



Understanding and Working With Autism: From Deficit to Neurodiversity

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Outline

- Traditional understandings of autism
- Autism as 'Neurodiversity'
- Working with understanding autism as neurodiversity
- Implications for practice



My Background

- Degree in Human Psychology
 - Assistant Psychologist working with young children with behavioural difficulties and autism
- Support Worker
 - Working with adults with autism living in a communal home run by a community trust
- Lecturer in Psychology
 - PhD research examining constructions of autism, current research projects drawing on understandings of autism as a form of neurodiversity

A note on terminology...

- Debates around the differences between Autism and Asperger's Syndrome in professional academic literature
- Also wider debates:
 - Siedel (2006) Autism Spectrum
 - Schafer (2005) Separate entities
- AS = Autism Spectrum
- NT = Neurologically Typical



Traditional Understandings of ASD

- 'Discovered' by Leo Kanner (1943) and Hans Asperger (1944)
- The 'Triad of Impairments' (Wing 1997)
 - Impairments in Communication
 - Impairments in Social Interaction
 - Impairments in Imagination
- Deficits in Theory of Mind

The Triad of Impairments (Wing 1997)

- Impairments in Social Interaction
 - Complex and diverse pattern
- Impairments in Communication
 - Issues with the pragmatics of speech
 - Contrast of written communication (Frith 2003)
- Impairments in Imagination/Rigid and Repetitive Behaviours
 - Hand flapping, need to ritualise behaviour, overly focused interests in specific topics or objects



Deficits in Theory of Mind

- Baron-Cohen et al (1985)
Sally/Anne Task
- 80% of children with autism in this study gave an incorrect answer
- Suggest a core feature of autism being the inability to understand that people may have thoughts and feelings that are different from their own

Intelligence

- Relationship between AS and IQ is complex
- Uneven profile on IQ tests
- Frith (2003) profile of peaks and troughs specific to AS
 - Peaks e.g. visio-spatial tasks
 - Troughs e.g. communication tasks
- Islets of ability complicate discussions further



Understanding AS

- Alderson (1999) numerous and varied characteristics proposed to describe AS
- Selfe (2000) gap between textbook descriptions of AS and the experiences of people with AS and their families
- Theory of Mind focus on *deficiency* rather than *difference*
- Triad of Impairments influential



Experiential Understandings

- Until recently experiential understandings largely absent
- Danger of 'losing' the individual voice within larger psychological theories
- Can glean information that may be overlooked in more broader approaches e.g. experience of sounds and textures

'Don't write me off' NAS Campaign

- Draws attention to real-life stories of people with autism
- Currently
 - Only 15% of people with autism have a full-time job
 - One third currently without a job or access to benefits
 - 79% of those on incapacity benefit want to work
- Government needs to:
 - Ensure that Employment and Support Allowance works for people with autism
 - Jobcentre plus staff to understand and meets the needs of individuals with autism
 - A national strategy to transform access to employment



Celebrating Neurodiversity

- Coined by Judy Singer (1998)
- Rejection of the presentation of people with autism as 'impaired' in particular traits
- Autism viewed as a *difference* rather than a *deficit*
- A questioning of the concept of 'normality' – neurologically typical?
- Celebration of autism as a type of neurodiversity
- Seeks to draw on the skills of many individuals with autism
- A change in the social nature of workplaces?

People with AS Online

- Increasing number of people with AS are using the internet as a forum for self-advocacy
- Strong movement has developed online drawing on ideas of neurodiversity
 - www.neurodiversity.com
 - Institute for the Study of the Neurologically Typical – <http://isnt.autistics.org/>
- Savarese and Savarese (2010) stress importance of internet in development of neurodiversity movement



Researching with People with AS

- Online research methods
- Frith (2003) written communication can be easier for some people with AS
- Can be enabling for some people with AS
- Removal of face-to-face NVC
- A useful way of being able to draw on the expertise of people with AS



Challenges to understandings of AS?

- AS seen as a difference rather than a deficit – no longer focusing on ‘impairments’ and what people with AS can’t do
- Opportunity to examine NTs as a ‘curiosity’ by people with AS



Examining 'Neurotypicality'

"My most amazing discovery lies with the fact that NTs often execute frequent queries (i.e. gossip) over their social network systems that try to discover more data about other nodes and networks.

Like the CIA, they keep a huge mental database and inventory of who does what, who goes where, and everything you can think about a person's relationships with another...they often have a rather good ability in providing misinformation, especially if such misinformation can please others. Apparently some of them do this under perceived duress that the other person will take offense at their words and reduce their relationship strength. This comes at a cost because they have to maintain a internal database of misinformation which they must look up on demand at very rapid speeds."

Edward in Brownlow (2010)



Examining 'Neurotypicality'

“Can you imagine what it would be like if, every time that one of your own kind was born, the parents of that child typically responded in shock and horror, as if a terrible tragedy had happened? That is typically what happens when a parent finds out that their child is one of my kind... in other words, that the child is autistic.”

Klein (2002)

Examining 'Neurotypicality'

“The biggest problem with most programs designed to assist autistic children is, as far as I can tell, that they were designed by NTs, and for NTs...They are, after all, the ones that will be paying the considerable bill for these programs, and it is their wishes that are catered to with regard to goals of that program... The goal should be to help the autistic child develop in a way that will make a relatively decent life possible, not to make him into an NT clone. That’s not real; a cat trained to fetch and wag his tail when happy is a trained cat, not a dog.”

Klein (2002)

The case of 'Specialisterne'

- Translates as 'The Specialists' and is an IT company employing people with autism
- Employs 60 people and has a turnover of almost £2million
- Sonne: "This is not cheap labour and it's not occupational therapy. We simply do a better job." (The Independent May 31st 2009)
- Importance of recognising some of the potential issues in working in a socially-dominated environment



A showcase of possibilities...?

- Specialisterne an example of what might be possible by adapting to the needs of people with autism
- Recognises the talents of some people with autism and the potential barriers to capitalising on these
- Re-thinking of how we organise the workplace



Transitions Project (O'Dell and Brownlow)

- Very little literature exploring transitions for young people with AS
- Seek to examine how pathways during the transition to young adulthood are experienced by young people with AS
- What role do families play in negotiating transitions for young people with AS?
- How might reframing AS as 'neurodiversity' impact on young people's transitions?



The Research Plan

- Stage 1: Online synchronous interviews
 - 3 groups of participants: young people with AS, parents/carers of young people with AS and professionals working with young people with AS
- Stage 2: Online discussion group and the development of a Wiki
- Research team will include a steering group of 'experts' (young people with AS and their families)



Transition services of the future...

- Important to carry out research with young people with AS and their families
- A focus on the understanding of difference rather than a focus on deficit and impairment
- Facilitating the transition of young people with AS into a range of options that best tap into the abilities of the individual



Thoughts so far...

- Traditional theories and understandings of AS typically focus on the impairments of an individual
- The movement towards understanding AS as neurodiversity has implications for an alternative framing of AS
- Drawing on the experiences and expertise of people with AS as their families important in furthering understanding
- Challenges of drawing on this re-framing of AS as neurodiversity for professional practice...?



Implications for Practice...?

- Wide and diverse range of skills and abilities of people with AS
- Complicated relationship between research and practice
- Alternative forms of communication can be enabling for some people with AS
- Way of reducing some of the difficulties posed through more traditional face-to-face social interactions



Implications for Practice...?

- Alternative views of 'autistic impairments' can feed into a more enabling vision of practice
- Less negative and less stigmatised view of AS presented
- Accessing the individual experiential voices of people with AS



Final thoughts

- Autism spectrum disorders represents a broad range of issues and capabilities
- Important to value differences and be aware of unique skills and attributes
- Need to open up and build upon the dialogue between practitioners and people with AS
- Drawing on the expert voices of people with AS and their families

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