The complex role of social care services in supporting the development of sustainable identities: Insights from the experiences of British South Asian women with intellectual disabilities

Kulsoom Jawaid Malik, Gemma Unwin, Michael Larkin, Biza Stenfert Kroese, John Rose *

School of Psychology, The University of Birmingham, Edgbaston, Birmingham B15 2TT, United Kingdom

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ABSTRACT

Background and aims: Carers and service users with intellectual disabilities from minority ethnic groups have typically been reported to be dissatisfied with the social care services they receive. However, service users themselves have rarely been asked directly about their experiences of social care. This paper aims to understand the meaning of social care services in the lives of South Asian women with intellectual disabilities, in the United Kingdom.

Method and procedure: 10 British South Asian women with mild-moderate intellectual disabilities were interviewed about their experiences of social care services. The transcripts were analysed using interpretative phenomenological analysis.

Results: The analysis produced three super-ordinate themes, which focus on how services facilitate the development of complex identities, how the participants explored their sense of being ‘stuck’ between cultures as they negotiated their journeys towards independence, and the triple disadvantage which they experienced as a consequence of the intersection between gender, ethnicity and disability. The participants were broadly satisfied with the role which services played in these domains, and appeared to find them valuable and helpful.

Conclusions: The results suggest that the participants successfully managed complex identity issues, such as acculturation processes, with the support of services. It may be helpful to give more explicit consideration to the positive role which good services can play in supporting people with intellectual disabilities in the development of their identities and goals, alongside the more traditionally ‘concrete’ objectives of such social care. Engagement with families in ‘positive risk-taking’ is likely to be an important component of success.

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1. The social care needs of people of South Asian origin with intellectual disabilities

This paper aims to reflect on the experiences of women of South Asian origin with intellectual disabilities living in the United Kingdom (UK), and focuses on the way in which they understand and evaluate the social care services which
they receive. The term ‘South Asian’ is used to describe people who identify themselves as originating from the following countries: Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka (World Bank, 2014). The largest communities in the UK originate from India, Pakistan and Bangladesh. It is a demographic convenience to group these communities under the label ‘South Asian,’ but it is not ethnographically meaningful. While the countries in this geopolitical region share many common challenges, the cultural, linguistic and religious characteristics of their populations are varied. Often, health and social care researchers in the UK do consider the needs of ‘South Asians’ as a cohort, however. This is because, even when clustered together, the diverse South Asian populations in the UK can be seen to share some priorities and preferences (e.g. regarding gender role and family structure) which distinguish their service needs from those of other large demographic groups, even if these dimensions mask many more within-group variations.

‘Social services’ refers to services which are provided with the intention of helping people to live in the community, such as help with budgeting, self-care, social activities, travel, housing and leisure. In the United Kingdom, social care is generally seen as separate to health care (Leutz, 1999), although some recent policy initiatives are attempting to integrate them. People with intellectual disabilities (and their families) may receive social care services from a range of sources (public, voluntary and third sector). The extent to which services are provided will depend upon the needs of the person and their family, and is likely to be shaped by formal assessment of the level of intellectual disability. Our study was conducted during the early months of a period of ‘austerity politics’, where service-users and families were anticipating that service provision would begin to shrink, and where many local authorities and service-providers were beginning to raise the threshold for provision of social care.

1.1. Views of care and support

A recent review concluded that few studies with satisfaction with services among people with intellectual disabilities have taken account of participants’ cultural background (Copeland, Luckasson, & Shauger, 2014). Satisfaction with social services amongst people with intellectual disabilities is likely to be shaped in part by cultural expectations about what sorts of support should be provided, with what aims, and by whom. Some cultural groups may also be more marginalised, in terms of the limited social capital available to them, thus reducing their access to services. Chamba, Ahmad, Hirst, Lawston, and Beresford (1999) found that South Asian families of people with intellectual disabilities experienced disadvantages with respect to housing, income, employment and health compared to their white counterparts. They were also found to be receiving fewer benefits and support services. McGrother, Bhaumik, Thorp, Watson, and Taub (2002) found that South Asian carers reported that the people they were caring for had greater skill deficits in areas such as washing, dressing, and toileting than those cared for by families from white backgrounds.

The majority of the research in this area has focussed on the views of carers (Hatton, Azmi, Caine, & Emerson, 1998; McGrother et al., 2002; Raghavan & Waseem, 2007) who report a high level of awareness of health services such as General Practitioners (GPs), dentists and opticians, but less awareness of specialist services such as community intellectual disability nurses (Hatton et al., 1998; Raghavan & Waseem, 2007). Generally, carers in these studies are reported to be unsatisfied with services. Very few studies which have focused upon minority ethnic groups have done so by collecting data from adults with intellectual disabilities themselves (Azmi, Hatton, Emerson, & Caine, 1997; Bonell, Underwood, Radhakrishnan, & McCarthy, 2012; Pestana, 2011; Raghavan & Waseem, 2007). In these studies, participants with intellectual disabilities reported social isolation, limited social networks, lack of leisure and recreational activities, unmet cultural needs and experiences of ‘double discrimination’ (in relation to disability and ethnicity), racism and stigma (Azmi et al., 1997; Pestana, 2011). However, these participants were broadly satisfied with the limited range of services received (for example, day services; Azmi et al., 1997) and mental health services (Bonell et al., 2012).

When we add the dimension of gender to this picture, it becomes more complex still. Mir, Nocon, Ahmad, and Jones (2001) suggested that South Asian women experience ‘triple jeopardy’ with regards to their ethnicity, disability and gender, and so their needs differ from the needs of South Asian males or from white women with intellectual disabilities. In one study, parents of Muslim daughters with intellectual disabilities preferred female staff to care for their daughters, and parents tended not to allow their daughters to attend recreational activities where alcohol might be served (Raghavan & Pawson, 2009). In another study, O’Hara and Martin (2003) found that Bangladeshi women were more likely to be married and living with an extended family than white women with intellectual disabilities in the United Kingdom. Bangladeshi parents in the study saw it as their parental responsibility to see their child married. These studies point to particular gendered expectations which may be shared by some parents and families of South Asian women with intellectual disabilities, and which may have implications for the women themselves, and for the service providers attempting to meet their needs.

There is little research on the views of people with an intellectual disability from South Asian backgrounds and even less from a female perspective. Much of the research that exists has been conducted from a parental perspective. There is an indication within the literature that people with an intellectual disability from South Asian background may have a different perspective and that women may have specific concerns. As a result it would seem important to develop research with a specific focus on women with intellectual disabilities from a South Asian background. This research sets out to develop and explore this research agenda.
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