Family and community in the lives of UK Bangladeshi parents with intellectual disabilities

Abstract

Background: Little is known about the lives of parents with intellectual disabilities from minority ethnic communities. Previous research suggests that what it means to live with intellectual disabilities varies across cultural contexts. The current research aimed to explore how cultural values and practices impact upon the experiences of parents with intellectual disabilities within the Bangladeshi community in London, England.

Method: Six members of the Bangladeshi community, four Bangladeshi parents with intellectual disabilities and four of their family members were interviewed. Thematic analysis was used to identify key themes.

Results: Both parenting and intellectual disability are thought about in this community in ways that makes parenting more accessible for people with learning disabilities, but also create tensions to be negotiated.

Conclusions: Bangladeshi family carers face dilemmas balancing the benefits and risks of promoting parenting for sons and daughters with intellectual disabilities, particularly in the context of service principles of autonomy and informed consent.

Introduction

The demographics of the UK have been changing for half a century. Greater proportions of people from ethnic minorities are reported in successive national census returns, with a doubling in the size of the population with an ethnic background other than white between the 1991 UK census and the most recent one in 2011 (Office for National Statistics, 2016). The NHS and all public services are legally and morally required to effectively treat and support all citizens from a range of backgrounds and to tackle discrimination and inequality. However, lack of cultural awareness and sensitivity among staff is one factor that impedes this goal (Gangadharan et al. 2011; King's Fund 2006).

Services for people with intellectual disabilities are likely to experience particular changes in the proportion of people from ethnic minorities who need to access them (Emerson & Hatton 2011). The rise in the number of people from South Asian minority ethnic backgrounds, within the young adult age range in particular, has led to predictions that the proportion of South Asian adults with intellectual disabilities accessing services will continue to increase, and in some areas constitutes the largest ethnic group amongst people with intellectual disabilities (Emerson & Hatton 1998; Tower Hamlets JSNA Reference Group 2015).

It is this younger age range of people with intellectual disabilities who are also most likely to become parents. Nevertheless, there is little published research that considers parenting and intellectual disability within a minority ethnic culture. O'Hara and Martin (2003) conducted a

five year retrospective study of parents accessing Tower Hamlets Community Learning

Disability Team. They found that 85% (22 out of 26) of children born to Bangladeshi mothers

with intellectual disabilities remained living with their birth families in comparison to 29% (8

out of 28) of children born to White British mothers. This was despite the fact that the

Bangladeshi mothers presented with more severe levels of disability. Further consideration of

these findings is important developing an understanding of risk or resilience factors in families

where parents have intellectual disabilities, particularly factors that might increase the

likelihood that parents with intellectual disabilities continue to parent (McGaw et al. 2010).

Historically parents with intellectual disabilities have faced a high and disproportionate risk of

termination of their parental rights (Booth et al. 2006; McGaw et al., 2010). An understanding

of why this is considerably less likely within a particular minority ethnic community in the UK

compared to White British families is likely to be instructive.

In explaining their findings O'Hara and Martin (2003) point to the role of the extended family

within the Bangladeshi community. In their study 12 of the 15 Bangladeshi mothers with

intellectual disabilities and all the fathers were living with extended family. In addition, all were

married to spouses who did not have an intellectual disability. The authors suggest that such

arrangements can mean that the person with an intellectual disability is excluded from the

parenting role and this is instead taken by the grandmother with little expectation that the

parent themselves function as a parent without considerable family involvement. Such

arrangements inherently challenge UK service ideals of independence and autonomy for adults

with intellectual disabilities , as articulated in policy documents such as the 2001 White Paper,

Valuing People (Department of Health, 2001; Hepper, 1999). Cross-cultural research and theorizing from disability scholars in anthropology and ethnography frames the category of intellectual disability less as a universally recognized condition and more as a concept that has emerged in specific historical, political, ideological, and administrative contexts in the Global North that may not necessarily be recognized or understood in the same way in different cultures (Jenkins 1998; O'Hara 2003; Rao 2001; Rapley 2004). Researchers have looked at the impact of culturally negotiated understandings of intellectual disability at different stages of the life course (Bowes & Wilkinson 2003; Hatton et al. 1998; Raghavan et al. 2013), though so far has not focused on parents with intellectual disabilities, despite the growing international reach of research in this field (McConnell et al. 2017).

Study Setting

The data for this study was collected in Tower Hamlets, an inner city London borough encompassing London's docklands area that has a rich history of settlement by immigrant communities. The borough has a vibrant multi-cultural identity, nevertheless it is ranked sixth most deprived borough in the UK, and has the highest rates of child poverty in the country (Tower Hamlets JSNA Reference Group 2015). Currently, more than two thirds of the residents of the borough belong to minority ethnic groups. The largest minority ethnic group in Tower Hamlets, comprising about a third of the population, is Bangladeshi, overwhelmingly from the Sylhet region of northeast Bangladesh who speak Sylheti, a dialect of Bengali. During the colonial period, Sylhet was a relatively remote area noted for its religious and social conservatism, with urbanisation taking place as a relatively recent development. Most British

Bangladeshi families retain strong and active links with family members in Sylhet, cemented through trips, transfer of remittances and transnational marriages. The impact of the Bangladeshi community on the lived environment of Tower Hamlets is immediately apparent, with street markets, shops, restaurants and cafes and mosques and other community organisations offering goods, services and support to these residents. However, ethnic identities here, as elsewhere are never uniform or static, and this is true for people with intellectual disabilities and their families (Malik et al. 2017) as for others facing challenges of globalisation and multi-culturalism.

It is against this background that the current study set out to explore parenting and intellectual disability within the Bangladeshi community in Tower Hamlets. More specifically we sought to establish how the terms 'intellectual disabilities' and 'parenting' were established in participants' narratives, and how they intersected as culturally specific concepts from the perspective of Bangladeshi community members, extended family and parents themselves. The study also aimed to explore how these understandings impacted on the experiences of parents and the support they did or did not receive.

Method

Participants and interview procedures

Ethical approval for the study was secured from an NHS Research Ethics Committee. All participants were recruited from the Bangladeshi community in Tower Hamlets. All spoke

Sylheti as a first or second language and identified themselves as having a Muslim faith. In order to understand the viewpoints of parents with intellectual disabilities, their extended family and community, as well as to achieve triangulation of perspectives (Barker & Pistrang, 2005; Farmer et al. 2006), participants were selected from three target groups: 'community members', 'parents' and 'family members'.

Participants in the different groups were recruited through a variety of means: via the Tower Hamlets Community Learning Disability Service, through a day centre used by Asian people with intellectual disabilities, and through word of mouth. Potential participants were sent an information sheet with an Easy Read version for parents with intellectual disabilities. If they were willing to participate the researcher met with them and gained consent before interviewing them for up to two hours. The interviews with the parents lasted up to one and a half hours over one to three meetings.

The inclusion criterion for all participants was self-identification as members of the Bangladeshi community in Tower Hamlets. Community members needed to have had contact with one or more parents with intellectual disabilities and the participants who were recruited worked either in health or social care setting or in community organizations. The parents who participated in the study had at least one child who was living with them, accessed services for people with intellectual disabilities, and were judged able to give informed consent. All parents were living in social housing, none were in paid employment and all were in receipt of at least one form of benefit. Community members and parents were interviewed in English using a

topic guide, though two parents chose to be interviewed with a bi-lingual support worker

present who was able to support the conversation by translating specific words or phrases into

Sylheti (P2, P4). As these parents were not comfortable with being audio-recorded, extensive

field notes were taken. One parent chose to be interviewed with her husband who also

contributed to the discussion (P3). As this parent's husband did not speak English, an

interpreter was present.

Each of the four parents was asked to identify a family member whom they felt knew them

well. Parents were assured that what they had discussed with the researcher would remain

confidential from the family member. Two family members (F2, F3) did not speak English and

an interpreter was used for these interviews. One family member (F3) chose to be interviewed

with his wife.

Table 1 summarises characteristics of all participants. Age ranges are given in order to protect

confidentiality.

Table 1 here

Analytic procedures

Interviews were transcribed verbatim. Where an interpreter was used the interpreter listened

to audio-recordings and checked transcripts both for accuracy of transcription and accuracy of

translation, correcting where necessary. Interview transcripts and field notes were analysed

using thematic analysis procedures as described by Braun & Clarke (2006) and used by

Whittington & Burns (2005). Thematic analysis is '*a method for identifying, analyzing and reporting patterns (themes) within data'* (Braun & Clarke, 2006, pp. 79). At the first stage of

analysis transcripts were coded line-by-line and field notes incidence-by-incidence. This stage of

analysis was influence by the grounded theory literature, which describes detailed

methodology for remaining close to a data set when generating codes (Charmaz, 2006). At this

stage the interpreter, who was a service provider and member of the Bangladeshi community,

acted as a 'cultural consultant' and explained any unfamiliar concepts.

A second stage of analysis was then deployed which involved collating codes with similar

content under more abstract codes. These more abstract codes were then mapped using 'mind-

mapping'. Mind mapping, as described by Buzan (1984) and Braun and Clarke (2006) and

conducted in this study, consists of creating a visual representation of related concepts. The

process of mapping codes generated three areas around which codes clustered. These areas

were gradually refined, checked against transcripts and their titles reworded until three

overarching themes were developed. This formed the third stage of analysis. An example of a

second level code, the first level codes and data that fed into it and the overarching theme that

encompassed it is presented in Figure 1.

Figure 1 here

Credibility checks were undertaken throughout the analysis (Barker & Pistrang 2005). Firstly, the three authors in turn checked the mind map against sections of transcript and against the first and second level codes they were derived from. Secondly, an independent researcher coded one transcript and these codes were compared against those generated by the researcher. Thirdly, once the themes had been fully developed a report was sent to the cultural consultant who gave positive feedback that the findings were consistent with her understanding of the Bangladeshi community's views and dilemmas.

Throughout the analysis the first researcher, who is female, White British and has an active Christian faith, held the perspective that whilst she attempted to put her own views to one side, they would inevitably influence the focus of the research. A process of constant personal reflexivity (Chinn, 2007) was employed to attempt to understand this influence.

Results

Theme 1: Learning disability is an 'alien concept'
Although the term 'intellectual disability' is the agreed usage in research contexts in the UK and elsewhere, in service settings for adults in the UK 'learning disability' is the term most commonly used. In this section therefore we use this term in order to stay close to the vocabulary of our participants.

An issue raised by all participants was that the concept of 'learning disability', which, although contested (Rapley, 2004) , is familiar to UK professionals and services, is 'alien' to the majority of the Bangladeshi community who unlike the participants themselves, had little experience of hearing the term used in NHS and local authority service settings. Participants explained that not only was there no word for learning disability or any of its synonyms in Sylheti or Bengali, but that abilities and impairments are understood and talked about in fundamentally different ways.

All community members concluded that people within the Bangladeshi community could be educated about the concept of 'learning disability' through being in the UK and its education system:

"I think it [understanding learning disability] depends kind of on how educated people are" (CM2).

However, there was a shared belief that the term 'learning disability' could not be easily explained:

"If it's broken down I personally doubt whether they [members of the Bangladeshi community] still get it, cos it's an alien concept" (CM1).

These statements suggest that it is not so much education about the term itself but rather acculturation to this concept of 'learning disabilities, and the values underpinning it, that enable members of the Bangladeshi community to understand and use the term with confidence.

Moreover, the categorising and labelling people according to their level of intellectual achievement (Jenkins, 1998) is a fundamental principle of service provision within the UK. Participants stated that the Bangladeshi community do not do this and do not categorise individuals as 'learning disabled' or 'non-learning disabled'. Instead, participants relayed how non-technical, 'everyday' language is used, based on descriptions of visible impairments and what people are not able to do:

> "It's everyday language oh 'slow, she's a bit slow' y'know, 'she's a bit dumb', y'know it's just normal language" (CM1)

Everyday language was described as serving to compare people with intellectual disabilities to those around them, rather than place them within categories of competence based on what they are not able to do. A parent was described by her husband as:

> "A little simple minded … don't have much understanding, that's all…she's much better than her Mum" (FM3).

Three community members stated that as well as using everyday language, impairment would also be understood through the Muslim faith, framed either as a punishment, or a test of faith (Heer, Rose, & Larkin, 2012):

> "It [learning disability] is not recognised in the Bangladeshi community, and they will all fall into … thinking that this is some form of punishment or thinking that it's a test in their life" (CM5).

In a community where interdependence and collective identity are highly valued, these descriptions may serve to emphasise what people have in common, rather than what is different, they do not prioritise a separate identity based on disability. Everyday language such as *"don't have much understanding" (FM3)* is a description that could be applied to everyone at some point in their lives. One family member captured this by saying:

> *"In Bangladesh if you're poor or have any disabilities it's regarded as a normal part of life" (FM4).*

The interviews with community members highlighted that there are also constraints associated with understanding impairment in this way. They all spoke about a lack of understanding and awareness of learning disability within the Bangladeshi community:

> *"Within the Asian and Bengali community … people with intellectual disabilities, it is hidden" (CM4).*

One community member also stated that:

> *"I feel a little embarrassed that this is how people look at it" (CM1).*

This embarrassment perhaps stems from an idea that using alternative understandings of abilities is in some way inferior to having a full understanding of the normative, expert-defined concept of 'learning disability'. Community Members shared an idea that if 'learning disability' is not 'understood', then a differentiated understanding of impairments and how these can best be ameliorated cannot be developed:

"If you don't know what the problem is you don't know how to fix it … if the idea is that

it's not even a problem that's the way she is, this is her, then there's no way you're going

to get any help" (CM1)

One parent gave an example of this in relation to her husband who had come from Bangladesh:

"You know how I am, if I've got learning disabilities, but he would say to me, oh she ain't

got learning difficulties, you're all lying, she looks normal to me, she looks fine to me"

(P1).

She then explained that despite her and her family's best efforts to explain the concept of

'having a learning disability' to him he did not understand and refused to give her the help she

needed.

Theme 2: Everyone joins the cycle of life

Participants highlighted how important marriage and parenthood are within the Bangladeshi

community, both culturally and religiously. These form part of the 'cycle of life'. Within this

main overarching theme two subthemes were developed to capture the important

qualifications and that participants related to 'joining the cycle of life'.

"I think it's the whole cycle of life, it's more than tradition, the way your life works out is

you grow up, you have kids and then later on the kids look after you" (FM4).

It was emphasised that in the Bangladeshi community everyone should join this 'cycle',

including people with intellectual disabilities. This was positioned as a contrast to White British

cultures where being labelled as having intellectual disabilities frequently excludes individuals

from many aspects of the 'cycle of life'.

In fact, joining this 'cycle' was stressed to be of increased importance for people with intellectual disabilities. Firstly, because by marrying and becoming parents it was felt people with intellectual disabilities could *"fulfil different potentials and have a fulfilling life" (CM2)*. The practice of families negotiating an arranged marriage was depicted as making it easier for people with intellectual disabilities to access this cycle and 'fulfil different potentials', compared to those from other communities.

> *"If my brother was from an English family, to get married would have been very difficult*
>
> *… but as he was born into a family of Bangladeshi religion we have managed to keep*
>
> *him in that cycle" (FM4).*

Secondly, by joining the 'cycle of life' future support could be secured. This was highlighted as something particularly important for people with intellectual disabilities. Community members described how parents in the Bangladeshi community viewed it as their duty to provide for their children, even beyond their own death:

> *"So they think if I get them [person with learning disability] married with some good*
>
> *people they might look after them … this is my duty" (CM3).*

"Good people" (CM3), who could provide support, were viewed as holding religious and cultural values and beliefs that would mean they continued to care for their spouse with intellectual disabilities. In particular the belief that *"if you look after someone you will go to heaven" (CM3)* was highlighted. To find a spouse who held such beliefs and associated values was a way of

guaranteeing continued care. Four community members explicitly stated that for the

Bangladeshi community this meant someone from Bangladesh:

> *"Girl from this country wouldn't look after him [person with learning disability], then I*
>
> *would go to Bangladesh … there are plenty of girls, my own relatives who would come*
>
> *forward and help" (CM3).*

All four of the parents interviewed had had arranged marriages to someone from Bangladesh

and all four family members spoke of welcoming children from the marriage:

> *"Everyone was really pleased … if was a relief because then they knew he was going to*
>
> *be looked after later in life" (FM4).*

Within this main overarching theme two subthemes were developed to capture the important
qualifications that participants placed on 'joining the cycle of life'.

Subtheme 2.1: A spouse may leave

Five community members highlighted that the UK has different values and opportunities to

Bangladesh and these present challenges to a marriage succeeding. The most problematic value

pinpointed was 'independence'. For participants, this meant placing one's own freedom of

choice above the needs of the spouse with intellectual disabilities:

> *"There is lots of options available to them, opportunities available to them. They will*
>
> *struggle with disabled family or disabled person, because there is a freedom of life to be*
>
> *maintained" (CM4).*

Two parents expressed a fear of being left by their spouses. Three family members also raised

this concern:

"They come here, and then when they get their British passport that's when they leave

you" (P1).

Parents attributed this possibility either to their spouse changing as a result of being in the UK,

or to their spouse revealing that their true motivation had been to start a new life in the UK .

Two family members spoke about how carefully they had arranged the marriage process in

order to avoid these challenges. For one of these families the marriage had still not been

successful:

"It looked like things were really good between her and her husband …[but] he wasn't

concerned at all … he was more into making his papers [applying for leave to remain]"

(FM1).

Three community members were clear that if this happened, the Bangladeshi community

would view the marriage as having created more problems than it had solved.

Subtheme 2.2: Understanding what marriage entails

Four community members spoke about their dilemmas around arranged marriage when it was

questionable whether the person with intellectual disabilities fully understood what was

involved:

"The person with the learning disability might say I don't quite understand I don't want

to get married … or they might say I do want to get married … and sometimes later on

down the line they might see it's all become quite difficult, and they might change their

minds, they might not have realised what it meant to be married or to be in this

relationship so that could throw up a lot of difficult issues." (CM2)

A person with intellectual disabilities entering a marriage without understanding of what it entailed would clearly challenge the concepts of informed consent and individual choice. These concepts form the keystones of intellectual disability services in the UK and are enshrined in the Mental Capacity Act (Department of Health 2005). Such concerns were highly relevant to one mother who did not understand the process of reproduction before she became pregnant:

"When the baby born, I didn't know what a pregnant means, bit upset" (P3).

The more severe someone's learning disability, the more they may be perceived to need the care and support of a spouse through having an arranged marriage:

One of the other massive challenges … is around arranged marriages and people with moderate to severe intellectual disabilities, and I think that what parents think it is the person with intellectual disabilities get married and they will have more support." (CM2)

This creates a dilemma and tension between the duty to care and informed consent. Such tensions are not easily resolved particularly when family's strength of belief in the duty to care may mean support through marriage is prioritised, whereas services' statutory obligations may lead them to prioritise understanding and informed consent.

Theme 3: Parenting is a shared task

Both community and family members emphasized that asserting individuality, and setting oneself apart from the norms and expectations of the family and wider social group, is not the approach the Bangladeshi community take. As one community member succinctly put it:

"It's like a societal thing, that's the idea that you're never alone, you're never alone"

(CM1).

The extended family, who are differentiated from the wider community, although not necessarily blood relations, are all likely to take on different parts of the tasks associated with daily living:

"We're like one big machine, all doing different things but helping each other out"

(FM4).

Parenting is viewed as one such task. This view means that people with intellectual disabilities are less likely to be excluded from taking a parenting role, as they are not expected to take on all the parts of the parenting task:

"It is okay if someone is not fully able to fully provide for that child. If they are around

and they can talk to the child, maybe that is enough" (CM2).

In line with this, all family members emphasised the tasks that the parents could do:

"She loves the children, that bit she can do … she plays with both the children, they enjoy

her" (FM2).

This view departs from the perspective of services, which have historically frequently judged parents with intellectual disabilities as lacking in individual capabilities that would allow them to become successful parents because of perceived personal deficits (Mayes & Llewellyn, 2009). The participants' arguments may therefore be more likely to open up opportunities for people with intellectual disabilities to take the socially valued role of being a parent, even if they can fulfil only some of the tasks associated with that role.

Subtheme 3.1: Restricting the parenting role

Three community members highlighted that there are also constraints associated with dividing the parenting role in this way. They stressed that for some parents with intellectual disabilities this meant they were only assigned certain simple tasks, such as loving the children and playing with them. If the parents wanted to take on more tasks, perhaps with the idea of becoming more independent, these community members felt that they were not given the opportunities to do so. These community members reasoned that the extended family would not anticipate a time might come when the parent with intellectual disabilities would be alone to fend for themselves. This was highlighted as potentially problematic:

> *"Promoting independence is something to aspire to cos if their cultural mind set is that everyone is going to help out, and everyone's always been helping me out, and I've never had to do anything, and suddenly this is taken away."(CM1)*

To be solely independent or to be dependent, and completely reliant on others, are two ends of a continuum of values. Three of the family members and the parents in this study were observed to negotiate this continuum. They expected the parent with a learning disability to assume the role of being a parent, even though they did not undertake all the associated tasks. Simultaneously they also encouraged them to learn new skills in order to be able to take on new tasks.

> *"From just regularly visiting [day centre name] there is a change in her. How much she'll improve, I don't think that she will be able to catch everything." (FM2)*

19

Subtheme 3.2: Sharing the parenting tasks requires shared values

Dividing the parenting task among a network of people requires others within the network to be willing to take on additional tasks, even though these may be perceived as more than their *"fair share (FM3)"*. Family members were observed to share values that facilitated them in taking on these additional tasks.

For two of the families it was clear that the highest value was that of genuine care and commitment between spouses. A second value, highlighted by three community members and three family members, was a religious one of being answerable in the hereafter:

> *"If I cause her any pain or grief or hurt I'll answer to Allah someday when I leave this world" (FM2).*

Both husbands and three community members talked about a belief within the Bangladeshi community that you should accept the *"lot in life" (CM1)* that Allah has given you. Its *"Allah's way…all the will of Allah" (FM3)* and should not be questioned. All of the families interviewed lived in relatively impoverished material circumstances. Three talked explicitly about how their faith encouraged them to focus on their blessings rather than focus on the things they lacked:

> *"I'm really grateful to Allah for the way He has looked after me. Yes I am struggling but that's nothing, I am happy and that's more important."(FM2)*

Discussion

This study aimed to explore parenting with an intellectual disability in the Bangladeshi community in Tower Hamlets. The findings have demonstrated that conceptualisations of both parenting and intellectual disability within this community present opportunities and challenges to parents with intellectual disabilities, their families, communities and therefore to the services they access.

A key finding from the current study is that 'intellectual disability' is a concept that is often not shared by, or easily explained to, the Bangladeshi community. That intellectual disability is not a concept that is fixed cross-culturally, or even that this term may be absent from other languages, is in line with previous findings (Jenkins, 1998; Mahotra & Vaidya, 2008). However, it is something that is still often overlooked in the intellectual disability literature and in service provision (Gangadharan et al. 2011; Mir et al. 2001). In a study of people with intellectual disabilities in India, Rao (2001) highlighted that, as found in this study, 'intellectual disability' is referenced using everyday language (in her study commonly 'a little inconvenience'). Use of such everyday language places intellectual disabilities within the range of difficulties that the majority of people encounter in themselves and others on a daily basis. Unlike diagnostic systems and service structures it does not construct intellectual disabilities as a separate category with an associated set of *dis*-abilities (Jenkins, 1998).

This study also found that within the Bangladeshi community people are expected to join a 'cycle of life', which includes marrying and having children. This allows people with intellectual disabilities to access socially valued roles (Edmonds, 2000) and is in contrast to findings of studies conducted with some White European family members and service staff, where the majority of participants express reservations about young people with intellectual disabilities getting married or having children (Aunos & Feldman 2002; Strnadová, et al. 2016). It is hypothesised that basing descriptions of 'intellectual disability' on everyday language, without a priori assumptions about what *dis*-ability precludes, make marriage and parenting more accessible to people with intellectual disabilities.

This study highlighted that marrying and becoming a parent was also a way to secure long term care for the future for the person with intellectual disabilities, with both spouses and the couple's children being expected to take on caring roles. It is worth noting that in the local authority where this research took place, people of Bangladeshi backgrounds are recorded as accessing specialist intellectual disabilities in line with their numbers in the local community (Tower Hamlets JSNA Reference Group 2015), though less is less take-up of extra-familial supported accommodation. A commonly cited hypothesis for underuse of services is that minority ethnic families perceive services as unable to provide culturally appropriate supports (Gangadharan et al., 2011; Mir et al. 2001). It was not clear this was a factor among participants in this study, perhaps because until recently Tower Hamlets had a unique 'Bangladeshi Parent Adviser' service that supported families and children from the initial diagnosis of intellectual disabilities into adulthood (Davis & Choudhury 1988). However, the

current findings suggest that a reluctance to turn to formal services for long term care needs

arises from complex interweaving motivations, one of which is a belief in a duty to care (Croot,

Grant, Mathers, & Cooper, 2012). This should not be confused with the idea that families

always have more resources available to them in order to provide care. Material circumstances,

geographical dispersion due to a lack of social or affordable housing being available in the same

area as family, and migration, mean that many families from minority ethnic communities,

including some in this study, have relatively few relatives available to support them beyond the

immediate family (Hubert 2006).

This study's third major finding is that within the Bangladeshi community parenting is perceived

as a constellation of tasks that could be shared, not as one role which people either have or

have not got the capacity to undertake. For the parents studied this meant they were able to

contribute to child-rearing even if they were not able to undertake all the tasks parenting

involves. Such a perspective is not unique to the Bangladeshi community. Booth and Booth

(1994) proposed an idea of 'distributed competence' whereby parenting and the competencies

required to parent are shared throughout a network rather than inherent to one individual, and

studies highlight the important contribution of grandparents (Wołowicz-Ruszkowska &

McConnell 2017) and other sources of informal support in the lives of parents with intellectual

disabilities (Collings et al. 2017; Llewellyn & Gustavsson 2010). The notion of 'parenting with

support', which it has been suggested should be applied to parents with intellectual disabilities,

draws on similar ideas (Tarleton & Ward, 2006). These ways of parenting require a support

network populated with people who share these ideas about parenting and the values on which

they are based. The findings suggest that it is perhaps here that the Bangladeshi community differs from local White British groups, as ideas of interdependence, extended family support and a religious duty to care, which should be prioritised above individual development, were talked about as fundamental shared beliefs.

This study identified several challenges faced by Bangladeshi parents with intellectual disabilities and their families. These seemed to particularly relate to negotiating between their own and service priorities . The first and most pervasive challenge was around independence. Independence, autonomy and individuality are central Western cultural values, and this influence permeates all levels of intellectual disabilities service provision since the publication of the Valuing People White Paper (Department of Health 2001). Such values do not necessarily cohere with ideas such as collectivity, 'distributed competence', or 'parenting with support', which rely upon an interdependent network (Klotz, 2003; Mehrotra & Vaidya, 2008). This tension can be productive and our study contributes empirically to the growing field of Critical Disability Studies (Shildrick, 2012) in that our exploration of the life experiences of Bangladeshi people with intellectual disabilities and their supporters '*offer[s] us exciting new ways of thinking about our humanness in relation to interdependence, mutuality and interconnection'* (Goodley & Runswick-Cole, 2016) rather than relying on taken-for granted assumptions that independent achievement, self-reliance and personal autonomy represent the ideals of human existence. However, there is perhaps a danger that if services prioritise independence and self-determination without fully understanding alternative perspectives, families where a parent has a intellectual disability could disengage from services (Saleeby,

2014).

These conflicting perspectives and achieving a balance between protection, family needs, and individual self-determination and autonomy can present dilemmas for people with intellectual disabilities from South Asian communities and their families (Malik et al. 2017). A finding of this study is that parents with intellectual disabilities can miss out on opportunities to develop new skills, or undertake more of the tasks of parenting, as others in their family may already undertake these. O'Hara and Martin (2003) felt that, taken to the extreme, in the Bangladeshi community this means the person with intellectual disabilities are supplanted by members of the extended family in all the tasks of parenting. Whilst this was not found in the four families included in this study, there is clearly a fine line to be drawn between 'distributed competence' (Booth & Booth, 1994), where the competence to parent is held within a network with the parent with intellectual disabilities at the centre, and a situation where the parent with intellectual disabilities is excluded from the parenting role.

Moreover, participants were concerned that the practice of excluding the parent with intellectual disabilities from the challenges of learning new skills would render them vulnerable if the network were to disappear whether through death or the break-up of relationships. Participants were realistic about the latter possibility. Indeed, although marital breakdown is less common in Asian Muslim communities compared to the rest of the population (Qureshi, et al. 2014), rates appear to be rising, and participants mentioned wider geo-political and economic factors and patterns of migration as contributing to this.

A second challenge highlighted by this research concerns informed consent. The Mental

Capacity Act (Department of Health 2005) requires that a person making a decision is able to

comprehend and retain relevant information, use and weigh this information in the decision

making process and communicate their decision. Marriage, sexual intimacy and parenting a

child are complex decisions as they can have many unforeseeable consequences. This study

found that marriage and parenthood, 'joining the cycle of life' and highlighting family, rather

than individual autonomy could be prioritised to the extent that families may overlook whether

or not a person with intellectual disability understood and consented to what they were

entering into. Some community members interviewed expressed awareness of these issues,

suggesting that concerns about informed consent among people with intellectual disabilities

regarding marriage, pregnancy and child rearing are not confined to service professionals.

On way to address this tension for us as researchers might be to suggest that we need to make

a judgement about the value of 'universal human rights' as set against local cultural practices. A

reviewer of an earlier draft of this paper suggested that failing to do so exposed us to a charge

of anything goes 'cultural relativism'. However we do not feel it is helpful to engage in this way.

We acknowledge that statements of human rights, for instance enshrined through the United

Nations Convention on the Rights of Disabled People (UN 2006) have a global reach and where

they have been adopted in local laws, they also have a legislative power. The cultural practices

we describe here are locally negotiated, though incidentally as we mention above, our data

suggests that they are negotiated in dialogue with other discourses from national and supra-

national contexts. Our aim in this project was not to judge, but to describe, using the accounts

of local experts, the context in which parenting happens for Bangladeshi mothers and fathers

with intellectual disabilities and to explore how these practices and discourses open up or close

down opportunities for particular experiences for these parents, their families and their

children.

Limitations

Whilst a small scale qualitative study such as this does not aim to create findings that can be

generalised on a wide scale, discussing the clinical implications of this study necessitates

implying generalisation of sorts. Whilst the Bangladeshi community in Tower Hamlets provided

an opportunity to conduct research amongst a group of people within a small geographical area

who share cultural values and beliefs, it is likely that such beliefs are not unique to this

community, even if they are not shared by every member of the group that is the focus of this

study.

However, even within our very specific target group some perspectives have been given less

scope. We were only able to include one father with intellectual disabilities among our

participants. Unfortunately fathers are generally underrepresented in research on parents with

intellectual disabilities (Mayes & Sigurjonsdottir, 2010) and further research is needed to

explore how discourses and experiences of masculine identity intersect with cultural

understandings of disability for fathers with intellectual disabilities.

The positioning of the researcher must also be considered. All three authors are White European in ethnic background, and 'outsiders' to the Bangladeshi community. Whilst attempts were made to explore the effects of this on the interviews with participants, it may be that they felt they had to either justify or obscure cultural practices that they judged might reflect less favourably on their community, in a way they might not have done to someone from a similar cultural background. This was noticeable particularly when talking about arranged marriage when participants took care to emphasise there was no element of coercion involved. However the researchers' positions as 'outsiders' may also have brought benefits in questioning concepts that would otherwise have been taken for granted. We found the input of a 'cultural consultant' invaluable in exploring our responses to participants' accounts from our 'outsider' position and checking the validity of our insights.

Clinical Implications

The findings of this study have important implications for services working with parents with intellectual disabilities from minority ethnic groups. Firstly, this research has suggested that services and parents with intellectual disabilities and their families may not have a shared understanding of the concept of 'intellectual disability' and it may even be 'alien' to them. Services need to spend more time negotiating a shared understanding of this concept and what this means for parenting. Services should also be mindful that the values that inform policies and often practice, such as independence and self-determination, might well be questioned by minority ethnic groups (Saleeby, 2014) . Accommodating different culturally specific understandings relating to social roles and patterns of care is a crucial part of developing

cultural competency for practitioners, as well as understanding that the concepts taken for granted by majority ethnic groups are themselves culturally and historically contingent (Skinner & Weisner, 2007).

Secondly, this study has begun to unpick O'Hara and Martin's (2003) finding that Bangladeshi parents with intellectual disabilities are far more likely to retain custody of their children than White British parents in Tower Hamlets. We suggest this is because of the way the parenting task is distributed across a network, which consists of the parent with intellectual disabilities and family members who do not have intellectual disabilities but who share values that maintain this network. An important question for services is how this model, which has been recommended elsewhere (Tarleton & Ward 2006, Booth & Booth 1994) can be implemented with parents with intellectual disabilities (from whatever ethnic group) who do not have such networks already in place and how services might to some extent 'fill the gap' (Collings et al. 2017a; Collings, et al. 2017b). Successful implementation of this would have vast benefits in terms of both human and service costs (Baum & Burns 2006).

Future research

This study has addressed a significant gap in the literature on parenting with a learning disability. However, it is only a beginning in understanding the complex interactions of culture, learning disability and parenting and how these impact on the lives of parents with intellectual disabilities. Future research needs to expand the scope of this research to include other black and minority ethnic (BAME) groups across the UK. Understanding also needs to be developed

around people with intellectual disabilities from the Bangladeshi and other BAME communities who do not marry or have children, how they are involved in decision-making around these life choices (Jamieson et al. 2015; Phillips et al. 2016) and whether not taking these roles mean that they face increased stigma or exclusion from these communities.

References

Aunos, M. & Feldman M. A. (2002). Attitudes towards sexuality, sterilization and parenting

    rights of persons with intellectual disabilities. *Journal of Applied Research in Intellectual*

    Disabilities, *15*(4), 285–296.

Barker C. & Pistrang N. (2005). Quality criteria under methodological pluralism: Implications for

    conducting and evaluation research. *American Journal of Community Psychology, 35*,

    201-212.

Booth, T. & Booth W. (1994). *Parenting under Pressure: Mothers and Fathers with Learning*

    Difficulties. Maidenhead: Open University Press.

Booth T., McConnell D., & Booth W. (2006). Temporal discrimination and parents with learning

    difficulties in the child protection system. *British Journal of Social Work*, *36*(6), 997.

Bowes A., & Wilkinson, H. (2003). 'We didn't know it would get that bad': South Asian

    experiences of dementia and the service response. *Health & Social Care in the*

    Community, *11*(5), 387–396.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in*

    Psychology, 3, 77-101.

Buzan, T. (1984). *Make the Most of your Mind*. New York: Fireside.

Chinn D. (2007). Reflection and reflexivity. *Clinical Psychology Forum, 178*, 15-17.

Charmaz K. (2006). *Constructing Grounded Theory: A Practical Guide Through Qualitative*

    Analysis. New York: Sage Publications.

Collings, S., Grace, R., & Llewellyn, G. (2017a). The role of formal support in the lives of children

of mothers with intellectual disability. *Journal of Applied Research in Intellectual*

Disabilities, *30*(3), 492–500.

Collings, S., Llewellyn, G., & Grace, R. (2017b). Home and the social worlds beyond: exploring

influences in the lives of children of mothers with intellectual disability. *Child: Care,*

Health and Development. Online in advance of print.

Croot, E., Grant, G., Mathers, N., & Cooper, C. (2012). Coping strategies used by Pakistani

parents living in the United Kingdom and caring for a severely disabled child. *Disability*

and Rehabilitation, *34*(18), 1540–1549.

Davis, H., & Choudhury, P. A. (1988). Helping Bangladeshi families: Tower Hamlets Parent

Adviser Scheme. *Journal of the British Institute of Mental Handicap, 16*(2), 48-51.

Department of Health (2001). *Valuing People*. London: HMSO.

Department of Health (2005). *Mental Capacity Act.* London: HMSO.

Edmonds, J. (2000). On being a mother: a positive identity in the face of adversity. *Clinical*

Psychology Forum, 137, 21-25.

Emerson, E., & Hatton, C. (2011). Estimating future need for social care among adults with

learning disabilities in England: An update. *Improving Health & Lives Learning Disabilities*

Observatory, Lancaster University: Lancaster. Retrieved 5th October 2016 from

http://www.improvinghealthandlives.org.uk/uploads/doc/vid_10673_IHaL2011-

05FutureNeed.pdf

Farmer, T., Robinson, K., Elliott, S.J., & Eyles, J. (2006). Developing and implementing a triangulation protocol for qualitative health research. *Qualitative Health Research, 16(3)*, 377-394.

Gangadharan, S. K., Bhaumik, S., Devapriam, J., Hiremath, A., Johnson, M., O'Hara, J., et al. (2011). Minority ethics communities and specialist learning disability services: Report of the Faculty of the Psychiatry of Learning Disability Working Group. *Faculty of the Psychiatry of Learning Disability of the Royal College of Psychiatrists*. Retrieved 3rd December 2016 from http://nrl.northumbria.ac.uk/5944/1/FR_LD_2%20for%20web.pdf

Goodley, D., & Runswick-Cole, K. (2016). Becoming dishuman: thinking about the human through dis/ability. *Discourse: Studies in the Cultural Politics of Education*, *37*(1), 1–15. https://doi.org/10.1080/01596306.2014.930021

Hatton, C., Azmi, S., Caine, A., & Emerson, E. (1998). Informal carers of adolescents and adults with learning difficulties from the South Asian communities: family circumstances, service support and carer stress. *British Journal of Social Work*, *28*(6), 821–837.

Heer, K., Rose, J., & Larkin, M. (2016). The challenges of providing culturally competent care within a disability focused team: a phenomenological exploration of staff experiences. *Journal of Transcultural Nursing*, *27*(2), 109–116.

Hepper, F. (1999). 'A woman's heaven is at her husband's feet'? The dilemmas for a community learning disability team posed by the arranged marriage of a Bangladeshi client with intellectual disability. *Journal of Intellectual Disability Research*, *43*(6), 558–561.

Hubert, J. (2006). Family carers' views of services for people with learning disabilities from Black

and minority ethnic groups: a qualitative study of 30 families in a south London

borough. *Disability & Society*, *21*(3), 259–272.

Jamieson, R., Theodore, K., & Raczka, R. (2015). Becoming a mother Supported decision-making

in context. *Journal of Intellectual Disabilities*, *20*(4), 313-328.

Jenkins, R. (1998). *Questions of Competence: Culture, Classification and Intellectual Disability*.

Cambridge: Cambridge University Press.

King's Fund (2006). *Access to Health Care and Minority Ethnic Groups*. London: Kings Fund.

Klotz, J. (2003). The culture concept: anthropology, disability studies and intellectual disability.

In *Disability Studies and Research Institute (DSaRI) Symposium* (Vol. 12).

Llewellyn, G., & Gustavsson, M. (2010). Understanding community in the lives of parents with

intellectual disabilities. In G. Llewellyn, R. Traustadottir, D. McConnell, & H.

Sigurjonsdottir (Eds.) *Parents with Intellectual disabilities: Past, Present and Futures,* 79-

94, Chicester: John Wiley & Sons.

Malik, K. J., Unwin, G., Larkin, M., Kroese, B. S., & Rose, J. (2017). 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. *Research in

Developmental Disabilities*, *63*, 74–84.

Mayes, R., & Llewellyn G. (2009). What happens to parents with intellectual disabilities

following removal of their children in child protection proceedings? *Journal of

Intellectual and Developmental Disabilities, 34*, 92-95.

Mayes, R., & Sigurjonsdottir, H. B. (2010). Becoming a mother—becoming a father. In

G.Lllewellyn, R. Traustadottir, D. McConnell & H. Sigurjonsdottir (Eds) *Parents with*

Intellectual Disabilities. Past, Present and Futures. Chichester, UK: Wiley-Blackwell, 17–

32.

McConnell, D., Feldman, M., & Aunos, M. (2017). Parents and parenting with intellectual

disabilities: An expanding field of research. *Journal of Applied Research in Intellectual*

Disabilities, *30*(3), 419–422.

McGaw, S., Scully, T., & Pritchard, C. (2010). Predicting the unpredictable? Identifying high-risk
versus low-risk parents with intellectual disabilities. *Child Abuse & Neglect*, *34*(9), 699–
710.

Mehrotra, N. & Vaidya, S. (2008) Exploring Constructs of Intellectual Disability and Personhood

in Haryana and Delhi. *Indian Journal of Gender Studies* , 15(2): 317- 340.

Mir, G., Nocoon, A., Ahmed, W., & Jones, L. (2001). *Learning Difficulties and Ethnicity: Report to*

the Department of Health. London: Department of Health.

Office for National Statistics (2016). 2011 Census aggregate data. UK Data Service (Edition: June

2016). DOI: http://dx.doi.org/10.5257/census/aggregate-2011-1

O'Hara, J. (2003). Learning disabilities and ethnicity: Achieving cultural competence. *Advances*

in Psychiatric Treatment, *9*(3), 166–174.

O'Hara, J., & Martin, H. (2003). Parents with learning disabilities: A study of gender and cultural

perspectives in East London. *British Journal of Learning Disabilities, 31*, 18-24.

Phillips, L., Goodwin, J., Johnson, M. P., & Campbell, L. E. (2016). Could I, should I? Parenting

aspirations and personal considerations of five young women with 22q11. 2 deletion

syndrome. *Journal of Intellectual & Developmental Disability*, 1–11.

Qureshi, K., Charsley, K., & Shaw, A. (2014). Marital instability among British Pakistanis:

transnationality, conjugalities and Islam. *Ethnic and Racial Studies*, *37*(2), 261–279.

Raghavan, R., Pawson N., & Small, N. (2013). Family carers' perspectives on post-school

transition of young people with intellectual disabilities with special reference to

ethnicity. *Journal of Intellectual Disability Research*, *57*(10), 936–946.

Rao, S. (2001). "A Little Inconvenience": Perspectives of Bengali families of children with

disabilities on labelling and inclusion. *Disability & Society*, *16*(4), 531.

Rao, S. (2006). Parameters of normality and cultural constructions of 'mental retardation':

Perspectives of Bengali families. *Disability and Society, 21(2)*, 159-178

Rapley, M. (2004). *The Social Construction of Intellectual Disability*. Cambridge: Cambridge

University Press.

Rauf, B., Saleem, N., Clawson, R., Sanghera, M., & Marston, G. (2013). Forced marriage:

implications for mental health and intellectual disability services. *Advances in Psychiatric

Treatment*, *19*(2), 135–143.

Saleeby, P. W. (2014). The Need for Culturally Appropriate Strategies in Promoting Self-

Determination Among Individuals with Disabilities. *Review of Disability Studies: An

International Journal*, *8*(1).

Shildrick, M. (2012). *Critical Disability Studies*. London: Routledge.

Skinner, D., & Weisner, T. S. (2007). Sociocultural studies of families of children with intellectual

disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, *13*(4),

302–312.

Strnadová, I., Bernoldová, J., Adamčíková, Z., & Klusáček, J. (2016). Good enough support?

Exploring the attitudes, knowledge and experiences of practitioners in social services

and child welfare working with mothers with intellectual disability. *Journal of Applied*

Research in Intellectual Disabilities, *30*(3), 563-572.

Tarleton, B., & Ward, L. (2007). "Parenting with support": The views and experiences of parents

with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 4*,

194-202.

Tower Hamlets JSNA Reference Group (2015) Joint strategic needs assessment summary

document: Life and health in Tower Hamlets.   Retrieved 12.12.2016 from

http://www.towerhamlets.gov.uk/Documents/Public-Health/JSNA-Summary-2015.pdf

Whittington, A., & Burns, J. (2005). The dilemmas of residential care staff working with the

challenging behaviour of people with learning disabilities. *British Journal of Clinical*

Psychology, 44, 59 - 76.

Wołowicz-Ruszkowska, A., & McConnell, D. (2017). The experience of adult children of mothers

with intellectual disability: A qualitative retrospective study from Poland. *Journal of*

Applied Research in Intellectual Disabilities, *30*(3), 482–491.