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Presentation

The socio-politics of Down syndrome: out and about with my disabled child

Speaker

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Abstract

This presentation will focus on the social model of disability and how it takes shape in the lives of parents when they have a child with Down syndrome. Social science research into issues concerning people with Down syndrome has traditionally been individualised, for example looking at how parents adapt to having a disabled child. Findings sometimes allude to the reactions of others, which can include mention of negative comments and beliefs about people with Down syndrome, but little is said about how this is perceived by families. The lack of academic literature contrasts with vibrant debates and discussions on the internet, often in response to newspaper articles written by journalists, some of whom have children with Down syndrome themselves. Drawing on the social model of disability, which argues for a clearer focus on the barriers society places on disabled people, a planned ethnographic study will consider the socio-political dimensions of Down syndrome from the perspectives of parents. Of particular interest will be how parents manage prejudice and stereotypes, not only for themselves but also when advocating for their children and in relation to other family members. The intention is for the research to look at how wider society has a bearing on the experiences (perhaps adaptation) of parents of children with Down syndrome. Rather than looking at the practical experience of bringing up a disabled child, which is guite well documented, the research will consider how outside influences might be re-evaluated, in a way that the social model of disability seeks to do.