



VIPER: a participatory research project with young disabled people

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VIPER: a participatory research project with young disabled people

- Policy advocates the involvement of young people in decision making and there has been an increase, but less so for disabled children and young people
- A three year project exploring the most effective ways of enabling the participation of disabled children and young people in the development and delivery of services in England
- Project partners: NCB Research Centre, Alliance for Inclusive Education (Allfie), Council for Disabled Children (CDC) and the Children's Society



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Objectives

- To undertake participation- not just research it!
- Explore ways in which young disabled people are involved in decisions about strategic and operational issues by services
- Explore the impacts and benefits of participation
- Understand the barriers to effective participation
- Identify good practice and to understand what works in supporting young disabled people's participation
- Develop tools and good practice guidance with young disabled people to support participation
- Spread good practice and build capacity



Method: Literature Review

- Search parameters: All services from planning to evaluation, covering children of all ages, literature in English language only, academic and grey literature
- Search terms: Various terms for participation and services eg: involvement, decision-making; education, environment, policy, health, transport
- Searches: databases, websites, contacted known researchers, call out for evidence



Method: Consultation

- Online questionnaire
- Topics included: purpose, methods, support, barriers and impacts of participation
- Distributed through networks – implications for generalising from findings
- From questionnaire selected qualitative research sites to explore practice in more depth
- Received 260 responses



Method: Qualitative interviews

- Nine case studies- across England.
- Sample based on 'good practice' criteria developed with Vipers- but less clear cut when you get out there!
- Interviews/ group discussions with young disabled people who have participated and interviews with adult service providers
- Young researchers involved in all aspects – conducting interviews, facilitating focus groups

Viper young researchers – fully involved in coding and analysing the data, now developing their recommendations



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Evaluation

- Inbuilt ongoing evaluation of the project:
 - Impact on practitioners awareness and skills
 - Impact of project of national policy and guidance
 - Impact on young disabled researchers skills, knowledge and confidence
- Also reflect and explore our own learning



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Young researchers participation

- Young researchers are a central part of this research projects plan. The Vipers have regular meetings during which they learn research skills and give advice around upcoming issues in the research.
- Currently we have 16 young researchers aged between 13-22 from across England
- All the young researchers are young disabled people



Definition of Disability

- Project uses the Equality Act (2010) definition of disability: someone who has a physical or mental impairment which has a substantial and long-term adverse effect on that person's ability to carry out normal day-to-day activities
- However research explores disability from a social model perspective, recognising that young disabled people are disabled by social, physical and attitudinal barriers rather than by their impairments



Journey so far



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Viper perspective

- How and why Emma got involved?
- What she has been involved in?
- What she has enjoyed and learnt in the project?



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Inclusion & accessibility

- The groups access needs are very diverse and part of the development work has been around creating a space where everybody feels included
- In addition to basic access questions we asked what people needed to be included and how the group can support them



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Inclusion & accessibility



- Using this information we have been able to deliver activities in a way that is accessible to the young researchers
- For example making sure activities mainly use verbal contributions
- We have banned PowerPoint
- Accessible information
- Timings of the meetings are also important



Challenges

- Definitions of disability
- Self image of the young people
- Time
- Venues
- Ownership
- Research language and processes
- Communication
- Parents
- Health
- Language
- Thinking about wide experience and service level oppose to day-to-day



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Some key findings

- There are many groups of disabled young people who are still being excluded from decision making due to their impairments and a perception they are too hard to work with
- Funding cuts are having an impact on practice – uncertain future, curtailing of activities, closing of projects
- Impact frequently anecdotal and therefore easily lost with staff change. Limited evaluation of practice and outcomes.
- Lack of opportunities for disabled young people in mainstream services

Key findings

What works!

- Maximising inclusive practices (social model)
- Embedding participation (not working in silos)
- Empowering young disabled decision makers
- Lots of different approaches to participation
- Encouraging participation
- Evidencing impact



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Some of the Viper recommendations

What they hope will change because of the research...

- More opportunities to participate in decision-making
- More inclusion
- More positive attitudes and a better understanding that disabled children and young people can participate



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What next?

- We are developing resources and materials for policy makers and practitioners
- We are developing resources for young disabled people to influence their MPs and services they use
- Launch event and web resource launched in Spring 2013



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