An Open Door / No Restraint System of Care for Recovery and Citizenship in Trieste, Italy

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Questions

• Why elderly people have to be institutionalized today?
• Is there a right to be supported in their own independence and to maximize quality of life in their social context and network?
• How services must be re-configuration in order to support pathways of care in the community particularly for elderly population with mental health problems?
Recovery and Life Stories

• Is it possible to apply the paradigm of recovery even to people with cognitive impairments?

• What is the true value of life stories?

• Holistic or wholistic approach

• How can people maintain or regain meaning in their lives?

• Is there a link between the concepts of citizenship, recovery, deinstitutionalisation, social inclusion?
The Anti-Institutional Thinking (Basaglia)

- The institution doesn’t respond to the needs
- Therefore emancipation
- A whole person, not an object
- A utopia to go beyond the emerging, visible needs
- Real practices and not ideologies
- Restitution of power – empowerment of the mentally ill
- Have a say, to be is to have
- The organic body is related to a social body
Social capital and mental health

• The concept of social capital refers to the relationship resources possessed by individuals, which support them in their actions and decisions (De Leonardis).

• It is composed of social networks and interactions, civil participation and commitment and institutions which enable cooperation among individuals.

• It is the network of personal and social relationships which an actor (individual or group) possesses and is able to mobilise in order to reach personal/group goals and improve one’s social position (P. Bourdieu, 1980).

• Social inclusion as European strategy (Green Paper, European Pact, national examples)
Region Friuli Venezia Giulia

(1.2 million inhabitants)
Trieste, Italy

- **Province of Trieste**
  - 6 municipalities
  - 212 km²
  - tot. pop. 236,500
  - density 1,116 /km²
  - average income: 20,000 € /p.c./yr

- **Municipality of Trieste**
  - 84 km²
  - tot. pop. 205,500 (- 2,000/yr)
  - density 2,432 /km²
  - 2.1 subjects / each family
  - over 65: n=65,647 (27.75)%
  - over 75: n=33,256 (14%)
  - ½ living alone
  - elderly index = 243
  - WELFARE EXP.: 2,300 €/p.c./yr
Elderly Index

ISTAT 2011

<table>
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<tr>
<th>Region</th>
<th>% 0-14</th>
<th>% 15-64</th>
<th>% 65+</th>
<th>Abitanti</th>
<th>Indice Vecchiaia</th>
<th>Età Media</th>
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<td>12,6%</td>
<td>64,0%</td>
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<td>Gorizia</td>
<td>12,2%</td>
<td>63,1%</td>
<td>24,7%</td>
<td>142.407</td>
<td>202,8%</td>
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<td>Trieste</td>
<td>11,4%</td>
<td>60,8%</td>
<td>27,8%</td>
<td>236.556</td>
<td>243,0%</td>
<td>47,9</td>
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A WHOLE SYSTEM for Health Protection
Trieste

- Trieste D.I. was mostly a process of change of thinking, practice and services.
- It includes innovative services and programmes in the area of recovery and social inclusion.
- It is recognised as a WHO Collaborating Centre and considered as a sustainable model for service development with a clear demonstration of cost-effectiveness.
The Mental Health Department and the Local Health Company

• The Mental Health Department (MHD) is part of the Local Health Company (LHC).

• The LHC is the organisation which co-ordinates all public health services in a specific and limited territory. The term “Company” had been created since 1992 with the aim of underlining some similarities in management style with the private trust.

• Specifically, the MHD is the operational structure of LHC which has the following goals: prevention, care and rehabilitation in the field of psychiatry and in the organisation of all interventions aiming to enhance the mental health of the citizens.
The Local Health Company is organised as follows:

- **4 Healthcare Districts** (each responsible for approx. 60,000 inhabitants), operating according to area (primary care and home care, the elderly, specialised medicine, Rehabilitation, Children and adolescents, Family counselling, District diabetes centre)
- **3 Departments** (Mental Health, Dependency, Prevention)
- **2 Specialised Centres** (Cardiovascular and Oncological).
- **118** Service for health emergencies
- **1215** employees.
- **Budget**: cash balance € 29,327,155.82
Trieste
243,500 inhabitants
The Mission of MHD

• The MHD shall operate for the elimination of any form of stigmatisation, discrimination and exclusion concerning the mentally ill persons.

• The MHD is engaged to actively improve full rights of citizenship for the mentally ill persons.

• The MHD shall ensure that the community mental health services of the LHC have a coherent and unique organisation as a whole, through a strict co-ordination of actions and links with the other services of LHC, particularly with general health districts and emphasising the relationships with the Community and its institutions.
Today’s Features of MHD are:

**Facilities:**
- 4 Community Mental Health Centres (equipped with 6-8 beds each and open around the clock) incl. the University Clinic
- 1 small Unit in the General Hospital with 6 emergency beds;
- Service for Rehabilitation and Residential Support (12 group-homes with a total of 60 beds, provided by staff at different levels);
- 2 Day Centres including training programs and workshops;
- 13 accredited Social Co-operatives);
- Families and users associations, clubs and recovery homes.

**Staff:**
- 215 people (26 psychiatrists, 9 psychologists, 130 nurses, 10 social workers, 6 psychosocial rehabilitation workers).
Where are the "beds" today?

Year 1971:
- 1200 beds in Psychiatric Hospital

Year 2012:
- 77 beds of different kind in the community:
- 26 community crisis beds available 24 hrs. Mental Health Centres (11 / 100.000 inhabitants)
- 6 acute beds in General Hospital (3,5 / 100.000)
- 45 places in group-homes (20 / 100.000)
Some Relevant Outcomes

- In 2011, only 16 persons under involuntary treatments (7 / 100,000 inhabitants), the lowest in Italy (national ratio: 30 /100,000); 2 / 3 are done within the 24 hrs. CMHC;

- Open doors, no restraint, no ECT in every place including hospital Unit;

- No psychiatric users are homeless;

- Social cooperatives employ 400 disadvantaged persons, of which 30% suffered from a psychosis;

- Every year 240 trainees in Social Coops and open employment, of which 20-30 became employees;

- The suicide prevention programme lowered suicide ratio 40% in the last 15 years (average measures);

- No patients in Forensic Hospitals.
The Co-ops: Activities

- Cleaning and building maintenance (diverse agencies)
- Canteens and catering, incl. Home service for elderly people
- Porterage and transport
- Laundry
- Tailoring
- Informatic archives for councils, etc.
- Furniture and design
- Cafeteria and restaurant services
- Hotel
- Front-office and call-center of public agencies
- Museums’ staff
- Agricultural production and gardening handicraft
- Carpentry
- Photo, video and radio production
- Computer service, publishing trade, CD-Rom
- Serigraphics
- Theatre
- Administrative services
- Group-homes (type A)
- Parking
How much does it cost?

1971:
• Psychiatric Hospital 5 billions of Lire (today: 28 million €)

2011:
• Mental Health Department Network 18,0 millions €
• 79 € pro capita
• 94% of expenditures in community services, 6% in hospital acute beds
## Costs of MHD - 2010

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<thead>
<tr>
<th>Category</th>
<th>Costs</th>
<th>%</th>
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<tbody>
<tr>
<td>Staff</td>
<td>€ 11.158.171,01</td>
<td>59%</td>
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<td>Medications</td>
<td>€ 1.077.500,03</td>
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<tr>
<td>General expenses</td>
<td>€ 2.920.853,95</td>
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<tr>
<td>Social expenses</td>
<td>€ 956.802,88</td>
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<td>Personal Health Budgets</td>
<td>€ 2.645.362,81</td>
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<td>Total</td>
<td>€ 18.758.690,68</td>
<td>100%</td>
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Mental Health Care: Practices and Procedures
PROGRAMS

- User training and involvement, promotion of self-help activities
- Programme for family members
- Prison consultancy service
- Promotion of social enterprise activities
- Creative/leisure activities, diffused day-care centre
- Relationships with the city’s cultural agencies
- Gender programmes
- Youth Mental Health
- Health care individual budgets, e.g. supported housing
- Liaison with Primary Care
- Collaboration with Drug Addiction Dept
- Prevention of “lonely deaths”
- Suicide prevention
Treatments

• Biological (mostly oral medications)
• Psychological (individual and group therapies)
• Family interventions & psycheducation
• Social network interventions (neighbours, employers etc)
• Cultural and vocational rehab - work placement
• Social support
• Peer support & networking
• Leisure time
Overarching criteria / principles of community practice in the MH Dept.

- Responsibility (accountability)
- Active presence and mobility towards the demand
- Therapeutic Continuity
- Responding to crisis in the community
- Comprehensiveness/Integrated Response
- Team work

Whole life approach
Resources
(Directly Provided by the Centre)

- Living Situation
- Money, Income
- Personal Hygiene
- Work Possibilities
- Free Time
A Value-based Service

The services are value-driven, in that their focus is on:

• Helping the person, not treating an illness.
• Respecting the service user as a citizen with rights
• Maintaining social roles and networks.
• Fostering recovery and social inclusion
• Addressing practical needs that matter to service users
• Change the attitude in the community
No Restraint General Framework

- **Open Door Choice** at all levels of the system
- Liberating care relationships
- Recognizing dignity and rights of subject
- Treating subject as a body, not an object
From Hospitalisation to Hospitality

- Institutional Rules
- Institutionalised Time
- Institutionalised (ritualised) Relations:
  - among workers / and with users
- Time of crisis disconnected from ordinary life
- Stay inside
- A stronger patients' role
- Minimum network inputs

- Agreed / Flexible Rules
- Mediated Time
  - According to user needs
- Relations tend to break rituals
- Continuity of Care
  - before/during/after the crisis
- Inside only for shelter /respite
- Maximum co-presence of SN
From Hospitalisation to Hospitality

Difficult to avoid:
• Locked doors
• Isolation rooms
• Restraint
• Violence

• Open Door System
• Crisis / life events / experience / problems
• Illness / symptoms / body-brain
Whole Life Approach

- Addresses individuals who are at risk of social drift as people with complex needs, incl. Serious and Persistent Mental Illness (SPMI), drug use, medical conditions, high social needs.

- Individual plans of care are scheduled and developed by the MHS together with the user, Healthcare District teams and Welfare Services.

- Personalized Healthcare Budget is created from high to low intensity.

- Implemented through NGOs’ partnerships competing for the best program, integrating the persons’ network resources.
Personalised Plan and Healthcare Budget

Personalized Plan (PP) is funded by Personalised Healthcare Budget and organised along 3 axis:

- Housing
- Work
- Socialisation

The PP accesses other services (mental health services, healthcare districts, social services) and community resources (volunteers, social coops, associations, families).

The Healthcare Agency must guarantee the quality of the PP.
Personalised Plan - Healthcare Budget

• The PP and related Personalized Healthcare Budget (PHB) shifts resources from the structure to the person
• It is easier to see where resources are invested
• It encourages personal living plan by supporting recovery processes
• Monitors quality control of actions to better manage PP’s goals and outcomes.
Partners

- 10 Co-ops
- 4 Volunteer Groups
- 2 Cultural Associations
  - 3 Foster Families

Total: 19 Partners
Housing

• Residences (transitional group – homes) sized according to a “home” model
• Guaranteeing residents a personalized space and subjective time.
• Residences are preferably located in town and integrated in the community
• Residences aim at discharge or the passage to less supported situations.
• Small residences facilitate personalised therapeutic-rehabilitative projects.
Mainstreaming Mental Health Care
Mental health and general health in the community

• The Healthcare Districts are integrated community services.

• Single strategy for the community they serve.

• They are located in the same catchment area of Community Mental Health Centers (CMHC).

• They include: elderly, home, child and adolescent healthcare; family counseling; handicap services; specialist medicine, and associated “Health Tutors” (GP).

• Joint plans of care with MH services.
ASS n.1 TS (L’ Azienda per i Servizi Sanitari)

- Experimentation of personalised healthcare budgets
- Individual care plans
- Hospital/community care continuity
- “case managers”
- utilisation of family/contextual resources
- ‘integrated’ organisation of activities, both internal/external to Agency (municipalities, ASP, volunteer groups, Social Coops, etc.)
- ‘one stop’ access points
- These represent new strategies for assuming full responsibility for care which cut across all of the Agency’s operations.
Target people and activities in the 4 districts

**The Target**
- All Citizens (not only ill)
- All Citizens (prevention programmes)
- Immigrants
- People with mental health disorders
- People with drug dependence

**Chronicity**
- Terminal patients
- Elderly
- Disabled
- Women
- Children
- Couples & families

**The Activities**
- Integrated care with volunteers
- Integrated care with GPs
- Integrated care with social care system
- Pharmac. care
- Prosthetic and rehab. care
- Health prevention and promotion
- Health in childhood
- Health for women
- Nursing care
- Spec. med. care
- Home care
- Residential health care (incl. intermediate structures)
- Community care
CENTRAL ROLE OF EACH INDIVIDUAL AND THE FAMILY

THIRD SECTOR

HEALTH SECTOR

SOCIAL SECTOR

NETWORKING
WHY IT IS NOT ENOUGH?

For **OLD PEOPLE** every day, in Trieste, on the average:

- 5,000 to GPs
- 3,000 to specialists
- 500 to reserv.points
- 5,000 in the farmacy
- 150 in Hosp. First Aid - 50 with “emergency” ambulance
- 600 on rehabilitation treatments
- 400 cared by district nurses
- 400 cared at home
- 1,800 connected with teleaid/telecontrol
- 167 in Rehab. homes
- 800 in hospital, 40/50 new admission/day
- 1,100 in nursing homes
- 1,800 in assisted homes

The new “TOTAL INSTITUTION?”
Home care in the health care districts for PHC and community oriented care

In each district (60,000 inhabitants):
- 100 employees
- 50 GPs
- 30 nurses & therapists for 24/7 home care;
- Teleassistance
- 10 cars
- 20 elderly residences
- annual budget 10 ml/€
University Hospital of Trieste

AOUTS: beds

The Decrease of Hospitalization Rate

• 1998: 236 / 1,000 – beds 1437
• 2012: 156 / 1,000 – beds 774

• 22,000 hospitalized people per year

• 5437 nursing services for continuity of care / protected discharge
The Community Service Increasing Capacity

Home Nursing Care:
• # of users: 7815
• Coverage (>65 population): 11%
• # of services: 117,763

Home Rehabilitation Service:
• # of users: 3,190
• # of services: 12,805
Special Projects and Innovations
Elderly and loneliness in Trieste

- Who should take care of “loneliness”? 
- Is it an unmodifiable situation?
- Is it a disease?
- “Home first!”
  - Is more doctors or nurses the right solution? OR
  - Are more “social” services/workers needed?
- Which balance between Health and Welfare services is needed to maintain independence and provide a necessary level of support?
- Is it a duty only of institutions?
- How is it convenient or possible to integrate health and social care in this case?

55,370 elderly
21,954 alone
8,000 – 12,000 at risk
7,684 At Risk

35% TO BE ABANDONED
50% TO NOT COPE WITH
MENTAL HEALTH CENTERS PROGRAM: Amalia – Special Phone Project

The AMALIA PROJECT is a “three edges” prevention program. It is partnership of health and social services with the cooperation of a private company expert in teleassistance.
The Elderly: Combating Institutionalisation and Supporting Home Care

- **Nursing and rehabilitation personnel** in the Type A poly-functional residences (certified)
- **Interventions in private and ‘poly-functional’ nursing homes**: a central issue is the rights of guests (self-determination, quality standards for cohabitation, personalised abilitative/rehabilitative processes aimed at maintaining an unbroken relationship with the city).
- **Physical restraint** in nursing homes: checks and revision.
Community Health and Development in a Whole System

- **Social determinants for health** – social deprivation and isolation, hence:
- **Microarea Habitat Project** (global, local, plural) activated in Trieste in collaboration with the City of Trieste and the Public Housing Agency (Ater): 10 areas of the city, with an average population of approx. 1000 persons each, for a total of 15,000 inhabitants.

- Interventions for learning about residents,
- Verifying health conditions,
- Guaranteeing good healthcare and social-healthcare practices,
- Reducing inappropriate hospitalisations or stays in nursing homes,
- Verifying the appropriateness of therapies, diagnostics and analyses,
- Promoting self-help,
- Developing collaboration among services and among other actors, such as volunteer groups and/or stakeholders, promote community cohesion.
Micro-areas

- It is a local welfare mix innovation, including:
  - Re-design of relationships and partnership among institutions and citizens.
  - Valuing the community and its resources.
  - Knowledge, opportunities and enhancing participation.
- Service integration.
- Activation of community resources, e.g. self help.
- Active participation of neighbors/inhabitants.
- Direct knowledge and social links with neighborhoods, usually socially-deprived.
- Reduction of hospitalisation, medication expenditures.
THE DREAMING PROJECT
ElDeRly-friendEndly Alarm handling and MonitorING

Partners of the Consortium

Co-ordinator
Tesan-Televita S.r.l. - Italy

Partners
- AGF - The European Older People's Platform - Belgium
- Azienda per i Servizi Sanitari n.1 - Italy
- County Council of Uppsala - Sweden
- East-Tallinn Central Hospital - Estonia
- Government of Aragon - Servicio Aragonés de Salud - Spain
- Health Information Management S.A. - Belgium
- Heby Kommun - Sweden
- Langeland Kommune - Denmark
- Pflegewerk Managementgesellschaft - Germany
- Region Syddanmark - Denmark
- TR Solutions Advanced Technology S.L. - Spain
- Telematici Rizzoli S.p.A. - Italy
Architecture of Telemonitoring Solution (Monitors)

Vital Monitors

**Wi-fi**

HIS Central Unit

**Ethernet**

**GPRS**

**Etc.**

HIS Portal

**Wi-fi**

Environmental Monitors

Introduction Basic Principles of Concept HIS Telemonitoring System Delivery & Installation Live Demonstration Requirements for Installation
The Sensors
TRIESTE CONTACT CENTRE 24h/7

- Manages Alarms (Type 1 and 2) and web clinical folders
- Activates network
- Maintains additional contacts with users also by video
- Monitors regular use of devices
- Provides first level Help Desk
- Support users and case managers
- Promotes social inclusion
Type 1 Alarm (not emergency) n=6.525

- Hypertensive blood values: 38%
- Hypoglycaemia: 0%
- Hypotensive blood values: 13%
- Tachycardia: 1%
- Bradycardia: 17%
- Respiratory insufficiency: 4%

1 hosp

Numbers taken over a 3 year period

Type 2 Alarm (immediate reaction) n=416

- Severe Tachycardia: 1%
- Absence of motion: 12%
- Punic Button Mambo 2: 8%
- Severe Bradycardia: 3%
- Smoke: 16%
- Severe Hypotension: 23%
- Severe Hypertensive: 8%
- Severe Hypoglycemia: 16%
- Severe Hyperglycemia: 13%

3 hosp
## CLINICAL EVENTS IN TRIESTE

### from July 09 to March 2012

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<th>Controls</th>
<th>Intervention</th>
<th>Difference</th>
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<td>99</td>
<td>66</td>
<td>-33</td>
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<tr>
<td>Total length of stay in hospital</td>
<td>1095</td>
<td>823</td>
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<td>Average length of stay in hospital</td>
<td>11,1</td>
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<td>Number of accesses to emergency rooms</td>
<td>18</td>
<td>16</td>
<td>-2</td>
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<td>Number of ambulance transports</td>
<td>65</td>
<td>51</td>
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<tr>
<td>Number of GP consultations</td>
<td>262</td>
<td>293</td>
<td>31</td>
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<tr>
<td>Number of specialist consultations</td>
<td>337</td>
<td>415</td>
<td>78</td>
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<td>1048</td>
<td>1219</td>
<td>171</td>
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<tr>
<td>Number of home visits by social operators</td>
<td>22</td>
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<td>Permanent transfers to elderly home</td>
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<tr>
<td>Number of falls</td>
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<td>Drop outs</td>
<td>14</td>
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SF-36 & HADS Questionnaires

SF-36 Summary

Mental components: (MSC) improvement in test group; physical components (PSC): n.s.

HADS subjects with three evaluations

In itinere reduction of scores, then stable
## HEALTH & SOCIAL COSTS

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<th>INTERVENTION</th>
<th>CONTROLS</th>
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<td>Hospitalization costs</td>
<td>330.000 €</td>
<td>495.000€</td>
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<tr>
<td>Cost of emergencies assistance</td>
<td>1.120 €</td>
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<td>Cost of GP consultations</td>
<td>4.688 €</td>
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<td>Cost of specialist consultations</td>
<td>16.600 €</td>
<td>13.480€</td>
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<tr>
<td>Cost of home visits by nurses</td>
<td>30.475 €</td>
<td>26.200€</td>
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<td>Cost of home visits by social operators</td>
<td>325 €</td>
<td>550€</td>
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<td>Permanent transfer to elderly home</td>
<td>93 €</td>
<td>0 €</td>
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<td><strong>TOTAL</strong></td>
<td><strong>383.301 €</strong></td>
<td><strong>540.682€</strong></td>
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LESSONS LEARNED

In the intervention group:

- lower number of deaths
- lower number of hospitalization
- lower total length of stay in hospital
- lower use of services (but higher number of GP and specialists consultations)
- lower total costs of care

- higher quality of life and self perception of safety
- higher sharing of relevant clinical information
- higher degree of personalized care
- more prevention and proactiveness in long term care
- higher contacts with the person (not lower!)
## PROS and CONS

### STRENGTHS
- new attitude for telemedicine and positive working atmosphere
- info on the web portal! and ++ professional integration (ASS1 + TTL: meetings, collaboration, etc) to solve problems
- user satisfaction (despite some problems with the use of devices)
- the majority of older participants feel more safer at their home thanks to the Dreaming equipments
- positive change of mind in health professionals about the DREAMING Project: a good experience for the future, a professional increase

### WEAKNESSES
- imperfect selection of frail participants
- the thresholds of type 1 alarms are too low and not with a real clinical impact and relevance for a clinical decision
- DLS lines connections (some criticisms, mainly solved; costs)
- difficulties for many to be trained in handling/using the devices (both for operators and subjects)
- difficulties for the set-up video conference - Our older users remain doubtful about the use of Videoconference
Beyond Trieste
Trieste: General Indications

• Community health from deinstitutionalisation

• **Comprehensive, holistic approach** which combines medicine with welfare systems for powerful synergies

• The **focus on individuals and the rights of citizenship** Creating personalised itineraries as organisational-strategic key.
Indications

• Avoid or reduce transitions in care: fragmentation of services system.
• Foster the service’s responsibility and accountability towards the community.
• Recognising the importance of social contexts as producers of the meaning of health actions and as bearers of resources
• Passage from reparative medicine to participatory health
• Developing the protagonism of individuals as stake- or shareholders in the healthcare system.
Indications

• Shift from institutions organisations
• Vision based on the person’s life (whole systems, whole life approach) with a low threshold, single access point (one-stop-shop)
• Developing home care, both network and networked, focussed on the person in their actual living context
• A system of possible options which diversifies responses, making them flexible and personalised.
Paradigm Shift

From
• Services provided, and measured by outcomes (effectiveness or efficacy)

To
• Options/opportunities
• A personal(sized) “route” toward recovery or emancipation
Community Services must be....

• Single access, unified and integrated strategic-organisational moment
  • Centrality of the user’s needs and desires
  • Horizontal organisations
• Flexible
• Responsive to change
• Non-Governmental Organizations (NGO’s) included
Recovery and citizenship

• **Citizenship** should be interpreted as a social process that brings about individual and social transformation.

• It is not a status but a ‘practice’, which is essentially the exercise of social rights (De Leonardis).

• Hence, it involves a **re-distribution of power, and the exercise and development of capabilities** (Sen).

• Basaglia affirmed that “**recoverability**” has a price.

• Lived citizenship, ‘having a whole life’ can be captured to be at the **heart of a recovery process**.
The concept of “epoché” (putting illness into parentheses) in Basaglia.

“Psychiatry’s current task might be that of refusing to seek a solution for mental illness as illness, and instead approach this specific kind of ill person as a problem which – only to the degree to which it is present in our reality – will require conceiving and inventing new forms of research and new therapeutic structures”. (F. Basaglia, op. cit.)
• The person and not the illness is at the center of the process of care for recovery and emancipation through users’ active participation in the services

• (up close, nobody is normal)