

Participant information Sheet (Parents)

Research Project Title

Mechanisms of change in intensive group intervention for teenagers who stammer.

Invitation

You and your child are being invited to take part in this research project. Before you decide to do so, it is important you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. There is a similar information sheet for your child to read as well. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the project's purpose?

This research project aims to explore how taking part in the Talking Out Residential affects the way that your child and you feel about stammering.

The project is being carried out by Ben Bolton-Grant. Ben is a speech and language therapist and a PHD student at Leeds Beckett University. This project is being carried out as part of Ben's PHD.

Why have I been asked to take part?

You have been asked to take part because your child has been referred to the Talking Out Residential in October. We are interested in talking to young people who are going on the residential and their parents.

What do I have to do?

We are asking both young people and parents to take part in this research. As a parent it's important that you understand how your child might take part in the research as well as understanding how you could take part.

Your child

1. Ben will join the residential in October as an observer. He will make notes based on his observations of the group. No names or specific details will be recorded about participants. This does not involve your child doing anything in addition to the activities involved in the residential.
2. Ben will be given a copy of the assessments your child will complete during the residential. These are a normal part of the residential and you will be asked to complete them in even if they don't want to be part of the research project. This does not involve your child doing anything in addition to the assessments involved in the residential.
3. Your child will be invited to take part in focus groups during the residential. There will be one focus group each day of the residential. It will last no more than 1 hour and your child can choose whether or not they want to take part each day. The conversation will be recorded so that it can be analysed later. These recordings will be kept secure and not shown to anyone else.

4. Photographs and videos will be taken as a normal part of the residential (if you have agreed to this on the referral form). Your child might be asked to look at them during the focus group to help the group reflect on the day.

Parents

1. Ben will join the online parent group each evening during the residential. He will observe the sessions and make notes. No names or specific details will be recorded about participants. This does not involve you doing anything in addition to the activities involved in the residential.
2. You will be invited to take part in an online focus group with other parents the week after the residential has finished. This will last for approximately 1 hour. The conversation will be recorded so that it can be analysed later. These recordings will be kept secure and not shown to anyone else.

Do I have to take part?

No.

It is up to you and your child whether or not you want to take part in any part of this research. If you / your child wants to volunteer for specific parts of the research but not everything, that's fine too.

Can my child still go on the residential if they don't want to take part in the research?

Yes. Your child can still go on the residential if they/you don't want to take part in the research. Their place on the residential and the activities and support they receive during it will not change if they/you do not wish to be part of the research.

Can I change my mind?

Yes, you can change your mind and opt out of the research. You can do this up until 5 days after the residential has finished. After this point your data will have been combined with other people's data and it will not be possible to remove it from the analysis.

What are the possible disadvantages and risks of taking part?

Taking part in the research probably won't feel very different from taking part in the residential or parent groups. However, if your child chooses to join in with the focus groups this will mean doing an extra session talking about the group each day. They might feel too tired sometimes, or feel that they don't want to talk about stammering anymore. It's ok to not join in if they feel that way.

Taking part in the research will not affect the activities and support you and your child receive on the residential in anyway.

What are the possible benefits of taking part?

Taking part in the research will help further out understanding of how the residential helps people to feel differently about stammering. This may lead to improvements to stammering therapy in future, which may support other young people who stammer.

Focus groups can be fun and it might be helpful to your child to think about what they have done on the residential and how this has helped them to feel differently about stammering. This may also be the case for parents joining the focus group.

What if something goes wrong?

If you have any complaints about the project then you can talk to Ben or one of the team on the residential. If you feel your complaint has not been handled to your satisfaction you can contact the Leeds Beckett University using the details below.

Will my/my child taking part in this project be kept confidential?

Yes. All the information that we collect about you/your child during the course of the research will be kept strictly confidential. This means that you will not be able to be identified or identifiable in any reports or publications. Any data collected about you the assessments, or recordings of the focus groups will be stored online protected by passwords and other relevant security processes and technologies.

What you or your child says in focus groups will be kept private and won't be shared with the residential staff.

Data collected may be shared in an anonymised form to allow reuse by the research team and other third parties. No information about who you/your child are will be shared with anybody.

The only time we will share information is if you/your child share something that raises concerns about your child's or somebody else's safety. We will talk to you if this happens.

Will I/my child be recorded, and how will the recorded media be used?

Yes, if you/your child take part in the focus groups these will be video recorded. These recordings will be used by Ben to look back on and use what you say to help him understand what being part of the residential is like. The videos will be kept in a secure file online and protected by a password. Nobody else will be able to see them. The videos will be deleted once the research project has finished.

What type of information will be sought from me/my child and why is the collection of this information relevant for achieving the research project's objectives?

1. Ben will join in with all the activities on the residential and make notes on what he notices happening. He won't use your or your child's name in these notes, and if you have not volunteered for this part of the study he will not include any notes about you at all.
2. The assessments that your child will complete as part of the residential will be shared with Ben who will use these to help find out what changes your child has noticed during and after the residential.
3. In the focus groups for young people Ben will ask questions about what has happened each day. These questions will ask about what things your child has enjoyed, which things they didn't like, what was helpful, what wasn't helpful and if there is anything about the day they would change. This will be kept private and your child can be as honest as you like. This information will help Ben to understand how going on the residential might help you to feel differently about stammering.

4. In the focus group for parents at the end of the week Ben will ask questions about your thoughts and experiences of the parents groups and how you feel about your child's experiences on the residential. This will be kept private and you can be as honest as you like. This information will help Ben to understand how going on the residential might help your child to feel differently about stammering.

What will happen to the results of the research project?

Results of the research will be written up as a thesis which will be submitted in fulfilment of Ben's PHD.

The results from the research may also be published as an article in a research journal. You and your child will not be identified in any report or publication.

Who is organising and funding the research?

The project is being organised and carried out by Ben Bolton-Grant. Ben is a speech and language therapist and a PHD student at Leeds Beckett University. This project will be written up and submitted as part of his PHD. The study is being supervised by Dr Sarah James and Dr Trish Holch from Leeds Beckett University.

Ethical approval

This design and plan for this project has received ethical approval from Leeds Beckett University.

Contacts for further information

If you have any questions or would like to discuss any of this information, or any elements of the project, please contact Ben in the first instance.

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