



Thriving Minds dsd Youth Support Research Project

User Representative Information Sheet

Who are the researchers and what is the research about?

Thank you for your interest in being a User Representative for this research project, which is a collaboration between the Centre for Appearance Research (CAR) at the University of the West of England (UWE), Bristol, and dsd Families. This research project is funded by UK Youth Awards Thriving Minds program and is being conducted by Emma Waite, who is a Trainee Health Psychologist and Research Associate at CAR, and Dr Maia Thornton, who is a Research Fellow at CAR.

The aim of this project is to better understand the support needs of young people with a dsd and to develop support based on this research.

What does being a User Representative involve?

We want to include the voices of people with lived experience as much as possible in the design and implementation of the research. To do this, initially we will ask you to complete an anonymous online survey about your experience, what kind of support is missing for young people with dsds, and what kind of questions would be helpful for us to ask so we can better understand their experiences.

We will then meet with User Representatives in two groups – one for parents and one for young people. These will be conducted virtually (via video chat or telephone) and we will talk about the responses from the surveys. We will give User Representatives time during this meeting to talk together without us present. Throughout the project we will aim to hold several of these meetings to continue getting your feedback and suggestions and these will be flexible to respect your school, work, and social commitments.

After each User Representative meeting, we will give you the opportunity to provide feedback via an anonymous online survey. This is to help make sure your voice is heard and the research project is going in the direction that you feel is right. Once we have created some research materials, we will also ask for your feedback on them. This would be a time commitment of no more than 5 hours total.

Who can be a User Representative?



We are looking for young people aged 16-25 years with lived experience of a dsd and their parents. We will be asking you to discuss your experiences and thoughts about support needs for young people with a dsd.

How will the information be used?

The amount of information you share is completely up to you. We will use the information to help make sure we are asking the questions that are important to young people with a dsd in a way that is accessible when it comes to the main part of the research project. It may be used to help us decide on the research aims, design, and methodology, such as how we approach participants, the terminology we use, and the questions we ask.

The findings from the research may be used in publications in academic journals, as well as presentations at academic conferences. All the information we receive from you will be kept confidential and will be anonymised. Similarly, you will be required to keep the information we share with you about the project confidential, which means you should not share it with anyone not involved in the project.

What are the benefits of being a User Representative?

As a User Representative, you have the opportunity to be part of a research project on an important topic and will be reimbursed for any time you spend working on the project at a rate of £23.61 per hour. You will be helping add to our existing knowledge base, which will inform support resources developed in the future.

How do I withdraw from being involved?

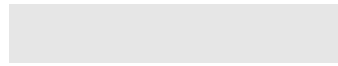
If you decide you want to withdraw from being a User Representative, please contact either Emma (Emma.Waite@uwe.ac.uk) or Maia (Maia.Thornton@uwe.ac.uk). Please note that there are certain points beyond which it will be impossible to withdraw from the project – for example, when the research has been published. Therefore, you must contact us within 2 weeks of providing feedback if you wish to withdraw it.

Are there any risks involved?

We do not anticipate any risks to you with being a User Representative; however, there is always the potential for involvement to raise uncomfortable and distressing issues. For this reason, we have provided information about some of the different resources that are available to you.

The website of the charity **Mind** enables you to find free or low-cost counselling in your local area via the Local Mind services. Search for your local mind:

<https://www.mind.org.uk/information-support/local-minds/>



Then, search for low-cost counselling via the website of your Local Mind (e.g., Local Mind for Bristol is: <http://www.bristolmind.org.uk/bsn/counselling>).

The **British Association for Counselling & Psychotherapy** (<http://www.bacp.co.uk/>) **It's Good to Talk** website enables you to search for an accredited counsellor or psychotherapist in your area: <http://www.itsgoodtotalk.org.uk/>

The website of the **British Psychological Society** enables you to 'find an accredited psychologist' in your area: <https://www.bps.org.uk/public/find-psychologist>

You can also contact your GP for support, or, for 24/7 support, Samaritans is available to free call on 116 123.

If you have any questions about this research, please contact us on the email addresses listed above.