

Speak Out Council

Consultation:
Your health and the support you get with it

December 2020



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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.

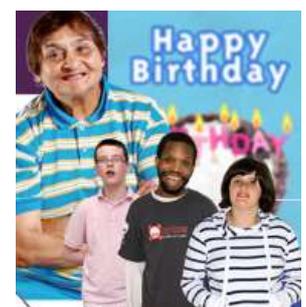
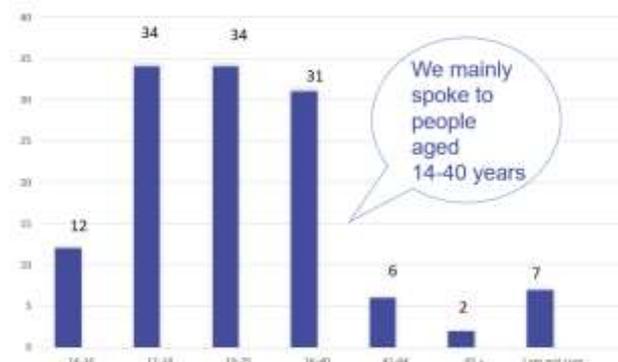
What did we do?

This time we chose to ask people about their health and the support you get with it. We chose this topic because people have told us that they think health unfairness has got worse since COVID-19.

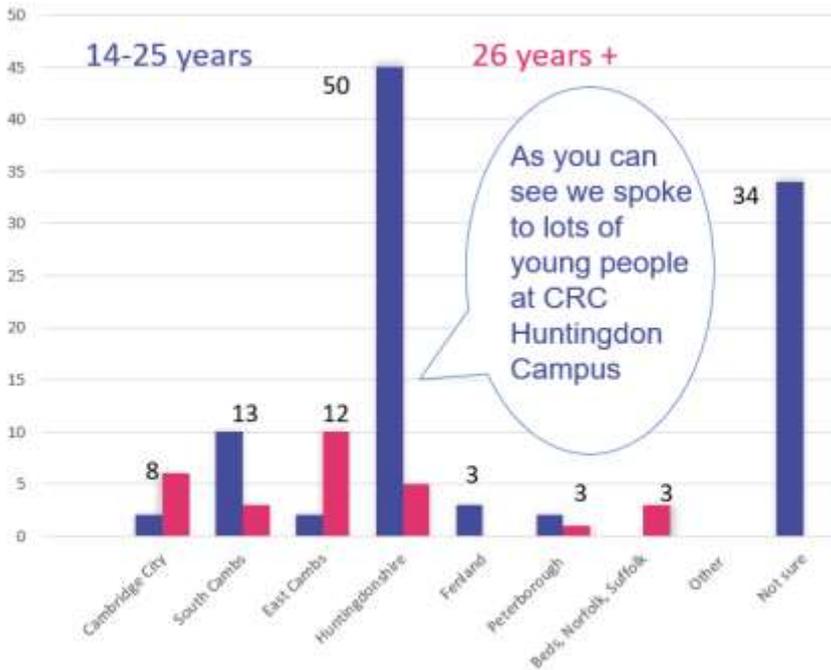


During November and December 2020 we heard from 128 people:

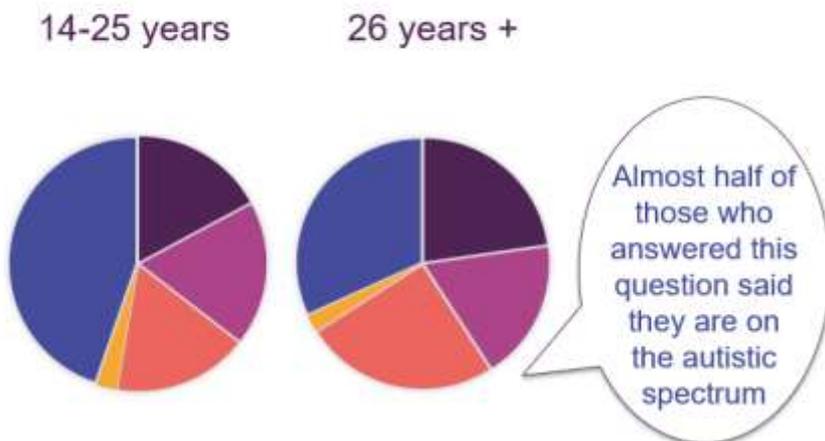
- 88 young people aged 14-25 yrs, and 40 people aged 26 yrs+
- 57 people did our on line survey
- We used Zoom and Microsoft Teams to talk to
 - Adults at Branching Out
 - Young people at Cambridge Regional College in Huntingdon
 - 40 students (aged between 16 and 24 years old) at Cambridge Regional College (CRC) during their online tutorial sessions
- Students at FACET and Spring Common School did our paper survey



- We spoke to people from across Cambridgeshire, including a lot from Huntingdon.



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



- learning disability
- autistic spectrum
- learning disability & autistic spectrum
- high support needs
- Not sure/prefer not to say/not asked

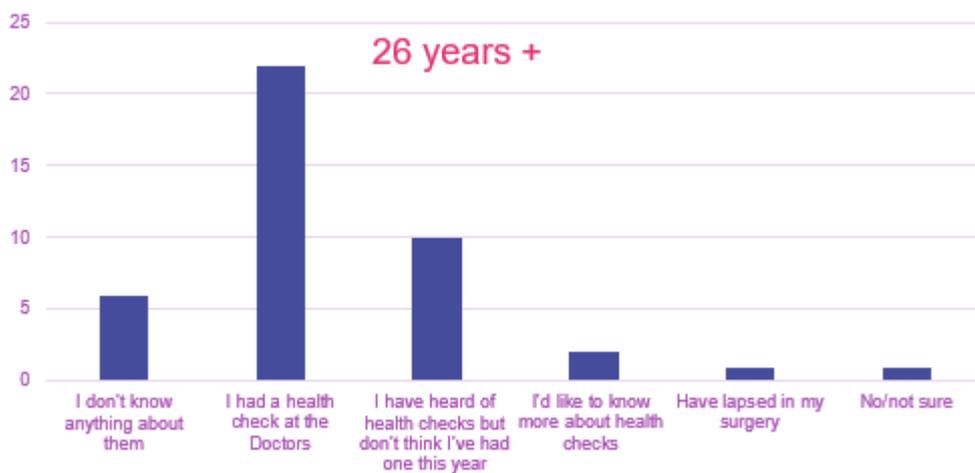
What did we find?



Health checks

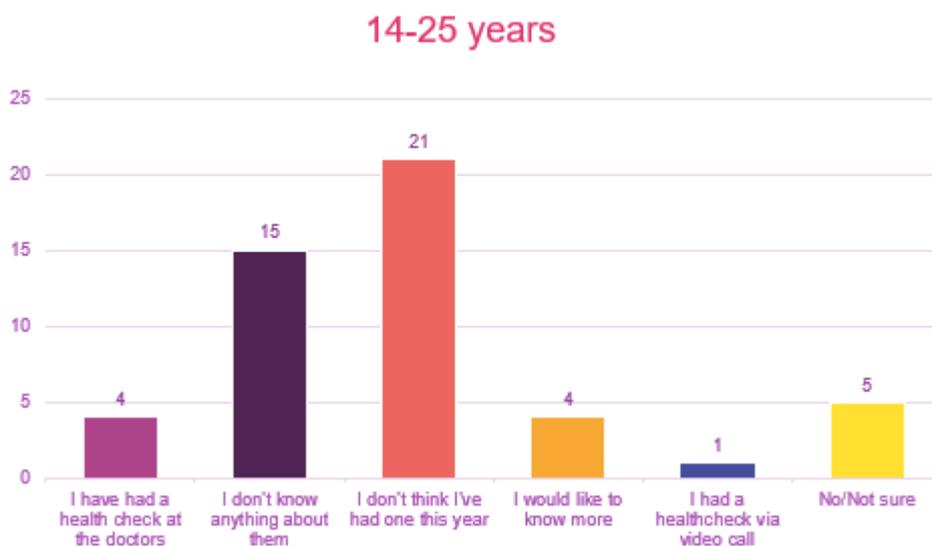
We asked people if they knew about health checks, and if they have had one this year.

Quite a lot of the people aged 26 years+ told us they'd had their check this year (22), and 10 had heard of them but were not sure they'd had one this year. 6 people didn't think they had heard of them.



Lots of people have had a check but some are not sure

But most (21) of the young people (aged 14-25 year olds) do not know if they have had a health check this year, and 15 didn't know anything about them.



Many people do not know if they have had a health check, a lot of people said they don't think they've had one this year.



We asked people why they hadn't had a health check. They told us:

- "COVID-19 possibly but don't know for sure?"
- "Priory Fields Sutton lapsed this year"
- "Drs not doing them"
- "I do not have a learning disability and as such do not qualify for one"
- "I don't feel the need"
- "Not sure Drs doing them, not contacted"

Young people also told us:

- "I haven't been asked"
- "COVID-19"
- "I was afraid"



We asked young people if an Education, Health and Care Plan (EHCP) should mention annual health checks. Many of them (24) said yes it should, 14 were not sure.



We think this means:

- A lot of people are not aware of health checks
- Some surgeries are not getting in touch to offer them
- It would be good if ECHPs mentioned health checks
- If you have autism but do not have a learning disability you might need to ask your Doctor for a health check, as you won't be offered one automatically.



Making a difference:

Since our meeting, the SEND Commissioner for Cambridgeshire has told us that they will be communicating through the SENCO briefings that annual health assessments need to be discussed in all 14+ Annual Reviews, so: has the young person had one, did they know they were entitled to one, the benefits of having one and what the blockers are for choosing not to participate.



Autism services



We asked people if they'd had an autism assessment or whether they were waiting for one:

- 29 people (15 young people and 14 people aged 26yrs+) told us they have had an autism assessment, and no-one was waiting for one
- 12 people (5 young people and 7 people aged 26yrs+) told us they are getting the support they need
 - 'She is very supported at school for her current needs.
- But others told us they need more help with:
 - Awareness of difficulties I experience, having things explained to me
 - In depth explanations so I can understand it better
 - Motivation, cleaning, someone to talk to sometimes
 - Phobias, and
 - Planning for the future

- 
- No one we spoke to was waiting for an autism assessment
 - But quite a few people with autism feel they need more support

Young people also told us about the help they need:

- "Help from school for my exams. No one has assessed me as no one has helped me get an EHCP although I have a diagnosis"
- "School don't help me"
- 3 people would like support strategies for anger, and
- 5 people said they did not need extra support.

We think this means:

- Many people with autism need more help, both with managing aspects of their personal lives and in their education/vocational lives.



Making a difference:

1. Since we did our research, we found out that the Cambridgeshire and Peterborough Clinical Commissioning Group (CCG) has funding to run a new service:
 - For post diagnosis autism support for adult – both health and social care
 - It will also be for people who have not had a diagnosis, or who are waiting for an assessment
 - There is also funding to support people with ADHD, and for more assessments.
2. Elspeth, our Speak Up Spectrum Leader has been invited to be part of the autism strategy board for Cambridgeshire and Peterborough which plans to pull together all the autism services across Cambs and Peterborough, creating an all age strategy, sharing best practice and starting to fill the gaps. Elspeth will share our consultation findings with the board.



The CCG has funding for a new adult autism service (health and social care) across Cambridgeshire and Peterborough



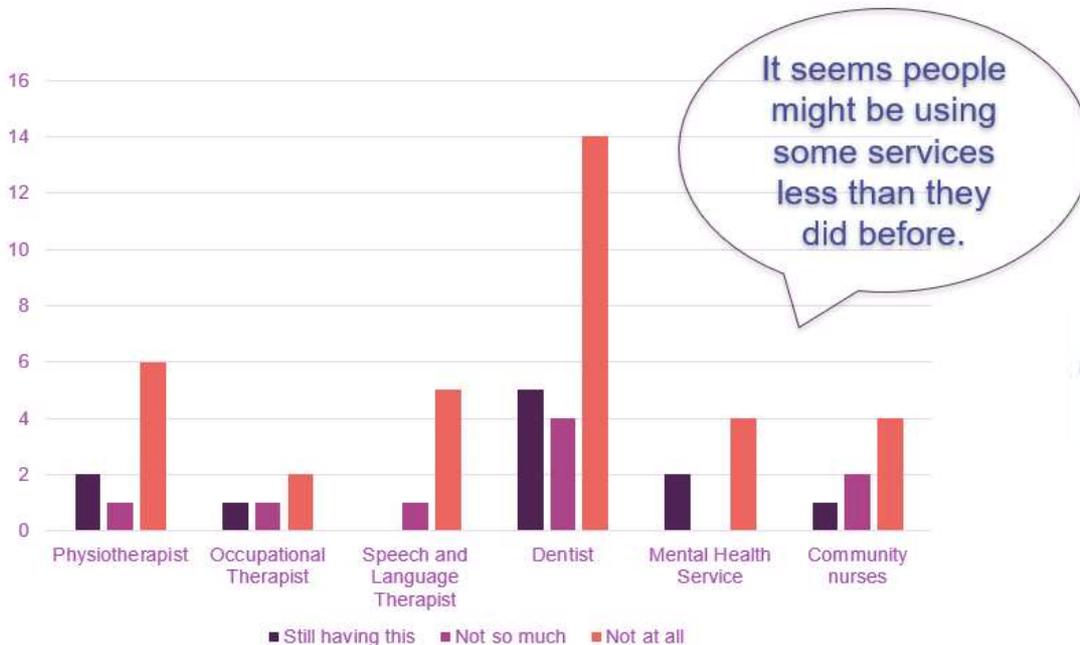


Community health services

We asked people what services they are getting from Physiotherapy, Occupational Therapy, Speech and Language and Community nurses:

- A few people said they are still getting the Community services they used to get.
- But many are getting less, and
- A lot say they are not getting a service at all anymore.

Not many young people said they are using community health services, those at school or college seemed to be most likely to do so. Young people also seem to be using some services less than before.



Specialist Dental Service

People told us that they did not feel they were getting the same service from the Specialist Dental Service. They told us:

- “Appointments have been cancelled because of covid”
- “Went to dentist last January and he said I needed an extraction under a G A but have not heard anything maybe because of covid”



So, we asked the Specialist Dentist what the situation is. They told us:

- They won the re-tender from October 2019
- Referrals have changed:
- In the past anyone could refer (care homes, LDP, GPs, health visitors etc)
- Now only dentists can refer you to this service, so you need to register with a dentist first. **But**, they told us they will

The specialist dental service is the same people offering a similar service but with a few changes. You should register with an NHS dentist who will refer you to this service.

still consider one off applications from individuals, GPs and care homes, and

- Treatment can still be arranged at home/supported living /care homes where needed.

They will not treat the whole family, just the person with a learning disability. They will share your care with your local NHS dentist.

They told us that the criteria has narrowed a bit:

- Only treating the young person with a learning disability who has been referred to them, and not the whole family
- If someone with a learning disability is happy with their NHS dentist they would not be expected to use the specialist dentist
- People might attend for a particular situation, or treatment, but would then return to the shared care of their usual NHS dentist



COVID-19 impacts:

- Services are now getting back to normal and they are catching up with the backlog
- In the meantime, they are making calls to patients to make sure they are OK and to find out what support they might need



The Specialist Dental Service told us "We want to reassure you that we are here to help if you need us"

We think this means:

- People need to register with a local dentist who can then refer them to this service if needed
- People who have used this service in the past, and are waiting for an appointment or treatment, should get in touch with them
- If you want to refer someone to them, get in touch to find out how this can happen

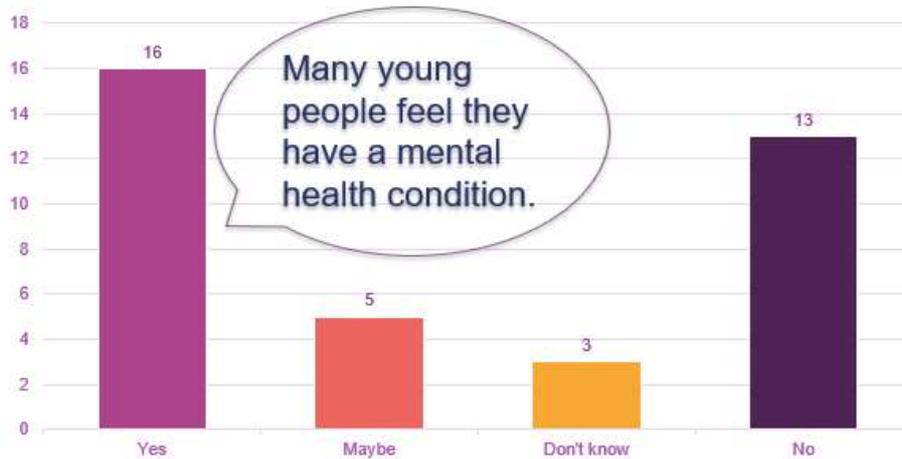


Mental Health

We asked if people thought they might have a mental health condition, such as feeling anxious or depressed.



16 young people, and 19 people aged 26 years+ told us they felt they have a mental health condition.



Many young people feel they have a mental health condition.

A lot of people told us they feel they might have a mental health condition.

Then we asked if these people felt they were getting the support they need:

- 13 young people, and 9 people aged 26 years+, told us they get the support they need, but
- 8 young people, and 9 people aged 26 years+, told us they get no support, or the support they get is not right for them.

Young people also told us:

School nurse is brilliant but school is rubbish. They are not communicating with the school nurse and the teachers think all autism is the same. They say to me that other children with autism are coping so I should be able to. Other children are getting extra time with their needs but I am not.

Someone better to talk to

When I am at home I feel I need more support with my anxiety, such as something calming.

We think this means:

- People of all ages may need more support to get the help they need for their mental health.



Hospitals

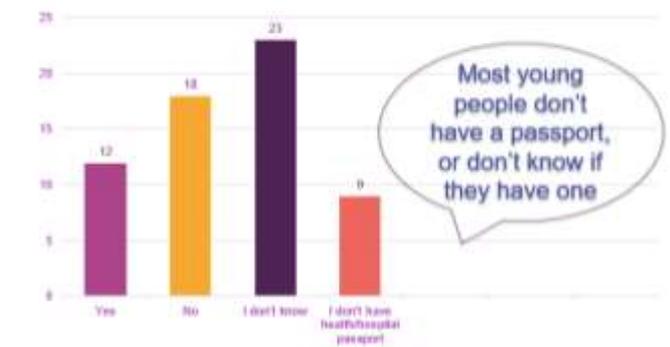
Health/hospital passports



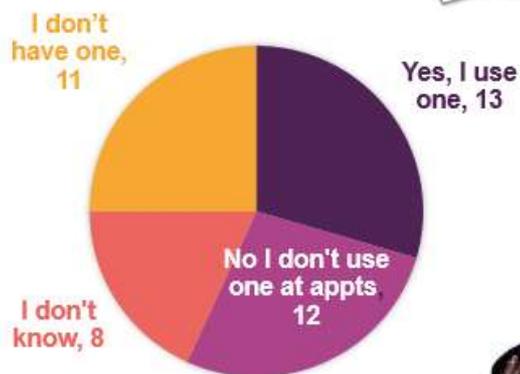
We asked people if they have and use a health or hospital passport:

- 25 people (12 young people and 13 people aged 26 yrs+) own and use passports, but
- 30 people (18 young people and 12 people aged 26 yrs+) said they don't use one
- 20 people said they don't have one, and
- 31 said they don't know anything about them.

Quite a lot of people have I passports and use them. But a lot of people don't use or have one. And some people don't know anything about them.



Most young people don't have a passport, or don't know if they have one



We asked the people that have health passports if people take notice of them. Some told us: "No", "Sort of" and "Sometimes":

- "No they ask my carer about me ..."
- "Sort of. They sort of glance at it and only really seem to be interested in the medication part and don't read the rest of it".
- "When I was admitted to hospital they didn't read it and didn't understand I am very anxious. It makes me really upset."
- "Sometimes, I always take it if I have to stay in hospital as I have no speech"

Do people take notice of them?
No,
Sort of, and
Sometimes!

Others told us "yes":

- "Yes they did when they were presented with it, when I was an in-patient"
- **"Yes and it has been commented on how good it was and helpful by paramedics"**
- "Yes they do, especially now with Covid-19"

Yes, some health staff do take notice of them !

We think this means:

- More people, and more health staff need to know about passports and how to use them

Making a difference:

Since our meeting the Co-Production Lead, Children and Young People Health Services Cambridgeshire and Peterborough NHS Trust told us they have passed on this information to the team who create health passports within our community paediatric services so that they can see how they might influence the inclusion of the passport into young people's EHCPs.



Learning disability specialist nurses

We asked if people knew that all the hospitals in this area have a nurse who helps people with learning disabilities:

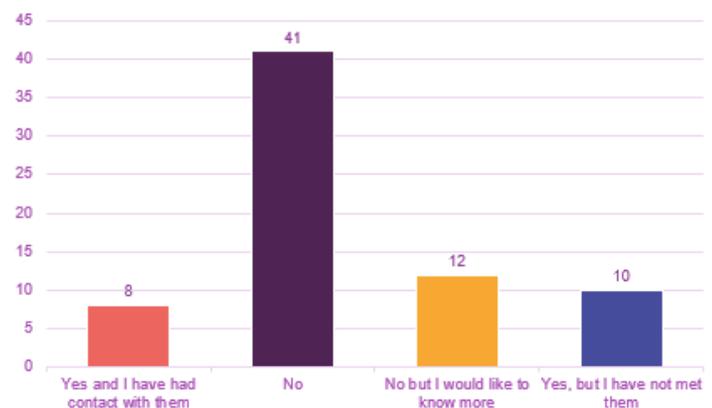
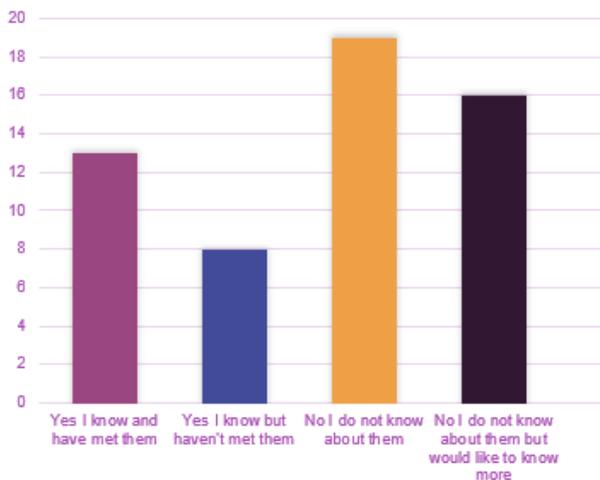
- 21 people (8 young people and 13 people aged 26 yrs+) knew about the nurses and had met them.
- 18 people (10 young people and 8 people aged 26 years+) knew about the nurses but had not met them (but this might be because they haven't been into hospital and haven't needed them)
- 60 people (41 young people and 19 people aged 26 yrs+) did not know about these nurses. Again, this might be because they have not visited the hospital.

Cheryl
Learning Disability
Specialist Nurse
Addenbrookes



Quite a lot of people knew about them but lots didn't. And many would like to know more

However, 28 people (12 young people and 16 people aged 26 yrs+) told us that they would like to know more about these nurses.



People also told us:

- "My mum has emailed the lady at Addenbrookes after being put in touch by Healthwatch but she can't find out how to contact them from the CPFT or hospital websites".
- "They are always very busy".
- "We need to have an LD Trained Nurse on each ward of every hospital on every shift".
- "The treatment one gets is dependant on who is the staff nurse and if they are trained in LD and autism and if they have staff to accommodate reasonable adjustments".

LD nurses are really great but one per hospital is not enough

- “Having an LD Nurse is great but they are usually not around at night or during A&E admissions. This is due to under resourcing. This needs to be improved”.



People also asked us:

- Question: What is the criteria for having a passport?
 - Answer: Anyone with additional needs can have one.
- Question: Where do we get one from?
 - You can get one from the LD Specialist Nurse at your local hospital, from some hospital websites and organisations like [National Autistic Society](http://NationalAutisticSociety.org) where you can download an autism passport.



We think this means:

- More people need to know about LD specialist nurses

Making a difference:

Since our Speak Out Day, Debbie Gallacher Project Support Manager for Learning Disability, Cambridgeshire and Peterborough shared this information about local LD nurses:



 Learning Disability Nurses/Advisors in Hospitals near where you live (Cambridgeshire) SUPPORT FOR PEOPLE WITH LEARNING DISABILITIES AND/OR AUTISM IN HOSPITAL		
WHAT ARE LEARNING DISABILITY LIAISON OR SPECIALIST NURSES AND ADVISORS? The Learning Disability Nurse understands the needs of people who have a learning disability and/or autism, and also understands how hospitals work. Nurses/Advisors can work with the hospital to help you get the care, treatment, tests you need.		
WHEN MIGHT YOU NEED TO GO TO HOSPITAL?		
 If you need to see a doctor/nurse in a clinic (outpatient appointment).	 If you are very ill or have an accident you may go to the Accident and Emergency Department.	
 If you are unwell you may come into hospital to stay until you can go home.	 If you need an x-ray or other tests.	
WHAT CAN THE NURSE OR ADVISOR DO?		
 They may support you when you are in hospital and help plan for you to go home again.	  Make sure you know what is happening to you. Make sure you have the right information you need about any care, treatment and tests you may have in hospital. Have your hospital passport , if you would like one, which is important to bring to hospital.	
  Tell the hospital staff if you need any special arrangements for the appointment, treatment or your stay in hospital.	 Talk to you, your relative or carer and the hospital about your care.	

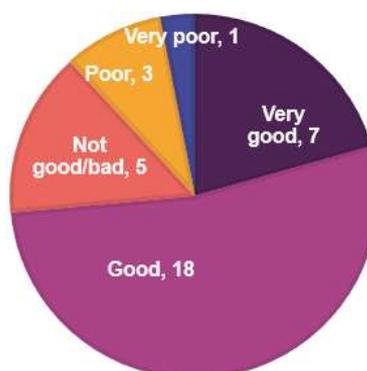
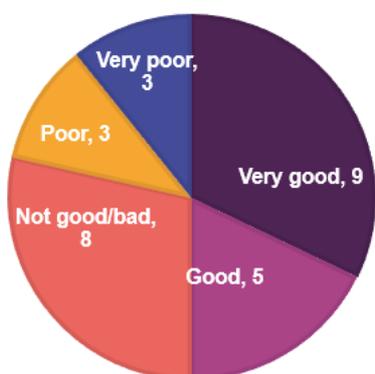
HOW TO TALK TO THE NURSES/ADVISOR			
 Monday to Friday The nurses normally work Monday to Friday (day time). If you leave a message and your telephone number they will call you back.	 Cambridge University Hospital Foundation Trust Addenbrookes Learning Disability Nurse Specialist – Cheryl Exley Telephone: 01223 245153 ext 2135 Direct Line Tel: 03225 216133		 North West Angle Foundation Trust, Hetchingbrooke Learning Disability Nurse Advisor – Marie Stokes-Davey Telephone: 01480 416438 ext 0581 Direct Line Tel: 03480 436581
 North West Angle Foundation Trust Peterborough and Stamford Hospitals Learning Disability Nurse Advisor – Sue Bates Telephone: 01753 678600 Direct Line Tel: 03253 673852	 The Queen Elizabeth Hospital/NHS Foundation Trust Learning Disability Liaison Nurse – Madeline Rudd Main switchboard: 02953 623613 Direct Line Tel: 03553 234984		
	 West Suffolk NHS Foundation Trust Safeguarding Lead Anthony Green Switchboard Tel: 01884 733000		

Full details are in the Appendix at the end of this report.

Staying on a hospital ward overnight

We asked people about their experiences of staying on a ward overnight.

- 14 people (4 young people and 9 over 26 yr olds) said it was good or very good.
- 8 people (2 young people and 6 over 26 yr olds) said it was not good or bad, and
- 6 people (2 young and 4 over 26 yr olds) said it was poor or very poor.



Staying in hospital overnight

Having tests at hospital

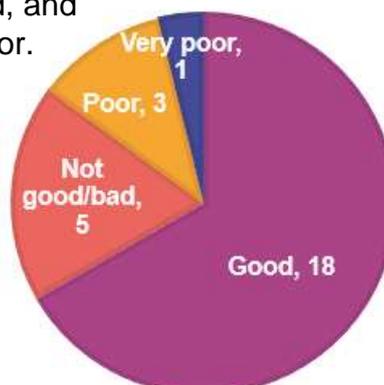
Having tests at hospital

- 7 people aged 26yrs+ said they had a very good experience,
- 18 people (5 young people and 13 people aged 26yrs+) said it was a good or very good experience,
- 5 people aged 26 yrs+ said it was not good or bad, and
- 4 people (1 young person and 3 people aged 26 yrs+) said it was poor or very poor.



Visits to A&E

- 18 people aged 26 yrs+ said it was good.
- 5 people said it was not good or bad, and
- 4 people said it was poor or very poor.



Reasonable adjustments

We asked people if they felt reasonable adjustments were made for them. They told us:

- “The waiting time was too much”
- “They allowed my mum in for the visit to A/E”
- “All good to my needs it was geared to”
- “I think reasonable adjustments were made. They let my mum visit during Covid restrictions. Having a general timescale of things would’ve made it easier (waiting 7 hours in A&E for a CT scan is not fun)”



We asked what would have made visits or stays better? They told us:

- “It would be better if there was someone available to communicate with me”
- “It would help if the staff read my hospital passport before I come to the hospital”
- “They didn't explain clearly so that I could understand what they were doing and they didn't try to understand or use my communication methods. They didn't have a suitable hoist and it wasn't easily available. Sometimes staff don't know how to use them. Sometimes they are out of charge”.



Hospitals hoists

We asked the local hospitals about hoists.

Hinchingbrooke and Peterborough told us:

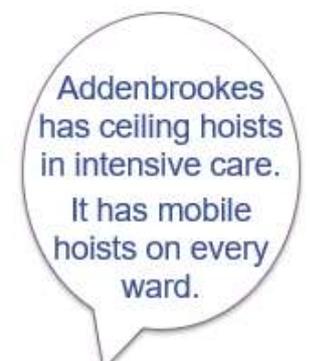
- They do not have any ceiling tracking hoists, they hire if they need them:
 - 2019 - 12 hired
 - 2020 - 6 hired up until October
- All clinical staff are trained to use the mobile hoist
- Moving & Handling trainers are on hand too
- Each hoist has two batteries – one on charge and one in the hoist

We do not know how long it takes to get a hoist delivered to the hospital



Addenbrookes told us:

- Only the intensive care area has ceiling hoists
- But every ward has a mobile hoist (so about 150 in total) and wards can request more
- They do not need to hire them unless something very specialist is needed
- Special attachments are available (loops and clips)



- All ward staff are trained to use the hoists and should be confident, clinic areas don't hoist as often but are still trained to do so
- The manual handling team can always provide support or training if needed

Young people's experiences

From the results in the sections above you can see that generally young people had good experiences in hospital but one young person told us:

- "I need a special bed to stay overnight in hospital. I was told they didn't have the bed I needed despite my mum telling the people in A&E about it early on.

"Instead, I was given one with partial sides, one of which fell off during the night. If my mum hadn't sat by my bed all night to raise the alarm I would have fallen out very quickly. Another bed did eventually arrive with some padding and I was asked to walk from one to the other despite not being able to walk at all, or even stand up without being in a standing frame. If all the people involved had read my hospital passport as I was passed from one person to the next, they would have known much more about me and been able to look after me better".

We think this means:

- People have had mixed experiences of hospitals
- Hospitals can be good at making adjustments but people need to ask for adjustments to be made. Using a health passport, and talking to the LD specialist nurse can help here
- More tracking for ceiling hoists is needed in all hospitals so that people can feel safe
- People need to know how to complain if they don't get what they need

Generally young people had good experiences in hospital, however some people had bad experiences and when it was bad it was pretty awful...



People need to know how to complain if they don't get reasonable adjustments



Tests and screening and bowel cancer screening

Smear tests

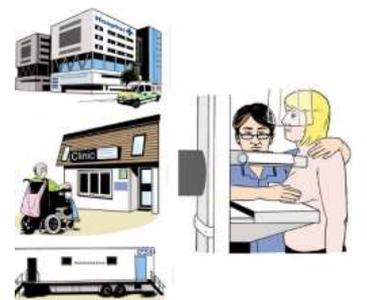
We asked people aged 25 years and over if they'd had a smear test:

- 15 people (1 young person and 14 people aged 26 yrs+) said yes.
- 5 people (1 young person and 1 person aged 26 yrs+) said no.



We asked those that said no, why that was. They told us:

- "I was scared to have it as it was so painful so I couldn't go ahead with it. The nurse at the time said not to worry about it as I wasn't sexually active then"
- "Mum and doctor don't think it necessary as I have no sexual experience"
- "I always thought it was for people who had had sex and I haven't"



Breast Screening

We asked people aged 50 years and over if they'd been for a breast screening:

- 4 people said yes, and
- 1 person said no.

Bowel cancer screening

We asked people aged 55 years and over if they'd done a bowel cancer screening test

- 1 people said yes,
- 5 person said no, and
- 3 people said they did not know if they had.



We think this means:

- People seem to know about smear tests
- Not so many people seem to be aware of breast screening and bowel cancer screening but we did not talk to many people aged 50 years+.





What else young people told us

Health services as young people become 18

We asked young people if things had changed with the health services they receive since they turned 18. They told us:

I feel it's the same. It's good.

Music therapy at school, was very useful, would have liked it to continue.

No support, or you have to really fight to get it.

They always talk to my parents.



When I was younger the doctors would just talk to my mum but now they talk to me too.

When I was younger, I required more developmental support. In my adulthood, the services I required were for mental health.

Yes - was having speech therapy and now don't :(



Very different....It is extremely time consuming to find the right person, clinic, team, email address, phone number, website page to tell me what I need to know. GPs have much less experience with learning disability than therapists attached to special schools so you feel you are starting from the beginning with some things and sometimes the rules eligibility criteria have changed.

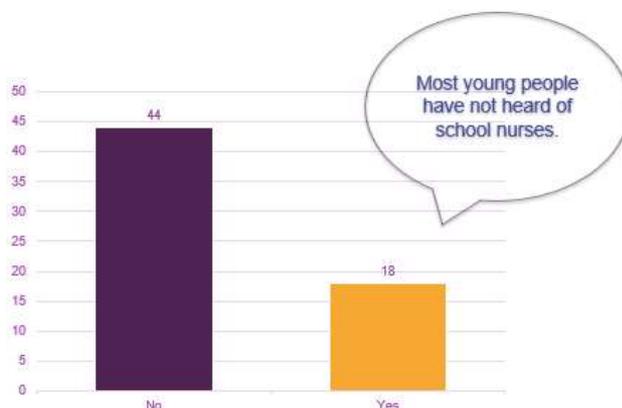
We think this means:

- Young people and their parents do not feel they always get the same service once they turn 18.



School nurses

We asked young people if they knew about school nurses



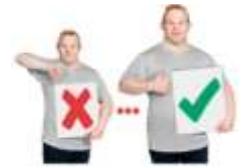
We think this means:

- Young people, and school/college staff need to be told about school nurses and the support they can offer.



Making a difference:

Since our Speak Out Day, Co-Production Lead, Children and Young People Health Services Cambridgeshire and Peterborough NHS Trust told us that they are going to film a couple of short videos for the colleges about school nursing and ChatHealth and they have invited us to co-produce it!



Video calls

We asked young people if they'd had any video calls with Community services this year.

- 2 young people told us they'd had a video call and would do it again, and
- 1 told us they had but would not want to do it again.

We asked young people if they'd had any video calls with Hospital services this year. They told us:

- 2 young people had a video call and would do it again, and
- 1 told us they had but would not want to do it again.



Their comments included:

- Yes, consultation with a consultant in June and specialist nurse appointment in November
- Yes. It is easier than going to the hospital and quicker, so it is good.
- Yes, from Great Ormond Street Hospital
- Yes for my epilepsy
- Yes, but I prefer face to face.
- Yes, and would like this to continue.

We think this means:

- Video calls can be really useful and suit some young people, but they are not right for everyone. A choice of video or face to face meetings (where possible) would be best.



Consent to share information

We asked people what they thought healthcare professionals mean when they ask them, or their family, for consent to share their information.

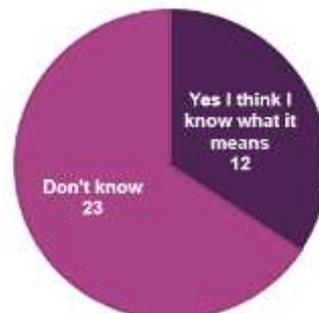


The young people told us:

- “For consent to share my information with other people involved in my care”
- “I think it is for 3rd parties who are not part of the NHS”
- “I think they need to share it for reasons that involve their work - for example, logging reports to supervisors and providing others within the organisation with the means to contact me”
- “If you need help that someone understands what you need to help me”
- “Permission for other specialists”
- “They want vocal permission from me first”
- “To ask other doctor/healthcare the information
- “To help other people, help people who want to do the same profession for training purposes”
- “To keep your information safe and only show people who need to see”
- “To not share anything publicly that could be personal?”
- “With other doctors asking permission to share info”

12 young people told us what they thought it meant. They told us:

23 young people said they had no idea what this meant



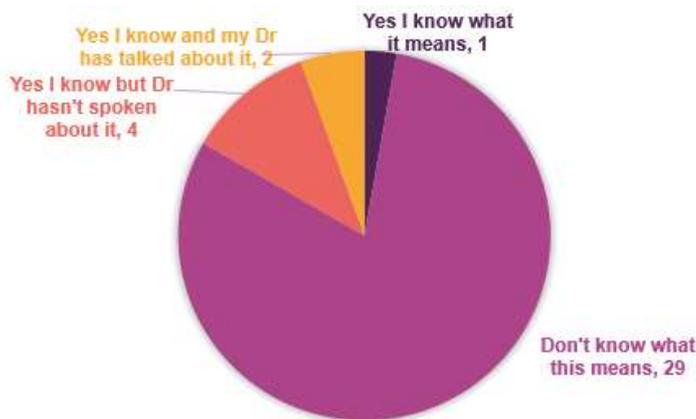
We think this means:

- Most young people don't know what “consent to share information” means. And some that think they know, may be incorrect.
- It is important that health professionals check that young people have understood them when they explain “consent to share information-It might be useful to have some Easy Read information about this.



Best Interests Decisions

We asked young people who were older than 16 years, if they knew what is meant by Best Interests Decisions. And we also asked if their Doctor had ever mentioned it to them. They told us:



We think this means:

- The majority of young people do not know what is meant by Best Interests Decisions
- It would be useful to have some Easy Read information available about this.

Finding information

We asked young people if they were able to find the information they need about their health, exercise and sports, going to hospital, food and diet, sex and relationships and mental health.

They told us that they can google the information or use books. They also say they can ask their parents and college.



We think this means:

Young people are good at finding the information they need. But as they rely on the internet it is very important that sites such as hospitals have accessible information.



Appendix

Here are some useful sources of information if you'd like to find out more.

- www.mencap.org.uk provides information for people with a learning disability, their families and carers. It also runs a campaign called "Treat Me Well" about transforming how the NHS treats people with a learning disability in hospital.
- [National Autistic Society](http://www.nas.org.uk) provides information and support for people on the autistic spectrum. You can download an autism health passport from here.
- Learning Disability specialist nurses:
 - Cambridge University Hospital Foundation Trust Addenbrookes, Learning Disability Nurse Specialist – Cheryl Exley, Telephone: 01223 245151 ext 2133 Direct Line Tel: 01223 216133
 - North West Anglia Foundation Trust, Hinchingsbrooke, Learning Disability Nurse Advisor – Marie Stokes-Davy, Telephone: 01480 416416 ext 6581, Direct Line Tel: 01480 416581
 - North West Anglia Foundation Trust Peterborough and Stamford Hospitals, Learning Disability Nurse Advisor – Sue Bates, Telephone: 01733 678000, Direct Line Tel: 01733 673832
 - The Queen Elizabeth Hospital NHS Foundation Trust, Learning Disability Liaison Nurse – Madeleine Rudd, Main switchboard: 01553 613613, Direct Line Tel: 01553 214584



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Learning Disability
Specialist Nurse
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To find out more or get in touch

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