

## South Asian People with Learning Disabilities: Why don't they access learning disability services as much as other groups in Kirklees?



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# Executive Summary

A learning disability is a reduced intellectual ability and difficulty with everyday activities, which affects a person's whole life. In the UK, the number of South Asian people (generally people of Pakistani, Indian or Bangladeshi descent) with learning disabilities is estimated to be three times higher than in any other group and is often linked with high levels of social deprivation.

Kirklees has a higher than national average number of ethnic minorities. These communities generally have lower interactions with services and for South Asian people with learning disabilities (numbers of whom are higher in non-white communities in Kirklees and particularly those of South Asian origin), this is further exacerbated since people with learning disabilities and their carers can be isolated socially and when it comes to accessing services.

Healthwatch Kirklees wrote an initial report on South Asian people with learning disabilities in 2017, but decided to conduct further research with the help of a peer researcher in order to gain more insight from South Asian people in Kirklees with learning disabilities and/or their carers.

From the research conducted in this report there is a general dissatisfaction by South Asian people with learning disabilities and their carers when it comes to accessing information, help and support. Although some people find the information they need easily, it seems that people find accessing services to be frustrating and difficult, which can result in feelings of isolation, mental health issues and poorer outcomes for people with learning disabilities, whose needs aren't being met.

A report by the Department of Health highlights the need for more outreach that is inclusive of people who can't attend groups, in addition to accessible and understandable publicity that increases the South Asian community's awareness of available services. In addition, service providers should accept that language and cultural barriers currently exist and address this in proactive ways that increase participation (and ultimately trust); it is felt that this could help to potentially narrow the gap for South Asian people with learning disabilities and carers when it comes to using learning disability services.

Some of the issues raised in this report overlap with those found in our report on emerging communities, which can be found here:

<https://healthwatchkirklees.co.uk/wp-content/uploads/2017/12/Emerging-Communities-Final-report.pdf>

## 1. Introduction

A learning disability is a reduced intellectual ability and difficulty with everyday activities, which affects a person's whole life<sup>1</sup>. In the UK, the number of South Asian people (generally people of Pakistani, Indian or Bangladeshi descent<sup>2</sup>) with learning disabilities is estimated to be three times higher than in any other group<sup>3</sup> and is often linked with high levels of social deprivation<sup>2</sup>.

Kirklees has a higher than national average number of ethnic minorities<sup>4</sup>. These communities generally have lower interactions with services<sup>3</sup> and for South Asian people with learning disabilities (numbers of whom are higher in non-white communities in Kirklees and particularly those of South Asian origin<sup>5</sup>), this is further exacerbated, since people with learning disabilities and their carers can be isolated socially and when it comes to accessing services<sup>2</sup>.

## 2. Why are we focussing on South Asian people with learning disabilities?

Kirklees Council were already aware that South Asian people with learning disabilities don't access support services and wanted to better understand the reasons for this, which is why Healthwatch Kirklees wrote an initial report on this subject in 2017. However, we decided to conduct further research, this time with the help of a peer researcher, in order to gain more insight directly from South Asian people in Kirklees with learning disabilities and/or their carers.



*“In the UK, the number of South Asian people with learning disabilities is estimated to be three times higher than in any other group and is often linked with high levels of social deprivation.”*



## 3. What did we do?

Healthwatch Kirklees recruited the help of a peer-researcher; a South Asian carer of a relative with a learning disability who also runs a carer support group, Masoom Care in Huddersfield, which primarily targets South Asian people but also attracts a few people from other ethnic backgrounds.



Masoom Care helped us to obtain 22 in-depth responses to a questionnaire we created in order to gain more insight into the experiences of South Asian carers of people with learning disabilities. They also helped to provide us with various case studies about the people they come into contact with and subsequently help.

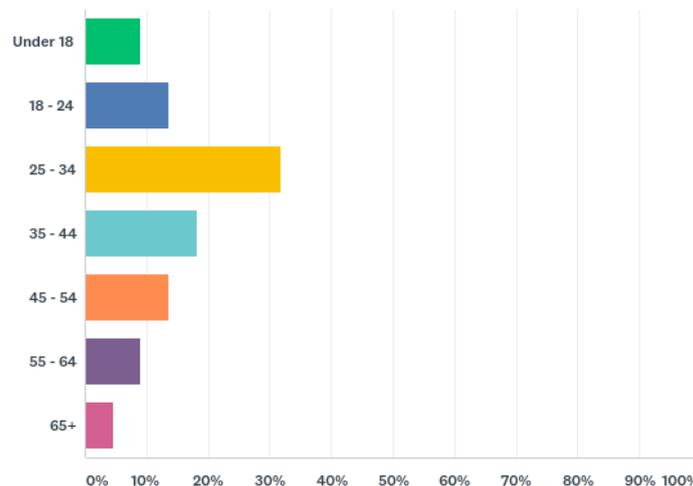
## 4. Results

### 4.1. Questionnaire responses

22 people answered our questionnaire (over three-quarters of whom are female), the vast majority of whom reside in Kirklees in their own home or family home and mostly classify themselves as Pakistani or British-Pakistani.

#### 4.1.1. About the respondents

Most of the people who responded to our questionnaire were aged between 25 and 34.



- 32% care for a person with a learning disability
- 41% have a learning disability
- 23% are a relative of someone who has a learning disability
- 4% identified themselves as “Other”

#### 4.1.2. Finding information on learning disability services

When asking people how they found information about learning disability services there was a very mixed response, with half of the respondents telling us that they can easily find information and the other half not finding this straightforward. From accounts given to us by Masoom Care, English language and IT skills are an issue, as well as being socially isolated, which corresponds with research in this area<sup>2,3</sup>.

*“Yes I can find it on social media websites easily.”*

*“Sometimes no time to find out information - only ask my GP.”*



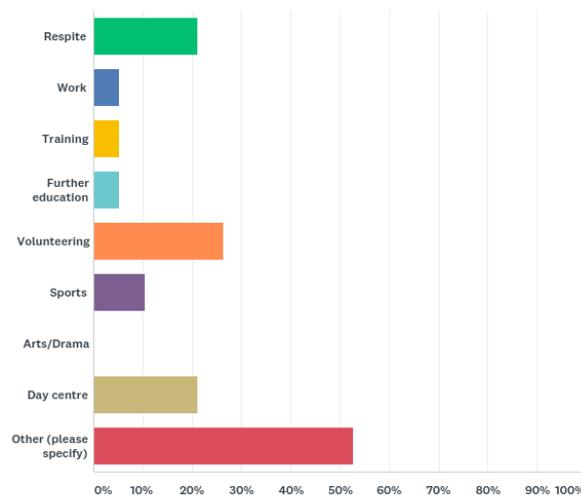
*“Masoom Care has helped with things and advice like that.”*

*“Sometimes - hard to read.”*

#### 4.1.3. Taking part

When asking people what activities they participate in, the most common were volunteering, which was mentioned by over a quarter of people, followed by respite care, attending day centres and learning English.

*“Our Asian community needs to be more alert of any activities available to them.”*



#### 4.1.4. Support to live in the community

Nearly half of the respondents felt that they did receive support to live in the community as opposed to just over half not feeling this way. This can lead to people feeling socially excluded<sup>2</sup> and could be linked with finding accessing information difficult<sup>3</sup>.

*“Only from my immediate family”*

*“I have very supportive in-laws with me”*

*“No support whatsoever”*

*“There are no facilities nearby my home”*

*“No schemes for myself”*

*“Why don't I get any support from social services? Only my children help me.”*

*“Where is the support?”*



#### 4.1.5. Where to live - choice of home and meeting needs

Over half of the respondents felt that they did have a choice of where they live and just over a quarter felt they did not.

*“Applied from a private housing association. Got rejected due to not having accommodation for my needs.”*

*“Because I am the only child and my parents make the decision”*

In addition, just over a half of the respondents felt that their home met their needs, whereas over a quarter felt that their needs weren't met at home.

*“No - too many hooligans in my area”*

#### 4.1.6. Accessing services

When asking respondents how easy it was to access services, over a quarter felt that it was neither easy nor difficult. However when adding the number of responses from those people who found it very difficult and difficult respectively, this made up half of all the responses, indicating a disparity and highlighting that barriers exist for South Asian carers and people with learning disabilities.

*“Not much information available. Only get information from my daughter.”*

*“Change of staff and different information is always provided even though I ring the services”*

*“None nearby”*

*“Nothing available. Always find out groups/centres closing.”*

*“Easy for me. Difficult for my parents - language”*

*“Nobody tells me - I ask the GP”*

*“I have tried to use women agency”*

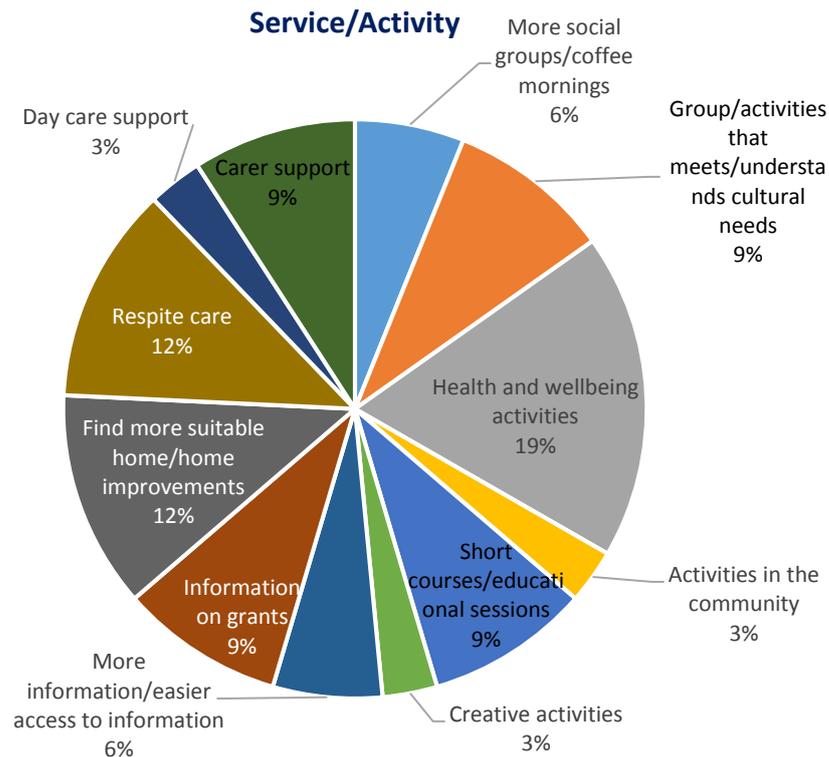
*“Nothing for us [ethnicity]”*

*“Day care service not the same as before.”*

*“There's a lack of communication between authorities and carers and services that may be available sometimes are limited.”*

#### 4.1.7. Services and activities

Healthwatch Kirklees asked respondents what services they would find helpful, or what activities they would like to participate in.



The main theme that emerged from all the comments we gathered above related to activities (almost half); the most popular being the desire to improve health and wellbeing. Other responses included:

- the desire for more social groups
- groups that were more culturally appropriate/sensitive
- activities within the community
- creative activities
- educational sessions and short courses

*“Carers need to be recognised more and need others to realise simple activities such as walking groups and additional exercise programmes would be so helpful for health and wellbeing we care for. Should be available to us freely.”*

*“Sports, dancing, painting.”*

*“...have activities like exercise...”*

*“Sports day centre”*

*“We need diet plans to lose our weight.”*

*“...small courses...”*

When combining all of the responses relating to accessing information, this provided over a quarter of comments; the most popular sub-theme being the



desire to obtain information on how to access grants to make positive changes to the home setting to suit the needs of the person with the learning disability.

*“Grants for extra facilities for special needs child.”*

*“Information on grants for extra toilet/bathroom for special needs person I live with.”*

*“I wanted to access services that meet my needs but feel left out as I don't know where to go. My IT skills are not good.”*

The third most popular theme was the desire for access (or increased access) to respite or day care services.

*“More respite is needed for my family.”*

*“I want respite for myself as I am 24 hour carer for my child. I am a single parent and I get no support.”*

#### **4.1.8. Funding**

We also asked people completing the questionnaire if there was anything else they would like to tell Healthwatch Kirklees. The subject emerging here, that was not explicitly mentioned previously, were frustrations with lack of funding or a perceived lack of help from the local council or government.

*“More funding is required in the local communities within Kirklees.”*

*“Not much help from the government.”*

*“I have tried to access agencies to support my son, but looking and accessing services, I have been refused due to a long waiting list and funding.”*

## **4.2. Accounts from South Asian carers in Kirklees**

Masoom Care provided Healthwatch Kirklees with a variety of accounts from South Asian people with learning disabilities and/or their carers, who look to them for support. These experiences have been broken down into themes, which are provided below.

### **Health**

#### *Mental health*

Almost all of the accounts that carers and some people with learning disabilities have provided to Masoom Care, describe people taking anti-depressants in order to tackle poor mental health caused by loss of identity, stress, anxiety and/or isolation. People feel that their requests for help are ignored and have lost hope or motivation, having to “take one day at a time” in order to cope.



### *Poor nutrition*

Vulnerable people who live alone can be very dependent on relatives and the goodwill of neighbours for their food. Accounts by Masoom Care, describe individuals who depend on consuming unhealthy snack foods such as chocolates, crisps and sugary beverages, until relatives visit their homes to provide them with meals, or friends and neighbours dropping in with donations of food.

### *Poor general health*

Carers and people with learning disabilities can experience poor health in general - accounts include people who constantly feel ill, tired or are unable to sleep.

### *Hygiene and dignity*

The importance of maintaining hygiene can cause carers to feel stressed and isolated but also challenge the cared-for person's dignity if they have to be helped by someone from the opposite sex+. One parent does not feel able to leave their loved one alone at all in fear of this impacting on the cared-for person's personal hygiene - the reasons for this were unclear, however research in this area shows that there is a need to prioritise cultural and religious needs of all service users including having same-sex carers when it comes to intimate personal care tasks<sup>6,7</sup>.

## **Pressure**

### *Carers*

Carers, mostly female but also male, experience great pressures on their time. They can care for more than one person with a learning disability at a time, but also have large families (sometimes up to six young children) to also look after, often for long periods on their own as their loved ones are working.

### *Impact on the cared-for and other family members*

Help with care is much appreciated, but is felt to be insufficient. For example, one child with high-spectrum autism only receives up to six hours respite care per month with a parent who also has other children to care for. This has proven to be very challenging and results with arguments in the home and the autistic child becoming bored, angry, frustrated and then lashing out or running out of the house. Other stories describe pressures in the home that have resulted in the break-up of the families, with male or female partners leaving as they feel unable to cope.

## **Accessing help and support**

People have expressed dissatisfaction with:

- Gateway to Care: People have not had assessments or don't feel that they are always conducted satisfactorily, either because assessments are made over the telephone or that outcomes are unhelpful to the individual or family
- Some people are living in homes that are felt to be currently unsuitable or unsafe



- Some families don't have an assigned social worker at all, whereas others have been told by their social worker that they are demanding or fussy because they are perceived to be asking for too much help.
- Some people have never received support of any kind to help cope or care for their loved one with a learning disability
- Lack of support and help at some schools, where bullying can also be an additional issue that needs to be tackled
- Citizens Advice Bureau are unable to help carers with unresolved issues relating to receiving support for their loved ones
- Authorities being unaware of people with learning disabilities conditions and situations

### Education

Family members don't always know how to improve the home environment for the person with the learning disability, e.g. having regular routines or creating a quieter area in the home for children with autism. This is also an issue that has been brought up in a conversation with staff working in Ravensthorpe Community Centre.

### Language

A barrier for some carers is their lack of English skills, which makes navigating the care system even more difficult and raises the importance of helping people to learn English in genuinely accessible and inventive ways that take carer pressures into account, such as time.

## 5. Conclusion

From the research conducted in this report there is a general dissatisfaction by South Asian people with learning disabilities and their carers when it comes to accessing information, help and support. Although some people find the information they need easily, it seems that most people generally find accessing services to be frustrating and difficult, which can result in feelings of isolation, mental health issues and poorer outcomes for people with learning disabilities whose needs aren't being met.

A report by the Department of Health highlights the need for more outreach that involves people who can't attend groups, in addition to accessible and understandable publicity that increases the South Asian community's awareness of available services<sup>8</sup>. Service providers should accept that language and cultural barriers currently exist and address this in proactive ways that increase participation (and ultimately trust), it is felt that this could help to potentially narrow the gap in South Asian people with learning disabilities and carers when it comes to using learning disability services.

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<https://healthwatchkirklees.co.uk/wp-content/uploads/2017/12/Emerging-Communities-Final-report.pdf>

## 6. Limitations of the study

The results from our questionnaire are based on the responses of 22 people, which is not a large number of people. However, using a peer researcher who is a carer and has access to what can be deemed as a “difficult to reach” group of people, due to language and cultural barriers helped us to gain real insight into the issues people with learning disabilities and their carers have to contend with.

## Acknowledgements

Healthwatch Kirklees wants to thank our peer researcher at Masoom Care and the people that provided their stories.

## Bibliography

1. Mencap. *What is a learning disability?* [Accessed 2 May 2018]. Available from: <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>
2. Sim, D. & Bowes, A. (2005). *Young South Asians with Learning Disabilities: Still Socially Excluded?* [Accessed 2 May 2018]. Available from: <http://ssrg.org.uk/wp-content/uploads/2012/02/rpp232/article4.pdf>
3. Heer, K., Rose, J., & Larkin, M. (2012). *Understanding the experiences and needs of South Asian families caring for a child with learning disabilities in the United Kingdom: an experiential-contextual framework*. *Disability & Society*, 27 (7), 949-963, DOI:10.1080/09687599.2012.699276
4. Kirklees.gov.uk. (2003). *Analysis of 2001 Census Key Statistics*. [Accessed 2 May 2018]. Available from: <https://www.kirklees.gov.uk/beta/information-and-data/pdf/census/key-statistics-report.pdf>
5. Kirklees.gov.uk. (2013). *Adults with learning disabilities*. [Accessed 1 May 2018]. Available from: <http://www.kirklees.gov.uk/you-kmc/partners/health/jsna/pdf/KirkleesJSNALearningdisability.pdf>
6. Hatton, C., Akram, Y., Shah, R., Robertson, J., & Emerson, E. [n.d.]. *Supporting South Asian families with a child with severe disabilities: A report to the Department of Health*. [Accessed 22 May 2018]. Available from: <https://webcache.googleusercontent.com/search?q=cache:88Zxawbzc70J:https://lemosandcrane.co.uk/resources/DoH%2520-%2520Supporting%2520South%2520Asian%2520families%2520with%2520a%2520child%2520with%2520severe%2520disabilities.doc+%&cd=7&hl=en&ct=clnk&gl=uk>



7. Carnaby, S. & Cambridge, P. (2006). *Intimate and Personal Care with People with Learning Disabilities*. Jessica Kingsley Publishers.
8. Mir, G., Nocon, A., Ahmad, W., & Jones, L. (2001). *Learning difficulties and ethnicity*. [Online]. Department of Health. [Accessed 30 April 2018]. Available from: <https://lemosandcrane.co.uk/resources/DoH%20-%20Learning%20difficulties%20and%20ethnicity.pdf>

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