

CECiLiA Study Newsletter

Issue 3: June 2026



Welcome to the third newsletter for the CECiLiA (An evaluation of Care (EduCation) and treatment reviews for people with Learning dIsabilities and Autistic people) research project.

This third newsletter covers:

- Our news
- How to take part
- What else Trusts/organisations can do
- Our Lived Experience Advisory Panels

Who we are

The project CECiLiA team includes people working at universities, NHS Trusts, and organisations for people with learning disabilities, autistic people, plus families & carers.

Find out more about us:

<https://cecilia.org.uk/who-we-are>



What we plan to do

We want to know if Care (Education) and Treatment Reviews (C(E)TRs) are helpful for people with learning disabilities and autistic people, and if they result in positive changes.

More information about what we plan to do is available in our first two newsletters from February 2026 and April 2026.

We have also now created easy-read versions of these two newsletters.

Previous newsletter can be found at:

<https://cecilia.org.uk/newsletters/>

More information

Find out more and see videos here:

<https://cecilia.org.uk/>

Follow us on LinkedIn:

[www.linkedin.com/
company/projectce
cilia](http://www.linkedin.com/company/projectcecilia)

Follow us on Facebook:

[www.facebook.com/
projectcecilia](http://www.facebook.com/projectcecilia)

Our news

Stage 1

550 people have completed a survey as of the end of May 2026. Of these:

- 96 were people with learning disabilities and autistic people
- 50 were family members or carers
- 404 were professionals



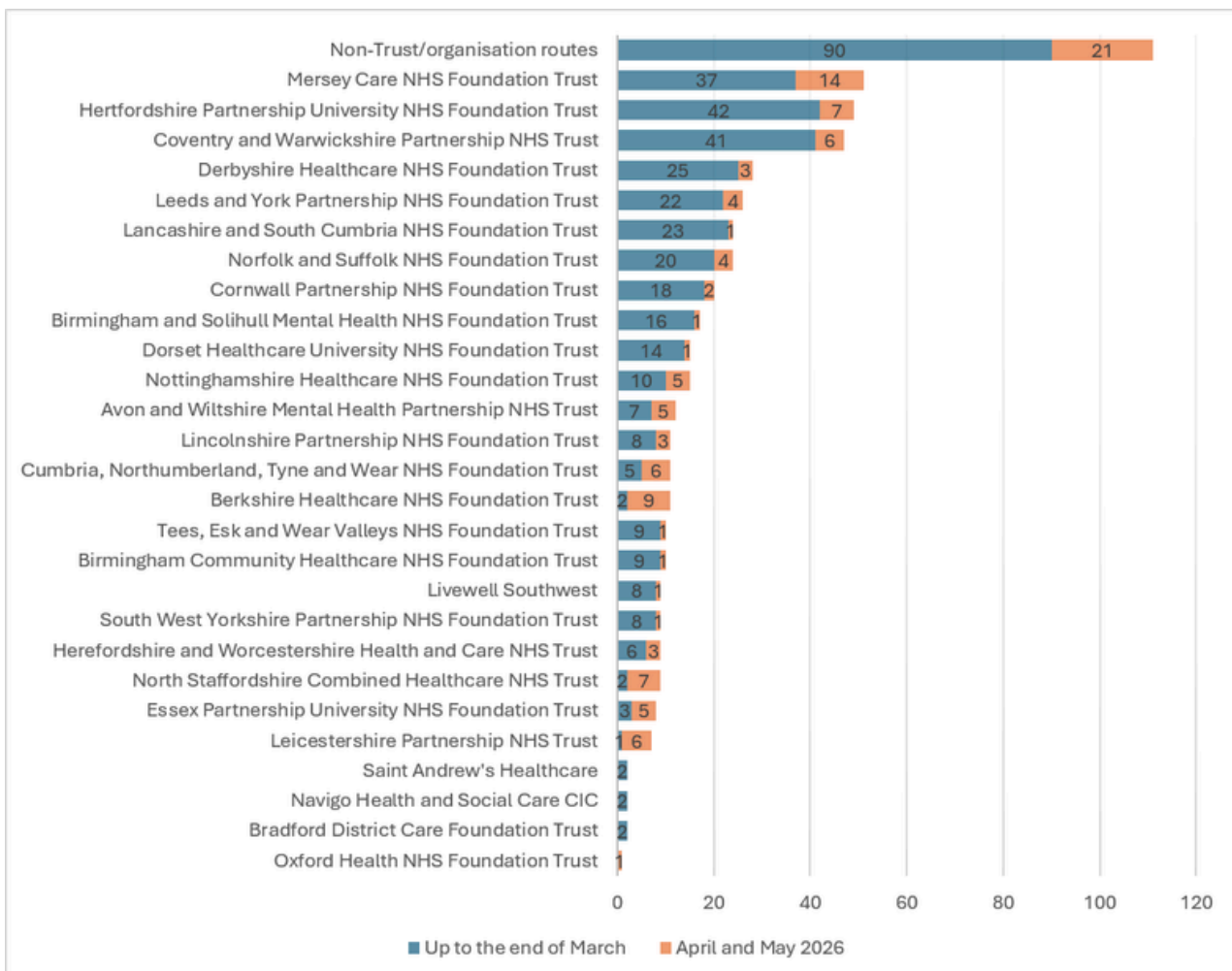
We are close to meeting targets for health, education and social care professionals but are still really keen to hear from more people with learning disabilities and autistic people, family members or carers and C(E)TR panel members - please do share with people from these groups if you can!

We have been finding people by:



- 27 NHS Trusts and non-NHS health and social care organisations advertising this research. We are still talking to a few more Trusts and organisations about being involved
- Advertising the study in various other ways not involving Trusts and organisations e.g., mailing lists and groups

The bar chart below shows where people have come from so far. Currently most people have come from non-Trust/organisation routes, but Trust/organisation recruitment continues to pick up pace...



Stage 2

We have begun to attend C(E)TR meetings to watch what happens and have talked to some of the people attending about their experiences. It has been really fantastic to make a start with this part of the project.

So far, 8 people with learning disabilities and autistic people have agreed to take part. We have started to collect data with one of these people, we have observed one C(E)TR and conducted one interview. This does take a bit of effort around co-ordinating to make sure that everyone knows what is happening, but we think it is really worthwhile to understand how C(E)TRs are working. Thank you to everyone involved in making this happen.



We currently have three Trusts involved, who are looking to identify suitable people to take part. We are still looking for more Trusts and organisations to be involved. We are looking for no more than 1-3 people to follow through C(E)TR meetings per Trust/organisation, to make sure we are following people throughout different parts of England. Please do get in touch if this is something you would be interested in finding out more about by emailing cecilia@contacts.bham.ac.uk.

Stage 3

We have been downloading new information as the NHS release it each month. This means that we will be ready to analyse this later in the project.



This is **aggregated data**. This means the information is about lots of people at once rather than about people individually. This information does not include any personal details e.g., names, addresses.

As well as collecting this aggregated data, we are still looking into whether it will be possible to get **individualised data**, which tells us about individual experiences. If we can get this, we would be able to look in much more detail about what type of things helped and hindered people and be much more confident in any conclusions we draw and/or any recommendations we make.

Stage 4

Once the other Stages are complete we will then consider what putting these together tells us about the whole story of people having C(E)TRs.

One thing we will do is make some best practice guidance for doing C(E)TR. We will make sure this is shared in different ways and to different people who need it.



How to take part

Complete a survey

Are you someone who has had a C(E)TR in the last 12 months? If so, have you completed our survey yet? We want to hear from people with learning disabilities and/or autistic people, families and carers, C(E)TR panel members, including experts by experience, and health, education and social care professionals.

You can find out more and complete an expression of interest form on our study website at:

<https://cecilia.org.uk/take-a-survey>

The survey should take **no more than 30 minutes** and you can receive a **£20 gift voucher** as thanks for taking part.



Tell people about our research

We want as many people as possible to know about what we are doing. The best way to tell people about our research is to give them a link to the study website, which includes videos:

<https://cecilia.org.uk/>

If you know anyone who could complete a survey or anyone who know others who could complete a survey tell them to go to:

<https://cecilia.org.uk/take-a-survey>

You can also tell them to follow us on LinkedIn or Facebook:

www.linkedin.com/company/projectcecilia

www.facebook.com/projectcecilia



Get involved

We are still looking for Trusts/organisations to be involved in Stage 1 and Stage 2 of this research.

If your Trust/organisation would like to learn more about being involved in either sharing information about surveys (Stage 1) or identifying 1-3 people for us to follow through C(E)TR meetings (Stage 2) please get in touch via:

cecilia@contacts.bham.ac.uk



What else Trusts/organisations can do

Attend monthly meetings

We have now held three monthly meeting to discuss study progress, consider common recruitment barriers, and share good practice. It has continued to be really good to discuss how different Trusts/organisations have been finding things. In response to Trust comments at these meetings we have:



- Created additional advertisement material, including separate Stage 1 and 2 posters and posters without voucher details
- Created accessible versions of these newsletters
- Sent physical copies of surveys to Trusts
- Assisted Trusts to reach out to people within their Trusts (e.g., clinicians) who the research team know

Next meetings are planned for:

Tue 23rd June 1000-1100

Fri 17th July 0900-1000

Tue 11th August 1000-1100

If you have not received an invite please get in touch via:

cecilia@contacts.bham.ac.uk

Organise a taster session from us

Our team continue to offer taster sessions tailored to site's needs. These outline CECiLiA to clinicians who are otherwise sometimes hard to bring together and contribute to Continuing Professional Development (CPD).

The type of sessions we can offer span **research** (e.g., introduction to research and evidence-based practice), **assessment** (e.g., models/assessment of speech language and communication), **positive behavioural support** (e.g., the importance of developing support in the community), and **learning disability and autism** (e.g., aetiology, characteristics and treatment needs of people with learning disabilities and autistic people with a history of deliberate fire setting).

Full details are available at <https://cecilia.org.uk/training-opportunities/>

If you would like to discuss arranging a taster session please contact:

cecilia@contacts.bham.ac.uk



Lived Experience Advisory Panels



Our Lived Experience Advisory Panels are one way that we are making sure that we are listening to people with lived experience.

These are three groups of people with learning disabilities, autistic people, and carers and family members who are involved throughout all stages of the research.

We have partnered with **Learning Disability England**, the **National Autistic Society**, and the **Challenging Behaviour Foundation** who each lead one of the three Lived Experience Advisory Panels.

What Our Lived Experience Advisory Panel have to say

We have recently finished creating videos in which members from all three Lived Experience Advisory Panels talk about why they are involved in the project and why your voice matters. These can be seen on our website at:

<https://cecilia.org.uk/>

Additionally, Anoushka, who works for the National Autistic Society and co-ordinates the Lived Experience Advisory Panel for autistic people has this to say about CECiLiA:

"The work that this study is doing is so important. If we can better understand experiences of CETR and identify, and share, good practice, we can influence change in inpatient care for autistic people and people with learning disabilities. The National Autistic Society are formally supporting this study, and I've been working with the research team since it got started. I am also working with a fantastic group of autistic people, or 'LEAP', and it is such a privilege to hear their hugely valuable insight, and to tangibly see how their views and experiences are influencing the project. It's an example of true collaboration and genuine engagement, which sadly isn't the case for every study involving autistic people. I'm really pleased to be a part of the CECiLiA study, and would urge anyone who is applicable and able to share their insight through a survey or talking mats interview to do so, and help us to make a difference."



Thank you for taking the time to read about this research

Reminder - How to take part

Those who have had a C(E)TR in the last 12 months

Complete a survey

https://cecilia.org.uk/take-a-survey_

Everyone

Tell people about our research

<https://cecilia.org.uk/>

Trusts/organisations

Take part
Attend monthly meetings
Arrange a taster session

cecilia@contacts.bham.ac.uk