Conclusions

Good practice services:

promoting human rights and recovery in mental health

Trieste, 23-26 September 2019

Best practices

- The United Nations High Commissioner for Human Rights in Geneva carried out a consultation on mental health and human rights (14-15 May 2018; OHCHR).

- Several programs like EU Compass, or organizations like Mental Health Europe are now issuing a collection of good practice examples.

- World Health Organization in Geneva is now providing an extensive review of those best practices and a **guidance** document.

Good practices services

- services and supports that are

- people-centered

- operate without coercion

- respond to people's needs

- support recovery

- promote autonomy and inclusion in line with international human rights standards

Dealing with power issues

- Most of the interventions used to reduce coercion have not been linked to or embedded in **structural or organisational changes of mainstream care, or "whole systems" approaches.**

- The success of dialogical approaches to care which have been used as alternatives to psychiatric admissions and coercive care,

- such as crisis and recovery homes,

- early support,

- de-escalation strategies,

- personalised and shared care plans

- is dependent on the capability of **dealing with power issues** and microsocial stresses and conflicts that trigger reactive or deviant behaviours.'

- This calls for a form of empowerment that recognises the legitimacy and agency of "**the Other**", **negotiation towards a therapeutic alliance that respects people's wills and preferences, that is developed in their living environments in the community (on 'their turf and terms')**.

- Co-production of services and shared decision making in individual care plans as part of "whole life projects" are essential to the success of such changes in practice and dynamics of care.

Alternatives to coercion?

- Usually these are considered to be "alternatives" rather than mainstreamed, generalized or systemic forms of approach and care.

- Individual or specialist interventions aimed to **reduce coercive interventions in routine clinical practice**, by themselves, are unlikely to be effective or can be sustained in the long term.

- This is because coercive practices in mental health are more likely to be linked to systematic problems such as **the culture and ethos** of prevailing clinical care and **organisation and delivery of mental health services.**

- For example, variations in the rates of coercive care, across countries and over time, may be the result of differences in policies and practice and the culture of metal health systems (e.g Italy).

Whole system in the living world

- There are no studies on the impact of a **whole system change** in the direction of no seclusion and restraint, while there are well documented **experiences and practices** that adopted ethical-based policies in the overall mental healthcare system and also minimized the rate of involuntary treatment.

- A systematization of strategies regarding supported and joint decision-making,

- advance directives,

- forming a therapeutic alliance and

- individual care / recovery / wellness plans

- offers an alternative approach to coercion, including seclusion and restraint.

- Equitable access to '**least restrictive care**', fostering service user's self-determination ensuring and his/her participation in all decision-making processes related to his/her treatment and living conditions and recognizing the role of families in providing support and key relationships are necessary to achieve this.

- This will amount to a **shift in psychiatry's focus** from the patient to citizenship, guardianship to free will, substitute decision making to supported decision making and shared responsibility.

- The social mandate of psychiatry thus changes from control of behaviours to social mediation between stakeholders and the public, or the community and the focus of care is increasingly centred on the whole person in the complexity of his/her living world and not just on illness.

Quality Rights and institutional care

- The World Health Organisation, through its *Quality Rights* initiative, has been at the forefront of reducing coercive and custodial care in mental health in several countries .

- This is a systematised programme that includes assessment, training and quality improvement measures that focus on human rights of people in mental health and social care facilities.

- A Quality Rights toolkit is central to this programme and is used to reduce coercion in clinical practice and improve the living conditions in hospital facilities.

- The recent European report assessing the quality of institutional care, using the Quality Rights toolkit, was capable to demonstrate the lack of fulfillment of many standards in majority of investigated psychiatric institutions.

- The findings reveal and confirm that long-term institutional care for people with psychosocial and intellectual disabilities in many European countries is far below the standard. A significant proportion of the assessed institutions were violating the fundamental rights of people with psychosocial and intellectual disabilities, including their legal capacity, autonomy, dignity, liberty and security of person, physical and mental integrity and freedom from torture and ill treatment and from exploitation, violence and abuse.

- Some of the most egregious violations reported were: use of mechanical and pharmacological restraints to manage difficult behaviour, a culture of impunity with regard to reported cases of sexual abuse, numerous irregularities concerning informed consent, discrimination and barriers to access to high-quality care for general and reproductive health, lack of alternative or complementary mental health treatment options and a general lack of opportunities for meaningful daily activities within or outside the institutions.

- **"Fewer than a third (28%) of the 2450 ratings of standards made by the 25 assessment teams were "achieved in full", indicating enormous scope for improvement throughout the European Region. This indicates that CRPD signatories are at risk or culpable of substantial breaches of the treaty". (WHO, 2017)**

Quality Rights

- Freedom from coercive interventions, respect for the right to legal capacity, and promotion of dignity, autonomy, choice, community inclusion and recovery are at the core of the initiative.

- Most importantly, Quality Rights, like other initiatives trying to reduce coercion within mental health care and ensure human rights compliant policies, recognises the importance of **capacity building in the sector as a prerequisite for change and provides extensive training packages for relevant stakeholders.**

- Positive outcomes are reported as a result of such approaches in several low and middle-income countries.

- Practices and services that are alternative to coercion can be innovative as regards to standard ones; they can be alternative programmes but sometimes they are embedded in a change of current mainstream care, toward a whole system approach.

- We can ensure this **not just developing piecemeal alternatives** that have anyway a little evidence, but by **completing the process of deinstitutionalisation in the widest sense.**

- More than closing institutional facilities (that is more correctly quoted as de-hospitalization), this means **dismantling the reductionist paradigm of "treating illness" in our practice and recognizing complexity of the whole person.**

Statement 1

- *We must create an "Epidemiology of rights"*
  Strict respect for the rights of individuals must be the foundation of any action in mental health.
  Professionals must know the rights that each person has and the laws that protect them.

- *The topic of migrants and ethnic minorities must be addressed*
  No person should have difficulty accessing mental health care for reasons of origin or for any reason. Migrants have the right to care that considers the uniqueness of their culture. The attention to the migrants must be done in the services that are common to all the subjects to avoid their stigmatization.

CRPD compliant services

- **Rights-based and person-centered services requires providing mental healthcare in living environments**

- Many different and equally relevant perspectives – **experiential, clinical, anthropological, social and historical** – can contribute towards the development, implementation and evaluation of good practices in rights-based, person-centered and community-based mental health services.

- There is **no perfect service**, but plenty of lousy ones, so we can all ask ourselves and learn how to improve quality, accountability and meaningful impacts.

Crisis – the case

- It has also emerged from the conversation the necessity for the person to go trough the crisis. In a sense, the **"right of suffering"**.

- Often, the services are trying to stop it or to implement treatments/interventions in order to **cross the crisis as fast as possible to make the person feeling better.**

- This not always underpin the "right of choice" for the person on how she/he would like to be helped.

- Another element is the difference between the "suffering" and the "crisis".

- Having crossed the suffering it is an important element to become a **peer supporter**. Anyway, it is not sufficient: a key element is what the person "wants to do with their suffering" that is how to use it for themselves and for helping others.

- We have talked about a person to person approach.

- We focussed on the experience of a professional, which found the time to be with a person in crisis, experience the emotions, being aware of them and embark in a relationship which was different: "in that moment, I was not the doctor, I was S."

- Another important element of the conversation was about the role peer support workers within or outside the services. With respect to the risk to be "colonized" by the system one peer said "Whatever will or will not happen, I will always be a peer".

What is a crisis?

- First of all the idea of **subjectivity**: it is the individual that define what a crisis is, indeed it is the subjective experience of the individual that bring them or their family in touch with a service. It is not possible to define through categories what define a crisis, often the person's themselves struggle to find the right words or to give voice to what they are experiencing.

- The crisis is also defined as a **"window of opportunity"**, in the sense that the crisis is an opportunity for change for the person and also to make meaning out of things which are not solved yet. It is also an opportunity for the network near to the person. l

- In fact, the crisis it is not just a matter of the individual who becomes unwell, but **meanings and solutions may arise from the different narratives of all those** who are connected to to the crisis.

CRPD compliant services

- A potential template for considering and codifying the strengths of different innovations should include:

- *Why?* The need for / rationale for the innovation in practice

- *Where?* The policy and service context within which the innovation has been developed

- *What?* The key principles, features or components of the intervention

- *How?* The process of the innovation's development and implementation in the local / target population, including overcoming of systemic barriers or sociocultural challenges

- *So what?* The impacts, effects and consequences of the innovation, based on application of both qualitative and quantitative methodologies.

Statement 2

- The need for legal and other structures of the mental health system has to be revised or updated to allow for **greater opportunities for rehabilitation, employment and supported housing** and for resources to better **'follow the patient'**, for example through the allocation of personal budgets.

- The principles of "**citizen psychiatry**" are put into practice via a number of supporting mechanisms including peer support workers, inter-communal councils and a charter of rights.

Statement 3

- We must continue in the process of:
  - Contrast to the violation of human rights, universal and absolute rights
  - Closure of psychiatric hospitals
  - Opening of Community Services
  - Increasing the budget for community mental health, starting from the reconversion of resources from the hospital to community services
  - Activation of social inclusion programs: home, work, training, education, etc. putting in practice the clinical biological paradigm.

Statement 4

- The user is the driver, through co-production

- The key outcomes being a place to call home, a purpose in life, and loving relationships - NOT treatment compliance and symptom reduction

- The need to address social determinants across spectrum to foster organismal wellbeing using kindness/caring

- It is needed to maintain links, to strengthen networks and connections among innovators and reformers, including citizens and stakeholders, starting from primary consumers.

Right to life and coercion

- *Objectives*
- Right to life means there should be **zero tolerance of violence and coercion within the mental health system. Right to life comes before the right to 'medical treatment'.**
- Mental health system should not be gatekeeper or the first entry point to link with or access various other services (e.g. housing).
- *Actions*
- Full compliance with the CRPD, and prohibition of coercion in all its forms.
- Medications given must not cause harm, and must help a person to thrive.
- A wide range of non medical services and support systems must be made available within the mental health system to facilitate full recovery.
- Other modalities of recovery such as arts based, body based therapies must be made available.
- Mental health legislation must be repealed, and prohibition of creation of more institutions, small or big.
- No more mental health laws are required

- *Objective:*
- *A shift in the conceptualization of healthcare for people with disabilities through a **human rights lens** should be a clarion call to medical professionals, and those who teach and train medical law and ethics, to alter care practices in the name of justice, beneficence and non-maleficence.*
- *Actions:*
- *Such a shift also requires the political will to address some very challenging dilemmas about how to move f**rom a model of proxy consent to one which truly respects the will and preferences** of the person with disabilities when accessing healthcare;*
- *It is also incumbent on **medical professionals to become acquainted with the current international human rights** standards in depth.*
- *When medical professionals are in a difficult position when their national law does not comply with international human rights standards, they can capitalize on the power and authority of their professional organizations and liaise with patients' rights organizations about how to instigate legal reform that better meets the healthcare needs of people with disabilities – their patients.*

Gender difference approach in the Community

- *1.Objective(s)*

- *We should focus on Human rights and Self Determination and Self Management, specifically on gender disparities in the society and on differences in (mental) health services and its effects. We observe that Depression in women and its specific risk factors aren't still enough notice and afford.*

- *We even notice that intimate partner violence is not considered a peculiar determinant for mental health, and that the interventions are not still effective.*

- *There are still common "inappropriate answers" to women mental problems, which are substantially based on genetic and hormonal hypotheses and on personality characteristics, although evidences on these associations are insufficient.*

Gender difference approach in the Community

- *2.Action(s)*

- *We propose to revamp and strength research on these topics in our health services, using a methodology gender sensitive, for example considering dis-aggregating all data collected (from diagnosis to rehabilitation, from each potential risk and protective factor to stigma and more...), reanalyzing and interpreting systematically by gender available epidemiologic data.*

- *We wish to involve in this research all the stakeholders (women suffering mental health disorders, associations, socio-sanitary services...) and istitutional and politic delegates.*

- *Moreover, we suggest to examine and show the best gender sensitive practices and experiences, especially in mental health services, in Italy, Europe and all over the world, in order to give visibility, and importance, to actions and pathways that actually changes, first of all promoting rights, health and women whole life.*

- *We even propose the sperimentation of a new service, in which previously formed female operator organize meeting focused on women risk factors for mental health, in wich women stories, and their routine daylife, could be priority respect the need to formulate a diagnosis or to prescribe a psychoparmacological, o psychological, therapy.*

- *The access to this service could be free, and the principal objective should be highlight the principal risk factors: i.e. intimate partner violence, stress related to double work and family overload, gender discrimination, mobbing, sexual abuse.*

- *These factors, according to international statistic, are strongly related to the principal women mental heahlt disorders (Depression and anxiety disorders, eating disorders, post-traumatic stress disorders). So, identification, and dealing with theme, avoiding the risk of conditioning by gender bias and sterotypes, as well as the risk of psychiatrization or psychologization, could take to develop an efficace strategy of secondary prevention.*

Principles / Conclusions

- A - we have to develop key-words, brought by constitutional law and international Conventions.

- B - inclusion, affirmative actions, personal needs, overall visions and integrating assistance programs as a fundamental right of the individual, providing care on a territorial base according to subsidiarity.

- C - all these principles could be concretely developed through avoiding: rigid legislation guidelines; normative patterns attached to groups of people or abstract categories; sectorial disciplines and institutionalization, or any form of implicit pre-trial detention of patients.

- D- in the end, it is necessary to call for norms which emphasize and grant individual faculties as well as personalized approaches preventing stigma and prejudice, legal capacity and personal responsibility should be established as a generally valid principles, especially for people with mental disabilities.

- Beyond psychiatric institutions, it is important to deplore the neglect of the severely ill that leads to their imprisonment and homelessness.

- Housing for the mentally ill should be regarded as a universal right.

- We emphasize the importance of work opportunities - especially offered within the mental health system itself as a bridge to the open market

Principles

- **A whole life is a right**

- The right to have a life requires opportunities and the prospect of a whole life. A person with a mental health problem has the same basic human needs as all of us.

- The Whole Life approach, as experimented in various countries and continents by IMHCN (www.IMHCN.org), promotes this by applying a Whole Systems methodology in the design, planning and implementation of a comprehensive integrated mental health system

- **CRPD: how to implement it in the real world**

- Many in psychiatry believe that CRPD is too idealistic and radical to be practically applied to present–day psychiatry.

- This is setting the direction not necessarily for today but it is the horizon.

- 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. But how this can be translated into actual effective strategies?

Principles

- **Advocacy**

- **Substantive rights are imperative, non-negotiable, and they represent mainly an individual freedom to do or to be without others' consent, but they can remain abstract.** Proclaiming equality can leave inequality based on power untouched.

- The advocacy of rights is connected to the **condition of citizenship (and recovery is connected to it) 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.

- Certainly the most relevant level is the (whole) **system** change (without large closed institutions) and not just a single isolate program; but **small programs and projects, even when they are certainly not mainstreaming in a whole system, can be exemplary, true seeds of change.**

Conclusions

- 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.

- We must point out that the main outcome is the vital and living presence of people, **subjects returned to a life, beyond and above of changes in institutions.**

- We also need **a different discourse on meaning, based on the person in his/her own World.**

Negative, positive and social freedom

- Apart from Isaiah Berlin definition of positive and negative freedom, here we can refer to Axel Honneth's threefold distinction of freedom (2014):

- the well-known *negative freedom* "to do as one pleases";

- the *reflexive freedom,* based on self-determination, self-realization, and authenticity that overcomes these faults, but is limited in other ways,

- which *social freedom* then overcomes.

- Freedom is not mere individual self-determination, an individual right regardless obligations, constraints and expectations, but also includes the right kinds of relations to others and to institutions. It is important that individuals have their private spaces for taking temporary leave from the social world, such sometimes happens in psychiatric conditions.

- These are provided by their legal freedoms and rights such as CRPD, which institutionalizes *negative* freedom in that regard, but their function is to provide protected and approved distance, of a temporary nature, from participation in the social world (lifelong only in cases where the available social worlds are wholly unacceptable).

- Whereas the point of negative and reflexive freedom is to provide a protected option to "get away", the point of social freedom is to enable participants to be free within the social world (
    - *Axel Honneth: Freedom's Right: The Social Foundations of Democratic Life. Translated by Joseph Ganahl. (New York: Columbia University Press, 2014).*

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 connecetd 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').

Nikolas Rose, Our psychiatric future, 2018

- *While it is true that Trieste is a small city, of fewer than 250,000 inhabitants, and that the implementation of the reforms inspired by Franco Basaglia to achieve this system took many years, this example, taken together with the arguments from within more conventional social psychiatry that I have just cited, shows that it is possbile for psychiatry to overcome that tension between care and control that Basaglia argued ran through his very existence – and to resolve it on the side of care.*

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- SEE YOU SOON !