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Study Information Sheet: What facilitates a positive experience of school for children and young people with Down syndrome educated in a mainstream setting?



For a video version of this letter, right click here and open the hyperlink:
<https://www.youtube.com/watch?v=KQKp-Lvh-cA&fbclid=IwAR3d8ngoyZJc4k9-pYUtrQWmYQkpPyjlmWBcc8lGnjPhabt3javgfugCV0k>

Hello. My name is Nicki.

I am doing a research project to find out more about how children with Down syndrome experience school and what they liked about school.

I am asking you to be in my study because you would be perfect for it as I need the help of people with Down syndrome that have been to a mainstream school – just like you!

You can decide if you want to take part in the study or not. You don't have to - it's up to you.

This sheet tells you what I will ask you to do if you decide to take part in the study. Please look at it carefully, with an adult who knows you well, so that you can make up your mind about whether you want to take part. Your parent or carer has received an information sheet too, so they can help you understand. I've also made a video for you about the study – right click on this link and open the hyperlink to watch it <https://www.youtube.com/watch?v=KQKp-Lvh-cA&fbclid=IwAR3d8ngoyZJc4k9-pYUtrQWmYQkpPyjlmWBcc8lGnjPhabt3javgfugCV0k>

If you decide you want to be in the study and then you change your mind before we start, that's ok. All you need to do is tell me that you don't want to be in the study anymore. You or your family or someone who looks after you can email me on Nicola.baker@uea.ac.uk

If you have any questions you can speak to me or your family or someone else who looks after you. If you want to, you can contact me on Nicola.baker@uea.ac.uk

What will happen if I say that I want to be in the study?



- I will invite you to come to an interview, where I will ask you some questions
- The interview will be in a place that you know well and feel comfortable
- I will ask you some questions about when you went to school
- All of the questions will be about your **positive** experiences in school, this means things you enjoyed, or that helped you to learn or feel welcome and happy
- You can bring anything you like to the interview to help you answer the questions, this might include objects, toys, letters, report cards etc.
- There will be some picture cards to help you answer too, you can also draw or write if it helps you
- If you don't want to do the interview on your own, you can bring an adult that you trust with you, they can help you to explain your answers
- You will be with me for around half an hour to an hour. You can stop the interview whenever you want

When I ask you questions, you can choose which ones you want to answer. If you don't want to talk about something, that's ok. You can stop talking to me at any time if you don't want to talk to me anymore.

If you say it's ok, I will record what you say with an audio recorder.

If you say it's ok, I may take some photos of the objects you bring in or any drawings/writing you might do.

After you have finished talking with me, I won't be able to take out the things you say after you have said them. This is because I will be talking to other young people too, and I will not know who said what. You can choose which questions you want to answer. If you don't want to talk about something that's ok

Will anyone else know what I say in the study?



I won't tell anyone else what you say to me, except if you talk about someone hurting you or about you hurting yourself or someone else or doing something you should not be doing. Then I might need to tell someone to keep you and other people safe.

All of the information that I have about you from the study will be stored in a safe place and I will look after it very carefully. I will write a report about the study and show it to other people, but I won't put your name in the report and no one will know that you're in the study.

How long will the study take?



The study will take around 30-60 minutes. You can choose how long you want to talk to me for and how much detail you answer in. You can have breaks if you need them.

Are there any good things about being in the study?



- This study will help the voice of people like you be heard!
- This study will help schools to understand what young people with Down syndrome find positive about mainstream school
- This study will help schools to understand how they can make school a positive experience for young people with Down syndrome
- You won't get anything for being in the study, but you will be helping me do my research

Are there any bad things about being in the study?



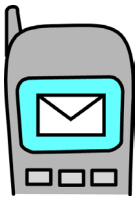
- This study will take up some of your time
- Sometimes, you may find it tricky to explain your answers
- If you didn't enjoy school, some questions might be tricky for you to answer

Remember – you don't need to answer anything you don't want to

Will you tell me what you learned in the study at the end?

Yes, I will if you want me to. There is a question on the next page that asks you if you want me to tell you what I learned in the study. If you circle Yes, when I finish the study, I will tell you what I learned by emailing you, or your parent/carer a one-page summary.

What if I am not happy with the study or the people doing the study?



If you are not happy with how I am doing the study or how I treat you, then you **or the person who looks after you** can:

- Write an **email** to me on nicola.baker@uea.ac.uk
- Write an **email** to my supervisor on ryan.cullen@uea.ac.uk
- Write an **email** to the Head of School Y.Lebeau@uea.ac.uk

Please read the next page to consent to take part in the study

This sheet is for you to keep.

