what their rights are, what obligations their Government has towards them and how they can use the Convention to claim their rights.

Q. Is there much awareness of human rights in general in Slovenia? And, more specifically, what is the level of awareness about the Convention among the key stakeholders – disabled people's organisations, service providers, authorities and the general public?

Awareness about the Convention is very poor in Slovenia. Just last week I had a chance to attend a meeting with professionals from the social care sector, university professors and others, and they were not even aware that Slovenia had ratified the Convention. Also, mainstream human rights organisations do very little to raise awareness about the rights of people with disabilities, so it would be important to get them on board.

There is little awareness amongst the public and disabled people about human rights. One of the problems we are facing is that the 'medical model' is still very strong in Slovenia. This is because traditionally, disabled people's entitlement to services and support were dependent on their medical diagnosis and people are used to thinking about disability in this way. This has led to a situation where discussions among disabled people and their organisations are more concerned with specific disability benefits (like free cinema and public transport), than their right to fully and equally participate and to have equal rights in all spheres of society (employment, education, housing, accessibility, etc). We are trying to change this perception and ensure that disabled people are seen as equal citizens, with

the same rights and obligations as other people. This is why cooperation with mainstream human rights organisations is so important – disability rights should be a part of the mainstream human rights agenda and not something delegated to special (disability) departments of public institutions and organisations. There will be no equality until the rights people with disabilities are considered along with all the other citizens of Slovenia, in all the areas of life. We do not need special treatment, but equal treatment.

However, I am a bit sceptical about how soon perceptions will change. Too many people and organisations benefit from keeping disabled people in a situation of dependency. The promotion of independent living and the mainstreaming of disability rights is therefore not seen to be in everyone's interest.

Potential impact of the Convention

It has been only two years since the Convention was opened for signature and the Committee on the Rights of Persons with Disabilities has had its first meeting in February 2009.

Q. The Convention is still in its early days, but it would be interesting to hear what impact you think it will have on the lives of people with disabilities in Slovenia. And more importantly, what do you think needs to be done for the Convention to have an impact in real life?

Disabled people are still not aware of their rights and need to be more determined and ask for more from the relevant authorities. YHD is the only organisation campaigning for the human rights of disabled persons, instead of special rights, which we believe lead to exclusion and segregation. We often have good cooperation with the authorities, but do not speak the same language with other disability organisations. This is a problem, because the public cannot understand why there is a conflict between disability organisations. In addition to larger organisations trying to protect their funding, there is a difference in opinion between organisations on how disabled people should live. For example, we campaign for inclusion of disabled people in the open labour market whereas some organisations promote 'sheltered employment' (environments in which only disabled people work).

As far as the Convention having an impact in real life, I think that nothing will happen by itself. We will need to work very hard to ensure that people with disabilities are able to enjoy all the rights from the Convention. In Slovenia, there is political will to change things, so we need to take advantage of that. As mentioned before, the Government is working on the Law on Personal Assistance. We just need to make sure that our views as disabled people and our experience of having personal assistants are taken into account.

Article 19: Living independently and being included in the community

Article 19 provides for the right of all people with disabilities to live in the community, with choices equal to others. It requires State Parties to take measures to facilitate full enjoyment of this right, by ensuring that people with disabilities have the opportunity to choose where and with whom they live, that they have access to a range of community-based services to support their living and inclusion in the community, and that community services and facilities for the general population are equally accessible to people with disabilities.

Q. How far does Slovenia have to go to implement Article 19? To what extent are people with disabilities in Slovenia:

a) able to choose their living arrangements

We cannot say that disabled people in Slovenia are able to choose where they want to live. Many people live at home with their families, but many young people with severe disabilities live in residential institutions for elderly people. Also, there are now a number of smaller living units, which function in the same way as large institutions.

The problem is that funds are tied into institutions. If a disabled person lives in a long stay residential institution, their living expenses are covered by the State, with these funds being given directly to the institution. Disabled people who choose to live at home or by themselves, lose this financial support. This means that disabled people who want to live independently need to have a source of income or be financially supported by their families. Although there are 'social apartments' (i.e. social housing), disabled people have to compete for places in these apartments, alongside all the other eligible groups, and there are simply not enough places for all who need them.

At YHD, we highlight the fact that supporting people to live in the community can be cheaper than living in an institution. We think that the money that the state is giving to institutions to care for disabled people should go directly to the person, so they can live at home and organise their own support. However, progress in this area is slow.

b) provided with a range of community-based services, such as personal assistance

In Slovenia, personal assistance is still a pilot project and very few individuals are able to benefit from this service. As a part of this project, at YHD, we support 97 people to employ their personal assistants. The situation is more difficult for people with intellectual disabilities, because there is little understanding about how they could benefit from this type of support. People with sight impairments have a right to personal assistance, but at the moment this is only for 10 hours per month!

- c) able to access mainstream services and facilities in their local community

Accessibility of public places and transport is very different from one place to another. In Ljubljana, the situation is much better than in smaller towns and rural areas. We have had legislation on accessibility of buildings and transport for a long time now, but implementation is a problem. For example, although trams in Ljubljana have ramps for wheelchair users, drivers often do not know how to lower them or they are out of order.

Involving disabled people

Organisations of people with disabilities played an important part in the drafting of the Convention, and one of the general obligations of State Parties under the Convention (Article 4) is to closely consult with and actively involve people with disabilities in its implementation.

- Q.** How is the Slovenian Government involving people with disabilities in decision making processes on issues that concern them? How is your organisation involved in implementation of the Convention?

One of the problems we have in Slovenia is that the disability community is organised along the medical lines, i.e. the different types of impairment. This is reinforced by the Law on Organisations of People with Disabilities, which gives formal status only to those organisations that are representative of the majority of people with a certain impairment. That means, for example, that almost all people with cerebral palsy are represented by a single association. This not only severely restricts the establishment of new organisations, it also fails to encourage the development of cross-disability organisations or organisations brought together by a specific interest, philosophy etc. Only groups of disabled people which are recognised under this legislation can participate in decision making processes.

YHD has successfully lobbied for formal status despite not being organised along the medical model, but our work is still made difficult because we do not belong to the main National Association of Organisations of People with Disabilities (we have established our own national organisation!). Our approach is that all organisations of disabled people should have the opportunity to take part in policy making, and there should not be a single group that speaks on behalf of people with very diverse needs and opinions.

National implementation and monitoring

Article 33 of the Convention sets out a framework for a national monitoring mechanism, which requires that State Parties designate one or more “focal points” for the Convention in the Government, but also that they establish one or more independent mechanisms to

promote, protect and monitor implementation of the Convention. People with disabilities and their representative organisations should be fully involved in the monitoring process.

Q. What has the Slovenian Government done to put Article 33 in practice? Have they established a focal point in the Government and, if yes, what Department has taken on this role? What other monitoring mechanisms are in place and how are people with disabilities and their representative organisations involved?

The Directorate for Persons with Disability at the Ministry of Labour, Family and Social Affairs is the focal point for the Convention in the Government. The Director of the Office, Mr. Cveto Uršič, is also a member of the UN Committee on the Rights of Persons with Disabilities, but this is a function which he should perform in his personal capacity, independently of his work in the Government.

I am not aware of any other monitoring mechanisms established by the Government. According to the Directorate for Persons with Disability, the monitoring body for the implementation of the Convention will be the Governmental Council for Persons with Disabilities (governmental body, set up to comment on, and oversee the implementation of disability policy). Information in this area is difficult to find and, surprisingly, we often find out more from abroad than directly from our authorities or other disability organisations in Slovenia.

Other departments that could possibly have a role are the Ombudsman's office and the Office for Equal Opportunities. Until now, this office was not actively involved in disability issues, and has focused primarily on equality between men and women, and other groups.²

Awareness about the Convention

As noted by YHD, there is still some way to go until people with disabilities are recognised as equal citizens, with the same rights and responsibilities. One of the barriers is the low level of awareness about the rights of people with disabilities and the Convention as an international human rights treaty ratified by Slovenia. In the last questions of this interview, we asked YHD for their suggestions on how to bring the Convention closer to disabled people and other stakeholders, and on how to make best use of ECCL's Position Paper on Article 19.

Q. What can be done to improve awareness about the Convention in Slovenia? Is your organisation planning any activities?

We have been promoting the right of disabled people to live independently long before the Convention was adopted, and we will continue doing so. Among our priorities is legislation on personal assistance. There is a lot of good practice in the organisation of personal assistance in Europe, and we are working within the European Network on

Independent Living in order to facilitate exchange of knowledge among countries in our region. Provided we receive the funding, we are planning to organise a conference in the Spring of 2010, where we will discuss how best to implement the right to independent living. We are also planning to agree on some standards for independent living and personal assistance that could be applied in different countries. Cooperation between countries in Europe is very important, and there should be much more exchange of existing expertise than there is at the moment.

YDH is also planning to work more with mainstream human rights organisations in Slovenia. There is a lot we can learn from them and such partnerships could be very useful in promoting and monitoring the implementation of the Convention. Also important is that we involve legal professionals in our work. After all, the Convention is a piece of legislation, and we need legal knowledge to explain to decision makers what obligations they have and what steps they need to take to implement the Convention.

Advocacy Manual on Campaigning for Community Living

In December 2008 the European Coalition for Community Living launched a manual on campaigning for community living, which can be used as a tool by organisations working towards implementation of the Convention. This Position Paper seeks to provide further clarity about the meaning of Article 19 and suggests what needs to be done to put it in practice.

Q. How can we make ECCL's Position Paper useful to organisations campaigning for community living in Slovenia and other countries in Central and Eastern Europe?

We need to promote our position on Article 19 of the Convention at European level. It is a disgrace that the European Union has a tightly regulated economy, for example, but does not insist on respect of fundamental human rights. As citizens of the European Union, we deserve more. And we think the EU should play a much bigger role in ensuring that the Member States respect the rights of their citizens. If the EU is striving towards progress in other areas, why not strive towards progress in equalisation of opportunities and social inclusion of people with disabilities and other marginalised groups? Commitments alone do not mean anything. The EU must find mechanisms, be it legislation or something else, to ensure that human rights of all citizens are respected in practice. For the moment there are a lot of good projects, studies etc., but progress is very slow.

With the European Network on Independent Living we have started a signature campaign for the right of disabled people to personal assistance. By signing our manifesto at www.enil.eu, people can voice their support for Article 19 of the Convention and encourage Governments to ensure that disabled people can live independently with the right kind of support.

BOX

YHD – Association for the Theory and Culture of Handicap is a Slovenian organisation led by people with disabilities. Established in 1996, it has a very diverse membership, brought together by a common understanding of independent living. YHD members oppose the patronising practices of charity and pity, and do not agree with the rhetoric of living healthy lives through institutional care and segregation of disabled people. Among YHD's main activities is supporting disabled people to live independently by employing personal assistants and advocating for the right of disabled people to personal assistance. YHD's objective is for the right to independent living to become a part of Slovenia's legal framework, thereby ensuring that each individual receives funding to employ their personal assistants. More information about YHD is available at: www.yhd-drustvo.si.

Endnotes

- 1 This interview took place in March 2009.
- 2 'Personal assistance' is translated as *osebna pomoč* (personal help) and 'independent living' as *samostojno življenje* (autonomous living), instead of *neodvisno življenje* (independent living).
- 3 In the Second Disability High Level Group Report on Implementation of the UN Convention on the Rights of Persons with Disabilities, published in June 2009, the following authorities are listed as responsible for implementation of the Convention in Slovenia: the Ministry of Labour, Family and Social Affairs, the Governmental Council for Persons with Disabilities, the relevant Ministries and the Slovenian National Council of Disabled People's Organisations. The Directorate for Persons with Disabilities at the Ministry of Labour, Family and Social Affairs is listed as the Focal Point.

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About the European Coalition for Community Living

The European Coalition for Community Living (ECCL) is a Europe-wide initiative working towards the social inclusion of people with disabilities by promoting the provision of comprehensive, quality community-based services as an alternative to institutionalisation.

ECCL's vision is of a society in which people with disabilities live as equal citizens, with full respect for their human rights. They must have real choices regarding where and with whom to live, choices in their daily lives and real opportunities to be independent and to actively participate in their communities.

Membership in ECCL is open to all organisations, individuals and institutions committed to the promotion of the right of people with disabilities to be included in society. To join ECCL, please visit **www.community-living.info** or write to the ECCL Coordinator at **coordinator@community-living.info**.

Since January 2008, ECCL has been based at the European Network on Independent Living (ENIL).

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All people with disabilities
have the right to live
in the community, with
choices equal to others.

Article 19 of the UN Convention
on the Rights of Persons with Disabilities

**European Coalition for
Community Living**

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