# Stories of Recovery and Participation - experiences and challenges

Editors Jean Pierre Wilken and Karin Hanga Stories of Recovery and Participation experiences and challenges

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### Foreword

This publication is a result of an international research project which took place from 2012-2014. Among the participators were four universities, number of service providers, NGOs and people with psychiatric and learning disabilities from Amersfoort and Maastricht in the Netherlands, Budapest in Hungary and Tallinn in Estonia.

The aim of the project was to explore the wishes and needs of persons with psychiatric or learning difficulties with regard to community participation, and how services could be (more) supportive in order to meet these needs. We also looked at local policies, especially from the perspective of the UN Convention on the Rights of Persons with Disabilities (CRPD).

From the research we learn that regardless of the country where people live, persons with disabilities have similar struggles to cope with vulnerability and deprivation. They also share the same desires as any other human being: the wish to live a good and valued life, to have meaningful activities and to belong to a social community.

The stories in this book were selected from the interviews which were conducted by researchers during the project. The portraits illustrate experiences of illness, disability and recovery. They also reflect experiences of using social- and mental health services, exclusion and inclusion. By reading these stories we see, how multifaceted life can be, and what are the challenges towards the real participation in community. Many thanks to Heli, Anneli, Oliver, Janine, Jan Cees, Gyula and Judit for sharing their stories! In this e-book we also share with you a number of notions which are important in order to focus professional services on supporting recovery and community participation. Together, these notions provide a new and valuable framework.

Among other things, you will find in this publication information about:

- The meaning of recovery, empowerment and participation
- Principles of recovery-based and person-centred services
- The importance of peer support and informal care
- The transformation from institutional to community-based care
- Essential qualities of professionals: vision, attitude, language, behaviour
- Support for community living
- The Rights of Persons with Disabilities and strategies to implement these rights

We thank everybody who has contributed to this book and hope it will be an inspiring resource for new practices to emerge.

Karin Hanga and Jean Pierre Wilken editors

### Recovery

Recovery has several meanings. It can be the process of regaining your health after having a disease. It can also be the process of overcoming bad experiences, developing self-esteem and selfconfidence, learning to cope with a disability, and regaining a meaningful life. The latter meaning is emphasized by persons who experienced serious mental health problems all over the world. They consider recovery as a personal journey. Services cannot 'provide' recovery, they can just support it.

The recovery approach is quite different from the traditional approach of mental health care. The next table summarizes the differences.

Traditional approach	Recovery approach
Values and power arrangements	i
(Apparently) value-free	Value-centred
Professional accountability	Personal responsibility
Control oriented	Oriented to choice
Power over people	Awakens people's power
Basic concepts	
Scientific	Humanistic
Pathography	Biography
Psychopathology	Distressing experience
Diagnosis	Personal meaning
Treatment	Growth and discovery
Staff and patients	Experts by training and experts by experience
Knowledge base	
Randomised controlled trials	Guiding narratives
Systematic reviews	Modelled on role models
Decontextualised	Within a social context

Traditional approach	Recovery approach
Working practices	
Description	Understanding
Focus on disorder	Focus on person
Illness-based	Strengths-based
Based on reducing adverse events	Based on hopes and dreams
Individual adapts to the pro- gramme	Provider adapts to the individual
Rewards passivity and compli- ance	Fosters empowerment
Expert care co-ordinators	Self-management
Goals of the service	
Anti-disease	Pro-health
Bring under control	Self-control
Compliance	Choice
Return to normal	Transformation

Source: Mike Slade (2009). *100 ways to support recovery*. London: Institute of Psychiatry, p. 6.

Personal relationships and the continuity of it have vital importance in the process of recovery. However we found it very interesting that while majority of professionals described themselves with their professional qualities (certifications, mastered methods) when we asked service users about them they rather recalled their personal qualities. We do not deny the importance of professional skills and knowledge but we found that the relationship dimension (accessibility, common language, continuous presence, reliability) has a relevant impact on the successful support of recovery. Importance of the good relationship was confirmed by a number of service users (the story of Heli, Anneli and Oliver), as well as support workers themselves.



#### **Resources:**

Geoff Shepherd, Jed Boardman & Mike Slade (2008). *Making Recovery a Reality*. London: Sainsbury Centre for Mental Health.

Mike Slade (2009). *100 ways to support recovery. A guide for mental health professionals.* London: Institute of Psychiatry.

We learned that it is important to define in each country the meaning of the notions of participation and community, since these can have quite different meanings. For example: in Estonia and Hungary the heritage of the soviet regime was that the 'community' was narrowed down to a functional, geographical entity, and had little social value. In the soviet era, people were not sure who could be trusted, because of the threat of a neighbour who was a member of the communist party, or possibly working for the secret service. Social control was turned into state control. Since social cohesion could be dangerous, social life was mainly restricted to family life. The challenge for post-soviet countries is to restore social values, and to create new vital social networks. Social professionals in these countries can play a valuable role here. However, we learn that most professionals tend to stick to traditional roles, e.g. maintaining a "clinical view" and thereby remaining part of the old system, rather than shifting to a community perspective. In order to make a transformation to a new professional identity, first awareness should be installed about the importance and values of community life. Social work education should pay much more attention to knowledge about social networks and community (re)-development. By the way, this is also necessary in the Netherlands, where the Social Support Act put a lot of emphasis on mutual support in the community. Professionals will play more of the facilitating roles instead of the caring roles.

The research identified that in every country and city, there are considerable barriers to remove enabling equal participation in the field of housing, work and leisure activities. As far as the provision of community-based services is concerned, we conclude that in all countries, professionals should develop a stronger focus on supporting the participation of their clients in public life. The

community-based mental health services that participated in the project operated mainly with a focus on individual support and were hardly using the opportunities in the community. Our project showed that by focusing on community resources, and collaborating with voluntary organisations and social welfare services, participation options can be increased considerably. Professionals should adopt and work from a focus on inclusion. Estonian part of study showed that professionals are interested in training which supports the paradigmatic change in practice from institutioncentred medical view to community-based practice. However, in addition to change in knowledge, skills and practice, the framework of social policy, priorities of decision makers and financiation of social welfare expenditures must be changed. Professionals assist people who, because of their vulnerability and history, have problems joining communities. Participation means: taking part in activities in different life domains, like work and education. Inclusion means that the environment welcome and enable people who are 'different' to be a full member of the community, respecting and valuing differences.

#### **Resources:**

Jean-Pierre Wilken, Marju Medar, Zsolt Bugarszki, Frans Leenders (2014). Community support and participation among persons with disabilities. A study in three European countries. *Journal of Social Intervention: Theory and Practice*, Vol 23, No 3.



## **The Story of Anneli**

My name is Anneli and I'm 50 years old.

My life has changed a lot since I fell ill. I was diagnosed in 1993 (I was 28 years old then); and I periodically needed psychiatric treatment up to 2008. After being diagnosed I worked for another 10 years. I was hospitalised several times, got divorced, I couldn't take care of my children. With the support I was receiving from my psychiatrist and activity therapist I started little by little to re-build my life. This took almost 6 years. I have thought a lot about my past, and although these were very difficult years, I have brought with me also positive memories – these give me a lot of strength. I'm grateful for all the painful experiences – these help me to find joy in my every-day activities.

I have adjusted to my situation in every way by now. I have started to enjoy my life, my home and living alone; my relationships with others are good.

### Work

After becoming ill, I tried different professions but none of them suited for me. Today I feel very fortunate working in my speciality again. I work as a teacher, approximately 20 hours per week. It's wonderful to see how fast children develop; I want to support them as much as I can. Of course, there are small tensions related to every kind of work, but I try to rise above them.

#### Leisure

Routine is very important for me and I feel that when I keep myself busy there is less time to worry. In my free time I occupy myself with various hobbies, which include music and different physical activities (for example bicycling, long walks, aerobics and swimming). I also enjoy music. On Sundays I go to a small village church, I sing in a choir and take part in the sermons. The church and music calm me and give me strength. From time to time I go to good concerts, but at home I enjoy silence, for example when I sit on my balcony and look at the sea.

### **Relations with my relatives**

It's a great joy that my children have grown into self-sufficient young people and our relations are very cosy; also my ex-husband is supportive. I see my father and my brother every week, I help them in the housekeeping tasks and we spend time together. People close to me are very important for me!

#### What supports my recovery and well-being

Every-day tasks in housekeeping, in work and society create small tensions from time-to-time. When I feel anxiety building up in me, I meet with my support person. I can call her any time and she is ready to listen to me, helping to find a solution to the anxiety or some other problem that has been troubling me. I can say that we have become good friends. When I first fell ill, we met more often, now we meet once a week or even less frequently. We do different things together, for example we discuss different topics. We have also washed windows



together or done housework. I know I can trust my activity therapist and it has been a big help for me.

I also meet with my psychiatrist regularly. It has been almost 20 years since we first met! My support person and psychiatrist are like neutral by-standers who see those aspects of my life that I do not necessarily notice myself. I'm very grateful that I'm able to share my thoughts with them.

I find that good relations with people close to me, intellectual issues, joy from every-day work, different hobbies and trusting relationship with activity therapist have been those aspects that have considerably supported me on my way to recovery and have helped to re-gain my self-confidence.

The pictures are taken by Õnne Männasalu.

Empowerment is the process of individuals and groups to become stronger and developing self-confidence, self-agency and other competences. The recovery process itself can be regarded as an empowerment process.

All kind of empowerment approaches and "bridge building" strategies can contribute to promote equality. As reviled from the interviews with support persons, they use different empowerment methods to build up service users' self confidence and trustful relationship.

Empowerment projects are for vulnerable people in society who are motivated to embark on processes to achieve greater independence in combination with reducing feelings of loneliness and isolation. To achieve their goals, these people interact and are being coached by volunteers, active members of society, and professionals. Professionals and active citizens can –next to be a backup for their fellow citizens- each obtain some form of synergetic advantage for themselves (for example, to gain meaning to one or more aspects of their lives, to earn income, gain recognition or respect, to combat loneliness, or to develop effective work methods). This is a positive credit they can achieve because of the involvement with the respective vulnerable social groups.

In our project, a number of good examples were represented, such as:

- An 'outsider art' gallery in the city of Maastricht
- About 40 users/entrepreneurs have participated in 'outsider art' activities as creators (painters, ceramists, poets etc.). Most of them have been involved in expositions. About 15 'creators'

are successful in creating an own lifestyle in which making art has a prominent -and for them satisfying and meaningfulplace. Ten artists have hired together their own atelier and sell every now and then art pieces to the public.

- Entrepreneurial activities in Maastricht include: bike repair, removals, (urban) gardening, running a coffee shop, organising little festivals and expositions. People with a disability are creating value by producing art or delivering a specific service to the community. In Tallinn, some members of the clubhouse are running a web design business. In Budapest, a laundry service is being created. These initiatives can develop as *social enterprises*, small businesses which have both social and productive aims.
- In Amersfoort peer support groups are running. In these groups, people are sharing experiences and supporting each other. This can either be mutual support with regard to daily living, or support focused on attaining personal goals.

Professionals can help service users to develop or join initiatives as mentioned above. The rehabilitation & recovery approach is a *Strengths-based approach*. Support workers are emphasizing the qualities knowledge and skills of the person, and actively helping to strengthen these.

#### **Resources:**

WHO (2010). User empowerment in mental health. Copenhague: WHO/ Europe.

Craig Dearden-Phillips (2012). *Start your Social Enterprise*. London: Social Enterprise UK.

### **Person-centred services**

Services should be 'person-centred'. This seems to be a platitude. It is obvious that services are aimed at serving the persons they are meant to serve, according to what is needed and desired. But also from the stories which we collected in our research, it becomes clear that often this is not the case. Many services still tend to offer standardised, impersonal care. In order to get access to services, the person has to go through a lot of bureaucratic procedures. And even if he or she will be allowed to get certain paid services, services are not always available, or people have to wait for a long time. Availability of services depends remarkably on collaboration between specialists of different institutions, personal resources and regional differences.

In Estonia we found several good examples about person-centred services and many shortcomings as well. Often reviled, that the support system of service users was not systematic and complex enough. The co-operation, continuity and relatedness between different services or professionals from different fields of practice (health sector / social sector / labour market sector / education sector) are not sufficiently developed. For example, one service provider is doing effective work based on care methodology and the person is already independent to manage on her own, then turns out that housing opportunities are very limited and the unemployment services are not supportive - the person who has left from service falls back in "hole" again. The lack and need of systematic support system was clearly drawn out from the story of Heli.

So it is important to make services really 'person-centred'. There are a number of guiding principles.

#### Principles - To Guide What Happens and How

- Authority to plan/pursue vision
- Authority to direct services
- Community membership
- Collaborative support delivery
- Valued roles for individuals/families
- Flexibility in support delivery
- Access to satisfactory support options
- Commitment to excellence/outcomes

#### Structures – Key Design and Policy Elements for a Person-centered System

#### Structures to:

- Fairly assess needs
- Provide fair and ample individual budget
- Offer fair and affordable provider rates
- Effectively pay providers
- Inform and train individuals/participants
- Provide person-centered planning
- Make available a stable and qualified workforce
- Assure quality
- Assure public transparency

#### Processes – Best Practices in Delivering Person-centered Services and Supports

#### **Processes that assure:**

- Individuals feel welcome and heard
- The exchange of information is adequate, yet not burdensome
- Practices are culturally competent
- Individuals control their budget
- Planning is person-centered
- Individuals choose supports and providers
- Money and services/supports are portable
- Supports are flexible to meet changing needs
- Supports are available in a crisis
- Informal community resources are utilized
- Peer support/mentoring is available
- Quality of supports is measured
- The public is kept informed

#### **Quality of Life Outcomes – What People Want**

- Relationships
- To feel valued
- To have access to a community life
- Meaningful things to do
- To be safe
- To have an ample amount of money
- A safe place to live and work
- To be as healthy as possible

At an individual level, person-centred care puts the person in a directing position. The person is the director with regard to plan for and pursue one's own vision for the future, and has the authority to direct the supports that help him to achieve goals and meet needs. Person-centred care recognizes the value of community membership, and the potential for individuals to include families, friends, neighbours, co-workers and others as possible supportive and collaborative resources.

At the systems level, person-centred services value flexibility to accommodate people's changing needs and preferences, meaningful roles for individuals and families, accessibility to an array of support options, and a sustained commitment to achieving service excellence and individual outcomes for service recipients.

In the figure above, the main elements of person-centred services are depicted.

#### **Resources:**

Human Services Research Institute (2010). *Principles and Practices in Person-Centered Services*. Towson MD: The Council of Quality and Leadership.



## The Story of Heli

My name is Heli and I'm 55 years old.

When I think of my life, then the last 10-15 years have been difficult. I had a husband, two daughters, a four-room apartment, and a job that offered challenges; I danced folk dance and did handicrafts. Life changed when my husband lost his job. It was difficult to cope only with one salary; in addition I started to suffer from a psychiatric disorder. The marriage that had lasted for 19 years ended with a divorce, my daughters left me. This was followed by the loss of my job and home; furthermore, I was hospitalised several times against my will. These were harsh experiences ... Nevertheless, I feel I have overcome a lot of losses today — the disorder is under control, relations with my daughters have been restored and I know I have come out of all this as a stronger person.

### One topic that creates contradictory feelings is working

I'm glad that I have the opportunity to work. Although my income is small, it's very important for me. I have several duties at work, some of which, for example communicating with other people, I like very much. Working makes me feel that I belong to a team and that my work is necessary.



But the way my employer treats me, creates considerable stress to me. I think, that my boss is disturbed by my disability. I'm often undermined. For example there are situations that some documents or other things have gone missing and I'm blamed for their disappearance! I don't understand how the employer can think this way? However, this never happens when other people are around; only when we are alone.

In addition, I sometimes feel, that my boss is manipulating with me. This is not the right kind of behaviour from an employer! He knows that it's not easy to find a new job, and that is why the employer indulges this kind of behaviour. So that I "would be scared" of losing my job, so that I would try to keep it with my every deed and word. This creates insecurity and stress for me. Vacancies in the labour market are such a big deficit namely for people like me with whom nothing seems to be wrong when just looking at the person, but who, nevertheless, have a disability. I think people with disabilities need bigger support in this respect.

### **Using Social Services**

I have used different social services for almost 5 years. I think our social services (for example housing services) still have room for development. I've been on a waiting list for social housing for several years now, but so far without any results. It's not possible to be satisfied with a thing that is only half-done — in a sense I'm being taken care of, but at the same time I'm not. I have felt like an annoying fly — no-one is directly interested in my problem, but at the same time they are trying to solve the situation, to place people in some sort of boxes.

There is a lot of duplicity and oversight in our social system, which is hidden behind fake actions. It's difficult to say ... but what is done doesn't seem to be done for people. It's only partly for people. Another part is only in order to do something. It's only an exterior, an appearance. A lot of time and resources are spent on what is only a facade ....

#### What supports me

I feel if I could not go to the Mental Health Centre and if I would not have my support person (activity therapist), it would be very hard to cope for me, indeed. I meet with my activity therapist on a regular basis. We discuss different topics that are related to my daily life, relations and work. The activity therapist is aware of the issues in my life and is supporting me in every way possible, although at times we both feel powerless when applying for other necessary services.

### My relations with relatives

I feel deeply happy that my relations with my children are good again. We meet frequently. We go walking or shopping, and sometimes we have dinner together. Can you imagine, I'm a grandmother now! This is wonderful!

I'm also happy, that I can spend time with my mother. I visit her almost every day. She is already old and I'm grateful that there is still time left for us to spend together. I feel my commitment to my relatives is the thing that gives me the most strength and has also supported my recovery the most.

### My wishes for others

I have travelled a lot in my previous life – from the Arabic countries to Greece, in Nordic countries and elsewhere in Europe. I think one's relationship with the world is very important. If people can travel and feel like citizens of the world, it helps to see one's own situation more clearly.

I wish that people could feel happy about their activities and lives. I feel happy about my life, but I cannot live fully yet. However, little everyday joys are still there.

And I wish everyone good health. I also think it's important to trust other people. When I'm helpful myself then this brings something back for me. When I help others then they help me to understand something, to go somewhere further. This is also very important. From the stories, it became clear that the support of 'good professionals' is highly appreciated. What makes one professional "a good professional"? A good professional is supportive, openminded, a good listener, and tries to find solutions and respects the clients' own choices. Appropriate education or special training definitely helps the professional to support the clients' recovery, relying on the strengths and needs of the person. For example in Tallinn Mental Health Center – all support workers have passed training how to work with clients with psychiatric needs and this helped to create trusting relationship between support worker and client, what is highly appreciated by the service users.

However, we also learn that many professionals (especially those who do not have special training or who have got their education years ago) are not well connected to the needs of clients today, and therefore do not provide the type of help desired by them. There are still many professionals in different sectors of mental health and welfare who lack the necessary skills and strategies to support persons with participation in the community.

Professionals generally lack the necessary skills and strategies to support persons with participation in the community. This is related to the fact that most professionals working in care sectors are trained in an institutional context, like mental health hospitals and homes for mentally disabled. In the education they followed there was also a strong institutional focus. They were taught 'clinical skills' rather than 'community skills'. Consequently there is a great need of information, change of perspective, knowledge and skills to support the community participation of persons with a disability in an effective way. Fortunately, the times are changing, and we have already good experiences to share: in Estonia, we found several good examples of practice where the working approach of specialists and practice is community-based – Tallinn Mental Health Centre, Estonian Psychosocial Rehabilitation Association etc.

Examples of traditional clinical skills include: making an assessment of disabilities and making a plan to care for the individual. New community skills are: making an assessment together with the person on his or her needs and wishes, assessing disabilities and strengths, looking for natural resources in the community, such as the possibilities which social networks and enterprises offer for support and participation. Of course there are differences between countries. In Hungary, there are still large institutions and hardly any ambulatory care, in the Netherlands an institutional focus is gradually changing to a community focus, but still clinical care is dominant. In Estonia, rehabilitation services for persons with mental disabilities have rapidly been developed over the past 10 years, but like in the other countries social professions and medical professions have to find better ways of cooperating. People receive support by rehabilitation team specialists (including physical therapists, special education teachers and others) during the recovery process. Multi- and interdisciplinary teamwork with a focus on community living and recovery is not well developed yet.

It is obvious that we need to change the professional workforce in social and mental health sector. In this e-book, a number of elements related to a focus on recovery and inclusion are described. This new focus requires a change of vision, attitude and language. It asks for a change of behaviour and for new methods. Service users expect an approach which is based on equality and respect. They want the worker to really understand their story and their needs. And they want the worker to provide effective support, attuned to what is needed. Especially persons with a psychiatric history are facing many forms of stigma and self-stigma. They also experience marginalisation with regard to participation as equal citizens. In mental health care the focus is shifting more and more towards supporting recovery processes. An important recovery support factor is the personal relationship between professional and service user, which should be based on equality and partnership. Our interviews with service users confirmed the importance of this - several stories that are published in this e-book speak of the importance of trust in relationships, and how that has helped. This way of working requires a "new language", which is based on a humanistic, social and empowerment paradigm, instead of on a medical deficit paradigm.

#### Deinstitutionalisation

If we talk about de-institutionalisation we usually mean the transformation of large institutions like psychiatric hospitals to community-based services. In many countries there still exist many institutions, were people live segregated from the community. Often these institutions are dominated by a medical approach. Moving people and staff from these institutions to smaller facilities like supported housing, can make a great difference. But de-institutionalisation means also: getting rid of "old habits" and implementation of new practices. A community-based service can be as institutional as the psychiatric hospital. De-institutionalisation is not only a physical but also a psychological process. Both professionals and 'patients' have to get rid of hospitalisation. Also the social-political arrangements and changes in financing schemes in state and local level have to be understood and implemented and it takes time. Only if new ways of thinking and behaving are installed, based on rehabilitation and recovery, de-institutionalisation will be a reality.

#### **Resources:**

Stephen P. Kliewer, Melissa McNally, Robyn L. Trippany (2009). Deinstitutionalization: Its Impact on Community Mental Health Centers and the Seriously Mentally III. *The Alabama Counseling Association Journal, Volume 35*, Number 1, p. 40-46.

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.

## **The Story of Janine**



Janine (left) and her neighbor (right)

Hi, my name is Janine and I'm 57 years old. I have been living in this district since 2001 after having survived 10 years of hospitalization in a large mental health institute due to a bipolar disorder. I honestly believe I would have been able to live independently earlier on. There have been several times I tried to make that step, but unfortunately my own fears and a lack of motivation towards independent living prolonged my stay there.

However, after all those years, I fortunately managed to live quite well on my own. At first I lived together with 2 male housemates in a sheltered housing project in the city of Amers-

foort. Then, eventually I wanted to have my own place and started renting a house nearby. First with my friend Wim - who also was a fellow housemate in the housing project - and later on, on my own.

I like to live by myself and I love my neighborhood, but I also feel lonely sometimes. I'm still searching for a mate that wants to share an apartment with me, like I had before, when I was sharing a house with Wim. My personal coach, Marjo says I should start speed dating, but I rather prefer to wait with that until I feel more comfortable to invite people at home.

That's why I'm quite occupied with several outdoor activities during the week, e.g. I'm participating in a recovery-group. This group offers me the possibility to make progress in my own recovery amongst peers and is also a very important source of natural support, besides the professional support I have. Unlike the way I was touched by stories of peers in the large institute, I'm now moved in a very positive way. I feel connected to other survivors and feel way a stronger acceptance for everything that has happened in my life.

Furthermore I also volunteer at a nearby primary school by doing craftactivities with children. Closer to home, I also spend some time with my neighbor, Truida who often takes care of my cat when I'm away and also likes to play some games at home with me in the evenings. She supports me and I support her, like today: she has a very bad headache and she stopped by to get some painkillers. We like to chat together and enter our homes easily at the back/garden side. That way we are almost always in reach and present when needed.

Apart from my neighbor I also feel great support from my coach Marjo, who has been by my side since 2001. I still see her weekly and she supports me both with practical questions, as well as mentally. If I would relapse, she would be one of the firsts to notice. She also joins me on appointments with the social services department and she once joined me when I visited my mother. She has a relativizing impact on me.

## **Community-based services**

What are community-based services? Community-based services are services which are both based *in* the community, work *with* the community, and work *for* persons in the community. Services can be aimed at people in the community who need assistance, for example because of problems related to poverty, health, disability, raising children or relationships. Services can also be aimed at ensuring safety in the community or assisting local groups to organise activities for improving the quality of the neighbourhood. Services can be supporting independent living, employment, education, sports, leisure or cultural activities.

In the field of mental health recovery, community-based services support recovery the most when they are tightly connected with the surrounding local community. Services like day care centres can provide a very warm, containing atmosphere which is important right after a psychotic episode. But later on, external links are more important in supporting the recovery process with real and natural opportunities in the community.

Estonia has a number of good examples of emerging strong communities and community-based services. However, the term "community living" is also used by several other services, which are not actually located in an open community but in separated area. However, it is positive that different services are developing and hopefully people can make a choice, about where they want to live and use those services – be it in the centre or in rural areas.

#### **Resources:**

Angela Cole, with Ann Lloyd, Barbara McIntosh, Molly Mattingley, Paul Swift, Ruth Townsley, Val Williams (2007). *Community-based day activities and supports for people with learning disabilities*. London: Social Care Institute for Excellence.

Graham Thornicroft & Michael Tansella (2003). *What are the arguments for community-based mental health care?* Copenhagen: WHO Regional Office for Europe.

National Technical Assistance and Evaluation Center (2009). *Community-based Resources: Keystone to the System of Care*. Washington: U.S. Department of Health & Human Services.

Rosemary Rogers & Tim Moore (2003). *Refocusing community based services for young children and their families*. Melbourne: Centre for Community Child Health.

## Support for community living

People with a disability often need some forms of support for living in the community. We call this a *personal support system*. This system consists of persons who have a personal relationship, like family members and friends, other people who provide support on a voluntary or professional basis, and material resources like a house or an income. Part of the components of a personal support system can be found in the community. These are resources which are available for every citizen, like transportation, shops, schools, and sport facilities. Some resources are special, because they are only made available when there is an impairment, for instance a disability allowance or adapted transportation. All the supportive resources which are available in a community together we call a community support system. The degree to which a community is supportive towards people with a disability is also determined by the attitude of the persons living there. A good community is a carina community. People are friendly for each other and are prepared to help each other.

In psychosocial rehabilitation, we consider the community as the primary place to live and to participate in different areas of life. Some communities however are more 'social' than others.

Professionals can help in promoting and developing caring communities. This will increase the possibilities for persons with a disability to lead a full life.

By *supported living*, we mean all the support a person needs to lead the life he/she wants. It is quite a simple idea. A person with dis-

ability gets the support they need to live in their own home. If the person's needs change, the support they get can also be changed. The most important thing is that the support matches the person's needs. This means the support is designed for the person... They fit the person; the person does not have to fit the support. This helps the person to live in their community.

Supported living is an approach to housing and support for people with disability based on the fundamental belief that every person has a right to lead their own life, to determine where, how, with whom they live and who provides him/her with support.

Common elements of supported living include:

- Separation of housing and support
- Support is provided by a combination of informal (non-paid) and paid support with intentional strategies used to develop informal support
- Paid support is individualised, flexible and under the control of the person with disability

Where a service provider is involved, it stands beside the person with disability and their family to develop and implement the quality of life the person wants.

Although there are positive developments in the provision of social services in Estonia, we are still in a situation where there are different problems in the provision of services - often the services do not meet the person's need, service is not accessible or services' capacity is not enough (E.g. the story of Heli). This makes the role of supportive community even more important - sometimes it is sufficient if the person has helpful neighbours who can provide support.

### **Housing opportunities**

The journey of recovery is a long non-continuous ride with many occasions of relapses and u-turns. The duration of the process most likely might be relevantly shorter if community-based programmes are available, especially housing opportunities within the community. From research, it became clear that obtaining decent housing is a relevant turning point in rehabilitation. The lack of proper, independent (or supported) housing seriously hinders recovery. Oppressive institutions or toxic family relations are real obstacles in many cases that could be effectively solved with new, independent housing opportunities only. If person manages and copes well in supported living / housing service - then the independent living housing opportunities such as affordable rental flats to be made available in the community.

As revealed from study results in Tallinn, the housing opportunities cause the most difficult problems to both the person with mental health difficulties and to his/her family. People are waiting in queue for several years to get a suitable supported living place or housing service (social or municipal flat) and it makes the recovery process very complicated. Very often people would cope with the support of community-based services in regular flats, but the high rent rates makes this option almost impossible for people who cannot work full-time. To increase the capacity of different housing services was one of the results that had been communicated to policy makers in Estonia.

#### **Resources:**

http://www.supportedliving.org.au/about-sl/

## The Story of Cees Jan

My name is Cees Jan and I'm 48 years old. At the moment I'm set to work by a supported employment center at Post.nl, postal services and 1 'm enjoying myself. Together with my colleagues I sort the mail and make sure the correct item gets into the right car. "Packages toss" we call it. I like the work and I'd like to continue it. I have to be up early in the morning, but I often finish early.

Every two weeks on Sunday you'll find me at the Arena in Amsterdam to support my favorite soccer team, Ajax. Since I've been doing this for several years now, I always run into familiar people and have a chat with them.



Cees Jan

Recently I started playing field hockey again, as a member of the G-team. 'G' stands for 'gehandicapt', which means 'disabled' in Dutch. I used to play hockey at this club when I was a child and played in the same team as my brother Robbert. Now, playing again, I meet a lot of people I used to know from that period.

My parents thought it was very important that I could join in ordinary things and facilitated me to experience and learn the same things as my brothers, Robbert and Bart, did. Thus I have been learning to ski at a

young age and I often played outside with my brother Robbert and his friends, for example. Furthermore I attended the same kindergarten as my brother before I went to a school for children with special needs.

At 19, I left home and went to live in assisted living facility of Humanitas DMH. First in a group and later in a studio on my own. During that period I also met my girlfriend. Nine years ago I moved in with my girlfriend to Vathorst and since then for a number of years, we've been taking care of our cat, Minouska. I like to live here because it is a quiet neighborhood.

We always have good contact with some neighbors in our street, and if there is a problem we can ask them for help. In the past nine years we have had many new neighbors, because they are always moving. This is not always easy. My girlfriend and I try to make contact with new neighbors again and again. Usually we start by making a chat with them when we see or meet them outside on the street and maybe invite them to visit us on our birthday. At the moment we have good contact with at least four neighbors who live in this street.

I think it is a pity that there is so little to do in the neighborhood, not that I want to participate in activities every week, but it would be nice to have the opportunity. When Amersfoort celebrated her 750<sup>th</sup> anniversary there was a party in the street, which was great fun. It would be nice if such kind of celebrations happened more often. My girlfriend likes to participate in activities every week, like eating at 'Resto Harte'. I like to do such things occasionally and do not feel the urge to meet new people. I'm pleased with how things are right now, I'm actually pretty contented.

At least once a week my support worker Wieko, from Humanitas DMH, visits me and we'll discuss or arrange all kinds of things, for example, things concerning my work. Since last year my brother Robbert is my mentor and he helps me and my girlfriend with practical things in and around the house. I see him every week and if I need something or there

is a problem I can call him. My brother and Wieko also have regular contact with each other. Because of that and the feedback my brother gets from Wieko, I've noticed he knows and listens more to what I think is important. As a result of that our relationship is much more fun than before. My brother likes to say that he, Wieko and me are a team, in which we have our own role. This team is not about them telling me how I should live, but how they can support me in directing my live the way I want to, together with my girlfriend.

From left to right: Robbert, Cees Jan & Wieko

The pictures are taken by Robbert Broekhuijsen;

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Peer support is the support given from persons with similar experiences. We know from the research that this is a very powerful form of support. In many countries, all kinds of peer support are developing quickly now, like mutual self-help groups, peer-run programmes and recovery colleges. A number of persons with experiential knowledge developed themselves as *peer support specialists*. They work as service providers and are role models for recovery. For mental health care teams, the presence of peer workers leads to an increased awareness of recovery principles, and helps the service to become more recovery-oriented. Also in the field of persons with a cognitive disability, peer support is developing.

Although the first peer support rehabilitation programs were successfully implemented in 1990 by the organizations of disabled people in Estonia, the policy-making level is only beginning to understand the content and necessity of the peer support. A few years ago, it was difficult to explain that peer-support counselling should be available and financed in an equal basis with other rehabilitation services (as individual counselling by social worker, psychologist, speech therapist etc), but today, peer support counselling is outlined in the draft of Social Welfare Act, and will hopefully be applied as one of rehabilitation service in 2016.



#### **Resources:**

Julie Repper (2013). *Peer Support Workers: Theory and Practice*. London: ImROC.

Julie Repper (2013). *Peer Support Workers: a practical guide to implementation*. London: ImROC.

# **The Story of Oliver**



That's me - Oliver.

My name is Oliver. I'm a peercounsellor. There have been great changes in my life, and when thinking about what has happened, I can only say that the employees of the Tallinn Mental Health Centre quite literally 'pulled' me out of a hole. At the moment I'm doing well.

I have currently three parttime jobs. One type of work is when my service is ordered - if it's necessary I go and talk to people. Second type is group work, when I attend discussions as peer-counsellor and lead the group. And third is project work

with the aim to support the network of peer-counsellors in Estonia. Altogether there are three tasks.

The activities of peer counselling take place either individually or in a group. When I talk to people, I do it alone or together with a specialist. Another possibility is group-work where I'm together with a specialist and there are several people in the group at the same time. Yes, all rehabilitation specialists all over Estonia say that this is a very important work.

## But why peer counselling?

Firstly, I like to come occasionally out of my apartment and do something. And secondly, I like to work with people and obtain all sorts of experiences. During peer-counselling people tell what kind of problems they have and how they live and what they need. These kinds of talks are necessary. It may contain wisdom to learn. And when listening to people I wish to contribute so that all goes in the right direction. That recovery is possible for them. This is what I contribute to.

Earlier, when I started, I was not able to tell my story so well, but at the same time I felt good after talking and that I had helped others. Just recently I went to do peer counselling and there was a girl who had fallen ill, I talked to her. And I saw from her eyes that she felt better after this talk. She was so young really.

Now, lately I have much more experiences, I understand peer-counselling in a greater detail. There are a lot of different aspects in it and after talking I sometimes feel a little bit sad. Well, I have been told before that this is usual and this should be so, and actually I was wondering why I didn't experience it, but, well, now I know. And I also have experienced that when a person is trying to tell something based on personal experiences, then I as a peer-counsellor have to indicate sometimes to the specialist where the person is very sensitive, where not to touch and when necessary I also have to protect the person in my care. Peer counselling is a very important work.

One thing I share all the time is that: "It's not said anywhere and it's not written that life should be easy, right?" This is a very good saying. My university chemistry teacher said this to my course-mate when she said that a task was too complicated.



Group work

#### Who supports me?

I live with my mother. Mother has been in our family the one who is active and she used to invite me everywhere, to the cinema, theatre, and some events. And also -1 used to have conflicts with my mother, but I discussed this with a psychologist and then she explained it to me. It was at first a big shock when she told that my mother is not always the one to blame, sometimes it's my fault ... She explained it and saw that it really is this way. I'm trying to help my mother now.

Who keeps me active now? I think that it's the Mental Health Centre and Estonian Union of Psychosocial Rehabilitation. We had a project called DUO and the project manager Külli has involved me and urged me to participate. When I didn't work, no one knew who Oliver was. Külli offered me work at the Duo project, where I scanned documents and did other things and with the help of this I started to do other things.

### What are my strengths?

For example I have quite a lot of patience. I have to be picked on for quite a while before I explode. But what else? This experience, the experience of a disease, that I can cope with it. And I can help society through this. I master peer-counselling. Send a person to my way who has a little problem or who suspects that there is something wrong with his health and I can talk to that person. I'm not a psychiatrist, I cannot diagnose, but I can compare on the basis of my experience what it is and what can be done about it.

What is the third thing? There should be at least three, three is a charm. I don't know if this brings so much joy for the society but I can make a film. Also, a film has been made about me, 12 minutes long. This film was in Estonian, with German or English sub-titles. I added the translation into Russian myself. The film is called "Living in Space" directed by Katre Haav.

The pictures are taken by Mairi Luhasoo

Language and meaning of social (and health) services are extremely important and we paid so little attention to it. We may be unaware of the impact our words have on our attitudes as well as upon those around us. The words we choose reflect our attitudes; that we do (or do not) truly value people, believe in and genuinely respect them. None of us should be defined by our difficulties or diagnoses, or by any single aspect of who we are; we are people, first and foremost.

Service providers are forced to use a rather clinical language as official language of the service most of the time. This is reflecting many times in the name of the services, in their entire administration and even in the spoken language they speak. Clinical language creates a distance between service users and professionals where the power of narration is obviously in the hands of professionals. On the other hand, one of the key elements of recovery is the opportunity to create a new, personal narrative. To promote the success of this process, we need to create space for new languages and narratives within our settings, thereby allowing users to develop their own narratives.

We must use words that convey hope and optimism and that support, and promote a culture that supports recovery and growth.

Our language needs to be:

- Respectful
- Non-judgemental
- Clear and understandable

- Free of jargon, confusing data, and speculation
- Carrying a sense of commitment, hope and presenting the potential for opportunity.

Our language conveys thoughts, feelings, facts and information. We need to give thought to how our language is read/heard by the person to whom we are referring, and could positively contribute to their health and wellbeing (or otherwise), and what meanings we present to people to live by.

#### **Resources:**

Mental Health Coordinating Council (2013). *Recovery Oriented Language Guide*. Rozelle: Mental Health Coordinating Council.

While we tend to believe that the most relevant help arrives from professionals in the process of recovery, we usually underestimate the impact of the informal community. We found that users many times prefer public places instead of professional services because they are more integrated, less clinical and they provide a wider range of opportunities to create a new identity beyond mental health care. Local pubs and restaurants, circle of friends, religious or hobby related groups, neighbourhood friends, colleagues and schoolmates are the natural resources for all of us and these resources usually provide a variety of possible new identities and life.

As revealed from study results in Tallinn, different hobby activities were considered very important. Many of the service users are singing in the choir, participated in religious activities or art. In that way, service users formed informal network around them what was supportive and gave a feeling of belonging.

Professionals working in community-based services can play a role in creating and supporting informal care, and linking persons with a disability to community resources.

#### **Resources:**

Linda Pickard (2011). *The Supply of Informal Care in Europe*. Social welfare policies, ENEPRI Research Reports.

## The Story of Gyula

I was 47 when I realized that I'm a unique person. And probably this is true even if I can't prove it. Realizing that I'm unique is much more interesting for me than my family background. My parents didn't give me good things. I wish them a happy life but their life is not my life anymore.



Once my father built a house but we have lost it later. Since then my dream is to have my own family house one day. I imagine a beautiful place in the mountains, having a cozy house there. But this is only a dream. I have no home.

I'm 50 now and I have a part time job in Budapest. I work as a helper in the kitchen of a famous Hungarian restaurant. As a trained cook, I like the atmosphere of the kitchen. I'm homeless, -I live in a half way house. My treasures are my poems. I'm a poet. When I write a poem, it is like God is whispering to me.

I'm on medication but pills are influencing very badly my sense of time. At times I have the feeling that I'm lost in time. I meet my psychiatrist regularly and this is the  $6^{th}$  medication we have tried in order to find a solution to this problem.

Some time ago I also visited the Clubhouse of Soteria Foundation but ever since I've started working, I have no time for that. Instead of the

Clubhouse, I would be more interested in going out with friends after work.

My social worker from the Clubhouse helped me a lot. Even nowadays when I'm working, she visits me at times. We have a very close relationship.

# **Convention on the Rights of Persons with Disabilities**

The *Convention on the Rights of Persons with Disabilities* (CRPD) was adopted by the United Nations in 2008. Until now, 150 countries and the EU have signed the convention.

People with different disabilities from many different countries worked together with their government to develop this Convention. The Convention's main objective is to promote, protect and ensure the full and equal enjoyment of all human rights and freedoms by all people with disabilities. The Convention follows decades of work by organizations of persons with disabilities and their families, NGOs and other agencies, to change attitudes and approaches towards persons with disabilities. It takes to a new height when the movement from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.

The Convention is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and in areas where their rights have been violated, and where protection of rights must be reinforced.

## **General principles**

The principles (main beliefs) of this Convention are:

- a) Respect for everyone's inherent dignity, freedom to make their own choices and independence.
- b) Non-discrimination (treating everyone fairly).
- c) Full participation and inclusion in society (being included in your community). Persons with disabilities have the right to participate fully and equally in society and economy.
- d) Respect for differences and accepting people with disabilities as part of human diversity.
- e) Equal opportunity. Denial of equal opportunities is a breach of human rights.
- f) Accessibility (having access to transportation, places and information, and not being refused access because you have a disability).
- g) Equality between men and women (having the same opportunities whether you are a girl or a boy, a man or a woman).
- h) Respect for the evolving capacity of children with disabilities and their right to preserve their identity (being respected for your abilities and being proud of who you are).

## **General obligations**

There should be no laws that discriminate against people with disabilities. If necessary, governments should create new laws to protect the rights of persons with disabilities and put these laws into action. If old laws or traditions discriminate against people with disabilities, governments should find ways to change them.

The overarching principle promoted by the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) is that services should be provided in the community, not in segregated settings. The CRPD promotes policies and institutional frameworks that enable community living and social inclusion for people with disabilities. Person-centred services are in preference, so that individuals are involved in decisions about the support they receive and have maximum control over their lives.

Many persons with disabilities need assistance and support to achieve a good quality of life and to be able to participate in social and economic life on an equal basis with others. A support worker, for instance, assists a person with a psychiatric disability to develop a personal recovery plan. A personal assistant, for instance, helps a wheelchair user travel to meetings or work. An advocate supports a person with intellectual impairment to handle money or make choices. People with multiple impairments or older persons may require support to remain in their homes. These individuals are thus empowered to live in the community and participate in work and other activities, rather than be marginalized or left fully dependent on family support or social protection.

Most assistance and support comes from family members or social networks. State supply of formal services is generally underdeveloped, not-for-profit organizations have limited coverage, and private markets rarely offer enough affordable support to meet the needs of people with disabilities. State funding of responsive formal support services is an important element of policies to enable the full participation of persons with disabilities in social and economic life.

The CRPD sees support and assistance not as ends in themselves but as means to preserving dignity and enabling individual autonomy and social inclusion. Equal rights and participation are thus to be achieved, in part, through the provision of support services for people with disabilities and their families. Article 12 restores the capacity of decision-making to people with disabilities. Respecting individual wishes and preferences – whether through supported decision-making or otherwise—is a legal imperative. Articles 19 and 28 are concerned with "the right to live independently and be included in the community" with an "adequate standard of living and social protection". Article 21 upholds rights to freedom of expression and opinion and access to information through sign language and other forms of communication.

### **Resources:**

United Nations Convention on the Rights of Persons with Disabilities

World report on Disability

*It's about Ability!* An explanation of the Convention on the Rights of Persons with Disabilities (UNICEF)

# European Disability Strategy 2010-2020

The *European Disability Strategy 2010-2020* (EDS) is based on the UN CRPD and describes how European countries can implement the convention. Every country should take measures designed to ensure autonomous living, social and occupational integration and participation in the life of the community.

Yet people with disabilities are poorer than other citizens of the EU, fewer of them have jobs, their opportunities to enjoy goods and services such as education, healthcare, transport, housing, and technology are more limited. The reason is the still existing discrimination as well as physical and attitudinal barriers. They affect one in six citizens of the EU, around 80 million people.

There are actions in eight priority areas:

- 1. Accessibility: make goods and services accessible to people with disabilities and promote the market of assistive devices.
- 2. Participation: ensure that people with disabilities enjoy all benefits of EU citizenship; remove barriers to equal participation in public life and leisure activities; promote the provision of quality community-based services.
- 3. Equality: combat discrimination based on disability and promote equal opportunities.
- 4. Employment: raise significantly the share of persons with disabilities working in the open labour market.

- 5. Education and training: promote inclusive education and lifelong learning for students and pupils with disabilities.
- 6. Social protection: promote decent living conditions, combat poverty and social exclusion.
- 7. Health: promote equal access to health services and related facilities.
- 8. External action: promote the rights of people with disabilities in the EU enlargement and international development programmes.

If we compare the local situations with the strategies intended by the EDS and the rights formulated in the UNCRPD, it is clear that there is a great gap. Policy should be translated into practice, in order to improve the situation of persons in marginalised positions.

As far as professionals are concerned, they report that they do not dispose of the right information to influenc e local policy. They are generally not familiar with EU- and UN-documents.

In our project we developed materials for professionals and service users to get more acquainted with the convention and how to use this in individual cases.

#### **Resources:**

European Disability Strategy 2010-2020



## The Story of Judit

I have been thinking recently a lot about how terrible my life has been since my childhood. I had bad parents. My father only dealt with his power struggles. My mother dealt with the religion and her priest lover. I was continuously anxious. Then I got married, but there was a dictatorship at home. Nevertheless I'm bound to him. I did not have strong points in my life.

I'm depressed. This is an endogen depression. I inherited the susceptibility. My mother had manic depression. My father left us, but in the mean time I gave birth to two children.

All my life, I was chasing love but I have never got it as I imagined. I dreamed about a perfect family, but it has not come true and I was a bad mother.

## Work and depression

I'm the type of person who could manage well if I had a boss who would help by taking over some of the burden and the responsibility. I was very anxious because of my work. I had to make decisions on my own. All that responsibility was too much for me.

But when I became pregnant I started to work as a physician's assistant where we worked with women who had cancer. That was great for me! The chief medical officer told me what to do. We walked step by step so I studied what I should do and when. I could ask for help when I needed, so I worked very well.

After my girls were born they dropped me in the deep end. I should have taught, published and I felt I can't take this, I felt I'm dead. I remember that I ate a lot of tranquilizers. My family doctor was so stupid that he prescribed all those medicines. I have come up from the depth compared to my condition then. Finally I was pensioned off.

At home there was a miserable situation as well - totally the same that had happened with my father. I was left alone with two daughters, one 10-year old and a 13-year old.

I was so depressed sometimes that I could not wake up from my bed. Whoever does not know this feeling will not believe that I could not wake up. Only those people who understand anxiety have experience with it. It is a terrible misery; I did not even dare to go out for the toilet.

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### **Role of the professionals**

My psychiatrist is a fantastic woman, incredible how she does this. She helped me to get back on my feet again. I could totally trust her. She helped me to quit tranquilizers. At the beginning we fought a lot. When I went back to her because I run out of tranquilizers, she said to me:

Do you think that I will prescribe that?

But doctor I will die without it!

No way! Only your hand will shake a little.

The Félsziget is a shelter and a safe cabin but it is not the flat of ours.

People finally get out of their apartments and they are surrounded with people. It was strange at the beginning because I felt that I'm so ill. Then came a period when I felt I'm not that ill.

Finally I realised that I should not care much about the opinions of others because it does not matter.





To be honest, I try various things to use my brain. The clubhouse has a newspaper. It was a huge sense of achievement that I wrote an article in it. There was a guy who defied cats and I got so pissed that I decided to write about what a cat is really like, nothing more or less. It was a great feeling that I have written it, so I'm planning to write more!

Dissolving inhibitions is very important. We, people with psychiatric problems have deeply ingrained inhibitions. I did not dare to open my mouth and now I can't stop talking during the meetings of the clubhouse to tell my opinions out loud. I'm already on that point that others have to tell me to stop. I also asked them to remind me when I talked too much because I have lived half of my life in silence and I don't want this anymore! Since half a year from now I started to open up. Slowly, bit by bit. I had godless fights at home for this as well. I would definitely like to work with people. I like people very much since I studied how to communicate with the grocery shop seller, the homeless person on the corner, because it is possible



to communicate with everybody, only we have to find the common voice and I learned that and I am not stress anymore.

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## **Collaborating partners**

Universities	Services and other organisations
Amersfoort: research group of HU University, Research Centre for So- cial Innovation	Professionals and service users of: Alliantie housing corporation, Amerpoort (agency for people with learning disabilities), CliëntenBel-
Leo Admiraal MSW Els Overkamp PhD Maria Peters Simona Karbouniaris MSc Sascha van Gijzel BSW Jeroen Knevel MSc Martine Ganzevles BSW Trudy Dankers MSc Jean Pierre Wilken PhD	ang (user advocacy organisation), Amersfoort Municipality, GGZ Cen- traal (mental health agency), Hu- manitas DMH (agency for people with learning disabilities), Kwintes (mental health agency and care for the homeless), MEE Utrecht Gooi & Vecht (services for persons with disabilities and their families), Rave- lijn (Voluntary Organisation), Reyer ter Burgh (user advocacy organisa- tion), Riagg Amersfoort (mental health agency), Salvation Army (care for homeless) and Welzin (so- cial welfare agency).
Budapest: research group of Fac- ulty of Social Sciences, ELTE Univer- sity	Professionals and service users of Soteria Foundation (mental health agency) and XII district Félsziget Clubhouse
Zsolt Bugarszki PhD Katalin Tausz - PhD Zsuzsa Kondor MSc Lucia Csabai MA Hajnalka Sátor MA	

Dalma Farkas MA Gábor Gombos Anna Légmán MSc

Universities	Services and other organisations
Maastricht: research group of Zuyd University	Professionals of Mondriaan (men- tal health agency), Trajekt (social welfare agency) and outsider art
Frans Leenders PhD Nol Reverda PhD Philippe Delespaul PhD Henk Geelen MSc	gallery Flow
Tallinn: research group of Tallinn University, Institute of Social Work	Professionals and service users of Tallinn Mental Health Centre (men- tal health agency)
Lauri Leppik PhD Marju Medar PhD Dagmar Narusson MA Koidu Saia MA Karin Hanga MA	





