PREPARED

RAPID. EFFECTIVE. ETHICAL.

Partington H, Garner J, Chatfield K (2023) Pushed closer to the edge:
How the COVID-19 pandemic contributed to the increasing marginalisation of disabled people and their carers in the UK, a report for PREPARED.

BACKGROUND

Rapid, effective, ethical research during global crises. The EU-funded PREPARED project develops a research ethics and integrity framework to support this mission. A collaboration between PREPARED researchers and the Comensus group, facilitated the gathering of authentic experiences from a key population to inform the development of the framework.

METHODOLOGY

Research question: How did disabled people and carers of disabled people in the UK experience the COVID-19 pandemic? The need to gather accounts of the experiences of disabled people and their carers during the pandemic necessitated a qualitative approach. We trialled the use of Inclusive and Sensitive Conversations/Contributions for data collection. This approach is designed to be sensitive to the preferences and needs of people taking part in research. Having flexibility in data collection methods promotes broad and ethical inclusion in research, even for those who might otherwise be marginalised or excluded from having a voice.

RESULTS

Disruptions and deteriorations in services:
Disrupted access to regular services. Delays in receiving treatment. The continuation of deteriorations in services. Feeling failed or abandoned.

Grappling with rules and information:
Confusion. Hard to keep up with and overwhelmed by information. Need for sign language interpreters on national briefings. Avoiding the news for mental health reasons. Sceptical about the reliability of the information and the trustworthiness of the rule makers. Annoyed about COVID-19 rule breaking.

Life got (and stayed) smaller:
Separation, isolation, missing social and physical contact. Deterioration in self-care. Becoming more cautious. Continued restriction of activities. Relief for those with social anxiety but concerns about the long-term implications. Impact on employment.

COMENSUS MEMBER:

"I HOPE THIS [STUDY] SOMEHOW HELPS AS A TESTAMENT TO WHERE THE GOVERNING BODIES AND HEALTHCARE SYSTEM FAILED ME AND COUNTLESS OTHERS WHO SUFFERED IN SILENCE WITH THEIR MENTAL HEALTH DURING THE COVID PANDEMIC."

CONCLUSION

Disabled people and carers were already disadvantaged prior to the pandemic and were pushed closer to the edge as a result of COVID-19. The restitution of services to pre-pandemic levels has been slow in the UK, there is still much ground to be made up.

Funded by the European Union

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Ethics approval - HEALTH 0376