

Care (Education) and Treatment Reviews

This is a write-up of discussions held during the Challenging Behaviour – National Strategy Group national meeting on May 1st. These discussions were facilitated by Dr Shobha Puttaswamaiah, a consultant psychiatrist in a CAMHS service.

Participants in these discussions included family carers, support providers, housing providers, commissioners, learning disability nurses, psychologists, psychiatrists, legal professionals, researchers, VCSE representatives, and representatives from both adults and children’s learning disability and autism services from local government/ICBs. Most attendees had direct experience of C(E)TRs as either a family carer, expert by experience, clinician, or other professional, with others having indirect experience from an academic/research side or from other areas of policy/practice.

Key Findings

- Attendees welcomed the move to put C(E)TRs on a statutory footing, but were concerned that if there was not also concurrent investment in community services, recommendations would not be effectively carried out
- Putting C(E)TRs on a statutory footing is an opportunity to provide oversight and analysis, identifying systemic barriers and common experiences at local, regional and national levels
- Attendees highlighted examples of good practice around oversight panels (with significant input from people with lived experience) which enable people to raise concerns at a high level
- Funding needs to be available to adequately fund community support and early intervention/prevention, rather than (as is too often the case currently) being solely tied up in crisis provision

Enablers, and what currently works (including examples of good practice)

Oversight Panels

Kent and Medway have established a C(E)TR oversight panel which has enabled people using their mental health services or who are at risk of being admitted to a mental health hospital to raise any concerns at a high level. The success of this oversight panel is partly

attributed to the panel employing people with lived experience to sit on the panel alongside other senior officers.

Attendees suggested that as well as replicating this in other areas, it would be beneficial to have a national oversight panel that would be able to examine complaints/requests by individuals and their families, and which ICBs should report to.

Ensuring relevant lived experience

While Experts by Experience are a key part of C(E)TRs, a family carer highlighted particular good practice in their area (in the North East) where they have a wide range of Experts by Experience with different experiences/demographics. This means that when a C(E)TR is being held, the Expert by Experience that is involved in the C(E)TR can be someone with experience that is relevant to that individual, improving the recommendations that are made.

Keyworkers

Attendees were positive about the role of keyworkers for children and young people, and felt that it would be beneficial to also roll this out to adults. Having a keyworker who have bring together different parts of the system and ensure recommendations are followed up would help address some of the barriers discussed in the section below, particularly regarding the impact on families.

Barriers – what factors prevent C(E)TRs from achieving their aims

Workforce/service issues

Attendees highlighted that in their experience, a key reason that recommendations do not get followed is that there are not existing services that can fulfil them, and there are not sufficient available resources to develop these. They felt that there was not enough clarity re: whether/how additional funding would be made available to develop and implement the services that will enable recommendations to be enacted, as this is dependent on e.g., the outcomes of the Spending Review.

“It is good that it has become a legal requirement, but without the necessary funding and resources being set up, we become stuck.” - Clinician

Particular issues identified were:

- Reduction in the number of learning disability nurses, and closure of learning disability nurse courses – the South East was particularly highlighted as a ‘learning disability nursing desert’
- Access to speech and language therapy
- Access to occupational therapy
 - Attendees also highlighted that as occupational therapists can work in multiple teams (e.g., social care, CAMHS, housing), there can be a lack of joint working and also issues with which team is going to be responsible for particular actions¹
- Lack of resourcing for CAMHS teams

Lack of power to enforce recommendations – accountability

Attendees stated that C(E)TRs often successfully identify issues and make positive recommendations that would address these, but that these recommendations are not then followed through. This was attributed to several factors, including that C(E)TRs are not always attended by people who are high-level enough to make decisions and act on these – it was felt that having this high-level input, and decision-makers having ownership of the recommendations that are made, would be a way of overcoming this barrier.

Related to this, attendees emphasised the importance of accountability – ensuring that if a recommendation is not followed, there are questions about why this is.

“It goes back to accountability, because otherwise we will continue to have people and local areas doing good stuff, and if you live in a local area that’s doing good stuff it’s great, but if you don’t, then what? It’s up to you to pursue it, to flag it, to go make a complaint” - Family carer

Both family carers and attendees who have been involved in C(E)TRs from a professional standpoint raised the impact that the current lack of accountability is having on people with learning disabilities, autistic people and their families in terms of putting the onus on them to chase and follow up. This links to issues of disjointedness between different parts of the system, but also to issues of how the system impacts on the families who have to navigate it.²

¹ Although this was highlighted in relation to occupational therapy, it is not unique to this field

² For further details see: [Broken](#) (Challenging Behaviour Foundation, 2020); [A survey of complex trauma in families who have children and adults who have a learning disability and/or autism](#) (Baker et al., 2021)

Related to the above point, families often experience trying to get C(E)TR recommendations followed without having been provided with copies of the report – the current duty within the Mental Health Bill requires reports to be provided to responsible commissioners, responsible clinicians, the ICB and the local authority, and states that it may also be given to other persons, but there is not a duty to provide either the individual nor their family with the report. Not having a copy of the report was identified as a barrier to ensuring the recommendations were followed – it would be beneficial if there was an equivalent duty to provide the person (in alternative/accessible formats if needed) and their family with copies of the report.

Families highlighted the overall impact of recommendations being made but not followed. This causes disillusionment and a loss of trust in the system, which makes it harder for the individual and their family to continue to engage/trust professionals and services. Ensuring that there is accountability and responsibility for following C(E)TR recommendations would help restore trust/prevent trust from being lost and therefore improve relationships between the individual, their family, and the services that support them.

C(E)TRs not sufficiently specialist/tailored

It was felt that in some cases, C(E)TR panels do not have the sufficient skills/experience to be able to identify what needs to be done to support an individual, due to the wide spectrum of needs and experiences of different people with a learning disability and/or who are autistic.

“A lot of the feedback we have is that C(E)TRs sometimes lack the necessary nuance, they may not necessarily understand the differences between, say, someone who has a severe learning disability and behaviours that challenge versus an autistic teenage girl who’s suicidal.” - Psychologist

As a result, recommendations can sometimes be generic and not tailored to the specific needs of the individual, which in turn makes them less effective at meeting these needs and preventing crisis/admission or enabling discharge. To address this, people that sit on C(E)TR panels should have the specific skillsets/experience needed to identify the needs of the individual – however, this also links with the issue identified above regarding workforce.

Lack of information about what options are available

Family carer attendees highlighted that a barrier to developing effective recommendations that would better meet their relative's needs is that there is insufficient information made available to families in an accessible way to inform them about how C(E)TRs work and what options are available.

“How can families and carers ask for something if they don't know what can be done and what is available? Part of the process should be going through the process, understand the system and options so they can actively take part and advocate as well.” - Family carer

An example of good practice in supporting families to meaningfully participate in C(E)TRs was shared from the North East, where workshops are held for parents and for young people that are going to be involved in C(E)TRs to explain the process in plain English. These workshops are organised by people with lived experience of C(E)TRs. A similar example of commissioning a 'family support worker' who could support families to understand the system was also shared.

Families stated that it would be useful to have case studies of 'effective' C(E)TRs that both they and other professionals involved in C(E)TRs could learn from and which would demonstrate the benefits of C(E)TRs when they are done well, and welcomed that NHS England were looking into producing these. They also suggested having a blueprint setting out what a good C(E)TR looks like in practice, with a focus not just on process but on outcomes as well, which was supported by other attendees.

Use of jargon, acronyms and abbreviations

The use of jargon, acronyms and abbreviations was highlighted as a barrier to meaningfully engaging with people with a learning disability, autistic people and their families.

Ways to maximise the benefits of C(E)TRs being placed on a statutory footing

Monitoring and oversight

Attendees highlighted that C(E)TRs being placed on a statutory footing should result in there being significant information/data available on the needs of children, young people and adults with learning disabilities and/or who are autistic and the factors that increase the risk

that they will be admitted or which are barriers to discharging them. Analysing this data at a local, regional and national level could provide useful information on whether there are recurring and/or systemic barriers and highlight where to intervene to have the greatest impact, which would support commissioners in fulfilling their duties (including the new duties under the Mental Health Bill). Attendees suggested that analysing this data could/should also inform workforce planning and support.

It was suggested that this could be accompanied by a duty on the Secretary of State to monitor C(E)TRs.

Community C(E)TRs

Attendees felt that putting C(E)TRs on a statutory footing was a positive step forward, but highlighted that this only applies to C(E)TRs that are held in hospital once someone has been detained under the Mental Health Act. Community C(E)TRs can play a significant role in preventing admissions if recommendations are made and followed, but there is no corresponding duty to hold a C(E)TR in the community. There was support for putting Community C(E)TRs on a statutory footing as well to support related measures/duties to prevent admissions.

Other related factors/points raised by attendees

Importance of early intervention

Throughout discussions attendees highlighted that intervention and support needs to be provided earlier in the life of someone with a learning disability/who is autistic, in particular in childhood. When this support is not provided at an early stage, it increases the likelihood of someone with a learning disability/who is autistic experiencing a (preventable) crisis. Clinicians highlighted behavioral support as a particular form of support which is not available early enough/to enough people, alongside packages of care/support more generally.

This was partially attributed to the fact that there is a focus on crisis, with individuals who are not currently experiencing crisis being seen as a lower priority; because they are lower priority when they are not in crisis, they are unable to get the support that they need early on which then leads them to experience a crisis which could have been avoided.

“The services are not really set up for children and young people with a learning disability or autism. They go to the bottom of the pile. Within CAMHS, adolescents presenting in crisis take priority, so [children and young people with a learning disability/who are autistic] are not within the priority list for services. And that is something we have been trying to highlight and bring attention to, that we need to build services for this group of young people” - Psychiatrist.

Some attendees shared views that a C(E)TR being necessary might indicate a failure to have provided support early on in someone’s life. There were discussions about the experiences shared by some professional attendees who had been unable to put in place support until an individual was on the dynamic support register (i.e., at risk of crisis/admission) - this not only causes harm to the individual and their family but can also reduce the effectiveness of the support if it is only provided when the individual and their family are already in crisis. Multiple attendees highlighted that inability to intervene early was linked to being unable to access funding.

Clinicians highlighted that when this early support is unavailable, as well as increasing the risk of crisis, this can lead to people, including children and young people, being inappropriately put on medication because there is no other support available.³

Role of schools

Attendees highlighted that schools are often the first opportunity to provide a child/young person with support. Family carers highlighted the importance of capable⁴ and non-punitive environments in schools.

³ see the STOMP/STAMP programme; also [STOMP: What progress has been made with the overmedication of people with learning disabilities? - Learning Disability Today](#)

⁴ For more information: [Capable Environments](#) (McGill et al)