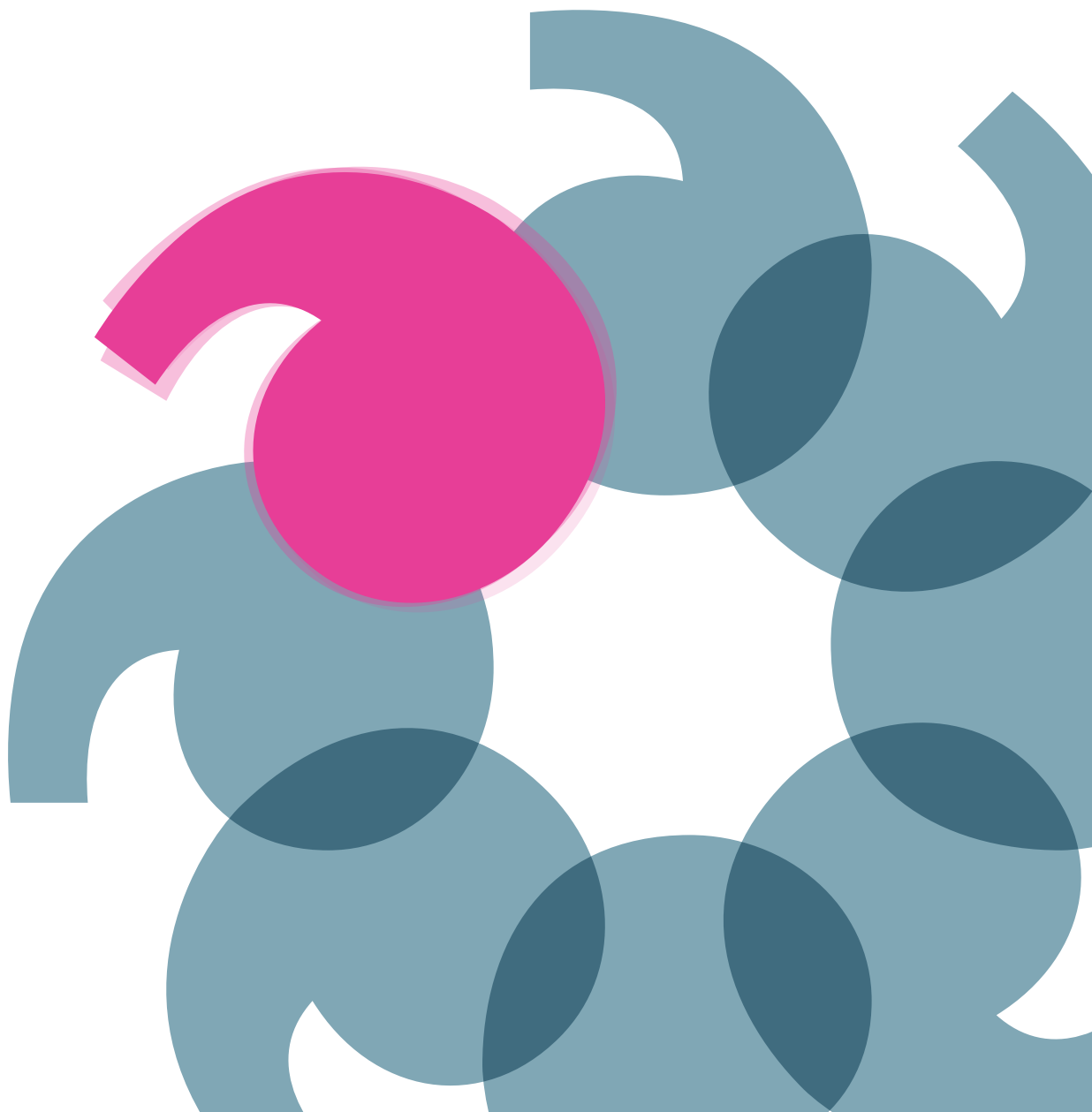


Carers Survey 2021
Feedback from local residents
with a caring role



Contents

Diverse Communities Health Voice is a consortium of Islington based organisations. The partners have many years of experience of advocating for clients and navigating them through health and social care services. Partners have a strong knowledge of how services work in practice, as well as a sound understanding of commissioning processes.

Healthwatch Islington is the partnership coordinator and is an independent organisation led by volunteers from the local community. It is part of a national network of Healthwatch organisations.

<https://healthwatchislington.co.uk>

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Who we spoke to

London Borough of Islington (LBI) are reviewing the services provided to local unpaid carers. They launched an on-line survey in December 2020 and ran focus groups in January 2021.

To complement this work Healthwatch Islington worked with Arachne, Community Language Support Services, Imece, Islington Bangladesh Association, Islington Somali Community, Jannaty and the Kurdish and Middle Eastern Women's Organisation to speak to local carers over the phone about their experiences and the services with which they engage. During January and February 2021, we spoke to 44 carers. None of the carers we spoke to had completed the LBI on-line survey.

Many carers were reluctant to come forward to take part. We offered phone based interviews to be more inclusive (of those who couldn't/ were reluctant to respond on-line) but even so there are carers whose views are not represented. Some people are reluctant to identify as carers and therefore to take part in surveys in general. The views we are sharing are only part of the picture.

We gave participants information on the Islington Carers Hub if they were not already aware of this service for carers.

Age of carers who spoke to us

18-24	25-49	50-64	65-79	80+	Total
1	23	12	8	0	44

Sex of carers

Female	Male	Total
36	8	44

Ethnicity

Arab	9
Bangladeshi	8
Eritrean	1
Greek/Greek Cypriot	11

Kurdish	2
Somali	8
Turkish	3
White British	2
Total	44

Disability and long term health conditions

Seven carers had a disability and 16 had a long-term health condition.

Findings

Most survey respondents were caring for one person (39), but four were caring for two people and one was caring for four. Most were caring for a family member and these tended to be parents or in-laws and included partners. Two were caring for a friend. One was a carer for a teenage son with autism. Most lived with the person they cared for (34 out of 44). For those that didn't, the person they care for was living in London. One had moved the person they care for in with them during the pandemic to reduce the risks of transmitting the virus.

Type of care given

Personal	40
Shopping/ collecting groceries	8
Accessing activities outside the house	29
Take to GP or other appointments	35
Wellbeing visits or calls	26
Other	34

The table above shows the number of survey participants providing each type of care to the person/people they care for. The category 'Other' mainly focused on cooking and cleaning, but also included collecting medication, offering emotional support, and offering support to socialise.

Hours of care provided each week

0 to 5	1
5 to 10	0
10 to 15	3
15 to 20	2
20 to 30	4
30 to 40	9
40 or more	25
Total	44

Needs of the person/people you care for

Physical/ disability	22
Frail	11
Mental health	18
Dementia	1
Learning Disability	2
Autism	1
*Substance needs	6

*This category was used by one participating organisation and probably refers to medication.

Other support (from friends/ family/ council/ GP/ charity/ faith groups)

Most respondents had had support of some kind and reported this support as being 'reliable'.

One participant had a Direct Payment, and three had paid carers coming in to support (one felt their carers needed more patience). One had arranged for a friend to take the cared-for person out once a week. Several could ask family members to support when taking the cared-for person to appointments like the GP. Sometimes it felt like participants were struggling to cope but were trying to reassure the community researcher that they were coping.

Often support was in the form of someone to talk to; friends/ family, a community organisation or a counsellor. For some this had included welfare advice covering housing, immigration and benefits through the community organisations involved in carrying out this research.

"Council social services help with supplying carers. My local community centre, Arachne, helps me with welfare advice/advocacy, someone to talk and attending social and information events prior to lockdown. Arachne support me by ensuring that my own well-being is taken care of. Going to Arachne gives me some respite from all my responsibilities and worries. I feel as if I can unload the burden when I am there, and I feel reinforced when I go back home."

[Respondent 1, Arachne]

"My sister-in-law sometimes comes and supports him physically and emotionally, which gives me time to look after myself. Also, Community Language Support Services provide home visits to provide translation and advocate with housing, welfare, and immigration matters."

[Respondent 17, Community Language Support Services]

What else would help?

“Previously, the GP referred my mother to aromatherapy which was very helpful but now this service is not available. It’s very important to improve the patient’s mood.” [Respondent 37, KMEWO]

People highlighted how lockdown had made things more difficult as there was less access to the usual kind of activities that benefit both the cared-for person and the carer. There was a desire for social, and well-being activities (massages were mentioned) as soon as things re-open.

- ▶ Respite/ someone to look after the cared-for person to give a little break (either full-time for a holiday or a couple of hours a week regularly).
- ▶ Knowing where to ask for help.
- ▶ Vaccination against Covid (we advised on this).
- ▶ To be able to live nearer the cared-for person.
- ▶ A bigger home.
- ▶ Easier access to repeat prescriptions.
- ▶ Interpreting if family members who speak English aren’t available to take the cared-for person to appointments.

“Make the process of prescription easier to order for over 75s who have health issues. At this age its very difficult to go online and type a long name of the GP and long complicated names of medication. I don’t see why it’s a problem to order over the phone for senior citizens.” [Respondent 34, Jannaty]

“My son needs more mental health support” [Respondent 41, Islington Somali Community]

What helps currently?

“The reassurance that I can always go there for support with any difficulties and I will be helped or referred to somewhere else that can help. The welcoming, inclusive and kind approach, I am not facing my struggles alone. The fact that they offer so many different services under one roof is such a blessing”. [Respondent 2, Arachne]

- ▶ Participants valued services that were holistic (could support them with a range of needs) and were welcoming and kind.
- ▶ Offering drop-in support so that participants didn’t have to wait a long-time if they needed to talk about a problem or ask for help.
- ▶ Responsive services that keep participants updated on their query and keep chasing for a solution.
- ▶ Being able to speak to someone in your first language (who can support you with interpreting too if needed) was appreciated.
- ▶ Welfare calls to check on people were also appreciated.

“The regular wellbeing calls that Islington Bangladesh Association make are extremely helpful to me and my family. They check in on me, my husband, and my children, and they listen to our worries and problems without making us feel like we’re a burden. They also promote a healthy lifestyle to us regularly, and also recommend workshops and events that will benefit us.” [Respondent 22]

- ▶ One respondent who had a social worker for the person they cared for noted the huge difference that the quality of the social worker makes in enabling carers to access what they need and are entitled to.

Accessing healthcare during the pandemic

Participants were very understanding of the pressure on the system during the pandemic and many had been satisfied with services. One commented on how safety standards had been excellent during this time. Some felt care had still been easy to access and that services were more attentive to needs.

“I’ve liked my experience with the health care services around me. GPs and hospitals have been much more attentive to their patients and it makes me happy to know that my son is being care for properly.”
[Respondent 24, Islington Bangladesh Association]

“I could not reach the GP on the phone” [Respondent 28, IMECE]

Some respondents reported finding it harder to speak to the GP by phone and felt that waiting times had been longer during the pandemic. One had found phone appointments more rushed and had spoken to different staff each time who didn’t understand the needs of the person being cared for. Appointments had been cancelled and services such as incontinence had taken longer to supply equipment. Language barriers had sometimes been exacerbated with face to face appointments not being offered.

“We had two contrasting experiences with the health care services. The GP service was great as the appointment went well with the doctor and an interpreter was provided which made it easier. Unfortunately, we a had poor experience with the hospital. We were scheduled to have an appointment with a mental health consultant at St Pancras Hospital in November 2020, about my husbands mental health issues. Sadly, when the appointment began, I explained to the consultant that my English is poor, and an interpreter was needed for this appointment. Unexpectedly, the consultant ended the telephone interview and to this day we have had no contact from the hospital. This was shocking as I have not experienced this type of service and I felt discriminated.”
[Respondent 13, Community Language Support Services]

“It’s been hard to access health care and support because all his specialist services closed and we had to cope alone with keeping him occupied and safe. Telephone medical services were not useful for my son as I could not express myself to them as clearly as I could had we been seen in person.”
[Respondent 4, Arachne]

Services being closed during the pandemic had made things harder as there were less ways to keep the cared for person occupied, and to give the carer a space to talk to others and get emotional support.

One participant had been able to access home-based counselling for the person they care for which had really helped.

Satisfaction with carers' own lives

We asked participants to rate on a scale of 1 to 5 how satisfied (with 1 being not at all satisfied) they were with various aspects of their lives. Participants were least satisfied with the amount of movement and/or exercise that they got, compared to the other aspects they were invited to rate

Social interactions

Scale	1	2	3	4	5
Number of respondents	3	16	9	8	8

Ability to enjoy the moment

Scale	1	2	3	4	5
Number of respondents	3	11	18	8	4

Ability to pursue work, education and leisure activities

Scale	1	2	3	4	5
Number of respondents	7	12	14	9	2

Amount of movement/exercise you get

Scale	1	2	3	4	5
Number of respondents	9	18	9	6	2

Observations

Our 2019 report, '[Social prescribing and navigation services in Islington](#)' demonstrated that many residents supported by the partner organisations prefer to access support in a familiar and culturally appropriate setting, rather than going to lots of different agencies. The feedback given by these carers about the types of support that they find most effective again demonstrates that preference.

We asked staff at the partner organisations whether the carers they supported were aware of Islington Carers Hub (ICH). The answer was different for different communities:

- ▶ Islington Carers Hub had provided an information session for the Greek/ Greek Cypriot community and awareness of their services was quite high amongst carers that Arachne supported, *"Some clients are aware of the carers hub, but not all. We have referred people and they have been to us and they did a talk for us about carers, which was very useful."*
- ▶ Islington Somali Community were aware of a small number of Somali carers who had used the carers hub to access a respite care scheme in the past. Staff felt that awareness of the services provided by ICH might have fallen over time within the Somali community, *"I haven't heard anyone talking about carers hub these days"*
- ▶ Jannaty and Community Language Support Services felt that the majority of their clients who were carers did not know about the hub or about the services it offered.
- ▶ There are cultural barriers that make carers services harder to access for some communities. *"Not understanding the concept of a carer and the rights they have with it is an issue for our service users - this is not very familiar to our service users. In Turkey it is a given that you look after the people in your family. [Our clients are] not aware about the carers hub and the services they provide."* [IMECE]
- ▶ Some partners were not clear whether language support was available for carers from their communities who wanted to access services from the carers hub.

Recommendation

1. It is important to ensure that the Islington Carers Hub continues to be well connected to these organisations, and similar culturally-specific support organisations. This should help make Islington Carers Hub services more accessible to more residents from these communities.

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