

1000 Voices

PARTICIPANT INFORMATION SHEET

Who is conducting the research?

Name Professor Lesley Chenoweth and Dr Naomi Sunderland
Griffith Abilities Research Program, Research Centre for Clinical and Community Practice Innovation
Contact Phone 07 3382 1485
Contact Email L.Chenoweth@gu.edu.au

The auDA Foundation has partnered with Griffith University and Q150 to fund this research project.

Why is the research being conducted?

1000 Voices is a public awareness raising research project. The purpose of this project is to collect and display 1000 life story narratives from people with a disability. The narratives will be presented in different formats that highlight the background, culture, and diversity of the narrators and the experiences of people with a disability. Narratives collected via this project will be used as content for the international *1000 Voices Website* being hosted by Griffith University. The study will be conducted over three years.

What you will be asked to do

The purpose of this research is to learn more about the lives of people with disabilities from around the world. If you agree to participate in this research you will be asked to create and share your life story with researchers and the broader public via the international public 1000 Voices Project website.

Your story can be about your whole life or about a specific part of your life or a set time period. You can construct your story using a range of media including for example, writing, photography, artworks, film, or audio.

You will be asked to give your consent to be involved in the research project and to have your life story displayed on the 1000 Voices website and analysed as part of the 1000 Voices research on lives of people with disabilities.

If you have any concerns or special needs regarding your participation you will be able to talk to a researcher in your country or region to get assistance before you agree to participate.

The basis by which participants will be selected or screened

The 1000 Voices project is targeted at displaying and studying life stories of people with disabilities in Australia and in other countries.

During this phase of the project we will only accept:

- a. Participants who are able to complete a simple questionnaire about themselves prior to uploading their story to the 1000 Voices website (or who have a family member or carer who is authorised to answer the questionnaire for them if they are unable to do so);
- b. Participants who are willing to have their story displayed publicly with their real name or a nickname via the 1000 Voices website;
- c. Participants who are over 18 years of age or who have the express consent of a parent or guardian to participate.

The expected benefits of the research

We expect that this research will produce the following benefits:

- Creating a public record of the experience of disability;
- Networking, peer support, and inspiration for people with disabilities and their families and community members generally;
- Providing opportunities for self expression and control of representation for people with disabilities;
- Rupturing of negative and inappropriate stereotypes regarding people with disabilities;
- Providing access to previously inaccessible rich data on lived experience for successful people with disability for researchers, policy makers, and service providers;
- Free public access to authentic and engaging stories of successful people with disabilities for media and other institutions such as schools.

Risks to you

Risks associated with participation in this research project are minimal. Although the life stories will be available publicly on the 1000 Voices website, you can choose to be identified only by a nickname if you do not wish to have your real name attached to the story. You will however have to use your full, real name when you fill in the survey prior to uploading your life story. Survey information will only be available to authorised researchers working on the project.

Your confidentiality

Because this is a high profile public project, the life story that you upload to the 1000 Voices website will be available to people who access the 1000 Voices website. If you choose to publish the story under your real name, or include details that may identify you to others, people who visit the site may be able to identify you. Information from the 1000 Voices project may also be repeated in promotional documents and media stories circulated by Griffith University.

Full research records of online surveys you complete as part of this research will be stored in a secure area in the Research Centre for Clinical and Community Practice Innovation at Griffith University for the duration of the 1000 Voices Project. These records are kept to ensure access to the original data generated from this project for future verification if required.

Your participation is voluntary

Participation in this research project is voluntary. Participants are assured that their decision to participate, or otherwise, in this project will in no way impact upon their relationship with Griffith University or the individual researchers involved. Participants are free to withdraw from the research project at any time. You will also have the opportunity to request that your life story be removed from the 1000 Voices website at any time in the future if you so desire.

Questions / further information

Should participants have any further questions, or require further information, they can contact:

Lesley Chenoweth
School of Human Services
07 3382 1485

L.Chenoweth@gu.edu.au

The ethical conduct of this research

This research project will be conducted in accordance with the *National Statement on the Ethical Conduct of Human Research* (2007) which is available at <http://www.nhmrc.gov.au/publications/synopses/e72syn.htm>. If you have any concerns or complaints about the ethical conduct of the project you should contact the Manager, Research Ethics, Griffith University on 3735 5585 or research-ethics@griffith.edu.au.

Feedback to you

A summary of findings will be distributed to all participants in the research via online research reports and papers. All presentations of research findings will also be made available to participants upon request. Manuscripts and reports can be obtained by contacting:

Lesley Chenoweth
07 3382 1485

L.Chenoweth@gu.edu.au

Privacy Statement:

The conduct of this research involves the collection, access and/or use of your identified or de-identified personal information for the purposes of education and public awareness raising. The information collected will be displayed publicly via a website and in associated promotional materials. Your real name or a nickname you choose will be displayed alongside your published life story material(s). All display of information relating to you is subject to your approval and written consent. You can choose to omit any confidential information from published materials at any time during the course of this project. For further information consult the University's Privacy Plan at www.gu.edu.au/ua/aa/vc/pp or telephone (07) 3735 5585.