



## **Creating diverse coalitions for equality in neoliberal times: locating the emancipatory city**

### **11:15 to 12: 55: Presentation session 2, Disability and Inclusion**

#### **Presentation 5: Knowledge and perceptions of mental health in the Black, Asian and Minority Ethnic (BAME) community: Are we any more forward than we were 10 years ago?**

*Dr Meredith Wilkinson (DMU), Kathleen Nthakomwa-Cassidy (DMU) and Dr Annemieke van den Tol (DMU)*

We report the first wave of data analysis of our research examining the barriers that individuals from Black, Asian and Minority Ethnic (BAME) groups face when accessing mainstream mental health services. Participants were recruited through an online anonymous survey consisting of a series of closed and open-ended questions. Qualitative responses were analysed through the use of Thematic Analysis.

Findings revealed that 74% of participants felt that BAME individuals did not possess a sound knowledge of mental health and 67% of participants felt there was not enough support for BAME individuals encountering mental health problems. Barriers that BAME individuals identified to accessing mental health services were; stigma associated with having a mental health problem, and a lack of knowledge about mental health & mental health services. Initial findings highlighted that the attitudes towards individuals with mental health problems in BAME communities was negative. These findings highlight the importance of addressing these issues as wider evidence suggests that early intervention can potentially lead to improved mental health outcomes, improved quality of life and reduction in suicide rates.

There are still huge barriers that BAME individuals experiencing mental health problems face. Disability research such as this can lead to social and political change through highlighting and seeking ways to address these barriers to help seeking. Change is especially important in terms of looking at mental health promotion, awareness raising and stigma reduction initiatives for and in collaboration with marginalised groups.

## **Presentation 6: 'Have you ever talked to any women with Turner Syndrome?' Photo-elicitation interviews and other adaptations in research with women with mild cognitive impairment**

*Kriss Fearon, DMU*

This paper describes the use of a visual method, photo elicitation interviews, along with other adaptations, in research on how Turner Syndrome (TS) affects reproductive choices within families. Most women with TS are born without ovaries, and consequently need to make an active choice about whether and how to have a family; this study explores how women with TS perceive and navigate those choices. As decisions affecting a girl's future fertility may need to be taken in childhood, this study also explores the role of mothers of girls with TS in facilitating their daughter's future reproductive options, for example by freezing their own eggs for their daughter's use in later life.

TS is a spectrum disorder associated with a profile of mild cognitive impairments that vary in degree from woman to woman. Some participants may have issues, such as social anxiety or difficulty with time management, that could affect the research interview. Care was taken to accommodate these needs through the research conduct and interview setting. In addition to its effectiveness with sensitive research topics, photo elicitation was also chosen because it addressed some of those needs.

19 women with TS and 11 mothers of girls with TS were each asked to bring three photographs to interview that helped them express their thoughts and feelings about TS, motherhood and fertility. Using example quotes and photos, this paper discusses how photo elicitation interviews can work as part of a wider methodological strategy to encourage and facilitate participation by participants with mild cognitive impairment, potentially making research more inclusive.

## **Presentation 7: On creating the artwork 'In conversation'**

*Sam Sharman-Dunn, Independent artist*

Sam Sharman-Dunn is a Leicester artist with a degree in Fine Art from DMU. She will be talking about how her experience of living with chronic illness led her to create the artwork for her final year show, which you can see in the exhibition.

"This work is an exploration of my feelings towards my invisible disability. The concrete block represents my illness. It is the 'elephant in the room', which I have been ignoring for years. It is finally time to speak up and to tell it how I feel.

These three still images are from a performance and originally accompanied my installation-sound piece, in which I explored how it felt to be crushed by the weight of my illness and how I struggle to emerge out from underneath it. The concrete block acts as an 'embodiment' of burden and the viewer is able to project their own experience onto the image.

Artists, such as Frida Khalo and the performance artists Bobby Baker and Liz Crow, deal with their own illnesses and disabilities within their art and have influenced me a great deal in my art practice, as has the work of Eva Hesse.

I have a desire to work with concrete, as its density and tactile nature excite me; however, my illness makes this extremely difficult because of its weight and the effort required to mix it. I have

played with ways of making concrete less heavy and in this instance, I have made my concrete block out of wood, canvas and cement skim, giving the illusion of density without the accompanying exhaustion.

The idea that my work would move away from sculpture and become much more about performance has surprised me somewhat, as it has happened at such a crucial stage in my development as an artist. I would like to do more performance and sound-installation work, again exploring more difficult and uncomfortable issues. It has been an exciting experience, giving free range to my emotions and seeing my sculptural language evolve into something new.”

### **Presentation 8: Education, Health and (Care-Less) Plan's**

*Kelly-Mae Savile, Aston University*

Between 2014 and 2018, the statement of special educational needs (SEN) was gradually replaced by an education, health, and care plan (EHCP) (DfE, 2015; Ko, 2015; Lithari and Rogers, 2016). Policymakers intended that the EHCP's would be 'much more personalised' as parents and carers would be 'supported to state their priorities and preferences', resulting in a 'person-centred approach' which aimed 'to meet their personal circumstances, and not as directed by professionals as in the previous process' (Ko, 2015: 446). Previously, research into parents' involvement and encounters with institutional professionals has discovered that disability provisions which are perceived as 'family-centred' (Whyte and Hart, 2003) are often saturated with barriers which are counter-productive to positive outcomes for both the child, and indeed, the family (Arango 2011; Kruijsen-Terpstra et al., 2016; Kuo et al., 2012; Lithari and Rogers, 2016; Rogers, 2007, 2011, 2016).

Utilising qualitative data from research undertaken during 2016 within this transitional period, this presentation focuses on the lives and experiences of mothers within the dwarfism community as they attempt to negotiate health, care, and education provisions following the birth of their child. This research extends upon Rogers' (2016) care ethics model of disability – which seeks to demonstrate how care should be understood relationally. Covering interactions from professionals within public spaces, to online dwarfism support networks, the findings from this qualitative investigation reveal how professionals can be seen to exploit the participant's mothering role, by removing or subverting their own care responsibilities; essentially leaving mothers to 'battle' for SEN provisions which benefit the school in terms of finances. Drawing on Rogers' (2016) theoretical model, the findings from this research further illustrate how the caring spheres are inter-relational: care-work undertaken within the dwarfism community often leaks into other spheres. The findings from this study suggest that specialist knowledge gained from the online dwarfism spaces are often used within the practical and socio-political caring spheres, where mothers face obstacles when trying to ensure appropriate education provisions are available for their child.