Trieste Whole Life-Whole System Experience

How was it developed, how does it work, and what are the outcomes?

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Roberto Mezzina
Director, Department of Mental Health, ASUITs - WHO Collaborating Centre for Research and Training, Trieste
WHO

• The WHO Mental Health Action Plan 2013-2020 recognises human rights as one its main cross-cutting principles, alongside a multisectoral approach and empowerment of people with MH issues and all stakeholders.

• Anyway the provision of comprehensive care anyway is still hindered by an ongoing legitimation of asylums by much of the psychiatric establishment and policy makers worldwide.
Evidence of practices and value-based-experiences

• In Trieste it all started in 1971 thanks to Franco Basaglia and his group, whose most significant achievement was the closure of the Psychiatric Hospital in 1980 and the creation of a completely new range of services, as an alternative to the Psychiatric Hospital.

• It developed in a two-fold way: towards the individual (and his subjectivity) as a social being, which implies a critical-theoretical approach to society and its norms, and towards the community.
Episteme

• Epistemology should be based on a **person-centred paradigm** valuing the personal and social experience of individuals as citizens, and not on a paradigm of disease.

• The person in the social context - **Whole life (in all domains), whole systems, whole community**

• Innovation in the field of deinstitutionalisation, social integration of individuals and integration of services into a coherent network that is able to respond to citizens’ needs should be studied and supported critically.
Italy

- 100,000 inpatients in 1971 in PHs
- 48,000 inpatients in 1978
- All PHs closed in 2000

1978 reform law:
- no Phs admission, no new PHs
- community based care
- human rights focus / involuntary treatment duration reduced (1 week +) – 2 pych. to mayor
- No police / justice involved – just health protection

2015: closure of forensic hospitals
Key lessons from Italy

• A clear policy with investments
• working directly within total institutions – not a simple administrative closure
• Total reconversion of staff and resources of PH into community MH Depts (no parallel systems “hospital-community”, no double spending);
• creating alternative networks of coherent services that work in synergy within the community, thereby
• avoiding useless and often harmful fragmentation and specialisations
• Avoiding implementation of general hospital services only, instead of comprehensive community mh centres and services.
Lessons from Italy (2)

• Coordination of services in a given area of the community (MH Department)
• A strong community service / Centre (up to 24 hrs) for delivering care in an integrated and comprehensive way. Then the components and contents of care can have a framework (not separate techniques)
• Citizen’s input through participation (users, carers, community)
• Health care and general health integration
Mental Health Departments

- They are rooted in areas of about 300,000 inhabitants and encompasses a number of components:
  - Small general hospital acute units (15 beds), 1/10,000
  - Community Mental Health Centers (up to 12hr, sometimes 24hr) 1/80,000
  - Group-homes 2/10,000 with a wide range of support up to 24hr (17,000 beds in Italy, mostly NGOs)
  - Day Centre (also with NGOs)
Number of psychiatric beds per 1 000 population – Italy 1975-2010.
Source: OECD health database
Psychiatric beds per 1 000 population in some OECD countries, 2004-2010.

Source: OECD health database.
Unplanned schizophrenia re-admission rate (< 30 days from discharge - same hospital) out of total schizophrenia discharges by region – 2010. SOURCE: MINISTRY OF HEALTH
Number of assistance days per user and psychiatric beds provided in RFs, 2005-2009.

SOURCE: MINISTRY OF HEALTH
Mental Health Care expenditure

• As most of OECD countries, overall health expenditures in Italy have unevenly increased over the last 10 years. The latest available data (2010) show that total health expenditures in Italy accounted for above EUR 130 million (OECD health database 2013), which corresponds to approximately **9% of GDP**. This is in line with the average of OECD countries.

• It was established through the Conference of Regions (Conferenza delle Regioni) that **no less than 5%** of the local health budget would be allocated to mental health services (WHO, 2011).
Trieste demonstration

- A town **without a psychiatric hospital** for 30 years.
- From total institution to a fully **community based service**, without barriers, immersed in the community, and a low threshold of access.
- Practice with the highest degree of **freedom**, following the principle of respecting user’s power of **negotiation**.
- There are places, like the CMHC, group homes, day centres, social clubs, where anybody can live **health and ill mental health** in their interface in people’s lives.
- Mental health issues are recognized in their intersections with **mental ill health and social inclusion** (with welfare systems), with justice, with general health and health needs.
- The paradigm of illness is broken in favor of that of the **person**.
- It is possible to open an issue of diverse **stakeholders** and collective subjects (users, families, networks, community, society) and of their power, while the vertical power of psychiatric institution has been dismantled.
Objectives / goals

• Replacing psychiatric institutions with a network of community services totally alternative to it.
• At the same time, enhancing rights of citizenship of people with mental health problems and providing a whole-life whole system response to their needs of care.
• The subjectivity of clients, their life stories and their aspirations are considered as the main tools for providing treatments and developing services.
Today’s features of the Mental Health Department in Trieste (236,393) are:

Facilities:
- 4 Mental Health Centres (equipped with 6/8 beds each and open around the clock) plus the University Clinic
- A small Unit in the General Hospital with 6 emergency beds
- A Service for Rehabilitation and Residential Support (5 group-homes with a total of 35 beds, provided by staff at different levels and a Day Centre including training programs and workshops);

Partners:
- 15 accredited Social Co-operatives.
- Families and users associations, clubs and recovery homes.

Staff: 214 people
23 psychiatrists, 7 psychologists, 111 nurses, 10 psychosocial rehabilitation workers, 8 social workers, 27 support operators, 12 administrative staff.
Where are the ”beds” today?

Year 1971: **1,200 beds** in Psychiatric Hospital, closed down in 1980 after a 9-year process of phasing out.

Year 2015: **67 beds** of different kind:

- **26 community crisis beds** available 24 hrs. Mental Health Centres (11 / 100.000 inhabitants)
- **35 places** in group-homes (14 / 100.000)
- **6 acute beds** in General Hospital (2,5 / 100.000)
Overarching criteria / principles of community practice in the MH Dept.

- Responsibility (accountability) for the mental health of the community = single point of entry and reference, public health perspective
- Active presence and mobility towards the demand = low threshold accessibility, proactive and assertive care
- Therapeutic continuity = no transitions in care
- Responding to crisis in the community = no acute inpatient care in hospital beds
- Comprehensiveness = social and clinical care, integrated resources
- Team work = multidisciplinarity and creativity in a whole team approach

*Whole life approach = recovery and citizenship, person at the centre*
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

<table>
<thead>
<tr>
<th>ETHICS</th>
<th>EVIDENCE</th>
<th>EXPERIENCE</th>
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</table>
| No restraint / Open door | Low rate of accidents and offense  
Low rate of compulsion / involuntary treatments | “Humane” negotiation  
Innovative practices to avoid closing doors  
Alternative crisis management  
Attention to welcoming services and social habitat  
High degree of freedom |
What is a 24hrs CMH Centre?

- An open door on the street
- A multidisciplinary team in a normalised therapeutic environment (domestic) for day care and respite, socialisation and social inclusion
- A multifunctional service: outpatient care, day care, night care for the guests, social care & work, team base for home treatment and network interventions, group & family meetings / therapies, team meetings, mutual support, relatives and other lay people visits, inputs and burden relief.
- Social cooperative home management
- Leisure and daily life support (self care; brekfast, lunch and dinner)
- And many other ordinary and straordinary things ...
Hospitalisation / 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’s inputs

- Agreed / flexible rules
- Mediated time according to user’s needs
- Relations tend to break rituals
- Continuity of care before/during/after the crisis
- Inside only for shelter /respite
- Maximum co-presence of SN
Hospitalisation / hospitality

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

Illness / symptoms / body-brain

- Open Door System
- Crisis / life events / experience / problems
How much does it cost?

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

2014:
• **Mental Health Department Network** 18,0 millions €
• 79 € pro capita
• 94% of expenditures in community services, 6% in hospital acute beds
## MHD Costs in 2014

<table>
<thead>
<tr>
<th>Category</th>
<th>2014</th>
<th>%</th>
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<tbody>
<tr>
<td><strong>Staff</strong></td>
<td>€ 9.920.000</td>
<td>59%</td>
</tr>
<tr>
<td><strong>Medications</strong></td>
<td>€ 424.055</td>
<td>3%</td>
</tr>
<tr>
<td><strong>General expenditures</strong></td>
<td>€ 2.371.984</td>
<td>14%</td>
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<tr>
<td><strong>Social expenditures</strong></td>
<td>€ 736.874</td>
<td>4%</td>
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<tr>
<td><strong>Personal Health Budgets</strong></td>
<td>€ 3.476.939</td>
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</tr>
<tr>
<td><strong>MHD Budget</strong></td>
<td>€ 16.929.852</td>
<td>100%</td>
</tr>
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</table>
Personal healthcare budgets

• In the last few years Trieste has built up the possibility of investing large sums of money to help particularly difficult patients using personalised healthcare budgets, by setting up special projects with the support of NGOs.

• 160 clients per year receive a personal budget in order to fulfil the aims of a joint and shared plan of recovery in the areas of housing, work and social relationships.

• This allowed the process of reducing group homes and developing independent living

• This represented about 17% of the overall budget of the DMH in 2011, while about 4% is devoted to economic aid, training grants, leisure and projects with NGOs (s.c. extra-clinical activities).

Moreover:

• About 180 people are in professional training every year on work grants, and 20-25 of these find proper jobs each year in the Trieste job market, many in the field of social cooperation and about a third in private firms.
From Residential Facilities to Supported Housing: The Personal Health Budget Model as a Form of Coproduction

Pina Ridente\textsuperscript{1} and Roberto Mezzina\textsuperscript{2}

\textsuperscript{1}CMHC, Dipartimento di Salute Mentale (DSM), Trieste, Italy

\textsuperscript{2}Dipartimento di Salute Mentale, (DSM), WHO Collaborating Center for Research and Training, Trieste, Italy

Abstract: During the deinstitutionalization process in Trieste, an array of different residential facilities were identified and used for different purposes in the course of time. They were integrated in the Mental Health Department and operated in close connection with 24-hour Community Mental Health Centres. Over the last decade, a steady decline in residential beds was achieved also thanks to the implementation of a health budget model in connection with a bespoke therapeutic rehabilitation program. The whole process was focused on reorganizing and transforming existing facilities...
### Dimensione storica della residenzialità

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<th>Anno</th>
<th>N. residenze</th>
<th>Persone ospiti</th>
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<tr>
<td>1997</td>
<td>30</td>
<td>174</td>
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<td>2011</td>
<td>10</td>
<td>71</td>
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<tr>
<td>2016</td>
<td>3</td>
<td>17</td>
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</table>
Diverse tipologie di abitare e genere

![Bar chart showing different types of living and gender]

- Abitare supportato: 10 Donne, 9 Uomini
- Abitare supportato - ID: 1 Donna, 2 Uomini
- Domiciliarità: 12 Donne, 13 Uomini
- Domiciliarità - ID: 16 Donne, 20 Uomini
- Domiciliarità innovativa: 2 Donne, 2 Uomini
2015 – Ospitalità sulle 24 ore nei DSM del FVG

<table>
<thead>
<tr>
<th></th>
<th>Utenti DSM</th>
<th>Archivio ricoveri SPDC</th>
<th>Ospitalità diurno - notturna CSM 24 ore</th>
<th>Presenze residenziali</th>
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<td>-</td>
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<tr>
<td>AAS3</td>
<td>3.376</td>
<td>-</td>
<td>-</td>
<td>378</td>
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<tr>
<td>AAS4</td>
<td>3.574</td>
<td>433</td>
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<td>AAS5</td>
<td>4.610</td>
<td>364</td>
<td>4.431</td>
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<tr>
<td></td>
<td>2015 Utenti DSM</td>
<td>Ammessi in TSO per residenza nel SPDC</td>
<td>Ammessi in TSO per residenza nel CSM</td>
<td>Dimessi SPDC in TSO/TSV per residenza</td>
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<td>FVG</td>
<td>19.760</td>
<td>96</td>
<td>39</td>
<td>562</td>
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</table>
Tassi (non standardizzati) di Ospedalizzazione per TSO per 100.000 residenti anni 2010-2014
Ministero Salute elaborazione banche dati SDO 2010 e 2014/ popolazione ISTAT
Posti letto totali (SPDC + Csm 24 ore)

The coops: 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 amd 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
Community health and development

- **Non-medical 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), and then expanded to include other Regional areas in the context of the Microwin project.

- 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.

- Beginning in 2008, 10 additional microareas promoted by other public/private actors (e.g. Enaip, Itis, Caccia Burlo, Salus Spa etc.).
Experience

Our purpose is to explore particularly the issue of liberty and freedom in care processes, as opposed to a vision of restraint and denial of subjectivity.

- Which practices can promote freedom?
- Can be described an operationalized?
- Which are related indicators?
- What connects key-words such as open door, open dialogue, free access, community engagement, co-production with stakeholders, recovery (also of the whole system) on one hand, and the contrast to restraint, coercion in care, special forensic psychiatry institutions?
- We need here to widen the chances for communication and acknowledge complexity.
Freedom is therapeutic

UGO GUARINO
Key words

Freedom,
Responsibility,
Democracy

(freedom is therapeutic)
Service networking with

- Beyond the acknowledgment of the value of the single individuals and the families, the need for the valorization of families and consumers as collective subjects gradually becomes imperative as far as they present themselves to the attention of the service.

- Thus at some stage in this process, a need for working out new strategies to open to more collective levels of participation starts emerging.
Peer support workers

- Peer support different from self-help
- 14 Peers trained for the CMH team and the intake
- Mediateurs de Santé paire – 3 years, Lille
- The French law on self-help
- RACT in Norway and Sweden (Ulf Malm)

- Coops in (from) the CMHCs – social inclusion workers for the diffused day care
- Associations of citizens – they also represent stakeholders
- Running clubs, cafes, music etc
Some relevant outcomes

- In 2014, only 19 persons under **involuntary treatments** (6.5/100,000 inhabitants), the lowest in Italy (national ratio: 19/100,000); 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**

- Every year 200 trainees in Social Coops and open employment, of which 10% became employees

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

- 142 “health budget” for individual rehabilitation plans

- The **suicide** prevention programme lowered suicide ratio 40% in the last 15 years (average measures)
Transferability, scalability and cost-efficiency

• This organization has become the regional model for all mh Services in Region Friuli-Venezia Giulia (1.200.000) but not for the whole country, despite the request of family and user organizations.
• Many organisations from all over the world visit Trieste every year (up to 900 persons as professionals, managers, politicians and stakeholders in general).
• Trieste is Lead WHO Collaborating Centre for service development from 2005.
• The sustainability is demonstrated because the overall cost of services provided by the MH Dept is no more than 60% of the cost of the former asylum.
• The number of people treated in a more humane system of care is more than 5000 as compared to 1200 in 1971.
Outlook & Transferability

• The practice was recognised as an experimental pilot area of mental health de-institutionalisation by the World Health Organization in 1974, became a WHO Collaborating Centre in 1987 and is reconfirmed as such until 2018.

• This means assisting WHO in guiding other countries in de-institutionalisation and development of integrated and comprehensive Community Mental Health services, contributing to WHO work on person centred care and supporting WHO in strengthening Human Resources for Mental Health.

• Because de-institutionalisation was so successful in Trieste, the community-based approach has been implemented in the whole Friuli Venezia Giulia region and is acting as inspiring model for services, organisations and countries in more than 30 countries - so far particularly in Europe, Asia, South America, Australia and New Zealand.
‘Freedom First’

• “Freedom is therapeutic” was in the 70s the motto in the Trieste experience, which is still preserving that legacy, and now “Freedom first” (as a pre-condition for care) can express some of the most significant movement stances, which over-turns power mechanism toward people empowerment.
Freedom First
A study of the experiences with community-based mental healthcare in Trieste, Italy, and its significance for the Netherlands Trimbos Institute, Utrecht, 2015
"the Trieste approach to therapy”.

1. *Ethical / rights based*

Empowerment - no restraint to recognize the individual and his/her subjectivity, recovery, autonomy, emancipation, QoL.

2. *Dialogical.*

• Open dialogue: building up a relationship on the basis of reciprocity and responsibility. Therapeutic alliance achieved through the pairity of those who speak; communicative acting (Habermas, Apel, Weick). Antipedagogical thinking. “Don't blame the victim”. Habilitation with/through
The approach

3. Meaningful
• Acting the meaning: participatory decodification of meaning between the therapeutic group and the system, including the interpretation of the service. Life-story, relevance, organized listening.

4. Ecological and systemic
• Involving the social network - Let's social system work. Factor of adherence. Mediation and therapeutic alliance, strategic interaction. Service as a network – nexus between organizational and therapeutic work.
• Social Habitat as construction of space of experience and interaction / integration.
The approach

5. Wholistic.

- Whole person whole life whole system. Perspective of a living being: Biological and complexity / identity (Morin).
- Tactical use of medication and self-administration as a value.
- Plastic modification of the brain?

In conclusion:

- From D.I. to social inclusion and recovery.
- Open door - open dialogue - open access;
- recovery and human rights.
- Passage from a medical model, based on specialization and invariance, as an application to the living being of the scientific method, based on specialization and invariance, to an olisitc approach based on the person (Theories of normalization and social role valorisation.)
Recovery and citizenship

- **Citizenship** should be interpreted as a social process that brings about individual and social transformation.
- 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, and is an economic-social fact more than a technical-scientific one.
- As we demonstrated in qualitative cross-cultural researches, a lived citizenship, ‘having a whole life’ can be captured to be at the **heart of a recovery process**, as stated by individuals themselves in their narratives.
What we would like to develop

- Coproduction (more) with families and peers, and also with community agencies
- Final closure of all residential facilities in favour of supported accommodation in people’s homes (also shared solutions).
- Overcoming the acute unit (SPDC) with a crisis team for the whole department.
- Diffusion of “freedom first” idea: a wholistic (person-centered), ecological, rights-based approach.
- More integrated youth mh services including drug addiction.
Conclusion

• This system promoted a “whole life – whole systems- whole community” approach, where ‘integration’ in a inter-multi-sectorial approach as a key word.

• All efforts in the care and social inclusion process aimed at enhancing the social capital of individuals and communities by making the best possibile use of their resources as well as the service input, and therefore propose an “ecological” approach.
Conclusion

• Comprehensiveness and community integration came first as regards to treatment specialisation and avoid the risk of service fragmentation.

• Deskilling and task-sharing, as well as task-shifting, described in low income countries practice, are operative in a western country context and proved to be effective.

• Theoretically, we can also argue that the action on social determinants is related to value of subjectivity that provides a meaningful context to care processes involving them.
A worldwide movement

• In almost every country a certain number of best practices in community mental health have grown and multiplied.
• These experiences can be defined as not only evidence-based, but also ‘values-based’.
• What they have in common is the investment in the person and his/her whole experience as citizen and community member.
Contact

• Roberto Mezzina, Direttore
• Dipartimento di Salute Mentale – ASUITS / WHO Collaborating Centre for Research and Training
• via Weiss, 5, 34125 Trieste, Italy
• +393488710355
• robottomezzina@asuits.sanita.fvg.it
• who.cc@asuits.sanita.fvg.it
• www.triestesalutementale.it