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

CONFERENCE PAPER · NOVEMBER 2015

DOI: 10.13140/2.1.2210.1443

READS 83

2 AUTHORS, INCLUDING:
Jaci Huws
Bangor University

SEE PROFILE

Available from: Jaci Huws
Retrieved on: 22 October 2015
The social construction of ‘autism’: Implications for service provision from a decade of research

Dr Jaci C. Huws¹ & Professor Robert S. P. Jones²

¹School of Healthcare Sciences, Bangor University; ²School of Psychology, Bangor University & Head of Learning Disabilities (Clinical Psychology), BCUHB.

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 normality, 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.

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.