



Norfolk SEND Youth Forum

Wednesday 15th May 2025 - 6:30pm – 7:30pm

Meeting Minutes

Attendees:

Bridget Robinson (Norfolk SENDIASS)

Belinda Coxall (Norfolk SENDIASS)

Katrina

Isaac

Charlotte

Callum

Lily

Alec

Charlie

Gabriel

Reece

Steven

Guests:-

Mark Gower - Senior Designated Clinical Officer (SEND), NHS Norfolk and Waveney ICB

Kate Brolly - MCA Lead/Deputy Designated Professional Safeguarding Adults, All Age Safeguarding Team, NHS Norfolk and Wavey ICB

Apologies: - Dawn Jones (Inclusion & SEND, NCC)

Welcome and Introductions

Everyone introduced themselves and Steven met some members of the group for the first time.

SEND Youth Voice Day – Friday 30th May 2025 – 10.00 a.m. – 4.00 p.m. **Diamond Centre, Sprowston**

On May 30th an event will be held for young people with SEND to find out what helps them access and attend events and activities.

Some of the questions to be asked are:-

- What challenges and barriers do young people with SEND face in attending activities and events?

- What kind of things work or might work for young people to be confident to attend activities and events?
- What tips would you give other young people with SEND?

On the day there will be opportunities to make videos, podcasts, artwork, poetry to share your views on this with other young people.

Reece, Steven, Lily and Charlotte said they would like to attend.

A pre-meeting on 20th May via Teams has been arranged and joining instructions are in the information pack. The pack will be emailed out after the meeting for anyone else who is interested in attending.

Professional Consultation – Mark Gower and Kate Brolly from NHS Norfolk and Waveney ICB – Norfolk Area SEND and Alternative Provision Strategy

Kate and Mark introduced themselves to the group.

Following the SEND Survey a group of professionals are looking to create health and your rights information for young people. Kate and Mark have come to the meeting to find out: -

- Where do you go to find out information about your health issues and concerns?
- How do you want to be given information, for example leaflets, websites, in person?
- What do you need to know?

Kate showed a video on the Mental Capacity Act and when you reach 16 you have the right to make your own decisions as it is the law set out in the Act.

In the video it showed how we make decisions all the time from every day from small decisions i.e. what to have for tea and big decisions i.e. consent to a medical operation. To make a decision we need to understand what we are doing and if someone is unable to make a decision the law is there to protect them.

To be capable of making a proper decision, the law says you need to have capacity, and these four questions are asked to check this: -

1. Can they understand the information to help make that decision?
2. Can they retain that information?
3. Can they weigh up that information?
4. Can they communicate their decision to others?

Just because someone is disabled or isn't used to making decisions or struggles with handling complicated information it doesn't mean they can't make some or all decisions for themselves with the right support.

The Mental Capacity Act has five rules to follow to check whether someone has the capacity to make decisions: -

1. Start by assuming that everyone can make their own decisions
2. Give the person as much support as possible to help them make their decisions
3. You can't stop a person making a decision just because you or someone else thinks it's wrong or a bad choice
4. If someone can't make a decision themselves and you have to do it for them, the decision must be made in their best interests
5. If you have to make a decision for someone else, it must limit their freedom or rights a little as possible

The group enjoyed the video and found it helpful and Kate asked some questions about the group's experiences.

Do people make decisions without you being involved?

- Some of the group said the doctors and nurses speak to their parents and some of them said they speak to them direct.
- My consultant at ENT at NNUH spoke to me and I was able to choose my treatment albeit the meds he prescribed were not available, so I have a substitute.
- Unfortunately, I have experienced people making medical decisions for me even though I didn't want to do something. And unfortunately, I'm still trying to undo the damage that was done! But also, me asking for medical help and not receiving it.
- I sometimes worry that people that are medics don't understand what I am trying to say and they do not always hear me.
- Waiting lists are long now.
- Some of the group had a positive experience at 16 and some had a negative experience.

Do you like people helping with your choices?

- I take advice from the GP and NHS website to decide and I also check what they suggest.
- Feel nervous speaking to Drs and want someone independent to come along who has got my back.
- I bring someone with me to the dentist but not the Drs as I mostly go there alone.
- I like people to help me understand but not force or influence me to make decisions
- I like my mum to come with me as sometimes I forget what they tell me, so I bring my mum along, so she knows exactly what they have said
- Yes, I'm happy to have support in making decisions, as sometimes I have to make big decisions especially with my epilepsy and I don't always ask the right questions.
- My mum always checks my understanding of things people have said to me
- Mum makes a list of questions that I want to ask
- I do not like filling in paper forms - I prefer to type forms.

Do people make decisions about you without you being there?

- When I was in recent crisis, I could not make decisions mum had to call two numbers to get help
- They didn't provide me with any helpful information beforehand and me being young assumed they knew what was best for me but didn't tell me the risks or give me a choice when I said no
- I find it difficult to make a decision about things sometimes though
- Not always listened to or understood and given choices and make assumptions because you are young.

Had you heard of Mental Capacity Act before this meeting?

- Yes - from my college course
- No
- Not really
- I sort of knew but have never been told specifically what it is but mum did
- Yes – through MIND

What would help you to know more about making decisions?

- Accessible videos aimed at young people
- Information to be put in the Health Leaflet at 14 years old
- Send a link with information sent out with the EHCP
- In doctors with some information about it on posters in waiting rooms or on the tops of forms
- LD Health Check
- Just One Norfolk – information page for Young People
- On a poster - like the Patient and Liaison Service is posted at 80 St Stephens
- Make it more clear by putting it around places that people visit most
- I probably wouldn't think to check doctors and hospitals - we always forget to look
- Same, anxiety is through the roof just want the meeting over and done with for sure, because you wouldn't go looking for it if you haven't been taught about it when we are already getting help from LD services
- Most people don't just want to look for the information because sometimes it could be something that you don't want to know about,

Kate and Mark thanked everyone for their contributions and were invited back in the future to update the group.

Any Other Business

Next meeting on 18th June 2025.

Thank you for all your contributions!