



Social Psychiatry Today – No Future Without Participation?

Participation – Involvement – Co-Production
Forms of collaboration between experts through experience and
experts through training

Jörg Utschakowski

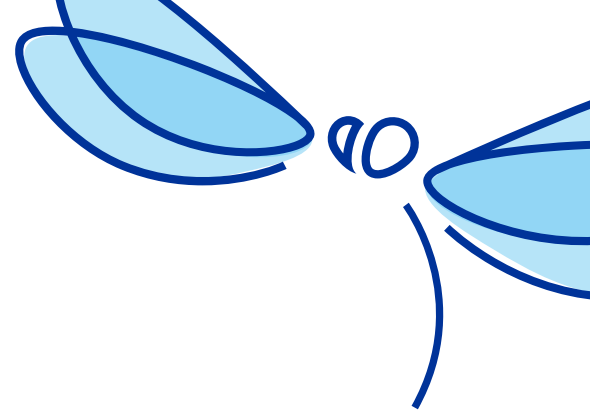


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WHO

Those affected have the right and the duty to participate individually and collectively in the planning and implementation of psychiatric services.

(WHO Alma Ata, 1978)



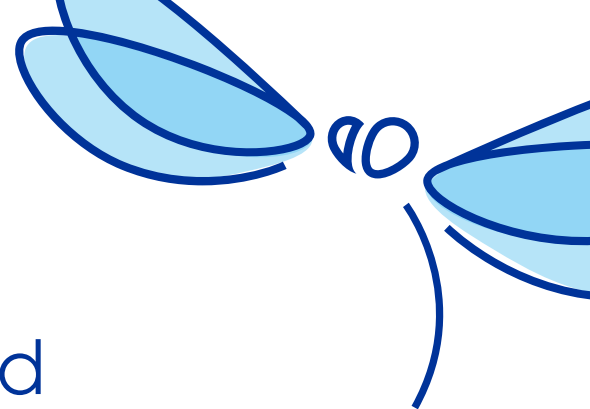
WHO

“The involvement of users of psychiatric services and their families is an important part of the reform process.

It has been proven that the active participation of people with psychiatric experience and their families improves the quality of care and services.

They should also be involved in the development and implementation of training programs to provide psychiatric staff with a better understanding of their needs.”

(WHO, 2005:108)



WHO Roadmap



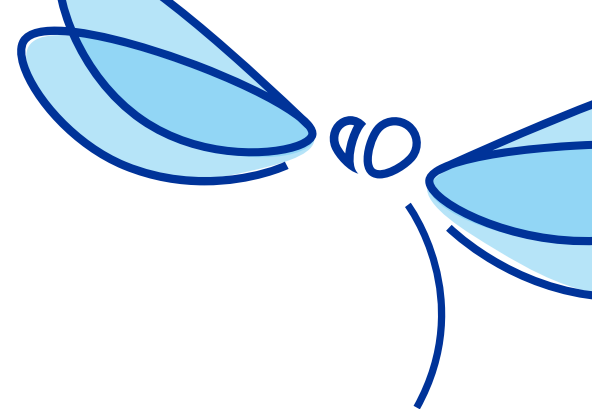
The WHO Roadmap defines “lived/living experience” as the personal knowledge gained through directly experiencing mental health conditions, psychosocial disabilities, or related challenges — including the use of services, supports, and recovery processes.

It emphasizes that this experience becomes *expertise* when people intentionally use it to improve policy, services, and community responses.

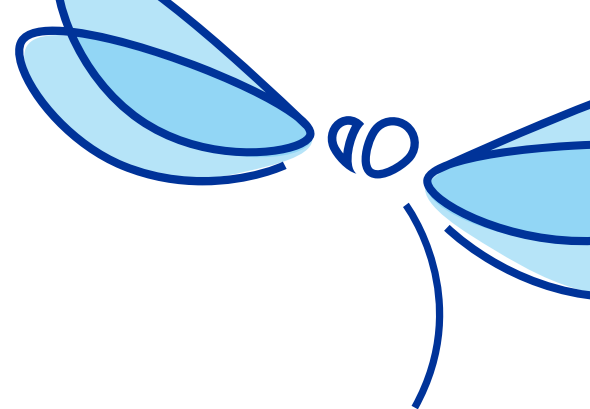
Training is important

Recovery

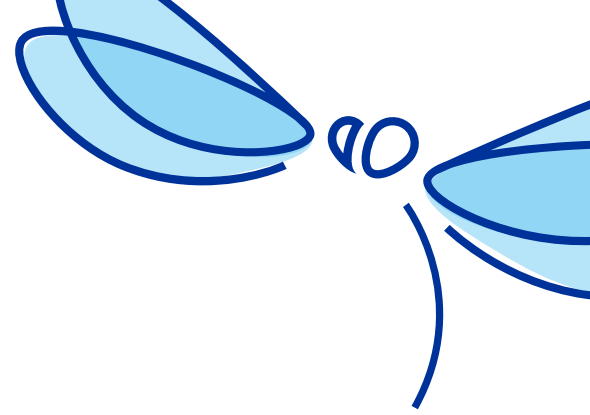
- The WHO Roadmap defines recovery as a *personal, holistic, and self-directed process in which people build meaningful, satisfying lives with or without ongoing symptoms.*
—not just clinical improvement



Recovery Oriented Services



- ‘A recovery-oriented service as one that supports people to be the *drivers of their own recovery*, focuses on personal meaning rather than symptom reduction, and embeds recovery values across every level of the mental health system’. (*National Framework for Recovery in Mental Health*, HSE Ireland)
- Involvement of PLE



Participation/ Involvement

National Institute for Mental Health (NIMH) – UK

Research veto – New Zealand

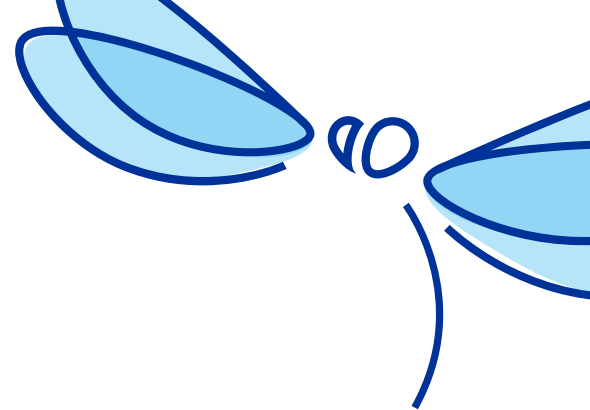
User council = Works council – UK

Health insurance advisors – NL

Peer-led services – USA/UK

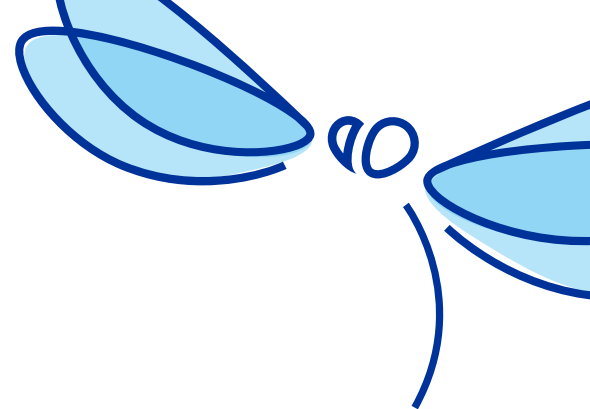
PLE involvement obligatory in MH services - UK

Research



- **Success of the involvement of peer specialists** Meta-study (Davidson 2008)
- **Case management** (USA): (Felton, Statsny, Shern et al. 1995)
- **Crisis intervention** (USA) (Greenfield/Stoneking/Humphreys/Sundby/ Bond 2008)

Research



- **Peer Support Group Interventions**

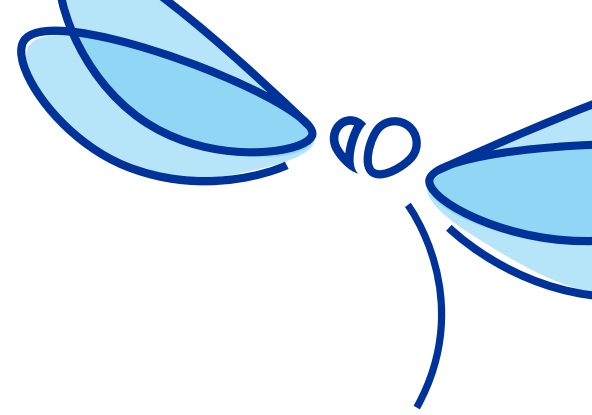
- psychoeducation, recovery-oriented, skills training, and anti-stigma.
- improvements in recovery outcomes, reductions in psychiatric symptoms, increased empowerment
- promise in reducing rehospitalization rates

Jagannathan, A. *et al.* Effectiveness of Peer Support Group Interventions for Persons with Mental Illness: A Systematic Review. *J. Psychosoc. Rehabil. Ment. Health* 2025

- **Current international studies support the PLE approach. Feasibility and sustainability only through continuous support and commitment of all**

Agyapong VIO. Peer Support in Mental Health: Literature Review. *JMIR Ment Health*. 2020 Jun 9;7(6):e15572.

Goals of PLE Involvement



Economical

- Improves Quality
- Help that really helps (use of resources in a meaningful way)
- Employment of PLE

Political

- Human Rights
- Improvement of healthcare
- Empowers disadvantaged groups, reduces negative stereotypes, enhances credibility and acceptability of plans,
- shifts power from professionals to citizens/people who use services.

Instrumental

- More impactful and feasible
- Increases a holistic understanding

New ways of working individual and service level change

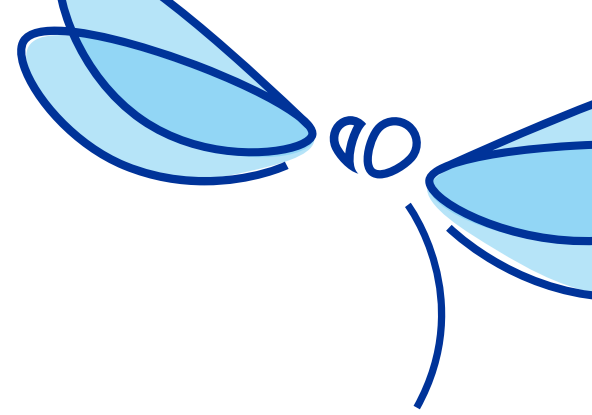


- Shared Decision Making
- Collaborative Care Planning
- Joint Crisis Planning
- Wellness and Recovery planning

Co-Production

“Co-production is an inevitable and ubiquitous feature of modern societies. It cannot not happen. **The only question is how it is designed and practiced – what processes are put in place, who the producers are and what roles they play (i.e., how power is allocated), and what products (knowledge, people, structures, plans) emerge as a result.**”

(Miller & Wyborn, 2018, cited from Emma Watson)



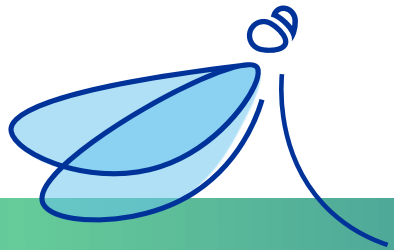
Co-Production-a new way of working

Old mindset:

- ‘Product’ delivered to a ‘customer’ from on high
- People using services are seen as helpless and demanding
- If we give power away, we lose it. There’s only so much to go around.

New mindset:

- Shared power and responsibility
- Power, choice, and control are devolved to those using the service, their communities, and frontline staff
- People, families, and communities are assets - they bring lived wisdom, skills, and resilience - often untapped
- Power grows when shared
- By enabling others, we all gain more — more capability, more solutions, more trust



Coproduction and organisational level

Top down *and* bottom up approaches:

- Enable leaders to understand what a Recovery focused culture is and why it provides answers and how they can contribute
- Support all teams to use Recovery as the underpinning philosophy of ongoing development
- Build Recovery into personal development and appraisal so that it is widely adopted as a values base.
- Build onto existing success and strengths – this is not new.
- Culture of curiosity and dialogue
- Encourage initiative, creativity and partnerships.
- See everyone using services and their families as potential resources to support the cause.
- Celebrate successes.

The three levels of deployment of recovery companions



Level 1: One of the core tasks of recovery companions is direct contact with those seeking help. Here, the clients' access to services as well as the services themselves should be improved in terms of recovery and empowerment.

Level 2: The recovery companions engage in a dialogue with the staff in order to improve contact and orientation for the clients.

Level 3: In exchange with management and committees, the recovery companions have the task of promoting recovery and empowerment throughout the organization in its processes and rules.

Impulses for the Further Development of Psychiatry

- Cultural Change
- Change Agents
- Services:
 - Clients (hope, intensive outreach, recovery)
 - Colleagues: interpreter, professional closeness, self-disclosure, hope
- Management (guidelines, documents...)
- Administration, Politics
 - Use money wisely
 - Planning and Evaluation

What to do?

Problem

Resistance from traditional models and fear of losing status

Hierarchical, risk focussed systems – stigma of lived experience roles

Lack of understanding about how to introduce change

What to do?

- Well established and growing evidence base for specific lived experience approaches
 - Clear best practice and examples of successful implementation
- Services/systems under pressure – we know that in times of economic insecurity, attitudes often harden, making this work even more difficult



What are good examples for implementation of PLE participation on an organisational/political level? What could be first steps?

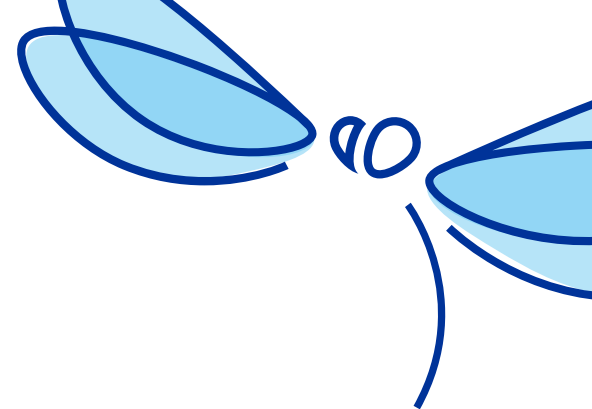
- Moldova – advisory councils
- Bologna – recovery college; cultural debate; not shared power yet
- ESTONIA – PATIENT LED CARE PATHWAY -
- Bremen – independent complaint office – participates in regional meetings of the psychiatric networks and in city wide committees; representatives

What are good examples for implementation of PLE participation on an organisational/political level? What could be first steps?

- Estonia – How to open the door for PLE participation?

What to do??

- Get some buy in
- Think strategically
- Don't just start at the bottom
- You don't have to change the world – start small and do it well
- Begin with co-production



Preparation

Prepare the teams

- introduction to the PLE Model
- enlist them as helpers and ask for their insights

Have a structure

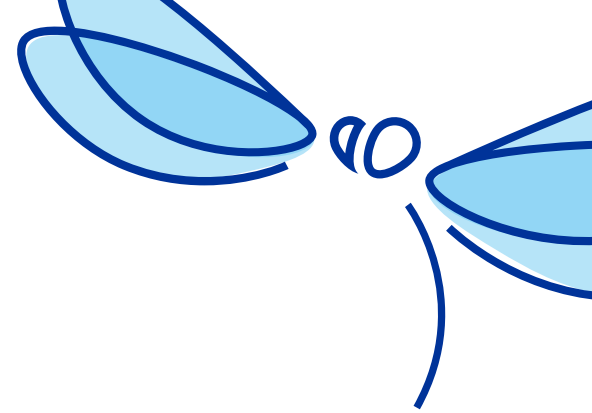
- Clear roles / role descriptions, clarity on organisational processes, mentor / tandem partner

Framework Conditions

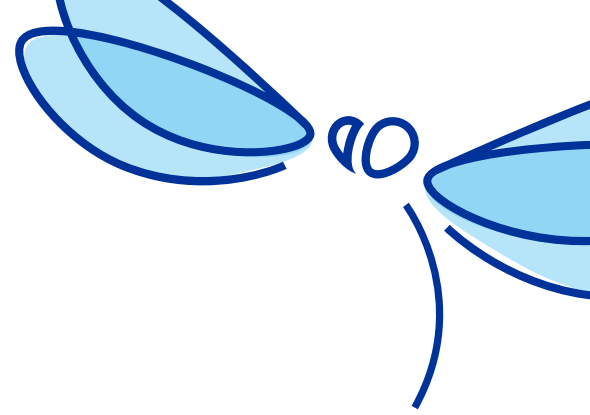
- development opportunities, networking, supervision and training

Lived experience infrastructure

- Visible and meaningful lived experience leadership roles

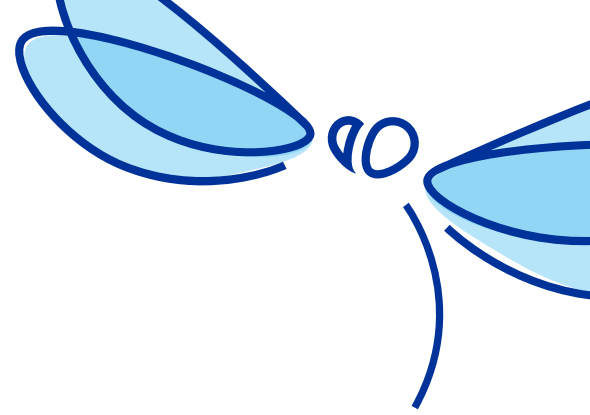


Key elements



- A Recovery focused service can only be effective when lived experience is integrated
- This goes beyond individual lived experience roles to:
 - Leadership
 - Co-production as a foundational practice
 - Integration the experiences of people who use services in all that we do
 - Enabling staff to work in empowering and creative ways

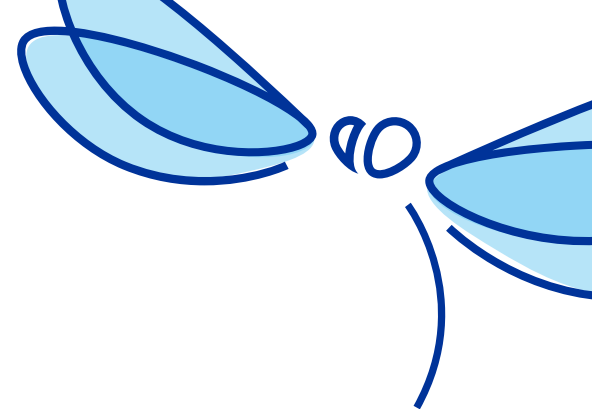
PLE Knowledge/Competence



- About the significance of information and choices
- About helpful and less helpful offers and structures
- About hidden and structural violence, external control, and coercion
- About the meaning of psychological 'disorders'
- About coping options and problem-solving strategies
- About the importance of hope
- Talking about experiences instead of symptoms

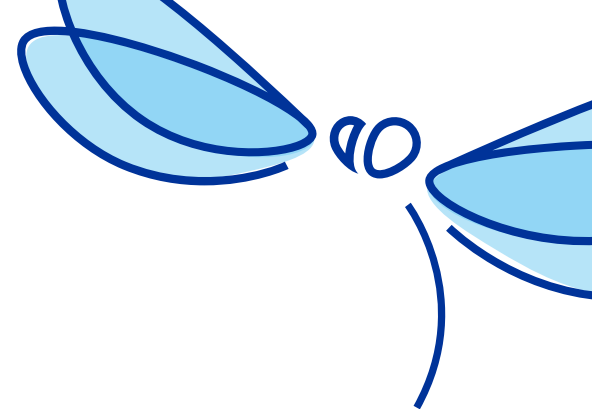
Quality

- Speaking the same language
- Authentic conveyance of hope
Emotional support (self-esteem, self-efficacy, empowerment)
- Advocacy
- Interpretation

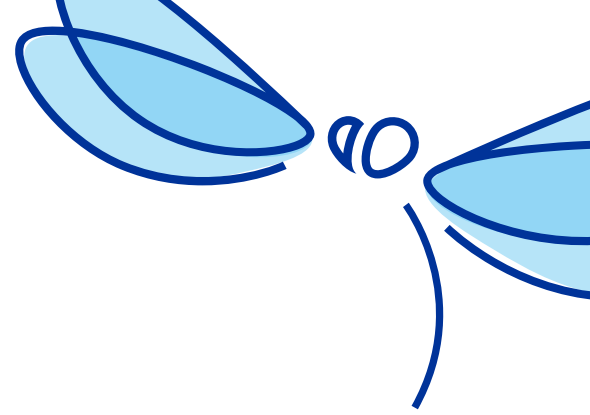


Structural level

- Participation in structural development
 - Public assumption of responsibility
 - Transparency
 - No conflicts of interest
 - Self-determination (empowerment, recovery)
 - More accessible and accepted services
 - Quality improvement: Patients with chronic illnesses have deeper, more holistic understanding than professionals
- (Entwistle, Hanley 2006 / Nilsen 2006)



Preconditions



- People with experience in psychiatry and relatives are full and equal partners
- Equal access to information
- Firm integration into the planning process
- The meetings are held in an appropriate manner
- Clearly agreed roles and responsibilities
- Information about what impact the influence had
- Qualification and training

Bremen

Education

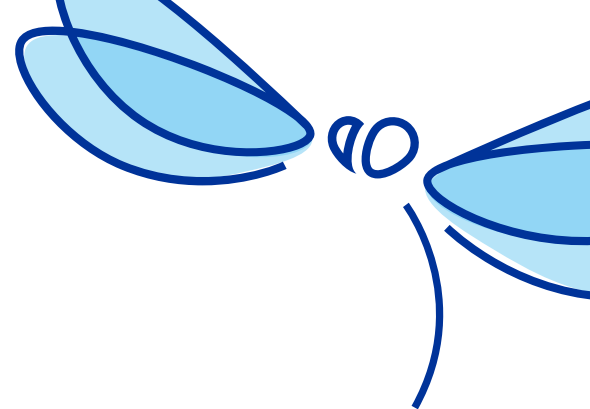
- PLE as trainers and instructors
- PLE as participants in training
- Empowerment College

Politics

- Expert partnership, Zwielight (Twilight)
- Implementation strategy UN CRPD
- Participation in committees

Society

- Network meetings
- Practice
- Recovery companions mental health services
- Advocacy





Thank you for your attention

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