

The social construction of 'autism': Implications for service provision from a decade of research

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Background

Policy developments and their implementation have improved the lives of people with autism in the UK (Autism Act 2009; WAG, 2009; DOH, 2010). However, some people continue to encounter inequitable access to health and social care (DOH 2014), thus countering recommendations for putting citizens first by providing effective, timely and quality services (WAG, 2010a; WAG, 2010b). Our research explores representation of autism from the perspectives of people with autism, health professionals, lay people and in media accounts. The findings of our research provide insights into the factors that influence the well-being of people with autism, their encounters in statutory/non-statutory services, and in society.

Method

Phase 1: Six studies focussed on autism interpretations and experiences (8 published papers: findings detailed in Box 1):

- A cyber-ethnographic study of an online group for parents of children with autism. 6142 messages sent from 374 email addresses over a 3-month period were collated and analysed using grounded theory.
- An interpretative phenomenological analysis study utilising semi-structured online interview methods with 11 adults diagnosed with autism.
- An interpretative phenomenological analysis study utilising semi-structured face-to-face interviews with 9 young people diagnosed with autism.
- A thematic analysis of semi-structured interviews with six psychiatrists caring for people with an autism diagnosis.
- An interpretative phenomenological analysis study and Foucauldian discourse analysis of semi-structured interviews with 10 lay people with no prior knowledge of autism.
- A Foucauldian discourse analysis of accounts of autism in a stratified sample of newspaper articles published over an 11 year period.

Phase 2: An interpretative synthesis of the findings of six of our studies (8 published papers: Box 1) using meta-ethnography (Noblit & Hare, 1988). This is the most widely used approach for synthesising qualitative data (Hannes & Macaitis, 2012). There are 7 iterative stages to meta-ethnography:

- Getting started – choosing an area to explore.
- Deciding what is relevant – scope of the review.
- Reading the studies – identifying key concepts.
- Determining relationships – convergence and divergence.
- Translation - focussing on original and new interpretations.
- Synthesising translations – synthesising the overall findings.
- Expression – summarising and dissemination of the synthesis.

Results:

Although the term 'autism' (and its derivatives) is a nominal category used to group heterogeneous people sharing similar behaviours deviating from expectations of normalcy, thresholds of complexity need to be considered because:

- ❖ 'Autism' is a socially constructed discourse rather than an objective phenomenon (even though individuals may have discussed it as such).
- ❖ It is shaped by the social meanings that individuals and societies attach to it
- ❖ Dualistic accounts of normality/abnormality indicate the presence of assumptions about what constitutes normality; these can position ability and behaviours as functional or dysfunctional.

Box 1: Summary of published studies

Study	Data sources	Data Collection and Analysis	Findings
Huws, J. C., Jones, R. S. P., & Ingledew, D. K. (2001). Parents of children with autism using an email group: A grounded theory study. <i>Journal of Health Psychology</i> , 6, 5, 569–584.	Parents of children with autism: 6142 messages over a 3-month period from 374 email addresses.	Online ethnography: Content of email text/discussion group. Grounded theory (Strauss & Corbin, 1998).	Core Category: Making sense of autism Categories: Searching for meaning Adjusting to changes Providing support and encouragement Narrative sharing of experiences
Huws, J. C. & Jones, R. S. P. (Under review). "It's my way of being!": Autism as conceptualised by adults with an autism diagnosis.	11 adults diagnosed with autism.	Asynchronous semi-structured email interviews. Interpretative Phenomenological Analysis (Smith et al., 2009).	(i) Autism as difference (ii) Autism is part of who I am (iii) The functions of the autism label (iv) Misconceptions about autism
Huws, J. C. & Jones, R. S. P. (2014). "I'm really glad this is developmental": Autism and social comparisons – an interpretative phenomenological analysis. <i>Autism</i> . doi: 10.1177/1362361313512426	9 young people diagnosed with autism aged 16 – 21 years.	Semi-structured face-to-face interviews. Interpretative Phenomenological Analysis (Smith et al., 2009).	Super-ordinate theme: Making Comparisons: Themes: (i) Changes over time: "I'm really glad this is developmental" (ii) Degrees of autism: "They've got it really bad" (iii) Degrees of ability: "I'm not really disabled-disabled"
Jones, R. S. P., Huws, J. C., & Beck, G. (2013). "I'm not the only person out there": Insider and outsider understandings of autism. <i>International Journal of Developmental Disabilities</i> , 59, 134-144.	9 young people diagnosed with autism aged 16 – 21 years 1 adult diagnosed with autism.	Semi-structured face-to-face interviews. Interpretative Phenomenological Analysis (Smith et al., 2009) AND Secondary analysis of findings by a person with an autism diagnosis.	Primary analysis: (i) The insider experience of autism (ii) The outsider experience of autism Secondary analysis: (i) Consequences of insider understandings: 'I'm not the only person out there' (ii) Consequences of outsider understandings: marginalization
Huws, J. C. & Jones, R. S. P. (2008). Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism. <i>Journal of Intellectual & Developmental Disability</i> , 33, 99-107.	9 young people diagnosed with autism aged 16 – 21 years.	Semi-structured face-to-face interviews. Interpretative Phenomenological Analysis (Smith et al., 2009)	Diagnosis, disclosure and having autism. (i) Disclosure delay (ii) Providing explanations; (iii) Potential effects of labelling; (iv) Disruptions and opportunities (v) Acceptance and avoidance
Huws, J. C. & Jones, R. S. P. (2013). "Not everybody memorises the phone book": Representations of autism in psychiatrists' accounts. <i>Clinical Psychology & People with Learning Disabilities</i> , 11, 53-63.	6 psychiatrists (2 with more than 25 years' experience; 4 with less than 5 years' experience).	Semi-structured face-to-face interviews. Thematic Analysis (Braun & Clarke, 2006).	(i) Diagnostic concordance and ambiguity (ii) Threshold of complexity (iii) Autism as an artificial construct (iv) The socio-relational context of care.
Huws, J. C. & Jones, R. S. P. (2010). "They just seem to live their lives in their own little world": Lay perceptions of autism. <i>Disability & Society</i> , 25, 331-344.	Ten adults with no knowledge or experience of autism. Aged between 26 and 39 years.	Semi-structured face-to-face interviews. Interpretative Phenomenological Analysis (Smith et al., 2009) & Foucauldian discourse analysis (Parker 1997).	(i) Autism as transgressing normative expectancies (ii) Dependency and functional ability discourse (iii) Autism and the discourse of mental status (iv) Autism and explanatory discourses
Huws, J. C. & Jones, R. S. P. (2010). Missing voices: Representations of autism in British newspapers, 1999-2008. <i>British Journal of Learning Disabilities</i> , 39, 98-104.	Newspaper articles: one-month periods at four 3-year time intervals.	Stratified sample of 255 newspaper articles. Discourse Analysis (Parker 1992; Willig 2001).	(i) The missing voices (ii) The burden of autism (iii) Sensationalising autism (iv) Infantilising autism

Implications for service provision

Representations of autism are temporal and social constructs, thus they are unstable and inconsistent. This can affect the way people with autism are perceived by others (be it in health and social care, or in society in general).

- ❖ People with autism and their families need to be involved in deciding research priorities, and in implementing service and policy initiatives.
- ❖ Greater focus is needed on optimising timely bi-directional knowledge exchange/transfer between people with autism, the research community, practitioners, lay people and the media.

Would you like to know more? Then please contact Jaci Huws at j.huws@bangor.ac.uk