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06 May 2023



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What facilitates a positive experience of school for children and young people with Down syndrome educated in a mainstream setting? A Reflexive Thematic Analysis study

Your young person has been invited to take part in a research study about the experiences of learners with Down syndrome who have been educated in mainstream education for at least a small part of their education. It does not matter if this was a very short part of their education, as we will chat about their whole education, including any alternative settings they attended. They can talk about whatever they remember best and feel comfortable chatting about.

They must be able to willingly consent to take part in this research themselves, in order to take part. To do this, they must understand what the study will entail and why they have been asked to participate. They also must understand the benefits and the risks involved with being in the study.

In order to ensure that your young person has the capability to consent, it is advised that you, as their parent or guardian, read through the following information about the study. You can then advise whether you believe that your young person is able to willingly consent to and understand this research.

In line with the Mental Capacity Act, in order for your young person's consent to be valid, you must believe that they:

- show some understanding of the information given to them
- are able to retain the information for long enough
- can weigh up information and use it to make the decision
- can communicate the decision

Please read the information below about the research and chat with your young person about it to decide whether you believe your young person is able to consent to take part.

(1) What is this study about?

Your young person has been asked to take part in this study about the experiences of learners with Down syndrome who have been educated in mainstream education for at least some of their education. This study will explore what learners with Down syndrome consider a positive experience in school. The study aims to use this information to build an understanding on how to best facilitate these positive experiences in school for all learners with Down syndrome in mainstream settings.

To do this, we are asking young people with Down syndrome, aged between 16 and 25, who have been educated in mainstream education for at least some of their education, to reflect on their experiences in a semi-structured interview. This interview doesn't need to involve only speaking. Your young person can use objects and pictures to explain their experiences too. They can talk about any experiences they want, including, but not limited to: primary school, secondary school, any specialist placements, any college or further education settings.

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Participating in this study is voluntary.

(2) Who is running the study?

The study is being carried out by the following researcher:

Miss Nicola Baker at the University of East Anglia
Trainee Educational Psychologist
Contact email: nicola.baker@uea.ac.uk

This will take place under the supervision of the following university tutor:

Mr Ryan Cullen at the University of East Anglia
Contact email: ryan.cullen@uea.ac.uk

(3) What will the study involve for your young person?

This study involves completing a semi-structured interview. The interview will take place at a location familiar and comfortable for your young person. In the interview, your young person will be asked questions about the **positive** experiences they person had at school. The researcher will take notes about what they say. If your young person struggles to answer verbally, they can use pictures, prompts, symbols and objects to help. Your young person can also be accompanied by an adult who knows them well, such as yourself. This adult can help your young person to express or explain their views but cannot add their own personal views.

(4) How much time will the study take?

The interview will take between 30 minutes and 1 hour, depending on how much your young person wishes to share with me. This can be shorter if they like. Your young person is also welcome to have a break whenever needed.

(5) Do they have to be in the study? Can they withdraw from the study once they have started?

Being in this study is completely voluntary and your young person does not have to take part.

The decision to participate or not will not affect your young person's current or future relationship with the researchers or anyone else at the University of East Anglia now or in the future.

If they choose to take part in the study, their answers will be anonymous. If they decide that they want to withdraw part-way through completing the interview, they can leave whenever they want, and their answers will not be stored. However, once data analysis of the interviews has begun, they will not be able to withdraw their answers from the study. This is because the answers will have been anonymised and used to find themes. Due to the anonymised data, it will not be possible to identify their answers and remove them.

(6) Are there any risks or benefits associated with being in the study?

I understand that answering questions about school and trying to remember back in time may be stressful for some people. While the questions are not designed to be sensitive, school could potentially be a difficult subject for some participants. Your young person will be encouraged to stop the interview if at any time they may feel uncomfortable. Moreover, the interview style will be flexible and adapted to your young

person's needs, in the aim to make a comfortable experience for them.

If they feel affected by or worried about anything discussed in the interview after it is completed, they should contact the researcher for support, who can discuss any key issues with the YP and/or their guardian. If they are unable to resolve any issues, they will signpost the young person/guardian to other organisations that will be able to help.

It is hoped that being in this study will also be beneficial. It is hoped that this research will further the understanding that schools and education settings have surrounding the education of young people with Down syndrome in order to help support a positive education for children and young people with Down syndrome in mainstream classrooms. Moreover, it is hoped that your young person will feel that their voice has been listened to and heard. In addition, the methods used to gather views will hopefully provide other researchers in Educational Psychology with confidence that it is possible to capture the views and experiences of those with Down syndrome or other learning or communication difficulties. This should provide methods for further research gathering the voices of these groups.

(7) What will happen to information provided by your young person and data collected during the study?

By consenting to participate, your young person is agreeing to their responses being anonymously collected and used for the purpose of this study. Personal data will be removed and data collected during the study will be studied in order to find key themes within the data and then report the findings of the study. Any data collected will only be used for the purpose of this study. All data will be stored on the UEA One Drive. Only Nicola Baker and Ryan Cullen will have access to the data. The overall results of the study will be written up into a thesis and submitted as part of the Educational Psychology Doctorate that the researcher is undertaking at UEA. Your young person's data and information will only be used as outlined in this Participant Information Sheet. Data management will follow the Data Protection Act 2018 (DPA 2018) and UK General Data Protection Regulation (UK GDPR), and the University of East Anglia's [Research Data Management Policy](#).

The information that your young person provides will be stored securely and their identity will be kept strictly confidential, except as required by law. Study findings may be published. All data will be anonymous.

(8) What if I would like further information about the study?

When you have read this information, Miss Nicola Baker (Nicola.baker@uea.ac.uk) will be available to discuss it with you and your young person further and answer any questions you or your young person may have.

(9) Will I be told the results of the study?

You and your young person can receive feedback in the form of a one-page lay summary in July 2024, once the research is complete, if your young person wants this. You will also be able to read the full thesis, should you want to, once it becomes available. The researcher will email you to notify you when this is possible.

(10) What if I have a complaint or any concerns about the study?

If there is a problem, please let the researcher know. You can contact them via the University of East Anglia at the following address:

Miss Nicola Baker
School of Education and Lifelong Learning
University of East Anglia
NORWICH NR4 7TJ
Nicola.baker@uea.ac.uk

Please email to arrange a telephone call

If you are concerned about the way this study is being conducted, you can contact the researcher's supervisor via the University of East Anglia at the following address:

Mr Ryan Cullen
School of Education and Lifelong Learning
University of East Anglia
NORWICH NR4 7TJ
ryan.cullen@uea.ac.uk

Please email to arrange a telephone call

If wish to make a complaint to someone independent from the study, please contact the Head of School of Education and Lifelong Learning:

Professor of Higher Education Research
Yann Lebeau
Contact email: Y.Lebeau@uea.ac.uk

(11) How do I know that this study has been approved to take place?

To protect your young person's safety, rights, well-being and dignity, all research at the University of East Anglia is reviewed by a Research Ethics Body. This research was approved by the EDU S-REC (School of Education and Lifelong Learning Research Ethics Subcommittee).

(12) What is the general data protection information I need to be informed about?

According to data protection legislation, we are required to inform you that the legal basis for processing your young person's data as listed in Article 6(1) of the UK GDPR is because this allows us to process personal data when it is necessary to perform our public tasks as a University.

In addition to the specific information provided above about why your young person's personal data is required and how it will be used, there is also some general information that needs to be provided for you

- The data controller is the University of East Anglia.
- For further information, you can contact the University's Data Protection Officer at dataprotection@uea.ac.uk
- You can also find out more about your young person's data protection rights at the [Information Commissioner's Office \(ICO\)](#).
- If you are unhappy with how your young person's personal data has been used, please contact the University's Data Protection Officer at dataprotection@uea.ac.uk in the first instance.

(13) OK, I believe my young person has the capability to consent– what do I do next?

Please sign this form electronically (using Microsoft word) and return via email to nicola.baker@uea.ac.uk

By signing this form, you are advising that you believe your young person has the capability to consent to take part in this research.

Once the researcher receives this signed form, along with your young person's signed consent form, your young person can take part on this study. The researcher will be in contact shortly to provide more details and organise an interview time and location.

Thank you,
Nicola Baker (Trainee Educational Psychologist)

(14) Further information

This information was last updated on 6th May 2023.

If there are changes to the information provided you will be notified by email.

(15) Consent

I agree that Is capable to consent to take part in this research

PRINT name:

Relationship to
young person:

Signature:

Date:

