Speak Out Day 1 July 2021
You and Your Home
Thank you to everyone who joined us on the day!
Neil Adams
Speak Out Council Leader: Young People
Young People’s News
and visit to Parliament
I’m going to tell you about what I have been hearing from young people.

I have been going to CRC to see students. We have also been chatting to Samuel Pepys School on Teams.

It has been really good to see people and we want to say a big thank you to all everyone!
We have been talking about Preparing For Adulthood (PfA)

We are working on a project with Cambridgeshire County Council to make sure that young people and their families have good experiences of Preparing for Adulthood. There are 4 topics and I will talk about them all next.
Good Health

Long waiting lists have made some people feel anxious.

Sometimes waiting at the doctor or the hospital is hard and hearing results is disappointing.

It is sometimes hard to understand words they use at the doctor’s.
Employment and careers

Young people want to do loads of different jobs like making music, being a games developer, or opening a cafe, a singer or working in the pub.

They are choosing college courses that will help them and thinking about the things they need to learn, ‘like taking responsibility’ and ‘being a team with my friends’
Independent Lives

Young people say they need some support with a lot of things like:

- Bus and train travel, but it’s a pain as they aren’t always on time.
- Paying the bills
- Planning trips out to places like cinema or a restaurant
- Using money
- Personal care
- Hoovering my room
- Getting enough exercise
- Cooking
- Medical appointments
- Support with medication
Community

Young people do a lot in their communities like:

• Go to the shop
• Dog walks
• Time with family and friends
• Swimming at the leisure centre.
• Fun on my own.
Other things young people would like to do in their communities

A club like a youth club where I can get to know people there.
Young people said some youth clubs stopped before the pandemic and they don’t know how to find out about things they can do.

Lots of the young people at Samuel Pepys school said they would like to do more after school and in the holidays.
We talked about the college holidays

Lots of young people are looking forward to spending time with family, friends and support workers.

Some young people were not looking forward to the holidays because they can’t see their friends and they don’t have any way to get to see anyone, or do anything else while their parents are working.
Independent Lives

Some young people said this:
Get my own place
Move to supported living and have new adventures
I’m thinking I might want to live by myself.
What I will do next

We have got lots of information to share with Cambridgeshire County Council SEND Partnership Group! They are deciding what the most important things are to work on, so I am going to tell them what we have heard from young people.

I will also share it with the Preparing for Adulthood project.
On Wednesday 15th June Mencap held an event at Parliament with the All Party Parliamentary Group for Learning Disability.

I went with some other self-advocates from VoiceAbility.

The event was all about how people with learning disabilities felt during the pandemic.
There were a few speakers and one of them called Brendan talked about how lonely he felt in the pandemic.

After the speeches I got to talk to the MP Mark Harper who chairs the group about Learning Disability.
I was talking to him about the pandemic and people’s mental health.

It is confusing when there isn’t Easy Read information straightaway.

Mark agreed that there should be Easy Read information at the same time as other information.

He even said that sometimes it would be better for all the government consultations to be Easy Read.
I also told him that people were feeling lonely in the pandemic. I know how I felt.

Some young people have told me that they are still lonely in the school and college holidays because they don’t live near their friends and there is nothing to do near to where they live.
I said people with a disability aren’t always getting vaccinated and I worry about that.

I talked to him about the fuel charges going up and I’m worried that people won’t be able to do everything they want to do.
I also gave Mark some information about other things that we think are important.

**Health waiting times** because people have told us they feel anxious about this

**Reasonable adjustments in hospital** like Easy Read and more training for all hospital staff about how to support people with a learning disability.
Employment because many people with learning disabilities want to work and we want employers to know and understand how to support us.

Training about Learning Disability
Speak Out Leaders feel there should be more training for everyone about living with a learning disability.
Anne Hunt
Speak Out Council Leader Fenland
My News
In March we gave a presentation to employers about employing and supporting people with a learning disability or autism.

We talked about our own experiences and gave employers advice about supporting people to get and keep jobs.
We helped the Adult Social Care Forum to set co-production standards to make sure good co-production happens.

We have been helping with information for the Stay Well This Winter pack, it will be online as well as printed this year.
I’m looking for a good place for a drop in in March, the town. I’m going to visit Tennyson Lodge and also meet with Thera.

I have been to CANEF meetings and Bill and I got a thank you for helping the meetings work well.
I help Sean with some of the East Cambs work, so I am going to do a walkabout in Littleport with Think Communities and visit people at Branching Out.

I also went to Soham station recently with Russell but he will talk more about that.

I met with Monika, Community Navigator for Fenland, she is going to invite us to some events so that we can reach more people.
• Thanks for listening
• Do you have any questions?
Sean Nightingale
Speak Out Council Leader: Huntingdonshire and East Cambs

My News
I’ve been making good links with Thera and Huntingdon Mencap.

I am looking for somewhere in Huntingdon for a new drop in.

I’ve been to Mencap’s Treat Me Well meetings and also the regional NHS Co-Production group.
I have been talking with Think Communities about Safe Places, and TING, the new on-demand bus service for the western part of Huntingdonshire.
Bill and I are sharing the new Speak Out Leader for Health role. The Clinical Commissioning Group are funding this until July 2023.

As the Clinical Commissioning Group becomes the Integrated Care Service, we will be working on co-production, finding new ways to reach more people.
Health Consultations

Over the next few months we are going to be asking people about Annual Health Checks.

After that we will do two more consultations.

All the health topics are things that people said are important to them in the Learning Disability Vision last year.
Our film about communication and participation in the Court of Protection was shortlisted for an award in the Best Co-production category at the Advocacy Awards.

We were in the top two out of 50 entries and are very proud of our achievement!
• Thanks for listening
• Do you have any questions?
I plan to relaunch my regular monthly drop in and I’m looking at the best venues for it, Think Communities are helping with this, along with Ashley our Sawston Safe Places volunteer.

South Cambs and Cambridge City Community Navigators and Social Prescribers are helping with the Safe Places scheme.
In case you were wondering…
Social Prescribers can help you:

be more active
be more socially connected
be healthier
live well and more independently
support your mental wellbeing
support with your finances

If you think you would like this kind of support you can contact your GP (doctors’ surgery)
Health Leader role - helping to design a new text messaging service for anyone who needs urgent support with their mental health. We have been working to decide a good word for people to text to get help.

Court of Protection film project – we went to a conference in London and did a question and answer session about our part in the film about Communication in the Court of Protection.

We are working with the LDP managers and Think Communities to find the best way of making sure everyone can hear about the issues that are important to people with learning disabilities.
Russell Henke
Speak Out Council Leader: High Support Needs

My news from people with high support needs
The High Support Needs Committee have been looking at how bad the pavements and kerbs are in some parts of Cambridgeshire. We have visited Histon and St Ives.

In St Ives we visited the Norris Museum where friends from sense college help to run the monthly pop-up café. We had tea and cake in the museum garden!
We are looking at problems some organisations in Cambridgeshire have had when applying for a group Blue Badge. Mark Taylor, the City Council Access Officer, is helping us with this.
I went to Soham station to see how easy it is for people with a disability to travel from there.

Anne met me at the station, and so did Christian from Think Communities.
The dropped kerb from the car park is smooth and level.

But it was difficult to see where the dropped part stopped and the regular high kerb started.

We felt the dropped kerb should be painted in a different colour to make it stand out.
There are no staff at the station.

Anne and I tested the Help Point.

We asked if there were any toilets at the station.
We found out that there is no toilet anywhere at the station.

The nearest accessible toilet is in a car park nearly half a mile away.

You need a key to use this toilet. The notice on the door says you can buy one from East Cambs District Council offices.

That’s no good if the offices are closed and you don’t already have a key!
The ticket machines were at a good height, but it was difficult reaching them in my electric wheelchair.

I would need to approach them sideways on, but then I might not be able to see the screen properly.
There is no waiting room at the station, and nowhere to get a drink or anything to eat.

There are two covered waiting areas which would not provide much shelter from bad weather.

The platform is quite narrow and very high, so you have to take care not to get too close to the edge.
There is a ramp to allow a wheelchair user to board the train

Staff on the train hold a key to unlock the ramp so that it can be used.

You would have to phone the train company before your journey to make sure there was someone on the train to help you to get on.
There is an emergency escape passage at the far end of the platform.

It’s behind a brick wall and we couldn’t see it very well from the platform, although Christian did try!

It is very narrow and you couldn’t turn a large electric wheelchair around in it easily.
The gate at the other end of the escape passage was locked.

If you didn’t have a helper or a mobile phone with you, we thought you might be stuck there for some time.
We thought that Soham station is not very easy for people with a disability to use.

We will send our full report to the local councillor for East Cambridgeshire.

We will also send it to the companies that are planning the new Cambridge South station at Addenbrooke’s hospital.
• Thanks for listening
• Do you have any questions?
Elspeth Jones
Speak Out Council Leader: Speak Up Spectrum

Autism News
Fun activity

We have a few questions about VoiceAbility, to find out how much you know about us!

It’s multiple choice – please put your answer to each question in the chat or call out your guess.
1) How many Speak Out Leaders are there?

• 6
• 10
• 5

ANSWER: 6

2) What is the name of the Speak Up Spectrum Leader’s dog?

• Marzipan
• Revels
• Smartie
• Bubblegum

ANSWER: Smartie
Elspeth – Speak Up Spectrum

We had 4 people at our last meeting, which was great as numbers had been low. We will be doing a survey to find out what people want to get out of Speak Up Spectrum meetings.

We talked about:

- What we can do to increase the government’s awareness of disability issues.
- The need for more supported internships for people over 25 living with autism.
I am helping Safe Soulmates to set up an autism group for their members. This will be another way to find out what people with autism want and need.
Sean Nightingale
Speak Out Council Leader: Huntingdonshire and East Cambs

Our consultation results
Welcome back!

Now we’re going to tell you about our consultation results.

Last year the LDP commissioners heard a lot about Housing in the Learning Disability Vision survey.

They asked us to find out what is important to people about their homes.

The information we found out will be used to make a checklist for housing developers so that new communities and houses work well for people with learning disabilities and autism.
We met with people at Special Choices OWL Abington Mill Lane Snakehall Farm Lots of people completed our survey online Thanks to Huntingdon Mencap who completed lots of paper copies of the survey.

We were really pleased to be able to see people face to face again!

77 people did our survey!
We heard from people in most areas. We hoped to speak to people in March, in Fenland but unfortunately Covid got in the way.
Most people said they lived at home on their own. Quite a few people said they live in Supported Living.
Consultation results:
What makes your home feel like home and what you do in your home.
What makes the place you live in feel like home?

- **Pictures, photos and my own belongings**: 40
- **Pets**: 16
- **Space to be alone**: 29
- **Space to be with other people**: 36
- **Outside space**: 37
- **Feeling my home is private**: 39

Having photos, pictures and their own things around them was important to lots of people. Privacy was also important too.
Other things people said make them feel at home

- Listening to music
- Having good food
- Having my room decorated in my special interest theme
- Using my sensory equipment
- Watching TV
- Being with my family
- Having someone to stay over
Neil Adams
Speak Out Council Leader: Young People

Consultation results:
What you need in your home and near your home.
We asked: Is it important to have these things where you live?

Lots of people want car parking, secure wifi, doorbell cameras or spy holes.
What else is important?

A telephone that tells me who is calling

Clear evacuation procedures so I can get out of the building safely in an emergency

A smoke alarm

A burglar alarm

The housing association should visit weekly to do things like repairs and keeping the area clean and tidy
Young people said they want Guides or youth clubs nearby. 3 people said they would like to be near their church. Not that many people said they wanted sports centres or day opportunities nearby.
What else is important?

I also have an energy disability, so longer travel times mean I may not be well enough to go as I can't be out the house for that long.

My day opportunities (Forest School and Snakehall) are far away, it would be good if there was something in Sawston. Having transport links nearby is important as I don't drive or own a car. I like to see my friends.
What we think this means

People with learning disabilities and/or autism want to be near to activities they enjoy and shops.

They need good transport links, like bus stops in easy walking distance.
Russell Henke
Speak Out Council Leader:
High Support Needs

Consultation results:
Equipment and being independent
We asked people what equipment might help in their home?

Quite a few people wanted non-slip surfaces, taps with colours on and cupboards that are easy to reach.
What would help you to be more independent in your home?

Lots of people said a smartphone or tablet with apps would be helpful.
People would also like these things:

- Hand rails on both sides of the stairs
- Physiotherapy equipment
- Padded floors or walls for people who may have seizures or falls
A Nest fire alarm with colour coded lights to tell me about air quality

A downstairs loo that is wheelchair accessible

Something to help me get in and out of the bath
What we think this means

Sometimes people’s needs change. People might need new equipment or changes to their home.

It is important that people can find information about how to get extra support, and find out about equipment or changes to their home that will help them to be independent.
Bill Jones
Speak Out Council Leader: Cambridge City and South Cambridgeshire

Consultation results:
Feeling Safe and things that are difficult about your home
Feeling safe in your home and neighbourhood

Some people said they feel safe because they have supportive neighbours.

Knowing where everything is helps some people to feel safe.

People said they feel safe because they live with other people.

Some people said they feel safe because they have supportive neighbours.
Some people felt safe because staff look after them.

Some people said they felt safe because they have a lock on their front door.
Things that make people feel unsafe at home

- Loud noises or noisy neighbours
- Unfriendly neighbours who don’t seem to like them
- Break-ins or vandalism nearby
- Knowing that people are selling drugs near their home
- I’ve had problems with people in the evenings before
Is there anything that is difficult about where you live?

Noisy dogs

I get shaky and nervous if people get rowdy

I am at risk of injuring myself at home but I’m still waiting for support from adult social care
Is there anything that is difficult about where you live?

Sometimes my neighbour plays really loud music

Stairs make it hard at home

Having to share staff
What we think this means

Some people live in communities where they feel safe and have supportive neighbours.

Other people are worried to go out in their community and have had problems which have made them feel unsafe.
If you have a learning disability and or autism you can sign up to the Pegasus scheme.

**Pegasus** is a **free** service for people who can find it hard to communicate with the police.
You can tell the police your **name, address** and information about how you prefer to **communicate**.

If you know of a shop or pub or other place near where you live that could be part of our Safe Places scheme, please tell us!
• Thanks for listening
• Do you have any questions, or anything to say about what we told you?
Anne Hunt
Speak Out Council Leader Fenland

Consultation results:
Supported Living and Support
But first for something fun!

Spot the Difference
We’re going to show you some pictures about support.

Then there’s a second slide with some of the pictures taken away.

Your challenge is to guess which pictures have disappeared!
Preparing food

Washing and dressing

Managing my bills

Cleaning

Using a computer, tablet or phone

Mobility

Planning appointments

Medication

Washing clothes

Food shopping

Letters and emails
A lot of people need help with their bills and doing other jobs like cleaning and preparing food.
People also need support with these things

Most things I’m struggling with are not always obvious but they affect me negatively.

Planning appointments days out, holidays

Everything

Letters and emails 2 people
People also need support with these things

- Medication: 5 people
- Mobility support
- Food shopping: 4 people
- Repairing things and organising people to do this: 4 people
- Gardening
We asked people what was important about their support.

Everybody said it is important to be able to choose their staff. Some people said they have been part of interviews to choose staff.

Some people said they don’t get to choose their staff.

People want to be able to have the same staff, so they can get to know them.

It is really important that staff have the right training and follow the rules.

People want staff who have a sense of humour and want to spend time with them and aren’t just there for the money.
How people want to be supported

Look after me well

Don’t judge me. Don’t patronise me.

Respect my choices and allow me to spend time alone when I want.

Ask me what I want to do and allow me to have choices 4 people

Listen to me
People also say this about support

One of my staff is just like me, he has a cochlear implant and tattoos. I need hearing staff who can use British Sign Language.

Encourage my development and independence but still give me the right support when needed.

Make sure that we have fun with other people, rather than just hiding.

Just having support other than my parents, the council have never replied to me.
What we think this means

Good support is really important to people.

People have told us that sometimes they have found it hard to get good support because of staff being poorly during the pandemic.

People would really like to be part of interviews or activities to choose the staff who support them.

Sometimes people have found it difficult to get support from Cambridgeshire County Council.
Elspeth Jones
Speak Out Council Leader:
Speak Up Spectrum

Consultation results:
Moving House
What people told us about moving home

Paperwork made moving home difficult for people who didn’t have family support. Some people said it was difficult to know where to get information they needed.

Easy Read forms, or someone to write or type for people is helpful.

Family, friends and support staff helped some people. So did housing associations and organisations like Mencap.
These things make moving home difficult

My dad is in a wheelchair so we had to find a home that fits his needs, mine and my brothers.

It is hard to bid for properties on the HomeLink scheme as I need support to do this but need to bid at 12 o’clock on a Friday but I don’t have support at that time! I have been on the list for 4 years. I did have an interview for one property but that wasn’t easy for me to take part in.

To get into housing (in Cambridge) is incredibly and unnecessarily difficult. The process could be made easier.
Who helped you move home?

- Family or friends found somewhere, 9
- I used the Council's Home-Link scheme, 4
- Through an estate agent, 2
- Other (lettings agency, local authority), 1
- Support staff, 1

Family and friends were the main source of help when it came to finding a new home.
How long did you have to wait to get your new home?

Most people who moved home had to wait more than a year for it to happen.
How did you feel during the process?

Most people found moving home frustrating, confusing and sad.
What we think this means

There should be more Easy Read information available about moving house.

The way people can bid on the Home-Link scheme needs to be easier to allow everyone a fair chance to find a house.

Interviews for houses on the Home-Link list need to be change, so that people with learning disabilities and or autism can take part in them fairly.

Easy Read forms and tenancy guides should always be available.
Elspeth Jones
Speak Out Council Leader:
Speak Up Spectrum

What happens next?
What happens next?

We will share the results of our consultation with the Learning Disability Commissioning team so that they can make a checklist for developers.

We will contact people who gave us their details to hear about any issues they are having.

We are also working with some developers who are designing a new development of 5,500 homes in Cambridge we will share all this information with them too!
Useful information

The Cambridgeshire Handyperson Service

Age UK Cambridgeshire and Peterborough / Cambridgeshire Handyperson Service

Help to prevent falls and accidents at home, so you can remain living independently. Disability equipment and adaptations fitted. Assistance with hospital discharge.

Technology Enabled Care (TEC) team provides guidance, training, and advice to citizens and professionals. When appropriate, we can loan assistive technology to support the independence and safety of people living in Cambridgeshire.

Equipment and technology for adults and older people - Cambridgeshire County Council; Technology Enabled Care - Cambridgeshire County Council It is also available to any adult over 18 in receipt of a disability benefit.
Useful information

Pegasus

Pegasus card scheme | Cambridgeshire Constabulary (cambs.police.uk)
Our Pegasus scheme is for people who find it hard to communicate with us – we keep your pre-registered information safe on our computer and we can access it quickly if you call us. You don't need to repeat all your details.

Safe Places

Safe Places - Keep Safe with Safe Places
A Safe Place offers help if someone is anxious, scared or at risk while they are out and about and need support.
Films

Speak Out Leaders were involved in two films about how to support people with a learning disability and or autism to be at the centre of decision making in the Court of Protection.

Communication and Participation in the Court of Protection
https://youtu.be/WuEtw2rnqBw

Making Values Matter in the Court of Protection

Treat Me Well films
Our films about how to support people with learning disabilities and/or autism in health services.

VoiceAbility | Speak Out Council