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Title: Social networks of adults with an intellectual disability from south Asian and white communities in the United Kingdom: a comparison

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ABSTRACT

Background Little research exists comparing the social networks of people with intellectual disability (ID) from south Asian and white backgrounds. This UK study reports on the barriers that south Asian people with ID face in relation to social inclusion compared to their white counterparts.

Materials and Methods. A mixed-methods research design was adopted to explore the social lives of 27 men (15 white; 12 South Asian) and 20 women (10 white; 10 South Asian with ID). Descriptive and parametric tests were used to analyse the quantitative data.

Results The average network size of the whole group was 32 members. South Asian participants had more family members whilst white participants had more service users and staff in their networks; 96% network members from white ID group were also of white background, whilst the south Asian group had mixed ethnic network members.

Conclusions Social networks of individuals with ID in this study were found to be larger overall in comparison to previous studies, whilst network structure differed between the white and south Asian population. These differences have implications relating to future service planning and appropriateness of available facilities.

INTRODUCTION

Previous research has shown that social networks can mediate social functioning, self-esteem and quality of life (Cummins & Lau, 2003), buffer life's stresses (Duck, Rutt, Hoy, & Strejc, 1991), and aid mental health (Ozbay et al., 2007; WHO, 2001). A functioning social network can additionally lead to greater access to services, leisure activities, employment, personal autonomy and enjoyment (McConkey, Grant, Goward, Richardson, & Ramcharan, 2005; Strathdee, 2005; Forrester-Jones et al. 2012; 2016). Nevertheless, some relationships may be unsupportive and abusive (Cambridge, 1999), and poor social support has been linked to loneliness, mental illness and suicide risk (Duberstein et al., 2004).

Whilst many studies have attempted to chart and examine the overall social relationships of people with intellectual disabilities (ID) (Robertson et al., 2001; O'Callaghan and Murphy, 2002; Forrester-Jones, Jones, Heason, & Di'Terlizzi, 2004; Forrester-Jones et al., 2006) research into the social lives of people with ID from south Asian communities has been sparse, out-dated and piecemeal, restricted to reports on satisfaction levels of individuals' social relationships (Azmi, Hatton, Emerson, & Caine, 1997). No studies have specifically explored the differences in social networks between south Asian and White people with ID in the UK. The term south Asian used in this paper, refers to individuals in the UK who originate from India, Pakistan, Bangladesh and Kashmir (British Sociological Association, 2005), whereas, the White population described in this study refer to those who originate from any of area of the United Kingdom (ONS, 2003).

Prevalence of ID in south Asian communities

Whilst reliable prevalence rates of people with ID from south Asian communities in the UK do not exist, studies examining the use of health services by people from ethnic minorities indicate that over half a million are of south Asian origin (accounting for 2.7% of the total population (Azmi, Hatton, Caine, & Emerson, 1996; Emerson et al., 1997)), with the number

of people with ID estimated as rising (McGrother, Bhaumik, Thorp, Watson, & Taub, 2002). Emerson (2012) further argued that rates of severe forms of ID among children of Indian, Pakistani and Bangladeshi backgrounds are up to three times more prevalent than in aged matched peers from other ethnic groups (Emerson, 2012). With regards to severe ID, Hatton et al. (2012) also estimated a prevalence in South Asian populations originally from India, Pakistan, Bangladesh, as well as Indian families who had lived in Africa for long periods, to be three times higher than the general population. Moreover, both Emerson (2012) and Hatton et al. (2012) predicted a substantial increase in the number of UK South Asian people with severe ID over the next 20 years. However, given the reliance on health service use for estimates, these figures may only reflect the tip of the iceberg.

The increase in the number of South Asian cases of ID have been linked to a number of social, historical, cultural and economic factors, such as social deprivation, poor housing, environmental pollution and diet as well as a lack of knowledge of ID and unfamiliarity with methods of genetic counselling (Nadirshaw, 2000, 2010; Nadirshaw, Newall, & Gournay, 2009).

Racism and discrimination

Hatton et al. (2004) argued that South Asian (UK) communities in general (and Pakistani and Bangladeshi communities in particular) suffer discrimination in relation to everyday living including housing, education and employment, as well as access to health and social services, compared to their White counterparts. For South Asian families with a child with severe ID, these disadvantages were found to be stark; with housing unsuitable for a child's needs, and financial resources inadequate to meet the needs of the extra costs of care. Issues surrounding misclassification due to bilingualism and language or cultural differences are also possible contributing factors (Nadirshaw, 2000; Hatton et al. 2004; Nadirshaw et al., 2009). For example, McGrother et al. (2002) found that 76.9% of south Asians with ID in

Leicestershire reported to have a main language other than English, and 74.1% were born outside of the UK and consequently disadvantaged by not gaining early special education. Stereotypical assumptions and misunderstandings about south Asian populations in general can also influence the way diagnosis occurs (Fernando, 2013; O'Hara, 2003) as well as provision of services. For example, the idea held by many in the general population as well as in clinical settings that south Asian people will 'look after their own' (Ahmad & Atkin, 1996) can lead to south Asian carers being more invisible, receiving less respite care and consequently experiencing more neglect than their non-Asian counterparts (Mir & Britain, 2001; Shah, 1992). This will inevitably affect the support and social connections that their child with ID receives.

Studies about south Asian children with ID have also indicated that racism occurs within the health care system (Baxter & Britain, 1990). Chamba (1999) noted that south Asian children with ID who were also deaf, received a later diagnosis than native British children with ID. Chamba reported that parents felt that, compared to their white counterparts, their child's health was not being taken as seriously by practitioners. It has also been reported that General Practitioners may withhold certain medical information and choices from Muslim families, for example when prenatal diagnosis occurs, as they assume that Muslims will not consider a termination of pregnancy (O'Hara, 2003). O'Hara (2003) also points to the misinformation and bias of professionals with regards to consanguineous marriages and their relation to intellectual disabilities which leads professionals to be unsympathetic towards parents, since the condition is regarded as partly self-inflicted. Baxter et al. (1990) and Azmi et al. (1997) therefore argued that 'double discrimination' (i.e. being treated differently because of their ethnicity as well as their disability) faced by many south Asians with ID, is a "painful reality" (O'Hara, 2003 p.170). Studies have also reported on the poor standards of communication and cultural and discriminatory inappropriateness of certain services for ethnic

minorities, leading to increased informal support from extended social networks of families (Fatimilehin & Nadirshaw, 1994; McGrother et al., 2002; Mir & Britain, 2001; O'Hara, 2003). Whilst some of the above studies are rather dated (there being a dearth of recent studies concerning South Asian families caring for people with ID), there is no reason to suggest that the situation of South Asians with ID and their families has improved radically.

Cultural issues

Perhaps as a symptom of systemic discrimination, whereby information is not appropriately provided, McGrother et al. (2002) found that South Asians tend to underutilise services available to them due to their own lack of knowledge of the cause or concept of having an ID, often interchanging it with mental health problems. In a study by Hensel, Krishnan, Saunders, Durrani, and Rose (2005) a large proportion of families had different understandings about ID, many were unable to provide diagnostic information on their child and only able to give vague descriptions. This issue may be confounded by belief structures within south Asian culture which include, for some, alter-casting (Goffman, 1963) linked to the fear parents from south Asian backgrounds have of being stigmatised for having a child with ID, as well as beliefs of 'past life wrong-doings', termed as 'karma' in the Hindu religion (Gabel, 2004).

Linked to fear of stigma of having ID, is the cultural norm of 'shame' attached to accessing health and social care provision and a fear that other people will 'find out' that a family member has an ID (Hensel et al., 2005). Although it is questionable as to whether this relates to all South Asian families (with no concrete data proving this), Gable (2004) suggests that overall South Asians' cultural desire for privacy is demonstrated in the ways they approach (and avoid) health professionals. Hatton et al. (2004) reported that less than half of parents of a child with severe ID had 'collaborative' working relationships with professionals due to linguistic barriers and feelings of having to constantly battle to access 'public' services leading to major frustrations. Just over a quarter of Hatton et al.'s sample reported having a social

worker or health visitor. Interestingly, it was found that this was more of a problem for Indian and Pakistani families living in the UK compared to Bangladeshi parents who perhaps had lower expectations of services from the outset. Whilst most of the children in Hatton et al's study sample were in special schools, many parents reported problems with language and religious needs. Parents were also not routinely accessing respite services; a lack of awareness being the issue.

Rather than acquiring help from health and social care providers, south Asian families often consult or resort to consulting religious or traditional healers in the hope of making their child 'better' (Raghavan & Waseem, 2007). These cultural and religious attitudes of families of children with ID, in the context of the predominant UK culture of accessing 'professional help', may further increase the separation between South Asian families and primary health professionals.

Given these cultural boundaries (which in and of themselves should not work against individuals with ID) it is perhaps unsurprising that in south Asian communities, life tends to revolve around relationships within the family. In many Indian and Pakistani families, it is common to emphasise the importance of friend and family memberships, and very often outsiders are adopted within the family network and given names such as 'auntie' or 'sister', which can become very confusing to western professional workers when trying to understand available social support networks (Rack, 1982). That said, Hatton et al. (2004) found a lack of awareness or participation in 'family support groups' although those who did access these drew some benefits from them.

Social networks

Social networks in south Asian ID groups have also been found to be limited compared to those from a white background. Hensel et al. (2005) found that south Asian individuals with ID were only able to go out if accompanied with another individual (normally a family

member), with the rest of their time spent at home or in an ID day care centre; having a 'social life' was deemed as culturally inappropriate, unless it entailed visiting family, family-friends or attending places of worship. Again, this was explained by parents' fear of the public's reaction and stigma. Whilst parents acting as 'gatekeepers' of the social networks of adults with ID is not extraordinary to south Asian families in the UK (some white parents will not wish their adult child to attend mainstream discos for fear of engaging in sexual behaviour for example), nor is it likely to be any different from south Asian families living in south Asia, it would appear that the social forums which individuals with ID might be 'allowed' to attend are further restricted within the south Asian context. Exploring the differences in family 'gatekeepers' for both south Asian and white communities with ID, is important in trying to understand the differences in social network structure between these two groups. Depleted social opportunities for adults with ID may be further confounded by the restricted social lives of parents (especially Pakistani families) who have been reported to often be in relatively poor health themselves compared to national data and, in the absence of informal support, are mainly required to 'stay in' to look after their children (Hatton et al. 2004). It would appear then that the social networks of people with ID and their parents may be more homogeneous (restricted in terms of the types of relationships) compared to White populations although hitherto this has not been researched in any great detail.

Research in social network structure may be helpful in gaining knowledge as to who people with ID have in their networks, where they gain these network members from and how much they interact with them. This knowledge should provide valuable information about appropriate interventions to facilitate individuals' social networks. The aim of this paper is to report on the social support networks and integration of people with ID from south Asian and white communities; exploring potential barriers that south Asians face, noting any comparisons to their white counterparts

MATERIALS AND METHODS

Participants

Forty-seven adults with ID were interviewed, 57% were male and 47% were from a south Asian background. The South Asian sample consisted of individuals from Indian, Pakistani and Bangladeshi backgrounds who were residing permanently in the UK. The 'White' participant group were those from an English/Caucasian background also residing permanently in the UK. The mean age of participants was 32.9 years (SD = 9.97, range = 19-60 years) and all had a primary diagnosis of ID (See Table 1).

Recruitment

Purposeful sampling was adopted by approaching day care services all over London and Kent, UK; both South Asian and white adults with ID being sought from both locations. The majority of the white sample recruited lived in Kent including Dartford (88%) whilst most of the recruited south Asian sample resided in London (86%) (see Table 1). These areas of London and Kent were chosen so as to broadly incorporate both urban and more rural areas; to see if the variable of place impacted on the study outcome. Over half of the south Asian participants lived with their parents whilst proportionately more white individuals lived in residential service settings (3:2 Asian:white ratio). The youngest participant was white and the eldest south Asian, though both samples were similarly matched in terms of age and gender.

[Insert Table 1]

Measures

The Adaptive Behaviour Scale (short form; SABS) (Hatton et al., 2001), was used to interview both family and paid carers of the person with ID to assess the sample for adaptive ability in

terms of independent functioning, physical development, understanding of numbers and time, domestic activity and socialisation. The Cronbach's alpha for this sample was 0.950, which indicated an extremely high level of internal consistency (reliability) for this measure, with high construct validity.

The Social Network Guide (SNG) was constructed by adapting the Social Network Map (SNM) (Tracy & Abell 1994), the Social Network Schedule (SNS) (Dunn et al. 1990), and by using network membership categories derived from a previous ethnography (Forrester-Jones & Grant 1995, 1997). The SNG maps the structural (size, membership) interactional (reciprocity, frequency, duration and closeness) and supportive (e.g. companionships and decision-making) components of individual's networks. Participants firstly define the members of their social network using a 'wheel of life'; by either naming them (by first or second name) or by referencing them situationally (e.g. the grocer). For each identified member, information is collected on the type of relationship (e.g. family, staff, neighbour, volunteer, friend), and the area of life from which they were derived (e.g. household, residential home, retail, such as cafes and pubs). Thus, a 'friend' might be a local publican or a member of staff. For each member identified by the participant, the type of relationship (e.g. family, staff and neighbour) is noted. In this way, each person was reporting their ties to other people including what support those people were providing them with. A fuller version of the SNG (used to chart the social networks of 213 people with intellectual disabilities and 85 people with mental health problems following deinstitutionalisation in Forrester-Jones et al. 2006; 2012) is published elsewhere (Broadhurst & Forrester-Jones, 2007). Each participant's SNG was completed at interview either alone (n=38) or supported by an informal carer or member of staff (n=9). The Cronbach's alpha for this sample was 0.751, which indicates a high level of internal consistency (reliability) for this measure, with high construct validity.

The SNG interview was conducted in a conversational open-ended style about individuals' typical day, and who they saw, met etc. Individual and accessible formats were used at interview (including signs, symbols and photographs) depending on the understanding and communication levels and styles of each participant. Concepts such as reciprocity were explained in a simple way, i.e. 'do they do things for you and you do things for them'? This was found to aid individual's memory about their social ties and helped to reduce acquiescence and the likelihood of receiving 'yes/no' answers. The researcher introduced prompts with the participants by asking them to explain the tasks they performed daily, how they felt about doing them and probing them to explain a topic further. This aided the completion of the SNG and reduced the chance of a low response rate. To ensure no information was missed during the face-to-face interviews, all interviews were audio-recorded if consent was granted.

A co-researcher recoded 20% of the interviews and there was 80% agreement of answers indicating a high degree of inter-rater reliability. The data were analysed using independent sample t-tests, correlations and one-way ANOVA, following checks for normality of data distribution.

Ethical considerations

The study gained ethical approval from the Research Ethics Committee at the University of Kent. Accessible information sheets and consent forms were used and only people with ID who were able and willing to consent were included. To reduce any power imbalance and to build up trust between interviewer and interviewee, the researcher visited and chatted informally to each participant before starting the interview, which were all conducted in English to reduce misunderstandings during translation. A trained Bollywood dancer, the researcher was also invited by managers of services to teach dance to participants by service managers as an

informal quid pro-quo for conducting the research. However, this occurred after interviews had been arranged to avoid any inducement.

RESULTS

Total ABS Scores

Although differences are noted, t-tests indicated no significant differences between the white and south Asian population for their mean total adaptive behaviour scores (see Table 2). The south Asian population had a greater range (181) from which their scores were obtained, compared to the white population (135), with one of the south Asian participants having the lowest ABS scores and one white participant the highest ABS scores.

[Insert Table 2]

ABS scores for Factor A, B and C

Independent t-tests indicated no significant differences between the white and south Asian mean ABS scores for factors A [Personal self-sufficiency (e.g. bathing, dressing and mobility)] and B, although mean ABS scores were close to being significantly higher for Factor B Community self-sufficiency (e.g. self-care and knowledge of numbers and speaking) and were significantly higher for Factor C Personal-Social responsibility (e.g. general responsibility, consideration and awareness of others) for the white population compared to the south Asian group (Factor B: White mean=102.5, Asian mean=85.2, t=1.869, df=39, p=0.06; Factor C: White mean=44.6, Asian mean=38.4, t=1.967, df=39, p=0.05).

Network Size

[Insert Table 3]

The average network size for the whole sample was 32. An independent t-test showed no significant difference in average network size between the two communities; Asian and White (t = -.284, df = 45, p = 0.778, two-tailed). Although not significant, the Asian participants had slightly larger sized networks compared to their white counterparts (32.41 versus 31.32). Higher network size also correlated positively with higher ABS scores, as expected.

Network Membership

[Insert Figure 1]

White participants' social networks were mainly made up of other people with ID (just under 1/3rd of total contacts) (see Fig 1). Other family members and staff each accounted for just under a quarter of the networks, whilst 12% were social acquaintances. Employers and service contacts (which were both significantly higher than in the Asian population p<0.01), specialist staff, other friends and volunteers all made up a total of just 17% of the white sample's networks.

On the other hand, for south Asian participants with ID, other family made up over a third of their social networks (35%) which is significantly higher than for the white population (t = -3.942, df = 45, p< 0.01, two tailed). Other service users also made up over a quarter of network membership. Staff (14%) and social acquaintances (13%) made up a lower proportion of the Asians' membership in comparison to the white population. Their remaining network members were other friends, volunteers, service contacts and specialists who made up a total of 10% of individuals' networks. No significant differences were found in the other membership categories.

Ethnicity of Network Members

[Insert Figure 2]

Figure 2 highlights the ethnicity of network members for each group. White participants' social networks were made up almost entirely of white network members with just 4% of members from other ethnic groups (social acquaintances (2%), other people with ID (1%) and staff (1%) making up this proportion). This differed from the Asian sample, whose social networks were more ethnically mixed, with over a third white (37%) and two thirds Asian (63%). Almost all other service users within the white samples' social networks were white (91%), compared to the Asian population who had 41% white service users within their networks. Similarly, 7% of family members in Asians' networks were white, whilst the white participants did not have any family members belonging to BME groups. Asian people with ID also had social networks made up of 59% of social acquaintances and friends who were white. The majority of staff for both groups were white.

Area of Life

Area of life denotes the social context from which people with ID gain social network members. Figure 3 shows that the majority of both groups' network members were derived from day centres, households or extended family. Forty-two per cent of white people with IDs' networks came from day centres and over a third of Asians' members were derived from this social context. Contacts within day centres included other people with ID, staff or volunteers.

[Insert Figure 3]

Whilst both groups of people with ID gained a high proportion of network members from 'extended family' (including grandparents, aunties/uncles and cousins), Asian people

with ID had a significantly higher number of members belonging to 'extended family' in comparison to the White group (t =-2.552, 45, p<0.05, two tailed). Household was also an area of life from which both communities gained a large number of their network members, although again Asian participants had a significantly higher proportion of family members and other residents (t =-2.433, 45, p<0.05). White participants with ID gathered the remaining third of network members from areas such as work place (which was significantly higher than the Asian population; t =2.560, 45, p<0.05), social care services, church, shops and cafes, and the neighbourhood. For the south Asian group, their remaining quarter of network members were derived from social care services, temples, and the neighbourhood. For both groups then, the number and variety of social contexts from which to derive social relationships were limited, though for white participants, work was an additional context which appeared to be closed to Asian participants with ID.

Social Support and Interactional Features

The frequency of social support behaviours was categorized as 'hardly ever/never' (score 0) and 'always/sometimes' (score 1). To assess reciprocity, participants were asked 'do you help each other' or 'do they just do things for you' or 'do you help them but they don't help you'? Responses were categorized as either 'both ways' (score 1) or 'not reciprocal' (score 0). Closeness is categorized as 'not very close' (0) or 'very /quite close' (1) and duration as ≤ 5 years (0) or >5 years (1).

[Insert Table 4]

Overall, both communities (Asian and white) received similar levels of support from their network members.

Social Support

No significant difference was found in terms of personal support (e.g. tying shoe laces) provided to both white and south Asian individuals with ID. Personal support was mainly provided by immediate family (over 50%), paid carers and specialist professionals. South Asians had a slightly higher number of network members (9.1%) providing household support compared to the white population (6.7%). A higher number of network members provided material support (total N=240) compared to household or personal support, with south Asian individuals receiving a significantly higher proportion of material support; 23.4% (X^2= 49.87, df= 1, p<0.001) compared to their white colleagues (9.8%). For both populations, 87% of this support came mainly from immediate/extended family. Decision making and feedback was given to the person with ID mainly by family (52%), specialists/professionals (23%) and paid carers (17%). On the whole, south Asians received more support in making decisions and receiving feedback compared to the white ID population. Network members that the ID participants felt they could confide in were derived mainly from family (39%), client's/service users (24%), staff (11%), specialists (9%), other friends and social acquaintances (12%). Whilst there was little difference between both communities in terms of levels of support, there was a difference in who each of the community confided in. Within the Asian community, nearly half of confidants belonged to family (45%), whilst only a third of confidants within the white population were family and under a quarter were service users.

Companionship, which could also be interpreted as a type of emotional support, like confiding (Willmott, 1987), was described to the participant as being about someone who they enjoyed being in the company of, and who they felt reciprocated this feeling, as well as being someone they spoke to on a regular basis. The main differences for this sample related to who individuals particularly liked spending time with. Participants from the white population

mainly enjoyed spending time with other client's/service users (35%), whilst south Asian participants enjoyed spending time with family (40%).

Invisible support referred to those network members who kept an eye on the person with ID or 'looked out for them'. Again, little significant difference between the two communities was identified, however, over 52% of family network members from the south Asian community were thought to keep an eye on their relative with ID, compared to 32% from white families.

Positively, it was found that only 5% of the total number of network members was reported as nasty or critical towards participants. South Asians had a higher proportion of at least one critical network member compared to white participants (74%, 26% respectively of the total 5%). Overall, family members and clients were most likely to be critical towards the participants; with family members from the south Asian group emitting a greater level of negativity than other network members.

Interactional Features

Both communities had similar levels of reciprocity with their respective network members (white; 37%, Asian; 35.6%) but who they reciprocated with, differed. South Asian individuals with ID reported higher levels of reciprocity with family (57%), much more so than their white counterparts (34%), however, the white ID sample had a more even dispersal of reciprocity between different network members. Both groups saw about two-thirds of their network members on a daily or weekly basis, with the majority of these network members consisting of service users, family, and staff/specialists. Both groups' highest percentage of network members came from services users who they saw daily (white; 43%, Asian; 42%). The white sample's second highest number of network members seen daily came from staff (15%), compared to south Asian's who saw family (23%). Unsurprisingly, 97% of the Asian

family members and 69% of white family members had known the person with ID for more than 5 years. The type of relationship someone with an ID says they have with a network member can reflect how they feel about this person and whether they do in fact get on with the network member and want them to be a part of their social life. Overall, 67% of the south Asian population felt they were 'best' friends with their family network members, compared to 49% from the white community.

DISCUSSION

The results from this study emphasise the differences in social network structure between two ethnic groups in the UK, White being the predominant ethnic group (48.2 million in 2011, or 86%) and south Asians making up only 7.5% of the total population in the UK (ONS, 2011). Although participants were sought from operationally similar services, and had similar levels of adaptive functioning of ID, the social make-up of network members were found to differ considerably.

The mean ABS scores for all participants was 211.5 (range 79-284) which in comparison to the general population of people with ID is rather high and comparative to those with a mild to moderate ID. This study does not therefore represent those from a wide spectrum of ID. However, using Pearson Correlation, it was found that higher ABS scores correlated positively with higher network size, therefore participants with higher adaptive behaviour scores also had a larger network size perhaps due to their adaptive behaviour functioning and communication skills.

The ABS scores in this study were somewhat similar (albeit slightly lower) than scores from participants in Forrester-Jones et al.'s (2004) supported employment study, where participants scored a mean of 269.5 (range 188-302) on the ABS. Participants in their study were however all in supported employment, and therefore higher adaptive behaviour is

expected. In comparison to Lowe, Felce, Perry, Baxter, and Jones's (1998) study though, scores on adaptive behaviour in the current study were considerably higher (90, range 21-178) despite both studies reporting similar living circumstances; i.e. family or residential/community housing. Similarly, participants studied by Robertson et al. (2001) had lower adaptive functioning scores than those in the present study. In their study people with ID living in village communities scored a mean ABS of 195.4; in residential campuses 103.9; and in dispersed housing 150.2. Therefore, overall adaptive functioning in the present study was fairly high compared to other similar studies reporting on social networks, which could have positive implications for the network memberships formed and activities both ethnic groups were involved in. A likely reason for this difference is the requirement for participants in this study to have the capacity to consent to participate and ability to be interviewed face-to-face by the researcher, leading to necessarily higher adaptive functioning.

It could also be argued that the higher scores on personal self-sufficiency were to be expected due to the recruitment process, in that, both groups were personally selected by "gatekeepers" or service managers, who tended to invite participants who were generally more physically able and cognitively competent to consent to research participation. As Becker, Roberts, Morrison, and Silver (2004) point out, this obvious limitation shows how bound researchers are to gatekeepers, whether in a service setting or by family carers. All participants interviewed were accessed via a day centre or ID organisation; were fairly physically able; and did not need the use of a personal carer whilst attending the day centre. Personal hygiene abilities were therefore expected to be high. This corresponds with results obtained on social support; the main type of personal support needed by participants involved hep with complex fine motor skills (e.g. help with buttons or tying shoe laces). The white participant group had higher overall ABS scores (although not significantly so) compared to the south Asian group. One possibility could be that most south Asian individuals still resided at home and appeared

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to be more dependent on family members for help in personal day-to-day care compared to their white counterparts who were overall more independent, living in supported residential homes or independently. This corresponds with data on people with ID living in dispersed independent housing (e.g. Robertson et al., 2000) where residents had an overall higher mean adaptive functioning score compared to other ID groups living in NHS campuses which are similar to some home settings by way of social connectedness, physical activity and expectations to behave independently. Findings by Duvdevany (2002) however contradicts both these results, where no significant difference was found in ABS scores between people with ID who lived in more segregated living conditions compared to those who were living within the community.

On the whole, the south Asian ID group interviewed presented as having generally lower levels of communicative abilities in regards to their formation of sentences and comprehension of spoken instructions, hence unsurprisingly, the white ID group obtained significantly higher community self-sufficiency scores compared to the south Asian ID group. One reason for the difference in scores is the south Asian ID group's bilingualism. A number of south Asian participants spoke more than one language, their second language being their native tongue, leading to possible discrepancies in the way they communicated or understood instructions or questions. It can also be argued that these differences in communication might impact on the levels of integration for the south Asian group, who would socialise more frequently with family and friends speaking their own native language, compared to integrating fully with the white community where English is preferred. These results correspond with the differences found in network membership between the two study groups.

Social network size for both study groups was 32, with little difference in size between the two groups. This number is very small compared to studies of 'ordinary populations' which deem average networks to consist of between 100 and 150 members (Sarason, Levine, Basham,

& Sarason, 1983; Hill and Dunbar 2003) with networks of less than 50 regarded as very limited (Burt & Ronchi, 1994; Duck et al., 1991). Since no other comparative study of social networks of south Asian and white people with ID currently exists, our results cannot be benchmarked, and can only be compared to a few studies regarding network structures of ID populations. Using studies with similar populations which employed the same methodology, network size for our study group compares favourably. For example, Forrester-Jones et al. (2006) found an average network size of 22 members for participants with a mean age of 51 years. whilst Robertson et al. (2001) recorded a median size of 5 (range 0-20), (although this population were more severely disabled and staff members were excluded from the network count). On the other hand, as noted earlier, Forrester-Jones et al. (2004) found an average network size of 46 persons, amongst those placed in supported employment with a mean age of 36 years. Murphy and O'Callaghan (2004) found a mean network size of 20.6 for 60 adults with ID residing in Kent and a London suburb (mean age 38 years). This highlights the impact of age as well as more socially inclusive activities on network size, whereby the more included a person is within the community, and involved in some sort of supported or voluntary employment or community activity, the greater the network size. As age increases, the number of network member's decrease, due to a number of reasons, such as, significant physical and mental health decline (Walsh, Heller, Schupf, & Van Schrojenstein Lantman-de Valk, 2001) resulting in an inability to socialise and engage in meaningful relationships. Health is a major factor in reflecting a person's social and economic circumstances and daily experiences. A number of services in the UK are not tailored to the ageing physical and mental health needs and social requirements of older adults with ID, resulting in lower social network size (as described in Robertson's study).

Network membership and the area of life from which they are derived also have implications for levels of social inclusion and involvement in different activities. The largest

proportion of network members for the white ID population came from service users; family and staff (71%) whereas for the south Asian ID group only family and service users (63%) formed the greatest number of network members. These results support the notion of family members being the gatekeeper to social inclusion for both groups yet network memberships might be very different for the south Asian population if 'allowed' to be involved in more community activities. A number of other studies (Forrester-Jones et al., 2004; Robertson et al., 2001) have however found similar results, in that staff, family and other members with ID made up the largest membership category of the total contacts; 68% and 83% staff; 72% family; and 54% other members with ID respectively, derived predominantly from day centres and other family/household. Studies focussing on the south Asian ID population have also found that most young ID south Asians reported being closest to their mothers who provided both emotional and practical support (Pawson, Raghavan, Small, Craig, & Spencer, 2005; Raghavan & Waseem, 2007).

Another aspect not previously reported in social network research is the ethnicity of network members. This study found the south Asian ID group to have a ratio of 2:1 Asian to white network members, whilst the white ID group's members were majority white. Although poignant, these results need to be considered with the location of services from which both groups were recruited. According to the ONS (2011), London houses a more diverse range of ethnic groups compared to Kent [White: 62.4% (London), 88% (Kent); South Asian: 10% (London), 2.4% (Kent)], hence, the white ID group from Kent may not have had as much opportunity to socialise and integrate with other people from ethnic minorities compared to the South Asian group residing in London, perhaps accounting for the limited numbers of ethnic minorities in the white group from Kent. This sampling limitation could paint a very different picture if all participants were recruited from a similar socio-economic area in the UK.

However, as this was not possible for this study, this is currently the best available data on ethnic network membership for people with ID.

Family structure and the involvement of the immediate and extended family varied between the white and south Asian ID group. South Asian's had a higher number of family members in their network, but the level of functional and interactional behaviours that was provided by family differed between the two groups. Overall, the south Asian group received more functional support from immediate and extended family, such as decision making, which Raghavan and Waseem (2007) similarly found, in that Asian parents took on most of the support needs. Similarly, south Asian participants confided most with their family members and enjoyed the company of their family more than any other network group, labelling them as their 'best friend', corroborating findings by Bowes and Dar (2000) who similarly found the importance that family played in the lives of people with ID from ethnic minority backgrounds. In Bowes and Dar's study south Asian people with ID preferred to live with their family and were dependent on them for household support and in some instances care. Many participants in their study discussed how their daily lives centred on family, explaining that they spent the majority of their time at home with family, watching Asian channels on television. However, white participants felt they could confide in a number of different network members from different areas of life, such as family, service users, friends and employers. Forrester-Jones et al.'s (2004) study reported similar results with their users, whereby a high level of confiding occurred between staff, family, other friends and work contacts. Reasons for the difference in whom network members of each group confide in; the type of relationship they had; and who they enjoyed spending time with, could be related to the proximity principle. The more time one spends with someone, the closer they get to them and more they open up.

CONCLUSION

It is only over the last two decades in the UK that the majority of 1st generation south Asians are grasping the language, culture and traditions of the UK. General involvement in the wider community and services is still progressing and south Asians may be regarded as playing 'catch-up' to the white community, in both allowing their child with ID to participate in a number of meaningful activities or move into independent and residential living, as well as receiving appropriate support for their loved ones with ID. They are also still experiencing stigma, fear and anxiety within their own communities in addition to racism (which arguably has increased more recently due to social and political anxieties over immigration and the decision of the UK to leave Europe).

Although, there are a number of limitations with this comparative study, the findings reflect the work that needs to still be put into practice with enabling both south Asian and white ID populations to participate in UK communities, enabling both groups to develop a greater network of social contacts within a range of areas of life. Further research on the type of formal and informal support that people with ID receive is required to determine the areas of life in which they want to enhance their social networks, and more work is needed to explore further differences within specific ethnic groups. The groups had similar numbers of network members, but membership differed greatly. It cannot therefore be argued that one ethnic group had a more diverse social network than the other, without exploring the social, emotional or practical support each individual network member provided. Given the fact that the social lives of individuals in this study relied on the cognitive abilities of participants to remember who their network members were and their perceptions of support received from each one, it could be argued that a more in-depth study is needed, where each network member named in the SNG is also interviewed to determine how they view their relationship with the person with ID. A more ethnographic study which charts how social relationships are played out behaviourally would also be beneficial. Nevertheless, this study reveals individual's social

networks from their own perspective which, it has long been argued is what matters most (see Henderson 1985:48; Murrell et al. 1992:568).

Mainstream services should actively work in partnership with south Asian organisations or groups to provide mutually inclusive services for all ethnic communities. Services and professionals should seek to listen and hear the views, concerns and needs of people with ID through the commissioning of further participatory research, or via formal and informal discussion and focus groups. This needs to be done with a view to providing tailored information of specific services responding to their needs (such as supportive employment agencies or sporting and activity clubs).

ACKNOWLEGEMENTS

TABLES AND FIGURES

Table 1 Characteristics of sample population

	White	Asian	Total
Sample Number	24	23	47
Gender:			
Male	15	12	27
Female	10	10	20
Mean Age	35.4	30.1	32.9
Age Range	19-54	20-60	19-60
Location:			
London	3	19	22
SE Kent	14	1	15
Dartford	8	2	10
Living Situation:			
Home	15	17	32
Residential Care	9	6	15

Table 2 Adaptive Behaviour Scores (N=41)

	White	Asian	Total Sample	t-test & Significance
Total ABS scores				
Mean (range)	227.3 (149-284)	197.8 (79-260)	211.5 (79-284)	t = 1.932
				P = 0.061
Factor A (Personal self-sufficiency)				
Mean	81.1	75.2	77.9	t = 1.455
Mean (range)	69-88	31-88	31-88	p = 0.154
Mode Rating	Very Superior	Very Superior	Very Superior	
Factor B (Community Self-sufficiency)				
Mean	102.5	85.2	93.2	t = 1.869
Mean (range)	46-143	23-128	23-143	p = 0.069
Mode Rating	Above Average	Average	Average	
Factor C (Personal-Social responsibility)				
Mean	44.6	38.4	41.3	t = 1.967
Mean (range)	23-56	16-51	16-56	p = 0.056
Mode Rating	Average	Average	Average	

Table 3 Social Network Size

	Total Sample	S. Asian	White
Mean Network size	31.83	32.41	31.32
Median	31	31	31
Standard Deviation	12.98	14.2	12.1
Range	13-67	13-64	13-67

Figure 1 Social network membership for White and South Asian group with ID
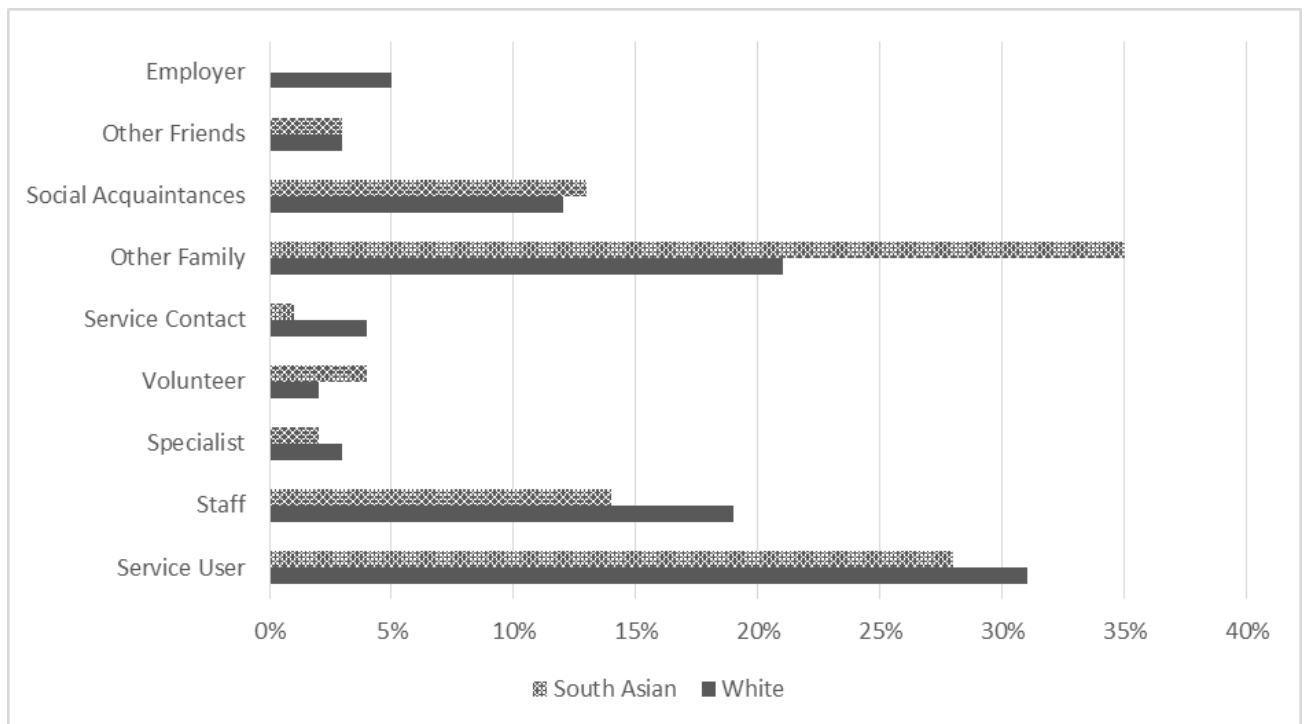
Figure 2 Ethnicity of the network members for both ID populations
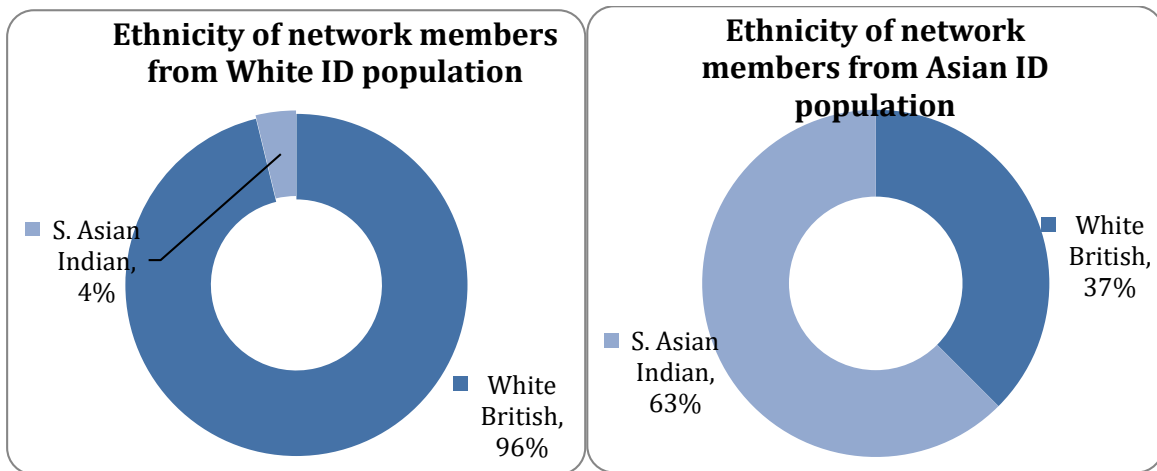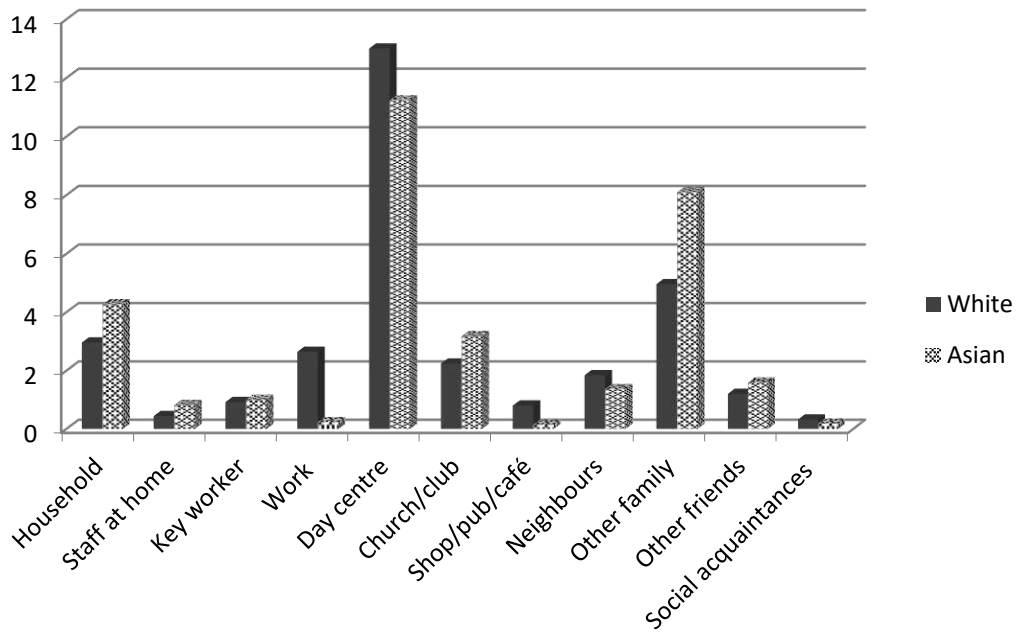
Figure 3 Area of life (social context) of both populations

Table 4 Frequency, support and interactional behaviours provided by network members

Support Behaviours		White	% (n)	Asian	% (n)	Total
			Ethnicity			
Functional Behaviours						
Personal support						
	Always/sometimes	3.0	(24)	3.4	(24)	48
	Hardly ever / never	96.9	(758)	96.5	(672)	1430
Household support						
	Always / sometimes	6.7	(53)	9.1	(64)	117
	Hardly ever / never	93.2	(729)	90.8	(632)	1361
Material support						
	Always / sometimes	9.8	(77)	23.4	(163)	240
	Hardly ever / never	90.1	(705)	76.5	(533)	1238
Decision and feedback						
	Always / sometimes	13.5	(106)	24.7	(172)	278
	Hardly ever / never	86.4	(676)	75.2	(524)	1200
Confiding						
	Always / sometimes	28.6	(224)	36.6	(255)	479
	Hardly ever / never	71.4	(558)	63.4	(441)	999
Company						
	Always / sometimes	83.9	(656)	86.4	(601)	1257
	Hardly ever / never	16.1	(126)	13.6	(95)	221
Invisible						
	Always / sometimes	33.4	(261)	37.8	(263)	524
	Hardly ever / never	66.6	(521)	62.2	(433)	954
Critical						
	Always / sometimes	2.7	(21)	8.5	(59)	80
	Hardly ever / never	97.3	(761)	91.5	(637)	1398

Interactional Behaviours

Reciprocity with contact

	Yes	37.0	(289)	35.6	(248)	537
	No	63.0	(493)	64.4	(448)	941

Frequency of Interaction

	Daily / weekly	69.8	(546)	68.1	(474)	1020
	Monthly / less	30.2	(236)	31.9	(222)	458

Relationship

	Best	35.8	(280)	47.8	(333)	613
	Ok	50.4	(394)	38.2	(266)	660
	Neutral	13.6	(106)	12.2	(85)	191
	Bad	0.0	(0)	0.2	(2)	2
	Very bad	0.3	(2)	1.4	(10)	12

Closeness

	Close/best friend	89.3	(698)	91.2	(635)	1333
	Not close/ don't know well	10.7	(84)	8.8	(61)	145

Duration of contact

	Less than a year	48.8	(382)	50.7	(353)	735
	More than 5 years	51.2	(400)	49.3	(343)	743

Ethnicity of network member

	White British	96.2	(752)	37.5	(261)	1013
	Asian Indian	3.8	(30)	62.5	(435)	465

Total number of contacts		782		696		1478

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