Paradigm shift

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Introduction
• The extraordinary Basaglia’s experience has shown how the total institutions, and the knowledge that justify them, are inevitably based on the systematic violation of human rights and on the denial of fundamental freedom.

• The word “dignity” appears today in international conventions and in the treaties that protect these rights.

• The closure of the psychiatric hospitals, that the Law 180 made possible, has led back to people the primogenital right, that is the right to have a life worth living.

• If life has no meaning or value, if the person is denied, then everything becomes an object and any abuse is possible.
History

• Italy pioneered deinstitutionalisation in the 60’s and the 70’s and enforced a famous mental health reform law in 1978.

• The Law 180 was the first Act worldwide to abolish the psychiatric hospital and to give back the full rights of citizenship to people with mental health disorders.

• De-institutionalization has been completed in Italy till the very closure of all Psychiatric Hospitals in two decades (1978-1999).

• After another 20 year period also forensic hospitals were overcome (2014-2017).
The multifaceted aspects of the “Basaglia” Law

• The reform encompassed:
  • -a new set of norms respecting full rights (the normative character)
  • -the climax of a crisis of psychiatric hospital as institution and the rising of community based mental healthcare (the policy character)
  • -a promise of a true paradigm shift in psychiatry, that is a model for all countries (the seminal character)
  • -a social and political movement for expanding civil and social rights (the citizenship character).
The Italian way to D.I.

• Why the ‘Italian way to deinstitutionalization’ remains a model of reform?
• Its community services and good practices derive directly from the process of deinstitutionalisation and the transformation that results, and not only in institutional terms (i.e. eliminating the asylum) but also with respect to the philosophy of intervention, the values expressed, and the role and social significance of the services.
The Italian constitution and the Law

• The Legislation of 1978 was based on the discovery of rights as the key tool in mental healthcare.

• **Law 180** has been a milestone for the affirmation of equality for people with mental disorders, as citizens, starting from the right to health and to receive adequate care, through voluntary treatment in the enjoyment of citizenship rights (Article 32 of the Italian Constitution) and the centrality of the person (Article 2 of the Italian Constitution).

• This happens through the total transformation of the institution and the asylum system into a network of community services, and the reduction of the conditions in which compulsory treatments are used and the reduction of their length. **Law 180** is based exclusively on the ground of mental health, avoiding motivations directly related to social control and “dangerousness”.

• It fostered not only the closure of all asylums, but also the lowest rate of involuntary treatment in Europe (17/100.000 in 2015) and the shortest duration (10 days).
The prospect of rights today

• The affirmation and the actual realization of rights is today more and more among the main tools of transformation of the psychiatric field, towards a mental health care “of”, not only “in” the community, also related to the updating of the contents made by the CRPD of UN.

• This is confirmed by the recent document of the UN Special Rapporteur on the right to health (Article 25 of the CPRD) declaring an open critique of biomedical psychiatric reductionism, and by the dissemination in many countries of the WHO Geneva program WHO QualityRights and the Mental Health Action Plan 2013-2020.

• This must be combined with the pursuit of policies and practices that continue the direction of deinstitutionalization, as dimmed by the history, still open in its implications, of the closure of the Forensic Hospitals and the consequent transformation of health systems towards true community-based mental health.
Services, from health care to mh promotion of the community

• It would be wrong to credit to **Law 180** the state of services for the protection of mental health in Italy, which is fundamentally the result of the mental health policies, or better said by their shortcomings.

• Added to these shortcomings are intellectual and moral lacks of the technicians; while the experimental implementations carried out in some places, and in all the innovative practices, although small and scattered, have not found adequate understanding and dissemination in a peculiar way in the administrative and political side.
Memory

• Here we will start from the roots and the testimonies of a journey, looking for all the useful tracks.

• There is a rupture, a form of heterogeneity, of disconnection, between (collective) memory and internalizing personal memory, wrote Derrida about Paul De Man.

• Memory is a **psychic power** directed towards one of the three modes of the present, the present past, which one could dissociate from the present and from the present future.

• **Memory projects itself towards the future** and **constitutes the presence of the present**.

• Indeed, memory is not essentially directed towards the past.

• It stays near the tracks in order to "preserve them", but these traces are traces of a past that has never been present, traces that have never been given, themselves, in the form of presence and always remain, in some way, to come, come from the future, from tomorrow. **Memory commits the future**.

• For this reason we will start from memory and history, with a "conversation" on the roots and testimonies of the movement that led to the great psychiatric reform in Italy, to question what content of that important season today can be revived.

• In this sense we could say with Baumann that we do not need **retrotopies**.

• The main experiences of today's Italian services will then be represented.
The 4 decades and the key-words

• D.I.
• Indignation: The institution denied, 1968
• The 180 inaugurates the 80s
• The power of madmen - the energy of the processes of liberation, the alliance with the oppressed
• De-institutionalization stops in the mid-1980s
• The invented institution, Rotelli, 1984
• 90's
• Rehabilitation - WAPR WHO consensus document (1996)
The 4 decades and the key-words

• 2000s
• Recovery (Anthony 1992); Romme Escher, living with voices
• it extends to organizations: position papers, ImRoc
• 2010
• Human rights / global life
• CRPD, SDH
• Self-advocacy and recognition of subjects
Democracy

• The underground processes today refer to the need to disembark in a new welfare, in a form of citizenship.

• Beyond rights, there is the theme of "real" empowerment - of equality (we are all involved, we are all the same: the levels of suffering, ill mental health, in the social), and of the differences (difference).

• The therapeutic alliance and / or oppression is combined with the question: "What is necessary to be a citizen (with equal opportunities)?".

• We know that "freedom is conquered every day".
Democracy

• However nothing can replace the power of movements, which in the past pushed the reform law.

• All the energies, nowadays, come from people “with lived experience”, and from the strident social inequalities that exist in the periphery of the world and of our societies.

• In recent years the rise of protagonism, linked to a new awareness and to important changes of perspective – that is putting the person at the center of his/her recovery pathway – has contributed to the creation of new collective movements which claim empowerment, participation and access to citizenship.
Democracy

• What is claimed “here and now” by people going through psychiatry? Which right does exist today to have a place to live, an occupation and a social role, as well as affective and social relationships?

• It is still necessary to dismantle the fear, the risk of loss of rights, the image and the representation of the illness linked to a dangerousness which comes back and is reaffirmed.

• For all this there are new practices, that are alternative to old models and inspired by the principles of dialogue, respect and dignity. There are collective subjects and enterprises with social value, which represent responses for young people who risk falling behind.
Democracy

• The topic of democracy, the re-balancing of power towards these people – both individual and collective – also active as “peer” facilitators of these pathways, as well the communities as fundamental elements to support, to involve and to “engage” in forms of participation, is the necessary prerequisite for the development of new practices and new ideas.

• It is also an assumption for further steps to be taken after the end of the era of total institutions in Italy, which still leaves open issues as freedom from need and from risk of exclusion, as well as from forms of oppression of bodies (restraint) and coercion, that remain constitutive facts of psychiatry.
Habermas

• We have thought of a personality like Jurgen Habermas for many reasons: his commitment to Europe and democracy (in an historical moment like this, so problematic), his critical thinking and in particular the Theory of Communicative Action, which today it seems more necessary than ever in a society in which a communication "that starts from the parity of the speakers" and that recognizes the Other, also different, excluded, as the subject of an agreement to be reached is a great paradigm for the mental health of a community that is such.

• It starts from the critique of an "instrumental reason", oriented to pursue a goal, which guides the Strategic Action, and which therefore exploits social relations within a loss of meaning and freedom (Weber), the foundation of modernity in a commodified society. Appealing to the worlds of life, creators of senses, and making them reflective (a dialogical reflexivity), the evolutionary possibility of democracy itself is traced.
• In the **ethics of discourse**, reason is reformulated at the level of communication, through conversation and dialogue. Equality of opportunity to expose one's own points of view and freedom of expression, together with the recognition of others as valid interlocutors, are the ideal premises.

• A fundamental consensus among the interlocutors must be recognized, based on the 4 "Pretenses of validity" of the discourse: comprehensibility (also of madness), truth, moral validity - correctness and honesty - and sincerity.

• The position described by Pierce of the "Self-surrender": in bracketing personal interests, recognizing others, I engage in the collective task of seeking the truth.

• A **"postconventional" moral development** for H. involves being aware of the existence of different values and opinions, to be respected within a social contract, but also that some values and rights that are not relative, such as life and freedom, they must be defended in any society and without considering the opinion of the majority.
• **When laws violate universal ethical principles** of justice, equality of human rights and respect for the dignity of human beings as individuals, **one must act according to the principle**.

• The idea of dignity is the foundation of human rights, as an evolution of Marshall's theory.

• For Habermas, human rights constitute a **realistic utopia** as they do not lead us to believe more than the images of collective happiness painted by social utopias, but anchor the ideal goal of a just society in the institutions of the constitutional states themselves, namely:
  1. Civil rights: equal subjective freedoms of action
  2. Political rights: status of a legal partner
  3. Fundamental rights to the enjoyment of individual rights - the ability to act on rights
  4. Political rights
  5. Social rights: referring to living conditions so as to use equal rights with equal rights. (From MJ Guerra Palmero, Habermas - the commitment to democracy).

• **The method is therefore also for us, the dialogue, the Communicative Action, which involves recognizing the subjects, and re-establishing the parity of the speakers towards an ethics of discourse.**
An international landscape

• The conference was organized in collaboration with the main national organizations that deal with community mental health. SIEP, AIRSAM, WAPR Italy and Europe, Democratic Psychiatry, Mental Health Forum, The Franca Foundation and Franco Basaglia, Legacoop social, UNASAM, "The words found", the network / movement "Rompiamo il Silenzio" of the Puglia services were involved, the "SPDC no restraint" CLUB, the Italian "Open Dialogue" network, StopOpg, COPERSAMM, the National Rems Coordination, the AISME, as well as the gender services networks, and many other organizations.

• Here are some of the most important international organizations, from IMHCN to Mental Health Europe to Gamian Europe, EUCOMS, WAPR and WFMH, the Nova Universitade Lisboa, WNUSP, the Confederacion Espanola Salud Mental, IAN, WHO Collaborating Centers, etc. they will expose their initiatives to support these paths in European and non-European countries.

• There is significant international representation here, in particular from countries that are undertaking or resuming reform paths.

• The current state of reforms will be presented in various countries, especially in the South and East of Europe, also in view of ESOF 2020 - Trieste European Science City - with the Czech Republic at the forefront, which adopted the Trieste model of CSM (Dr. Mezzina, director of DSM Trieste, was appointed by the Minister of Health of the Czech Republic as an international member of the Reform Board).

• The network of Latin American countries, with Brazil and Argentina at the forefront, will question the implementation of reforming laws and the final closure of mental hospitals and application criticalities.
• The WHO will report on the WHO QualityRights program which has completed the assessment in 25 European countries and will outline its strategy following the recent report on the status of services and rights.

• Significant meetings will concern the network of social cooperation and the network of associations, subjects essential to the completion of the reform process, as well as the implementation of a new community welfare that helps the pathways of care and reintegration of people with mental disorder, their right to work, to housing, to social inclusion.

• Great attention will be given to innovations, from the Open Dialogue approach with the presence of its leader, the Finnish Seikkula, to the various forms of co-management and co-production of services with users, enhancing experiential knowledge and peer support; from the CSM 24 hours as architrave of the Trieste and Friuli model, to the gender approach also from a cross-border point of view.

• The Coordination of REMS has been convened here, for a correct application of the reform of the relationship between psychiatry and justice, avoiding the creation of new OPG containers, up to the topic of new forms of exclusion - homelessness and migrants.
• From the conference will be launched several significant initiatives: from the Conference of Services, request to the Ministry of Health promoted by the union of family members and UNASAM users, to the network ROMPIAMO IL SILENZIO of Puglia that claims attention to services and mental health policies; from campaigns for rights and against restraint "And you ... untie it immediately!"; the declaration for "Zero COERCION", the general abolition of forms of forced treatment that rejects the addendum to the Oviedo Protocol.

• Finally, a committee promoting the **Nobel Peace Prize** to the experience of Franco Basaglia will be launched.

• Over 500 participants are expected from 31 countries (Argentina, Australia, Croatia, Denmark, Philippines, France, Georgia, Germany, Greece, Ireland, Israel, Kenya, Liberia, Macedonia, Malta, Holland, Poland, Portugal, United Kingdom, Republic of Korea, Czech Republic, Republic of Moldova, Romania, Serbia, Slovenia, Spain, Sweden, Switzerland, Turkey, Hungary).
The issues in the regional model of mh healthcare

• Our experience in Trieste and in the whole Region Friuli Venezia Giulia (1,200,000) for reform implementation is based on:
  • A clear action for deinstitutionalisation of PH
  • The development of 24 hrs CMH Centres
  • The development of a network of services for rehab and social integration, e.g. group homes, day centres and social cooperatives
  • The creation of “strong” MH Departments in order to co-ordinate all services according to principles of contrasting social exclusion, stigma and discrimination and promoting social inclusion.
The exemplar “local to global” model

- Mental health departments include CSMs open 24/7, with 6-8 beds each (for a population of 50-80,000), including mobile and crisis teams. This model is now widespread throughout the region and is almost completed (17/21 Centers are 24 hours).

- Trieste is the pioneering experience, with the first total psychiatric institution to close in Europe, and was initially established as a pilot area of the WHO and then as a Collaborating Center for the past 45 years.

- The current DSM of ASUITS (model for the entire Friuli region) has therefore been **working without an asylum since then, with a totally open-door system**, CSM with 6 beds for each sector, a system of supported housing and a small service of Diagnosis and Care of 6 beds, usually not very busy.
Trieste and the Region

• The **personal healthcare budget system** has helped social recovery and inclusion, as well as the integration of mental health services into a system of health districts for primary care (elderly, young and adolescent, disabled, specialized medicine, etc.).

• **Social cooperatives** provide a system of training and real work opportunities for around 200 service users each year, with around 1/10 becoming members.

• Currently in Trieste 94% of the mental health budget is spent in the community (18% directly for the BIS), with only 6% of the budget allocated to the small hospital service. This is just 39% of the previous psychiatric hospital costs.

• There is also a **widespread day center** in the areas of well-being, participation, expressiveness, gender, social clubs, realized with community agencies and associations, including sports and cultural ones, as active partners for human development and social inclusion.

• Throughout the Friuli Venezia Giulia region, only 6 **forensic beds** are available in three community structures that are operated with the door open.
Trieste ct’d

• A clear transition from residential structures to transitional houses to supported housing, to independent living flats, also thanks to personal budgets,

• and the regional resolution to overcome restraint in all health and social structures, etc. including nursing homes and general hospitals

• are some of the key facts that have been determined.

• Involuntary treatments show some of the lowest rates in Italy (7 / 100,000) and about 40% of them are managed in the CSMs.

• The adoption of the WHO guidelines on primary care (mhGAP) is underway, with training for GPs, but also for nurses in MS and the Districts (especially on the issue of non-pharmacological treatment of depression).

• District integration is advanced for the elderly, adolescents, disabilities, autism, and addictions.
• The protection of mental health achieved through a public system, in coproduction with the private social, and which invests in the territory and on people, with 24-hour services, as realized in FVG, costs less than the national average (3.43% of the FSN compared 3.49%).

• Certainly more resources (at least the fateful 5%) but also useful policies and well-founded approaches that do not distract them to passive chapters, as the overabundant psychiatric residency shows in almost all regions.

• I would like to remind you instead that CSM 24 hours, personalized projects and the elimination of restraint are the main points of the report of the Parliamentary Commission on the State of the NHS that visited all of Italy in 2011-2013 and started the closure of the OPG, and which are included in the bill for the implementation of the 833, filed in the Senate in the last legislature signed Dirindin, Manconi and others, to which I have contributed.

• Recently, this approach has been globally confirmed by the Regional Plan for Mental Health - PRSM (which you find online with all epidemiological data).

• The Trieste model has been adopted this year in the Czech Republic, Wales, Los Angeles, and other places.
Freedom is therapeutic

UGO GUARINO
Liberty as a fundamental value

• “Liberty is therapeutic” was the original motto in the Trieste experience. The experience of Trieste can be emphasized especially as far as principles such as open door, hospitality, negotiation and alternatives to coercion are concerned.

• Service should also recognize the value of participation of all stakeholders, through networking, forms of coproduction, cooperation and exchange.

• ‘Freedom first’ (Muusse, Van Rojen) can be a new slogan of the international movement for better care in a rights-based and person-centered approach, emphasizing that personal liberty is not the outcome but a pre-condition for care which overturns control mechanisms and supersedes them with people empowerment.
The Law 180 and the CRPD

- In many ways, the reform law anticipated the CRPD, issued by UN in 2006. The fundamental right to health care, including MH care, is highlighted in a number of international covenants and standards (WHO, 2005).

- Chiefly, the right to health is now also included in the promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to personal, social, economic, cultural and political development (United Nations, 2017).

- Even the WHO Resource Book has been withdrawn because of the CRPD, as far as it legitimated involuntary treatment, no coercion in care is now admitted by the Committee of CRPD (2015) and this is a clear direction also for WHO Quality Rights Programme (WHO, 2017).

- In the Law 180, involuntary treatments are made possible through a substitute decision-making, seen as a denial of legal capacity.
Human rights and coercion

• The United Nations High Commissioner for Human Rights in Geneva has carried out a recent consultation on mental health and human rights, with the aim of identifying the strategies of system change that can promote this horizon, of which Trieste (and Italy) they are exemplary demonstrations.

• Despite the widespread use of the CRPD, the Convention on the Rights of Persons with Disabilities, that includes mental health, which strongly reiterates the theme of self-determination, dignity and recognition of the person as a subject of full rights in every condition, the battle on subjective rights it is still long, as indicated by the abuse of restraint, of involuntary treatments without guarantees, of the dominant pharmacological model (it would be too much to define it biological), of the denial of the same right to receive mental health care.

• On this front should be noted the passive position of the Italian delegates to the European Bioethics Committee, which is concluding its work on the draft Additional Protocol to the Oviedo Convention which brings back the framework of the rights of the 180, through the legitimacy of placement beyond treatment, the reasons for public order and the dangers underlying mandatory care, their indefinite duration, the mere regulation of restraint.
The Law 180 and the CRPD

- The CRPD is based on substantive rights: they are imperative and non-negotiable, but they can remain abstract
- unless they are connected to citizenship and participation to a society, challenging social exclusion, acting on social determinants of health (Marmot, 2005; WHO & Calouste Gulbenkian Foundation 2014) to achieve greater equity of quality and stability of home, work, income, supports (Mezzina et al. 2018).
- These political, legal and social action has to be combined with our own emancipation as clinical professionals from institutional thinking and practices in MH and social care (Mezzina et al. 2018).
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 epistemiology 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.
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.
Interventions on inequalities

• Recognition of the need for collective interventions on health inequalities, supported by social factors and quality of life, is now an unspeakable aspect for new policies and territorial actions.

• This with particular attention to the development of transnational laboratories (above all European) for policies of socio-economic development of the same communities, of their social capital and of their services, in an inclusive direction, that contrasts the inequalities and processes of exclusion towards weak subjects and minorities subject to discrimination with respect to those rights enunciated above.
Paradigm shift

• Not just a single but many paradigm shifts:
  • from the institutions to the community, and from the illness to the person - its subjectivity and social being
  • can bring a move toward a “gentle” Psychiatry.
• Therefore:
  • choice, eg offering consistent home care;
  • negotiation as a main principle, but with a citizen with rights, instead of coercion and locked doors, or mechanical restraint;
  • psychosocial interventions, eg work, home, talking therapies;
  • shared responsibility, supported decision making, guarantees for treatment;
  • shared alternatives, dialogical approaches, crisis and recovery homes, early support, de-escalation of crisis, easy accessibility of services.
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 driver 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.**
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.
Key principles

- Among key principles there are: full (walk-in) accessibility, low threshold, proactive and assertive care, rapid response (to crisis), open door, no restraint, and continuity of care.

- The involvement of all stakeholders as partners (NGOs like social cooperatives for work and support, carers and users associations) for service provision is also crucial in the area of social inclusion (housing, work, social relationships) with the use of negotiated, personalised and budgeted plans of care.

- The service must promote a “whole life – whole systems - whole community” approach, where ‘integration’ in an inter-multi-sectorial approach as a key word.

- It is needed to scale up psychosocial intervention and addressing social determinants regarding work, home, social capital.
Basic values related to democracy
- as the main shift in mental healthcare

• 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. Knowledge is based on information, that must be provided to all stakeholders, starting from the person in need.
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, 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.

- 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’).
“The fact remains that getting people right is not what living is all about anyway. It's getting them wrong that is living, getting them wrong and wrong and wrong and wrong and then, on careful reconsideration, getting them wrong again. That's how we know we're alive: we're wrong. Maybe the best thing would be to forget being right or wrong about people and just go along for the ride. But if you can do that—well, lucky you.”

(Philip Roth, American Pastoral)
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