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Risk of forced marriage amongst people with learning disabilities in the UK: Perspectives of South Asian carers

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Abstract

Background: People with intellectual disabilities are at increased risk of forced marriage compared to those without intellectual disabilities. In the UK, this risk is particularly, though not exclusively, associated with South Asian communities and is linked to the desire to secure long-term care.

Method: Focus groups and semi-structured interviews were undertaken with South Asian parents and family carers ($n = 22$) of adults with intellectual disability and the resultant data thematically analysed.

Results: Although securing care for their intellectually disabled relative was identified as a key motivator for forced marriage, other important themes also emerged. These included cultural and religious beliefs about disability and marriage, and limited understanding of relevant laws. Factors militating against forced marriage were also identified, including fears of abuse and neglect.

Conclusions: Implications for the provision of services and the need for improved access to information on forced marriage of people with intellectual disabilities are highlighted.

KEYWORDS

capacity and consent to marry, ethnicity, forced marriage, intellectual disability, South Asian carers

1 | INTRODUCTION

This paper explores South Asian carers' perspectives on forced marriage of people with intellectual disabilities, by which we mean their outlook, position or stance towards the phenomenon. The findings presented are from the My Marriage, My Choice¹ project which explored forced marriage of adults with intellectual disabilities in the UK. Its aim was to develop knowledge, policy and practice to support professionals and family carers in keeping vulnerable adults

safe. Key objectives of the project were to better understand the risk factors which may contribute to forced marriage amongst people with intellectual disabilities and to raise awareness amongst those involved in the education, care and support of people with intellectual disabilities, so that they can recognize risk of forced marriage at an early stage and prevent such marriages from occurring.

It is important to emphasize that forced marriage is different from arranged marriage. In an arranged marriage, parents or other family members help to identify a potential husband or wife, but the

¹www.mymarriagemychoice.co.uk

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individuals involved choose whether or not they wish to marry. By contrast, forced marriage is where “one or both people do not (or in cases of people with learning disabilities² or reduced capacity, cannot consent to the marriage” (Foreign & Commonwealth Office and Home Office, 2018a). People with intellectual disability who have the capacity to consent to marry have the right to marry, and in some cases, they and their families may choose an arranged marriage. However, the focus of this paper is on those people with intellectual disability who, owing to the severity of their cognitive impairment, lack the capacity to consent to marry and therefore, in the UK, cannot lawfully marry. Parents or others who facilitate or arrange a marriage for a person who lacks capacity to consent to marry are guilty in UK law of the offence of forcing that person to marry; this is a crime punishable by up to 7 years imprisonment (<https://www.gov.uk/stop-forced-marriage>).

Globally, forced marriage occurring within non-disabled populations is largely understood in the context of oppression and violence against women and girls (Chantler, Gangoli, & Hester, 2009). This is because, in the developing world, forced marriage is strongly associated with child marriage (UNICEF, 2018) and, worldwide, the majority of victims of forced marriage are female (UNICEF, 2018) with particularly high rates of forced marriage evident in conflict zones (UN, 2017). Within the global literature on forced marriage, the intersection of gender and ethnicity is highlighted, but disability is largely overlooked (Clawson, & Fyson, 2017; Erturk et al., 2012). However, forced marriage is not a phenomenon which is limited to developing countries. Although UNICEF reports that the number of forced and child marriages in South Asia³ is falling (UNICEF, 2018), forced marriages of people with intellectual disabilities from this ethnic group continue to be reported within the UK (Foreign & Commonwealth Office and Home Office, 2018).

A small number of UK researchers papers have explored the epidemiology, causes and consequences of forced marriage for people with intellectual disabilities (Clawson, Patterson, Fyson, & McCarthy, 2020; Groce, Gazizova, & Hassiotis, 2013) and suggested that the majority, though by no means all, forced marriages of people with intellectual disabilities in the UK involve people from South Asian communities. The number of people of South Asian heritage in the UK has risen in the past decade (Office for National Statistics, 2019), with a concomitant increase in the number of South Asian people with intellectual disabilities. Reported cases of forced marriage have also increased over the past decade (Foreign & Commonwealth Office and Home Office, 2018), though this may be due to increased awareness of reporting procedures rather than an actual increase in forced marriage.

As part of its efforts to eliminate forced marriage, the UK Government has collected statistics since 2009 on cases of forced

marriage known to involve at least one spouse with a disability (Clawson, Patterson, Fyson, & McCarthy, 2020). These Forced Marriage Unit (FMU) statistics show there has been a year on year rise in the number of people with intellectual disabilities reported who are at risk of, or the subject of, forced marriage (Patterson, Clawson, McCarthy, Fyson, & Kitson, 2018; Clawson et al., 2020). Moreover, when disability is examined within the UK forced marriage statistics, it is evident that unlike non-disabled victims, men and women with intellectual disabilities are equally likely to be victims of forced marriage (Foreign & Commonwealth Office and Home Office, 2018; Patterson, Clawson, McCarthy, Fyson, & Kitson, 2018; Clawson et al., 2020); and that people with intellectual disability face a five times increased risk of forced marriage compared to those who are non-disabled (Clawson, Patterson, Fyson, & McCarthy, 2020).

The consequences of forced marriage can be severe, for both the person forced to marry and their family. Anyone forced to marry is known to be at risk of harm, including domestic violence, marital rape and abandonment (Chantler, 2009; Rauf, Saleem, Clawson, Sanghera, & Marston, 2013). In addition, the Anti-social Behaviour, Crime and Policing Act 2014 made it a criminal offence to force someone to marry; specifically, s.121(2) of the Act makes clear that any marriage of a person who lacks the capacity to consent (within the meaning of the Mental Capacity Act 2005) is a forced marriage. This means that families and carers of people with intellectual disabilities are at risk of breaking the law if they encourage someone who lacks capacity to consent to enter into marriage. Given these obvious disincentives, it is important to understand why people with intellectual disabilities are still forced to marry.

Previous research with health and social care professionals has suggested that the motivations for such marriages are often (but not always) benign. According to professionals, the main reasons that some parents “force” their adult child with intellectual disabilities to marry is that they are seeking to secure a long-term carer and/or seeking to ensure that their intellectually disabled offspring have the same life chances as non-disabled siblings (Clawson, & Fyson, 2017; Patterson et al., 2018; Rauf et al., 2013). This is in a context of unmet need for adult social care services amongst black, Asian and minority ethnic (BAME) communities (Mir, Nocon, Ahmad & Jones, 2001), and evidence that the poverty associated with BAME communities in the UK is further associated with increased identification of intellectual disabilities (Emerson, 2012). There are a range of factors which inhibit South Asian families from accessing formal health and social care services (Devapriam et al., 2008; Raghavan & Waseem, 2007) with cultural and religious attitudes being significant in how and whether care is sought out, offered or accepted (Singh & Orimalade, 2009). Nevertheless, the potential and actual harms caused to people with intellectual disabilities within forced marriages mean that whilst motivations need to be understood, they cannot provide justification (Clawson, & Fyson, 2017; Rauf et al., 2013); the human rights, feelings and safety of the person with intellectual disabilities should be of paramount concern.

²‘Learning disability’ is commonly used in the UK in preference to the term ‘intellectual disability’.

³For the purposes of this study South Asia is defined as India, Pakistan, Bangladesh and Sri Lanka.

TABLE 1 Themes and sub-themes

Themes	Intellectual disability and South Asian communities?	Cultural/religious views on disability and marriage	Knowledge of the law	Marriage, care and risk
Sub-themes	Acceptance vs. stigma The “burden” of care Lack of knowledge/ trust in services	Marriage can alleviate disability Marriage is an expectation for everyone Marriage is a union of two families, not two people Cultural beliefs are changing Spouses from abroad	Awareness of law (Mis) understanding of capacity and consent Arranged marriage vs. forced marriage	Hope of seeing son or daughter “settled” Fears regarding non-disabled spouse Fears regarding spouse with intellectual disabilities

In this context, there is a need for increased understanding and awareness of the factors which contribute to risk of forced marriage of people with intellectual disabilities in order to prevent its occurrence. This study is the first to report the perspectives of South Asian family carers, rather than the views of professionals.

2 | METHOD

This research with family carers was one part of a larger study, which involved statistical analysis of the data held by the FMU, and qualitative research with key stakeholder groups, namely adults with intellectual disabilities, family carers, faith and community leaders, health and social care professionals and marriage registrars. A summary of the findings from the wider study can be found at ([website-anonymized for review](#)) and analysis of FMU data has been published elsewhere (Clawson, Patterson, Fyson, & McCarthy, 2020). This paper will report data gathered from South Asian family carers of adults with intellectual disabilities. This workstream was intended to address the research questions: (i) how do South Asian carers conceptualize disability and how does disability affect their lives? (ii) what do South Asian carers understand about the legal constructs of “informed consent” and “forced marriage?”; and (iii) what factors do South Asian carers believe contribute to forced marriage of adults with intellectual disabilities?

In seeking to answer these questions, South Asian family carers of adults with intellectual disabilities were recruited through pre-existing South Asian carer organizations and were offered a choice of participating via either a focus group or an individual interview. The same core questions were asked in both the focus group and the semi-structured interviews; these were developed following extensive consultation as part of the wider research study. Participants were each given a £20 High Street Voucher as compensation for their time. Overall, 22 South Asian family carers were recruited; 16 participated in two separate focus groups and six were interviewed individually. Participants were 20 women and 2 men, all directly involved in the care of a family member with an intellectual disability. Female participants were mainly mothers, although one was a sister and another an aunt; male participants were one father and one brother. Participants were not asked to identify their religious affiliations; comments made during data collection indicated that most were Muslim, but other faiths including Sikh

and Hindu were also represented. Focus groups lasted approximately one hour; interviews were between 30 and 50 min.

It is important to stress that participants were recruited simply on the basis of their status as South Asian carers of an adult with intellectual disability. We did not seek to interview carers who had unlawfully forced a family member with intellectual disabilities to marry; to do so would have been unethical. The data reflect a nuanced discussion of the experiences, attitudes and expectations of South Asian carers in relation to factors believed to be associated with forced marriage. It does not report the experiences of South Asian carers who had forced their intellectually disabled family member to marry. However, participants were aware of cases of forced marriage of people with intellectual disabilities within their communities and talked freely about this.

All group and individual interviews were audio recorded and transcribed verbatim. The data were thematically analysed, using the process outlined in Braun and Clarke (2006). Initial coding was carried out independently by two members of the research team, and a high level of agreement was found in codes and themes. The resultant codes were clustered into sub-themes, and sub-themes were then grouped in terms of similar meanings across all participants, so that over-arching themes could be created which reflected the whole group. There was no discernible difference in the sub-themes from focus groups as compared to interviews, and all over-arching themes were present in both data sets.

2.1 | Ethics

Participants were given information about the study, and opportunities to ask questions, prior to the completion of consent forms. Ethical approval for the whole study was given by the Social Care Research Ethics Committee, reference number: 16/IEC08/0014.

3 | FINDINGS

The analysis of data from carers resulted in the identification of four over-arching themes, each composed of a number of sub-themes; these are detailed in Table 1. Each of the themes will be discussed in turn.

3.1 | Theme 1: Intellectual disability and South Asian communities

As noted in the introduction, previous studies have reported professionals to believe that some parents “force” their adult child with intellectual disabilities to marry in order to secure a long-term carer (Clawson, & Fyson, 2017; Patterson et al., 2018; Rauf et al., 2013). In this context, both community acceptance and support for individuals with intellectual disability and the availability or otherwise of public services are important areas of consideration, because they affect whether parents feel the need to consider marriage as a means of securing long-term care.

Most carers reported that they experienced a lack of acceptance for their disabled son or daughter. A typical example was that “*When my son goes out, everybody looks at him, keeps staring*” (G1). Negative responses could come from all sections of the population, including from within what participants referred to as their “community” that is, their local area and other people from similar ethnic, religious and cultural backgrounds:

When he was little, people used to comment on what's wrong, is he mad, what's wrong with him?...so I stopped to going to people's houses, because I just didn't want to answer the questions, because I didn't really know at that stage what was going on myself. And I was very isolated. I didn't think our community was understanding of it. And I didn't get any support or anything from any of our faith organisations or anything...

(4)

There were also mixed experiences of family acceptance and support. Some participants spoke of close relatives being very supportive:

Family who are close to you tend to understand.

(G2)

My parents can understand, so I have no problem, I can manage with her and my husband is very helpful with me, and my family

(G1)

While for others, it was clear that there was a lack of understanding and acceptance of intellectual disability even within their own extended families:

There's like cousins or outside family, they want to push them away, they don't care

(G2)

I've got 3 children ...two have learning disability, the middle one she is OK, goes to normal school. My

in-laws prefer her, if they are going out, they take her and I say that is not right actually, my other ones, they feel it. In my eyes, they are all the same.

(G1)

Some participants expressed the view that “back home”⁴ there is widespread lack of knowledge about intellectual disability (see also Durling, Chinn, & Scior, 2018). However, ironically, the increased awareness of intellectual disability in UK communities did not necessarily lead to more acceptance:

I would say back home in mum and dad's country in Pakistan, where we're originally from, people don't know what learning disability is, so they are included. Here people know...so it's all about acceptance. Who's going to accept my son

(7)

Whilst many of the experiences of these South Asian parents and carers are similar to those of other parents and carers of people with intellectual disabilities, who also face negative social attitudes and feel their children are stigmatized (Cantwell, Muldoon, & Gallagher, 2015), there were aspects of experience which participants believed were particular to them. Some thought that it was especially difficult for people with intellectual disabilities to be accepted because disability per se is considered a misfortune in South Asian communities and thus not something to be spoken about (see also Heer, Rose, & Larkin, 2015):

“In our community, no one wants to talk about it...it's really difficult. It's sort of frowned upon when I say my niece has learning disabilities, people say ‘oh really, I'm so sorry to hear that.’”

(7)

Others spoke of a cultural belief, which they said was widely shared in their community that disability is a punishment and/or a test from God (see also Bywaters, Ali, Fazil, Wallace, & Singh, 2003):

Maybe you have done something wrong in your life and then you are punished for it. And that's why you've got somebody who's got a disability. Or whether it's test for you...I don't know, there's lots of different ways people in our community look at it

(4)

Regardless of beliefs about disability, it was largely women who took the lead in providing care for family members with intellectual disabilities. However, the stereotype of extended South Asian families being close and sharing responsibility for elderly or disabled members was not borne out by the participants in this study (see

⁴“Back home” was the most commonly used term by the participants to refer to their or their parents' countries of origin.

also Hubert, 2006). Most participants reported that shared care and shared responsibility for a relative with intellectual disabilities were uncommon:

My brother and sister don't want to know, so I don't talk them because of this issue. Before our parents died they both said they will look after her fair and sharely. But...this is the seventh year, and they haven't took her

(6)

Most often the “burden” of care fell to one person (Katbamna, Ahmad, Bhakta, Baker, & Parker, 2004) and in the vast majority of cases, this was a woman, usually the mother or another close female relative. Of the two male carers who took part in this study, one made it clear that it was his wife who did almost all of the care; this was partly because it was not seen as permissible for intimate personal care to be provided by a male relative unless the relative was a husband.

Part of the reason that caring responsibilities fell on family members was that participants had little trust in public services. Most described how they did not make much, if any, use of respite or residential services for their adult sons or daughters, though some did use day services. Others had set up services for themselves, though these were mostly for carer support rather than direct services for people with intellectual disabilities. In some cases, participants simply did not know about the possibility of services:

Because we didn't know of any services that could have been available to X, so everything that needed to be done, we did it on our own back.

(7)

Whereas others were deterred from using public services because they had heard negative reports about the quality of care:

I've seen on the news, these parents, their son was autistic and he went to a home or hospital and they didn't look after him, they didn't feed him properly, they falsely inject him, so the parents got concerned and took him out

(G2)

Notably, some participants made a direct link between lack of services or lack of knowledge about available services and forced marriage:

I think that if the people think that government do more for disabled people, that there is a care for them when they are getting older or when their parents are not there for them, so they will be more secure, then they will not force marriage. If they think there is nobody there to look after my son or daughter, then

maybe will more force their son or daughter to get married because of their future.

(G1)

3.2 | Theme 2: Cultural/religious views on disability and marriage

The majority of respondents within this study were practising Muslims and a number of them spoke openly about how they interpreted Islamic teachings on disability and marriage. Central to this was a belief that the severity of a disability could be alleviated by virtue of being married. The mechanism by which marriage was thought to alleviate disability was not explained, but the belief was sincerely held and is also reported elsewhere in the literature regarding marriages of people with intellectual disabilities (Manor-Binyamini, 2018). Participants reported that some families are swayed by these beliefs, especially when espoused by a religious authority figure:

Someone told my parents that X might get better if you get her married...it was an Imam in Pakistan...so they went along with that

(6)

In Bangladesh, the thought is when she gets married ...she is going to be better

(G2)

They thought “maybe something is happening when she'll get married, she'll change

(G2)

However, it was also recognized that hoped-for improvements in individual abilities did not in fact materialize after marriage:

Especially mother and father, they think their child's life could be changed after marriage, that they grow wiser or something...but it's not happened

(G2)

And evidence of families resisting the pressure to conform to these beliefs:

People was saying 'oh if you get her married, she will be alright, she won't behave this way'. What do they know? I would have liked to believe all this...but...

(3)

Part of the reason that these erroneous beliefs are so influential within South Asian communities is because, culturally,

marriage is held in high esteem. There was unanimous agreement amongst participants that marriage was a central tenet of their faith and culture:

Because in our culture, we are Muslim, you have to get married.

(G2)

Everybody gets married

(G1)

However, when participants were asked whether the strong religious and cultural imperatives for marriage applied as much to people with intellectual disabilities as to non-disabled people, there were divergent opinions. Some said that general exceptions were made for people with intellectual disabilities:

Normal persons like us, if they don't get married, people say 'you should, you should'. But if they have a problem [disability] then they don't force that.

(G1)

Others, however, thought there was pressure for people with intellectual disabilities to be married:

People say 'oh your daughter has grown so old and you haven't got her married until now'...so there is a cultural issue, there is family pressure

(G1)

Notably, some participants felt that this cultural or community pressure directly led to a lack of openness about marriages, including forced marriages, involving people with intellectual disabilities:

There is a lot of pressure in Asian families. But nobody talks about it. People keep to themselves what they're doing until it's unfolded, if they do anything bad

(6)

It was also explained that within South Asian faiths and cultures, a marriage was understood as more than a commitment between two people:

...in our culture, marriage isn't just about two people, it's about two families coming together.

(7)

Whilst this was true for disabled and non-disabled people alike, the notion that "*family is more important than partner*" (G2) had a special resonance when it came to people with intellectual disabilities. One participant explained how, because marriage was understood to be an

arrangement between two families and not just the two individuals, this could directly contribute to the forced marriage of someone with an intellectual disability; she described how, in relation to bringing a non-disabled spouse from Pakistan:

It will make their family's life better there, because we support the family, send them some money if they're poor. And it makes our family better here because they will care for our son

(4)

In this way, a marriage involving a person with intellectual disabilities could help two families financially, practically and culturally.

Despite the significance of religious and cultural beliefs about marriage in contributing to the risk of forced marriage, it is important to remember that neither religious nor cultural beliefs remain fixed over time. Most participants expressed the view that cultural attitudes and practices were changing, both between the generations, and between the UK and their families' countries of origin. In relation to marriage, these changing attitudes were moving towards a greater emphasis on individual choice and self-fulfilment:

It's like my generation, so committed to making something work not because it makes you happy, but because it makes everybody else happy. But I think a lot has changed and children now aren't doing that.

(4)

I'm not going to say that there no Muslims now in this country that don't have boyfriends and girlfriends. They do it, that's fine, that's their choice

(G2)

Moreover, specifically in relation to forced marriage, many participants expressed the view that it did not happen so much now as compared to the past, and did not happen as much in the UK as compared to "back home":

But it's not like 20, 30, 40 years ago [when] people went back home and got able bodied person for very disabled people, just for sake of getting them married, and having a child so they can carry on what you call family name. Those days are over now

(3)

I don't think forced marriage happens that much now, because there was a time when it used to happen. Especially in this country, you can't do it anyway... that's what I like about this country, because the

authorities can take over...they can get the police involved...the authorities keep an eye, you know
(G2)

However, despite these assertions, figures from the FMU (Clawson et al., 2020) and the high demand for support services such as those offered by *Karma Nirvana*⁵ suggest that forced marriage is very much still an issue in the UK today.

Participants were aware that people from abroad would marry a British person with intellectual disabilities for immigration purposes. They knew of cases where this had happened within their communities, sometimes within their own extended families, and concerns about this practice were expressed by all. Participants emphasized that because such marriages were not genuine, the person with intellectual disabilities would most likely be abandoned as soon as the spouse had the legal right to remain in the UK (see also Durling et al., 2018).

Before the marriage, they agree with everything, once they get married, then the problem starts...if you are bringing someone from India, Pakistan, Bangladesh, they are happy to get married and come here, then once they get their rights, it all changes, they just run away
(G2)

Some participants felt that marriage where both parties were already in the UK was inherently safer “so you know people aren't just doing it to get into this country” (4). However, despite this, it was acknowledged that people might still look overseas for a spouse, because non-disabled people born and brought up in the UK were more likely to be educated and have aspirations for themselves that were incompatible with marrying someone with intellectual disabilities:

It's quite easy go to Pakistan, you'll find a lot of girls, they'll say yes, yes, so they can get married and come over here...but girls from here already? No.
(4)

Unless you are poor background, unless you are very needy, you won't let your child marry somebody like that [person with intellectual disabilities], will you?
(3)

3.3 | Theme 3: Legal issues

Few participants were familiar with the law as it applies to forced marriage. Consent was often understood as assent or agreement

on the part of the person with intellectual disabilities and the idea of mental capacity, both in and of itself and as the defining factor in the ability to give or withhold consent, was not one with which many participants were familiar. However, legally, consent to marry requires the individual to understand what it is they are consenting to, and therefore, simply agreeing to marry is not the same as lawfully consenting to it.

Even some participants who understood that a person with intellectual disabilities had to consent to marriage still thought that parents' views could, and perhaps should, prevail: “*The thing is the parents do not want anything bad happening to their child. They know their child better than anybody else...parents always know better than everybody*” (G2). Others expressed the view that even where someone with intellectual disabilities was not able to consent, the willingness of a non-disabled spouse to take on a caring role could override issues of capacity:

I think if the other person says that ‘yeah, I can manage it’, then I [as a parent] am happy.
(G1)

Being formally judged as not able to give consent to a marriage was also thought to be damaging to the self-esteem of someone an intellectual disability:

I don't want her feeling lonely and feeling like she's been rejected by society, just because she doesn't know what marriage is. Does she still not have the right to love someone? The right to be in a partnership with someone? How is she going to handle that? Someone telling you ‘you can't get married because you don't understand what it means’. How damaging is that to her confidence?
(7)

Others found that capacity assessments were not only painful for the individual with intellectual disabilities but also for wider family, who found the outcomes hard to understand and accept:

Mum and dad were very upset...to get married is our life purpose...this is it, and it happens with everyone. Everyone gets married, who doesn't get married?
(7)

He [the participant's father] was finding it very difficult to get his head around. ‘What do you mean she doesn't have capacity? What is there to understand about marriage? We never had capacity assessments in my day, what are you talking about?’
(6)

However, not all participants felt this way. One in particular expressed the opposite view and described how, after a relative with

⁵Karma Nirvana is a support and advice organization which supports victims of honour-based abuse and forced marriage. <https://karmanirvana.org.uk/help/>

intellectual disabilities had been in some very risky situations (sexting, meeting men online, etc) a capacity assessment was done and the family found it a relief when she was found not to have capacity to consent to sex or marriage:

“It gave us time to think, step back, put a plan in place....I was relieved she didn't have capacity at that point...because in a sense it protects us as well for any decisions that X could have taken.”

(7)

The issue of genuinely informed consent is, of course, relevant to both parties to any marriage and consideration also needs to be given to the non-disabled spouse. For those from abroad, who may have little or no information about the (dis)ability of their intended spouse, informed consent is also relevant. Not only may they not be fully aware of their spouse's disability and dependency, but they may also have little context for whatever information they are given (see *Forced Marriage Awareness Film* for a first-hand account of the effects of forced marriage on the non-disabled spouse). Participants often described a non-disabled spouse using terms such as “village girl,” suggesting someone uneducated and poor. Seen this way, forced marriages involving a person with intellectual disabilities could have two victims:

That girl will look after him at least when his parents are gone, she'll take care of him, but it's very cruel for the girl

(3)

3.4 | Theme 4: Marriage, care and risk

As has already been shown, cultural and religious beliefs may encourage some South Asian carers to view (forced) marriage as a solution to the future care needs of their loved one. Participants spoke about their desire to secure stable, long-term care for their adult children with intellectual disabilities:

If they think oh no, there is no care, nobody is going to look after my son or daughter, then maybe they will force their son or daughter

(G1)

It's something that every parent wants for their child is for them to be happily settled in life with someone who's going to look after them when we're not around..

(4)

However, despite the cultural expectations of marriage, some participants were nevertheless clear that their own son or daughter should not marry:

My son doesn't understand how to treat a wife...that is why he should not get married

(8)

She can't look after herself even, so how can she look after another person? It's not fair

(5)

This resistance to marriage was not only associated with perceived characteristics and abilities of individual relatives with intellectual disability, but also with participants' wider fears about the potential consequences of marriage.

Firstly, there were fears that if the person with intellectual disabilities married a non-disabled spouse, they could be exposed to neglect and abuse. These fears were voiced mostly (but not exclusively) in terms of women with intellectual disabilities marrying non-disabled men:

They might not look after her

(4)

I used to think if she ever gets married to a man, he won't really tolerate all her little ways, and he might not be kind to her, he might be nasty and do things

(3)

Sexual abuse within marriage was never directly mentioned but was alluded to. Referring to a woman with severe intellectual disabilities who was taken to Pakistan and married there, one participant said:

Apparently she had had two miscarriages along the way, which makes you think, because she obviously didn't have any idea of what all this is, a strange man and you know what... Obviously it makes you wonder what happened...

(4)

And, considering a marriage for her own daughter, another said:

Most of our fear was how will she be treated by a man? That was her father's most fear and he didn't want her to get married to able-bodied person, because able bodied person have a lot more need. They will have wanted children, X couldn't give it to them

(3)

The second set of fears were associated with the possibility of a person with intellectual disabilities marrying someone else with intellectual disabilities. Fears here centred not on the needs and wishes of people with intellectual disabilities but on those of carers, who were afraid that they would end up with a double burden of care that is,

looking after the disabled spouse as well as their own child (plus any possible children from the marriage):

I have spoken to a lot of parents about it and they've said 'well if I am going to get them married, then I want somebody...more able than mine, because I'm not caring for two people. I'm getting older, that's not something I want, so that's not going to work

(4)

The way the parents are thinking, to marry their son, they want somebody to look after their son. But instead, now the parents have two to look after, it's too much.

(6)

We're lucky that she hasn't got any children from when she got married...otherwise, we have to look after the kid as well, as well as her...that would have completely ruined my life

(5)

Despite feeling that another person with intellectual disabilities might be more compatible with their relative, some participants felt stuck as *both* families were hoping for a partner who was more able than their own relative. Whilst this contributed to caregiver fears for the future, it may also have acted in some instances as a protection against forced marriage.

4 | LIMITATIONS OF THE STUDY

This study had limitations, as all studies do. The participants were predominantly female carers which reflect the gendered division of caring roles in many families in England, whether from South Asian or other ethnic backgrounds. However, given the roles of both fathers and mothers in making decisions about marriage for their (adult) children, it would have been valuable to have more input from men. Moreover, although data from the FMU suggest that the phenomenon of forced marriage involving people with intellectual disabilities is concentrated in South Asian communities, which therefore justifies the sample of participants, it must be recognized that cases of forced marriage of people with intellectual disabilities involve people from many and diverse ethnic backgrounds—and these findings may not reflect the experiences and motivations of family carers from other ethnic and cultural backgrounds. Given evidence of the importance of faith/religious beliefs about marriage, it would also have been useful to explore differences between Muslim, Sikh and Hindu family carers, in order to enable more nuanced differentiation between the impacts of religion and culture.

5 | DISCUSSION

These data from South Asian family carers support the findings from previous studies of professionals, in noting that a key motivator for forced marriage of adults with intellectual disabilities can be the desire to secure long-term care. However, this study has also provided new insights into reasons why marriage is seen by some families within UK South Asian communities as the “solution” to care needs.

Taggart, Truesdale-Kennedy, Ryan, and McConkey (2012) use the term “*unremitting apprehension*” (p.225) to describe the constant worry about the future faced by parents and carers of adults with intellectual disabilities. It is known that as the parents of adults with intellectual disabilities approach and reach old age, their concerns for the future wellbeing of their son or daughter increase, yet their knowledge of alternative sources of support for their relative may remain low (Hubert & Hollins, 2000; Pryce, Tweed, Hilton, & Priest, 2017). Based on data from this study, it is reasonable to suggest that whilst all carers of adults with intellectual disabilities experience similar stressors and respond with similar emotions, it is likely to be cultural and religious beliefs that steer South Asian carers towards marriage as a solution to unmet care needs. The idea of marriage as an alternative to public services is not found amongst family carers of all ethnicities in the UK (Hubert, 2006; Pryce et al., 2017); it is associated with BAME communities, particularly those with roots in South Asia. This calls into question whether public services are doing enough to offer culturally appropriate services for BAME people with intellectual disabilities in the UK.

Despite evidence from this study which showed that people from South Asian communities consider marriage to be normal, natural and (crucially) expected of everybody, there was also evidence that participants were aware of the potential for highly negative outcomes from forced marriage of people with intellectual disability. This supports previous findings in relation to the associations between forced marriage, abuse and neglect, particularly in cases where one spouse is intellectually disabled and the other is not. It also provides new understandings of parents' fears of a “double burden” of care if their son or daughter with intellectual disabilities was to marry another intellectually disabled person with similar or higher support needs.

In relation to the law, there was only limited awareness and understanding of laws prohibiting forced marriage and even less of the legal constructs of capacity and consent. Some simply do not recognize capacity as relevant; others thought that the views of parents and family members should prevail. This lack of legal knowledge has the potential to lead to negative consequences for family carers. Where the “solution” of marriage does not take into account the law regarding forced marriage, carers risk being criminalized. There is a need for South Asian carers to have access to clear information about the law in relation to forced marriage.

6 | CONCLUSION

All those involved in supporting people with intellectual disabilities need to be aware of forced marriage and understand the

association with cultural and religious beliefs which are prevalent within some South Asian communities. Whilst many of the factors which precipitate such marriages are benign, they may nevertheless lead to outcomes which harm people with intellectual disabilities. As has been noted elsewhere (Clawson, & Fyson, 2017) people with intellectual disabilities have the same universal human rights as other people and in the UK this includes the protection of the law against forced marriage. In order for these rights to be made a reality, a more widespread understanding of the risk of forced marriage, including the reasons why carers may opt for forced marriage, is needed. At the same time, there is a need for improved access to public services for BAME communities, so that marriage is no longer seen as the only practical solution to unmet care needs.

By better understanding the likelihood of negative outcomes for their son or daughter and better understanding the legal consequences for themselves, South Asian carers may be less likely to consider marriage as an option for their adult child with intellectual disabilities. At the same time, a better understanding on the part of professionals regarding factors which may drive some families to seek marriage for someone with intellectual disabilities is needed. This would not only encourage the provision of culturally appropriate services, but also enable professionals to identify risk of forced marriage in individual cases. A key outcome of the wider research project is that both family carers and professionals now have access to a range of free resources about forced marriage of people with intellectual disabilities (see: website anonymized for review). This includes information about UK law; workbooks to support training activities with family carers of adults with intellectual disabilities; and specific guidance on how to assess capacity to consent to marry, which is applicable to those working with all people with intellectual disability and not just to those from South Asian communities.

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CONFLICT OF INTEREST

The Authors declare that there is no conflict of interest.

DISCLAIMER

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