Participatory autism research: from ideological tensions to practical opportunities.

Dr. Damian E M Milton
Introduction

- This presentation reflects upon the involvement of autistic people in research and what autistic people have to say when able to raise their voices in regard to autism research, theory and practice.
- I will also reflect upon the various barriers and difficulties involved in participatory research.
- In the field of autism studies, a mass of competing and contradictory accounts can be found.
- By reflecting on a number of studies, this presentation will seek to address the ideological tensions that have formed within and between various ‘stakeholder’ groups and delve into some of the deeper reasons as to why such tensions exist.
A note on participation

• “Some of us aren’t meant to belong. Some of us have to turn the world upside down and shake the hell out of it until we make our own place in it.” (Lowell, 1999).
A growing understanding

- Obtaining the views of disabled people – requirement of policy / legislation both nationally and internationally (UN, 2006).
- Lack of involvement and representation in organisations ‘for’ autistic people.
- Conflict between growing autistic voice and the discourse of dysfunction, deficiency, and dependency.
- The Shaping Autism Research UK project.
Nothing about us, without us

- Having an autonomous voice – an essential requirement for individual well-being.
- For people on the autism spectrum however, there can be a number of barriers to participation in wider social life.
- People on the autism spectrum have often been excluded from contributing towards the decisions that directly affect their own lives.
- This has led many autistic-led advocacy groups to rally behind the slogan: ‘Nothing about us, without us’.
Aspects of social participation

• Acceptance and understanding – a sense of belonging.
• Engagement in public and political life – being able to express oneself and affect change.
• Individual and collective concerns.
• Present lived realities – a more collaborative future?
### Arnstein (1969)

<table>
<thead>
<tr>
<th>Degrees of citizen power</th>
<th>Citizen control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delegated power</td>
<td></td>
</tr>
<tr>
<td>Partnership</td>
<td></td>
</tr>
<tr>
<td>Degrees of tokenism</td>
<td>Placation</td>
</tr>
<tr>
<td>Consultation</td>
<td></td>
</tr>
<tr>
<td>Informing</td>
<td></td>
</tr>
<tr>
<td>No power / non-participation</td>
<td>Therapy</td>
</tr>
<tr>
<td>Manipulation</td>
<td></td>
</tr>
</tbody>
</table>
Aims and objectives – controversies in the field

- Normativity or the acceptance/celebration of diversity?
- Baggs (2012) - communication page.
- Scientific trials and/or building collaborative communities of practice (Wenger, 1998).
Have you heard about that Social Model of Shape Difference all the squares are talking about?

You mean the idea that all differences between shapes are imaginary?

Exactly. See that guy over there? According to this theory, he can't roll as well as we do because of our attitudes toward him!

Have you ever heard anything more ridiculous?

I guess when we are not looking, they bounce around like basketballs. Ha Ha Ha Ha!

Oops, I thought I saw four right angles on that one. I must be hallucinating! Ha Ha Ha Ha Ha!

Actually, that's not at all what the social model is about. It's about how minority shapes are excluded from decision making roles, and therefore our needs are considered extraordinary while yours are seen as normal.

It's about power. The ways squares are silenced or ignored. How some shapes are subjected to treatments that would be considered abusive if they were done to circles.

So the social model is all about how squares are superior to other shapes. Can you believe he had the nerve to say that?

That's what I call rectangular logic. Ha Ha Ha Ha Ha Ha.

He probably bounced too high and hit his head on something! Ha Ha Ha Ha Ha Ha Ha Ha!

Look at me! I've got corners! I'm invincible! Ha Ha Ha Ha Ha Ha!

Please get off of me!
The concept of neurodiversity

- Variations in neurological development as part of natural diversity, rather than something to be pathologised.

- This is not to say that those who identify as autistic people or other forms of neuro-identity do not find life challenging. Autistic people are significantly disadvantaged in many aspects of life.
## AET consultation data

<table>
<thead>
<tr>
<th>Stakeholder group</th>
<th>Understanding the individual pupil</th>
<th>Building relationships</th>
<th>Curriculum and learning</th>
<th>Enabling environments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practitioners</td>
<td><strong>Staff training</strong></td>
<td>Involving and supporting parents</td>
<td>Differentiated curriculum (social skills)</td>
<td>Quiet and safe spaces</td>
</tr>
<tr>
<td>Parents</td>
<td>Staff training and understanding the individual</td>
<td><strong>Communication between staff and parents</strong></td>
<td>Individually tailored curriculum</td>
<td>Structure and routine</td>
</tr>
<tr>
<td>Children and young people</td>
<td>Understanding from staff</td>
<td><strong>Bullying (including ‘friends’)</strong></td>
<td>Subject content and delivery</td>
<td>Crowds and personal space</td>
</tr>
<tr>
<td>Common ground</td>
<td><strong>Staff training needed</strong></td>
<td>Better communication needed and understanding</td>
<td>Differentiation / tailored curriculum</td>
<td>Structured break times and safety</td>
</tr>
<tr>
<td>Tensions</td>
<td>Potentially what staff are trained in</td>
<td>Communication not being good enough and a lack of understanding</td>
<td>Social skills training</td>
<td>Differences in view regarding how environments should be managed</td>
</tr>
</tbody>
</table>
Mutual incomprehension

- “95% of people don’t understand me”.
- “Friends are overwhelming”.
- “Adults never leave me alone”.
- “Adults don’t stop bullying me”.

Quotes taken from Jones et al. (2012).
The ‘double empathy problem’


- Empathy problems as a ‘two-way street’ (Sinclair, 1992).

- In this theory, it is not only the autistic person who struggles to read the intentions and motivations of non-autistic people, but the same can also be said in reverse.

- Theory of autistic mind can often leave a great deal to be desired.

- ‘Fork ‘andles’!
Stakeholder perceptions

- Findings from PhD research.
- Significant tensions over a number of issues:
  - Celebrating the diversity of learners and not trying to ‘normalise’ them.
  - Radical change in society.
  - Pupil-led vs. teacher-led activities.
  - Social skills training and the appropriateness of behaviour.
  - The ‘three-way dispositional problem’!
Spectrum of educational views

- Radical
- Progressive
- Prag-Eclt
- Functionalist
- Behaviourist

- Autistic adults
- Non-autistic parents
- Non-autistic practitioners and academics
Common ground?

- Not a great deal!
- Against extreme normalisation?
- Enabling environments?
- Building relationships, communication and mutual understanding.
The autistic voice and the production of knowledge

- People on the autism spectrum rarely in the role of researcher, traditionally seen as passive subjects.
- The ‘glass sub-heading’ (Milton and Bracher, 2013).
Co-production

- "Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours" (New Economics Foundation).
- To what extent is this currently possible?
- To what extent is this ideal taken seriously in service provision or research?
Participatory research

- A range of theoretical and methodological approaches.
- Yet with the main objective of handing power from the researcher to research participants, who are often community members or community-based organisations.
- In participatory research, participants have control over the research agenda, the process and actions taken.
- Most importantly, people themselves are the ones who analyse and reflect on the information generated, in order to obtain the findings and conclusions of the research process.
Emancipatory research

- “By definition emancipatory disability research should be judged mainly by its ability to empower disabled people through the research process, but whether this is achievable is a highly contentious issue.” (Barnes, 2001)
Difficulties in the involvement of autistic people in research

- Sampling and representativeness – diverse breadth of experiences of those on the autistic spectrum.
- Cognitive and linguistic demands may impair full involvement for those with learning disabilities, yet hearing views is important for participation/contribution (Lewis and Porter, 2004).
- Representativeness of peers and familiar adults as proxy informants (Lewis and Porter, 2004).
- Pictures and schedules – not always sure that views reported were the children’s own (Preece and Jordan, 2009).
- Episodic memory and ‘recency’ effect (Jordan and Powell, 1995).
- Questions regarding wishes and aspirations may be meaningless or even threatening (Beresford et al., 2004, cited in Preece and Jordan, 2009).
- Trouble understanding use of language (literal, echolalia, idiosyncratic).
- Preece and Jordan (2009) found that participants were best at identifying preferences regarding concrete objects (something tangible and not vague). Emotions and reasons for liking and disliking others more difficult for participants to answer.
Consent

- Individualised letter explaining the research and an introductory meeting (Preece and Jordan, 2009).
- Ongoing process rather than one-off agreement (Lewis and Porter 2004; Preece and Jordan, 2009).
Recommendations for involving autistic people in research

- Lewis and Porter (2004) suggest the very minimum should be establishing the value of research for those with learning disabilities – how is it useful? Avoiding harm.

- Participants should be able to provide responses to initial analysis and receive feedback from the outcomes of a study (and in an accessible format).

- Observational research where a child had little or no speech (Preece and Jordan, 2009).
• Accessible outlines of interview questions given in advance. Or time to give a considered response / use of the Internet (Lewis and Porter, 2004).


• Concrete manipulation – piles of like and dislike. Photographic narratives / scrapbooks (Preece and Jordan, 2009).
Practicalities

• How can controversies be handled ethically?
• Not everyone wishes to be a researcher (although some will), but do want their views heard, understood and utilised to help others.
• Variety of consultation and participatory methods can be used – yet may need to start with small steps.
Are the assumptions made by researchers justified?

- Theory of mind deficit or the double empathy problem (Milton, 2012b)?
- The capacity of less verbal autistic people to participate.
Collaboration

- Setting the research agenda.
- Design and development of strategies and methodologies.
- Avoiding tokenism...
Participatory methods in practice

- The Autism Education Trust (AET) and the Transform Autism Education (TAE) project.
- The Ask autism project.
- The Theorising Autism Project.
- The Autonomy journal.
- The Cygnet mentoring project and the use of Personal construct theory (PCT).
- The Participatory Autism Research Centre (PARC) at London South Bank University.
- The National Autism Project (NAP) and Westminster Commission.
The Participatory Autism Research Collective (PARC)

- Network initially based at LSBU promoting participatory research in the field of autism studies.
- Involving autistic adults and researchers, guest researchers and students.
- Held meetings, presentations and book launches.
- Led to publications and stream at Learning Disability Today conference.
- Shortlisted for ‘most creative community project’ at National Autistic Society annual awards 2017.
- Leading a stream at the next CeDR disability studies conference in September 2018.
The Research Autism Cygnet Mentoring Project

- A two year pilot project designed by people on the autism spectrum to evaluate a mentoring intervention.
- After mentor training, selection, matching and completion of the Melbourne Personal Wellbeing Index (PWI), 12 pairs met for one hour per week over 6 months. Supervision was built in throughout.
- 3 Goals were set initially and reviewed throughout project.
- Meeting record sheets jointly completed and a reflective journal were individually completed after each session.
- After the final mentoring session, research assistants completed another evaluation and PWI with participants.
- Data has been collected and analysed by the research team with input from The Advisory Group.
## Personal wellbeing index results

<table>
<thead>
<tr>
<th>PWI</th>
<th>All – pre-intervention</th>
<th>Pre (who finished)</th>
<th>Post</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?</td>
<td>5.08</td>
<td>6</td>
<td>7.8</td>
<td>1.8</td>
</tr>
<tr>
<td>How satisfied are you with what you are achieving in life?</td>
<td>5.08</td>
<td>5.4</td>
<td>7</td>
<td>1.6</td>
</tr>
<tr>
<td>How satisfied are you with how safe you feel?</td>
<td>6.42</td>
<td>7.4</td>
<td>8.8</td>
<td>1.4</td>
</tr>
</tbody>
</table>
Average progress toward goals

<table>
<thead>
<tr>
<th>All – pre-intervention</th>
<th>Pre (who finished)</th>
<th>Post</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.75</td>
<td>4</td>
<td>8</td>
<td>4</td>
</tr>
</tbody>
</table>
“…this helped me dig my way out of a life threatening hole that I could not see any way out of. It reminded me to make progress towards goals. [The mentor] Listened when I needed it, was a regular weekly marker in my chaotic life, provided an opportunity to reflect and plan and self manage. I wouldn't have done this otherwise.”
Conclusion

- “Traditional methods of consulting and working in partnership may not always be effective, and new avenues for connection may need to be sought, however when collaborative ventures are pursued, and when people on the autism spectrum feel included and empowered, the ability to live as one chooses greatly increases.” (Milton, 2014b).
References

• Milton, D. (2014b) What is meant by participation and inclusion, and why it can be difficult to achieve. NAS Ask autism conference: Participation and inclusion from the inside-out: autism from an autistic perspective, London Jan 2014.