



Inclusive Research into Practice

Presentation to KSS

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Aims

To introduce inclusive research

- To identify reasons for working people with learning disabilities and their families to do research
- To describe a range of methods and techniques
- To consider what you will need to get started





About Jan

30 years of working with people with learning disabilities on 'inclusive research'

About Danielle



Has a learning disability and a visual impairment and works with Brighton and Hove Speak Out. Started doing research in lockdown

Human Rights

Where it all started.

*The United Nations Convention on the Rights of
People with Disabilities Article 19:*

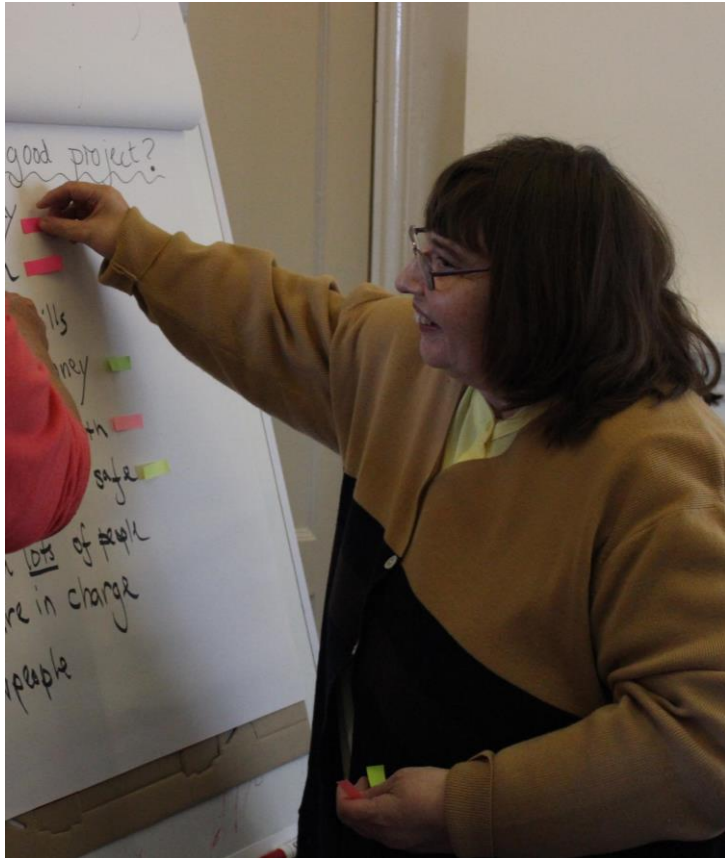
Full inclusion and participation in the community

Why not full participation in research?

And all other activities?



What is inclusive research?



- Research which is important to the people it is about
- Research which will make a difference
- Research done in partnership, where disabled people work alongside academic researchers
- Reports which everyone can understand!

Changing Relations of Research Production

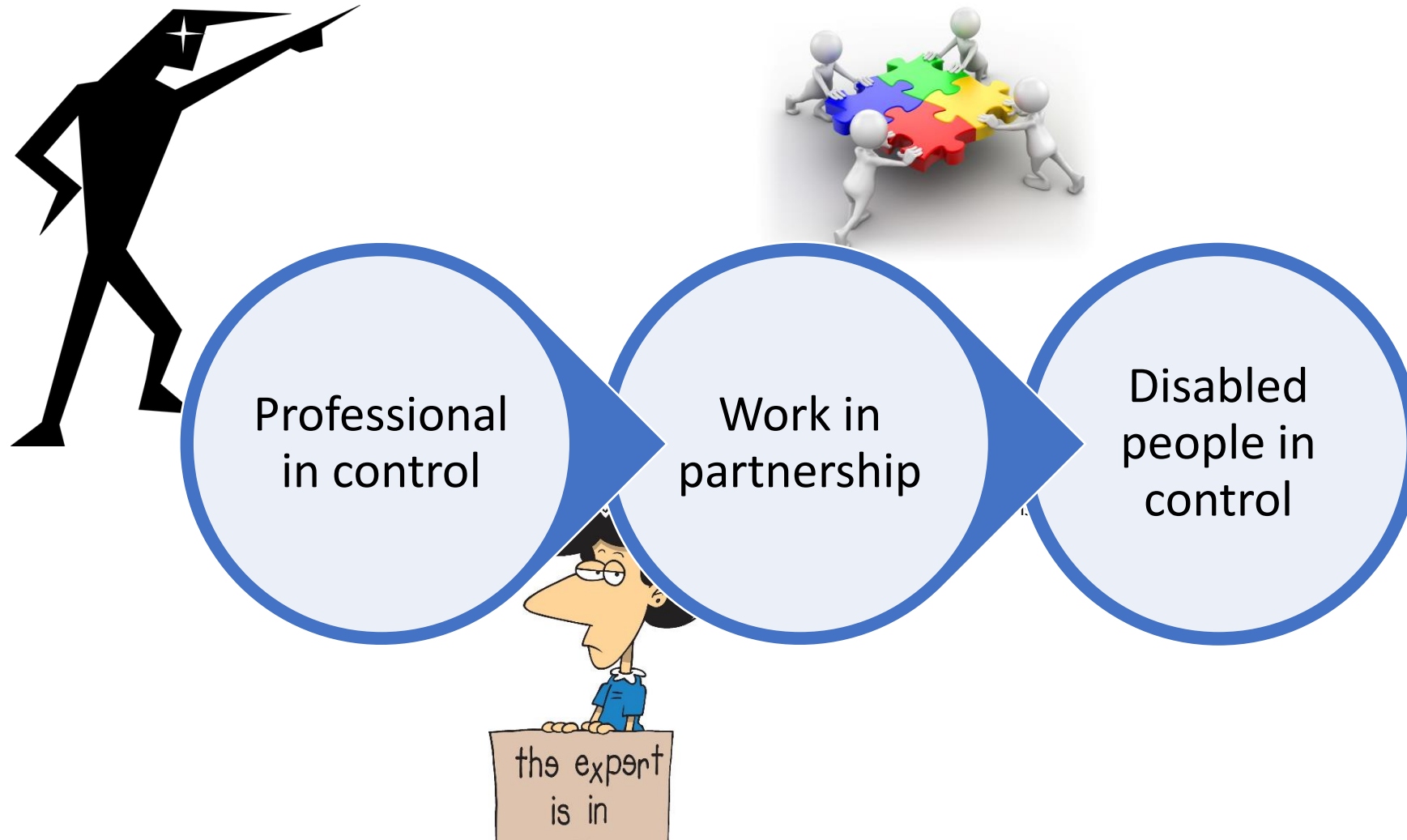


RESEARCHERS STUDY
DISABLED PEOPLE

DISABLED PEOPLE ADVISE ON
RESEARCH

DISABLED PEOPLE DECIDE
WHAT TO RESEARCH, HOW
AND WHAT TO REPORT

A spectrum of involvement



Reasons to work inclusively

- Answer the right questions
- Understand the world from the point of view of the people who live in it
- Reach more people
- Show how to work inclusively
- Opportunities for valued work to some people with learning disabilities



Why do it?

Example 1: Improving access to health care



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Why do it?

Example 2 Getting the words right

- Researchers wanted to find out more about people with learning disabilities and dementia.
- They worked with a group of people with learning disabilities to design information to help them reach the right people



I want to find out how people experience dementia and the services that help and support them.



You can help by agreeing to meet me and talk with me **twice**.



If you choose to talk to me you will have some with you. This person could be a friend, member of your family or an advocate.



You can also say where you want to talk.



You can stop this talk at any time you want.

Example 3 Check suitability of research tool

- Tested EQ-5D measures for advice on how suitable to use with self advocates in a study on well being
Included questions like

I have no problems washing or dressing myself

I have some problems washing or dressing myself

I have a lot of problems washing or dressing myself

Asked 3 self advocacy groups to advise:

Self advocacy groups will question the use of “problems” and why there is no questions on what their strengths are.

It felt a bit like a PIP (benefits) assessment which made it difficult to answer because there you have to say you do find things difficult

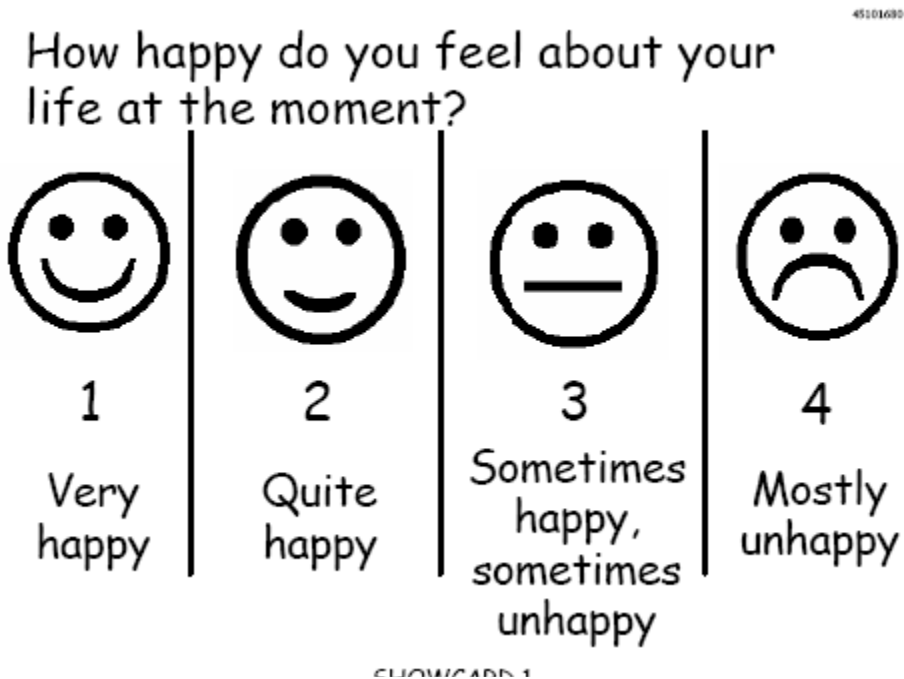
The questions seem to be based on the medical model of disability

Concern about possible impact if a person has poor self esteem

The research team decided these tools were not suitable!

Why do it?

Example 4 Getting the Questions Right and Understanding the answers – the National Survey 2005



http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_4120033

A Place to Live

We think too few people (less than one in seven) live on their own or with a partner. Too many young people still live with their parents and too many older people live in supported accommodation. Living independently makes many choices possible but, just like everyone else, people with learning difficulties worry about safety in the area they live in. We don't think this should stop people living independently. They should have the choice of being independent and safe.

We were not surprised that so many people's privacy was not respected and that most people in supported accommodation did not have a choice about who they lived with and where. As people with learning difficulties the right to have choice about a place to live and to privacy are very important.

Ian Davies & Karen Spencer

We asked people about where they lived and who they lived with.

Just over two in three people (69%) were living in private households. This means that they were living alone, with a partner or with their parents or other relatives. Just under one in three people (31%) were living in some form of supported accommodation.

Of the people living in private households:

- nearly three out of four people (73%) were living with their parent(s)
- one in six (17%) were living with other relatives



Why Do it? Example 5

Experts by Experience and Quality Checkers

People with learning disabilities are trained to inspect services

The principles are

1. people with learning disabilities have experience they can draw on when considering the quality of services
2. People who use services are more likely to open up to an inspector with learning disabilities
3. It provides paid work and builds skills and confidence

This link gives more details

<http://peoplefirstdorset.org.uk/home-page-2-5>

"I'm pleased about being an expert by experience. Because I know hopefully this will make a difference to people's lives." (Expert by experience)

Everyone involved has increased their understanding of engagement and communication with people who use services, and it has made them more aware of their own practices. Service providers and managers told us that they thought experts by experience are good role models for people who use services.



Adapting methods

Easy read and plain English

Focus groups and dot voting

Mobile interviews

Being there

Visual methods

On-line

Cancer and people with intellectual disabilities

The research team included people with learning disabilities who had experience of cancer

They helped design the study and run Focus Groups

They produced guidelines for health professionals working with people with intellectual disabilities who have cancer



Information about the study

Version 1, 22/04/09



Hello, our names are Irene, Gary, Amanda and Niki.



We are doing a study.
A study is a way of finding things out.



Do you want to be in the study?
This information sheet tells you about the study.
It helps you to decide if you want to be in the study or not.



What is the study about?
Living with someone with cancer
What is it like for people with learning disabilities if someone they live with has cancer?



Doing it together (DM Special Issue) 137

Why do we want to find out?

Lots of people get cancer. Many cancer patients live at home with their family or friends. We know it is often difficult for family and friends. They need a lot of help. We don't know what it is like for family or friends with learning disabilities. What help do they need? We need to find out.

What happens in the study?

There will be a group of people with learning disabilities.
We will meet with the group.
We will ask questions. We will listen to your stories.
It doesn't matter if you don't know any answers.
You can still listen to what other people say.



These things will help us think about the questions:

- We will look at some pictures about cancer and about how people feel.
- We will ask the people in the group to tell us their stories of what happened to them.
- We will think about ways in which people can help, and vote for the best ideas.












How often will we meet?

We will meet the group 4 times.
1. Meet you all and explain things.
Look at pictures.



Easy Read Consent Form

- Used to gain consent from people taking part in research
- May need to involve an advocate or family member if uncertain about the person's capacity to understand this information

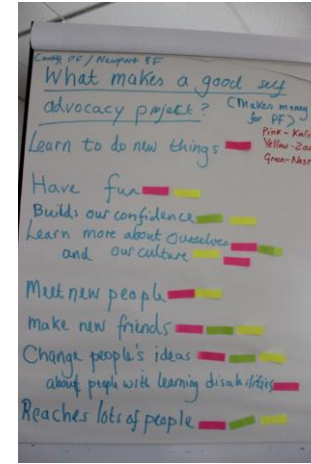
	<p style="text-align: center;">Contraception Research Consent form</p> 
	<p>I agree to take part in the research</p>
	<p>I agree to recording my words</p>
	<p>It is ok to use my words for 5 years <input type="checkbox"/></p>
	<p>It is not ok to use my words <input type="checkbox"/></p>
	<p style="text-align: center;">Anything else to say?</p>
 Name	
 Address	
 Signature	<p style="text-align: right;">Date</p>

Focus Group – what makes a good project



Dot Voting

- Each person has Post It notes
- Places Post It note next to the point they agree with
- Makes sure that everyone's view is recorded

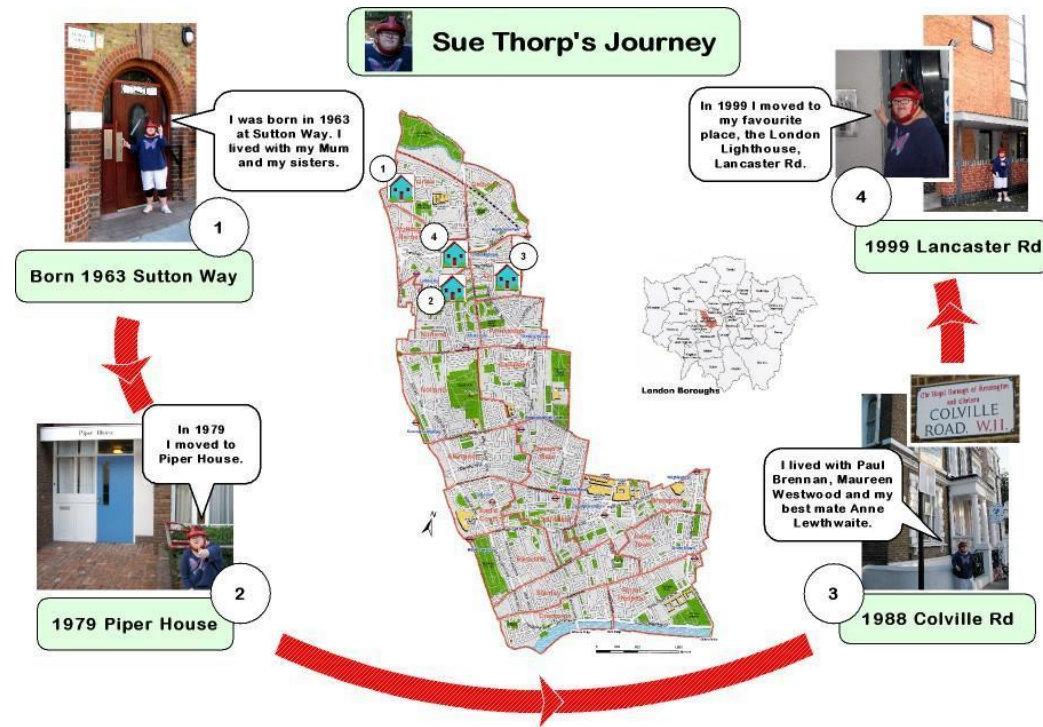




Prompt sheets for focus groups

- Pilot questionnaire with another group of people with learning disabilities

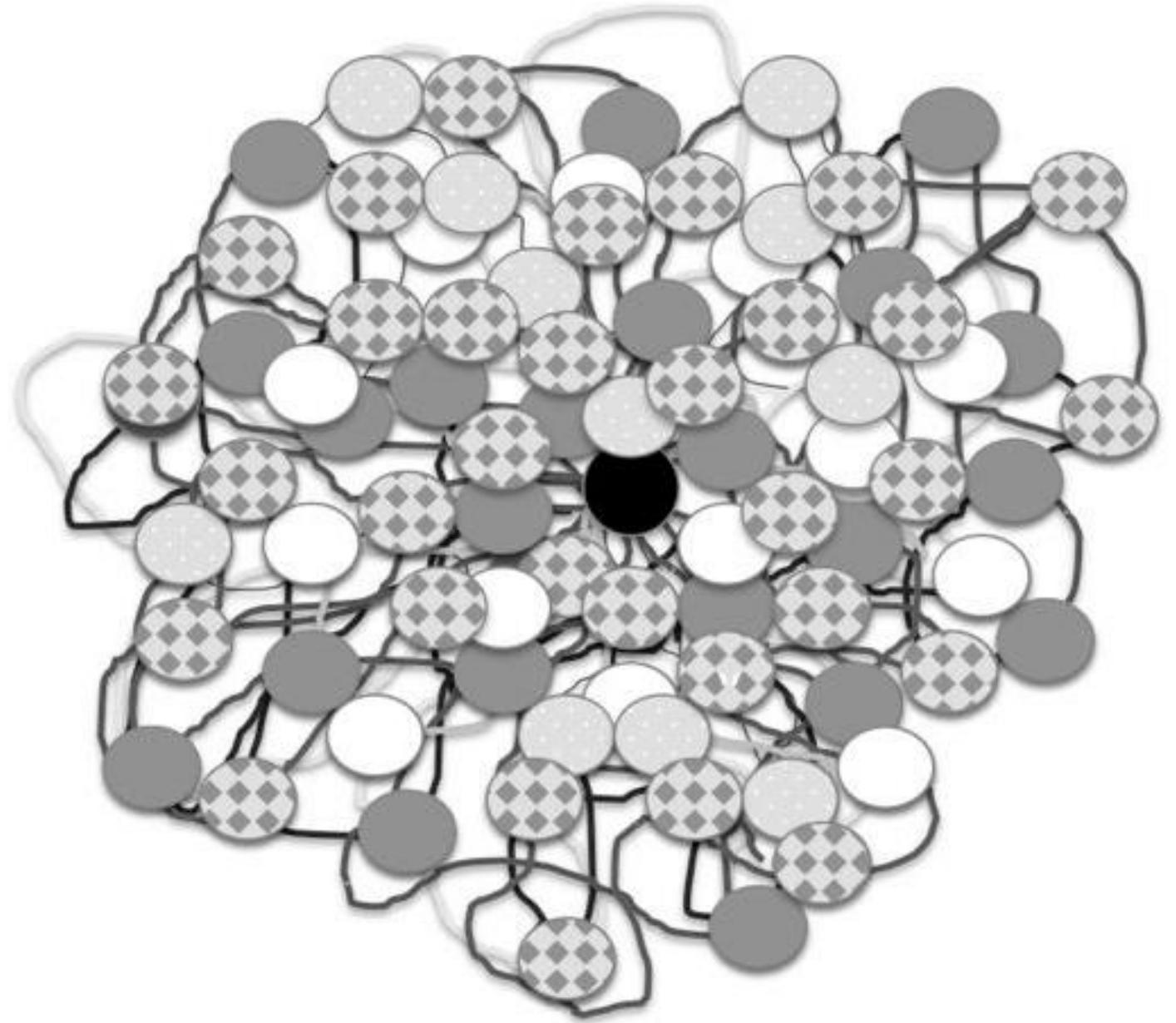
Mobile Interviews



Sue Ledger pioneered mobile interviews with people with high support needs. She used them to draw up life maps

Being there / alongsider research

- To understand the lives of people with learning disabilities living in rural areas
- Liz Ellis PhD 2015 The experiences of people with learning difficulties living in a rural area
- Researcher alongside the person as they live their lives. Person provides a commentary
- Diagram illustrates one man's connections
- Ideas of 'kith'



Visual Methods

People used photos
to record the barriers they experienced in realising the rights
guaranteed by the UN Convention



On-line

- Has opened doors once very expensive to open
- Danielle will tell you how we worked on-line to interview leaders of the self advocacy movement

Building capacity?

- Self advocacy groups and community interest companies are the bedrock of inclusive practice
- Build skills and confidence
- Provide practical assistance to co-researchers
- Can reach populations that are hard to reach
- Partners for organisations looking to pioneer inclusive practice



Learning Disability England Principles of Inclusive Research

We will work alongside self advocates and/ or families to decide what to research

We will involve self-advocates and/or families in doing the research, as advisors and / or as co-researchers

Where we have a budget we will pay self advocates and family members (and / or their organisations) for their work. Where we do not have a budget we will find other ways to thank them for their time and knowledge

We will prioritise research which matters to self advocates and families

Nobody should be excluded from research.

We will make payments in fair and flexible ways

We will work hard to make sure that people with different needs and from different backgrounds are included in our research.

We will learn together how to do research

We will support each other

We will invest in developing people's skills

LDE Principles



We will share what we find out in accessible ways

We will consult with our partners before we publish

We will recognise the work of self advocates and families in everything we publish or produce.

We will plan how the research can help people with learning disabilities and their families get better lives





Thank you for
your kind
attention

We look forward to your questions