Fragile X Association of Australia

CDS
Centre for Disability Studies

Building sector capacity to facilitate adults living with Fragile X syndrome age well with supports

Staff Survey

PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

The *Fragile X Association of Australia* and *Centre for Disability Studies* are carrying out a research study about adults with Fragile X Syndrome, their families, carers and staff and healthcare practitioners. This study is exploring what it is like to age for adults living with Fragile X Syndrome. You are invited to take part in a research study about people ageing with Fragile X Syndrome. This study wants to establish insights from those with lived experience, capture the knowledge of experts and explore the effectiveness of existing supports and associated supports for people with Fragile X Syndrome as they age. This participant information sheet gives you information about the purpose of the research so that you can decide if you would like to take part. Please take the time to read this information carefully. You may ask questions about anything that is unclear or that you want to know more about before proceeding. Knowing what is involved will help you decide if you want to take part in the research.

The aim of this research is to explore your views about the existing systems of support (both formal and informal) for people ageing with Fragile X Syndrome. The study also aims to explore the experiences of families and carers who care for and provide support for people with Fragile X Syndrome as they age. This study aims to explore, and help address gaps, which may impede best outcomes in care.

We hope that the results of this study will raise awareness, inform policy, support advocacy on issues surrounding Fragile X Syndrome, disability, and ageing.

You have been invited to participate in this study because you are someone whose activity or work involves adults living with Fragile X Syndrome.

Participation in this research study is voluntary. Whether or not you decide to participate, your decision will not disadvantage you. If you begin participating but change your mind, you can also stop at any time during the data collection process.

By giving your consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

(2) Who is running the study?

The study is being carried out by the following researchers:

1. Mary-Ann O'Donovan PhD, MPhil, BSc (Mgt), Executive Director | Centre for Disability Studies, Associate Professor for Disability Studies
2. Wendy Bruce, B. Soc Sci., Executive Director | Fragile X Association of Australia

An advisory group supporting the project will include an expert steering committee as well as a lived experience expert advisory panel.

This study is being funded by a private philanthropic donation made to the Fragile X Association of Australia.

(3) What will the study involve for me?

You will be asked to participate in online anonymous survey. You can decide if you would like to complete the survey by telephone or by post. You will be asked to read the participant information statement. By completing the survey you are consenting to participate in this research study. The survey will record information including your experiences and knowledge in the area of Fragile X Syndrome. If you would like to complete the survey by telephone or post, you can contact Fragile X Association of Australia by phone 1300 394 636 or by email support@fragilex.org.au or the Centre for Disability Studies by email to fragilex@cds.org.au All information you provide will be anonymous and confidential. However, should you wish to include your personal details so that we can contact about future research activities and with the results of the study, your responses will not be anonymous. Your personal details will be treated confidentially and will not be shared with anyone other than researchers from the Centre for Disability Studies, an affiliate of the University of Sydney.

You will be asked about your experiences in providing care and/or support for adults living with Fragile X syndrome, their families and carers. Here are some examples of the questions we might ask you:

- Tell me about your experience of caring for/supporting a person/people with Fragile X Syndrome
- Could you tell me about training you have received for people living with Fragile X Syndrome?
- Tell me about the services and supports available for people with Fragile X Syndrome

(4) How much of my time will the study take?

We expect that the survey will take approximately 30 minutes of your time.

(5) Who can take part in the study?

Family members, carers, front line staff, managers, and healthcare practitioners whose work or activity is connected to people with Fragile X Syndrome, their families, or carers. Specifically, such activities should involve providing care and/or support for people with Fragile X Syndrome. Unfortunately, you will be excluded if your work or connection does not focus on adults with Fragile X Syndrome.

(6) Do I have to be in the study? Can I withdraw from the study once I've started?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the Fragile X Association of Australia or the Centre for Disability Studies at the University of Sydney, or any of the organisations through which you heard about this project.

If you do decide to participate, you may withdraw from the research at any time (e.g., right up until the researchers start to analyse the data, at which point all identifiable information is deidentified) without giving a reason and you will have the option of withdrawing any interview data, which identifies you as assigned to the code used to track interviews. You can do this by informing the research team by emailing fragilex@cds.org.au that you don’t want to be involved in the study anymore.

(7) Are there any risks or costs associated with being in the study?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study. If you feel discomfort discussing your experience, you can at any stage ask to cease the interview or take a short break.

(8) Are there any benefits associated with being in the study?

We hope that once the study is completed, the results will broadly provide the first-ever picture of the population of adults with Fragile X Syndrome in Australia. It is hoped that the results of this study will enhance workforce capability to provide best practice supports and provide clear pathways for family members when navigating adult care supports. Finally, it is hoped that this study will enhance the quality of life for adults who are ageing and influence policy and practice in disability, aged care and health.

(9) What will happen to information about me that is collected during the study?

The survey responses will be anonymous and therefore, any information gathered will not include any information that will identify a participant.

The findings will be published as a report, academic paper, and conference presentation. You will not be individually identifiable in these publications. Your information will be stored securely, and your identity/information will be kept strictly confidential, except as required by law and stored securely at the University of Sydney on a secure server.

Individual participants will not be identified in any reports arising from the project. However, quotations, sometimes called excerpts, may be presented in the reporting of findings. No names will be linked to the quotations.

Non-identifiable data such as excerpts may also be shared with other parties to encourage scientific scrutiny, and to contribute to further research and public knowledge, or as required by law.

Collected data will be stored for five years after study completion on the University of Sydney's Research Data Store (RDS). The RDS is a secure, enterprise-grade Network Attached Storage device located within NSW. Physical copies of documents will be digitalised and stored on the RDS. The hard copy documents will be securely disposed of. Only members of the research team will have access to the secure server and the filing cabinet. After five years, all personal information that was collected will be deleted. If you want to access any personal information from the study, you can do so up to 5 years after the study by contacting CDS on cds@cds.org.au

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

(10) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study. In fact, we invite you to inform colleagues or other people you know who might be interested in participating in this study.

(11) What if I would like further information about the study?

When you have read this information, the research team will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact the research team at the Centre for Disability Studies, fragilex@cds.org.au

(12) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by emailing the research team at the Centre for Disability Studies at fragilex@cds.org.au

We will also aim to inform you about the research results via the Centre for Disability Studies newsletter. A summary of the results will also be made available within the storeroom of the Centre for Disability Studies, The Medical Foundation Building - K25, The University of Sydney, NSW 2006 AUSTRALIA. Telephone: +61 2 9036 3601

(13) What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney Project No. 2023/892. As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007).* This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent of the study, please contact the university using the details outlined below.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** human.ethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

This information sheet is for you to keep

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