Warm regards to our Swedish friends from our wonderful Trentino!

Patients and families involvement in the mental health department of Trento: how their 'experiential knowledge' improves the quality of care

Jönköping, 3-4 March 2011

Renzo De Stefani, Kathleen Bertotti, Ornella Baldo, Maurizio Capitanio
Healthcare Trust of the Autonomous Province of Trento (Italy) - Mental Health Department -
It starts with Franco Basaglia, a very well known Italian psychiatrist. Basaglia was the promoter of Law n.180/1978.

This Law was a crucial Law for Italian psychiatry
The Law established three basic issues

1. It closed psychiatric hospitals (for the first time in the world)
2. It moved the treatment and rehabilitation to community services
3. It opened small wards in general hospitals for situations of crisis (maximum 15 beds for 1 ward; 1 bed every 10,000 residents)
The basic principles of the Italian Community Psychiatry are:

- Integrating all interventions into a sole mental health department
- Continuity in the case management in the different areas of the mental health department
- Treating the Patient in the place where he/she lives and works
- Providing a range of treatments based on the needs
- Enabling work in cooperation with other local services in the community
- Valorisation of the knowledge and of the resources of users and family members, and their active involvement

In the development of the Italian Community Psychiatry many good practices took root:

- Good information about the presence of MHD in the community.
- All possible networks with local community
- Strong “actions” against stigma and prejudice
- Friendly and warm reception always and everywhere
- Real time management of the crisis
- Sharing and subscription of every care pathway by the patient, the family member, the professional and 1 external guarantor
- Particular attention to Housing
- Particular attention to Working
- Particular attention to Sociality

Attention! It is not the same in all Italian region
In this slide you can see the graphic representation of MHD of Trento and its approach.

This are the number of MHD of Trento:

1. Mental health center
2. Community team
3. Day care facilities
4. Residential facilities
5. Ward general hospital
6. Empowerment
7. UFE (Expert Users and Family member)

<table>
<thead>
<tr>
<th>Service</th>
<th>Number</th>
<th>Hours/day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental health center</td>
<td>10</td>
<td>12h/day</td>
</tr>
<tr>
<td>Community team</td>
<td>30</td>
<td></td>
</tr>
<tr>
<td>Day care facilities</td>
<td>10</td>
<td>12h/day</td>
</tr>
<tr>
<td>Residential facilities</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Ward general hospital</td>
<td>20</td>
<td>24h/day</td>
</tr>
<tr>
<td>Empowerment</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>UFE (Expert Users and Family member)</td>
<td>50</td>
<td></td>
</tr>
</tbody>
</table>

The best standard is of 1 operator every 1,500 inhabitants:
- Psychiatrists 1/10,000
- Psychologists 1/25,000
- Nurses & Educators 1/2,000
Mental Health Service of Trento
Data and priorities

Main data 2010

- Catchment area: 150,000
- Users: 1,800
- Staff: 100
- UFE: 50
- Database users: 40%
- Users seen at home: 25%
- Users CD & DH: 10%
- Sheltered housing users: 127
- Users included in projects of working: 232
- Hospitalisations: 231
- Average stay in hospital day: 15
- Compulsory treatments: 3

Priorities

- Crisis intervention as soon as possible
- Integration and continuity of treatments in complex cases
- Network of sheltered housing
- Vocational training and job placement services
- Assessment tools (1° PCC)
- Psychotic onsets
- CBT depression and panic attacks
- Doing together
- Quality group

Table 1: Key performance data

<table>
<thead>
<tr>
<th>Year</th>
<th>Total Users</th>
<th>Zero</th>
<th>Hospital admissions</th>
<th>Emergency admissions</th>
<th>Total of MH admissions</th>
<th>Rate per 10,000 inhabitants</th>
<th>Percentage of total MH admissions</th>
<th>Rate per 100,000 inhabitants</th>
<th>Percentage of total MH admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>1,380</td>
<td>1,446</td>
<td>1,086</td>
<td>701</td>
<td>477</td>
<td>273</td>
<td>2,5%</td>
<td>312</td>
<td>29%</td>
</tr>
<tr>
<td>2011</td>
<td>1,090</td>
<td>1,126</td>
<td>1,000</td>
<td>680</td>
<td>420</td>
<td>200</td>
<td>2,2%</td>
<td>300</td>
<td>28%</td>
</tr>
<tr>
<td>2012</td>
<td>1,000</td>
<td>1,080</td>
<td>920</td>
<td>650</td>
<td>400</td>
<td>190</td>
<td>1,9%</td>
<td>290</td>
<td>27%</td>
</tr>
<tr>
<td>2013</td>
<td>900</td>
<td>940</td>
<td>840</td>
<td>590</td>
<td>350</td>
<td>170</td>
<td>1,7%</td>
<td>280</td>
<td>26%</td>
</tr>
</tbody>
</table>

* CBT: Cognitive Behavioral Therapy
* PCC: Primary Care Coordination

1. Data not available.
The “doing together” approach at the Mental Health Department of Trento, since 2000. The basic principles

- “doing together” are all the activities promoted by the Mental Health Department of Trento where users, family members, operators and citizens are involved equally.

- “doing together” is a way of facing the mental disease that recognizes the experience, and therefore the knowledge of everyone;
The “doing together” approach:

- values collaborations
- trusts everyone’s resources
- believes in the change that is always possible
- believes that the assumption of responsibilities is a positive value

“doing together” recalls the principles of empowerment and of health promotion

During the years, a growing number of activities of “doing together” took root in the Mental Health Department.

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Doing together: good thought

1) Consistency between words and deeds
2) Involvement of everyone in the whole system
3) Be the change you want to see in the World
4) A good climate is healthy. Conflicts do not lead us anywhere
5) Money is important, but it is not everything
6) Research is not an option. We need to evaluate what we do to improve our interventions’ quality
Doing together

During the years, the “doing togheter” principles and activities positivly involved the whole system and the whole MHD.

People are starting to work together in all the areas of MHD.
The example of Housing

In our organization we try to:

► Offer different opportunities and different housing solutions to our patients

► Focus on personalized solutions to promote autonomy

► Focus on looking all together for the best solution for everyone

Housing map

This tool helps professionals, patients and family members to discuss and find out together the best solution. When a patient needs an accommodation we use the map.
Working, another example

In our organization we offer two different working solutions:

1. Job placement **OUTSIDE** the MHD: private and cooperative companies or special programs promoted by local authorities
   - 150 users are currently working outside the MHD

2. Job placement **INSIDE** the MHD with many different activities like catering, cleaning, gardening, car wash, social tourism, border-bags and so on
   - 100 users are currently working inside the MHD

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Working

Job placement **INSIDE** the DSM has some advantages:

- We offer these activities to the most severe patients
- No waiting list
- Gratifying and empowering activities
- Balanced budget
- Weekly meetings to plan job activities and where everyone can propose new ideas
Meeting for the job planning

Catering
Catering

Our car wash
Border-bag
The craziest bags in the world!

Expert Users and Family members (UFE)

Doing together

Italian Community Psychiatry
And finally UFE’s “birth”

- The experiences described seem “niche” activities, but they’re tied together very evidently.
- During the years these experiences progressively involved an increasing number of users and family members.
- The more they felt involved, the more they wanted to be part of the ‘family’ of the MHD.

**From being “members of the family” to “service providers” side by side with the operators the step was short, and so UFEs were born!**

- Evidently, the UFEs are absolutely not a “niche” presence!
- They are a ‘strong’ presence in the system, and they are changing and remodelling the system itself.

Who are the UFE?

_The UFE_ are all those users and family members of the MHD of Trento that have gained awareness of an “experiential knowledge”.

UFE in this way can provide services, side by side with the operators, in different areas of the MHD of Trento.

They work as “professionals expert”, expert not because of a study career but because of their mental illness experience.

They are formally recognized by the Provincial Healthcare Trust of Trento, and they get paid by a partner association through a collaboration contract.
The "natural birth" of UFE

The growing trust and the emotional participation to the MHD "Family" ...

...more people will to be part of the system and to get actively involved in every area of the MHD

Nobody invented UFE. UFE borned from the bottom and this is a successful point.

Knowledge system for "DOING TOGETHER"

Professionals
- Knowledge derived from education and working practice

Users and Families
- Experiential knowledge derived from disease experience

Recognizing and valuing the knowledge to each other improve the collective knowledge. The system change and the quality of the care increase.
Who are the “UFE”?  

Of course not all the patients and the family members become UFE. Only who wants to become a UFE and who has some features:

- receptiveness (available time and passion)
- affectivity
- well-controlled clinical conditions (for users)
- top awareness of their experiential knowledge.

UFE can deliver in a structured and continuative way professional performances in all the areas of the MHD of Trento.

Currently, among the 50 Expert Users and Families, 35 are patients and 15 are family members, 35 are women and 15 men

In Italy, in Sweden and everywhere there are similar and relevant problems in psychiatric services

Compliance to treatments

Improvement of relationship

Active participation of patients and families

Role of stakeholders in the governance system

UFE help the services to face and win these challenges!!!
### Activities performed - 2010

<table>
<thead>
<tr>
<th>AREA</th>
<th>ACTIVITY</th>
<th>NUMBER OF UFE</th>
<th>HOURS/YEAR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Health Centre</td>
<td>Front office</td>
<td>6</td>
<td>2,350</td>
</tr>
<tr>
<td>Mental Health Centre</td>
<td>Call center</td>
<td>4</td>
<td>1,500</td>
</tr>
<tr>
<td>Mental Health Centre</td>
<td>Accompaniment in crisis situations</td>
<td>3</td>
<td>2,000</td>
</tr>
<tr>
<td>District care teams</td>
<td>Help in complex situations</td>
<td>2</td>
<td>2,000</td>
</tr>
<tr>
<td>Hospital ward</td>
<td>Accompaniment in crisis situations</td>
<td>4</td>
<td>1,500</td>
</tr>
<tr>
<td>Sun House</td>
<td>Night shift</td>
<td>5</td>
<td>4,380</td>
</tr>
<tr>
<td>Sun House</td>
<td>Day time activities</td>
<td>3</td>
<td>1,095</td>
</tr>
<tr>
<td>Mutually sheltered flats</td>
<td>Accompaniment in daily activities</td>
<td>2</td>
<td>1,825</td>
</tr>
<tr>
<td>Shared Care Pathways</td>
<td>Guarantor</td>
<td>6</td>
<td>500</td>
</tr>
<tr>
<td>Families</td>
<td>Facilitator in meeting cycles</td>
<td>3</td>
<td>50</td>
</tr>
<tr>
<td>Awareness initiatives</td>
<td>Testimonials in campaigns against stigma</td>
<td>10</td>
<td>1,700</td>
</tr>
<tr>
<td>Total</td>
<td>Activities</td>
<td>48</td>
<td>18,900</td>
</tr>
</tbody>
</table>

The Mental Health Service of Trento
Front Office

Front office
Call Center

The “doing together” apartments
The “crisis area”

The Sunhouse
The Sunhouse

The hospital ward
Shared Care Pathways

Awareness activities in schools
1. new recommendation of an aspiring UFE made by:
   - himself/herself,
   - a professional,
   - another UFE.
2. knowledge meeting:
   - to clarify the meaning of being UFE
   - to underline the importance and value of the experiential knowledge.
3. Evaluation:
   - motivation and expectations

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**UFE pathway - 1: knowledge meeting**

**UFE pathway - 2: evaluation outcome**

Does the evaluation show continuity and reliability?

**YES**
- The person is proposed to take a “touristic tour”.

**NO**
- The person is suggested to perform more activities of “doing together”.
UFE pathway - 3: “touristic tour”

The UFE is accompanied to visit different areas of the Service with the aim of:

- understanding clearly which is the role of UFE in every area,
- getting a direct contact with staff coordinators of every area,
- learning “rules of engagement”.

During a follow up meeting with the UFE’s Coordinator it is planned a new engagement.

UFE pathway - 4: supervised training

- The new recruitment is followed by a supervised training period of three days in which the aspiring UFE follow an UFE in the chosen area observing tasks and works performed.

- Once completed the supervised training, the opinions of the aspiring UFE, of the UFE who followed him/her and operators (including the professional coordinating the area) are collected for an evaluation.
**UFE pathway - 5: supervised training**

Is the outcome of the supervised training positive?

**YES**
- The UFE is officially put on duty
- The UFE enters the waiting list for that area

**NO**
- The UFE is suggested to test himself more in volunteering activities and/or to perform more "doing together" activities

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**Learning activities**

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>Number of UFE</th>
<th>Hours/year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Service meeting</td>
<td>48</td>
<td>336</td>
</tr>
<tr>
<td>&quot;Ufologic day&quot;</td>
<td>40</td>
<td>280</td>
</tr>
<tr>
<td>Book photos and testifying</td>
<td>25</td>
<td>100</td>
</tr>
<tr>
<td>Education courses in Italy</td>
<td>10</td>
<td>270</td>
</tr>
<tr>
<td>Conferences in Italy</td>
<td>10</td>
<td>70</td>
</tr>
<tr>
<td>&quot;Found words&quot; activities</td>
<td>30</td>
<td>240</td>
</tr>
<tr>
<td>Residential lessons for chinese delegations</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Presentation of the experience to external visitors</td>
<td>10</td>
<td>200</td>
</tr>
<tr>
<td>Meetings without operators</td>
<td>15</td>
<td>150</td>
</tr>
<tr>
<td>Supervision with the UFE Coordinator</td>
<td>48</td>
<td>60</td>
</tr>
<tr>
<td>Television, radio and local newspapers interviews</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>&quot;Free the mind&quot; magazine contributions</td>
<td>5</td>
<td>46</td>
</tr>
<tr>
<td>Filming the movie &quot;Beyond&quot;</td>
<td>8</td>
<td>24</td>
</tr>
<tr>
<td>Travels abroad</td>
<td>5</td>
<td>80</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td><strong>1,896</strong></td>
</tr>
</tbody>
</table>

Data are based on the last two years
## Learning activities of the UFE Coordinator

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>Hours/year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Periodic checks</td>
<td>138</td>
</tr>
<tr>
<td>Annual Service meeting</td>
<td>7</td>
</tr>
<tr>
<td>Book photos and testifying</td>
<td>4</td>
</tr>
<tr>
<td>Education seminars in Italy</td>
<td>90</td>
</tr>
<tr>
<td>Conferences around Italy</td>
<td>70</td>
</tr>
<tr>
<td>Residential lessons for chinese delegations</td>
<td>20</td>
</tr>
<tr>
<td>Coordinator supervision</td>
<td>60</td>
</tr>
<tr>
<td>Travels abroad</td>
<td>40</td>
</tr>
<tr>
<td>Other (i.e. &quot;Ufologic day&quot;)</td>
<td>7</td>
</tr>
<tr>
<td><strong>TOTALE</strong></td>
<td><strong>436</strong></td>
</tr>
</tbody>
</table>

*The calculation is based on the average activity of the last two years.*

## Check meetings

- Regularly performed in each area (once or twice a month)
- Participated by UFEs working in that area, UFE coordinator, and operators (or referring people)
- Equal discussion where to underline critical aspects and to find together solutions to them
- Evaluation of the work performed by the UFE
- Permitting to identify and to share strategies and methods to promote the integration among people and to improve the quality of services provided
**Strengths**

**For professionals:**
- improved attention and emotional proximity to the world of users and families.

**For patients**
- 1. greater proximity and trust towards services delivered as expert users and families are seen as peers;
- 2. significant better compliance to treatments;
- 3. enhanced personal decisional capabilities on treatments, self-management, sense of self-efficacy and opportunity to reshape in a positive way the representation of their condition of mental patient.

**Strengths**

**For expert users and families:**
- a meaningful improvement of quality of life

**For the whole Mental Health Department**
- 1. better relational climate;
- 2. increased assumption of responsibility by everybody.

**For the Community**
- various moments of public visibility led to increased attention, knowledge and awareness on psychic disease.
**Strengths**

- Majority of people who have participated or are participating to “doing together” activities think that it had a positive impact on their *quality of life*.

- Joining such activities seem to have conditioned changes in people leading to higher faith in themselves, a better hope in the future, a feeling of higher usefulness for others and better capability to defend their rights.

- Most of people would strongly recommend with enthusiasm activities of “doing together” to friends or relatives with the same problems.

**Weaknesses**

We didn’t encounter major problems, although flags could be raised on the followings:

a) difficulty in finding new users and family members to face the growing demands;

b) an average age of expert users and families quite advanced (many people can do the job as they are retired);

c) need for a better harmonisation of expert users and families with active citizens working in the MHS (these represent a growing number of ‘traditional’ caregivers operating in the Service, but without any disease experience).
Patient-centred care ... “proper incorporation into new healthcare designs will involve some radical, unfamiliar, and disruptive shifts in control and power, out of the hands of those who give care and into the hands of those who receive it”...

DM Berwick, What 'Patient-Centered' Should Mean: Confessions Of An Extremist, Health Affairs 2009

Dimensions of quality in healthcare - WHO, 2006

Quality of care: a process for making strategic choices in health systems

UFE and patient centeredness

Health improvement for the patient, family members and the whole community

Professional and experiential development

All the different stakeholders

System performance

UFE

Dimensions of quality in healthcare - WHO, 2006

Quality of care: a process for making strategic choices in health systems
Making results visible and spreading the change

Involving a growing number of people

Promoting working together, free expression by everybody and prejudices dissipation

Seeing problems and challenges in a new way

Finding concrete ideas in going about to change

Sharing issues and planning methods and tools for going from words to action

Executing actions

Measuring results

THE UFE’S IMPROVEMENT

SYSTEMATICALLY IMPROVE OVER THE TIME ALL THE RESULTS THAT HAVE BEEN REACHED

DOING TOGETHER

GUARANTEE THE GROWTH OF THE UFE’S PRESENCE

PROMOTING THE INTEGRATION OF THE UFE’S ACTIVITY INTO DAILY PRACTICES

DEVELOPING A CO-PRODUCTION APPROACH
**IMPACTS OF THE UFE’S PRESENCE**

- Improvement of the climate of the organisation
  - Exchanging good practices with other organisations
    - Emotional proximity towards UFE
  - Learning experience for the whole system
- Ri-definition of the activities in the different areas
  - Personalization of the interventions

**What to bring home ...**

- Expert users and families can promote the sharing of learning resources and the shaping of a patient centered system where different kinds of knowledge are mixed up adding value into the care processes

- Active engagement of users and families into clinical teams and services delivery requires a “warm” and emotional environment to be effective and sustainable

- We want to share our experience with others and begin new learning collaborations to harvest new models and ideas from elsewhere

- Many extraordinary things can happen when we do things together!
**UFE ...**

they are many  
they are strange  
they are mysterious  
they are everywhere

later you’ll meet some of them!

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**Trasferibility of the experience**

- Already transferred, although still in early stages of development, to other Italian mental health services

- Implementable in different kinds of services

- UFE’s experience led to external recognition and aroused interest also in mental health services of foreign countries
**“Ufologic” Days**

The UFE are more and more present in many Italian regions. For that we organize several regional and national “ufologic” days.

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**2nd National “Ufologic” Day**

Trento, 17th June, 2011

special guests
Göran Henriks from Jönköping (Sweden) and UFE from Beijing (China)

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**The dissemination of “doing together”: UFE landed in China**

In January 2010, the 1° Community Mental Health Centre was inaugurated in Beijing. The model follows the “doing together” of Trento, and there are already some UFES!
MENTALLY ILL PATIENTS WHO ARE ON STABLE CLINICAL CONDITIONS CAN COUNT ON A FAIR SOCIAL INTEGRATION

In Haidian the first “Workshop for social rehabilitation” of mentally ill patients can be spread out to all the city.

Ideas for the future:
To spread quickly the “socialized rehabilitation model” of mentally ill patients

The case / Focus:
An ex-patient is today a group leader in rehabilitation programs.

Another part of the whole / another voice of the choir: The Italian “doing together”

In Italy, the Mental Health Service was able to spread out successfully the principles of the “doing together”, a social network that involves doctors, nurses, expert users and family members, and all those citizens who wish to join in. It is a network that works for rehabilitation within the society of mentally ill people.

Those who in the past have experienced on themselves a mental disease, and their family members constitute the group of the so-called UFEs, “Expert Users and Family members”. After getting the necessary training, they are at disposal of all the activities that concern the reception and the listening of mentally ill people. UFEs consult with each other, and they are an important source of information for doctors, besides being a bridge between the doctor and the patient. With their activity they offer a concrete help in the patient’s rehabilitation path.

Notes / What people think about it:
1. Mentally ill patients who are on stable clinical conditions can go back to normality.
2. Social rehabilitation is not only recovery.
The on-going collaboration with Jönköping (Sweden)

and soon we will see many Swedish UFE !!!

Extraordinary events

Last but not least the doing together organizes every year an extraordinary event. When we ‘do together’, even extraordinary things become possible. Moreover, these events help fighting stigma and prejudice.
Extraordinary Event 2006: Crossing the Atlantic Ocean

Extraordinary Event 2007: that special train to Beijing
Muyeye is a very poor village in Kenya and the people of MHD of Trento and other Italian cities joined for a fund raising to build a school. Over 250 people went to Muyeye to follow the construction of the school. On 17th February 2011 the school was inaugurated!!!
Extraordinary Event 2011
UFE & the Coast to Coast in US

Map showing locations across the United States and Mexico.

Extraordinary Event 2011
UFE coast to coast in US

Images of UFE & CTC logos with the text "From New York to Los Angeles, the greatest coast to coast event!"
The appeal of a mythical journey, always present in people’s imagination, the coast to coast

A system that has tried to understand and implement at best the principles of community psychiatry and has developed its own approach to partnership ("fareassieme" or “doing together”) in the co-production of services with users and family members

The central presence of UFE, from suffering and outcast people to driving force behind a “bottom up” transformation of an entire system of care

“Doing together” and UFE as messengers of hope and testimonials of change

The presentation of the “doing together” experience and of the results achieved, through the voices of its main protagonists

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The project involves about 25 people from the MHD of Trento together with some Swedish friends, who will cross the United States from the East Coast to the West Coast

The project will be realized in September 2011, the journey will last for about 3 weeks

Video production: As for all previous events, the journey will be documented with the production of a video that will subsequently be distributed to international circuits.
“doing together” is healthy!

So many EXTRA-ORDINARY things can happen when we do TOGETHER !!!

www.fareassieme.it
fareassieme@apss.tn.it

Thank you for your attention !!!

Looking at the future

- Be the change you want to see in the World -