

Seminar of the European Coalition for Community Living

User Involvement

Involving people with disabilities in the development,
provision and evaluation of quality community-based services

20 - 21 April 2007 • Zagreb, Croatia

Four Points Sheraton - Panorama Hotel Zagreb



Report

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ECCL would also like to thank all the speakers, moderators and rapporteurs at the seminar for their contribution to making the event a success.

Further information

All the presentations from the seminar can be downloaded from ECCL's website www.community-living.info.

Introduction

The User Involvement seminar took place on 20 - 21 April 2007 in Zagreb, Croatia, and was organised by the European Coalition for Community Living (ECCL) in cooperation with the Association for Promoting Inclusion, Zagreb.

The aim of the seminar was to look more closely at the involvement of people with disabilities in the development, provision and evaluation of community-based services. During the one and a half day seminar, which was divided into five plenary sessions and six parallel working groups, participants had the opportunity to learn about good practices in user involvement, and to discuss challenges and ongoing developments in community living in Europe.

The seminar brought together more than 130 participants, half of which were from Croatia and the rest from 21 other European countries. Participants came from disability organisations, self-advocacy and user organisations, service providers, academic institutions, ministries and residential institutions for people with disabilities.

The city of Zagreb was chosen as the venue for this year's seminar in order to encourage the development of community-based services in Croatia and support organisations and individuals involved in efforts to develop community-based services for people with disabilities in the country. It was also significant that a number of participants from the neighbouring countries (Bosnia and Herzegovina, Serbia, Slovenia, Macedonia and Kosovo) were able to participate in the seminar and discuss strategies for the development of community-based services in their countries. The host of the seminar was the Association for Promoting Inclusion, a community-based service provider and advocate for community living in Croatia. Representatives of Zagreb's Association for Self-Advocacy were also involved as participants and speakers at the seminar.

Setting the scene

The seminar was opened by **John Evans**, a member of ECCL's Management Committee and the President of the European Network on Independent Living. He welcomed participants to Zagreb, adding that he wished for the seminar to facilitate exchange of good practice and challenge participants' thinking and organisation of community-based services in their countries.

Words of welcome were also spoken by the co-organisers of the seminar - **Borka Teodorović** from the Association for Promoting Inclusion and **Zdenka Petrović** from the Association for Self-Advocacy. Ms. Petrović, who herself spent decades living in an institution, reminded participants that community living is a very important issue for all persons with intellectual disabilities. Many of them still live in institutions, secluded from others and not able to make decisions about their own lives. Speaking on behalf of the Croatian self-advocates, she expressed hope that the seminar would demonstrate how important it is for all individuals to have control over their own lives.

Following these introductory remarks from the organisers, the audience was addressed by the **Assistant Minister Dragutin Keserica** from Croatia's Ministry of Health and Social Welfare. He spoke about the actions of the Croatian Government in the field of social inclusion of people with disabilities, providing some indication that his Government would support recommendations of the seminar, with the aim of developing a system of community-based services in Croatia.

Ines Bulić, the Coordinator of ECCL followed by introducing ECCL and outlining the objectives of the seminar. She invited participating organisations to join ECCL in order to strengthen the lobby for more and better community-based services in Europe.

Ensuring quality

The first plenary session focused on the issue of quality in the delivery of community-based services, with speakers from Germany and the United States.

Christian Zechert, from Dachverband Gemeindepesychiatrie (an umbrella organisation of community-based psychiatry) posed two questions to the audience - what is 'good quality' for people with disabilities and how can we ensure that 'user involvement' gives people with disabilities the oppor-

Objectives of the Seminar

- To highlight the crucial importance of user involvement in the development of quality community-based services;
- To consider the challenges to user involvement and how to address these;
- To share examples of best practice in user involvement in the development of community-based services;
- To consider how ECCL can ensure that good practices are shared and promoted among service providers, disability organisations, policy makers and other stakeholders;
- To share information about ongoing deinstitutionalisation initiatives in Europe.

tunity to influence service provision. Giving the example of Germany, a country which does not yet have a system of comprehensive community-based services in place, he pointed out that, while *quality assurance* is an already established concept, the idea of *user involvement* is still at its very beginnings. To support his claim, he pointed out that there is no legislation which would ensure the involvement of users and their families in evaluating the quality of services, no obligation to publish the results of evaluations and no obligation to involve people with disabilities in quality management. Mr. Zechert further highlighted the differences between the 'real' and 'pseudo' user participation by asking who benefits from user involvement - whether it is the provider, for good presentation, the user, for good understanding of his/her interests, or both the provider and the user for better practice. As a means to ensure meaningful participation, Mr. Zechert pointed out the importance of real communication and embracing the fact that the knowledge of users and their families is as important as professional knowledge. Moreover, he stressed the need to acknowledge that user involvement is about the ability to make one's own decisions, to be respected and to have a role in the process, as well as about allowing for the right to take risks and make mistakes.

After discussing the relationship between ensuring quality and user involvement, the discussion turned to how to measure the quality of services. **Michael S. Chapman**, from Chesapeake Management Consulting in the United States, started by asking what is quality and who defines it. He went on to compare the traditional approach to quality based on uniformity, consistency and compliance with the process, with the approach to quality as defined by people with disabilities. In the latter case, quality is measured by the level of choice and control, the quality of relationships, the level of community participation and the ability to exercise one's rights. Mr. Chapman continued by pointing to different outcomes one can measure in order to evaluate the quality of a service. Whereas many measures focus on management and administrative outcomes, he emphasised that it is the personal, functional and clinical outcomes that are important. From the concept of quality, Mr. Chapman turned to the concept of quality assurance and the difference between quality improvement, which is about choice, control and decision making, and basic assurances, focused mainly on health, safety and welfare. He stressed that, while basic assurances are preconditions for quality, they do not ensure good quality services. Mr. Chapman concluded his presentation by calling for partnerships and emphasising the importance of deciding what to measure, as this is what in the end determines the quality of the service provided.



Speakers in the Opening Plenary Session

Current developments

In order to present ongoing projects and current policy developments in community living, speakers from the United Kingdom and the Council of Europe were invited to present the work of their respective organisations.

Julie Beadle-Brown from the Tizard Centre (University of Kent) in the UK presented the Comparative Cost Analysis project (financed by the European Commission), the aim of which is to provide scientific evidence to inform and stimulate policy development in the reallocation of financial resources to best meet the needs of people with disabilities, through a transition from large institutions to a system of community-based services and independent living. The project is collecting and analysing information in 28 European countries and is currently in its second phase, during which the economic, financial and organisational arrangements necessary for a transition from a system of large institutions to community-based services are being studied (using the regions of England, Germany and Italy as case studies). Ms. Beadle-Brown announced the publication of project results, in the form of a report, for later this year.

These will be presented at an international conference on community living, to be held in Prague on 15 - 16 November 2007.



Promotional stand of the Association for Self-Advocacy

Angela Garabagiu, from the Council of Europe, focused on the CoE Disability Action Plan 2006 - 2015 and the possibilities for the involvement of users of services and their representatives in policy development and decision making. Using the example of the right to education, she pointed to the various instruments (such as the UN Convention on the Rights of Persons with Disabilities, the European Convention on Human Rights and the European Social Charter) and monitoring mechanisms that can be used to ensure access of disabled children to education. In relation to community-living, Ms. Garabagiu highlighted the recommendations of the Committee of Experts on Community Living (De-institutionalisation) of Children with Disabilities and the St Petersburg Declaration of September 2006¹. Action Line No. 8 of the CoE Disability Action Plan, on community living, can also serve as an advocacy tool, since it contains a

number of recommendations to the member states, with the aim of 'enabling people with disabilities to live as independently as possible, empowering them to make choices on how and where they live'. Finally, Ms. Garabagiu announced the establishment of the European Co-ordination Forum for the CoE Disability Action Plan 2006-2015 (the first meeting of which took place on 26 - 27 April) and encouraged organisations of people with disabilities represented at the seminar to get involved in the implementation and the follow-up to the Action Plan.

Challenges and solutions

The second day of the seminar began with a presentation of challenges and obstacles to the involvement of users in the planning and the delivery of services. Divided into six smaller parallel working groups, the participants went on to discuss in more detail some of the obstacles (Bulgaria, Hungary, Croatia), at the same time presenting examples of good practice from several European countries (France, Croatia, Serbia, Austria and the UK).

Ingemar Färm, from the European Disability Forum, presented the situation in Sweden and, using the right of a disabled person to choose his/her own accommodation, spoke about the difficulties in the implementation of this right in practice. Although the right to live in an accommodation one has chosen him/herself is guaranteed by Sweden's Act Concerning Support and Services for Persons with Certain Functional Impairments (LSS, 1993), a number of problems persist which, in effect, mean that a disabled person has much less control over the service he/she uses. Among the problems Mr. Färm pointed to is the lack of clarity in the complaints system, the inability to influence the selection of contact persons on the local level and the lack of clarity among the staff in different types of housing of the objectives of community living. In addition to accommodation, Mr. Färm spoke about difficulties with the implementation of legislation with respect to meeting individual needs, cooperation on various levels (individual, group accommodation and municipal level), participation in the life of the community, the use of aids and appliances, and staffing and skills levels. By pointing to gaps between policy and practice, he emphasised the need for continual quality monitoring and quality assurance.

Conclusions from the Focus Groups

FG 1: Policy frameworks for community living

- It is necessary to ensure that users of services have the opportunity to participate in policy development, service planning and design - both at national and local levels;
- It is important to build the capacity of service users (through training programs) and to ensure a democratic selection of service users who participate in the policy development;
- It is important to empower people who have lived in institutions to express their views and choices;
- In addition to involving people with disabilities, it is important to educate families and relatives of people with disabilities and NGOs on how to influence policy development;
- It is necessary to adopt a holistic approach to policy development that meets the needs of all stakeholders;
- There is a need to ensure real implementation of legislation that promotes user involvement. For example, in Romania, the legislation provides for users of services to be on the Board of Directors of institutions. However, in practice, the person is appointed by the Director of the institution, which goes against the original intention of the legislation;
- Before we can talk about the involvement of users in service delivery, we need to promote the development of strategies that are based on the real needs of people with disabilities.

Conclusions from the first day

- There is a need for real involvement of users of services in the provision and evaluation of services;
- There is a need to rethink quality measurement and ensure that it leads to a better quality of life for service users;
- The importance of research to inform policy development and transition from institutional care to community-based services;
- The importance of the role that service users can play in ensuring the implementation of European and international standards which protect the right of disabled people to live in the community.

Questions for discussion

1. What are the key components of policies that reflect the rights, views and interests of people with disabilities?
2. How can users of services meaningfully participate in policy development?

¹ See Final Declaration of the European Conference on "Improving the quality of life of people with disabilities in Europe: participation for all, innovation, effectiveness", St. Petersburg, Russian Federation, 22 September 2006 (ED CONF(2006)4 final)

FG 2: Self-advocacy as a precondition to inclusion

- Self advocacy is important for raising society's awareness that people with disabilities are equally entitled to rights, including the right to live within the community as active citizens;
- Self advocates are best placed to speak about their needs. Support structures are necessary to enable that the focus remains there;

Questions for discussion

1. Why is it important that we advocate for user-led services?
2. How can self-advocacy organisations support the process of de-institutionalisation?
3. How can we ensure that the views of people with all types of disabilities, including those with complex dependency needs, members of ethnic minorities and other marginalised groups are sought and taken into account?

- It is only when one can act for oneself and represent one's own needs and interests that one can become an active member of society;
- Of great concern is the system of guardianship in many countries, which prevents individuals from having their own voices and takes away their right to act on their own behalf;
- Additional problems are faced by people with mental health problems, since the mental health field is still heavily dominated by the medical model and people with mental health problems are often not recognised as having a disability.

FG 3: Guardianship as a barrier to social inclusion

- Guardianship is a system based on the medical model of disability, by which decision making is taken away from an individual and renders him/her legally incapacitated. As such, it is in violation of the UN Convention on the Rights of Persons with Disabilities;
- Some of the rights affected by guardianship are the right to marry, vote, work, compose a will, go to courts, own property etc. Guardianship effectively results in 'civil death';
- In practice, a person with disabilities is often placed under guardianship for financial reasons, in order to be eligible for disability benefits;
- The procedure for placing someone under guardianship should not be administrative, as is the case in some countries, but a court procedure with due process safeguards;
- There is a question of how effective, necessary and proportional guardianship is;

Questions for discussion

1. How does guardianship prevent social inclusion?
2. What needs to be done to address such barriers?
3. How can we ensure that people with all types of disabilities, including those with complex dependency needs, are able to participate meaningfully in the development and evaluation of services?

- It is necessary to abolish full guardianship and legally recognise both independent and interdependent (supported) decision making;
- It is important to encourage families, religious bodies and NGOs to implement supported decision making, as an alternative to full or partial guardianship;
- If people with disabilities are not respected as individuals by law, they cannot be socially included.

FG 4: Community for All Initiatives in South Eastern Europe

- There is a need for a transition from the system of institutional care to a system of community-based services - action towards de-institutionalisation and decentralisation of services must be taken on the local, regional (intermunicipal) and central levels;
- It is important to strengthen local stakeholder capacities and to form partnerships between public, non-governmental and private sectors, as well as ensure participation of users of services in decision making;
- Importance of new legislation based on the social model of disability was highlighted, in order to ensure the development of community-based services. As a result, new services can be established that did not exist in the old legislation (such as personal assistance and community-based supported housing);

Questions for discussion

1. What strategies can be adopted to bring about the development of community-based services in South Eastern Europe?
2. What can be done to ensure that people with disabilities are involved in the planning and implementation of de-institutionalisation policies and the development of alternative community-based services in South Eastern Europe?

- There is a need for innovative projects through partnerships between relevant ministries, non-governmental organisations and local governments, which will inform policy development and new legislation.

FG 5: Freedom and Independent Living through direct payments and personal assistance schemes

- There is a difference in accessibility of different groups of people with disabilities to direct payments (personal budgets). People with mental health problems are often not eligible for direct payments;
- There are different practices across countries in the use of direct payments - the variety of services direct payments can be used for and how one needs to account for the money spent varies from one country to the other;
- In countries without direct payments and personal assistance schemes, it is important to advocate for the possibility to establish pilot projects, in order to show the benefits of both systems for people with disabilities;
- Positive outcomes of both systems - direct payments and personal assistance - need to be highlighted. They include giving more choice and control to the person, putting the person at the centre of their care needs, empowering people to think positively and creatively about their lives and supporting de-institutionalisation;
- The importance of forming user groups, speaking to those who make decisions and using evidence of success was highlighted as step towards introducing direct payments and personal assistance, and ensuring access to them.

Questions for discussion

1. What needs to be done to ensure that direct payments and personal assistants are truly accessible to all people with disabilities?
2. What role can people with disabilities play in improving the system of direct payments and personal assistance?

FG 6: Involvement of users in the delivery and evaluation of services on the national and local levels: good practices

- Service users must have access to training, in order to be involved in evaluating services. The content of the training should be defined by users themselves rather than by training professionals. An example given was that training in developing communication skills should take place *before* training in how to arrange, carry out and record interviews;
- Service users can be involved in any aspect of the evaluation process - from planning, photocopying, interviewing, to data analysis and report writing. It is important to ensure that a variety of communication methods are available, e.g. picture cards, sign language, to ensure maximum participation and engagement. Data will be richer and have more validity when user-researchers work with others who also use services;
- It is necessary to ensure that service users are supported practically, emotionally and financially;
- User-led evaluation means that professionals should be there as a resource for users, rather than traditional evaluations where professionals carry out research on service users;
- Evaluation is not about generating a lot of data that has no practical value - one must demonstrate that evaluations will have relevance and utility for the future development of services;
- A good idea alone is not enough - evidence from evaluations makes providers and authorities listen, learn, plan and make changes. Authorities have to take users' views more seriously;
- Know, understand and anticipate the arguments which may be put forward against user-led evaluations and service developments;
- The increasing experience of users as researchers means that service users develop a knowledge of the services available, such as different types of housing options and they can make informed decisions about future opportunities and life choices, i.e. make comparisons between services;
- The increasing experience of users as researchers means that service users become expert researchers. This can lead to employment opportunities. Skills can be transferred to evaluating other services;
- Service evaluations provide evidence that alternatives to institutions have physical, emotional, social and financial benefits in both the short and long term.

Questions for discussion

1. What are the key components of successful cooperation between users of services, service providers, authorities and other stakeholders?
2. How can good practices in user involvement be replicated in other countries and how can they contribute to the process of de-institutionalisation?

Call for action

Closing the conference, **John Evans** repeated some of the main points made by the participants during the seminar and presented ECCL's proposal for the seminar statement. In addition to what is included in

Recommendations to ECCL

- It is important to continue lobbying for the use of EU funding (namely the structural funds) for the development of community-based services, rather than the renovation or building of new residential institutions for people with disabilities;
- Lobbying for community-based services is equally relevant and important in the old EU Member States as in the new EU Member States and other countries of Central and Eastern Europe;
- ECCL should lobby for the implementation of recommendations that will come out of the Cost Comparison Study, which will contain strategies on how to deal with transitional costs of moving from the institutional system of care to a community living model;
- In addition to lobbying activities, it is important that ECCL promotes examples of best practice, so that policy and decision makers can see how community living works in practice;
- There is a need to work with the parents' organisations, considering that there is a lot of opposition towards community living among families of people with disabilities, and promote early intervention;
- ECCL should adopt the principle of leadership by people with disabilities, and promote at the European level the principle that not all the stakeholders in service development and delivery are equal, i.e. that people with disabilities must have a leading role.

the statement, he stressed that, as users of services, people with disabilities must have a central place in the design, provision and evaluation of services for people with disabilities. When speaking about stakeholder involvement, it is necessary to recognise that views of the different stakeholders should not have the same weight - it is the view of the user of the service in question that should count the most. During the seminar, the concepts of 'choice' and 'control' were brought up a number of times, as was the importance of different groups of people with disabilities working together. Finally, Mr. Evans asked all the participants to take the messages of the seminar back to their organisations, governments and service providers, as a step

Statement of the User Involvement Seminar

Following the one and a half day User Involvement Seminar, focused on involving people with disabilities in the development, provision and evaluation of quality community-based services, and organised by the European Coalition for Community Living and the Association for Promoting Inclusion in Zagreb, Croatia participants of the seminar declare:

- Involvement of people with disabilities as users of services in the development, provision and evaluation of services for people with disabilities is crucial in order to ensure that services are controlled by those who use them;
- In this respect, it is necessary that service providers, decision and policy makers, and disability organisations recognise the key role of users of services in the development, provision and evaluation of services and ensure that they can meaningfully participate in the process;
- It is necessary to recognise and support the work of user and self-advocacy organisations to ensure that the views and interests of all people with disabilities are represented;
- It is important that good practices in user involvement are shared among all the stakeholders, using initiatives such as ECCL to disseminate and promote them.

Participants also affirm their commitment to:

- Promoting and developing quality community-based services for people with disabilities;
- Ensuring that all available funding is used for the development of quality community-based services, rather than the opening of new or improvement of old institutions for people with disabilities;
- Exchanging examples of best practice in de-institutionalisation and the development, provision and evaluation of quality community-based services through initiatives such as ECCL.

The European Coalition for Community Living commits to continuing to work in this direction and will, as the first step, adopt a Position on User Involvement.

Final Programme

Friday, 20 April 2007

Opening Plenary

Chair: John Evans, European Network on Independent Living

- **Welcome speeches** - John Evans (ECCL), Borka Teodorović (Association for Promoting Inclusion), Zdenka Petrović (Association for Self-Advocacy)
- **Opening remarks** - Assistant Minister Dragutin Keserica, Ministry of Health and Social Welfare, Republic of Croatia
- **Introduction to the Seminar** - Ines Bulić (ECCL)
- **Ensuring Quality in the Delivery of Community-Based Services** - Christian Zechert (Dachverband Gemeindepsychiatrie)
- **Measuring Service Quality in the 21st Century** - Michael S. Chapman (Chesapeake Management Consulting)

Plenary Session II

Chair: Josée Van Remoortel, Mental Health Europe

- **Community Living and User Involvement: the human rights context** - Angela Garabagiu (Secretary to the Committee of experts on community living (deinstitutionalisation) of children with disabilities, Council of Europe)
- **Community-Based Alternatives to Institutions for People with Disabilities: preliminary results of the European cost-comparison study** - Julie Beadle Brown (Tizard Centre, University of Kent)
- **Report from Day One** - Paul Trehin (Autism Europe)

Saturday, 21 April 2007

Plenary Session III

Chair: Judith Klein, Open Society Mental Health Initiative

- **Challenges to the Involvement of Users in the Planning and Delivery of Services** - Ingemar Färm (European Disability Forum)

Parallel Focus Groups I

Policy frameworks for community living

Chair: Geert Freyhoff, Inclusion Europe

Rapporteur: Raluca Bunea, Open Society Mental Health Initiative

- Slavka Kukova (Open Society Mental Health Initiative, Bulgaria)
- Neil Coyle (Disability Rights Commission, UK)

Self-advocacy as a precondition to inclusion

Chair: Josée van Remoortel, Mental Health Europe

Rapporteur: Victoria Lee, Mental Disability Advocacy Center

- Zdenka Petrović (Association for Self-Advocacy, Croatia)
- Martine Dutoit (Advocacy France, France)

Guardianship as a barrier to social inclusion

Chair: Paul Trehin, Autism Europe

Rapporteur: Tina Coldham, Mind

- Gábor Gombos (Mental Disability Advocacy Centre, Hungary)
- Neda Mišćević (Association for Promoting Inclusion, Croatia)

Plenary Session IV

Chair: Paul Trehin, Autism Europe

- **Rapporteurs' reports from the Focus Groups followed by discussion**

Parallel Focus Groups II

Community for All Initiatives in South Eastern Europe

Chair: Judith Klein, Open Society Mental Health Initiative

Rapporteur: Jonathan Bureau, Hamlet Trust

- Vladan Jovanović (Fund for Social Innovations, Serbia) and Ljubomir Pejaković (Ministry of Labour, Employment and Social Policy, Serbia)

Freedom and Independent Living through direct payments and personal assistance schemes

Chair: Ingemar Färm, European Disability Forum

Rapporteur: Jacques Geurts, Ado Icarus vzw

- Ivanka Jovanović (Centre for Independent Living, Serbia)
- Tina Coldham (Mind, UK)

Involvement of users in the delivery and evaluation of services on the national and local levels: good practices

Chair: Ingrid Körner, Inclusion Europe

Rapporteur: Jane Shears, Changing Minds Education Centre

- Klaus Candussi and Agyby Waltraud (atempo, Austria)
- Mandy Hooper (Commission for Social Care Inspection, UK)

Closing Plenary Session

Chair: Ingrid Körner, Inclusion Europe

- **Rapporteurs' reports from the Focus Groups followed by discussion**
- **Statement of the European Coalition for Community Living - John Evans (ECCL)**