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What we really mean when we say "users' participation": vignettes from Slovenia

ENTER conference, "Working together for new pathways in mental health", Nordland Hospital, Bodø, Norway, Thursday 13th of June, 2019

Key concept
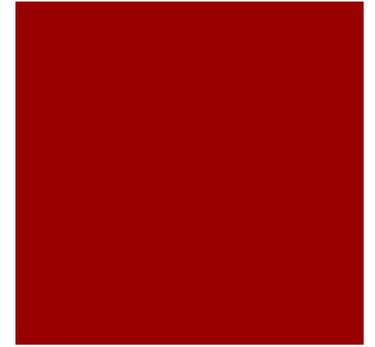
- *Participation, involvement, inclusion* – all these being the terms which are frequently and sometimes very lightly dealt with.

- A trademark of contemporary European social and mental health policy.

- But the question is whether they are really in place and how appropriate they are.

Do we have to do with:
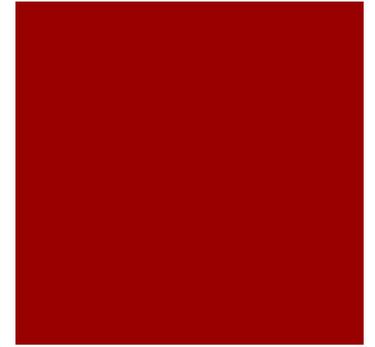
- On the one hand emptied, depleted concepts and tokenistic policies which do not transform services but feed the idle run of ideologies about inclusion?

- And on the other hand with brave, minority experimental practices and pilot user projects?

Shifts in Europe
… on the one side …
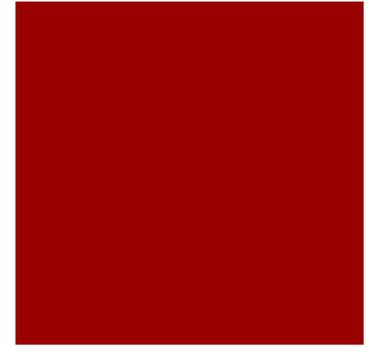
- The shifts made in the area of user participation in Europe as well as Slovenia are enormous.

- »Thinking beings« vs. »disfunctional beings«

- New relationships were encouraged: the relationship between the professional and the user was transformed, and at the collective level the user participation in user associations, in education, in research, in the drawing of legal acts was strengthened.

…while on the other …
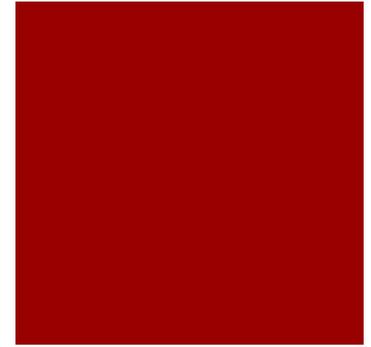
- ….we have to do with the reality of everyday life courses of a large majority of silent/unheard people within the system of social and health services who seem to have been left completely untouched by this wave or its impact.

- This silent majority does not participate, and is not expected to have anything to say.

- Lack of studies looking at how service users and professionals perceive the outcomes of user involvement policies.

Research studies on participation
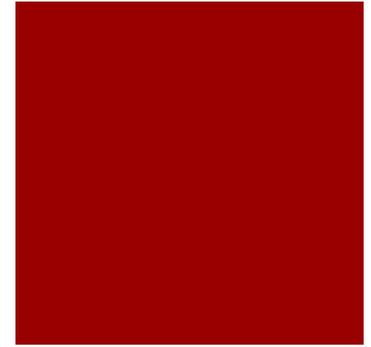
- Most commonly the term 'participation' covers different types and levels of involvement, involving different types of engagement, including representation, consultation and advocacy in widely differing situations.

- Integrated vs. hierarchical approach

- It is aimed at achieving different outcomes, from empowerment in individual decision making or participation in everyday activities, to organisational or structural change.

- Concept embraces notions of both process and outcome.

- User involvement as a part of consumerist ideology.

1990-2000 User-led alternatives as experiments and innovations in Slovenia
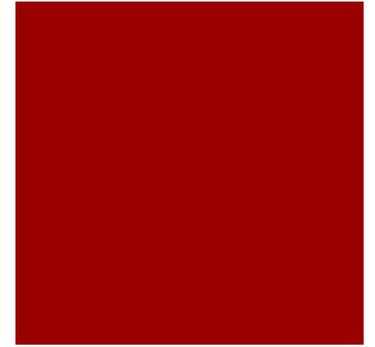
Emergence of pioneering user-led projects:

- lay advocacy,

- self-help,

- user-led crisis center,

- crisis teams,

- books

At the turn of the new decade...

- Opening up of the social care home and changing the role of the residents (users in the role of key workers and peer advocates)

- Adoption of the *Mental Health Act* (2008), new profiles:
  - coordinator of community care at Centers of Social Work
  - Professional advocacy (statutory advocate for users' rights in mental health)

- *Convention of the rights of people with disabilities:* newly defined role of the users, user representatives

- *New roles in the research:*
  - more systematic inclusion of users in education and research

Co-productive and user research

- **Co- productive research study of NGO's group homes by** Petra Videmšek and The Mostovi Association (2007-2009)

- *Findings:*

- users were stuck in group homes, due to the system of integrated community care being underdeveloped,

- The structures that were meant to be intermediary structures on one's way to independent life, mainly became a permanent solution.

- **Autonomous user research study by** The Mostovi Association (lead: Nika Cigoj) (2010)

- *Findings:*

- high degree of disability retirement and unemployment after the onset of mental difficulties.

- In order to cover their basic living expenses, and sometimes also in order to remain active, the users are often forced to work illegaly and to enter risky working relationships, typically as security or cleaning staff.

2010-2020 The gap between the systemic reforms and grassroots knowledge

systemic reforms

- Requirement of the EU, CRPD

- The Resolution on the National Programme for Social Care 2013-2020: a substantial reduction of institutional capacities

- Resolution on the National Mental Health Programme 2018–2028 foresees user participation at all decision-making levels,

- the »voice of the users« seems to have been only declarative

grassroots knowledge

- »*Big changes led by the ministry may be alright, I don't know, but only experience matters... When you have the experience that doors are closed for you.*«

- "*The system puts up front some strange, ideal user that does not exist.*"

- »*We depend too much on institutions, and we learn too little from our own practice. We forget, how we have overcame crises, and how we have helped ourselves.*«
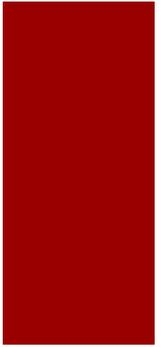
Where have all the users gone, long time ago?: a discussion on 30 years of user participation

formal user representative participation will not be able to become the tool of changes if the awareness about rights and the need to take action will not include a larger number of users

that impact is only visible where participation really becomes an integrated part of the philosophy of an organisation and people who work there, and not only something 'added-on' to services.

Users' involvement and participation can become caught up in contradictions: Participating in what? In:
- neoliberal framework of care system,
- closing and coercion?

ENTER network?