



Special United

The voice of young people with special educational needs and/or disabilities and their siblings

Special United Zoom Meeting – 29th September 2021

Thirteen young people joined us for the event and two more were unable to join. We had the following to talk with us:

- ✚ Heidi Francis, Interim Project Manager, NHS Berkshire West CCG
- ✚ Gill Seagrove from the Local Offer.

1. We discussed the new keyworker scheme which is being set up for young people with Autism, ADHD and/or a learning disability and mental health difficulties. The keyworker will work with a young person and their family when they are a risk of needing a hospital bed or a residential school.

The Keyworker will look at all the agencies supporting a young person, gather information and meet with the young person and their family to work out what is causing difficulties and what would help.

Young people said that communication, commitment and a non judgemental worker were vital. The following was important:

- ✚ Not having to wait ages for an appointment and someone who returns calls
 - ✚ Someone who is not judgemental and just assuming one thing is the problem such as home-schooling.
 - ✚ Someone who is committed – don't close the work because we are too anxious to meet with you.
 - ✚ Someone who is polite and not rude or sarcastic. Don't make rude comments about our siblings either.
 - ✚ Someone who understands disability and anxiety. Someone who understands that, unless you have had a mental health crisis, you can't understand how it feels.
 - ✚ Someone who doesn't look down on us.
 - ✚ Support with education – it is stressful without support – one young person had been kicked out of college and her family had been left with no support to find anything else.
2. Young people said that the Royal Berks was not autism friendly although posters say it is autism friendly. We need staff to understand that being autistic is not our fault and treat us like a human beings.
 - ✚ Sometimes young people find it difficult to express themselves at appointments – please give us time and let us bring a parent or family member to help us communicate.
 - ✚ Pictures of emotions can help us express how we are feeling. Don't ask us really hard questions like "What do you mean when you say you feel empty?"
 - ✚ Sending questions before an appointment will help us prepare and make us feel less anxious.

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✚ Ask us if we have understood. If we haven't understood, tell us in another way.

Things need to change and we need to make sure things improve for disabled people at the hospital.

3. Young people also asked: What can we people do if others are teasing them at school and they are struggling to manage their anger? This is common for young people with additional needs. Talk to the school and ask them for support.

Next session

We will ask Specialist CAMHS to come and talk to us. Then Katie Laws about social activities for 18 – 25 year olds with additional needs.

Special United would welcome Heidi back for another session if she needs this. It was good to have someone who listened to us.

RB 10/10/21

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