COVID Complexity

Learning from lockdown to support those who think differently

Who we are

Embracing Complexity is a coalition of 58 organisations supporting people with neurodevelopmental conditions (NDCs) – conditions such as ADHD, autism, Down Syndrome, dyslexia, dyspraxia, learning disability, Tourette Syndrome and many more which affect how people think and interact with the world. In September-October 2020, 160 people with NDCs, relatives and carers took our survey on the impact of COVID-19 and measures to slow the spread of the virus on their everyday lives.

Easing restrictions has changed little for those hit hardest

In every topic covered by the survey except education, most respondents who experienced negative changes said **restrictions easing caused "no change" to their situation.**

"Lockdown easing has not had much impact for me personally"

"The constant unknown is still there"   *"The services I need are barely happening"*

Personalisation is needed for varied, complex experiences

Changes have affected different people in different ways, with most respondents experiencing a mix of negative and positive changes that does not necessarily fit polarised debates around lockdown.

"People not adhering to social distancing make my son uneasy, and people with masks"

"All my usual coping mechanisms went out the window"   *"He was the calmest I've ever seen…. no meltdowns, no sleepless nights"*

We asked people to list up to five areas of their lives that had been most negatively and most positively changed since March. The results for both questions were similar:

Most negatively affected areas:
1. Mental health
2. Education
3. Sleep
4. Physical health
5. Public spaces

Most positively affected areas:
1. Digital and virtual communication
2. Public spaces
3. Mental health
4. Education
5. Physical health/Sleep

Our recommendations

Virtual attendance should remain an option. The post-pandemic world must continue to support those who can most effectively work, learn and participate remotely, whilst ensuring that face-to-face services are reinstated when it is safe to do so.

"I would work best flexibly… being in an office once or twice a week, then having space to work from home"

"It isn't easy to get out – meetings online mean we can still join"

Your service users communicate differently. Services should provide a range of options for communication – telephone, video call, e-mail, text, in-person – from the start, and readily available information about those options.

"Both my children became extremely isolated as neither can engage with digital communication"

"I can meet people via video, so no travelling or crowds and no noisy rooms"

People can't follow guidance they don't understand. Information on preventing the spread of COVID-19 should be available in clear and accessible formats. Guidance should relate to the decisions people need to make in everyday life, including the situations faced by people with NDCs, their families and carers, with concrete examples from the outset.

"People in supported living just seem to have been forgotten"

"I am too frightened to go to the hospital at the moment… I struggle with keeping up with the endlessly changing rules"

The needs of people with NDCs will persist beyond the pandemic. Many who are not at higher risk from COVID-19 itself are at higher risk of facing adverse outcomes from the knock-on effects. Mental health services should prepare to offer accessible, appropriate support to a larger proportion of people with NDCs.

"My daughter is on a downward spiral and there is no safety net"

To find out more, visit embracingcomplexity.org.uk.