

Family Wellbeing as Autistic Children Transition to School

The research is being carried out by the following researchers:

Role	Name	Organisation
Principal Investigator	Dr Cherie Green	La Trobe University (LTU) School of Psychology and Public Health (SPPH) Department of Psychology, Counselling & Therapy (DPCT)
Co-Investigator	Lillian Bridie	
Co-Investigator	Benjamin Lam	
Co-Investigator	Dr Lauren Lawson	
Co-Investigator	Assoc Prof Kristelle Hudry	
Co-Investigator	Dr Catherine Bent	
Co-Investigator	Dr Melanie Muniandy	
Co-Investigator	Alex Aulich	
Co-Investigator	Ellen Richardson	
Co-Investigator	Prof Amanda Cooklin	LTU, School of Nursing and Midwifery, Judith Lumley Centre
Co-Investigator	Dr Jodie Smith	LTU, SPPH, DPCT; School of Allied Health, Human Services and Sport (SAHHS), Speech Pathology
Co-Investigator	Katherine Pye	LTU, SAHHS, Speech Pathology
Co-Investigator	Dr Jessica Riordan	University of Melbourne
Co-Investigator	Dr Emma Baker	Stanford University, Stanford Medicine, Psychiatry and Behavioral Sciences – Child and Adolescent Psychiatry and Child Development
Research funder	This research has received \$12,000 from the School of Psychology and Public Health (SPPH) and in-kind support from La Trobe University.	

1. What is the study about?

You are invited to participate in a study of wellbeing in families of young Autistic children. The transition to school can be a challenging time for families. We hope to learn what factors within the family, as well as factors outside of the family, contribute to family wellbeing as children transition into the school year.

Specifically, we want to understand:

- 1) Which factors are associated with family wellbeing as Autistic children transition school?
- 2) Which factors are associated with improvements in family wellbeing as children transition to school?

2. Do I have to participate?

Being part of this study is voluntary. If you want to be part of the study, we ask that you read the information below carefully and ask us any questions.

You can read the information below and decide at the end if you do not want to participate. If you decide not to participate this won't affect your relationship with La Trobe University or any other listed organisation.

3. Who is being asked to participate?

You have been asked to participate because:

- You are a parent or caregiver of a child who will be starting school soon
- You child has a diagnosis of Autism OR is in the process of receiving a diagnosis of Autism
- You live in Australia

If possible, we would also like to invite the following family members to participate:

- Your child's other parent/caregiver/legal guardian (maximum of 2 caregivers can participate)

4. What will I be asked to do?

If you want to take part in this study, we will ask you to complete some questionnaires and a brief interview. You will be asked questions about yourself, your child, your relationships, your support networks, and about your child's transition to school. We will ask you questions at two timepoints: before your child starts school, and again in the middle of the school year.

Time 1: Before your child starts school, we will ask both you and the other caregiver (if applicable) to complete the questionnaires and a brief 5-minute interview. Some questionnaires can be completed by either one or both caregivers, depending on your preference. It will take approximately 1 – 1 ½ hours.

Time 2: After your child starts school, we will ask you to complete questionnaires about your wellbeing and stress, your child's transition to school, and about your experience so far with your child's teacher, which will take approximately 20-30 minutes.

5. What are the benefits?

You will receive a \$20 Coles gift card for your time upon completion of the study. This study aims to benefit the community through a better understanding of family wellbeing. By doing so, professionals who work with families with Autistic children may be able to provide more suitable and appropriate supports to promote overall wellbeing.

6. What are the risks?

With any study there are (1) risks we know about, (2) risks we don't know about and (3) risks we don't expect. If you experience something that you aren't sure about, please contact us immediately so we can discuss the best way to manage your concerns.

Name/Organisation	Position	Telephone	Email
Dr Cherie Geen La Trobe University	Lecturer	(03) 9479 3648	c.green@latrobe.edu.au

We have listed the risks we know about below. This will help you decide if you want to be part of the study.

- Risk of identification: We will collect information like your name, your child's name, and date of birth. All information will be stored securely on La Trobe University's server for research data. Your contact details and personal information will be stored separately from your data (e.g., survey responses). Any information that could be linked to your identity will be removed from the transcript of your audio recording. Only the research team will have access the data. No identifiable information will be published.
- Due to the sensitive nature of some of the topics that you will be asked about, it is possible that you may experience emotional discomfort or distress, depending on your unique situation and past experiences. If you feel uncomfortable answering any questions, you can stop the survey or interview at any time. A list of resources will be provided to you upon completion of the survey questions.

Resources Available: Your General Practitioner (GP), a mental health treatment plan, Carer Gateway (1-800-422-737 or www.carergateway.gov.au/), and Carers Victoria (www.carersvictoria.org.au/).

7. What will happen to information about me?

We will **collect** information about you in ways that will reveal who you are.

We will **store** information about you in ways that will reveal who you are.

We will **publish** information about you in ways that will not be identified in any type of publication from this study.

We will **keep** your information for 7 years after the project is completed. After this time we will destroy all of your data.

The storage, transfer and destruction of your data will be undertaken in accordance with the [Research Data Management Policy](https://policies.latrobe.edu.au/document/view.php?id=106/) <https://policies.latrobe.edu.au/document/view.php?id=106/>.

The personal information you provide will be handled in accordance with applicable privacy laws, any health information collected will be handled in accordance with the Health Records Act 2001 (Vic). Subject to any exceptions in relevant laws, you have the right to access and correct your personal information by contacting the research team.

8. Will I hear about the results of the study?

We will let you know about the results of the study by a newsletter summarising group findings. We will include the links to any publications.

9. What if I change my mind?

You can choose to no longer be part of the study at any time until your data have been analysed.

You can let us know by:

1. Completing the 'Withdrawal of Consent Form' (provided at the end of this document);
2. Calling us; or
3. Emailing us

Your decision to withdraw at any point will **not** affect your relationship with La Trobe University or any other organisation listed.

When you withdraw we will stop asking you for information. Any identifiable information about you will be withdrawn from the research study. However, once the results have been analysed we can only withdraw information, such as your name and contact details. If results haven't been analysed you can choose if we use those results or not.

10. Who can I contact for questions or want more information?

If you would like to speak to us, please use the contact details below:

Name/Organisation	Position	Telephone	Email
Dr Cherie Geen La Trobe University	Lecturer	(03) 9479 3648	c.green@latrobe.edu.au

11. What if I have a complaint?

If you have a complaint about any part of this study, please contact:

Ethics Reference Number	Position	Telephone	Email
HEC24393	Senior Research Ethics Officer	+61 3 9479 1443	humanethics@latrobe.edu.au

Consent Form – Declaration by Participant

I (the participant) have read (or, where appropriate, have had read to me) and understood the participant information statement, and any questions have been answered to my satisfaction. I agree to participate in the study, I know I can withdraw at any time until my data have been analysed. I agree information provided by me or with my permission during the project may be included in a thesis, presentation and published in journals on the condition that I cannot be identified.

I would like my information collected for this research study to be:

- ☐ Only used for this specific study;
☐ Used for future related studies;
☐ Used for any future studies

☐ I would like to receive a copy of the results via email or post. I have provided my details below and ask that they only be used for this purpose and not stored with my information or for future contact.

Name	Email (optional)	Postal address (optional)

☐ I am interested in being contacted for future research studies that I or my child may be eligible for

Participant Signature

Please sign your name in the box below using your mouse. You can download a signed copy of the Participant Information Statement and Consent Form to keep.

Participant's printed name	
Participant's signature	
Date	

I agree, start questionnaire

Withdrawal of Consent

I wish to withdraw my consent to participate in this study. I understand withdrawal will not affect my relationship with La Trobe University of any other organisation or professionals listed in the Participant Information Statement. I understand the researchers cannot withdraw my information once it has been analysed.

I understand my information will be withdrawn as outlined below:

- ✓ Any identifiable information about me will be withdrawn from the study
- ✓ The researchers will withdraw my contact details so I cannot be contacted by them in the future studies unless I have given separate consent for my details to be kept in a participant registry.
- ✓ The researchers cannot withdraw my information once it has been analysed

I would like my already collected and unanalysed data

- ☐ Destroyed and not used for any analysis
☐ Used for analysis

Participant Signature

Participant's printed name	
Participant's signature	
Date	

Please forward this form to:

PI Name	Dr Cherie Green
Email	c.green@latrobe.edu.au
Phone	(03) 9479 3648
Postal Address	Department of Psychology, Counselling, & Therapy (DPCT) La Trobe University Bundoora, VIC 3086