

PLAIN LANGUAGE STATEMENT
Melbourne School of Population and Global Health

The Pursuit of Wellbeing (POW) Study
Staff & Parent Wellbeing in Disability Services

Project Manager: Dr Elise Davis

The Jack Brockhoff Child Health and Wellbeing Program
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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 stop at any time.

What is this research about?

Yooralla is running a new program to support the wellbeing of parents of children with a disability and the wellbeing of their staff. The program includes training for Key Workers and Managers about ways to support parents' wellbeing and training for Managers to help them to support Key Workers in this area. Key Workers and Managers will receive the training at different times throughout 2017. Researchers from the University of Melbourne are working with Yooralla to see if the program is useful. We would like to invite you to be part of this study.

What will I be asked to do?

Should you agree to participate in this study, you will be asked to fill out an online survey four times over a period of 9 months. This survey will ask questions about your wellbeing, satisfaction with Yooralla's services and use of other healthcare resources. This will take approximately 15-30 minutes to complete.

At the end of the 9 months, you will be invited to take part in a focus group discussion with researchers to share your views on the Key Worker service provided by Yooralla. You can indicate in the consent form whether you are interested in being involved in this. This focus group will be held at Yooralla and is expected to take between 45 – 60 minutes. This focus group will be audio-recorded and will be accessed only by the researchers.

How will my confidentiality be protected?

We intend to protect your anonymity and the confidentiality of your responses to the fullest possible extent, within the limits of the law. Your name and contact details will be kept in a separate, password-protected computer file from any data that you supply. This will only be able to be linked to your responses by the researchers. In the final report, you will be referred to by a pseudonym. We will remove any references to personal information that might allow someone to guess your identity. You should note that as the number of people we seek to interview and gather data from is small, it is possible that someone may still be able to identify you. The data will be kept securely in the Academic Centre for Health Equity at the University of Melbourne for five years from the date of publication, before being destroyed.



Risks and Benefits

Although there are no benefits for you in being involved in this study, your participation will provide important information in understanding the usefulness of the program and may help shape the program. You will be given a \$20 Coles/Myer voucher to acknowledge the time taken to complete each questionnaire. If you choose to attend the focus group, you will be given a \$30 Coles/Myer voucher for your time.

In the questionnaire, some of the items on wellbeing are sensitive and personal and may be difficult to complete. A list of support services are below in case you do become upset.

Parentline Victoria	http://www.education.vic.gov.au/about/contact/Pages/parentline.aspx	13 22 89
Lifeline	www.lifeline.com.au	13 11 14
Mental health line	www.health.vic.gov.au/mhal	1300 280 737
beyond blue	www.beyondblue.org.au	1300 224 636
National Carer Counselling Program	http://www.carersvictoria.org.au/	1800 242 636

Will I hear about the results of this project?

Once the study has been completed, a brief summary of the overall findings will be sent to you in the post. It is also possible that the results will be published in academic journals and/or presented at academic conferences.

Will participation prejudice me in any way?

Please be advised that your participation in this study is completely voluntary. Should you wish to withdraw at any stage, or to withdraw any unprocessed data you have supplied, you are free to do so without prejudice. Your decision to participate or not, or to withdraw, will not affect access to services with Yooralla.

Who is conducting this research?

This project is in partnership with Yooralla, and is led by a number of leading researchers which include Dr Elise Davis and Associate Professor Lisa Gibbs from the University of Melbourne, Professor Rob Carter from Deakin University, Professor Katrina Williams and Professor Dinah Reddihough from the Royal Children’s Hospital; Dr Jane Tracy from Monash Health, Associate Professor Rachael McDonald from Swinburne University, Professor John Reynolds from Monash University and Rod Carraher and Paul Ireland from Yooralla.

Who is funding this project?

This project has received ethics approval from the University of Melbourne. This project is being funded by an NHMRC partnership grant with Yooralla.

Where do I get more information?

For more information and to participate in the research please email or call Dana Young at dana.young@unimelb.edu.au/9035 9870

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, Office for 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.

Consent Form

The Pursuit of Wellbeing (POW) Study *Staff & Parent Wellbeing in Disability Services*



Primary Researcher: Dr Elise Davis, The University of Melbourne

Additional Researchers: A/Prof Lisa Gibbs from the University of Melbourne; Prof Katrina Williams and Prof Dinah Reddihough from Royal Childrens Hospital; Dr Jane Tracey from Monash Health, A/Prof Rachael McDonald from Swinburne University; Prof Rob Carter from Deakin University; and Prof John Reynolds from Monash University and Mr Rod Carraher and Mr Paul Ireland from Yooralla.

1. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written plain language statement to keep.
2. I understand that the purpose of my participation in this research is to investigate parental wellbeing and satisfaction with the service provided by Yooralla.
3. I understand that my participation in this project is for research purposes only and will not affect my access to services at Yooralla.
4. I acknowledge that the possible effects of participating in this research project have been explained to my satisfaction.
5. In this project I will be required to complete four online surveys over the period of 9 months.
6. I understand that the focus group interviews will be audio recorded.
7. I understand that my participation is voluntary and that I am free to withdraw from this project anytime without explanation or prejudice and to withdraw any unprocessed data that I have provided.
8. I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements; my data will be password protected and accessible only by the named researchers; but due to the small sample size there is a risk of identification.
9. I understand that the data from this research will be stored at the University of Melbourne and will be destroyed after 5 years.
10. I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements; my data will be password protected and accessible only by the named researchers.
11. I understand that after I sign and return this consent form, it will be retained by the researcher.

After you have spoken with Dana Young and have agreed to participate in this research your consent will be obtained via the online survey.