



Co-producing Communities with Disabled Researchers and Citizens

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A collaborative project....





Project Aim

To develop a clear understanding of the demand for current and future disability services across the county of Suffolk.

The project builds on an initial audit of existing services conducted by SCODP in 2014/15



Project objectives

- For disabled people in Suffolk to identify the issues most pressing for disabled people – what works and what does not work in their lives.
- To gain a better understanding of what it is like to be a disabled person living in Suffolk, through engaging disabled researchers who have ‘insider’ knowledge.
- To support and train Expert Researchers who are disabled or are affected by long-term health conditions to undertake the research with their greater understanding of disability issues



Outcomes

- The voices of disabled people can be heard and have influence.
- Future Health and Social Care services commissioned will truly reflect the needs of people and carers in Suffolk communities.
- Services that are timely and effective will therefore reduce future demand.



Research approach

Factors shaping the research approach:

- emancipatory disability research tradition (arising out of the Disability Movement in the UK)
- social model of disability (socio-political interpretation of disability and disability as social oppression (Barnes 2003 p5))
- research and power – collaborative research, equalizing the research relationship – expert researchers and expert participants
- co-production of project



Epistemological considerations

- Emancipatory research(Oliver 1992) – transformative aim (barrier removal and individual/collective empowerment)
- Co-operative inquiry (from humanistic, person-centred psychology) – informative inquiry (adds to our knowledge) and transformative (change-making) (Heron 1996, p48/9) – these are interdependent.
- Feminist research
- Developmental – personal growth of the researchers (Wilkins 2000 p20)
- Democratisation – power relationships and control of the research agenda

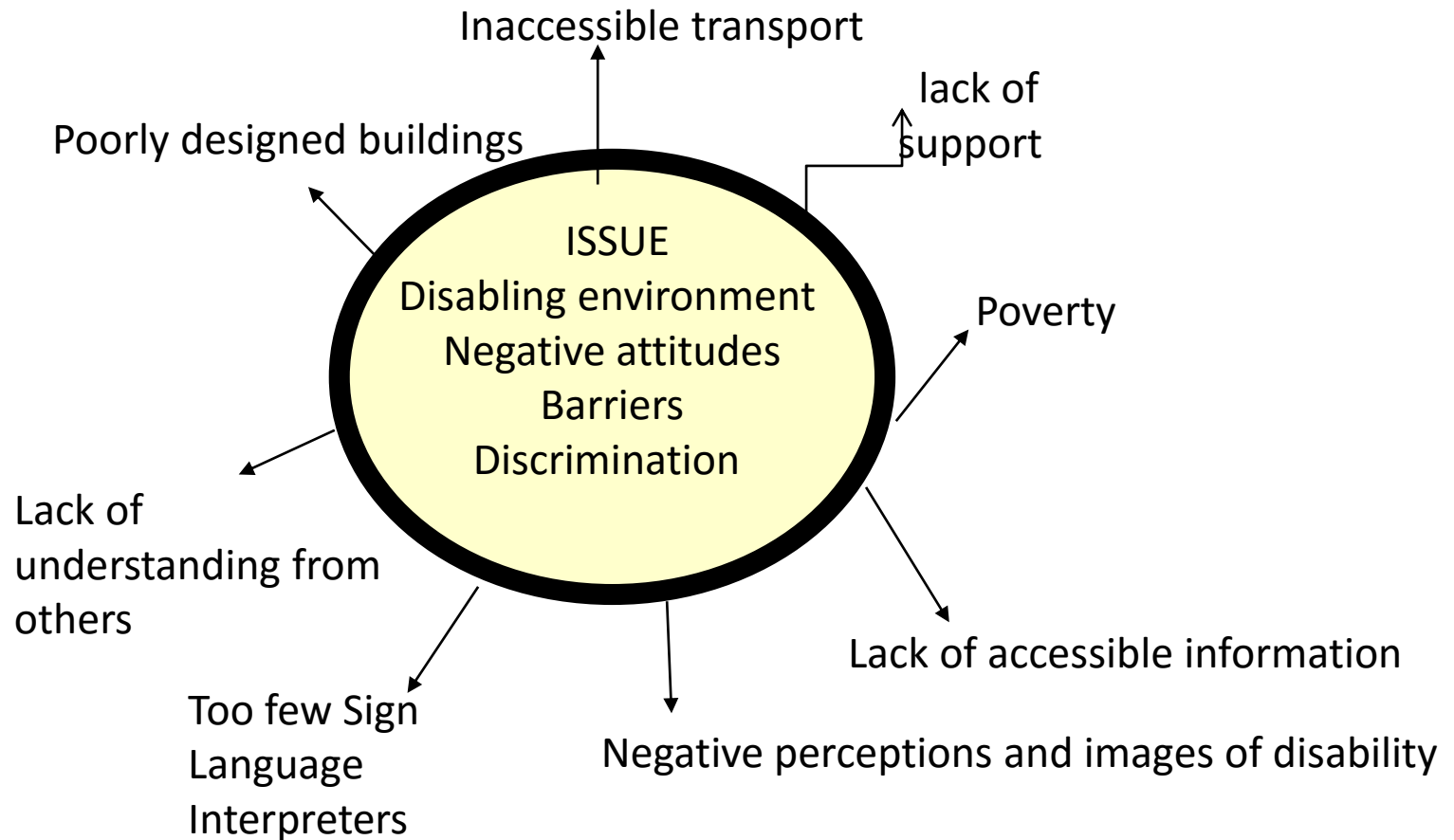


Emancipatory research

Key characteristics (Barnes 2003)

- Accountability to organisations controlled and run by disabled people (SCODP)
- Commitment to the social model of disability
- Choice of methodology and methods – tend to be qualitative
- Emancipatory – meaningful practical outcome for disabled people

Social Model of Disability





Methodology

- Builds on an initial audit of existing services conducted by SCODP in 2014/15
- Adult and Community Services already hold quantitative information on the support they provide in the community to current customers.
- The second part of the project intends to develop this data by providing more qualitative information.
- To undertake qualitative interviews across the county to capture the real experience of living in Suffolk with a disability.



Research phases

- Reflective phase - discussions between SCODP, UoS and SCC on clarifying the problem. Collaboration agreed.
- Planning phase – how to conduct the research and deciding on the most useful areas of inquiry (scoping exercise with qualitative interviews).
- Funding issues – initial pilot phase in Ipswich.
- Clarifying theoretical basis for the research (social model of disability and collaborative approach combining different kinds of knowledge and expertise – knowledge and experience of disability; research theory and research experience. Collaborative learning.



Project planning

Co-produced meetings which progressed:

- funding applications
- budget management
- job description and advertising for researchers
- advertising for participants
- research governance application
- recruitment of researchers and training sessions
- setting up the interviews



How we have developed our research

- Recruitment and training
- Blogs
- Devising interview questions
- Matching researchers and participants
- Cameras
- Data collection – taped semi-structured interviews
- Data analysis



Data Collection

Experiences of the researchers:-

“Feeling nervous but once past the introductions the nerves went.”

“Enjoyable – I had a lot of laughs...”

“It was the best day of my life”

“The photos helped to get the conversation going”.



Data analysis

Thematic analysis

Reviewing transcriptions as a group

Identifying codes and themes

Grouping initial themes into larger themes

Expert researchers identifying with the participants – overlapping stories

Reflexivity within the process

Member checking meeting with participants and researchers



Emerging themes

Accessibility

Transport

Attitudes (self and others)

Social Exclusion

What works and why?

Financial issues

Technology

Work

Personal care/relationships

Risk

Frustrated independence

Emerging themes - accessibility

Sports

Services

Leisure

Toilets

Shops

Places of worship

Car parks

Education

Work

Communication/alternative languages

Built environment/House design



Emerging themes

Transport



What works and why



Emerging themes accessibility/attitudes







Crown Car Park
Passenger lift operating times
Monday to Saturday 8am-5pm only
No lift available on Sundays and bank holidays
IN THE EVENT OF FIRE DO NOT USE THE LIFT



Overarching themes

- Quality of life/well-being
- Having the same experience as anyone else
- Additional demands on energy to confront barriers
- Dignity undermined
- Lack of spontaneity



Dissemination

- Photos
- Exhibition – reaching as wide an audience as possible.
- Podcast for visually impaired
- Report



Any questions?



References

Barnes, C. (2003) 'What a Difference a Decade Makes. Reflections on doing emancipatory disability research'. *Disability and Society*, 18(1),13-17.

Heron, J. (1996) *Co-operative Inquiry: Research into the human Condition*. London: Sage.

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Wilkins, P. (2000) 'Collaborative Approaches to Research' in B. Humphries (ed) (2000) *Research in Social care and Social Welfare. Issues and Debates for Practice*. London: Jessica Kingsley.