



An evaluation of **Care (EduCation)** and treatment
reviews for people with **Learning disabilities** and
Autistic people

LAY Summary



Aims

In this research project, we will determine whether Care (Education) and Treatment Reviews are helpful for people with learning disabilities and autistic people and their families.

Background

Care (Education) and Treatment Reviews were started in 2014 to help get autistic people and people with learning disabilities out of psychiatric hospitals and to prevent their admission to psychiatric hospitals. Care (Education) and Treatment Reviews involve an independent panel including an Expert by Experience, a clinician, and a commissioner who is responsible for paying for an individual's care. The autistic person or the person with learning disability and their family also attend the meeting. The focus of a Care (Education) and Treatment Review is to either prevent a person from being admitted to a psychiatric hospital in the first place, or to help someone who is already in hospital, get out. They do this by trying to work out ways to overcome barriers that might be stopping someone from leaving hospital. However, we do not know if Care (Education) and Treatment Reviews stop people from being

admitted to a psychiatric hospital in the first place, or help people already in hospital get out.

Method

Our project has four stages.

In Stage 1 we will work with the members of our Lived Experience Advisory Panels to co-produce survey questions. We will design surveys for people with learning disabilities and autistic people, families and carers, Care (Education) and Treatment Reviews panel members, and health and social care professionals to complete. We will share these surveys with as many people as we can nationally. We will make adjustments so that people with learning disabilities can take part in our surveys. We know that individuals with moderate to severe learning disabilities and younger children will not be able to complete the surveys and so we will use other ways to gather their views and experiences. We will also try to work out how much it costs to have a Care (Education) and Treatment Review .

Within Stage 2, we will find out how patients in hospital are doing over time, by attending Care (Education) and Treatment Reviews, CPA, and other patient meetings. We will ask people, including people with moderate and severe learning disabilities to take part in some

interviews with us, ensuring we adapt the interview process, so it is accessible. We will use the information from these interviews to work out whether Care (Education) and Treatment Reviews are helping people and making things better.

In Stage 3, we will look at the anonymous data that is collected by the NHS about everyone with a learning disability or autism who is admitted to hospital. We will work out what sorts of things helped them and what sorts of things did not help them get out of hospital. We think we will have data that covers over 11 years.

Within our final stage, Stage 4, we will bring together all of the information we have collected from the different stages of the research to work out what it tells us. We will use the information along with input from our Lived Experience Advisory Panel members to co-produce and share reports and information about what we have found out. We will also co- develop and publish good practice guidance for doing Care (Education) and Treatment Reviews and make sure our guidance is shared in different ways and to different people who need it.

Patient/public involvement

We have partnered with Learning Disability England, the National Autistic Society, and the Challenging Behaviour Foundation who will each lead one of our three Lived Experience Advisory Panels: (1) people with learning disabilities, (2) autistic people, and (3) carers and family members. We will have regular meetings with each Lived Experience Advisory Panel to make sure we they can provide input throughout the study. They will help us to design the surveys and interviews, interpret our findings, share the findings and co-produce and publish our good practice guidance in different formats for different target audiences. Each advisory panel will meet separately but we will bring them together once a year to benefit from their combined input.

Our project has been developed collaboratively with Learning Disability England, the National Autistic Society, and the Challenging Behaviour Foundation who all have experience of being involved within Care (Education) and Treatment Reviews. Learning Disability England, the National Autistic Society, and the Challenging Behaviour Foundation will be core members of our study management and study steering committees. Further, a nurse with significant learning disability and autism experience, Expert-by-Experience, and Care (Education) and Treatment Review panel chair

is a co-researcher. A carer of a man with severe learning disability is also a co-researcher.

Dissemination

We will work with our Lived Experience Advisory Panel members to co-produce a communication plan to ensure that our findings are shared with the people who can and should use them. We expect information to be produced in different formats. We will place information about our study on Learning Disability England, the National Autistic Society, and the Challenging Behaviour Foundation websites and within their newsletters. We will develop accessible videos about our study and our findings and share them with wide audiences and through many networks. We will hold joint dissemination events following the completion of this project to reach as many people as possible. We will also have specific events to showcase our good practice guidance.