



From Tokenism to Meaningful Participation

The role of Service Users in the design and development of Health Services


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Overview

Share the learning of 20 years in practice as an organisational development consultant with regard to developing a culture of meaningful service user involvement in the design and development of health services





What service users want?

- ▶ Opportunity to bring ideas forward
 - ▶ Involvement in decision-making
 - ▶ Involvement in how services are organised
 - ▶ Access to information
 - ▶ Equal relationship within the team
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Experiences of service user involvement



Mother and children's hospital service

Primary care teams

Community mental health teams

Disability services

Range of service roles: designer, evaluator, co-trainer, care planner team member, partner



Facilitators



- ▶ Trust and respect
- ▶ People support change they help to create
- ▶ Authenticity
- ▶ Openness to learn together
- ▶ Clear contract
 - ▶ Clarity of purpose, role, timescales, operational guidelines etc
- ▶ Set up-time to explore resource available, expectations etc
- ▶ Organisational readiness-whole systems approach



Challenges/Barriers

Conscious

- ▶ Time commitment
- ▶ Lack of trust
- ▶ Size and complexity of the task
- ▶ Expectations
- ▶ Meaningfulness
- ▶ Defensiveness/lack of openness
- ▶ Fear of litigation
- ▶ Talk shops-no action
- ▶ Role underutilisation
- ▶ Confidence and competence
- ▶ Knowledge, skills, and attitudes
- ▶ Advocacy-who is representing who?

Unconscious

- ▶ Anxiety about complexity, ability to deliver
- ▶ Power and fear of loss of control, expert role
- ▶ Transference-powerlessness
- ▶ Paternalism and infantilization



Learning



- ▶ Need to move from “have to” to “want to”
- ▶ Involvement needs to be more meaningful for all stakeholders
- ▶ Service initiatives should validate time spent with service users and display more tangible and flexible commitments to meeting their needs.
- ▶ More listening and follow-through.
- ▶ Need to recognize that involvement takes time and long term commitment
- ▶ Needs whole system change-organisational ,service and individual level



When we are not listening, we are not learning



Thank you for listening!

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