Recommendations for the phasing out of psychiatric hospitals: results from a qualitative research

Good Practice Services: Promoting human rights and recovery in mental health
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The Trieste Declaration 2011

The Trieste Declaration 2011 was approved and signed by all the delegates attending the meeting “Beyond the walls: the transition from hospital to community based care. Deinstitutionalisation and International Cooperation in mental health”, Trieste, 13 – 16 April 2011, that was attended by 300 participants from 28 countries - 21 of them European - representing national and local institutions, projects and civil society organizations, the World Health Organization, the European Commission (Directorate General for Health and Consumers - DG SANCO), governments, NGOs and international networks.

It has been signed by the Director of the WHO Department of Mental Health and Substance Abuse in Geneva, Dr. Shekar Saxena, and Regional Director for Mental Health-WHO Copenhagen, Dr Matt Muijen, as well as by organizations like IMHCN, MHE, GIP, WAPR among others.

The Declaration was officially sent to WHO and the European Commission.
Methodology of the research

- Qualitative research

- Aims:
  - To verify the content and the theoretical background of the Declaration
  - To gather evidence, know-how and good practice of deinstitutionalisation

- Semi-structured in-depth questionnaire on the process of gradual phasing out mental hospitals

- Purposive sampling of protagonists of the process of deinstitutionalization with a specific experience in working on the field

- 2 cohorts: 2011 and 2018

- From:
  - 12 European countries
  - 3 from the American countries
  - 2 from Asia
  - 2 from Australia and New Zealand
Participants 2011

- Jan Pfeiffer, Consultant Psychiatrist, Czech Republic
- Theodore Megaloeconomou, Psychiatrist, Psychiatric Hospital of Attica, Agii Anargiri Mental Health Centre
- Francis Silvestri, President and CEO of International Initiative for Mental Health Leadership (IIMHL)
- Hristo Hinkov, Deputy Director of National Center for Public Health Protection, Bulgaria
- Stojan Bajraktarov, Psychiatrist, ass.Prof. University Clinic of Psychiatry, Skopje
- Esmina Avdibegović, MD neuropsychiatrist and social psychiatrist, Department of Psychiatry, Faculty of Medicine University of Tuzla, Bosnia and Herzegovina
- Alexandru Paziuc, psychiatrist, Romania
Participants 2018

- **Abdul Kadir Abu Bakar**, Psychiatrist, Medical Director at Permai Hospital, Malaysia
- **Vladimir Jović**, Professor at the Faculty of Philosophy, University of Priština (K. Mitrovica), International Aid Network, Belgrade
- **Lille – WHO.CC Staff** EPSP Lille Métropole
- **Víctor Aparicio Basauri**, Psychiatrist (Former Regional Mental Health Director from Asturias Region-Spain)
- **Margaret Fleming**, Fellow of the Faculty of Nursing, Royal College of Surgeons of Ireland
- **Steven P. Segal**, Professor and Director of the Mental Health and Social Welfare Research Group, University of California, Berkeley, USA & Professor University of Melbourne, Australia
- **John Jenkins**, CEO IMHCN, United Kingdom
- **Rossana Seabra Sade**, UNESP University, Marilia, Brasil
- **Milan Stanojković**, Neuropsychiatrist, Director of Special Psychiatric Hospital “Gornja Toponica”, Niš, Serbia
- **Peter McGeorge**, Associate Professor Univierities of New South Wales and Notre Dame (Sydney)
- **Hugo Cohen**, Psychiatrist, Master in Public Health; Mental Health Advisor In El Salvador; México and WDC, 2000/2006; Pan American Health Organization-PAHO; Mental Health Advisor for South America, 2006/2015; PAHO; Mental health Program Coordinator; Ministry of Health, Río Negro Province - Argentina 1985/2000
- **Ernesto Venturini**, Ex Direttore DSM Imola, Esperto della Cooperazione Italiana allo Sviluppo (Ministero Affari Esteri), Consulente OPAS/OMS per l’America Latina
- **Tasneem Raja**, Job Title LEAD- Mental Health, Health, Tata Trusts (Regional Mental Hospital, Nagpur)
Six areas of investigation:

1. The meaning of ‘deinstitutionalisation’
2. How to deinstitutionalise
3. How transform hospital-based psychiatry (staff culture)
4. Changing relations with the user
5. Changing the organisation of life in the hospital
6. Macro interventions and deinstitutionalisation policies
Two Analysis methods

1. Categorical analysis using the principles of *Grounded Theory* and

2. Thematic analysis

- Inductive identification of:
  - key-words
  - national and local examples
  - discrete definitions
  - diversions and contradictions
  - controversial issues
  - essential system components (services and programs)
  - quotations from texts or official documents
Preliminary results

1. The meaning of ‘deinstitutionalisation’
1.1 In what way and to what extent do certain ‘contextual’ characteristics of psychiatric hospitals influence deinstitutionalisation?

- Social and economic impact of psychiatric hospital on the community
- Isolation and detachment from community and other services
- Being alone in the place: lack connections with others community resources
- Psychiatric hospital as place for acute/chronic
- Public/private management of psychiatric hospital
- Psychiatric hospital as a static element in its own right
- Institutional thinking and practices: rigid and paternalistic style of work/staff focus on illness and control
- Psychiatric hospital’s disabling setting hinders recovery and civil rights
- “hospital-centrism” of financial, social and human resources
- Staff personal personal needs preserving the status quo
Psychiatric hospital with its characteristics of long term (sometimes a life-long) treatment and accommodation of patients with mental disorders; its patronising approach; isolation; application of violence; directing the treatment only towards the illness and a hospital staff – patient controlling relation; role of a society guardian from patients with mental disorders; abuse of power; and its non-profitability mainly influenced the beginning of the deinstitutionalisation process. EA

The decrease of psychiatric hospitals accompanied with changes within the approach towards persons with mental disorders and creation of alternative services within the community represents deinstitutionalisation. EA

Abolishment of psychiatric hospitals without changes of praxis in respect to the approach towards persons with mental disorders represents only an administrative act which can result in forming new institutions with the same or similar praxis but without the psychiatric character. EA
1.2 Can the downsizing of phs, to the extent of closing them (suppression) be considered deinstitutionalisation even if not accompanied by a reconversion into networks of alternative community services?

- De-hospitalisation as administrative deinstitutionalization leading to trans-institutionalisation / worsening users’ lives
- Real deinstitutionalisation when changing practices toward recovery and human rights respect and users’ needs support
- Real deinstitutionalisation when community alternatives are developed
Not just downsizing, de-hospitalization or trans-institutionalization, but reconversion to a comprehensive CMH System that meets all the needs of people with different MH issues; change the approach, empowerment and active role of users. Preparation for community living - *except for a relatively small number of people (PMG)*; reconversion of human resources most difficult, better new staff?
1.3 Is the contribution/support of political-administrative decision-makers necessary in order to guarantee the process, or can/should technicians operate autonomously?

- Role of national and local political/administrative decision-makers in:
  - Declarative support to deinstitutionalisation process
  - Implementing new laws/policies and shifting the organizational culture
  - Planning and financing alternative services in the community
  - Support integration with other social institutions

- Role of technicians in starting the process (but need connections to carry on it)

- Role of community stakeholders involvement in policy framework and implementation of this "health democracy"

- Complex synergy of political, administrative, technicians and community in successful deinstitutionalization process
1.4 Explain your understanding or give a broad definition of the concept of deinstitutionalisation

- Downsizing and closure of psychiatric hospitals
- Reorganisation of mental health services and change in staff's style of work
- Development of a comprehensive range of alternative services in the community
- Users/family involvement in services development and management
- Focus on rehabilitation, recovery and civil/human rights
- Cultural shift on mental health
- Support users’ decision-making and social inclusion
- Focus on prevention
- Moving resources to the community services
• On one hand: the process of closure or downsizing of large psychiatric hospitals and the establishment of alternative services in the community. *The deinstitutionalization is just in one part related to downsizing and final closing of psychiatric hospitals.*

• On the other hand, it is *the expression of a holistic and integral vision of human being.* It could be described as a full humanization - in the widest sense - as antithesis of dehumanization of PH, with a focus on the whole person, promoting independence, personal growth, achievement of personal potential; where users are experts and active participants in care, personal life and wellbeing, free from stigma ad discrimination, for their own recovery and citizenship.

• A radical paradigm shift, changing the old institutional thinking and practices - against the risk of reproducing the old culture in the new community services. *A complete change of attitude and culture: The whole society with its all possibilities take responsibility for comprehensive treatment.*
- Go beyond seclusion, segregation in MH; change the where and how care is delivered, centrality of users: sense of individuality, control and power on their life, as normal life, social life and contribute to community.

- Choose the system of support they need - not just clinical options; involve also families and the social; re-establish civil rights and status as any other vulnerable person.

- Changing the old relation between PH and persons with MD (and the society): a person with mental disorders needs to be recognized as a person with all social values, as individuals with personal history, individual vs institutional needs, through reciprocity, negotiation, normal conditions of life, social inclusion. It requires a comprehensive list of (local) community services.

- Not only: transformation of exclusion presented as a treatment into a proper care by the community; development of support for mental health disorders in the community by all social actors (not just the health sector).

- It requires more than a healthcare system, a coordinated interdependent whole systems approach which includes multi sectoral collaborative alliances. Empowerment: the promotion and inclusion of users and families in policies elaboration and treatment decision.
Exemplary shared definition

- **In summary, D.I. is**

- 1) a process to help the users to recover all human rights and the role like citizens with a new type of mental health services in the community where the users are the active subjects to decide their care;

- 2) a process that seeks to unleash the potential of people to know and express themselves as individuals, have their strengths and personhood recognised and respected, allows them to make and participate in critical choices that affect their personal lives and well-being, be free from stigma and discrimination and participate in and contribute to society as citizens.

- 3) Far beyond a mere humanization, it is an individual and collective process of emancipation and liberation, from the denounce of institutional violence to the fight against norms and disciplines that regulate collective life and affect social relationships.
The deinstitutionalisation process offers people with mental health disabilities the chance to feel respected, encouraged and helped in their effort to have a normal life, the permission to live in the community and to enjoy a social life, at their own rhythm, offering them the opportunity to work, to feel useful and responsible, to contribute to the wellbeing of the whole community.

AP

The deinstitutionalization is a process to help the users to recover all human rights and the role like citizens with a new type of mental health services in the community where the users are the active subjects to decide their care. VAB
1.5 indicate some possible negative effects of an incorrect or distorted deinstitutionalisation process

- No change (system continues as previous)
- Hinder future deinstitutionalisation attempts
- Go back to reinstitutionalisation and revolving doors
- Trans-institutionalization in forensic, social, private institutions
- Double system (when surviving of psychiatric hospital): more fragmented and less efficient system
- Lack of alternative services in the community
- Bad services in the community: poor quality, unsafe conditions, inadequately designed/equipped

- Bad working conditions: untrained/insufficient staff
- Bad practices: seclusion/restraint, no integration with others, no recovery-focus and individualised practices
- Abandonment/homelessness
- No social inclusion nor human rights support
- No adequate care/rehabilitation/rehabilitation paths
- Worsening of physical and mental health and of living conditions in the community
- Negative effects on families
- Negative effects on community: stigma arising
Trans-institutionalization is defined as the moving of mental health clients from one institution, such as a mental hospital, to being dependent on another type of institution, such as a shelter, community hospital, jail, nursing home facility, room-and-board facilities. It is a consequence of an incorrect D.I. and / or not carefully planned alternatives and staff practice changes. Distortions are: investment in improving institutions only, not developing (sustainable) cmh services, not targeting inpatients of MH (leaving them behind), not changing institutional culture – procedure and processes (leading to small institutions in the community eg residential or social care), developing cmh services not reducing capacity on PH. Shifting responsibility for severe patients. Lack of consumer & family support. No preparation of society to accept patients. Transfer to social institutions (for “incurable cases”), prisons, forensic, residential care. Renaming institutions eg social care. No recovery, no rehabilitation. Staff training and recovery (of their own humanity and professionality). Rapid shifts of environment. EFFECTS: “Falling through the cracks in the system” leads to unmet needs, isolation, stigma, discrimination, homelessness, absence of relationships. Increasing relapse.
Definition of trans-institutionalization

- Trans-institutionalization is defined as the moving of mental health clients from one institution, such as a mental hospital, to being dependent on another type of institution, such as a shelter, community hospital, jail, nursing home facility, room-and-board facilities. MF

- If the deinstitutionalization would be understood, first of all, as a process of decreasing of hospitals bed number and closing-out of psychiatric hospitals, I'm convinced that, although CMHCs will be formed, many of psychiatric patients with chronic psychoses will be still institutionalized in some way. MS

- The process can get stuck resulting in it being incomplete with people remaining in hospital care and/or those that have been transferred not having access to services of sufficient quality to maintain their recovery process. PMG
Preliminary results

2. How to deinstitutionalise
2.1. Can PHs be downsized or suppressed only if community structures/services are already in place and functioning, or can the reconversion process take place contemporaneously? Is a new allocation of funds required?

- Contemporaneous and parallel PH downsizing and alternative services developing
- Using PH functions to implement community
- Develop new community services before closing down PH
- Inverse temporal relationship PH - alternative services
- Uncertain
- Frail community services
- Change hospital approach to prevention/treatment
- Specific strategies to implement alternative services in the community in relation to a population’s needs
- New funds allocation specific for community services
- Reconversion: transferring funds from psychiatric hospital to community services
- Risk lack of resources: financial and human
Re-conversion is required and will take place at any step, after careful planning. CB service development must resonate with changes/closures within the hospital e.g. closure of beds/wards. Bridging funds are necessary for initiating the process; gradual and parallel development of CB services; possibly with precommunity services. CMHCs will appear as new services and psychiatric hospitals will still provide inpatient treatment for great number of long-term hospitalized patients. Two parallel systems create increase of costs, concurrent relations and strengthening resistance of institutions towards the transformation. Money should follow the user, but austerity measures and lack of clear policy guidance can hinder. Anyway CB services already in place can not expose to the risk of failure and regression. Alternatives to hospitalization; defining duration of hospitalization; secondary prevention, housing.
2.2 is it necessary to operate from within the institution or can the process be activated externally?

- **Within:**
  - Vision and leadership
  - To mobilise institutional resources and change institutional mechanisms
  - Institution’s staff has to take responsibly
  - Patients involvement and empowerment

- **External:**
  - Political/administrative support
  - Community sensitisation, awareness and involvement
  - Ngos and associations
  - Other public services involvement/pressure

- **Uncertain**

- Complex internal and external cooperation and antagonism
• Complex system: systematic and wide process, involving political supports and intersectorial cooperation. Institutions as closed systems resistant to change, and only inherent willingness of the institution allows evolution.

• Vision and strong effective leadership are required, but also know how of international bodies.

• Primary interventions start from inside, initiated by professionals (work with patients and staff), also helped from outside: legislation, campaign, advocacy, social action for social inclusion, work with NGOs, families, partnerships with community organisation and groups. Often starts outside and even can be stimulated by stakeholders.

• Focusing on patients’ rights, on inhuman treatment in huge institutions can accelerate through awareness in the whole society that mental inpatients are excluded and isolated.
• The winning strategy is naturally to operate simultaneously from within and from outside. I called this process to bring the outside in and the inside out. This is what we spontaneously started doing in Trieste by opening the doors of the PH. Pre-community services for transition on 3 axes: 1. Bring back inpatients to the community; 2. Stop new hospitalizations; 3. Create services for patient with less autonomy capacity. EV

• The process of deinstitutionalisation can be started with activities outside the institution and activities inside the institutions. No matter where the process is started parallel activities within the institution but also outside the institution are necessary. Within the institution, especially important are activities related to the work with patients in respect to their strengthening, raising motivation and faith into a life possible outside the institution, also the work with professionals in respect to adopting new professional skills and rolls, involvement of volunteers and family. EA
2.3 Can the number of beds be reduced in ways other than by administrative acts?

- Clinical ways of bed reduction: range of community services and specific treatment interventions/models
- Non clinical ways of bed reduction: supporting patients’ needs to live the community
- Administrative way of reducing beds: strategies and limits
- Focus on prevention
- Working with community to promote awareness and wellbeing: formal and informal actors involvement
- Innovative approaches to mental health issues
- Replacing beds solution in the community
• Administrative decision and way of financing are factors affecting the number of beds. *Without administrative acts and pressure there is no ground for real de-institutionalisation.* Reduce beds reduces demand of - It can accelerate the process, e.g. to shift out the long stay beds, but it is also a risk; better plan how to replace with corresponding comprehensive CB services with related resources. Beds can be reduced *if there is in place a community care system.* Hospital staff must be retrained as community workers—i.e. deinstitutionalized. *New community service system and introduced in the first 2 to 4 years of the change process to see the results of reducing hospital bed numbers before the number of beds in the community are decided.*

• *The problem today is no longer to fill the beds, but to prevent people from being hospitalized.* This if we could start with new practises to enhance discharge and stop admissions first.
• A CB MH service must address prevention, early detection, early intervention and mental health promotion.

• Community teams (proved to be cost-effective) to provide crisis home treatment, EIP, and GH units, PHC, also self help, IPS, peer support, crisis houses, foster families, even church, and specific practices (OD, hearing voices, trauma informed care etc) etc but also prevention in the city: local community mental health awareness & promotion, antistigma and discrimination campaigns, local health councils.

• Partition of responsibilities between CMHC and psychiatric ward (GH) in Serbia.

• *Enhancing acute care community services with holistic appraisal of a person’s needs, assertive outreach, strategies aimed at improving the general health and well-being of consumers and formal collaboration with GPs and NGOs.*

• Reduce the need of institution in the social field by looking at the non-responses to needs in person life story.
• Bed use can be reduced **if there is in place a community care system.** Housing placement is a necessary condition and the ability of have **hospital staff (retrained as community workers—i.e. deinstitutionalized)** provide monitoring, respite care, vocational and social opportunities. SS

• Some **community teams** have shown to have an effective of reducing acute beds, home treatment, crisis teams, crisis houses, host families. Some **practices** are also showing effective means of avoiding hospital admissions, Open Dialogue, Recovery tools, Hearing Voices approach, Trauma Informed Care, Psychological therapies. etc.

• These need to be a part of the **new community service system and introduced in the first 2 to 4 years of the change process to see the results of reducing hospital bed numbers before the number of beds in the community are decided.** JJ
2.4 What happens if the implementation of the process is incomplete, i.e. if the ph remains, but with a reduced capacity?

- Psychiatric culture replaces deinstitutionalisation
- Delays in complete closure of ph
- Risk future reversal of the deinstitutionalisation process
- “Perverse opportunity”: ph kept as the last option of the mental health services
- More expensive two parallel models system
- Distortion of community services: persistence of the old institutional culture in the new services
- Maintenance of stigma on people with mental illness
- Risk of transinstitutionalisation / homelessness
2.5 Is it possible to resolve the problem of the ‘hard core’ of patients?

- Individualised approach with consideration of patient’s needs
- Not use it as a justification for ph survival
- Specific residential facilities for long term support
- Collaboration with social services
- Complex community recovery-focused interventions
- Organisational issue in planning community services
- Expensive issue
- Ethical issue: no abandonment
2.6 Do high-, low-, or mid-income countries each have their own specificity?

- Differences linked to national income level:
  - Amount of available resources
  - International organisations influence
  - Institutional answers to the population needs
  - Sociocultural aspects

- Differences linked to political decision about social and health system

- Deinstitutionalisation as a goal despite income differences

- Limits despite high-income

- Ph are the same everywhere: “invariance” of the ph issue
Preliminary results

3. How transform hospital-based psychiatry (staff culture)
• criticism of psychiatry’s custodial mandate and the re-elaboration of the mandate for control;

• abolishing practices of violence and restraint as a form of institutional management vs ‘no restraint’ at all levels;

• top-down vs bottom-up lead of change;

• contributions of new, diverse actors who are not part of ‘normal’ institutional life (e.g. volunteers, citizens, artists, intellectuals, family members, non-profit organisations).
3.1 Is the criticism of psychiatry’s custodial mandate and the re-elaboration of the mandate for control a prerequisite for the active deinstitutionalisation process?

- Strong criticism essential to institutionalisation process
- Avoid excessive criticism: finding alternatives and setting examples of mainstreaming work
- Criticise ph design and functioning
- Educational process of the staff and indirect approach to the issue
- Staff change view/attitude toward patients needs and human rights
- Cultural resistance of the institutional approach
3.2 Is it possible to abolish practices of violence and restraint as a form of institutional management vs ‘no restraint’ at all levels?

- Violence/restraint abolition as a goal of deinstitutionalisation
- Complete abolishment of violence/restraint or nothing change
- Validity of some form of violence/restraint in specific situations
- Wide range examples of restrictions still existing
- Barriers to complete abolishing of violence and restriction

- Social focus on risk and security
- Abolish restraint/violence through:
  - Users participation in individualised care and recovery plans
  - Culture and respect of human rights
  - Moving toward a different approach: dialogue and negotiation
  - Environmental changes
  - Different policies forbidding them
  - A completely different staff training
  - Patients/family education and involvement
  - Prevention by community mh services
3.3 Top-down vs bottom-up? What kind of leadership?

- **Top-down:**
  - Need of political support
  - Historical way to deinstitutionalisation

- **Bottom-up:**
  - Community pressure to politicians,
  - Users and families empowerment and involvement in decision-making
  - Team members taking roles and responsibilities
  - Need of a proper coordination

- **Both directions**
  - Having the right leaders at each level
  - Participate leadership and shared responsibilities
  - Strong single leader in chief
3.4 How empower staff?

- Staff meeting and shared work
- Staff training and supervision
- Visits and comparisons with other experiences
- Staff valorisation: role, responsibility, reward, satisfaction
- Relationship with users
- Staff involvement in decision making and service planning
- Role of the leaders in staff empowerment
- Removing “bad” colleagues
3.5 How and how much can the contributions of new, diverse actors who are not part of ‘normal’ institutional life, influence the process?

- Who (formal and informal actors of the community)
- Conflicts: institutional resistance to the new actors
- Roles/functions of other actors collaborating with mental health services
- Influence policy makers
- Community
- Sensibilisation/awareness to mental health issues
- Reduce stigma in the community
- How to include new actors in the deinstitutionalisation process:
  - Included as part of the mental health team
  - Local and national forums
- Training
Preliminary results

4. Changing relations with the user
Changing institutionalised behaviour, responding to needs, listening and reconstructing life stories, restoring voices, instigating and sustaining empowerment, creating participation
4.1 How can institutionalised behaviour be changed?

- Adopting new principles in mental health services
- Changing service organisation
- Staff education/training
- Staff composition and hierarchy
- More equal relationship users-staff
- Focus on users rehabilitation
- Promote users empowerment and decision making
- Community services’ relationship with community and social inclusion
- Fighting stigma
- Change culture
- Long process
4.2 What is important for transforming the institutional relationship?

- Service values focused on human rights and community practices
- Service reorganisation
- Innovative leadership
- Political/administrative support to community services
- Work on staff attitude toward patients
- Promote users’ empowerment and decision making
- Put users’ needs at the centre
- Good communication between professionals, users, families and community
4.3 How restore voices, instigate and sustain empowerment, create participation?

- Users involvement in community services’ planning and management: the peer support workers role
- Co-construction of the mental health system: users, professionals and representative of the civil society
- Support users empowerment and social roles
- Meaningful activities by the community services aiming at users’ real recovery
- Family involvement
- Staff approaching users as whole person
- Staff exploring a more creative role
- User movement/associations
- Support users’ voice into their community
- Research demonstration
Preliminary results

5. Changing the organisation of life in the hospital
• ‘humanisation’ (e.g. dignity of habitat; personalising patient living spaces; private possessions, clothes, keys, wardrobes; managing own money, contacts with outside world; first outings; finding life stories)

• ‘liberalisation’ (e.g. opening up wards; mixed m/f wards; therapeutic community-type meetings; break up totalised life of patients; giving patients a voice; focus on primary needs such as income and housing; individual and group outings; parties; invite family members)

• deinstitutionalisation (e.g. planning the phasing out and suppression of the PH through sectoralisation and internal reorganisation; closing wards and a gradual reconversion moving towards community services; transfer resources to services and directly to users, guaranteeing life in the community through economic resources for subsidies and training; opening the first group homes and single residences, with appropriate support; create social enterprises / coops, etc.)
5.1 Create more humane conditions in the hospital (s.c. ‘humanisation’)

- Users’ freedom: allowing personal control over oneself during admission:
  - Private space
  - Individual possessions
  - Self-managed daily routine and meaningful activities

- Remodelling existing facilities in a more human way:
  - Reducing security devices/measures
  - Arrange comfortable habitat

- Remodelling staff style of work:
  - Therapeutic relationship
  - Individualized/care recovery plan
  - Staff roles and functions

- Respect of users’ human rights and personal dignity

- Users involvement and real decision-making

- Staff training

- Create new mental health services in the community

- Take the risk to changes (and even fail)

- Hospital humanisation risk to postpone real deinstitutionalisation

- Good leadership and improving rules
5.2 Give greater freedom in the hospital (s.c. ‘liberalisation’)

- Same elements for humanisation
- Respect of users’ human rights and duties
- Allowing personal control over oneself during admission:
  - Freedom
  - Decision-making
  - Going out
- Remodelling existing facilities:
  - Open wards
  - Normalized spaces
- Create new mental health service in the community
- Remodelling hospital staff’s style of work
- Staff training
- Improve therapeutic relationship
- Facilitate users’ contacts with the community
- Users involvement in decision making about their care plans
- Organise real work for users
- Liberalisation as second choice in comparison with real deinstitutionalisation process
- Immediate action toward liberalisation: do not wait for official authorisation
5.3 How guarantee life in the community?

- Appropriate legislation and funding
- Aim at having a normal life in the community:
  - Real work and protected job
  - Real house in the community
  - Residential facilities for the not autonomous ones
  - Financial support: income, benefits, disability pension
  - Social network to avoid isolation in the community
  - Education
  - Leisure e culture
- Available primary health care
- Users organisations/clubs
- NGOs
- Supportive community sensitized about stigma
- Comprehensive community mental health system for treatment and recovery-based programs:
  - Creation of community services before closure of ph
  - Staff support (be guaranteed they will not lose their job)
  - Individualised support project based on the person’s needs
  - Integrated welfare system: collaboration with social services
  - Rehabilitation following recovery principles
5.4 What are the basic requirements for community support systems?

- **Essential needs:**
  - Psychosocial needs/social network: family and friends
  - Real house in the community
  - Residential facilities
  - (Meaningful) work
  - Leisure activities
  - Education
  - Income and financial support
  - Feelings: love
  - Human and civil rights

- **Comprehensive system of mental health services constantly supporting users living in the community:**
  - Rehabilitation
  - Staff training
  - Integrated work with the community social services
  - Specific treatment and support

- **Community involvement and support:**
  - Principles of community support system
  - Implementation strategies for a community support system
  - Monitoring community support system

- **Available primary health care**
- **Advocacy for users**
- **Users association**
- **Legislation/political level**
- **Programs**
  - Users involvement in decision making
  - Sustainable funding
  - Trusting relationship
5.5 What are the basic components of community services models and what is their role in supporting the shutting down of mental hospitals?

- 24-hours CMHC as the coordination point for users’ community support:
  - Mental health services’ sectorial approach to the community
  - Mental health services arranging an inclusive support in the community
  - Multidisciplinary responsible staff
  - Individualised treatment plans
  - Available crisis support
  - Users at the centre: needs and resources
  - Specific therapeutic/social interventions in the community
- Social support: house, work, money
- Users legal protection and advocacy
- Research
- Mental health services’ integrated work in the community:
  - Gp/primary healthcare
  - Social services
  - General hospitals
  - Local community
- Risk of a fragmented system
Preliminary results

6. Macro interventions and deinstitutionalisation policies
• involving and influencing administrations and policies, administrative management of transformation;
• involving civil society, creating public awareness and fighting stigma;
• contaminating the judicial and forensic psychiatric system;
• changing the legal framework for Mental Health and inclusion;
• integrating Mental Health into general healthcare (e.g. at the community level / primary care and not just hospitalisation for acute cases);
• integrating Mental Health with welfare systems (e.g. inter-sectorial link with social services for housing, work, free time, education and cultural training);
• reconverting or restoring psychiatric hospital sites to the community.
6.1 How involve and influence administrations and policies or, if empowered, how manage the administrative level to achieve transformation?

- Lobbying on the political level
- Support new guidelines/rules/policy for community system
- Support people in the community as ethical principle
- Adequate funding for mental health policy
- Define mental health system management
- Define services access
- Make real change in daily work in the mental health services
- Coordination with other social services
- Spread knowledge on mental health issues
- Awareness and involvement strategies
6.2 How involve civil society, create public awareness and fight stigma?

- Through NGOs / civil society organisations
- Through media and communication strategies
- Specific programs against stigma
- Services working in the community

- Strategies for community involvement
- Involvement of families
- Education
- Contribution of culture/arts
- Concrete examples
6.3 How contaminate the judicial and forensic psychiatric system?

- Improving collaboration mhs - judicial system:
  - Discussion/sharing experiences in mhs-justice meetings
  - Education and training for police and judiciary
  - Mental health services’ staff working in jail
  - Psychiatric evaluation in the courts

- Humanising forensic psychiatric institution

- Psychiatric hospital as a bridge from forensic hospital to community

- Cultural change in the community

- Political and social action: advocacy and political pressure

- Changing laws

- Inspiration by international examples

- Improve prevention, treatment and rehabilitation in the community
6.4 How change the legal framework for mental health and inclusion?

- Take inspiration from international conventions/entities
- Application of existing laws (not applied though existing)
- Explicit support of mental health users’ civil rights through laws
- Strategies for changing laws
- Lobbying on policy makers/legislators
- Economic impact argument
- Evaluation of community mental health services’ effectiveness
- Education: improving CRPD knowledge in sanitary, social and law sector
- Professional resistance
6.5 How integrate mental health into general healthcare?

- Users referrals and responsibilities mh-general healthcare

- Sharing space in general hospital

- MH services as a bridge between general healthcare and other services

- Training of healthcare staff

- Examples of mh services integrated within health system

- Continuous collaboration GPs-mhs

- Support of political level

- Use of financial incentives

- Support from others (pharmaceutical companies)

- Obstacles/resistance to integration
6.6. How integrate mental health into welfare systems?

- Critical issue in the present time
- Political decision/legislation
- Real collaboration in the local community
- Cooperation at various level
- Shared plans
- Building relationships and knowledge between actors
- Educations on mental health
- Change approach to mental health issues
- Users at the centre of different services
- Citizens involvement
6.7 Suggestions for reconverting or restoring psychiatric hospital sites to the community. Give some positive examples that you know of personally, as well as some emblematic negative cases.

- Giving sense to the place/Opportunity for the city
- Government offices
- Primary healthcare services
- Training: schools, university, education centers
- Only refurbish without function change
- Immigrants reception
- Cultural activities
- Youth associations
- Accommodation for fragile people (mentally ill, elderly)
- Correctional facility
- Sold off to privates and reinvest money for mh
- Failure examples
6.8 How human rights approach (e.g. WHO quality rights program) could be helpful in deinstitutionalization?

- Training/education staff on who quality rights program
- Political involvement needed
- Human rights respect on daily practice
- Implement international recommendations in the mental health services
- Apply as an evaluation instrument of the mental health services
- Good results in MHS of human rights approach
- Critical issue: human rights approach as a justification for abandoning responsibility toward severe mental illness
- No deinstitutionalisation without human rights approach
Conclusions: deinstitutionalisation as a process

The process of the deinstitutionalisation of PHs necessarily implies a **major involvement on the part of both the general population and psychiatric operators**. In fact, these latter do not necessarily have a decision-making role in cases involving a purely administrative deconstruction and the emptying of hospitals, which can only be activated by policymakers.

By deinstitutionalisation we mean that **process** which aims at the gradual transformation of living conditions, treatment and care and the restoration/construction of patient rights, together with the progressive substitution of the rules of internment with procedures based on a full negotiability between patients and operators.
• The decisive step in the process of phasing out PHs is identifying where to accept or admit new psychiatric cases.

• Generally, one opts for a mix between the use of specific wards (or beds) in general hospitals and hospitality in mental health centres or in other types of non-hospital residential structures, with preferably a very limited number of beds.

• The suppression of the PH should coincide with the creation of networks of totally alternative services capable of providing care for a given population (as in sector policies), but which stress the recovery and reinclusion of patients/inmates (as opposed to the sector model).
Despite international recommendations, even those of the WHO (The Optimal Mix of Services for Mental Health, 2011) which stress that PHs can be reduced or suppressed only if community services and structures have already been established – and thus thanks to new funds specifically allocated for that purpose – we believe that a contemporaneous process of reconversion which can impact profoundly not only on the renewal of services but also on the community and its culture, is not only practicable but desirable.

Despite the significant disparities due to national and local contexts, we believe that while this process can be instigated by a top-down impetus and be guided by a responsible institutional leadership, it can only be fully achieved thanks to a bottom-up process which mobilises actors and resources.
working directly **within total institutions** but without deceiving ourselves that their closure can come from outside or due to a *natural death*;

creating alternative networks of **coherent services that work in synergy within the community**, thereby avoiding useless and often harmful fragmentation and specialisations, and thus working not according to preconceived models but by processes that are verified collectively by users, families and caregivers, and the community and its institutions;

**avoiding priority implementation of hospital services for crisis/emergencies instead of community structures.**

assign to the community services the task of **taking responsibility for persons who come from their territory of competence, who are still interned in the PH**;

plan the phasing out of PHs at the local, regional and state levels, with specific **time-frames** and the possibility of applying administrative sanctions in cases of non-compliance.
• The deinstitutionalisation process is not only downsizing or even suppressing psychiatric hospitals, but undertaking a complex process of removing the ideology and power of the institution by **putting the person over the institution** with their subjectivity, needs, life story, significant relationships, social networks, social capital.

• In order to do that, it is necessary to **shift the power** in order to empower people with mental health problems, shift resources from hospitals to a range of community based services useful for his/her whole life. It opens pathways of care and programs that integrate social and health responses and actions.

• This complex process of change **involves users, carers, professionals and the general citizenry**, and extends to the legislative and political level.
This latter means no longer managing processes for exclusion through the segregation of persons, but placing the individual at the centre of the system, with their human and social rights, and their needs, in a perspective which is based on the person’s ‘whole life’ and on recovery from the experience of a mental disorder.

Based on what we have described above, the transformation process takes place at the following multiple levels:

- movements (civil society)
- political
- legislation
- service models and practices
- networks and organised actors, autonomously or through the institutions, and community development, as a general raising of awareness regarding these issues, and the activation of non-technical resources and initiatives.
Abolishing coercion

- The abolishment of coercion per se can generate eventually a **Psychiatry with spotted weapons. It can recognize the power of the individual** even he or she is a state of extreme need to be understood, loved and cared.

- We desperately need a gentle way of dealing with persons and delivering care. If organizations are driven by principles and values embedding human rights approach, their practice can prove to be inherently **healing**.

- So elements of change are rights, opportunities, empowerment of users and other stakeholders as leaders.

- The new frontier is about **not only fighting against asylums on one hand, and on the other hand advocating rights, but a convergence of both strategies.**
Equality and social determinants

- Only proclaiming equality can leave inequality based on power untouched.

- The advocacy of rights is connected to the condition of citizenship, that is a contractual nature in the relationship with the State, and related duties and responsibilities of individuals who is entitled of rights.

- It is framed into a welfare state, and linked to participation to a society, hence to democracy and social justice and equality.

- Achieving equity of human rights also entails **challenging social exclusion and inequality**.

- Acting on **social determinants** of health to achieve greater equity of quality and stability of home, work, income, supports, relationships, and social participation.
Whole life

- To achieve social inclusion we must engage all-of-community and whole-of-life strategies and opportunities. The person in the social context call into action a whole life (in all domains), a whole systems, a whole community (IMHCN). Human rights must be valued in the prospect of “the person as a whole”, as a citizen.

- We know that HRs can be healing as far as they "recognize the person”, and thus refer to shared basic values of humanity.

- A new epistemology of a mental health should be based on a person-centred paradigm valuing the personal and social experience of individuals as human beings and social actors, and not on a paradigm of disease.
Recommendations for the phasing out of psychiatric hospitals: results from the qualitative research

- Interestingly, some of the conclusions differ from previous documents based on working groups, consensus conferences and the use of structured questionnaires, often submitted to clinicians with no specific expertise, thus underlying the profound complexity and diversity of the process of D.I. in various continents, nations and local contexts and the relevance of the value base including human rights considerations.

- Moreover, it provided a remarkable amount of indications, analyses, suggestions, narratives that came from live experience, from positive as well as negative aspects of those processes.

- The meaning of D.I., its possibilities and caveats (do’s and dont’s), the “how to do it” related to staff culture, and the several concurrent levels of action are clearly pointed out by the interviewees.

- As a specific contribution of the WHOCC of Trieste to the QualityRights initiative, the research issued a set of guidelines and recommendations for de-institutionalization and related training.
What drives changes in institutionalised mental health care? A qualitative study of the perspectives of professional experts

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Abstract

Background Since 1990, the provision of mental healthcare has changed substantially across Western Europe. There are fewer psychiatric hospital beds and more places in forensic psychiatric hospitals and residential facilities. However, little research has investigated the drivers behind these changes. This study explored qualitatively the perspectives of mental health professional experts on what has driven the changes in Western Europe.

Methods In-depth interviews were conducted with twenty-four mental health experts in England, Germany and Italy, who as professionals had personal experiences of the changes in their country. Interviewees were asked about drivers of changes in institutionalised mental health care from 1990 to 2010. The accounts were subjected to a thematic analysis.

Results Four broad themes were revealed: the overall philosophy of de-institutionalisation, with the aim to overcome old-fashioned asylum style care; finances, with a pressure to limit expenditure and an interest of provider organisations to increase income; limitations of community mental health care in which most severely ill patients may be neglected; and emphasis on risk containment so that patients posing a risk may be cared for in institutions. Whilst all themes were mentioned in all three countries, there were also differences in emphasis and detail.

Conclusions Distinct factors appear to have influenced changes in mental health care. Their precise influence may vary from country to country, and they have to be considered in the context of each country. The drivers may be influenced by professional groups to some extent, but also depend on the overall interest and attitudes in the society at large.
Chow et al. found out four broad themes:

1. the **overall philosophy of de-institutionalisation**, with the aim to overcome old-fashioned asylum style care;
2. **finances**, with a pressure to limit expenditure and an interest of provider organisations to increase income;
3. **limitations of community mental health care** in which most severely ill patients may be neglected
4. emphasis on **risk containment** so that patients posing a risk may be cared for in institutions

- **Our research** confirms these themes, but our participants enlarge the focus on:
  - Users role
  - Staff commitment/reaction to the change
  - Community and stakeholders involvement
  - Focus on human rights
Similar methodology… but some differences

- Our research embrace a wider perspective and collect more experiences (Chow et al.: 3 countries: England, Italy, Germany)

- Our research focused on deinstitutionalisation (Chow et al. focus on institutional changes after 1990: i.e. more on re-institutionalisation)
Results indicate that there are several successful paths to deinstitutionalization. Most respondents emphasized—directly or indirectly—the importance of political skill and timing.

five principles for deinstitutionalization were identified:

1. community-based services must be in place;
2. the health workforce must be committed to change;
3. political support at the highest and broadest levels is crucial;
4. timing is key;
5. additional financial resources are needed.
Limitations

- Not a worldwide investigation: i.e. what about Africa?
- Written in-depth semistructured interview: lack of further investigation face to face
- Purposive sampling limited the investigation to experts of deinstitutionalization processes “close” to Trieste model
Further perspectives

- Complete analysis to achieve a broader conceptualisation
- New research testing the emerged themes with the same/other experts
- Guidelines/Manual for deinstitutionalisation