Speak Out Council

Communication consultation
September 2020 v1
Who are we?

VoiceAbility’s Speak Out Council (SOC) is made up of six employees with learning disabilities and/or autism, who work together to give people a say on the issues that are important to them. They do this by running consultations and drop ins with local people, and by talking to professionals and organisations who can make a difference. They are supported by a co-ordinator and a young person’s project worker.

The Speak Out Council carries out 4 consultations a year. Each quarter it focusses on a subject that people with a learning disability and/or autism have told them is important in their lives.

What did we do?

- Following our previous consultation about how lockdown had affected people, we asked people for their views on communication.
- We included questions about the news, websites, healthcare, education, social care and information from the government. We also asked about different formats, including letters, emails and phone calls.
- Because we were not yet able to meet with many people face to face due to coronavirus restrictions, we also carried out our survey online. We also sent paper copies to some services which had reopened, and spoke to some people over the phone.
- The survey ran from the end of July until early September.
- As it was the school and college holidays, and because day services are only slowly returning, we found it harder to reach as many people as in some of our previous surveys.
- By 15 September we had heard from 63 people, 32 young people and 31 people aged 26 and over.
- Our survey was long as we had included questions from our partners in many different services. Some people found the survey too long, in future we will create shorter surveys!

- We have put our recommendations in boxes like this throughout the report.
Who did we speak to?

We spoke to 63 people from across Cambridgeshire.
- 19 people said they were between 14-18
- 13 said they were aged 19-25
- 23 said they were aged 26-40
- 6 said they were 41-54
- 1 person was 65 +, and
- 1 person was not sure

Everyone we spoke to had a learning disability and/or autism. Of the young people:
- 6 people told us they were on the autistic spectrum,
- 15 said they have a learning disability
- One person said they have high support needs.

What did we find?

Ways of communicating – letters, emails and phone calls

We asked people if they receive letters, emails and phone calls and whether they find them easy to understand.

- People told us that they generally find it is easy to understand letters, emails and phone calls. Many of them have support.

Do you receive emails, letters and phone calls? Do you find them easy to understand?
If you are 16-25 years old, do letters and emails come addressed to you

- Interestingly, many young people said they don’t use emails and/or receive phone calls.
- When we asked young people who letters and emails were addressed to there was a fairly even split. Worryingly, about a third of young people aged over 16 told us letters and emails are addressed to their parents.

What would make letters, emails and phone calls easier to understand?

<table>
<thead>
<tr>
<th>Letters need:</th>
<th>Emails need:</th>
<th>Phone calls need:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Less information</td>
<td>• Larger font</td>
<td>• People to talk slowly and check that I have understood before moving on</td>
</tr>
<tr>
<td>• Easier words</td>
<td>• Key points highlighted – especially the things I need to do, and</td>
<td>• Video calls rather than just voice calls</td>
</tr>
<tr>
<td>• Larger print</td>
<td>• Someone to read and explain them</td>
<td></td>
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<tr>
<td>• Picture clues</td>
<td></td>
<td></td>
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<tr>
<td>• Highlighted key points</td>
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<tr>
<td>• Picture boards, and</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• To be kept simple!</td>
<td></td>
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</tbody>
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Finding out about the news

We asked people how they find out what is happening in the world. And what would make the news easier to understand.

Where do you find out about the news?

- Many people told us they find out about the news from social media.
- There were many comments about fake news and needing to separate facts from fiction, and the confusion caused by conflicting sources.
● People said that simple language and short sentences would help them to better understand the news in general.
● People find subtitles very useful and would like them on all the time.
● Someone suggested a tv channel for “people with all kinds of disabilities”.
● Young people also told us:
  o At school or college people said it would be good to be informed about things with more notice and appreciate being able to talk things through.
  o One young person told us that teachers are good at explaining news but said that she finds it harder to understand news from her friends because they talk quickly.
  o Most young people said they find out what is happening in their local area from family or friends, with a few looking at posters or local magazines.

What would make the news easier to understand?

- Supporting us to separate fake news from real news
- Use easier words
- Give us information in good time
- Check we have understood

We asked if people found it easy to understand information from the government about COVID-19.

● Less than half of people aged 26 years + found it easy to understand.
● But most of the young people we heard from told us they did find it easy to understand information from the government about coronavirus and keeping themselves safe. We think this might be because many of them are living at home and have quite a lot of support.

<table>
<thead>
<tr>
<th>Young people</th>
<th>People aged 26 years+</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
</tr>
</tbody>
</table>

What would make the information about COVID-19 easier to understand?

- Have more information specifically for disabled people.
  (See Appendix for a link to Aurora Meldreth Manor’s personalised communications)
- Stickers on the floor are helpful for social distancing.
- Clear and consistent messages.
- Clearer rules would help - people talked about “mixed messages”
- “A lot of contradicting statements make it difficult to understand what the facts are.”
Websites

We asked people about the Cambridgeshire County Council website and how easy they find it to use.

We also asked young people about the Local Offer website – which provides information for children and young people with special educational needs (SEND) and their parents or carers in a single place.

- Very few people had heard about it and only one person said they had used it.
- People asked what ‘Local Offer’ means.

We asked about how easy it was to use and we believe people must have visited the site when answering this question, as we had several responses.

- A few people did not find it easy to use but several said it was easy with, or without support.
- There were comments that it did not feel like a website for young people.
Could you find the information you were looking for?

- Young people do not know what ‘Local Offer’ means - this needs explaining.
- People said the website does not feel it is for young people.
- Work with young people to make it easier to use.

Communicating with social care

We asked if someone from social care had asked how people would like to be communicated with. And if so, have they done as they were asked?

- Well over half of those 26 years + said that they were communicated with in the way they had asked, but quite a lot less than half of young people agreed.
We asked if people knew how to contact their social worker, and asked if they would like to chance to see them at college or their day service.

Many people told us that they do not know how to get in touch with their social worker which we found worrying but there didn’t seem to be much demand to be able to see social workers at school or college.

We wanted to know if people are asked for feedback on the services they receive from social care.

Almost half of the adults had been asked for feedback but not many young people are sure that they have been asked.

- Promote how to contact social care workers.
- Ask young people for feedback
- Tell young people how their feedback has made a difference.
Communicating with health services

We asked people if they knew that everyone, 14 years and over, can have a health check every year?

Slightly over half of the older groups knew about health checks, but less than half of the younger group knew about them.

Many people had not had a health check, or were not sure if they had had one, in the last 12 months.

- Keep telling people about health checks.
- GPs need to make it clear when someone’s appointment is a health check.
We asked how young people how they would prefer to have health appointments.

How would you prefer to have appointments with a health professional like a GP or School Nurse?

- Face to face, 19
- Telephone, 1
- Video call, 6

Most young people told us they would prefer face to face appointments.

We asked young people if they had heard about, or used, Chat Health (a confidential and anonymous text messaging service that is run by school nurses and the Emotional Health and Wellbeing Team)

Have you heard of, or used, ChatHealth?

- Yes, I have heard about it but not used it, 5
- No, I have not heard about it, 24
- Not many people had heard of Chat Health, and no-one we spoke to had used it.

- When face to face appointments are not possible, video calls are preferable to phone calls.
- Keep promoting ChatHealth!
We asked people if they had found their Drs website easy to understand during COVID-19

Most people, some with support, can understand the information. But many people do not know if their Drs surgery has a website.

We asked if people that had used their dentist’s website during COVID-19 and if the info easy to understand. We also asked if they were able to book an appointment.

Some people (8) were able to book an appointment but quite a few (5) were not able to. Most people did not know their dentist had a website. This was particularly true of young people who said they did not know their Dr or dentist had a website.

Young people - Does your Dr or dentist have a website? And are they easy to understand?
We asked if people find it easy to understand info about health appointments and procedures

Health appointments - Most of the people who receive this type of information can understand it, although almost half of those responding have support to do this.

Do you find it easy to understand information about health appointments?

- **Yes**
- **Yes with support**
- **No**
- **Don’t know**
- **I don’t receive this info**

Health procedures - Of the people who receive this info (so not counting the purple segment), most of them understand it (some with support).

Do you find it easy to understand information about health procedures?

- **Yes**
- **Yes with support**
- **No**
- **Don’t know**
- **I don’t receive this info**

- See Appendix for Healthwatch’s GP website report.
- People need to know in advance what to expect at health appointments and procedures
  - “I had blood tests that I had no information about until I got there”
  - “I had an out of hours appointment where he didn’t tell me what he was doing or going to do, which was really stressful”
- See Appendix for Healthwatch’s COVID-19 report, “…we are asking that communications with patients is at the top of the priority list and that the information is clear and people know exactly what to expect.”
Next steps

- The Speak Out Council is going to use this information, that young people and adults have given us, to produce some guides about communication. We will share these on our website.
- We will share this report with VoiceAbility, Cambridgeshire County Council, Healthwatch Cambridgeshire and Peterborough, CCG, Cambridgeshire Constabulary, hospitals, schools, colleges and day services, as well as other organisations.

Appendix and resources

Healthwatch Cambridgeshire and Peterborough

1. Covid-19 survey; briefing 1- 6 July 2020
   “It’s clear that local people really value and have huge gratitude for the people that have helped them during the pandemic. But it’s also very clear that there is quite a lot of anxiety and worry about their treatment and appointments. So as the system starts to put itself back together again, we are asking that communications with patients is at the top of the priority list and that the information is clear and people know exactly what to expect. Sandie Smith, CEO Healthwatch Cambridgeshire and Peterborough”

2. Covid-19 survey; briefing 2 - 3 August 2020
   https://www.healthwatchpeterborough.co.uk/report/2020-08-03/covid-19-briefing-2
   “Most said health care was good or excellent – but communication around changes was less positive”.

   “People tell us that they have found it harder to keep up to date with the changes to information and advice around how to keep safe”.

4. Giving GP Websites a Check-up – 16 September 2020
   https://www.healthwatchpeterborough.co.uk/report/2020-09-16/giving-gp-websites-check
   “Two out of three sites did not have good examples of accessible information for patients with sensory loss or learning disabilities”.

Understanding the messages around COVID-19

5. James A and James HG present their experiences of Aurora Meldreth Manor’s approach to personalised COVID-19 communication:
6. Mencap guides to COVID-19, most of which are accessible and in easy read format: www.mencap.org.uk/advice-and-support/coronavirus-covid-19/coronavirus-resources-support-workers

COVID-19 and mental health


Speak Out Day—Communication.
9. All presentations from the Speak Out Day on 11 September 2020 can be found here: https://www.voiceability.org/about-advocacy/types-of-advocacy/general-advocacy/speak-out-council

Speak Out Council’s videos about communication

10. Public transport
    https://www.facebook.com/SOCCambs/videos/236034874498221

11. The news
    https://www.facebook.com/SOCCambs/videos/1461327927390065

12. Cooking dinner
    https://www.facebook.com/SOCCambs/videos/369703437405848

13. Calling the healthcare centre
    https://www.facebook.com/SOCCambs/videos/606093043421449

13. The transport film mentions autism cards which some people might find useful when travelling. More info about these and face cover exemption cards can be found here: https://static1.squarespace.com/static/5e74a4169b3712658a63f54f/t/5eeb87d9e8f478511e292ab8/1592494047048/Mask-Exemption-Cards-V2.pdf

To find out more or get in touch

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