Towards equal and active citizenship: pushing the boundaries of participatory research with people with learning disabilities: ESRC funded seminar series

Notes on Seminar 2: Participatory Data Analysis,
University of Manchester, Tuesday April 23rd 2013

Programme for the Day

<table>
<thead>
<tr>
<th>Speakers</th>
<th>Title</th>
<th>Timings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rohhss Chapman and Louise Townson (Partnership Steering Group)</td>
<td>Welcome to the University of Manchester and outline of the morning sessions</td>
<td>10.00am</td>
</tr>
<tr>
<td>Jane Seale, Melanie Nind, Rohhss Chapman</td>
<td>Brief Overview of the Seminar Series</td>
<td></td>
</tr>
<tr>
<td>Christopher Blunt, Louise Townson, Louise Frost, Richard Hughes, Darren Hayward, Barbara Perry, Craig Blyth, Rohhss Chapman (University of Manchester Partnership Steering Group)</td>
<td>Stepping into analysis - reviewing articles for the British Journal of Learning Disabilities Special Issue</td>
<td>10.15am</td>
</tr>
<tr>
<td>Time</td>
<td>Session</td>
<td></td>
</tr>
<tr>
<td>------------</td>
<td>--------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>10.30am</td>
<td><strong>Val Williams</strong> <em>(Norah Fry Research Centre)</em> and *<em>Andrew Barbour</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Analysing Videos Together: Skills for Support Research</td>
<td></td>
</tr>
<tr>
<td>11.00am</td>
<td><strong>GROUP DISCUSSION OF KEY ISSUES</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>EVERYONE – WITH COFFEE!</strong></td>
<td></td>
</tr>
<tr>
<td>11.30am</td>
<td><strong>Hanna Bertilsdottir</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Doing it Together? An Aspie eye on the neurotypical researcher’s analysis</td>
<td></td>
</tr>
<tr>
<td>12.00noon</td>
<td><strong>Marie Wolfe, Josephine Flaherty, Siobahn O’Doherty &amp; Edurne Garcia Iriarte</strong> <em>(The Irish Inclusive Research Network)</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Involving People in Data Analysis: The All We Want To Say Project</td>
<td></td>
</tr>
<tr>
<td>12.30pm</td>
<td><strong>GROUP DISCUSSION OF KEY ISSUES –</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>EVERYONE talking about the morning presentations.</strong></td>
<td></td>
</tr>
<tr>
<td>12.50pm</td>
<td><strong>LUNCH</strong></td>
<td></td>
</tr>
<tr>
<td>1.30pm</td>
<td><strong>Barbara Perry and Darren Hayward</strong> <em>(Partnership Steering Group)</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Introduction to the afternoon</td>
<td></td>
</tr>
<tr>
<td>Lou Townson, Rohhss Chapman, John Dias, Chloe Brownlee-Chapman (Carlisle People First Research Team)</td>
<td>Brief Notes on our Different Approaches to Analysis</td>
<td>1.40pm</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Gudrun Stefánsdóttir, Ólafur Snaævar Aðalsteinsson and Embla R. Hakadóttir (University of Reykjavik)</td>
<td>Data Analysis from a Disability Course for University Education for People with Learning Difficulties</td>
<td>2.00pm</td>
</tr>
<tr>
<td><strong>GROUP DISCUSSION OF KEY ISSUES</strong></td>
<td><strong>EVERYONE – WITH TEA!</strong></td>
<td>2.30pm</td>
</tr>
<tr>
<td>Ruth Garbutt (University of Leeds)</td>
<td>Analysing Drama – important points and ideas for a play</td>
<td>3.00pm</td>
</tr>
<tr>
<td><strong>GROUP REFLECTION</strong></td>
<td><strong>EVERYONE – WHAT HAVE WE LEARNED?</strong></td>
<td>3.30pm</td>
</tr>
<tr>
<td>University of Manchester Partnership Steering Group</td>
<td>Summary of the key points of the day</td>
<td>4.00pm</td>
</tr>
</tbody>
</table>
Slides from each of the presentations given on this day can be downloaded from our project blog at:
http://participat.blogspot.co.uk/2013/11/seminar-2-participatory-data-analysis.html

The presenters were asked to talk about some of these things:

- Which projects have had people with learning difficulties included in data analysis (this is called participatory data analysis), and how?
- How have people with learning difficulties been included in data analysis, and
- How can we share good ideas in a helpful way?
- Are there limits to people with learning difficulties being included in data analysis?
- Who or what makes these limits?
- Can and should the boundaries of these limits be tested and pushed back?
- How can we let funders know that having people with learning difficulties included in data analysis, adds to research?
Stepping into analysis - reviewing articles for the British Journal of Learning Disabilities Special Issue: Christopher Blunt, Lou Townson, Louise Frost, Richard Hughes, Darren Hayward, Barbara Perry, Craig Blyth, Rohhss Chapman (University of Manchester Partnership Steering Group)

When people talk about analysis it is not just data that needs to be analysed. Other areas of research that require analytical skills include reading literature. One example is reviewing papers for the special issue of BJLD.

Through analysis of the 20 papers the team identified some common issues:

- the terms partnership and inclusive mean different things to different writers
- the term people with learning disabilities is sometimes used as if all people with learning disabilities have the same needs

The team had a dilemma about whether to allow people to use jargon such as epistemology or whether to require simpler terms were used: the academic versus the accessible. It was decided that academic terms should be used but also explained.

Observations about the process:
It was hard work and members of the team needed breaks as they got tired.
Some members of the team with learning disabilities found papers about cancer and abuse upsetting and chose not read. Their choice was supported and respected by the group. This raised the issue of people needing to be supported but not shielded.
Analysis is not a separate part of research, it is integral. (Is this why we don't talk much about participatory data analysis, because we don't see it as separate?)

Data analysis is not magic, it does not have to be done by scientists and there are no right methods

Generally, analysis is always from somebody's point of view so there should be no issue when people with learning disabilities engage in analysis. Furthermore, they bring with them, their direct experience, which enriches analysis. ("The Artists of Our lives"). We should not apologise or worry about this, be "we" do need to be reflective.

Val and Andrew described a project called "Skills for Support" looking at the skills support workers have.

Andrew brought the idea that support equals friendship and respect and this informed the thematic analysis of videos that were taken of support work in action. The whole team, however, decided the themes.

Once the themes were decided, Kerry and Lisa, two co-researchers, questioned the data, by asking "what is new about that?"

Lisa and Kerry looked at the videos and chose extracts that interested them. Val then did conversational analysis on these extracts. She then took this analysis back to Lisa and Kerry to see that they thought.
Of team work Val said: We all had different roles, just because Val did something on her own, does not mean the others were rejected.

Good inclusive research has its own quality standards
Doing good inclusive research has an impact
Not all inclusive research is good
Inclusive research should not pretend to be the same as other academic research.

**Doing it Together? An Aspie eye on the neurotypical researcher’s analysis: Hanna Bertilsdottir**

Hanna shared her experiences of the difficulties of doing her fieldwork in a Swedish school. She was interviewing students with Asperger’s Syndrome, focusing on identity politics.

She used "research circles" as a method to invite students to discuss her research with her.

The difficulty was that the group would ask what is it you want to know? People were anxious about a lack of a clear question.

The group suggested that Hanna put her fieldnotes on the school intranet for students to read them and then discuss. This worked to some extent, the students responded by telling Hanna where she had got bits wrong or offering differing interpretations; but Hanna wanted more.

Hanna then decided to choose a theme from her fieldnotes to ask the group to talk about, e.g use of humour.

She found that the students ran out of energy, at the start there were four to five participants, by the end there were just two. These
two attended because they "thought they should" raising issues of perceptions of obligations and power. Some students also had difficulties reading the lengthy fieldnotes.

Hanna reflected on the issue of "what was in it" for her participants. She experienced tensions in deciding how much she could actively encourage the students to discuss her research with her, without it appearing to look like "force" or coercion. There was no payment for taking part, but perhaps payment would have been better. Hanna noted that participants were interested until she started writing papers for publications. Being involved in a book perhaps would have been more motivational for them, but Hanna was unable to get a publisher.

**Involving People in Data Analysis: The All We Want To Say Project: Marie Wolfe, Josephine Flaherty, Siobahn O'Doherty & Edurne Garcia Iriarte (The Irish Inclusive Research Network)**

The *All We Want to Say* project aimed to explore what life is like for people with learning disabilities in Ireland and how life could be better.

There were 168 participants across 23 focus groups (16 in South Ireland and 7 in Northern Ireland).

A committee of people with learning disabilities and academics decided the questions for the focus groups.

Workshops were held to recruit and train people with learning disabilities to run the focus groups. These were recruited from advocacy groups.
The focus groups were recorded with dictaphones. All the files were transcribed by university researchers and the academics then picked out 19 themes that they thought were important.

Everyone got together with the academics, looked at the 19 themes and decided which were important: 8 themes were decided upon.

They then presented their results to the local community.

There were problems:

- At the beginning everybody was really involved and interested, but this interest did peter out.

- Sustainability: When the funding finished, university support lessened. The group helped meetings with local community groups, to see if they would take up action, but this never took off.

- Accessibility: Use of pictures does not always guarantee accessibility.

**Brief Notes on our Different Approaches to Analysis: Lou Townson, Rohhss Chapman, John Dias, Chloe Brownlee-Chapman (Carlisle People First Research Team)**

The first project the group described was about self-advocacy support. The methods involved:

- interviews
- focus groups
- observation
- drawing life size maps of individuals
Speaking about the interviews the group said that analysis can be done in many ways it doesn’t have to rely on writing. Analysis is just another word for understanding and explaining what we found out.

They listened to tapes
With flipcharts on walls, they wrote down themes from all the interviews - this was good but exhausting
The sessions were structured with an agenda
Prior to fieldwork they had discussed what might happen in the groups - power relationships and this influenced their thematic analysis
They discussed key extracts and what different people see and understand from the extracts

The second project was called the War Memories Heritage Project. Chloe and John explained that they felt analysis was a complicated word, so we chose to say instead “what we found out about what found out about”! They:

- made sure that they had pictures of things that people had talked about in their interviews
- used simple words
- used summary sheets - one sheet will all the information in one place
- cut out things they didn't want or need and then colour coded, then took all the colours and put them together as themes
- John said five hours of listening to the interview tapes was painful!
Data Analysis from a Disability Course for University Education for People with Learning Difficulties: Gudrun Stefánsdóttir, Ólafur Snævar Aðalsteinsson and Embla R. Hakadóttir (University of Reykjavik)

Gudrun described a programme at the University of Reykjavik, where people with disabilities and others learn together: People with learning disabilities study for a diploma, others study for a BA.

As part of the course, students work together on a research project and do joint data analysis. They use methods they have learnt about including Cartoon Conversations (Carol Grey), where balloons are used to record "talk, thought, emotion".

Gudrun said there is no one way to do data analysis, this was just one idea.

Olufur and Embla shared the poem and pictures they had created to disseminate the findings from their joint project.

Analysing Drama – important points and ideas for a play
Ruth Garbutt (University of Leeds)

Ruth described a project about sex and relationships. CHANGE, an advocacy group, had got Lottery Funding to find out the views of young people with learning disabilities about sex and relationships. They then engaged with Leeds University.

The project team consisted of an academic researcher, two co-ordinators (one with a learning disability) and one illustrator.

The methods used were:
- interviews with parents
- focus groups with teachers
• survey of special groups (schools)
• using drama to talk about sex and relationships

The drama workshops were videoed, then watched and transcribed.

The transcripts were used as a checking tool, to refer to when the team wanted to know the context of what they were watching. It saved having to re-wind the video (i.e. words have a role).

The researcher made a long list of "important" points, collected from watching the videos and gave it to the team. The team reduced it down to a shorter list of points. These points were compared to the points from the focus groups, interviews and survey, when there was agreement across all four, the point made the short-list.

Ruth said that the analysis took a long time, but it is important to do it properly, the report is based on things they found out, not just their views.

WHAT DO WE LEARN ABOUT DATA ANALYSIS METHODS FROM THESE PRESENTATIONS?

1. All the projects used qualitative methods to collect data or capture information

• Videos
• Interviews
• Focus groups
• Observations

The data produced lends itself to accessible ways of doing data analysis
Questions:
Can participatory data analysis only happen with qualitative data? Where is the quantitative data in participatory research?

2. Methods used to try and make data analysis accessible were varied and included:

- research circles
- using life sized body maps
- cartoon conversations
- identifying and prioritising themes

3. Transcriptions can be used to support data analysis in different ways

For the Carlisle People First Research Team, reading transcripts was difficult for some. The team started off going through the transcripts but it became clear that this was not effective. Some people were unable to read or relied on others to read. So the team thought it was better to listen to recordings of the interviews. They made lots of copies of the tapes, so that members could take them home and listen to them at their leisure.

Ruth Garbutt explained that transcriptions were used as a checking tool, when something was not clear on the video. She argued that it was important to transcribe the videos, to know "that what we say is correct".
4. Projects differed regarding whether the academic researcher conducted the first round of analysis and then consulted with people with learning disabilities or vice versa

Questions:
- Does it matter who does the preliminary analysis?
- If academics do the preliminary analysis will they always run the risk of excluding or rejecting people with learning disabilities, or being accused of doing so.

5. Participatory data analysis depends on good support

Support important but it has to be the right support.
Support moves to different people.
"To be fair not everyone can be involved -there is not enough support".
Support for research should be part of funded support packages for people with learning disabilities.
Perhaps it’s an unrealistic expectation for people with learning difficulties will be involved in research if they have not done it before.
People with severe disabilities should get more support.

Questions
- Do we need full time paid university researchers for support?
- Why do co-researchers have to take turns? (Not enough work for researchers to do in some groups? Not enough co-researchers?)
6. Participatory data analysis is time consuming

There are time and cost issues in using videos as a data capture tool and then enabling analysis by people with learning disabilities.

Listening to audio files and reading transcriptions can be very tiring for people (and perhaps especially for some researchers with learning disabilities).

7. It can be difficult to talk about the process of data analysis

Jane’s observations: Talking about the results seems to be more interesting to others/seminar participants than talking about the process of participatory data analysis. If this is the case, how do we advance participatory data analysis methods if few people want to talk about them?

Edurne said that separating analysis from everything else was hard, it is hard to put down what part of the process is analysis.

The Carlisle People First Research Team argued that analysis is just one part of the process; it is not separate and more important.

From the group discussion, there was one argument that by using creative methods we can do data collection and data analysis at the same time.

8. There can be a tension between making analysis accessible and ignoring the complexities of analysis

Lou from the Carlisle People First Team said: I thought analysis was complicated; for some people it might be. Some assume only academics do analysis and don’t find it difficult but even they can find it difficult. Researchers with learning disabilities may not get a
chance to do it because others make an assumption that it is too difficult or there is no time for the process.

Melanie argued: Accessible research is about making things simple, but analysis is not always about making things simple, it is about understanding all that is complex and messy.

Questions:
• Is there a place for doing different kinds of analyses for different audiences?
• If data and data analysis are complex how can we equip people with learning disabilities to meaningfully participate?
• How would people with high support needs be included?

9. There are current moves in research funding that may support participatory research

Perhaps the Impact agenda will support inclusive research
Open access may help?

Questions:
• What outputs should there be? What do funders expect or value?
10. Barriers to participatory research

Ethics
The role of politics in driving decisions
Not equipping people with the appropriate skills to undertake research themselves
Still issues about involving people with high support needs
How being paid can have consequences on your benefits – could become less of an incentive for people to be involved
There are ways of being paid while still being on benefits

Questions:
• Are we too protective / risk averse in the way we include people with learning difficulties in research?

Jane Seale, Melanie Nind, Liz Tilley & Rohhss Chapman, April 2013