

ENABLING DISABLED PEOPLE TO HAVE A VOICE IN THEIR CARE AND TO RECEIVE SUPPORT DURING COVID-19

Participation Information Leaflet

We invite you to take part in a research study. Below is some information about why this research is being done and what it would involve for you. Please take the time to read this document carefully and talk to others if you wish. Please ask us if there is anything that is not clear or if you would like more information. You can then decide whether or not you wish to take part. Please remember that involvement in this study is completely voluntary.

Background

This research is being funded by the Economic and Social Research Council (ESRC) Impact Acceleration Account (IAA) at the University of Birmingham.

During these unprecedented times it is essential for advocacy providers and related stakeholders to be consulted to understand how they have adapted their practices to social distancing and other restrictions as a result of COVID-19 to ensure that people from marginalised groups are able to have a voice in their care. This includes older people in care homes, people with learning disabilities, and people detained under the Mental Health Act. Without careful consultation, the views of these typically marginalised groups are at risk of being dismissed or not listened to, further deepening existing inequalities and raising profound ethical issues about our handling of COVID-19.

What is the research about?

This study will engage third sector and public sector bodies with existing research relating to advocacy to understand how adjustments in advocacy (between advocates and people who require their support to have a voice in their own care) have been made in response to COVID-19. This study builds on a body of research investigating advocacy to: (1) ensure that vulnerable people have a voice; (2) promote and protect their rights; and (3) enable them to have greater control and choice in their life.

Who is undertaking the research?

This research is being undertaken by Dr Benjamin Costello and Dr Karen Newbigging who are members of staff at the University of Birmingham.

What involvement is required?

We would like to invite you to take part in an interview to discuss your views, opinions, and experiences of providing advocacy and engaging with people who require support to have a voice in their own care during COVID-19. You will be asked to participate in a one-to-one interview, involving only you and one researcher from the University of Birmingham.

Prior to interview, you will be asked to complete and return a consent form either electronically via email or provide recorded verbal consent prior to your interview. During the interview, you will be asked some questions by a member of the Research Team who will discuss your answers with you. Your interview will be audio recorded and will last no longer than 45 minutes. Interviews will take place either online via Skype or Zoom or via telephone. You can tell us which method of communication works best for you. You can stop the interview at any time and you can take breaks whenever you like.

Please note that your participation is voluntary and we are unable to compensate you for your time.

What happens to the information I give you?

The findings from this research will provide useful information to help understand the impact of COVID-19 on advocacy and what adaptations have been made between advocates and people who require their support to have a voice in their own care. The information you provide will help us to make recommendations to improve support and provision.

Will my information be kept confidential?

Your data will be stored pseudonymously so that the Research Team can match participant data (i.e. interview transcripts) to the relevant participant. This means that your identity will be known to the Research Team but we will only share anonymised data outside of the Research Team – this means that you will not be identified in any way in any report or publication of the research findings. Each interview participant will be assigned a unique Participant Identification Number (PIN) and their responses will be referred to by this number.

All interviews will be anonymised in any reports, presentations, or publications. During the writing-up of the research, any direct quotation will only be attributed to PINs. The data will not identify participants by name. Your information is therefore kept confidentially. We can reassure you that everything you tell us will be kept completely confidential and will not be passed on to anyone else. The only exception to this is if you tell the researcher that you intend to do something that will harm yourself or another person, or put yourself or another person in danger, or disclose a safeguarding issue.

Data from the research will be held securely by the Research Team for a maximum period of ten years before being destroyed; this is in line with the University of Birmingham's Code of Practice for Research.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part in an interview. Your participation in the study is entirely voluntary. If you do consent to take part in an interview then you will be asked to complete and return a consent form. You can withdraw from the interview at any point during the interview if you decide you no longer want to take part. If you would like your data to be withdrawn/deleted after your interview, you have 2 weeks from the date of your interview to inform the Research Team.

Are there any risks involved?

There are no known risks associated with your participation in the study. If you become distressed or upset during the interview, then the interview will be paused or terminated. If you have any concerns, please contact one of the researchers using the details below.

What happens next?

If after reading this information leaflet you decide that you would like to take part, please email Dr Benjamin Costello at B.D.Costello@bham.ac.uk to confirm that you would like to participate in the study. You will then be contacted to find a suitable time for your interview.

More information

If you would like more information about the research or have any questions about your participation, please contact: Dr Benjamin Costello at B.D.Costello@bham.ac.uk or Dr Karen Newbigging at K.V.Newbigging@bham.ac.uk

Thank you for taking the time to read this information sheet, which you should keep if you decide to take part in the study.