



Development of guidelines for considerations when providing mental health first aid to a person with an intellectual disability

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Introduction

Thank you for your interest in participating in this research project. The following few pages will provide you with further information about the project, so that you can decide if you would like to take part in this research.

Please take the time to read this information carefully. You may ask questions about anything you don't understand or want to know more about.

Your participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can also change your mind and withdraw from the study.

What is this research about?

The aim of this research project is to develop mental health first aid guidelines for how a family member, friend, concerned community member or disability worker without specialist mental health qualifications should give initial assistance (mental health first aid) to a person who has an intellectual disability and is experiencing mental health problems.

The guidelines will be available for download on the Mental Health First Aid Australia website (mhfa.com.au) and will be used to inform a specialised Mental Health First Aid course.

Who we are

Researchers from Mental Health First Aid Australia and The Centre for Mental Health at the University of Melbourne are collaborating to develop guidelines for how to provide mental health first aid to a person with an intellectual disability. Mental Health First Aid Australia is a not-for-profit organisation focused on mental health training and research. The Centre for Mental Health is based at the Melbourne School of Population and Global Health at the University of Melbourne. The researchers on this project are:

A/Prof Nicola Reavley – Associate Professor, Centre for Mental Health, Melbourne School of Population and Global Health
Ms Nataly Bovopoulos – CEO, Mental Health First Aid Australia
Dr Claire Kelly – Youth Programs Manager, Mental Health First Aid Australia
Ms Louise Kelly – Specialised Programs Manager, Mental Health First Aid Australia
Dr Kathy Bond – Senior Research Officer, Mental Health First Aid Australia

Ms Fairlie Cottrill – Research and Projects Officer, Mental Health First Aid Australia
Ms Anna Ross – Research Assistant, Centre for Mental Health, Melbourne School of Population and Global Health
Joan Broughan - Mental Health First Aid Instructor
Kimberley Davies – Research Officer, School of Psychiatry, UNSW

Who we are looking for

We are inviting people from Australia, UK, Canada, Denmark, Finland, Ireland, The Netherlands, New Zealand, Sweden, Switzerland, France and the USA who have an expert level of knowledge about the topic of intellectual disability and mental health to be panel members in this research project. This includes people who have cared (unpaid) for or provided significant support to an adult or adolescent with an intellectual disability who has experienced mental health problems, intellectual disability advocates who represent the voice of people with an intellectual disability, professionals with research, education or clinical experience in the field of intellectual disability and mental health.

To participate you must be able to read and write English **AND** be 18 years or over **AND**:

1. Have experience in caring (unpaid) for or providing day-to-day support to an adult or adolescent with an intellectual disability who has experienced mental health problems **AND** have had current or past engagement in activities that give you a broader exposure to the experiences of people with an intellectual disability and mental health problems, e.g. are a member of a carer support group, through a professional role, or carer advocacy organisation, etc.

OR

2. Be a mental health professional, disability professional, educator or researcher with at least 3 years' experience in the area of intellectual disability and mental health.

OR

3. Have at least 3 years' experience working or volunteering for an advocacy organisation in a formal role as an advocate in the area of intellectual disability **AND** have experience working with people with intellectual disability and mental health problems.

If you meet these criteria, we would be grateful if you would consider being involved, as well as nominating other people you know with similar expertise.

How we are doing it

The guidelines will be formed on the basis of expert consensus. We are using the consensus of unpaid carers and significant support people, intellectual disability advocates, and mental health professionals, educators and researchers with expertise in the area of intellectual disability and mental health. These experts will complete online surveys to provide their opinions on a range of strategies for how to help a person with an intellectual disability who may be developing mental health problems or is in a mental health crisis. The strategies that receive a high level of endorsement will be included in the guidelines.

The strategies to be rated in the surveys are obtained from websites, books, fact sheets, brochures, scientific journal articles and training course materials. Some of the statements may seem contradictory or controversial. However, these are included because they reflect the wide range of people's beliefs about intervention and care. They do not necessarily reflect the researchers' opinions.

What will I be asked to do?

If you agree to participate, you will be asked to complete three online surveys over about 4-6 months (so no travel or meetings!) and the total estimated time commitment is approximately 2-3 hours.

What are the possible benefits?

Participants who complete all three rounds of the survey will receive a AU\$200 honorarium. The guidelines will also be made publicly available and may benefit your work.

What are the possible risks?

We do not anticipate that you will experience any risk or discomfort by participating in this research. In the unlikely event that you become distressed at some stage during your participation, you can contact the crisis support service in your country:

Australia: Lifeline on 13 11 14

Canada: National Suicide prevention Lifeline on 1800 273 TALK (8255)

Denmark: Suicide hotline 70 201 201

Finland: SOS Crisis Centre 010 195 202

France: Suicide Écoute 01 45 39 40 00

The Netherlands: Suicide hotline 0900 0113

New Zealand: Lifeline Aotearoa on 0800 543 354

Republic of Ireland: Samaritans on 116 123

Sweden: Suicide hotline 020 22 00 60

Switzerland: PARSPAS 027 321 21 21

UK: Samaritans on 116 123

USA: National Suicide Prevention Lifeline on 1800 273 TALK (8255)

Do I have to take part?

Participation in this project is voluntary. If you change your mind about participating, you are free to withdraw from the project at any time until the last survey is closed. You may also withdraw your data if you wish, up until the individual survey is closed. Simply contact the project coordinator, Fairlie Cottrill (fairliec@mhfa.com.au).

Will I hear about the results of this project?

Participants will receive an electronic copy of the guidelines, as well as having access to them through the Mental Health First Aid Australia website (all guidelines are freely available at <https://mhfa.com.au/resources/mental-health-first-aid-guidelines>).

What will happen to information about me?

Any data we collect from you will be held under password protection and not divulged to others. We are interested in the consensus views of the panels, rather than the views of individual members, so your individual answers will never be reported. We will only present the results in statistical summary form. We occasionally use participant quotes in published journal articles. When this occurs, we do not publish any identifying information with the quote.

Due to research code requirements, we will be storing the information collected for five years after publication, as this is the recommended time period by the University of Melbourne and the Australian Code for the Responsible Conduct of Research. This information will not be deleted, however, until all continued interest in the information (if any at all) ceases.

Is there any potential conflict of interest?

A number of the researchers are employees of Mental Health First Aid Australia (MHFA) and one is an MHFA Instructor. The Responsible Researcher of this project, however, is not employed by MHFA. MHFA Instructors may participate in this project and MHFA accredits them as Instructors. However, this conflict of interest is minimised because the researcher who is coordinating the project is not involved in the accreditation of instructors.

Who is funding this project?

The research project is funded by The National Mental Health Commission.

Where can I get more information?

If you would like more information before deciding to participate, or if you are interested in participating, please contact Fairlie Cottrill (fairliec@mhfa.com.au).

Who can I contact if I have any concerns about the project?

This research project has been approved by the Human Research Ethics Committee of The University of Melbourne. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Manager, Human Research Ethics, Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 3 8344 2073 or Email: HumanEthics-complaints@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence please provide the name of the research team or the name or ethics ID number of the research project. The ethics ID number of the research project is 1853020.1.