Meeting Boundaries and Social Inclusion: An Empirically Grounded Reflection on the Role Transformations of People with Mental Health Problems

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1. Context

Mental health systems have undergone important transformations over the last few decades. An international paradigm shift that values service user participation and autonomy now promotes the inclusion of people with mental health problems within society. The redefinition of service users' social roles in the context of deinstitutionalisation and reorganization of mental health care is simultaneously redefining the roles of health professionals. Indeed, the provision of specialized care within home environments, the reinforcement of primary care, and the involvement of professionals from a growing array of disciplines and sectors, are changes which are profoundly altering relationships with service users and between professionals, who bring together different types of experience and expertise.

In Belgium, the voice of service users has been increasingly acknowledged over successive reforms supporting the transition towards community mental health care. The "107 reform", launched in 2010, initiated the development of mental health care networks and circuits according to a functional model of organization based on service users' needs. This model stood out from the previous structural model which was based on the interests of existing services. Concerned about defining service users' needs appropriately for the whole Belgian territory, and about enhancing their decision-making authority in the reform's implementation, Federal authorities commissioned the representation of people with mental health problems within each local network.

Since the "107 reform", serious efforts have been made to give service users a central role in mental health policy processes. However, research evaluations of the mental health system have recently evidenced the exclusion of specific subgroups of the population, most often combining social and psychological dimensions, sometimes associated with substance abuse or physical impairment. Including the voice of specific subgroups in order to appropriately address mental health needs remains a critical challenge for rethinking contemporary mental health systems. This challenge is tightly related to the difficult inclusion of these subgroups within policy decision-making and within research evaluations of mental health systems.

2. Methods

This contribution draws on a qualitative evaluation research of the mental health care system in the Brussels Region, which was carried out between January and September 2018. The aim of the Parcours.Bruxelles research (Walker et al., 2019), that was based on service users' lived experiences, was to identify which organizational aspects of the system had a determinant impact on service users' social

and care trajectories. This research combined semi-structured interviews, focus groups and ethnographic meetings which involved 27 encounters with professionals and 29 encounters with service users.

In order to include the experiences of people with mental health problems, regardless of their inclusion within the mental health system, participants were recruited through (a) traditional mental health care services and (b) other services or *alternative spaces* part of the voluntary or cultural sectors. These spaces can be defined as spaces which are open to the public, including to people with serious mental health problems. Their formal mission is not therapeutic; their aim is to offer opportunities to build social ties within a local community, namely by organizing cultural activities. Throughout this process, alternative spaces strive to eliminate or deemphasize diagnostic and social categories.

3. Results

Meetings involving people with a history of mental health problems emphasize the development of two distinctive roles as they engage in social interactions (Mead, 1934): the patient role (A) and the impatient role (B), which are illustrated in the image and corresponding extracts below.

A. The patient role

Emily, service user representative : *"In the beginning**, I was aware that I didn't know where I was going professionally, I was lost, and I didn't know what was wrong with me. When the doctor told me I was having a burnout, at least I could put a name on what it was.** […] Had they told me six years ago, 'get ready to stay home for a few years', I never would have believed it. I tried different things to put myself back together. I was admitted at [psychiatric hospital] and after that, I saw a therapist. **After two years or so, my home felt like a prison** and so my therapist suggested I go to a day hospital. At that point, it's a matter of accepting the situation, even just the word 'hospital'. I learned so much during those two years at the day hospital. After a while**, I wanted to try out some volunteer work, to challenge myself at work again.** […] **Since then, I've been involved in projects here at [association], I arrived as a mental health service user.** […] At times, I'm very happy with volunteering two days a week but **sometimes it's a problem because it's just volunteer work, not a real job!** I mean it feels like a real job to me, but legally speaking, it's not a real job. **I think they could pay me for what I do.**"*

B. The impatient role

- Paul: *"When I was thirty-four, I went through a terrible breakup and I was having trouble at work. **I was deeply depressed and thought about suicide**, so I asked for help. I joined a day hospital, and then I felt better."*
- [Paul questions the difference between a day hospital and the professional reinsertion association he has been going to this past year]: *"**I ask myself more and more, is it really that different? It also keeps you busy, gets you up in the morning, forces you to get dressed, to meet other people and chat. […] Except there's no medical jargon around it all, that's one thing out of the way. If I had to tell the difference, I'd say we engage in activities but they're not medicalized. We're not seen as patients!**"*
- Researcher: *"How do people see you at [association] ?"*
- Paul: *"**Like a man**".*
- Oliver: *"[Association], what's that? Is that one of those places where you cook, take out the trash and that kind of stuff?"*
- Paul: [Laughs] *"That's one way of putting it…"*
- John: *"Those are things everybody needs to do!"*
- Paul: *"Yeah, sort of. It's a place where we get together and chat…"*
- John: *[…] I think I found the answer at [association]. **People compliment me for my wisdom** there, they welcome me, I feel at home. That's what I need!"*

4. Discussion

Patient roles (see A) are performed when personal life narratives are expressed on the basis of references employed within the mental health system, that is, from a medical perspective which is based on a medical diagnosis. In order to make sense of problems she went through at work, Emily refers to her physician's diagnosis, which gave her access to an uninterrupted journey within the mental health system. The collected interactions highlight that service user representatives dominantly perform this patient

role, which shapes the way they define and voice the needs of mental health service users.

Impatient roles (see B) are performed when life narratives are expressed using non-medical references, which are explored within the chains of communication that shape meetings. These roles can develop when communication is reflexive (Luhmann, 2006), that is, when it supports the self-observation of experiences which unfolded in *alternative spaces*. Reflexive communication gradually introduces a difference by using the following distinct references to interpret the same daily activities: on the one hand, medical references typically used in mental health care services; on the other hand, alternative references which are explored in *alternative spaces*. Based on this difference, the articulation of social interactions contribute to transforming the role of service users. The dotted line illustrates this transformation, which gives rise to the expression of needs that can be fulfilled beyond the mental health system's boundaries.

Meetings lay the foundations to reflect upon mental health as collective action, which is constructed and deconstructed within different social systems that include the health system but also the employment sector. As they mediate the transformation of service users' roles, meetings revise contemporary understandings of mental health and question the simultaneous transformations within roles and relationships between service users and professionals from health systems and beyond.