

Creating Successful Campaigns for Community Living



An advocacy manual for disability organisations and service providers

ECCL

European Coalition
for Community Living

NOVEMBER 2008

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The European Coalition for Community Living

The European Coalition for Community Living (ECCL) is a Europe-wide cross disability initiative working towards the social inclusion of people with disabilities by promoting the provision of comprehensive, quality community-based services as an alternative to institutionalisation. ECCL was founded in 2005 by Autism Europe, the Center for Policy Studies of the Central European University, the European Disability Forum, the European Network on Independent Living, Inclusion Europe, Mental Health Europe and the Open Society Mental Health Initiative.

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

ECCL works as a network of disability organisations, service provider organisations, research institutes and individual supporters. Thanks to its diverse membership, ECCL is able to monitor developments across Europe, influence the national and regional policy and support the efforts of its members by exchanging information and examples of good practice. ECCL publishes a Newsletter, organises an annual conference and maintains a website at www.community-living.info.

As from the beginning of 2008, ECCL has been part of the European Network on Independent Living (ENIL). Members of its Advisory Council are renowned disability activists and experts. ECCL is able to carry out its activities thanks to generous financial support of the Open Society Mental Health Initiative (Budapest, Hungary).

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Last but not least, ECCL would like to thank all the organisations that sent us descriptions of their advocacy activities. Unfortunately, for reasons of space, we were not able to include all of them. We will, however, create a space on our website www.community-living.info, where experiences like this can be shared in the future. Please note that the views expressed in the case studies do not necessarily represent the views of ECCL.

Preface

“Twenty-five years ago, John Evans made history when he moved out of residential care into his own flat. In doing so he was paving the way for thousands of others to follow suit...”

The Guardian, UK (22 October 2008)¹

An extract from John Evans’ account on how he achieved his vision of living in his own home is set out below.

From institutionalisation to community living:²

I came to Le Court³ in August 1978, and remained there until December 1983. Five years. It had never been my intention to stay that long. When I arrived I made it plain to everybody that my stay was only temporary and that I did not see myself spending the rest of my life there. I had a two year period in mind. I did not know how I was going to get out, but I was quite confident that I would find a way.

About a year after I arrived, a group of us began discussing the future. Well actually, we were always talking about “ways out” right from the beginning but we did not come up with anything until 1979. In the summer of that year I went to Taylor House, a small hostel for severely disabled students in Oxford. Something came alive from that experience.

¹ David Brindle, *Tireless champion of autonomy*, The Guardian, October 22, 2008. Available at: www.guardian.co.uk/society/2008/oct/21/john-evans.

² This is an extract from *Project 81 – One Step On* by John Evans, published by Hampshire Centre for Independent Living, available at: <http://www.leeds.ac.uk/disability-studies/archiveuk/HCIL/one%20step%20on.pdf>.

³ Le Court was a residential institution for 54 adults with physical and sensory impairments run by the charity Leonard Cheshire.

A number of us went there separately, and we all felt that if four students could live in a house and be supported with unskilled care, so could we. From then on there was no stopping us.

Project 81

This was the beginning of Project 81. Our small group set out to discuss other ideas with numerous other people, both in and out of Le Court. It was the beginning of a long and hard learning process.

At this time we tended to separate discussion of care needs from housing. This helped us to consider different ways of proceeding with each. So we never got caught up with orthodox solutions. We did not have any firm ideas how, for example, the care could be arranged, but we could see that just as the students at Taylor House received care, so could we.

We floated the idea that: if the authorities would give us a fraction of what they paid to support us at Le Court, we could find another way of meeting our needs. This was the first thing we really latched on to. We saw it as a wonderful idea. The general reaction though was that it was totally unrealistic!

First steps

Our first step in search of support was when we met with some of the Cheshire Foundation Trustees. Two were encouraging, but the remainder were extremely sceptical. The fear seemed to be that we would establish some sort of premises that would bring the name of the Cheshire Foundation into disrepute.

Later that year, we talked further with the Head of the Le Court Home, and the Cheshire Foundation counsellor, Gill Corney. Both were encouraging. Gill was particularly supportive of the alternative living plans that we were putting forward. She agreed with our wish to live in the community and thought it was our right to do so.

Early ideas

Our idea was to have a home like Taylor House, where a small group of disabled people could live together. We thought Southampton might be a good location, because it was a big city with a university. We thought that might make recruiting staff easier as well as having some “life”.

Formal recognition

Early in 1980 Peter Wade, a former resident of Le Court, joined our discussions, and we began to meet informally with Ann Parkes, the General Manager of the Cheshire Foundation Housing Association. We asked the Le Court Residents' Association to support an application for our formal recognition by the Home's Management Committee. In April 1980 this was granted. Project 81 was established as a Housing and Care sub-committee

of the Le Court Management Committee. We had our first official meeting in May 1980. By now we had decided to work with Ann Parkes and the Housing Association to get our group home.

A warning

Later that year we met Ken and Maggie Davis, a disabled couple who live in their own flat in Nottingham. They warned us against the group home idea as it had been something that they had thought about some five years previously, and found there was a real danger that it would end up just another institution. These warnings remained at the back of my mind from then on. However we still thought of Taylor House as a model and felt that what we were trying to do would not become another residential home because the people involved were aspiring to something different. Also, I could not see any other way of getting a home through the Housing Association, as the cash guidelines appeared too restrictive. I did not consider Local Authority housing because I did not think they would consider me. Somebody else at Le Court had recently been turned down by the Local Authority on the grounds that they were already adequately housed, and it seemed that if I went that way I would have to wait forever.

Westwood road

Immediately after we started looking for property in Southampton a suitable house in Westwood Road came to our attention. We set about trying to purchase it through the Housing Association. Exciting and hectic days followed as we worked on the planning and adaptations. I even went and lived in the area for a week to familiarise myself with the neighbourhood. All this was a learning process and I think each of us was slowly putting together what were at first just hazy ideas of alternative ways of living.

Early experiences of the statutory authorities

We began meeting with the Health Authority in the area as we knew our plans would involve them. Some of them thought our scheme was not financially viable and that there was no way we could get the support to cover the amount of care that we needed. They only thought of care support in terms of medically trained staff. Some of them told us that many of our demands were quite selfish and unrealistic, others just thought that we would not be able to cope.

We worked hard at selling our ideas to these people, attending numerous meetings over a long period. It was tough having to go to such lengths to promote something which we were all sure was going to work but we needed the support. After each meeting it always seemed to take so long before we got to the next stage in our negotiations. Fortunately we did not give in. Right from the start Peter Wade insisted that we should never compromise on the original vision. We never did really. We stuck to our guns right the way along and in the end, we did achieve our objective.

Why John's story is so important: Achieving change may take time but can happen with planning and persistence

In the late 1970s, when John Evans arrived at Le Court, it was standard practice in the UK for people with his level of support needs to be placed in long-term residential care homes, such as Le Court. As John recounts, he and the other members of Project 81 met with many practical difficulties and, more challengingly, had to negotiate with people who did not believe that he and his colleagues could achieve their goal of living in their own homes. The success of Project 81 was not only that the group were able to show that they could do so, but that they made sure that their ideas were widely disseminated, which in turn inspired many other people with disabilities to challenge the assumption that they should live their lives in institutional care.

The action of this small group of people has also led to substantial changes in law and policy. Some 25 years after John moved into Le Court, all the countries of the UK (England, Wales, Scotland and Northern Ireland) have national policies which promote independent living. Legislation on 'direct payments' (see the Glossary) now entitles people with disabilities to choose the kind of support they receive and where they receive it (they receive money instead of social care so that they can arrange their own services and support). Their campaign is described in more detail in Chapter 3.

All the original pioneers of Project 81 have continued to live independently, running their own personal assistants system schemes for more than 26 years. Sadly, Liz Briggs died in 2002. The other two members of the group – John Evans and Philip Mason are still high profile disability activists. Philip runs his own business. John is one of the founders of the European Network on Independent Living and the European Coalition for Community Living.

While people with disabilities in the UK have come a long way since John's stay at Le Court, there is still much to do to ensure that all people with disabilities in the UK and across Europe are able to live with the same rights and freedoms as other citizens. As John's story shows, achieving this vision is possible, but this requires concerted efforts on the part of those individuals and organisations committed to community living. This manual seeks to provide ideas on the range of campaigning, lobbying and other forms of advocacy activities that can be used to turn this vision into a reality.

Advocacy for Community Living: Key Messages

Advocacy for community living is about:

- ▶ Promoting full citizenship and enabling disabled people to participate in everyday life of the community.
- ▶ Changing policies that maintain exclusion and segregation of people with disabilities from society.
- ▶ Improving the lives of people with disabilities and ensuring that they are able to live independently.
- ▶ Challenging the misconceptions around institutional care and community living, and showing why community living is better for people with disabilities.

Advocacy for community living can:

- ▶ Lead to change in legislation and the development of quality supports in the community for people with disabilities. It can also result in reallocation of public monies from institutions to increased support for community provision.
- ▶ Include monitoring the implementation of existing community living or de-institutionalisation policies and programmes.
- ▶ Raise awareness about the rights of people with disabilities and encourage debate about the situation of people with disabilities in society.

When planning advocacy for community living remember:

- ▶ It is useful to consider how existing policies impact on the lives of people with disabilities. Then one can show what aspects of these policies contribute to the institutionalisation and segregation of people with disabilities and what needs to change for community living to become a reality.
- ▶ Most organisations can find ways to undertake some form of advocacy – it does not have to be about big national campaigns. It can (and should) involve a broad range of issues at different levels, including the local level.
- ▶ Such work does not have to cost a lot of money. There are different means to achieve one's goals and objectives. Think about what you can do with the resources that you have that will most effectively deliver the results that match your organisation's mission and goals.
- ▶ People with disabilities should be at the centre of any advocacy activity and be involved in all steps of the process. Organisations led by disabled people should be encouraged and supported.
- ▶ Advocacy for community living is not complicated, but good planning increases its likelihood of success. All it takes is for you to define your goals and objectives and plan the action that you need to take, having identified your potential allies and checked that you can do this within available resources.

CHAPTER 1

Introduction

A recent report, supported by the European Commission, estimates that across Europe more than 1.2 million people with disabilities (regardless of the type of impairment), including children and young people, still live in institutions.⁴ The report confirms that institutional care is often of an unacceptably poor quality and represents serious breaches of internationally accepted human rights standards.

The segregation of people with disabilities is in itself a violation of their human rights and is contrary to both national and European social inclusion policies. Despite this, there is too little action being taken to develop alternatives to institutional care.

The purpose of this manual is to assist individuals and organisations who want to achieve the changes that are needed to ensure that people with disabilities can participate in community life as equal citizens. It provides information and advice on how to conduct campaigns and other activities to attain the goal of community living for all people with disabilities. We refer to this range of activities as ‘advocacy’ (see Chapter 2).

⁴ Mansell J, Knapp M, Beadle-Brown J and Beecham, J (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent. Available at: http://ec.europa.eu/employment_social/index/vol2_web_report_en.pdf.

Why Do We Need to Take Action to Promote Community Living?

In many European countries, the rights of people with disabilities are a very low priority for policy makers. There might be government policies which support social inclusion of people with disabilities, but what is written on paper and what happens in practice are often two very different things. For example, some countries continue to build new long-stay residential institutions for people with disabilities and fail to develop services in the community despite having a national de-institutionalisation policy in place. In addition to the lack of political will to develop quality community-based services for people with disabilities, there is often resistance to change on other levels, for example among service providers, staff of institutions, professionals and the general public. Moreover, organisations of people with disabilities are rarely consulted about decisions that concern them. This makes providing input into policy development and implementation very difficult.

The UN Convention on the Rights of Persons with Disabilities (“the Convention”) is an example of what can be achieved through lobbying, awareness raising and cooperation among different groups, to name just a few factors which led to its adoption in 2007. Thanks to the efforts of the global disability community over many years, the right to live in the community – contained in Article 19 – is now protected by this Convention which as from May 2008 is a legally binding treaty.

As the case studies featured in Annex 3 of the manual show, across Europe many organisations are already working towards making the Convention a reality – they are involved in getting new legislation in place, raising awareness about the importance of social inclusion of people with disabilities and promoting innovative models of services in the community as alternatives to institutionalisation. These case studies illustrate the important role disability organisations and service providers can play in advocating for community living.

What we mean by ‘community living’

The term ‘community living’ is used in this manual to mean 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. (For additional information, see the Glossary in Annex 1).

The importance of developing quality community services

The reason why so many people with disabilities are institutionalised is because in many European countries there are little, or no, community-based services. Accordingly, institutions are often the only available option. Quality, comprehensive community-based services must therefore be developed as alternatives to institutionalisation.

This manual is not intended to advise on how community based services can be developed. It can, however, be used to create an environment where the development of quality community-based services for people with disabilities is possible, or where it will be easier or take less time to achieve. For example, in order for a shift from institutional care to community living to take place, countries must adopt strategies for the development of services in the community and the closure of institutions. As part of their advocacy work, organisations might decide to influence how these strategies are being developed – reminding their government that it should involve people with disabilities in this work, that such strategies must respect the human rights of people with disabilities and promote their social inclusion.

Using the Manual

The manual provides a range of ideas that are intended to be useful to everyone wishing to advocate for community living. It is designed to help readers think about how they can apply, and where necessary adapt, the ideas and suggestions to the particular situation. The manual covers the basics of advocacy work, as well as issues specific to advocating for community living. It can therefore be used both by those new to advocacy and those who are just looking for some new ideas for future advocacy activities.

The following chapters describe the three main components of advocacy work. Chapter 2 explains what we mean by advocacy and user led or self advocacy. Chapter 3 then takes you through seven steps in advocacy planning. These start with advice on how to choose what issue to work on and end with ideas on how to structure your advocacy strategy or plan. Chapter 4 then goes on to activities you can use to implement your strategy, such as lobbying, running a campaign, staging a protest etc.

The chapters include definitions of relevant terms, practical tips, questions to consider and examples illustrating how different ideas can be applied in practice, as well as suggestions for further reading.

The manual also includes some key messages to give when advocating for community living as well as information about why community living should be considered a policy issue. The manual has four annexes – a Glossary of relevant concepts (Annex 1), International policies relevant to advocating for community living (Annex 2), Case studies (Annex 3) and

Notes for trainers (Annex 4). The manual can be used without going through a training session, but those who would like to organise a workshop might find it useful to look at the points arising from the September workshop.

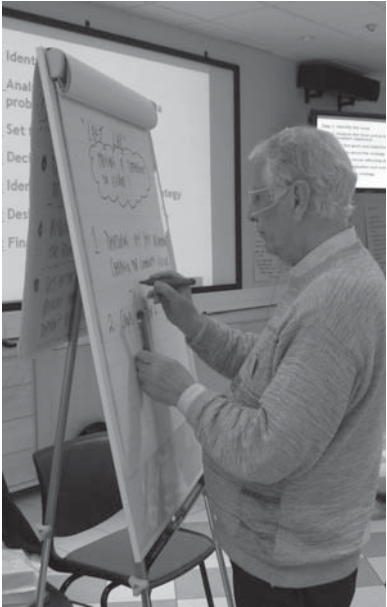
How to get copies of this manual

The manual can be downloaded from the website of the European Coalition for Community Living www.community-living.info. The annexes with case studies and policies will be regularly updated, to make sure that the information included is relevant.

The manual is currently available in an English easy-to-read version. In the future we hope that it will be translated into other languages. Please check ECCL's website for updates.



Discussing advocacy strategies at the ECCL workshop on 11 September 2008 in Drammen, Norway



CHAPTER 2

Advocacy: An Introduction

What is Advocacy?

Advocacy is an organised course of action to achieve change. In the context of this manual, advocacy is about concerned citizens joining with others to campaign for community living and social inclusion of people with disabilities by changing policies, practices and attitudes that perpetuate their exclusion and segregation.⁵

If we imagine the situation where many people with disabilities still live in long-stay institutions as Point A, and the situation where people with disabilities have the opportunities and support to live their lives as part of a community as Point B, then advocacy will be about arguing for a course of action that will get us from Point A to Point B. It would, however, be unrealistic to expect that a single advocacy strategy could cover a process as long and complex as this one. More often, advocacy strategies will be focused on one or more of the range of steps that need to be taken in the process of moving from Point A to Point B. Each of these steps will lead us closer to the final goal (people with disabilities living as equal citizens in society). For example, an organisation in Croatia (see case study at the end of this chapter) worked towards changing the law relating to “guardianship” (see the Glossary for an explanation of this term), so that people under guardianship could regain their right to make decisions for themselves and have more control over their lives. This is an important step in ensuring that people with disabilities can live in the community as equal citizens.

⁵ It is possible that in your language there is no equivalent to the word ‘advocacy’. This does not mean that the concept of advocacy itself does not exist, it is simply that you might refer to it in a more descriptive way, such as ‘fighting for one’s rights’, ‘campaigning’, ‘lobbying’ and so on.

We refer to the process of deciding how best to design the campaigns and other activities required to influence public policy and other processes required to get from Point A to Point B as ‘strategic planning’. This involves specifying objectives and working out the best ways of achieving them.

Top Tips for Disability Policy Advocacy⁶

- ▶ Understand the historical and policy context, and use it to explain what change is necessary and why. For example, this can mean being familiar with the country’s social inclusion policies, which you can use to show that changes are needed, so that the policies are properly implemented. You can then show what is needed to make this happen (for example, the provision of particular services to people with disabilities).
- ▶ Articulate values, principles, and goals of disability policy. For example, what you understand by independent (or community) living might be different from what is understood by policy makers. It is, therefore, important that you have a clear idea about what you want to achieve, that you are able to explain it to others and convince them to support you.
- ▶ Understand that policy is made in a political context. This means being aware of how the system works (i.e. how law and policy is developed), who the key players are in this process and how to motivate them to support your demands. If you do not know how the system works, it is important to find people who can help you understand it.
- ▶ Understand the needs of policy makers. For someone to support you, they need to be motivated. It is important to understand this in advance, so that you can build a good relationship with policy makers. Before starting a campaign, you might want to draw up a list of things that could make a key policy maker be supportive of your goals.
- ▶ Make alliances. If you are able to show that many people are in agreement with what you are asking for, you are more likely to succeed in achieving your goals.
- ▶ Prepare a plan/strategy. While being flexible and being able to react to new circumstances is very important, it is also crucial to have an overall plan with short and long-term objectives, activities, expected outcomes, the needed resources and key moments.
- ▶ Understand the power of personal stories tied to policy objectives. Use personal stories to demonstrate positive impact of proposed policy change.
- ▶ Understand the importance of long-term relationships with stakeholders.
- ▶ Recognize your strengths and limitations.

⁶ Adapted from the following source: Robert Silverstein, *Top Ten Tips for Disability Policy Change Agents on How to Influence Policymakers and the Policymaking Process*, Center for the Study and Advancement of Disability Policy. Additional information: <http://www.disabilitypolicycenter.org>.

There is a range of activities that can be used to highlight the issue that you have decided needs to be addressed and help you engage with decision makers at the local, national, European or international level. These are explained in more detail in Chapter 4.

Principles of Good Advocacy⁷

- ▶ **Focus:** set specific objectives; use your energy and resources effectively; make sure that you have the information that you need (if necessary carry out additional research);
- ▶ **Clarity:** your objectives and strategy must be communicated clearly (both within your organisation and to the public); all actions taken should be a step towards reaching your objectives;
- ▶ **Credibility:** the information you produce must be trusted and reliable; your motivation (for the actions you are taking) should be clear;
- ▶ **Relevance:** it is important to have a real connection with the people whose interests you are trying to advance and offer a solution relevant to the problem;
- ▶ **Timing:** remember that the same action will have different effects at different times;
- ▶ **Commitment:** if something does not work, try a different strategy or technique; you should always think of who you are trying to influence.

What is User Led and Self Advocacy?

User led advocacy refers to actions that are designed and implemented by people with disabilities.

Self advocacy is the name commonly given to user led advocacy, designed and implemented by people with intellectual disabilities.

Some of the reasons why advocacy by people with disabilities can be a major factor in achieving change are listed below. Case studies in the main text and in Annex 3 describe the establishment of user led or self advocacy groups and give an account of activities they undertook – they range from advocating for direct payments in the UK, lobbying for change in the guardianship system in Croatia and speaking to politicians running in elections in Romania.

⁷ Adapted from the following source: Amnesty International, *Amnesty International Campaigning Manual*, 1997. Available at: <http://www.amnesty.org/en/library/asset/ACT10/002/1997/en/dom-ACT100021997en.pdf>.

Reasons to promote and support user led and self advocacy groups:

- ▶ Advocacy empowers people and makes them ‘visible’. This is especially important in countries where people with disabilities are marginalised and segregated from the rest of society;
- ▶ Hearing a person speak from their personal experience can have a bigger impact on those in a position of power;
- ▶ By being organised in user led or self-advocacy groups, people with disabilities stand a better chance of getting on various governmental committees and working groups, from which they can voice their concerns and demands.

Examples of Activities Run by Self Advocates⁸

- ▶ Speaking up about their rights and telling other people about their rights.
- ▶ Helping people to speak up for themselves and helping and supporting people to make choices and decisions.
- ▶ Training and talking to other people about self-advocacy and issues concerning people with intellectual disabilities.
- ▶ Making information more accessible.
- ▶ Helping to make changes to improve people’s lives.
- ▶ Representing the views of people with intellectual disabilities on committees in the governmental and non-governmental sector.
- ▶ Working to improve the quality of services.
- ▶ Planning conferences and attending other self-advocacy conferences.
- ▶ Producing newsletters.
- ▶ Speaking up about bad things that were happening to them.

⁸ Source: Linda Ward, *Innovations in Advocacy and Empowerment for People with Intellectual Disabilities*, Lisieux Hall Publications, 1998.

Activities of a Self-advocacy Group (Croatia)

This case study describes the work of the Association for Self-Advocacy (ASA) in Croatia. ASA was established in 2003 and is still the only association of persons with intellectual disabilities in the country.

It is very difficult to establish an association of persons with intellectual disabilities in Croatia and the region. When a person with intellectual disabilities turns 18, s/he is almost automatically deprived of legal capacity by being placed under guardianship (see Glossary). Among other things, this means that they cannot be members of, or form, associations. ASA therefore introduced a special membership category, which allows people without legal capacity to participate. However, they cannot be elected to the organisation's governing bodies (as this is prohibited by Croatian law).

ASA provides the space and the necessary legal framework for participation of people with intellectual disabilities in public life, on their own terms and together with other groups. This is different from being represented by parent organisations, professionals or service providers, as it allows people with intellectual disabilities to take part in the society on equal terms with others.

ASA has 35 members. The majority spent most of their lives in institutions but now live in community based settings. The experience of living in institutions has determined the main goals of the association. These are deinstitutionalisation and the right to live and to receive quality support in the community. In addition, ASA advocates for the revision and abolishing of the guardianship system. ASA believes it is important that people with intellectual disabilities show how the system of guardianship violates their rights, and at the same time fails to secure the necessary legal protection.

ASA has been successful in cooperating with other parts of civil society, especially mainstream human rights organisations. This has resulted in joint projects between disabled and non-disabled people and has helped move away from a discourse focused on disability to the one focused on human rights. It has also led to a change in public perception. People with intellectual disabilities are now seen as equal partners in projects rather than a group dependent on someone speaking on their behalf. It has also helped increase the visibility and influence of people with intellectual disabilities in the Croatian society.

In addition to working on the national level, ASA has been successful in establishing an international presence by working through Inclusion Europe, Inclusion International, the European Platform of Self-Advocates (EPSA) and ECCL. Because of this, ASA was able to expand its activity areas, which are still limited in Croatia (because of legal restrictions).

While ASA's lobbying for revision of the guardianship system has not as yet been successful it has resulted in guardianship being perceived as a human rights issue in Croatia.

Further information: Association for Self-Advocacy, e-mail address: samozastupanje@zg.htnet.hr, website: www.samozastupanje.hr.

Questions for discussion:

- ▶ Is there a self-advocacy organisation in your country? Is there an organisation of users or survivors of psychiatry in your country?
- ▶ Are there any legal restrictions which would make the establishment of such groups more difficult? If yes, how could these be overcome?
- ▶ How can your organisation encourage the establishment of user-led or self-advocacy organisations?



A meeting of self-advocates from the Association for Self-Advocacy in Croatia

© Association for Self-Advocacy

Community Living as a Policy Issue

The promotion of community living involves the wide range of policies⁹ that impact on people's every-day life. They include education, employment, housing, health, transport, social policy, and anti-discrimination. This is in contrast to life in an institution, where everything is dealt with within the institution itself and the residents do not have access to services used by other citizens. Accordingly, before embarking on advocacy work, think about what aspects of these policies are relevant to the issue that you want to address, in particular, the action that needs to be taken to effect the necessary change.

Given the range of policies relevant to community living you may need to work with a number of government departments. Which ones will depend on the political-administrative system of your country. You will need to decide whether the issue you wish to address needs to be raised at local, regional or national level and find out which department, body or individual is responsible for this issue. For example, the national or regional government is usually responsible for legislative reform. If you want to lobby on local issues, for example expanding existing support services, or making public buildings accessible for people using wheelchairs in your town etc., the issue probably needs to be raised at the local level (council, mayor etc.). The table below will help you identify who to target with your advocacy activities.

⁹ The word 'policy' is generally used to describe a field of government activity with a set of decisions and a common long-term objective (or objectives) affecting or relevant to a given sector, such as education policy, employment policy etc. The implementation of policies is supported by legislation, plans, programmes and projects.

Actors in Policy Making

- ▶ The legislature – the national Parliament, regional assemblies – is responsible for passing laws.
- ▶ The executive – the Prime Minister or the President, the Government, the local Mayor – is responsible for the implementation of policies.
- ▶ The judiciary (the courts) is responsible for the interpretation of laws and enforcement of laws.
- ▶ Government administration – made up of civil servants – is responsible for the preparation and administration of programmes, and works together with the legislature and executive to develop legislation.
- ▶ Other potentially important actors include the media, universities, disability organisations, professional organisations, non-governmental organisations, powerful individuals etc.

To engage in successful advocacy, it is important to have a good understanding of the policy environment of community living in your country. The following questions might be helpful in this.

- ▶ *What policies influence community living in your country? Which of these are helpful or not helpful?*
- ▶ *Which authorities are responsible for them? How is responsibility divided between different levels of government?*
- ▶ *Are there any formalised opportunities for participation in policy-making (such as public consultations etc.)? What are these opportunities? Does your organisation participate in any of them?*

International policies (conventions, resolutions, recommendations, action plans, commitments etc.) can be valuable tools to legitimise and support demands at the national level. European or international commitments can be an effective perspective for reaching policy makers when national policies are unlikely to be passed. For example, the process of EU enlargement in 2004 (Czech Republic, Estonia, Cyprus, Latvia, Lithuania, Hungary, Malta, Poland, Slovakia and Slovenia) and 2007 (Romania and Bulgaria) – and the need to meet the accession criteria – provided a good opportunity to raise the issue of human rights abuses in institutions and demand government response.

An example of this is the campaign against the use of cage beds in mental health and social care institutions in four EU accession countries (Czech Republic, Hungary, Slovakia and Slovenia), carried out in 2003 by the Mental Disability Advocacy Centre (MDAC). They

produced a report entitled “Cage Beds: Inhuman or Degrading Treatment or Punishment in Four EU Accession Countries”¹⁰ and presented its findings to the European Parliament. Since then, the four countries covered in the report have banned the use of cage beds in most (but unfortunately not all) of their institutions for people with disabilities.

Annex 2 presents the international context of community living in the policies of the European Union, the United Nations and the Council of Europe.

CASE STUDY

Strasbourg Freedom Drive (Europe-wide initiative)

This case study is an example of a European lobbying event, organised by the European Network on Independent Living (ENIL). It brings together people with disabilities and consists of meetings with Members of the European Parliament, the European Parliament Disability Intergroup and officials from the Council of Europe.

In 2003 and every two years since then (2005 and 2007, with a further event being planned for 2009), people with disabilities from across Europe gather in the democratic centre of Europe – Strasbourg. During the “Strasbourg Freedom Drive”, as the event is called, members of the European Network on Independent Living (ENIL) go to the Council of Europe and the European Parliament, where they meet with their national MEPs and members of the Disability Intergroup. By doing so, they aim to encourage the European Union and the Council of Europe to promote and develop new policies and strategies, which will include ENIL’s “key demands” for independent living of people with disabilities.

The key demands of the 2007 Freedom Drive were: deinstitutionalisation; the right to personal assistance for people with disabilities across Europe; setting aside of 5% of foreign development aid for disability concerns; ratification of the UN Convention on the Rights of Persons with Disabilities; adoption of a disability specific anti-discrimination directive; and the freedom of movement for Personal Assistance services in the EU. Although ENIL welcomed recent developments in the form of treaties and action plans, it highlighted the need for progressive action on many issues.

¹⁰ The report is available at: http://www.mdac.info/documents/118_MDAC_Cage_Bed_Report.pdf.

Components of the 2007 Freedom Drive

The 2007 Freedom Drive began with an informal gathering at the provisional headquarters in Strasbourg (the European Youth Centre). This provided an opportunity for participants to examine the agenda, to meet people from other countries and share experiences. Speeches were made by the leading activists on the purpose of upcoming meetings and encouragement was given to participants to challenge their MEPs.

Following the introductory meeting, participants made their way to the European Parliament for meetings with their national MEPs. Participants represented Germany, Sweden, Portugal, Belgium, UK, Bulgaria, Ireland and Norway. All meetings were prepared well in advance by the organising team of the Freedom Drive, which contacted individual MEPs.

The main component of every Freedom Drive is the march. This year, it began in the morning at one of Strasbourg's parks – Parc du Contades – where participants in the march (the so-called Drivers) rehearsed chants and prepared signs and banners. A participating organisation from Norway (ULOPA) handed out T-shirts with the logo of the Freedom Drive to all the Drivers. After this, everyone made their way along the streets of Strasbourg for around 3 km to the European Parliament. After arriving, the Drivers stopped outside the Parliament for a short break, before crossing and entering the Parliament square. Here, speeches were made by representatives from different countries and much media attention was received (the Parliament has its own journalists and Member States also have journalists who report from the Parliament). Richard Howitt, President of the Disability Intergroup, Jan Andersson, Chairman of the Committee on Employment and Social Affairs, and the President of the European Parliament, Hans-Gert Pottering came out to meet the Drivers and accept the petition. All of them were also contacted well in advance by the organising team and asked to meet with the Drivers.

After this, the Drivers attended the meeting of the European Parliament Disability Intergroup. Keynote speeches were given by representatives of the European Network on Independent Living Network and the European Coalition for Community Living. After the presentations, delegates were able to ask questions directed at MEPs. Meetings of the Disability Intergroup are open, therefore representatives of other organisations could also take part (by registering in advance with the Parliament).

Two meetings were also held at the Council of Europe, with representatives of the unit responsible for disability issues. Both meetings were attended by a smaller

group of Drivers and focused largely on the implementation of the Council of Europe Disability Action Plan 2006–2015.

The next rally of disabled activists in Strasbourg is planned for 2009. In these two intervening years, ENIL will follow the extent to which its demands have been met and continue working with the relevant stakeholders. ENIL members were asked to actively campaign in their own country and to do a national equivalent of the Freedom Drive. In this way, activities at the European level could be complemented by those at the national level – something that is very important, as most legislation in the social policy area still comes from the national governments.

***Further information:** European Network on Independent Living, e-mail: secretariat@enil.eu, website: www.enil.eu.*

Questions for discussion:

- ▶ Have you considered organising a Freedom Drive in your country or approaching the European institutions in a similar way?
- ▶ Would you be interested in joining ENIL's Freedom Drive in Strasbourg? (The next one is in 2009.)



A meeting with the President of the European Parliament during the Strasbourg Freedom Drive

CHAPTER 3

Planning for Advocacy

Preparation, patience and persistence increase the likelihood of positive policy change.¹¹ Preparation might simply mean writing down a few thoughts before a meeting but it might also include the preparation of an advocacy strategy. This chapter¹² presents the steps of planning that can be useful for drafting an advocacy strategy, planning a campaign or other advocacy activity (including local actions, such as addressing neighbourhood opposition against new services etc). It might be particularly helpful to organisations considering larger-scale campaigns or applying for funding to carry out advocacy-related activities.

Planning is the process of setting goals and deciding on how to achieve them. Although good planning alone does not guarantee success, it helps to achieve better results. Planning helps to:

- ▶ clarify goals and objectives;
- ▶ measure progress;
- ▶ use resources more efficiently;
- ▶ respond to changes in circumstances and environments, and
- ▶ find allies and build coalitions.

¹¹ Source: Robert Silverstein, *A Congressional Insider's View: How to Be an Effective Disability Policy Change Agent*. Additional information: <http://www.disabilitypolicycenter.org>.

¹² The chapter is based on *The New Weave of Power, People & Politics: The Action Guide for Advocacy and Citizen Participation* by VeneKlasen, Lisa and Valerie Miller (Stylus Publications, 2007).

How to Plan Well

- ▶ **Keep it simple.** Planning does not need to be a lengthy and complicated exercise. Use simple tools and common sense.
- ▶ **Clarify jargon at the start.** Avoid jargon or technical terms as much as possible. But if you have to use them, explain what you mean by them. Words such as deinstitutionalisation, community living etc. are widely used in policy documents, but people might mean different things by them. (The Glossary in Annex 1 will help to clarify some of these terms.)
- ▶ **Make your values and assumptions clear.** Advocacy is never a value-free process, make your motivation and values clear from the beginning of the process.
- ▶ **Bring in people with different backgrounds, skills and expertise.** Consider the benefits of building coalitions with various other stakeholders, people or organisations which have an interest in the issue. (Coalition building is discussed in more detail in Chapter 4.)

Ensuring Participation and Involvement of People with Disabilities

There are two types of disability organisations – organisations *of* disabled people, which are led, managed and mostly staffed by people with disabilities, and organisations *for* disabled people, which might not have any people with disabilities among their staff or leadership. Organisations *for* disabled people are often parent organisations or charities representing the interests of people with disabilities. There are also other organisations – such as human rights organisations, children’s and women’s rights organisations, minority rights organisations – which might carry out disability-related activities.

Regardless of who is doing advocacy for community living, it is important that people with disabilities are consulted and involved in the planning and design of activities.

This is important for the following reasons:

- ▶ Everybody has the right to be involved in decisions about issues affecting their lives.
- ▶ To challenge the general view that people with disabilities are passive recipients of care. People with disabilities will be able to show that they are capable of formulating opinions and expectations regarding policies that impact on their lives.
- ▶ To make sure that you are on the right track and lobbying for issues of real importance.
- ▶ To give strength to your demands by showing the support of those most affected by the issue.

Ways of involving people with disabilities in planning

There are different ways of involving people with disabilities in the planning process, depending on the profile and resources of your organisation. Some of them are:

- ▶ Supporting user-led or self-advocacy. (See Chapter 2.)
- ▶ Making an alliance with organisations of people with disabilities. (See Chapter 4.)
- ▶ Making people with disabilities part of the team responsible for planning.

Difference between active and passive participation

Not all forms of participation are good. There is a fundamental difference between engaging people with disabilities in advocacy or just asking them to comment on your proposals.

Make sure you **AVOID**:

- ▶ **Passive participation** – when people are invited to sit at meetings but they are not consulted or are prevented from contributing (either because they do not receive information or information is not accessible for them, or they are not provided an opportunity to express their views), or they contribute but their views are ignored.

Instead, **ENSURE**:

- ▶ **Interactive participation** – giving people the opportunity to participate on an equal basis and the power to influence the process.

You can also **SUPPORT**:

- ▶ **Self-mobilisation** – people with disabilities themselves initiate action and control the process.

Finding a good way to involve people is a challenge for all organisations, including organisations of people with disabilities. Participation should give a real voice to people with disabilities and empower them to contribute. Participation should also ensure that the views of disabled people of all ages, women and men, and people from different ethnic and cultural backgrounds are represented in the planning process and in the advocacy strategy.

How to make participation work in planning?

- ▶ Involve a broad range of **people from diverse backgrounds and positions**.
- ▶ **Ensure accessibility**. Select the most appropriate and accessible methods to work with people with different needs. Whenever possible, work in small groups and use participatory methods.
- ▶ **Value different perspectives**. Everybody has the right to participate and express their views. Create an environment where everybody is free to communicate and is treated with dignity and respect.

- ▶ **Build commitment.** Show people that their contribution and involvement in the process is important and their input makes a difference.
- ▶ **Allocate adequate resources to planning.** Participation requires time and skills.

Steps in Planning an Advocacy Strategy

Planning is presented here as a series of steps that follow each other in a sequence. Each step builds on the previous steps:

- Step 1: Identify the issue
- Step 2: Analyse the issue and produce a problem statement
- Step 3: Set the goals and objectives
- Step 4: Decide about the Strategy
- Step 5: Identify forces affecting the Strategy
- Step 6: Design evaluation and monitoring
- Step 7: Finalise the Strategy

Step 1: Identify the issue

Begin by identifying the issue that you would like to change. Issues or problems can be identified in a number of ways:

- ▶ From your own experience by either facing them in your everyday life or in the work of the organisation.
- ▶ Users of services or people whom the organisation represents can raise problems informally (e.g. in conversations) or in more formal consultations.
- ▶ By doing relevant research, such as “desktop” research (e.g. analysis of statistics) or participatory research, including interviews, surveys, focus groups, budget analysis etc. For example, through a budget analysis, you might find out that even though your local government has made a commitment to start a supported employment programme, there is no money allocated for it in the budget proposal.
- ▶ The “Toolkit for Community Living”, produced by the Tizard Centre (University of Kent) can help you explore and identify areas and issues for policy change. The toolkit goes through recommendations of the project ‘Deinstitutionalisation and Community Living – Outcomes and Costs’¹³ and suggests a number of questions that organisations can go through to identify where their country stands in relation to these recommendations.

¹³ Mansell J, Knapp M, Beadle-Brown J and Beecham, J (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent. Available at: http://ec.europa.eu/employment_social/index/vol2_web_report_en.pdf.

The Toolkit can be downloaded from http://www.kent.ac.uk/tizard/research/eu_decl_conference/Toolkit%20for%20change.pdf.

Step 2: Analyse the problem and produce a problem statement

Once you have identified the issue, explore and analyse it and produce a problem statement. A problem statement is a short description of the problem in a specific context, based on a more in-depth analysis of the issue.

It is useful to consider the following aspects:

- ▶ Who is affected?
- ▶ What are the consequences of the problem (direct and indirect)?
- ▶ What is the cause (causes) of the problem?
- ▶ What is the extent of the problem?

The problem statement needs to:

- ▶ be as specific as possible;
- ▶ be as objective as possible using facts and figures;
- ▶ avoid jargon as much as possible or explain any technical terms used.

The formulation of problems is crucial because it determines how policy makers will see the problem and their response. For example:

- ▶ If the emphasis is on poor living conditions and inadequate resources in institutions for people with disabilities, it might encourage policy makers to allocate more resources to institutional care rather than promoting community provision. However, if the problem identified is that the institutional model is inadequate and violates the rights of people with disabilities, the focus is moved away from buildings and requires that community alternatives to institutionalisation are considered.
- ▶ Similarly, if accessibility of public transport is presented as predominantly a transport issue, it might lead to the creation of special solutions such as subsidised taxi or dial-a-ride services, which might not respond to the needs of all people with disabilities. However, if the lack of accessible public transport is discussed within the broader framework of the right to accessible services, it should result in policies that will ensure access of people with disabilities to physical environment, transportation, information and communication technologies, and other facilities and services (as required by Article 9 of the Convention on the Rights of Persons with Disabilities).

Framing problems correctly makes a big difference for effective advocacy.

Step 3: Set the goals and objectives

The goals and objectives of advocacy should be developed on the basis of the problem definition and analysis. Goals and objectives guide action, help to measure progress and define success.

- ▶ A **long-term goal** is the vision, the change that the strategy aims to bring about. (For example: People with disabilities can live independently in the community by having access to direct payments and personal assistants schemes.)
- ▶ A **short-term goal** is the intended outcome of the advocacy. (For example: New legislation on direct payments.)
- ▶ An **objective** defines what will be accomplished, with whom, how and in what period of time. A strategy often has more than one objective that guides different activities. (For example, a round table with all the stakeholders in order to explain what the new legislation should look like and get support for the issue.)

While goals are more long-term and general (but still specific enough to show what is intended to be achieved), objectives should be ‘SMART’. This stands for:

Specific
Measurable
Achievable
Realistic
Timebound

Step 4: Decide about the Advocacy Strategy

An advocacy strategy is a plan of action designed to achieve goals and objectives. The strategy can use one or a combination of advocacy activities (see Chapter 4).

Problems can be addressed in a number of ways that differ in terms of the necessary resources – time, people and money. In certain contexts, some strategies might be more effective (i.e. more likely to achieve the desired goals) or efficient (i.e. achieve similar results at a lower cost or achieve better results at the same cost) than others.

Matching the strategy to the moment

Important events or key dates offer unique opportunities for advocacy, because the problem is already on the agenda or can easily attract attention. To find out what they are, it is useful to follow the local or national news, check the websites of the authorities and international organisations (such as the EU, Council of Europe or UN) for regular updates on their

agenda and activities, or check the websites of organisations that monitor events relating to disability and community living (such as the European Disability Forum, ECCL and others).

It is also important to know how decisions, policies and legislation are made in your country, if you want to influence them. If you are lobbying for a change in legislation, it is important to time your activities well, so that you do not miss opportunities to provide input. Some organisations miss these important opportunities due to poor planning or lack of information about how the system works.

Events you should look out for when putting together your strategy include:

- ▶ Adoption or reviews of policies, legislation or programmes: these are often accompanied by public consultations that offer an opportunity for organisations to put forward their position and proposals.
- ▶ High profile events, such as ministerial meetings, international conferences or the publication of important documents, (e.g. a Progress Report by the European Commission on a candidate country) or other remarkable dates (such as the International Day of Persons with Disabilities on December 3 each year): these provide an opportunity to issue press releases and engage in other media work, linking the issue you wish to be addressed with the event that is taking place.
- ▶ Scandals, tragedies and accidents: these can be used to highlight what is wrong with institutions, raise awareness about the situation of people with disabilities in institutions and propose solutions.
- ▶ National and municipal election campaigns: they are a good opportunity to ask political candidates about their plans to promote community living. (A case study from Romania in Annex 3 provides an example of advocacy work during an election campaign.)

Step 5: Identify forces affecting the Advocacy Strategy

The strategy needs to take into account forces that might help or hinder its implementation. It also helps to refine the strategy and prepare for potential conflicts or difficulties.

A useful **tool to assess the environment** is the “SWOT analysis”. This considers the internal strengths and weaknesses of a plan or a project in terms of skills, leadership, material resources, interpersonal relations, commitment etc., and the external opportunities and threats including the political and policy context, potential allies and opposition. SWOT analysis is widely used in strategic planning because it allows organisations to identify areas they can build on and areas that need particular attention to avoid risks or failure. This exercise works best if a small group works together. They need to consider the following four points:

<p>Strengths¹⁴</p> <p><i>Positive factors that might be of importance in different campaigns or actions.</i></p> <p>For example: a good relationship with the relevant Ministry, support from a well known musician, contacts in the media, efficient organisational structure, financial resources etc.</p>	<p>Weaknesses</p> <p><i>Factors that inhibit your ability to take action generally or on specific issues.</i></p> <p>For example: lack of staff experienced in advocacy, lack of (or no) funding, poor public image etc.</p>
<p>Opportunities</p> <p><i>Factors about your society that might affect your advocacy work.</i></p> <p>For example: process of EU accession, public consultation on new legislation, interest in the issue among other organisations, interested and sympathetic media etc.</p>	<p>Threats</p> <p><i>Factors in your society that may have a negative impact on your ability to carry out an advocacy activity. They will usually be out of your control, although you may hope to change at least some of them.</i></p> <p>For example: a hostile government, an intolerance of non-governmental organisations, a political or economic crisis, danger of withdrawal of funding by the government (in case of service providing organisations) etc.</p>

Set out below are explanations of commonly used terms when discussing advocacy:

- ▶ **Stakeholders:** organisations and individuals who have an interest in the outcomes of advocacy. Successful community living advocacy takes a multi-stakeholder approach and a collective perspective. Building trust and establishing good relationships with all the stakeholders (including opponents) contributes to the success of advocacy efforts. Stakeholders include targets, allies and opponents.
- ▶ **Targets:** influential individuals or groups that have the power to respond to your advocacy demands. Ministers, mayors or high-level civil servants are often primary targets of community living advocacy activities. Understanding the policy process and context of your issue is very important for identifying the targets correctly.
- ▶ **Allies:** individuals or organisations supporting your cause for different reasons:
 - They personally benefit from your advocacy: for example, persons with disabilities and families with disabled family members;

¹⁴ Definitions are adapted from *Amnesty International's Campaigning Manual*, 1997. Available at: <http://www.amnesty.org/en/library/asset/ACT10/002/1997/en/dom-ACT100021997en.pdf>.

- They share the same values: for example, disability and human rights organisations;
- You have a common interest: for example, organisations providing community supports.

Individual allies are typically opinion leaders, insiders from within the structures you want to influence (for example a civil servant in a Ministry who is committed to promoting community living), and other influential individuals supporting inclusion of people with disabilities, such as celebrities, prominent professionals, academics etc. For example, a local Member of Parliament (MP) or a Member of European Parliament (MEP) can be an important ally. The European Parliament has a Disability Intergroup with members committed to disability issues.¹⁵

Probably the most important allies are “insiders” within the system. Policy forums, conferences, meetings, consultations etc. organised by the authorities can be a good opportunity to meet policy makers who are committed, or can be persuaded, to support community living.

Individuals who have a personal experience of disability – they themselves have a disability, or are friends, siblings or parents of persons with disabilities – are often more open to the issue of community living. If you know of such individuals who are working in Government or in other influential positions, you might want to approach them and seek their support.

Organisational allies/partners are central to advocacy. Building and maintaining alliances/coalitions is not easy, you need to devote time and resources to make partnerships work. There are pros and cons of working in alliance with other organisations. You need to weigh these up before you decide on cooperation. In the next chapter you will find additional information about creating coalitions and working with allies. Several case studies in Annex 3 also provide examples of successful coalitions.

- ▶ **Opponents** are individuals or groups who are likely to oppose your advocacy efforts for different reasons. This could be because:
 - They have different values and disagree with yours. For example, some policy makers and professionals still believe that institutions are the right place for people with disabilities and that they should be segregated from the mainstream society for their own safety, happiness etc.
 - They have an interest in maintaining the status quo. Institutional providers and professionals working in segregated services often see community living as a threat to their position.

It is important to consider who your potential opponents are, their motivations, powers and what steps they may take to prevent you from achieving your goals.

- ▶ **Fence sitters** are individuals or organisations that have no strong views on the issue but might be persuaded to support your case.

¹⁵ You can find out whether your MEP is member of the group here: <http://www.disabilityintergroup.eu/>.

The following matrix can help you map your *allies* and *opponents*.

Allies				
Person/organisation	Level/type of support	Motivation/agenda (Why do they support you? What are their agendas?)	Degree of influence (How powerful are they?)	Other (Potential areas of conflict, disagreement?)
Opponents				
Person/organisation	Level/type of opposition	Motivation/agenda (Why do they oppose you? What are their agendas?)	Degree of influence (How powerful are they?)	Other (How can you deal with their opposition?)

Step 6: Evaluation and monitoring

Evaluation means collecting information and using it to appraise the value or merit of something. Monitoring is the regular and systematic collection of information about what is happening. Evaluation and monitoring should be planned in advance, together with the strategy.

Evaluation and monitoring can serve various purposes:

- ▶ Provide feedback on current activities. You need to know what worked well and what did not work to improve future advocacy.
- ▶ Inform your members and others supporting your organisation, such as volunteers etc. about the outcomes and success of your activity.
- ▶ You might be required to report on your activities to external funding bodies (if advocacy activities were financed by a grant etc.) or your board.

What can evaluation and monitoring focus on?

▶ Outcomes

What was the impact of your advocacy? Has anything changed? Have your goals and objectives been achieved? Have they been achieved in time? Are there any unintended outcomes?

Clear base-line data (for example N people with disabilities have personal assistance at time A), and specific and measurable objectives (N+X people with disabilities have a personal assistant by time B) make evaluation easier. However, policy goals are not always easy to quantify or measure and base-line data are sometimes not available or cannot be collected (because it would be too lengthy or expensive). In these cases it is useful to agree on some “success criteria” and translate your long-term and medium term goals into more specific and measurable outcomes or “milestones” that can be used in the evaluation.

► **Methods**

What methods did you use? What worked, what didn't work?

Methods should be understood broadly and besides advocacy tools they should include working methods (i.e. whether you worked in a coalition etc.) and use of resources (how much money was spent, who was involved in the activity etc.). It is useful to evaluate the methods even if the advocacy has been successful, because understanding what worked and what did not helps to design future strategies and activities.

Evaluation/monitoring tools

The choice of evaluation/monitoring tools depends on the issues to be evaluated and the availability of resources, particularly time and money. Often more than one tool is used in an evaluation. Common tools include:

- **Statistical data** can be collected to describe trends or events, e.g. how many people moved to the community, how many people attended your awareness-raising event, how many people signed your petition asking the government to stop the building of new institutions etc. Their main advantage is that they are usually a cheap and easy way of getting and providing information.
- **Questionnaires and surveys** can be used to explore views of people. In evaluation they are frequently used to explore satisfaction or change of attitudes or awareness. Their advantage is that they are relatively cheap, easy to design and can be administered easily, e.g. by distributing them to the participants of an event etc. However, response rates can be quite low and that might bias the results.
- **Focus groups** can also be used to explore views of people. Their advantage is that they are relatively cheap and allow an in-depth discussion of issues. The disadvantages are that it requires special expertise and it can take quite long to organise them.
- **Interviews** are useful to explore the views and change of attitudes of key targets, e.g. government officials etc. They can also be used to explore changes in the life of people with disabilities. These personal stories can be very powerful in demonstrating the effect of changes on people's life.

Some Useful Tips for Designing Evaluation Questionnaires

- ▶ When you design the questionnaire, keep in mind the people who will be responding to your questions. Make sure it is adequate for the target group both in terms of content (how easy it is to understand) and layout (how clear it is to fill it out).
- ▶ Explain to people why you are asking them to fill in the questionnaire.
- ▶ Give clear instructions on how to fill in and return the questionnaire.
- ▶ If you ask for any personal details (e.g. name etc.) explain how you are going to use data and personal information. In general, for evaluation it is easier and better to use anonymous questionnaires.
- ▶ Keep self-administered questionnaires short, preferably 1–2 pages.
- ▶ If possible, use mainly multiple choice questions (where possible answers are listed) or rating scales (when people have to show agreement, satisfaction etc. on a scale). Use plain language and easy-to-read signs. Include 1–2 open questions so that people can share their opinion and raise issues they consider important.
- ▶ Think of ways to motivate people to respond. For example, you can make it mandatory after a training session or create other incentives, for example a prize draw for people who return the questionnaire.

Step 7: Finalise the Advocacy Strategy

If you have worked through the steps of the planning process, it might be useful to have the final strategy in writing. This helps implementation, gives you more flexibility to monitor and if necessary review the actions, the timeline or the budget. But remember to keep it simple and concise – the strategy does not need to be a lengthy document!

Components of an advocacy strategy/plan

A good advocacy plan clearly answers these questions:

- ▶ What policy/issues do you want to change?
- ▶ What change do you want to achieve?
- ▶ Who are the targets/stakeholders?
- ▶ Who are the partners or allies?
- ▶ What are the obstacles? Do you have opponents/competitors? How are you going to deal with any opposition or difficulties?
- ▶ What are the politically important moments ('the momentum')?
- ▶ What is the timeframe of the proposed action?

- ▶ What resources (money and skills) do you have and are you planning to allocate to the implementation of your strategy?
- ▶ What activities are you planning to implement? Who is responsible for these?
- ▶ What are the success criteria? What are the important milestones? How will you know when you reached your goals?

Structure of an advocacy strategy/plan

- ▶ Analysis of the situation: overview of the relevant historical and policy context. This should be brief and as factual as possible, using indicators and statistics wherever available and possible.
- ▶ Problem statement: a short and concise description of the problem in its specific context.
- ▶ Goals and objectives of the strategy.
- ▶ Action plan setting out who does what and when.
- ▶ Budget: an estimation of the costs of implementing the proposed activities.
- ▶ Indicators and procedures for monitoring and evaluation, including base-line data where available.
- ▶ Annexes might include planning documents that you think are useful, for example the SWOT analysis, or any other documents that are relevant for the strategy, for example an agreement with coalition partners etc.

What Makes a Strategy Good?

- ▶ It is timed well – it uses the moments and opportunities when change is more likely to happen,
- ▶ It takes into account the context,
- ▶ It builds on the resources of the organisation,
- ▶ It has a good combination of activities, and
- ▶ It does not have any unintended negative consequences or cause harm to anybody.

When you think about the strategy, you also need to consider the budget and how you are going to secure the funding.

Campaign for Direct Payment Schemes 1989–1996 (UK)

This case study illustrates several steps involved in advocacy planning – from identifying the issue, setting the goals and objectives, identifying allies – to running a long term campaign. In this case, the campaign resulted in legislation on direct payments in the UK.

The pioneers of the independent living movement in the UK were disabled people living in institutions in the late 1970s. The most notable group of these campaigners (Philip Mason, Philip Scott, Tad Polkowski, Liz Briggs and John Evans,¹⁶ known as ‘Project 81’) were based in the Cheshire Home in Hampshire. Frustrated with not being able to live independently, they successfully negotiated a financial package with the appropriate authorities who had been funding their places in the institutions so that they could move out of the institution and into the community. The authorities agreed to provide them with an amount of money (agreed following an assessment), which they could then use to pay for the support they needed by employing their own personal assistants. It took the group almost three years to reach this agreement.

Centers for Independent Living (CILs)

At the same time, the ‘Project 81’ Group also embarked upon an intensive exploration of what other disabled people were doing around the UK. They wanted to share their experience and change of lifestyle with other disabled people seeking similar solutions to their lives. This is how the Hampshire Centre for Independent Living (HCIL) – the first of its kind in the UK – was founded in 1984. One of the defining principles of the new organisation was that it must be run and controlled by disabled people. Among the main concerns and therefore activity areas were housing and personal assistance. In addition, together with the Derbyshire Centre of Independent Living (a group established around the same time, but with a slightly different focus), HCIL wanted to encourage the creation of a national network and movement for independent living.

As a result, during these developmental years, a number of other CILs started emerging in other parts of the country. Most of these developed around the needs of local disabled people, and used the social model of disability and independent living principles to plan their development. The first CILs also developed links with their counterparts in other European countries, particularly Sweden and Germany, who were also trying to establish independent living.

¹⁶ Whose story is reported in the Preface.

Direct Payments Campaign

The Direct Payments Campaign in the UK was started in 1989 by the British Council of Disabled People (BCODP)¹⁷ Independent Living Committee. While the first independent living schemes were set up in the early 1980s, most authorities were reluctant to apply them because they either considered them too risky or were cautious about handing over all the control to disabled people. Another factor which restricted the growth and development of independent living schemes was that the legislation was unclear. The confusion was caused by the 1948 Social Security Act, which stated that a local authority can only provide services and cannot provide cash payments. The situation was made worse in 1992, when the Minister of Health sent out a circular to local authorities stating that direct payment schemes were illegal. Those authorities who were still willing to pay direct payments had to pay them to a third party, who would then pass it to the disabled individual.

In the early 1990s, when the Direct Payments Campaign started, the first priority of the Independent Living movement was the introduction of comprehensive Civil Rights legislation, followed by a change of legislation regulating direct payments.

At the beginning of the campaign, BCODP worked with the Spinal Injuries Association (SIA). They drew up a strategy for bringing about direct payments legislation. Disabled people running their own direct payments schemes worked together with a lobbying expert from SIA, targeting possible key allies among MPs and politicians who would support the cause. A huge mail shot campaign was launched, with many letters sent to local and national politicians. Numerous awareness raising and briefing meetings were arranged and relevant publicity materials drawn up to make the issues clear. Also, many articles were published in both the mainstream and disability press.

Through these efforts, the group was able to find a supporter in one of the Conservative MPs. He agreed to put together a Private Members Bill¹⁸ on Direct Payments Legislation. However, even though he tried this approach twice in three years, both attempts failed. During this time, the campaign group organised a number of meetings with key politicians to try and influence them about the issues. These included the Minister of Health and the Minister for Disabled People. Again, neither was prepared to take serious action and publicly support them. The group was, however, able to gain support from a number of important national statutory organisations, in particular the Association of Directors of Social Services.

¹⁷ BCODP is the national, democratic representative organisation of disabled people in the UK.

¹⁸ In the UK, this is a way of introducing legislation that is not part of the Government's proposed agenda.

Adoption of the Direct Payments Act in 1996

After the failure of the Private Members Bill, BCODP felt that the best way forward would be to commission a piece of social policy research to come up with some good evidence about the cost implications and effectiveness of Direct Payment schemes and how they improved user satisfaction and the quality of life. A proposal was drawn up and funding granted from a private foundation. The Policy Studies Institute (PSI), an influential research unit, was asked to do the research. It was felt that this way the research would have a bigger impact on politicians and policy makers.

The report, entitled “Cashing in on Independence”¹⁹ was the first study to combine the issues of cost and quality. It showed that on both counts Direct Payments are preferable. Information from the report was used by the campaign group’s allies (in the Parliament and among Directors of Social Services) to lobby other politicians. A week before the BCODP/PSI launch of the report, the Minister of Health announced that it is the Government’s intention to bring about Direct Payments legislation in the next parliamentary year. Finally, after five years of campaigning, the group came close to achieving their goal!

The announcement led to a proliferation of seminars and conferences, organised by both policy makers and the Independent Living movement. Also, numerous research projects on independent living issues were launched.

The Government then set up a body called the Technical Advisory Group (TAG) to work on the research and implementation of the Direct Payments legislation. BCODP was one of the three disability organisations invited to the group. The TAG group, formed in June 1995, looked at all the key issues involved and worked on drawing up guidance for the appropriate civil servants and Government Ministers. It eventually drew up the Government’s consultation document on Direct Payments, which was distributed for comment. The Direct Payments Act 1996 was finally implemented on 1 April 1997.

While this was a huge achievement for the disability movement, there were also a number of issues they were not happy with. Namely, the direct payment schemes were not inclusive of older people. The group was also concerned about the availability of support services and rules on who may be employed as a personal assistant. Further campaigning was necessary to make more changes (older people were included from 2000 after more successful campaigning).

¹⁹ Available at: www.leeds.ac.uk/disability-studies/archiveuk/Zarb/cashing%20in%20on%20indep.pdf.

Overview of the Direct Payments Campaign

To conclude, the original Direct Payments Campaign was on two levels – the campaign group worked with the Parliament, allying themselves with paid lobby workers from other organisations. They also worked through their own networks, getting the members to approach their MPs. A big part of the campaign was educating large charitable bodies concerned with disability about independent living as they also wanted to comment on the legislation.

The group's biggest victory was to convince the Government that people with intellectual disabilities should be included in the bill.²⁰ The organisation controlled by people with intellectual disabilities, People First, did some very effective lobbying on the subject.

During the campaign, the group kept their supporters fully informed so that they could contact their MPs to press for change. Lengthy briefings were written to assist opposition MPs. Research was also helpful, as it gave the group good background material, but being in regular touch with personal assistance users was also essential. This way the group was always able to get new quotes and up-to-date facts.

Throughout the campaign, the group responded not just to the Government, but to social workers and traditional service providers who were concerned about direct payments. The case for full eligibility, across all disability groups, had to be argued over and over again, as well as the principles of Independent Living movement. What helped was having very clear principles and a united disabled people's movement.

Further information: This is a brief summary of a paper written by John Evans, entitled "Independent Living Movement in the UK". The full version of the paper is available at www.independentliving.org/docs6/evans2003.html.

Questions for discussion:

- ▶ What do you think were the main factors that contributed to the success of the campaign in the UK?
- ▶ Could you take a similar course of action in your country? If so, how could you adapt the campaign so that it addresses the specific issues that you would like to change in your country?

²⁰ It is worth noting that UK is one of the few European countries that is implementing direct payment schemes to user groups other than disabled people with physical and sensory impairments.

CHAPTER 4

Advocacy in Action: Using Different Means of Raising Issues of Concern

Once you have identified the issue you want to work on and set your goals and objectives (Steps 1–3 in Planning for advocacy), you will need to decide how you will achieve them. There is a whole range of activities you have at your disposal, and it is important to choose one or more that will be most effective in getting you there. This chapter will present activities you might find useful in your work, with references to case studies.

The activities suggested here are not exhaustive. They have been selected to highlight what could be especially useful when it comes to promoting community living. By paying attention to what other disability organisations and human rights groups in your country are doing, you might get additional ideas for what actions to take. Additional advocacy activities (at the European level) are suggested in Annex 2 of the manual.

It is important to have in mind that the same objective might call for different activities in two different countries or even within the same country. As pointed out in the previous chapter (Step 5), there are numerous factors that will influence the success of your advocacy work, from internal ones (for example, how well organised you are within your organisation and how much resources you have) to external ones (the political climate in your country, how strong organisations of disabled people are etc.). When choosing the activities you will carry out, you should therefore consider all the other elements of the planning process.

Lobbying

Lobbying is about persuading decision makers or those who have influence on decision makers to support an issue or proposal.

The first step in lobbying is finding out who has influence – both direct and indirect – in the area you are seeking to address. You can lobby at the local level (Mayor, other local Government officials and bodies), regional level (County/District authorities, depending on how your country is organised), national level (Government officials, Members of Parliament) or at the European level (Members of the European Parliament, officials at the European Commission). Lobbying can be done by writing letters, briefings, statements, position papers or petitions, or by meeting decision makers in person.

An important part of any lobbying work is building relationships with policy and decision makers. It will not help if you are seen as an ‘opponent’ or an ‘enemy’. This is why any lobbying work should begin with some thinking of who you are targeting and what is the most strategic approach that will make them receptive to your concerns and suggestions, and help you to build a good relationship with them.

Four Key Lobbying Steps²¹

1. Familiarise yourself with the system procedures, timelines and key leaders and players;
2. Classify the players on the basis of where they stand on your issue and how much influence they have either as key decision makers themselves, or in persuading others (such as civil servants);
3. Inform and build relationships through visits and briefings to help them understand your issues and to gain their trust in you as both a reliable source of quality analysis and as a representative of people’s views;
4. Get attention and show your power by timing your media, outreach (activities towards other parts of the community, such as schools, universities, churches, community clubs etc), and mobilisation activities in such a way that decision makers are aware of the support behind your proposals.

²¹ Adapted from *The New Weave of Power, People & Politics: The Action Guide for Advocacy and Citizen Participation* by VeneKlasen, Lisa and Valerie Miller (Stylus Publications, 2007)

A. Letter writing, statements, briefings, petitions

Letters can be used to raise an issue and to suggest possible actions. When writing letters, make sure these are addressed to the person who is responsible for the issue you are raising in the letter. Be persistent in getting a response. Asking a celebrity – a prominent writer, sports person, musician, business person etc. – to write a letter on your behalf can help to give a higher profile to the issue.

You might want to ask other individuals or organisations to sign the letter with you, as a way of showing their support. If decision makers see that the issue has a large backing, they might be more willing to respond. Sometimes organisations write **Open Letters**,²² which are not only sent to the individual they are addressed to, but also to the media.

Statements and position papers²³ are used to explain the position of your organisation on a specific issue. They can be used, for example, in public consultations, if there is a discussion in the Parliament on the issue, during the elections, as a response to a report that just came out, to a story in the media, etc.

Briefings²⁴ are used to keep decision makers informed about the issues for which they are responsible. A briefing note is a short paper that clearly and concisely informs a decision maker about an issue. The information should be presented in a short, well structured document.²⁵

Petitions are useful when you want to let decision makers know that an issue has widespread support. This support will not necessarily be confined to nongovernmental organisations. For example, trade unions, churches or other faith groups, universities and the members of the public may be willing to sign the petition. However, you cannot turn every issue into a petition. It has to be something that can be easily explained and a wide range of people are likely to be willing to support it. If you are using a petition, you can invite famous people to sign it and in this way attract more attention. Petitions have a certain format that you need to respect (for example, in some countries there is a legal requirement to include an identification/passport number of the signatories), and must be very clear in what they are

²² As an example of the Open Letter, we suggest you look at the Open Letter sent by QUIP – Association for Change to the Minister of Labour and Social Welfare in the Czech Republic (in response to the use of cage beds in institutions for children and adults with disabilities). The letter is available on ECCL website by following this link: <http://www.community-living.info/index.php?page=233&news=249&pages=&archive=>.

²³ For examples of Position Papers, we suggest you read Inclusion Europe's Position Paper on European Statute for User Councils in Special Services for People with Intellectual Disabilities (<http://www.inclusion-europe.org/documents/PositionPaperUserCouncilsEN.pdf>) and EASPD Position Paper on Strategies Facilitating the Development Of Community Based Settings And Person Centred Services Services (<http://www.community-living.info/?page=283>).

²⁴ For examples of different briefings, please visit the ECCL website (under Resources), by following this link: <http://www.community-living.info/?page=284>.

²⁵ Source: *Writing for Government – How to write a briefing note*, available at: <http://web.uvic.ca/~sdoyle/E302/Notes/WritingBriefingNotes.html>.

asking people to support. Nowadays, many petitions can be signed online (most commonly on the organisation's website), and in this way can reach a wider audience.

Whether you are writing a letter, statement or a petition, you might want to include a quote from a disabled person. This can be someone who is now living in the community, or someone who is still living in an institution.

Consider putting your concerns in writing because...

- ▶ They allow you to present the problem clearly and to specify what you think needs to be done to resolve it.
- ▶ You can take your time in preparing what you want to say and, if appropriate, consult with other organisations and individuals who might be helpful (such as academics, lawyers or other experts).

Bear in mind that...

- ▶ Letters sometimes end up in bins. You might need to follow up with a phone call to get a response.
- ▶ Petitions do not attract signatures by themselves. You will need to organise signature collecting actions to make sure you achieve your target for the number of signatures (this is especially important if you have publicised the petition). (See case study in Annex 3 – petition to the Scottish Parliament – for examples of activities that you can organise.)



A participant in the Strasbourg Freedom Drive collects signatures on a petition during the march

B. Lobbying through meetings

Face-to-face meetings with decision makers are often the most effective way to get your message across. At the meeting, you are in a position to explain what needs to be done and ask for a response. You can, of course, say much more in a one hour meeting, than in a letter.

If possible, you should prepare some materials for the meeting. This will allow you to focus on the main points. In a briefing (see page 51), you can write the background to the issue, list the main issues and specify what it is that you are asking the decision maker to do. Even if you do explain everything at the meeting, the decision maker will have something in writing when you leave.

Often, one meeting is not enough. Before leaving, you should agree with the decision maker what the next steps will be and when it would be useful to have a follow-up meeting.

Making the most out of a meeting²⁶

- ▶ Be fully prepared and ready to explain what you want (proposed legislation, public support, etc.).
- ▶ Express your expectations clearly and provide further information for the person to take away from the meeting.
- ▶ Whenever possible, identify specific steps that can be taken by the government to bring about positive change, referring to specific policies.
- ▶ Use information (especially solid facts and statistics) that you have gathered in research, as well as powerful personal stories and accounts.
- ▶ If you feel sufficiently informed about this area, relate the issues to international human rights standards.
- ▶ Be professional, organised, persuasive and offer recommendations.
- ▶ Always follow up with a letter of thanks, reiterating any agreements or commitments made during your meeting.

²⁶ Adapted from the European Roma Rights Centre manual *Knowing Your Rights and Fighting for Them: A Guide for Romani Activists*, available at: <http://www.errc.org/db/00/D6/m000000D6.pdf>.

Protest

One of the ways of attracting public and media attention to the issue is by organising a protest. This can be in front of a government building, such as the Ministry of Social Affairs, the local authority, a large residential institution for people with disabilities or in a place where people meet, such as a town square. You need to be aware that each country has procedures that need to be followed when organising a protest. For example:

- ▶ It might be necessary to specify in advance where and when the protest will be held, how many people you are expecting and who is responsible.
- ▶ You might need to obtain permission from the authorities to go ahead with the event. It is important that you comply with the relevant laws, otherwise you risk facing fines or other penalties.

However, freedom of assembly is a fundamental right and protests are commonplace in democratic countries. You should therefore not be discouraged by the procedures.

Consider organising a protest because...

- ▶ A protest of disabled people can make people with disabilities visible and help gather public support for the issue. Especially in countries where many disabled people are hidden in institutions, a group of disabled people who used to live in an institution and are now speaking about their new life in the community and demanding their rights in public can help to persuade policy makers to take action to address the issue of concern.
- ▶ It is a good way to get media coverage of your campaign.

Bear in mind that...

- ▶ A protest of a handful of people is not recommended, since it might create the impression that the issue you are campaigning for does not have much support.
- ▶ It is important to be strategic. A protest can be perceived as something negative by the authorities (as it usually results in negative publicity), and you need to be certain that this is the course you want to take. An alternative to holding a protest can be a march, which has a less confrontational character. A march usually ends in a meeting with a high profile politician, the handing of a petition, etc. (The case study Strasbourg Freedom Drive is an example of a march held in front of the European Parliament.)

Monitoring and Reporting

Doing research on what happens in long-stay institutions for disabled people is a way of exposing human rights abuses faced by people with disabilities. Institutions are often in remote locations and are rarely visited by outsiders, let alone politicians or the media. Providing evidence on the situation in institutions can therefore be helpful, particularly if policy makers are denying that there are any problems.

Findings can be published in a report or shown in a film documentary, depending on what resources you have at your disposal. However, monitoring the current situation is unlikely to achieve the changes you want. This is why before embarking on a monitoring activity, you need to have a plan on how you will use the findings, for example producing a report with recommendations for how to address the problems the monitoring has identified.

Some organisations have been very effective in producing what are known as ‘shadow reports’ or ‘alternative reports’. As an example, governments have a duty to periodically report on the implementation of international treaties that they ratified to the relevant treaty monitoring bodies at the United Nations, or the Council of Europe (under the Revised Social Charter). Such reports are public and can be downloaded from the websites of the relevant organisations, or obtained from authorities in your country. Your organisation can send an alternative report to the same body, setting out your views on whether the government has met its obligations under that treaty (or you might want to prepare a joint report with other organisations).

When reporting, governments are required to comply with a format prescribed by the treaty monitoring body. It is recommended that ‘shadow reports’ follow the same format, so that it is easier for the monitoring body to find the relevant information. For examples of reports, it is worth checking the websites of the treaty monitoring bodies²⁷ (such as the Human Rights Committee, the Committee on Economic, Social and Cultural Rights, the Committee on the Rights of the Child, the Committee Against Torture, or the European Committee of Social Rights at the Council of Europe). The first Committee on the Rights of Persons with Disabilities (which will monitor implementation of the UN Convention on the Rights of Persons with Disabilities) was elected on 3 November 2008.

²⁷ Links to all the UN treaty monitoring bodies can be found at: <http://www.ohchr.org/EN/HRBodies/Pages/HumanRightsBodies.aspx>.

Consider writing a monitoring report because ...

- ▶ Exposing human rights abuses can help to raise public awareness of the problems and create pressure for change, both among decision makers and the public.

Bear in mind that...

- ▶ To use this tool effectively, careful planning and adequate resources are required to ensure that the research is thorough and reliable. You will also need to explain what action is needed to address the concerns you have identified.
- ▶ There may be negative consequences of such work. For example, a report describing human rights abuses in an institution might be limited to the government responding by taking steps to improve the conditions in the institution, without any further actions to close the institution and develop alternative services in the community.

Coalition Building

Making alliances with other stakeholders will help show that the issue has a strong backing and help create impetus for change. If you and other organisations can agree on a common message, this is much more likely to be listened to by policy makers. Coalitions/alliances are also a good way of pooling resources, financial and human, as different members are likely to bring in different expertise.

Coalitions/alliances can be formed on all levels, from local to European. They can be short term or long term, formal or informal. In the short term, coalitions/alliances can use meetings, conferences and workshops to promote an issue. Alternatively, campaigns and actions can be undertaken over several years.²⁸

Possible allies to form coalitions/alliances include: organisations, institutions and individuals sympathetic to the cause (not just from the disability sector!), service providers that are committed to providing quality services that promote community living, prominent members of society, community leaders etc.

²⁸ For more information on coalition building, see “*Advocacy in Action: A toolkit to support NGOs and CBOs responding to HIV/AIDS*” by the International HIV/AIDS Alliance, available at: <http://www.aidsmap.com/en/docs/6F2FA05C-8B05-4136-9048-27B0C95091E4.asp>.

There are some important issues that should be kept in mind if you consider working in a coalition/alliance:

- ▶ Ensure that all organisations represented by the coalition/alliance are committed to the agreed objectives and willing to provide resources for advocacy (not necessarily money, but most importantly, staff time and expertise).
- ▶ To ensure that the work of the coalition/alliance is properly planned, establish a steering group of key individuals representing organisations, which meets regularly. It might also be helpful to have sub-groups that work on specific areas. For example, a group to work with the media, prepare press releases etc. and a group that can do the detailed work of drafting briefings, amendments etc.
- ▶ Have consistent key messages for the government, media etc. about what it is you are campaigning for. Ensure that all organisations that are part of the alliance give consistent messages.
- ▶ Communicate regularly with members of the alliance and supporters. This keeps people involved and aware.

Make sure you are not doing something that others are already doing. Be clear about your aims and be clear what you are NOT going to do.

Some ways of involving people with intellectual disabilities in your campaign²⁹

- ▶ Hold a meeting with people with intellectual disabilities and their supporters to find out their views. Explain exactly what is going on and what the different issues are. Use these meetings to help identify the issues and the action you want to take. People may need support to express their own opinions. Many people, even if their intellectual disability is relatively moderate, will find it hard to follow what's going on in a large meeting.
- ▶ Keep in touch with people with intellectual disabilities throughout the campaign to make sure they understand what is going on and can say what they think.
- ▶ Find people with intellectual disabilities who would like to talk about their experiences to people in local government, Members of Parliament, the media and other people or organisations that might be interested in your campaign. Many people, with or without disabilities, find this daunting, so make sure anybody taking on this role has the right support.
- ▶ If you are producing documents like newsletters for your campaign, make sure they are accessible to people with intellectual disabilities.

²⁹ Adapted from Mencap, *The Good Campaign Guide*, available at: www.mencap.org.uk.

Consider forming or joining a coalition/alliance because ...

- ▶ They represent a wider range of views and interests.
- ▶ They give stronger legitimacy to your demands and activities. By being a part of the Coalition, you will be able to show that the issue has large backing.
- ▶ Pooling of resources (expertise, skills, funding etc.) will provide you with more opportunities and make your message stronger.

Bear in mind that...

- ▶ Conflicts can arise among the members of the coalition. Coalitions are not easy to sustain, as different members might have different goals. It is therefore very important to set the rules from the very beginning, so that, for example, the work of the Coalition is not hijacked by one or two more powerful organisations.
- ▶ You might have to make compromises. Make sure that the joint message is still acceptable to you as an organisation. If you feel that the position of the coalition compromises the values and mission of your organisation and/or the common goals, voice your concerns or consider leaving the coalition.
- ▶ Resources are necessary to cooperate with others. For example, you will need time to consult with the members of the coalition.

CASE STUDY

The Making Decisions Alliance (UK)

This case study describes the work of an alliance of 40 national and regional organisations, which was formed in order to lobby for new legislation on mental capacity (see Glossary) in England and Wales.

The Making Decisions Alliance (MDA) was formed in 2002 to campaign for the introduction of new legislation on mental capacity to both protect and empower people with illnesses and disabilities, such as mental health problems, intellectual disabilities, dementia and brain injuries in England and Wales. The Alliance comprised of nearly 40 national and regional non-governmental organisations working with disabled and older people.

MDA lobbied the Government through a planned programme of activity between 2002 and 2007 to change mental capacity legislation in England and Wales. This included a formal launch of the campaign with a range of campaign information

putting forward the reasons why mental capacity legislation was needed. The work included publishing the results of a public opinion poll which showed that most people believed they had legal rights which did not actually exist – but which mental capacity legislation would help with. The launch also involved publicity work through national print and broadcast media (newspapers, radio, television etc).

Before and after the launch, MDA had regular contact with Government officials who were working in this area of policy and legislation. At these meetings, and other public consultative forums set up by the Government, MDA consistently argued for the need for mental capacity legislation. In addition to this, MDA organised high level seminars where they invited academics, legal, policy, and other professionals, as well as Government officials and advisors to discuss issues around mental capacity legislation.

Because the MDA represented all the big NGOs that worked with people who might lack capacity, as well as their family carers, it was recognised as being a key stakeholder. This in turn enabled MDA to meet with the Government Ministers responsible for this area of legislation and policy. MDA regularly asked the membership of the different organisations they represented to write to the Government and their Members of Parliament (MPs) asking for new legislation. It also provided briefings and lobbied MPs and members of the House of Lords to raise their awareness of the issue.

The campaign proved successful. A draft Bill (proposed legislation) was published in 2003. MDA gave written and oral evidence to a committee of MPs and members of the House of Lords that had been asked to scrutinise the draft Bill and report on its findings. As a result of the evidence given by MDA and others, the Bill was redrafted significantly before being introduced to Parliament in 2004. MDA continued with its campaigning activities throughout the Bill's passage through Parliament including extensive media work, face to face lobbying, and writing briefings that were circulated to all members of Parliament.

MDA also encountered some difficulties in the campaign. There was a significant campaign for a time against the Bill because of concerns about how it addressed decisions about life-sustaining treatment. This campaign claimed that the Act would allow euthanasia, which is illegal in the UK. Some organisations, which were not part of the MDA, were also concerned that the Act would not protect the rights of people with disabilities enough. MDA met with members of both of these counter-campaigns to try and allay their concerns and find some common ground. They succeeded with those organisations concerned about the rights of people with disabilities and worked with them to improve the Bill further. Finally, the Bill was passed by the Parliament and became an Act in April 2005. However, MDA continued to lobby on issues of secondary legislation and raise awareness of the new legislation until the Act came into force in 2007.

Further information: Making Decisions Alliance, website: www.makingdecisions.org.uk/index.html (the full campaign pack is available on the website). The Mental Health Foundation (which incorporates the Foundation for People with Learning Disabilities) works towards improving the mental health of children, adults of working age and older people through research and development, policy, campaigns, information and community work. Between 2004 and 2005 the Mental Health Foundation co-chaired MDA. E-mail: mhf@mhf.org.uk, website: www.mentalhealth.org.uk/.

Questions for discussion:

- ▶ Have you been successful in working with other organisations? What can you do to develop effective links with other organisations that may share your goals?
- ▶ What are some of the issues a coalition in your country could take up? Who would you invite to join the coalition (from the disability and non-disability sector)?

Pilot or Model Programs

One of the ways of influencing the change of policy is showing your government, service providers and the public that the changes that you are seeking can work in practice. For example, if you are already providing quality community-based services – whether as a pilot programme or otherwise – this can be an important part of your advocacy strategy. You could show the relevant authorities and other target groups (such as other service providers, the media and the public) how the community based services that you are providing benefit the people who use them and how this can be replicated on a local or a national level. A powerful way of doing this would be for those people using the service to talk about the services that they are receiving and explain why they think such services are so important (if they are willing to do so).

Consider demonstrating how your services work because ...

- ▶ By showing decision makers how community based services can be delivered provides a real and practical answer to possible arguments such as ‘this person is not capable of living outside the institution’, ‘our country is too poor for this’, ‘this doesn’t work here’ etc.
- ▶ It will establish your expertise in the area and show you to be a credible partner.

Bear in mind that...

- ▶ If you are not a service provider, you might want to work with an organisation which already provides quality community-based services.

Co-operative on Personal Assistance (Norway)

This case study describes how an organisation in Norway used their pilot personal assistance programme to lobby for the universal right to personal assistance for people with disabilities.

Beginning of the pilot programme

Personal assistance started in Norway as a project of the National Disability Organisation and the Department of Social Affairs. The National Disability Organisation visited other Scandinavian countries and the USA and prepared a report on personal assistance and possible ways of implementing it in Norway. On the basis of this report, the Department of Social Affairs encouraged organisations to pilot different models of personal assistance. This is when ULOBA started as a co-operative. There were 15 people at the first meeting in 1991, but ULOBA grew, receiving more contracts and developing their model of working with personal assistance. They learnt a lot from organisations in Sweden and applied this knowledge in Norway.

ULOBA sees personal assistance as a tool for liberation and freedom. People with disabilities are the stakeholders – owners – of the co-operative and their main objective is to make sure that all the stakeholders get the assistance they need to function as well as possible and live as independently as possible, without depending on services controlled by municipalities and those service providers that mainly focus on healthcare.

ULOBA has a network of peer counsellors, all of whom use personal assistance. They deliver training on legal and practical aspects of having personal assistants, and give advice and information to ULOBA's stakeholders and other interested people. Everyone who wants to become a stakeholder in ULOBA must receive this training. ULOBA employs all the personal assistants that the stakeholders hire. Altogether, ULOBA has approximately 800 stakeholders and employs 4,500 personal assistants all over Norway. There are also 400 "subscribers" – these are people who are in the process of applying for personal assistance with ULOBA and are negotiating the terms with their municipalities. In the administration, ULOBA employs around 80 people.

Initially, ULOBA's activities were centred around Oslo (the Eastern part of Norway), but now they cover a much larger geographical area. So far, no similar initiatives have developed in other parts of the country.

Lobbying for the right to personal assistance

ULOBA did a lot of campaigning and lobbying in order to include personal assistance in Norway's social legislation. They wanted personal assistance to become an individual right, which would ensure that every person with disabilities has access to it. They used their pilot programme to show what personal assistance is about, why it is important to people with disabilities and how it can be organised so that disabled people have control over it and can live independently. ULOBA targeted mainly members of the Parliament, but also politicians in municipalities. They held seminars to which they invited politicians and prepared short information materials for politicians and the public.

Much of ULOBA's lobbying work involved meetings with smaller groups of politicians. They felt it was important to establish contacts with individuals who could support ULOBA's vision of what personal assistance is and how it should be organised. According to ULOBA, personal assistance is simply practical assistance, and has nothing to do with health care, home nursing, special needs etc.

Results of ULOBA's lobbying activities

As a result of, among other, ULOBA's lobbying efforts, personal assistance was incorporated in the Social Services Act (in 2000) and is funded by local authorities. However, ULOBA has only partially achieved their goal. Despite being included in social legislation, personal assistance is still not an individual right. A person can apply for it and negotiate with the municipality, but they do not have to be given the right to receive personal assistance. There are about 430 municipalities in Norway, which means that many people are involved in making this decision. There are three ways of receiving personal assistance: one can employ their own personal assistants, the municipality can employ personal assistants or a co-operative like ULOBA can employ them. Municipalities have very different resources, which heavily influences how many hours of personal assistance one can get. Also, because personal assistance is a type of social service, municipalities are required to control its provision and quality.

For this reason, ULOBA continues to campaign for the change of legislation. Its position is that personal assistance should become an individual right and that it should be taken away from municipalities to the state level. ULOBA believes that personal assistance is different from other social services provided by the local authorities and no one else should take control of it besides the individual with a disability. The growing number of stakeholders that ULOBA has is evidence of the fact that services controlled and run by users are preferred by people with disabilities and supported by local authorities.

Further information: ULOBA, e-mail: adm@uloba.no, website: www.uloba.no.

Questions for discussion:

- ▶ If your organisation is already running a pilot programme, how can you use it to influence policy change?
- ▶ Are there any organisations in your country providing quality community-based services that you could work with on lobbying activities?

Other Suggested Activities

Awareness raising

It is likely that any advocacy work you do will seek to raise awareness about the rights of people with disabilities and the human rights violations that they suffer on a daily basis. However, another important area of advocacy will be to challenge stereotypes and negative images of people with disabilities. An example of an awareness raising activity is a publicity campaign with images of disabled people living and working in the community (using leaflets, posters and promotional videos). Some groups also organise benefit concerts, award ceremonies, exhibitions and other cultural events that are open to the public, thereby bringing the issues to the attention of a wider audience than more specialised events. Awareness raising events can also be used as fundraising opportunities. (See examples at the end of this chapter and in Annex 3.)



*Games in the Ability Park, Hungary
(see case study in Annex 3)*

© Ability Park



Speaking tours

This is another example of an awareness raising activity. It is often used in the human rights movement, with victims of human rights violations speaking about their experience in local communities, schools, universities, churches and at important events, attended by decision makers and other important stakeholders. Some disabled people are also willing to talk about their experience. For example, during the anti-bullying campaign in Scotland (described in Annex 3), people with intellectual disabilities (self-advocates) went to local schools to speak to children and young people about how they are affected by bullying.

Celebrity support

Finding somebody famous to act as your ‘ambassador’ might help decision makers and the public to become more sympathetic to your work. There is still widespread prejudice and discrimination against people with disabilities, in particular people with intellectual disabilities and/or mental health problems. Some celebrities are willing to help address such negative attitudes. A famous disabled person or someone with a disabled family member might be especially willing to help.

Litigation

This is a very specialised activity and is undertaken only by organisations with the relevant expertise and legal staff. However, favourable court decisions can also help change policy and treatment of people with disabilities. In addition to litigating cases in domestic courts, cases can be brought to the European Court of Human Rights and collective complaints can be made to the European Committee of Social Rights at the Council of Europe (where the country has signed the additional protocol). The European Court of Justice decides cases under the European Union legislation. Successful court cases can put pressure on the government to change a policy or enact new legislation, or to implement existing policies or legislation. They can also help bring public attention to the issue.

What is a campaign?

A campaign is generally a longer-term activity which combines many of the activities discussed above. Campaigns can last up to several years, depending on how long it takes to reach the main goal. Some campaigns combine monitoring and reporting (usually in the preparatory phase) with lobbying activities, awareness raising, protests and media work, and often seek the support of well-known individuals who become promoters of the issue. Campaigns require more resources than individual activities (given that they take longer to organise and implement), which is why they are often organised as a collective effort of a number of organisations.

Working with the Media

Media work is a way to complement your other advocacy activities. It is important for many different reasons (see box below). Be aware that people with disabilities – especially people with intellectual disabilities and mental health problems – are often portrayed very negatively in the media. Before doing media work, you should therefore ensure that the journalists you are working with understand the issues you wish to discuss. One way of addressing misunderstandings about disability and combating negative attitudes portrayed in the media is to offer guidance and/or training on disability issues to journalists.³⁰

The main element of working with the media is to give a clear message to the readers (or, in case of television/radio, the viewers/listeners).

Why is Media Work Important?³¹

- ▶ To get your issue on the political agenda;
- ▶ To make the issue visible and credible in policy debate;
- ▶ To inform the public about your issue and proposed solution;
- ▶ To recruit allies;
- ▶ To change public attitudes and behaviour;
- ▶ To influence decision makers;
- ▶ To raise money for your work.

Useful tips on how to develop your message³²

1. **Know your audience.** You need to consider who is or could be interested in your issue at the local, regional and national level. These are likely to be the same people as those you identified as key stakeholders (see Chapter 3). Before you develop your message, you should also consider what your audience already knows, as well as what is likely to be of interest to them.

³⁰ The project Real Live Media aims to empower people with intellectual disabilities to work effectively with the media, and to use the media as a partner in promoting social inclusion of people with intellectual or multiple disabilities. Further information: www.realivemedia.org.

³¹ Adapted from *The New Weave of Power, People & Politics: The Action Guide for Advocacy and Citizen Participation* by VeneKlasen, Lisa and Valerie Miller (Stylus Publications, 2007).

³² See previous footnote.

2. **Know your political environment and moment.** This means being sensitive about how you develop your message. If there have been many stories in the media about abuses in institutions, you might not want to add another one, but focus on solutions and alternatives.
3. **Keep the message simple and brief.** Essentially, this is about making sure that everyone, regardless of their familiarity with the subject, can understand what you are saying. It is important to avoid jargon and terms which can be misinterpreted. For example, when discussing “independent living”, make sure it is clear that this does not mean that people with disabilities want to live in isolation, without any support.
4. **Use real life stories and quotes.** For example, the Association for Promoting Inclusion (Croatia) created a publicity campaign with quotes from disabled people who used to live in institutions and now live included in the community. One quote said “In the institution I had no PRIVACY...now I live in my apartment” and was accompanied by Article 12 of the Universal Declaration of Human Rights which reads: No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation.
5. **Use precise, powerful language and active verbs.** For example, the Association for Promoting Inclusion (Croatia) created a slogan *Institutions are Dead End Streets*. This slogan implies that there is a preferred alternative. It is better than saying *Close Down Institutions*, because this creates an impression that the biggest problem are the buildings themselves rather than the lack of services in the community.
6. **Use clear facts and numbers creatively.** Questions that should be answered are: What is the problem/issue? What are the causes? Who is affected and how? Who is to blame? What is the solution and what can the public/decision makers do to help? To answer these questions, you might have to do some additional research, but you might find that you have sufficient information, for example in existing reports.
7. **Adapt the message to the medium.** This involves considering what works best on television, the radio, internet and in the printed media. If you are not sure, you might want to consult a friendly journalist or another media expert.
8. **Allow the audience to reach their own understanding.** It is not advisable to be dogmatic, but rather to present the facts and let the audience make up their own mind about the issue. Your task is to produce convincing arguments, not tell people what to think.
9. **Encourage the audience to take action.** You must be clear about what the decision makers, the public and other members of the audience can do to support your issue.
10. **Present a possible solution.** In simple language, you need to be able to state what you propose as a solution.



A Board member of the European Network on Independent Living gives interviews in the lobby of the European Parliament during the Strasbourg Freedom Drive

How to work with the media?

The two most common media activities you can undertake are issuing a **Press Release**³³ and organising a **Press Conference**. Press Conferences are in most cases used to launch a report or a campaign. They can also be organised to respond to an issue that has already received a lot of public attention, when the media is asking for your response or you feel it is important.

Because of a large number of Press Conferences that journalists attend every day, they are not likely to attend yours unless the issue is newsworthy. In most cases, it is better to issue a Press Release and send it to your personal contacts in the media. Building your personal contacts (journalists interested in social affairs and the situation of people with disabilities) is preferable to sending Press Releases to anonymous desk officers.

In some countries, a good way to get publicity is also by writing a **Letter to the Editor** (usually published at the beginning of the newspaper or a magazine). Letters to the Editor have to be in response to an article/news item in a recent edition of the publication, but they can be a good way to publicise issues which would not otherwise be covered. For example, a letter to the editor could respond to an article about an incident in one of the institutions by pointing out that the way to address such concerns is to provide alternatives to institutional care and explain how such community based services can be developed.

³³ For examples of Press Releases related to community living, please visit the News section of the ECCL website, by following this link: <http://www.community-living.info/?page=233>.

Materials useful in media and advocacy work:³⁴

Whatever advocacy activities you undertake, you will need some materials to explain who you are, your mission, your main activity areas and where people can find out more about your organisation.³⁵

- ▶ **Leaflets.** These can be general, about your organisation, or they can be connected to a specific action or campaign.
- ▶ **Fact sheets.** Fact sheets can be used to explain in more detail the terms or concepts that you are using in your work. You can, for example, have a fact sheet on the UN Convention on the Rights of Persons with Disabilities, Community Living, Direct Payments etc.
- ▶ **Reports.** When going to meetings with decision makers or when working with the media, reports can be a useful tool to provide more information.
- ▶ **FAQ (Frequently Asked Questions).** Put together a list of questions that frequently come up in lobbying or in the media, and provide concise answers. You can select the questions in such way as to cover the most important points relevant to your issue. Similarly, you can produce Myths and Facts connected to the issue that you are working on. (See for example the common misconceptions about independent living in the Glossary.)
- ▶ **Newsletters.** A printed or a web based newsletter is a good way to publish updates about your advocacy work. You can also ask experts, disabled people and other supporters for contributions on topics relevant to your advocacy activities.
- ▶ **Videos.** Examples of videos that have been used in this way can be downloaded from the website of the European Coalition for Community Living. They include a video made by the Association Promoting Inclusion, Croatia entitled “Living Proof: The Right to Live in the Community” (screened at the UN General Assembly on the occasion of the entry into force of the UN Convention on the Rights of Persons with Disabilities) and ULOBA’s video on personal assistance in Norway.
- ▶ **Press releases.** They are used to inform the public about an issue or an activity you are carrying out. Press releases are usually issued at the beginning of an action or a campaign or at a key moment during your lobbying work. Before you write your first press release, it is worth consulting with someone working in the media about what information to include and what format to use (length, style, etc.).
- ▶ **Website.** Websites are a great way of communicating with other organisations and the public. It is worth having a general website about your organisation or a website especially dedicated to your campaign. You should bear in mind, however, that not everyone has access to Internet, therefore information in other formats should also be available (such as leaflets, posters etc.).

³⁴ Some of the suggestions have been adapted from the European Roma Rights Centre manual *Knowing Your Rights and Fighting for Them: A Guide for Romani Activists*, available at: <http://www.errc.org/db/00/D6/m000000D6.pdf>.

³⁵ “*Community for All*” Toolkit, produced by a group of organisations in the United States, contains resources produced by organisations campaigning for community living (such as letters, statements, websites etc.). It will provide you with additional ideas on the type of materials you can use in your media and advocacy work. The toolkit is available at: <http://thechp.syr.edu/toolkit/>.

- ▶ **Posters.** Good campaigns also have a strong visual component. Posters can be used to inform the public about your campaign and at the same time raise awareness about the issue you are campaigning for.

T-shirts produced by ULOBA, Norway



Poster produced by the Association for Promoting Inclusion, Croatia

Examples of Awareness-raising Activities

The Daily Basket, Romania

In order to raise awareness about the poor living standard of people with disabilities in Romania, the Pentru Voi Foundation from Timisoara organised a campaign called 'the Daily Basket'. They created a basket which contained examples of what could be bought with the daily income of a person with disabilities. This demonstrated that this amount of money was only enough to buy breakfast for one person – a small loaf of bread, some yoghurt and 100g of salami. As a result of this awareness raising campaign, the monthly allowance for people with disabilities was increased from 8 to 50 Euro a month.³⁶

³⁶ Additional information about Pentru Voi's advocacy activities can be found in the publication *Advocacy and lobbying for community living for people with intellectual disabilities* by Laila Onu, Pentru Voi and Inclusion Romania, 2006. The publication is available upon request from ECCL.

Exhibition of photographs, Croatia

In September 2007, a photography exhibition entitled 'Life All Inclusive' was organised in Zagreb, Croatia featuring works by a well known photographer Damir Fabijanić. In cooperation with the Association for Promoting Inclusion (API) he documented the everyday lives of people with intellectual disabilities living in the community. The exhibition marked both 20 years of the artist's work and the 10th anniversary of API, and was sponsored by the Ministry of Culture, the Municipal Department for Culture, Education and Sport, the Open Society Mental Health Initiative and API. The photographs were exhibited in the gallery of the Croatian Academy of Arts and Sciences.

Further information: Pentru Voi Foundation, e-mail: pentruvoi@pentruvoi.ro, website: www.pentruvoi.ro/index_en.htm; Association for Promoting Inclusion, e-mail: inkluzija@inkluzija.hr, website: www.inkluzija.hr.

Questions for discussion:

- ▶ Can you incorporate awareness raising into any of your existing programmes?
- ▶ How can you adapt your awareness raising activities to different audiences, such as children and young people, staff in institutions for people with disabilities, transport workers, teachers etc.?

**The most important thing to remember is that
you CAN make a difference. NOW is the time to start!**

Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.

Margaret Mead

ANNEX 1

Glossary of the Relevant Concepts

As highlighted in Chapter 3, a key success factor in bringing about policy change is delivering clear messages. This glossary explains fundamental concepts such as ‘community living’, ‘independent living’, ‘social model of disability’, ‘institution’ and ‘deinstitutionalisation’.

Community Living

The term ‘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 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 they need access to mainstream opportunities and services available to the general population, and also to tailored individual support.

We use the term ‘community living’ in the manual, as many people are familiar with it. 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 life.

Deinstitutionalisation

Deinstitutionalisation is the “replacement of institutions by services in the community”.³⁷ It is about bringing people out of institutions and helping them to live in the community by creating the necessary supports. Deinstitutionalisation is also about recognising the variety of needs of people with disabilities and supporting them to live an ordinary life in the community.

Deinstitutionalisation does not end with the closure of institutions. There is a long way to go to ensure high-quality, individualised support for people with disabilities to live an ordinary life in the community. It is important to ensure that institutional practices are not replicated in the community.

Direct Payments

Direct payments (also known as ‘personal budgets’) are cash payments made to individuals with disabilities (or in some cases to parents of children with disabilities) to enable them to purchase self-directed support (i.e. personal assistance) instead of being told what services to use. Direct payments give individuals greater choice and control over how their support is organised and enable people to live independently in the community. Without direct payments most people with disabilities cannot afford to have personal assistance and are forced to rely on institutional services.

Direct payments are available in a number of European countries including the UK (see case study in Chapter 3), Sweden, Norway and the Netherlands.

Guardianship

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, form 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 person.

³⁷ Mansell, J. (2006). *Deinstitutionalisation and community living: Progress, problems and priorities*. Journal of Intellectual and Developmental Disability, Vol. 31(no. 2), pp. 65–76.

One of the alternatives to guardianship is ‘supported decision making’. In this case, a person is provided with the necessary support to be able to make decisions on their own.

Human Rights Violations in Institutions

When making a case for the community-based model, a strong point to make is that people living in institutions are denied many of their basic human rights. Article 19 (Living independently and being included in the community) of the UN Convention of the Rights of Persons with Disabilities sets out the right of people to live in the community, but there are many other rights in the Convention that are denied to a person living in an institution. Even if a country has not ratified the UN Convention of the Rights of Persons with Disabilities, it will be bound by domestic legislation (such as the Constitution, anti-discrimination legislation etc.) and other international treaties that it has ratified, such as the European Convention on Human Rights, International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of the Child etc. (see Annex 2 for additional information.)

Some of the human rights violations that commonly occur in institutions are:

- ▶ ***Lack of access to education and employment***
People in institutions have limited or no opportunity to access education, training and employment opportunities. Children with disabilities who grow up in institutions are often denied education and the opportunity for a healthy development.
- ▶ ***Lack of individualisation in services***
Institutions operate on the basis of “one size fits all” principle with little to no adjustment to meet the needs of individual residents. Block treatment and rigidity of routine are a part of everyday life. Residents have to do things at set times that are adjusted to the requirements of staff, and they have limited choice in everyday issues, such as what to wear, when to wake up and go to bed, what to eat etc.
- ▶ ***Abuse and neglect***
Abuse can happen both in institutions and the community. However, depersonalisation and isolation, which characterise institutional life increase the likelihood of abuse. Institutions are also less open to public scrutiny than services in the community.

Independent Living

This is another term commonly used to refer to having an ordinary life. Independent living is a basic human right and it means people with disabilities having the same choice, control and freedom as any citizen at home, at work and as members of the community.

The concept of independent living makes clear that people with disabilities are not expected to live without support. It does not mean disabled people ‘doing everything for themselves’, but it does mean that any practical assistance people need should be based on their own choices and aspirations.³⁸

Independent Living is based on the **social model of disability** and it was developed through the disabled peoples’ movement. Independent living is based on the following principles:³⁹

- ▶ Those who know best the needs of people with disabilities and how to meet those needs are people with disabilities themselves;
- ▶ People with disabilities should be involved in policy-making and all decisions on issues concerning their lives;
- ▶ Disabled people should be fully integrated into the community with equal citizenship;
- ▶ People with disabilities should have equal access to goods, services, and structures, including housing, health care, assistive devices, personal support services, education, employment, communication, transportation, the physical and cultural environment.

Common Misconceptions About Independent and Community Living

- ▶ **MYTH** *Independent living is only for people with mild or moderate disabilities who can live by themselves. Some people are too disabled to live independently in the community.*

FACT Independent living is not the same as living independently. It does not mean that one has to do everything alone. Independent living means having the support one needs and when one needs it. Independent Living is about people having control and choice over the decisions they make about key issues in their lives. Independent living is for everyone.

- ▶ **MYTH** *It is enough to re-provide services in the community (for example to close an institution and move people to live in ordinary houses in ordinary streets) to ensure high quality community based services.*

FACT The location is not everything. Living in a small home in the community is not necessarily community living. Community services can also become institutional if they have rigid routines and are not based on the needs and aspirations of the people using the services.

³⁸ Source: Office for Disability Issues, *Independent Living: A cross-government strategy about independent living for disabled people*, February 2008, p 29, available at: http://www.officefordisability.gov.uk/working/independentlivingstrategy.asp?cids=Google_PPC&cre=DPAC_ODI.

³⁹ Source: Independent Living Institute, Sweden. Additional information: <http://www.independentliving.org>.

- ▶ **MYTH** *People with disabilities like to live in institutions together with many other people with disabilities. This is also safer because people should be protected from the risks of living in the community.*

FACT Many people have had to live their whole life in institutions, without any opportunity to make choices and they do not know about life in the community. They should be given the opportunity to experience community living and have a choice over where and with whom they live. Research has consistently shown the institutions offer poorer quality of life for people with disabilities.

- ▶ **MYTH** *People with severe and profound disabilities are unable to make choices.*

FACT Everybody is able to make choices with the right support. People with severe and profound disabilities are able to express preferences. The people around them need the right skills and knowledge of the individual to understand the person's wishes and feelings. However, many people who lived in institutions were never allowed to make choices, they do not know what other options exist. Until people have had the opportunity to experience these alternatives, they cannot make real choices.

- ▶ **MYTH** *Independent/Community living is very expensive, only rich countries can afford it.*

FACT The cost of support varies country by country. In general, the amount of support in community can be tailored to the needs of the individual. This means that for some people community living is cheaper than institutional provision, while for others it is more costly. Community living provides a better life for people with disabilities and it is better value for money.

- ▶ **MYTH** *Community living works well in some countries but might not work in other countries with different traditions, culture and administrative systems.*

FACT Community living has been successfully implemented in many countries with very different traditions and administrative systems. It is not bound to any specific welfare state model. There are local variations (for example who provides support, how provision is financed etc.) but the basic principles are the same everywhere.

Institution

There are various approaches to defining an institution. Some definitions are based on the number of places in a facility, e.g. an institution is a facility with 30 or more places. This definition can be useful when it comes to collecting data, describing trends and monitoring progress in deinstitutionalisation. However, an institution is not defined only by its size. Size – particularly large size – is just an indicator of something more fundamental that makes a service 'institutional'.

A better way to define an institution is to say that: An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions.⁴⁰

The institutional model is seen as inadequate in many countries and institutions are replaced with support services in the community. In these countries it is recognised that no matter how much money is spent on institutions, and how good and committed staff are, the characteristics of institutional care make it extremely difficult or impossible to provide a good quality of life for people with disabilities (which is also the meaning of Article 19 of the UN Convention on the Rights of Persons with Disabilities).

Mental Capacity

The term ‘mental capacity’ refers to the ability to make decisions. Some countries have developed legislation to provide for decision making on behalf of those who are not able to make decisions for themselves. For example, in England and Wales, the Mental Capacity Act 2005 provides for the circumstances in which decisions can be made on behalf of a person who lacks capacity, including a requirement that any decision taken must be in the person’s best interests. However, it also provides that individuals must be assumed to have capacity to make decisions for themselves unless proved otherwise and that a person is not to be treated as unable to make a decision unless all practicable steps have been taken to help the person make that decision.

Personal Assistance⁴¹

Personal assistance helps people with disabilities to live independently by providing practical assistance in activities of daily living, such as getting up, getting dressed, eating, getting around, working etc.

Personal assistance is distinguished from other services that provide practical help in that it is self-directed and fully controlled and designed by the individual user. The person decides about who supports him/her, what support he/she receives, when, where and how. This also means that individual users can recruit, train, manage and if necessary fire their personal assistants.

⁴⁰ This is the definition of the European Coalition for Community Living.

⁴¹ Source: John Evans, *Independent Living and Direct Payments in Europe*, presented at Rethink Disability Annual Conference, Ipswich, November 7, 2003, available at: <http://www.leeds.ac.uk/disability-studies/archiveuk/evans/Ipswich%20Talk%2003..pdf>.

Personal assistance is not limited to people with physical or sensory impairments – it is also used by people with intellectual disabilities and mental health problems. It is important that those who need support in managing their personal assistance receive it.

There are different models of personal assistance: people with disabilities can use **direct payments** to employ their personal assistants or it can be organised through user-led organisations or other agencies.

Social Model of Disability

The social model of disability emerged as a response to the traditional, medical model of disability which saw disability as a medical problem of the individual. The social model sees the barriers in society – the lack of adequate housing, accessible transport and personal assistance as well as discriminatory attitudes – as the main problems that exclude individuals with different physical, mental or sensory impairments from full participation in society and restrict their opportunities. Although the social model does not deny impairment and limitations in one’s functioning, it views disability as a product of our society and argues that most problems people with disabilities face in life are not a result of their individual impairment, but are created by the barriers of the environment.

This table illustrates the difference between the two models.

Medical model	Social model
Unable to get into buildings because cannot climb steps	Unable to get into buildings because there are no ramps or lifts
Unable to open heavy doors because cannot use hands	Unable to open doors because they are too heavy and lack power-assisted doors
Difficulties in getting around in the city due to poor vision	Unable to get around in the city because there are no voice-assisted signs in busy junctions and on public transport
Unable to understand complex written text because of learning difficulties	Texts are too complicated when they could use plain language and easy-to-read format

Supported Living⁴²

The term ‘supported living’ is used particularly in relation to people with intellectual disabilities. It means a form of (organised) support that enables people with intellectual disabilities to live in their own homes as an alternative to shared residential homes. The key

⁴² For more information about supported living, see: <http://www.jrf.org.uk/knowledge/findings/socialcare/SC94.asp>.

feature of supported living is that it separates housing and support, which allows for more flexibility in responding to the needs of the individual. People can choose where and with whom they live and what support they get.

ANNEX 2

International Policies Relevant to Advocacy for Community Living

This chapter presents the international context of community living in the policies of the European Union (EU), the Council of Europe (CoE) and the United Nations (UN). It also highlights some ideas on how these can be used in advocacy.

The European Union (EU)

The following section will be relevant to countries that are members of the European Union (at the timing of writing this manual, there were 27), but also to other European countries that aspire to join the EU, particularly candidate and potential candidate countries (see page 83).

In all the relevant policies, the EU supports the social inclusion of people with disabilities and encourages the creation of person-centred services for people with disabilities that will allow them to live independently (in the sense of ‘independent living’, as explained in the Glossary). The EU policies have also adopted the motto of the disability community ‘Nothing about us, without us!’, which means that they require or encourage involvement of people with disabilities and their representative organisations in all decisions and actions concerning them.

Below is a summary of the relevant EU policies that you might find useful when advocating for community living policies in your own country. Links to the policies and additional information are given in the footnotes. This is followed by some information on candidate and potential candidate countries, the relevant contact points in the EU and suggestions for advocacy activities.

1. Summary of the relevant policies

- ▶ Disability Strategy
- ▶ Social Protection and Inclusion Process
- ▶ Anti-discrimination legislation

The European Commission Disability Strategy

The European Commission adopted a Disability Strategy in 2003, following the European Year of People with Disabilities.⁴³ The strategy focuses on:

- ▶ Promoting the cooperation between the European Commission and the Member States in the disability field – through the collection and exchange of information and good practice, and awareness raising of disability issues;
- ▶ Promoting the social inclusion and full participation of people with disabilities – by supporting EU level organisations of people with disabilities (such as the European Disability Forum, Inclusion Europe, the European Network on Independent Living etc.) and by providing additional financial support for national policies from the Structural Funds (it is important to note that Member States decide how this money is spent and the Commission has relatively little say in it); and
- ▶ Facilitating mainstreaming and cooperation on disability issues within the Commission.

The strategy has the form of a “communication”⁴⁴ and outlines the actions that European Commission is planning to take. It is implemented through biennial action plans, with the current plan covering the period of 2008–9.⁴⁵ The Action Plan is based on the following priorities:

- ▶ Improving access of people with disabilities to employment (through anti-discrimination legislation and providing financial support for employment and training programmes) and to mainstream goods, services and infrastructures (such as transport and information technology);

⁴³ The European Action Plan is available at: http://ec.europa.eu/employment_social/news/2003/oct/en.pdf.

⁴⁴ “Communication” is a part of the decision making process in the EU. It is considered to be “soft law”, which means that it is only a recommendation and is not legally binding. The binding documents are “regulations”, “directives” and “decisions”. Source: EUABC, available at: <http://en.euabc.com/>.

⁴⁵ The Action Plan 2008–2009 is available at: http://ec.europa.eu/employment_social/index/com_2007_738_en.pdf. The previous Action Plan (2006–2007) can be accessed here: http://ec.europa.eu/employment_social/index/7003_en.html.

- ▶ Sponsoring studies and data collection that will improve the Commission’s capacity to develop and implement social inclusion policies;
- ▶ Promoting and implementing actions towards disabled people’s full enjoyment of human rights;
- ▶ Facilitating the implementation of the UN Convention on the Rights of Persons with Disabilities in the EU and among the Member States. The EU signed the Convention in March 2007 and is preparing to ratify it in 2008 or 2009. If this goes ahead it will be the first international treaty ratified by the EU;
- ▶ Adopting new anti-discrimination legislation.

There is also an increasing political commitment in the EU to support de-institutionalisation and the development of quality community-based services. In March 2008, the European Council adopted a **Resolution on the Situation of Persons with Disabilities**⁴⁶ (during the Slovenian Presidency). The Resolution invites Member States and the Commission to ensure that “*persons with disabilities enjoy their human rights in full by [...] (e) taking measures to allow persons with disabilities, as far as possible, to live independently, to be included in the community, and to have access to quality care and support services [...] (g) further supporting the Member States and regional and local communities in the deinstitutionalisation process whenever this is in the best interest of people with disabilities.*” To achieve these objectives it calls for “*encouraging the gradual replacement of care institutions by community-based alternatives*”.

The EU Social Protection and Inclusion Process

The EU’s social protection and inclusion process is not limited to people with disabilities. It is useful to know the stages of the process, as it provides opportunities for disability organisations to monitor their country’s priorities and how well they are implemented.

The social inclusion process was launched in 2000 and reviewed in 2006. It is implemented through the **Open Method of Coordination (OMC)**. Under the OMC, the EU provides a framework for the development and coordination of national policies.

Each Member State’s national policy objectives (based on the common EU objectives⁴⁷) are set out in the **National Strategy on Social Protection and Social Inclusion** (formerly National Actions Plans). Strategies cover a period of three years and are coordinated with other national reporting mechanisms (for example, National Reform Programmes for Growth and Jobs). In the years in-between the OMC focuses on more in-depth analyses of specific issues and on disseminating policy findings.

⁴⁶ Text of the Resolution is available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2008:075:0001:0004:EN:PDF>.

⁴⁷ The list of common objectives is available at: http://ec.europa.eu/employment_social/spsi/common_objectives_en.htm.

Member States then prepare **national strategic reports** showing the efforts they have made to achieve the objectives.⁴⁸ These reports are jointly evaluated by the European Commission and Member States.

Based on the national strategies and the report, the Commission drafts the **Joint Social Protection and Social Inclusion Report for Council/Commission**. This summarises the main issues and trends and evaluates Member States' progress in reaching the common objectives.⁴⁹ It is an opportunity to highlight good practices and identify those countries that have not performed well.

The EU objectives – which are agreed together by the European Commission and the Member States, and contain a set of indicators and benchmarks to measure progress – are revised periodically to reflect progress and new challenges.

The EU **helps Member States implement social inclusion and protection objectives** by:

- ▶ Adopting legislation, for example in the field of anti-discrimination;
- ▶ Facilitating policy learning, exchange of ideas and good practices, and cooperation of stakeholders, including the representatives of the civil society (the so-called Peer Review Programme⁵⁰ or the PROGRESS programme⁵¹);
- ▶ Providing additional financial support for national social inclusion and protection policies from the Structural Funds of the European Union (European Social Fund and European Regional Development Fund).

Anti-discrimination legislation in the EU

The EU anti-discrimination legislation is binding on all the Member States. It has to be transposed into domestic legislation and implemented, and if that does not happen, Member States are held accountable. The European Commission can initiate the so-called 'infringement procedure' against the Member State, whereas the Member State is first given an opportunity to implement the legislation (within a given timeframe) and if it still fails to do so, the case is transferred to the European Court of Justice (ECJ). If the ECJ upholds the case, the Member State can end up facing a fine. Individuals can also take a case to ECJ if their rights under EU anti-discrimination legislation are violated.⁵²

⁴⁸ See guidelines from the European Commission for preparing national strategy reports at: http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/080207_guidance_note_nsrs_cln_en.pdf.

⁴⁹ Commission and country reports can be downloaded from http://ec.europa.eu/employment_social/spsi/strategy_reports_en.htm and http://ec.europa.eu/employment_social/spsi/publications_en.htm.

⁵⁰ Further information about Peer Review is available at: http://ec.europa.eu/employment_social/spsi/peer_review_en.htm.

⁵¹ Further information about the PROGRESS programme is available at: http://ec.europa.eu/employment_social/progress/index_en.htm.

⁵² Further information, including guidance for victims of discrimination and tips for organisations are available at: http://ec.europa.eu/employment_social/fundamental_rights/rights/robli_en.htm or at the website of the Fundamental Rights Agency of the EU at: <http://www.fra.europa.eu/fra/index.php>.

At the moment, there are two EU anti-discrimination directives⁵³ – one that provides protection on the grounds of race and ethnic origin (the Racial Equality Directive, 2000/43/EC) and another that protects against discrimination in employment on the grounds of disability, age, sexual orientation or religion or belief (the Employment Equality Directive, 2000/78/EC). A new directive, which will protect people with disabilities (and other groups still not covered by legislation) from discrimination in education, social protection, access to goods and services is being considered.⁵⁴

The **Employment Equality Directive** protects people with disabilities from discrimination in employment and training. The Directive contains definitions of *direct and indirect discrimination* and *harassment*. It allows for *positive action* (specific measures to compensate for disadvantages arising from an individual's disability) and gives the right of *legal redress* to victims of discrimination. The Employment Equality Directive requires employers to make *reasonable accommodation*⁵⁵ to enable a disabled employee to have access to employment or training unless this would impose a 'disproportionate burden' on the employer. For example, to enable a blind person who uses a guide dog to get to work more easily, the employer could change their working hours so they do not have to come in the rush hour.⁵⁶

2. Information relevant to candidate and potential candidate countries

Countries that aspire to join the EU have to prove that their political, legal and administrative systems are ready for membership or the start of the accession process.⁵⁷ Candidate countries and other European countries that are not members of the EU work together with the European Commission in the framework of an accession partnership (Croatia, the Former Yugoslav Republic of Macedonia and Turkey) or European partnership (Albania, Bosnia and Herzegovina, Montenegro, Kosovo, Serbia). The European Commission regularly reviews their progress towards accession criteria and indicates where further efforts are needed.⁵⁸ In the field of social inclusion (see page 81), candidate countries must prepare a **Joint Inclusion Memorandum (JIM)** that identifies the main challenges and policy priorities in social inclusion and protection, including the social inclusion of people with disabilities.⁵⁹

⁵³ The Directives are available at: http://ec.europa.eu/employment_social/fundamental_rights/legis/lgdirect_en.htm.

⁵⁴ The draft text of the new anti-discrimination Directive is available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:DKEY=473800:EN:NOT>.

⁵⁵ For a glossary of terms from the Employment Directive, see: http://ec.europa.eu/employment_social/fundamental_rights/rights/gloss_en.htm.

⁵⁶ Source: Human Rights Consultancy Group and Migration Policy Group, *Combating Discrimination – A Training Manual*, available at: <http://ec.europa.eu/social/main.jsp?catId=423&langId=en>.

⁵⁷ These are known as the Copenhagen criteria. More information is available at: http://europa.eu/scadplus/glossary/accesion_criteria_copenhagen_en.htm.

⁵⁸ Progress reports can be downloaded from: http://ec.europa.eu/enlargement/how-does-it-work/progress_reports/index_en.htm.

⁵⁹ Joint Inclusion Memoranda submitted by candidate countries can be downloaded from: http://ec.europa.eu/employment_social/spsi/enlargement_en.htm.

Candidate and potential candidate countries receive financial and technical assistance from the European Union. The Instrument for **Pre-accession Assistance**⁶⁰ supports projects that help countries reform and adapt their legislation and administration to EU membership. These projects might include the creation of community-based alternatives to institutions. Initiating such projects could be a key goal for advocacy at the national and EU level. The **PROGRESS Programme** is also open to candidate and potential candidate countries. There are also a number of so-called **technical assistance** instruments that are designed to help countries develop the structures, strategies and management skills needed to strengthen administrative and social capacity. These programmes involve transfer of knowledge and good practices from the Member States.⁶¹

3. Contact points in the European Union

The main contact point when it comes to disability policy in the European Commission is the **Unit “Integration of People with Disabilities”** within the **Directorate General (DG) Employment, Social Affairs and Equal Opportunities**.⁶²

For candidate countries, the main points of contact on most issue areas are **DG Enlargement**⁶³ and the **EU delegations in the countries**. However, some funding issues are dealt with by the DG Employment, Social Affairs and Equal Opportunities.

The forum for exchange between the Commission and the Member States in relation to people with disabilities is the **High Level Group of Member States’ Representatives on Disability** which meets on a regular basis in Brussels and comprises of senior representatives of national governments, the Commission, the Council of Europe and some NGO representatives (such as the European Disability Forum and the European Association of Service Providers for Persons with Disabilities). It has no mandate to take binding decisions, it only puts forward recommendations, formulates opinions and fosters exchange of information.⁶⁴

The European Parliament has a **Disability Inter-group**⁶⁵ which is an informal grouping of members of the European Parliament and political parties working on disability issues. It

⁶⁰ Further information on Pre-Accession assistance is available at: http://ec.europa.eu/enlargement/how-does-it-work/financial-assistance/instrument-pre-accession_en.htm.

⁶¹ Further information on technical assistance is available at: http://ec.europa.eu/enlargement/how-does-it-work/technical-assistance/index_en.htm.

⁶² You can find contact details to the Disability Unit here: http://ec.europa.eu/employment_social/disability/contact_en.html#o.

⁶³ Information on DG Enlargement can be accessed here: http://ec.europa.eu/enlargement/who_does_what/index_en.htm. The list of delegations can be found here: http://ec.europa.eu/enlargement/who_does_what/delegations/index_en.htm.

⁶⁴ You can find out who represents your Government from the Disability Unit. The updated list of members is not published on the Commission’s website.

⁶⁵ The list of MEPs on the Disability Intergroup and contact details are available at: <http://www.disabilityintergroup.eu/>.

is not a formal committee of the Parliament and has no formal powers. But an MEP that is a member of the Intergroup might be a helpful ally in getting an issue on the agenda of the European Parliament or getting support of other MEPs for a specific issue.

Suggestions for Advocacy Activities

Below are some ideas how the EU can help to promote community living in current Member States and candidate countries:

- ▶ Reference to EU objectives from the Disability Strategy or in the field of social inclusion gives justification and added weight to policy demands. It is useful to show how community living fits into the policy agenda of the European Commission and point to national policies which do not conform to EU policies. The legitimacy of the European Union is particularly strong in candidate countries and the more recently joined Member States. Those countries are often keen to show conformity with European policy trends.
- ▶ The Structural Funds or Pre-Accession assistance might be used to finance the creation of community-based alternatives to institutions in Member States or candidate countries. However, it is up to the governments how they use this money – they might even decide to use it to improve conditions in institutions. To influence how this money is spent, advocacy should be targeted at the national level, to the authority responsible for managing and monitoring the spending of EU funds. (The example below illustrates how the European Social Fund is used in the Czech Republic to encourage change in institutions.)
- ▶ In candidate and potential candidate countries, progress reports provide an opportunity to highlight issues of concern to people with disabilities (such as institutionalisation). The European Commission is keen to hear the views of organisations representing people with disabilities. Organisations could monitor the implementation of Commission's recommendations and highlight any failure in achieving sufficient progress. (Case studies in Annex 3 show how Croatian and Bosnian organisations lobbied at the European institutions in Brussels.)
- ▶ European funding (e.g. PROGRESS programme, Daphne programme) might be directly available to support advocacy activities, particularly awareness raising and combating discrimination in Member States and candidate countries.⁶⁶ (See Annex 3 for an example of such work in Scotland.)

⁶⁶ Information on Commission grants is available at: http://ec.europa.eu/grants/index_en.htm and http://ec.europa.eu/employment_social/emplweb/tenders/index_calls_en.cfm.

Example of a Project Supported by the European Social Fund

The competition ‘Hope for the Change of Institutions’ is a part of a European Social Fund (ESF) project called *For Change*, and is supported by the Czech Ministry of Labour and Social Affairs. The project is implemented by the Czech organisation QUIP – Association for Change.

In the project, institutions for people with intellectual disabilities are invited to decide upon some basic principles for transforming their services, and to describe their experiences with person centred planning and supporting people in leaving institutional care. They are then asked to consider their residents’ situation and to come up with the initial steps they would need to take in order to transform themselves into a community provider. The three best projects receive staff training, are taken on a study trip to a community service provider abroad and receive financial support to take the first steps in the process of closure.

The project is now in its second year and is open to institutions all over the country.

Further information: QUIP – Association for Change, e-mail: info@kvalitavpraxi.cz, website: www.kvalitavpraxi.cz.

Council of Europe

The Council of Europe (CoE) is an international organisation established in 1949 with the aim of “promoting democracy and protecting human rights and the rule of law in Europe”. It has 47 members, including countries that are not members or (potential) candidate countries of the European Union, such as the Russian Federation, Ukraine, Azerbaijan, Armenia, Moldova and Georgia.

The CoE has adopted a number of human rights instruments, including the European Convention for the Protection of Human Rights and Fundamental Freedoms and the European Social Charter. When it comes to social inclusion of people with disabilities, the most relevant document is the Disability Action Plan 2006–2015.

1. Summary of the relevant policies

- ▶ Disability Action Plan 2006–2015
- ▶ European Social Charter
- ▶ European Convention on Human Rights

Disability Action Plan

In 1992, the CoE adopted a recommendation on “**A coherent policy for people with disabilities**”.⁶⁷ This urges governments to develop “comprehensive and co-ordinated national disability policies” taking into account all areas and stages of community inclusion and rehabilitation, for example education, vocational training, employment etc.

More recently, in 2006, the Committee of Ministers adopted 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** (also referred to as the Disability Action Plan).⁶⁸ The Disability Action Plan is intended to serve as a practical tool to develop and implement strategies and actions to realise the full social inclusion of people with disabilities and ensure that the rights and interests of people with disabilities are represented in all policies and policy-making. It also aims to help Member States implement the UN Convention on the Rights of Persons with Disabilities by suggesting specific actions that must be taken. All Member States should be involved in implementing the Action Plan.

The Plan addresses a wide range of areas, referred to as “key action lines”. Under each key action line, the document sets out objectives and specific actions that should be implemented by the States. There are 15 key action lines (such as participation in political, public and cultural life, education, employment, transport, health care, rehabilitation, legal protection etc.), including an action line on community living.

The **Action line Community living** focuses on: enabling people to live as independently as possible in their community, having a broad range of quality support services at community level and paying special attention to the situation of families that have a child with disabilities and families of disabled parents. A number of initiatives are suggested in order to fulfil the main objectives of this action line. For example, Member States should:

- ▶ implement a co-ordinated approach in the provision of community-based quality support services to enable people with disabilities to live in their communities and enhance their quality of life;
- ▶ ensure community-based quality service provision and alternative housing models, which enable a move from institution-based care to community living; and

⁶⁷ The policy is available at: <https://wcd.coe.int/ViewDoc.jsp?id=612929&BackColorInternet=9999CC&BackColorIntranet=FFBB55&BackColorLogged=FFAC75>.

⁶⁸ For full text and available translations see: http://www.coe.int/t/e/social_cohesion/soc-sp/integration/o2_council_of_europe_disability_action_plan/Council_of_Europe_Disability_Action_Plan.asp#TopOfPage.

- ▶ promote schemes which will allow disabled people to employ personal assistants of their choice.

The Action Plan acknowledges that the governments of Member States have the primary responsibility for the implementation of policies and actions. To monitor implementation, the Council of Europe set up a reporting mechanism which is based on an initial self-evaluation of Member States' current disability policies. Furthermore, Member States should adopt a national strategy to achieve the objectives of the Action Plan and should make regular progress reports on implementation. However, the Action Plan is a recommendation only, which means that Member States will not suffer any consequences if they do not implement it (apart from receiving a 'warning' from the Committee of Ministers and being shamed in front of other Member States).

To assist the Member States with implementation, a **European Coordination Forum for the Council of Europe Disability Action Plan 2006–2015** (CAHPAH) has been set up. It meets once a year and is composed of Member States' representatives (Ministry officials, representatives of National Human Rights Institutions or other experts appointed by the Government), representatives of the Council of Europe, European Commission, various UN agencies and other intergovernmental organisations.⁶⁹ Civil society is represented by two representatives of the Grouping of NGOs accredited with the Council of Europe and the European Disability Forum. The meeting minutes are not public, but the information about the next meeting is available on the CoE website.

Member States are encouraged to translate the Action Plan into their official languages and make the translations available in alternative formats, such as easy-to-read or audio.⁷⁰ They are also expected to involve all stakeholders in the initial evaluation and the implementation of the strategy, particularly organisations of people with disabilities. Governments might also use financial assistance from the Council of Europe Development Bank for the implementation of the Action Plan.

The European Social Charter

The **European Social Charter** was adopted in 1961 and revised in 1996 (the revised Charter came into force in 1999).⁷¹ A total of 40 countries have signed and ratified the Charter (either the 1961 Charter or the revised version).⁷²

⁶⁹ The list of officials sitting on the Forum cannot be obtained from the Council of Europe, but you should be able to find out from the relevant Ministry who is representing your country.

⁷⁰ There is now an easy-to-read version of the Action Plan available in English and French at: http://www.coe.int/t/e/social_cohesion/soc-sp/integration/02_council_of_europe_disability_action_plan/Council_of_Europe_Disability_Action_Plan.asp#TopOfPage.

⁷¹ For full text of the Charter and the Revised Charter see: http://www.coe.int/t/dghl/monitoring/socialcharter/Presentation/TreatiesIndex_en.asp.

⁷² The list of signatories is available at: <http://conventions.coe.int/Treaty/Commun/ChercheSig.asp?NT=163&CM=8&DF=2/20/2007&CL=ENG>.

The Charter⁷³ sets out social and economic rights, such as the right to work, the right to collective bargaining, the right to social security, the right to social and medical assistance, the right to the social, legal and economic protection of the family, and the right to protection and assistance for migrant workers and their families. In 1996, new rights were added, such as the right to protection against poverty and social exclusion, the right to housing etc.

States have a certain degree of freedom in choosing which articles to ratify. They have to accept at least 6 of the 9 articles of the “hard core” provisions of the Charter⁷⁴ and select an additional number of articles or numbered paragraphs to be bound by. The total number of articles or numbered paragraphs by which every state is bound is not less than 16 articles or 63 numbered paragraphs.

The “**right of persons with disabilities to independence, social integration and participation in the life of the community**” is set out in Article 15 of the Revised Charter, and is not part of the “hard core” articles (which means that States can opt out of ratifying it). It aims to ensure that people with disabilities, regardless of their age and the nature and origin of their disability, can exercise their right to independence, social integration and participation in the life of the community.

Countries that ratified the Charter are required to submit yearly implementation reports. A new reporting system has been in place since 2007 and States now report on four thematic areas in turn (each year, a different thematic group is selected): employment, training and equal opportunities (Group 1); health, social security and social protection (Group 2); labour rights (Group 3); children, families, migrants (Group 4). The timetable is decided by the Committee of Ministers.⁷⁵

European Committee of Social Rights

Reports are examined by the **European Committee of Social Rights** (the Committee), a body of 15 independent and impartial experts elected by the Committee of Ministers.⁷⁶ The Committee judges the conformity of national law and practice with the European Social Charter and the Revised Charter and adopts “conclusions”.⁷⁷

⁷³ Unless otherwise indicated the word “Charter” refers to both the 1961 and the Revised Social Charter.

⁷⁴ The “hard core” provisions are: Articles 1 (right to work), 5 (freedom of association), 6 (collective bargaining), 7 (right of children and young persons to protection), 12 (right to social security), 13 (right to social and medical assistance), 16 (right of the family to social, legal and economic protection), 19 (right of migrant workers and their families to protection) and 20 (right to equal opportunities and equal treatment in matters of employment and occupation without discrimination on the grounds of sex).

⁷⁵ The timetable and the required format are available here: http://www.coe.int/t/dghl/monitoring/socialcharter/ReportForms/FormIndex_en.asp.

⁷⁶ For more information about the European Committee of Social Rights, see: http://www.coe.int/t/dghl/monitoring/socialcharter/ECSR/ECSRdefault_en.asp.

⁷⁷ Conclusions of the Committee are available at: http://www.coe.int/t/dghl/monitoring/socialcharter/Conclusions/ConclusionsIndex_en.asp.

In 1995, the mechanism of **collective complaints** was introduced⁷⁸ that gives the right to lodge a collective complaint with the Committee to, among other, international non-governmental organisations with consultative status with the Council of Europe.⁷⁹ However, the collective complaint procedure is only relevant in those countries which signed the additional protocol to the Charter – at present, there are only 14 of them.⁸⁰ Among the collective complaints lodged by disability organisations is *Autism Europe vs. France*, which resulted in the Committee ruling that France was in violation of the right of children with disabilities to education.⁸¹

If a State fails to implement or violates any of the provisions of the Charter, based on the conclusion or decision of the Committee, the Committee of Ministers of the Council of Europe calls upon the State to take action to correct the situation – to adopt a new law or change its practices.⁸²

European Convention on Human Rights

The **European Convention for the Protection of Human Rights and Fundamental Freedoms**⁸³ was signed in 1950 and was ratified by all 47 member states.⁸⁴ The Convention contains rights such as the right to liberty and security, the right to respect for private and family life, the right to marry, prohibition of torture, prohibition of discrimination and others.

In 1959, the **European Court of Human Rights** was established by the Council of Europe in Strasbourg. The Court is successfully used in legal advocacy for the rights of people with disabilities by non-governmental organisations specialising in legal advocacy.

Cases of violation of rights set out in the Convention by the Member States can be brought to the Court by individual applicants (including individuals, groups of individuals and NGOs), provided they satisfy the prescribed admissibility criteria. If the Court finds that the case is admissible and there has been a violation of rights, it can award a “just satisfaction”, a sum of money to compensate for certain forms of damage.⁸⁵

The Court is an important forum for international legal advocacy. Individual cases of human rights violations against people with disabilities can be used to highlight more widespread, systemic problems. A Court decision can also provide a good momentum for an advocacy campaign or other advocacy activities.

⁷⁸ For text of the Additional Protocol, see: <http://conventions.coe.int/Treaty/EN/Treaties/Html/158.htm>.

⁷⁹ Information about organisations entitled to lodge complaints is available at: http://www.coe.int/t/dghl/monitoring/socialcharter/OrganisationsEntitled/OrganisationsIndex_en.asp.

⁸⁰ For a list of signatories, see: <http://conventions.coe.int/Treaty/Commun/ChercheSig.asp?NT=158&CM=8&DF=5/27/2008&CL=ENG>.

⁸¹ More information about the complaint is available at: <http://www.autismeurope.org/portal/Default.aspx?tabid=644>.

⁸² For more information, see: http://www.coe.int/t/dghl/monitoring/socialcharter/CM/CMIndex_en.asp.

⁸³ The full text of the Convention (in different languages) is available at: <http://www.echr.coe.int/ECHR/EN/Header/Basic+Texts/Basic+Texts/The+European+Convention+on+Human+Rights+and+its+Protocols/>.

⁸⁴ Information on CoE legal instruments and ratifications is available at: <http://conventions.coe.int/Treaty/Commun/ListeTraites.asp?CM=8&CL=ENG>.

⁸⁵ For more information, see: <http://www.echr.coe.int/ECHR/EN/Header/Applicants/Information+for+applicants/Frequently+asked+questions/>.

2. Contact points at the Council of Europe

The main contact point for disability related issues at the Council of Europe is the **Integration of People with Disabilities Unit**.⁸⁶ You can also contact the CoE **Commissioner for Human Rights**⁸⁷ to report violations of the rights of people with disabilities in your country. The Commissioner periodically visits Member States and publishes reports on the state of human rights. Country visits are announced on the Commissioner's website and he can be asked for a meeting during the visit. Another useful contact point is the **European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment**⁸⁸ (the so-called CPT), which also periodically visits Member States and inspects all places of detention, including residential institutions for people with disabilities and psychiatric hospitals. Visits of the Committee are not announced in advance, but suggestions on places to be inspected and requests for a meeting can be submitted to the Committee.

Suggestions for Advocacy Activities

Below are some ideas on how the CoE legal instruments and policies can help advocacy for community living. Some of these are areas that require specialist legal expertise and would therefore need collaboration with organisations specialising in legal advocacy.⁸⁹

- ▶ Participating in the monitoring of the Disability Action Plan 2006–2015 by sending the relevant information to your country's representative in the European Coordination Forum for the Council of Europe Disability Action Plan 2006–2015 or one of the representatives of the civil society on the Forum.
- ▶ Sending information about human rights violations in your country to the Commissioner for Human Rights and the Committee for the Prevention of Torture (relating to practices in institutions and psychiatric hospitals).
- ▶ Using the complaints mechanism of the Revised Social Charter (if the country has signed the additional protocol). The complaints mechanism provides an opportunity to raise awareness of human rights violations and discrimination against people with disabilities and put issues on the government's agenda. (Requires legal expertise.)
- ▶ Making a complaint to the European Court of Human Rights (ECHR). (Requires legal expertise.)

⁸⁶ Contact information is available at: http://www.coe.int/t/e/social_cohesion/soc%2Dsp/integration/II_contact_us/presentation.asp#TopOfPage.

⁸⁷ Contact information is available at: http://www.coe.int/t/commissioner/Office/contact_en.asp.

⁸⁸ For more information about the Committee for the Prevention of Torture, see: <http://www.cpt.coe.int/en/>.

⁸⁹ Such as the Mental Disability Advocacy Centre in Hungary (www.mdac.info) and Interights in the UK (www.interights.org). Both organisations work Europe-wide.

United Nations

The UN is the largest international organisation with 192 Member States from Afghanistan to Zimbabwe.⁹⁰ It aims to maintain international peace and security, harmonise the actions of nations, cooperate in solving international problems, and promote respect for human rights.⁹¹

The UN has adopted a number of human rights treaties, such as the *International Covenant on Economic, Social and Cultural Rights* (ICESCR), the *International Covenant on Civil and Political Rights* (ICCPR), the *Convention Against Torture* (CAT), the *Convention on the Elimination of All forms of Discrimination against Women* (CEDAW), the *Convention on the Rights of the Child* (CRC). (All these treaties apply to persons with disabilities.)

In the field of disability, the UN has two important instruments: the **Convention on the Rights of Persons with Disabilities** (the Convention) and the **Standard Rules on the Equalisation of Opportunities for People with Disabilities** (the Standard Rules).

The Convention is the first ever legally binding international treaty that is specifically focused on the human rights of persons with disabilities. It was adopted in 2006 and came into force in May 2008. The Convention makes community living a right for all people with disabilities. The Optional Protocol, which is attached to the Convention, allows individuals to file complaints against their country to the monitoring body. The Optional Protocol is not ratified automatically when countries ratify the Convention – this needs to be done separately.

Unlike the Convention, the Standard Rules are not a legally binding instrument, but they are meant to serve as an instrument for policy making and a basis for technical and economic cooperation. They also provide for the appointment of a Special Rapporteur (this position is currently held by Sheikha Hissa Khalifa bin Ahmed al-Thani), who monitors their implementation.

1. Summary of the relevant policies

- ▶ Convention on the Rights of Persons with Disabilities
- ▶ Standard Rules on the Equalisation of Opportunities for People with Disabilities

⁹⁰ List of countries which are a part of the UN is available at: [://www.un.org/members/list.shtml#z](http://www.un.org/members/list.shtml#z).

⁹¹ For more information about the UN, see: http://www.un.org/Overview/uninbrief/chapter1_intro.html.

Convention on the Rights of Persons with Disabilities (CRPD)

The Convention on the Rights of Persons with Disabilities⁹² was adopted by the UN General Assembly in December 2006, opened for signature by Member States in March 2007 and entered into force in May 2008 after 20 countries ratified it.⁹³ The aim of the Convention is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (Article 1).

The Convention defines people with disabilities as “persons including those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (Article 1).

In Article 3, the Convention lists the principles that it is founded on, and which are then upheld in the articles that follow. Among them is the “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons”.

The Convention does not create any new rights.⁹⁴ However, it enumerates all the rights that must be upheld if people with disabilities are to live included in society, with opportunities equal to others. It guarantees people with disabilities:

- ▶ Equality before the law without discrimination
- ▶ Right to life, liberty and security of the person
- ▶ Equal recognition before the law and legal capacity
- ▶ Freedom from torture
- ▶ Freedom from exploitation, violence and abuse
- ▶ Right to respect physical and mental integrity
- ▶ Freedom of movement and nationality
- ▶ Right to live in the community
- ▶ Freedom of expression and opinion
- ▶ Respect for privacy
- ▶ Respect for home and the family
- ▶ Right to education
- ▶ Right to health

⁹² The full text of the Convention in English and some national translations can be found here: <http://www.un.org/disabilities/default.asp?navid=12&pid=150>.

⁹³ List of countries that ratified the Convention can be viewed here: <http://www.un.org/disabilities/default.asp?navid=18&pid=257>.

⁹⁴ United Nations, *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities*, Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol, 2007. Available at: <http://www.un.org/disabilities/default.asp?id=212>.

- ▶ Right to work
- ▶ Right to an adequate standard of living
- ▶ Right to participate in political and public life
- ▶ Right to participate in cultural life

The real importance of the Convention is that it not only re-affirms the human rights of people with disabilities but sets out concrete steps that governments have to take to achieve equality of rights. The article that is most relevant to those advocating for community living is **Article 19: Living Independently and Being Included**. In order to enable “*all persons with disabilities to live in the community, with choices equal to others*” the article asks the State Parties to “*take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community*”. It goes on to state the concrete steps State Parties should take. This includes ensuring that people with disabilities can choose where and with whom they live on an equal basis with others, that they are not obliged to live in a particular living arrangement, that they have access to a range of community support services (including personal assistance) and that they have equal access to community services and facilities for general population.

Optional Protocol to the Convention

The Optional Protocol to the Convention (which is not ratified automatically with the Convention) establishes a complaint and an inquiry procedure. The complaint (or “communications”) procedure allows individuals or groups to submit complaints to the Committee on the Rights of Persons with Disabilities if the government has violated any provision of the Convention. The Committee examines the complaint and the response of the state. After that, it formulates its opinion and recommendations, which are communicated to the state and made public.

In the inquiry procedure the Committee may investigate systematic violations of the Convention. The Committee may issue reports and visit the country. All findings and observations are made public. However, States that ratify the Optional Protocol can opt out of the inquiry procedure.

Implementation of the Convention

By ratifying the Convention, Governments undertake to take a range of steps, including: adopting new legislation, promoting the rights of people with disabilities in all policies and programmes, ending any practice that violates the rights of people with disabilities and ensuring that the rights of people with disabilities are respected. The Convention also requires that people with disabilities are involved in developing and implementing legislation and policies and in decision-making processes that concern them.⁹⁵

⁹⁵ See Frequently Asked Questions regarding the Convention on the Rights of Persons with Disabilities, available at: <http://www.un.org/disabilities/default.asp?navid=23&pid=151>.

The Convention recognises that States might not have all the necessary resources to implement the provisions at once. But the lack of resources cannot be a justification for taking no action or continued discrimination against people with disabilities. States must “*take measures to the maximum of their available resources [...] with a view to achieving progressively the full realization of these rights*” (Article 2 (4)).

The real strength of an international instrument lies in its implementation. The implementation mechanisms of the Convention are quite novel and promising because they give a stronger voice to individuals with disabilities and NGOs.

At the **national level**, governments are required to set up a ‘**national framework**’ to promote, protect and monitor the implementation of the Convention. Governments have freedom in deciding about the framework, but it should include at least one independent body and involve civil society, in particular people with disabilities and their representative organisations.

Governments have to submit an initial **report** within two years after the Convention enters into force, explaining the framework that has been set up for the implementation of the Convention, enumerating the policies and programmes adopted and indicating progress made after the ratification. After the initial report, governments must submit periodic reports at least every four years. Periodic reports should respond to the concluding observations of the Committee on the Rights of Persons with Disabilities to previous reports, indicate progress made in the implementation of the Convention and highlight any obstacles faced.

At the **international level**, the Convention establishes a ‘**Committee on the Rights of Persons with Disabilities**’. Initially the Committee is made up of 12 independent experts, which after an additional 60 ratifications will increase to 18. The Committee has the task of reviewing periodic reports submitted by governments. The Committee also has the authority to examine individual complaints and conduct inquiries in relation to those states that have ratified the Optional Protocol.

The Convention also establishes a ‘**Conference of States Parties**’ comprised of the representatives of governments that have ratified the Convention. The responsibilities of the Conference include electing the members of the Committee on the Rights of Persons with Disabilities and deciding on proposed amendments to the Convention.

UN Standard Rules

The Standard Rules on the Equalisation of Opportunities for People with Disabilities⁹⁶ were adopted in 1993 by all (at that time) of the 191 Member States of the UN. The Standard Rules are a predecessor to the Convention. They are not legally binding but represent a

⁹⁶ The text of the Standard Rules is available at: <http://www.un.org/esa/socdev/enable/dissre00.htm>.

moral and political commitment and serve as an instrument for policy-making. The Standard Rules consist of 22 rules based on the World Programme of Action Concerning Disabled Persons adopted in 1982. The Rules are based on the human rights perspective of disability and cover all aspects of life of people with disabilities. The Rules provide for the appointment of a Special Rapporteur on Disability to monitor their implementation. The Special Rapporteur reports yearly to the Commission for Social Development.⁹⁷

2. Contact points in the UN

The unit responsible for coordination of disability policy at the UN is the **Secretariat for the Convention on the Rights of Persons with Disabilities**.⁹⁸ Besides the implementation of the Convention, its mandate includes the implementation of the Standard Rules, promoting national, regional and international programmes and activities; providing support to governments and civil society; and mainstreaming disability issues into UN policies. Another point of contact is the office of the **Special Rapporteur on Disability**.

Suggestions for Advocacy Activities

Below are some ideas on how UN policies can help advocacy for community living:

- ▶ Campaigning for the ratification of the Convention and the Optional Protocol in countries that have not done so as yet.
- ▶ Using the Convention to raise awareness about issues affecting people with disabilities.
- ▶ Promoting the implementation of the Convention in countries that ratified it by reviewing national legislation, setting up implementation mechanisms and monitoring the implementation.
- ▶ Reporting on the implementation of the Convention to the monitoring bodies – both on the national level and to the UN Treaty monitoring body (Committee on the Rights of Persons with Disabilities) – by writing “shadow reports” (see Chapter 4), and making use of the complaints system in countries that ratified the Optional Protocol (requires legal expertise).

⁹⁷ To download the 2008 report and for more information about the work of the Special Rapporteur, see: <http://www.un.org/disabilities/default.asp?navid=9&pid=183>.

⁹⁸ For contact information, see: <http://www.un.org/disabilities/default.asp?id=175>.

ANNEX 3

Case Studies

This chapter presents activities carried out by organisations from around Europe. Some of them have been successful in their work, some less successful. Many activities are still ongoing and are a part of a long term effort towards social inclusion of people with disabilities. At the beginning of each activity, you will find a brief description.

We hope that these examples will inspire you to take action and would like to invite you to send us descriptions of your own advocacy activities to be posted on the ECCL website. Contributions can be sent to coordinator@community-living.info.

I. Lobbying and Campaigning

Lobbying week in Brussels (Croatia)

These case studies illustrate how accession to the European Union can be used by organisations as a lobbying opportunity.

Croatia is in the process of accession to the European Union (EU), which means that it is being assessed by the European institutions for its readiness to join the EU. As part of this process, a range of its policies, including social inclusion policies, are being scrutinised, to ensure that they are in line with those of the EU. Any concerns about barriers to the social inclusion of people with disabilities can be raised with the European Commission, which can then include these concerns in a regular progress report on the country's readiness to

join the EU and make recommendations to which the government is expected to respond. Accordingly, this is a good opportunity to advocate for community living.

For this reason, self-advocates from the Association for Self-Advocacy (ASA) and advocates from the Association for Promoting Inclusion (API) decided to use the recently published Report on Human Rights of People with Intellectual Disabilities in Croatia⁹⁹ to bring the issues affecting people with intellectual disabilities to the attention of European institutions. In order to reach all the relevant EU officials, a lobbying week was organised in Brussels, with the support of Inclusion Europe.

Inclusion Europe brings together organisations of people with intellectual disabilities and their families, and API is one of its members. Inclusion Europe is based in Brussels and has good connections at the EU institutions, and was therefore able to support ASA and API in organising the meetings. If this had not been the case, ASA and API could have turned to the Croatian Ministry of Foreign Affairs (Department for European Integrations), which could have assisted them with the necessary contact information. In order to arrange the meetings, Inclusion Europe contacted all the main persons dealing with Croatia.¹⁰⁰

Before leaving for Brussels, ASA and API prepared extensively for the meetings. The delegation included a self-advocate (a person with intellectual disabilities), as it was important to have someone able to speak from their own experience. During the four days of the lobbying visit, the delegation met with representatives of the European Commission, the European Parliament, the European Economic and Social Committee,¹⁰¹ the Croatian Permanent Representation to Brussels (Mission of Croatia to the EU), and the European Disability Forum.

The main topics of discussion were deinstitutionalisation and community living, as well as decentralisation of social services (including issues such as enabling choice for users, user involvement and needs-based services). These are included in the Croatian Joint Inclusion

⁹⁹ The Report, published by Inclusion Europe and ASA, was unique, because the first part was written entirely by self-advocates (people with intellectual disabilities). Twelve of them were trained to interview their peers, after which they were able to interview more than 100 other people with intellectual disabilities. A strong focus in these interviews, and therefore in the final report, was on housing and the importance of community-based services. The Report is available at: <http://www.inclusion-europe.org/documents/HR-FinalReport-EN-web.pdf>.

¹⁰⁰ To find out who is responsible for each accession country, organisations can consult the website of DG Enlargement, at http://ec.europa.eu/enlargement/who_does_what/directorate-general/index_en.htm and the website of the European Parliament Committee on Foreign Affairs at <http://www.europarl.europa.eu/activities/committees/homeCom.do?language=EN&body=AFET>. It is also useful to visit the website of the Delegation of the European Commission to your country, in order to access key documents (previous progress reports, already adopted policies and documents, etc.) and information on negotiations chapters.

¹⁰¹ The European Economic and Social Committee (EESC) is a consultative body that gives representatives of Europe's socio-occupational interest groups, and others, a formal platform to express their points of views on EU issues. Its opinions are forwarded to the larger EU institutions – the Council, the Commission and the European Parliament. It thus has a key role to play in the EU's decision-making process.

Memorandum (JIM),¹⁰² which Croatia adopted during the accession process. By focusing on issues included in JIM, organisations could make sure that they speak about those issues that are relevant to the accession process.

Another topic of high importance was legal capacity. Because Croatia was one of the first countries in Europe to ratify the UN Convention on the Rights of Persons with Disabilities, it was important to raise awareness about the consequences of Croatia's guardianship laws (see Glossary) for people with intellectual disabilities and the necessity to reform these laws. All these issues were also raised in the Report on Human Rights of People with Intellectual Disabilities in Croatia. Participants took copies of the report with them to the meetings to support their presentations with the research findings as set out in the report.

On the occasion of the lobbying week, participants prepared a press release in Brussels that was widely disseminated by e-mail among the network of Inclusion Europe and all the European stakeholders dealing with disability issues (such as the European Commission, European Parliament, Council of Europe and disability organisations). It was also distributed in person during the European Parliament EU-Croatia Joint Parliamentary Meeting. In this respect, the support of Inclusion Europe was important, because of its large network. If such support is not available, organisations can build their own contacts database over time or by doing Internet based research.

The lobbying week of the two Croatian organisations in Brussels was a success. The European Commission showed an interest in the situation of people with disabilities in large residential institutions and asked for more information about the situation in the country and the people who still live in institutions.

As another result of the meetings, a self-advocate from ASA was invited to present conclusions of the Report at the third meeting of the EU-Croatia Joint Consultative Committee. The main topic of the meeting was Chapter 19 of pre-accession negotiations with the European Union, entitled Social Policy and Employment. The recommendations adopted at the end of the meeting stressed the need for individualised support services for persons with disabilities and their families. Upon the request of the self-advocate and with support of the other members of the Committee, the implementation of the UN Convention on the Rights of Persons with Disabilities was also added to conclusions.

Lobbying week in Brussels (Bosnia and Herzegovina)

With support of Inclusion Europe, a lobbying week in Brussels was organised for Bosnia and Herzegovina (similar to the one arranged for Croatia – see the above case study). Bosnia

¹⁰² The Memorandum outlines the principal challenges in relation to tackling poverty and social exclusion, presents the major policy measures taken by Croatia in the light of the agreement to start translating the EU's common objectives into national policies and identifies the key policy issues for future monitoring and policy review.

is a potential candidate country, which means that the EU has not yet started accession negotiations. Nevertheless, the EU monitors developments in the country in order to decide whether it is ready to move to the next stage of accession (i.e. become a candidate country).

The central message of the lobbying week was that given the particular circumstances and many pressing human rights issues in Bosnia and Herzegovina, the rights of people with intellectual disabilities are easily overlooked. In addition, people with intellectual disabilities and their families in Bosnia receive little or no support to participate in the political process and speak up for their rights. Findings of the Report on the Rights of People with Intellectual Disabilities in Bosnia and Herzegovina,¹⁰³ published by Životna Pomoć (a national cross-ethnic organisation) and Inclusion Europe, were presented during the meetings and the report was distributed to meeting participants.

As in the case of Croatia, Inclusion Europe helped organise the meetings in Brussels for their Bosnian member. The staff of Životna Pomoć met with representatives of the European Commission, the European Parliament, the European Economic and Social Committee, and the European Disability Forum.

As a result of the meetings, the chair-person of the European Parliament's Committee for the Balkans, a German MEP, invited the representative of Životna Pomoć to meet her in Bosnia. She also raised the issue of the situation of people with intellectual disabilities at meetings of the Committee and distributed the Report on the Rights of People with Intellectual Disabilities to all members of the Committee.

Anti-bullying Campaign (Scotland)

This case study is an example of a campaign against bullying of people with disabilities, which involved cooperation with local schools. The campaign was carried out by ENABLE Scotland, an organisation which campaigns to improve the lives of people with intellectual disabilities, their families and carers.

ENABLE Scotland has an Advisory Committee (ACE) of adults with intellectual disabilities that ensures that the views of people with intellectual disabilities are not only taken into account, but that they influence the direction of the organisation. A few years ago, members of the Advisory Committee raised the issue of bullying as a big problem for people with intellectual disabilities, and ENABLE decided to organise a campaign on the issue.

The first step was to find out how widespread the problem was and who were the main 'perpetrators'. ENABLE worked in partnership with another organisation – Mencap in England – to develop a survey. They distributed this among their networks of self advocates

¹⁰³ The Report is available at: <http://www.inclusion-europe.org/documents/BiH-Report-EN-web.pdf>.

and held a one off event to discuss it. As a result, they found out that it was usually children who bullied people with intellectual disabilities.

ENABLE then applied for money from the DAPHNE Initiative of the European Union and from the Diana Princess of Wales Memorial Fund to develop a programme that trained people with intellectual disabilities to go to schools to talk to children about bullying and the impact it had on people's lives.

They contacted schools to tell them about their programme. Some schools never responded but others were very keen to have them visiting, sometimes on a regular basis. Overall, it was relatively easy to get access to schools, particularly because bullying (among children and young people) was very high on the agenda of schools at that time.

To evaluate the programme, ENABLE designed an evaluation form for pupils to complete and return to them after the presentation. Generally, the feedback was very positive, mainly because many pupils had never properly met anyone with an intellectual disability. The work was accompanied by a powerful postcard campaign highlighting bullying of people with intellectual disabilities which was very well received by the public.

Lobbying for the Law on Foster Family Care (Croatia)

This case study describes the lobbying efforts of the Association for Promoting Inclusion, Croatia to change legislation on foster family care. This example highlights the successes and failures of API's lobbying work.

According to the statistics of the Ministry of Health and Social Care (as of 31 December 2006), around 1.550 children with intellectual disabilities in Croatia live in institutions, while 378 live in foster families.

Specialised Foster Family Care is a program which aims to deinstitutionalise children with intellectual disabilities and complex dependency needs. In Croatia, the only such program for children with intellectual disabilities is run by the Association for Promoting Inclusion (API), which established it in 1998. The program covers four different counties, in which three mobile teams support 46 children with intellectual disabilities placed in 27 foster families. API's program is not a part of the social care system. It is an alternative program funded exclusively from donations and project grants.

For a long time there have been discussions in Croatia about the need for a law which will regulate foster family care, as an important and specific form of care outside of one's biological family. To this end, API carried out a qualitative analysis of foster family care for children with intellectual disabilities in Croatia, and compiled the findings in a publication. These clearly showed what the situation in the country was and suggested a number of measures that need to be taken to ensure that the rights and needs of children are met.

To point to the shortcomings of the existing Law on Foster Family Care and offer solutions that could be worked into the new law, API organised round tables and participated in media debates. One of the round tables brought together representatives of the Ministry of Health and Social Care, who participated in the drafting of the new law. At the same time, API took part in radio and TV programmes, to explain what changes the new law should introduce.

Finally, the new Law on Foster Family Care was adopted and came into force in October 2007. Unfortunately, it failed either to increase the quality of foster family care or to increase the number of foster families. On the contrary, since the new Law was adopted, the number of foster families has decreased. The changes that API called for, such as the professionalisation of foster family care, the provision of training and professional support to the children and their foster families (in cooperation with Centers for Social Care), were not adopted.

In conclusion, despite four years of discussion about the importance of foster family care, and the work of API and many other foster family care associations (which targeted the relevant ministries for children, Members of the Parliament and the media, organised rallies and round tables), the new Law did not bring any major changes. The Law also failed to recognise the existing good practice provided by API, which continues to function as an alternative programme.

API considers this to be due to the lack of political will and the government's unwillingness to decentralise services. Another reason given by the government was the lack of resources, even though API was able to prove that placement in foster families was less expensive than institutionalisation. For this reason, even though the new Law came into force only at the end of the last year, API considers it is important to lobby for new amendments.

Petition to the Scottish Parliament (Scotland)

This case study illustrates how a signature collection campaign can be organised and what elements a successful collection might have. In this case, it was the use of personal stories and involvement of a broad range of stakeholders in the campaign.

In June 2007, two members of ENABLE Scotland – Joan Mulroy (an independent advocate) and Lesley Learmonth (a self-advocate) – with support from others in the organisation, launched a campaign to raise awareness and understanding about advocacy.¹⁰⁴ In addition to its awareness raising component, the campaign targeted the Scottish Parliament, which was asked to give people with intellectual disabilities a legally enforceable right to an independent advocate.

¹⁰⁴ In the UK context, advocacy can refer to speaking or arguing on behalf of another person (in addition to being identified with social and political action). This is different from the term we are using in this manual.

Signatures on the petition addressed to the Parliament were collected face-to-face. This meant that many members and supporters of ENABLE could take part in the campaign and allowed ENABLE to tell people more about the benefits of advocacy (while asking them to sign the petition).

Blank copies of the petition were sent to members of ENABLE and other organisations that were likely to be interested in supporting advocacy for people with intellectual disabilities. They were asked to gather signatures from family, friends, colleagues, clubs, churches etc. (one member even asked his postman to sign) and send the sheets back by a specific date. The petition was also available for download from ENABLE's website and could be signed online (before doing this, ENABLE made sure that online signatures would be accepted by the Parliament). The link to the online petition was sent to members and other organisations, with a request to sign and forward to anyone that might be interested. A street stall was also planned, but there was not enough time to organise this.

The signature collection campaign was accompanied by the gathering of personal stories. The aim of the stories was to show how essential advocacy is and to encourage debate about when an advocate was essential (for example, when a person is moving out of a long stay hospital or when a service changes). They were also trying to find examples of situations where advocacy has saved money for the State. Some of the stories were put on ENABLE's website, while some were used to explain to politicians why advocacy was important.

Throughout the campaign, ENABLE has held regular meetings with self advocates and explained the campaign's progress. A question and answer sheet in easy read was produced to help self advocates deal with the types of questions they might be asked while collecting signatures.

In the end, nearly 2500 signatures were gathered from all over Scotland. These were handed to the Scottish Parliament for consideration by the Petitions Committee. The role of this Committee is to look at the issue raised by the petition and decide what, if anything, should be done next. ENABLE spoke to the Committee at the beginning of March 2008 and found out that the Committee had asked a number of other organisations for information. Among those are advocacy organisations, the Prison Service, the Health Boards and the Mental Welfare Commission.

Following this consultation, in September, the Committee made a decision to write to the Scottish Government asking whether there is adequate guidance on the procedure to challenge a lack of provision of independent advocacy and what practical steps it has taken to ensure that Health Boards and local authorities work together to implement advocacy plans. Further, the Committee agreed to write to two Health Boards seeking a response on the petition.

II. Coalition Building

Networking for change (Ukraine)

This case study is an example of how forming a national coalition (or a network) can help civil society representatives gain access to services for people with disabilities and can help tackle feelings of distrust by the Government towards civil society initiatives.

There are around 10 million children in Ukraine, of which around 142,000 have disabilities. Approximately 62,000 of these children live in state-run institutions. Children with disabilities are the most vulnerable group in the country due to the lack of adequate services. There is a lack of community-based services and skilled professionals, which could provide disabled children with the necessary services and help create opportunities for their social integration.

At the end of 2005, several NGO representatives who had become aware of the situation in institutions for children with disabilities started informing Government officials about the conditions in these institutions. The first reaction of the Government was to prevent NGO representatives from accessing institutions and to deny existence of severe problems in these services.

This situation encouraged local, national and international NGOs working in Ukraine to combine efforts and create a network which would coordinate lobbying activities aimed at improving the situation of children with disabilities in the state-run institutions. This cooperation dates back to the beginning of 2006, when several NGOs started raising awareness about the issue and asked for support from the national and international NGOs, UN offices in the country, churches, private sector, politicians, a famous singer, governmental bodies and the Council of Europe. They used photo and video evidence, a report and an example of good practice (positive results from a pilot therapeutic feeding program).

All the above-mentioned stakeholders were encouraged to join the network and work together. Each organisation maintained their full autonomy, but was encouraged to take coordinated action. The message to the Government was that these organisations all agreed that reform was needed and that they were willing to provide the Government with support. In the meantime, there was some political and international pressure and little by little this has led the Government to be more open towards NGOs. It was a complicated process, which took a lot of patience and perseverance, but it was important to be able to have dialogue with the Government on these issues. To this end, several meetings, conferences and round tables were held in the course of two years, with the aim of establishing cooperation between the Government and the civil society. The media were not involved, because the network feared that negative press coverage at this stage could jeopardise their relationship with the Government.

One of the results of the network's lobbying efforts is that professionals and volunteers from NGOs are now given access to some state-run institutions, and are able to show good practices in working with the children. The promotion of community-based services as the best alternative for disabled children has resulted in Government's financial support to some NGO service providers. Thanks to the efforts of the network, two project proposals have been submitted with the aim of improving the situation of disabled children in state-run institutions in the short term, and improving the quality of life and standards for social services in Ukraine in the long-term. This will be done through capacity building, strengthening of civil society and policy changes.

Coalition OKTAGON (Kosovo)

This case study is an example of a local cross-disability coalition which focuses on mainstreaming disability in local policies.

In Prishtina, the capital of Kosovo, eight disability organisations established the Coalition OKTAGON. It is a broad cross-disability coalition involving "Klubi Deshira" (a community service provider for people with mental health problems), Handikos (an association of people with physical disabilities), Kosova Down Syndrome Society, an association of deaf people, an association of blind people, OPFAKOS (a parents' organisation) and Handicap Kosova. The Coalition has a rotating presidency for six months.

In 2008, the Coalition is implementing a project called "Advocacy for mainstreaming disability in local policies". The aim of the project is to reach consensus with the national and local authorities on what needs to be done to fulfil the needs of persons with disabilities, and to agree on specific action points.

Still in its early days, the Coalition has so far contacted national and local authorities and met with the head of the Municipality of Prishtina. A working group was also established in order to develop a local action plan on disability. Other activities organised by the Coalition are round table discussions and distribution of leaflets about the initiative aimed at the wider public.

It is still too early to evaluate the success of the Coalition, but its establishment is an important first step in bringing together the disability community in Kosovo.

Learning Disability Alliance (Scotland)

This case study is an example of a regional coalition focused on working with the Parliament and ensuring that MPs are aware of the issues affecting people with intellectual disabilities.

The Learning Disability Alliance Scotland is a coalition of organisations which campaign on issues that affect people with intellectual disabilities. The initiative to form the Alliance came from ENABLE Scotland, which wanted to improve access of people with intellectual disabilities to the Parliament. ENABLE had experience in working with the Scottish Parliament since it first met in 1999, when it carried out a project on voting.

Before setting up the Alliance, ENABLE sent out a questionnaire to other organisations of and for people with intellectual disabilities, asking them how much access people with intellectual disabilities had to the Parliament. Most organisations came back with a negative response. ENABLE then called a meeting to discuss the results of the questionnaire and the Alliance was formed.

The purpose of the Alliance is to make sure that the Scottish Parliament is aware of the views of people with intellectual disabilities, their families and carers on all major policies and laws which affect them. Its activities include:

- ▶ Providing support to the Cross Party Group on Learning Disability of the Scottish Parliament.
- ▶ Speaking up for voluntary organisations of and for people with intellectual disabilities in Scotland.
- ▶ Putting forward the views, rights, interests and concerns of such organisations to the Scottish Parliament.
- ▶ Organising specific campaigns to advise the Parliament about what people with intellectual disabilities think. (Recently the Alliance campaigned on getting free bus travel for people with intellectual disabilities.)

The Alliance currently has 18 member organisations that pay a fee depending on their size, and employs a part time worker. It maintains its own website at www.ldascotland.org.

Network of Independent Service Providers for People with Disabilities – CÉHálózat (Hungary)

This is an example of a national coalition, which brings together community-based service providers for people with disabilities and is focused on promoting their interests.

The Network of Independent Service Providers for People with Disabilities is an informal alliance of organisations providing community services to people with intellectual disabilities, mental health problems and autism. Its mission is to represent the interests of non-profit community-based service providers in the area of social policy. The Network was established in 2006 and currently has 29 members. It is open to all independent service providers that respect and implement the following principles in their services:

- ▶ People with disabilities have the right to live an ordinary life in the community;
- ▶ Participation of people with disabilities in the design and provision of services;
- ▶ Person-centeredness;
- ▶ Providing services in one's community, close to one's family.

Members are not required to pay a fee but they commit themselves to contribute with their resources to the joint activities of the Network. The Network has a rotating presidency and Board, and coordination and secretarial tasks are carried out by Hand in Hand Foundation. The same organisation monitors and keeps the members up to date in latest policy initiatives, public consultations etc.

The Network's latest campaign aimed to change the discriminatory funding regulations of independent service providers that are threatening the survival of some of the organisations. This would in turn lead to institutionalisation of users of their services.

As part of the Campaign, the Network produced a policy paper summarising discriminatory provisions of the current legislation and demonstrating its consequences by comparing budgets of independent community-based providers and institutions. It also put forward concrete proposals to amend legislation, in order to eliminate institutional bias and introduce measures to create equal conditions for community providers. The policy paper was sent to policy makers and was discussed at meetings and discussion forums.

The Campaign is still on-going at the time of writing of the Manual, therefore no results can be reported so far.

European Coalition for Community Living (Europe-wide initiative)

This is a brief description of the establishment of the European Coalition for Community Living and the way it aims to advance the community living agenda in Europe.

The European Coalition for Community Living (ECCL) was established in August 2005. The idea for establishing the network came from the Included in Society project,¹⁰⁵ which carried out research into institutions for people with disabilities and community-based services in a number of European countries (with support of the European Commission).

The Included in Society project highlighted that, in order to replace long stay residential institutions with comprehensive, quality community-based services, there is a need for a joint effort among various stakeholders – the local, national and regional governments and

¹⁰⁵ More information about the Included in Society project and the final report can be found at: <http://www.community-living.info/?page=226>.

administration, the European Union, non-governmental organisations, service providers and others. For this reason, it recommended that ECCL should be established so that it could act as a long-term action centre, which would advocate for the development of quality community-based services and keep the importance of de-institutionalisation high on the agenda of policy and decision makers across Europe.

ECCL is a cross disability initiative. This is reflected in the founding organisations, which include Autism Europe, the Center for Policy Studies of the Central European University, the European Disability Forum, the European Network on Independent Living, Inclusion Europe, Mental Health Europe and the Open Society Mental Health Initiative.

After two years of being led by the seven founding organisations, ECCL changed its structure and since the beginning of 2008 it has worked as a project of the European Network on Independent Living (ENIL). However, the founding organisations have continued their involvement in ECCL by joining its Advisory Council, which gives advice to the ECCL on questions of strategy and policy. ECCL employs one staff person – a Coordinator – who is currently based in London, UK.

ECCL's activities include:

- ▶ Publishing position papers and briefings on the right of people with disabilities to live in the community and making recommendations on the steps required to achieve this.
- ▶ Advocating at the European level (i.e. at the European Commission, the European Parliament and the Council of Europe) for the development and implementation of policies that ensure the shift from institutional care to community based services and highlighting the crucial importance of involving people with disabilities as equal partners in this work.
- ▶ Supporting ECCL member organisations in their advocacy activities at the national level.
- ▶ Facilitating exchange of information and the promotion of best practice in the development of community based services by holding seminars and publishing newsletters for members of ECCL and other organisations interested in promoting the social inclusion of people with disabilities.
- ▶ Launching a campaign calling for the right of all people with disabilities to live in the community to be recognised and for governments to commit to shift their funding and support from long stay institutions to the development of community-based services. The commitment can be signed on ECCL's website www.community-living.info.

ECCL works as a network of disability organisations, service provider organisations, research institutes and individual supporters. The role of the members is of crucial importance, as they promote the network's mission and positions in their countries and contribute to its work with their specific expertise. ECCL's member in Romania has initiated the founding of the national coalition – Romanian Coalition for Community Living.

Between 2005 and 2007, ECCL was funded from contributions of the founding organisations and membership fees. In 2008, ECCL's main funder is the Open Society Mental Health Initiative. The membership is free of charge.

III. Pilot or Model Programs

Piloting community-based supported housing (Serbia)

This case study illustrates how pilot community-based service projects can be combined with lobbying efforts to change social care legislation and the development of quality standards for community-based services for people with disabilities.

The Serbian Association for Promoting Inclusion (SAPI) is a non-governmental and non-profit organisation promoting the social inclusion and human rights of people with intellectual disabilities. SAPI activities are focused on the development of new community-based social services, including community-based supported housing.

The SAPI Team, within the Expert Team of the Serbian Down Syndrome Aid Society, has been developing community-based supported-housing for the last four years in the project “Deinstitutionalisation of People with Intellectual Disabilities and Community-Based Supported-Housing”. This was one of the priority projects of the Fund for Social Innovations of the Ministry of Labour and Social Policy of Serbia (MLSP).

The Project started in early 2007. In the first stage of the project, called “Initiative for All – Serbia”, a strategy and a plan were developed for the creation of community-based supported housing services throughout Serbia. The strategy (spanning from 2008 to 2010) aims to de-institutionalise 300 people with intellectual disabilities and prevent institutionalisation of 100 individuals. Since the end of the first stage in April 2008, SAPI has supported 23 individuals with disabilities to live in the community.

SAPI also participated in the development of Standards for Community-Based Supported Housing. They developed and accredited a training programme for support workers in community-based supported housing. The training is partly carried out by service users and involves extensive practical training, demonstration and site visits to existing services.

In parallel with the other two activities, SAPI (in collaboration with the Open Society Mental Health Initiative, Budapest and the MLSP) proposed a Bill on Amendments of the Social Welfare and Social Security Law. The suggested amendments were aimed at regulating community-based supported housing. Some of the points included in the proposal were: implementing community-based supported housing as an alternative to living in social welfare institutions; defining the content of services; defining eligibility; ensuring a wider

range of service providers; making it possible for non-governmental organisations to become service providers; specifying the financing methods for services; and establishing standards and regulations of the services.

SAPI's lobbying efforts are supported by good cooperation with the media, which report positive stories of people who have moved out of institutions with SAPI's support and now live in the community.

The Bill on Amendments of the Social Welfare and Social Security Law is expected to be adopted by the end of 2008. The city of Belgrade has already responded to the proposal by giving community-based supported housing equal status with other social services provided in the city.

IV. User Led and Self-advocacy

The Cambridgeshire Parliament (UK)

This case study shows one way of strengthening the voice of people with intellectual disabilities in the policy making process. The Cambridgeshire Parliament was organised by Speaking Up, an organisation that supports and empowers people with disabilities to speak up for themselves. Speaking Up provides advocacy services, organises projects for self advocates and develops resources for people with intellectual disabilities, mental health problems and physical disabilities.

The Parliament was set up in 2000 in Cambridgeshire, England. It consists of people with intellectual disabilities, who act as Members of Parliament (MPs). In their role as MPs, they represent users of services for people with disabilities. There is also an 'independent' MP, who represents those people who do not access services. Candidates for the position of an MP have to go through campaigning and competitive election. There are currently 35 MPs and seven Ministers who specialise in a particular area, such as transport or high support needs.

The MPs determine the topics for each bi-monthly Parliament based on issues they feel are most important to their 'constituents'. Previous sessions focused on direct payments, bullying and being person-centred.¹⁰⁶ The Parliament has also campaigned for Changing Places toilets¹⁰⁷ in the community that are specially adapted for people with high support needs. All the Parliament sessions are run by people with intellectual disabilities with support from Speaking Up staff.

¹⁰⁶ Additional information about the work of the Cambridgeshire Parliament is available at: <http://asp.selesti.com/speakingup/v2/innovative-projects/index.php?action=40>.

¹⁰⁷ 'Changing Places toilets' are toilets with enough space for disabled people and their carers or assistants, and the right equipment. (Source: Changing Places, http://www.changing-places.org/the_campaign.asp)

The Cambridgeshire Parliament regularly engages with representatives of the local authorities and services. The main Parliament meetings are attended by representatives of the local government as invited guests of the MPs. Representatives of other relevant agencies also participate in the sessions. For example, at a Parliament session covering transport, representatives from bus and train companies attended. This brings people with intellectual disabilities into dialogue with mainstream groups in an environment that might surprise those who have limited contact with people with intellectual disabilities. It also brings together the full range of agencies responsible for the well being of people with intellectual disabilities, who are able to get feedback on the quality of services directly from those who use them.

Romania votes SMART (Romania)

This case study illustrates how elections can be used to get community living on the political agenda. It is an example of good timing, as well as involvement of people with intellectual disabilities in advocacy activities.

The “Romania votes SMART” Campaign was an initiative of Pentru Voi Foundation, Timisoara, in cooperation with the Institute for Public Policy (IPP), Bucharest and Inclusion Romania. Pentru Voi is a non-governmental organisation that provides community-based services in partnership with the Timisoara Municipality and advocates for the rights of persons with intellectual disabilities in Romania.

The campaign took place between May and June 2008 and aimed at creating a means of communication between the voters and the candidates for the County Council and Bucharest Sectors elections. In this way, it aimed to help Romanians vote in an informed way.

According to the law, the responsibility of developing social services for people with intellectual disabilities in Romania belongs to the County Councils and to the Bucharest Sectors administrations in Romania. Almost half of the County Councils’ budgets are allocated to the General Directorates of Social Assistance and Child Protection. People with intellectual disabilities, their families and the organisations which represent them have the right to know how this money will be used.

The Campaign offered the candidates of 5 counties (Timis, Giurgiu, Hunedoara, Mures, Sibiu) and Bucharest the opportunity to present to the voters specific actions which they will take to promote social inclusion of persons with intellectual disabilities.

In Timisoara and in Bucharest, a group of self-advocates, members of their families and of NGOs which organised the campaign met 5 candidates for the position of Timis County Council President and, respectively, 6 candidates at the Bucharest Sectors administrations. The candidates received a list of concrete questions about what they intended to do for the social inclusion of persons with intellectual disabilities, if elected. At the same time,

questions were sent to all the candidates who ran for the Timis, Giurgiu, Hunedoara, Mures and Sibiu and for the Bucharest Sectors.

Questions included:

- ▶ How many community-based social services, such as group homes, respite services, supported living programs, day centres do you intend to create in the next four years?
- ▶ In what way will you involve persons with disabilities, their families and disability organisations in the creation, implementation and monitoring of public policies in this field, on the basis of the principle “Nothing about us, without us!”?

A summary of the responses was published in the national and local press, on the websites of Pentru Voi and IPP, and on mailing lists, to help voters make an informed choice before the elections.

Establishing a user led advocacy group (Republic of Moldova)

This case study describes the process of establishing an organisation of users of mental health services.

Advocacy Center in Mental Health (run by the Mental Health Center Somato) in the municipality of Balti, Republic of Moldova, aims to improve the overall quality of life of people with mental health problems through the following activities: the promotion of services which encourage their integration into society with full respect of their rights; fighting against stigma and discrimination; and raising awareness among people with mental health problems and their families about their rights.

In order to raise awareness about the rights of people with mental health problems, the center organises training sessions with topics such as rights and responsibility, stigma and discrimination, users’ movements and associations etc. As one of the results of the training sessions, the first users’ organisation in the municipality of Balti was formed, with the name “Movement of the Soul” (“Mișcarea Sufletului”).

The goal of the users’ organisation is to improve the overall quality of life of people with mental health problems. People involved in the organisation’s activities have a direct interest in advocacy and other work – as users, they are affected by different problems and will therefore directly benefit from the results of advocacy activities. Involvement in the Movement of the Soul also helps transform members from ‘beneficiaries’, or passive receivers, into active agents of change.

All the activities carried out in the framework of the user-led organisation are supported by the Mental Health Center Somato. They benefit from this partnership with the Movement of the Soul, because it helps them become more effective in solving problems in the country’s mental health system.

V. Awareness Raising

Community Awareness Raising Programme (Greece)

This case study shows how awareness raising can be a major component of community-based services, and help fight stigma against, in this case, people with mental health problems.

The Society of Social Psychiatry and Mental Health (SSP&MH) is a non-governmental organisation, which has been operating since 1981 and works according to the principles of social-community psychiatry. It actively participates in Greece's psychiatric reforms and deinstitutionalisation of patients with chronic mental health problems. The services of the Society of Social Psychiatry and Mental Health are funded by the Ministry of Health and Social Solidarity.

In 1981, SSP&MH established Mobile Psychiatric Units (outreach services). The aim of these units is to meet people's needs in the area where they live – to stop people from suffering from psychosocial problems and prevent their placement in psychiatric hospitals. Each Mobile Psychiatric Unit has an interdisciplinary group of staff members who regularly visit small cities and villages in three Greek prefectures (Fokida, Evros and Rodopi). One of the characteristics of Mobile Psychiatric Units is that it is a service that belongs to the community. Therefore, local staff are employed and work directly with the local population.

The results of a recent research evaluating the quality of the services in one of the prefectures (Fokida) showed that both the users and the staff feel that respect, understanding, confidentiality and a comfortable environment characterise their relationship. The experience and knowledge which is acquired from the provision of services is used in order to encourage and influence the reform of mental health services in Greece. In addition, meetings with the local services and institutions are undertaken in order to discuss how better communication and cooperation can be established, in order to improve the co-ordination of activities. The outcome of these meetings was the establishment of a local network for better needs assessment, early intervention and planning of ways to meet these needs.

A fundamental aspect of the services offered by the therapists working for the Mobile Psychiatric Units (M.P.U.) is awareness raising (referred to by SSP&MH as “community sensitisation”). This can be defined as the work that is done in co-operation with the local population, with the aim of raising awareness and changing their attitude towards mental illness. It is a form of training that is targeted towards the population at large, as well as towards special groups within the community, such as teachers, doctors, the clergy, the police, the local government etc. Activities that are undertaken within the framework of the awareness raising programme include: discussion groups, impromptu discussions at coffee shops and other local gatherings and cultural events. The co-operation and meetings with these groups are a long-term activity that SSP&MH undertakes on an ongoing basis.

The emphasis that is placed on awareness raising activities stems from the fact that deinstitutionalisation of people with mental health problems will not be effective without measures to assist their social inclusion. Therefore, one of the main aims of the awareness raising programme is the population's attitude change towards mental illness, which will eventually result in the change of behaviour towards people with mental health problems.

Ability Park (Hungary)

This case study illustrates how interactive games can be used to explain the social model of disability and raise awareness about the obstacles people with disabilities face in the everyday life.

Ability Park was opened in 2002. Its purpose was to use the increasing interest in thematic parks and people's enjoyment of games to change attitudes towards people with disabilities. The Park aims to promote the change in attitude required for the social integration and inclusion of people with disabilities. It also endeavours to change indifference, aversion and pity often displayed towards people with disabilities into understanding and recognition, by presenting their abilities, opportunities and demands in a way which visitors can experience themselves.

The park has games which present the world of the visually, hearing and mobility impaired as well as people with intellectual disabilities.¹⁰⁸ It gives visitors an opportunity to try out what it is like to have a disability, to experience some of the barriers and find ways to overcome them. The aim of the games is to show that a person is disabled only to the extent the society and the environment are disabling.

Ability Park is a complex equal opportunities project: on one hand, its education and training program translates the obstacles experienced by people with disabilities into the language of various professions (architecture, education, media, IT) and illustrates that disability is created by the barriers in our society. On the other hand, it is an employment program playing a significant role in the workplace rehabilitation of people with disabilities through the employment of people with sensory, intellectual disabilities and mental health problems in various positions including as guides, technical staff etc. It is also a tourist attraction offering a meaningful and pleasant experience through its permanent games (blind labyrinth, wheelchair labyrinth, sign-post, Wonder Town) and other games of logic and dexterity, workshops and information services for all the visitors who wish to play, have a good time and test their abilities.

The Park has had more than 250,000 visitors since its opening.

¹⁰⁸ Photographs of the Park are available at: www.abilitypark.hu/english/about-us/.

Contact Details and Links

Association for Promoting Inclusion (Croatia)

e-mail: inkluzija@inkluzija.hr

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Children’s Rehabilitation Center Dzherelo (Ukraine)

e-mail: rhcentre@mail.lviv.ua

website: www.dzherelocentre.org.ua

ENABLE Scotland (UK)

e-mail: enable@enable.org.uk

website: www.enable.org.uk

Hand in Hand Foundation (Hungary)

e-mail: kezenfogva@kezenfogva.hu

website: www.kezenfogva.hu and www.fogadj-el.hu (in Hungarian)

Inclusion Europe (Belgium)

e-mail: secretariat@inclusion-europe.org

website: www.inclusion-europe.org

“Klubi Dëshira” Clubhouse (Kosovo)

e-mail: clubhousedeshira@hotmail.com

Mental Health Centre Somato (Moldova)

e-mail: somjana@mdl.net

website: www.mhc.somato.md/eng/index.htm

Pentru Voi Foundation (Romania)

e-mail: pentruvoi@pentruvoi.ro

website: www.pentruvoi.ro/index_en.htm

Serbian Association for Promoting Inclusion (Serbia)

e-mail: sapi@nadlanu.com

Society of Social Psychiatry and Mental Health (Greece)

e-mail: ekpsath@otenet.gr

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Speaking Up (UK)

website: www.speakingup.org

Životna Pomoć (Bosnia and Herzegovina)

e-mail: info@zivotnapomoc.org

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ANNEX 4

Notes for Trainers

In this chapter you can find some ideas about how to present the manual at a workshop. These are based on ECCL's pilot training session in September 2008 in Norway. In addition, we explain how ECCL plans to support workshop facilitators with additional resources on its website and providing opportunities for the sharing of information.

Before producing the final version of the manual, ECCL organised a one-day workshop on 11 September 2008 in Drammen, Norway. The workshop was open for representatives of disability organisations and service providers working on the local or national level, with or without previous experience in advocacy work. An experienced group of trainers from across Europe were recruited to design and deliver the Programme, working with one of manual's authors. They were assisted on the day by a fourth trainer.

Workshop Preparation

Before the workshop in Norway, the trainers worked together to agree on the objectives and contents of the Programme. There were a number of points that they took into account – these will be relevant to those wishing to hold similar workshops in their countries:

- ▶ **Time** – The workshop was limited to one day, which meant that there was no time to go through the entire manual. The trainers decided to spend more time on those parts which they thought would be most relevant to the group (taking into account the previous experience of participants in advocacy work and the type of organisations they were representing). *If you have more than one day, you can go into much more detail with the participants and, for example, work with the participants to develop a real strategy, action plans or a campaign, by the end of the workshop.*

- ▶ **Experience with using the manual** – The participants did not have a chance to read the manual before the workshop. The Programme was therefore designed so that they could be taken through the main elements of the manual (using a Power Point presentation). *If participants have already used the manual, trainers can simply refer to the information, rather than present it.*
- ▶ **Experience** – The fact that many participants were both knowledgeable about advocacy and community living meant that it was not necessary to spend time on discussing questions such as *What is advocacy?*, *What kind of activities can you carry out?*, *What are the elements of strategic planning?* etc. *If you can find out before the workshop how experienced participants are in advocating for community living, this will help you plan the workshop much better.*
- ▶ **Background** – The breadth of diversity in the group (with people coming from different countries from all over Europe and different types of organisations or institutions, both non-governmental and governmental) made it difficult to explore in depth any particular organisational or national campaigning strategy. Focus was therefore placed on exchange of experience and identifying common barriers and solutions in advocating for community living. *When organising local or national workshops, it is equally important to consider participants' previous experience with advocacy, their background (the type of organisation they are coming from) and motivation for attending the workshop. Ideally, this information should be collected from participants before the workshop (during the preparation stage).*
- ▶ **Trainers** – The fact that there were altogether five trainers meant that smaller groups could simultaneously explore different issues (i.e. each group could choose which planning step they wish to focus on). *The number of trainers needed for each workshop will depend on the number of participants, the length of the workshop and the methodology you want to use (for example, into how many groups you would like to divide the participants).*

Programme

Below are some suggested workshop objectives and programme elements. These were used at the workshop in Norway where participants came from all over Europe and were already experienced in advocating for community living. However, they can be adapted for local and national workshops or where participants have less experience in advocacy work.

Objectives

- ▶ To help participants understand community living as a policy objective and explore the process through which policies can be influenced;
- ▶ To help participants plan how they and their organisations can strengthen their advocacy strategies for community living;
- ▶ To explore ways of sharing ideas and experiences after the workshop.

Programme elements

- ▶ **Campaigning for Community Living: What are we learning from our experiences in different parts of Europe?**
Groups share experiences of campaigning and identify what is contributing to success and what is getting in the way.
- ▶ **Formulating a clear message about Community Living as a policy objective**
Participants share ideas on the meaning of community living and are introduced to the basic concepts important for advocacy for community living.
- ▶ **Advocating for Community Living in practice**
Presentation of a case study of an advocacy activity by the representative of the organisation undertaking this advocacy work, followed by discussion.
- ▶ **Developing effective campaigning strategies**
Participants share ideas about the different steps that need to be taken in order to arrive at effective campaigning strategies. They are then introduced to the seven key planning steps for developing effective campaigning strategies. In groups, they work on one of the steps (for example, “Understanding the policy environment”, “Producing a problem statement”, “Planning a course of action”)
- ▶ **Developing our own local and national advocacy strategies**
Participants draw on the day’s work to identify key points they are taking home to strengthen the advocacy work of their own organisation and its allies.
- ▶ **Building on this workshop**
Participants discuss how they can use the manual in their countries and identify how they might support each other in the future.

Recommendations for Trainers

Similar workshops conducted locally, nationally or regionally – especially if spread over more than a day – would permit more attention to sharing experience in constructing common or similar strategies. With the shared interest, the group can work through each of the seven planning steps (Chapter 3), in order to develop a strategy that is practical and has clear outcomes.

The programme should be based on how much experience the group already has in advocacy for community living. For those unfamiliar with the topic, more time should be spent on going through the actual content of the manual (understanding what advocacy is about, understanding what is community living, going through the different planning steps, going through possible activities, understanding the relevant community living policies), while more experienced groups can go straight to developing practical strategies.

Attention should be paid to making the workshop inclusive for all participants. This will include physical accessibility, personal support to participants who need it and ensuring that trainers are aware of needs of different participants.

Resources for Trainers

Based on the feedback ECCL received after the initial workshop, the following resources will be available from www.community-living.info.

- ▶ Full report from the Workshop on 11 September 2008, including the Programme and the list of participants.
- ▶ Examples of local and national workshops shared with ECCL (see below).
- ▶ Updates on the European and international policy context for community living (updating Annex 2).
- ▶ Additional case studies shared with ECCL (see below).
- ▶ Links to useful training resources for organisations without experience in conducting workshops.

What We Need from You?

In order to facilitate exchange of experience in using the manual, we would like to invite you to send us the following information:

- ▶ Examples of local and national advocacy workshops (where the manual was used)
- ▶ Examples of recent advocacy activities (using the template posted on the website)
- ▶ Any other feedback on the manual

You may contact us by e-mail at coordinator@community-living.info or by post using contact details available on our website www.community-living.info.

Community living: people with disabilities being able to live in their communities as equal citizens, with the support that they need to participate in everyday life (living in their own homes, going to work, going to school, taking part in community activities etc.)

Advocacy for community living: working towards community living and social inclusion of people with disabilities by changing policies, practices and attitudes that perpetuate their exclusion and segregation.

This Manual was produced by the European Coalition for Community Living with the financial support of Socires Foundation, the Netherlands (www.socires.nl). The purpose of the Manual is to assist individuals and organisations who want to achieve the changes that are needed to ensure that people with disabilities can participate in community life as equal citizens. It provides information and advice on how to conduct campaigns and other activities to attain the goal of community living for all people with disabilities.

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