

NICE Conference 2023

Mental health

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Views and experiences of a carer

Carer's experience

- In my home life: both of my own children are on the autistic spectrum. Both my children have used cognitive behavioural therapy (CBT) technologies.
- In my work life: adoption panel, teaching assistant support and supporting young people who have additional needs in high pressure GCSE and A-level examinations.

Usability

- It is estimated that 1 in 7 people are neurodivergent. Children and young people (CYP) who are autistic are more likely to have significant mental health needs.
- They look at technologies differently and digital products need to meet the need their needs.
- People with autism find it more challenging to socially communicate and interact. Having digital support may well be a means of support that CYP with autism may find more attractive. Some find the visual content more appealing.

Safety

- What safety features are contained in these apps to support CYP? If their mental health deteriorates, will this be picked up by a practitioner to keep them safe from significant self-harm or suicide?

Views and experiences of a carer

Views on digital cognitive behaviour therapy (dCBT)

Positives

"I can do it anytime I like, it is easily accessible as it is on my phone, and I do not have to talk to another person."

"Educational simplified solutions, the software is user friendly and very interactive. I like how I am able to record my feelings and thoughts and look back to how far I have come. Good communication through the app." There is instant support.

Negatives

"No one is forcing me to do it, it is uncomfortable to do and there are many other things I would rather do on my phone. It feels weird."

"The modules do not specifically target my actual problems and make me think I have more mental anxiety when actually it was mostly physical (...) I understand they are linked but there is too much focus on the mental side, and I struggled to relate."

Views and experiences of a carer

Views on dCBT

Access to treatment

"I had to wait at least 2 months before any intervention could take place, I relied too much on my GP practice who failed me. I self-referred myself out of desperation."

"It felt horrible waiting for so long to see a professional to help as I had no idea what was wrong at the time."

"As a parent, having to wait and see my son deteriorate was not good. My daughter though, she got offered digital CBT straight away as she was going to university. Now, her local authority also offered her CBT with her low mood deteriorating, without any waiting time."

Digital technologies

"The digital technologies were overall good. As an autistic man, I am a fan of online interaction that replaces human socialising. Just wish CBT would help."

"As a parent, you are grateful for anything that is offered."

"Similarly, as with in-person therapists, as a parent I would want to be working in partnership and be informed of a summary of the work or information needed to keep my child safe (for example, risk of self-harm of suicide)."

Views and experiences of a carer

Ability to engage with users

- CYP are not allowed to have mobile phones at school. It can be a stressful time and can cause emotional and behavioural dysregulation if they are not allowed to input their feelings or thoughts. How can this be addressed?
- Duration of the intervention: how long with CYP still be able to use the technology?
- What makes the user respond to notifications? How easy is it to ignore them?
- What motivates CYP to use the app instead of the instant relief or distraction of TikTok?
- Does the intervention run on the smartphone or in the cloud? Is the data backed up? Will it sync to multiple devices? What will happen to the data if the device goes missing?
- What about confidentiality? Are the digital interventions password protected?

Thank you.