

THE RIGHT TO LIVE IN THE COMMUNITY:

Making it happen for
people with intellectual disabilities
in Bosnia and Herzegovina,
Montenegro, Serbia and Kosovo

2008

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THE DISABILITY MONITOR INITIATIVE

www.disabilitymonitor-see.org
editor@disabilitymonitor-see.org

HANDICAP INTERNATIONAL REGIONAL OFFICE FOR SOUTH EAST EUROPE

Hakije Kulenovica 22
71 000 Sarajevo, Bosnia and Herzegovina

Acknowledgements

Author

Lisa Adams

Coordination

Handicap International

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Bojana Rozman, the Association for Promoting Inclusion

Resmije Krasniqi, Hader

Slavica Marković, Milan Petrovic

Anka Djurisić, the Parent's Association of Montenegro

Bojana Bego, Handicap International

Diana Chiriacescu, Handicap International

Logistics and technical support

Aida Hakimi-Osmanbegović

Nexhat Shatri

Sonja Vasić

Zoltan Mihok

Translation

Suzana Stojković, Etleva Bisha and Merita Myftari

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Executive summary

This report concerns the situation of people with intellectual disabilities in Bosnia and Herzegovina, Croatia, Kosovo under UN Security Council Resolution 1244¹, Montenegro and Serbia (the region)². It describes how five organisations working in the region have successfully developed innovative services to support people with intellectual disabilities to live in their communities as equal citizens³. The purpose of this report is to:

- Highlight the importance of developing a range of client-focused community-based services as alternatives to institutionalisation;
- Demonstrate that such services can successfully be developed in the region;
- Identify barriers to the development of such services; and
- Make recommendations on how to address such barriers.

Context

The right to live in the community is a fundamental right for all people with disabilities. This is made clear by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) which recognises the right of all people with disabilities, regardless of the type or degree of their physical, mental, intellectual or sensory impairment, to live in the community⁴. It is also underpinned by the policy objectives of the European Union and the Council of Europe that seek to ensure the active inclusion and full participation of disabled people in society⁵.

However, in reality most people with intellectual disabilities in the region continue to be segregated in long-stay institutions such as social care homes, special schools and orphanages, often for life. These institutions are typically situated in remote areas where residents have little or no contact with the outside world. These institutions tend to provide very poor quality of care⁶. Residents usually live in inhumane and degrading conditions with little or no choice over the way they spend their time, and with little or no habilitative or therapeutic activities. Those who are not placed in institutions are often isolated in their homes due to the lack of community-based services. As, the former Special Rapporteur on Health, Paul Hunt, has commented, people with intellectual disabilities 'are among the most neglected - the most "invisible" in our communities⁷'.

Making community living a reality

Community-based services, such as supported employment services (support for people with disabilities to work on the open labour market), supported housing services, and independent living skills training (such as cooking, handling money, using public transport) must be developed to provide the alternatives to the institutionalisation and social exclusion of people with intellectual disabilities. These services must enable people with intellectual disabilities to be included in their communities and achieve their fullest potential. Thus they must promote 'community living', which means:

'...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 activities⁸.'

¹ Kosovo under UN Security Council Resolution 1244' will be referred to as 'Kosovo' for the remainder of the report.

² Handicap International South East Europe has a regional programme in Albania, Bosnia and Herzegovina, Macedonia, Montenegro, Serbia and Kosovo (South East Europe). However, this report focuses only on Bosnia and Herzegovina, Montenegro, Serbia and Kosovo as this is the geographical area covered by the European Instrument for Democracy and Human Rights (EIDHR)'s financial support to Handicap International. Nonetheless, the findings are likely to be relevant to the other countries in South East Europe. Croatia is included because the Croatian organisation, the Association on Promoting Inclusion (API), has worked very closely with organisations in South East Europe and has faced similar challenges.

³ The findings of this report are based on in-depth interviews with representatives of these organisations. Interviews were carried out by Handicap International during 2008.

⁴ See in particular Article 19 CRPD 'Living independently and being included in the community'

⁵ See for example, Equal Opportunities for People with Disabilities: A European Action Plan, COM(2003)650 final and Recommendation Rec(2006)5 on the Committee of Ministers to Member States on the 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.

⁶ Jim Mansell, Deinstitutionalisation and community living: progress, problems and priorities, Journal of Intellectual and Developmental Disability, 31(2), (2006): 65-76.

⁷ E/CN.4/2005/51, 11 February 2005, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

⁸ ECCL, "Creating Successful Campaigns for Community Living: An advocacy manual for disability organisations and service providers", (ECCL: November 2008).

To achieve the goal of community living, the development of quality community-based services must be founded upon the core values of equal citizenship and social inclusion⁹. Services must be tailored to the individual's needs, wishes and aspirations, providing assistance in whatever way best helps the person achieve their own goals, adapting the kind and level of support, as required, over time.

Examples of community-based services that promote community-living

The experience of the organisations profiled in this report demonstrates that it is possible to develop quality, sustainable community-based services as alternatives to long stay residential institutions in the region¹⁰. The services provided by these organisations include:

- Supported living services that enable people with intellectual disabilities to live in the community: the Serbian Association for Promoting Inclusion
- Inclusive education programs to support people with intellectual disabilities to attend school: the Milan Petrovic School and
- Supported employment services to make it possible for people with intellectual disabilities to find and maintain work on the open labour market: the Association for Promoting Inclusion Croatia

Although they are providing different services, a common feature of the organisations profiled here is that their services address the individual needs of their clients. Through this individualised approach, the organisations aim to support each client to best help that person participate in community life and achieve their fullest potential.

Action is needed to realise the right to community living for all

To date, governments in the region have made little real commitment to providing the necessary resources for the development of community-based services nation-wide. Existing legal and financial frameworks are inadequate to support the development of comprehensive community-based services that meet the needs of people with intellectual disabilities. Furthermore, there is an overall lack of awareness about the rights of people with intellectual disabilities, especially their right to live in the community and participate in everyday activities that people without disabilities take for granted. As a result people with intellectual disabilities continue to be excluded from society, often for life.

Although the organisations whose work is profiled in this report have faced difficulties that are particular to their countries, some of the significant barriers to community living are common to the region. These are highlighted below, together with recommendations on the action that governments should take to address them¹¹.

Developing a range of community-based alternatives to institutions

The case studies in this report show that governments have yet to develop cohesive strategies or provide the necessary resources to develop a range of community-based alternatives to long-stay institutions.

Recommendation 1: Commit to community living

Governments should develop policies and legislation to support the transition from a system of segregated institutional care to community-based services. Such policies should be developed in line with the rights set out in the Convention on the Rights of Persons with Disabilities (CRPD). Policy should be developed in consultation with disabled people, their families and the organisations that will implement this transition by operating community-based services.

It is critical that Ministries and other authorities responsible for health, social welfare, education, employment, and housing work together to plan and implement the necessary steps to achieve this transition.

1. Removing the obstacles to the provision of community-based services

A major barrier for all five of the organisations profiled in this report is the lack of effective financing and implementation mechanisms to support sustainable community-based services. This has led to difficulties in obtaining government funding for community-based services, resulting in a reliance on donor funding or one time government grants and concerns about sustainability. As a result of their tenacity, vision and commitment, these organisations have found ways to overcome some of the barriers. As one of the organisation's representatives explained: "*If the service does not exist in the law, it does not mean you cannot do it.*" The challenge is achieving sustainability by advocating for a shift in financing mechanisms from institutions to community-based services.

Recommendation 2: Take action to encourage the development of innovative and sustainable community-based services

Governments should consider what actions are required to support the provision of sustainable community-based

⁹ Inclusion Europe, Autism Europe, Mental Health Europe, the Open Society Mental Health Initiative, "Included in Society: Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People", (Included in Society: 2003).

¹⁰ It is important to note that across the region, thousands of people with intellectual disabilities are unjustifiably detained in long stay residential institutions, often for their entire lifetimes.

¹¹ For a useful resource that sets out a range of recommendations on how to develop services in the community that promote community living and social inclusion see: Jim Mansell, Martin Knapp, Judie Beadle-Brown and Jeni Beecham, "De-institutionalisation and community living – Outcomes and Costs: report of a European Study. Volume 2: Main Report", (Canterbury: Tizard Centre, University of Kent).

services, in particular to ensure that non-governmental organisations (NGOs) as well as government agencies have opportunities to develop such services. This will require a range of measures such as reviewing existing financial and legal arrangements that are designed around institutional care and removing any restrictions on the development of community-based services.

2. Addressing the outmoded assessment procedures

The procedures for assessing and diagnosing children and adults with intellectual disabilities in the region are outmoded and need to be reformed.

Recommendation 3: Update the assessment procedures in line with outcome focused, person centred practices

Assessment procedures should be conducted by trained multidisciplinary teams. Assessments should be holistic, taking into account a person's strengths, wishes, goals and interests. The client and their family must be actively involved in the assessment process. The assessment process is dynamic, and outcomes should be evaluated on a regular basis vis a vis the individual's goals.

3. Preventing serious human rights abuses arising from the guardianship system

The guardianship system prevalent in the region gives rise to serious human rights abuses, including the arbitrary detention of people in long-stay institutions, with no right of appeal.

Recommendation 4: Reform guardianship

The guardianship system should be reformed into a legally recognised supported decision-making system that is based on the presumption that people have capacity to make decisions for themselves, supports people in making decisions for themselves and sets out clear safeguards when decisions are being made on a person's behalf¹².

4. Developing a more inclusive education system

Children with intellectual disabilities continue to be segregated in special schools where the quality of the education is often very poor. Children with more severe intellectual disabilities often have no access to even special education in the region. Although in theory children assessed as having mild intellectual disabilities are eligible for mainstream education, in practice, many are placed in special schools. Children with intellectual disabilities who live in institutions often have no access to any form of education.

Recommendation 5: Adopt and implement an education policy that provides educational opportunities to all children, regardless of disability.

Education policies and legislation should be reviewed and amended so that all children with intellectual disabilities can receive education in their local communities, with the necessary support to enable their inclusion.

5. Ensuring access to employment for people with intellectual disabilities

There are significant barriers to people with intellectual disabilities obtaining paid employment, such as the lack of assistance available to people seeking employment and the lack of adequate on-the-job support, the guardianship system, and high general unemployment rates in the region.

Recommendation 6: Adopt measures to promote access to employment for people with intellectual disabilities

Legislation, policies and other measures should be adopted to enable people with intellectual disabilities to become employed. This should include the provision of vocational training and the development of supported employment services.

Conclusion

Through their courage, vision, leadership and long-term commitment, the organisations profiled in this report have shown what is possible now, despite the many barriers. They have developed models of best practice which can be disseminated across the region. However, achieving the transition from institutional care to the provision of community-based services on a national scale will require concerted effort from governments. It will be essential that people with intellectual disabilities and their families are equal partners and are actively involved in this process¹³.

It is imperative that governments commit to the promotion of community living without delay. In the meantime, NGOs, self advocates and organisations of people with intellectual disabilities will need work together to demonstrate to governments that action must be taken to ensure that people with intellectual disabilities have the same right to participate in their communities as everyone else.

¹² Such reforms will need to be undertaken in accordance with the UN Convention on the Rights of Persons with Disabilities (CRPD), in particular Article 12 CRPD (Equal Recognition before the law).

¹³ Chapter Six of this report highlights the importance of self-advocacy, providing, by way of example, information on the work of a self advocacy organisation in Croatia. Annex 3 is a DVD that includes helpful tools and resources for advocacy. It includes a tool kit for advocacy, a practical resource created by the European Coalition for Community Living and published in 2008, 'Creating Successful Campaigns for Community Living: An advocacy manual for disability organisations and service providers'. It is available in English, Albanian and Serbian.

Chapter 1: Introduction

This report concerns the situation of people with intellectual disabilities in Bosnia and Herzegovina, Croatia, Kosovo under UN Security Council Resolution 1244¹⁴ Montenegro and Serbia (the region)¹⁵. It has been written and researched by Handicap International¹⁶.

The report describes how five organisations working in the region have successfully developed innovative services to support people with intellectual disabilities to live in their communities as equal citizens¹⁷. The report will be of interest to policy-makers, service providers and other individuals and organisations seeking to promote the rights of people with intellectual disabilities to live in the community and participate fully in society.

Purpose of the report

The purpose of this report is:

- To highlight the importance of developing a range of client-focused community-based services as alternatives to institutionalisation;
- To demonstrate that such services can successfully be developed in the region
- To identify barriers to the development of such services; and
- To make recommendations on how to address such barriers.

Terminology

This report focuses on the development of community-based services for people with intellectual disabilities. The term 'community-based services' covers a wide range of services, aimed at providing people with the support that they need to live in the community. They include:

- early intervention services (for babies and young children with intellectual disabilities),
- foster family care,
- inclusive education (to enable children with intellectual disabilities to be included in mainstream education),
- supported employment services (support for people with intellectual disabilities to work on the open labour market),
- supported housing services,
- advocacy and support for self-advocacy
- independent living skills training (such as cooking, handling money, using public transport)
- counselling for families; and
- respite care.

A definition of intellectual disabilities is provided in the box below.

Intellectual disabilities

This term refers to a condition that is characterised by lower than average intellectual ability, resulting in difficulties in learning and understanding. Intellectual disabilities are usually present from birth or develop before the age of 18. With appropriate support, people with intellectual disabilities can live independently and participate fully in society. Some people may need more support than others. All people with intellectual disabilities are able to express their needs and wishes even if some people do not express themselves verbally¹⁸.

¹⁴ Kosovo under UN Security Council Resolution 1244' will be referred to as 'Kosovo' for the remainder of the report.

¹⁵ Handicap International South East Europe has a regional programme in Albania, Bosnia and Herzegovina, Macedonia, Montenegro, Serbia and Kosovo (South East Europe). However, this report focuses only on Bosnia and Herzegovina, Montenegro, Serbia and Kosovo as this is the geographical area covered by the European Instrument for Democracy and Human Rights (EIDHR)'s financial support to Handicap International. Nonetheless, the findings are likely to be relevant to the other countries in South East Europe. Croatia is included because the Croatian organisation, the Association on Promoting Inclusion (API), has worked very closely with organisations in SEE and has faced similar challenges.

¹⁶ The research for this report was carried out in 2008 by local non-governmental organisations in Bosnia and Herzegovina, Montenegro, Serbia and Kosovo. These organisations are working to promote community living for people with intellectual disabilities. The group was comprised of service providers as well as individuals working to address disability rights issues in the region. They examined the laws in each of the countries and carried out interviews with people with intellectual disabilities and their families as well as with organisations and service providers working with people with intellectual disabilities.

¹⁷ The findings of this report are based on in-depth interviews with representatives of these organisations. Interviews were carried out by Handicap International during 2008.

¹⁸ Adapted from Inclusion Europe, Autism Europe, Mental Health Europe, the Open Society Mental Health Initiative, "Included in Society: Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People", (Included in Society project and the European Commission: 2003): 12.

Common values of the organisations taking part in this study

The organisations included in this study were selected because they provide examples of the range of services that are needed to enable people with intellectual disabilities to live in the community. They include three programmes that provide housing and support to individuals who would otherwise be institutionalised; a programme that implements inclusive education for children and a supported employment programme.

Four of the organisations are from the region: the Association for the Social Inclusion of Persons with Developmental Disabilities (ASIT) from Bosnia; Hader, from Kosovo, the Serbian Association for Promoting Inclusion (SAPI) and the Milan Petrovic School from Serbia. This report also profiles the supported employment service operated by the Association for Promoting Inclusion (API) in Croatia. Although Croatia was not included in Handicap International's field research, the work of API is included in this report because it works closely with three of the other organisations (ASIT, Hader and SAPI), providing each of them with training and technical support for the past number of years. API has eleven years of experience in providing community-based services for people with intellectual disabilities and in delivering training and technical assistance to other organisations in the region.

Although the research for the report includes Montenegro, there were no organisations identified providing community-based services to people with intellectual disabilities there.

Common to all five organisations profiled is their approach to service delivery. They share a commitment to the protection and promotion of clients' rights and ensuring that support provided to each client meets that person's individual needs.

Community-based services are key to social inclusion and respect for human rights

Community-based services and support are essential if governments are to meet the policy objectives of the European Union and the Council of Europe to promote equal opportunities for disabled people, in particular, to ensure the active inclusion and full participation of disabled people in society¹⁹.

In reality, these policy objectives have little meaning for most people with intellectual disabilities in the region. This is because, despite government policies that purport to promote the social inclusion of disabled people, the fact is that many people with intellectual disabilities continue to be segregated in long-stay institutions such as social care homes, special schools and orphanages, often for life. Those who are not placed in institutions are isolated in their homes due to the lack of community-based services.

Research has shown that institutional care is often of unacceptably low quality²⁰. Moreover, a fundamental objection to long-stay institutions is that they represent an insurmountable barrier to disabled people in exercising their rights, in particular their right to live and participate in the community as equal citizens.

The right to live in the community: a fundamental right for all people with disabilities

The importance of developing comprehensive community-based services is iterated in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) which came into force on 3rd May 2008²¹. The CRPD underlines the importance of ensuring that all people with disabilities can exercise their human rights and fundamental freedoms on an equal basis with others and recognises the right of all people with disabilities, regardless of the type or degree of their physical, mental, intellectual or sensory impairment, to live in the community.

CRPD Article 19, '*Living independently and being included in the community*' requires States to take appropriate measures to ensure people with disabilities can exercise their right to full inclusion and participation in the community. This article calls for the development of support services to facilitate inclusion in the community and provides 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.

¹⁹ See for example, Equal Opportunities for People with Disabilities: A European Action Plan, COM(2003)650 final and Recommendation Rec(2006)5 on the Committee of Ministers to Member States on the 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.

²⁰ See for example Inclusion Europe, Autism Europe, Mental Health Europe, the Open Society Mental Health Initiative, "Included in Society: Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People", (Included in Society project and the European Commission: 2003).

²¹ UN Convention on the Rights of People with Disabilities, full text of the convention available at: <http://www.un.org/disabilities/convention/conventionfull.shtml>

To date 137 countries have ratified the Convention²². By doing so, they have undertaken 'to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities'. This includes adopting new legislation and other measures to enable the implementation of prescribed rights, and involving persons with disabilities in the development and implementation of relevant laws and policies.

States are required to submit periodic reports to the Committee on the Rights of Persons with Disabilities detailing their progress in implementing their obligations under the Convention. States will need to explain what action(s) they have taken to ensure that people with disabilities are able to live and participate in the community. The development of a range of community-based services as alternatives to institutionalisation will be key to ensure compliance with this right.

Making community living a reality

Although community-based services are essential to ensuring that disabled people are able to exercise their rights, services alone are not enough. Services must be focused on enabling people with disabilities, including people with intellectual disabilities, to be included in their communities and achieve their fullest potential. Thus, they must promote 'community living' (also known as 'independent living'). In essence community 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 activities²³.'

Research studies 'overwhelmingly' show better results for people receiving community-based services, their families and the staff supporting them²⁴. To achieve the goal of community living, the development of quality community-based services must be founded upon the core values of equal citizenship and social inclusion²⁵. The box below sets out some key principles for the development of such services.

Key principles for community-based services²⁶

- They are *person-centred*. (They are tailored to the individual's needs, wishes and aspirations, providing assistance in whatever way best helps the person achieve their own goals and adapting the kind and level of support, as required, over time.)
- They *support family and community life*. (They provide extra help to the person, their family and friends to enable them to live in and be part of their community, augmenting their resources rather than displacing or disrupting them.)
- They adopt *a social model of disability* (This means that that barriers, prejudice and exclusion by society (purposely or inadvertently) are the ultimate factors defining who is disabled and who is not in a particular society. It recognises that while some people have physical, intellectual, or psychological differences from a statistical mean, which may sometimes be impairments, these do not have to lead to disability unless society fails to accommodate and include them in the way it would those who are non disabled.)
- They *holistically address people's lives*. (They provide whatever support is needed to overcome the effect of impairment and disability to enable people to have a good quality of life. They recognise that all people, regardless of ability need support in certain life activities.)
- They *ensure these principles are implemented in the day-to-day assistance provided to the individuals they support*.

Action needed to realise the right to community living

Due to pressure from international agencies, governments in the region have acknowledged the need to take action to address the poor quality of care and human rights violations in long stay institutions. However, as highlighted above, this recognition is not enough to enable most people with intellectual disabilities to live in the community as equal citizens. This is because governments have made little real commitment to providing the necessary resources to develop community-based services nation-wide, and current legal and financial frameworks are inadequate to support the development of comprehensive community-based services that meet their needs.. This leaves people with intellectual disabilities still segregated from society. Furthermore, there is

²² United Nations Enable, www.un.org/disabilities/ Croatia has ratified the CRPD and the optional protocol, Montenegro and Serbia have both signed the Convention and the optional protocol.

²³ ECCL, "Creating Successful Campaigns for Community Living: An advocacy manual for disability organisations and service providers", (ECCL: November 2008).

²⁴ Jim Mansell, Martin Knapp, Judie Beadle-Brown and Jeni Beecham, "De-institutionalisation and community living – Outcomes and Costs: report of a European Study. Volume 2: Main Report", (Canterbury: Tizard Centre, University of Kent): 3.

²⁵ Inclusion Europe, Autism Europe, Mental Health Europe, the Open Society Mental Health Initiative, "Included in Society: Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People", (Included in Society: 2003).

²⁶ Adapted from, Jim Mansell, Martin Knapp, Judie Beadle-Brown and Jeni Beecham, "De-institutionalisation and community living – Outcomes and Costs: report of a European Study. Volume 2: Main Report", (Canterbury: Tizard Centre, University of Kent): 3.

an overall lack of awareness about the rights of people with intellectual disabilities, especially their right to live in the community and participate in everyday activities that people without disabilities take for granted.

The experience of the organisations that are profiled in this report demonstrates that it is possible to develop quality, sustainable community-based services as alternatives to long stay residential institutions in the region²⁷. However, achieving the transition from institutional care to the provision of community-based services on a national scale will require concerted effort from governments. They will need to work closely with individuals and organisations that promote community living. It is essential that people with intellectual disabilities and their families are equal partners and are actively involved in this process²⁸.

The strategies required to replace institutions with community-based services were considered in a report published in 2007, *Deinstitutionalisation and community living – outcome and costs: report of a European Study*²⁹ (the DECLOC report). This report is a useful resource for governments, as well as policy makers, service providers and human rights and disability organisations working to promote community living in the region. It sets out a range of recommendations on how to develop services in the community that promote community living and social inclusion. These are set out in Annex 2. Recommendations to address specific concerns identified in this report are set out in Chapter Seven.

²⁷ It is important to note that across the region, thousands of people with intellectual disabilities are unjustifiably detained in long stay residential institutions, often for their entire lifetimes.

²⁸ Chapter Six of this report highlights the importance of self-advocacy, providing, by way of example, information on the work of a self advocacy organisation in Croatia. Annex 3 is a DVD that **includes helpful tools and resources for advocacy. It includes a tool kit for advocacy, a practical resource created by the European Coalition for Community Living** and published in 2008, 'Creating Successful Campaigns for Community Living: An advocacy manual for disability organisations and service providers'. It is available in English, Albanian and Serbian

²⁹ Jim Mansell, Martin Knapp, Judie Beadle-Brown and Jeni Beecham, "De-institutionalisation and community living – Outcomes and Costs: report of a European Study. Volume 2: Main Report", (Canterbury: Tizard Centre, University of Kent)

Chapter 2: Barriers to Community Living in Bosnia and Herzegovina, Croatia, Kosovo, Montenegro and Serbia: An Overview

This chapter seeks to provide the context in which the organisations are working. It does so by summarising the main barriers to people with intellectual disabilities being able to live in their communities as equal citizens³⁰.

The institutionalisation of people with intellectual disabilities

The most significant barrier to the social inclusion of people with intellectual disabilities is the continued practice of long-term institutionalisation.

For over half a century, government policy in the region has been to place people with intellectual disabilities in large long-stay institutions such as orphanages, social care homes and psychiatric hospitals. These institutions are typically situated in remote areas where residents have little or no contact with the outside world. The existing institutions are, for the most part poorly financed resulting in very poor quality of care³¹. Residents of institutions usually live in inhumane and degrading conditions with little or no choice over the way they spend their time, with little or no rehabilitative or therapeutic activities.

Reports over the last decade have highlighted serious concerns about the human rights abuses of residents in institutions in Central and Eastern Europe including the use of cage beds³² and/or people being tied to beds indefinitely³³, other forms of physical and mental abuse, unacceptable living conditions and lack of medical care³⁴. There are insufficient safeguards to protect people with intellectual disabilities from arbitrary detention in institutions. For example there is no independent review of involuntary placement in institutions. Under current guardianship laws in the region, people with intellectual disabilities can be detained in institutions indefinitely without due process or judicial oversight³⁵.

Data on the numbers of people with intellectual disabilities in these countries is lacking and the figures that do exist are often unreliable as there is little to no coordination between the responsible ministries. For example it has been noted that the numbers of people living in institutions may be underestimated because this data is provided by social welfare ministries and do not include those people who are detained in facilities that are under the responsibility of the Ministry of Health³⁶.

It is clear, however, on the basis of available information, that there are thousands of people with intellectual disabilities in institutions across the region. According to government figures, there are approximately 5,500 people with disabilities residing in long-stay residential institutions in Serbia of which approximately 4,068 are people with intellectual disabilities³⁷. In Bosnia and Herzegovina, there are three long-stay residential institutions accommodating approximately 1,250³⁸ people with disabilities³⁹. Montenegro has one long-stay residential institution which accommodates just under 140 people with intellectual disabilities of all ages⁴⁰ and one long-

³⁰ This chapter draws upon the field work carried out by Handicap International in the region during 2008 and recent relevant reports.

³¹ Jim Mansell, *Deinstitutionalisation and community living: progress, problems and priorities*, *Journal of Intellectual and Developmental Disability*, 31(2), (2006): 65-76.

³² Mental Disability Advocacy Center, "Use of Cage Beds: Inhumane and Degrading Treatment in Four EU Accession Countries", (MDAC: 2003).

³³ Ahern and Eric Rosenthal, "Torment Not Treatment: Serbia's Segregation and Abuse of Children and Adults with Disabilities", (*Mental Disability Rights International*: 2007): iii.

³⁴ Amnesty International, "Far From the Eyes of Society: Systematic Discrimination against People with Mental Disabilities", (*Amnesty International*: 2002): 2.

³⁵ Laurie Ahern and Eric Rosenthal, *ibid*: iii.

³⁶ Camilla Parker and Judith Klein, "Making Social Inclusion a Reality: The Challenges for People with Mental Disabilities in Central and Eastern Europe" *Eurohealth* Vol. 9 No. 3, Autumn 2003: 16.

³⁷ Based on data from the Ministry of Labour and Social Policy of Serbia in 2008. See also, Jurij Bajec, Gorana Krstic, Ljiljana Pejcin-Stokic and Goran Penev, "Social Protection and Social Inclusion in the Republic of Serbia", manuscript for the European Commission Directorate-General for Employment, Social Affairs and Equal Opportunities, (European Commission: 2008): 55.

³⁸ Based on data from the Ministry of Labour and Social Affairs of the Federation of Bosnia and Herzegovina. See also: Davorin Pavelic, Nikolina Obradovic, Amil Kamenica, "Social Protection and Social Inclusion in the Bosnia and Herzegovina", Manuscript for the European Commission Directorate-General for Employment, Social Affairs and Equal Opportunities, (European Commission: 2008): 148.

³⁹ According to official data, the people accommodated in the long-term institutions are people with intellectual and/or physical disabilities.

⁴⁰ The institution was established to accommodate children and young people with intellectual disabilities and autism but now houses people of all ages.

stay geriatric institution for older people and people with disabilities that accommodates 290 people. Kosovo has one long-stay institution which currently accommodates 175 people with disabilities (primarily people with intellectual disabilities and people with chronic mental health problems)⁴¹.

Isolation, exclusion and stigma

Widespread stigma and discrimination present major barriers to the social inclusion people with intellectual disabilities. As, the former Special Rapporteur on Health, Paul Hunt, has commented, people with intellectual disabilities 'are among the most neglected - the most "invisible" in our communities⁴²'.

In addition to the thousands of people with intellectual disabilities living in residential institutions, many people with intellectual disabilities are isolated in their homes. This is mainly due to the lack of community-based services available to them and their families but often it is also because their families keep them at home, sometimes out of shame, and in other cases, to protect them from potential abuse⁴³. In cases where a baby is born with a visible disability, it is common for the parents to be told by physicians at the maternity ward that they should place their child in an institution because this is the only option⁴⁴.

The segregation of people with intellectual disabilities in institutions and their isolation at home reinforces societal prejudices them and perpetrates their social exclusion.

Negative attitudes and the medical model of disability

A significant factor in the discrimination and stigma faced by disabled people is that they have traditionally been viewed as objects of pity and charity rather than being seen as individuals with their own views and aspirations. This approach, which focuses on the person's impairment, is commonly described as 'the medical model of disability'. It was perpetuated by the belief that people with disabilities are incapable of leading independent lives or of succeeding in mainstream society⁴⁵.

Disabled people have developed an alternative model of disability. The 'social model of disability' rejects the medical approach and instead shows that people with disabilities are disabled by society's negative attitudes towards them, as well as the physical and other barriers that prevent them from participating fully in society. This has led to the recognition that people with disabilities are not "objects" of protection, treatment and charity, to be excluded from society. Rather, the social model of disability makes clear that all people with disabilities have the right to participate actively in political, economic, social, and cultural life in a way that is respectful and accommodating of their differences⁴⁶.

However, the 'medical model of disability' still dominates in the region and government policy and funding is still oriented towards segregated services for people with intellectual disabilities, following the medical model.

Outdated means of assessment and diagnosis of intellectual disability

A similar system for the assessment and diagnosis of intellectual disabilities is used in all of the countries in the region. A multi-disciplinary commission (made up of medical doctors, psychologists, social workers, speech therapists and teachers) determines the type and degree of a person's disability. These commissions continue to apply the medical model of disability to assessment and diagnosis, relying on an assessment process that focuses on the extent of individual's impairment rather than assessing what the person might be capable of doing with adequate support⁴⁷.

The commissions (referred to in this report as the 'categorisation commission') use four categories for intellectual disabilities: mild, moderate, severe and profound. The category of impairment that the person is assessed to have will determine many aspects of their life, for example whether the child is placed in a special school or is allowed to attend a mainstream school and, when an adult, whether s/he is considered able to work or is eligible for disability benefits.

Guardianship

The guardianship system is a major barrier to community living for many adults with intellectual disabilities living in the region as it prevents them from making decisions for themselves, thereby depriving them of the chance to control their own lives. This is because people placed under guardianship are deemed to lack capacity to

⁴¹ Based on data from the Ministry of Labour and Social Welfare of Kosovo in 2005.

⁴² E/CN.4/2005/51, 11 February 2005, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

⁴³ Based on field research carried out by Handicap International in 2008. See also Camilla Parker and Judith Klein, *ibid*: 16.

⁴⁴ Based on field research carried out by Handicap International in 2008.

⁴⁵ Theresia Degener and Gerard Quinn, "A Survey of International, Comparative and Regional Disability Law Reform" in *Disability Rights Law and Policy; International and National Perspectives* (Papers Conceived and Commissioned by the Disability Rights Education and Defense Fund (DREDF), eds. M.L. Breslin and S. Yee, (Ardsley, NY: Transnational Pub., 2002): 3-125. See also Mike Oliver, "The Individual and Social Models of Disability" Paper presented at Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians, July 1990: 3

⁴⁶ Theresia Degener and Gerard Quinn, *ibid*: 125

⁴⁷ Based on field research carried out by Handicap International in 2008. See also: Chiriacescu, Diana, "Shifting the Paradigm in Social Service Provision: Making Quality Services Accessible for People with Disabilities in South East Europe", (Handicap International: 2008).

make decisions for themselves and a guardian is appointed to make decisions on their behalf. Individuals placed under plenary (full) guardianship are deemed unable to make any decisions of a legal nature, such as entering into employment, getting married or opening a bank account. They are deprived of their right to own or rent property, the right to family life, to marry, to vote, to associate freely, to access courts and to make a will⁴⁸.

The lack of proper safeguards for guardianship has led to widespread abuse. For example, individuals subject to plenary guardianship can be placed in a social care institution by their guardian without their consent, for life and without the right of appeal. In practice, many people with intellectual disabilities in long-stay institutions are detained with no legal process or judicial oversight⁴⁹. In long-stay institutions in the region, it is common practice to appoint the director of the institution as the guardian for hundreds of residents.

Lack of community based services

Although community-based alternatives have begun to develop in the region, the institutional model of care still dominates. There is still insufficient focus on the development of community-based alternative services at the government level. Governments tend to use available funding to refurbish existing institutions or to create new smaller institutions⁵⁰. This situation is compounded by difficulties faced by non-governmental organisations (NGOs) wishing to provide community-based services on behalf of government agencies. In many countries, there is still no system allowing government agencies to contract with NGOs for the provision of community-based services. This prevents them from receiving government funds to provide such services⁵¹. In this scenario, community-based services are limited to small-scale initiatives that are dependent on donor funding⁵². Where community-based services do exist for people with intellectual disabilities, they tend to be limited to larger cities⁵³.

Lack of access to education

Children with intellectual disabilities continue to be placed in special schools where the level of education provided is often inadequate. Many of the thousands of people with intellectual disabilities in long-stay institutions have had no access to education at all⁵⁴. There are insufficient policies and funding to support the development of inclusive education. Furthermore, there is a lack of community-based services to help children with intellectual disabilities attend mainstream schools such as such as educational counselling, speech therapy, physiotherapy and qualified staff to support a child in a mainstream classroom⁵⁵.

Being deprived of a decent education and of the opportunity to grow up with their peers severely restricts opportunities for people with intellectual disabilities to secure meaningful employment or participate in community life. Thus, the denial of the right to education often leads to life-long dependency, poverty and social exclusion for people with intellectual disabilities⁵⁶.

Lack of access to employment

Very few people with intellectual disabilities living in the region have any form of employment. It is difficult to know the exact number of people with intellectual disabilities who are unemployed because official data is unreliable. The data available is based mainly on the numbers of people who are registered as unemployed. While people with intellectual disabilities are entitled to register at the local employment centres, they rarely do⁵⁷.

⁴⁸ Mental Disability Advocacy Center, "Guardianship and Human Rights in Serbia: An analysis of Guardianship Law and Policy", (MDAC: Budapest, 2006): 6.

⁴⁹ "Torment Not Treatment: Serbia's Segregation and Abuse of Children and Adults with Disabilities" (Mental Disability Rights International: 2007): iii.

⁵⁰ Based on field research carried out by Handicap International in 2008.

⁵¹ Chiriacescu, Diana, "Shifting the Paradigm in Social Service Provision: Making Quality Services Accessible for People with Disabilities in South East Europe", (Handicap International: 2008). See also the reports from the European Commission Directorate-General for Employment, Social Affairs and Equal Opportunities on Social Protection and Social Inclusion in the Western Balkans available at: http://ec.europa.eu/employment_social/spsi/enlargement_en.htm

⁵² Although some NGOs receive government funding to provide community based services, this is on a 'pilot project' basis, and the services will end when the financing ends.

⁵³ Based on field research carried out by Handicap International in 2008. See also the reports from the European Commission Directorate-General for Employment, Social Affairs and Equal Opportunities on Social Protection and Social Inclusion in the Western Balkans available at: http://ec.europa.eu/employment_social/spsi/enlargement_en.htm

⁵⁴ Based on field research carried out by Handicap International in 2008. See also reports published by the Open Society Institute EU Monitoring and Advocacy Program and Open Society Institute Mental Health Initiative, "Access to Education and Employment of People with Intellectual Disabilities Summary Reports" (Open Society Institute EU Monitoring and Advocacy Program: Budapest) 2005: 4. These reports cover: the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia, Slovenia, Bulgaria and Romania, Croatia, Greece, the Netherlands, and the United Kingdom.

⁵⁵ Based on field research carried out by Handicap International in 2008.

⁵⁶ Open Society Institute EU Monitoring and Advocacy Program and Open Society Institute Mental Health Initiative, "Access to Education and Employment of People with Intellectual Disabilities Summary Reports", (Open Society Institute EU Monitoring and Advocacy Program: Budapest) 2005: 4.

⁵⁷ Based on a disability and statistics survey in South East Europe carried out by Handicap International in 2006. More information available at: http://www.disabilitymonitorsee.org/documents/journal03/Journal_decemberengweb.pdf

People with intellectual disabilities are generally categorised as having either reduced work capacity or no work capacity. Those found to have no work capacity means that they are excluded from participating in the mainstream labour force⁵⁸. Those that are assessed as having reduced work capacity are usually told that the only form of 'employment' available to them is in a sheltered workshop⁵⁹. These workshops are often attached to special schools, and the work is always unpaid.

Although some of the countries in the region have programmes designed to encourage the employment of people with disabilities, few are designed to meet the needs of people with *intellectual* disabilities. Furthermore, the programmes are often misused in practice so that people with intellectual disabilities rarely benefit from them⁶⁰. There are also quota systems in some labour laws, but in practice, fines for non-compliance are not punitive and the laws are not systematically enforced^{61 - 62}. Vocational training programmes that are open to people with intellectual disabilities, tend to take place in sheltered workshops or special schools and the skills that are taught have limited to no practical use for those wishing to be employed on the open labour market. In some countries, such as Serbia, vocational training programmes are available only to people with mild intellectual disabilities.

Lack of understanding of the goal of community living

Although action has been taken in parts of the region to address concerns about living conditions and poor quality of care in long-stay institutions, there is insufficient understanding of the need to develop community-based services as alternatives to such institutions. Furthermore, there seems to be a major misunderstanding of the concept of community living amongst many donors and governments. This is illustrated by the tendency to invest in new, smaller institutions as alternatives to the older, larger ones. It is important to note that community living is not simply about services being delivered outside an institution. The fundamental principle of community living is that services allow the person to exercise control over their lives and make their own decisions with appropriate support.

This failure to understand the point of community living has led to the development of services that reproduce, rather than remedy, the short-comings of institutions. These include group homes (where all services are provided solely within the building in which a person is accommodated and have rigid staffing structures regardless of clients' actual support needs), sheltered workshops and day centres where little to no meaningful activities are provided. Such services continue to segregate people with intellectual disabilities from society and fail to enable them to participate in community life.

Lack of involvement of people with intellectual disabilities and their families

To date there is insufficient recognition of need to enable people with intellectual disabilities and their families to be involved in the development of community-based services. The development of self-advocacy groups (groups whose members are all people with intellectual disabilities) who are able to advocate for the rights of people with intellectual disabilities and inform policy makers and politicians on what reforms are needed, is crucial.

⁵⁸ Based on field research carried out by Handicap International in 2008. See also Association for Self-Advocacy Croatia, Association for Promoting Inclusion Croatia and Inclusion Europe, "Human Rights of Persons with Intellectual Disabilities: Country Report Croatia", (Zagreb: 2007): 25-27.

⁵⁹ A sheltered workshop is a segregated environment, common throughout South East Europe, in which people with disabilities carry out minimally paid or unpaid work.

⁶⁰ The success of such programmes remains unclear because there are indications that retention of employees with disabilities is poor beyond the incentive period when the state co-finances salaries. There are also indications that employers misuse state co-financing by listing people with disabilities as employed but without actually engaging them in the workplace.

⁶¹ Based on field research carried out by Handicap International in 2008.

⁶² Open Society Institute EU Monitoring and Advocacy Program and Open Society Institute Mental Health Initiative "Access to Education and Employment of People with Intellectual Disabilities: Country Report Croatia" (Open Society Institute EU Monitoring and Advocacy Program: Budapest) 2005: 16-18.

Chapter 3: Challenging the Institutionalisation of People with Intellectual Disabilities: Steps towards Change in Bosnia and Herzegovina, Kosovo and Serbia

A. Overview

People with intellectual disabilities continue to be placed in long-stay institutions, often for life. For others living in their families' homes, the lack of community-based services to support people in carrying out daily activities in their own local communities means that they have little choice in what they can do, and have limited opportunities to socialise. This, together with the widespread stigma against people with intellectual disabilities and their families, often leaves people with intellectual disabilities isolated in their own homes.

This chapter profiles the work of three organisations in the region that seek to support people with intellectual disabilities to exercise their right to live in the community by developing community-based services as alternatives to institutions:

- Association for the Social Inclusion of Persons with Developmental Disabilities of Tuzla (ASIT) in Bosnia and Herzegovina
- The Serbian Association for Promoting Inclusion (SAPI)
- Hader in Kosovo

B. Community Living in Bosnia and Herzegovina

This case study examines how a small NGO, the Association for the Social Inclusion of Persons with Developmental Disabilities of Tuzla (ASIT), has established a model for community living as a viable alternative to institutionalisation by providing services that enable people with intellectual disabilities to live in the community.

a. The situation for people with intellectual disabilities in Bosnia and Herzegovina

Approximately 1,250 people with intellectual and/or physical disabilities are accommodated in long-stay residential institutions in Bosnia and Herzegovina⁶³. Placements in long-stay residential institutions are widely assumed to be the only solution for people with more severe disabilities and for people with multiple impairments. In most cases there is no alternative to institutionalisation if a family cannot take care of their disabled relative. There are no services to support people with intellectual disabilities after their parents or family members die, and they are often placed in long-stay institutions for lack of an alternative after having lived their whole lives in the local community⁶⁴.

Children and adults with intellectual disabilities who remain at home usually face extreme isolation as there are no community-based services in place to support them and their families. The few day centres for people with intellectual disabilities that exist in Bosnia and Herzegovina, (generally limited to larger cities), often focus on occupying them during the day, rather than helping them develop independent living skills⁶⁵. Although government policy in Bosnia and Herzegovina is to promote inclusive education, in practice children with more severe intellectual disabilities are very rarely included in mainstream schools⁶⁶.

b. The work of the Association for the Social Inclusion of Persons with Developmental Disabilities of Tuzla (ASIT)

ASIT provides community-based alternatives to institutionalisation in the Tuzla canton of Bosnia and Herzegovina. Established in 1998, with the support of the Open Society Mental Health Initiative (MHI) ASIT has worked with Tuzla canton authorities to ensure that eleven residents of a long-stay institution who were originally from Tuzla were able to return to live in their local community. The Association for Promoting Inclusion (API), an NGO based in Croatia that has many years of experience in providing community-based services, has provided training and support to ASIT since its inception.

ASIT provides supported housing services to the former residents of the long-stay institution and also operates a day centre for people with intellectual disabilities who are otherwise at risk of being institutionalised. The day

⁶³ Based on data from the Ministry of Labour and Social Affairs of the Federation of Bosnia and Herzegovina. See also: Davorin Pavelic, Nikolina Obradovic, Amil Kamenica, "Social Protection and Social Inclusion in Bosnia and Herzegovina", Manuscript for the European Commission Directorate-General for Employment, Social Affairs and Equal Opportunities, (European Commission: 2008): 148.

⁶⁴ Interview with Fata Ibralic in Belgrade, October 24 2008.

⁶⁵ Based on Handicap International's field visits to day care centres throughout Bosnia and Herzegovina in 2008.

⁶⁶ Based on interviews with parents of children with intellectual disabilities in research carried out in Bosnia and Herzegovina on the situation of people with intellectual disabilities in 2008 for Handicap International.

centre provides training on independent living skills and supports people to participate in community life. Both the housing programme and the day centre are now financed by the Ministry of Labour and Social Affairs of Tuzla canton.

Currently, ASIT has three apartments in Tuzla with three to five people living in each apartment. A multi-disciplinary team of four people manages the supported living programme and the day centre. In addition to the staff, ASIT receives regular support from cantonal medical staff who have established a mobile team that provides regular medical care for clients in the supported housing programme.

Most of ASIT's clients are over 50 years of age and have spent almost their entire lives in residential institutions. Although moving back into the community has been a major change for them, all of the clients have successfully adjusted to community living. Since leaving the institution, two clients have married and one client has found a paid job on the open labour market.

c. Overcoming the barriers to community living

Starting the deinstitutionalisation process in Tuzla

In 2000, with the support of MHI, ASIT began its activities to promote community living by relocating people originally from Tuzla canton who were accommodated in the long-stay residential institution in Pazaric to apartments in Tuzla and provide them with the support that they need to live in the community. API provided technical assistance and training to assist ASIT in developing a plan for deinstitutionalisation (enabling residents of institutions to live in the community and to prevent other people from being institutionalised).

Achieving legislative reform

ASIT successfully lobbied for amendments to legislation that would permit NGOs to provide day services and accommodation to people with disabilities in the community. With this amendment in place, the Ministry of Labour and Social Affairs of Tuzla entered into an agreement with ASIT, allowing ASIT to move all the residents originally from Tuzla canton out of the Pazaric institution, into rented apartments in Tuzla. The programme has been financed by this Ministry since 2001, with ASIT receiving per capita funding that is equal to the cost of accommodating the person in the institution. Unfortunately, this progressive practice has not been replicated in any other canton in Bosnia and Herzegovina.

Supported housing: meeting individual needs and promoting inclusion

ASIT's services are aimed at supporting clients to live independently to the greatest degree possible.

Eligibility for services in Bosnia and Herzegovina is based on type and degree of disability rather than the needs of the person, but funding that ASIT receives from the Ministry is a flat per capita rate that assumes that all individuals have the same support needs. Despite this, ASIT provides services that are individually tailored to all of its clients, regardless of the degree of their disability. Recognising the reality that clients have different needs, ASIT reallocates the funding accordingly so it can be more flexible with the level of support it provides. ASIT has planned the mix of residents in the apartments so that in each apartment there is at least one person who has some independent living skills and can assist others as needed. With very limited funding, this is one of the ways ASIT maximises resources while continuing to provide person centred community-based services⁶⁷.

Developing skills for community living

The activities in ASIT's day centre aim to help clients acquire independent living skills so that they can live in their homes and take active part in community life. Enabling people to learn such skills and make decisions for themselves is critical to a supported living programme. The day services operate daily from 8AM to 5PM and include: vocational activities, a creative workshop and training on independent living skills. The day centre also has self-advocacy activities to help clients learn to make decisions about their life as well as to help them realise they have a right to stand up for themselves and voice their opinions, needs and wishes. ASIT hopes that this may lead to the creation of a self-advocacy group that promotes the rights of people with intellectual disabilities.

ASIT's day centre provides services to clients in the supported housing programme and to other people with intellectual disabilities who are at risk being institutionalised. In the beginning, the day centre was financed by international donors as a pilot project. Today, the day centre is financed by the Tuzla Canton as a part of its prevention of institutionalisation initiative. The local Centre for Social Work refers clients to ASIT as part of ASIT's service agreement with the Tuzla Canton.

d. ASIT's future plans for deinstitutionalisation

ASIT is lobbying for changes to legislation that will permit it to provide services to all people with intellectual disabilities, whatever their level of disability (mild, moderate, severe or profound). This is not possible at the moment because under current legislation only those individuals who are assessed as having "moderate to severe mental retardation" are eligible for ASIT's services.

⁶⁷ Person-centred community-based services, commonly called "person-centred planning" refers to a model of community-based service that puts the client at the centre of the life-planning process so that the process can be tailored to the needs and wishes of the person.

ASIT is also seeking to promote its model of deinstitutionalisation throughout Bosnia and Herzegovina. ASIT's director, Fata Ibralic, is serving as President of Sumero, the Federal Union of Associations Assisting People with Mental Retardation of Bosnia and Herzegovina. Working with Sumero, ASIT hopes to build a strong alliance amongst member organisations to lobby their cantonal governments for support to deinstitutionalisation initiatives throughout the country.

C. Community Living in Serbia

This case study demonstrates how an NGO in Serbia is successfully providing supported living services that enable people with intellectual disabilities to leave institutions and live independently in the community.

a. The situation for people with intellectual disabilities in Serbia

Although the government has made a commitment to initiate the process of de-institutionalisation, to date, there are no policies to close existing institutions and redirect resources to the development of comprehensive community-based services for people with intellectual disabilities. Resources are still being used to renovate institutions and to building smaller congregate care units. These smaller facilities are generally located in the vicinity of long-stay institutions and operate in the same way.

Serbia has adopted a law that prohibits discrimination against people with disabilities (including people with intellectual disabilities and/or mental health problems). The government has also adopted a national disability strategy which calls for the inclusion of people with intellectual disabilities in the community and the creation of foster family services. However, the strategy does not explicitly require the development of a comprehensive range of community-based services to support people with intellectual disabilities to live in the community.

The Ministry of Labour and Social Policy is investing, through the Social Innovation Fund (SIF)⁶⁸, in the establishment of day centres for people with disabilities and a foster family care system⁶⁹. SIF also supported, on a pilot project basis, personal assistance services and supported living services⁷⁰. However, no community-based services to support people with intellectual disabilities to live in the community are being developed. Furthermore while there are some government initiatives to move children from institutions to the community, there has been little progress in the deinstitutionalisation of children with disabilities⁷¹. In 2007 according to official data, approximately 150 children were transferred from residential institutions to foster families, but only three are children with disabilities⁷².

In Serbia, local categorisation commissions assess a child and recommend whether the child should go to a mainstream school or be placed in either a special school or in a long-stay institution. The Centre for Social Work is the administrative body responsible for arranging placements in residential institutions.

By law, the government is responsible for the care of people with intellectual disabilities in long-stay institutions. If the categorisation commission recommends placement in an institution, the family can refuse the placement and choose to keep the child at home. If the family wants their child placed in an institution, the commission will often categorise the child as having a more severe level of disability to make the child eligible for institutional placement. Given that there are so few community-based support services, a child's placement in a residential institution is often seen by parents as the only choice. In practice, the majority of families who choose to have their child placed in an institution are living in, or close to, the poverty line, and do not have sufficient financial means to care for their child⁷³.

In Serbia, most people with severe and profound intellectual disabilities are deprived of their legal capacity and placed under plenary guardianship. Although guardianship laws were reformed in 2005 they still contravene human rights standards because wards are subjected to significant and arbitrary deprivation of their human rights⁷⁴.

b. The work of the Serbian Association for Promoting Inclusion (SAPI)

The Serbian Association for Promoting Inclusion (SAPI) provides community-based supported housing services to people with intellectual disabilities who were previously living in a long-stay residential institution.

⁶⁸ The Social Innovation Fund (SIF) is a programme established by the Ministry of Labour and Social Policy in 2003 as a mechanism for funding innovative services as a part of social protection reform in Serbia. SIF is implemented in cooperation with the United Nations Development Program (UNDP) and supported by the European Agency for Reconstruction (EAR), the Government of the Kingdom of Norway and the UK Government.

⁶⁹ Jurij Bajec, Gorana Krstić, Ljiljana Pejin-Stokić and Goran Penev, "Social Protection and Social Inclusion in Serbia", Manuscript for the European Commission Directorate-General for Employment, Social Affairs and Equal Opportunities, (European Commission: 2008): 50.

⁷⁰ Jurij Bajec, Gorana Krstić, Ljiljana Pejin-Stokić and Goran Penev, *ibid*: 50-51.

⁷¹ Reima Ana Maglajlić Holiček, Anna Nordenmark Severinsson and Dita Reichenberg, "Child Care System Reform in South East Europe: A Sub-Regional Analysis Based on Country Assessments in Albania, Bulgaria, FYR Macedonia and Serbia", (UNICEF: 2007): 155.

⁷² Based on field research carried out by Handicap International in 2008.

⁷³ Based on field research carried out by Handicap International in 2008.

⁷⁴ Laurie Ahern and Eric Rosenthal, "Torment Not Treatment: Serbia's Segregation and Abuse of Children and Adults with Disabilities", (Mental Disability Rights International: 2007): iii.

SAPI provides its clients with accommodation in rented apartments in different parts of Belgrade and supports them to live as independently as possible. Three to five people share each apartment and an assistant supports them in their day to day activities. The goal of the support is to develop and reinforce individual competencies in independent living skills such as cooking, handling money, taking care of the home, using public transportation and developing positive relationships. The support staff is available up to 24 hours a day, depending on the level of assistance needed.

This supported housing programme was initiated by the Down's Syndrome Aid Society Serbia (DSAS) in 2004 and is now managed by SAPI. DSAS began its programme in 2004 by relocating residents of a long-stay residential institution near Belgrade, Sremcica, into apartments in the community. SAPI was formed as a subsidiary group of DSAS to manage the programme. Today SAPI provides supported living services to 23 adults with intellectual disabilities.

The supported living programme was initially financed by MHI. The funding included the provision of training on community living and technical support, which was delivered by the Association for Promoting Inclusion (API), Croatia. API supported the development of SAPI's programme and monitored the quality of their services. The programme has since received additional financing from other sources such as SIF. At this writing, Municipal authorities in Belgrade and the Ministry of Labour and Social Policy are still arguing about which should be responsible for the long term financing of this programme.

C. Supported living services work in practice

Individualised planning

SAPI's team talks with each client to find out about their background, their family, the environment in which they live, their capacities, and their wishes, as well as the potential obstacles to living independently. After the assessment is made, a programme coordinator elaborates an individual support plan. This plan sets out what the client wants to achieve and what is needed to reach these goals. These plans are monitored by SAPI staff to ensure short and long-term goals are reached and to assess what might need to be adapted.

Enabling people to take part in community life

One of the main goals of the supported living services is to help clients participate in community life and to realise their aspirations. Whenever possible, SAPI has helped clients to re-establish contact with family members and build new relationships in the community.

All clients are given opportunities to participate in spiritual, religious, cultural or sports activities. After leaving the institution, three clients were baptised upon their request. SAPI supported one woman to explore the possibility of joining a monastic order, a life-long desire she wished to explore after leaving the institution. Since joining the supported living programme, two clients have become a couple and live together in an apartment. Another client realised a life-time achievement by becoming the first disabled woman to climb the highest mountain in Europe. After expressing a strong desire to be involved in mountaineering, SAPI, with the support of the Association for Sport and Recreation of Persons with Disabilities and the Extreme Sports Club assisted this client in realising her goal.

Developing new skills and support in employment

SAPI also provides training in skills such as carpentry, computers and baking. In addition, it operates a creative workshop where clients can participate in ceramics, painting, sewing and needlework. SAPI also support the continuing education for adult clients who wish to complete their primary school education.

Despite very high unemployment rates in Serbia, SAPI has succeeded in implementing a successful supported employment programme, securing paid work on the open labour market for 21 clients and supporting them in their jobs. State funding is not yet available for this service so support is provided by the assistants employed in the supported living programme.

d. Overcoming Barriers

Advocating for legislative reform

In 2004, when the supported living service was first established there was no legal basis for it. SAPI has had some success in addressing this challenge as it persuaded local authorities in Belgrade to amend relevant by-laws to so that NGOs are eligible to provide supported living services in Belgrade. SAPI was also involved in the drafting of new social welfare legislation that will permit the provision of supported living services.

At this writing, however, this problem has not been resolved at the national level. Currently there is no law regulating NGOs to be service providers in Serbia. This means that NGOs cannot be contracted by the government to provide services. This threatens the sustainability of SAPI's programme.

When supported living services are included in national legislation and receive adequate funding from the state, accreditation and quality standards will help SAPI provide community-based supported living services on an individual basis to a larger number of clients in Serbia.

Recognition as a model of good practice

In 2008, as a part of the reform of the social welfare system, the Ministry of Labour and Social Policy issued a call for tenders for innovative services and invited NGOs and service providers to apply. SAPI's application was

successful and its programme was accredited by the Ministry as a future service provider for supported living services and as a trainer for other potential service providers.

As a part of these reforms, the Ministry of Labour, Employment and Social Affairs intends to pilot innovative community services and develop minimum quality standards for each service. Supported living services have been included in the piloting programme as this has been identified by the Ministry as a priority area. SAPI drafted the minimum quality standards for supported living services in the pilot phase.

Overcoming resistance to change

In Serbia, professionals working within residential institutions have not had adequate training on community-based support services and are resistant to changes that will be necessary to develop and deliver such services⁷⁵. Many fear that they will lose their jobs as a result of deinstitutionalisation.

To overcome this resistance, SAPI worked in partnership with the residential institution Sremcica to explain their services and to discuss any concerns. This partnership has helped to develop an understanding by institution staff that community-based support services are an integral part of deinstitutionalisation. Working together on the relocation of clients from the institution to the community has given staff a better understanding of the process as well as the importance of services that are individually tailored to meet the needs of people with intellectual disabilities.

e. Future activities

SAPI hopes to build a strong coalition for lobbying local and national authorities on the need for the social protection system to provide for community-based supported housing services. In November 2008, SAPI organised, in partnership with "Milan Petrovic", a special school in Novi Sad that provides comprehensive inclusive education services, a meeting of all supported housing service providers in Serbia. The participants of this meeting agreed to work together as a coalition of supported housing service providers to address common areas of concern.

With technical support from API Croatia, SAPI is now providing weekly training on self-advocacy for its clients. Clients learn about their rights and gain decision making skills. SAPI hopes that by gaining self-advocacy skills, individuals will be better equipped to participate in decisions about their lives and to advocate for their needs.

D. Community living in Kosovo

This case study explores how a small NGO in Kosovo developed a community-based day centre for people with intellectual disabilities with very limited funding and under challenging economic and political conditions.

a. The situation of people with intellectual disabilities in Kosovo

The specific socio-political situation in Kosovo

Kosovo is the poorest territory in the Balkans and one of the poorest in Europe. According to the latest Human Development Report (2006), the unemployment rate in Kosovo is between 40-50%. Approximately 45 percent of the population lives below the national poverty line and a further 18 percent are vulnerable to poverty, while about 15 percent of the population is estimated to be extremely poor⁷⁶. In addition to the difficult economic situation, Kosovo's political status is still uncertain following the region's declaration of independence from Serbia in 2008. The complex socio-political situation in Kosovo places vulnerable groups including people with intellectual disabilities at risk of being further marginalised without adequate community-based services to address their needs.

Widespread stigma leading to extreme isolation in the home and vulnerability

Due to the stigma associated with disabilities, people with intellectual disabilities are often hidden in their homes, especially in rural parts of the region⁷⁷. Life in the community is therefore generally restricted to the home⁷⁸. People with intellectual disabilities are also at risk of neglect when their families are living in poverty and not able to meet their own basic needs⁷⁹.

Lack of community-based support services

There are no government supported community-based services to support people with intellectual disabilities in Kosovo⁸⁰. People with intellectual disabilities from Pristina who were interviewed as part of this study said that they stay at home all day because there are no other activities or services available to them in the community⁸¹.

⁷⁵ There have been some training for personnel of residential institutions as a part of social protection reform but the focus of the trainings has been on transforming the institutions so that the premises can be used for alternative forms of care such as foster family services or day centres. See also: Reima Ana Maglajlić Holiček, Anna Nordenmark Severinsson and Dita Reichenberg, "Child Care System Reform in South East Europe: A Sub-Regional Analysis Based on Country Assessments in Albania, Bulgaria, FYR Macedonia and Serbia", (UNICEF: 2007): 156.

⁷⁶ World Bank Poverty Reduction and Economic Management Unit Europe and Central Asia, "Kosovo Poverty Assessment Volume 1: Accelerating Inclusive Growth to Reduce Widespread Poverty", (World Bank: 2007).

⁷⁷ Interview with Resmije Krasniqi, president of Hader day centre in Prizren, November 2008.

⁷⁸ Based on field research carried out by Handicap International in 2008.

⁷⁹ Based on field research carried out by Handicap International in 2008.

⁸⁰ There are community-based Mental Health Centres being developed as part of the reform of the mental health system in Kosovo.

⁸¹ Based on field research carried out by Handicap International in 2008.

There are no early intervention services for children under the age of 6, and only one NGO offers 'play therapy' for young children with intellectual disabilities⁸².

With substantial funding from various international organisations, some former residents of Shtime, a long-stay institution, have now been relocated. However they have been placed group homes that only provide accommodation and do not enable the residents to participate in community life.

Lack of access to adequate education

Access to education for people with intellectual disabilities is extremely limited⁸³. Primary and secondary education for people with intellectual disabilities is mainly offered in special schools and in special classes attached to the mainstream schools. Very few, if any, children with intellectual disabilities are educated in mainstream schools⁸⁴.

b. About Hader

Hader is an NGO that operates a community-based day centre in Prizren that provides services to people with intellectual disabilities of all age groups from various ethnic and religious backgrounds since 1999. Hader was established by a group of mothers of children with intellectual disabilities. Recognising the need for community based services for people with intellectual disabilities, one of the mothers established a day centre in her home with the support of the women's group. Initially relying on donations, the group implemented educational activities and a creative workshop for 42 children with intellectual disabilities from the Prizren community. In 2005, after lobbying the municipality, the organisation received a plot of land and with the financial support of MHI, they built a day centre.

As there is no single administrative body that keeps a register of people with intellectual disabilities living at home, Hader used community networks to identify potential clients who might benefit from their services. With financial support from donors, Hader established a summer camp in the countryside close to Prizren in order to organise outings for clients and give them an opportunity to socialise outside of their homes. The camp provides clients a chance to enjoy leisure time in an outdoor setting, often for the first time in their lives.

The day centre also provides accommodation and food to people with intellectual disabilities who are living in extreme poverty. Initially the day centre accommodated a family of seven, including people with intellectual disabilities, who had been living in cardboard boxes and surviving from food scraps found in the garbage. The family has been supported to live independently and they now live in a rented apartment in Prizren with Hader's support. Currently 9 people are living in the day centre, including individuals who have been transferred from the Shtime institution until a more appropriate solution can be found.

The day centre activities have been supported by the MHI and the Fund for an Open Society Kosovo since 2003. Hader has received technical support and training from the API (Croatia) and the ASIT of Tuzla Bosnia and Herzegovina. However, save for the land donated by the municipality, the day centre receives no financial support from the government. Hader relies solely on funding from international donors which threatens the sustainability of its services and makes it very challenging to expand services to a larger group of people.

c. Hader's day centre and related services

Day centre activities

Educational activities, creative workshops, physiotherapy as well as training on independent living skills including cooking, housework, shopping and personal hygiene are provided at the centre. Of over 200 clients who are registered at the day centre, 30 clients attend the day centre on a regular, daily basis.

Hader also provides physiotherapy and speech therapy to clients according to their needs. Hader offers educational activities which include teaching clients to read and write. Six of Hader's clients now attend a mainstream school. The day centre activities are carried out by ten staff, including special education staff, psychologists, physiotherapists and speech therapists.

Supporting families

A large part of Hader's work is to support families in understanding the right of people with intellectual disabilities to live in the community. Staff work with families to overcome stigma or fears they may have about supporting their relative be a part of the community. Hader also provides them with assistance in learning to give their family member a participatory role within the family. Hader also provides mobile support to families with members who have more severe intellectual disabilities in their homes.

d. Overcoming barriers

Providing community-based services against the odds

In 1999 when Hader was founded, there were no community-based services available to people with intellectual disabilities. In fact, many of Hader's clients had never had the opportunity to leave their homes until the day centre was established⁸⁵. Despite the lack of support for alternatives to institutionalisation from local and national

⁸² Based on field research carried out by Handicap International in 2008.

⁸³ Kosova/Kosovo Association of Psychology Students, *ibid*: 7.

⁸⁴ Based on field research carried out by Handicap International in 2008.

⁸⁵ Interview with Resmije Krasniqi in Prizren in November 2008.

authorities, Hader has continued to provide services even when resources were scarce. It is this commitment to persevere that has enabled Hader to provide innovative services regardless of the difficulties.

Breaking down stigma

Since it was established, Hader has worked to address the marginalisation of people with intellectual disabilities and their families. Today in the community of Prizren, largely thanks to the work of Hader, people with intellectual disabilities are a part of the community and the general public is more aware of their right to be included in the community. Hader also uses media to communicate this message which has helped to dismantle societal prejudices towards people with intellectual disabilities and their families.

e. Future plans

Advocating for legislative reform

Although the government is working to move away from placing disabled people in long-stay institutions, the situation of people with intellectual disabilities in Kosovo is at risk of worsening rather than improving. This is because the government is investing in the creation of group homes (where all services are provided solely within the home and regardless of clients' actual support needs) rather than community-based support services. Hader is therefore actively lobbying at local and national levels for community-based services to be developed as a part of the deinstitutionalisation process.

Hader is seeking to ensure that government and donors understand the range of services that are needed in order to have comprehensive and diverse support services at the community level. It is part of a government working group considering draft legislation on the rights of people with disabilities and has highlighted the importance of community-based services as alternatives to institutionalisation.

Awareness raising

Hader continues to carry out activities at the local and national levels to raise awareness about the rights of people with intellectual disabilities to community living, self-representation and self-determination.

Chapter 4: Access to Education: Making Education more Inclusive in Novi Sad Serbia

The case study in this chapter considers how the Milan Petrovic School, a special school in Novi Sad Serbia has made its educational programme more inclusive for all children with intellectual disabilities and has secured local government support to continue this programme.

A. Access to Education: An Overview

Very few people with intellectual disabilities living in the region have access to adequate education. Despite on-going education reforms, people with intellectual disabilities continue to be placed in special schools, many of which are 'boarding schools' where children live. The quality of the education in such schools is often very poor⁸⁶. Special schools generally lack the funding to properly train and motivate teachers. Furthermore, the majority of special schools lack proper facilities and modern curricula⁸⁷. Although legislation requires that people living in residential institutions (other than special schools) are provided with some form of educational and vocational activities, in reality, they often have no access to education or activities⁸⁸.

Although in most countries data on the number of children in special schools is available, it is not clear how many of them have intellectual disabilities. It is not known how many people with intellectual disabilities receive education in mainstream schools because educational data is not disaggregated by disability type⁸⁹. Nor is it known how many children with intellectual disabilities receive no education.

Inadequate procedures for assessment

As discussed in Chapter Two, in all of the countries included in this report, access to education is still based on assessment processes that are based on the medical model of disability. The assessments focus on the type and degree of a child's disability rather than on their capacities and potential. The body undertaking this assessment is multi-disciplinary and is commonly referred to in Bosnia and Herzegovina, Montenegro and Serbia as the 'categorisation commission'. In Kosovo, assessments are administered by 'Special Education' offices⁹⁰.

The assessment of the categorisation commission is used to determine a child's eligibility to attend a mainstream school, to be sent to a special school or to a residential institution. (In some areas of Kosovo, a child may be able to join an 'attached classroom' which is a separate classroom for children with disabilities that is attached to, or a part of, a mainstream school.) In Montenegro, educational reforms are being introduced to adopt an individualised approach to assessment of children that involve evaluating each child on the basis of his or her abilities and potential⁹¹.

Insufficient promotion, or understanding, of inclusive education

In all of the countries in the region, the laws on primary education call for all children, including children with disabilities, to be included in mainstream schools. However, the laws also state that children with intellectual disabilities may be educated in special schools. In reality, very few children with intellectual disabilities are given the chance to attend mainstream schools. Children with mild to moderate intellectual disabilities are usually placed in special schools while children with severe to profound intellectual disabilities are still considered "uneducable" and placed in residential institutions, special boarding schools or remain at home⁹². Segregation is therefore still prevalent in the region. Mainstream schools that provide adapted curricula for children with disabilities are generally restricted to urban areas and larger cities, leaving children in rural areas without access to any form of education⁹³.

⁸⁶ EUMAP report: "Access to Education and Employment of People with Intellectual Disabilities" and UNICEF Innocenti Research Centre report: "Children and Disability in Transition in CEE/CIS and Baltic States".

⁸⁷ Based on field research carried out by Handicap International in 2008.

⁸⁸ EUMAP report: "Access to Education and Employment of People with Intellectual Disabilities Summary Reports". These reports cover: the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia, Slovenia, Bulgaria and Romania, Croatia, Greece, the Netherlands, and the United Kingdom.

⁸⁹ Based on field research carried out by Handicap International in 2008.

⁹⁰ Based on field research carried out by Handicap International in 2008. See also: Kosova/Kosovo Association of Psychology Students, "The Situation of People with Mental Health Problems and People with Intellectual Disabilities in Kosova/Kosovo: A Needs Assessment Report" (MHI: 2006): 45-46.

⁹¹ Jadranka Kaludjerovic, Danilo Sukovic, Ana Krsmanovic, Milica Vukotic, Vojin Golubovic, Ivana Vojinovic, "Social Protection and Social Inclusion in Montenegro", Manuscript for the European Commission Directorate-General for Employment, Social Affairs and Equal Opportunities, (European Commission: 2008): 35.

⁹² Based on field research carried out by Handicap International in 2008. See also: Veliki Mali's report: "Qualitative Education for All" (2005).

⁹³ Based on field research carried out by Handicap International in 2008.

Although parents are not required to accept the categorisation commission's recommendation that their child is placed in a special school, their ability to place their child in a mainstream school is dependent on the willingness of the school principal and teachers to accept the child. Even if a school accepts a child, the child is often neglected because the teachers are not adequately prepared to work with children with intellectual disabilities and do not have access to appropriately adapted curricula and materials. Parents are then often told that their child is not able to successfully complete education in a mainstream school which often ends in parents deciding to withdraw their child from the school⁹⁴.

Inclusive education

There have been some reform efforts aimed at making education more inclusive in all of the countries in the region. Most of these efforts have been focused on developing special classrooms for children with disabilities within a mainstream school rather than supporting children with disabilities in mainstream classes alongside their non disabled peers. There has been limited training of teachers and school administrators to support the implementation of inclusive education and many schools are still physically inaccessible⁹⁵. In addition, not enough has been done to raise awareness of children, teachers and families on diversity and tolerance.

There have been some campaigns to raise community awareness about the need for inclusive education, but widespread confusion remains on what inclusive education means amongst both policy makers and educators in the region. Many believe that inclusive education is achieved by placing students with disabilities in separate classrooms within mainstream schools. In addition to the confusion, many educators have expressed fear of inclusive education or unwillingness to accept an inclusive approach in the classroom⁹⁶. Thus, much work remains to be done to ensure inclusive education is understood and that resources are dedicated to providing appropriate support to ensure children with intellectual disabilities can succeed in mainstream schools.

The box below provides a description of inclusive education.

Inclusive Education⁹⁷

Inclusive education is a system in which children with disabilities attend their local schools and learn in the classroom alongside their peers. The following support the successful implementation of inclusive education:

- Ongoing training and mentoring for educators to support implementation of inclusive education in preschools and primary schools;
- Integration of special educational services (for example, physical, occupational, and speech therapies) into the mainstream school system;
- Development of in-service training programmes to train and retrain teachers;
- Development of services, training, and information to support families of children with disabilities and strengthen their role as advocates for their children;
- Awareness-raising and anti-bias training to promote school-wide acceptance of children with disabilities;
- Dissemination of best educational practices for children with different types of disabilities;
- Development of fiscal and administrative procedures to sustain inclusive programmes; and
- Development of advocacy and community- awareness programmes to affect policy.

Lack of early intervention services

Comprehensive early intervention services for children with intellectual disabilities and their families are almost non-existent in the region. A child with an intellectual disability does not enter the social welfare system until the age of 6 or 7 (when they are of school age) when they are assessed to determine their eligibility to attend school.

Early intervention includes a wide-range of multi-disciplinary services that support children with disabilities and their families between birth and school age. They include diagnostic and assessment services, medical assistance, developmental therapy, physical therapy, physiological therapy, occupational therapy, early education services, and support and information for families⁹⁸. They aim to:

- Prevent the development of some disabilities;
- Diminish the long-term effects of disability and to assist children with disabilities in key areas such as physical, cognitive, linguistic, social and emotional development;
- Support families in maximising their children's development and in fostering the development of their children's independent living skills to promote social inclusion; and
- Facilitate inclusion in mainstream education for children with developmental disabilities.

⁹⁴ Based on field research carried out by Handicap International in 2008.

⁹⁵ Based on field research carried out by Handicap International in 2008.

⁹⁶ In the report "Disability in the press: How disability and people with disabilities are depicted in print media in Bosnia and Herzegovina, Montenegro and Serbia in 2006", (Handicap International: 2007), from the findings on of the report, there was great confusion over the issue of inclusive education reported in the press throughout the region.

⁹⁷ Open Society Institute and International Step by Step Association, "Inclusion: Children with Disabilities Latvia, Mongolia and Ukraine" (Open Society Institute: 2006).

⁹⁸ More information on early intervention available at: <http://www.osmhi.org/?page=133>.

Access to early intervention services is critical for facilitating the inclusion of children with intellectual disabilities in mainstream schools.

Lack of special education curricula and training

One of the main challenges in implementing inclusive education in the region is the lack of human capacity and resources to properly train educators and to develop appropriately adapted curricula⁹⁹. Without the proper skills and knowledge to work with children with intellectual disabilities, educators will not be able to support children to succeed in mainstream schools. Furthermore, training is necessary to help to break down fears and prejudices teachers and other education specialists may have about inclusive education.

B. Education: The situation in Serbia

To date, Serbia has no strategy for promoting inclusive education of people with disabilities. Although the laws governing education at pre-school, elementary and high school levels provide that parents can decide what type of schooling their child should receive, this 'choice' is undermined by by-laws that set out conditions that must be met before a child is eligible to attend a mainstream school. In effect this means that only children with mild to moderate intellectual disabilities are eligible to attend mainstream schools.

Although in some municipalities, children with mild intellectual disabilities are placed in mainstream schools, in other parts of the country they are sent to special schools. Children with severe or profound intellectual disabilities and children with multiple disabilities are ineligible to attend mainstream high schools, and adults with intellectual disabilities are ineligible to attend university¹⁰⁰.

Although the Government has developed curricula to be used by mainstream schools that wish to include children with intellectual disabilities in their classes, no support or training is available for those teachers working with these children. Furthermore, there are insufficient numbers of teachers or other professionals with expertise in supporting children with intellectual disabilities in mainstream schools. While legislation provides for the employment of special educators and specialists such as speech therapists, physiotherapists and psychologists in special schools, this is not the case in mainstream schools.

The curriculum used in special schools is out-of-date. It is focused on the diagnosed impairment of the child and allows no flexibility for education to be provided on the basis of the individual child's capabilities. Nor does it correspond to the curriculum used in mainstream schools. For example, in a special school, students do not learn a foreign language and do not reach the same level in mathematics. This makes it very difficult for a child to move from a special to a mainstream school and follow the curriculum in the mainstream school. Children who graduate from special schools receive only a certificate that states the name of the school they attended, rather than a diploma¹⁰¹.

C. The Milan Petrovic School, Serbia

The Milan Petrovic School was established as a special school in 1958 in Novi Sad, Serbia. The school's mission is to provide continuous education and rehabilitation to all children whatever the degree of their impairment, from an early age to adulthood. The school implements inclusive pre-school, elementary and high school educational programmes for all children with disabilities, regardless of their level of disability. The school has just over 800 students and 350 staff members. It provides a range of services to support children with intellectual disabilities for the transition to mainstream schools.

The school premises are fully accessible and are designed to be stimulating for children, with sensory rooms and various therapies including speech therapy, physical therapy and occupational therapy. The school is equipped with assistive devices such as communication devices for children who do not use verbal communication and mobility devices for children with physical disabilities. The school makes efforts to respond to the needs of each individual child, including offering various forms of curriculum adapted according to the individual capabilities of their students. The school also offers one-to-one courses such as speech therapy for students with particular needs.

The school employs professionals with a range of expertise to provide support to meet the individual needs of all students, such as special educators, speech therapists, physiotherapists, social workers and psychologists. It has also developed a range of services to support children with intellectual disabilities in mainstream schools. The school currently cooperates with 23 mainstream schools and supports 87 children with intellectual disabilities in mainstream schools.

The school is financed in part by the Ministry of Education as well as by the city of Novi Sad and neighbouring municipalities. The school receives additional funding from the Vojvodina Secretariat for Education which publishes calls for proposals for pilot projects in education. The school has also received grants from international donors including the Open Society Mental Health Initiative and Save the Children.

⁹⁹ Based on field research carried out by Handicap International in 2008.

¹⁰⁰ Based on field research carried out by Handicap International in 2008 and from information given in an interview with Slavica Markovic, principal of Milan Petrovic School in Novi Sad, October 2008.

¹⁰¹ Based on field research carried out by Handicap International in 2008 and from information given in an interview with Slavica Markovic, principal of Milan Petrovic School in Novi Sad, October 2008.

D. The school's inclusive education program

Individualised approach

A team of experts assesses each child, together with the child's family, to determine the child's capacities, to understand their educational interests, likes and dislikes, and to consider how they can support the child to reach their potential. Based on this assessment the team develops an individual educational plan that sets out goals and time-frames for monitoring the child's progress. The services are designed to be flexible in order to respond to individual needs.

Inclusive curriculum

The adapted curriculum provided by the government for special schools is out-dated, and not based on individual needs¹⁰². Thus, the Milan Petrovic School developed inclusive curricula from pre-school to high school by adapting educational methodologies from various countries.

Different levels of education

Unlike other special schools in the region, the Milan Petrovic School enables children with intellectual disabilities to complete the mainstream education system's curriculum and these children receive a mainstream diploma upon graduation.

Services provided by the Milan Petrovic School

The Milan Petrovic School provides education to children from pre-school to high school:

Pre-school

Since 2006, education policy in Serbia has required all children to attend a pre-school programme to prepare them for elementary school. However, in practice, teaching staff in pre-schools are unprepared to include children with disabilities, and the Government does not enforce this policy¹⁰³. Milan Petrovic fills this gap by providing an inclusive pre-school programme for all children with intellectual disabilities from Vojvodina, regardless of their impairment¹⁰⁴. This service is financed by the local municipality. A mobile team visits children who live far away and cannot come daily to Novi Sad for schooling to elaborate an individual educational plan that will be implemented in their local community schools.

Elementary school

The Milan Petrovic School uses the curriculum taught in mainstream schools rather than the special school curriculum. This means that children with disabilities who are assessed as requiring placement in special schools can receive the same education as children in mainstream schools. Milan Petrovic assesses each student, placing some on the "mainstream track" and others on a special education track. Students who complete the mainstream curriculum receive a diploma as if they had graduated from a mainstream school.

For children living in other parts of the country, Milan Petrovic has established attached classrooms, which are adjoined to mainstream schools in their local communities. The educators and experts working in the attached classrooms are employed by Milan Petrovic and the attached classrooms are paid for by the local municipality.

High School

The high school programme at Milan Petrovic is inclusive of all children with disabilities, irrespective of impairment or diagnosis. As in the elementary school programme, children can complete either the curriculum of mainstream schools or an adapted curriculum that professionals at Milan Petrovic develop according to each child's needs. Children completing the mainstream programme receive a high school diploma.

Even if a child is being educated through the special school programme, the school I support the child to attend mainstream school classes in subject areas that the child is able to learn in a mainstream environment. As there is no legislation to support this kind of educational programme, the Milan Petrovic School elaborates a memorandum of understanding with the mainstream school on a case by case basis. The mainstream schools that participate in this programme are generally those that have collaborated with Milan Petrovic in other projects and are aware of the importance of inclusive education.

Services to support people with intellectual disabilities in mainstream schools

The Milan Petrovic School also operates a service to support children with intellectual disabilities who attend mainstream pre-schools and elementary schools. When a teacher or other school staff member identifies a child who needs additional support in the classroom, they request permission from family members to contact Milan Petrovic for support. Milan Petrovic staff work alongside the child's teachers to assess the child. Based on this assessment, they develop an individual educational plan with the child and parents. Sometimes support is provided in the classroom, other times the support is provided in the Milan Petrovic School on a one-to-one basis. In some cases, the child is provided a place in Milan Petrovic. Milan Petrovic also provides support and

¹⁰² Based on field research carried out by Handicap International in 2008 and from information given in an interview with Slavica Markovic, principal of Milan Petrovic School in Novi Sad, October 2008.

¹⁰³ Interview with Slavica Markovic principal of Milan Petrovic School in Novi Sad, October 2008.

¹⁰⁴ Vojvodina is a unique region in Serbia as it enjoys some degree of autonomy with its own parliament and regional government.

counselling to teachers in mainstream schools on working with children who need more support. These services are currently financed by the Vojvodina Secretariat for Education on a pilot project basis. Since there is no legal framework for providing this type of support service within mainstream schools in Serbia, funding must be requested on an ad-hoc basis.

Training staff on inclusive approaches to education

The school continuously seeks funding opportunities to enable its staff to receive training on inclusive education approaches in other countries. Through project funding from the Vojvodina Secretariat for Education, Milan Petrovic has provided overseas training for its staff on innovative educational methods including Montessori and Marte Meo. Staff completing these training courses are licensed and registered by educators abroad, but these licenses are not yet officially recognised in Serbia.

E. Overcoming barriers

Developing services despite inadequate legislation

The current Serbian education legislation does not provide for an adequate education to children with intellectual disabilities. The provision of support services required to assist children with intellectual disabilities in school is not covered by the current legislative framework.

Because Milan Petrovic is registered as a special school, it can provide education and support services to all children with intellectual disabilities regardless of their diagnosis. It has also been successful in obtaining local funding for these services. The school has been able to expand its services beyond those of a special school as defined in the current legislation by negotiating each of the different types of services it provides with local and provincial authorities.

The staff team at Milan Petrovic works with local authorities including the Secretariat for Education, as well as the local categorisation commissions to raise awareness about the types of services they provide, as well as to share experiences and encourage the development of inclusive educational practices elsewhere. As a result, local authorities have a better understanding of inclusion and have been supportive of the services Milan Petrovic provides

Securing local support

Milan Petrovic has become well known in Vojvodina for providing inclusive educational services despite being registered as a special school. Early on in the school's history, it took an inclusive approach to education, following international trends in inclusion. The school has found that working at the local level allowed it to negotiate the types of services it offers and to develop services that are not yet regulated by legislation. The school monitored the needs of children and parents and develops and registers services according to actual needs. This practice helped it become recognised by professionals and local authorities as a resource centre on inclusive education. As such, Milan Petrovic was asked to establish an advisory board, reporting to the mayor of Novi Sad, about care of people with intellectual disabilities. The board has 11 members including non-governmental organisations, people with intellectual disabilities and their parents, private sector representatives and government authorities. The board carried out a needs assessment about people with intellectual disabilities in Novi Sad and proposed a strategy for their inclusion that was adopted by the city in 2000. Milan Petrovic was able to secure project funding provided by the city to implement the strategy and has expanded both the range of services it offers as well as the number of people participating.

Becoming a resource centre to promote inclusive education

Milan Petrovic has made it a priority to develop training programmes on inclusive education to support professionals in the shift toward inclusive education. At the faculty of Defectology¹⁰⁵ in Novi Sad, the principal of Milan Petrovic, participated in drafting a programme on inclusive education that is now a part of the formal curriculum. In Belgrade, while the faculty of Defectology, recently renamed the faculty of Special Education, has begun to discuss inclusive education, it is not yet a formal part of the national curriculum.

The staff at Milan Petrovic has developed a programme to train students at the faculty of Defectology in Novi Sad to develop expertise in including children with disabilities in mainstream schools. They also developed curriculum for a teacher training on inclusive education for educators who are currently unemployed and want to attain a prequalification. The training programme is supported by the National Bureau of Unemployment and provides 160 hours of training to participants. Milan Petrovic is hoping to use this training programme to stimulate a group of new educators to implement an inclusive approach to education in mainstream schools in Serbia.

In addition to assisting the faculty of Defectology in adopting a more inclusive approach, Milan Petrovic developed a course on transforming special schools into resource centres for inclusive education. This course supports and trains educators on inclusive education and in making mainstream classrooms truly inclusive. The course is focused on the Milan Petrovic experience, teaching other special schools to use this knowledge into their own communities. Through this course, Milan Petrovic is influencing professional development towards a more inclusive approach in education.

¹⁰⁵ The discipline of Special Education was called 'Defectology' in the region. Defectology is a Soviet era discipline that promotes special, segregated education as the best option for children with disabilities. 'Defectology' is an archaic term that it not used in contemporary practice, but some of the Faculties of Special Education/Rehabilitation in the region continue to use it.

F. Future plans

The leadership of Milan Petrovic will continue to lobby for the development and adoption of an inclusive education strategy in Serbia. The principal was part of a working group for the development of such a strategy for the Ministry of Education. Although the strategy has not yet been adopted, the Ministry is supporting its implementation through pilot projects. Milan Petrovic plans to use this opportunity to pilot inclusive education services and through their successful implementation, lobby for changes in policy at the national level.

Milan Petrovic actively works to strengthen collaboration between parents associations, disabled peoples organisations and other NGOs, to encourage partnerships and cooperation in future projects. They believe that by strengthening cooperation among stakeholders, they will be able to raise greater awareness and to have greater influence on policy makers.

Milan Petrovic aims to expand its services to include adults with intellectual disabilities, so that learning can continue throughout a person's lifetime. They wish to create learning options for adults with intellectual disabilities and to support them in the continuation of their studies beyond the elementary school level.

Chapter 5: Access to Employment - Making Supported Employment a Reality in Croatia

A. Access to Employment: Overview

There are numerous barriers to employment for people with intellectual disabilities living in the region. These barriers include widespread stigma and discrimination, lack of access to education, massive, long term over-institutionalisation of people with intellectual disabilities, and very limited development of community-based services as alternatives to institutionalisation. The provision of supported employment services is crucial to ensuring that adults with intellectual disabilities have access to meaningful, paid work. The box below describes what is meant by 'supported employment services' and describes the range of services that are usually provided in such programmes.

Supported employment services:

Supported employment services are designed to enable people with disabilities to obtain and maintain employment on the open labour market. These services provide a range of assistance such as job seeking and coaching, equipment to help the person carry out their tasks, specialised job training and individually tailored support and supervision¹⁰⁶.

To date, there are very few examples of supported employment services in the region¹⁰⁷. The case study included in this chapter shows how the Association for Promoting Inclusion (API)¹⁰⁸, an NGO, has successfully piloted the first supported employment programme in Croatia that assists people with intellectual disabilities to obtain employment on the open labour market.

B. The situation in Croatia

Croatia is undergoing a period of intensive reform within the EU accession process. Despite this, the pace of reforms affecting people with intellectual disabilities is slow, and more focus must be given to supporting their inclusion in society. Although there are government action plans and strategies that call for deinstitutionalisation, decentralisation of services and the social inclusion of people with disabilities, these are not put into practice. A national disability strategy has been adopted but its implementation has been irregular and legislative reform has been both inconsistent and slow. Furthermore, the lack of coordination between the various responsible authorities leaves people with intellectual disabilities without support for their participation in society. The authorities responsible for employment lack the mechanisms to implement their own policies. The obstacles and discrimination people with intellectual disabilities face when trying to access jobs is very challenging because Croatia, as other countries in economic transition, has a high unemployment rate (12.4% in 2008)¹⁰⁹.

Access to employment

Croatia's constitution guarantees the right to work for all adults and the Law on Professional Rehabilitation and Employment of Persons with Disabilities provides for professional rehabilitation and employment training for people with disabilities. However, eligibility for social welfare benefits and professional rehabilitation programmes are based on the medical, rather than the social model of disability, and therefore do not take properly into account a person's capacity to do a specific job. Because many people with intellectual disabilities are deprived of their legal capacity, this also precludes their employment. People under guardianship can only be employed if their guardian agrees.

C. About API

API is an NGO that delivers comprehensive community services to people with intellectual disabilities with the aim of empowering them to realise their human rights and to participate in society as equal citizens. API's mission is to promote a society in which people with intellectual disabilities have equal opportunities, their contributions are valued, and their human rights are respected. API operates a sophisticated network of services that include: supported living for adults with intellectual disabilities, a prevention of institutionalisation programme, specialised foster family care and supported employment.

¹⁰⁶ More information is available on the Open Society Mental Health Initiative's website at: <http://www.osmhi.org/index.php?page=160>

¹⁰⁷ Open Society Institute EU Monitoring and Advocacy Program and Open Society Institute Mental Health Initiative, "Access to Education and Employment of People with Intellectual Disabilities: Summary Report for Croatia", (Open Society Institute EU Monitoring and Advocacy Program: Budapest) 2005 :1.

¹⁰⁸ Association for Promoting Inclusion Croatia (Udruga za promicanje inkluzije), more information available at: inkluzija@inkluzija.hr

¹⁰⁹ Source: Croatian Employment Service and Central Bureau of Statistics

With international donor support, API has established the first supported employment programme in Croatia to enable people with intellectual disabilities to work on the open labour market. Since 2000, when this programme started, API has found paid work or vocational activities for more than 100 people with intellectual disabilities in Croatia.

API currently provides supported employment services to people with intellectual disabilities who receive supported housing services, and to young adults with intellectual disabilities who have finished their vocational training (supported through an EU funded CARDS project in cooperation with a secondary vocational school). API also engages the media to inform both potential clients and potential employers about its supported employment services.

D. API's supported employment service

API believes that access to paid employment is an important way of enabling people with intellectual disabilities to live in the community as equal citizens. Therefore, it has made the development of supported employment services a key priority.

API defines supported employment as:

'...paid employment/vocational activities in which people with disabilities work in a mainstream work environment and receive support in accordance with her/his needs for as long as such support is necessary. The support is provided by a qualified job coach and gradually, when possible, the person's co-workers take over the role of providing support'¹¹⁰.

API's supported employment model assumes that all individuals, regardless of the nature or extent of their disabilities, should have the opportunity and support to work in the community. This means that there are no pre-requisite skills needed for job success. In practice, the task is not to identify and place trained and "work ready" individuals in jobs, but rather to locate and/or modify meaningful jobs in the community and provide training and supports to clients on the job site¹¹¹.

Establishing the supported employment programme

Receiving training on planning and delivering supported employment services from an experienced service provider was critical for API. API was aware that supported employment services for people with intellectual disabilities exist in other countries with similar socio-economic conditions to Croatia and they wanted to learn from those experiences. Through the Mental Health Initiative's Model Sites programme, API staff received training on supported employment services from the Salva Vita Foundation¹¹², an NGO that has provided supported employment services to people with intellectual disabilities in Hungary for over 15 years. Once trained, API adjusted its service provision to fit the Croatian context.

At first API's supported employment programme was closely linked to its supported living programme. API trained its staff who provide assistance in community living to also undertake the role of supporting people in their workplaces.

The supported employment programme is currently funded through the *CARDS Access to Employment: Social inclusion of people with intellectual disabilities*¹¹³ and with state funding that clients receive as part of the supported housing service (these funds cover each person's day to day support needs, and for some people this support includes the support of the job coach at their workplace).

Provision of support according to individual need

Each client who seeks employment through API's programme is assessed by the supported employment team. API assesses each individual using standardised tools that it has adapted from materials used by supported employment services in other countries. API also assess whether any adaptations will be required in the workplace.

The team talks to the client to find out about their background, their family, the environment in which they live, their capacities, their wishes, as well as the potential obstacles to finding a job. For example, if the client does not like loud noises or bright lights, the person making the assessment notes this in their file so that this information is taken into consideration when matching the client with a job.

After the assessment is made, an individual support plan is prepared which sets out what the client wants to achieve in employment and what is needed to reach this goal. The client's assessment is then entered into a database and compared with available jobs. If there is a match, API trains the client for the job. The type of training will depend on the person's needs but generally, it includes:

¹¹⁰ More information available on API's website at: http://www.inkluzija.hr/Html_Pages/Inkluzija_Program02.htm

¹¹¹ Zana Marie Lutfiyya, Pat Rogan, and Bonnie Shoultz, "Supported Employment: A Conceptual Overview", Center on Human Policy Research and Training Center on Community Integration Syracuse University, (Syracuse: 1988): <http://thechp.syr.edu/workovw.htm>.

¹¹² More information about Salva Vita Foundation is available at: http://www.salvavita.hu/?oldal_tipus=text&oldal_id=23

¹¹³ The EU funded CARDS project "Access to Employment: Social inclusion of People with Intellectual Disabilities" aims to support people with intellectual disabilities to find and maintain work/vocational activities in the open labour market. The project will be implemented through a partnership with the Centre for Education Zagorska and the Association for Self Advocacy. More information on the EU funded CARDS project is available on API's website at: http://www.inkluzija.hr/IndexENG_od2.htm.

- How to get to work, using public transportation
- How to dress appropriately
- How to become acclimatised to the new working environment
- How to carry out the job tasks and responsibilities.

Flexible and continuous support

The main type of support used by API is the “group support” model. Clients are placed in a group of no more than five people in one workplace with one job coach. The job coach provides support for each person in the group by accompanying the clients to their job and supporting them in their working environment. While API is aware that the individual model of supported employment is better because each client is given one to one support by a job coach, unfortunately financial resources are insufficient to provide this level of support to all clients.

Once a client has secured a job, the supported employment service continues to provide support by assisting the person in their interactions with the employer and helping the client become accustomed to the work environment. The level of support is designed to be flexible so that it meets the needs of each individual client and, when possible, continues or decreases according to the needs of the individual over time. In many cases, support from a job coach is permanent while the person is employed and in others, the support decreases over time.

The decision to end the support of a job coach is made by a team consisting of the client, the supported employment team, the job coach and the employee’s manager. Everyone on the team must be satisfied that the client is ready to work on their own.

Employment is not static in anyone’s life. Sometimes a client may wish to move to a different type of work or to a different position within the workplace, and support is needed for these transitions. In other cases, employment ends and support is required to help an individual find new work. API supports clients to move to new jobs if the current one does not suit them or they would like to try something else. API also supports employers to solve issues that may arise during employment, with the goal of ensuring long term employment.

Training and evaluation

API’s supported employment programme has eight job coaches who receive support from an expert team led by a Supported Employment Project Coordinator. Each job coach must attend the in-house training on supported employment when they join API. This is followed by practical training in which they shadow other job coaches for several days to learn about the specifics of their role.

An evaluation of the service and the staff is made annually. The aim of the evaluation is to assess whether each client’s needs are being met and to consider what changes could be made to improve the quality of the service. API also offers ongoing support and consultation to employers and co-workers to assist employees with intellectual disabilities to succeed in their jobs. In addition, informal evaluations are conducted by talking to the clients, employers and job coaches to assess how the services are working and what should be adapted to better suit the needs of the clients.

Working with families

In addition to supporting clients in establishing and maintaining relationships with employers, co-workers and job coaches, the service also recognises the importance of supporting clients by talking to their families about what kind of work they want to do and what they want to achieve. Whenever possible, the client’s family and home life are taken into account in developing an individual plan of support as there are aspects that might have an impact on the client’s ability to work. While recognising the importance of family support, API wishes to ensure that as far as possible each client is able to make their own decisions with regard to their work life, ambitions and goals.

Establishing strong links with employers

API has found that the best way of identifying potential employers is through contacts with the community and potential employers. Establishing contact with employers and maintaining good relationships is essential to the success of the supported employment programme.

At first, API focused on engaging employers with whom it had personal contacts and who had an interest in supporting the initiative. API also approaches large firms and international companies that have the capacity to hire people and might be interested in supporting the project as a part of their corporate social responsibility. Maintaining relationships with existing employers has been particularly helpful in API’s experience for breaking down stigma and forging new relationships with potential employers.

E. Overcoming barriers: API’s work to address the key barriers to equal access to employment

Addressing barriers created by guardianship

API has devised a way to overcome the obstacle of guardianship that prevents many people with intellectual disabilities from signing an employment contract. API has negotiated with employers to provide API a ‘donation’ that is equal to the salary of the employee. API then pays the salary to the client with this ‘donation’.

Demonstrating that people are able to work, with support

API seeks to challenge the widespread misconception that people with intellectual disabilities are not capable of contributing to the workforce by showing employers that they can work if provided appropriate support.

F. Future plans for the supported employment programme

Increasing job opportunities

API hopes to diversify employment opportunities for people with intellectual disabilities to ensure a wider choice in the kinds of work available. However, without Government funding for supported employment services, the number and type of employment opportunities that API can secure for its clients is limited. API therefore seeks to reach out to new employers by maintaining its profile in the business community by using media to raise awareness about the supported employment programme, targeting trade unions, employment bureaus and employers.

Securing a sustainable programme

API is working to ensure that supported employment services become part of the employment system in Croatia. One of the aims is to gain state support by becoming registered as a Supported Employment Agency that offers services to people with disabilities who have their legal capacity, a sustainable solution within the current Croatian legal framework. The goal is to provide services using an individual employment model with a job coach who is flexible in the amount of support they provide. In addition, through the formal establishment of the Work Centre, API intends to ensure that people deprived of legal capacity who have been categorised as having diminished work capacity can realise their right to work through paid vocational activities on the open labour market. Current legislation supports the establishment of such Work Centres which are to be financed through the Fund for Professional Rehabilitation and Employment of Persons with Disabilities.

Advocating for reform

API actively advocates and lobbies for change at the state and local level, such as amendments to the Law on Professional Rehabilitation and Employment of Persons with Disabilities related to the legalisation of paid supported work activities on the open labour market for people with reduced work capacity.

Chapter 6: The Importance of Self-advocacy for Community Living

This chapter describes the development of a self-advocacy movement in Croatia that challenges the perception that people with intellectual disabilities cannot advocate for their rights or speak for themselves. The work undertaken by the Association for Self Advocacy (ASA) in Croatia has shown that, with appropriate support and training programmes, people with intellectual disabilities can successfully develop and use self advocacy skills.

A. Self-advocacy: An overview

All people have the right to speak for themselves, to voice their opinions, and to make decisions that affect their lives. The concept of self advocacy is based upon this right. Self-advocacy for people with intellectual disabilities means people speaking out for themselves, either directly, or with support. Through advocating for themselves, people with intellectual disabilities can achieve self-determination by taking control over their life, making choices and having their voices heard¹¹⁴.

People with intellectual disabilities in the region often do not have the opportunity to speak for themselves, as the prevailing belief is that they are not capable of making decisions for themselves, or that professionals 'know better' what they want and need than they do. Therefore, in the region, the voices of people with intellectual disabilities are often missing from important debates¹¹⁵.

Self-advocacy defined by Self-Advocates Becoming Empowered (SABE), a US national self-advocacy organisation

"...independent groups of people with disabilities working together for justice by helping each other take charge of our lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It teaches us about our rights, but along with learning about our rights, we learn about our responsibilities. The way we learn about advocating for ourselves is by supporting each other and helping each other to gain confidence to speak out for what we believe in."

(Source: SABE 1991)

The types of activities self-advocates undertake include:

- Speaking about their rights and organising campaigns to raise awareness on issues affecting their lives
- Representing the views of people with intellectual disabilities on non-governmental and governmental committees
- Testifying about what life is like for a person with intellectual disabilities and talking about abuse and neglect they have experienced
- Supporting/training others to become self-advocates and supporting people to make choices and decisions for themselves
- Working to improve the quality of services
- Organising conferences and publishing newsletters¹¹⁶.

B. Beginning a self-advocacy movement in Croatia

The Association for Self Advocacy (ASA) in Croatia was established in 2003 with the support of the Association for Promoting Inclusion. ASA is the first and only NGO of people with intellectual disabilities in the country and in the region. ASA has 35 members, most of who spent the majority of their lives in institutions and now live in the community with support. The experience of living in institutions has united the members and has driven the focus of the group's work toward deinstitutionalisation and the right to live and to receive quality support in the community. Another focus issue is advocacy for the reform of the guardianship system in Croatia¹¹⁷.

API began to support self-advocates by establishing five self-advocacy groups (two in Zagreb and one in Bjelovar, Osijek and Sibenik) which met once a week. API provided them with training and support to learn self-advocacy skills including learning to speak up, learning to make decisions and learning about their rights. The self advocacy groups raise awareness about the rights of people with intellectual disabilities and publish a newsletter "Nas List" (Our Newsletter).

¹¹⁴ Open Society Mental Health Initiative self-advocacy brochure, "Self-Advocacy for People with Mental Disabilities", available at: <http://www.osmhi.org/contentpics/148/Self%20advocacy%20briefing.pdf>

¹¹⁵ Based on field research carried out by Handicap International in 2008.

¹¹⁶ European Coalition for Community Living, "Creating Successful Campaigns for Community Living: An Advocacy Manual Disability Organisations and Service Providers", (ECCL: 2008): 21. See also Open Society Mental Health Initiative: <http://www.osmhi.org/?page=148>

¹¹⁷ European Coalition for Community Living, "Creating Successful Campaigns for Community Living: An Advocacy Manual Disability Organisations and Service Providers", (ECCL: 2008): 21.

As the self-advocates became more empowered through the self-advocacy groups, they wanted to create their own association. In Croatia, people who have been deprived of their legal capacity (having been placed under guardianship) do not have the right to establish an association, so the formal association was established by those members who have their legal capacity. All people with intellectual disabilities regardless of legal capacity can participate in the association¹¹⁸.

ASA has worked on many national campaigns about the rights of people with intellectual disabilities, often in collaboration with partners, including mainstream human rights organisations. These partnerships have helped to highlight disability as a human rights issue and have brought visibility to the issues affecting people with intellectual disabilities in Croatia. Most recently, ASA, in cooperation with the Association for Promoting Inclusion, the Human Rights Centre and UNDP Croatia, launched a project on the implementation of the Convention on the Rights of Persons with Disabilities (CRPD). Self-advocates from Zagreb, Bjelovar, Osijek and Slavonski Brod will receive training on the CRPD and human rights. One of the products of this campaign will be a brochure on the rights guaranteed by the CRPD in easy-to-read format to make the text of the convention accessible to people with intellectual disabilities.

In addition to working at local and national levels, ASA has worked with several international organisations supporting people with intellectual disabilities including: Inclusion Europe, Inclusion International, the European Platform of Self-Advocates (EPSA) and European Coalition for Community Living¹¹⁹.

¹¹⁸ Ibid: 21.

¹¹⁹ More information about the Association for Self-Advocacy Croatia available at: www.samozastupanje.hr

Chapter 7: Conclusions and Recommendations

This report describes the work of organisations that have established innovative community-based programmes for people with intellectual disabilities in the region. While providing different services, a common feature of their models is that the focus of their services is to address the individual needs of their clients. Through this individualised approach, the organisations aim to support each client to best help that person participate in community life and achieve their fullest potential.

Although the organisations whose work is discussed in this report have faced difficulties that are particular to their countries, there are some significant barriers to community living that are common to the region. These are highlighted below together with recommendations on the action that governments should take to address them.

Developing a range of community-based alternatives to institutions

The case studies in this report show that governments have yet to develop cohesive strategies or provide the necessary resources to develop a range of community-based alternatives to long-stay institutions.

Recommendation 1: Commit to community living

Governments should develop policies and legislation to support the transition from a system of segregated institutional care to community-based services. Such policies should be developed in line with the rights set out in the CRPD. Policy should be developed in consultation with disabled people, their families and the organisations that will implement this transition by operating community-based services.

It is critical that Ministries and other authorities responsible for health, social welfare, education, employment, and housing work together to plan and implement the necessary steps to achieve this transition.

1. Removing the obstacles to the provision of community-based services

A major barrier for all five of the organisations profiled in this report is the lack of effective financing and implementation mechanisms to support sustainable community-based services. This has led to difficulties in obtaining government funding for community-based services, resulting in a reliance on donor funding or one time government grants and concerns about sustainability. As a result of their tenacity, vision and commitment, these organisations have found ways to overcome some of the barriers. As one of the organisation's representatives explained: "If the service does not exist in the law, it does not mean you cannot do it." The challenge is achieving sustainability by advocating for a shift in financing mechanisms from institutions to community-based services.

Recommendation 2: Take action to encourage the development of innovative and sustainable community-based services

Governments should consider what actions are required to support the provision of sustainable community-based services, in particular to ensure that NGOs as well as government agencies have opportunities to develop such services. This will require a range of measures such as reviewing existing financial and legal arrangements that are designed around institutional care and removing any restrictions on the development of community-based services.

2. Addressing the outmoded assessment procedures

The procedures for assessing and diagnosing children and adults with intellectual disabilities in the region are outmoded and need to be reformed.

Recommendation 3: Update the assessment procedures in line with outcome focused, person centred practices

Assessment procedures should be conducted by trained multidisciplinary teams. Assessments should be holistic, taking into account a person's strengths, wishes, goals and interests. The client and their family must be actively involved in the assessment process. The assessment process is dynamic, and outcomes should be evaluated on a regular basis vis a vis the individual's goals.

3. Preventing serious human rights abuses arising from the guardianship system

The guardianship system prevalent in the region gives rise to serious human rights abuses, including the arbitrary detention of people in long-stay institutions, with no right of appeal.

Recommendation 4: Reform guardianship

The guardianship system should be reformed into a legally recognised supported decision-making system that is based on the presumption that people have capacity to make decisions for themselves, supports people in

making decisions for themselves and sets out clear safeguards when decisions are being made on a person's behalf¹²⁰.

4. Developing a more inclusive education system

Children with intellectual disabilities continue to be segregated in special schools where the quality of the education is often very poor. Children with more severe intellectual disabilities often have no access to even special education in the region. Although in theory children assessed as having mild intellectual disabilities are eligible for mainstream education, in practice, many are placed in special schools. Children with intellectual disabilities who live in institutions often have no access to any form of education.

Recommendation 5: Adopt and implement an education policy that provides educational opportunities to all children, regardless of disability.

Education policies and legislation should be reviewed and amended so that all children with intellectual disabilities can receive education in their local communities, with the necessary support to enable their inclusion.

5. Ensuring access to employment for people with intellectual disabilities

There are significant barriers to people with intellectual disabilities obtaining paid employment, such as the lack of assistance available to people seeking employment and the lack of adequate on-the-job support, the guardianship system, and high general unemployment rates in the region.

Recommendation 6: Adopt measures to promote access to employment for people with intellectual disabilities

Legislation, policies and other measures should be adopted to enable people with intellectual disabilities to become employed. This should include the provision of vocational training and the development of supported employment services.

Conclusion

Through their courage, vision, leadership and long-term commitment, the organisations profiled in this report have shown what is possible now, despite the many barriers. They have developed models of best practice which can be disseminated across the region. However, achieving the transition from institutional care to the provision of community-based services on a national scale will require concerted effort from governments. It will be essential that people with intellectual disabilities and their families are equal partners and are actively involved in this process.

It is imperative that governments commit to the promotion of community living without delay. In the meantime, NGOs, self advocates and organisations of people with intellectual disabilities will need work together to demonstrate to governments that action must be taken to ensure that people with intellectual disabilities have the same right to participate in their communities as everyone else.

¹²⁰ Such reforms will need to be undertaken in accordance with the UN Convention on the Rights of Persons with Disabilities (CRPD), in particular Article 12 CRPD (Equal Recognition before the law).

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Annex 1: Glossary of terms

Community-Based Services are any services that are provided in a community, rather than in institutional settings. They include: early intervention services (for babies and young children disabilities), foster family care, inclusive education (to enable children with disabilities to be included in mainstream education), supported employment services (support for people with disabilities to work on the open labour market), supported housing services, advocacy and support for self-advocacy and self-determination, independent living skills training, supported decision making services, counselling for families and respite care¹²¹.

Community living is the term that refers to people with disabilities being able to live in their communities as equal citizens, with the support that they need to participate in every-day life, such as living in their own homes, with their families, going to work, going to school and taking part in community activities. It also means having choices and living with dignity. To support individuals to live an ordinary life, in addition to having individualised support, they need access to mainstream opportunities and services that are available to the general population. The term 'community living' is used in the report but another commonly used term is 'independent living' or, when referring to people with intellectual disabilities 'supported living'. Like community living, there is no precise definition of these terms – in essence, all of them mean having an ordinary life¹²².

Guardianship is a legal arrangement that allows a person ('the guardian') to make decisions on behalf of a person who has been found by a court (or in some cases an administrative body) to be unable to make decisions for themselves. People placed under guardianship lose their legal capacity (either partially or completely) to act or make decisions for themselves. In many cases this means that they cannot vote, get married, open a bank account, establish an organisation etc. In effect, many people under guardianship are denied their fundamental human rights. Often, a decision about placing someone under guardianship is made without the knowledge of the person¹²³.

Inclusive Education refers to a philosophy of education that recognises the right to education for all people, and addresses the educational needs of all learners in a non-threatening, supportive learning environment, including learners who were formally disadvantaged and excluded from education for various reasons. The practical implementation varies from context to context, depending on human and material resources, the state of development of the educational system and other factors, but inclusive education generally occurs in mainstream schools. It is an educational method that includes many different kinds of learners in the same classroom, instead of separating students according to their learning abilities. In an inclusive classroom, all children learn together in the same classroom¹²⁴.

Independent living is a philosophy and a global movement that advocates for the right of people with disabilities to live in a community, and their right to self-determination and is based on the premise that even people with the most severe disabilities should have the choice of living in the community. Living independently means a person with a disability living in the community, with appropriate supports, so that s/he may live with dignity and may make personal life decisions to the best of her/his ability. Support for the right of all people to live as independently as possible is integral to the process of deinstitutionalisation of people with intellectual disabilities¹²⁵.

Person-Centred Planning is a model of community-based service that puts the client at the centre of the life-planning process so that it can be tailored to their needs and wishes.

Supported Decision-Making is an alternative to archaic guardianship systems. It is an accommodation in a legally regulated decision-making process to protect a person's right to exercise self-determination. Supported decision making provides legal recognition and status to trusted others to assist in any aspect of protecting the personhood of an individual. It presumes that all individuals of legal age are persons before the law and have a right to self-determination and respect for their autonomy, irrespective of disability; that all adults are entitled to the presumption of capacity, irrespective of disability, and to the decision-making supports necessary to exercise capacity and reveal identity; that decisions are made interdependently with family, friends, and trusted others chosen by the individual, and will be recognized and legally validated¹²⁶.

Supported Employment services are designed to enable people with disabilities to obtain and maintain employment in the open labour market. These services provide a range of assistance such as job seeking and coaching, equipment to help the person carry out their tasks, specialised job training and individually tailored support and supervision¹²⁷.

¹²¹ Open Society Institute Mental Health Initiative Glossary of Terms: <http://www.osmhi.org/?page=309> Ibid

¹²² European Coalition for Community Living (ECCL), "Creating Successful Campaigns for Community Living: An advocacy manual for disability organisations and service providers", (ECCL: 2008): 71.

¹²³ ECCL, *ibid*: 71. European Coalition for Community Living

¹²⁴ Open Society Institute Mental Health Initiative Glossary of Terms: <http://www.osmhi.org/?page=309>

¹²⁵ Open Society Institute Mental Health Initiative Glossary of Terms: <http://www.osmhi.org/?page=309>

¹²⁶ Michael Bach, Canadian Association for Community Living, 2006.

¹²⁷ More information is available on the Open Society Mental Health Initiative's website at: <http://www.osmhi.org/index.php?page=160>

Supported living services for people with intellectual disabilities are an essential part of independent living. These services enable people to live in their own homes and help them participate in community life with flexible individualised support wherever needed¹²⁸.

¹²⁸ Open Society Mental Health Initiative Glossary of terms: <http://www.osmhi.org/?page=309>ibid

Annex 2: Recommendations of the Deinstitutionalisation and community living – outcome and costs: report of a European Study¹²⁹ (the DECLOC report)

Introduction to the DECLOC report

This annex sets out key recommendations made by a report published in 2007, *Deinstitutionalisation and community living – outcome and costs: report of a European Study*¹³⁰ (the DECLOC report). The purpose of the DECLOC report was to:

'...provide scientific evidence to inform and stimulate policy development in the reallocation of financial resources to best meet the needs of people with disabilities, through a transition from large institutions to a system of community-based services and independent living'.

Chapter 7 of the DECLOC report summarises the conclusions of the study and presents recommendations on how governments can take forward the process of developing effective services in the community as alternatives to long-stay institutions. Recommendations 1 and 2 are addressed to the European Commission and concern the collection of data and publication of statistics and are not included in this annex.

Recommendations 3 to 16 are addressed to Governments. The DECLOC report stresses the 'central role for vision and leadership by national and regional governments, working in close collaboration with representatives of users and their families'; the 'need for a comprehensive, long-term perspective, which considers all the costs and all the benefits of the process of transition', the 'need for creativity in developing solutions to the wide range of implementation problems which may emerge and learning from the process as experience and knowledge are gained of how to provide good services in the community'. The report also states:

'...the available evidence is that, once comparison is made on the basis of comparable needs of residents and comparable quality of care, there is no basis for believing that services in the community will be inherently more expensive than institutions¹³¹.'

The DECLOC report identifies four main areas of work that Governments must consider when taking forward this agenda for change:

1. Strengthen the vision of new possibilities in the community
2. Sustain public dissatisfaction with current arrangements
3. Create some practical demonstrations of how things can be better
4. Reduce resistance to change by managing incentives for the different actors in the process

For each of these four areas, the report makes a series of recommendations to governments, which are reproduced below. The report comments that these recommendations *'are derived not only from the evidence presented in this report but also from the growing literature on modernising services for disabled people and from the authors' experience as actors in this field'*.

Recommendations to Governments

Strengthening the vision of new possibilities in the community

3. Adopt policies in favour of inclusion

- 3.1 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.
- 3.2 Commit to stop building new institutions or new buildings in existing institutions, and to spending the majority of available funds to develop services in the community.
- 3.3 Specify the overall timetable and plan for transition from institutions to services in the community.

4. Develop legislative support for inclusion

- 4.1 Adopt legislation that promotes independent living and social inclusion.
- 4.2 Ratify the UN Convention on the Rights of Persons with Disabilities.
- 4.3 Prohibit discrimination against disabled people in services and facilities.
- 4.4 Prohibit use of public monies to build new institutions.

¹²⁹ Jim Mansell, Martin Knapp, Judie Beadle-Brown and Jeni Beecham, "De-institutionalisation and community living – Outcomes and Costs: report of a European Study. Volume 2: Main Report", (Canterbury: Tizard Centre, University of Kent): 101-104.

¹³⁰ Jim Mansell, Martin Knapp, Judie Beadle-Brown and Jeni Beecham, "De-institutionalisation and community living – Outcomes and Costs: report of a European Study. Volume 2: Main Report", (Canterbury: Tizard Centre, University of Kent)

¹³¹ DECLOC report, 100-102

- 4.5 Ensure that government agencies responsible for serving the population in defined local area are made responsible for serving disabled people as well.
5. *Strengthen the voice of disabled people, families and their advocates in policy*
 - 5.1 Support groups that commit to inclusion and the replacement of institutions with community services.
 - 5.2 Appoint disabled people, family members and their advocates who are personally committed to inclusion to official bodies.
 - 5.3 Provide training for disabled people and their families in how policy-making works and how they can influence it.
 - 5.4 Require policy-makers and civil servants to regularly meet disabled people, family members and their advocates who are personally committed to inclusion and to identify how to strengthen their voice in policy.
6. *Require professional bodies to make their policies consistent with supporting inclusion*
 - 6.1 Require that bodies representing or training or accrediting the professional practice of personnel working with disabled people adopt a commitment to supporting the inclusion of disabled people in their work. This should include both specialist staff working with disabled people and others who may provide services to disabled people in the course of their work (e.g. police officers, nurses in general hospitals).
 - 6.2 Ensure that arrangements for training (including continuing professional development as well as initial training) and accreditation include disabled people and are based on the principle of inclusion.
7. *Encourage media interest in and support of inclusion*
 - 7.1 Promote the policy of replacing institutions with services in the community through official information and public education programmes.
 - 7.2 Help people providing good-quality services in the community and the people they serve to publicise their work.
8. *Learn from best practice in other countries*
 - 8.1 Support visits by disabled people, families, advocates, service providers and decision-makers to learn from good practice in community-based services in other countries, and reciprocal visits from those countries; instead of visits to and from providers of institutional care.
 - 8.2 Support participation in international networks (such as the European Coalition for Community Living) which will enable people to learn about best practice.
 - 8.3 Require that professional training for personnel working with disabled people includes the study of best practice in services in the community in other countries.

Sustaining public dissatisfaction with current institutional arrangements

9. *Open institutions to independent scrutiny*
 - 9.1 Require institutions to permit members of the public, non-governmental organisations and the media to visit them and to meet residents, families, advocates and staff who wish to do so.
 - 9.2 Encourage institutions to promote their replacement with services in the community.
10. *Create inspectorates to protect and promote the rights of individuals*
 - 10.1 Create inspectorates (which include disabled people and other 'experts by experience') to visit services, meet residents, families, advocates and staff and monitor their living conditions and quality of life
 - 10.2 Publish the results of inspection visits.
 - 10.3 Enforce the findings of these inspectorates where individuals require protection or redress.
11. *Emphasise comparisons of quality of life*
 - 11.1 Encourage the description of living conditions and the quality of life of residents in institutions compared with (i) non-disabled members of the population and (ii) people of similar levels of disability receiving services in the community (elsewhere in the same country or in other countries); instead of the comparison with the same institutions in the past or with other institutions elsewhere.

Creating some practical demonstrations of how things can be better

12. *Create innovative services*
 - 12.1 Fund the development of independent and supported living in the community, using ordinary housing and providing the level of staff support each individual needs.
 - 12.2 Ensure that demonstration projects reflect best practice both in how they are set up and how they are run.
 - 12.3 Ensure that demonstration projects both bring people back home from institutions and serve local people on 'waiting lists', so that members of the community in which services are developed are more likely to be supportive and helpful.
 - 12.4 Ensure that demonstration projects include options both for accommodation and for occupation (education, employment or other day-time activities) to increase the likelihood of success.
 - 12.5 Support new forms of training and professional qualification to ensure that there are sufficient staff to support people well as new services develop
 - 12.6 Monitor the quality and costs of new services

13. *Include everyone from the start*

- 13.1 Ensure that schemes include people with more severe or complex disabilities early in the development process, so that experience of meeting their needs is gained from the outset.

Reducing resistance to change by managing incentives for different actors in the process

14. *Create new funding opportunities*

- 14.1 Set up mechanisms for individual budgets so that people can be supported to plan their new lives in a personally-tailored way
- 14.2 Create opportunities for new organisations to get involved in providing services in the community, outside the existing framework of institutional care, to pioneer the new models of support needed
- 14.3 Create financial incentives for local government to get involved in the inclusion of disabled people in their own community

15. *Remove obstacles to development of services in the community*

- 15.1 Create arrangements for contracting for innovative, local services, so that existing rules designed for institutional care systems are waived or modified to permit the development of services in the community.
- 15.2 Review rules for other relevant services such as planning, housing, employment, social security and health care to ensure that disabled people supported in the community can get equal access.
- 15.3 Work with the European Commission to ensure that EU rules on employment, health and safety and other areas of EU competence support rather than hinder the development of good services in the community.

16. *Make funding of new services contingent on quality*

- 16.1 Ensure that new services are only funded if they are of good quality, that quality is reviewed (using the experience of disabled people supported by the service as the primary measure of quality) and that funding is discontinued if services do not maintain acceptable standards.
- 16.2 Resist pressure to redevelop institutions or build new institutions as 'temporary' expedients.
- 16.3 International bodies, such as the World Bank and the European Commission, should not permit use of their funds to redevelop institutions or build new institutions.

