

Participant Information Sheet – General (Extended)

Registered Nurses

Project Title: Professionalisation and nursing in intellectual and developmental disability in Australia 1960 - 2016

Project Summary:

You are invited to participate in a research study being conducted by Dr Peter Lewis of the School of Nursing and Midwifery at Western Sydney University and Associate Professor Kathryn Weston from the Graduate School of Medicine at the University of Wollongong. The research is about the emergence of nursing in the field of intellectual and developmental disability as a distinct sub-specialty of nursing practice in the 1960s. The stories of nurses who have worked in the field of intellectual and developmental disability during the period 1960 – 2016 will make a valuable contribution to the understanding of nursing practice and the development of nursing as a profession during this period. This study is intended to be a celebration of the contributions that nurses have made in the field of intellectual and developmental disability. The researchers would like to talk to anyone who worked as a registered or enrolled nurse for at least ten years between 1960 and 2016 in the field of intellectual and developmental disability about their experiences of practice and their professional identity.

How is the study being paid for? This is a collaborative project between the Professional Association of Nurses in Developmental Disability Australia Inc (PANDDA) and the School of Nursing at Western Sydney University. Funding is provided by PANDDA and in-kind support provided by Western Sydney University.

What will I be asked to do?

You will be asked to participate in one or two interviews with one of the investigators on this project, Dr Lewis or Associate Professor Weston. The interview will be informal and will be guided by your memories and experiences of your practice as a registered or enrolled nurse working with people with intellectual and developmental disability. The researchers will also have some general questions about what nursing was like when you first started to practice and throughout your career. You can bring items to the conversation, such as photos, certificates, and tools that you might have used in practice, that might help the interviewer to understand your experiences and help you to remember what you want to talk about. We will not ask to keep your items; they are just for you to discuss.

Sometimes after people have had a conversation with a researcher about their memories and experiences, they think of things that they would like to share a few days or weeks later – after they have had time to reflect on the conversation they have had. For this reason, we also invite you to participate in a second interview during which you have an opportunity to continue your discussion with the researcher. You can discuss aspects of your experiences that you had not thought of during your first interview but that you have subsequently remembered and wish to tell; you can recant anything that you talked about in the first interview that you've had second thoughts about sharing; you can elaborate on points you made in the first interview that you did not discuss as fully as you wanted to.

The interview(s) will be audio-recorded. The recording will be transcribed into a word document. Your information will be added to other transcripts of recordings from other nurses. The researchers will study the words said and identify general themes that reflect the experiences of the nurses who were interviewed.

In addition to your personal experiences of delivering care to people with intellectual and developmental disability, we'd also like to discuss your memories of your nursing education, the process of deinstitutionalisation, and your membership of PANDDA (if you are a PANDDA member)

How much of my time will I need to give?

Each interview will vary in duration depending on how much you want to share about your memories and experiences. The first interview is likely to last between sixty and ninety minutes as you discuss a wide range of topics related to your nursing career. The second is likely to be shorter and more focused and last between thirty and forty minutes. If you wish to meet the researcher in person, then you might also add travel time to this depending on where you would like to meet. Otherwise, interviews can be conducted on a computer-based meeting platform, like zoom, or over the telephone.

What benefits will I, and/or the broader community, receive for participating?

You will not be paid for the interview(s). Although some people find sharing their experiences of professional practice rewarding and appreciate having their stories heard and recorded, you may not benefit personally from participating in this research. The broader benefit is to reconnect the current generation of nurses working with people with intellectual and developmental disability with the practices and achievements of the past to enhance a sense of professional identity. This is about establishing a continuity of care across generations for the benefit of people with intellectual and developmental disability.

Will the study involve any risk or discomfort for me? If so, what will be done to rectify it?

There is the potential that you might become uncomfortable or upset when remembering aspects of your practice that you found especially difficult or when remembering people you have worked with who have passed on. If you anticipate that you might become upset, we recommend that you consider having a support person stand by in case you would like their support. If you wish, the interview(s) can be suspended while you process your feelings and then recommenced after a short time. If you wish to discontinue the interview at any time, you may do so without giving any reason at all.

If you do experience distress during or after the interview has finished, please contact your General Practitioner for an appointment or call Lifeline on 13 11 44.

There is also a possibility that you might remember instances of abuse or neglect of people with intellectual disability that you have observed or heard about in the past. If you disclose any instances of abuse or neglect of people with intellectual disability, please understand that the interviewer will be obliged to tell the police.

How do you intend to publish or disseminate the results?

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that the participant cannot be identified, except with your permission.

You will not be personally identified in any publications or presentations about the results of the study. You will be provided with a false name – a pseudonym – so that your real name will not be used. Any reference you make to institutions where you've worked will be generalised, for example, by referring to "a residential institution in New South Wales". The names of any colleagues or clients that you use will also be removed from the findings, publications, and presentations. Data will be aggregated and presented in the form of themes. Only short segments of what you actually say might be used to illustrate the general points that all participants have made.

Will the data and information that I have provided be disposed of?

Please be assured that only the researchers will have access to the raw data you provide. However, your data may be used in other related projects for an extended period of time. For example, researchers in the United Kingdom have recently conducted a similar study to this one by interviewing nurses in England and Northern Ireland. There may be an opportunity to collaborate with those researchers on a comparative study between the professionalisation of nursing in intellectual and developmental disability in the UK and Australia.

Can I withdraw from the study?

Participation is entirely voluntary and you are not obliged to be involved. If you do participate you can withdraw at any time without giving a reason.

If you do choose to withdraw, any information that you have supplied can be deleted, but only up until the time when data analysis is complete and results are being published and presented.

To withdraw from the study, simply send an email to either Dr Lewis or Associate Professor Weston stating that you wish to withdraw. You do not have to give a reason and we will not contact you unless you specifically ask us to.

Can I tell other people about the study?

Yes, you can tell other people about the study by providing them with a copy of the e-mail invitation that you have received inviting you to participate or by forwarding them the contact details of Dr Lewis or Associate Professor Weston so that they can contact the researchers themselves.

What if I require further information?

Please contact Dr Peter Lewis should you wish to discuss the research further before deciding whether or not to participate.

Dr Peter Lewis, Senior Lecturer, School of Nursing and Midwifery, Western Sydney University
Phone: 02 4570 1927
e-mail: p.lewis@westernsydney.edu.au

What if I have a complaint?

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through Research Engagement, Development and Innovation (REDI) on Tel +61 2 4736 0229 or email humanethics@westernsydney.edu.au.

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

If you agree to participate in this study, you may be asked to sign the Participant Consent Form. The information sheet is for you to keep and the consent form is retained by the researcher/s.

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is H15151.