

Zuyd University ZU of Applied Sciences YD





■ IMPROVING COMMUNITY SUPPORT AND PARTICIPATION OF PERSONS WITH DISABILITIES

A study in three European countries

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1. Introduction

This project builds upon a collaboration which has been established since 15 years in the field of social work between teachers and lecturers of Zuyd University, HU University and Elte University.

Another network joining this project was CARe Europe, an NGO aimed at improving community care throughout Europe. Before the start of the project already HU University, Tallinn Mental Health Centre and Kwintes were participating in this network. In the course of several international meetings (e.g. CARe Europe conference in Prague in 2005, ENSACT conferences in Dubrovnik in 2009, and Brussels in April 2011, ESN conference in Brussels in March 2011), and many local meetings, it became clear that professionals in the social sector have difficulties to change current practices. There is a great need to develop new methods, which professionals can use to create community care.

Although there is a clear EU policy on deinstitutionalization and developing community care for persons with disabilities, in reality professionals in the social service sector and the mental health care sector find it difficult to make transformations from an old way of working to a new approach.

During a conference in Bratislava in September 2010 and a conference in the Netherlands, in July 2011, representatives from the different organizations participating in the networks which were mentioned came together to work on this proposal. The group consisted of professionals, teachers, professors and researchers.

A consortium was formed consisting of four universities and six NGO's working in the field of social work and mental health care. The universities are: HU University for Applied Sciences Utrecht (Research Centre for Social Innovation), Zuyd University of Applied Sciences (CESRT/research centre social integration), Faculty of Social Sciences, ELTE University, Hungary, and Tallinn University, Estonia.

The major European partner was CARe Europe. Local NGO's which joined the project at the start were: Tallinn Mental Health Centre in Estonia, Soteria Foundation in Hungary, Kwintes and Humanitas DMH in Amersfoort, Mondriaan and Trajekt in Maastricht, the Netherlands.

In March 2012 the project proposal was granted funding by the Dutch Ministry of Education, Culture and Science, under the RAAK International programme executed by the Stichting Innovatie Alliantie (Ref. 2011-3-05int). The project started in April 2012 en ended December 2013.

In this report we first describe the background of the project, its goals and intended activities.

Then we describe the project process and the overall European activities. Consequently for each city the research methods, activities and results are described. Also attention is paid to the dissemination of results and intended follow-up activities.

We finish with conclusions and reflections.

For more detailed accounts of the study we refer to our website www.communityparticipation-hu.nl and our publications.

We thank all the professionals, service users, family members, students, researchers, managers, government officials, and others who have contributed to the success of this project. We hope that the results will encourage going on improving the quality of life of persons with disabilities.

On behalf of the four universities, prof. dr. Jean Pierre Wilken

2. Background

The current situation on a regional level and state of the art

On a regional level the situation differs strongly from country to country, and even within countries there are differences with regard to participation of persons with disabilities as citizens in the community, but on the whole persons with disabilities find themselves in marginalized positions. Professionals in the field of social care and mental health care (social workers, mental health workers, employment specialists) are, besides the persons with disabilities themselves, important to realize this transformation. However they feel hampered by a lack of know-how, poor local policy, impeding rules and regulations.

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 in an effective way community participation of persons with a disability.

Traditional clinical skills include for example: 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 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 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. Multi- and interdisciplinary team work with a focus on community living and recovery is yet not well developed.

The model of Assertive Community Treatment (ACT) is a model for ambulatory mental health care which is widely used in the Netherlands, but it is more focused on care than on reintegration (Stein & Santos, 1998).

The current situation on a European level

Demographic, epidemiological, social, and cultural trends in European countries are changing the traditional patterns of care. The next decades will see increasing rates of care-dependent older people and non-communicable diseases as the leading cause of chronic illness and disability. The break-up of the traditional large family group and urbanization will also lead to gaps in the care of older or disabled family members.

These changes in needs and social structure require a different approach to health and social sector policy and services since a disease-oriented approach, alone, is no longer appropriate. An answer to these issues could be home care, a sustainable approach to prevent the need for unnecessary acute or long-term institutionalization and maintain individuals in their home and community as long as possible. Technological innovation together with new and modern forms of service delivery organization can represent a viable solution to developing home care in Europe provided that health care systems can further enhance integration and coordination (WHO, 2008).

The <u>European Disability Strategy 2010-2020</u> (EDS) was adopted on 15 November 2010. Persons with disabilities have the right to participate fully and equally in society and economy. Denial of equal opportunities is a breach of human rights.

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.

By signing the <u>United Nations Convention on the Rights of Persons with Disabilities</u> (UNCRPD), the EU and all its EU countries have committed themselves to create a barrier-free Europe. Even though the EU countries have the main responsibilities, EU action is needed to complement national efforts. The EU Treaties provide for combating discrimination of people with disabilities and the Charter of Fundamental Rights refers to their right to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community. The Strategy for the period 2010-2020 is a comprehensive framework committing the Commission to empowerment of people with disabilities to enjoy their full rights, and to removing everyday barriers in life.

Its objectives are pursued by 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 not disposing of the right information to influence local policy. They are generally not familiar with EU- en UN-documents.

3. Research questions, aims and expected results

The above can be translated into the following research questions:

- 1. What are effective components of community support programmes?
- 2. Which body of knowledge is necessary for professionals in social work and mental health care to effectively develop community support programmes and support individuals and groups?
- 3. How can the EDS strategy and the UNCRPD be translated into local policy, and be used to improve the position of persons with disabilities in the local communities?¹

Answering these questions will help us to develop new knowledge about translating EU-policy into effective components of community support programmes, effective professional methods, and translating this knowledge into bachelor and master programmes at the universities in the different countries, thereby also strengthening the international dimensions of these programmes.

Specific aims of the project were:

- To develop new knowledge about effective components of community support programmes and professional interventions
- To transfer this knowledge to professionals of social and mental health services in the three countries, and to teachers from the different universities and professional members of CARe Europe
- To transfer this knowledge into teaching materials which can be used in bachelor and master programmes at the universities in the different countries.
- To increase mobility of lecturers, trainers, students and professors across Europe.

The expected results were:

 Knowledge about professional methods contributing to successful community support programs.

- Knowledge about: cultural and nation specific factors and non-specific factors influencing developing successful community support programs.
- Knowledge about how to translate EU-policy and the <u>United Nations Convention on the Rights of Persons with Disabilities</u> into national and local policy implementing EU-policy and the UN Convention.

¹ These questions have come forward from a number of both local and European meetings (as mentioned before) and are confirmed by a number of publications and cross-national studies (e.g. WHO, 2008; EU, 2010, Van Ewijk et al., 2002; Van Ewijk, 2005; 2006, 2010; Van Ewijk & Wilken, 2005).

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- Increased mobility of lecturers, trainers, students and professors across Europe.

This project also served to strengthen the existing relationships and enlarge the European network. The intention of the consortium is to continue collaboration after finishing this project. Sustainability will also be assured by the frameworks of the European associations of social work, CARE Europe and CARPE.

4. Project design

This project was designed as both a local and a multisite study with an action learning design involving four cities in three countries (Amersfoort and Maastricht in the Netherlands, Budapest in Hungary and Tallinn in Estonia). The target group concerned people with psychiatric disabilities with a desire to live in the community as equal citizens. In Amersfoort, also people with learning disabilities and acquired brain damage were included in the study. The study focused on participation in (paid or voluntary) labour and social networks.

The cities were chosen on the basis of their location and their socio demographic and institutional characteristics. The variation includes: being situated in Western Europe, Eastern Europe and Northern Europe; being in different stages of transformation from institutional care to community care; differing in population size (Maastricht: 120.000; Amersfoort: 147.000; Tallinn 400.000; Budapest 1.750.000).

The original plan was to choose in each city a particular neighbourhood were interdisciplinary teams of professionals would be formed. The teams would use the form of a Communities of Practice (CoP) according to the model of Wenger (1998, 2002). Due to different reasons we had to change this design. In Budapest community services are still rare and finances for community teams are not available. In Tallinn, the Mental Health Centre serves the entire population of the city. There is no policy to organise services on a district level. In Amersfoort en Maastricht during the project a transition was in progress from working on a city level to working on a district level. On an experimental base, community district teams were formed in some districts. In the project these developments were supported and monitored. At this stage of development however, the needs of the professionals and agencies was foremost to learn how to collaborate better, and how to focus more on the participation of clients.

Organisation

In each city a research group and a project group were created. The research group consisted of researchers from the university. The project group consisted of representatives of the agencies and the university. This group functioned as a Community of Practice and Research, using the model of the Best Practice Unit (Wilken, 2009; Van Gijzel et al. 2011). This is a model in which creation and improvement of practices is combined with research. In the appendix this model is described more in detail.

Research	Practice
Amersfoort: research group of HU	Professionals and service users of: Alliantie
University, Research Centre for Social	housing corporation, CliëntenBelang (user
Innovation	advocacy organisation), Amersfoort
	Municipality, GGZ Centraal (mental health
	agency), Humanitas 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), Ravelijn
	(Voluntary Organisation), Reyer ter Burgh (user
	advocacy organisation), Riagg Amersfoort
	(mental health agency), and Welzin (social
	welfare agency).
	In the course of the project two more
	organisations joined the project: Amerpoort
	(agency for people with learning disabilities),
	and Salvation Army (care for homeless).
Budapest: research group of Faculty of	Professionals and service users of Soteria
Social Sciences, ELTE University	Foundation (mental health agency) and XII.
	district Félsziget Clubhouse
Maastricht: research group of Zuyd	Professionals of Mondriaan (mental health
University	agency), Trajekt (social welfare agency) and
	outsider art gallery Flow
Tallinn: research group of Tallinn	Professionals and service users of Tallinn
University	Mental Health Centre (mental health agency).

Each research group and pilot group had a coordinator. Together with the overall coordinator these people formed a coordination group.

Research	Practice / pilots
Amersfoort: Leo Admiraal	Amersfoort: Edgar Grijzen
Budapest: Zsolt Bugarszki	Budapest: Dalma Farkas
Maastricht: Frans Leenders	Maastricht: Frans Leenders and Henk Geelen
Tallinn: Marju Medar	Tallinn: Anu Rahu

The overall coordinator of the project was dr. Jean Pierre Wilken of HU University for Applied Sciences.

Research

Mainly a participatory action research design was used. This means that researchers and practitioners work together in a creative way to assess current situation, to set goals for improvement, to design and try out new ways of working, and to look at the effects of these new working methods.

In the research part, data were collected on: demographic characteristics, local policy with regard to participation, citizenship, mental health care and social care, methodology used by professionals and results of the interventions. For the collection of the data the researchers used semi-structured interviews, based on topic lists, questionnaires, and transcripts from meetings.

The original plan was to collect data at baseline, during the pilots and after 18 months. Due to the late start of the project the period of data collection was too short to do an effect study. Therefore we only collected data on policy and policy developments, experiences and needs of service users, and experiences and ways of working of professionals.

5. European activities

Timeline

The spring of 2012 was used to form the different groups and to develop a Plan of Action. After summer 2012, the operational phase started. 2013 was the year most of the activities took place. In each of the four sites professionals and researchers worked together with service users and other stakeholders on the development of a community support practice. More details can be found in the next paragraphs.

Meetings of coordination group

The research and pilot coordinators met four times to discuss the progress of the project and to coordinate research issues.

Working conferences

In the preparatory phase of the project, the project coordinator had meetings with the representatives of the different pilot sites. During the operational phase four working conferences were organised, three large one and one small one. In the conferences people participated from all four cities:

1. Maastricht: January 2013

2. Tallinn: May 2013

3. Budapest: September 2013

4. Amersfoort: December 2013

These conferences were very inspiring and provided excellent learning opportunities. The conferences were combined with site visits, to get to know daily practices in the cities.

Seminars

Around the conferences, seminars were organised for a larger audience of professionals, researchers, lecturers, service users and family members. In May 2013, a seminar was organised by CARe Europe on recovery and the transformation of services. One of the keynote speakers was prof. Shepherd from the U.K. In September 2013, a seminar was organised by Elte University about the preliminary results of the project. In December 2013, a seminar was organised by HU University around the UN Convention for Persons with Disabilities, with keynote speaker Gabor Gombos.

Symposium

In April 2013 we organised a symposium at the international ENSACT conference in Istanbul, Turkey. The symposium was comprised of the following contributions:

- Marju Medar, PhD(SW), Dagmar Narusson, MA(SW), Koidu Saia, MA(SW), Karin Hanga MA(SW Estonian Experiences in Community Support for Persons with Disabilities
- Katalin Tausz PhD: Social inclusion, community participation and empowering support in a post-socialist country, Hungary.
- Frans H.R. Leenders PhD: integrating the input of (para) professionals, supporting citizens, persons with disabilities and institutions.
- Jean Pierre Wilken PhD: Concepts of social inclusion, community participation and empowering support.

In July 2013, Katalin Tausz and Zsolt Bugarszki participated in a regional symposium of IASSW in Ljubljana called: International Symposium Against Social Suffering. Here the preliminary results of the research project were presented.

Information exchange

For information exchange and knowledge circulation different media were used:

1. Website www.communitysupport.eu (since 2014 continued as:

http://www.communityparticipation-hu.nl)

2. LinkedIn group and Dropbox for internal use

Mobility

The mobility objectives of the project were realised by organising conferences in four cities and adjacent seminars. Furthermore students and lecturers-researchers from different universities went to other universities to participate in research, seminars and site visits.

Dr. Zsolt Bugarszki from Elte University and dr. Jean Pierre Wilken from HU University were invited to teach at Tallinn University.

Research on the UN Convention

In our research project we have looked at the content and implications of the UN Convention on the Rights of Persons with Disabilities. In each country the research teams have looked at the status of national policy with regard to the content and ambitions as well as ratification and implementation in the countries legislation.

From the principles and content of the convention a set of guidelines has been developed, to be used for social professionals. De guidelines have been formulated in a way that it stimulates people to think from the framework of social inclusion and community support.

This has resulted in two publications: (1) The UN convention on the Rights of Persons with Disabilities: Implications for Social Inclusion and support in the community. (2) Guidelines Social Inclusion & Community Support.

The last publication is still a draft version, since we want to develop it more. We would like to publish an article in an international journal, in which we connect the convention with the European Disability Strategy 2010-2020. We focus on the area of action of: Participation and Equality in Politics and Policy making, and want to describe how Estonia, Hungary and Netherlands are operating.

6. Description of project process and activities per city

6.1 Amersfoort

(report by: Leo Admiraal MSw)

The project in Amersfoort had its focus on three target groups. These were people with psychiatric disabilities, people with intellectual disabilities and people with brain damage.

On the policy and organisational level, the project could build on an existing structure of a collaborative network of a number of organisations working together as 'Community Support System Amersfoort'. This network consisted of a *steering group* consisting of managers, civil servants and service user representatives, and *three working groups* of professionals, focusing on increasing meeting opportunities, on opportunities for voluntary work for clients, and on increasing opportunities for housing.

During the project the steering group turned more and more into a community of practice, discussing developments in the city with regard to the improvement of participation and support, and methodological content. It became also an advisory body for the municipality.²

The three working groups went on during this project. The meetings of the working groups were attended by researchers of the HU. The researchers gave theoretical input. They also facilitated the process of the working group, by supporting the professionals with their reflections (the professionals wrote logbooks), and by systematising effective interventions.

Besides the research done by members of the research team³, four groups of students did research on several subjects concerning Community Support. They were linked to the working groups.

We started a Community of Practice with a group of professionals that worked together in the project Wijk en Psychiatrie (District and Psychiatry). The group was extended with professionals supporting clients with brain damage and intellectual disabilities. The CoP worked on the issue of building a social network for clients and working with volunteers and the social network of the client. The meetings were facilitated by a facilitator and researchers of HU University.

We initiated a peer-support group initiative for clients with psychiatric disabilities. Two clients and two professionals (from HU University and Kwintes) formed an initiative group.

² Members of the City Network: Edgar Grijzen (chairman), Harold van Driel, Jolien de Fijter, Janet Arkenboom, Anne Tuk, Mia van den Heuvel, Ineke Hooijschuur, Sylvia Cox, Tonny de Jong, Henk Ossendrijver, Gitte van den Boom, Martien de Graaf, Anton Janssen, Sylvana Josipovic, Erik Bax, Eunee Dil, Marjon van den Berg, Kitty Stijnen, Eelco Wobben, Hanneke Renes.

³ The research team consisted of: 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.

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After a short period of intensive professional support the peer-support group has now its own meetings with only a small amount of support on distance.

6.2 Budapest

(report by: Zsolt Bugarszki PhD)

In Budapest Community Support Program was designed as the following. Participating partners were ELTE University Faculty of Social Sciences⁴ and Soteria Foundation/XII. district Félsziget-Clubhouse⁵.

This core team has created a Community of Practice that besides conducting research has been working on development work on policy, organizational and practice level during the duration of the project.

Policy level work. ELTE University of Sciences has been involved into the official co-ordination committee of the Hungarian government dealing with deinstitutionalization (DI) in Hungary. Deinstitutionalization has been started in Hungary by 2010 using the Structural funds of the European Union. The first wave of the DI process will be implemented during the next coming 3 years when 6 large long term care institutions will be closed down and replaced with community based alternatives. We are expecting relevant development works in the field of disability and mental health care and through our participation in this committee we could have an impact on the plans.

Organizational and practice level. Our working group has organized meetings regularly were we have discussed the opportunities how to improve the practice in our partner organizations. Time to time we also visited the services where we had detailed discussions with the staff members and users there exchanging our experiences. Being inspired by the international examples we saw in this project a future social enterprise started to be planned with the leadership of Dalma Farkas, the head of Félsziget Clubhouse. Relying on the network of CARe Europe, Dalma has spent 3 weeks in Bolzano, Italy studying their experiences with a public laundry service as social enterprise. Using the expertise of our Community of Practice we kept working on this idea which might be implemented within the framework of a larger EU fund in the near future.

Another relevant influence on practice was that with the active involvement of users our working group gave a good example to the professionals working in the field building new type of relationship with their users. The Hungarian mental health system is still pretty much influenced by the patterns and attitudes of institutional care. Even if we have worked with one of the most progressive service providers in Hungary this project brought new things for all of us.

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⁴ Zsolt Bugarszki - lecturer, coordinator of the program; Katalin Tausz - dean, researcher; Zsuzsa Kondor - PhD student (Social Policy); Lucia Csabai - MA student (Community and civil studies); Hajnalka Sátor - MA student (Social Work)

⁵ Dalma Farkas - social worker; Gábor Gombos - self-advocate; Anna Légmán - sociologist

The same effect we could see in the University, too. The method to work closely for a relatively long time with practitioners of the field created a new atmosphere at the University initiating changes in the rather closed academic world.

6.3 Maastricht

(report by: Frans Leenders PhD)

In Maastricht we first conducted a document analysis describing the current situation in the city, seen from the standpoint of the municipality and service providers.

Second, during the project three types of interventions have been followed and described, which contribute successfully to community participation. The first is an intervention called 'Crazy good neighbours', which aimed at a greater acceptance of persons with a psychiatric disability in the neighbourhoods of the city. This approach is part of a number of activities aimed at building bridges between persons with a psychiatric background and other citizens (in Dutch: Kwartiermaken).

The second is the FACT model of case management, which is based on the ACT-model developed in the U.S. but adapted in the Netherlands as a broader service model.

The third is an approach which can be typified as 'Synergy & Empowerment Projects en Activities' based on eclectic recovery & rehabilitation principles.

In Maastricht three organisations were involved in the community support project⁶:

- 1. Trajekt, a social work agency providing welfare services
- 2. Mondriaan, a large mental health agency providing all kinds of mental health care, which cooperates closely with the Academic Hospital in Maastricht
- 3. Gallery Flow, a private initiative which provides opportunities for recovery and entrepreneurship.

With respect to Community Supporting Systems (CSS) and approaches in Maastricht one can distinguish 3 relatively innovative types of approaches, and producing agencies and projects. The agencies developed their own tradition and way of working and have been (on the basis of professional agreement) chosen as the more innovative.

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⁶ The project team consisted of: Frans Leenders PhD, Nol Reverda PhD, Renee van Dalsen, Philippe Delespaul PhD, Marcel Hilwig, Petra Maas and Henk Geelen MSc.



The first agency is 'Trajekt' identified as a typical social work centre and professional welfare organisation, with roots in social work methods and theory (i.e. mostly prevention and empowerment oriented). In the last few years Trajekt is reorganising their community approach and services in separate district centres in which empowerment and support of 'citizens' and groups are central themes. Essential central issues are: outreaching work, reference to 'presence theory' (Baart, 2001)⁷ and stimulation of driving power of volunteers and clients (manpower) as well as managerial power (administration and continuity of work facilities, 'bridge building' as responsibilities of professionals).

The target groups of Trajekt can be defined as socio-culturally vulnerable or at risk. Other specific problems (i.e medical and/or psychiatric, labour or housing concerned) are referred to related and specialised disciplines and agencies —if possible- organised and cooperating within the newly erected district centres.

The second agency involved in the region is 'Mondriaan', a Mental Health (MH) hospital trust with all (poli) clinical and outreaching facilities. Also because of changing policy (aforementioned decentralisation) and budget cuts, more effort has invested to outreaching care and developing programs that stimulate community support and resiliency.

The treatment and support procedures of '(Flexible) Active Community Treatment' ((F)ACT) are quickly becoming more popular and seem to have a number of effective advantages. The FACT program is chosen in this description as the most potential approach appropriate for a wide range of SMI (severe mental illness) target groups.

⁷ Baart A., *Een theorie van de presentie*, Utrecht: Lemma 2001 (derde vermeerderde druk 2004; her- en bijdrukken in 2006, 2009 en 2011)

Improving community support and participation of persons with disabilities - Description of project process and activities per city

The FACT method, aiming at treating the patient in its own environment and ecology, is well described and standardised and also well evaluated as well (inter) nationally widespread. Also in the adherence area of Mondriaan, FACT can relatively easy upgrade to a more intense treatment variant, the so called ACT option (a.o. team load of 1/10 instead of 1/15), for more intensely impaired SMI individuals. ACT and FACT have basically the same important elements such as:

- 1. Multidisciplinary teams offering multi-disciplinary team-case management,
- 2. Daily mutual consultation of disciplines,
- 3. All types of care delivered by own (F)ACT team members,
- 4. 4 Assertive and Outreaching approach and
- 5. Local or regional implementation.

FACT is an interesting and widely used practise, well described and at this point of history ready and willing to intermingle with other regional or district approaches (i.e. Trajekt services). Apart from social work methods, psychiatric, nursing and psychological approaches are dominant counterparts in this way of working.

The third approach can best be typified as 'Synergy & Empowerment Projects en Activities' (SEPA) based on eclectic recovery & rehabilitation principles' (ERRP). These projects still have a short history in the region and consequently still work on a relatively small to medium scale. The projects are initiated and organised by (mental) health workers together with patients/ clients. Sometimes initiated from hospitals, mostly not. (Mental health) workers experience relatively often a disappointing and frustrating history in overly bureaucratic and over controlling healthor welfare agencies. These projects include various activities that independent entrepreneurial patients and clients potentially may be able to organise. It is fair to say that most clients still have reasonable competences and less severe impairments. Working with this group of relatively privileged users is in this approach also a strategic choice. These potential 'entrepreneurs' one hopes, will be able to function as role models, formal and/ or informal leaders and future sociometric stars for their less privileged peers who feel a greater acceptance and reassurance in projects they may initiate. As possible projects one can think of gardening projects, recycling activities, transport and removals by specialised bikes in (polluted) city centres, ateliers and workshop, but also 'violin building', caretaking of elderly people or running a 'cat comfort' project exchanging cat litters every week or two for a descent price. In fact anything that may be fit as a developable competence potential in a potential market niche. (Community) support often is found among (pre) pensioners, unemployed or dismissed professionals, senior citizens or peers who don't want to retire with specialized skills that may be wanted.

In these projects a number of starting points are important:

- 1. Recovery principles are leading;
- 2. Patient/ client search an individual autonomy within and with help of a supporting environment (synergy & empowerment procedures); this has consequences for (self-) labelling, e.g. the choice of the 'entrepreneur' role instead that of that of a patient, client or -even worse- an 'autist' or a 'schizophrenic';
- 3. Entrepreneurs are selected on having a substantial recovery potential and –next to other personal motives- wish to use this potential in being a role model for other peers;
- 4. Entrepreneurs may/ will need practise or training to be successful as a resilient human being.

This ERRP approach seems to be growing in the region, though still has a relatively small scope. Satisfied patients in combination with relatively low costs and overhead may become distinguishing features of ERRP. These complex processes have to be proven however. But these developments seem to be interesting for insurance companies. A restriction is obviously is that mainly high potential patients seem fit for this approach, which creates ethical questions.

In a way any of the three approaches (Social Work, FACT or Synergy & Empowerment) match best for a specific target group (differential approach). SMI patients with a high need of intensive care are probably best helped by a FACT approach or patients with frequent remissions; more or less recovered or balanced patients with remains of a strong personal ambition and recovery potential may favour an 'S & E' project. Socio-culturally deprived citizens may best be helped by a social-work-and-neighbourhood or district-centred-approach or even ways of self-initiated activities.

During the lifespan the sensitiveness for certain approaches may change for clients, which make questions of 'input, throughput and output' of clients in specific programs or approaches in a region more important. At this moment however these services are not equally distributed within the Maastricht area or districts, nor is there a systematic assignment from one program to another in the region. Our project aimed to analyse the accessibility and impact for citizens and residents to these different approaches.

6.4 Tallinn

(report by: Marju Medar PhD, Dagmar Narusson MA, Koidu Saia MA, Karin Hanga MA) Intensive preparatory work for the project "Community Support for Persons with Disabilities" started from October 2012, after which meetings were held with the project research team and the Tallinn team in order to specify areas of responsibility, develop plans of action (incl timetable) and start with preparatory activities for the research part.

In October 2012 we organised an introductory training of the project together with project manager professor Jean Pierre Wilken for the specialists of the Tallinn Mental Health Center and the project team in general (16.10.2012 training of CAR method at Tallinn University, TU).

In October 2012 the final formulation of research group took place and putting together of the group of community of practitioners. Additional specification of the conditions of project agreement was undertaken for TU with project manager Jean Pierre Wilken. At the end of October the meeting of project cooperation team (managers, employees, service users of Tallinn Mental Health Center; research team of the Institute of Social Work of TU)⁸ in order to specify project objectives, planned activities, roles of different parties took place. The issues of research design and data gathering methods were additionally discussed with the project manager.

In November the data gathering started (about activities and priorities of national and local policy level), research instruments were refined. By the 16th of November the analysis "Description of Estonian national government policy" and by the 23rd of November the analysis "Description of local government policy in Estonia" was completed. At the end of November a meeting of the research team was held in order to coordinate analyses and amend them. By the 30th of November the analyses "Description of Estonian demographic situation" and "Description of local policy and demographic situation in Tallinn" were completed. On the 3rd of December the research group met in order to review and coordinate the aforementioned analyses.

On the 20th of December the service providers, service users and research group of the Institute of Social Work of TU met in order to discuss the content and results of analyses compiled in November. At the end of December the focus was on data gathering and analysis of materials (on the topic: UN Convention on the Rights of Persons with Disabilities, EU and UN policy documents related to the areas of persons with disabilities, citizenship and community integration) and preparations were made for compiling the report "Estonian local policy and local situation of persons with disabilities".

On the 21st of December data analysis was started (incl documents, publications on EU and UN policies about people with disabilities, citizenship and community integration).

On the 28th of December a report was prepared on Estonian local policy and local situation in the area of people with disabilities.

Period: January – March 2013

16.01 – meeting for project team with researchers, professionals and service users: preparation of presentations for joint work conference in Maastricht.

⁸ Research team in Tallinn: Lauri Leppik (PhD), Marju Medar (PhD), doctoral students: Dagmar Narusson (MA), Karin Hanga (MA), Koidu Saia (MA). The project was conducted in co-operation with Tallinn Mental Health Center (Anu Rahu, Margit Kirja, service providers, service users and their families) and other service providers in Tallinn.

Improving community support and participation of persons with disabilities - Description of project process and activities per city

- 30.01.-01.02 participating in joint conference in Maastricht, meeting of coordination group.
- 04.-08.02 the research team prepared a service map regard to mental health care and social care, community care and described important frameworks and paradigms in these fields.
- 11.02 the final selection of participants representing the target groups in the study was made (service users, relatives, service providers, policy makers and developers).
- 12.-20.02 the research group prepared the questionnaires in Estonian and Russian languages.
- 21.02— the meeting of Estonian project team (incl researchers, service users, professionals) was held (preparing the data collecting process).
- 25-28.02 the research team prepared the interview questionnaires for interviews with service users, service providers, relatives, professionals.
- 13.03 the meeting of research group was held with the focus on the process of data collection of local situation, discussion and feedback.
- 13.03.-05.04 the baseline assessment of current situation, experiences, wishes, support needs with regard to participation was implemented: questionnaire, interviews with service users, focus group interviews with service providers and policy makers, developers
- 04.04 mid-term evaluation was held (meeting: researchers, service users, professionals)
- 08-11.04 the data analysis process: process monitoring, evaluation of trajectories of participants, documenting learning experiences
- 12.04 meeting of research group was held (focus on documenting experiences, working methods and outcomes). Also the preparation of presentation for ENSACT conference in Istanbul was done.

Period: April – June 2013

- 17-19.04 the meeting of coordination and research group in Istanbul was held (combined with the presentations at ENSACT Conference).
- 13.05 the meeting of research group was organised, focusing on topics: analysis of facilitating and impending factors, successful working methods etc.
- 01.-06.05 the joint work conference in Tallinn was held (incl planning, preparations, coordination, presentation of process).
- 22.05 meeting of project team with researchers, professionals was held (incl feedback about ENSACT conference, Istanbul work meeting and Tallinn meeting).
- 06.06 the data analysis of interviews was done.

Period: July - September 2013

16.07.-20.08 – the research team was working with data: writing transcripts and preliminary analysis

26.08 – meeting of research group was held (focus: developing new knowledge about effective components of community support programmes and professionals interventions). The preparation for action research and 07.10 meeting was done.

29.08.-08.09 – preparations for Budapest meeting were done (incl presentation)

24.09.-06.10 – meeting of Tallinn project team was held (focus: preparations for 07.10 seminar and action research activities)

07.10- project seminar was held in co-operation with professionals, researchers, organisations, service users, students in Tallinn. Focus on transferring knowledge between various interest groups in Estonian mental health and linked fields.

Period: October - December 2013

16.10.-15.12 – Evaluation on the basis of research data was continued. Also evaluation of the process and analysis of the results in the pilot, identification of specific and common factors.

16.10.-31.12 – preparation of training materials and publications.

16.10.-01.12 – meetings of research group were held: transferring knowledge into teaching materials (used at TU in Institute of Social Work – in BA and MA levels).

06-07.11 – transferring knowledge to professionals of social and mental health services and Estonian universities in Estonian Social Work Annual Conference (incl presentations and workshops).

22.11 – the meeting for researchers and professionals was held (incl the development of guidelines how to apply the convention in daily practice – report and guidelines)

28-29.11 – the final seminar of the project for professionals, researchers, organisations, service users and students was held. Incl discussion about increasing mobility of lecturers, trainers, students, professionals across Europe.

16.10.-31.12 – Dissemination by websites (www.tlu.ee/sotsiaaltoo), lectures (course for MA and PhD students), articles (In Estonian professional journal "Social Work) was implemented

02.-06.12 – preparations for joint conference in Amersfoort (08.-10.12) were done.

08.-10.12 – participating in joint conference in Amersfoort.

11.12.-30.12 – Preparations of final report and digibook were done.

01.12-30.12 – preparations for publications in pre-reviewed articles concerning CoS project were done (incl meetings of research group, international Skype meetings etc).

■ Improving community support and participation of persons with disabilities - Description of project process and activities per city 26

30.12 – conclusive meeting of research group (incl evaluation of project results, discussion of next activities – research report, digibook, publications, dissemination of results in Estonia).

Period: January – March 2014

Working with final project report, digibook, increasing international mobility (incl preparation of joint master curriculum "Community-Based Services"; staff and students 'exchange and mobility), publications (1 article coordinated by J. P. Wilken and 1 article about UN Convention) and dissemination of results (incl training materials, courses in BA and MA studies and introducing results in professional conferences, seminars) have been continued.

[■] Improving community support and participation of persons with disabilities - Description of project process and activities per city 27

7. Research methods per city

7.1 Amersfoort

(report by: Leo Admiraal MSw)

In Amersfoort we used several research methods. At first we did research on the policy of the municipality of Amersfoort concerning participation and community support. Also we did some desk research concerning the presence of facilities for community support e.g. special facilities for activities and meeting.

Quantitative research was done among service users by using the PAS questionnaire. We collected 46 forms to get an overall view on Participation, Autonomy and Social support.

There was a strong emphasis on qualitative research. We had a lot of interviews with clients, professionals, persons from de social support system of the client and managers. Depending on the respondent the emphasis was on experiences concerning participation and support (clients), or the methodology of support (professionals) or the policy of community support (managers). During the meetings of the study group focusing on increasing social meeting possibilities, logbooks were discussed. This led to a report in which best practices are described. Also during de CoP's cases were discussed. This also led to a report describing best practices.

Besides the research mentioned above, we have done a study on the UN Convention, looking at the implications for the work of professionals.

7.2 Budapest

(report by: Zsolt Bugarszki PhD)

At the beginning of our research programme we have analysed the situation of community-based mental health services in Budapest. This policy level analysis helped us to understand the context of the involved service providers and its users.

We have conducted structured interviews with 9 users. One of them later changed her mind and we couldn't use the interviews we made with her. Users were recommended by our partner organizations. Social workers were asked to recommend users who are in different phase of their recovery process.

In case users accepted our request for an interview we followed their recovery process during the entire year. Beside the interviews we also used the PAS questionnaire in order to create individual personal profiles as a framework of our work. Some volunteering users were also involved into our photo-story project where users could describe themselves with different, more personal narratives.

Users were asked to name those professionals, services or any other relevant persons in their life that played a relevant role in the personal recovery.

Our research team (having the concern of users) contacted these persons, or visited those places and we have conducted interviews with them trying to explore the key elements of a successful recovery.

We also explored the background and history of the involved community-based services by conducting interviews with their leaders/founders.

Beside the personal interviews and questionnaires focus group interviews were conducted with a special community that has created an art-magazine editorial in of the clubhouses in Budapest.

Results and preliminary results were continuously discussed within our research team, with our international and local partners and also with the involved users.

During the research programme altogether 20 individual interviews were conducted and two focus group interviews with 5-6 participants each.

7.3 Maastricht

(report by: Frans Leenders PhD)

Our research consisted of different parts:

- A desktop research studying documents from the municipality and the different service providers
- Document analysis and interviews with professionals and users around the three components of a community support system which we choose for this study.

During the summer and fall of 2013 we interviewed a number of patients/ clients, active citizens and also professionals. They were recruited within the facilities/ programs of the three 'district affiliated' programs of Trajekt and Mondriaan.

From the 'S&E' projects some clients with experiences in the district affiliated programs were interviewed. In this condition we'll elaborated on procedures, methods and phenomena within the programs. Interviewing these clients was partly impossible, because the clients have taken up their lives and have –partly new- existence outside the area of the welfare- and care programs.

At the time that the interviews, questionnaires and/or observations were collected no specific national or communal project plans or concretisations for the introduction of decentralisation have been introduced. From national level (e.g. governmental, provincial and city level, knowledge institutions, universities etcetera) a vast amount of ideas, pilot ideas, projects and / or essays have been produced and spread all over the country. The nature of this input can be

characterised as proposing, essayistic or tentative formulating hypotheses. These ideas, in general favoured autonomy resiliency of the individual, stimulated or mediated by empowering activities presented to the subjects and or active and compassionate fellow citizens. These fellow citizens in most approaches are recruited from the near social relational vicinity of the individual and may vary from relatives, spouses, children etcetera up to peers in the neighbourhood, ranging from (pre) pensioners, active citizens, senior citizens.

Professionals, active citizens in the projects as well as users were at that time not able to react on concrete and specified plans and approaches, but reacted on more or less complete information of national distributors of ideas. One of the spare and most concrete propositions in the autumn of 2013 was that the year 2014 was a year that financing could be secured, but from 2015 on no financial commitments could be guaranteed. In this 'existential' atmosphere quite a number of the reactions of interviewees and questioned participants may have been coloured a bit defensive, even negative. The organisation of a focus group has been cancelled because of that reason. A focus group presupposes a bit more realisable and concrete options participants may choose to discuss.

A number of users (6 from the total of 10) who were invited for an interview and to fill in a questionnaire didn't react or showed up after the first invitation. All these respondents were approached a second time by e-mail. None of them decided to respond additionally. In the end professionals who had contact with the non-respondents were activated to motivate these users or otherwise try to detect because of what reasons they did not show up. Three of these respondents in the end did show up, the other 3 indicated they had no ambition or possibility to participate. The last three had personal, psychosocial reasons not to take part, the first three who did participate had some incidental personal crisis at the moment or were initially intimidated by the title 'psychologist' in the e-mail address of the inviting researcher; something to hold in mind for the future. The 7 remaining interviewed users will be reported in the analyses of the PAS of the overall project

Seven professionals (n=7) invited all participated in the interviews. They did not completed questionnaires that were constructed just for users. Also 3 active citizens (n=3) were invited and all participated in the interviews.

Respondents are selected who have had experience with more than one of the different types of professional cure or care programs. In these interviews we want to elaborate the match between professional help, own needs and satisfaction of the client and possible connections with lifespan characteristics. Also questions with respect to accessibility, type of help or need and own individual characteristics and parameters (i.e. professional proficiency, expert expertise, 'lifespan of learned helplessness') are taken into account. The results of these analyses may lead to reorganise the availability of professional cure and care in the districts. These may be completed with insights and suggestions acquired from comparisons with the

three other participating cities in Europe, Tallinn, Budapest and Amersfoort. They all differ in urban scale, adherence characteristics and social cultural backgrounds.

7.4 Tallinn

(report by: Marju Medar PhD, Dagmar Narusson MA, Koidu Saia MA, Karin Hanga MA)

Instruments used for data collection:

- 1) Questionnaire in Estonian and in Russian (translations), incl PAS (Wilken & Karbouniaris Version 2.2. 2012) and questionnaire for fulfilling
- 2) Semi-structured interviews:
 - a. For service users (in Estonian and in Russia)
 - b. For supportive workers (tegevusjuhendajad)
 - c. For relatives
- 3) Focus group interviews
 - a. For service providers and policy makers

Collecting data: samples

- Individual interviews with specialists case managers (researcher and Tallinn Mental Health Centre specialist, n=7)
- Interviews with persons in vulnerable position (selected in cooperation with Tallinn Mental Health Centre), 3 (or 4) participants: person, supportive worker and researcher (or 2) n=15
- Interviews with relatives: n=6 (1 focus group with 2 Russian speaking relatives and 1 focus group with 4 Estonian speaking relatives)
- Focus group interviews with service providers: n=11 (included: Social Insurance Board, Tallinn Social Work Centre, the Estonian Patient Advocacy Association, Tallinn City Property Department, social welfare specialist of one of Tallinn city district governments (8 in total), social worker of Tallinn Psychiatry Clinic, supportive supervisor of the Tallinn Mental Health Centre, social worker of rehabilitation team, representative of Estonian Association for Psychosocial Rehabilitation, care manager of one of Tallinn social centres (social houses). Policy developers were invited to the interview, but they were unable to participate.
- Focus group interviews:
 - 1) about implementation of UN Convention guidelines (n=8 client-workers, 6 service users, 2 mental health professionals-supervisors
 - 2) about best practices for client-workers (n=5)

In spring in parallel with the process of data collection was started the process of writing transcriptions and preliminary analysis.

The process of data collection and analysis was implemented in following stages:

I Collecting data and writing analysis on topics:

- 1) The situation of Estonia and Tallinn
- 2) Implementation of UN CRPD guidelines in practice

II Data collection (PAS instrument and interviews)
III Data analysis and interpretations

Methods used for data analysis:

- 1) Format for description of results (PAS analysis) (incl for clients and for professionals)
- 2) Format for case description and trajectories (Wilken)
- 3) Qualitative analysis: content and discourse analysis for interviews
- 4) Analysis of using UN CRPD guidelines in practice

During the process of data analysis the focus was on following topics:

- ▶ Involvement of people using mental health services at the moment
- ▶ Facilitative factors <u>supporting</u> being/living in community
- ▶ Restrictive factors <u>restraining</u> living in community
- Work methods that contribute to social inclusion

When conducting data analysis the analysis focused on the following research questions:

- 1. What are effective components of community support programmes?
- 2. Which body of knowledge is necessary for professionals in social work and mental health care to effectively develop community support programmes and support individuals and groups?
- 3. How can the EDS strategy and the UNCRPD be translated into local policy, and be used to improve the position of persons with disabilities in the local communities?

In terms of research results the focus was in addition to research questions also on the following more specific themes:

- ▶ Needs of mental health service users
- Needs of family members and/or next-of-kin
- ▶ Needs of practitioners, challenges of the system

8. Results per city

8.1 Amersfoort

(report by: Leo Admiraal MSw)

As a result of the project a 'community support system' in Amersfoort has been strongly supported in its development. Now there is a strong network of collaborating organisations, operating under the name City Network Social Support and Participation. Managers of these organisations are meeting on a regular base to steer and initiate developments, together with representatives of the municipality and service users.

City Network Social Support and Participation

During the project this group evolved to a broader group with more organizations represented (working with people with intellectual disabilities and brain damage). The cooperation with HU University gave more direction to their activities, for example the research gave more insight in the perspectives of clients. Also a peer-support group initiative was encouraged.

At the beginning of the project, 10 organisations participated in the network. At the end of the project, 13 organisations had joined the network.

Study groups

The study group <u>Voluntary Work</u> developed an improved method for matching clients with a wish to do voluntary work with employers. They introduced a voluntary mediator who matches clients with organizations which need volunteers. This mediator works with the client, but also tries to make organizations more adaptable to clients with disabilities. Some clients who were mediated were interviewed by our researchers. They were very satisfied about this method. A lot of people with disabilities found their way to voluntary work.

The study group <u>Meeting Opportunities</u> worked on improving the meeting places and places for activities for the target groups. It became quite clear, due the research we did on this theme, that activities with low thresholds are very popular. It seemed that activities organized by clients themselves are very successful. Clients appreciate places where they can sometimes be a visitor and sometimes be a volunteer. Being a volunteer encourages contact with others people and gives meaning to their lives.

The main concern of the study group <u>Housing</u> was to improve housing opportunities for clients (with psychiatric disabilities). After hospitalisation, clients can receive a declaration of urgency, which entitles them to get a house faster. Rules for distributing the houses with an urgency status were however not satisfying, and also many professionals were not familiar with these rules. During the project care organizations and a housing corporation made an agreement. The study group also discusses the topic how clients must be supported when they start living on their own. The experience of the housing corporation was that often troubles popped up like not paying rent or getting in trouble with neighbours.

Community of Practice of Professionals

During the project a group of professionals, formerly known as Wijk en Psychiatrie (District and Psychiatry), evolved to a group not only with focus on people with psychiatric disabilities, but now also on people with intellectual disabilities and brain damage. The focus of this group is improving the collaboration of care and welfare workers. During the project this group of professionals became a Community of Practice (CoP). Professionals of different organisations and disciplines meet each other regularly in the CoP. Getting to know each other, to be acquainted with each other's role and competences, makes it easier to support clients in a more integrated way.

The main result of the CoP is that care and welfare professionals working with the target groups of this project changed their focus towards participation and inclusion. At first, many professionals were resisting the transition in the way of working (changing the emphasis to the use of own strengths of clients, their social network and of the society). They blamed the budget cuts of the government for the changes. Now budget cuts are also considered as an opportunity for empowerment and inclusion. Professionals also discover that new ways of providing support have a lot of advantages. The CoP chose as a goal to use the social network of the clients more and improving the role of the social network. They successfully implemented some new methods. They also collaborate better now.

Results of research

The network was supported by research done during the project. In the first phase of the project desk research was done to depict the actual situation in Amersfoort. The conclusions of the study were:

- A lot of collective facilities are supplied by the care organizations for only their own target group.
- The participation of vulnerable people in initiatives by citizens (to improve their welfare) is very low.
- There are a lot of bureaucratic procedures and also the website of municipality is too complicated for people with disabilities.
- The municipality itself hardly has employees or volunteers with a disability.
- Participation of people with disabilities (mental and intellectual) in policy making is low.

The most important results of the research done among service users, professionals and managers were:

- Care professionals still have a strong focus on caregiving. Less on participation of the client and using social networks and volunteers. Better collaboration with welfare and voluntary organisations helps to change this focus.

- Clients appreciate support that is: being accepted, attainable, has a focus on autonomy and self-control, empowerment, focus on meaningful activities, encouraging to participate, be a buddy to visit activities
- Clients are satisfied about the special facilities for meeting and activities. But only few visit
- Clients are anxious to visit regular places in the community for meeting other people and having activities because of stigma. There should be more efforts to make environments more open and hospitable.

These insights were used as input for the city network, the study groups and the CoP.

UN Convention

We have studied the UN Convention and its meaning for Dutch policy and social work. The Dutch government has signed but not yet ratified the convention. There is strong pressure to ratify the treaty soon.

We have also looked at the local policy in Amersfoort and to what degree it focuses on participation and inclusion of persons with disabilities. The conclusion is that although there are a number of policies which influence positively the participation, the rights as stated in the convention can nowhere be found in an explicit way.

We have transferred the knowledge about the convention into two modules for the bachelor programme of Social Work.

Continuation

The network, the study groups and the CoP, decided to continue the activities done during this project. The main objective is to get clients more involved in society, and to find effective ways of support to use the resources in the community. The network wants to aim at an inclusive society. Also, because of budget cuts, clients should be encouraged to use general collective facilities available for all citizens instead of facilities offered by care institutions. Only when general facilities are not appropriate, special facilities can be used.

8.2 Budapest

(report by: Zsolt Bugarszki Phd)

We have summarized our key results in five main dimensions:

Connectivity - 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 outside links are more important supporting the recovery process with real opportunities in the community.

Time frame - In Hungarian context a successful rehabilitation process lasts for 6-8 years usually. The journey of recovery is a long non-continuous ride with many occasions of relapses and uturns. The duration of the process most likely might be relevantly shorter if Hungary would pay more attention on the development of community based programmes, especially housing opportunities within the community. According to our Estonian partners' findings 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.

Relation - Personal relationships and the continuity of it has 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 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.

Language and meaning - Language and meaning of social (and health) services are extremely important and we pay so little attention to it. Service providers most of the time are forced to use a rather clinical language as official language of the service. 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 hand 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 allowing users to develop their own narratives.

Informal care - 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.

Beside the findings of our research activity, maintaining our Community of Practices brought the following results:

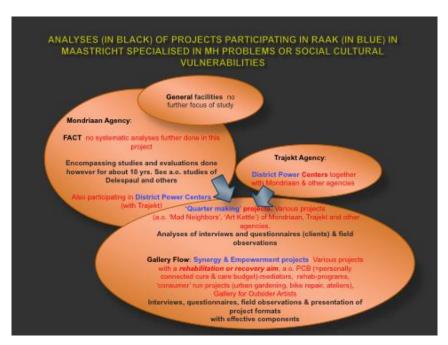
 Created a stronger link between academics, professionals working in the field and service users. This new links helped all participants to build new methods of works and teaching

- based on mutual partnership and continuous encounters. The connections established during the project will remain alive even after the closure of the research.
- New user initiatives have been established in the Félsziget clubhouse. Based on the example
 of Holland and Estonia peer-support workers may appear in Hungary in the new future. The
 project generated huge interest and enthusiasm among the involved service users.
- Concrete development plans has conducted during the project period. New social enterprise
 will be initiated with the participation of our working group using the inspiring experiences
 of our Dutch partners in this field.
- On behalf of education a new co-operation seems to be created between three universities
 of the project. With the leadership of ELTE University, having the University of Applied
 Sciences of Utrecht and Tallinn University as partners a new Joint Community Based Services
 Master program will be aimed. This program is based on the co-operation of our current
 community support program.

8.3 Maastricht

(report by: Frans Leenders PhD)

In Maastricht, we evaluated three projects: the FACT teams, the district initiatives of Trajekt and Mondriaan and the synergy and empowerment initiatives of Gallery Flow.



In the above figure an overview is given of these projects. (F)ACT analyses are excluded from this report and can be found elsewhere, i.e. in Delespaul (2009, 2012, 2013)⁹.

⁹ -Delespaul, Ph. A. E. G. (2009). Planning van wijkgerichte integrale zorg voor mensen met ernstige psychiatrische aandoeningen op basis van (F)ACT. In N. Mulder & H. Kroon (Eds.), Assertive Community Treatment Bemoeizorg voor Patiënten met Complexe Problemen (2 ed., pp. 103-126). Amsterdam: Boom.

Improving community support and participation of persons with disabilities - Results per city

We want to direct the reader to these publications. Below, analyses of interviews and observations will be given of the district oriented projects organised from the District Power Centres coordinated from the agencies Trajekt & Mondriaan. From the 'Synergy & Empowerment' (S&E) projects some first impressions will be given based on interviews and especially participative & field observations. Also a more detailed formatting will be presented of the various phases the S&E projects are tailored in.

In the 'district oriented projects' of Trajekt and Mondriaan we interviewed, questioned (by means of the PAS¹⁰) and field observed three groups of participants, i.e. professionals, active citizens and users.

This was also done in the analyses of the 'Synergy & Empowerment' projects. In these projects however only questionnaires and field observations have contributed to the analyses.

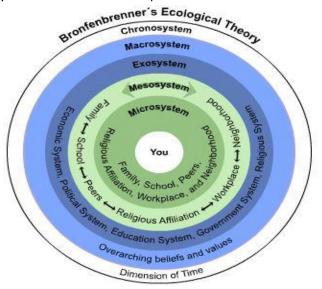
This was done predominantly because data gathering was troubled because of prolonged intake, throughput and out stream of participants over 3 to 4 years. The analyses of these projects will take place with semi structured interview data and field observations. These analyses results in a first draft of project phase sequence that clients/ users will walk through in achieving a greater autonomy and entrepreneurial action radius. Here also professionals, active citizens and users are approached for experiences and additional data.

⁻Delespaul, Ph. A. E. G., & Consensusgroep EPA (Cahn, W. D., G; Drukker, M.; van der Gaag, M.; van Heugten, T.; van Hoof, F.; Keet, R.; Kroon, H.; Mulder, N.; van Os, J.; Slooff, C.J.; Sytema, S.; van Veldhuizen, R.; van Weeghel, J.; Wiersma, D.; Willemsen, E. & Wunderink, L.),. (2012 (submitted)). Consensus over de aard en omvang van de EPA populatie. Tijdschrift voor Psychiatrie.
-Ph. Delespaul, en de consensusgroep epa, (2-13), (2013), Consensus over de definitie van mensen met een ernstige psychische aandoening (epa) en hun aantal in Nederland, Tijdschrift voor Psychiatrie 55.

een ernstige psychische aandoening (epa) en hun aantal in Nederland, Tijdschrift voor Psychiatrie 55.

¹⁰ Questionnaire Participation, Autonomy and Support, Wilken J.P. and S. Karbounaris, HU University of Applied Sciences Utrecht, 2012.

In the descriptions and analyses we will seek for inspiration from Bronfenbrenner's Ecological



Theory¹¹, see figure below.

We analysed our data within three layers of analyses as is given in the figure, i.e. the Microsystem, the Mesosystem, and the Macrosystem. Similar to the biopsychosocial model, Bronfenbrenner's Ecological model presupposes developments and interactions within the layers of analyses (Micro to Macro) as well as between these layers. Phenomena within layers lying next to each other can be better understood than phenomena in layers on a greater distance. Individual development of children in school for example can be better described and explained from family and parenting parameters than from sociological or cultural events. Though these last ones in the end may have substantial effects on family- and parenting parameters.

¹¹ For a short introduction see: http://faculty.weber.edu/tlday/human.development/ecological.htm

[■] Improving community support and participation of persons with disabilities - Results per city

Basic results per project: 'District oriented projects' by agencies Trajekt & Mondriaan

Results from the interviews and field observations

In the tables below we will summarize the results of the interviews with –were possible-additional impressions of the questionnaires and field observations. The status of the information given is primarily directed on exploring the atmosphere and possibilities of the projects and its participants. In the knowledge-development we dwell in one of the first empirical loops, mainly consisting of peer experience and plausible professional findings. These loops in time may give input on more specified concept and theory building and possible resultant (quasi) experimental designs (Bryman, 2004)¹².

In the table below we will firstly present impressions and findings from users, secondly from active citizens, mostly working on voluntary basis and thirdly from the perspective of professionals. For the three groups of participants we'll make a distinction in phenomena found on micro, meso- or macro level as was described earlier forthcoming from Bronfenbrenner's Ecology Model.

¹² Bryman A., Social Research Methods, 2nd Edition, Oxford University Press, Oxford New York, 2004, ISBN-019-926446-5.

[■] Improving community support and participation of persons with disabilities - Results per city

Impressionistic results from USERS in 'district oriented' projects (a.o. 'quarter making', 'bridge building', 'Art Kettle') of Trajekt and Mondriaan agencies. (Based on interviews, questionnaires and field observations)

Micro	Meso	Macro	General Remarks
-Profile target group: Age range	-Lower (upper) working	-Projects situated in lower	-Study was
from end thirties until sixties	class background	(upper) working class	probably planned
with modus in fifties;	-Most are reasonably	districts, partly stimulation	too early.
balancing in between chronic	satisfied with housing,	areas (in Dutch:	National and
existential socio economic	work, leisure time	'krachtwijken').	communal plans
challenges & MH	conditions (upper) lower		haven't been
vulnerabilities.	class)	-No information exists (yet)	specified and
		about governmental/	distributed yet.
-Reported individual grow	-Immigrant influx has	communal plans with resp	Focus group
moments; single one reports	positive (quick integration	to Decentralisation. Users	approach misses
growing detachment with	of young Moroccan girls)	don't feel accepted as	focus.
partner	& neg effects (low	serious partner, not	
	education of older group)	attributed to professionals	-Peer contact as
-Most do voluntary work;			basis for relapse
aspire experienced paid work	-District oriented projects	-Users have no information	programs
assignment; some do art	give > resiliency &	about future national &	
projects & courses (love idea of	stability; are able to	communal reorganisations	Projects now
becoming independent art	accept help.		sometimes
entrepreneur).			evaluated as
	-Participants are relatively		'middle of the
-Well aware & informed about	best functioning in the		road', preferably
own vulnerabilities &	district & are eager to		a bit more
sensitiveness towards possible	participate in stimulation		naughty.
potentialities.	& enrichment projects.		
	Professionals & active		
-Recovery oriented, but also	citizens easily pick them		
alert with respect to individual	out in acquisitive		
vulnerabilities. Life is seen as a	procedures.		
'give and take' accepted with			
certain assertiveness with	-Professionals' qualities		
respect to own qualities.	are broadly appreciated in		
	various fields of		
-Project facilities are seen as	functioning.		
'enduring entertainment', not			
much urge to leave them; a.o.			
because of experience of			
certain isolation and loneliness			

Impressionistic results from ACTIVE CITIZENS in 'district oriented' projects (a.o. 'Quarter making', 'bridge building', 'Art Kettle') of Trajekt and Mondriaan agencies. (Based on interviews and field observations)

Micro	Meso	Macro	General Remarks
-Profile target group:	-Sensitiveness in using 'bridge	-More information in	Active citizens mostly
Age range:	building' methods	neighbourhoods needed	senior citizens;
predominantly 70 & 80		(some progress is	younger citizens
yr old citizens, mostly	-Lack of facilities (meeting	observable).	needed, (pre-)
with (semi-) professional	places, soccer fields, play		pensioners & workless
social work background.	grounds etc.)	-Cynicism towards policy &	individuals, also
'Originals', resilient!		politicians ambitions ->	postgraduates without
	-Investment in relapse	creates barriers.	work.
-Irritated by	programs run by peers		
stigmatisation in district,		-Tend not to embark on	-More volunteers
Island culture	-Reported hinder sometimes	nationwide 'hysteria'	needed, how to
	by ineffectivity of	(regarding policy change).	attract them? Kind of
	professionals.		'Rotary'-systems?
		-"2015 is the year we hear	Facilities for training &
	-Hardly any regular & work	the super tanker to crash	schooling?
	related communication	the coast!" -> "Alienation	Introduction of more
	between active citizens yet.	lingers around"	immaterial value
			systems instead of
			material ones.

Impressionistic results from PROFESSIONALS in 'district oriented' projects (a.o. 'Quarter making', 'bridge building', 'Art Kettle') of Trajekt and Mondriaan agencies. (Based on interviews and field observations)

Micro	Meso	Macro	General Remarks
-Profile target group:	-Relatively small proportion of	-'Annoyance in	-Intense cooperation
Age range users: 50s	(part time) professionals	combination with bad	with (F)ACT, social
& 60s, mostly social	participating in innovative	weather' are bad omens	psychiatric
workers;	methods (a.o. district oriented	for wellbeing.	approaches,
	working, client oriented		'HERSTEL" & 'ECHT'
-Professionals most	motivating techniques, de-	-agencies often too much	etc.
between 40 and 50	stigmatisation, recovery);	self-centred'.	
yrs.		-Combat '9 to 5'	-Overall picture
	-Substantial part directed on		organisational and
-Highly motivated	management & coordination.	-Invest in specification and	financial not specified
and very creative		concretisation of various	yet
profs. Are resilient.	-Important issues: a. Finances, b.	methods (destigmatisation	Implementation of
	Mental hygiene, c. Coping with	etc.), also of importance	innovative methods
Also high	loneliness d. living & housing.	because of budgeting &	(client oriented) will
uncertainty about	-Create 'Toolkits'	program evaluation;	take longer than is
perspective after	-Cooperation with agency for		now planned.
2014, frustrates	'sheltered work & living' should	-Lack of meeting places;	
professionals.	be improved.	lack of long time vision on	-Professionals & users
		work development; Lack	are eager to start new
-Main concern about	-Hesitation about middle and top	of plans & money	participating
users' destinies &	management input: estimated as		programs, communal
own living.	'not-long-term' oriented.	-Introduce trainings	& national policy
		'Coping with loneliness';	makers need a lot of
-Certain degree of	-Among profs 'super stars', they		time to decentralise
immunization for	claim more autonomy and work	-Work 'Recovery' inspired;	and make proper
political bla bla bla!	relatively unorthodox.		plans and divide
		-Decentralise	money -> gives
	-Create pools of volunteers/	competencies of	frustration
	active citizens that operate on	professionals and create a	
	project basis;	more integrated offer	
		from agencies responsible	
	-Lot of trainings organised;	for treatment, housing,	
		social services etc.	
	-Use active citizens more as Para		
	professionals.	-Be patient and take time	
		to introduce new	
	-Client directed methods	approaches, it will take	
	('Nieuwe stijl' etc.) have the	years!	
	future.		
	-Databank for 'best practices';		

Summarised, professionals, active citizens in the projects as well as users were at the time of data collecting not able to react on concrete and specified plans and approaches, but reacted on more or less incomplete information of national and local policy makers. One of the spare and most concrete propositions in the autumn of 2013 was that the announcement that the year 2014 was a year that financing could be secured, but from 2015 on no financial commitments could be guaranteed. In this 'existential' atmosphere quite a number of the reactions of interviewees and questioned participants may have been coloured a bit defensive, even negative. At the same time only very few time is scheduled to specify and implement new approaches in which more participation and self-regulation are the main goals. Demotivation of professionals and users is a realistic option.

'Synergy & Empowerment' (S&E) projects by various agencies under coordination by Outsider Art 'Gallery Flow'

Description (and development) of samples of S&E projects

During the five years that the S&E projects have started about 75 patients/clients have visited our centre 'Gallery Flow', a small 'outsider art' gallery in one of the suburbs near the centre of Maastricht, capital of the province of Limburg (Netherlands).

In these 5 years about 40 users/ entrepreneurs have participated in 'outsider art' activities as creators (painters, ceramists, poets etc.). Most of them have been involved in expositions and vernissages in Gallery Flow. About 15 'creators' are relatively successful in creating an own lifestyle in which making art has a prominent -and for them satisfying and meaningful- place. None of them at this moment can fully live from the earnings of making art. Ten of them, however, have hired together independently an own atelier and sell every now and then art pieces to the public. Two of these 10 consider hiring an own atelier. Relatively speaking they are also the most successful creators of that group. A major problem is that most of the creators are dependent on Social Service allowances and every 'honestly earned dime' has to be adjusted in line with Social Service fees.

Apart from these 40 patient-creators about 35 (former) patients/ clients were not skilled art creators, but were interested in developing own individual qualities that could be used in entrepreneurial activities. They mostly are friends of peers from the creators, who had an entrepreneurial interest in earning a dime and so obtaining important assets as friends, respect and a regular life style. The activities they are involved in imply bike repair, removals, (urban) gardening, running a dog coiffeur facility, housekeeping activities for paying clients, running coffee shops and organising little festivals, expositions etc. The division of the 35 clients is tentatively as follows: 1/3 is more or less successful in doing 'entrepreneurial' projects during more than half of the year, 1/3 is ambivalent, i.e. more successful periods are followed by less successful periods and 1/3 is not able to involve in regular projects and show relatively severe relapses.

The analyses in this study have been based on participating observations and field observation and unstructured interviews and give an impressionistic, mostly qualitative kind of findings and results.

The originally planned focus group in this project has been cancelled. The reason here was that most of the participants took part —shorter or longer- within a time span of 5 years. Their frames of reference were too scattered to create a homogeneously enough common base of experience and reflection.

Results concretised in a hypothetical sequential plan of recovery of entrepreneurial involvement based on unstructured interviews and field observations

Synergy & 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 (see, for example, Kwekkeboom, 2008; Van Regenmortel, 2009, 2012; Van Weeghel, 2010; and J.P. Wilken & T. Dankers, 2010 for further details).

In S&E projects, we focus on the three participating groups within which the expected synergy and empowerment interchange will take place.

- 1 The first target group, usually patients, clients with mental problems, or people with any form of physical or social and/or cultural vulnerability. For the time being, we shall primarily focus and select people in the target group who are evidently sufficiently capable of recovery and who, because of their relative positive development and competences. They can lead reasonably easy to independent and enterprising lives. We call these people 'users' or because of our intention and invitation to enrol them in entrepreneurial processes as 'entrepreneurs'. The people in this group are further on referred to as 'Es' for short.
- 2 The professionals: In most cases, these are experts with practical and specialised experience. They work for care and welfare institutions. A minority consists of workers with an own MH experience expertise as patient. The whole group of professionals may vary from current and former user group members who managed to recover to some degree unto social workers, nurses and psychologists and psychiatrists. These people are referred to below as 'Ps'.

In this respect, a discussion is going on about the distinction between having personally experienced mental health problems and being a trained expert with practical experience. Useful information regarding this topic has been given among others by Annette Plooij (2012) and Nicole van Erp et al. (2011). Incidentally, it is a well-known fact that so-called 'para- or proto professionals' (experienced laymen with self-taught expertise) can sometimes provide better support for people with mental disabilities than genuine professionals. The latter often provide too much assistance; tend to have a greater distance to users, which leads to an increase in the 'learned helplessness' referred to elsewhere (Seligmann, 1975).

3 The third group consists of volunteers, local active citizens and residents, retired and semi-retired pensioners and active members of society, unemployed volunteers, etc. These people contribute in one way or another to S&E projects and are referred to below as 'Vs'. Their involvement with users and entrepreneurs reduces their loneliness and isolation and enriches them with personal inspiration and fulfilment. Sharing their competencies with other people can help target group members to acquire professional or life-focused competencies.

Results from the participant and field observations as well as unstructured interviews
In the tables below we will summarize the results of the interviews with –where possible-additional impressions of the questionnaires and field observations. The status of the information given is primarily directed on exploring the atmosphere and possibilities of the projects and its participants. In the knowledge-development we dwell in one of the first empirical loops, mainly consisting of peer experience and plausible professional findings. These loops in time may give input on more specified concept and theory building and possible resultant (quasi) experimental designs (Bryman, 2004)¹³.

In the table below we will firstly present impressions and findings from users, secondly from active citizens, mostly working on voluntary basis and thirdly from the perspective of professionals. For the three groups of participants we'll make a distinction in phenomena found on micro, meso- or macro level as was described earlier forthcoming from Bronfenbrenner's Ecology Model.

¹³ Bryman A., Social Research Methods, 2nd Edition, Oxford University Press, Oxford New York, 2004, ISBN-019-926446-5.

Improving community support and participation of persons with disabilities - Results per city

Impressionistic results from USERS/ Entrepreneurs in 'Synergy & Empowerment' projects in Gallery Flow and related agencies. (Based on unstructured interviews, participant and field observations)

Micro	Meso	Macro	General Remarks
-Profile target group: Age	-SES is widely scattered	-Project coaching is not	-Projects illustrate
range from thirties until		knitted to fixed locations.	ways of motivating
early seventies, modus in	-Most are reasonably	Project activities often	patients/ clients with
forties; balancing in	satisfied with housing, work,	are.	considerable rest
between chronic existential	leisure time conditions		competencies
socio economic challenges	(upper) lower class)	-Image of projects in	('Entrepreneurs').
& MH vulnerabilities.		society and social	First results show
	-Participants are relatively	surrounds is expected to	that it may take 1 tot
-Most do voluntary work;	well functioning in reso- en	be relatively positive.	more than 3 yrs.
aspire experienced paid	rehab-programs. They easily		before some first
work assignment; Eager to	slip in acquisitive procedures.	-Steady exploring &	successes can be
develop own competencies		concentration on local	observed. Relapses
	-SWOT analyses of E's,	and regional initiatives.	(of motivational,
-Recovery oriented, but	business plan development,		psychosocial or
also alert with respect to	& long term planning is	-These seem to be	psychiatric nature)
individual vulnerabilities.	standard in peer groups but	attractive and become	are frequent.
	painstaking with cyclic	successful and sources for	
-Perspective on life is	relapses.	new initiatives & projects.	-Peer contact as
dependent on situational			basis for relapse
mental state, mostly with	-Elaborate evaluation is,	-Intensive 'compliant'	programs
positive tendencies that	because of small number of	coaching in the beginning	
become stronger during	projects, not possible yet! It	is necessary, esp. directed	-Projects are mostly
the project.	will take more time.	on local and national	defined as 'exiting'
		initiatives. Needs:	and give a positive
-Project facilities should be	-Urban gardening and art	schooling & training (not	image to the
seen as 'situational	atelier and a number of small	yet developed	participants in their
opportunity.	projects however are stable.	systematically)	peer environment.
	First 'Sputnik'-projects.		
Entrepreneurs are (self-)			-Entrepreneurs and
selected on criteria of			volunteers aim at
entrepreneurial ambitions			nihil budget, except
(a.o. autonomous			from social
functioning), functional			allowances, only the
competences during a 2/3-			earned money is
yr-taking incubator phase.			available
Relapse is part of peer			
monitoring and			Total trajectory
competence of			takes 1 to 3 yrs
professionals.			

Impressionistic results from ACTIVE CITIZENS/ VOLUNTEERS in 'Synergy & Empowerment' projects in Gallery Flow and related agencies. (Based on unstructured interviews, participant and field observations)

Micro	Meso	Macro	General Remarks
-Profile target group: Age	-Often have to combat	-At this moment only few	-Active citizenship
range: predominantly	bureaucratic	information in	(workless alumni,
youngsters between 25 to 40	institutions (Social	neighbourhoods about	workless
yrs or oldies: 50+ yrs, often	Service, Insurances	active/ civil citizenship.	professionals, (pre-)
with (semi-) professional social	etc.)	·	pensioners) may
work background or other		-Old institutions as 'gilds',	create a 'fifth
professional background	-Mean participation	rotaries etc. need new input	column'
(alumni's from college, (pre)	time of Citizens is		
pensioners, professional	about 2 to 4 yrs; After	-Cynicism towards policy &	-More volunteers
craftsmen, chronically ill):	that partner or	politicians ambitions ->	needed, how to
'Characters/ Originals',	profession wants to	creates barriers, that have	attract them? Kind
resilient!	have its share.	to be broken down.	of 'Rotary'-systems?
'stand alones', 'loner with a			Facilities for training
cause'	-Struggle between	-Tend not to embark on	& schooling?
	professionals and	nationwide 'hysteria'	
-Looking for meaningful	Volunteers/ Active	(regarding policy change).	-Introduction of
existence, not for income. Love	citizens about		more immaterial
freedom and independency	competencies needs	-"2015 is the year we hear	value systems
	clear procedures.	the super tanker to crash	instead of material
Irritated by stigmatisation in	·	the coast!" -> "Alienation	ones.
district, Island culture	-Hardly any regular &	lingers around", needs	
	work related	realistic plans and patience	
Acquisition and participation of	communication	to make them work.	
volunteers has recently started;	between active citizens		
double or threefold occupation	yet.	-Volunteers as well as	
of schedules with other peers		Entrepreneurs see S&E	
reduces drop out.		projects as investment in	
		mankind, meaningful work	
Volunteers aspire meaningful		and possibility to prevent	
work, being part of group and		own isolation.	
some moral prestige (a bit like			
'rotary' experience).		-Alternative to lack of	
		regular work and old age	
-'Rotaries' still have to start up.		isolation. A possibility of	
Evaluation incomplete, but first		mixed firms of care & cure	
results seem promising.		professionals, together with	
		Entrepreneurs, seems a	
		guarantee for a fulfilled old	
		age, social inclusion.	
		Strongly ideology driven!	

Impressionistic results from PROFESSIONALS in 'Synergy & Empowerment' projects in Gallery Flow and related agencies. (Based on unstructured interviews, participant and field observations)

Micro	Meso	Macro	General Remarks
-Profile target group:	-Important issues: a. Finances,	-Meeting places can be	-Intense cooperation
Professionals mostly	b. Mental hygiene, c. Coping	erected at home or in	with (F)ACT, social
recruited from ranks of	with loneliness d. living &	places with business	psychiatric
active citizens; Age	housing.	activities	approaches, programs
range 50 ⁺ yrs.			like 'HERSTEL" &
	-Create 'Rotaries' or	-Introduce trainings	'ECHT' etc.
-Highly motivated and	'Brotherhoods'	'Coping with loneliness';	
very creative profs.			-Overall picture
Meaningfulness and	-Hesitation about middle and	-Work 'Recovery' inspired;	organisational and
sustainability are	top management input:		financial will have to
important drives;	estimated as 'not-long-term'	-Be patient and take time	be raised in own
resilient.	oriented. One is not going to	to introduce new	initiatives. Main
	wait for improvement in 'S&E'	approaches, it will take	financial guarantees
-Also high uncertainty	programs!	years!	are the allowances,
about perspective after			pensions etc. from
2014, but because of	-Among profs 'stand-alone-	-A lot of S & E work is seen	professionals and
their lower dependency	combat-units', they claim	by active 'citizens and	active citizens.
on external budgets is	more autonomy and work	entrepreneurs' as an	
this less a problem.	relatively unorthodox.	alternative to existing Cure	-Implementation of
		and Care programs.	innovative methods
-Main concern about	-Create pools of volunteers/		(client oriented) will
users' destinies & own	active citizens that operate on	-Professionals often had a	take longer than is
living.	project basis;	work history in one of the	now planned,
		existing care or cure	hindrance of national
-Certain degree of	-Lot of trainings to be	agencies but bumped into	policy echelons.
immunity for political	organised;	agency bureaucracy or –in	
bla bla bla!		their perspective- not	
	-Use active citizens more as	client directed working	
-Objectively speaking:	Para professionals.	programs. Their credo:	
weak proposition: all		better earning a bit less	
work for the	-Client directed methods	money, but more on your	
meaningfulness &	('Nieuwe stijl' etc.) have the	own terms (autonomy).	
sustainability, 'honour'	future. 'S&E' may give some	Unclear how this will work	
& 'prestige', hardly any	answers.	out, but it may become a	
funding or		manifest alternative	
organisational	-Databank for 'best practices'	movement.	
resources. But also:			
anarchistic tendency.			
Takes some time to let			
citizens/ volunteers get			
acquainted with the			
immaterial incentives of			
this work.			

Summarised, professionals, active citizens in the projects as well as users were at the time of data collecting not able to react on concrete and specified plans and approaches, but reacted on more or less complete information of national distributors of ideas. One of the spare and most concrete propositions in the autumn of 2013 was that the announcement that the year 2014 was a year that financing could be secured, but from 2015 on no financial commitments could be guaranteed.

In the 'district oriented programs' (see earlier) participants, professionals and volunteers tend to wait until a further specification of 'participation oriented' plans will be given from communities and national authorities. In the 'S&E' projects one tends to start more entrepreneurial projects, in which the main security consists of (social) allowances, pensions the people concerned may enjoy anyhow. In a lot of cases these incomes are (very) meagre. Getting permission to earn some small income for entrepreneurs, without instant loss of possible Social Service allowance takes a lot of the bureaucratic energy.

The projects have been developed in the last four years. Not much can be said about long-term effects at this point. At this moment the (social-) economic crises in many countries do create growing numbers of workless people at relatively young ages. Also the 'baby-boomer' generation reaches its pensioned age period. So, a quite an large number of citizens of these origins do join the ranks and deliver a substantial potential of working force in the categories 'professionals', active citizens and volunteers as well as possible entrepreneurs. Making sure that these people will be able to participate in meaningful and sustainable activities gives a double benefit.

8.4 Tallinn

(report by: Marju Medar PhD and colleagues)

8.4.1 Effective components of community support programs

The effective components of community support programs have been analysed on three levels:

- 1. Level of service users and professionals
- 2. Level of network of organisations
- 3. Level of policy and policy makers.

1. Level of service users and professionals

With regard to effective components at the level of service users and professionals, the study emphasises several good working practices.

According to the opinion of clients and specialists the necessary supportive *social services* are effective if these are *available for the service users, close to the community and non-labelling by their nature*. The services are provided in the efficient cooperation of support specialists, in a systematic way and they are safe.

In supporting the clients it is important to notice the problems in time, associate the services with the needs of the client and to support possibilities of the community. Here it can be mentioned as a positive experience that if a doctor notice signs related to mental disorder and assists the person in getting assistance from the support system, then clients do not get into difficult situations from which it is impossible to exit. In putting together the services (incl. housing, children day care and other services) the skilful "placing together" of service providers and service users is important as it enables to release tensions. Positive experiences are those where the official, e.g. social worker in local government, listens to the service user and understands the living situation of the person (e.g. housing problems, small income, increased expenses on medicines, health problems, tensions in relations, difficulties in finding suitable work, etc., or the combination of the aforementioned problems) and is able to take all the problematic situations and aspects into account when solving the case.

Strengths-based approach is very important in the work with clients with mental special needs that is based on the strengths of clients, acknowledging also the limitations. Both clients and specialists stated that when the noticing and taking into account the strengths is put into practice then this supports the finding of wright solutions for the client and the recovery process. The aforementioned basic approach is supported by different support programs that help to cope with limitations stemming from mental disorders, taking at the same time into account the objectives and wishes of the service user. Through the step-by-step support for the independence, engaging in hobby activities (strengths) and for inclusion of the service user, the independence of the client increases and the recovery process is more efficient.

Both clients and specialists emphasise the work of *activities supervisor* as a key professional specialist supporting the recovery of service user. The activities supervisor creates a bridge with necessary services, specialists; helps the service user to cope as independently as possible in the community, "keeps the door open" to society (does not create the classical specialist-client distance relationship). The client experiences trust, security and possibilities towards the activities supervisor. However, using the professional title "activities supervisor" creates some confusion. The study showed that support person would be a more precise name for the work of activities supervisor in the work with clients with special needs. According to clients cooperation with those activities supervisors runs smoothly who are very honest and at the same time caring towards the service user. Good relationship is the basis for long-term cooperation with activities supervisor and enables the client to be better informed and included into the community (for example helps to find possibilities for visiting cultural events free of charge). In the centre of the work of activities supervisors is the development of people's own resources (incl necessary living skills) so that the service user could lead his/her life as independently as possible.

Both clients and specialists value the work of *peer-counsellors*; this counselling is considered trustworthy and necessary experience for the recovery of clients. The work of peer-counsellors is used in the Tallinn Mental Health Centre for supporting the clients and their relatives in the work of support groups of service users and their family members. Family members value cooperation when the specialists understand, do not blame, are trusting, share information and treat family members as cooperation partners.

Both clients and specialists emphasise the *cooperation of different specialists in a team* (for example in a psychiatry hospital primary doctor, psychiatric nurse, social worker as a team; in the Tallinn mental Health Centre the networking of activities supervisors with social workers in local governments, NGOs, the Chamber of Disabled People, police, psychiatric hospital nurses (on duty), ambulance, etc). If the cooperation of specialists in the team and networking are taking place, then clients are also able to receive more efficient help.

In terms of the need of development the clients and specialists emphasised that the *need for* real developmental activities (for example: involving volunteers to support service users in evenings and weekends) is seen, but this activity is not yet taking place in Estonia.

In Estonia there is a tendency that more and more children fall out of the basic school, incl children with Asperger syndrome, and people who have found a job are not able to keep it due to health-related reasons. This result in problems being not noticed in time and as a result of this a complicated situation emerges for the clients from which it is difficult to find a way out. There is therefore a *need for the training of teachers and employers* so that they would be able to notice the problems of people with mental special needs in time and help them to connect with the support system.

Also in case of specialists working with people with mental special needs, the study indicated the problem of *lack of specialists*, the need to *decrease the work load* of specialists and the *need to train* specialists, incl. in case of social and care workers, activities supervisors, support persons, etc. It was also pointed out that specialists from different fields could introduce to each other the specifics of each other's work in order to better support the clients, e.g. raising awareness of psychiatrists about social welfare and other support services and the possibilities of connecting people with them; the superficial nature how psychiatrists pass judgements and also that nurses can no longer specialize on psychiatry.

When providing services it is not possible today to take sufficiently into account the special needs of the client, although the course of recovery relies on this. For example housing services in which case people with mental special needs live together with persons with alcohol or drug addiction and at the same time families with coping difficulties live next door. This kind of mixes increases coping and recovery risks, and do not support recovery.

The study stated the *need to develop more effective measures for supporting the next-of-kin and family of the client*, incl. care services in case of crises, 24 h counselling by phone, etc. The relatives need training, counselling to support family members with mental disorders (incl. supporting them to become more independent) and to strengthen their family ties.

Training needs

At the level of service users and professionals the study pointed out several necessary suggestions and topics for training:

- It is necessary to raise through trainings the awareness of psychiatrists, ambulance workers, police, psychiatric nurses and teachers about networking, cooperation with social welfare system, early noticing and connecting with the support system;
- It is necessary to raise through trainings the *awareness* of clients and next-of-kin *about ways* of support, rights and duties of clients (in the area of social insurance, social welfare; in health care and education, etc.) and about the so called *orientation in the system*;
- When training the specialists working with service users (social workers of local governments, activities supervisors, support persons, care workers, etc.) it is necessary to raise their awareness about *strengths-based approach*, *taking into account the personal objectives of service users and supporting the participation and inclusion of clients*;
- Both in the main education and executive training of specialists and in developing the
 documents of the area it is necessary to raise the awareness about UN, WHO
 recommendations, concepts, documents and values;
 - The clients need the support of volunteers and it is therefore necessary to increase the training and mentoring of volunteer support persons;
 - It is necessary to carry out executive *training for the specialists of Unemployment office* (Töötukassa) in order to raise the capability of these specialists to work with persons with mental disorder and provide support for them;

- The *training* and constant *mentoring of employers* is also important in order for the persons with mental disorder to be hired and their working to be supported;
- It is also necessary to *train specialists working with people with special needs* about specific themes that could accompany a mental disorder (Asperger syndrome, autism, elderly 65+ with dementia, service users with addiction problems, etc.), incl on the topics of worker safety and protection of personal data (how to exchange necessary information) so that the safety of clients and specialists is guaranteed;
- The specialists mentioned in the study acknowledge the need for training of specialists in rehabilitation teams. The proposal of case manager of Social Insurance Board is that training is necessary about the topics of preparing rehabilitation plans for persons with mental disorder as well as providing services (currently there are mistakes/ shortcomings in a lot of rehabilitation plans that are an obstacle for receiving the necessary special care services). At the same time the specialists are in need of specialised knowledge for coping with clients placed in special care institutions (incl. clients who are aggressive, have addiction problems, autism, Asperger syndrome) as specialists are currently lacking necessary knowledge and skills for that.
- Psychiatrists need to be trained in connection with making assessments and writing certificates. At the moment these are written with different degrees of detail and this could prevent the use of necessary services (proposal of case manager of Social Insurance Board).

The next-of-kin of service users with mental disorder made the following suggestions for executive training:

- o In training it is necessary to *pay attention to the development of trust-based relationships* of activities supervisors and support persons with persons with mental disorder and their families to support the greater independence of clients in cooperation with each other;
- The activities supervisors should be trained to organise coping education for persons with mental disorder in order to contribute to increased independence of clients, e.g. managing with money, taking into account the community, healthy way of life, etc.
- o Parents and next-of-kin should be trained how to *support becoming independent safely* taking into account the specifics of the mental disorder (e.g. with what the child / next-of-kin can manipulate with), what are the methods of effective support that do not harm or limit becoming more independent, etc.

2. Level of network of organisations

At the level of the organisational network the study reveals good working practices, but also areas in need for development.

The study stated some *positive examples of progressive services* in which case it is possible for the client to move forward on service-to-service bases and organisations cooperate with each

other. For example success stories where the client has been in the beginning in the support home, then moved from there to group home and then to independent social living space. As an example of good practice the clients mention the work of Tallinn Mental Health Centre, where it is possible to move between different support services. The service providers and service administrators have good experiences of service provision also in case of the activities of Camphill village (the service of living and working in a community).

The clients mentioned in the study as a positive aspect the work practice of activities supervisors, in which case there is *effective exchange of information* with psychiatrist and local government and next-of-kin of service users. In cooperation with district administrations of Tallinn city it is possible to direct service users to use the service of a support person, but there is a further need for specific executive training and for its funding preparing for work with service users with mental disorders. The training would offer employers the knowledge how to take into account the strengths and needs of clients. The specialists who participated in the study consider the level of cooperation between service providers in the area of social welfare to be good.

In terms of needs for development the clients and specialists we conclude that the need for practical development activities is seen, but currently it is not yet taking place:

Despite the fact that some specialists consider the level of information exchange and cooperation between institutions to be good, according to others this still needs to become more efficient, e.g. at times in the cooperation of activities supervisors with local governments, doctors and Töötukassa (Unemployment office) the *exchange of information is limited* and the client perceives the ignorance of uninformed specialist as lack of will or competence.

In the area of organisational cooperation the developmental needs are as follows: greater efficiency in terms of early noticing and intervening, developing the cooperation between specialists in the areas of health care, education and social welfare and creating in their cooperation greater trust and improving the accessibility to services so that extreme interventions would not be used (forceful hospitalising with police and ambulance) and that cooperation would not depend only on cooperation relationships created between specialists on personal level (e.g. special agreements of activities supervisors with psychiatrists, psychiatric hospitals, police, ambulance, etc). It is important to increase the efficiency of information exchange, e.g. for the provider of housing service to be aware of the specifics and needs of the client that receives the service (e.g. addiction problems, etc).

The next-of-kin of service users feel the need to increase the efficiency of cooperation between ambulance and police, e.g. in case there is a call to take the client to a psychiatric hospital. It is important that the service user (especially if it is the first time the person has fallen ill) does not suffer from trauma in the helping process, that intervention is carried out at professional level and next-of-kin and/or activities supervisor is trusted. The person with mental disorder can temporarily calm down for the time the ambulance and police arrives, but the reason for making

the call was a health problem. The study showed that clients have experienced excessive use of force by the police during the intervention.

The specialists emphasised in the study that there is a need for implementing the plan of risk assessment and management. It has been developed by Tallinn Mental Health Centre as a pilot project, but it would be necessary to find finances for the training of specialists and for the implementation of the plan. The follow up project proposals for such kind of funding submitted by the Tallinn Mental Health Centre have not been granted so far.

The cooperation with entrepreneurs and employers needs to become more efficient. The employers are expected to provide flexible working modes (incl. part-time work) for persons with mental disorders (but the activities to create part-time work places is not supported by juridical framework in Estonia). As a good example here would be connecting people studying at the Astangu Vocational Rehabilitation Centre with employers already during the study period in which case the employer is informed and supported. The study clearly indicated both in terms of clients and specialists the mismatch of services provided by the Unemployment office with the needs of clients and employers and the need for the training and supporting of employers in order to raise their awareness in case of hiring people with mental disorders, providing support for them and also offering flexible modes of work. The limited nature and lack of flexibility of the retraining system was pointed out as a problematic area.

The clients and specialists emphasised in the study as a problem the availability of services and lack of connecting services. For example part of necessary services are totally lacking; e.g. in case the service user with mental disorder has alcohol and/or drug addiction, Asperger syndrome, autism, or in case the age of the client is 65+, then the possibility of home visits by psychiatrist or psychiatric nurse is absent in Estonia. At the same time this is necessary, especially if the client is not acknowledging the problems. A wider problem is the limited nature of progressive and flexible services, i.e. transferring from one service to another. A problem here is mainly the need for services with different characteristics (unstandardized services) that would be meant for people with varying degrees of needs of support. The problem is lack of public services (incl. availability of social housing options). When a person is left without help when moving from one service to another then there is a danger that those who have recovered fall back. The current situation in Estonia is in general that old clients often return because there is a lack of further services that would support the healing process based on the previous ones. It is necessary to find flexible solutions in terms of services (e.g. in rural areas, specifics of services according to the needs of clients).

The specialists proposed *the establishment of a competence centre*, where rehabilitation teams counsel next-of-kin, service providers and different specialists.

Training needs

At the level of organisational network the study brought also out several suggestions for the training of specialists:

- The specialists find it necessary that explanatory work is carried out in terms of implementing the *requirements of personal data protection* so that the necessary exchange of information is possible in the interests of the service user and their next-of-kin (e.g. from the psychiatrist to the next-of-kin of service user, etc.);
- It is necessary to raise the awareness of managers of organisations in terms of developing and making more efficient the progressive and integrated characteristics of services in order to better develop a network supporting the clients;
- The specialists expect the training about implementing piloted risk management plans;
- The specialists stated in the study the need for inter-disciplinary trainings, incl. care workers of special care homes and social houses, support persons (in local governments), providers of support services for every-day life (in day centres), specialists of Unemployment office (Töötukassa), employers and entrepreneurs, families and next-of-kin, employees in the education system (especially in the area of basic and vocational education), medical workers, police, ambulance, workers of rehabilitation teams, etc, so that specialists would see the benefits and possibilities of mutual cooperation. These trainings should be carried out on the topics of increasing the efficiency of *networking and cooperation* in an inter-disciplinary manner (institutions in the area of social welfare, health care, labour market, education);
- In terms of case management of local government the service providers see *the need for executive training of social workers in local governments* in order to develop their knowledge and skills for the inclusion of stakeholders, for networking, and for developing and implementing an efficient plan of intervention for persons with mental disorder.

3. Level of policy and policy makers

At the policy level the study emphasised good working practices, but also areas in need for development.

As a good example the cooperation between some local governments in the administration of services in rural areas was pointed out (but in general in rural areas the lack of services is more significant problem than in cities). The specialists also value that the training of specialists (main education at higher education institutions) corresponds to the practical needs and prepares them for cooperation with different areas (e.g. new generation of doctors, nurses, social workers, etc, see the need and possibilities for cooperation).

In terms of needs for development the clients and specialists emphasised that the need for practical development activities is seen, but currently it is not yet taking place.

The problem in Estonia is the absence of a national basic document of mental health policy (its development has been already initiated) and joint housing policy in Tallinn and little cooperation between local governments and specialists in the social fields in terms of planning the services.

For example there is a need for town/rural parish property department to plan in cooperation with specialists in the social field more social housing spaces as there is a need for small and affordable housing.

The specialists see the need for *practical executive training*, in which case there would be no waiting lists and which would be state-funded, e.g. state funds the executive training of activities supervisors, but the waiting list is long, the institution is not able to afford organising its own training as the budget for executive training is very small. As part of the main education of specialists psychiatric nurses are not trained any more, but the specialists in this area see the need for continuing this kind of training. In case of the main and executive education of specialists as well as the preparation of documents related to the field *it is necessary to raise awareness of UN, WHO recommendations, concepts, documents and values.* At the moment these topics are almost absent from trainings. The service users and their next-of-kin emphasise the *need for training of employees in the education system* so that specialists would be able to notice problems related to mental disorders, be more supportive and that flexible ways of acquiring education would be developed in the education system. In the absence of this the educational path of a young person falling ill for the first time during the studies in basic, secondary or vocational school could easily disrupt.

It is positive that there are in Estonia five state-funded special care services, but often the necessary special care services are not accessible enough, i.e. they are not provided in rural areas, the spectre amount of services is small and different services are not integrated. The service providers experience in the work with persons with mental disorders the "pushing" of clients and responsibility from the area of administrative responsibility of local governments to the state level, as often the resources of local governments are limited. Therefore the access to necessary services is uneven in local governments and depends on the capability, resources and priorities of local government (e.g. the possibilities of Tallinn or some small rural parish for service provision differ considerably). The developers of services for people with mental disorders (in case of both national special care services and services administered by local governments) do not take sufficiently into account the needs of the clients, and the stakeholders (service users, their next-of-kin, specialists related to services) are not enough included into the planning process. Therefore, the person with mental disorder is often adjusted to fit the existing system (and the system is not adjusted to meet the needs of the person). The system of special care services should enable the provision of specific special care services, e.g. for persons with addiction problems (incl. alcohol), Asperger syndrome, autism, elderly with mental disorders over 65-years-old suffering from dementia. The specialists mentioned that when developing services the specifics of service users should be taken more into account, e.g. varying activities in case of support service for organising every-day life according to the level of education as these services are provided to people who have basic education or multiple higher educations, different interests and strengths and a service system provided on the same principles is not fit for all of them.

It is necessary to move towards more flexible, combined and integrated provision of national and local government services that would enable to save both the resources of clients and local governments. At the moment there are obstacles in using simultaneously and in a combined manner the national and local government services. As a problem related to the accessibility of special care services excessive bureaucracy, long waiting lists (especially in case of special care services, incl. 24-hour special care and housing services), complicated nature of paper-work and lack of clarity among clients and specialists was pointed out. Problematic is also lack of integration between welfare and health care services as a result of which there are in institutions providing welfare services for people with special needs big difficulties in terms of availability of health care services (intervention of ambulance e.g. in case of clients not following the agreed treatment scheme).

The measures supporting the coping of family and next-of-kin are more as single positive cases and in reality there is a need for the counselling and training of relatives, work of support groups, developing family care and monetary benefits. The next-of-kin of clients feel the need for support programs that would provide persons with mental disorders and their family members the security and clarity in terms of future (e.g. when parents pass away). The lack of knowing and security that is present today creates tensions and worries. Both specialists and clients see the need for developing the support system of voluntary support persons, e.g. so that the service user could go safely with the volunteer to the cinema, concert, etc.

The specialists emphasised in the study the need for developing different measures in order to decrease the poverty risk and labelling / stigmatization of people with mental disorders (income is very small, salaries tend to be small, unemployment benefit and disability benefits are small) and support their participation, involvement and integration to the community.

At the client level it is necessary to do more efficient work related to explaining the requirements of *personal data protection* in the society so that the exchange of important information (e.g. from psychiatrist to the next-of-kin of service users, etc.) would not stop because of misunderstandings. There is a *need to develop support measures for clients with mental disorders who do not acknowledge their problems* so that people would not be left out of the health care and welfare system (incl. social insurance and benefits). Both specialists and clients have high expectations in terms of cooperation (incl. in terms of case management), but these do not materialise in practice (incl. *the need to increase the efficiency of case management*). Good solutions developed in the framework of pilot projects are often not implemented due to legislative gaps or lack of funding (e.g. risk management plans for persons with mental disorders). In the health care system it is considered necessary to foresee the need for funding the home visits of psychiatrist or psychiatric nurses.

The training needs of professionals for developing effective community support programs in the area of social work and mental health and for supporting persons and their groups

For knowledge development it is firstly necessary to create an executive training system that corresponds to the practical needs of specialists, is available and of high-quality for specialists

working with service users with mental disorders and their next-of-kin. The study states that at the moment the availability of executive training for specialists is limited and uneven and depends on the resources and priorities of the institution. At the same time the existence of specialists with necessary knowledge and skills is the precondition for providing high-quality and efficient services.

Training needs

On the policy level the study indicated also several training needs:

- The training of decision makers, how to plan and develop services (incl. the funding and choice of services, etc.) in cooperation with network partners consisting of service users, their next-of-kin and specialists working with them. It is necessary to raise through trainings the awareness of policy makers in terms of developing and financing support mechanisms since otherwise the danger of "loosing people" will develop in communities. The trainings have to focus on the development of support systems and should contain topics about "filling" legislative gaps, developing the progressive side of services, decreasing bureaucracy, developing funding and education system in connection with services;
- The local governments (especially in rural areas) should be trained in terms of *raising the efficiency of cooperation* across the boundaries of local governments when providing services for persons with mental disorder and their next-of-kin;
- Also specialists administrating the home visits of psychiatrists and psychiatric nurses in health care system (if organising home visits would become possible) require training.

8.4.2 UN Convention on the Rights of Persons with Disabilities

How is it possible to "translate" and implement into local politics the European Disability Strategy and the UN Convention on the Rights of Persons with Disabilities? And how is it possible to improve the position of people with disabilities in local communities?

The first step has to be to raise the awareness about the importance:

- Raising the awareness of the people with special needs and their family members about the principles of the convention; working on empowerment.
- Distributing information materials to the associations of disabled people; inclusion in the process of mapping the needs of disabled people and developing services.
- Raising the awareness of specialists working with disabled people (social workers, activity supervisors, providers of different services) about the principles of the convention – both with written information materials and in seminars, work-related meetings, supervision or in other events.

- Taking information and needs to the local level policy makers (managers of institutions, agencies, etc.).
- Enhancing cooperation between different levels (associations, policy makers, university).

Discussing the topics related to the convention in the specialty-related trainings of social and child protection workers and rehabilitation specialists (incl. planning and developing studies) and in executive trainings (e.g. activity supervisors, support persons).

9. Intended dissemination of results (publications, educational materials)

9.1 Amersfoort

(report by: Leo Admiraal MSw)

As said before we worked with study groups and a CoP of professionals. These are methods where research and dissemination of knowledge come together. Facilitators coaching these groups and CoP bring in theoretical knowledge; researchers bring in analyses on the basis of quantitative and qualitative data. This knowledge enables the professionals to improve their methods. The professionals disseminate this knowledge in their own organizations to their colleagues.

A website was started where everyone can find a lot of information about the project (not only Amersfoort, but also the three other cities of the project).

We intend to write articles for Dutch magazines for professionals in care and welfare. The topic will be the role of the professionals to use the UN Convention as an instrument to support clients with regard to the rights they have.

Also we have developed, and are developing, some educational materials. One module is about social isolation and social participation (A module which can be chosen by Social Work students. Every year 30 students attend this program). Also we developed two modules about the UN Convention.

In November 2013 we gave a workshop during a national conference about empowerment of clients with intellectual disabilities. A group of 25 professionals and teachers from Universities from all over the Netherlands attended the workshop.

We will organize a conference in Amersfoort in June 2014. HU-researchers and social professionals engaged in the project collaborate in the organization. The goal of the conference is to engage the social work professionals of Amersfoort with Community Support. A lot of results of the project will be presented; issues will be discussed during workshops.

9.2 Budapest

(report by: Zsolt Bugarszki PhD)

During the project implementation we shared our preliminary results at the following places:

- International Conference of the IASSW in Istanbul, Turkey (2013 April)
- International Conference of the Ljubljana University in Ljubljana, Slovenia (2013 July)
- Mental Health Day, Tallinn, Estonia (2013. October)
- Social Work Day, Tallinn University, Tallinn, Estonia (2013. November)

A publication was published in the largest Hungarian journal on Social Policy called ESÉLY about the Recovery model of Mental Health problems. In this article there was a reference to our research programme.

In 2014 we are planning to publish more publications and conference presentations about our research.

Planned publications:

- United Nation Convention on the Rights of Disabled Persons Gábor Gombos in cooperation with Dutch and Estonian colleagues. (title and journal to be clarified later)
- Community support Lucia Csabai in cooperation with Dutch and Estonian colleagues (title and journal to be clarified later)
- Resilience, effectiveness and community development Katalin Tausz and Zsuzsa Kondor. Hungarian publication (title and journal to be clarified later)
- Language and Identity Zsolt Bugarszki in cooperation with Dagmar Narusson (title and journal to be clarified later)
- Community support and Community Care Zsolt Bugarszki, Katalin Tausz, Zsuzsa Kondor, Lucia Csabai, Hajnalka Sátor, Gábor Gombos, Anna Légmán ESÉLY Folyóirat (Hungarian publication to summarize the results of our research title to be clarified later)
- Publications will be inserted into the curriculum literature list of our Social Work and Social Policy Masters Program and the results will be presented in our courses.

9.3 Maastricht

(report by: Frans Leenders PhD)

The discussions that took place in the various phases of the study, the interim reports as well as the communication with users, professionals, active citizens and management of the agencies more or less accelerated the awareness around problems and solutions connected with issues of 'decentralisation' and 'participation'. The many presentations and reports found a fairly impressive welcome in a number of the project groups involved. In a way it raised the consciousness of all people participating and it may well be that this may raise the pressure on the policy making desks either to deliver specified programs or to give more space to the process of finding own solutions in the project groups.

The 'S&E'- projects follow another routing and are more based on private initiative. Nevertheless also in these projects acceleration in 'spreading messages and ideas' has taken place and will continue for sure the coming years. A number of the intermittent reports are meanwhile used in the communication with students that take part in the projects.

Parts of the final report and interim reports will be prepared for publication. One is planned for an internal journal, two or three for national journals for various types of profession.

9.4 Tallinn

(report by: Marju Medar PhD, Dagmar Narusson MA, Koidu Saia MA, Karin Hanga MA)

The project "Community Support for Persons with Disabilities" has provided bases for subsequent research activities in the area of mental health. The cooperation with the Tallinn Mental Health Centre that started during the project is continued in the framework of a new project "Entrepreneurial spirit as basis of social entrepreneurship in the area of social work and rehabilitation" (financed by Enterprise Estonia). The new planned project focuses on fostering social entrepreneurship of people with psychic special needs through the development of entrepreneurship education and cooperation with service providers. The activities of the project include developing rehabilitation methods for supporting and implementing community-based entrepreneurship of persons with psychic special needs in Estonia, developing in-service training curriculum in the area of community-based social entrepreneurship in the framework of "Open University" for institutions and specialists operating in the area of social work and rehabilitation in cooperation with the Tallinn Mental Health Centre and curriculum development based on the Institute of Social Work of TU bachelor and master program.

In the development of the curriculum the expert knowledge and experiences of international academics that participated in the RAAK project are used, incl. lecturer of social policy Zsolt Bugarszki from ELTE University (Hungary) and professor Jean-Pierre Wilken from Utrecht University (the Netherlands). Both of the aforementioned academics have agreed to contribute to the development of the direction of mental health at TU also during the academic year 2014/2015. With the assistance of experienced international expert academics the new social entrepreneurship courses directed at the rehabilitation of people with psychic special needs both at the bachelor and master level curricula will be developed in the Institute of Social Work of TU. The project will provide the support of the academics that participated in the TU RAAK project for the social entrepreneurship of persons with psychic special needs through counselling on social entrepreneurship, also through teaching students the contemporary rehabilitation methods and community-based social entrepreneurship in the framework of the developed courses.

In conclusion it can be said that RAAK project has provided the basis for developing the field of mental health both at the university and in the social work practice. The project has enabled to strengthen the provision of services for people with psychic special needs in Estonia and has provided the basis for developing a modern rehabilitation method based on social entrepreneurship for vulnerable groups in the community. The students of social work have been given the opportunity to become more aware of those methods, by having both knowledge as well as skills for innovative initiatives and by combining the ideas of entrepreneurship for effective rehabilitation.

9.5 CARe Europe

CARe Europe has a training programme which consists of a number of modules and workshops which are delivered on demand in any country of Europe and Central Asia. The knowledge generated by the project will be used in this programme.

10. Intended follow-up activities / sustainability aspects

10.1 Amersfoort

(report by: Leo Admiraal MSw)

We will continue a lot of activities started in the project in a follow-up project. All stakeholders in Amersfoort (municipality and care- and welfare organizations) agree that issues of Participation and Community Support are important and should be followed-up with the development of more interventions and implementation of these new methods. Recently 6 district teams started in Amersfoort. A lot of social professionals will do their job working in a district team. The district teams have to collaborate with other professionals (in the district and in care- and welfare organizations) and with voluntary initiatives in the district. HU University will support these district teams with research and education to improve their attitude and skills concerning community support. The main issue will be improvement of participation of clients in society with the use of the own strengths of clients, their social network and voluntary workers.

During this follow-up project the method of voluntary mediation for clients with intellectual disabilities will be introduced (to match them with a voluntary work). Also we are going to monitor clients who are successfully mediated. Main question is: how do they do on the job? What kind of support do they need?

10.2 Budapest

(report by: Zsolt Bugarszki PhD)

Being inspired by the research program a group of users and professionals started a new initiative in the Félsziget Clubhouse of the XIIth District of Budapest. The new user group intend to start recovery oriented activities, promoting peer-support and self-advocacy among users and professionals in Hungary.

10.3 Maastricht

(report by: Frans Leenders PhD)

The 'district oriented projects' and the 'S&E' projects will continue in the direction they already took. The first type of projects will focus on the deliverances coming from community and national level, but are also involved in creating own ideas and concepts in their projects. Along with the information gathered from the RAAK program this will give possibilities for a critical reflection on the program activities of the last few years.

The 'S&E" program is starting up and has not built up too much history. In a way it is easier than to change and develop new ways of working. On the other hand, the chosen paradigm of 'userautonomy' implies that material and financial resources have to be erected from the scratch.

For both type of programs the special and separate role of users/ clients, citizens (active, senior, fellow etc.) and professionals has been clarified once again. Certain changes in the respective profiles may be part of the efforts during the next five to ten years. One can think of

professionals who, more than they did before, concentrate on coordination and facilitator-type-of-work in their projects. Citizens/ volunteers may feel more responsible for their participation than they did before. If this may bring us to the brink of a society that is more oriented on non-materiel incentives than on material ones and reintroduces more of the responsibilities, as we knew them after WW2 is an interesting perspective. The developments on the economical level are of a great importance to this question. We think the RAAK project has been helpful to clarify a number of these 'paradigm' issues and made us more resilient to handle them.

Plans have been made to incorporate S&E projects and activities that will be set up in organisations to allow entrepreneurship and autonomous management to flourish optimally. In this way, organisational legal entities (foundations, limited companies, general partnerships, etc.) may be established as a successful result of the activities of one or more users/entrepreneurs, in the same way as other start-up business. This can also take the form of a self-employed person operating a company with or without additional personnel. If aspired, these small companies can join or form a group that offers a certain amount of support in acquiring and developing widely ranging business activities, such as expertise development, tax issues, quality management and certification, arranging group meetings, etc. This type of trade organisation is already existent for regular self-employed people working in the care sector, for example, for the existing client-linked budget (in Dutch: PGB) welfare and care organizations. A future model for integration and social cohesion could consist of a federation of self-employed people with a professional background and hands-on experience.

This model does not yet exist however. In the meantime, we should think about assigning the present care and welfare organizations (e.g. Trajekt and Mondriaan) an additional transitional role. As stated above, this means these organisations may have to adopt what is for them an 'almost unnatural' entrepreneurial attitude. This will require additional attention, as will detailing the successful conditions related to fulfilling the aforementioned transitional role.

S&E projects and activities have the following distinctive aspects:

- 1. Allowing the rediscovery and creation of favourable circumstances (catalysts) in order to motivate vulnerable patients/users to apply their autonomy and entrepreneurship. This can be done in projects and activities that are meaningful and economically interesting to them (e.g. to help them gain financial independence), such as small companies or service providers. S&E projects will start with users who have demonstrated sufficient recovery potential. Within a relatively short period of time, they will be able to pass on their experiences to users who have less recovery potential ('Münchhausen' phenomenon).
- 2. Volunteers and members of society who are looking for a purposeful way of filling their time will be invited to provide support in this respect. This will counterbalance their own social decline and offer them, in the same way as the users, interesting ways of

- improving their self-confidence, self-esteem, prestige, and respect, and the feeling of being part of a home/work community.
- 3. Professionals trained in a compliant coaching style and an assortment of stress inoculation methods will be used for marginal monitoring and stimulation and making referrals if necessary.

Compared with similar methodologies, such as (F)ACT, S&E projects will initially focus on less vulnerable patients/users, but are expected to contribute to self-supporting projects and activities more quickly, to help curtail the growing demand for care and welfare in society and, in this way, ultimately lead to cost optimization.

Project continuation, organization, and financing all require separate attention.

10.4 Tallinn

(report by: Marju Medar PhD, Dagmar Narusson MA, Koidu Saia MA, Karin Hanga MA)
We have initiated new project applications, focusing on increasing international mobility among students and lecturers and developing the training materials, and courses.

- 1) Project proposal "Development of international master program" in cooperation with ELTE University (Hungary), Utrecht University of Applied Sciences (Netherland), Ljubljana University (Slovenia), King's College (UK). The objective of the project is to develop an English language master program in the framework of which the students can learn and practice in different countries during one semester. The size of the module is 30ECTS, half of which consist of theoretical courses and 30ECTS is internship. The budget of the project is 1600eur and its duration is 01.01.-01.06.2014.
- 2) Project proposal "Entrepreneurial spirit as basis for social entrepreneurship in the area of social work and rehabilitation" submitted 5.03.2014 to Enterprise Estonia. Partners are the Tallinn Mental Health Centre and academics that have been included are lecturer of social policy Zsolt Bugarszki from ELTE University (Hungary) and professor Jean-Pierre Wilken from Utrecht University (the Netherlands) who participated also in the RAAK project.
- 3) The Institute of Social Work of TU has applied for financing in order to invite the lecturer Zsolt Bugarszki from ELTE University (Hungary) as visiting academic in the framework of ESF DoRa application round 15.10.2013. The visiting period for lecturer Zsolt Bugarszki at TU is 1.01-31.05.2014 (5 months). The lecturer teaches the following courses at TU: "Community Based Mental Health Services" 6ECTS for MA and PhD students, "The Critical Analysis of Social Work Management and Administration" 6 ECTS for MA and PhD students.
- 4) The Institute of Social Work of TU has applied for financing in order to invite professor Jean Pierre Lambert Wilken from Utrecht University (the Netherlands) as visiting professor in the framework of ESF DoRa application round 25.02.2014. The visiting period for the professor Wilken as part-time lecturer at TU is 1.09.2014–30.06.2015 (10 months). The professor teaches the following courses at TU: "Research and Development in Social Work" 6ECTS and

"Action Research in the Field of Social Work and Social Policy" 6ECTS for PhD students; "Rehabilitation of Clients with Special Needs" 4ECTS and "Rehabilitation of Criminal Offenders" 4ECTS for MA students and conducts an in-service training for the practitioners from the field of rehabilitation and social work.

11. Conclusions and reflections

The European project 'Community Support for Persons with disabilities' has generated an impressive number of results. In summary, these results are:

- 1. Local partnerships and networks have been developed and strengthened
- 2. A European network around community care and community based services has been strengthened
- 3. New methods of research have been introduced in Estonia and Hungary
- 4. The project has demonstrated that working on multiple levels (practice, organisation, policy) provides not only insights but also shows how these levels should be connected in order to provide good quality of services and to facilitate community participation
- 5. We learned a lot about notions of participation and community; these notions are universal but coloured by local and cultural factors.
- 6. In order to support recovery processes of persons with psychiatric disabilities, personal accounts show what is important in the attitude and behaviour of professionals.
- 7. Professional practices in the different countries show considerable differences, but the study shows that they can all be improved, shifting the focus from an individual and disability perspective, to a community and empowerment perspective. The study offers a number of important elements of this new perspective.
- 8. The knowledge gathered in the project is transferred to the education of social professionals

We will describe more into detail the points mentioned above.

1. Local partnerships and networks have been developed and strengthened

In three countries the project was building on already existing relations between universities and NGO's. In Tallinn, the collaborationship between Tallinn University and Tallinn Mental Health Centre was new. In Amersfoort and Budapest the project contributed to strengthening the existing network. In Amersfoort during the project more agencies joined the network. It is also important to mention that the participation of service users increased during the project. We believe that improving the services for people with disabilities can only be done with a strong participation of the users themselves. Networks can only be developed and maintained by establishing personal relationships. People have to believe in the good cause of the work being done, and to be willing to invest time and energy in the relationships. Good collaboration is based on personal relationships and the ambition to work on the basis of a common mission. In this project we wanted to have a closer look at the position of people with mental and learning disabilities with regard to citizenship and social inclusion.

Our research shows that, despite local, national and global policy documents and legislation, this position is still very weak. These insights lead to the belief that we wanted to contribute with our project to improvements. The research proved that improvements have to be made on different levels. Professionals are very important in supporting service users, but they can only do their

work properly if they are facilitated by an organisation which enables them to respond adequately to the needs of their clients. Professionals and service agencies can only serve clients well if there are sufficient means, and if the rights of persons with disabilities are secured.

A partnership between a university, local agencies, consumer organisations and local government bodies can lead to concrete improvements. In Amersfoort, a strong collaborative network has been developed. When we compare the situation in Amersfoort with the situation in the three other cities, we note that the conditions for support and participation are much better when organisations unite in a 'community participation and support system' than if there are weaker forms of collaboration. In Maastricht, where the number of services, the financial means and the legislation are similar to those in Amersfoort, on a city level services still operate in a fragmented way. There is not, like in Amersfoort, a strong coalition of organisations joining in a common endeavour. However, on a district level, in both cities more and better collaboration develops between mental health care, social care, voluntary organisations and the municipality. Due to the introduction of the Social Support Act, the municipalities in the Netherlands are taking the lead in (re)organising community services. A strong tendency is to form new district teams, consisting of professionals with different disciplinary and organisational backgrounds. Often these teams operate from a public location in the district, like a community centre.

In Budapest, there is still a weak infrastructure of community based services, since the deinstitutionalisation process in Hungary is just about to start. Hungary has legislation in agreement with European agreements, but is only slowly putting this into practice. There are little means available for community based services, like day centres, home care and rehabilitation programmes. The few rehabilitation centres which exists like Soteria and the Félsziget Clubhouse are examples of good practices which can serve as models for new services in Hungary.

Advocacy organisations are mostly focusing on human rights, and seem to pay little attention to patient empowerment, nor to advocate strongly for better community support services. Service users are not well organised. Our project has encouraged users to organise themselves and to organise peer support initiatives. CARe Europe has started a new project to strengthen the position of service users. The position of social research at Elte University is weak. The university is much oriented towards physics, and is more theory oriented than practice oriented. The research group at the Social Faculty of Elte showed however that empirical research embedded in real life situations of users and professionals, provides rich data and is a promising form of research.

The situation in Tallinn is comparable, but a clear difference is that Tallinn University has a strong Institute of Social Work. PhD students are offered the possibility of combining research with teaching at the faculty. The collaborationship which developed with Tallinn Mental Health Centre was evaluated as valuable by both partners. For Tallinn Mental Health Centre, the research done provided useful feedback for the quality of their work. For Tallinn University, the

collaboration offered the opportunity of connecting directly to the practice of professionals and service users, as well as their family members. The data which were collected provided important insights in the situation and needs of both parties, and led to a number of important recommendations. In the report of Tallinn University, the corner stones are presented of a policy which is needed to improve the services.

From the study, it also becomes clear that the means which are available for social care, rehabilitation and (re)integration are quite modest. Estonia has a rather fragmented system of services. This means that means are distributed among many different organisations. The system of rehabilitation services in Estonia seems paralyzed by an extensive and expensive assessment procedure, and long waiting lists for services.

In Amersfoort and Tallinn, partners have already made plans for a follow-up of the project. The local networks which have been established will be continued.

2. A European network around community care and community based services

The project contributed considerably to the development of a European network which promotes community based services, recovery and social inclusion of persons with disabilities. This network is known as *CARe Europe*.

During the project 4 conferences took place, where participants from the four cities met. Participants included professionals, researchers, lecturers, students and service users. These meetings not only strengthened the personal relationships between the participants, but formed also important sources of knowledge and inspiration. In each city, good examples could be found of services, activities and working methods of professionals.

Besides the conferences, study visits, seminars and symposia were organised. The meetings expressed great enthusiasm for the project and its ambitions.

The coming years, CARe Europe will go on with a number of activities which have started in the project.

3. New methods of research

The Research Centre for Social Innovation of HU University for Applied Sciences has developed in the past 10 years a tradition in the field of practice based research (PBR). The model of Communities of Practice combined with action research has been applied in many different research projects and has proven to be successful (Wilken, Van Slagmaat, & Van Gijzel, 2013). The model was proposed in the project to the other partners. The project was used by Tallinn and, to a lesser extent, by Budapest, to get acquainted with the methodology and to experiment with the application. This enriched the way research was done at the universities. Especially the research group in Tallinn was quite enthusiastic about the new methods of practice centred research. Professor Jean Pierre Wilken of HU University was invited to come over and teach the

methodology more in detail to researchers, lecturers and students of the Institute for Social Work.

4. Working on multiple levels

The project has demonstrated that working on multiple levels (practice, organisation, policy) provides not only insights in the status of the different levels, but also shows how these levels should be (better) connected in order to provide good quality of services and to facilitate community participation. In this respect, it was interesting to find from the analysis that in all three countries there is a considerable gap between the policy level and the practice level. On a policy level, we looked at international documents, like the European Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities. We looked at national policies of governments with regard to inclusion, participation and services. We also looked at the policy papers of service organisations. Cross-level analyses provide insights in the complex interaction between policy (at different levels) and practice (as perceived by service leaders, professionals, and service users).

The organisational level of service agencies is an interesting in-between level. The organisations have to cope on the one hand with guidelines and legislations from the government, as well as conditions of funding agencies, and on the other hand with the codes and requirements of the professionals. Specialised service providers, for example mental health agencies, have the tendency of focusing on one particular area, namely their area of expertise. Mental health care institutions might choose to focus only on the treatment of mental disorders. Doing this, an integral view on health and social functioning of a person can get lost. Highly specialised services generally see little use in collaborating with other services. If the importance of the social system and of participation for the health of the person is acknowledged, this immediately widens the scope. National governments can stimulate the development of a comprehensive system of health and social care through policy and legislation.

From our study it seems important that the leaders of service providers have a broad, comprehensive view on health and care, including awareness about the importance of human and legal rights. They should be able to bridge the policy level and the practice level.

It seems that European policy papers and UN Conventions are still far away from local governments and service providers. In the project we explored the possibilities the UN Convention on the Rights of Persons with Disabilities offers for professionals and service users to work on improvement of their situation. Our conclusion is that the Convention provides a useful framework to claim legal rights, but we need a lot of efforts to make it known. We are working on a tool which can be used by professionals to use the Convention in daily practice.

Zuyd University in Maastricht has used Bronfenbrenner's Ecological Theory to make analysis of the micro, meso and macro level in the local context of the city's community participation initiatives, and form the perspectives of different stakeholders. Although not analysed in depth, this kind of mapping provides a clear idea of the many factors involved in the change of the social system actually taking place in the Netherlands.

5. Notions of participation and community

We learned a lot about notions of participation and community; these notions are on the one hand rather universal but on the other hand coloured by local and cultural factors.

During our meetings language issues came up, for example when a research instrument called the Participation, Autonomy and Support Scale (Wilken & Karbouniaris, 2012) had to be translated in Estonian, Russian and Hungarian. In the PAS one of the items is "I have the feeling that I belong to the community in my neighbourhood". It turned out to be difficult to translate community, and also it seems that a neighbourhood is not always considered to be a community, or the community is merely regarded as a physical environment, leaving social aspects out. Another interesting word is 'belonging'. What does it mean when you 'belong' to a certain social or physical entity? The interpretation of terms like these appears to vary depending on the context of language and culture.

We learned from our project that language sensitivity is important. In every language notions should be discussed and defined in a careful way, taking into consideration the cultural and political context.

A similarity in the four cities is that it appears that the 'community' needs to be reinvented, although there is a distinction between the Netherlands and the two post-soviet countries. In Hungary and Estonia, the old soviet regime has caused considerable mistrust in society. People were not sure who to trust, 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 'community' was thereby narrowed down to a functional, geographical entity, and had little social value. The challenge for post-soviet countries is to restore social values, and to create new vital social networks. New bonds of trust should be developed. This is a slow process; much will depend on the new generations.

In the Netherlands, and other western European countries, traditional communities have weakened over the past decades because of mobility, the level of welfare facilities, and individualism. The community was for many persons not a source of social and financial capital which was really needed for existence. Social security facilities, health care and social services were arranged at a national level, through legislation and insurance systems. Since the turn of the millennium and the economic crisis we see three tendencies. The first is that there is an increasing awareness that social values, like meaning something to other persons in your environment, are important for the quality of life. The second is that due to the crisis, huge budget cuts in the social welfare and health care system were unavoidable. The third is that money and power are transferred from the national to the local level. Since 2007, with the

introduction of the Social Support Act, the municipalities have become responsible for establishing a system of community care and community support. The coming years, more tasks will go to the local government like labour reintegration, youth care and community support for persons with disabilities. These developments stimulate community life. The tradition of voluntary work, which is very strong in the Netherlands, is acknowledged as being an important asset of social capital.

A specific modern phenomenon in social relations is the position of social media, which play an important role in communication. Social media like Facebook and twitter create new types of social networks. In the Netherlands we see that the possibilities internet offers can be supportive for community development. In villages and towns, internet is used to provide services to community members among each other. Examples are: doing small tasks for another (like gardening, shopping, fixing something in the house, babysitting), organising community events (like a lecture, a dance party or a barbeque), or offering specific services (like home cooked mails which can be collected at a small price).

Social professionals can play a valuable role in supporting community development. They can help connecting people to each other, to help local groups to get organised, and help to start new local initiatives.

6. The personal perspective of service users

In order to support recovery processes of persons with psychiatric disabilities, personal accounts show what is important in the attitude and behaviour of professionals.

The language of 'common people' is quite different from the language of professionals. Professionals use their own language, which is often part of their professional status and behaviour. The world of psychiatry has a language of its own, dominated by medical jargon. People using mental health care services often don't understand this language. They see their problems and life situation translated into a language (e.g. a diagnosis) which transforms, and often narrows down, their personal experiences to one specific professional kind of perspective. People using mental health care services for a longer time often tend to adapt to the world of psychiatry, and are going to use professional language themselves. They become 'paraprofessionals'.

Language and meaning of social (and health) services are extremely important and we pay so little attention to it. Service providers most of the time are forced to use a rather clinical language as official language of the service. 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 hand of professionals.

From the narratives we collected in this study and from many other studies (see Wilken, 2010), we learn that the recovery processes of persons with a history of mental illness require a new language. One of the aspects of recovery is that a person develops his own narrative, a personal identity which may include living with a mental disability, but is not identical to the illness or disability.

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 allowing users to develop their own narratives.

The personal perspective of service users also includes ideas about what to change or achieve, and ideas about how these ideas can be turned into reality. Sometimes these ideas can be still vague, they might be no more than a dream. Then, the professional can help clarifying and concretising the ideas. Dreams and wishes can be turned into concrete goals, plans and actions. The methodology how to do this is available (see for example the CARE Methodology, Wilken & Den Hollander, 2005; Den Hollander & Wilken, 2014).

Also for persons with learning disabilities, a participation and development perspective can be used.

7. Shifting to a recovery and participation perspective

The professional practices in the different countries show considerable differences, but the study shows that they can all be improved, shifting the focus from an individual and disability perspective, to a community and empowerment perspective.

Personal relationships, offering understanding, support and encouragement are of vital importance in the process of recovery. From the interviews we conducted we see that the majority of professionals describe themselves in terms of their professional qualities, while users mostly value professionals in terms of their personal qualities and the way they engage in a relationship. Professional skills and knowledge are important, but at the same time we found that the relationship dimension (accessibility, common language, continuous presence, reliability) has a relevant impact on the recovery process.

The shift from a clinical, illness focussed approach to a social, recovery focussed approach is a change which requires a lot of efforts. This new focus should be at the heart of professional educations in social work, mental health care and disability care. It should be in the heart of the mission of service agencies. It should have continuous attention in individual and team supervision.

From our study, and other studies about recovery, it becomes clear that a supportive network is very important. Valuable support can be offered by peers, family members, friends and professionals. All those people together can be regarded as a 'social support system'. From the

Budapest report we learn that persons in different positions can be part of this support system. One narrative from Budapest shows for example that the bartender in a local pub plays an important role in the life of the person.

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.

In the Netherlands, as said before, there is a growing awareness that the existing tradition of voluntary work is very valuable. From the research done in Amersfoort and Maastricht we learn that voluntary work offers a number of opportunities. First, volunteers can be connected to clients as a *buddy*. There are many buddy projects in which for example the client and the buddy are meeting once a week. They just can drink a coffee together, have a walk, or engage in other activities. A volunteer can also help with specific tasks, like shopping, taking care of the household and managing expenses. Second, the client can become a volunteer himself. Unlike a paid job, voluntary work can often more easily be adapted to the capabilities. There is less pressure and there is often a great reward in terms of appreciation and satisfaction. Voluntary work is also valuable in the process of reintegration. It helps connecting to 'real environments', and to build a rhythm.

There are clients who have a volunteer as a buddy, and at the same time do voluntary work themselves. Voluntary work (and other types of activities) emphasises reciprocity. It places the person with a disability not only in the position of a dependent citizen, but also in the position of an *active* citizen, someone who can contribute to society.

8. Education of professionals

In the project knowledge has been collected on different themes. We summarize the topics which are relevant for bachelor and master curricula, and for post graduate education.

- The role of professionals in the framework of community support is changing. They act more and more as 'supporters' and 'facilitators'. They offer personal support to a person, but they also *organise* support in and by the community.
- This means that they have to know a lot about *recovery factors* and *recovery processes*, that they have to be able to relate on a personal level, and that they are able to make a good assessment of needs and strengths. They should be able to support a person with regard to strengthening self-confidence, the (re)development of the identity, to improve competences, and to obtain desired roles in society.
- The basis for working with clients is the *personal knowledge* of the user. Often, this knowledge not only contains useful information for the professional, but the experiences of

- the person can also be used as strengths in the recovery process. Professionals have to learn that the personal knowledge of the client is as important as the knowledge of the professional.
- Professionals focus not only on the individual but on both the individual and his environment. Knowledge about the environment includes: being able to connect to significant persons, making an assessment of the strengths and needs of environments and social networks. The actions of the professional are based on this assessment. Professionals should have the competences to mobilise and support the social network. Social network strategies are aimed at mobilising, strengthening and supporting the persons connected in a social network. These networks might be centred on family, peers, the neighbourhood, the work place, the sports club or the work place.
- Part of the work of the professional can be to build bridges between the client and the
 desired environment. For example: when a client wants to have a job in a specific part of the
 labour market, the professional can help him looking for a suitable place, and to take
 barriers away. The examples from Maastricht show the relevance of these 'bridge building
 activities'.
- Professionals should adopt and work from a focus on participation and inclusion. They assist
 people who, because of their vulnerability and history, have problems joining communities.
 Participation means: taking part in activities in different life domains. Inclusion means that
 the environment welcomes and enables people who are 'different' to be a full member of
 the community.
- Professionals have to learn to use an *empowerment perspective*. The strengths of the client are acknowledged and increased. Empowerment also takes place if skills are developing, if users join peer groups, or engage in meaningful activities and valued social roles.
- Professionals have to work on the basis of human rights in general, and the specific rights of
 persons with disabilities in particular. In our project materials have been developed for this
 purpose which can be used for educating students and professionals.

Epilogue

We are happy that the project has brought many results and promising insights. Although the situation and process in each city was quite different, there was a shared ambition to use the project as an opportunity to get to know more about issues of participation and professional support. The project was also grasped as a chance to learn from each other and to build collaborative networks. The project teams were very engaged to make a contribution to the improvement of the situation of persons with disabilities, and to the development of support services assisting in improving quality of life and social participation.

The enthusiasm which was generated by the project, not only fuelled the results, but also leads to a number of activities to give this project a follow-up.

12. List of publications and presentations

Joint publications:

Wilken, J.P., Tausz K., Leppik L., Medar M., Narusson D., K. Saia & F. Leenders (2013). *Community Support for and with persons with disabilities*. Abstract Symposium 3rd ENSACT Joint European Conference Social Action in Europe. Istanbul/ Turkey: 18 April 2013. In preparation:

- article on notions of community and participation
- article on UN Convention

Joint presentations:

Wilken, J.P., Tausz K., Leppik L., Medar M., Narusson D., K. Saia & F. Leenders (2013). *Community Support for and with persons with disabilities.* Parallel Symposium at 3rd ENSACT Joint European Conference Social Action in Europe. Istanbul/ Turkey: 18 April 2013.

Amersfoort

Publications:

Admiraal, L. & Wilken, J.P. red. (2014). Community Support. Eindrapport Amersfoort Utrecht/Amersfoort: Kenniscentrum Sociale Innovatie.

Dankers T. & Peters, M. (2013). *Meedoen in Amersfoort. Een beschrijving van het lokale beleid en voorzieningen ter ondersteuning van mensen in kwetsbare posities in Amersfoort.* Utrecht: Kenniscentrum Sociale Innovatie.

Dankers, T. & Peters, M. (2013). *Community Support in Amersfoort. A description of local policy and local services.* Utrecht: Kenniscentrum Sociale Innovatie.

Karbouniaris, S. & Gijzel, S. van (2013) *Een gastvrij onthaal in de wijk voor mensen met een Niet-aangeboren hersenletsel. Naar een brede toepassing van de methode Wijk en Psychiatrie.* Utrecht: Kenniscentrum Sociale Innovatie.

Knevel, J. (2013). *VN verdrag, sociale inclusie, community support*. Utrecht/Amersfoort: Kenniscentrum Sociale Innovatie.

Knevel, J. (2013). The UN Convention on the Rights of Persons with Disabilities: Implications for social inclusion and support in the community. Status of the convention in the Netherlands. Research Centre for Social Innovation: HU University of Applied Sciences.

Wilken, J.P., Slagmaat, C. van, & Gijzel, S. van (2013). The Best Practice Unit: a model for learning, research and development. *Journal of Social Intervention: Theory and Practice* – 2013 – Volume 22, Issue 2, pp. 131–148.

Wilken J.P. (2013). Kantelen met kwartiermaken. Kansen voor sociale wijkteams. In: Kal, D., Post R. & Wilken, J.P. red. (2013). *Verder met Kwartiermaken; naar de verwelkoming van verschil.* Amsterdam: Uitgeverij Tobi Vroegh, pp 196-201.

Wilken, J.P. (2013). Social Inclusion, community participation and empowering support. Abstract 3rd ENSACT Joint European Conference Social Action in Europe, p. 211.

Wilken, J.P. (2013). Communities of Practice and Research. Abstract 3rd ENSACT Joint European Conference Social Action in Europe, p. 201.

Presentations:

Admiraal, L. (2013). Research on Community Support in Amersfoort. Tallinn: 6 May 2013.

Admiraal, L. (2013). Community Support System Amersfoort. Budapest: 10 September 2013.

Admiraal, L. (2013). Report from the research: highlights. Amersfoort: 9 December 2013.

Dankers, T., Peters, M. & S. Karbouniaris (2013). *The local situation in Amersfoort with regard to disability, policy and participation.* Maastricht: 30 January 2013.

Grijzen, E. (2013). Community Support in Amersfoort. Maastricht: 30 January 2013.

Grijzen, E. (2013). Developments Community Support in Amersfoort. Tallinn: 6 May 2013.

Grijzen, E. (2013). Activities in the Community Support Project. Budapest: 10 September 2013.

Grijzen, E. (2013). Community Participation in Amersfoort. Amersfoort: 9 December 2013.

Wilken, J.P. (2013). *Community Support, Participation and Support, objectives of the project and theoretical framework.* Conference Community Support. Maastricht: 30 January 2013.

Wilken, J.P. (2013). *Community of Practice. A model of research and development*. Conference Community Support. Maastricht: 31 January 2013.

Wilken, J.P. (2013). *Social Inclusion, community participation and empowering support.* 3rd ENSACT Joint European Conference Social Action in Europe. Istanbul/ Turkey: 18 April 2013.

Wilken, J.P. (2013). *Community Support Introduction to the second work conference*. Conference Community Support. Tallinn/Estonia: 6 May 2013.

Wilken, J.P. (2013). *Refocus: transformation of services in a new era*. European Conference CARe Europe. Tallinn/Estonia: 8 May 2013.

Wilken J.P. (2013). Support for people with disabilities to participate in the Community. Seminar Elte University. Budapest/Hungary: 9 september 2013.

Wilken, J.P. (2013). *Community participation for persons with disabilities. Introduction to the final conference*. Final Conference Community Support Project. Amersfoort: 9 December 2013.

Wilken, J.P. (2013). The UN Convention and its significance for persons with disabilities. Introduction to Gabor Gombos. Amersfoort: 9 December 2013.

Wilken, J.P. (2013). *Community Support. Results and key themes. Wrap up & concluding remarks*. Final Conference Community Support Project. Amersfoort: 10 December 2013.

Budapest

Publications:

Bugarszki, Zs. (2013) A mentális problémák felépülés alapú megközelítése ESÉLY 2013/5 p. 68-86. Budapest http://www.esely.org/kiadvanyok/2013_5/tartalom.pdf

Presentations:

- International ENSACT Conference of the IASSW in Istanbul, Turkey (2013 April)
- International Conference of the Ljubljana University in Ljubljana, Slovenia (2013 July)
- Mental Health Day, Tallinn, Estonia (2013. October)
- Social Work Day, Tallinn University, Tallinn, Estonia (2013. November)
- "Kulcskérdések a társadalomkutatásban" (Key issues of social research) Conference in Budapest. 2014. April 3-4.

Planned publications:

- United Nation Convention on the Rights of Disabled Persons Gábor Gombos in cooperation with Dutch and Estonian colleagues.
- Community support Lucia Csabai in cooperation with Dutch and Estonian
- Resilience, effectiveness and community development Katalin Tausz and Zsuzsa Kondor. Hungarian publication
- Language and Identity Zsolt Bugarszki in cooperation with Dagmar Narusson
- Community support and Community Care Zsolt Bugarszki, Katalin Tausz, Zsuzsa Kondor,
 Lucia Csabai, Hajnalka Sátor, Gábor Gombos, Anna Légmán ESÉLY Folyóirat (Hungarian publication to summarize the results of our research)

Publications will be inserted into the curriculum literature list of our Social Work and Social Policy Master's Program and the results will be presented in our courses.

Maastricht

Publications:

Leenders, F.H.R., Zuyd/ Cesrt Maastricht Netherlands, "Actual situation regarding care and wellbeing arrangements in the Maastricht area, 2013" ("Actuele situatie rond zorg- en welzijnsarrangementen in Maastricht, 2013"), 22 pp., June 2013, internal publication.

5. Delespaul, Ph. et al. (2013). Consensus over de definitie van mensen met een ernstige psychische aandoening (epa) en hun aantal in Nederland, *Tijdschrift voor Psychiatrie*, 55 (2013)

6. Leenders, F.H.R., Senior Researcher/Lecturer Cesrt/ Zuyd Maastricht, Independent Consultant, Outsider Art Gallerist / Social Entrepreneur, "Synergy & Empowerment (S & E) Projects": Community Supported Care & Cure arrangements for 'Entrepreneurial' Users/ Patients in Long Term Projects Elaboration of Starting Conditions, Assessment and Management, 14 pp., internal publication.

Presentations:

Leenders, F.R.H. Dr., Dr. A. Reverda, (both University for Applied Sciences Zuyd/ CESRT, Maastricht Netherlands), H. Geelen, M Sc., Trajekt, Maastricht, Prof. dr. Ph. Delespaul, Mondriaan and University of Maastricht (Caphri), Community Support for vulnerable people: innovative care & cure arrangements in Maastricht, Netherlands; Contours of the final report, presented December 2013

Hilwig, Marcel, psychiatrist, Bea Vanderschuren, social psychiatric nurse, FACT in the Neighbourhood: a short Introduction of Community Psychiatry Practice in South Limburg, Department of Research & Innovation, Mondriaan, presented Maastricht subconference, January 2013.

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Presentations:

Presentations at Estonian Social Sciences IX annual conference (ESAK) in Tartu on the 25th and 26th of April 2014. The theme of the conference is "Estonian social sciences in changing times: breaking out of the spell", which is dedicated to the Max Weber's 150th birth anniversary (see: http://www.yti.ut.ee/et/esak).

Presentations in the session: "Welfare and social support in competitive society"

- 1) Implementation of the principles of the convention on the rights of persons with disabilities in the area of mental health (Dagmar Narusson, Karin Hanga, Marju Medar, Koidu Saia)
- 2) Community support for persons with mental health problems in Tallinn (Lauri Leppik; Dagmar Narusson; Koidu Saia; Karin Hanga; Marju Medar)
- 3) First assessment of the need for rehabilitation of persons with disabilities overview of the results of developmental research in Estonia (Karin Hanga)