

**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.**

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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.

Keywords: Intellectual disabilities; learning disabilities; South Asian women; qualitative, social care services; culture; IPA.

Running header: Supporting the development of sustainable identities.

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.

Views of care and support

A recent review concluded that few studies of satisfaction with services among people with intellectual disabilities have taken account of participants' cultural background (Copeland, Luckasson and 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 et al., 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 et al, 1997; Bonnell et al, 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 (Bonnell 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.

Aims

Our study forms one part of a larger study which aimed to engage with service-users with intellectual disabilities from minority ethnic groups, and to explore their experiences of social care services. We take the view that service-users are experts in their own experiences. Understanding their needs and views is important for the development of more acceptable and effective services. The aims of this paper are:

- To explore the experiences of British South Asian women with intellectual disabilities in receipt of social care services.
- To explore how the participants make sense of their cultural identities in the context of these services.

METHOD

Approach

The project adopted an Interpretative Phenomenological Analysis (IPA) approach. According to Smith et al. (2009), IPA aims to study experiences (i.e. it is phenomenological) through interpretation (i.e. it subscribes to the hermeneutic tradition of phenomenology) of the particular meaning-making of persons-in-context (i.e. it prioritises an idiographic commitment to depth and context). Independent ethical review was obtained prior to the study commencing via the U.K. National Health Service research ethics service.

Design

Research interviews were conducted with an opportunity sample of women with intellectual disabilities from South Asian backgrounds living in the West Midlands. Flexibility was employed by the interviewers so that participants could be interviewed alone, or with a companion (a fellow participant, or a carer), as they preferred.

Sampling and recruitment

Potential research participants were approached through seven organisations across the West Midlands including education, social care, local authority, charities, private service providers and health services some of which provided services only for women of South Asian origin. The details of individuals who were interested in taking part in the research were forwarded to the researchers. A meeting between each potential participant and the

interviewer was arranged to assess suitability for the research and to gain informed consent. Two volunteers did not demonstrate the capacity to provide informed consent, and were not invited to take part in a research interview.

A time was arranged for the interview at least one week after the initial screening meeting, to allow the participants an opportunity to change their minds about taking part. Details on how to cancel the interview were given to the research participant and to those who supported them.

Participants

Participants were women, over the age of 18 who identified themselves as South Asian through the geography of their own or their parents' origin in India, Pakistan or Bangladesh. They were able to give informed consent and had a mild/moderate intellectual disability. Participants were given the option of conducting the interview in any language. All the participants opted to speak in English with the exception of one participant who opted to converse through an interpreter in Bengali. Despite the majority of the interviews being conducted in English, participants also used Urdu and Punjabi words intermittently.

Data collection

Twelve participants were assessed as suitable and interviews were arranged with these participants via five organisations (see Table 1).

Two interviews were not included in the data analysis: the first interview was not included in the data analysis as it was conducted in Bengali with an

interpreter who did not translate the interviewer's questions, but instead asked her own questions. The second interview was not included due to concerns around safeguarding issues being raised in the interview by the participant. The interview was terminated after 10 minutes and the staff involved in the participant's care were informed and the appropriate safeguarding procedures were implemented. A total of 10 participants were included in the analysis.

Assessment of intellectual disability

All the participants were believed to present with mild or moderate intellectual disabilities as defined through their service use and their response to a checklist of functional and academic skills (Unwin, unpublished) completed with participants and/or informants and based on the ICD-10 criteria of intellectual disabilities. Table 1 details a summary of the participants' demographic details. All of the participants were born in the United Kingdom but identified themselves as South Asian.

[INSERT TABLE 1 ABOUT HERE]

Interviews

Individual semi structured interviews were conducted with seven participants. One group interview was also conducted with three participants who wished to be take part together.

The interview consisted of two parts. The first part began by exploring a culturegram (Unwin, Larkin, Rose, Stenfert Kroese & Malcolm, 2016) which

provides a simple visual map to be used as prompts for exploring a respondent's preferences and identifications with some of the key elements of culture (such as family, religion, language, diet, leisure and festivities). Our culturegram is part of the 'Tools for Talking' resources (toolsfortalking.wordpress.com) developed during the wider project.. The results from the culturegram discussion were included in the general analysis and used to inform further questions. The second part of the interview used open ended questions (See Figure 1 for main questions) with 'nested' sets of prompts and probes, to minimise acquiescence, inconsistency and social desirability (Shanly & Rose, 1993).

[INSERT TABLE 2 ABOUT HERE]

Additional adaptations to the interview schedule to support participants with intellectual disabilities

It was anticipated that some participants who struggle to communicate verbally would find it difficult to answer some of the interview questions. The interview schedule was designed to support participants with limited communication difficulties, through the use of simple language and additional supplementary questions and visual cues.

Data Analysis

The interviews ranged from 29 to 52 minutes long. They were audio recorded and transcribed verbatim. Pseudonyms were used.

Participants tended to develop their answers in short bursts, in collaboration with the researcher's questioning. Most answers were brief and required further prompting to explore their meaning and context. Participants shared information and developed their views via small layers of dialogue. In order to foreground their voices within the constraints of this article, these segments of text are largely quoted below *without* the additional scaffolding questions from the researcher.

The 1:1 interviews were analysed using the six stages proposed by Smith et al. (2009). The group interview was analysed using an existing protocol developed for group interviews and IPA (Palmer, Larkin, de Visser & Fadden 2010). Both of these approaches are well-established. Each makes the systematic identification and interpretation of experiential concerns their central concern, but the Palmer et al. procedure also requires the analyst to attend to the social 'layering' of meaning making in group interviews.

In order to ensure that the principles of IPA were adhered to, several quality checks were implemented, in line with the quality markers of triangulation, credibility checking and reflexivity, as proposed by Smith (2011).

Contributions

The first author conducted the interviews and analysis presented here. The second author co-ordinated the data collection for the encompassing project and provided triangulation and on the data collection process. The third author designed and managed the wider project, provided training on

IPA, and contributed to the analysis and write-up. The fourth and fifth authors provided supervision and credibility-checking to the first author during the conduct of the project, including the analysis and write-up.

ANALYSIS

Three inter-related super-ordinate themes emerged from the analysis. The first theme relates to how “*services facilitate the development of more complex identities*”. This theme explores how the participants experienced their cultural identities to be dynamic, rather than static. They were able to use services as a medium through which they could either take up, or push against traditional cultural values, which were sometimes perceived to be set by their family and religion. The second theme relates to how the participants explored their sense of *Finding a place on the spectrum of independence*. ‘Negotiations’ took place with both families and services, and could be direct and/or indirect. The participants showed how they managed the conflicting messages which they received (from both services and their families) about independence, to find their own preferred balance. The third theme reflects the idea that our participants experienced ‘triple inter-sectionality’ (Crenshaw, 1991) as they noticed disadvantages due to being a woman, coming from a South Asian background and having an intellectual disability.

Each theme will be briefly described below, including the key sub-themes, and illustrated and discussed in the context of indicative data extracts.

[INSERT TABLE 3 ABOUT HERE]

Theme 1: Services can facilitate the development of more complex cultural identities.

All the participants in the study presented their cultural identities as a dynamic concept. In the interviews, it became apparent that many experienced a push-pull effect between traditional values and more typically contemporary-British values.

This theme includes four sub-themes. The first sub-theme, *Being seen as a religious person: rules for living*, relates to how some aspects of an individual's identity may be very strictly defined, such as through what one eats and drinks. The second sub-theme is *Taking part in religion: activities are up for negotiation*. The participants appeared to have knowledge about religious/cultural values and customs, but opted in and out of activities in negotiation with their families. The third sub-theme is *Families provide the culture*. The participants made reference to how their families helped them to develop their cultural values, and so there was no expectation for services to facilitate this. The last sub-theme explored how the participants were able to *Reject traditional values through services*. Engagement with services provided participants with the opportunity to make choices about those aspects of culture and religion which wished to accept and those which they wished to reject.

Theme 1 (sub-theme 1): Being seen as a religious person.

It appeared to be important for all of the participants to demonstrate that they were following their religion appropriately. Boundaries around food and drink appeared to be very clear, possibly because one might be making a statement about religious orientation based on deciding to consume or reject particular food or drink. For example, Wajeeha described the strict boundaries between what Muslim people may eat and what non-Muslim people might consume: *"We can't have like Christian food; white people eat their own food"*. Similar understandings are in play when Sophia says, *"Normal meat, like English people have, we're not allowed to- to have these things"*. For Sophia, the term 'normal' suggests that she is aware that eating Halal meat is unusual, that she belongs to a minority in this context, and that special provisions need to be made for her. The terms 'Christian' and 'English' denote differences that the participants use to demonstrate the boundaries between self and others. Observed dietary differences were not just restricted to the Muslim participants. For other participants, such as Poonam, who is Hindu, diet was also shaped by religious expectations: *"I eat pork, but I don't eat beef and I don't eat lamb because of my religion"*.

Other participants described how their religions provided them with rules for living, in the shape of activities, such as prayer, reading the Quran and fasting. For example, Kanwal described how, *"I read Namaaz [Islamic prayer offered five times a day] you have to be cleaned and you know covered properly"*. Similarly,

Saddaf's religion guided her in aspects of her life, *"Not allowed to have boyfriends, no (laughs quietly), because of our religion"*.

Theme 1 (sub-theme 2): Taking part in religion: activities are up for negotiation.

Participants did not necessarily adhere to their knowledge about religious doctrine or cultural expectations. Their judgements about appropriate behaviour were sometimes context-dependent. Sometimes the knowledge itself was inconsistently stated or inaccurate. For example, in the group interview, Nusrat and Nabiha both stated that they prayed *"five days a week,"* while Saddaf stated that she prayed *"five times a day."* The latter is the correct frequency according to Islamic principles. Both Nusrat and Nabiha may have wanted to be seen to know about their religion, even if they did not engage in the activities themselves or have the correct knowledge. The desire to 'prove' knowledge about Islamic values and principles may have been intensified due to the discussions taking place in a group setting where all the participants were Muslim, including the interviewer.

Demonstrating knowledge of religion appeared to be sufficient for participants to feel like they belonged to a particular faith even when they did not necessarily take part in the activities. Poonam reported that *"My parents pray every morning"* but went on to explain that, *"I only take part when it's special"*. Faiza also stated that she had knowledge of fasting, but did not feel the need to

keep fasts herself: *“Ramadan [Islamic religious festival where able bodied Muslims fast from Dawn to Dusk for one calendar month], fasting, um my family do, I don't know (laughs)”*. Some families may make exceptions for their adult children, due to their intellectual disabilities. In other cases, there were additional contextual factors. For example, Ayshas's reason for not participating in some religious activities appeared to be based on a practical consideration: *“I don't fast, because of my medication.”*

Theme 1 (sub-theme 3): Families provide the culture

With the exception of two accounts, participants appeared satisfied with services and did not want services to support their cultural needs. One of the reasons for this may be because the majority of the participants lived with their families, who appeared to provide modelling and education on religious and cultural activities. For example, Poonam appeared satisfied that her family supported her with her religious and cultural activities: *“I celebrate Diwali with my parents. And all the family and friends”* When asked about what she celebrates with the day services she attends, she replied *“Services? Oh, I don't ask them. I don't know if they do. I prefer it with my parents, not with anyone else”*.

The importance of how families facilitate the development of cultural identity becomes evident by the accounts of what life is like when families are no longer involved. These participants shared a sense of loss with regards to their cultural identity. For example, Meena lived in supported accommodation, no

longer had contact with her family, but wished to speak Punjabi and to keep that part of her alive: *“When I used to live at home, I thought it was important because at the end of the day it’s your parents’ language, so really you should speak it, but um I don’t really speak it.”*

Theme 1, (sub-theme 4): Resisting traditional values through services.

All the participants were born and raised in the United Kingdom and they all seemed to experience a dilemma between how to manage the conflicting demands of traditional values with contemporary British values. For example, Wajeeha was caught between her family not wanting her to watch films, and her own desire to watch them. At the daycentre she attends, *“Sometimes they go to the cinema, only I don’t go. Or like the other girls go, only I don’t go. I don’t- I don’t watch any movies like I love to go to the cinema only my dad and mum don’t let me go to the cinema. They said films are not good to watch”*. Much to her delight, however, when movies were shown at the daycentre, she was able to watch them. She was able to sidestep the rules imposed on her by her family, and make choices based on her personal preferences, within the service context.

In another example, Kanwal described how she tried to make sense of contravening her family’s expectations about her not having a boyfriend. Living in supported accommodation meant that she was able to have a secret relationship. She was torn between this relationship and the expectations of

her family: *"It's just- it's boyfriend just eh, how can I explain to you? I go see him and come back. He- he makes me dinner and it doesn't-, he has cats as well, two cats, nice cats."* She is aware that her family would not approve: *"They won't like it. Because if I tell them, they might get upset or- although they're already upset with me about- with lots of things, I don't want them to get upset again ."*

Theme 2: Finding a place on the spectrum of independence.

The second theme relates to how the participants see themselves on a the spectrum of independence. There was a sense that while services tried to promote learning and independence, often families were reported as being more cautious, encouraging daughters to take a more passive role.

This theme has two sub-themes. The first sub-theme relates to *Families wanting to protect*. From our participants' perspective, some of their families wanted to provide practical support, but they wanted to do this in their own homes and on their own terms.

The second sub-theme relates to *Moving forward: accepting help, but doing some things independently*. This concerns how the participants reflected on the support they received: they wanted to do some activities on their own but did not mind receiving support to do other things.

Theme 2 (sub-theme 1): Families wanting to protect.

All the participants labelled themselves as having an intellectual disability. In the family interactions which they described, the term 'intellectual disability' appeared primarily to signify things which were not possible, or not permitted. For example, Nusrat described wanting to go to college, but her mother did not encourage or support her daughter in this: *"I stopped going about a week now, I don't go to college. It's too far for me and I need to have a taxi to take me there. And the taxi doesn't come. I wait for the taxi and my Mummy says- she says, 'Go and sleep in bed. If the taxi doesn't come, if- if the taxi isn't early- early, doesn't come to the door, ring the doorbell - go back to sleep'."*

It is possible that, sometimes, families' protective priorities impeded their daughters' intellectual and progress. For example, at the daycentre, Sophia engaged in various activities: *"Play a game or something, a jigsaw, or you can do knitting in there or sewing in there. Or you can play table tennis. Or you can go in the snooker or like bowling here"*. Yet at home, she was not allowed to take part in washing her own clothes: *"We do it home like that. My mum, my brother says you are not allowed to"*. This account suggests that at home, the learning of new skills was not always encouraged.

Theme 2 (sub-theme 2): Moving forward: accepting help but doing some things independently.

Services were viewed as helpful and positive. Poonam summarised this, from her perspective: *“They’re excellent: they help me with money, they help me with food, they help me with food hygiene, um they help me in lots of ways”*.

Service support appeared to facilitate learning. For many of the participants, a sense of ‘moving forward’ was important. For example, Meena described her experience of having support from services as invaluable: *“When I left home I was near enough completely blind and I couldn’t read or write or nothing or budget. They supported me with eye hospital appointments, spending hours and hours there. They help you. They encourage you actually to budget, to do your own shopping, but if you can’t do it on your own the staff are there to support you.”*

In some cases there was a tension between making progress, and feeling supported. For example, Kanwal was aware that there were limits to what she could do on her own, and she valued being supported to achieve things: *“No I can’t do everything. The staff it helps me. They help me going out. Today I went shopping and they help going shopping”*. She also longed to be independent (*“I want to move next door, and I, I want to go to the house really, having my own place really”*) but she sometimes resented staff not doing things for her. For example: *“Some other people they’re cooking for, they think ‘she can do everything herself, why should we do it?’, that’s what I think”*. Most of the time, in her home, Kanwal was alone, and her main social interactions were with staff when receiving support. Kanwal had many capabilities, and appeared to feel torn between wanting to

be supported and wanting to do things on her own. This dilemma was conflated for her, by her lack of other social contacts and activities.

Theme 3: Triple inter-sectionality: The impact of having an intellectual disability, being South Asian and being a woman.

This theme explores how the participants made sense of three aspects of their identity: their gender (female), their ethnicity (South Asian) and their disability. Whilst participants did not report that they felt discriminated against by services, this last theme looks at how the participants notice experiences where they might have been disadvantaged. This section suggests that the participants in this study noticed that their gender, ethnicity and disability intertwined with each other and that they experienced disadvantages due to this. This sense of overall disadvantage is explored through two sub-themes: *following rules* and *noticing the difference between men and women*.

The sub-theme *families wanting to protect* from the previous theme also links with this. Many of the participants' perceived disadvantages were experienced in the family context. This is complex, because the families may want to *protect* their daughters *because* of their disadvantages and disabilities, but it is difficult to tease out the impact of each of these dimensions individually, as they are closely related and interlinked.

Theme 3 (sub-theme1): Following and noticing rules.

The dilemmas reported here around making choices and following rules seem to mirror the literature on adolescents' experiences of pushing boundaries to decide whether to follow parental rules or not (Smetana, 2010). All the participants in this study are adults but they are still being parented, and the theme of following rules - and sometimes breaking them - suggests that they share some experiences with younger people.

Families may worry about women becoming too 'westernised,' which may conflict with the families' cultural values. 'Independence' (and the various ways in which that can be construed) was an important area of disagreement for our participants, and their families appeared to counterbalance their concerns by imposing rules.

All the participants living with their families made references to following rules imposed by their relatives. For example, Saddaf would like to wear jeans but she does not have permission from her family: *"I could wear like jeans but I don't. My family, they won't let me though"*.

The rule of not wearing western clothing may be based on religious principles or cultural values. For example, Islamic values require that both men and women dress modestly. During the interview, Saddaf was dressed in shalwar kameez, which is a loose long flowing top with baggy trousers. Shalwar

kameez is not specifically Islamic, but it is traditional Pakistani clothing and worn in many Pakistani families. Thus, Saddam's clothing was shaped by both her religion and her cultural-familial background. In terms of disability, Saddam may not have the resources to make other choices about her clothing, due not being able to travel independently and not having her own money. This restricts her ability to disregard the expectations of her family. We may assume that someone with a disability is likely to have fewer opportunities and resources with which to challenge the expectations of others, especially if they do not live independently. Thus external expectations about gender, culture and disability all interact to reduce Saddam's options for self-development here. Undercutting familial expectations in such circumstances risks disapproval, and potentially even the withdrawal of some support.

Rules around clothing were not restricted to the Muslim participants. For example, Poonam also followed rules about clothing imposed by her mother: *"My mum helps me with clothes shopping. I can't buy my own clothes because I'm always buying what she doesn't like, and then she doesn't let me keep it, so she has to buy for me, but she won't let me buy any more clothes"*. In other domains, such as social activities, similar expectations were at work. For example, Aysha described her prohibition from clubs: *"I don't go club. I'm not allowed. I don't go clubbing. Because people drink, and then they vomit. And then they take drugs and then they fight, they kiss, it's really bad."* For Aysha, drinking is considered inappropriate because she is part of a Muslim family. Going to pubs and clubs

is viewed as an unsuitable place for women due to the possibility of seeing behaviours like kissing and fighting. This extract suggests that Aysha's family do not want her exposed to such things, but of course, it could also be related to her having an intellectual disability and the belief that she should be protected from such environments. In this examples we can see that the restrictions upon our participants' activities and choices are complex: some may be genuinely protective of their wellbeing; others may be overcautious, and place unnecessary limits on the development of otherwise independent selves.

Theme 3 (sub-theme 2): Noticing differences between men and women.

Our participants were attuned to one particular source of inequality in their lives, which was that often there were different rules for males and females. For example, Nursrat remarked on a rule about when a woman should cover her head. She had learned the this by observing her mother: *"You should have a scarf around your head. Every time. Yeah. When you're going out you should wear a scarf as well. My Mummy wears a scarf going to my uncle's house"*. The word 'should' connotes rules. The fact that her mother wears a headscarf at her uncle's house may relate again to Islamic principles around modesty but it can also be seen as a way of showing respect to elders or males. Nusrat goes on to demonstrate that she is aware that males do not have to wear scarves. Sophia noticed that there are subtle differences between her family's perception of her brother getting married and their perception of her getting

married: *"My brother said it's not allowed. Mum won't like this, my dad said can't like that, my brother can if he wants to do okay, but she can't"*. It is possible that she is *"not allowed"* to marry due to her having an intellectual disability. Noticing disadvantages which arise from having an intellectual disability, being a South Asian, or being female, was a consistent theme for Sophia. When Sophia was asked what special occasions she celebrated, she stated *"Birthdays, my brother's birthday"*. Sophia did not say that she celebrated her own birthday or other females' birthdays. It is possible that her brother's birthday was a recent or memorable event, but it is also possible that Sophia may have found that special emphasis is given to her brother's birthdays.

Often, rules and restrictions were clearly delineated as female-focused. For example, Faiza says that, *"Pakistani women not allowed er staying out late at night because it's dark and um erm the time its night."* Faiza uses the term 'Pakistani women' rather 'Pakistani people,' which suggests that these rules are applied to women but not to men. When asked if she would like to stay out till late, she laughed: *"Er yeah, but not too long"*.

DISCUSSION

The dilemmas associated with managing multiple identities.

The first super-ordinate theme explores the development of complex cultural identities. Some aspects of participants' culture are well defined, such as what they eat and drink, while other aspects appear to be negotiable (such as whether they pray or fast), with their families supporting them to develop their cultural identity. This supports the argument that a sophisticated view of cultural identity negotiation is required. The concepts of 'culture clash' (Marshall & Yazdani, 1999) or a categorical account of 'acculturation' (Berry, 1997) are unhelpful here. Certainly, the participants' accounts detail the difficulties that they experience in integrating contemporary western values with more traditional South Asian values. However, Berry (1997) argues that there are four acculturation strategies: integration, assimilation, separation/segregation and marginalisation. The findings from the current research suggest this is too simplistic. The participants do not fit neatly into any of these acculturation strategies, but rather adopt an amalgamation of different elements. For example, in one setting, integration may be pursued, but in another, segregation (the previous example of watching films at the care centre, but not at the cinema, illustrates this neatly). Issues of cultural identity for South Asian women are not unique to those with intellectual disabilities, of course. Our findings echo the literature on the experiences of South Asian women in general, some of whom may also struggle with negotiating

identities as they move between different cultural frames (Gilbert, Gilbert & Sanghera, 2004).

In this context, our participants reported that families were fulfilling their cultural needs, and that services were acting in culturally appropriate ways to support this. With the exception of two participants, who were no longer living at home, none were dissatisfied with services. This is in contrast with the views of parents from previous research, who have expressed dissatisfaction with services (Hatton et al, 1998, Hensel et al, 2005 and Raghavan & Waseem, 2007).

The results from our study can also be compared with those reported by Azmi et al. (1997). The Azmi et al. study described the experiences of participants who claimed a strong ethnic identity, and were dissatisfied with services. The participants in our study expressed a more dynamic relationship to the cultural aspects of their identities, and appeared to be largely satisfied with services in general. Participants from both studies were born in the UK. There are several tentative hypothesises that may explain the differences in findings. Firstly, Azmi et al.'s research was conducted almost twenty years ago. During this time period, services may have responded to the sorts of dissatisfaction expressed in the earlier paper. Secondly, the samples in the two studies are different. Azmi et al.'s participants included male and female adults and adolescents (14-44, mean age 22 years old). The participants in our study were

all females (24-46, mean age 33 years old). It is possible that older females with intellectual disabilities consider that their needs are better met both by services and their families, than younger people with intellectual disabilities.

Conflicting views of services and families

The second super-ordinate theme in this paper explores how the participants in this study were sometimes 'stuck in the middle' as they noticed differences between their expressed wishes to participate in activities provided by services and the conflicting wishes of their families with regards to independence. The participants were encouraged to learn to be more independent by services, and they appeared to want to do this, despite the views of their families.

Previous research informs us that service users are dissatisfied (Azmi et al., 1997), families are dissatisfied (Hatton et al., 1998) and that service providers experience conflicts with families on issues such as promoting choice and individuality (Heer et al., 2014). An 'experiential-contextual framework' proposed by Heer et al. (2012) attempts to understand the tension between service providers and families, in terms of their differing understandings, priorities and values. The current findings suggest that although the female service users noticed differences between their own preferences and preferences of their family, they were happy to have the 'best of both'. The participants *noticed* that their families did not encourage them to learn new

skills, but did not express dissatisfaction. They may have felt that it is the role of services to help them learn, rather than families. The families' lack of encouragement for their daughters' further learning may be based on their views of disability. For example, if families have the view that someone has a learning disability for theological reasons such as karma (Fatimilehin & Nadirshaw, 1994), they may also have the view that people with intellectual disabilities cannot learn and progress, because their fate is predetermined and not in their control.

This suggests that when services focus on promoting learning and the development of skills, but ignore cultural identity, then tensions may arise. Families may worry that if their daughters become more independent this is a sign that are becoming too westernised (Chesler, 2009). It may be possible for services to encourage families themselves to support such steps, if they are able to enlist them as partners in 'positive risk-taking,' and to share with them the planning, pacing and development of learning.

Inter-sectionality

The third super-ordinate theme relates to "triple inter-sectionality". Inter-sectionality is a feminist sociological theory developed by Kimberlé Crenshaw (1991). It is the methodology of studying "the relationships among multiple dimensions and modalities of social relationships and subject formations" (McCall 2014). The theory looks at how various cultural and social

categories such as gender, disability and culture interact with each other on varying levels to create a sense of injustice or inequality (Knudsen, 2006). From the findings of this research, it appears that the participants experienced triple inter-sectionality. To date there is a lack of research that integrates feminist approaches with intellectual disability research and ethnicity (Traustadottir & Johnson, 2000).

Research findings concerning women of South Asian origin who do not have intellectual disabilities suggest that they experience a double disadvantage (regarding gender and culture), having to negotiate issues of honour and shame, subordination and entrapment (Gilbert et al., 2006). This is echoed in the current findings, with participants having to follow rules, and experiencing gender differences in terms of power and freedom within the family. Having an intellectual disability presents further disadvantage and limited access to resources, but it also adds complexity (such as needing to ask for help, concerns about not meeting milestones like getting married, and concerns about safety). The participants in this study provided evidence that they were aware of the disadvantages that go with their gendered, cultural, and disabled status. They did not have access to the same experiences, choices and opportunities enjoyed by people without these disadvantages. A capabilities model (Nussbaum, 2000), might well be a useful framework for services to use when assessing the needs of service-users in such situations, and could be a good basis for brokering conversations with families about the benefits of

change and development. In this respect, we might think of 'good' cultural position as being one which enables to the person to develop, fulfil their potential, and explore their capabilities. This is an identity project that can be sustained and developed by the person themselves, but it also needs to be one which allows them to maintain good relationships with people who are important to them.

Strengths and Limitations

The main strengths of this paper included that it researched a group of people that have to date been neglected. The research participants were mainly from a Pakistani background, and the interview attempted to explore many areas of the participant's lives in considerable detail, giving them a voice which suggests an alternative viewpoint. The paper also considers the context of the research and the difficulties inherent in conducting research of this type.

The main limitation of this study is that the sample is not entirely homogenous. Due to recruitment difficulties, British women from more than one part of South Asia were included. Despite this, the sample does have some similarities in terms of age, and they were all born and raised in the United Kingdom. The sample size was modest, but consistent with the recommendations for IPA.

It is worth noting that 6 out of 10 of the participants in this study were recruited from 'South Asian women'-only services, mainly run by South Asian service providers. We should expect satisfaction with such services to be good. In large UK conurbations, such focused services are more common than they once were. The parents in Hatton et al.'s (1998) study suggested that increasing South Asian staff would also increase their satisfaction with services, and this appears to have taken place.

Research and Clinical implications

The findings suggests an agenda for future research, IPA papers tend not to make generalizable statements with regards to findings. Research using quantitative methodologies with larger sample sizes would aid generalisation. This paper did not look at service utilisation, all the participants were recruited through services. This may have impacted on the positive view of services. Further research to build on this could involve recruiting "non-service users" to look at the experiences of people not in receipt of services. In addition, further research could interview Women of South Asian origin and their families separately and then look at the impact of families of the experiences of the person with a learning disability.

Our findings demonstrate that British South Asian women with intellectual disabilities have to contend with the same cultural, religious and gender issues as those without intellectual disabilities. However, they also notice additional disadvantage with regards to having an intellectual disability. The participants in this research raised complex issues that can be used to help families and service providers think about some of the difficulties which service users experience and how these can best be addressed.

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Table 1: Information regarding the participants using pseudonyms

Pseudonym	Age	Interview type	Organisation	Religion and Ethnicity	Ethnic group	Marital status and living arrangements
Nusrat Malik	35	Group	Private women only, day service 1	Islam	Bangladeshi	Single Living with parents
Nabiha Begum	43	Group	Private women only, day service 1	Islam	Bangladeshi	Married to cousin who lives in Bangladesh Living with parents
Saddaf Akif	24	Group	Private women only, day service 1	Islam	Pakistani	Single Living with brother and sister in-law
Faiza Khan	34	Individual	Private women only, day service 2	Islam	Pakistani	Married, husband lives in Pakistan Living with parents
Sophia Mughal	42	Individual	Private women only, day service 2	Islam	Pakistani	Single Living with parents
Wajeeha Shareef	39	Individual	Private day service for Asian people	Islam	Pakistani	Single Living with parents
Aysha Aslam	33	Individual	Charity 1	Islam	Indian	Single Lives in supported accommodation
Poonam Aggarwal	32	Individual	Charity 1	Hinduism	Indian	Single Living with parents
Meena Ralhan	48	Individual	Charity 1	Sikhism	Indian	Single Lives alone in flat with support
Kanwal Baig	46	Individual	NHS	Islam	Pakistani	Divorced, husband who lives in Pakistan Lives in supported accommodation
Summary	Mean age 33	7 individual interview 3 group	5 different service providers	8 Islam 1 Sikhism 1 Hinduism	5 Pakistani 3 Indian 2 Bangladeshi	7 single 3 married

Table 2: Main interview questions for all participants (augmented by prompts and visual cues)

- What sort of things do you like to get help with?
- Who usually gives you help with these things?
- Outside your family and friends, do you get help from other people?

For those who use services at present:

- Here's a logo for [service]. Tell me a bit about what it's like.
- Are there any other things/services you'd like to do/attend?

For everyone

- What are your plans for the future?
- Do you want your life to stay the same or do you want it to be different?

Table 3: The three super-ordinate themes and eight sub-themes

The experiences of women of South Asian origin with intellectual disabilities in receipt of Social Services			
Super-ordinate themes	1	2	3
	Services facilitate the development of more complex identities	'Stuck in the middle' negotiating a journey towards independence	Triple intersectionality
Sub-themes	1 Being seen as a religious person	1 Families wanting to protect	1 Following rules
	2 Taking part in religious activities is up for negotiation	2 Moving forward: accepting help but doing some things independently	2 Noticing differences between men and women
	3 Families provide the culture		
	4 Pushing against traditional values		