

Health, Disability and the Other

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For people with learning disabilities in the UK, living on the edge of society is part of everyday life. This paper puts forward the idea that this lived experience is positioned at the margins of society and is represented as a contemporary other, in part by the terminology used to refer to it. Learning disability is by no means a universal term. A plethora of terms exist within academic research, policy, legal documents and everyday language. Terms such as learning difficulty, mental retardation, developmental delay and mental ill health are frequently used interchangeably or in replacement of learning disability. This is not just pedantic nit picking; confusion and tensions arise when replacement terms are value laden or mean something different entirely. Indeed, the language of learning disability exists within a semantic tangle of definitions, concepts, colloquialisms, political ideology and attitudes fraught with historical, social and political tensions, that in turn impact upon the lives of people with learning disabilities and those working in learning disability practice. It is argued that such confusion is underpinned by a power imbalance, the particular characteristics of which are unique to learning disability. The paper presents current learning disability discourse as a tautological muddle and works backwards in time to seek clarification and explanation.

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Accounts of 'otherness' in stories of Gypsy and Traveller health

There is a growing fascination in the 'otherness' of Gypsy and Traveller lifestyles in popular culture, as exemplified by the hugely popular channel 4 television series 'My Big Fat Gypsy Weddings'. Such portrayals have provoked widespread criticism for fuelling misconceptions and stereotypes of Gypsies and Travellers. Alongside this broader fascination with Traveller Community culture, interest is increasing in the health of Gypsies and Travellers in public health policy and research. The literature points to competing discourses attempting to define how Gypsies and Travellers 'are' with respect to health. Such attempts at definition hinge on oppositions such as adherence to deficit or strength models of health; the similarity or 'otherness' of Traveller Communities; and power and resistance. The presentation describes the rationale for adopting a narrative approach, informed by poststructuralism, in order to understand how Traveller Community members and public health practitioners position themselves within this contested territory of Gypsy and Traveller health, through the stories they tell. The adoption of a poststructuralist narrative approach is argued to enable an open-ended examination of the ways that practitioners or Gypsies and Travellers may draw on multiple, interacting and co-existing constructs, practices or identities with respect to health, depending on the social context. The challenges of researching 'otherness', including consideration of my positionality as a 'settled' researcher, and the paradox of (re)presenting groups while simultaneously seeking to destabilise discourses positioning groups as 'other' will be discussed, as well as possible strategies for navigating such challenges.

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"Social Inclusion" is a term used in government policy (DoH 2001, 2009) indicated and measured by the number of people with learning disabilities in employment and settled accommodation (DoH 2009). However, the relevance of these indicators for people with profound and multiple learning disabilities (PMLD), deemed to be the most disabled in our society (Mansell 2010) is not yet known.

People with PMLD are poorly represented in research and policy due to their complexity of needs resulting from longstanding sensory and physical impairments in conjunction with severe and profound cognitive disability. Ultimately, this is deemed to reduce their capacity to consent (Mental Health Act 2005) thus preventing this under represented group to participate in research which has the potential to elicit their perspectives to understand their experiences of social inclusion.

This talk will summarise current provisions of social care for people with PMLD as well as addressing the barriers currently in place that prevent people with PMLD being research participants. It will then introduce a research project which aims to use interviews with parents, carers and support staff to develop a definition of social inclusion. This definition will then be used to generate measures to apply in observational studies of people with PMLD.

This is a timely study as recent research has shown that there are more people with PMLD than ever and this number is set to continue increasing (Emerson, 2009). Research needs to identify how to represent people with PMLD in order to develop services that effectively meet their needs and also those of their families and carers.