

ARTICLES

Deinstitutionalization – will it ever be given real priority?

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Introduction

The publications and innovative work of Vincenzo Chiarugi (1793-94) and Philippe Pinel (1800) led to the development of a more human approach to the custody and care of mental health based on the view that mental suffering should be seen as a matter of health. They not only named and described the symptoms of mental disorders that until then weren't recognized and classified, but also suggested possible treatments that were to be carried out in specialised institutions. Subsequently, Jean-Etienne Esquirol, a pupil of Pinel, was central in promoting a programme of reforms in France that required the establishment of special hospitals in which psychiatric patients could be medically treated and cared for by specialists. The time had come for the spatial transition of psychiatric care from essentially custodial hospices to the operational and theoretical context of a hospital bed as the point of interaction (“mutual capture”) between patient and doctor (Tremine, 1991). Like other medical disciplines, psychiatry could define its scientific status on the basis of the classical clinical dimensions of observation, knowledge, and the transmission of knowledge, and patients could be examined and treated in the setting of traditional clinical practice.

However, although the trust that these pioneers of modern psychiatry placed in the therapeutic value of such psychiatric hospitals has since then been rightly questioned, the institutions themselves stubbornly remain and “beds” remain at the centre of mental health care even now, two centuries later. The Mental Health Atlas 2020 (WHO, 2021) shows that the median number of mental hospital beds is 10.8 per 100,000 population and is unequally distributed: 28.6 in high-income countries, 1.9 in the low-income countries, and 3.8 in low/middle-income countries. The global figure may have decreased from the 12.5 per 100,000 population, but the number of admissions in the same period increased from 62.4 to 71.8 per 100,000, and 10% of these were involuntary. This widespread use of psychiatric hospitals is confirmed by the percentage of government mental health expenditure allocated to specific services over the same period: 67% of countries allocated no more than 20% to community mental health services, more than 80% allocated less than 20% to primary health care and mental health prevention and promotion programmes. More than 70% of national budgets on mental health was allocated to mental hospitals in upper- and lower-middle income countries, compared with 35% in high-income countries.

This marked imbalance in mental healthcare costs, and the limited investment in primary care and community-based mental health services, clearly highlight the persistence of the custodial model and the difficulty of adopting an evidence-based model that fully respects human rights. The co-existence of the two models is highly problematic because the consequences go beyond the intrinsic harmfulness of mental hospitals, anti-therapeutic interventions, and violations of human rights. Mental hospitals not only absorb resources that could be better spent otherwise, they also encourage the maintenance of a view of people experiencing mental health issues, on mental suffering and its treatment that negatively affects every many aspects of people's lives as well as of community care.

Need for change

The need for change came to light many years ago in several countries and contexts like at the Social Rehabilitation Unit of Belmont Hospital (Surrey, UK), which Maxwell Jones transformed into therapeutic community. Rapoport's (1960) study of the functioning and social environment of this unit defined four themes that effectively expressed the ideology of the experience: democratisation, communalism, permissiveness, and the confrontation of reality. Democracy allowed patients to exercise power over decision making and take responsibility for the treatment of other patients; communalism favoured the development of new social relationships and the abandonment of fixed social roles; permissiveness increased self-awareness and the ability to regulate the boundaries of one's behaviour; and confronting reality allowed patients to experience themselves in real life, trying to solve problems and establish constructive relationships. Although identified in a mental hospital unit, these themes are still highly relevant to all aspects of community mental health as they fully reflect the shared decision making, empowerment, user responsibility for every type of choice, and the right to fully live one's life that inspire the principles of evidence-based rehabilitation practices and respect for human rights. They are therefore also capable of promoting the renewal of assistance and the activation of community resources.

The anti-institutional movement of the 1960s led to a new understanding of the excluding and violent nature of the inter-relationships of individual suffering, mental hospitals, and society. Franco Basaglia (1968) defined mental hospitals as institutions of violence within which people suffer a process of objectification that is strictly related to the passive role of patients. His focus "was the dominance of psychiatric power and the unequal dynamic between the institution of psychiatry and the psychiatric patient" that is characterised by "the lack of recognition of the patient's subjectivity" (Saraceno & Sashidharan, 2020). He also wanted to go beyond the idea of a therapeutic community as an operational model subordinate to a larger psychiatric institution, and put an end to the exclusion and imprisonment of individuals on the margins of society. Mental hospitals had to be denied.

The anti-asylum movement dialectically opened up a space for non-hospital interventions in which new methods of care could be defined both practically and theoretically. This included criticisms of biomedical reductionism, and a recognition that psychiatry was unable to respond to patient needs because it failed to recognise the importance of social determinants in each individual's personal history. Deinstitutionalization had to go well beyond denouncing the inhuman treatments taking place in psychiatric hospitals. In order to ensure the acquisition of rights and the assumption of responsibility, psychiatry had to be centred on individual subjectivity and self-determination, and the dehumanisation of institutions had to be replaced by social relationships and participation in real life (Mezzina, 2020).

The experiences of the 1960s clearly showed that deinstitutionalization was a dynamic and multi-dimensional process, and created the conditions that allowed the development of a multiplicity of services and professional skills in order to respond to patient needs. The care that was previously delivered in a single, centralised and hierarchical setting was returned to the community, which had the task of identifying new organisational models (Bachrach, 1981). Deinstitutionalization is not limited to de-hospitalisation and reducing the number of beds in mental hospitals, but involves a broad and non-linear transformation that provides an integrated network of inter-connected primary and secondary mental and other healthcare and social services, and is supported by the redistribution of resources from hospital- to community-based care.

What we have learned about deinstitutionalization

The WHO has long pushed for the introduction of health policies and interventional programmes aimed at putting an end to human rights violations and implementing effective therapeutic measures, but has obtained only limited consensus for deinstitutionalization strategies. International comparisons allowed by a quantitative evaluation of the progress made towards deinstitutionalization in 30 European countries has

shown wide variations: there are still very many mental hospital beds, and the number and training of mental health workers is still insufficient (Taylor Salisbury et al., 2016).

As many countries throughout the world dedicate many of their financial and human resources to mental hospital-based care, the WHO and the Gulbenkian Global Mental Health Platform (2014) carried out an expert survey to collect information and "lessons" from people involved in deinstitutionalization projects.

The results can be summarised in the form of five principles:

1) community-based services must be in place (discharged people must be able to easily access mental health, health and social services, and obtain community integration); 2) the health workforce must be committed to change (the protagonism of professionals and their associations should avoid actions that conflict with deinstitutionalisation projects); 3) political support is crucial at all levels (a process involving various spheres of society is not possible in the absence of local and national political will); 4) timing is key (critical phases such as emergencies or political changes can provide a favourable context in which to start institutional transformations); and 5) additional financial resources are needed (implementing community-based services and structures requires additional resources to ensure the transition from one model to another).

The timing and characteristics of projects intended to overcome the limitations of psychiatric institutions cannot be rigidly determined as they depend on specific institutional events and national and local policies creating the conditions necessary for the implementation of a network of health services and social integration. However, with the agreement of the other main stakeholders, there is also scope for the reformist will of mental healthcare professionals to promote a different vision of mental suffering and its treatment in everyday life.

Some concluding remarks

Deinstitutionalization cannot be properly understood if it is only considered in the context of a healthcare system based on primary, emergency and hospital services and diagnostic-therapeutic activities. It needs to be seen in terms of a public health policy whose objectives are to prevent disease, improve living and social conditions, and promote public health by means of collective action. Institutional, economic, socio-political and religious factors all contribute to defining the legal and health norms on which new health structures and a new model of society can be based (Carboni, 2021).

A deinstitutionalization project should not only define healthcare services and activities, but also promote a new relationship between people and institutions that affirms human rights and allows even the most vulnerable to experience a different balance of power. The end of reclusive and pathogenic institutions opens up new social scenarios in which the ethical dimension of public mental health is strengthened by overcoming stigma, giving substance to empowerment, and reducing health inequity (Kratsley & Radden, 2022). An awareness and fundamental belief that everyone can gain greater control over their own lives can be nurtured in a social and institutional environment marked by crises and change. If institutions are not immutable, but respond to the emerging physical and mental health needs of a community, they assume the fundamental function of promoting individual emancipation and the evolution of citizenship.

In the field of disabilities, institutionalization should never be considered a form of protection because factors such as segregation from independent life, the lack of control over one's everyday destiny, the impossibility of choosing one's own care, and the large number of people with similar disabilities concentrated in one building are all conflict with Article 14 of the Convention on the Rights of Persons with Disabilities (CRPD), which establishes the right to personal liberty and security. Institutionalisation also violates Articles 15-17 and 25, according to which people with disabilities must not be subject to abuse, violence or inhuman or degrading treatment, their physical and mental integrity must be fully respected, and their right to obtain the highest standard of health without any form of discrimination protected.

These principles and other crucial aspects of deinstitutionalization have been addressed in a recent document published by the Committee on the Rights of Persons with Disabilities (2022). This states that impairment-based institutionalisation conflicts with the right to legal capacity "on an equal basis with others in all aspects of life" (Art. 12), to the point that any admission to a psychiatric facility involving the loss of personal freedom (even for the purposes of observation or treatment) has to be considered a form of institutionalization. The CRPD's binding indications for deinstitutionalization are that the people involved must acquire autonomy, decision-making powers, and the ability to control their own lives with or without support of persons of their choice. One fundamental condition is access to community-based services and decision-making support which, by means of careful personalisation, promotes everyday activities and the exercise of legal capacity. Social and healthcare services should offer personalised programmes that identify the level of support required to ensure participation and independent collocation in the community. At the same time, it is very important to recognise the role of the informal support provided by other users on the basis of their shared living experiences.

Authentic institutional transformation programs require the participation of citizens with lived experience on mental health issues, family members and social networks, survivors, municipality members and representative organizations. When individuals are involved in their own care, their relationships with staff acquire a qualifying role and help to change the way in which users understand life with a mental disorder; furthermore, the possibility of influencing the decisions concerning them improves their self-esteem and self-confidence. The shared interventions and activities carried out at various operational levels define an area of new skills that requires continuous updating and reinforcement, and challenges the ability of professionals to enhance the subjectivity of users and create a constructive synthesis of theory and experience (Rocca, 2021). This can promote a change in the balance of power from professionals to people with lived experience like service users and the other subjects involved in the social dynamic, and allow their greater participation in all of the aspects of health- and social care. User involvement positively affects multiple areas of mental health by their experience-based knowledge, improving treatment outcomes, allowing the best subjective conditions of users and staff, and ensuring the greater appropriateness of services and their greater responsiveness to people's needs, all of which can benefit more general public health measure. Early user involvement and the acknowledgement of experience-based knowledge, is also essential to ensuring the quality of any service because it allows the acquisition of the experience and expertise of people with irreplaceable personal knowledge of real-world circumstances.

However, although these principles have been studied in depth, there is still no consolidated agreement concerning the most appropriate models of user involvement, which are characterized by local experiences and policies, and are still awaiting validation. Nevertheless, they have been fundamental in shaping some public mental health policies and have contributed to substantiating an awareness that "user involvement in service planning presents many challenges in terms of cultural changes" (Ridley & Jones, 2003).

The role of people with lived experience and the need to respect human rights are the most authentic reasons for the actions of professionals as they imply choices that go beyond the narrow limits of the biomedical approach and define new skills that are free of institutional conditioning. This implies a collaboration that enhances their respective roles and gives the protagonists a real value. In order to promote this model of intervention, the value of the subjectivity and human rights of users in relation to the subjectivity of professionals needs to be recognized within a relationship that is therapeutic in terms of its equality and its ability to place people and their personal histories at the center of collaborative practices and care. Going beyond the traditional role of professionals and recognizing a new patient identity are starting points for the provision of mental health services characterized by effectiveness and equity.

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