How do policies and mental health systems in Europe lead to empowerment?

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User Empowerment in MH, WHO Euro

• The importance of empowerment in disease prevention and health promotion is well recognized in the Declaration of Alma-Ata and the Ottawa Charter on Health Promotion.
• WHO Euro: “people should be empowered to promote their own health, interact effectively with health services and be active partners in managing disease”.

• The Mental Health Declaration for Europe, the Mental Health Action Plan for Europe and the European Pact for Mental Health and Well-being
• all identify the empowerment of people with mental health problems and those who care for them as key priorities for the next decades.
• Empowerment needs to take place simultaneously at the population and the individual levels.
• Empowerment is a multidimensional social process through which individuals and groups gain better understanding and control over their lives.
• As a consequence, they are enabled to change their social and political environment to improve their health-related life circumstances.
the population level

• Being **included in the society** in which one lives is vital to the material, psychosocial, and political empowerment that underpins social well-being and equitable health.

• As health is a fundamental human right, empowerment of patients and their families, friends or other informal carers is a societal task that encourages **all communities, employers, trade unions, schools and colleges, voluntary organizations to respect health and well-being of individuals** and populations and act in ways that empower individuals and groups to respect their own and other people’s rights to health and well-being.
Empowerment is an important element of human development. It is the process of taking control and responsibility for actions that have the intent and potential to lead to fulfilment of capacity. This incorporates four dimensions:

1. self-reliance
2. participation in decisions
3. dignity and respect
4. belonging and contributing to a wider community.
For the individual, the empowerment process means overcoming a state of **powerlessness and gaining control of one’s life**.

The process starts with individually defined needs and ambitions and focuses on the development of capacities and resources that support it.

The empowerment of individuals is intended to help them adopt **self-determination and autonomy**, exert more influence on social and political decision-making processes and gain increased self-esteem.
Community

• **Communities** can support individuals in this process by establishing **social networks** and mobilizing **social support**;
• these promote **cohesion** between individuals and can support people through difficult transitions and periods of vulnerability in life.

• In a **mental health context**, empowerment refers to the level of *choice, influence and control that users of mental health services can exercise over events in their lives*.
• The key to empowerment is the removal of formal or informal **barriers** and the transformation of power relations between individuals, communities, services and governments.
Outcomes

At the individual level, users and carers need to take back control by:

• developing or strengthening ways of coping with their difficulties (e.g. through personal recovery planning);

• having a real say in the treatment and care that they receive, and planning for crises so that they can exert an influence even at times of acute distress (e.g. through advance statements); and

• working towards their own ambitions and goals, which may well include employment, education, enhanced family roles and relationships.
Equality

Equal status in society by fostering:

1. respect, independence and protection in the forms of:
   – the right to **privacy**, receiving and exercising the full rights and **responsibilities of citizenship**, and being free from any kind of discrimination;
   – benefits guaranteeing a **decent standard of life**, and choice of residence and housing with full tenancy rights;
   – secure property rights, access to free or affordable **legal representation** and an absence of coercion;

2. **choice and opportunities** for personal development and social inclusion in the form of equal access to information, **employment** and peer support;

3. personal development through **opportunities** for **education and leisure**: schools, universities and libraries, and access the Internet, various leisure activities and travel; and

4. social inclusion in terms of **access to public activities**, no restriction on club membership, and no limitation on health insurance or securing loans from banks.
Theories

• Social determinants of health: social participation
• Social capital
• Social network and support
• Co-production
• Power issue (Basaglia)
• Adoption
• Human rights and empowerment
• Community development
Deinstitutionalised culture

• Community care and those practices derived from deinstitutionalization as alternatives to mental hospitals tend to overcome the separation between the "illness" and the comprehensive existence of the consumers inside the community.

• To this end they endeavored to deeply change the whole of the scientific, legal, administrative apparatus which were based on such a separation.

• As much triggered many different strategies to **restore the rights** to the consumers and to integrate the latter into social exchanges again. Therefore, a real emancipation process for clients has become feasible, even though it is far from being fully achieved.
Basic issues related to the system and the practice

To what extent empowerment is conditioned or limited by:

• The possibility of using detention and compulsion – the legislation
• The presence of locked units
• The lack of a clear open-door policy
• The lack of low-threshold, easy and friendly access to services
• The lack of rights e.g. social rights
• The lack of a discourse based on negotiation within trusting therapeutic relationships
Barriers: can a service be empowering

- If it uses seclusion and compulsion as means to regulate behaviors?
- If it is reconfirming the gap in power that users had?
- If it is driven by a paternalistic attitude?
- If it does not provide access to opportunities and resources (‘clinical’ vs ‘comprehensive’ or ‘integrated’)?
New alliances

• A peculiarity of these situations lies in the real interactions and in the new possible alliances promoted by deinstitutionalization between services and consumers.

• Most innovative community services during recent years aimed at developing their very social life, work organization and contacts with the community in a way to optimize exchanges and relationships:

  • between mental health workers,
  • between mental health workers and primary consumers,
  • between the latter and other citizens - family members, neighbors, social services, boards and associations, volunteers, etc.-).

• As much has led to the search for the access to a real participation: from setting up of therapeutic programs to any significant activity of the service.
General issues

• The passage from psychiatry to mental health is characterized in fact by the emergence of different social subjects, either individually or collectively considered.

• The plurality of the "social actors" who are involved must come to terms with the services in terms of claims and needs.
Deinstitutionalization and empowerment

• In the new scenario of community care there has been a shift from the relationship of domination/control to the therapeutic relationship, seen as a reciprocal relationship and not merely its objectification in the illness, and the rediscovery of the whole person and their subjectivity.
• From this point of view, deinstitutionalization can be seen as the change in relations of power.
Pedagogy of power (Basaglia)

- In order to transform the actors of the institutional scene and the link between knowledge and power, Basaglia examined the pedagogy of power (Basaglia and Gallio, 1992).
- By this he meant the ways in which all the actors involved, including the patient/user, can learn to use power for the transformation of existing conditions.
- Power is something that can be divided, shared, delegated, or offered as a choice in a strategy of empowerment.
- Dismantling the psychiatric hospital’s apparatuses of oppression and its hierarchy through a power-transfer was clearly a bottom-up / top-down process which aimed at this form of empowerment.
## Cross-cutting Principles

<table>
<thead>
<tr>
<th>Universal health coverage</th>
<th>Human rights</th>
<th>Evidence-based practice</th>
<th>Life course approach</th>
<th>Multisectoral approach</th>
<th>Empowerment of persons with mental disorders and psychosocial disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regardless of age, sex, socioeconomic status, race, ethnicity or sexual orientation, and following the principle of equity, persons with mental disorders should be able to access, without the risk of impoverishing themselves, essential health and social services that enable them to achieve recovery and the highest attainable standard of health.</td>
<td>Mental health strategies, actions and interventions for treatment, prevention and promotion must be compliant with the Convention on the Rights of Persons with Disabilities and other international and regional human rights instruments.</td>
<td>Mental health strategies and interventions for treatment, prevention and promotion need to be based on scientific evidence and/or best practice, taking cultural considerations into account.</td>
<td>Policies, plans, and services for mental health need to take account of health and social needs at all stages of the life course, including infancy, childhood, adolescence, adulthood and old age.</td>
<td>A comprehensive and coordinated response for mental health requires partnership with multiple public sectors such as health, education, employment, judicial, housing, social and other relevant sectors as well as the private sector, as appropriate to the country situation.</td>
<td>Persons with mental disorders and psychosocial disabilities should be empowered and involved in mental health advocacy, policy, planning, legislation, service provision, monitoring, research and evaluation.</td>
</tr>
</tbody>
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## Objectives and Targets

**To strengthen effective leadership and governance for mental health**

**Global target 1.1:** 80% of countries will have developed or updated their policy/plan for mental health in line with international and regional human rights instruments (by the year 2023).

**Global target 1.2:** 50% of countries will have developed or updated their law for mental health in line with international and regional human rights instruments (by the year 2020).

**To provide comprehensive, integrated and responsive mental health and social care services in community-based settings**

**Global target 2:** Service coverage for severe mental disorders will have increased by 20% (by the year 2020).

**To implement strategies for promotion and prevention in mental health**

**Global target 3.1:** 80% of countries will have at least two functioning national, multisectoral mental health promotion and prevention programmes (by the year 2020).

**Global target 3.2:** The rate of suicide in countries will be reduced by 10% (by the year 2020).

**To strengthen information systems, evidence and research for mental health**

**Global target 4:** 80% of countries will be routinely collecting and reporting at least a core set of mental health indicators every two years through their national health and social information systems (by the year 2020).
WHO QualityRights
Objectives

- Improve the quality of services and human rights conditions in inpatient and outpatient mental health services.

- Create community based and recovery oriented services that respect and promote human rights.

- Build capacity to understand and promote human rights, recovery and independent living in the community.

- Develop a civil society movement to conduct advocacy and influence policy-making.

- Reform national policies and legislation in line with best practice, the CRPD and other international human rights standards.
Assessing and improving services

- WHO QualityRights Toolkit
- Preparing and implementing improvement plans for service change
Capacity building

**The core mental health and human rights modules:**
- Understanding human rights
- Promoting human rights in mental health
- Improving the mental health services environment and community inclusion
- Realising recovery and the right to health in mental health services
- Protecting the right to legal capacity in mental health services
- Creating mental health services free from coercion, violence and abuse

**Specialised/Advanced modules:**
- Realising supported decision making and advance planning
- Promoting recovery in mental health and related services
- Setting up and running peer support groups
- Providing individualised peer support within services and the community
- Setting up and operating a civil society organization
- Implementing strategies to end the use of seclusion and restraints and other coercive practices *(in progress)*
- Strengthening advocacy for promoting mental health & human rights *(in progress)*
<table>
<thead>
<tr>
<th>Art</th>
<th>Accessibility</th>
<th>To be able to access and participate in all areas of life as would a person without disabilities.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Art 10</td>
<td>Right to life</td>
<td>To have the same chance as anyone else to live their lives.</td>
</tr>
<tr>
<td>Art 12</td>
<td>Equal recognition before the law</td>
<td>To be treated equally by the law and to have equal access to legal representation as well. To make decisions and choices for themselves. To identify people that they know and trust who can support them to make decisions.</td>
</tr>
<tr>
<td>Art 14</td>
<td>Liberty &amp; security of person</td>
<td>To be free &amp; safe, not be locked up just because their disability or prejudice about dangerousness.</td>
</tr>
<tr>
<td>Art 15</td>
<td>Freedom from torture or cruel, inhuman or degrading treatment or punishment</td>
<td>To be free from neglect and abuse eg. in institutions, as well as to restraint practices.</td>
</tr>
<tr>
<td>Art 16</td>
<td>Exploitation, Violence &amp; Abuse</td>
<td>To ensure people with disabilities are protected from violence and abuse in the home and in the community.</td>
</tr>
<tr>
<td>Art 19</td>
<td>Living independently and being included in the community</td>
<td>To make the same decisions about where they live just like everyone else &amp; they should be part of their communities. To they must access the full range of supports and services to enable them to lead independent lives in the community.</td>
</tr>
<tr>
<td>Art 21</td>
<td>Freedom of Expression</td>
<td>To have the right to say what they want. To have their voices listened to.</td>
</tr>
<tr>
<td>Art 23</td>
<td>Home &amp; Family</td>
<td>To lead normal family &amp; sexual lives, and personal relationships.</td>
</tr>
<tr>
<td>Art 24</td>
<td>Education</td>
<td>To have the opportunity to go to mainstream schools and have their learning and educational needs met in those schools.</td>
</tr>
<tr>
<td>Art 25</td>
<td>Health</td>
<td>To access health services on an equal basis with everyone else, and get the same standard of service as others, with their informed consent to treatment. Services must be close to where people live to make it easier for them to access and make them more effective.</td>
</tr>
<tr>
<td>Art 26</td>
<td>Habilitation/rehabilitation</td>
<td>To lead an independent and healthy a life as possible and to receive services and supports in health, work, education and social services to help that happen. To have access to peer support services.</td>
</tr>
<tr>
<td>Art 27</td>
<td>Work &amp; Employment</td>
<td>To have the right to work on an equal basis as others.</td>
</tr>
<tr>
<td>Art 28</td>
<td>Standard of living and social protection</td>
<td>To have an equal right to the same standard of living and social protection as everyone else, eg. to housing.</td>
</tr>
</tbody>
</table>
Examples of innovative practices for HRs and Recovery: toward a CRPD compliant service

• **Supported decision-making**
  - Personal Ombudspersons in Skåne, Sweden
  - Traditional models of healing, Western Maharashtra, India
  - Non-coercive alternatives to crisis by shared risk and responsibility and pre-crisis planning, UK
  - Peer advocacy (relates also to Article 13 on Access to Justice)
  - Advanced Directives

• **Reasonable accommodations**
  - Reasonable Accommodation in the Criminal Justice System
  - Custody matters
  - Reasonable accommodations for employment

• **Stakeholders involvement in care**
  - Peer support workers
  - RACT in Norway and Sweden

• **Coproduction**
  - Personal Budgets for co-planning and delivery (Trieste, Italy, National Disability Insurance Scheme, Australia)
  - Recovery services, incl. recovery of carers, recovery houses and crisis respite homes, sponsor or host families

• **Dialogical approaches**
  - Open Dialogue (Finland)
  - Trialogue (Germany, Austria)
  - The assembly model (Italy) - Have a say, a voice

• **Advocacy**
  - Associations of citizens and stakeholders: social action and advocacy against stigma and human rights violations (Italy, Spain)
Italy after reform

• Law 180 and the closure of all M. hospitals in 1999

• Implications for empowerment at the level of rights

• Association of families in the 70-80s

• User National Network in 2011

• User and carer involvement in services: Trieste, Trento (UFE), Latiano, the social cooperative movement

• The bill of a new Act that includes participation (n. 2233) has been proposed
Freedom is therapeutic

UGO
GUARINO
There is a relationship between deinstitutionalization and rehabilitation and empowerment.

- REHABILITATION AS:
  - a) A NETWORK OF RESOURCES.
    - personal resources
    - instrumental resources
    - overcoming barriers vs. handicap
  
  - b) ACCESS STRATEGIES.
    - The whole network of mental health services can be seen as a SYSTEM OF OPTIONS - an integrated system of therapeutic responses.
    - Therefore, increasing the freedom of choice for the user among different opportunities; but also
There is a relationship between deinstitutionalization and rehabilitation and empowerment.

- d) **EMPOWERMENT**: it is in relation with
  - resources
  - involvement in the services
  - training
  - information
  - social relations
  - a wider vision of the social reality
  - (socio-cultural rehabilitation)

- Opportunities **to get out of the psychiatric "circuit"** through **emancipation**: a real work, a social network, a positive social role/identity.
- Moving from tutorship to an increasing power for the user.
Social determinants of mental health
WHO and the Calouste Gulbenkian Foundation

Overview

• Good mental health is integral to human health and well being. A person’s mental health and many common mental disorders are shaped by various social, economic, and physical environments operating at different stages of life.

• Risk factors for many common mental disorders are heavily associated with social inequalities, whereby the greater the inequality the higher the inequality in risk.

• It is of major importance that action is taken to improve the conditions of everyday life, beginning before birth and progressing into early childhood, older childhood and adolescence, during family building and working ages, and through to older age.

• Action throughout these life stages would provide opportunities for both improving population mental health, and for reducing risk of those mental disorders that are associated with social inequalities.
Broad themes

Macro-level context

Wider society

Systems

Life-course stages

Accumulation of positive and negative effects on health and well-being over the life-course

Prenatal | Early years | Working age | Older ages
Family-building

Perpetuation of inequities
Global monitoring of action on SDH (2016)

• The Social Determinants of Health (SDH) are the conditions in which people are born, work, and grow old, and the power and resources that shape these daily living conditions.

• The inequitable distribution of the underlying SDH is the root cause of inequities in health.

• Action requires strong national governance, public participation in policy-making, health sector orientation, and strong global leadership, always maintaining the focus on improving health equity.
Social capital and mental health

• a person’s **social capital** is often destroyed by illness in its dynamics with the social context, in terms of discrimination and marginalization

• 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).
• It is thus a sum of relationships that an individual or group can use to advance their own interests and in this sense it can be considered ‘productive’. It is thus situated within the structure of relationships (J. Coleman, 1988).

• Social capital is measured by values such as trust, reciprocity and civil participation, and many studies have correlated it positively with conditions of mental and physical health.

• Bonding, bridging and linking s.c.
Community networks

- **Power and class structure**
- building or strengthening of networks: creating community, networking, new networks
- *culture-sensitive* and *culture-bound* programmes and the struggle for universal access to *mainstream services*, without any form of discrimination, but instead making them more flexible.
- **Tension between specificity** (ethnic origin, gender, language) and **universality**, between diversity and equality.
Exchange

• The passage towards the satisfaction of more complex needs by means of **NEGOTIATION and agreement**, and in which individuals with different aims and goals achieve those aims by satisfying the aims of others.

• It is particularly theorized by S. Enterprise.
Cooperation

• **Sharing the goals** of others

• “A reciprocal relation in which one helps the other, not for love or friendship or compassion nor, instrumentally, through some contractual form (like in exchange), but because the subjects involved have a **common interest** in realizing a goal” (C. Castelfranchi).

• **Adoption** processes in social networks.
Co-production

• ‘Co-production’, a term coined in the USA by 2009 Nobel Prize for economy Elinor Ostrom (Ostrom & Baugh, 1973; Parks et al., 1981), means:
  • **delivering public services in an equal and reciprocal relationship** between professionals, people using services, their families and their neighbours (where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change” - Boyle and Harris, 2009);
  • **recognising people as assets**, promoting reciprocity, giving and receiving (trust between people and mutual respect) and building social networks, because people’s physical and mental well-being;
  • depends on enduring relationships (Boyle and Harris, 2009).
Co-production is transformative

• Co-production has the capacity to transform public services;
• it has to be **potentially transformative, not just for the individuals involved as active and equal partners, but also for the professionals and the system**, which are required to change their attitudes, priorities and training, and act as facilitators.
• “In order to be effective, it must enable everyone to participate, not just those who are already more able, articulate and socially advantaged” (Boyle and Harris, 2009).
The Trieste model

• Trieste is an internationally known experience that started in 1971 under the direction of the great figure of Franco Basaglia, and resulted in the first closure of a psychiatric hospital in Europe in 1980 (Bennett, 1985; Dell’Acqua & Cogliati Dezza, 1986; Rotelli, 1988; Dell’Acqua, 2010). Moreover, it was also a process of change of thinking, practice and services.

• Trieste showed a different way for an innovative community mental health, that has moved from a narrow clinical model based on the illness and its treatment to a wider concept that involves the whole person – a whole life and a whole system engaging the social fabric (Zero Project, 2015; The Economist Intelligence Unit, 2014).

• The Mental Health Department is recognized as a WHO Collaborating Centre for 30 years and it is considered as a sustainable model for service development – even in a context of economic crisis, because of its clear demonstration of cost effectiveness (Mezzina, 2010, 2014, 2016).

• According to the WHO (WHO, 2001), Trieste is one of the clearest examples of how the Italian movement achieved deinstitutionalization, intended as a complex process “from within” a psychiatric hospital resulting in the gradual relocation of its economic and human resources, and the creation of 24 hour community based services together with the development of social inclusion programs (Rotelli et al. 1986).
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
Rehabilitation in Trieste

- Rehabilitation in Trieste is conceived as a program of **restitution and (re)construction of full rights (political, civil, social) and citizenship** for individuals disabled by mental illness, and the material construction of these rights. This implies:
  - a) the legal recognition of **civil and social rights**
  - b) acquiring resources (houses, jobs, goods, services, relationships) primarily through a
  - deinstitutionalization process which reconverts total institutions to community services
Rehabilitation in Trieste

- c) improving access to resources, mainly by
- developing user capabilities through
  - training (living and vocational skills, education);
  - information (psycho-education, social awareness).
- The creation of social support networks, which are managed by comprehensive community services totally alternative to the mental hospital, facilitates the delivery of resources.
Rehabilitation in Trieste

- In order to achieve these goals, it is essential to:
- **empower primary consumers**;
- provide support for family members;
- re-skill and re-orient professionals;
- provide health education and bring about a cultural change in attitudes, especially in those directly involved in providing services.

All these actions must minimize the limitations and social barriers which contribute to produce handicap and stigma, and which reinforce ill behaviour (long-term institutionalization, forensic hospitals).
Trieste

• The organization and philosophy of 24 hrs CMHCs is based on the principles of:
  • (1) easy access, non selection of demand and low threshold (i.e., not based on particular diagnoses, severity thresholds, or other exclusion criteria);
  • (2) non hospitalization and alternatives to it;
  • (3) service flexibility and mobility, proactivity and assertiveness - toward crisis and long term support;
  • (4) the involvement of multiple comprehensive resources, such as a wide range of welfare provisions, in the therapeutic and support programs (Mezzina & Vidoni, 1995; Mezzina & Johnson, 2008) and, moreover,
  • (5) continuity instead of transitions in care (Segal, 2004).

• Presently in Trieste, 94% of the mental health budget is spent in the community (18% directly to personalized and budgeted packages of care), with only 6% of the budget going to a 6-bed general hospital-based service that acts as an emergency first aid station at night.
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.
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
DSM Trieste - Data 2016

- 4,470 users in the year, mean age 55, 56% women.
- 2,439 users contacted outside the service locations, mostly in living environments
- 23 persons involuntary treated (10/100,000 adult inhabitants), 1/3 treated in the 24 hr CMHC
- Open doors, no restraint, no ECT in every place including the Hospital Unit
- No psychiatric users are homeless
- 316 users engaged in place-and-train (social co-operative societies and for-profit); out of them 25 employed in the year.
- 151 users with Personal Health Budgets.
- 18 persons in the 6-months program of Recovery House.
- The suicide prevention programme lowered suicide ratio 40% in the last 20 years (average measures).
From Residential Facilities to Supported Housing: The Personal Health Budget Model as a Form of Coproduction

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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
Personal healthcare budgets

- From 2005 **PHB have been developed** to help particularly **people with complex needs** using personalised healthcare budgets, by setting up special projects with the support of NGOs.

- **150 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 20% of the overall budget of the DMH in 2017, while about 4% is devoted to economic aid, training grants, leisure and projects with NGOs (s.c. extra-clinical activities).

Moreover:

- About 300 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.
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.
- 20 areas of the city, with an average population of approx. 1000 persons each, for a total of 15,000 inhabitants.
- **Interventions:**
  - learning about residents, verifying health conditions,
  - guaranteeing integrated 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 development and cohesion.
**REGRESSIONE DI COX**

**RISULTATI**

Hazard ratio: Microaree/Non microaree

**PSICOSI**
(ICD-9-CM 290-299)

PRIMI RICOVERI URGENTI (n. 21)
Hazard ratio **0.49** (IC95% **0.19-1.27**)

**PERICARDITI, ENDOCARDITI, DITIMIOCARDITI**
(ICD-9-CM 420-429)

PRIMI RICOVERI URGENTI (n. 197)
Hazard ratio **0.72** (IC95% **0.54-0.97**)

*Analisi aggiustata per età, indice di Charlson e indice di deprivazione*
RISULTATI

REGRESSIONE LOGISTICA

- Microarea vs Non microarea
- \geq 2 ricoveri vs 0 ricoveri

Odds ratio 0.93 (IC95% 0.89 - 0.98)
Odds ratio 0.98 (IC95% 0.93 - 1.03)

7% 7%

RICOVERI MULTIPLI

TUTTI I RICOVERI

<table>
<thead>
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<th>RICOVERI MULTIPLI</th>
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*Analisi aggiustata per età, indice di Charlson e indice di deprivazione
A parallel empowerment

• Clients' empowerment through their active participation in mental health also means accepting their contribution to further modifications of a mental health service in a common action
  - against inertia and passive dependence ties,
  - against the overall medicalization of individual and social needs and daily life problems,
  - against the new forms of institutionalization.

• It is necessary also to work on the institutional relationships.

• The room for the critical advancement of the client goes toghether with modifying the mental health worker's role: deinstitutionalizing his knowledge, his actions, demystifying his power or using it in other directions as compared to the "control of the patient", e.g.

• favouring a comprehensive approach of client's problems toward a whole life approach, by meeting the needs and by re-acquiring a status of right (that is citizenship).
Users and Community PARTICIPATION AND EMPOWERMENT

• plurality of the individuals (the emergence of the subjects)
• real interactions and alliances promoted by deinstitutionalization
• To optimize both exchanges and relationships, within the range of action of the services
• the casting of active roles, the activation and the productivity of those values which are used in relationships
• participation as a contribution to further modifications of a mental health service
WORKERS' EMPOWERMENT IN CMHS

• Developing a shared therapeutic culture.
• Not only a multi-disciplinary approach but optimization of human resources
• overcoming of the rigidities of professional roles
• different subjectivities
• different points of view
• power: decisional spaces and initiatives
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 a some stage in this process, a need for working out new strategies to open to more collective levels of participation startes emerging.
THE WORK WITH HEAVY-BURDEN FAMILIES

- As far as expulsive attitudes by consumers' relatives are over because of the comprehensive nature of community work, they are increasingly present in the services as active subjects.
- Asking questions about their experience and their role of support, they do not shirk the involvement and offer their availability for keeping their distressed next of kin within their family even in conflictual situations.
- Furthermore, family members can propose themselves as a collective subject on all accounts. They have then to be recognized as interlocutors for the service and as a therapeutic resource to be activated to a greater extent.
Working with families

• collaborative form of association and advocacy had emerged among families and it led to an active participation in the life of community mental health services, submitting problems and needs, sharing strategies for the achievement and the redistribution of resources.

• On one hand, focusing the experiences and the problems of clients' family members shouldering a heavy burden by a group-work together with professionals which aims at developing more adequate coping strategies with a view to psychoeducation and mutual-support.
Working with families

- on the other hand, the valorization of the subjective participation of the parent:
- discussion of the sense of the therapeutic work done by the service with individual families
- the burden problems;
- participated knowledge of the problem, attaching value and sense to different life paths and identifying the complexity of the meanings connected to a psychiatric crisis and condition.
Working with families

• Finally, the real opportunity of increasing the single families' social network.
• Solidarity networks emerge and self-help actions create exchanges between family members, for instance they go out together (social activities) or they support each other in case of negative events (buffer effect).
• Demands to the service can be influenced by this procedure:
  • modification in the crisis representation and relative alarm and tension; also family expectations can overcome the bi-polarity of requests, e.g. between "immediate change and recovery" or "resignation and lack of expectations".
AGGREGATION, SELF-ORGANIZATION, ACTIVE INVOLVEMENT OF PRIMARY CONSUMERS

• In our opinion, the process of change in mental health cannot deny the need for joining, aggregating particularly long term consumers who already meet in the Service and have relationships between them.

• Also when a social support is found in the service network, it is not substantial enough to enable them to overcome their social isolation.

• The use of the service can often deemed too passive, institutionalized, anomic and individualistic.

• The Others: volunteers, friends, relatives, guests, invited "experts", etc.) in order to widen the range of social roles and informational and communicative inputs proposed to the group.

• These are also "other elements" that can insert into the bipolarity of the institutional relationship (professional-user).
The first *clients' forums and group-meetings* can took place inside the Mental Health Services, guided and directed by mental health workers - or with the mediation of other agencies (volunteer organizations, consumers associations or forums, etc.).

The participation must nonetheless remain a free choice.

- Mutual support groups
- Peer support / helpers
- Young people programme: groups and psychoeducation
- Social activities
- New social spaces as clubs (CLUB ZYP): self organisation and association.
- **Self-advocacy group**: awareness of being citizens entitled to social rights and represent them to the community, e.g. media, politicians etc (ARTICLE 32).
- National conference on these issues, recovery, antistigma, rights, service improvement etc.
Human development or “THE PERMANENT WORKSHOP FOR CITIZENSHIP” (1995)

- **SOCIAL-CULTURAL REHABILITATION FOR COMMUNITY ACCESS THROUGH EMANCIPATION**
  - defined as the (re)learning and (re)utilisation of tools for decoding and interpreting (reading) reality;
  - (re)learning and gaining access to strategies of communication;
  - developing the capacity to care for oneself, and for self awareness and self expression.
“THE PERMANENT WORKSHOP FOR CITIZENSHIP”

• Specific courses, led not specialists in the area of psychiatry but *teachers*, artists and specialists in other disciplines.

• These courses are aimed at strengthening social and cultural abilities, as well as providing user access to individual itineraries of job training and pre-training.

• Various aspects of social participation, opposing trajectories of desocialisation and exclusion.
“THE PERMANENT WORKSHOP FOR CITIZENSHIP”

• Themes:
  • Social and gender identity
  • the knowledge and discovery of the community in both natural and cultural terms
  • the acquisition of linguistic and expressive abilities
  • the use of media.
THE PERMANENT WORKSHOP FOR CITIZENSHIP

AREA OF PARTICIPATION / SOCIALIZATION

ATTENDANCE AT M.H.C. / D.C.
AGGREGATION
AMUSEMENTS
HOLIDAYS
INFORMATION
INVOLVEMENT
ASSOCIATIONS
SELF HELP
VOLUNTARY SERVICE

PARTICIPATION COMMITTEE

AREA OF TRAINING / QUALIFICATION

VOCATIONAL TRAINING
VOCATIONAL SCHOOL
VOCATIONAL GRANT
COOPERATIVES
EXTERNAL FIRMS
EDUCATION
PRIMARY SCHOOL
SECONDARY SCHOOL
MONOGRAPHIC COURSES

TRAINING COURSES

ART WORKSHOPS

THATRE
PAINTING
MUSIC
SERIGRAPHY

SELF CARE / BODY EXPRESSION

LANGUAGE / MEDIA

COMUNICAZIONE SOCIALE
CURA DI SE' 1
CURA DI SE' 2
PROGETTO DI SE'

VIAGGIO NEI TEMPI...
LA FATTORIA...

ACCESS TO TERRITORY

TERRITORY / CULTURE
ENVIRONMENT

VILLA PRINZ

SPECIFIC KNOW-HOW

MODELLATURA
MAGLIERIA
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.
The importance of the "social issue" (participation, rights, power, inclusion) is linked to the role of community (mental health and welfare) service in supporting personal changes - functioning as a sort of mediator, an agency for integration. Again, the concept of social capital.

Recovery research shows that turning points in recovery experiences often coincide with interventions of the Service, when this open opportunities and activates resources (e.g. working in coop, social activities, mutual help, sports, joy, a social role, community experiences, sense of belonging, new identities, etc.).
Social participation

• The sense of belonging to a place, or a group, can provide a sense of *communality* with other people’s experiences.

• The ways of participation to the community (and of social integration) are connected to an awareness to be a citizen, and to be *part of a community*.

• Social participation can be mediated by *affiliations* to a club, to a day centre, to a shelter, to the “internet community”.

• A *political awareness* is sometimes important, as a struggle for a better society, or as a faith and trust in the welfare state provisions and opportunities; but also for a *social commitment* in various social projects to help people in need.
The passages toward social participation

• **Peer-operated or self-help groups are often the first support networks**
• These are the passages towards forms of aware social participation - to be a part of a community of peers, of a club or collective both within and outside of psychiatry
• These are characterised by a unity of values, such as diversity or gender identity, and underscore the need to belong and to adhere to a *social world*. 
Work

- From the point of view of the social reintegration, the topic of job is crucial but remains highly subjective and related to the actual job placements and the capability of the service system to afford it.
- Recovery can be seen as a by product of work, especially because of a sense of joy or happiness afterwards. Any form of structured activity can indeed hinder empowerment and recovery. The right to try different kinds of job is also important, because the adjustment to these can not be simple.
Material means and resources

- **Job** is highly subjective and related to the actual job placements and the capability of the service system to afford it.
- At least, forms of *structured activity*.
- The right to *try different* kinds of job is also important, because the adjustment to these can not be simple.
- **Educational goals**, like the desire to go back to school and learn a profession are ways for self-help and empowerment.
- A house as a **home**: a place for growth and development; a place of control; it allows balancing privacy and social life.
Work, citizenship and recovery

- Therefore a work “as a citizen” is the mainstream for defeating stigmatisation; but also education strategies can be considered.
- Work is the most important way-out of the psychiatric “circuit”
- It is not linked to a progression, as a goal; better seen an instrument, a chance during the pathway of recovery and emancipation
- Training as a discovery of self, self-exploration
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 and call-center of public agencies
- Museums’ staff
- agricultural production and gardening handicap
- carpentry
- photo, video and radio production
- computer service, publishing trade, CD-Rom
- serigraphics
- theatre
- administrative services
- Group-homes (type A)
- Parking
Peer support workers

- Peer support different from self-help
- 14 Peers trained for the CMH team and the intake
- 24 de Santé paire – 3 years, Lille (2016)
- 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
Development of coproduction of services

- **PH Budgets** for co-planning and also delivery (social coops B). Coops in the co-production.
- Recovery services: the prospect of recovery changed a lot – a framework and a direction for involvement, also recovery of carers
- **12 point Recovery charter** developed by users and in the real services
- **Recovery houses** and crisis homes: in Trieste from 2015 on, 18 persons a year
- Sponsor families
- Open Dialogue
Empowerment college

• Since December 2016, the Mental Health Department of Trieste is partner of the experimental project "Empowerment College: strategic partnership and cooperation for the promotion of innovation and exchange of proven practices", with 5 other European countries (Germany, Poland, England, Bulgaria and Holland.

• Development of training modules for people who go through or have experienced mental illness, their family members, operators and other citizens interested in mental health.

• The college is built on the basis of the Co-production and the trainers work in pairs: a specialist with a professional qualification alongside an expert by experience (experiential knowledge and professional experience valued at the same level).

• Development, implementation and evaluation of individual training modules, lasting 15 to 20 hours each, on the topics: "Let's talk about money", "My life, my rights", "Stigma and Empowerment", in collaboration with one of the group countries.
Empowerment college

• The aim is to promote and develop courses of Empowerment College to reach people who are excluded from participation in social life, and therefore from education, employment and employment, because of their mental illness and their socialization difficulties.

• The initiative can be seen as an innovative change of perspective: the symptoms, the experience with the discomfort, the scholastic dispersion, elsewhere perceived as deficiencies and inadequacies, are in this context recognized as life experiences and constitute a resource.

• not intended as a "corrective" of disorientated or disfigured lifestyles, but aims at consolidating the experience gained so far, strengthening a profitable self-determination and the revaluation of the life path (and therefore of power in the management of the process of treatment of mental illness).
The diffused day centre

• Co-production in the areas of:
• Participation, recovery and self-help (collective activities)
• Wellbeing and physical health (Gym, movement, healthy weeks, sport)
• Gender
• Expression and antistigma (Theater)
• 10 association involved
The “mens sana” Project

• 340 people
• Low dose medication (eg antipsychotics)
• Physical checks (metabolism, cardiovascular, diabetes)
• Healthy lifestyles
• Sport
The right to citizenship

- Eventually, **the right to be a citizen is the right to have a life**. Thus we must speak about entitlements: we need a social and human development that could converge, not conflict, with substantive, individual rights.

- A **possibility seems to be a focus on exclusion in society**, therefore a focus on social determinants like home, work, supports, relationships, participation and many other aspects.

- A **political and social action** must be combined with a change of institutional practice and thinking in mental health and social care.
Conclusions

A new service organization in the community:

• recognizes the **social actors** with whom it relates (in their integrity)

• implements those strategies which enable them to acquire again **sense and value** and the opportunity of representing this sense and value to the others, to the community again

• make a better use of the skills and the human resources (what we could call "**health valence**") of primary consumers and relatives, can lead therefore far beyond a **democratization** of the access to community services and an external control on the part of the community.
Conclusions

• Clients' empowerment through their active participation in mental health also means accepting their contribution to further modifications of a mental health service in a common action
  - against inertia and passive dependence ties,
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Democracy
- as the main shift in mental healthcare - implies:

• A shift from (unmet) needs to (affirmed, declared) rights - through laws. This point is connected to addressing social determinants of health, that is “the way people live”, their quality of life, and it is now addressed in several ways, e.g. through personal budgets.

• A shift from hospitalization of an “inpatient” to hospitality of a guest” in a community facility, such as CMH Centre.

• A shift from the monologue of psychiatry (and of the psychiatrist), that is based on a judgement of diversity, to listening and dialogue (not only as a specific therapy), and trustee relationships.
Shift

• A shift from **power on** - (a person subjected to a power), through the pedagogy of power (Basaglia), toward empowerment, that is bottom-up, or **power with** - (shared power, power of the subjects).

• A shift from seclusion and restraint to **freedom first!** as the fundamental move of deinstitutionalization. Acceptable care is the first step to achieve an accessible care, and then to fulfill the right to the highest attainable degree of health.

• A shift from **individual to collective rights**: awareness of citizenship, self reflection on a person social life. Citizenship is exercising rights and acting rights, not just a status but a development, and it includes civil and social rights (work, house, social roles).

• All of this can be called human rights.
Shift

- A shift from guardianship to free will, from imposition to negotiation (working out micro-conflicts), toward a therapeutic alliance, shared decision making and self determination.
- Finally,
- The paradigm shift from illness to the person in a whole life view (the kind of life we want) and a whole system of care and support, with all stakeholders involved and the community.

- Capability to deal with power issues and microsocial conflicts (Mezzina et al. 2018; MHEN, 2017) is based on a form of empowerment that recognizes “the other” in a conversation and a negotiation towards a therapeutic alliance that respects people’s wills and preferences and that is displayed in their living environments (on ‘their turf and terms’).
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