



Your Voice Network Neurodiverse group

Thursday 4th January 2024

Attended by

Self-advocates from Gloucestershire
Self-advocates from Wiltshire
Self-Advocates from North Somerset
Self-advocates From Devon
Self-Advocates from Cornwall

Represented groups

Dimensions for Autism
Your Voice
NDTI

Ice breaker question

Goals for new year? People Losing weight, dry January, 30 day yoga with Adrienne, do hobbies, go to one comic con, stop making resolutions, self-improvement and getting well, bathroom fixed

Main Discussion **Vitual Wards**

Feedback given by the group

○ **Madaline Cooper from The National Development Team for Inclusion (NDTi) Joined the meeting to talk about Virtual wards and find out what Neurodiverse people feel about them. She shared a presentation about what virtual wards are. Two questions: What would be great about virtual wards and what could be a challenge? What things need to be taken into account/what reasonable adjustments would be good?**

○ Gloucestershire was shortlisted for an award because of a virtual ward used during Covid. It might be good to track some of the 6000 people down who used it to find out what they thought about it. I have also become a governor of the Glos health and care NHS trust so I would be interested in this. As an Autistic person my perspective is that any additional options are a good thing for many people. The use of virtual technologies during COVID has improved things in other areas.

○ Madaline asked If you became ill would it work for you? We are going to have to imagine scenarios and give pointers to the NHS as not many people have used them.

○ Someone had been thinking about the gap in between primary care and secondary care mental health services. Does this also apply to mental health services? Madeline said "Not yet, it has only been around for 2 years in clinical practice"

• Someone said when they were younger and might have considered having children the thought of being in hospital was a sensory nightmare. I found it very off putting. So they quite like the idea of a virtual ward being at home with my spouse and my cat. But had a concern is what safeguards are in place to ensure people don't fall off the radar. If you are in hospital and nurses and doctors see you are in crisis they will attend to you, is there a way this can happen at home?

• Madeline said There are dedicated teams who only work on the virtual wards and you have 24 hour access to get hold of them. Would those worries outweigh the relief of being at home? Would you want them to take into account you spouse and cat's needs?

It was asked If you are at home and ill as an outpatient the district nurses attached to primary care might be coming to visit so how do they balance this?

Feedback given by the group

- Some one said advice or guidance to anyone's partner or housemate would be extremely helpful because then you wouldn't feel like you're in the way in your own house and they can aid recovery.
- Some one said that in theory I think it's a great idea, but their concern is that although there is 24 hour access to contact, reaching out for that would be quite difficult. It is really hard to get contact with health professionals as it is and as autistic people we are often told we are that we're the problem When things have happened it is overshadowed and labeled as anxiety The issues of interoception could be an issue and they don't trust that the NHS will have that covered
 - Madaline asked what are reasonable adjustments regarding interoception that would help the NHS
 - It was suggested that the health passports can be helpful if we cover interoception issues.
- Someone said the Health passport is really critical. What would be good if there was someone who was an OT who could go through building a health passport specific to this. If you are going to improve the outcomes have a specialist person who could do this and they could go around the different
 - teams. If they have had a planned procedure like an operation and then they go on a virtual ward it would be useful. This would be an opportunity for raising the profile of the health passport. It is often very difficult for autistic people to raise the issue of needing help. The triangle of care is even more applicable.
- Someone said On one hand there are so many creature comforts that would make it really conducive to healing but I'm wary about the medical establishment. Autistic people are often victims of the establishment. What is the right time to be the 'squeaky wheel' because from childhood we have been conditioned to be quiet and stop complaining because things are not an issue. There is a lot of patting on the head and telling me they know better by medical professionals. Because they don't have an autism diagnosis its difficult to know when to advocate and when not to. Others are able to self advocate for themselves, but what about the people who can't or haven't got that far? It makes their heart rate go up thinking of having a zoom call with a medical professional and trying to get themselves understood. OT's have the training to listen to people's experience and work with it. For the neurodiverse community it would be key to involve OTs, this would help with raising complaints about the process.

Feedback given by the group

- It was asked “How often do OTs get mentioned in your in the NDTI survey?” Madeline said that until this meeting, no one has mentioned it in the survey. This is quite a small piece of research. I am going to be talking to the people who run virtual wards. It seems like those are the people (OT) who can tie all these issues together
- There was some discussion about the reliance on technology for virtual wards. Technology is only ever good when it works. This is an opportunity to trial technologies and approaches. This may rely on internet access and availability. There is a big infrastructure issue, can it be rolled out as widely as they wish? There are medical devices on the market that can monitor your health autonomously. It’s an area of opportunity but it needs a bit of time thinking about what we could do.
- Some one said Its probable that you would want a technical person supporting the process to make sure you are connected. Part of the tasks of the daily medical visitors is that they would also check on the equipment.
- In Devon (and more rural areas of the south west) we are not very well connected with technology. The people who might benefit from this the most are also the people who might be most likely to be in poverty. Your conditions at home might not be up to this, you might not be able to afford broadband or you might be on a prepayment meter for electricity and this might prevent them from using a virtual ward. Things can happen that knock broadband out for months. Digital poverty is a big problem for autistic people and people with learning disabilities. In hospital you rely on their resources even if it is detrimental to your mental health. It would be really unjust that this could be a barrier and it would be a luxury that only certain people could have. Its got to be available to the most available. .
- Someone said it was important to trial it rather than roll it out universally There might also need to be specialized food support when they are at home and this could be particularly relevant for neurodiverse people. It would be important to have PALs available to people at home too. There might be a need for virtual chats as well so there is an holistic approach.
- Madeline said She doesn’t know where they will be trailing this. They want to expand beyond the initial conditions that they trailed it with. I don’t know if they are now considering that it will be rolled out or trialed. It will only ever work where the equipment for the condition is portable enough to go into a home. One individual with learning disabilities and autism’s sister felt that it might have saved his life as he would be so distressed about being in hospital. There is something about how they help people to make the decision and how our families would know what we want if we are unable to tell them.

Feedback given by the group

- Someone said I don't like people in my house so I would have to make the choice when I am quite ill of being in a place where my sensory overload would kick in quite quickly or having people in my home. Having to choose between two situations they don't like. Having something to help you make that choice when you are ill as well. Maybe it goes back to having the hospital passport or other pre planning forms so you could think about it when you are well.
- Someone asked Is the decision reversible – if someone chooses to be at home and it doesn't work out. If someone knows it's not the final decision it might be a less stressful process. A lot of neurodivergent people have not got a diagnosis and so it's important that it's not medicalised and not based on diagnosis. It would be really good if everybody got OT support. It would be beneficial regardless of the medical need. Everyone should have a health passport it then becomes the norm to think about the reasonable adjustment that everyone needs.
- Someone asked about the reasonable adjustment flag as they had recently had a letter that suggested that they didn't need a reasonable adjustment. We have talked before about the LD flag and the possibility of an autism flag but some autistic people didn't identify as disabled. But the reasonable adjustments flag has only just been rolled out in roughly November

Conference planning

- Sammy has put together some surveys to work out timings, dates and topics, for the conference that we are planning Topics - <https://forms.office.com/e/Y8RZx9qAtR>
- Time and dates survey <https://forms.office.com/e/sQexS87ztQ>
- Aut-isms and DFA are going to do 20 minute sessions on their work and what they can offer to the autistic community.

Next meeting

- Next meeting is Thursday 1st February 2024 – 6:00-7.30