Experiences of health, care and support services in Sheffield during the Covid-19 pandemic

Since March 2020, the Covid-19 pandemic has brought about sudden changes to Health and Social Care services in Sheffield. Healthwatch Sheffield has been publishing regular summaries of emerging issues, based on feedback that we have received from individuals, as well as issues that have been brought to us via voluntary and community sector partners.

Between late May 2020 and late July 2020 we did a dedicated piece of work to get a more in-depth understanding of local people's experiences of health and social care during the pandemic. This report is a summary of key findings.

What we did

567 people across Sheffield completed our survey. The survey was widely advertised through local voluntary and community groups and organisations, and on social media.

There were **different ways to complete the survey**, which allowed us to gather the views and experiences of seldom heard groups.

➢ More than four-fifths of respondents completed the survey **online**.

➢ Around 1 in 8 completed the survey **over the phone**.

➢ A small number of people completed a **short paper version** of the survey. The paper surveys were distributed via foodbanks with free post envelopes

In terms of *who* completed the survey:

➢ More than three-quarters completed the survey **on their own.**

➢ Around 1 in 6 people were **supported by someone** (e.g. staff from a local organisation, relative, etc.) who went through the questions with them and wrote down their answers.

➢ A small number of people completed the survey **on behalf of someone else** without going through the questions with them.

The number of people who answered each question varied because people only completed those questions and sections of the survey relevant to them (e.g. questions about using health services, social care services, etc.). In addition, people were able to skip questions.

Some details about survey respondents:

➢ 343 people told us their **gender.** 69% were women and 30% were men. Under 1% were transgender or non-binary.

➢ 420 people told us their **age**. As the graph shows, the largest group of respondents were aged 45-54.

Age range
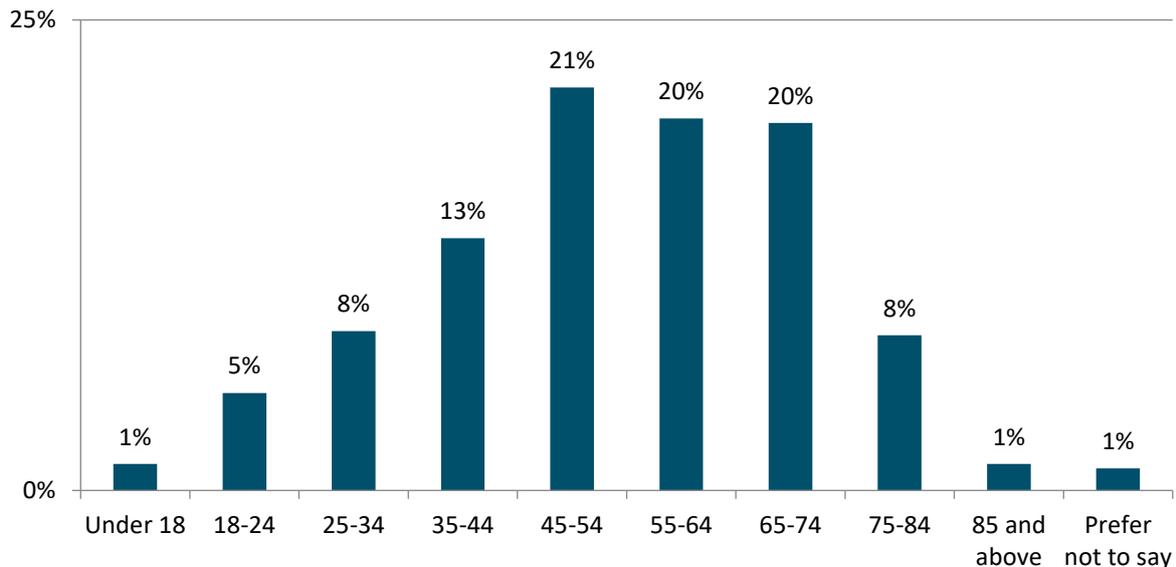
➢ 408 people completed the question about **ethnicity**.

Arab	1.7%
Asian / Asian British: Bangladeshi	1.2%
Asian / Asian British: Chinese	0.5%
Asian / Asian British: Pakistani	11.5%
Asian / Asian British: Other	1.0%
Black / Black British: African	2.2%
Black / Black British: Caribbean	0.7%
Black / Black British: Other	0.7%
Mixed / Multiple ethnic groups: Black African and White	0.5%
Mixed / Multiple ethnic groups: Black Caribbean and White	0.3%
White: British / English / Northern Irish / Scottish / Welsh	69.4%
White: Irish	0.7%
White: Other	5.2%
Other	1.5%
I'd prefer not to say	2.9%

➢ Out of the 420 people who answered the question about disability status, 25% said they had a **disability**.

➢ Out of the 417 who responded to the question about carers, 15% said they were an **unpaid carer** for an adult/s, 6% said they were an unpaid carer for a child/children and around 1% said they cared for both an adult/s and a child/children.

In addition to our survey, we gathered **feedback from 19 virtual Zoom meetings and phone conversations**. This allowed us to hear from diverse groups including people with learning disabilities, young carers and young people from the Asian community.

We have also been continuing to provide our information and signposting service throughout the pandemic, where we spoke to members of the public about the issues they were facing. In addition, our partner organisations across the city shared some of their experiences with us. Many of the conversations we had are relevant to themes raised by survey respondents, so we have included some of these topics in the findings under "What we heard from other sources".

What we found

These are the key messages from our findings:

➢ The Covid-19 pandemic has impacted people's mental health more so than their physical health.

➢ Some people were not accessing services due to fear of catching the virus.

➢ Telephone appointments were welcomed by some but were not always a suitable option.

➢ There was lack of clarity around social care support during the pandemic but front-line staff were praised for their good work.

➢ Charities, community groups and organisations provided valuable support for people during the pandemic.

➢ These have been particularly challenging times for carers, for whom there was lack of respite provision.

Covid-19 Status and shielding

Out of the 536 people who responded to the question, 2% said they had **tested positive** for Covid-19, while 15% said they had had symptoms but hadn't been tested. Around 2% said their test was negative but they thought they had Covid-19:

> *I want to tell you that this virus isn't just a 7 day thing (as the government leaflet suggests) it has been a long term condition with severe and continued physical and mental health implications for me and also for my sons who were asymptomatic for C19 but suffered indirectly because I was unable to do caring.*

Out of the 537 people who answered the question, 19% said they received a text, letter or a phone call advising them to **shield**. However, one person explained that this wasn't followed-up:

> *After receiving shielding letter, no further information or check-ups from anyone, neither the council, the government nor the NHS/GP. No help accessing food parcels, felt very much left to my own devices. Had to rely on the media for updates on shielding.*

One person was advised to shield with a considerable delay:

> *I thought getting a letter from the council about shielding 7 weeks into lockdown rather pointless. If I was in the extremely vulnerable group surely I should have been notified much sooner.*

Out of the 537 people who responded to the question, 34% felt they were at **high risk** from Covid-19. People stated such concerns as medical reasons, age, working in health and social care, being from a Black Asian, Minority Ethnic and Refugee (BAMER) background, and the uncertainty surrounding the disease. Some people were also worried about someone close to them.

> *A lot of people dying, no vaccination found. It is a new situation for all of us and it is scary.*

What we heard from other sources

We heard a lot about shielding through our enquiry line:

- Letters and texts telling people to shield caused confusion and distress for some. People also shared that conversations about Advanced Care Planning were being raised in inappropriate or upsetting ways by their care providers.
- Apparent inconsistencies in who should shield - some people who felt 'high risk' did not receive a letter, while others were surprised to receive one.
- Some people told us about the support they were offered whilst shielding. We heard about inconsistent advice and signposting for help with food and medication deliveries. Some people told us they did not receive a phone call offering them support until several months into the pandemic.
- As lockdown restrictions began to ease, some people who were shielding told us they felt forgotten about by the government.

People's mental and physical health during the pandemic

➢ Mental health

Out of the 519 people who answered the question, the largest group (42%) felt that their **mental health** has been slightly worse during the pandemic (see the graph on the next page). People reported feelings of loneliness and isolation, as well as sleeping problems. Apparently the pandemic had a mixed effect on anxiety:

> *I have experienced anxiety regarding coronavirus and also stress re: home schooling, but I have also found that a lot of usual stressors and anxieties have been lifted due to not having to live to set routines, very limited social contact and less expectations upon me.*

Others described more positive experiences and told us about doing activities which they had enjoyed:

> *My wife and I have a daily routine, (walking, gardening, zoom calls) and just get on with things. The good weather has enabled us to think we're on holiday.*

What we heard from other sources

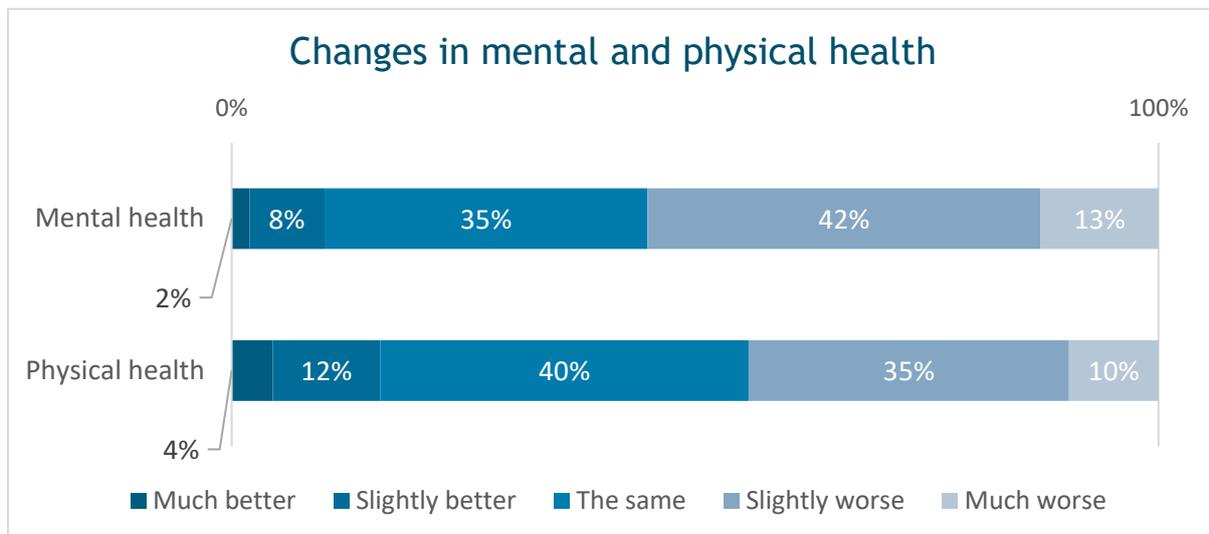Mental health is another topic we heard a lot about through our enquiry line:
- People in need of mental health crisis care told us they are unsure of what support is available to them, and a lack of clear information about what they can expect is making them fearful of accessing services when they need them.
- People have told us about cancelled appointments with no alternative support being offered, which made them worry about their mental health deteriorating.
- Others who have not accessed mental health services before told us they felt lost trying to navigate the system during the pandemic.
- Many people shared concerns about the long term impact of isolation on their mental health.

➢ Physical health

Out of the 518 people who responded to the question, the largest group (40%) felt that their **physical health** has been the same. Some people said they tried to stay active but for some this was difficult due to not being able to go to sports facilities.

> *It helps me start the day feeling really good after a half hour work out.*

The graph below shows how people feel their mental and physical health has been during the pandemic, compared to normal:

Changes in mental and physical health

	Much better	Slightly better	The same	Slightly worse	Much worse
Mental health	2%	8%	35%	42%	13%
Physical health	4%	12%	40%	35%	10%

0%   100%

Accessing support

52% of the 494 people who answered the question, said that the Covid-19 pandemic has **prevented them from accessing health services, social care or support**. For some this was because their appointment was cancelled, while others didn't access services because they feared catching the virus.

> *The risk of catching coronavirus, or of passing it on to anyone else, was always in my mind so sometimes I didn't seek help when I should have done. The media message, i.e. not to overwhelm the NHS, also put me off - as did the sudden appearance of staff wearing so much PPE in settings where it hadn't previously been necessary. I felt the climate of fear as medical facilities locked their doors, making other non-contact arrangements for essential appointments.*

24% (out of the 492 people who answered the question) **had extra or new care and support** because of the pandemic. 15% didn't get additional support despite needing it. 61% said they didn't need any extra care and support. Many people received help from local Charity and Community Sector groups and organisations such as food banks. Some were supported by family, friends and neighbours.

> *A friend helped by getting money out a cash machine for me and then the carers could get my shopping for me. I couldn't get out to get it myself because I was shielding and couldn't get a taxi anyway.*

However, there was still a lack of support for some:

> *I haven't heard a single word from any service organisation or government body. I am in receipt of highest rate care and highest rate mobility PIP and my needs have grown exponentially as the severity of my mental and physical health problems have been amplified in all ways during Covid.*

Experiences with health services

➢ Stopping treatment

For many people during the pandemic treatment was stopped, postponed or cancelled, resulting in unmet need:

> *I was waiting for a knee operation. I have been in severe pain and I was desperate for this operation, however, as a result of the pandemic I had to cancel it and I am putting up with the pain.*

In particular, some people couldn't access dental care. One person whose dental treatment was delayed commented:

> *I know it might not make a difference now but dental care needs to be taken more seriously.*

What we heard from other sources

Dentistry is a topic we heard a great deal about through our enquiry line:
- In the early months of the pandemic we received several queries each week about how to access urgent dental care as well as when ongoing courses of treatment could resume.
- Many people told us that communication with their regular dentist was extremely difficult.

➢ Non-Covid-19 issues being neglected

Some people felt that provision had been focused on Covid-19 issues while other needs remained unmet:

> *Had no contact from hospital about daughters allergies, [I] can understand they are busy with Covid-19 patients but still need a way forward with my daughter's needs.*

Delaying treatment could have long-lasting complications:

> *In a bid to combat COVID, the government has ignored all the other major illnesses or any other illnesses that could lead to major life changing, catastrophic issues like my daughter's eye tumour because it's something that could have been dealt with easily but now she's slowly going blind.*

➢ Remote appointments

Some people welcomed alternatives such as online and telephone appointments:

> *Use of phone appointments for GP was really helpful as it's usually hard for me to get to appointments with my child or for myself due to childcare so for some needs, a telephone appointment was much better.*

For others these alternatives were not suitable. We learnt that Deaf people couldn't access telephone appointments, and one Deaf person explained that face-to-face appointments are an accessible option.

Another person told us that the appointment alternative they were offered was not suitable because there was limited opportunity to provide information:

> *I had my asthma review by text questionnaire. This was missing an important section and there was no option to comment.*

Some people felt that confidentiality was an issue with remote appointments:

> *I had to have a confidential assessment over the phone whereby I was worrying people in my own household would be listening.*

➢ Waiting times

We heard that for some people, waiting times seemed shorter than normal:

> *I have been referred to two different hospital departments in the past month and have been seen very quickly - there appears not to have been a waiting list.*

➢ Restrictions on accompanying and visiting

People were not allowed to see their loved ones during times such as childbirth or during their relative's last moments. One person explained how the restrictions affected parents:

> *I have 2 children including a toddler and you are only allowed to have one parent at a time. Also for some services you can't see a professional face to face which makes it difficult to explain especially when it's something is to do with the children.*

What we heard from other sources

A partner organisation told us about a negative experience of a Deaf person, who needed additional support but wasn't allowed to have a family member with them during an appointment.

Experiences with Social Care services

➤ Difficult to arrange support

We heard it was difficult to arrange social care support because of issues such as staffing and the lack of Personal Protective Equipment (PPE). One person explained that the pandemic hasn't prevented them accessing support, but added:

> *It's made my social care more erratic because a lot of staff had covid or have an underlying condition or were scared.*

➤ Lack of support for new clients

It may have been difficult for new clients to access social care:

> *We don't access social care because I have the help of both parents but during Covid it was me on my own all the time - didn't even know who to contact. All support was aimed at people already in the social care system.*

➤ Access to needs assessments

One person who couldn't get a needs assessment for their child said "we are not considered a priority". One person said a phone assessment led to inaccuracies.

➤ Uncertainty around funding

One person explained they had to pay for care they were not using:

> *Still continued to pay contributions to direct payments for a service we were not getting and when asking social services if we had to carry on paying it we were told we must continue paying.*

At the same time another person's needs were not funded:

> *I had to pay for additional carers to come in on the days I used to go to Day Care. This has cost me a lot of money as no one helps with the cost.*

What we heard from other sources

Issues with care packages and direct payments came through our enquiry line:
- We heard about people for whom the community support part of their package had been reduced because some activities weren't possible.
- Some social workers have reportedly been creative and supportive in how to meet these needs in other ways, but others were not able to discuss alternative support options.
- For some, where this reduction has meant they didn't have support to go shopping, they had to rely on foodbanks.
- People who receive direct payments to fund their social care have been telling us that they are still being charged for care they don't receive, and do not feel that the reasons for this have been explained clearly, leaving some people confused or frustrated.

➢ Praise

We also heard positive feedback for front-line staff:

> *My carers have been great. They have managed to keep a full supply of PPE and have even made their own masks. They have taken over administration of my medication during the pandemic as I was getting very confused due to my dementia and having to take my medication.*

Experiences with Charity/Community Group support

➢ Supporting in a range of ways

Charity and community organisations offered practical support (e.g. shopping) but also emotional support:

> *I have been supported by community groups in a different way, bring me food parcels, contacting me weekly to see how I am and chat. I understand that the groups I used to attend at the community groups cannot take place but what they have been doing is helpful and been positive.*

➢ Being person-centred

Charity and community organisations provided tailored support to local people:

> *A local charity found out how ill me and my daughter were and started sending colouring stuff I get a phone call each week checking on my mental health.*

➢ Creative ways of engagement

To adapt to the circumstances, online meetings were organised but we also learned about some more interesting ways to engage the community:

> *Being part of a community gardening group allowed me to interact with other people, at a safe distance, and participate in a joint activity.*

➢ Not reaching everyone

Despite the wide reach, some people may still have been left without support. For example one person told us they didn't receive information about available support for around two months into the pandemic. Other organisations simply suspended their activities. One person was concerned about digital exclusion:

> *I am concerned with the lack of support available to people who cannot access the internet. Many of the temporary support measures put in place have been wholly dependent on internet access, which means they are*

inaccessible to people who cannot access the internet for whatever reason. I am aware that this has been a big issue for many isolated older people.

➢ Giving to the community

In these difficult circumstances we also heard from an individual who supported their local community:

I haven't had any communication, but I know how hard it is for some people financially. So as somebody who is so fortunate to have financial means, I've been supporting food banks and other charities.

Communication from services

➢ Changes to health services

39% (out of the 306 people who responded to the question) **were happy with the communication about changes to health services**. However, there may have been limited consideration for people with no access to technology:

I do not have a computer and I cannot remember how to turn on the TV. No one seems to think that dementia sufferers may like a good old fashioned letter from the GP.

➢ Changes to Social Care Services

36% (out of the 80 people who responded to the question) were **unhappy with the communication about changes to social care services.**

I received a really useful guide and FAQ on how my personal budget could be used and about employing my PAs [Personal Assistants] etc. - but 3 months after lockdown started! This was far too late and caused huge problems for me managing my PAs…

➢ Changes to Charity/Community Support

80% (out of the 147 people who responded to the question) were **happy with communication about changes to Charity/Community Support**.

I received a newsletter telling me about the support offered and after speaking to them I was referred to the local food bank which helped me and my family tremendously.

➢ Understanding the changes

People with Learning Disabilities told us they struggled to understand the Covid-19 situation:

> *My support workers explain to me what is happening and why my life has changed, but this is hard for me to understand.*

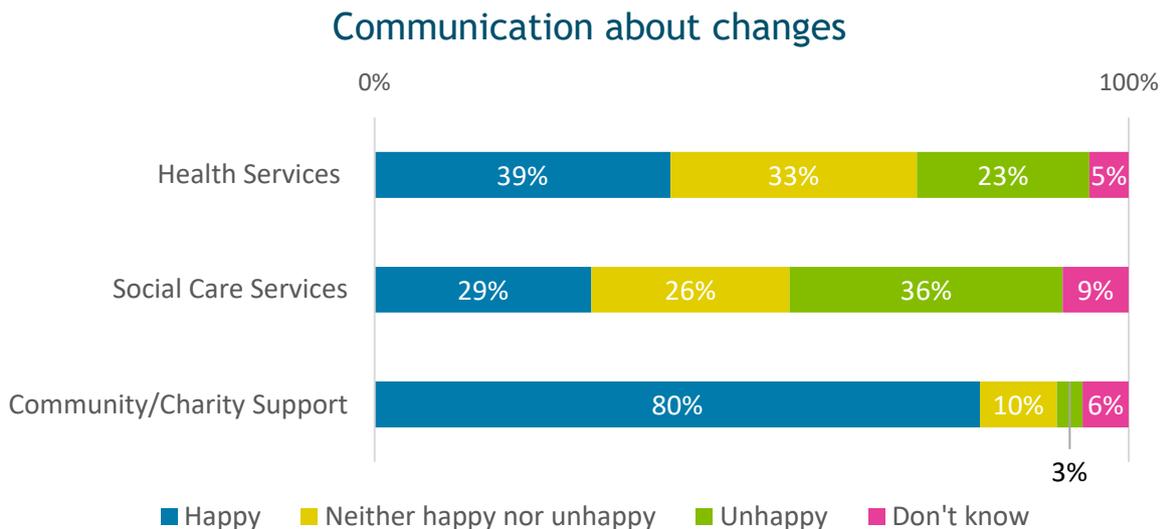**What we heard from other sources**

We heard from organisations and relatives who were concerned about the safety of people with Learning Disabilities. They told us that:

- Telephone support is not always suitable for people with autism or a learning disability.
- Confusing guidance made it hard for people to understand what they could or couldn't do. For some people, this meant that they went outside more than government guidance advised, or returned to their normal routines early. We heard similar concerns for people living with Dementia.

➢ Accessible communication for Deaf people

One person suggested that there need to be accessible communication alternatives for Deaf people. They explained that the ways to access information were mostly *"please phone this number, etc."* (which is not accessible for Deaf people). This person described feeling *"left behind"*.

This graph shows how happy or unhappy people felt about the way services communicated changes to them:

Communication about changes

0%   100%

	Happy	Neither happy nor unhappy	Unhappy	Don't know
Health Services	39%	33%	23%	5%
Social Care Services	29%	26%	36%	9%
Community/Charity Support	80%	10%	3%	6%

■ Happy ■ Neither happy nor unhappy ■ Unhappy ■ Don't know

Overall experiences of changes with services

➢ Health services

37% (out of the 314 people who answered the question) were **overall "Neither happy nor unhappy" with health services.**
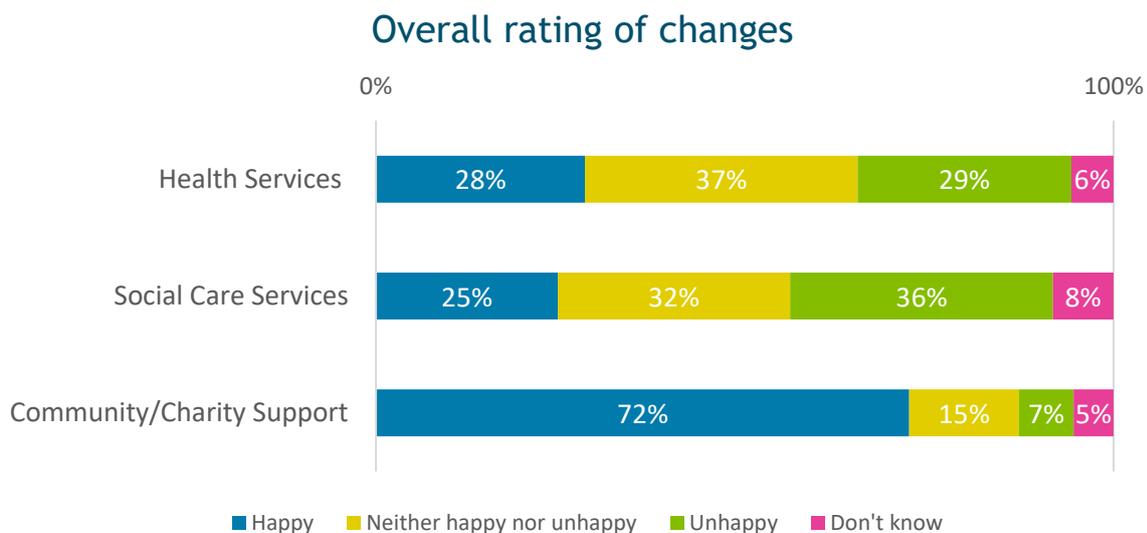
➢ Social care services

36% (out of the 73 people who answered the question) were **overall unhappy with social care services.**

➢ Charity/community group support

72% (out of the 148 people who answered the question) said they were **overall happy with the Charity/Community support.**

The graph below shows how happy or unhappy people told us they were with their support overall:

Overall rating of changes

Health Services	28%	37%	29%	6%
Social Care Services	25%	32%	36%	8%
Community/Charity Support	72%	15%	7%	5%

■ Happy   ■ Neither happy nor unhappy   ■ Unhappy   ■ Don't know

➢ Unusual times

Some people were understanding of the unusual circumstances and acknowledged that services had to change the way they work during unusual times:

> *I understand there has had to be changes in how services are delivered. I feel the health services have worked hard to adjust how services work for the benefit of the patient.*

Another person said:

> *Overall, it has been a learning curve for everybody and under the very difficult circumstances I feel that people have done their best.*

Experience of caring for someone

➢ Challenging times for unpaid carers

We heard that the pandemic has been challenging for some unpaid carers:

> *Looking after someone shielding on my own has been an extremely stressful challenge, especially when I have other physical disabilities and a history of bad mental health.*

One person explained that there was lack of support for their mental health:

> *Mental health services are involved with my partner by telephone - as is GP. However no one has spoken to me to ask how I am or how I am managing/offer me support as carer.*

➢ Lack of respite

Carers shared that there has been a lack of respite provision during the pandemic:

> *All respite for my three children stopped with no explanation and no alternative. They could have done video activities, offered parents the money for entertainment in the house- e.g. Ipad, games console, video club. I have been appalled! Not even a phone call to see how we were.*

➢ Shopping

Some carers also had difficulties with shopping and delivery of medication

> *Food and milk deliveries have been a nightmare. Accessing anything really like medicines. If we receive carer allowance we should get some priority in home delivery services to keep us away from areas where we risk infection. We have to keep safe to keep the person we're caring for safe. Who cares for the carers?*

➢ Young carers

We heard from young carers that during the pandemic it has been more difficult to take a break from their caring responsibilities. One young carer explained that (before the pandemic) a family friend used to come every week for meals and talking which was their *"weekly de-stress chatting and enjoying food together"*. This person also explained that Zoom was not the same thing because *"you can't create the same comforting atmosphere over video"*.

The impact of Covid-19 on specific communities

We had a closer look at data from different communities and some specific themes came up. These unique experiences are relevant to particular communities but are not necessarily representative of everyone in these communities.

➢ Fear of catching the virus

Two people said they felt at high risk from Covid-19 because they were from a Black Asian, Minority Ethnic and Refugee (BAMER) background. Other people from BAMER backgrounds expressed fears about catching the virus but did not explicitly link this to their ethnicity.

> An Asian man told us:
> *I did not need to access any service, but if I did, I would be naturally fearful of catching covid from health service providers.*
> A Black woman said:
> *I think of [what] could happen to my children if I caught it or what would happen if my children caught it. I have been really paranoid and this has mentally affected me. I think of it too much.*

What we heard from other sources

Other people have spoken to us about race and how this relates to Covid-19. They shared fears about a disproportionate risk of becoming unwell from the virus, but also discussed more systemic problems:

- We interviewed four local people to better understand the impact of Covid-19 on People of Colour:
  - Overall, interviewees felt that Covid-19 has highlighted social inequalities, sustained through different social systems. One interviewee noted: *"Covid-19 isn't racist, but it is very good at exposing racism."*.
  - Interviewees felt that there is a refusal to acknowledge racial inequalities and reluctance to research these issues in more depth.
- The Sheffield Chinese Community Centre used a grant to interview 39 Chinese residents in the city. Some of those interviewed shared worries about "increased discrimination and attacks on all people of East Asian origin".
- Through our enquiry line, we heard from one young black man about new rules mandating face coverings in shops. He told us he felt unsafe covering his face in shops, due to the suspicion he already faces from staff.

➢ Digital exclusion

Telephone appointments may not be accessible for people whose first language is not English:

> *It is difficult as English in not my first language to communicate the medical terminologies over the phone.*

Digital exclusion may have particularly affected asylum seekers:

> *Can't access anything online cause I'm an Asylum seeker. I couldn't access regular stores government didn't provide any assistance.*

One person explained that having to call the doctor is challenging:

> *Sometimes you might not have the credit to call the surgery and yet you need to see the doctor.*

What we heard from other sources

A local voluntary group told us about Refugee and asylum seeker's digital concerns:
- Limited access to technology for health advice and support.
- The cost of phones/laptops is a barrier, as is the lack of WiFi in asylum housing.
- NHS charges are deterring people from seeking essential health care. Applying for help with health costs is difficult – the application form (HC1) is complex, and the resulting certificate (HC2) has to be kept up to date. This is made more difficult by support services having to move online.

➤ Keeping in touch with family

Participants from different communities spoke about keeping in touch with family and how being away from family was challenging:

> *Good and bad, at the beginning it was bad because I was ill and had to isolate from my family but once I got better, it was ok because I am able to spend time and get closer to my daughter and husband.*

One person explained how their family kept active together:

> *As a family we make it a point now to do some physical activity and at least 30min cardio activity everyday. We NEVER do this pre lockdown!*

➤ Language support from young family members

A young person explained how they supported older family members:

> *I have to translate for the older generations and they are uncomfortable asking other people (non-family) to go to appointments with them.*

What we heard from other sources

We heard wider concerns about language barriers – including concerns about Refugee and asylum seekers' access to reliable health advice in different languages, and difficulties in challenging unreliable information.

➢ **Difficulties getting Halal food through foodbanks**

One person told us that there is limited availability of foodbanks offering Halal.

What we heard from other sources

We heard about other issues where, due to the particular needs of a community, facilities might be lacking or putting them at risk:
- Concerns were shared about a local Traveller community:
  - We heard that people no longer have access to water and toilets at the supermarkets they used to use.
  - Many are without income now they can't sell The Big Issue, and they haven't been able to sign up for Universal Credit due to lack of address.
- We also heard about the psychological impact of lockdown on Refugee and asylum seekers in poor quality accommodation, who may be very isolated and may have a history of trauma, including imprisonment.

Changes to be kept and things to go back to normal

Lots of things have changed as services adapt to new ways of working. We asked people about the future - which changes they wanted to keep, and which changes they did not want to keep. Below is a summary of what people said.

Changes to keep	Changes not to keep
➢ Phone appointments where appropriate, but have face to face appointments if necessary	➢ Cancellation of appointments
➢ Quick hospital referrals	➢ Cancelled activities or unsuitable alternatives
➢ Prescriptions being sent to pharmacy	➢ Social distancing
➢ Home visits from GP	➢ Lockdown
➢ Support from Charity/Community groups and organisations	➢ Wearing face coverings
➢ Remote meetings	➢ Healthcare services concentrating on Covid-19 while other issues left untreated
➢ Carers being able to work from home	➢ Lack of Personal Protective Equipment and Sanitiser products
➢ Information about local groups and activities	➢ Unavailability of testing
➢ Community spirit	➢ Inconsistent communication on what to do
➢ Volunteering	

Recommendations

> Health services should keep remote appointments, but ensure access to face to face appointments are also an available option.

> Services should take active steps to ensure the inclusion in their activities of people affected by digital exclusion.

> The social care system needs to be able to respond more effectively to changing needs. This could be done by:

  1. Giving people a clear and simple route to quick re-assessment when there is a change in their needs, with readily available information about how this process works.
  2. Evaluating the impact of the 7-hour rule which allows care providers to be responsive to changing need – has this produced better outcomes for people, and if so could it be more widely used?

> People with eligible social care needs would benefit from more information about their options for accessing support. This includes people who haven't accessed social care support previously. The system needs to be clear and accessible for people seeking support for the first time.

> Charity/Community organisations should capture and share good practice around reaching out to those in need and providing flexible and person-centred support.

> People have shared their experiences about Covid-19 widely, with Healthwatch Sheffield and many other agencies in the city. Statutory partners should be clear and open about how they are using this information to drive improvement – for example via a dedicated page on their website.