

CECiLiA Study Newsletter

Issue 4: September 2026



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

This fourth 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 are doing

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 previous newsletters from February, April, and June 2026.

There are also easy-read versions of these 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](https://www.linkedin.com/company/projectcecilia)

Follow us on Facebook:

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

Our news

Stage 1

638 people have completed a survey as of the end of August 2026. Of these:

- 138 were people with learning disabilities and autistic people
- 66 were family members or carers
- 434 were professionals

THANK YOU
SO MUCH

We have now met our maximum target for health, education and social care professionals.

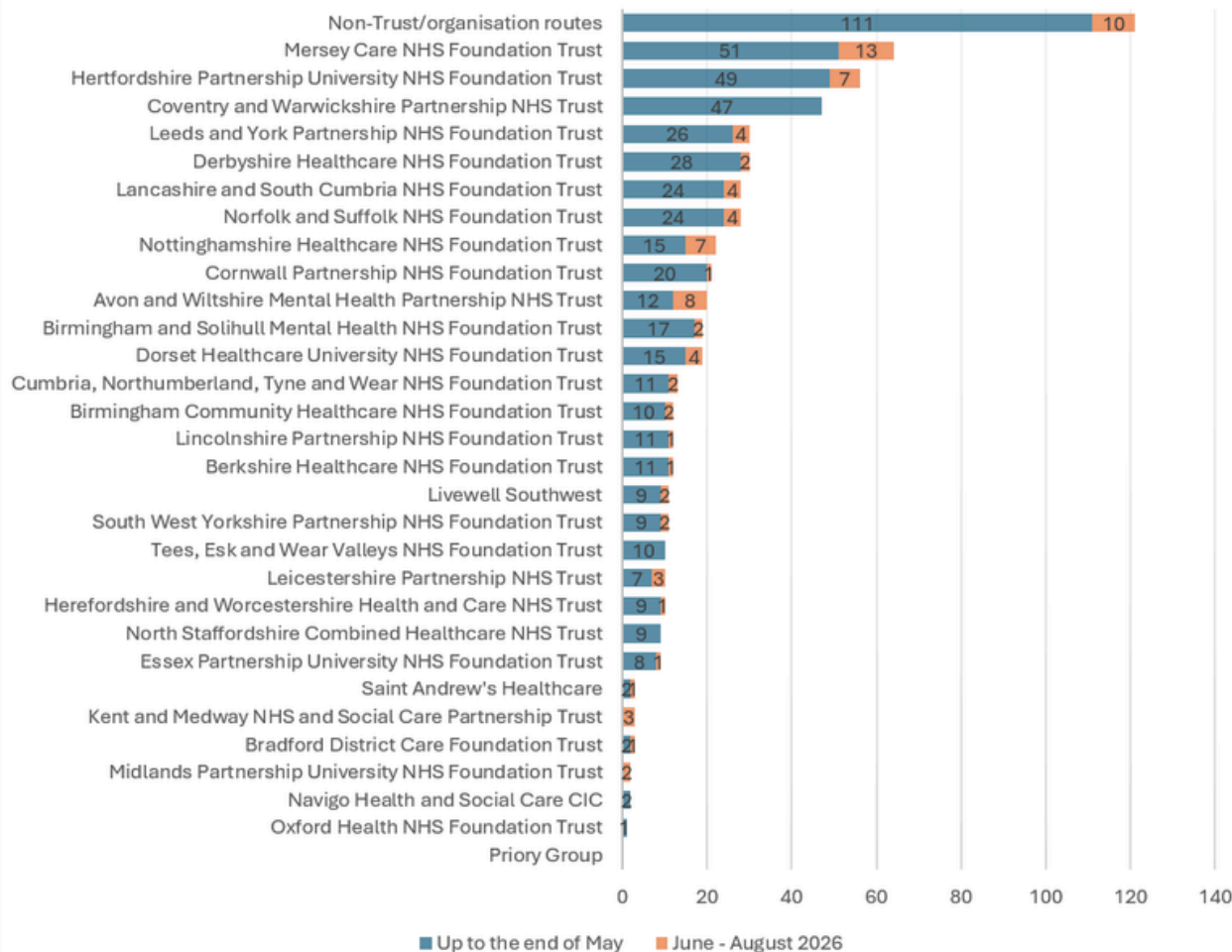
This means that recruitment has now stopped for this group. Thank you to everyone who completed one of these surveys or helped us find people to complete them!

We 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. We will be looking for people to complete surveys until **30th April 2027**. Please do share with people from these groups if you can!

We have been finding people by:

- 30 NHS Trusts and non-NHS health and social care organisations advertising this research. This is three more than at the time of the last newsletter, we still might add a small number more.
- 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. The combined efforts of all Trusts / non-NHS health and social care organisations makes up around 80% of responses.



Stage 2

We have continued to attend C(E)TR meetings to watch what happens and have talked to some of the people attending about their experiences.

So far, thirteen people with learning disabilities and autistic people have agreed to take part. We have **observed four C(E)TRs** and conducted **seven interviews**, including with **three people with learning disabilities and autistic people**.

Recruitment so far has been at Coventry and Warwickshire Partnership NHS Trust and Hertfordshire Partnership University NHS Foundation Trust - thank you again to both Trusts for getting recruitment started so quickly.

We know it takes a lot of effort around co-ordinating to make sure that everyone knows what is happening, but it is clear we can make this work and we still think it is really worthwhile to understand how C(E)TRs are working.



Since the last newsletter **four more Trusts have become involved**, meaning we now have **seven Trusts** actively looking to identify suitable people to take part. **Four other Trusts are formally setting up to take part**, and there are more we are talking to about being involved.

Do get in touch by emailing cecilia@contacts.bham.ac.uk if this is something your Trust would be interested in finding out more about, we are looking for no more than 1-3 people to follow through C(E)TR meetings per Trust/organisation.

Beyond the thirteen people with learning disabilities and autistic people who have agreed to take part, **a further eleven people have been identified as potential participants**. Trusts are working hard to talk to them about the study before, hopefully, them agreeing to take part. It really feels like the pace has picked up in recent months, which is testament to the hard work and effort of Trusts/organisations involved.

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. We are still looking into whether it will be possible to get **individualised data**, which tells us about individual experiences.



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, and C(E)TR panel members, including experts by experience. You can find out more 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, and tell them to follow us on LinkedIn or Facebook:

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



Attend monthly Trust/organisation meetings



We have now held six monthly meetings with Trusts and organisations to discuss study progress, consider common recruitment barriers, and share good practice. Next meetings are planned for:

Fri 18th September 0900-1000
Tue 13th October 1000-1100

Fri 13th November 0900-1000
Tue 15th December 1000-1100

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

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.

Videos of members from all three Lived Experience Advisory Panels talking about why they are involved in the project can be seen on our website at: <https://cecilia.org.uk/>

Capacity to consent

Recently we have talked to a few Trust's about capacity to consent. We thought it would be useful to share some additional information about how this works in research studies:

The Mental Capacity Act 2005 (MCA) provides a legal framework for involving adults who lack the capacity to decide whether to take part in a research study.

Researchers must begin by presuming that a person has capacity and should take all practicable steps to support them to make the decision themselves. However, if a person is assessed as lacking capacity, the process is different from what happens in clinical practice. In clinical care, decisions about treatment are made in the person's best interests. In research, we do not make a best interest's decision, and instead, researchers must seek advice from a **consultee**. There are two types of consultees: a personal consultee and a nominated consultee.

Researchers should first try to seek advice from a **personal consultee**. This is usually someone who knows the person well and has an interest in their welfare, such as a family member or close friend.

If a personal consultee is not available, researchers can seek advice from a **nominated consultee**. This is usually a professional who has agreed to be consulted and has no connection with the research project.

The consultee is asked to consider what they believe the person's **wishes and feelings about taking part in the research would be if they had capacity**. They are also asked for **their advice** about whether the person should take part.

The researchers remain responsible for deciding whether the person should participate, but they must take the consultee's advice into account. If a consultee advises that the person would not have wanted to take part, or believes that they should not take part, the researchers **cannot include that person in the study**.

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