

## EDITORIAL

# A focus on the rights to self-determination and quality of life in people with mental disabilities

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At world level, health systems have not been able to respond effectively to the burden of mental disorders and there is an important gap to be filled between the need for treatment and its delivery [1]. The pandemic we are currently facing has additionally put mental health on the spot as a sector much neglected so far and most in need for innovative and multi-strategy approaches [2].

Mental health and mental disorders include not only individual traits, such as the ability to manage one's thoughts, emotions, behaviors and interactions with others, but also social, cultural, economic, political and environmental factors determined by national policies, such as social protection, living standards, working conditions, and community social supports, among others. Community-based mental health and social support services need to innovate themselves in order to encompass a recovery-based approach emphasizing the promotion of human rights and quality of life. Employment, housing, educational opportunities and participation in community activities ultimately support individuals with mental disorders and psychosocial disabilities to achieve their own aspirations and goals [1, 3].

The ground-breaking work initiated by the charismatic psychiatrist Franco Basaglia led to a cultural shift in Italy, culminating in the Law 180/1978, which imposed the closure of mental hospitals, restoring dignity to people with mental health problems, and promoting the role of therapeutic communities. Since then, there has been an increasing coverage of evidence-based interventions indicating that, in order to implement community-based mental health, we need to build a recovery model based upon the establishment of interdisciplinary mental health teams supporting individual self-determination. The delivery of "integrated and responsive care" meeting both mental and physical needs, promoting the right to employment, housing and education plays a fundamental role for the inclusion of people with psychosocial disabilities in their services and programs. In the current issue of the journal, the

monograph "Life planning for people with neurodevelopmental and intellectual disability: effective support, quality of life, and community engagement" highlights the most advanced examples of good practices towards this aim [4]. As suggested, the availability of person-centered actions, even providing a health budget directly managed by individuals and their families, appears as a promising strategy for addressing person's rights to self-determination [5]. The health budget is defined by the Italian National Observatory on the condition of people with disabilities as a "quantitative and qualitative tool for defining the economic, professional and human resources necessary to trigger a process aimed at restoring centrality to the person, through an individual global project". Certain individuals and groups in society may be placed at a significantly higher risk of experiencing mental health problems. Thus, standing for the rights of people with serious intellectual and neurodevelopment disabilities [6] requires a major effort in terms of tailoring the socio-health services to individual needs with a life-span vision to support the main life transitions. This can be achieved, for example, using constructs such as "Quality of Life" (QoL) that since 2002, the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) proposed as reference frame of all therapeutic and rehabilitative interventions providing assessment and analysis tools, useful for guiding the modulation of individual supports and to suggest guidelines for innovation at the macro-system level. The QoL framework should play a prominent role in education and training of mental health professionals [7].

The health budget methodology places the emphasis on co-planning, co-management and co-financing, as well as on the evaluation of the processes and projects to be set up and implemented also through public-private partnerships [5, 8]. In order to achieve this goal, individual plans must be set up by multidisciplinary teams and shared with the person and his/her family, while appropriate administrative tools have to be developed for the direct management of financial and welfare

resources. The principles of “integrated and responsive care” and the potential for public-private partnership in mental health have been perfectly exemplified by Social Farming (SF) experiences promoted in many regions of Italy and which represent a phenomenon widespread throughout Europe. Rural areas are a perfect place to promote health and build social interventions in mental health. It should be remembered that the European Commission has recently underlined the key role of rural areas – which represent a large part of the European territory and of the population of the Member States – in facing the current and future challenges of society in terms of the supply of public goods, sustainability and improvement of social well-being for the inhabitants of rural and urban areas. Access to the natural environment and outdoor spaces has begun to be considered vitally important for mental health, reducing the effects on stress, lowering anxiety and promoting physical activity, with cascading effects on immune functioning and general physical health. Natural environments – including urban green spaces – also provide opportunity for social engagement and are indeed increasingly recognized for their role in contrasting isolation and loneliness and promoting social integration. By providing de-institutionalized care, SF is increasingly recognized as an innovative way to respond to the cultural shift from institutional psychiatry to community-based mental health care, in line with the recommendations of the WHO’s Mental Health Action Plan. SF has the potential to foster the farming sector and to generate informal care being able to promote and generate social services to local communities. In 2015, the first Italian National law on SF was approved by the Italian Parliament [9], providing a framework to support cooperation among health services, farmers, social cooperatives and voluntary associations. The current challenge is to use this legislative framework to exploit SF as a means to envision and develop future strategies for the evolu-

tion of the National Health Service in terms of its capability for health delivery and social inclusion and to conjugate this with economic sustainability.

In conclusion, one step further needs to be taken, steered towards the re-orientation of services and the strengthening of local community actions to offer a wide spectrum of welfare solutions depending on the local context, individual desire and skills [8]. This challenge requires a significant innovative impulse in the area of social and health care as well as in civil society itself. As a first step, we need to reorient and facilitate administrative procedures, for example, to promote a health budget approach, avoiding the prevailing of bureaucracy over the needs of personal care. Overall, greater emphasis should be placed on satisfying individual needs, such as housing, friends, social networks, education, and employment alongside clinical care and treatment. Furthermore, social innovation models oriented towards a more participative welfare should promote human and social capital, avoiding “dependence traps” and social isolation.

In Italy, a specific legislation has been produced on this topic, which is based upon the principles of person-centered care, community welfare, and the promotion of a greater control from the end users [10]. A similar welfare system and a convergent definition of the strategic ‘pillars’ of the regional welfare scheme are shared across Italian regions. Access, assessment, planning, and monitoring are the main steps of the path governing individual care and they may represent the means to align the social and health programs, as well as resources within the local environment, which is where the implementation of the individual path takes place. However, implementation of current local and national legislation is lagging behind. Thus, national policies capable to harmonise, boost and monitor person-centered approaches in the mental health field are urgently needed.

## REFERENCES

1. World Health Organization. Mental Health Action Plan 2013-2020. WHO; 2013. Available from: [www.who.int/mental\\_health/publications/action\\_plan/en/](http://www.who.int/mental_health/publications/action_plan/en/).
2. Holmes EA, O'Connor RC, Perry VH, Tracey I, Wessely S, Arseneault L, et al. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science *Lancet Psychiatry*; 2020. doi: 10.1016/S2215-0366(20)30168-1
3. World Health Organization. Mental health: a state of well-being. WHO; 2016. Available from: [www.who.int/features/factfiles/mental\\_health/en/](http://www.who.int/features/factfiles/mental_health/en/).
4. Venerosi A, Cirulli F (Eds). Life planning for people with neurodevelopmental and intellectual disability: effective support, quality of life, and community engagement. *Ann Ist Sup Sanità*. 2020;56(2):158-250.
5. Adinolfi P, Starace F, Palumbo R. Health outcomes and patient empowerment. The case of health budgets in Italy. *J Health Manag*. 2016;18(1):117-33.
6. United Nations. Convention for the Rights of Persons with Disabilities (CRPD). UN; 2006.
7. Schalock RL, Brown I, Brown R, Cummins RA, Felce D, Matikka L. et al. Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities. Report of an international panel of experts. *Ment Retard*. 2002;40(6):457-70.
8. Prandini R, Orlandini M. Personalizzazione vs individuazione dei servizi di welfare: fasi, attori e governance di una semantica emergente. *Studi di Sociologia*. 2015:353-73.
9. Italia. Italian National law on SF was approved by the Italian parliament. Law n. 141, 8 August 2015. *Gazzetta Ufficiale* n. 208, 8 settembre 2015.
10. Italia. Ministero della Salute. Piano di Azioni Nazionale per la Salute Mentale (PANSM). Available from: [www.salute.gov.it/imgs/C\\_17\\_pubblicazioni\\_2448\\_allegato.pdf](http://www.salute.gov.it/imgs/C_17_pubblicazioni_2448_allegato.pdf).