Indicators of Empowerment
A European project

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Trieste, September 25, 2019
### About WHOCC (Lille, France)

<table>
<thead>
<tr>
<th>Term of reference (ToR) 1</th>
<th>ToR 2</th>
<th>ToR 3</th>
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<tbody>
<tr>
<td>To contribute to WHO's work on promotion of Community based mental health services</td>
<td>Capacity-building in quality assessment and quality improvement of institutional care for persons with psychosocial disabilities in French-speaking countries outside of Europe (WHO QualityRights programme)</td>
<td>Assist WHO to promote the participation of users and citizens in mental health services, research and training</td>
<td>Contributing to the knowledge and development of e-mental health as an innovative technology</td>
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A long story…

- 2009-2012: Joint project WHO – European Commission
  ⇒ 19 indicators
- 2014: WHOCC 4th International Congress
  ⇒ test of the indicators
  ⇒ collection and dissemination of good practices
  ⇒ collection of 200 recommendations
- 2016:
  ⇒ 21 recommendations
- 2018: WHOCC 5th International Congress
  ⇒ +4 = 25 recommendations
What we’ve learnt...

• Separate indicators for users and carers
• Operationalize the indicators
• Increase participation
• Ensure understanding
What we’ve achieved...

- 25 recommendations for users and carers
- Literature review: pool of indicators
- Partners network: Finland, Greece, Hungary, UK, Luxembourg, France
Defend Fundamental Rights

1. Protect fundamental rights in mental health and social care facilities.
   1bis. Ensure such rights are enforced and provide and implement penalties in the event of violation.

2. Guarantee the self-determination and the legal capacity of users and carers.

3. Defend full citizenship of users and carers.

4. Supply the resources for users and carers to be free to call on the health care and social service providers of their choice.

5. Identify, in order to restrict, the use of isolation and restraint.

6. Assess, in order to limit, the use of compulsory psychiatric care.

7. Develop services in the community close to where people live and encourage alternatives to hospitalization.

8. Develop legal aid systems for users and carers, including persons imprisoned.

9. Guarantee access to mental health services in prisons.

23. Train users and carers in participatory methods and public policies, and encourage citizen engagement.
Participate in the organization and evaluation of services

10. Ensure the effective participation of users and carers at all levels and guarantee the conditions for their effective participation. (+co-construction)

11. Assess the quality and organization of services and patient safety using instruments designed together with users and carers.

12. Include the contribution of users and carers in both initial and on-going training programmes designed for mental health professionals, as well as in research. (+ recovery-oriented)

13. Encourage cooperation in the field of prevention at the level of local territories, together with users, carers, professionals, social workers, elected officials and wider civil society.

14. Ensure that users' and carers' organizations have their place in mental health services.

15. Develop networks and mutual support groups (clubhouses, "Groupes d'entraide mutuelle" in France, etc.).

22. Adopt recovery-oriented objectives in individualized care projects.
Inform and communicate

16. Provide and widely disseminate appropriate information on mental health using different media: print, images, films, social networks, blogs, etc. (+ different targets)

17. Provide and widely disseminate international conventions and treaties that apply to the human rights of mental health service users.

18. Make information accessible on the actual supply and demand of mental health services in given territories.

19. Create an observatory of empowerment of users and carers, with an international database of assessment tools.

20. Create observatories to monitor how the media treats information on mental health issues and encourage a response from users and carers. (+ tackle stigma)

21. Recognize and promote the fact among the general public and health professionals that users and carers are experts by experience.

24. Promote the use of digital tools that strengthen the capacity of users and caregivers to act.

25. Value evidence from participatory research and international recommendations on community mental health.
### First results of the FGs with users

<table>
<thead>
<tr>
<th>#</th>
<th>Recommendation</th>
<th>Description</th>
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<tbody>
<tr>
<td>+</td>
<td>Rec 1: Protect <strong>fundamental rights</strong> in mental health and social care facilities</td>
<td>Well understood but need for definition (fundamental rights)</td>
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<td><strong>Rec 7:</strong> Develop services in the community close to where people live and <strong>encourage</strong> alternatives to hospitalization.</td>
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<td>Push things forward: encourage &gt;&gt; promote</td>
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<td>-</td>
<td>Rec 19: Create an <strong>observatory of empowerment</strong> of users and carers, with an international <strong>database</strong> of assessment tools.</td>
<td>Not understood (observatory, empowerment, database)</td>
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<td>Rec 18: Make information accessible on the actual supply and demand of mental health services in given territories.</td>
<td>Not understood, rephrasing: <strong>Make public information on services available in a territory</strong></td>
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What we’ve planned...

• Focus groups with users / with carers
  ➞ Understanding
  ➞ Rephrasing

• Design a web survey
  ➞ interest
  ➞ prioritization

• Link indicators with the selected recommendations

• Mapping of indicators in Europe
Call for volunteers!

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