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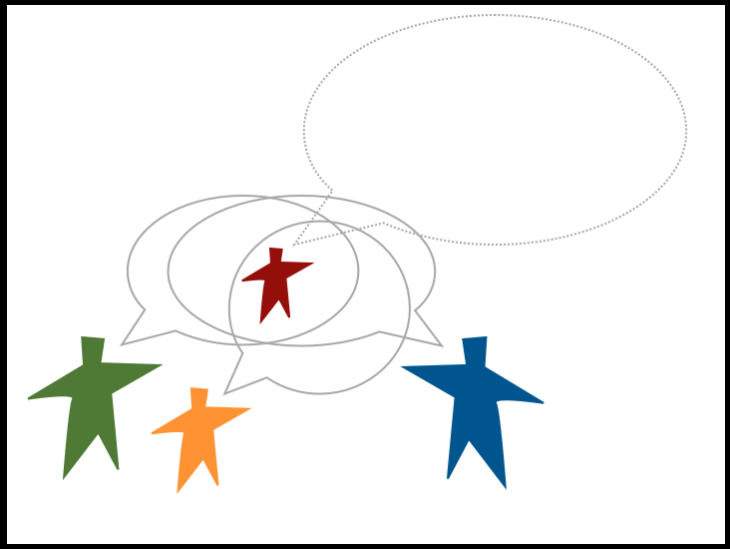
Inclusive practice for autistic students in HE



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A note about 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).

Introduction

- This presentation will draw upon a number of projects.
- Review of issues regarding participatory research in the field of autism studies.
- An introduction to the Participatory Autism Research Collective (PARC).
- Introducing the concept of Universal Design (UD).
- Findings from a research project regarding mentoring for autistic adults.

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'.
- More recently it has led to a number of autistic-led initiatives to further the academic voices of autistic people, such as PARC and #autisticsinacademia

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?
- Barriers to participation in the academy.

Arnstein (1969)

Degrees of citizen power	Citizen control
	Delegated power
	Partnership
Degrees of tokenism	Placation
	Consultation
	Informing
No power / non-participation	Therapy
	Manipulation

The concept of neurodiversity

- Variations in neurological development as part of natural diversity, rather than something to be pathologised using a purely medical model of disability, defined by one's deviation from statistical or idealised norms of embodiment or observed behaviour.
- 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.
- Strongly relates to the social model of disability.

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.
- Yet a level of consensus:
- Against extreme normalisation?
- Enabling environments?
- Building relationships, communication and mutual understanding.

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 HE 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)

Are assumptions made by researchers justified?

- Repetitive behaviour and obsessions or monotropism, interests and flow states? (Murray et al. 2005, Lawson, 2010, Milton, 2012a, McDonnell and Milton, 2014)?
- 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…
- "…place the voices and perspectives of self-advocates at the centre of the autism conversation, as we can speak with unique legitimacy and voice about our own lives." (Ne'eman, 2011).

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 National Autism Project (NAP) and Westminster Commission.
- Shaping Autism Research UK project.
- The Cygnet mentoring project and the use of Personal construct theory (PCT).
- The Participatory Autism Research Centre (PARC) at London South Bank University.

The Participatory Autism Research Collective (PARC)

- Network 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.
- Has yet to be funded (in and of itself).
- The potential for peer support for early-career researchers and autistic activists.

Reasonable adjustment

- An alteration made to enable a disabled person to carry out normative responsibilities, such as the duties of a job role.
- Employers must make 'reasonable' adjustments to make sure disabled workers are not 'seriously disadvantaged' in performing their roles.
- 'Within reason' and normativity.
- In practice, alterations to cultural norms are often exceptions rather than the rule.

Examples in the workplace

- "Allowing someone with social anxiety disorder to have their own desk instead of hot-desking." (1)
- "Letting a disabled person work somewhere else – e.g. on the ground floor for a wheelchair user." (2)
- "Displays of annoying behaviour can leave a person isolated. Don't be afraid of mentioning the behaviour that you are finding difficult but remain respectful. Do not confront the person in front of others or shout." (3)

- Citations from Gov.uk (1) and (2) and North Lincolnshire Council (3).

Universal Design (UD)

- Originated in the field of architecture.
- Environments need to be designed to be accessed, understood and usable to the greatest extent possible by people of all ages, sizes and abilities.
- Not making 'special requirements' to meet the perceived needs of a specified grouping of people.

- UD is based on the premise that environments that are accessible, usable, convenient and pleasurable lead to benefits for all.
- By increasing the number of people whose needs are being addressed, UD takes an integrative approach rather than looking for multiple solutions to meet need.

- “Universal design is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.” (Mace, 1997).

Seven principles of UD

- Equitable use
- Flexibility in use
- Simple and intuitive use
- Perceptible information
- Tolerance for error
- Low physical effort
- Size and space for approach and use.
- Cited from universaldesign.com

Examples of UD

- Curb cuts.
- Automatic door openers.

What is not UD

- Creating ways to exclude use and access.

Issues that remain

- With UD, there will still be times when people will need specific adjustments made so that they can access opportunities usually available to others.
- Need for autistic input in design practice – without understanding of needs, designers are unlikely to know how to design in a more 'autism-friendly' way.
- Universal design differs markedly from designing for specific need – yet are elements of both needed?
- Can UD be useful for creating 'autism-friendly' environments that do not mark autistic people out as 'special'?

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.
  - The use of Personal Construct Theory (PCT) and the 'Salmon Line'.
  - 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

PWI	All – pre-intervention	Pre (who finished)	Post	Difference
Thinking about your own life and personal circumstances, how satisfied are you **with your life as a whole?**	5.08	6	7.8	1.8
How satisfied are you **with what you are achieving in life?**	5.08	5.4	7	1.6
How satisfied are you **with how safe you feel?**	6.42	7.4	8.8	1.4

Average progress toward goals

All – pre-intervention	Pre (who finished)	Post	Difference
3.75	4	8	4

- “…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).

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