Speak Out Day Wednesday 21st June 2023
Health in Hospitals
Neil Adams
Speak Out Council Leader: Young People

Young People’s News
SEND Partnership Group

The SEND Partnership Group are thinking about starting a young people’s SEND Partnership Group so that they can hear from more young people.

We are part of a group looking at the ways that young people’s voices are heard at the moment and whether there are things that we can do to hear from more young people.
I spoke to over 200 staff from SEND services at Cambridgeshire County Council about what I have heard from young people.

We want all schools, including mainstream schools, to know what true reasonable adjustments are for people with autism.

We need good information about mental health, especially when we need to wait a long time to get an appointment.

We want to work, we need good information about how to find out about working and applying for jobs.
Preparing for Adulthood Event

I was part of a group who organised an event for parents and carers of young people.

This was because we had heard from a lot of young people and their families that they would like more information about Preparing for Adulthood. Over 200 people came to the event.
The SEND Information Hub

We have been helping Cambridgeshire County Council to improve the local offer website. It is now called the SEND Information Hub.

It is a useful place to find information about all sorts of things like activities to do, training, advice and support.

You can find it here:

[SEND Information Hub (Local Offer) (cambridgeshire.gov.uk)](https://cambridgeshire.gov.uk)
Anne Hunt
Speak Out Council Leader Fenland
My News
We visited to do a drop in and we spoke to 4 people. We told them about our survey.

We gave some information to a tutor at Ely College so that she can find some support for one of her students.
Facet and Tennyson Lodge

We visited Facet and Tennyson Lodge and spoke to about 20 people.

We asked them what a good day opportunity should look like.

Claire Cluer had asked us to check a document about this.

People generally liked it but had some ideas to add.
This is what they said:

✓ It is important that people are a big part of deciding how their services work.

✓ Some people want day opportunities to be in buildings that are just used by people with learning disabilities and or autism and other people don’t mind if they are in shared buildings.

✓ They should have respectful staff who have a good sense of humour and are caring and support people well.
Core Site Meeting

We went to a workshop with a team of developers.

They are making plans for a new development of 5,000 homes in Cambridge.

We are helping them to make sure it works well for people with learning disabilities and or autism.
Russell Henke
Speak Out Council Leader: High Support Needs
My news from people with high support needs
We went to Histon and Impington Wellbeing Festival. We ran a stall and I spoke to people about my job. I enjoyed talking to people and having a biscuit.

I met with Sarah who works at Papworth Hospital, and we talked about visiting and talking to patients about their experiences there. We'll probably do this in the summer.
High Support Needs Committee News

We wrote a letter to lots of care homes, inviting them to join the High Support Needs Committee.

We attended the Day Opportunities Provider Forum.
I spoke about the work that I do with the High Support Needs Committee to see if anyone wanted to join.
We will be doing some work on day services that are available for people with high support needs in the summer.
Liz from Access St Neots came to talk to us in March. She is doing some good work. We have done some access work with her on the 22nd May. We have made a video to show you all what we have done.

https://clipchamp.com/watch/Hfgtveu1Xta
Sean Nightingale
Speak Out Council Leader:
Huntingdonshire and East Cambs

My News
We have been working with the Forensic Psychiatry Team.

We are going to do some filming in the summer to answer some questions about working with people with a learning disability and/or autism.

We had another look at the paperwork they’ve been developing as well.
I’ve done some filming for the Shared Care Record. This was a short Question and Answer video with 3 questions that the Speak Out Council had agreed.

I really enjoyed this!

The rest of the team helped with some Easy Read information about the Shared Care Record.
Drop Ins

We went to the Mencap Service User Forum, Special Choices and Switch Now in St Neots.

We listened to people and had a chat and also did our Health in Hospitals survey.
Adult Co-Production Collaborative

Adult Co-production Collaborative 11th May.

I made some recommendations about how to make meetings work better for us. Some of my ideas were making Easy Read agendas and minutes and providing a pre-meeting to discuss things before a meeting.
Bill Jones
Speak Out Council Leader: Cambridge City and South Cambridgeshire

My News
Preparing for Adulthood Event

Here’s what we thought of this event:

Sean - We gave a presentation to two groups of people.

Bill - We got great feedback and people loved what we had to say about our homes.

Elspeth – there were a lot of people, we think that we reassured people with our presentation and top tips.

Ashley was also there, telling people about his experience of finally finding a job at Scotsdales café, he said that finding a job is ‘a marathon, not a sprint!’
Lewis and I went to the Empowering Communities Conference in Cambridge. We got involved in discussions about how healthcare can be better managed in the community.

I went with Lewis to Rowan Humberstone in Cambridge to do our consultation on Hospital Appointments.

The people we spoke to there, all had recent experiences to share which was great to hear about.
As mentioned in the last meeting, our funding for Safe Places has come to an end.

Safe Soulmates are interested in taking over that work. I’ve been involved in discussions for that.
Reaching more Autistic people

Lots of people have told us that they do not like meetings, so we are trying to change how we reach autistic people.

We have had some good one-to-one conversations with people recently. We have created a survey to help people tell us what life is like for them.

We met Ben, a Clinical Psychologist from the Cambridgeshire Lifespan Autism Spectrum Service (CLASS). He and his colleagues will hopefully help us to reach more people by sharing what we do.

Last weekend we met people at the National Autistic Society Social Group in Cambridge. Thank you to everyone who shared their experiences, we’re looking forward to coming again.
Me, Anne and Kate went to March to train the guys from Twenty20 Productions about how to work with and include people with Learning Disabilities and/or Autism. Anne and I led the training.

I feel our training went well. We included some videos about Learning Disabilities, and Autism. We also had some small quizzes (mainly to check that people were still paying attention!)

At the end, Twenty20 Productions said that they were going to make changes to how they work. They also gave us really good feedback!

We might do more training like this in the future.
Neil Adams
Speak Out Council Leader: Young People

Here are the results from our consultation on Health in Hospitals.
This has been a 6-month consultation.

74 people took part in the consultation – thank you to everyone who took part.

We talked to lots of different people across the county for their feedback on all the hospitals in Cambridgeshire.

They’ll be opportunities to ask questions throughout at the end of each section.
We met with people at:
Special Choices
Rowan Humberstone
Switch Now
Huntingdon Mencap at their Service User Forum
Orchard Manor
National Autistic Society

Lots of people completed our survey online as well. Thank you to everyone who shared this with us.
We spoke to people of different ages.

- 14 - 17: 24
- 18 - 25: 10
- 26 - 40: 20
- 41 - 65: 16
- Over 65: 3
We spoke to people who had been to different hospitals.
People went to hospital for lots of different reasons.
Bill

Appointments
If you received an appointment letter, was it easy to understand?

- Yes: 19
- No: 9
- Not Sure: 22
- Didn’t receive a letter: 2

Just over a quarter of people felt their appointment letter was easy to understand, a lot of other people said no, or were not sure.
These are some of the comments people made about appointment letters:

- I didn’t understand the directions to the department.
- The letter was not friendly to people with learning disabilities.
- Complicated vocabulary and unclear instructions.
- My mother had to read it to me.
- Non-accessible format.
Who usually organises your appointments?

- My family helps: 34
- My support staff helps: 12
- Me: 5

People we spoke to often need help to organise their appointments.
Did you understand what your appointment was for?

Some people were not sure if they understood what their appointment was for.
How did you feel before your appointment?

16 people said they felt nervous.

8 people felt the wait was too long.

6 people said they felt anxious.
How did you feel before your appointment?

Waiting area isn't very good, lots of time waiting. Stressed.

Lots of people waiting, especially when doctors are on their breaks. Looking forward to getting out of here.

Looking forward to seeing good people - smiley.
How did you feel before your appointment?

Frustrated - long wait for an appointment and referral to a specialist. Lots of referrals - over a year with no solution.

Quite apprehensive, as this was major surgery, but all at the hospital were very reassuring and supportive throughout.
What we think this means

• Letters should be in Easy Read and contain Easy Read information about things that might happen at appointments.
• Knowing how long it will take to get an appointment would be helpful.
• Waiting areas could be better, with quieter areas.
Russell

Arrival at the hospital
Were you allowed to take someone with you to support you?

- Yes: 48
- Not sure: 1
- I don’t need support: 3

Almost everyone had support if they needed it.
When you arrived at the hospital did you know where to go?

Lots of people knew where to go, but some people didn’t know.
Were there any signs or maps to help you know where to go?

Most people found the signs/maps to be helpful.
Were there any staff around if you didn’t know where to go?

Most people found that staff were helpful in finding their way.

- **Yes**: 48
- **No**: 3
- **Not sure**: 9
- **Not applicable**: 16
Addenbrookes Wayfinder App

We tested an App to help people find their way around Addenbrookes.

It is called ‘CUH Directions’ it’s on Google Play and the App Store, so anyone with an iPhone or Android can use it.

Some of us have used it and found it very helpful.
If you use a wheelchair, were the facilities suitable for your appointment?

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<td>No</td>
<td>8</td>
</tr>
<tr>
<td>Not sure</td>
<td>2</td>
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Quite a lot of people felt facilities weren’t suitable for a wheelchair user.
If you said no, what wasn’t suitable?

Nowhere in the waiting room to park my chair. Waiting room too small for me and my carer.

Better awareness of wheelchair needs and assigned spaces in the waiting room. Not using the disabled toilet as a storage cupboard!
Not enough room in the waiting area or in the room.

More blue badge spaces. All the parking spaces were full. Mum had to drop me off. Addenbrooke's needs a marshalled wheelchair parking bay. Lack of drop curbs near the entrances to the hospital also a problem. Porter also tried to take my wheelchair thinking it was a hospital wheelchair.
What we think this means

- Other hospitals should think about creating wayfinding apps to help people get to their appointments.

- Blue badge parking needs improving.

- Hospitals should ask people who use wheelchairs to check how accessible they are.
Anne

Your appointment/support at the hospital
Hospital passports

A hospital passport is a way of telling healthcare professionals about the best way to support you while you are at an appointment or spend time in hospital.

We will add links in the chat for where to download Hospital Passports.
Did staff follow your hospital passport?

Lots of people either don’t have a hospital passport or don’t know what one is.
Reasonable Adjustments

Sometimes it may be harder for people to do things if they have a disability or mental/physical health condition.

Reasonable adjustments is changing the way that things are done to make sure people are able to use services.

This ensures that people who have difficulties can access a service like anyone else.
Do you think reasonable adjustments were made for you?

Quite a few people said that the hospital did not make reasonable adjustments for them.
If you said no, what adjustments would have been helpful?

- Read my hospital passport correctly.
- Explain things to me rather than my supporting person. Explain things as you are doing them.

Taking the time to listen to my needs would have improved my experience. It would also have been good if the consultant had communicated what my problem was clearly without evasion. I was given heparin injections against my wishes. I felt ignored and anxious. I checked myself out before being discharged as it was impossible for me to stay under the circumstances I found myself in.
I was bored and very angry because I had to be sent to three different places.

Felt frustrated at first as staff were not interest on reading Hospital Passport and finding my needs, my carer had to explain it over and over again. Support workers/nurses didn’t seem to know proper moving and handling.

Extremely anxious. My mother had phoned them to inform them about my autism and make sure that she could go with me because the rules about Covid were still very strict. But I was still worried that they wouldn't understand my difficulties.

Staff were over-stressed, made me stressed.

I was frustrated by the impolite doctors.
I felt lied to when I found out I was taking medication I could have done without.

After a few hours, felt relieved and good as everyone had listened and did their best.

I recuperated well from the operation, the chemo-therapy (tablets) took quite a toll as I developed brain 'chemo-fog' which I am only getting clear of (recognised side-effect) which exacerbated by autism, plus associated agitation and anxiety; the MacMillan nurses at Addenbrooke's provided excellent and sympathetic support during my chemo treatment, being aware of my High Functioning Autism and associated Social Phobia disabilities too.

I like staying at the hospital - like the electric beds - sad to leave.

I never want to go back to Addenbrooke's A and E.

Felt better afterwards - less nervous.
What we think this means

• More people need to know about Hospital passports. This includes people with learning disabilities and or autism, their families and supporters and health professionals.

• Everyone should be asked about their hospital passport when they arrive at hospital and the information should be shared with all health professionals.

• Hospital staff should have up to date moving and handling training.
Sean
Feedback on staff
Most people had good experiences and seem to have been supported well. Not many people said their hospital passport was used.
Do you think staff at the hospital did well or could they do better?

- They were good: 51
- They could do better: 13
- Other: 3
- I would prefer not to say: 4

A lot of people said staff were good, but some people felt they could do better.
What could they do better?

Ensure they follow my hospital passport. Staff to speak to me rather than the support staff with me. I have my own opinions!

Have more training and knowledge about disabled people. Ask about hospital passport because the paramedics know about it!! If the disabled person has a carer/family member with them, make sure both of them are alright, especially if it’s someone non-verbal. Have more knowledge about people with gastro feeding/nil by mouth.

Listen to my needs. Accept that interventions such as injections should be negotiated and respect the choice of the patient if they say no.
What could they do better?

More respect for people, talk to people better. I had some problems with language barriers.

People went straight to talk to my dad rather than me, only 1 out of 12 people actually spoke to me. Staff explained what they were doing whilst doing it rather than beforehand. No one spoke to me nevermind listening to me. Lots of inaccessible forms/info makes it hard for me to understand.

They did not identify that my wrist was broken and I had to go back again a few days later.

I guess a bit more reassurance about timescales would've been nice.

Talk professionally about health issues
Would it help you to feel more comfortable/confident if you could visit the hospital when you are well?

- Yes: 29
- Not sure: 23
- No: 16

Most people said yes to this idea.
999 Club at Hinchingbrooke Hospital

This used to be a tour of the hospital taking you to all the different areas you may use.

You didn’t have to have an appointment coming up but it was helpful if you did.

This was organised through local day services and schools.

A similar club is still run for children to help them feel comfortable at hospital.
What we think this means

- Staff are generally doing a good job.
- Staff to ensure they talk to the individual first rather than their supporting person.
- More training on learning disabilities and autism for staff.
- Respect the choices that people make.
- People should have the opportunity to visit the hospital prior to their appointment.
First a bit about how autistic people might experience pain

• Why 1-10 pain scales won’t always work for autistic people and what is helpful.

• Hyper-sensitivity
An autistic girl’s experience

You may have read this in the news recently. Molly, who is 16 and is autistic, and spent time in a hospital in Portsmouth said this about her experience:

She described the loud, bright, busy hospital environment as like "living in hell". "It feels like they're torturing you," she said. "It's almost like the hospital room is like a small box, and you're not allowed to leave it. There are phones going off, alarms, children screaming."

Hospital stays can be incredibly challenging for autistic people.
Learning from other areas

East Cheshire NHS Trust worked on a project with the National Autistic Society to make hospital experiences accessible for autistic people. These are some examples of how things work now:

• They have an email helpline so people can let them know their needs before planned appointments.
• People can tell staff what things might be difficult and what they can do to support them.

This might include:
• Arranging visits before pre-planned appointments
• Taking equipment like blood pressure cuffs or oxygen masks home to get used to them
• Sharing likes and dislikes.
We recommend these things to improve hospital visits for people with autism:

• Letting people visit first
• Letting people know they can ask for a side room
• Letting people know how long they might need to wait when they arrive for their appointment
• Giving out an email address and phone number so that people can contact the hospital to share helpful information about themselves and ask for support.
• Offering people the opportunity to take equipment home to get used to it before their appointment.
This is what people in general told us would make their hospital visits better

Have more learning disability nurses working at the hospital, ready to meet the disabled person in the A&E or at the wards.

Please read my hospital passport on arrival and speak to support staff for information.

Not sure if staff knew I had a learning disability or just saw support staff badge.

More comfy hospital beds. Some staff following my hospital passport, but some didn't - more consistency.
Is there anything that would make your next hospital visit better?

Not enough staff. Better during tests - talk to people better.

Maybe if the nurses and doctors could talk to me like an actual person.

13 week stay - staff training required to improve awareness of hospital passports. Ideally staff to read hospital passports before seeing the patient. Reasonable adjustments made but only because sister advocated strongly and kept showing hospital passport. Lots of delays with scans - apps to run on time.
We recommend these things to improve hospital experiences for people with a learning disability and/or autism:

- Hospitals need to be more accessible for all – whether this is accessibility for wheelchairs or just so that people with a learning disability and/or autism feel less nervous/anxious about coming.
- Training for staff, so that it isn’t just learning disability nurses who are the experts as they aren’t always around, especially for those with hidden disabilities.
- Letting people know how long they may need to wait if there is a delay.
• Training for staff about Hospital Passports.
• Making sure people with learning disabilities and/or autism, and the staff who support them, are aware of hospital passports, including autism hospital passports.
• A way for Hospitals to record that someone has a Hospital Passport and make sure information is shared between areas/wards.
• Making sure information is accessible – appointment letters, using Plain English when speaking to patients.
Are there any issues, or anything great that you have come across that you’d like to share before we finish?

If you can’t think of them now, you can always email us at

speakoutcouncil@voiceability.org
And that’s the end of Speak Out Day
Thank you and goodbye!