Is information enough?

Exploring the information priorities of families of people with a learning disability from Pakistani communities.

A collaborative project between Mencap and the International School for Communities, Rights and Inclusion based at the University of Central Lancashire

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The voice of learning disability

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1 Introduction

This project came about because of Mencap's need to create a set of guidelines, backed up by research evidence, for working with black and minority ethnic (BME) and migrant communities. Mencap was aware of the conflicts in the existing evidence, including central government policy (for example, for translated materials) and the practices and approaches adopted by other independent organisations. Mencap needed to define how it could most effectively engage with, and truly support, communities defined by ethnicity, in line with their self-defined needs and priorities.

Understanding the information needs of different ethnic groups is complex. In the past, many organisations have produced information in community languages. Some organisations reported that this was a poor way to use their resources when there was little interest from those communities. In fact, the language needs and issues of different generations within a particular ethnic group can be as large, or even larger, than the needs and issues across ethnic groups. So Mencap is keen to make sure that any future decisions about information needs (including translation) are based on reliable evidence.

Before this study, Mencap completed two pieces of research about working with BME communities – *Reaching Out* and *Emapp*. Each of these projects identified that language is a barrier for many BME family carers and suggested that information needs to be translated. A national seminar in Birmingham held in partnership with ARC and National Autistic Society, and supported by the Valuing People team, also formed some of the background to this work.

This project is part one of a four-stage project to explore the information needs of a number of different communities defined by ethnicity, starting with Pakistani family carers. The overall project has been developed to answer the following questions:

- Does ethnic background influence the needs or priorities of families?

- What priorities would family carers from different ethnic groups choose in terms of their need for information about learning disability?

- How important is translation to family carers from different ethnic groups?

- Do family carers from different ethnic groups have preferences for different formats and technologies for the delivery of information?

- What approach can Mencap, using its current resources, realistically use to maximise its impact and support for families from different BME communities?

2 Methods

This section explains the data sources we used for this study and our approach to data analysis for the report.

2.1   Research design

This project was a collaboration between Mencap and the International School for Communities, Rights and Inclusion (ISCRI) at the University of Central Lancashire (UCLan). As well as the aim to learn more about our subject, another important objective of this project was to develop Mencap staff's ability to understand and deliver research.

The project had the following core elements:

- Planning meetings to define the scope and parameters of the project and to design the methodology.

- Strengthening staff capability – including research training for Mencap staff delivered by UCLan.

- Identifying a method for recruiting participants.

- Producing resources and materials to support the focus groups.

- Getting approval from the ISCRI's ethics committee.

- Mencap delivering the first focus group with group facilitators and interpreters.

- Transcribing the discussions from the focus groups.

- Analysing (individually and in groups) the results of the focus groups.

- Mencap holding the second and third focus groups with group facilitators and interpreters.

- Transcribing and analysing (in groups) the focus groups.

- Producing a draft report.

- Producing a final report including recommendations.

2.2   Data sources

The project included a brief review of relevant literature to support the analysis of the data gathered in the focus groups. We explored the perspectives of Pakistani family carers on all issues relating to information and other needs.

We recruited participants through community organisations who were already in contact with Mencap. We asked each organisation to recruit as many Pakistani carers for the discussion groups as possible.

2.3   Ethical issues

The research plans and methods for this project were reviewed and approved by the ISCRI's ethics committee at UCLan.

We gave potential participants written information about the focus of the study to help them make an informed decision about whether or not they wanted to take part. We gave them clear information about data protection and confidentiality and told them that their participation was entirely voluntary. We also got written consent from every research participant.

Research about issues that carry certain stigmas must be fair. So we asked participants to think about what they were happy to share in a group setting.

2.4   Data analysis

We collated qualitative data, relevant literature and other documents thematically, according to the most consistent themes that were relevant to the focus of the study. So our analysis is firmly grounded in the data we got from the participants in this study.

Using thematic analysis made it possible to report on a wide range of experiences and perceptions about these themes. It also enabled us to identify areas of agreement and disagreement on specific issues, and to recommend how Mencap might address the issues raised in the research.

3 Findings

3.1   Introduction to the findings

The title of this report asks 'is information enough?' This question emphasises the main theme in this research – that the way information is delivered is as important as its content and quality, and that in many cases information is no substitute for practical and emotional support.

The focus group discussions helped us to understand that Pakistani family carers face many of the same issues and challenges as other groups of family carers. However the findings also suggest that in many cases these issues and challenges, whether cultural or practical, seem to be barriers to carers getting involved in social and community life. Also, some of the issues and subjects the participants discussed had specific implications, either for this group or in some cases for South Asian carers generally.

In our report we do not want to simplify the rich picture we got from the discussions into just a series of uniform findings. This would distort the different experiences. Instead we have drawn out some themes which families identified as important, as well as areas of agreement and disagreement wherever possible. The findings attempt to describe both the information needs people in the groups identified, as well as their context – which we feel is likely to influence the effectiveness and impact of any information given out to carers.

We have presented the findings in two sections: 'Information needs' and 'Needs beyond information'.

3.2   Information needs

3.2.1 Diagnosis

Diagnosis was the main concern of many families who participated in the focus groups. Their concerns related not only to the age at which their child was diagnosed, but also the way that information about diagnosis was provided and the level of support they received. For example, a number of families complained that they had problems getting a diagnosis. Previous research suggests that white British families are more likely than South Asians to receive a medical explanation for their child's disability (Fatimilehin and Nadirshaw 1994).

Parents also described large differences in the ages at which children had been diagnosed. Some children were referred to specialists by a midwife in the first months of their life, while others had not been diagnosed until 13 or 14 years of age. For families whose child had not been diagnosed in early childhood, many family carers had sensed that something was

wrong and talked to GPs and other health professionals about their concerns. Some had been told that there was nothing wrong and/or that they were imagining symptoms or exaggerating.

"… we took him to the doctors and they said he'll be fine and that nothing's wrong, he'll be fine. 13 years had passed and they were still saying he will be fine."

'It was only when he started school that the teachers picked up that something was not right… [Even then] my GP still refused to acknowledge anything was wrong with him."

Others recalled the way that health professionals had spoken to them.

"And I went to my GP and I said the consultant at the hospital has diagnosed him with autism, so when does he start his course of antibiotics or whatever it is that he needs to do to get better? He actually used a very harsh word to get through to me [saying] 'your child is disabled for the rest of his life.' And that hit me hard and I just sort of walked out of the surgery."

South Asian families had sometimes been told by white health professionals that their child had a learning disability because of the patterns of marriage between different families who were related. Two parents said that they resented this as it was the only explanation they were given. They felt this showed that the professional concerned held discriminatory views about South Asians. The professional did not address the reality that members of other ethnic groups also have children with a learning disability. In other cases parents were not sure whether explanations they were given were true or a reflection of cultural stereotyping. General levels of discrimination experienced from white health professionals contributed to this confusion.

3.2.2 Combatting shame and denial

Many parents said they found it hard to accept that their child had a learning disability and many described feelings of shame, denial and embarrassment. These feelings, as well as a lack of credible culturally-appropriate information, often left people feeling socially isolated. They realised they did not understand learning disability and that others in their communities had negative views about it. Many also described cases where community or family members had been judgemental towards their child or family.

"In the holidays we don't go out, we stay home. We don't go out at weekends and I feel ashamed. Lately… I've come to love my child… [but] I used to hide away from society."

"It's like with my daughter … when she's been in to the mosque and, there was a few neighbours and er, they said something to us, so I went really angry."

"I mean I don't take him to weddings anymore, but when I used to I'd get that sort of pity from other women… gossip if you like, one lady will come up and she'll ask me, 'what's wrong with him? Why are you holding him?' And then she'll go off (and gossip to others), that is just nastiness."

Families complained that the wider community often did not recognise the disabilities that their children had or, if they did, held skewed views about what it meant. These findings suggest that information also needs to be targeted at the wider community to help break down some of the stigmas and barriers to families of children with a learning disability.

"If you tell them that your child is autistic, [all] they think [is] Rainman. They think that means that they [the child] are intelligent."

"If you've got kids in wheelchairs you can see their disability. If you see my daughter you'd think there's nothing wrong with her... If she was in a wheelchair or something, then they'd feel sorry for her."

It also seemed clear that feelings of shame and stigma increased the likelihood that parents would seek alternative (non-medical) explanations for their child's learning disability, and/or cures. Many of these Pakistani families used these explanations to make sense of their situation. Some offered spiritual or religious explanations, some suggested having a child with a learning disability was a punishment for past sins and others saw it as a test from God.

"I know it sounds bad but I think God gave him [my son] to me to test my patience and I'm really proud of him. I used to hate it when people would say to me, even to this day, you're getting punished because of what you've done badly in a past life. But now I've accepted it, it's a blessing."

"Yeah, I get that every time. You're being punished."

One family felt that their child had got autism from immunisation against MMR, an issue which has had media coverage in recent years. Some felt that they had done something wrong (for example during pregnancy) and were somehow to blame. Without the opportunity to discuss these feelings with others, many families said they had felt guilty for many years. For example, one mother described blaming herself for her son's condition because she took anti-depressant medication when she was pregnant.

In a small number of cases, shame and denial had led parents to search for cures. Two parents said they had paid large amounts of money for expensive treatment which hadn't worked.

"That's put me in financial debt because I was conned by a man; he said to me, I can cure your son and I believed it. I was conned out of thousands of pounds and [told] it was guaranteed to cure my son in two to three months, but it was all a hoax."

3.2.3 Coping with challenging and difficult behaviour

Many of the families were coping with extremely difficult and challenging behaviour from their child with a learning disability, sometimes on a daily basis. Families said that the situation became more difficult as their child grew up. Most had not received information or training on how to manage challenging behaviour. Even when parents had received some training, they wanted professionals to recognise that one-off courses were not enough to be able to cope with changes in behaviour with a growing and developing child. This often had an impact on both the carer and siblings and meant they were reluctant to look for support services. Some parents' main concerns were about personal safety and physical attack at home.

"For a 15 year old, his body's like a man. His mind is like a one and a half year [old]... He damaged my whole house. You know, the telephone, clocks, table, chair, anything. He throws dishes, he kicks the headboard and breaks it ..."

"Well my son, the other day he got a fork and stabbed me. So as he gets older he's getting more and more violent... What happens if he gets a knife, you know... he won't be able to help it will he?"

Other parents were more concerned about dangers when they took their child out of the house, in particular in the car.

"His behaviour was very difficult to deal with. Lots of temper tantrums, he was always hitting doors, windows. He won't let anyone into the house. He starts screaming. He won't let me use the telephone. He won't let me talk to anybody. And even when I take him out, I take him out in the car but he runs off in front of the cars and that really scares me."

"He can't go out in the car because he's a big lad, he's clever, he gets out of his seatbelt and attacks me when I'm driving."

Concerns about their son's or daughter's violent and/or difficult behaviour led many families to worry about accepting any form of respite care. This was often due to the behaviour of their child, which led to fears about the child's safety or fears about the safety of respite carers.

"I can't leave her with anyone. It's not because I don't trust the person that's looking after her, it's her I don't trust. She's capable of doing anything and everything."

"He used to trap his own fingers in doors. He used to love pain so that's why I wouldn't let anybody look after him at that time."

Problems with aggressive behaviour often led to more isolation for parents and it was clear that this was a source of great stress and anxiety for many families. It was also a barrier to seeking help or finding out more about services. Parents were often worried about what might happen to their son or daughter in respite care if they weren't there to look after them. For many the fear was that if the parent, with their knowledge of the child, could not manage

the behaviour then how could they expect other people to manage? Some were fearful about how a child might behave around other people and their children. Others were concerned for their own safety or the safety of other family members as the levels of violence escalated.

The following quote emphasises the double bind many parents found themselves in. A desire to comply with cultural expectations and 'be a good Muslim' clashed with the reality that there was a strong need for respite care and no other forms of support were available.

"Dad's saying yes he does want overnight respite because he's realised [that he's not going to live forever] but then Mum got tearful… There was one parent saying we need to look to the future and start getting used to a care home."

Parents often understood that poor behaviour was linked to their son's or daughter's needs and emotions, and were looking for support to help them understand and communicate with their child. However they were not sure how they would be able to overcome the problem.

3.2.4 Planning for the future

Many of the families we spoke to were so busy dealing with the 'here and now' that they had little time to think about or plan for the future. However, when asked, it was clear that many were worried about what would happen to their child. There were three main issues: the child with a learning disability leaving school, supporting them into adulthood and planning for care when the parents died. There was very little expectation of services or support outside of the family and/or community.

Many parents saw school as a major source of respite and were worried about what would happen once their child got to school-leaving age. They recognised that a lack of appropriate support would increase the pressure on the family.

"Now he's in school … 9am-3pm. Hooray! What happens when he's 16-17? What help's gonna be given then? That's what worries me. That's coming fast for me now."

Many parents were concerned about the challenges of adolescence, such as providing personal care for a child of the opposite sex entering puberty, with all the accompanying physical and emotional challenges. However we felt that this was an issue which had extra relevance for South Asian parents because of cultural values and religious beliefs. For example, many parents expressed concern about how they would cope with the increasing sexual awareness of their child as they got older.

"I'm worried about my son - when he's grown that he's gonna get sexual feelings. And I'm scared about that because he's 7 and he runs to my daughter's bedroom and sleeps in her bed and she's 13."

"But imagine if your son gets an erection when you're touching him [providing personal care]. That's shame isn't it. I'd probably break down on that day."

It was clear that the day-to-day caring was seen primarily as the role of the mother. In many cases, cultural values and expectations clashed with the reality that no one else was available to provide personal care for their adolescent child of the opposite sex. This left parents feeling obliged to provide personal care as their child grows older and shamed by doing so.

In terms of managing a child's expectations of adult relationships, parents often found themselves in a double bind. They were uncomfortable about allowing their child to attend local social groups and respite care because of the cultural expectations about single-sex mixing.

Clearly parents were aware that at some point they would be unable to continue providing care for their child either because of ill-health or death.

"I want my children to get used to the fact that I won't be around all the time."

Discussions about children growing up and moving on reflected cultural expectations of marriage as the appropriate place for adult relationships. However there was little expectation or talk of marriage opportunities for children with a learning disability. Instead these parents talked about the possibility of other siblings taking on caring roles in the future, once they were married. This showed they expected their child with a learning disability to remain dependent. None of these parents had sought information about independent or semi-independent housing options. When this was discussed in the focus groups, these families were more interested in support in the home than semi-independent living.

Some carers suggested that they needed information and support to help them bring up the subject with their own extended families. People described how, within the South Asian community, there is a belief and value system that expects families to 'look after their own'. We came across plenty of evidence to suggest that, despite this, there are many instances where extended families are reluctant to take on the responsibility of caring for a child with a learning disability. For example, one set

of parents reported that their extended family had told them that, should anything happen to them, they would look after their daughters but not their son who had a learning disability.

"You can put him in a home because we're not looking after him."

People felt hurt by the reactions of immediate family which then reinforced feelings of shame and isolation. The expectations of support by the immediate family were not met in reality. This was also the experience families faced from the wider community.

"I've got three children altogether. My family will ask about my two normal children, how they're doing at school… generally, friend-wise. They actually don't ask about my disabled child anymore and I don't like this."

Once again this often left parents feeling unable to plan for the future. The cultural expectations acted as a barrier that prevented them from even considering taking up other forms of support. Many families related to a cultural assumption that if you can't cope with looking after a child with a learning disability, you are a bad parent. Parents mentioned a need for 'information from a trusted source' (for example a family carers' support group). Participants suggested that in this context other possible caring options could be set out in a non-judgmental way and with an understanding of cultural norms and values.

It is clear that cultural expectations can make it especially difficult for South Asian families to make alternative arrangements. The following quote emphasises the difficulties parents face in asking their other children to adopt caring roles.

"I know my son [the one who does not have a learning disability]. He's alright [and would be happy to care for his brother]. But when he's going to get married, the daughter-in-law, she's not mine, she's from a different family. I know if she's alright she can help but if… but it's his life as well so we can't depend on the children."

3.2.5 Information on resolving family conflicts

The stories parents told us emphasised that having a family member with a learning disability affects everyone in the family, but often in different ways. There may be conflict – different family members may have different views about what is best for the person with a learning disability, or the family as a whole. It was clear that families need to have information and support which helps them to consider the options and resolve their differences.

"Sometimes they'll (my other children) say 'shut up' and 'you're stupid' and I'll say 'Don't say that. Don't ever say that to her.' On and on until she's not understanding what they're on about."

"My kids'll say 'I wish you were dead' to my son sometimes or 'we hate you'. So that really hurts 'cos he can't help the way he is."

"Maybe I do need some time away from him. Not just for myself, for his other siblings because they're losing out. And it's affecting my children, a lot, tremendously a lot."

Many families complained that they had not been given information about the services that could provide support and help with conflict within the family.

3.2.6 Information about rights and entitlements

Many families indicated that they had not been sure about their rights and entitlements to benefits until they joined support groups. Many suggested more information about this would be helpful. For example, many carers were unaware of their rights to a carer's assessment, or what this might entail.

"We were unaware of where to get help from or from where we were going to fulfil his expenses."

"Carer's assessments should be done, if not every year, then every two to three years."

One carer said that there was too much information – letters and phone calls that they were unable to respond to.

"I want the information to come to me. When someone gives me leaflets I'll skim through them but I don't have the time… I don't even have a chance to cook a proper meal."

3.2.7 The format and language of information

We found that on the whole, people liked information to be delivered face-to-face and in support groups. This is because it provides the opportunity to develop a rapport with the person giving the information, ask questions and clarify things. With support groups there are extra benefits as the information is delivered in the context of a trusting relationship, with people facing similar challenges. When people first joined the groups they enjoyed the structure of support and the opportunity to be consulted or help to shape services.

Regardless of the format of the information given to carers, it was clear that language was a major concern. Although many participants could speak English to some extent, for many it was not their preferred – or first – language. This meant they did not feel comfortable discussing technical issues around diagnosis and treatment, or exploring difficult concepts and emotions, in English. These families made it clear that if they could choose which language to communicate in it would improve their experience of using services.

"I feel very fortunate that I can actually speak English… But if I was in a position where I was unable to speak English… to this day, my son's gonna be 17 years old… I probably would not know what his disorder is. I couldn't have found out more about it if I didn't have the language skills. I probably wouldn't be sitting here today."

In one focus group, parents suggested that they were happy getting information in audio formats like CDs. In another group people suggested that they would like information delivered over the telephone as long as it was provided by someone who could speak their language. Information provided on DVDs was popular – people liked the fact that they could play the disc at a convenient time and play it several times if they had not understood something. Groups varied as to their preference for leaflets. Many South Asian people do not read and write in their mother tongue and so, for them, translated written material can often be of limited value.

3.3 Beyond information needs

3.3.1 The need for supportive professionals

One of the clearest findings that emerged from this research was that many parents felt they had to battle the system to get appropriate support and services for their child with a learning disability. Many families found that even the services that were supposed to help them were yet another hurdle that they had to jump over. This was summed up simply by one parent who said:

"Those who did know did not tell us anything."

Many Pakistani parents and carers hadn't understood either the diagnosis or information they had been given about it by health practitioners. The quote on page 7 shows how the parent of a child diagnosed with autism asked her GP which medication the child needed to cure the condition. This is a good example of the low level of understanding many Pakistani parents have about learning disability at diagnosis, despite verbal information from health professionals at the time. Other parents had similar stories:

"Until this day, they have still not told me what type it is. So I don't know anything because they only give you a name of what they've got. They don't explain to you what it is."

"I wasn't given any information whatsoever. It was just a little leaflet just generally what autism is, like development, slowing down. Just very, very tiny little leaflet. The basics."

"I was told he was autistic, [given] a little leaflet on autism and sent home. I'd never heard of autism. I didn't know what it meant. [I had questions like] is there a cure that can fix this disorder?"

Many parents expressed the need for both information and support to help them get the best out of the system, and to challenge services and professionals where necessary. It was clear that many families had a poor overall understanding of the health and social care system and the relationships between different services. Many parents said a single point of contact to help them understand and manage their way through the system would be very useful. Many parents also said they felt intimidated by some professionals and by the language they used. A combination of language barriers and authority issues often made it difficult to question and/or challenge professionals appropriately.

"I just used to think oh, ok, he's the consultant and he knows best."

There was an overwhelming desire from families to feel that the services they approach and use are 'on their side'. Several families that took part in this study were able to name specific workers who had made 'all the difference in the world' to them. These workers were seen as those who would go the extra mile - do whatever they could to meet the family's needs. They had been consistent and reliable, and had not allowed themselves to be overly restricted by professional boundaries or the specific responsibilities of their role. They had also taken time and care to build an understanding of the whole family.

"We got a lot of help from (name of social worker)."

"(Name of social worker) helped us."

"My health visitor helped me a lot."

Poor professionals were seen as those who dismissed parents' concerns, left them feeling at fault and embarrassed,

or demonstrated a poor understanding of either learning disability or the parents' cultural needs.

People said they needed professionals to work assertively with them and particularly valued professionals prepared to make home visits. It is clear that when parents receive information from a professional they trust they are more likely to understand and act on it.

"The health visitor told me that there are these things that you can do, but I didn't do them. Then she literally forced me and said that these are your rights. Then she bought a person to the house."

Overall, the experiences of parents who took part in this research show that GPs, health visitors, teachers, social workers and other professionals can significantly help or worsen the experience of a parent with a child with a learning disability.

3.3.2 The need for practical and emotional support

Many parents emphasised the need for appropriately delivered emotional and practical support. The section above describes how this can be provided by good professional workers. However, in many cases participants expressed the value of support provided by other family carers.

For many families the task of coping was so all-consuming that they didn't have time to stop and think, and make sense of the implications (for example future planning or challenging behaviour). This issue is crucial because, unless families are given enough practical support, they are unlikely to be able to make the most of the information given to them, however well designed and delivered it is.

"You don't get time to think about anything, you have a 24-hour routine, so you get up and know you have to do this and that. At night you just want to drop off to bed so you don't have time to think."

"I'm totally like a zombie. I'm always tired. I can't keep myself focused. I'm always looking forward to getting home and sitting on the settee and relaxing for five minutes. When my son comes in it's all over again. That's the thing. I can't be bothered to look for information. I want the information to come to me."

One reason families gave for the importance of support alongside information is that they often need help to think through what information means and how to make sense of it. Almost daily, parents have to make difficult decisions.

"Having information may help to make the process of decision making more informed, but it doesn't necessarily make it any easier."

A face-to-face discussion with someone who can help the family work through issues and dilemmas is something that this group of carers would value very highly. Meeting with other parents and carers gives them the chance to discuss things with people in similar situations who had faced similar challenges.

"I know it sounds a bit selfish but that made me a bit happy because I thought I'm not the only one in the world with a disabled child anymore."

Family carer groups were a good way of getting support and information about rights and entitlements for their family. But they also gave parents a collective voice and the chance to get involved and have their say.

4 Summary

The findings from this research clearly show the range of different challenges faced by these groups of family carers. The main issues included:

- a poor experience of the process of diagnosis – that left family carers with a limited understanding of their child's condition and what it meant for them

- negative views about learning disability in their communities, which made some feel embarrassed and stigmatised

- having to deal with challenging, aggressive, sometimes violent behaviour from their child with a learning disability and resentment and anger from their other children

- a fear of making plans for their child's future care and supporting them into adulthood in a culturally appropriate way

- trying to come to terms with their child's disability through their faith.

Many parents described learning to live with a new reality after a diagnosis. It was clear this required relevant information delivered in appropriate ways. It also required having enough time and support to understand the information and its effect on the whole family in the context of their community. All the things parents had to deal with meant many felt overwhelmed by the demands put on them and could only manage from day to day.

So the question is, how can commissioners act upon these issues in delivering appropriate support and services? Against a backdrop of a wider approach within the learning disability community, which embraces the concept of 'normalisation', it appears that what is deemed 'normal' for Pakistani (and quite possibly other South Asian) families may not be the same as what is deemed 'normal' for many white British families. None of the family carers in this research mentioned the concept of normalisation although, like most families, these parents were keen to support the best outcomes for their own children.

One example of the challenges families face is the provision of education, support services and leisure opportunities for people with a learning disability. As discussed in section 3.2.4 many South Asian (and in particular Muslim) families do not believe that it is appropriate for men and women to mix together. There are very strict rules within the community that govern what is acceptable and appropriate behaviour. These families expect these rules to be applied equally to people with a learning disability. However this situation often places parents in a double bind. Cultural values and norms have to be balanced against the reality that there are few culturally appropriate avenues to support their children as they develop into adults.

Some of the issues to come out of this research go well beyond information. Although information is vital, it is often not enough on its own. For this group of family carers, a lack of appropriate provision increased the burden on parents and also the exclusion of people with a learning disability from Pakistani communities.

Families said that alongside information they needed a combination of practical and emotional support from two different groups:

- Proactive and culturally informed professionals. In particular those professionals who are not overly restricted by their professional responsibilities and are committed to understanding the whole family system.

- Peers. Many families particularly value the support from other family carers from the same community because they see them as people who face similar challenges to them. This then gives them the confidence to try to get involved in the wider community.

5 Recommendations

Mencap welcomes the opportunity to work with BME groups and other organisations to develop these guidelines and recommendations.

Recommendation 1: Develop information which addresses parents' main concerns

Mencap should support the development of information which helps families in the following areas:

Understanding learning disability and getting a diagnosis

- Make families fully aware of the factors which may increase the chances of having a child with a learning disability.

- Explain which professionals can diagnose a learning disability.

- Explain the different tests available for learning disability.

- Explain the reliability of those tests.

- Explain why diagnosis can sometimes be problematic.

- Describe parents' experiences of going through the process of diagnosis to prepare families and enable them to make sense of their own experiences.

- Help parents make sense of the diagnosis and its implications.

Ongoing help and support

- Help families to support their child's communication and development.

- Make parents aware that they may encounter aggressive or difficult behaviour and help them to develop ways to manage it.

- Describe the resources, support and services which are available locally and how to access them.

- Describe the types of support other parents found they needed after a diagnosis and how it helped.

- Encourage families to think about culturally-appropriate services for future planning.

- Help to combat shame and denial in the wider population.

- Co-produce and deliver learning disability awareness training for Pakistani communities.

Recommendation 2: Provide essential information in audio and visual formats

This research suggests that translation is not the main barrier to families accessing relevant information, although some older South Asian carers would prefer information in community languages.

Mencap could support the co-production of relevant information in audio and/or DVD formats. This information should be produced in accessible English and should address the information needs identified above. It should include contributions from Mencap, relevant professionals and also

family carers.

Recommendation 3: Support the relationship between the Pakistani carer community and health and social care workers

Effective face-to-face support from health and social care professionals is vital to the wellbeing of this group of carers and is often not available.

Mencap should look for opportunities to work with GPs and other health and social care professionals to provide training around the specific needs of Pakistani family carers. One way would be to run pilot carer support groups in GP surgeries, supported by healthcare professionals. Due to the high level of stress and social isolation that these carers reported, GPs should be encouraged to give carers an annual health check to make sure they can continue to give care.

Many families could not contemplate their son or daughter using local authority services such as supported living and were stuck in a double bind. A lot of work needs to be done by commissioners, service providers and communities to address the needs of these carers.

Many families need practical training workshops which look at subjects including:

- communicating with children with a learning disability

- techniques for managing aggressive and challenging behaviour

- culturally appropriate approaches to supporting children to adulthood

- planning future care.

Recommendation 4: Commissioners should support the development of appropriate peer support for carers

Families told us that the opportunity to meet with other Pakistani family carers was crucial because they face similar difficulties. This was often the first step towards accepting their child's disability, developing an awareness of the child's potential and taking positive practical steps towards managing challenging behaviour.

Meeting with other carers helped people to develop a sense of community, and they often 'looked out for each other' beyond the peer support group meetings. Carers said they developed confidence, friendships, and a better knowledge of services and other forms of support from the meetings. These things led to a better quality of life for the whole family.

Peer support helps families:

- understand information about learning disability –including diagnosis

- understand and cope with changing patterns of behaviour and develop action plans to deal with them

- plan for the future

- develop confidence.

Peer support groups can also help the relationship between family carers and the wider community. This is necessary to increase understanding and awareness of learning disability and challenge stigma and discrimination.

Other models of family support such as 'circles of support' should also be explored.

6 References

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