



Systematic review: Involving disabled children and young people as partners in research

Tuesday 26th February 2013, Veysey room 006, 10.30am-12.30pm

Attendees: Tricia Stone, Antonia East, Camilla McHugh, Kate Boddy, Simon Briscoe (SBr), Sarah Bailey (SB).

Apologies: Julia Melliush, Lucy Buckle, Lynn Pashby.

Purpose of meeting:

1. Introduce the project and systematic reviews
2. Discuss findings from the scoping review
3. Shape the systematic review by discussing and developing ideas for research questions and search criteria

Introductions: Everyone in the group introduced themselves and SB explained that there are other parents who are interested in being involved in this project, but cannot attend the meeting.

Information about systematic reviews: KB gave a summary about the purpose of systematic reviews and the aims of a systematic review. We discussed the need to clearly define the research questions and criteria before the search can be carried out and that this is one of the most important stages where parents can be involved in the research project.

Background to the project: SB gave some background information about the project and how the project has come about – in part to inform the work of the unit in involving disabled children and young people in research. A scoping review was carried out earlier this year, which was a brief, broad search for information to see what is available. SB gave an overview of the findings of the scoping review.

Shaping the review

Research questions

The group discussed possible research questions for the project, informed in part by the scoping review.

The primary research question was suggested as:

- How have disabled children and young people been involved as partners in research?

The group suggested five secondary questions to answer this main question:

1. How have disabled children and young people been accessed, recruited or selected for involvement in research projects?
2. How have the practicalities of involving disabled children and young people in research been addressed?
3. What are the challenges of involving disabled children and young people in research and how have these been overcome?
4. What impacts, positive and negative, has involving disabled children and young people in research had on research projects?
5. What impacts, positive and negative, has involving disabled children and young people in research had on the children and young people involved?

The group wanted to include a statement which made it clear that the answer to these questions may vary depending on the needs of the children involved, or the exact nature of their disabilities (for example, mental or physical disabilities). A possible wording for this statement could be:

‘While considering all of the questions above we will bear in mind that the answer may vary depending on the needs or disabilities of the children and young people involved’

The exact nature and wording of this statement will need more thought and consideration before it is finalised and we welcome any suggestions .

Inclusion and exclusion criteria

- Include papers that have involved disabled children and young people aged 5-25.
- Include papers that have involved disabled children and young people in one of the acknowledged approaches to involvement (see INVOLVE link <http://www.invo.org.uk/posttyperesource/approaches-to-public-involvement/>)
- Exclude papers that have involved disabled children and young people in research as subjects, rather than as partners in research.

- Include peer reviewed papers, but also grey literature to answer the questions.
- Include papers that have involved disabled children and young people with all kinds of disabilities.

Sources of information

Several possible sources of information were suggested including Mencap, the British Institute for Learning Difficulties, NASA and the UN.

If you have any other suggestions for websites that would be useful to include in the search, please email Sarah.

Next steps:

The notes from this meeting will be circulated to attendees and interested parents for feedback on the research questions and criteria. Once feedback on these notes has been collected and any amendments have been made, the draft protocol will be put together. This is a plan which details exactly what is going to be done in the systematic review, and how. There will be an opportunity for everyone to comment on the draft protocol before it is finalised and the literature search begins.

We are hoping to have another meeting for this project to discuss the preliminary findings from the literature search within 3-4 months, but the exact time scale for the project will depend on how much information is found in the literature search.