The person in the community: a paradigm for recovery and social inclusion 30 years after deinstitutionalization in Trieste, Italy.

Roberto Mezzina,
Director, WHO CC, MH Dept., Trieste
A paradigm shift, between rights and institutions

• The existence of a scientific status for psychiatry
• Psychiatric knowledge and existing institutions
• Franco Basaglia’s “destruction of PH as a place of social exclusion” (1964)
• Italian way of deinstitutionalisation
F. Rotelli

• - mobilising all the actors involved in the system of institutional action;
• - giving absolute priority to transforming the power relations existing between the institution and all the subjects with which it is involved, beginning with the patients;
• - understanding deinstitutionalisation as a homeopathic process that uses the internal energies of the institution in order to dismantle and deconstruct it;
• - ‘freeing society from the need for internment’ by establishing completely alternative services.
Paradigm clash?

• the neo-positivist and reductionist view of ‘illness’ as a mere biological fact
• The complexity of existence and innovative cross-cutting research
• What do we mean by “mental health” today?
• The question of universal human rights
• From danger to risk, the issue of social control
• Legislation and whole life
Paradigm clash?

• Social exclusion
• Community healthcare
• Mental illness as a disability?

Comprehensive community mental healthcare systems
• Inter-sectorial integration and collaboration among services, and between services and a specific NGO
• How can a community’s human, economic, social and cultural resources be activated? And sustained?
Experiences and innovation - managing contradictions

• strategic political-healthcare governance vs. general population focus;
• professionalism vs. the inclusion of all main stakeholders;
• clinicalised, specialised, centralised, hospital-based services vs. integrated, comprehensive, decentralised, small-scale, low-threshold services
• a budgeting system based on individual services and DRG vs. a personalised integrated budget
• institutional resources vs. energies of community, if services are capable of catalysing and activating them.
Related questions

• is the mental healthcare system separate from or integrated with the general healthcare services?
• Is it organised in specific service locations/structures or is it provided within the community?
• are services generalised or specialised?
• is the tension between the community and specialised services resolved?
• are there places for acute and crisis care outside of the hospital?
• are there “user-led” programmes, where service users play a leading role, and the third and fourth sectors effective partners, co-decisionmakers and co-managers in the healthcare system, with the aim of promoting a more democratic participation?
evidences

• Qualitative ad quantitative research
• medicalisation, technocracy, political-economic blocs, healthcare policies linked to performance indicators and the involvement of experts in government decision-making
• Do all stakeholders have a voice?
• are true ‘health’ indicators drawn up and adhered to?
Comprehensive community mental healthcare systems

• Beginning with local mental health, to what extent was it possible to create a level of inter-sectorial integration and collaboration among services, and between services and a specific NGO, so as to guarantee a systemic impact/approach to community healthcare? What were the key elements involved?

• In what way is a systemic approach to healthcare not limited to merely creating a system of services? What are its strengths, sources of energy and components?
Comprehensiveness and resources

• Is it possible to create a comprehensive healthcare system for a specific community which can respond to the healthcare needs and personal aspirations of users, while promoting health in the community as a whole? And if so, how?

• How can a community’s human, economic, social and cultural resources be activated, mobilised and co-ordinated in operational terms? Are there mechanisms which can guarantee economic sustainability, especially in poor countries?
Crisis and human development

- The current historical-social situation, characterised by the present **social and economic crisis**
- **personal and collective security, lifestyles, values and the possibilities of survival.**
- The general issue of **society and risk**
- The personal crises taking place within the global one, contain either the possibility of **new solutions or a return to institutional expulsion**
- The global crisis underscores the need for a **different development model**, both for advanced capitalistic countries and those with low/medium incomes.
Issues

• Recovery of people with complex needs using **personalised healthcare budgets** – possibly by direct payments - as tools for addressing rehabilitation and comprehensive responses

• Development of a full range of community dwellings and **supported housing**, from sheltered homes to individual home daily life support

• Mental health departments should promote **social enterprises** in Italy (results from a national research indicate that this is the main way for work inclusion).
Challenges and opportunities

• In the specific area of social-healthcare services, the question of resources
• How recover wasted resources, to providing essential social and healthcare responses that reduce the increasing levels of inequality
• How free-up the human and professional resources present in the community and hospital healthcare services, and in local social services
• How re-think the structures and places where care is provided, and how create social habitats
Psychiatry is a form of social action or practice?

- How recover the ethical and political dimension in healthcare work, opposing those who commit ‘peace crimes’ against men and women, old and young alike, by experimenting innovative practices that benefit both the individual and the whole community?
- How bring together and give effective form to the planning and practices that arise out of individual and collective crises (economic and “natural” disasters, wars) and the daily life of our communities?
Towards the global network

• Networks of innovators, regional experiences, individuals
• A platform and key-elements transmitted also to society at large
• Literature and real experiences
• IMHCN, 2001
IMHCN requisites

• 1) Developing public mental health systems that met the following standards:
  • Psychiatric hospital either shut down or on the way to being eliminated
  • Development of a network of community services, integrated in its components as well as with local social-healthcare services, capable of responding on a 24hr basis and operating out of structures which are as non-restrictive as possible.
• 2) Recognition that the primary value is the person, the primary goal the quality of life and the primary reference accountability to the community.
• 3) Reciprocal exchanges with the many collective entities the services enter into contact with: users, family members, associations and other social/political actors within the community.
• 4) Commitment to disseminating innovative practices and providing the necessary training for operators.
• 5) Commitment to working to change mental health and human development policies at the regional/national level, including modifying the legal framework.
A new know how

• Alternative practices to asylum
• Vision and local-global issues
• Transformational knowledge / know-how
e.g.

✓ integrated CMHC, social cooperatives, deinstitutionalization of the mental hospital (Trieste),
✓ host family schemes, practices for community integration (Lille),
✓ user involvement, 24-hrs. opened centres (Stockholm), integration with primary care, social firms (Oviedo, Andalucia),
✓ recovery and peer support programmes by networking with all community organisations (Plymouth),
✓ mobile integrated teams as a total alternative to institutions in a rural community (Monaghan)
✓ etc
Networking

• Risk of isolation and exclusion
• Operators hope and view – not the illusion of medicine in psychiatry
• Consumers and carers active role, ‘actors’
• Mental health and whole life, that values human experience
• Act in the community, that is called upon to participate
Today’s features 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 2011:**
  - 90 beds of different kind in the community:
  - 24 community crisis beds available 24 hrs. Mental Health Centres (14 / 100,000 inhabitants)
  - 6 acute beds in General Hospital (3 / 100,000)
  - 60 places in group-homes (23 / 100,000)
Some relevant outcomes

- In 2010, 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.
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
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.
The passage from psychiatry to mental health can be seen as a movement from total institutions to organizations of human services, featured by programs, provided by resources, based on relations, which define the pathways of the "demand" for mental health as a "circuit".
Shift No 2

- from “specialized” services (taylorism)
- → fragmentation

- to comprehensive services:
  - person as a unity
  - vision of human beings
  - continuity of care
    (“projects for life” more than mere therapeutic or rehabilitative programs)
Shift No 3

• from services provided, measured by outcomes (effectiveness or efficacy)
• to options/opportunities
• A personal(sized) “route” toward recovery or emancipation
Shift No 4

• from formal (civil) rights, guaranteed by legislations

• to social rights – house, work, etc (citizenship)

• therefore to all politics contrasting social exclusion and providing resources and access to

• social inclusion
Outcomes: how people experience the paradigm shift

Levels of freedom:

• choice
• Opportunities
• alternatives at each phase of the process
• access and way out of the service network / patient’s role (informal, self refer, walk-in, no waiting lists, no selection).
Outcomes: how people experience the paradigm shift

• Power is not only now avoiding institutional seclusion but having a voice, a say through participation and involvement
• in own individual care plan
• in the services’ life
• in any moment of direct democracy
Conclusions - The Paradigm shift

- The neo-positivist illusion, which sought to govern illness by acting upon the symptoms and/or otherwise confining the ill person in extremely restricted spatial-temporal limits.
- The paradigm shift:
  - the passage from the model for simply “treating illness” to the model of a response to real, tangible needs, and thus also the psychological and highly subjective needs (or, as the sociologists say, post-materialist needs) of the person who is in a state of suffering, helping them in their often long and difficult journey of recovery and, if need be, of emancipation.
P Shift

• Our choice is founded on the simple but radical observation that, by now, the greater part of the life-cycle of a person who suffers from a severe mental disorder takes place outside of the institutions.
• Once the community is accepted as the new scenario, the challenge will be to demonstrate the ability to adopt practices that are alternative to segregative and total institutions.
• Functional, effective, acceptable
The person and not the illness at the center of the process of care for recovery and emancipation through users’ active participation in the services

(up close, nobody is normal)