Involving children young service users in research: opportunities, challenges & opportunities

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Presentation

• Rationale for involvement
• Children and young people
• Gatekeepers
• Issues before the research begins, during the research and following data collection and analysis
• Opportunities
Dame Sally Davies — Director General of Research and Development DoH (Staley, 2009:4)

- I have always taken the view that public involvement in research should be the **rule not the exception**, it is fundamental to ensure high quality research that brings real benefits for patients, the public and the NHS.
Opportunities - Involving Young People in Research

• Every child has the right to say what they think in all matters affecting them, and to have their views taken seriously. (Article 12, UN1989)

• Article 4 notes that the ‘best interests of the child must be the top priority in all things that affect children’ (UN, 1989).
Children and Young People

- Are not mini adults or potential adults they are ‘actors’ – people who do things, who enact, who have perspectives on their lives. They also have agency including powers, to influence and organise events – to both be shaped by the structures which shape their lives and to shape those structures.
Power

- Children inherently **vulnerable**
- Physically, lack of knowledge
- Lack of economic or political power
- Dependency on adults
- Adults greater experience
- Adults been children
- Children experts on own lives
Involving children and young people in decision making...

Based on the 'Degrees of Participation' by Phil Trezeder

**INVOLVE**

**Children and young people initiated and directed**
Children and young people have the initial idea and decide how the project is to be carried out. Adults are available but do not take charge.

**Children and young people initiated shared decisions with adults**
Children have the ideas, set up projects and come to adults for advice, discussion and support. The adults do not direct, but offer their expertise for young people to consider.

**Assigned but informed**
Adults decide on the project and young people volunteer for it. The young people understand the project, they know who decided to involve them and why. Adults respect young people's views.

**Adult initiated, shared decisions with children and young people**
Adults have the initial idea, but young people are involved in every step of the planning and implementation. Not only are their views considered, but children are also involved in making the decisions.

**CONSULT**

**Consulted and informed**
The project is designed and run by adults, but children and young people are consulted. They have a full understanding of the process and their opinions are taken seriously.

**INFORM**
Benefits of Service User Research

- Offer different perspective from adult researchers
- Focusing and prioritising the research
- Access and peer recruitment
- Accessibility of research tools
- Enhancing range and quality of data
- Analytical meanings and connections are not misunderstood
- YP raise issues with other young people they would not raise with an adult
- Ownership of recommendations
- Dissemination
- Empowerment – participation agenda
Why researchers don’t involve service users in research – challenges

- Lack of representativeness
- The usual suspects
- Research not objective
- Too expensive/time consuming
- Children have unrealistic expectations
- Research excellence framework
Challenges

- Recruitment and training
- Types of research
- Education
- Disclosure and barring checks
- Ethical approval
- Gatekeepers
- Support e.g. transport
Gatekeepers

• Parents, teachers, social workers, health staff
• When does gatekeeping become an interference in the rights of children or when does bypassing parents deprive children of protection?
• ‘Gillick’ competency
• Children’s right to confidentiality (sexual health)
• Once aware can’t be made unaware
• Gatekeeper abuse
• Multiple gatekeepers
Adult supporter

- Help child researchers arrive at ethical research questions
- **Withdraw** support from unethical projects
- Don’t make rash promises
- Help child researchers to keep projects feasible
- **Ensuring wellbeing** of child researcher
- Clear the way with **gatekeepers**
- Disclosure of **abuse**
- **Support** child researchers with secure data storage
Challenge

• It is as absurd to believe that children’s (co-)researchers will necessarily improve the research, this is as misguided as believing only academic researchers can undertake ‘real’ research.
Before the Research Begins I

- Who decides?
- Funds?
- RGF – dignity, rights, safety and well-being
- Rewards
- Expenses
- Recruitment
- Training
- Safeguarding-DBS
Before the Research Begins 2

- Morally active researcher
- Informing-for-consent
- Anonymity and confidentiality
- Gatekeeper consent
- ‘Peerness’ and ‘sameness’
Ethical issues During the Research

• Exploitation
• Unanticipated issues
• Drop out of YP
• Support needs of YP
• Confidentiality
• Researcher discomfort
• Health and safety
Ethical issues following collection and analysis of data

• Authorship
• Anonymity
• Publication risks
• Presentation of research findings
• Endings
• Outcomes
Opportunities 1

- Inadequate attention
- To go beyond ‘voice’ impact as well as processes
- Complementarity and additionality
- Restrained by our imagination
- Not to be entered into lightly
Opportunities 2

If we accept that differing types of knowledges and experiences contribute to a full understanding then everyone has something to learn from everyone else and that includes learning form children and young people as co-researchers! The challenge becomes; ‘How do we do it?’ Not if, but how.
Useful publications


McLaughlin, H. (2005) Young service users as co-researchers: methodological problems and possibilities; *Qualitative Social Work*, 4: (2) 211-228.