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## **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 ethnic minority communities. Previous research suggests that experiences of living with intellectual disabilities vary across cultural contexts. The current research aimed to explore how cultural values and patterns impact upon the lives 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 Great Britain 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 1991 and 2011. 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 (King's Fund 2006). Yet research that attempts to understand the beliefs and attitudes of people from different cultures within Great Britain regarding intellectual disability still contains significant gaps (Gangadharan et al. 2011).

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 ethnic minority 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 has formed an ethnic majority 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 an ethnic minority culture. O'Hara and Martin (2003) conducted a five year retrospective study of parents accessing Tower Hamlets Community Learning Disability Team. Their findings were startling. Eighty five percent of children born to Bangladeshi mothers with intellectual disabilities remained living with their birth families in comparison to 29% of children born to White British mothers. This is despite the fact that the Bangladeshi mothers presented with more severe levels of disability. Whilst this was a small scale service based study, with the limitations that inherently accompany such research, its finding that the children of Bangladeshi parents with intellectual disabilities were almost three times as likely as children of White British parents to remain living with their birth families demands exploration.

Such exploration is not only important to develop the cultural competency of services for parents with intellectual disabilities, but also for developing understanding of risk or resilience factors in such families, particularly factors that might increase the likelihood that parents with intellectual disabilities continue to parent. (McGaw et al. 2010). Currently parents with intellectual disabilities across the general UK population face 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 ethnic minority community in the UK compared to White British families may 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. Such arrangements inherently challenge UK service concepts of independence and, when someone has a more severe intellectual disability, informed consent (Heer et al. 2016; Hepper 1999). However, It has been noted, that intellectual disability is a concept that has emerged in specific historical, political, ideological, and administrative contexts in the Economic North and is not necessarily 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 ethnic minority 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. Specifically to begin to establish what the community, extended family and parents themselves thought about being a parent with an intellectual disability. It also aimed to explore how these groups negotiated the term intellectual disability and the impact that this had on 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 participants 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 then through word of mouth. Potential participants were sent an information sheet that was produced in 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 inclusion criterion for all participants was that they identified themselves as members of the Bangladeshi community in Tower Hamlets. Community members needed to have had contact with one or more parents with intellectual disabilities. 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, 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 (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 who 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: Characteristics of Participants**

Community Member	Role	Gender	Age Range
CM1	Bi-lingual health/social care employee	Female	31 - 40
CM2	Bi-lingual health/social employee	Female	21 - 30
CM3	Local Authority care manager	Male	31 - 40
CM4	Bi-lingual health/social care employee	Female	41 - 50
CM5	Community worker	Male	31 - 40
CM6	Bi-lingual health/social care employee	Female	41 - 50
Parents	Role	Living Circumstances	Age Range
P1	Mother	With two children (separated from husband)	21 – 30
P2	Mother	With spouse and two children	31 – 40
P3	Mother	With spouse, one child, parents, siblings and their families	31 – 40
P4	Father	With spouse, three children, parents and one sibling	41 – 50
Family Member	Role		Age range
FM1	Sister of P1		21 – 30
FM2	Husband of P2		31 – 40
FM3	Husband of P3		31 – 40
FM4	Brother of P4		21 – 30

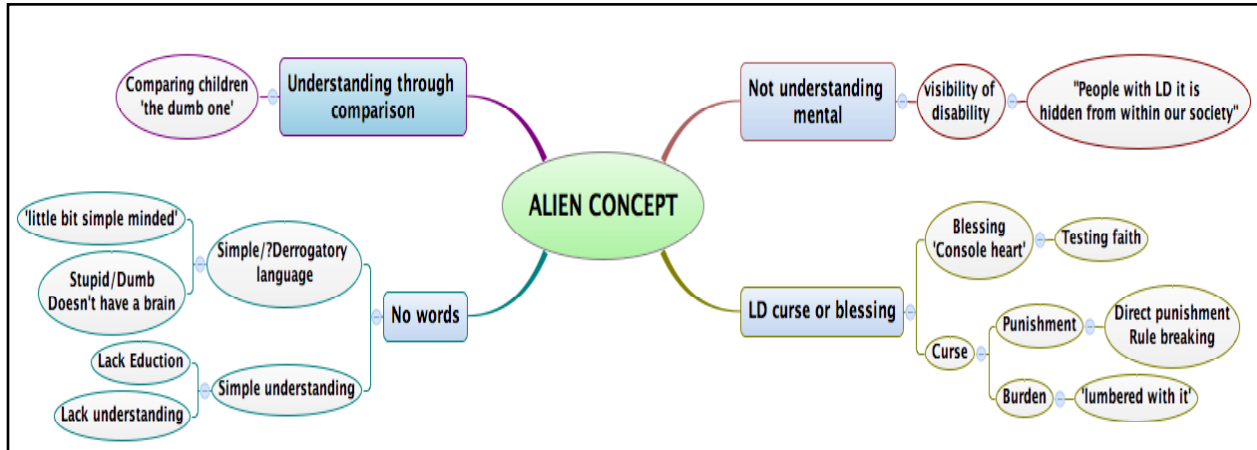
### *Analytic procedures*

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 influenced 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: First and second level codes



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 often highly contested, is familiar to UK professionals and services, is ‘alien’ to the Bangladeshi community. It is not just the fact that there is 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).*

Rather than education about the term itself, it is perhaps acculturation to this concept, and the values underpinning it, that enable members of the Bangladeshi community to understand and use the term learning disability.

A concept inherent to services in the UK is that of categorising and labelling people according to their level of intellectual achievement (Jenkins, 1998). 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 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 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. Not getting any help may not only stem from family not understanding the difficulties that are faced, but also from an incompatibility with professional services, where a ‘diagnosis’ of ‘learning disability’ is often needed before resources can be accessed.

### *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 ... it 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 gain a British passport. 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 you are entering into*

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 learning 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. This dilemma has been thrown in to even sharper focus since the criminalisation of forced marriage in 2014 since the definition of

forced marriage extends beyond using duress to involving someone in a marriage when they do not have the capacity to consent.

*Theme 3: Parenting is a shared task*

Both community and family members emphasized that to be an individual, left alone with the task of parenting, 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 is radically different from the perspective of services, which have historically frequently judged parents with intellectual disabilities as capable or not capable of being parents (Mayes & Llewellyn, 2009). It has the potential to empower 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 develop the skills required, mainly because these tasks were allotted to other people within the extended family network. 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 a parent who is completely independent and not reliant on others would involve developing the skills that are needed to take on any of the tasks of parenting. 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)*

### *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 learning 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 learning disability is not a concept that is fixed cross-culturally, or even that there is a word for in other languages, is in line with previous findings. However, it is something that is still often overlooked in the learning 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 stark contrast to findings of studies conducted with 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 'learning 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 presence 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 ethnic minority 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 point of the initial diagnosis of intellectual disabilities and 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. This should not be confused with the idea that families 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 ethnic minority families, including some in this study, have relatively few relatives available to support them (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, 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 service provision, being the core values that have permeated UK intellectual disabilities since the publication of the Valuing People White Paper (Department of Health 2001). Such values sit uncomfortably alongside ideas such as 'distributed competence', 'parenting with support', or 'parenting is a shared task', which rely upon an interdependent network. There is perhaps a danger that if services prioritise independence without fully understanding alternative perspectives, families where a parent has a learning disability could disengage from services.

These conflicting perspectives and achieving a balance between protection, family needs, and individual self-determination and autonomy presents 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 does not parent at all as others within the extended family take on 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 by others taking over.

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 could be prioritised to the extent that families may overlook whether or not a person with learning 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 and pregnancy are not confined to service professionals. As mentioned above this research was undertaken before the legislation that made entering a person unable to give informed consent into an arranged marriage a criminal offence in England and Wales. It is too early to assess the impact of this legislation on the lives of Bangladeshi families and their relationships with support services, though some service staff have expressed worries that such legislation might undermine trust and openness between service structures and Bangladeshi families with sons and daughters with intellectual disabilities of marriageable age (Rauf et al. 2013).

### *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. It is therefore important to note that this study focused on people with intellectual disabilities within the Bangladeshi community who have become parents and retained custody of their children and participants were purposively sampled to

address the research questions. 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.

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.

Credibility checks were undertaken throughout the research; however it is recognised that participant validation was not sought (Barker & Pistrang, 2005). This is due primarily to not being able to translate the findings into accessible language for the varying needs of the participants involved within the timescale of the project. A 'cultural consultant', who was a service provider and member of the Bangladeshi community, was used in an attempt to offset this limitation.

### *Clinical Implications*

The findings of this study have important implications for services working with parents with intellectual disabilities who are from Bangladeshi or other 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, might well be questioned by minority ethnic groups.

Secondly, this study has begun to explore 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 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 intellectual disabilities. However, it is only a beginning in understanding the complex interactions of culture, intellectual disabilities 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 (BME) groups across the UK. Understanding also needs to be developed around people with intellectual disabilities from the Bangladeshi and other BME 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. Finally, the current research has begun to unpick O'Hara and Martin's (2003) finding that people with intellectual disabilities within the Bangladeshi community are more likely to retain custody of their children. It has reached the tentative conclusion that not prioritising an identity based on intellectual incapacity and dis-ability, as well as conceptualising parenting as a shared task and therefore distributing competence across a network, creates more opportunities for people with intellectual disabilities to take, and be supported in, a parenting role. Future research needs to extend the scope of this study and perhaps investigate how such values are maintained longitudinally and how they cohere with service philosophies, values and practices.

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