

INFORMATION SHEET AND INVITATION TO PARTICIPATE

Adult Transition Project for people with disabilities in New South Wales: An assessment of support needs and experiences during transitions (Story submissions)

Researchers (Investigators):

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What is this study about?

This study explores experiences of “transition”. A transition is a period of change in work, living situation, significant relationships, and/ or health that causes you to change the way you live, what you do, where you live, or with whom you live.

Some examples of situations that might trigger a transition are:

- Getting a new job or losing a job
- Retiring
- Losing abilities due to ageing or long term illness
- Moving house
- Moving into or out of supported care accommodation
- Falling in love or getting married
- An unexpected windfall or opportunity (for example, an inheritance or winning a contest)
- A personal desire to have an adventure or to chase a lifetime goal
- A profound spiritual experience that provokes a change of heart or a change in your life's direction

Transitions can affect anyone. Sometimes they are expected and sometimes they are a surprise. Sometimes you can seek out a change and sometimes it is beyond your control.

Adjusting to change affects people differently. We want to understand what transition is like for people aged 40 – 65 years who have had a disability since childhood. We want to find out what can help people during times of transition.

What does participation involve?

If you choose to be involved, you will be asked to submit a story of a transition experience you have had. You can choose to submit or tell your story by any of the following ways:

- a) Providing a written story via the post (using the return envelope provided)
- b) completing the online survey at: https://www.surveymonkey.com/s/Adult_transition_project

- c) emailing a written, or audio, or video file to cwilding@csu.edu.au
- d) complete a phone interview with Clare (This option will mean that you have to pay the cost of a local phone call. The phone interview will be audio-recorded.)

Your story can be as long or as short as you decide. The length of your story and the method you use to tell your story will affect how long it takes you to participate in this study. It is likely that it will take you between 30mins and up to 2 hours depending on the length and method you choose. You can use the *Guide for telling your transition story* or you can just respond to the question: Please describe a transition experience you have had.

How will the information be used?

The researchers are collecting transition stories from people with disabilities, who are aged between 40 – 65 years, from across New South Wales. They will read or listen to each story and compare all the stories to find common ideas and themes.

By collecting people's stories of their experiences of transitions, we hope to better understand the range of experiences that people have with transitions. And we hope to understand the challenges of transitions and supports people need during transitions.

The findings of this study will be reported to the New South Wales Government Department of Ageing, Disability, and Home Care and Northcott Disability Services. This report will be used by the NSW government to assist them in planning services for people with disabilities.

It is also likely that the study will be reported in academic journals that are read by health workers who provide services for people with disabilities. The study may also be presented and discussed at health and disability conferences in Australia and overseas.

Is there any risk if I participate?

You will be asked to speak about or write about an experience of transition and what support you think would be useful to you for future transitions. If you have had unpleasant or upsetting past experiences of transitions, then talking about or writing about these experiences may bring back unpleasant memories. You may feel upset remembering and talking about these times. You might also realise that supports for future transitions would be helpful, but you may be unsure if any support is available.

You can choose how much or how little you write or say. You can also choose what you write or say. After writing or telling your story, if you feel upset or confused, or you would like to talk more about the issues raised, Northcott Disability Services staff member, Michele Wiese (registration PS0018995), who is a certified psychologist, can provide you with initial counselling and referral to local counselling services if required. Michele can be contacted by phone on (02) 9890 0530 or email: michele.wiese@northcott.com.au

Alternatively, you may choose to contact Lifeline: 13 11 14

How will my privacy be protected?

To protect your identity, a made-up name (a pseudonym) will be linked to your story. Your real name will not be used in public reports about the study. The main themes and ideas that people spoke or wrote about will be reported. In public reports, some people's stories may be retold, using the words they used in their story. As much as possible, the researchers will leave out details that might identify you as the teller of a story. There is a chance that other people who know you may be able to guess that a particular story or words are yours.

The stories will be stored in a locked office at Charles Sturt University, and after the study, in a locked office at Northcott Disability Services. Digital files will be stored on the university's secure system and protected by passwords known only to the researchers.

What happens now?

You are welcomed to participate in this study, but you do not have to participate if you do not want to. Your participation is entirely voluntary. There is no penalty if you decide not to participate. Your submission of a story by post, by the Survey Monkey website, or by email is taken to mean that you have voluntarily consented to participate. If you wish to tell your story by telephone, Clare will ask you at the beginning of the call if you still give your consent. You may choose to finish the call whenever you want to. You can say as much or as little as you choose.

Would you like to participate in this study? If you have questions you can ask Clare by telephoning her on 02 6051 9256 or email: cwilding@csu.edu.au or ask the person who gave you this information sheet.

If you are willing to participate, please submit your story

by completing the online story submission at
https://www.surveymonkey.com/s/Adult_transition_project

OR email your story (in a word, pdf, digital audio/video file) to cwilding@csu.edu.au

OR ask for a copy of the *Guide for telling your transition story* (or print this from the Northcott website: www.northcott.com.au)

OR tell the person who gave you this sheet that you would like to do a telephone interview (or contact Clare directly on 02 6051 9256 or cwilding@csu.edu.au to let her know you would like to do a telephone interview). If you want to complete a telephone interview, you will need to agree to your name and contact details being passed on to Clare so she can contact you to organise the interview.

NOTE: Charles Sturt University's Human Research Ethics Committee has approved this project. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Executive Officer:

The Executive Officer
Human Research Ethics Committee
Office of Academic Governance
Charles Sturt University
Panorama Avenue
Bathurst NSW 2795

Tel: (02) 6338 4628
Fax: (02) 6338 4194

Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.