Speak Out Council

Consultation:
My life my future

March 2021
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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?

We wanted to know what is important to people now, and what they want to do in the future.

We asked people about:
• the things they like to do
• what they would like to change, or do in the future, and
• the support and information they feel they would need to make those changes.

We ran this survey through February and early March 2021.

We chose this topic because 1) we wanted to see how people were feeling during the latest COVID-19 lockdown and 2) because we want to use the answers to help our work when we look at things like day opportunities, housing and employment in more detail later in the year.

We heard from 103 people but we wrote a lot of this report after we had heard from more than 90 - some more answers came in after we had finished. As we have lots of different ways of getting people’s views, not everyone answers all the same questions, so some results summaries will show lower numbers.

We used Zoom and Microsoft Teams to meet on line with people at
• Eddies
• Huntingdon Community Centre, Shortsands (St Neots) and CATS (St Ives)
• And young people at Cambridge Regional College in Huntingdon and Cambridge and Samuel Pepys school (St Neots)

Branching Out and Prospects Trust kindly sent out our paper surveys.
• We mainly spoke to people aged 14-64 years of age. We only spoke to one person aged 65 years or over. We would like to hear from more people in that age group in future.

44 young people told us about themselves, and 13 parents or carers told us about their young people.

We spoke to people from across Cambridgeshire. We’d like to speak to more people from The Fens.
Most people told us they lived at home with their family.

- With my family: 49
- At home with carers/PAs coming: 5
- At home on my own: 3
- In residential or supported living: 6
- Other: 1

We spoke to people with a learning disability, who are on the autistic spectrum and who have high support needs.

- I have a learning disability: 47
- I am on the autistic spectrum (and): 16
- I have high support needs: 8
- I am not sure/I'd prefer not to: 5
- Other: 7

Most people filled the survey in about themselves but some parents and carers responded on behalf of the people they care for.

- I am filling this in about myself: 64
- I am a parent/carer: 17
- I am a PA/Support worker: 2
What did we find?

Your life in lockdown

Last April and May we asked people how they were coping in lockdown. We asked them the same things this year too.

- People were missing their usual activities and their families and friends.
- People told us their mental health was getting worse, and
- they were worried about returning to normal again.

People also told us about a lot of good things they have enjoyed during lockdown.

- Compared to the first lockdown people were pleased to be able to keep in touch within their bubble
- many people were able to return to
day services on-line, and some were able to go back face to face.

When we started this survey schools and colleges were mainly online although they have since started going back into the classrooms.

Students at Samuel Pepys school told us they are enjoying being back at school and seeing their friends. They miss two students who are still at home and said one of the hardest things about going back to school has been having to get up early.

What would make it easier to go back to “normal”?

We asked people what support might make life easier as we return to “normal”. They told us:

- Transport and Travel
  - “Help with travel costs so I am not having to use public transport again in the first instance”
  - “It’s hard to leave mum, would prefer her to drive me and not take the bus”
  - “Not having too many people in my taxi”

- School, college and day services
  - More IT/tablets for services so that people can start to join in again very soon
Having a “quiet room” to help me adjust to the noise with everyone going back at the same time

Making a difference: we have passed this information back to people at Cambridge County Council and have shared some information about IT funding and support with day service providers.

Things we are looking forward to doing soon

(This might be things we have done before and want to do again soon, or new things we’d like to start doing)
Support and training we need to do this

Activities we’d like to do:
- Learn to read
- Golf
- Mending my car
- Making more friends
- Sign language
- Film making
- Music, drums and piano

Training we need:
- IT and game development
- Cooking so I can cook for myself
- Assertiveness
- Apprenticeship
- First Aid training
- Work experience
- Typing skills
- Hospital work
- Bricklaying
- Bike mechanic qualifications
- **Advice and guidance:**
  - Apprenticeships
    - Work experience
    - Finding out which jobs I could do

Things that young people would like to keep doing, or start doing
Activities young people would like to stop doing or don't enjoy

- Cooking: 4
- Walking: 3
- Gardening: 10
- No internet: 18
- Family time: 1

Additional activities:
- Library: 1
- Bounce: 1
- Go to Pride: 1
- See grandparents: 1
- Church: 1
- Sleepovers: 1
- Paintballing: 1
- Go to beach and amusements: 1
The future - things we’d like to be doing in 5 year’s time

Volunteering and paid work
What young people would like to learn and work as in the future

- Not sure what I want to do yet, 3
- Jobs we would like, 5
- Apprenticeships and training for specific jobs, 7
- University, 7
- Sports related, 2
- Finding out about how to get a job, 6
- Catering, 2

Some young people know exactly:
• what they would like to do, and
• how to train for it.
But quite a few people would like more information about how to find work.

- Designing cars or games
- Nursing apprenticeship
- Be famous musician
- Bricklaying training
- Online business, work for google
- Being a Support Worker
- I need skills training around getting a job! Job interviews, CV
- Singer, Vet, work in a zoo, work in a library
What new things would young people like to start doing?

- Art, 4
- Dance, 4
- Music, 2
- Drama, 3
- Film making, 1

What new hobbies would young people like to try?

- Archaeology, 1
- Dungeons and Dragons, 1
- Photography, 1
- Beekeeping, 1
- Science, 1
What sports would young people like to take part in?

- Swimming, 4
- Sport, cricket, netball, volleyball, rugby, tennis, football, 6
- Horse riding RDA, 2
- Skiing, 1
- Ice skating, 1
- Archery, 1
- Gym, 1

The young people we heard from are interested in lots of different sports!

Friends, relationships and going out

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boy/Girl friend</td>
<td>14%</td>
</tr>
<tr>
<td>New friends</td>
<td>16%</td>
</tr>
<tr>
<td>Great daytime activities</td>
<td>17%</td>
</tr>
<tr>
<td>Great evening activities</td>
<td>16%</td>
</tr>
</tbody>
</table>
Young people’s friendships and relationships

- Have a girlfriend/boyfriend, 13
- Meet new people, 23

Lots of young people would like to meet new friends or find a girlfriend or boyfriend. We told people about Safe Soulmate.
Where would we like to live?

- At home with family: 26
- On own/with partner: 27
- With friends: 18

I do this now but don't want to do it in 5 years' time: 7
I hope to keep doing this: 9
New things I’d like to do: 1

A lot of people would like to start living on their own, with a partner or with friends.

Quite a few young people are happy to stay living with their family but some people would like to move out in the future.
Living in my own home

<table>
<thead>
<tr>
<th>I do this now but don't want to do it in 5 years’ time</th>
<th>I hope to keep doing this</th>
<th>New things I’d like to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>1</td>
<td>12</td>
</tr>
</tbody>
</table>

Living with friends

<table>
<thead>
<tr>
<th>I do this now but don't want to do it in 5 years’ time</th>
<th>I hope to keep doing this</th>
<th>New things I’d like to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>12</td>
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</tbody>
</table>
How would we like to spend our holidays?

- **Holiday with partner/family**: 23 (23%) 19 (19%)
- **Holiday with friends**: 25 (25%)

Lots of people told us they would like to go on holiday with their friends at their day service.

Lots of young people would like to go on holiday with their friends and also their families.
Lots of people are travelling independently but many more would like to do so.

Being able to travel independently is important to young people.

Independent travel
What else would young people like to do and what support do they need?

The support young people feel they need

- Alternative learning methods for large amounts of information
- Life and independence skills
- Work experience in hospitable places that universities will find attractive
- Support to go out in the evenings inc transport
- I would like some support in meetings

People would like all sorts of support, including work experience, support to live independently, support in meetings, going out in the evenings and building their own support networks.

Physical support to be living independently, research into M.E./C.F.S. so that my health outcomes improve, coping mechanisms for anxiety, a therapist who is skilled in working with autistic people, building support networks.
What did parents and carers of young people tell us?

- They are worried about support for their young people when they move on to university.
- They would like to know more about supporting young people to find a job.
- They would like more information about what happens when EHCPs finish at age 25 and support to plan for their young person’s future.
- They are worried about their young people’s mental health and making friends.
- They would like clearer information about benefits.
- Some parents would like Speak Out Council to link with some new schools and colleges.
- Some parents would also like to join the Speak out Group for people with more complex needs so that their young people’s voices are heard.

What else did people with high support needs tell us they want?

Access to the internet

- Some people in Supported Living still do not have access to the internet.
- They have not been able to take part in any online activities at all.
- We think residential or support living contracts, or individual’s own care packages, should include a specific mention of IT equipment:
  - regular access to wifi and
  - well qualified support to use it so we can make the most of the opportunities available.

Great news – we were able to share some information about funding for internet access.

The Good Things Foundation is working with Learning Disability England, the Voluntary Organisations Disability Group and Digital Unite to fund IT equipment, data and support. It is for organisations that already support at least 10 people with a learning disability who are digitally excluded.
Changing place toilets

Finding safe clean public toilets is important to everyone. For people with high support needs Changing Places are vital so they can enjoy going out and about.

Pets

How to find safe clean public disabled toilets is hard

We think there might be some funding for them. We are looking into it.

Lots of us have pets, but many more would like one in the future.
What do we think this means?

Over the next couple of years:
- People want to get back to their usual activities and try new things.
- There are lots of things they would like to try but they might not know how to do that.
- People need more information about training, work experience and job options.
- Sometimes the support people need to do something different can be something as simple as just having someone to go with them.

Learning, training, work experience and jobs:
- Lots of people would like training to travel independently, and to learn to drive
- People have great ideas about the volunteering or jobs they’d like
- They need more information about training, work experience and job options

Activities and sports:
- People want to try lots of new and unusual activities and hobbies
- Try a wide variety of sports - sometimes the support people need around sport is just someone to go with them
- Changing Places are vital for people with complex needs so they can go out and about

Friends:
- People would like to meet new friends, and to have a girlfriend/boyfriend.

Home:
- Lots of people would like to live on their own, with partners and with a group of friends

Training and support:
- People would like all sorts of support, including work experience, support to live independently, support in meetings, going out in the evenings and building their own support networks.

Internet:
- Everyone needs access to the internet (connection, equipment, support and training) so they can take advantage of all the opportunities available

Parents of young people:
- Want to know more about
  o support for their young people when they move on to university
  o young people’s mental health and making friends
  o supporting young people to find a job
  o what happens when EHCPs finish at age 25
  o planning for their young person’s future
  o clearer information about benefits.
To find out more or get in touch

- Email: Speakoutcouncil@voiceability.org
- Call or text: 0786 700 2124
- Visit: www.voiceability.org/speakout

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