

Focus on the Right of Children with Disabilities to Live in the Community



ECCL
European Coalition
for Community Living

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Introduction

Ines Bulić

Coordinator of the European Coalition for Community Living

This Focus Report on the Right of Disabled Children to Live in the Community is a part of the ongoing advocacy efforts of the European Coalition for Community Living (ECCL). As a network of organisations and individuals in twenty two countries, ECCL seeks to ensure that across Europe, *all* disabled people have access to comprehensive, quality community-based services.

ECCL decided to focus on the right of children with disabilities to live in the community in order to highlight the appalling fact that there are still thousands of disabled children in Europe who spend their childhood, if not their lives, segregated in long-stay, residential institutions. The UN Committee on the Rights of the Child, which oversees the implementation of the Convention on the Rights of the Child, has on numerous occasions raised its concerns about institutionalisation of children with disabilities. In its General Comment on the rights of children with disabilities of September 2006, the Committee has urged the State parties to the Convention 'to set up programmes for de-institutionalisation of children with disabilities, replacing them with their families, extended families or foster care system.'¹

ECCL's Position on the Right of Disabled Children to Live in the Community calls on the governments, funding agencies and other stakeholders to respect the rights of disabled children. It gives recommendations on how to ensure a successful transition from institutional to community-based care and stresses the crucial importance of providing support to the families of disabled children and ensuring that all children with disabilities have access to education.

The article 'Lack of inclusive education leads to institutionalisation: Perspective of a parent' points to the link between 'special education' of children with disabilities and institutionalisation. Recommendations on how to support the families of disabled children, in order to ensure that children with disabilities can grow up in a family environment, are included in the preceding article.

The article on the initiatives of the Council of Europe highlights its Action Plan to promote the rights and full participation in society of people with disabilities in Europe 2006–2015 and reports on the results of the Ad Hoc Group of Experts on Community Living (Deinstitutionalisation) of children with disabilities. This article is followed by an analysis of the potential impact of the draft UN Convention on the Rights of Persons with Disabilities on the protection and promotion of the rights of disabled children.

¹ See Committee on the Rights of the Child, General Comment No.9 on The rights of children with disabilities, 29 September 2006, available at: www.ohchr.org/english/bodies/crc/

Finally, we bring you a story of a teenage girl Petra from Croatia. She now lives with her foster family, largely due to the efforts of one of our member organisations, the Association for Promoting Inclusion. Despite the existing regional and international human rights standards protecting the rights of children with disabilities, many are still segregated in institutions. Petra is one of the lucky children who has been able to leave the institution in which she was placed and continue her life in a loving, family environment.

ECCL welcomes the fact that this year's European Commission conference on the occasion of the European Day of People with Disabilities is devoted to young people. We hope that such initiatives will help improve the situation of children and young people with disabilities in Europe and most importantly, give them the opportunity to be involved in the process of introducing the necessary changes.

We invite you to join the European Coalition for Community Living and strengthen our efforts in advocating for the right of disabled people to live in the community, not segregated in institutions. You will find more information about our activities in 2006 in this report, as well as on our website www.community-living.info.

Thank you for your support.

ECCL Position on the Right of Disabled Children to Live in the Community

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.

The European Coalition for Community Living advocates for and monitors progress towards de-institutionalisation in Europe, campaigns for, and provides information on, the development of comprehensive, quality community-based services and de-institutionalisation¹.

Introduction

The European Coalition for Community Living believes that all children² have the right to live in the community and be included in society. However, this is far from reality for many children with disabilities. Across Europe, thousands of children with disabilities are placed in large residential institutions which are often situated in remote areas so that residents have little or no contact with the outside world. Thus these children are excluded from community life and separated from their families. It is unacceptable to place any child in such segregated environments. ECCL therefore considers that urgent action is required at all levels of government to ensure that appropriate quality community-based services and family supports are available as alternatives to these institutions.

¹ We use the term 'de-institutionalisation' to mean the replacement of institutions for people with disabilities with comprehensive, quality community-based services.

² We use the terms 'children' and 'child' to cover individuals who are under the age of 18. This reflects Article 1 of the UN Convention on the Rights of the Child (1989).

Key steps for the transition from institutional care to community-based services

1. The most important principle is not to perpetuate the existing institutional system. **Governments must "close the front doors" of all institutions** for children by preventing any new admissions to institutions. The European Union and the Council of Europe should recommend to their Member States to call a halt to any new admissions of children to institutions and to use any available resources to establish appropriate community-based services for all newborn children with disabilities in their countries. This fundamental decision will create an investment in new forms of services and avoid future costs of institutionalisation and re-integration of these children.
2. ECCL strongly urges the European Union and other potential **funding agencies to focus on the provision of inclusive community-based services** for disabled children. This needs to include family support services.
3. Investments in and support to existing institutions for disabled children must be limited to targeted interventions – to health and life safety – in the framework of a plan to close the institution within an agreed time frame. The time frame for closure of an institution must be considered as inseparable from the development of the community-based alternative services. **Unconditional support to existing institutions is not acceptable.**

The right to live in the community: a fundamental right for all disabled children

Article 23 of the UN Convention on the Rights of the Child makes clear that disabled children, regardless of the type or degree of their disabilities, have the right to live in the community. It requires States to:

'...recognise that a mentally or physically disabled child should enjoy a full and decent life, in conditions that ensure dignity, promote self-reliance and facilitate the child's active participation in the community'

The draft UN Convention on the Rights of Persons with Disabilities highlights the importance of ensuring that children with disabilities are able to exercise their human rights and fundamental freedoms on an equal basis with other children (Article 7). It also recognises 'the equal right of all persons with disabilities to live in the community' (Article 19).

The negative effects of institutionalisation on disabled children

ECCL defines an 'institution' as follows:

'...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.'

ECCL considers that institutions have no place in modern European societies. **We strongly oppose the notion that some children will always need institutional care.** 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 they need can be provided in the family home, foster care or small community homes.

If governments introduce a policy of maintaining institutions for those children considered to have 'severe and profound' disabilities, they will create environments which do little more than "warehouse" such children. Children living in these institutions do not receive an acceptable level of care, support or education. Often they are abandoned because their parents are encouraged to forget about their existence. Those families who do want to maintain contact find it difficult to do so because many institutions are situated in rural areas with limited access by public transport. The children in such institutions have little or no opportunity to experience contact, let alone friendship with non-disabled peers. Nor are they enabled to make decisions for themselves, which is crucial to the development of every child.

Numerous studies show that the **institutionalisation** of disabled children leads to **serious delays and impairments** in their personal development³. Thus those children who have been institutionalised will have more difficulties in participating in society than their peers who have received the support that they need while living in the community with either natural or foster families.

People with disabilities face widespread stigma and discrimination. The segregation of disabled people compounds the ignorance, fear and prejudice of non-disabled people towards disabled people. Only by ending the institutionalisation of all disabled children and adults and promoting their social inclusion will it be possible to overcome such negative attitudes. By enabling disabled and non-disabled children to play together, go to school together and grow up together, they will learn and accept that it is normal to be different.

For these reasons, ECCL considers that action must be taken to close all institutions for disabled children in Europe and develop an appropriate range of alternative community-based services as alternatives to institutional care. Any investment in institutional care for disabled children will perpetuate the situation and hinder the development of quality community-based services for them. Thus policies and resources must be focused on the planning and provision of community-based services which are responsive to the needs of disabled children and adults.

4. Existing institutions and all other services for disabled children must be subject to regular monitoring, involving appropriate representative NGOs of disabled people and their families. Governments should be encouraged to establish a **compulsory quality assurance and monitoring system** for all services for disabled people. Such a system must be financed or co-financed by governments. The European Union and the Council of Europe should include the issue of quality of services in regular monitoring reports and publish comparable data from all Member States, which addresses at a minimum the following basic indicators:
 - Total number of disabled children;
 - Number of disabled children in institutional care;
 - Number of disabled children receiving services in the community;
 - Number of disabled children receiving education;
 - Death rate of children in residential services and institutions financed by the State.
5. Finally, all European countries should **mainstream support and policies for disabled children** into all general children, educational, family and health policies. The European Commission and the Council of Europe should lead the way by explicitly including disabled children in all documents and statements regarding these policy areas.

³ See, for example, UNICEF/Innocenti Research Centre Report *Children and Disability in Transition in CEE/CIS and Baltic States*, 2005, page 14, available at: <http://www.unicef.org/ceecis/Disability-eng.pdf>.

Making community living possible: supporting disabled children and their families

Provision of community-based services

A range of community-based support for disabled children and their families will need to be developed, such as early intervention services⁴, health and social care and assistance to enable disabled children to be included in mainstream education. The **right of all children to appropriate support and health care** must be emphasised. It is not acceptable that disabled children have to leave their families in order to receive the care and support they need. States must provide early intervention services to minimise the disabling effects of an impairment and to further the inclusion of disabled children in society.

Supporting families

Families play a fundamental role in ensuring and supporting the development of disabled children. A crucial element of the development of all children (whether disabled or non-disabled) is to be part of family life and to interact with other children⁵. It is also crucial for the cohesion of society that all citizens have the opportunity to meet each other and to live in an inclusive environment. Families provide a significant level of support and care for their disabled children as well as enabling them to participate in community life. Thus it is important that governments promote policies that support family life and in particular provide assistance to families with disabled children (for example promoting employment practices which enable parents to combine work with providing care to their disabled child).

Education

Both the European Convention on Human Rights⁶ and the UN Convention on the Rights of the Child⁷ provide for the **right to education. This applies to all children. Children with severe or profound disabilities are not exempt.** In practice, however, the majority of European States are not providing adequate, or in some cases any, education to this vulnerable group of citizens.

The Position Paper on the Right of Disabled Children to Live in the Community was adopted by the ECCL Management Committee, in consultation with the membership, in October 2006.

⁴ The term 'early intervention services' covers a wide range of multi-disciplinary services provided to infants and young children and their families that aim to maximise the child's development and inclusion.

⁵ The right not to be separated from one's own parents, unless 'such separation is necessary for the best interests of the child' is enshrined in Article 9 of the UN Convention on the Rights of the Child.

⁶ European Convention for the Protection of Human Rights and Fundamental Freedoms, Protocol 1, Article 2.

⁷ UN Convention on the Rights of the Child, Article 28.

Supporting Families of Disabled Children

From Institutionalisation to Positive Community Life in the Enlarged European Union

Malgorzata Kmita¹

10–15% of the total European population are people with disabilities². In the United Kingdom, a child is diagnosed with a severe disability every twenty-five minutes³.

Until relatively recent times, it was common practice in Europe for disabled children to be moved from the family home at a very early age, often at birth, to face an uncertain future in a large institution, either state-run or organised by charitable bodies. In these institutions therapeutic intervention and support are minimal or, at times, virtually non-existent. The children who are placed in such institutions are in effect contained. Ultimately they are isolated from their birth family and separated from the wider community.

Children with disabilities can now be regarded as having increased opportunities for equal access to the rights articulated in the United Nations Convention on the Rights of the Child. Respect for difference and acceptance of disability as part of human diversity can be regarded as being rooted and nurtured in the family environment in which parents, siblings, the extended family and carers work together to promote approaches to care for the disabled based upon principles of dignity, equality and non-discrimination. In such an environment, parents are the key agents and active partners in the process of emotional, social, intellectual and spiritual development of their children.

In the context of a developing and enlarging European Union, the care for disabled children and young people can be considered in terms of the extent to which the family environment has access to, and connections with, support systems, networks, developments and initiatives – locally, regionally, nationally and Europe-wide. It can be regarded as being the responsibility of all European Union Member States to establish coherent, integrated and well-resourced family support structures and strategies, which aim to facilitate the strengthening, stabilising and normalising of the lives of children with disabilities.

¹ Malgorzata Kmita is the President of Mental Health Europe.

² 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, 5 April 2006.

³ For more statistics, see the website of Contact a Family, available at: www.cafamily.org.uk.

It is therefore essential for all European Union Member States to close the large institutions, which all too often have been the expression and legacy of anachronistic political and economic ideologies and policies, and the antithesis of care. Disabled children should never again have to experience the levels of social oppression, emotional abuse, discrimination, stigma and exclusion which often characterise such institutions.

While it is the right of every disabled child and young person to have the opportunity to be cared for in their family environment, one should not be tempted to romantically idealise the concept of care in the community. Meaningful community care requires money, time, energy and a range of practical structures and support systems to be in place, in order for disabled children to thrive and fulfil their potential.

Practice has shown that, in reality, caring for children and young people in the community is a very demanding and stressful process. Families often face real uncertainty and insecurity about the future of the young person in the event of parental illness or death. A significant feature of care in the community, therefore, should be the development of family support strategies which would aim to offer a broad repertoire of services to help families respond to the very challenging circumstances they face, often on a daily basis. Parents and carers, therefore, need to be provided with the resources to act in partnership with the range of social services, both statutory and voluntary, together with education and training providers, leisure services, advocacy agents and local planners.

In addition, parents may also require support and training in order to become familiar with the best techniques and strategies for supporting their child on a daily basis. A practical expression of such help could be, for example, the opportunity for every parent to have access to a help line which would guide them through the challenges they face, such as the Contact a Family initiative in the United Kingdom⁴.

Such an initiative could be complemented by, for example, day centres, alternative and complementary therapies, respite care, short stay centres and a pool of well trained and vetted community volunteers. In addition, employment law in the European Union should aim to strengthen opportunities for parents and carers of disabled children in terms of being provided with flexible working arrangements and patterns of working which facilitate a work-life balance.

Although some parts of the European Union still adopt a centralised institutional approach to the care of disabled children and young people, there are examples of good practice in providing care and support in family settings. Research could be undertaken to explore the efficacy of these community care initiatives and the findings disseminated widely in order to learn of their strengths and weaknesses, so that informed policy decisions can be made in the future.

Some of the existing projects and services regarded as models of good practice include the following elements:

- (i) Direct payments to parents of disabled children to cover the costs of daily living, care and support, day car costs, short term breaks and live-in carers.
- (ii) Disabled facilities grants, to improve home living such as installing a lift or an extra toilet.
- (iii) Care co-ordination and key working so that parents have a single point of contact in order to, for example, access information, review assessments, involve advocacy services or receive the services of a therapist.

⁴ For more information, see the website of Contact a Family, at: www.cafamily.org.uk/helpline.html.

- (iv) Short term breaks for children to enable parents to regain strength, cope better with stress and prevent burnout and breakdowns.
- (v) Access to advocacy services for carers, parents and children and young people in order to ensure understanding of rights and responsibilities and to facilitate delivery of services characterised by the principles of empowerment and justice.
- (vi) All services working together on the basis of harmonised assessments which are reviewed and monitored regularly to enable children and their families to work towards achieving their potential, personally and professionally.

Central to coordinated approaches to care for disabled children and young people in the community, therefore, are early intervention and assessment which are locally based. As the cost of raising a disabled child is three times that of a non-disabled child⁵, such local care services need to be delivered in tandem with strategies, both from national and local governments, which respond practically to the effects of poverty and deprivation.

The scale of the challenges facing an enlarged European Union, therefore, is significant. Closure of the old institutions has to go hand in hand with new, workable, accountable, community based and family-friendly approaches to care for disabled children and young people, which provide opportunities for children, parents and carers to access the opportunities which the emerging Europe brings. The new, enlarged European Union will, inevitably, require a reappraisal of its past and a focused vision for its future. There is the opportunity in this emerging future for development of policies and strategies which will allow the disabled children of Europe to have universal access to high quality community based care programmes which prevent them from being marginalised, excluded and forgotten.

Children are the future of Europe. Disabled children and young people have every right as citizens of the emerging new European Union to be recognised and valued participants in this future. There exists at this moment in history the opportunity, indeed, the privilege, for us to be agents of change which sees institutional care being consigned to the past and approaches to care for the disabled being commensurate with the emerging vision of the twenty first century.

⁵ New Philanthropy Capital, *Ordinary Lives: Disabled Children and their Families*, 2005, page 1.



The Lack of Inclusive Education Leads to Institutionalisation

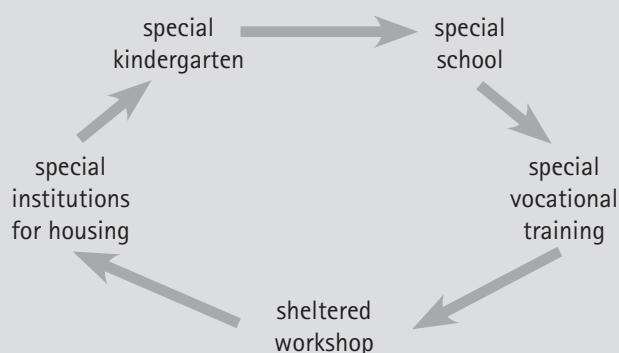
The Perspective of a Parent

Ingrid Körner¹

The right to education is indisputable and universal. It is enshrined in Article 26 of the Universal Declaration of Human Rights, Article 28 of the UN Convention on the Rights of the Child and other international and European human rights instruments.

However, in many European countries, access to education is denied to disabled children living in long stay residential institutions. This is because governments often consider children with disabilities as 'uneducable', in other words not worthy of receiving education because of their disability. This situation must change.

Figure 1: The system of special education can be described as a vicious cycle, from which it is very difficult to escape.



It has been clear for a long time that every child is able to learn, irrespective of the severity of his or her disability. Still, there is a question about what type of education is in the best interest of a child with disabilities –special school or an inclusive school?

After many years during which children with disabilities attended special schools, segregated from their non-disabled peers, a strong movement has emerged in favour of inclusive schools. Disabled adults, who describe themselves as special school survivors, are also among those demanding an end to segregated education, with the slogan "don't special me".

Inclusive education, where children with disabilities attend school together with their non-disabled peers

and receive appropriate support, is now recognised as a human right. We now know that there is no reason to educate children separately on account of their disability.

As parents of children with disabilities, what we experience in our families is that children with and without disabilities belong together in families and in schools. Generally speaking, parents do not want their disabled child to be sent away from the family and home to receive an education. Parents know that by being enrolled in a special school, their disabled child will be labelled and will therefore be devalued and socially excluded.

Another issue in favour of inclusive education is the fact that children who have attended special schools have difficulties in developing relationships with their non disabled peers and are at a disadvantage in preparing for life in the mainstream community. Disabled children are best prepared for life in society when they stay in the family, the kindergarten and the school, together with their non disabled peers.

We must understand that people with disabilities of any age are ready and able to follow the same principle as non disabled people – **learning by doing!** For this reason, it is important that we demand inclusive education for all children with disabilities.

¹ Ingrid Körner is the President of Inclusion Europe.

Council of Europe actions to promote community living (de-institutionalisation) of children with disabilities¹

Council of Europe Disability Action Plan 2006–2015

On 5 April 2006 the Committee of Ministers adopted the recommendation Rec(2006)5 on the Council of Europe's "Action Plan to promote the rights and full participation in society of people with disabilities in Europe 2006–2015". The Recommendation is addressed to all 46 member states of the Council of Europe. The Council of Europe Disability Action Plan 2006–2015 has a broad scope, encompassing all key areas of the life of people with disabilities. These key areas are duly reflected in 15 action lines which set out key objectives and specific actions to be implemented by member states: from participation in political and public life to education, employment, vocational guidance and training; from community living to rehabilitation, social and legal protection, etc. It comprises recommendations to take specific actions at national level, and also stresses the needs of some specific vulnerable groups of people with disabilities – those who may face specific barriers or two-fold discrimination. These specific groups of people with disabilities, in particular, children with disabilities, require a horizontal response to ensure their inclusion in society. When speaking about children with disabilities, the Disability action Plan makes a clear link with the United Nations Convention on the Rights of the Child.

Children with disabilities

The Convention on the Rights of the Child is based on four fundamental principles – the child's right not be discriminated against; the best interests of the child to be considered in all decisions; the child's right to life and development; and the right to express its opinion. Boys and girls with disabilities also have the right to access these same rights, member states need to build knowledge about their needs to inform planning, decisions and practices across a wide spectrum of policy areas. The Council of Europe Disability Action Plan 2006–2015 calls for the attention of responsible authorities to carefully assess the needs of children with disabilities and their families with a view to providing measures of support which enable children to grow up with their families, to be included in the community and local children's life and activities. Children with disabilities need to receive education to enrich their lives and enable them to reach their maximum potential. It is important that policy makers take into account the needs of children with disabilities and their families when designing disability policies and mainstream policies for children and families.

¹ This article was contributed by the Integration of People with Disabilities Unit at the Council of Europe. For more information, please go to: http://www.coe.int/t/e/social_cohesion/soc-sp/.

Box 1.
Specific Actions by member states under Action Line 8 on Community Living

- i. To ensure a co-ordinated approach in the provision of community-based quality support services to enable people with disabilities to live in their communities and enhance their quality of life;
- ii. to develop and promote housing policies which enable people with disabilities to live in suitable housing in their local community;
- iii. to support formal and informal help, making it possible for people with disabilities to live at home;
- iv. to recognise the status of carers, by providing them with support and relevant training;
- v. to have the needs of families as providers of informal care thoroughly assessed, especially those with children with disabilities or caring for persons in need of a high level of support, with a view to providing information, training and assistance, including psychological support, to enable life within the family, paying particular attention to the reconciliation of private and professional life and to gender equality;
- vi. to ensure community-based quality service provision and alternative housing models, which enable a move from institution-based care to community living;

Another principle promoted by the Disability Action Plan is the need to consult people with disabilities, including children and young people, when designing policies for them. The voices of young people with disabilities should be heard in all matters which concern them. In accordance with the European Charter on the participation of young people in local and regional life, the active participation of young people in decisions and actions at local and regional level is essential for building more democratic, inclusive and prosperous societies.

Community living

The Council of Europe Disability Action Plan 2006–2015 addresses the issue of community living as one of its key action lines. This action line focuses on enabling people with disabilities to live as independently as possible, empowering them to make choices on how and where they live. This requires strategic policies which support the move from institutional care to community-based settings ranging from independent living arrangements to small group homes. As stressed in the Action Plan, such policies should be flexible, covering programmes which enable persons with disabilities to live with their families and recognising the specific needs of individuals with disabilities requiring a high level of support.

In general, a family's day-to-day life differs considerably depending whether or not it has a child with a disability: guidance and care, for instance, take up a great deal of time, visits to therapists, doctors, etc., are necessary, the child needs supervision in recreational activities and assistance with the practical aspects of daily living, etc. It is important that parents of children with disabilities can have access to suitable training enabling them to acquire the requisite proficiencies to lead a life as close as possible to normal with their disabled child.

Member states are recommended to take some specific steps towards de-institutionalisation of people with disabilities, including children (see Box 1).

Relation to the UN draft Disability Convention

The Council of Europe Disability Action Plan 2006–2015 was officially launched in St Petersburg on the 21st of September 2006. Launching the Action Plan shortly after the United Nations ad hoc Committee had adopted the draft Disability Convention was a timely initiative. The Council of Europe Disability Action Plan can play a vital part in the implementation of the UN Disability Convention in the European Region: it could become a European regional implementation tool, an operational

instrument to help member states in meeting their commitments in relation to the UN instrument.

Specific policy recommendations on the de-institutionalisation of children with disabilities

The Council of Europe Ad Hoc Group of Experts on Community Living (Deinstitutionalisation) of children with disabilities (P-RR-CLCD) was set up with the view to providing an overview of the developments in member states concerning the de-institutionalisation of children with disabilities. As a follow-up to the European Convention on the exercise of children's rights (ETS No. 160) and as stated in the Council of Europe Committee of Ministers Recommendation Rec (2005)5 on the Rights of Children Living in Residential Institutions, adopted in April 2005, as well as in the European Convention on Contact concerning children (ETS No 192), the Recommendation No R (98)8 On Children's Participation in Family and Social Life, the Council of Europe clearly states its position that *all* children have rights and that *disabled* children have the *same* rights as other children even though they may need different kinds of assistance in order to exercise these freely. Most importantly they have the right to live in their own families and in their own communities where they should be able to access education, health care and vocational training on the same basis as their peers. Institutional provision therefore creates an environment within which disabled children's rights are routinely abused. This lies at the heart of the international commitment to change.

The Council of Europe Ad Hoc Group of Experts on Community Living (Deinstitutionalisation) of children with disabilities (P-RR-CLCD) has addressed these issues and came to some conclusions, which will serve as a basis for the future Council of Europe policy development work in the field of de-institutionalisation of children with disabilities. Amongst them are the following recommendations:

- all disabled children should live with their own family unless there are exceptional circumstances which cut across this: a timetable should therefore be drawn up to phase out new institutional placements and replace these forms of care with a comprehensive network of community provision;
- adopt a coherent and comprehensive strategic approach, defining the distinct responsibilities of national, regional and local governments. A cooperative framework involving all stakeholders should be developed to enable a network of service provision that meets the needs of disabled children alongside other children in their local communities;

- vii. to ensure that individuals can make informed choices with the assistance, when appropriate, of a skilled advocacy service;
- viii. to promote schemes which will allow disabled people to employ personal assistants of their choice;
- ix. to provide complementary services and other facilities, for example day centres, short-stay centres or self-expression groups, offering suitable forms of therapy, to give people with disabilities and their families periods of support and respite;
- x. to provide people with disabilities, in particular those in need of a high level of support, with tailored support provision, including advocacy, in order to reduce any risk of social exclusion;
- xi. to implement the relevant provisions included in Recommendation No. R (96) 5 of the Committee of Ministers to member states on reconciling work and family life.

- this cooperative approach should take into account the following guidelines:
 - a clear legislative framework and timetable for change
 - measures to uphold the interests of disabled children across all relevant policy domains
 - ensuring coordination and quality in service provision
 - mechanisms to include disabled children and their families as stakeholders in the process of service development
 - set aside funds for research, monitoring and evaluation
- make sure that a reformed system of assessment and admissions is put in place in order to re-orientate families towards community based provision and support;
- ensure that services for disabled children are provided primarily in mainstream settings and "sector responsibility" is viewed as the norm and not the exception. Agencies serving *all* children should be helped to build their competence and capacity so that they can meet the needs of children with disabilities on an equitable basis;
- adopt principles of integration and universal design in relation to all public facilities designed for children and all publicly funded housing and neighborhood projects;
- actively manage the transition from institutional to community services, anticipating resistance to change and acting to challenge prejudices and remove barriers.

Introducing change requires serious efforts and investment of time and resources. Certain caution in introducing change is needed as well. As stated by the Council of Europe Ad Hoc Group of Experts on Community Living (Deinstitutionalisation) of children with disabilities (P-RR-CLCD), change on this scale is bound to provoke concern amongst stakeholders, whether families and/or paid workers. Parents may fear that new, more flexible, services will not be reliable or sufficient to meet their needs. Some families may not be able to support a child returning home from an institutional placement. Paid workers may fear that they will lose their jobs or workers in mainstream services may have concerns that they will face unfamiliar situations that they have not been equipped to deal with. Negotiations around these perceptions and concerns should be carried out with sensitivity and patience. For example, career planning and comprehensive training programmes should be built into the process of change with regard to social workers. Transition planning is essential if governments are to succeed in creating an environment within which disabled children's fundamental rights can be assured.



Disabled Children, Community Living and the Draft Convention on the Rights of Persons with Disabilities

Camilla Parker¹

Introduction

On 25th August 2006 the text of the draft Convention on the Rights of Persons with Disabilities ('the draft Convention') was agreed by the Ad Hoc Committee. This Committee had been established by United Nations (UN) in 2001 to consider proposals for a 'Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities'². Once it has been formally adopted by UN General Assembly (expected later this year) the draft Convention will be open for ratification by States and will come into force after it has been ratified by twenty States.

This paper explains how the draft Convention relates to disabled children and its particular importance to the thousands of disabled children who are segregated in long stay institutions.

Purpose and overview of the draft Convention

The draft Convention builds upon existing human rights instruments, including the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of the Child. Its purpose is:

'...to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.'

The draft Convention covers a wide range of issues such as the promotion of equality and protection from discrimination, measures to generate more positive attitudes towards disabled people, freedom from torture or cruel or inhuman treatment or punishment, the right to liberty, the right to privacy and the right to an adequate standard of living.

The rights of disabled children are promoted throughout the draft Convention. For example, the Preamble to the draft Convention recognises that disabled children should be able to exercise their human rights on an equal basis with other children and makes clear that such rights should be considered alongside States' obligations under the Convention on the Rights of the Child. Furthermore, while one of the draft Convention's general principles is:

'Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.'

Article 4 of the draft Convention emphasises the importance of States taking measures to eliminate discrimination against disabled people and involving disabled people (including children with disabilities), through their representative organisations, in the development of legislation, policies and programmes affecting them.

Article 7 provides a specific right for disabled children, requiring States to take:

'...all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.'

In all matters, the best interest of the disabled child shall be a primary consideration. Furthermore, the importance of listening to the views of the child is emphasised. Article 7(3) requires states to ensure that all children with disabilities have the right to express themselves freely on all matters affecting them, that their views are given due

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² General Assembly resolution 56/168 of 19 December 2001.

weight in accordance with their age and maturity, on an equal basis with other children, and that they are provided with disability and age appropriate assistance to realise that right.

Institutionalisation: the fate of many disabled children

UNICEF estimates that across the 27 countries of Central and Eastern Europe and the Commonwealth of Independent States, at least 317,000 children with disabilities live in institutions, 'often for life'³. Recent reports have highlighted the poor quality of life in institutions across Europe⁴ and, in some cases, the severe human rights abuses faced by those incarcerated there⁵. In many cases children in institutions receive little or no education⁶. UNICEF stresses the serious negative consequences for children placed in institutions: it is deleterious to their happiness and their development (for example they can suffer from emotional and psychological disturbances, learning disabilities and physical health problems). The UNICEF report also found that many disabled children, especially those with intellectual disabilities were excluded from education.

Challenging institutionalisation: promoting community living for disabled children

The draft Convention makes clear that measures must be taken to address the institutionalisation of disabled children. One of the most significant articles in the draft Convention is Article 19 which recognises the equal right of all disabled people to live in the community, with choices equal to others, and requires States to:

'...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.'

This right is supported by many of the other rights in the draft Convention. For example States are required to:

- Take measures to enable disabled people to live independently and participate fully in all aspects of life, such as ensure that disabled people have equal access to facilities and services provided to the public (Article 9);
- Provide early and comprehensive information, services and support to children with disabilities and their families to prevent their exclusion, neglect and abandonment, so that they can realise their rights to family life (Article 23(3));
- Ensure that disabled children are not separated from their parents against their will, except when competent authorities subject to judicial review determine in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child (Article 23(4));
- (Where the immediate family is unable to care for a child) take every effort to provide alternative care within the wider family, and failing that, within the community in a family setting (Article 23(5));
- Ensure an inclusive educational system at all levels and life long-learning (Article 24);
- Take all appropriate measures to ensure access for disabled people to health services, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities (Article 25);
- Take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life (Article 26).

Conclusion

Although not yet in force, the rights set out in the draft Convention have gained widespread consensus and can guide current work on developing policies and legislation concerning disabled people. If used to underpin policies to promote and develop appropriate community based services as alternatives to institutional care, the draft Convention will have the potential to make a significant difference to the lives of disabled children, in particular those disabled children currently placed in long stay institutions.

³ UNICEF Innocenti Centre, *Innocenti Insight, Children and Disability in Transition in CEE/CIS and Baltic States*, 2005, available at: <http://www.unicef.org/ceecis/Disability-eng.pdf>.

⁴ *Included in Society: Results and Recommendations of the European Research Initiative on Community-based Residential Alternatives for Disabled People*, October 2004, available at: www.community-living.info.

⁵ See, for example, Amnesty International Bulgaria, *Far from the eyes of society: Systematic discrimination against people with mental disabilities*, Amnesty International, 2003.

⁶ See for example, *Access to Education and Employment for People with Intellectual Disabilities*, Open Society Mental Health Initiative, October 2006, available at: <http://www.osmhi.org/index.php?page=202&news=245&pages=&tarchive=&tpastevent=>

Petra's Story

Ljiljana Pap¹

Petra was born in 1990 in Zagreb. As a three month old baby she was separated from her family due to the lack of basic care. At first, Petra was placed in a hospital, since she required intensive care. After that, she was moved to the Home for Children and Youth. In 1994, Petra was placed in a foster family, but after several months, the foster family returned her to the institution. In the fall of 1995, Petra was placed in the Center for Rehabilitation Zagreb. Petra's sister J., after having had a similar childhood experience, had been placed in the same institution a year before.

Petra met her one year older sister for the first time in the institution, when she was five. Because of occasional visits by her father, she also met some of her remaining brothers and sisters. Petra, the youngest of the children, was excluded from the occasional weekend visits to her mother's home.

Having spent over seven years in the institution, Petra was left without any feeling of family belonging or attachment. The Association for Promoting Inclusion (API) suggested that Petra should be placed in a specialised foster family care as this would be much better for her emotional and social development. Therefore in April 1998, together with her sister J., Petra left the institution and entered a specialised foster family, supported by API's multidisciplinary team.

Once she had her new family, Petra had so much to make up for. For the first time in her life, she had a space of her own and her shelf, which meant that she didn't have to carry her few belongings around all the time. She now had the opportunity to become independent in those activities which did not exist in the institutional setting: she could go and visit the neighbours and her foster grandmother, take care of the pets, bring milk from the shop, pick vegetables in the garden and help prepare meals – all of which prompted the development of Petra's awareness about her own abilities. She has also made many friends in the new environment.

Petra was enrolled in the first grade of a special school, but her great motivation and resistance to her "special" tasks prompted API to enrol her in a regular school. As a result of her great efforts and the constant support and assistance from the family, Petra continued to attend regular classes, and was taught according to a program that was prepared on the basis of her own needs and abilities.

Petra actively participates in all the family events and celebrations, her initiatives are stimulated and her attempts praised. The foster family is trying hard to enrich her experiences now that she is living with them, as she had very limited experiences from a life in the institution. Therefore, during summer vacations, they go to the seaside, take trips abroad, go to the movies and visit theatre.

Today, Petra is a high school student, enrolled in the first grade, according to the individualised program. She now lives with her foster family with three of her sisters. Petra is a happy girl. When asked about the future, her answers always include her foster family. She considers her foster mother and father to be her real parents.

The institution as a traditional "solution" for children with intellectual disabilities, the negative attitudes towards change, the fear of failure of foster family care, insufficient financial support to foster families – these are all barriers to wider development of specialised foster family care program. In spite of these barriers, one can see the smiles of children, their ability to handle daily situations, their great achievements at school, and the fact that they know where they belong, that they are accepted, loved and happy with the people surrounding them – all this points to an improvement in the quality of life of these children, as well as their foster families.

This motivates API to further develop and improve the Program of Specialised Foster Family Care. Children have a right to live in the family. The life in institutions is inhuman and is an extremely damaging 'solution' for the child.

¹ Ljiljana Pap is a Disability Specialist–Coordinator in the Program of Specialised Foster Family Care of the Association for Promoting Inclusion, Zagreb, Croatia.

Activity Report of the European Coalition for Community Living 2005–2006

Introduction

The European Coalition for Community Living (ECCL) was established in August 2005. The idea for establishing the network came from the Included in Society project, which carried out research into institutions for people with disabilities and community-based services in a number of European countries¹.

The Included in Society project highlighted that, in order to replace long stay residential institutions with comprehensive, quality community-based services, there is a need for a joint effort among various stakeholders – the local, national and regional governments and administration, the European Union, non-governmental organisations, service providers and others. For this reason, it recommended that ECCL should be established so that it could act as a long-term action centre, which would advocate for the development of quality community-based services and keep the importance of de-institutionalisation high on the agenda of policy and decision makers across Europe.

Vision and mission

ECCL is a cross disability initiative which works towards the social inclusion of people with disabilities by promoting the provision of comprehensive, quality community-based services as an alternative to institutionalisation. It was founded by Autism Europe, the Center for Policy Studies of the Central European University, the European Disability Forum, the European Network of Independent Living, Inclusion Europe, Mental Health Europe and the Open Society Mental Health Initiative.

ECCL's mission is to advocate for and monitor progress towards de-institutionalisation in Europe, campaign for, and provide information on, the development of comprehensive, quality community-based services and de-institutionalisation.

ECCL uses the following definition of the term 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. 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 only by its size.

¹ The Included in Society project conducted research in the EU/EEA countries, including the acceding countries, Romania and Bulgaria. The project was funded by the European Commission and its results can be obtained from http://www.community-living.info/contentpics/226/Included_in_Society.pdf.

Tool for change

ECCL works as a network of disability organisations, service provider organisations, research institutes and individual supporters. The role of the members is of crucial importance, as they promote the network's mission and positions in their countries and contribute to its work with their specific expertise.

Thanks to its diverse membership, ECCL is able to monitor the developments across Europe, influence the national and regional policy and support the efforts of its members by exchanging information and examples of good practices. By promoting the principle of user led services, the network can also ensure that people with disabilities are involved in the process of de-institutionalisation and any action taken in relation to the provision of community-based services.

ECCL is funded solely from contribution fees of its Management Partners and members.

Strategic planning

In June 2006, following the Right to Live in the Community Seminar, ECCL adopted the Strategic Plan 2006–2008. The plan sets out ECCL's long term objectives, as well as its human rights and organisational strategy for the upcoming two years.

Long term objectives for living in the community

- Disabled people have the same opportunities as other citizens to exercise their rights and participate fully in the society in which they live.
- Comprehensive, quality community-based alternatives to institutional care are available and accessible to all disabled people.
- All stakeholders are involved in establishing appropriate community-based services and in developing policies to support them.
- Services are designed and provided on the basis of individual's rights and requirements, and controlled by the individual with disabilities and/or their family when appropriate.
- The principles for positive change are central to any action taken in relation to planning, providing and reviewing community-based services. These are: respect, choice, participation, independence and regional/local responsibility for people with disabilities.
- Peer support and advocacy efforts of user organisations are supported and encouraged.
- User organisations and their representatives are involved in developing policies for community-based services and directly engaged in the planning of these services.

Areas of activity

In order to work towards these long term objectives, ECCL has decided to focus its activities on:

- Advocating for the development and implementation of policies and action plans that promote community inclusion and the development of community support systems as an alternative to institutions.
- Promoting the Commitment to Stop the Building of New Institutions.
- Raising public awareness about human rights violations perpetrated in institutions for people with disabilities in Europe.
- Promoting the development of comprehensive, quality community-based services.
- Advocating for independent systems of quality monitoring and accountability in the delivery of services for disabled people.
- Supporting disability organisations, service providers and governments in their efforts to provide comprehensive, quality community-based services.

The Right to Live in the Community Seminar 2006

On behalf of my colleague and myself, I want to thank you for the seminar yesterday. While we are in the middle of a huge changing process (the old buildings will be closed and new (smaller) houses will be build, which is one step to "living in the community") we heard and learnt that it is just one step in the process. We have to move on to a total inclusion of our mentally disabled clients. So thank you very much for organising and inviting us for the seminar.

[A statement from one of the participants
in the Right to Live in the Community Seminar]

On 17 May 2006, ECCL organised its first public event, the Right to Live in the Community Seminar. The seminar, which took place in Brussels, succeeded in bringing together around 80 participants from across Europe (including three participants from the United States and New Zealand). It was organised with the logistical support of Inclusion Europe and thanks to financial support of the Open Society Mental Health Initiative.

The Right to Live in the Community seminar dealt with the issues of quality in services delivery, strategies for de-institutionalisation and the role of disabled people as a driving force for de-institutionalisation. Speakers included representatives of disability organisations, service providers, research institutes and the European Commission (Wallis Goelen, Head of the Disability Unit and Jan Jařab, a member of the Cabinet of Commissioner řpidla).

The seminar participants concluded that comprehensive, quality community-based alternatives to institutions must be made available and accessible to all people with disabilities and stressed that being able to live as an equal citizen is a human right. In order to achieve this goal, the participants highlighted the need to promote user involvement, quality monitoring and the collection of best practice. Participants also called for advocacy and awareness-raising activities which would lead to change in the many countries where disabled people are still segregated in institutions.

ECCL will hold its second seminar in April 2007. This event will have a more practical approach and focus on the specific issue of how to make the transition from institutions to living in the community.

Advocacy and monitoring

In April 2006, ECCL submitted its response to the European Communities Green Paper *Improving the mental health of the population: Towards a strategy on mental health for the European Union*. Cooperation was also established with the Disability Unit at the European Commission and the Cabinet of the Commissioner for Employment, Social Affairs and Equal Opportunities Mr. Vladimř řpidla.

Publications and other resources

In preparation for the collection of information about policy and other developments in the provision of community-based services around Europe, as well as the gathering of good practices in de-institutionalisation and living in the community, ECCL has launched a new website on www.community-living.info. The website features a news section, as well as information about ongoing projects, campaigns, events and publications. In addition to the website, ECCL issues a regular Newsletter, which is distributed widely to its members, the European policy and decision makers, and other interested organisations and individuals.

Join the European Coalition for Community Living!

Since its establishment, ECCL has grown into a network of member organisations and individual members in twenty two European countries. Membership in ECCL is open to all organisations, individuals and institutions committed to the promotion of quality community-based services for people with disabilities.

ECCL's members:

- Promote the policy and mission of ECCL.
- Contribute to the development of ECCL policy positions/papers and activity plans.
- Participate in ECCL monitoring and lobbying activities.
- Participate in ECCL Working Groups, meetings and conferences.
- Receive the ECCL Newsletter and other ECCL publications.
- Benefit from other ECCL activities.

To join ECCL, download the application form from www.community-living.info or write to the ECCL Coordinator at coordinator@community-living.info.

Break Down the Barriers C a m p a i g n Community Living for All

Join ECCL's Europe-wide campaign for the development of quality, comprehensive community-based services for people with disabilities and against the establishment of new long stay institutions for any group of disabled people.

TO SIGN THE PETITION and find out about other ways of supporting or getting involved in the campaign, visit:

www.community-living.info

Starts in December 2006

New members of the European Coalition for Community Living

- ADO Icarus vzw, Belgium
- Association for Helping Persons with Developmental Disabilities Gradačac – "Kutak radosti", Bosnia and Herzegovina
- Association for Help to People with Mental Handicap in the SR (ZPMR v SR), Slovak Republic
- Association for Promoting Inclusion, Croatia
- Association for Self Advocacy, Croatia
- Association for Social Inclusion of Persons with Mental Retardation Canton of Tuzla, Bosnia and Herzegovina
- Association for the Psychosocial Health of Children and Adolescents (A.P.H.C.A.), Greece
- Association "Inclusion" of the Brcko District, Bosnia and Herzegovina
- Pierre Belpaire, Belgium
- Brothers of Charity Services, Ireland
- Center for Innovations in Education, Azerbaijan
- CHANCE, Bulgaria
- Down's Syndrome Aid Society, Serbia and Montenegro
- Erivajadustega Inimeste Toetusühing Tugiliisu (MTÜ Tugiliisu), Estonia
- FDUV, Finland
- HADER, Kosovo
- Hand in Hand Foundation, Hungary
- Hungarian Society of People with Golden Heart, Hungary
- Interessenvertretung Selbstbestimmt Leben in Deutschland e.V. (ISL) – German Council of Centers for Self-Determined Living, Germany
- Klubi "Deshira" Clubhouse, Kosovo
- MDAC (Mental Disability Advocacy Center), Hungary
- Open Society-Georgia Foundation Public Health Programs, Georgia
- "Pentru Voi" Foundation, Romania
- Public organisation "Somato", Republic of Moldova
- Real Life Options, United Kingdom
- Regional Society for Support of People with Intellectual Disabilities, Bulgaria
- Rehabilitation Foundation "Speranta", Romania
- St. Anne's Service, United Kingdom
- Steven M. Eidelman, United States
- The Latvian Centre for Human Rights (LCHR), Latvia
- Tizard Centre, University of Kent, United Kingdom
- Renate Weber, Romania
- "Woman and children - Protection and Support", Republic of Moldova

Note: Member organisations and individual members who expressed the wish for their name not to be made public are not listed here.



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