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Participant Information and Consent Form

The Hidden Histories of Late-Diagnosed Autistic Adults: An Oral History Study

Most autistic people are now diagnosed as children. Yet, there are many older people who were not diagnosed until they were adults. There is not much known about these people's lives. We would like to find out more! We want to better understand the reasons why people seek out a diagnosis later in life. We also want to know whether their lives have changed since diagnosis. Findings from this project will help to increase community understanding about Autistic lives.

What are the aims of this research?

The Cooperative Research Centre for Living with Autism (Autism CRC) is funding this project. The project researchers will:

- a. Conduct **oral history interviews** with late-diagnosed autistic adults. These interviews will help to explore how life was before and after their diagnosis. It will also place people's views and experiences within a particular time and place in history.
- b. Prepare these interviews so that they can be made available on the Internet. This way, future generations can learn about these individuals' stories and experiences.

We want to interview people who:

- were born before 1975;
- were over 35 when they got a clinical diagnosis of autism;
- are English-speaking; and
- have spent most of their childhood and adult life in Australia.

If you meet all these criteria, we are keen to hear *your* life history.

Who is conducting this project?

This research is co-produced by researchers from three different universities. It is also overseen by an Advisory Group who are all Autistic. Approximately half of the researchers are Autistic. The researchers involved in this project are from:

- Macquarie University, Sydney, Australia
 - Professor Liz Pellicano
 - Dr Wenn Lawson
 - Dr Rozanna Lilley
 - Gabrielle Hall
 - Joanne Mahony
- University of New South Wales (UNSW), Sydney, Australia
 - Professor Julian Trollor
 - Dr Sam Arnold
- Drexel University, Philadelphia, USA
 - Professor Michael Yudell
 - Catie Davis

What will happen if I take part?

If you decide to be a part of this study, we will ask you to take part in FOUR sessions on four different days, taking about 3-4 hours in total.

The main things that will happen at each session are:

Session 1 will take about 30 minutes. It will probably be done by video-conferencing over the Internet. But it could also be done face-to-face (if that's feasible), on the phone or over email. We will be guided by your preferences about how we meet. During Session 1, we will:

- get your written consent to take part in the project;
- talk about whether you would like to bring along any photos or objects to the main interview (Session 2). You might like to bring things like this to help to tell your story;
- talk through any supports or needs you might have to help the interview be as comfortable as possible for you;
- talk about a looking after yourself before and after the interview, because talking about the past may bring up strong feelings; and
- ask you to complete a Life History Background questionnaire. This questionnaire will include the sorts of questions that you often see in official paperwork including your:
 - age
 - highest education level
 - income
 - ethnicity
 - diagnoses
 - communication preferences.

We will keep the information you provide in this Background questionnaire confidential. This means that links between you and your information will not show in published documents or archives. But, if you do mention any of that information during the recorded interview (Session 2), it might be included in project outputs. This would only happen with your permission.

Session 2 will probably take between 1-2 hours. This session will include the main life history interview.

During this session, we will ask you questions about your life before and after your autism diagnosis. Things to note about this session:

- before the interview, we will give you a list of the of the main topics we would like to ask you about. This will give you a chance to think about them, and also tell us if there is a topic you do not want to talk about;
- we can do the interview by web-conferencing (Zoom) – but we can also do it face-to-face in a place of your choosing (depending on feasibility), over the phone or even via text-based chat, depending on your preference. We will record the interview, and it will be typed-up. You'll be asked to read and comment on this in Session 3;
- the interview will be recorded, with your permission, and the audio-visual recording will also be digitally archived on the Internet at the end of the project – again, with your permission;
- you can also choose not to have the recording done – in which case, the interviewer would take notes of what you say;
- you can bring photos and/or objects along to the interview if you wish to include them in your story;
- Gabrielle Hall or Joanne Mahony will be interviewing you. Photos and some information about them are near the end of this document.

Session 3 should take about 30 minutes. Before this session we will send you a typed-up version of your interview. During this session, we will talk about the recording and the typed-up version. You can remove anything that you aren't comfortable with sharing. We will also check with you about any other items you would like included with your digitised oral history. This session will also be a chance for us to re-check that you understand what things you have agreed to by being a part of this project.

We will pay for any travel expenses involved in doing the interview. You will also be given a \$100 gift card for your time over the four sessions.

Session 4 will be a short follow-up chat of about 15 minutes. We will ask you a few questions about what you thought and/or felt about having your story recorded and shared. We will record this discussion, with your permission.

Are there any risks involved in this research?

From experience, we know that many people feel empowered by telling their story. But some of the things you talk about might also be difficult.

To support you during this process, we invite you to take a break anytime during the interview. We have prepared a list of possible things to do, to let us know if you'd like a break. We will discuss these with you during Session 1 and have them ready for Sessions 2, 3 and 4. Also, please tell us if you don't want to answer a particular question. You can also stop at any time without giving a reason.

Involvement in an oral history project might bring back some unwelcome memories. This can happen even though you want to be involved in the project. It can also happen

both before and after the interview. We therefore want you to take extra care of yourself during the process and will talk about ways you can do this during each of the sessions. We also encourage you to put some supports in place. To help you do this, we will give you a letter explaining your role in this project. You can use this letter to tell others that you may need their support. These others might be family, friends, health professionals and/or community members. We will talk about this part of the project in more detail during Session 1.

What happens to the results of the research?

Usually in research, we assure participants that their responses will be anonymous. This is not the case in oral history research projects. People usually choose to make their story and history public in such projects. **Because this is an oral history project, we will use your real name in the recording, the typed-up interview and any resulting publications. We will do this unless you tell us to use a made-up name instead.** You can choose whether or not you agree to have this done. We will check this with you before the interview to make sure that you are clear on the process. We will also check this again with you during Session 3 when you review the typed-up interview.

When we have finished all the interviews for the project, we will send you a summary of our findings. We will also send you details about where you can access your interview on the Internet. We may also use the results of this study in conference papers, journal articles and reports.

Do I have to take part?

It is ok if you decide not to take part. It is up to you whether or not you want to be involved in the project.

If you choose to join now, you can change your mind later and leave the project. We will not use your interview if you let us know of your decision to leave before:

- the interview data have been analysed; and/or
- the interview has been made accessible on the Internet.

If you withdraw before your interview has been analysed, we will delete your transcript. This means that we will not use it in our results or publications.

You can withdraw from the project without giving a reason. There will be no consequences if you choose to stop your involvement in the project. If you do withdraw, we will ask you to complete a 'Withdrawal of Consent' form. Someone from the research team will give you this form. A decision to stop at any time is your right. A decision not to take part will not affect your access to services. A decision not to take part will not affect your relationship with the researchers or with the Autism CRC in any way.

What should I do next?

If you would like to take part, please complete the consent form and sign it.

If you have questions at any time, please email either:

- Liz at liz.pellicano@mq.edu.au
- Wenn at wennbe2@outlook.com

CONSENT FORM

**Please tick
the appropriate box**

I have read the <i>Participant Information and Consent Form</i> sheet. I understand the information in it. Any questions I have asked have been answered to my satisfaction.	<input type="checkbox"/> Yes <input type="checkbox"/> No
I agree to take part in all four sessions associated with the research.	<input type="checkbox"/> Yes <input type="checkbox"/> No
I understand that my participation is voluntary. I understand that I am free to withdraw up until the time the data have been analysed and the materials have been made accessible on the Internet. I understand that I do not need to give a reason for withdrawing. I understand that stopping will not affect my access to services in any way.	<input type="checkbox"/> Yes <input type="checkbox"/> No
I understand that the information I provide in the Life History Background questionnaire will remain confidential. I understand that this information will not be directly linked to me in reports or publications.	<input type="checkbox"/> Yes <input type="checkbox"/> No
I agree to my main interview (Session 2) and follow-up interview (Session 4) being recorded and typed up.	<input type="checkbox"/> Yes <input type="checkbox"/> No
I understand that I will be able to review the recording and the typed-up interview transcript from my interview. I understand that I can make changes to the resulting materials if necessary.	<input type="checkbox"/> Yes <input type="checkbox"/> No
I give permission for my recording, typed-up interview and any associated visual materials to be digitally archived and made publicly available on the Internet for future access.	<input type="checkbox"/> Yes <input type="checkbox"/> No
I give permission for my real name to be used in all resulting materials (recordings, typed-up interviews, publications and reports).	<input type="checkbox"/> Yes <input type="checkbox"/> No

Participant/Interviewee's Name: _____

Participant/Interviewee's Signature: _____ Date: _____

Interviewer's Name: _____

Interviewer's Signature: _____ Date: _____

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics & Integrity (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Interviewer Profiles



This is **Gabrielle Hall**. If you choose to take part in an interview, Gabby might be the person interviewing you.

Gabby is Autistic, and was diagnosed in her early 40s. She is a trained nurse and naturopath, and worked in the areas of psychiatry and community health. Gabby has a love of research. She has worked in medical research because she is dedicated to contributing to innovative and best practice health care. Gabby greatly values the process of empowering people to create their own path of wellbeing.

In 2013, Gabrielle's son was diagnosed as Autistic. She then realised that she and her daughter were also Autistic. This exciting new identity started a passionate and ongoing exploration of autism. Gabby's evolving understanding of neurodiversity has become a personal and professional focus. She also believes that Autistic people's own insights are the key to guiding current and future supports and acceptance. This project ties together her loves of people, wellbeing, research and Autism. She very much looks forward to sharing space, and caretaking the sharing of your unique and important story.



This is **Joanne Mahony**. If you choose to take part in an interview, Joanne might be the person interviewing you.

Joanne has had a life-long interest in History. She particularly likes social history which looks at people's stories and how they lived. And for her whole life, she's loved to ask "Why?" about anything and everything! Seriously! She loves to ask questions! And is actually interested in your answers!!

Having first wondered, during the late 1990s, if she and two of her three children might be Autistic, Joanne didn't seek a diagnosis for herself until 2016. She did this after lots of research. During all that research, she learnt that Autism might not always look like the stereotype presented in most of the readily-available information. This seemed to be particularly true for Autistic women. Months (ok, maybe years!) of reading and investigating finally led to her getting an answer to why she's always been a little out-of-step with mainstream expectations. This project gives Joanne the opportunity to use her love of history with her favourite question (Why?). She hopes you'll feel comfortable enough to share your stories with her so together we can make a difference in other Autistics' lives as we begin the process of telling our stories.

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Consent for Release Form

You have agreed to take part in the “*The Hidden Histories of Late-Diagnosed Autistic Adults: An Oral History Study*” project. We would like your permission to make use of materials created with you during Session 2. We want to digitally archive your interview with the other participants’ interviews. We will do this by storing them on the Internet. This means that future generations and communities can learn about all of the project participants’ stories and experiences.

This consent form asks for your permission to use the materials resulting from your Session 2 interview in the manner described in the first paragraph of this document. These materials are the recording, the typed-up interview transcript and any associated visual materials you may have provided. Please read through the list of (formal) statements below and tick either ‘Yes’ or ‘No’ to record your consent response.

1. I understand that the interview will be recorded and a typed-up transcript of the recording will be made. I also understand that I can include visual materials, such as photographs or objects. These are collectively called the “Materials”.
2. I hereby grant permission to Macquarie University, its employees or representatives to use my Materials for research purposes. For good and valuable consideration, I hereby waive all rights of privacy in and to my Materials by the ‘Hidden Histories’ project team and I hereby give consent to and authorise the aforementioned persons to use the same or any part therefore subject to the following restriction:
 - Prior to submitting my Materials or any part of them to be copyrighted and/or published, that I give specific approval of the recording, typed-up transcript and any associated visual materials.
3. I understand that this release is binding upon myself, my heirs, legal representatives, licensees and assigns.

I agree to open the Materials to the public on the completion of the project.	<input type="checkbox"/> Yes <input type="checkbox"/> No
I agree to allow the Materials to remain open in perpetuity.	<input type="checkbox"/> Yes <input type="checkbox"/> No

Participant’s Name: _____

Participant’s Signature: _____ Date: _____

Investigator’s Name: _____

Investigator’s Signature: _____ Date: _____