User involvement in the field of childhood disability research

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Today

- Introduction
- 2 research examples of service-user participation
- Take home message

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Participation

as an end

as a means

Recognition of service-user participation

Liberating the NHS: Legislative framework and next steps

Presented to Parliament by the Secretary of State for Health by Command of Her Majesty

December 2010
Identify topics

Set priorities

Research design

Carry out research

Analysis & Interpretation

Disseminate results

Presentations

Implement results

Service-user education

Service-user Advocate

Evaluation

Empirical research circle

Review research protocol

Recruitment

Research questions

Develop Research agenda

Service-user Advocate

Research questions

Recruitment

Implement results

Coding transcripts

Service-user Advocate

Advocate

Service-user Advocate

Codex

Research Partner

Assess questionnaires

Service-user Advocate

Advocate

Service-user Advocate

Advisor
Service-user participation

- identify relevant citizens;
- share information and communicate it in adequate way;
- see them as a partner
- listen to citizens views;
- involve them in processes of agenda setting, development, planning, decision-making, executing and evaluation;
- contribute to their capacity-building;
- empower them to initiate, manage and control their own self-development.
Shier’s model

1. Are you ready to listen to children?
   - Do you work in a way that enables you to listen to children?
   - Are you ready to listen to children?

2. Are you ready to support children in expressing their views?
   - Do you have a range of ideas and activities to help children express their views?
   - Are you ready to support children in expressing their views?

3. Are you ready to take children’s views into account?
   - Does your decision-making process enable you to take children’s views into account?
   - Are you ready to take children’s views into account?

4. Are you ready to let children join in your decision-making processes?
   - Is there a procedure that enables children to join in decision-making processes?
   - Are you ready to let children join in your decision-making processes?

5. Are you ready to share some of your adult power with children?
   - Is there a procedure that enables children and adults to share power and responsibility for decisions?
   - Are you ready to share some of your adult power with children?
Benefits

research project, (Ennis and Wykes (2013))

service users themselves (Hewlett et al., 2006) (Thornicroft and Tansella, 2005).

as well for the entire population (Domecq et al., 2014, Ennis and Wykes, 2013, Beresford and Croft, 2012).
✓ A mother of a child with CP
✓ A parent organisation
✓ Parent’s panel
✓ Study participants
What Barbara did so far

**Literature study:**
- Discuss the results of the scoping review

**Cross-sectional study**
- Design, decisions about instruments, information for parents, discussing sampling procedure, discussing about outcomes

**Qualitative studies (diary & interviews)**
- Design of the interview guide & diary, information for parents, informed consent, pilot training

7/4/2016
“Bundeling van individuele ervaringskennis naar collectieve kennis.”
SCHOUDERS
voor elkaar
User-centred design process methode

Identificeer
End-users & Context

Concept Development

Tool(Re)Design

Evaluatie
Pilot

Bruikbaarheid en tevredenheid (Nielsen 1992)

Prototypes

Project groep
Ouders, ICT en andere experts, mensen uit Community of practice

Mogelijk Extra Prototype

40 ouders & stakeholders

- Literatuur
- Focusgroepen ouders
- Focusgroepen stakeholders/experts
- Interviews ICT experts
- Interviews onderzoek/ innovatie health experts

Gebaseerd op 't's Life! User Centered Design proces (van der Weegen, et al. 2013; Schmitz et al., Collaborative alternate reality gaming, in progress)
Enabling service-user participation

- Facilitate processes that involve all stakeholders
- Setting clear roles and responsibilities
- Giving support and offering a training that will enable individuals to be engaged
- Setting up policy in the institute
Enabling researcher program

Masterclass
Participation of service-users
Take home message

Inclusive research methods

User involvement is a must

“Nothing about us without us”
Thank you!

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