

The People's Network adult social care and you

Summary of an online community
forum hosted by Healthwatch Dudley
& Dudley Council during the
COVID-19 pandemic

September 2020



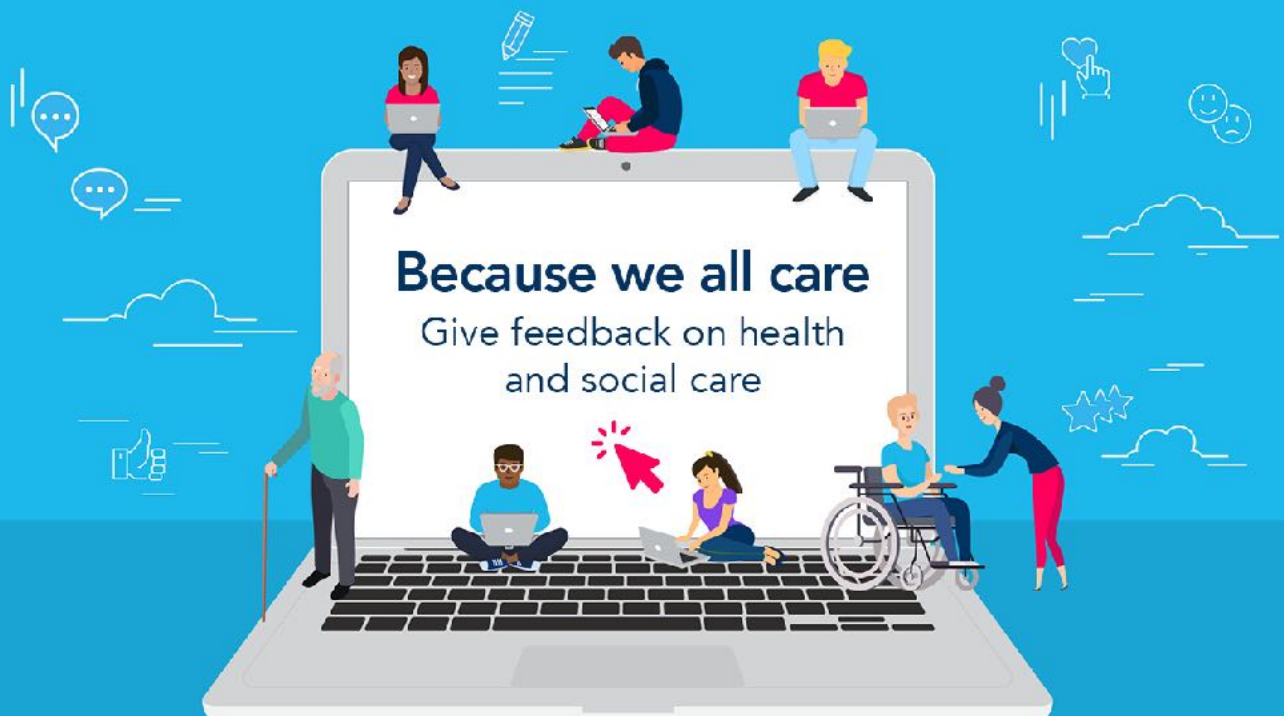
The event

In August 2020, Healthwatch Dudley and Dudley Council teamed up to host an online community forum. People with experience of or an interest in adult social care services and getting access to help since the start of the Covid-19 pandemic, were invited to join a friendly online community conversation using Zoom.

We were especially interested to hear from people who could tell us about:

- * Shielding during the pandemic
- * Looking after someone getting support at home from paid carers
- * A friend or a relative living in a local care home
- * Living with a disability or caring for someone who has
- * Using an alarm or other Telecare service provided by the council
- * A family member who had been discharged from hospital during the pandemic and needed extra care or support
- * Going out to work when someone else in the household was shielding

The event was linked to the Healthwatch England and Care Quality Commission (CQC) national [#BecauseWeAllCare](#) campaign, which set out to encourage more people to give their feedback about health and care to improve local services. The statistics presented in this report have been taken from research carried out specifically for this campaign between 11/05/20 and 16/06/20 with a sample of 2000 adults in England.



35 people zoomed into the event which was signed by British Sign Language (BSL) interpreters, enabling six deaf people to join the conversation. Attendees were predominantly white British, middle-aged and older people, with either an interest in, or direct experience of accessing adult social care services.

Participants were split into five breakout rooms each with a note taker and someone to help each group consider the following questions:

- * What has the lockdown experience been like for you, what has worked well, what could have been better?
- * Thinking about your care and support needs - or those of someone you care for - what has been working differently, what has been good, what could have been better?
- * How have you been communicating during the pandemic, have you been connecting with friends and with local services online, what have you been using, how has this been for you?
- * Now we are coming out of lockdown is there anything that has been happening differently that you would like to keep and what ideas have you got for making adult social care services better moving forward?

Lockdown experience: What it's been like

During the event people talked about their anxiety and the difficulties they had faced since the start of lockdown. They had been closely following the lockdown guidelines. One of the most challenging things at the start of the lockdown had been getting groceries. Many people had not been going out for shopping since the lockdown was announced in March.

Participants shared how it had been a bit of a rollercoaster with ups and downs coping with the impacts of lockdown on people's lives, especially not being able to meet face-to-face with family and friends. In the early days of lockdown there were those who were vulnerable and fortunate enough to have family or neighbours to help with shopping. Not everyone was lucky enough to have such help at hand.

"I'm over 70 and live on my own. I'm used to coping. I have people who do my shopping."

People valued that you could get advice and help from Dudley Council through the 'Pleased to Meet You' telephone helpline, support with shopping and medicine through Dudley CVS and the Government food parcel scheme at a time when everything was hectic.

Remarks were made about being used to coping and finding the first few weeks okay but for some this was counterbalanced by increased feelings of isolation as time went on. And not wanting to be a burden on family or neighbours.

“We are not shielding, but both of us are in our mid-seventies so have been cautious and, until the Government guidelines allowed, only seeing family in the garden and with social distancing.”

Those who were able to get out for walks or to do things in the garden said it had helped with their mental health and wellbeing.

“Our own mental health has been pretty good, but I do notice with us and our friends that everyone has lost a bit of sparkle, all of us appear more reflective...”

Challenges and difficulties

People shared how it can sometimes be difficult asking for help.

“You don’t want to be a nuisance. Everyone has their own lives to live and their own problems to deal with.”

“Shopping can be a challenge. People isolating were initially in a tight spot with some things like toilet rolls being in short supply.”

Participants shared how a sudden feeling of isolation was often the biggest problem. Then it was a question knowing where to go to get information on shielding and staying safe and how to get help with food and medications deliveries.

“As time has gone by it has been more about trying to look after yourself, children if you have any and dealing with not having the usual contact with extended family and friends.”

“The last few weeks have been tough. I have three school age children and it is like they have had holidays since March. My parents-in-law have been marooned in Spain for four months so it has been isolating being separated from them.”

Getting to know about what help was available with shopping and medications deliveries had not been easy for everyone. There were some good stories about how people had got help from a pharmacy but in a few instances the service had not met expectations with comments on the wrong or late delivery of medicines.

At the start of lockdown getting information on care and how to stay safe was a priority for many, although this wasn't for some as straightforward as one might expect.

“I got in touch with the doctor at the start of lockdown and I was told to stay in. A letter we were told we would get never turned up. We could not get online shopping deliveries. Our health conditions were not on the Government list, it is ambiguous.”

Some people, later on in lockdown, did not like having to wear a face mask finding it uncomfortable to wear. For deaf people the masks were a particular problem since it meant they were unable to lip read if someone was wearing one. Others were anxious because some regular ongoing care and treatments had stopped.

“There are people I know who have had regular treatment stopped ... eye injections for macular degeneration and iron injections. I was a nurse, hospitals are not doing as much as they did, and consultants are not doing so many appointments.”



Almost three-quarters

of people say they've noticed changes in their health and social care during the coronavirus emergency

#Because we all care

People said they were increasingly feeling a long period of lockdown had affected their health and wellbeing but they didn't want to be a burden on others.

“I don't feel I can keep asking my good neighbours to support me it's difficult to ask people for help, it's having an effect on my mental wellbeing having to confine myself to home ... I am anxious about going out.”

“It's about the effects of a long period of isolation and juggling what you can or can't do and what that means for your health and mental wellbeing.”

Here access to information technology and the internet can be vitally important. However, what happens to the digitally excluded and those who are unable to or can't get online?

Care and support: Living differently

People talked about having to try to get along and get on with things despite the virus and needing to socially distance or isolate. The change, for some, though, has impacted adversely on their self-esteem and confidence. It has been especially challenging for those with physical and mental health conditions.

A big difference has been how people had been able to contact their GP and not visit a surgery, which is what was felt many people prefer to do. Whilst there are many reports of good help provided over the telephone, there are those who do not feel comfortable about getting help that way. At the same time, there are questions about getting help online.

“Some people may find online GP appointments difficult ... getting access to digital services and their confidence in using them has an impact on people's connectedness and experience getting help.”

“There is a danger of people not following up on their illness. People prefer face-to-face contact, not everyone can use a telephone to articulate their symptoms.”

Participants discussed how digital exclusion is a worry with a certain people people who will miss out on the help and support that is provided online.

Others who have experienced difficulties with communications include those who are deaf and prevented from lip reading when someone is wearing a face mask.

As people begin to venture out again, trying to stay safe, some were worried about the further easing of lockdown restrictions and in particular what happens when children and young people return to school in September.

“My older neighbours and those with dementia have been concerned about children going back to school and how they can still be safe...”

People had also noticed how being out less has meant they are sometimes less physically fit or their mental health had deteriorated.

Good things happening

Good things were happening, people remarked, with regard to personal health and support during lockdown. Some commented on the good support they had had from paid carers continuing to visit them at home after the lockdown had been announced.

It was pointed out though how some paid carers are expected to visit too many people and are unable to spend much time with them. And individuals employing a personal assistant to help them with their care needs and not receiving any services directly from the council had not been contacted to see how they were coping.



35% of people

are more likely to donate to health and social care charities as a result of coronavirus

#Because we all care

Others had benefitted from having access to Telecare services and good GP care using the telephone. One person who had had a fall described how they activated their Telecare fob and had then been taken to hospital by ambulance for a check-up and treatment.

“It is good in that you are not having to wait for an appointment. Doctors will ring back...”

“Mum, who is one hundred, still had carers coming ... there was a shortage of carers during lockdown, but the carers have kept coming.”

There were discussions about the many people getting help from volunteers with shopping and medication deliveries that supplemented the help they were getting from statutory organisations and others.

“My brother has benefited hugely from Dudley Council for Voluntary Service volunteer help with shopping as have two of my friends, all have been absolutely delighted and so impressed with this service.”

“We need to say a big thank you to everyone in the community who has been helping others since the start of the pandemic.”

Risks and opportunities

Participants shared how they felt there had been plenty of time to organise but there still seemed to be some parts of business and health and care organisations that could have adapted better to the developing pandemic. There were remarks about how organisations needed to be able to quickly respond to changed public needs and provide all the extra help they could.

“I’m not blaming organisations, but they have had a length of time now to organise, they have time now to think differently.”

Some people were concerned about the very severe restrictions on face-to-face contact, especially with healthcare professionals, the detachment and anonymity of the telephone, or only being able to get access to help online.

“I feel it may be bad if it ends up you only get face-to-face meetings after going through things on the telephone ... The phone can be an excellent way to do things but it can be a problem for some people.”

People shared concern individuals who have been separated from the wider community and the help they might need to make them feel a part of it again.

“We need to ensure these individuals are not forgotten or left behind when things change.”

How we've been communicating

Participants discussed how one size does not fit all when it comes to communicating with others including extended family and friends. For some living alone, it has been a particular challenge keeping in touch with others. Wherever possible it is about telephone calls or getting online if you can.

“I've been using Zoom... I'm using text messaging, WhatsApp and emails and Skype... I'm using Microsoft Teams... Facetime has been good.”



Three-quarters (76%)
of people think feedback is an
important way to help improve services

#Because we all care

People discussed how for those who are older, are deaf or have sight loss it is not easy to communicate in hospital with clinicians when everyone is wearing a face mask. At the same time, it had not been possible for people to visit loved ones in hospital so they couldn't help with communications.

“Coronavirus has changed life dramatically - lots of barriers... I was due a hospital review and was told not to come in and to do it by phone. I said I couldn't use the phone because I'm deaf and asked to use Zoom but the hospital said they would not use it.”

One idea shared was for the council to have its own signed video service for deaf people to use.

Who we've been connecting with

People talked about how during lockdown they had been finding ways to stay in touch with family and friends. For those able to get online some had set up groups, organised quizzes, coffee mornings and Pilates classes.

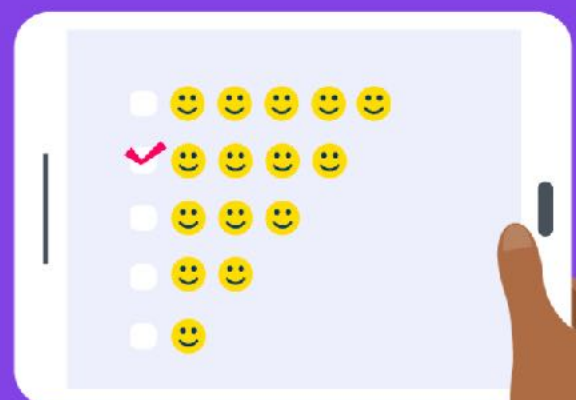
“I have been using Zoom to keep in touch with my relatives abroad ... I have begun to shop online ... I'm doing Zoom chats with family ... I'm doing quizzes on Zoom ... I am part of two drama groups that meet on Zoom ... I've found information searching on the Internet.”

“There is a shop in Halesowen, I ring them and food is delivered fresh.”

Two-thirds (61%)

of people are more willing to support NHS and social care services as a result of coronavirus by actively providing feedback on their care

#Because we all care



How things have worked

Participants discussed how for many, the Internet had been a lifeline and Zoom had been a very popular means of keeping in touch.

“Zoom has been good for my wellbeing ... I have learned new skills ... It is brilliant though not the same as physically meeting ... I have made use of text messages, WhatsApp, Skype and FaceTime - they have been a blessing to keep in touch and feel less isolated.”

Many had been using online platforms to keep in touch, which had worked well for them in the time they have been confined to their homes.

There was however much reflection on how it is not always possible, desirable or easy to connect with people providing help and support or family and friends online.

“I would not want this online to be the norm, you do need physical contact, interaction ... Sometimes coming together physically you learn more about each other than doing things online ... The challenge is how to encourage people to become more digitally aware and how people can be trained and supported.”

There were also concerns regarding the exclusion and isolation of people who who can't or don't want to go online to get access to health and care or other services.

“It would be good if there were more computers - laptops and tablets - that people in care homes could use to get access to information and services or communicate with their family and friends.”

Coming out of lockdown - Change for the better

People remarked that now as lockdown is easing there is beginning to be more moving around outside and meeting up with close family and friends. But, others still shielding worried about their health and catching the virus.

The good work that the NHS, Dudley Council and volunteers have been doing was recognised and applauded. It was discussed how strong community spirit will hopefully continue to mean different sorts of help will still be available to call on if people need support to stay safe and well.

“People are kinder. The voluntary sector was at the heart of everything that has happened, volunteers stepped forward and kept the show on the road.”

“Red tape and bureaucracy has reduced. It would be good to keep this momentum going.”

“In the hospital they brought in ‘Attend Anywhere’ virtual clinics and virtual outpatient appointments, which are now being rolled out.”

“We’ve been able to have meetings online and sometimes more people have been able to participate than if a physical meeting had been held.”

Participants discussed that during the pandemic, communities and individuals had all pulled together to get on with what needed to be done to keep health and care services working.

As the lockdown eases we can start to reflect on what has happened and take advantage of learning opportunities to ensure those services are robust and resilient moving forwards.

There was also a strong feeling that we need to make the most of technology and innovations in the development of online services that can help us to look after ourselves and each other.

More work needs to happen to support more people to get connected to the internet and accessing online services, whilst ensuring those who for whatever reason are not able to get online are not disadvantaged.

Making services better

There was recognition that dealing with the fallout from the pandemic is going to be a long-term problem and anyone needing help will need to know what is available and where to go to get it.

“The different organisations providing help must start or get better at working together to help to ensure services work well for communities and individuals.”

“Covid-19 will keep ‘popping’ up so we need to enhance what has been developed whilst it’s been around.”

People concluded that it was important to listen to what people have to say about their Covid-19 pandemic experiences, to understand how health and care services can work better to meet their needs in the future and be more prepared to deal with any new spikes in infections.

“We need to avoid silo working between health and social care and understand the importance of engagement with the local community and patients, to ensure services are developed around them.”

Council service information presented at the event

Queen’s Cross Network and the Pleased to Meet You helpline, which are managed by Dudley Council adapted their service at the start of the pandemic. Local people aged over 18 who were shielding or found it difficult to get out and about, were linked to support to help them receive food and medications. The helpline continues to offer help to those experiencing loneliness or mental health problems by putting them in touch with others who can offer support.

At the peak of the pandemic the helpline was providing 1500 offers of help each week with more than 10,000 offers of help provided during the crisis.

The council run Dudley Carers Hub, which had to stop face-to-face interactions with individuals, was able to maintain an advice line service to support unpaid carers with guidance on Covid-19 matters. It was also involved in wellbeing calls with carers and setting up virtual carers groups - to support individuals with getting online and accessing services.

Feedback and next steps

- * Individuals reported feeling anxious, isolated and sometimes lonely with worsening physical or mental health.
- * Communications on what support is available to help with everyday living and how to get access to it must work well for people.
- * The Covid-19 pandemic caught organisations and individuals on the hop, there were varying degrees of readiness to deal with its consequences.
- * It has been possible for individuals to get help with health and care matters using the telephone or by going online. But, some people may be disadvantaged if they are not able to get face-to-face appointments and are not comfortable with the new or alternative ways of getting help.
- * The NHS has done a lot of good work during the pandemic but there is scope for more public engagement learning. The aim should be changed ways of working that means it is better able to help individuals using technology and through improved communications.
- * It would be good to find ways to make the most of all the growth in community networking and volunteering activity that has occurred since the start of the pandemic and helped people with their health and care or other day-to-day needs.
- * Many organisations have started or are working better together in collaborative and joined-up ways that are benefitting the individuals they help and should be sustained and further developed.
- * There is risk of some individuals being left behind if they can't access digital services and are not online. Nobody should feel excluded or left out.

One-third (36%)

of people are reluctant to provide negative feedback on care in case it increases pressure on services or staff

#Because we all care



“ One size doesn't fit all, individuals have different communication needs. They might, for example, be deaf, sight impaired or have dementia. We need to better understand who can and can't engage with technology or use online services to get access to help with their health and care. In light of the pandemic there are new opportunities to look at:

- How we involve individuals in health and care discussions
- The ways that we communicate with people
- What it is we do to gauge a person's health and care needs
- How best we can support carers
- The support we give to community and voluntary organisations
- How we can make the most of a strong community spirit
- Keep new volunteers enthused and wanting to carry on doing what they are doing

Dudley Council will, for example, continue to: work with supermarkets to ensure that local people with health and care needs are able to get priority for shopping deliveries; further develop the Telecare Service that 8,500 individuals currently use; and have a local Track and Trace system ready to use in addition to or instead of the national testing system if that is an appropriate thing to do.

At the start of the Covid-19 pandemic it was a case of all hands to the pump to get things done to help vulnerable individuals, it brought out the best in the people of Dudley borough.

The future is going to be full of challenges and sometimes very difficult for organisations and individuals. Regarding getting help with health and care we need to understand what has worked well for individuals during the pandemic and ensure that learning and innovation is not lost. ”

Matt Bowsher
Director of Adult Social Care
Dudley Council

Share your experiences of care... Because we all care

We all care about the NHS and social care...



...but coronavirus has placed these services under enormous pressure



There are lots of restrictions when it comes to visits and inspections to services and healthcare is being delivered digitally



It's more vital than ever that we understand people's experiences of care

People in England are grateful for NHS and social care services and want to support them in the future.



Three-quarters (76%)

of people think feedback is an important way to help improve services



Almost two thirds (61%)

of people are more willing to actively provide feedback on their care



Over a third (35%)

of people are more likely to donate to health and social care charities



But, what stops people feeding back on care?



A third of people are reluctant to provide negative feedback in case it increases pressure on services or staff



A fifth of people are less likely to provide negative feedback on care due to coronavirus



Over half recognise the challenging circumstances health and social care staff face



42% don't want to cause further issues for services to deal with

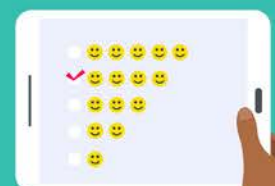
What can I do to help?

Now, more than ever, we need your feedback – both good and bad - to help services adapt to coronavirus.

Why should you share your feedback?

- Help services to identify and address issues during COVID-19
- Improve support for yourself, your loved ones and your community

You have already made a difference



7,200

recommendations from Local Healthwatch about improvements people want to see were shared with services in 2018/19

Call Healthwatch Dudley: 03000 111001, Tweet us or find us on Facebook: @HWDudley

To help improve services for everyone, give your feedback on care at:
www.healthwatchdudley.co.uk/your-experience or speak to services directly