Participation of Mental Health Service Users in a Research Evaluation Process

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Health and Society Research Institute (IRSS-UCL)
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This presentation

I. Background: Organisation of mental health care
   - Interational context
   - Belgium: the 107 reform

II. Participation of service users in policy-making in Europe and Belgium

III. Research evaluation: Projet.Parcours – mobilising service users

IV. Discussion and conclusion

Background: Organisation of mental health care
Deinstitutionalisation

- Supported by the WHO: promotion of a global, biopsychosocial approach to mental health, community care and **service users' integration and participation within society**
- Deinstitutionalisation: a **paradigm shift** (Hall, 1993) at the international level
- Paradigm shift: a change in the cultural, institutional and organisational dimensions of a system designed to address a particular social need or problem, such as justice, education and health.
  - *Cultural*: definition of mental health, a « global » approach
  - *Institutional*: from hospital to community-care; from supply to demand-driven systems
  - *Social*: change in the power balance between different professional groups and between professionals, services users and their relatives.
- In practice: how reforms are carried out differs depending on national cultures and political systems – from closing hospitals to diversifying the care offer and creating networks to facilitate connections.

I. Background: Organisation of mental health care
The « 107 reform » in Belgium

WHY ?

- 158 beds/100 000 inhabitants in Belgium (WHO, 2008)
- Main aim: To further orient mental health care towards a reduction of residential hospital care in favour of *recovery* and *reintegration* in the community.
- Five goals*:
    - **Desintitutionalisation**: reinforce community mental health services, described as alternatives to hospital care.
    - **Inclusion**: achieve social rehabilitation, through collaboration with education, culture, employment and social sectors.
    - **Decategorisation**: reduce fragmentation within care supply.
    - **Intensification**: intensification of hospital care, in order to reduce the need for long-term stays.
    - **Consolidation**: integration of federal, community and regional pilot projects within the global reform of mental health care.

* « Guide vers de meilleurs soins en santé mentale par la réalisation de circuits et de réseaux de soins », 2010

I. Background: Organisation of mental health care
The « 107 reform » in Belgium

WHAT ?

- A « functional » model of MHC organisation:
  - Based on service users' needs, as opposed to care supply represented by professional and sectorial associations and federations.
- Five care functions.

I. Background: Organisation of mental health care
The « 107 reform » in Belgium

WHAT ?

- Function 1: « Activities related to prevention, mental health promotion, early detection, screening and diagnosis. »
- Function 2: « Mobile teams providing intensive care, both for acute and chronic mental health problems. »
- Function 3: « Rehabilitation teams aiming for social integration and inclusion. »
- Function 4: « Intensive units for residential hospital treatment, both for acute and chronic mental health problems, when hospital care is inevitable. »
- Function 5: « Specific residential formulas providing care in situations where organising care within home or alternative environments is impossible. »

I. Background: Organisation of mental health care
The « 107 reform » in Belgium

HOW ?

- 2010: Call for exploratory projects to create **mental health care networks**.
- Explore ways of implementing the functional model :
  - Involve relevant *care* and *social* services.
  - Develop new work procedures, communication and coordination instruments.
  - Develop acute and chronic mobile teams.
- 2016: Generalisation

Background: Organisation of mental health care
The « 107 reform » in Belgium

HOW ?

- **Representation of service users** in each (107) regional network.
- All relevant services addressing the needs of service users, whether or not they form part of the mental health sector:
  - *First level organisations*
    - Psychiatric Hospitals
    - Community Mental Health Services (« SSM »)
    - Psychosocial Rehabilitation Centres (« CRF »)
    - Sheltered Housing (« IHP »)
    - Psychiatric Nursing Homes (« MSP »)
  - *Second level organisations*
    - Social services
    - Medical Centres
    - Professional insertion services
    - Others included in the legal and employment sectors

I. Background: Organisation of mental health care
The « 107 reform » in Belgium

- Organisational model based on service users' needs through the development of care networks and circuits.
- **Relies heavily on integration of services** through the development of collaborative practices.
- Strong concerns related to **fragmentation**:

> I remember after I was first hospitalized, I was discharged but I didn't have a job. It was like nothing had happened. A sort of parallel world, a huge bracket. I went back home and I was lost. I shifted from an environment where I could talk to people at all times, whenever I felt down […] Of course, social workers provide social follow-ups for people without a home or a job [...] *but what about a real follow-up*, when people are physically out of hospital ? Most often these people don't have relatives or friends, they have no geographical landmark (December 2015, service user, Brussels).

I. Background: Organisation of mental health care

- How can the **participation of service users** in *policy-making and research* contribute to achieving a model of care *based on mental health needs* as opposed to services' and professionals' definition of their needs ?

II. Background: Participation of MHC service users
European context*

- Mental health and family associations often developed in line with anti-psychiatric movements in the 1960s-70s.
- Recognition and public funding, according to their ability to maintain long-term involvement of their members.
- < 1990s: mental health service user and family associations have been increasingly involved in decision making at policy and institutional levels (Rose & Lucas, 2007).
- 1991: Federation of European organisations of (ex-) users and survivors of psychiatry (ENUSP); received legal recognition in 1998.
- 1992: European Federation of Associations of Families of People with Mental Illness (EUFAMI)

* « La réforme des soins de santé mentale en Belgique et le projet participation: pas complètement convergents, mais concrètement interdépendants » (Thunus, nd)

II. Background: Participation of MHC service users
European context*

- Mental Health Declaration for Europe (WHO, European Ministerial Conference on Mental Health, 2005)
- Among the main priorities and actions:
  - « Recognize **the experience and knowledge of service users** and carers as an important basis for planning and developing mental health services »
  - « Offer people with mental health problems **choice and involvement** in their own care, sensitive to their needs and culture »
  - « Collectively tackle stigma, discrimination and inequality, and empower and support people with mental health problems and their families **to be actively engaged in this process** »

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II. Background: Participation of MHC service users
Belgium*

- Public authorities mandate service user associations to formulate political recommendations for mental health policy.
- < 2005 : « Participation Project »
- Associations recruit service users on a voluntary basis.
- Provide training:
  - Interaction with professionals
  - Develop legal and organisational skills
- Main difficulties:
  - Difficulty in being heard during meetings with professionals
  - 107 reform – **representation of local service users**

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III. Research evaluation: Parcours.Bruxelles

- Parcours.Bruxelles (Prof. Sophie Thunus, UCL-IRSS)
- Qualitative evaluation of the mental health system and of service users' trajectories in the Brussels Region
- Jan 2018 – Sept 2018

III. Research evaluation: Parcours.Bruxelles
Background of the research

- > HSR52: Organisation of mental health care for the adult population in Belgium – KCE, UCL-IRSS (Prof. V. Lorant), KUL-LUCAS
  - Deliverable 1: qualitative evaluation (Prof. Sophie Thunus)
  - Focus groups: diverse profiles of participants representative of the local networks (incl. service user representatives)
  - *Organisational level of analysis, with a focus on the health care system*.
  - Key result: **increased formalisation leads to increased exclusion of subgroups of service users – substance abuse, socially vulnerable, homeless.**
  - Expert meeting: « they are represented everywhere, but their voice is not heard ! »

III. Research evaluation: Parcours.Bruxelles
Methods

- Draw on **service users' trajectories** to examine the organisational level.
- Inclusion of excluded service users entailed moving beyond the health care system.
- Methods:
  (1) Semi-structured interviews with network coordinators/service managers (n=27)
  (2) Focus groups with service users (n=9) + Ethnographic interviews (n=20)
  (3) Focus groups with professionals (n=16)

III. Research evaluation: Parcours.Bruxelles
Representation of service users

- Methods:
  - (1) Semi-structured interviews with network coordinators/service managers
  - **(2) Focus groups with service users**
  - (3) Focus groups with professionals
- Recruited through:
  - Mental health care services (inpatient and outpatient)
  - Service user associations
  - Professional insertion associations
  - Associations working with substance abuse
  - NGOs working with migrant populations
  - « Alternative spaces »

III. Research evaluation: Parcours.Bruxelles
Representation of service users

- « Alternative spaces »

III. Research evaluation: Parcours.Bruxelles
Representation of service users

- Strong difficulty in mobilising service users :
  - Stigma attached to mental health
  - Fear of being instrumentalized
  - Service user representatives strongly sollicited
- Ethnography through direct person-to-person recruitment.
- Examples of non-represented service users/silent voices.
  - High introverts
  - Speech or cognitive impairment
  - Migrant populations

III. Research evaluation: Parcours.Bruxelles
Representation of service users

- Two types of discourse amongst service users (Walker & Thunus, 2018):

A. « Patients » – strongly identify as service users :

When the physician told me I was having a burnout, I could finally put a label on what I had [...] Had I been told several years ago that I was going to have to spend many years at home, I never would have believed it. [Enumerates all the mental health services visited during this period] I had to accept that I was in hospital, even just the word « hospital ». The day-hospital taught me a lot [...] I wanted to do some volunteer work to try working again, and since then, I've been a member of a group of service users. [...] Come to think of it, I should be paid for doing this, like any other job (service user, free translation).

III. Research evaluation: Parcours.Bruxelles
Representativity of service users

- Two types of discourse amongst service users (Walker & Thunus, 2018):

B. « Im-patients » – do not identify as service users and highly critical of MHS :

> It's been fourty years now since I graduated from my Masters in civil engineering, and my diploma led me nowhere. I was so anxious that I had a vision, a « discontinuity », and so I became a psychiatric patient. They tried to drive me crazy, but from where I stand, psychiatry is just a social service giving me a salary [...] When I ask them what my problem is, they refuse to help me, they laugh at me ! But I think I've found the answer, a solution, at [alternative space]. I know people there, they give me compliments for my wisdom.

III. Research evaluation: Parcours.Bruxelles
Results – Trajectories

« Transitions » in and out of the mental health system not primarily attributed to services, according to service users, but to three main turning points:

- Housing
- Work
- Social relations and stigma

III. Research evaluation: Parcours.Bruxelles
Results – Trajectories

Housing

- Lack of housing as a major difficulty affecting the MH system.
- Hinders transition between hospital and community care, care continuity and social inclusion.
- Critical for socially vulnerable populations/homeless, most of whom also suffer from mental health problems.
  - Revolving doors between hospital and the streets;
  - Or extended duration of hospital stays.

III. Research evaluation: Parcours.Bruxelles
Results – Trajectories

Housing

- Access to *independent housing* limited for financial reasons or discrimination.
  - « Landlords aren't allowed to do it, but they ask for pay checks, they all do. And if you refuse, they say it's taken. Patients count on sickness funds to prove they have an income. I tell them 'Never say you have a mental health problem. Never! Say you have a health problem' » (psychiatrist, psychiatric hospital).
- Access to *social and sheltered housing, and psychiatric nursing homes* limited due to strict admission criteria; leading to informal practices.
- Squats and « maisons pirates »

III. Research evaluation: Parcours.Bruxelles
Results – Trajectories

Work

- « Nowadays, if you find a job, you get a burnout; If you don't, you become psychotic » (service user)
- A major turning point for all service users, importantly affecting MHS.
- Access to the job market or working conditions.
- Professional reinsertion: a controversial topic
  - « Are service users capable of reinsertion ? »
  - « Are employers capable of adaptability ? »

III. Research evaluation: Parcours.Bruxelles
Results – Trajectories

Work

- Incentives for employers ?
- GPs faced with a growing number of work-related mental health problems and *call for the need to use preventative measures for the general population*.
- **Work as meaning** broadens the issue :

  « Occupation is essential, we know that. Besides from mental health care, there are obvious things that can help, that aren't available enough. Some of our patients want to volunteer in urban farms, but there are waiting lists, meanwhile we know that's what they need and instead they're getting drunk in 'Gare du Midi'. There's something therapeutic that happens outside of mental health services, it's brilliant ! » (GP, association for the homeless).

III. Research evaluation: Parcours.Bruxelles
Results – Trajectories

Social relations and stigma

- Discrimination: housing and labour market – contributes to MH problems through social exclusion.
- Strong perceived support from the cultural sector and alternative spaces:
  - Stimulate interactions with the general population.
  - Demedicalisation and focus on strengths.
  - No obligation to show up.

III. Research evaluation: Parcours.Bruxelles
Results – System

- Reaching out to excluded service users evidenced two interdependent systems:
  - **The mental health care system – or « frontstage »**
    - Described in administrative, legal and scientific documents (psychiatric hospitals, CMHS, sheltered housing, psychiatric nursing homes) based on medical knowledge.
    - Defines categories of people who can legitimately receive mental health care; uses admission criteria; combined with complexity and lack of visibility, leads to the exclusion of subgroups of service users.
  - **The MHC system's environment – or « backstage »**
    - Includes services and associations with no formal mission to address mental health problems or that deliberately displace mental health problems to their cultural or social aspects.
    - Low or no admission criteria, they address critical situations that are not addressed by MHC system; faced with sometimes severe mental health situations.

IV. Discussion and conclusion

- Mental health beyond mental health.
- Dessin

IV. Discussion and conclusion

- Fronstage and backstage as two separate systems
  - **Fronstage:**
    - *Organisational level* – Institutional system based on medical knowledge inscribed in administrative categories enacted by services – exclusion or hindered transition towards society.
    - *Individual level* – Making sense of one's identity as a service user.
  - **Backstage:**
    - *Organisational level* – emerging system in practice developing through marking a difference with fronstage
      - « Here, there are no patients, there are only members. In fact, the moment you stepped through the doorway, you became a member » (coordinator of alternative space).
    - *Individual level* – Making sense of one's identity alternatively.

IV. Discussion and conclusion

- Fronstage and backstage are **interdependent systems**
  - Systems remain as long as they maintain a difference with their environment (Luhman, 2006)
  - No backstage without exclusion

IV. Discussion and conclusion

- How can fronstage and backstage stimulate adjustments in the mental health system ?
  - *At the organisational level*:
    - **Through meeting !**
      - Research: Focus groups between professionals and service users.
      - Professionals: Inter-organizational meetings and immersions.

IV. Discussion and conclusion

- How can fronstage and backstage stimulate adjustments in the mental health system ?
  - *At the individual level:*
    - **Through meeting !**
      - Research: Focus groups and ethnographic meetings.

IV. Discussion and conclusion

[Moderator]: Can you tell us how the day-hospital helped you?

[Paul]: I no longer had a job, I was no longer busy and I had no family… The day-hospital helped me take care of myself, to get up in the morning and get myself busy. It's really basic stuff, but very helpful. I believe that having something to do during the day is still very helpful, that's why now I still go to the [alternative space].

[Moderator]: How does the day-hospital differ from the [alternative space] ?

[Paul]: I keep on wondering, is it really that different ? [stares into space for a few seconds] If I had to tell the difference I'd say we have things to do, but there's no medical jargon, we're not seen as patients !

[Moderator]: How do people see you at [alternative space] ?

[Paul]: Like a man.

[Keith]: [Alternative space], what's that ? Is that one of those things where you have to cook, take out the trash and that kind of stuff ?

[Paul]: That's one way of putting it…

[Georges]: These are things everybody needs to do, aren't they ?

[Paul]: Yes, among other things… It's a place where we get together, where we sit and chat…

[Georges]: What we need is a place in the community, where we're accepted and where we feel at home. It can be work, or even a real job […]

IV. Discussion and conclusion

- How can the participation of service users in *policy-making* and *research* contribute to achieving a model of care **based on mental health needs** as opposed to services and professionals' definition of their needs ?

Participation of Mental Health Service Users in a Research Evaluation Process

Thank you for your attention