

A history of nursing in intellectual and developmental disability 1960 - 2016

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Professional Association of Nurses in
Developmental Disability Australia Inc

Acknowledgement

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The logo for PANDDA, featuring the word "pandda" in a bold, lowercase, teal-colored sans-serif font.

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An alternative title

Their best lives

Outline of presentation

- Aims
- Our participants
- Timeline and background
- Findings and themes
- Where to from here?
- A way of seeing the world



Aims

Aim of study:

To explore how nursing in the field of intellectual and developmental disability got to where it is today.

Aim of presentation:

To report progress and to describe preliminary findings from analysis of interviews with registered nurses.

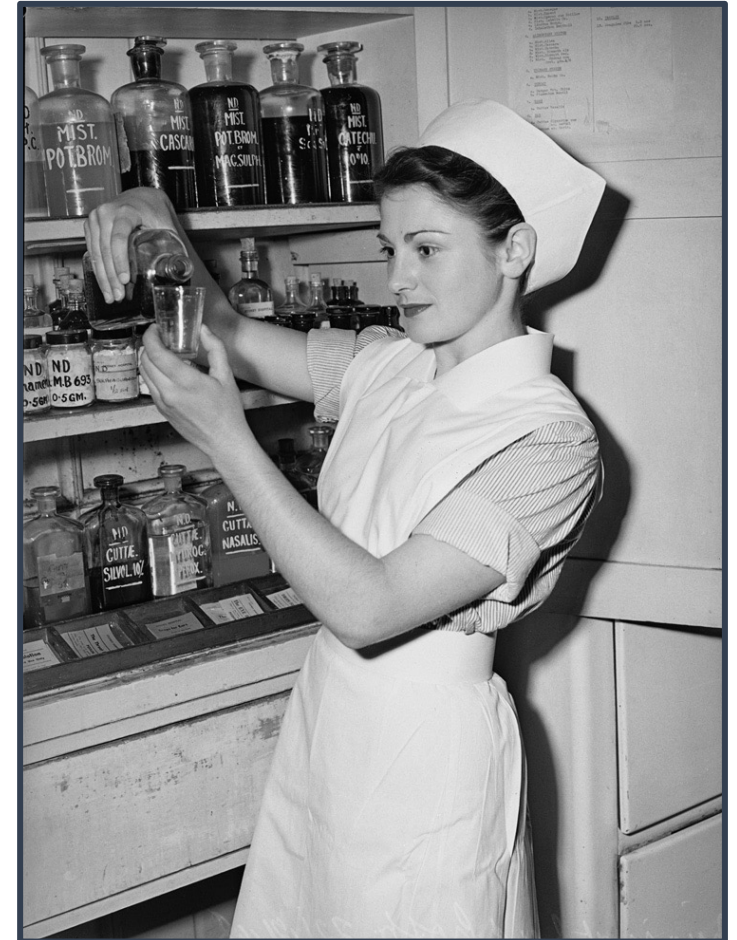
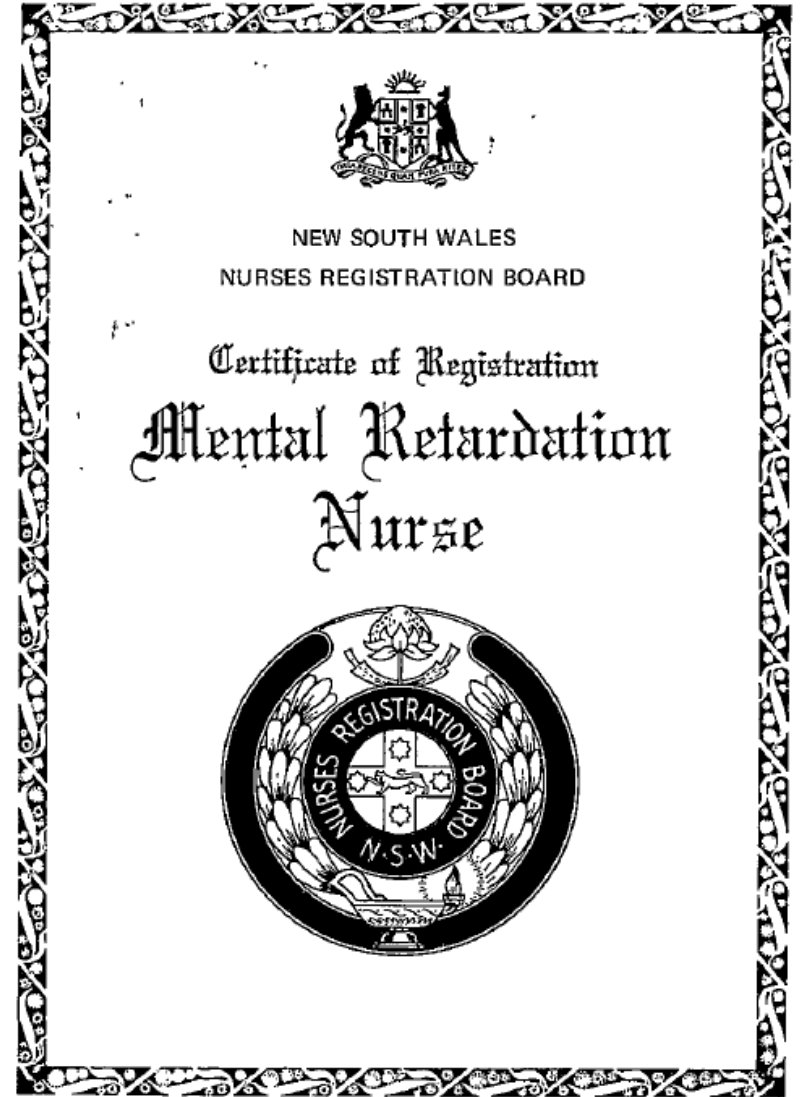


Image: Trainee nurse Dorothy Way preparing medicine at Sydney Hospital December 1948 From the collections of the [State Library of New South Wales](#) [ON 388/Box 008/Item 027]

The participant group

- Twenty-four interviews (19 women; 5 face-to-face)
- Duration 70 – 90 minutes, audio and video recorded
- First practiced: NSW (n=17), VIC (n=4), QLD (n= 3)
- Twenty-one educated in hospital; three educated in university
- Career duration 28 – 51 years



The mental retardation nurse participants

- Research limitations in qualitative interviews – self-selection; one group
- Many had a pre-existing normalisation of intellectual disability – significance?
- Many were very young when they started out, or just there to get a job
- Devolution was unsatisfying for some, others embraced it. Recognition of limitations in healthcare then and now.
- Varied roles in transition and later career opportunities
- Sense of privilege working in the sector
- Overall, a deeply personal and meaningful career and life experience

- Many had a pre-existing normalisation of intellectual disability – significance?

a big bus that used to be a few streets down and all the sort of kids with disabilities would get on this coach. And I used to say to mum, who are those nice people because, you know, they were over friendly and saying hello and people would be making noises and spinning around. So I thought, Oh, who are these people? They're fascinating as a kid... Theresa

So when I was a teenager and at school I would work as a nanny for her for Suzie, who had the severe autism, and Suzie's friend who had Down Syndrome. Belinda

I had a brother who ... had a profound intellectual disability and physical disability. ... he looked like a normal baby, same as my other brother and myself. Colette

- Many were very young when they started out, or just out to get a job

I was 16 in year 10 at high school 4th form ... and probably going down the teaching track ... there wasn't a lot of choices for the girls back then, and our school had just started a new work experience program and XXX Hospital was one of the places that, you know, offered a two week period of time. Renee

leaving before Year 12 in those days, 6th Form it probably was, nursing was a way to get a piece of paper and train and earn money at the same time. Tina

XXX was a place where we grew up and so did the children who had been put there, you know, and we had a lovely time. May

- Devolution was an unsatisfying experience for some; others embraced it. Recognition of limitations in health care then and now.

Quite often I was told that, you know, institution nurses are old school. Whether that meant ... we wanted to get rid of that institutional culture and the nurses were tarred, as you said, tarred with that institutional brush. John

a lot of people that moved out of XXX into the group homes, felt ... their nursing was being ripped out from under them. Renee

The de-institutionalisation has had a huge effect and for the better really for many of the children who have gone into group homes. May

we were all institutionalized as staff. You got in, you did the tasks and home you went and a lot of that really hasn't changed a lot. Tina

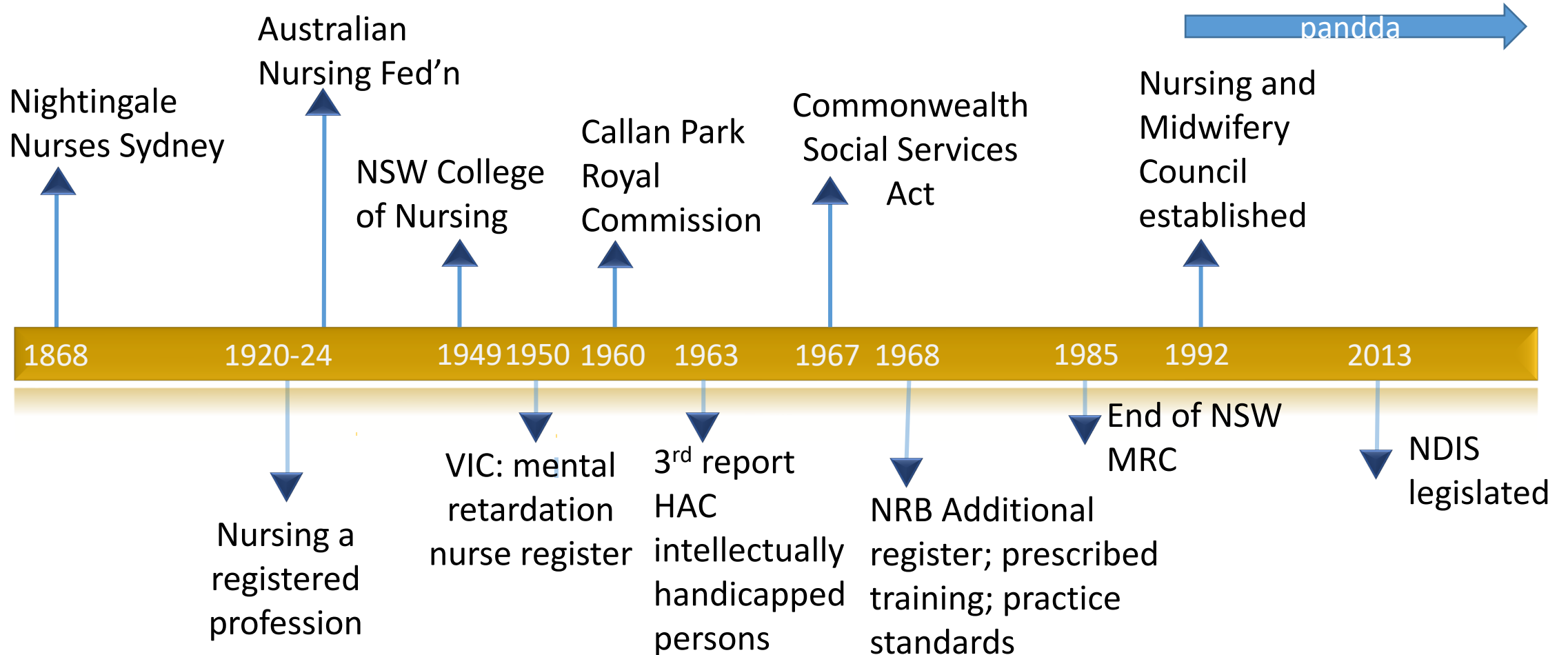
- Sense of privilege working in the sector;
deeply meaningful and personal

... the joy and the privilege of working with people with intellectual disability, and that's been a reason to have stayed with it, you know, right through. Don

I still feel, very, very cross when I see notes, 'Oh disability-related'. You see it all the time. And I think for me that was something that I wanted to challenge. Jennifer

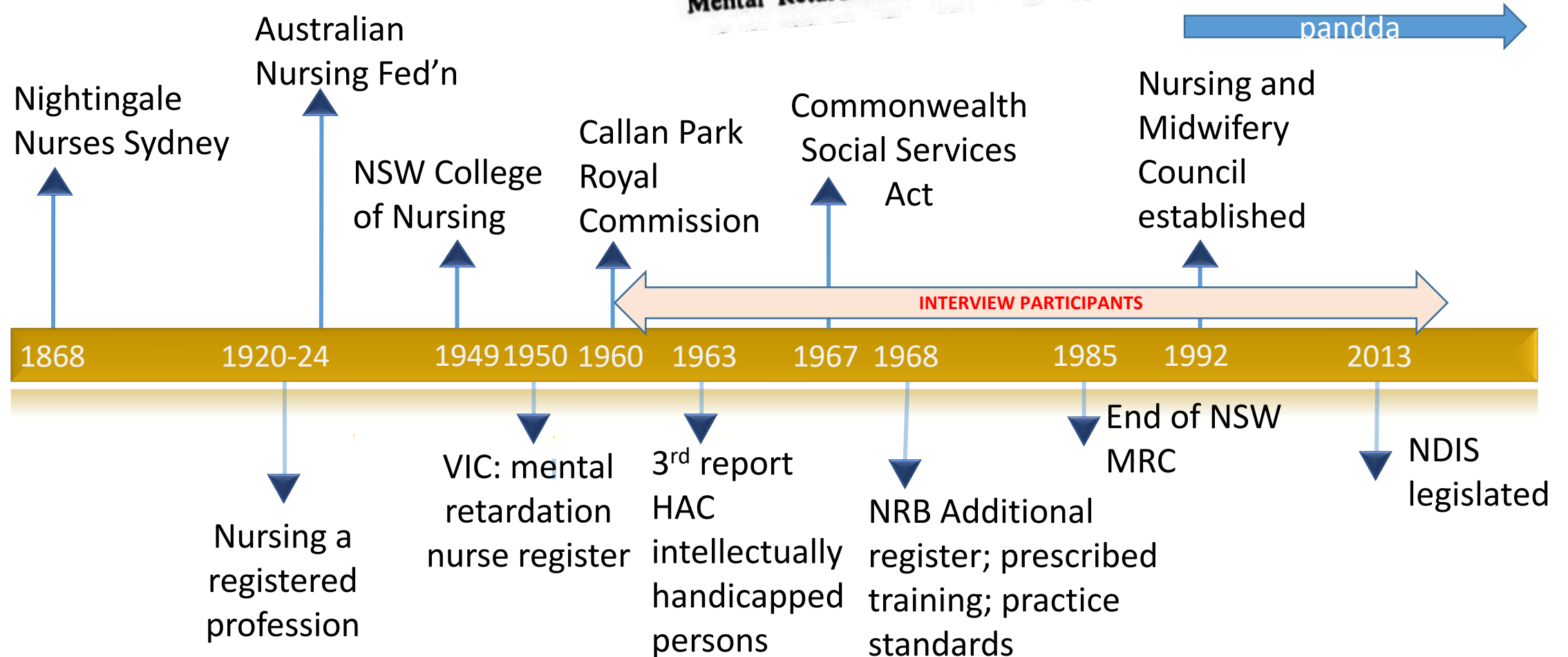
Timeline and background

Timeline



Timeline

Register of Mental Retardation Nurses
1. The name of the additional subdivision of the Register established by this Proclamation shall be the "Register of Mental Retardation Nurses".



1960s training locations for mental retardation nursing

NEW SOUTH WALES NURSES REGISTRATION BOARD TRAINING SCHOOLS FOR NURSES

IN pursuance of the provisions of the Nurses Registration Act, 1953, as amended, the New South Wales Nurses Registration Board has withdrawn recognition of Peat and Milson Islands Hospital and Stockton Hospital as training schools for psychiatric nurses and Bellinger River District Hospital, Bellinger, as a training school for general nurses.

The Board has approved of Grosvenor Hospital, Summer Hill, Peat and Milson Islands Hospital and Stockton Hospital as training schools for mental retardation nurses and Bankstown District Hospital and Lismore Base Hospital as training schools for nursing aides.

(5426)

C. M. ANABLE, Registrar.

NEW SOUTH WALES NURSES REGISTRATION BOARD TRAINING SCHOOLS FOR MENTAL RETARDATION NURSES

IN pursuance of the provisions of the Nurses Registration Act, 1953, as amended, the New South Wales Nurses Registration Board has approved of the Gladesville Hospital as a training school for mental retardation nurses.

(2971)

R. WILLETTS, Registrar.

NEW SOUTH WALES NURSES REGISTRATION BOARD TRAINING SCHOOL FOR MENTAL RETARDATION NURSES

IN pursuance of the provisions of the Nurses Registration Act, 1953, as amended, the New South Wales Nurses Registration Board has approved of the Marsden Hospital, Westmead, as a training school for mental retardation nurses, with effect from the 20th October, 1969.

(8352)

M. A. MORRISON, Registrar.

NSW Nurses Registration Act as amended – Regulations

19th January 1968

Part 8.

Nursing the mentally retarded (40 hours).

Aim:

To provide the nurse with a clear concept of her nursing role and responsibilities in the hospital care of mentally retarded patients.

Topics:

- 1. History of mental retardation nursing.**
- 2. The hospital—its departments and surroundings.**
- 3. Role of the hospital and range of community services.**
- 4. Voluntary workers and patients' relatives in ward programmes.**
- 5. Principles of mental retardation nursing.**
- 6. The role of the nurse in hospital and community care of the retarded.**
- 7. Procedures for reception, admission, transfer and discharge of patients.**
- 8. Nurse-patient relationship.**
- 9. Role of the nurse in the clinical team.**

Preliminary findings and themes

Preliminary findings and themes

Overall theme: Giving people their best lives

... we hadn't quite got as far as we wanted to with giving people their best lives, but we were getting there. Florence

1. Experiences of nurses entering the profession as trainees in institutions

2. Devolution and roles and responsibilities of nurses as clients were moving into community settings

Findings and themes

1. Experiences of nurses entering the profession as trainees in institutions

Two phases

- Learning the ropes
- Going above and beyond



Learning the ropes

It was 24/7 care, the bathing, the feeding, the lifting and there was no lifting equipment at all. There was no specialised seating or anything like that, so it was basically a sea of bodies on mats on the floor or on like a modified sun lounge or something like that. Stephanie



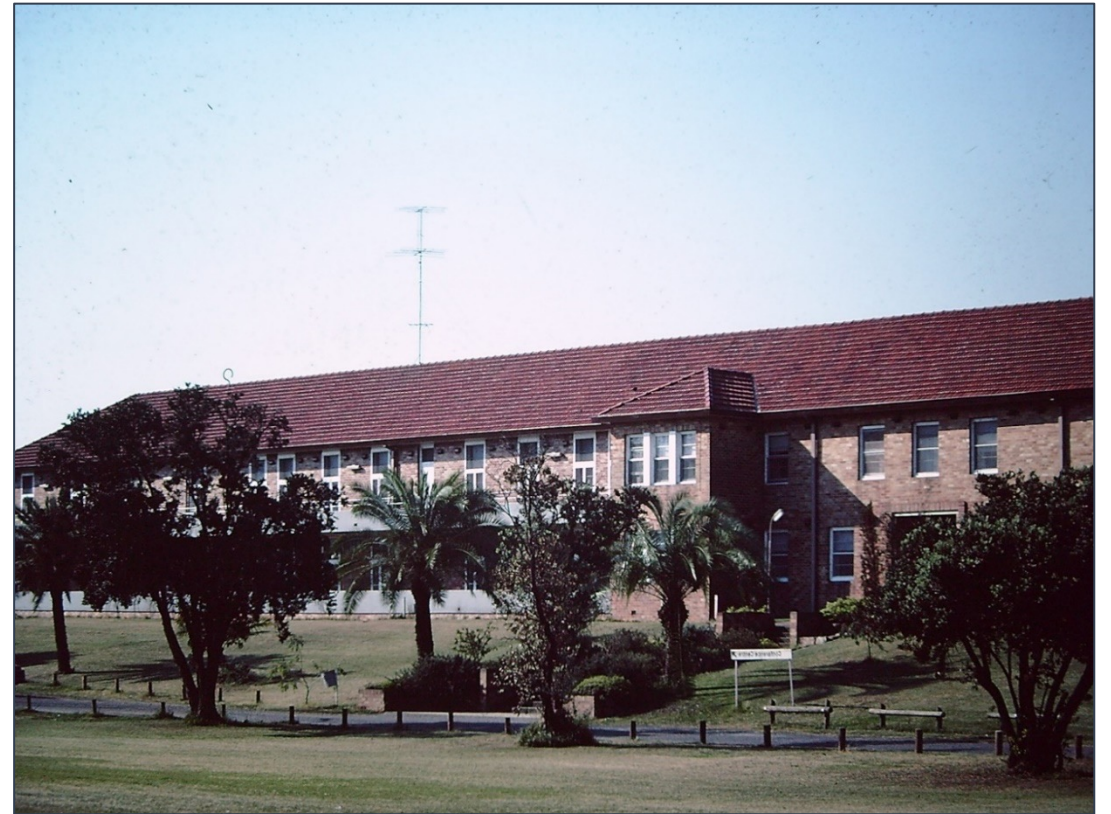
Learning the ropes *continued*

And had to go through you know, that first few months of the selection process because they obviously only nominate and put a certain [number] of applicants through the process ...

I remember quite fondly apart from the learnings and the supporting you know we were all running around with ... you know you'd be assigned to 'Peter' for the day, and you'd have 4 clipboards to get through with 'Peter' for the day and they were all developmental programs, reverse training and you know. That would start with the showering, there'd be one for the toothbrushing, potentially one for dressing and then there might have been one for you know something else but you know we were ... I just remembered being very clipboardy. Melanie

Learning the ropes *continued*

A lot of it was around that developmental programming, which is a term I only thought about the other day actually. And it's where the students (and I was taught) where you had to write a program. So, whether it was a discrimination program or a forward chain or a backwards chain and how you would teach someone a skill. A lot of that was around that skills building stuff that we did on placement. Pauline



Going above and beyond

In those days you know, some of the senior nurses used to take someone home for dinner as part of that socialisation stuff, you wouldn't even think of that today. It's not professional. John

When I was a kid and if I was sick, you know, I'd be upstairs, brought to work upstairs above the intake ward at [hospital]. So, I was very used to those environments. I was very used to engaging with people with mental health issues, all the rest of it. Mum would always be bringing somebody home who didn't have somewhere to go on Christmas Day. We always would have somebody for Christmas and those sorts of things. Belinda

Going above and beyond *continued*

I used to take [resident] home regularly and all my friends knew him ... And on the day of the grand final, I came in to pick him up and the staff had dressed him up in blue and white and decorated his wheelchair for him in blue and white. Bonnie



Findings and themes



2. Devolution and roles and responsibilities of nurses as clients moved out to community settings

Three phases

- Family liaison
- Preparing the way
- Transfer and closure

Family Liaison

I was talking back with families, and I'd been around for so long I knew a lot of families ... my boss at the time ... said to us all the time, this isn't one giant leap to perfection, this is an incremental step that the families can cope with at this point. The focus was about having those families on board and settling them to be comfortable with the move. Tina

Preparing the Way

We had a whole range of people that moved on from the large residential setting out into the community. We had to put together, like we were putting together sort of profiles of people, looking at how that transition should go. John

They put these portfolios together and they extracted information out of them and they were black folders and they put in every conceivable thing that, and in very 'basic speak', [no jargon], you know just telling stories. Tina

So we all had a role in transition. You might get the NGOs saying, "we're not going to do that". Well, yes you are, because I'm not going to release them for transition unless you do that. We did have some training role, like a bit of shadowing and stuff like that, particularly around things like PEG feeding, positioning ... Stephanie

Preparing the Way *continued*

I mean we'd identified the ones who were able to live in a house without a registered nurse on staff 24/7. But then there were so many who needed 24/7. We needed to work out how best to do that. And really it was really advocating with the department that it was in the department's best interests to make sure that the people who had the high medical support needs were well supported and from an economic perspective, it was better for them to have a 10 bed unit like a nursing home. May



Transfer and Closure

I was supporting the people moving out into their new homes and worked with them for the last three years whilst they were in their home. Renee

... it happened to a large extent through the staff transferring and devolving, like moving into the new group homes, etc with along with the clients. So they were taking their relationships with the clients into the new setting. Bonnie

Concluding remarks

- Nursing care of people with severe intellectual and physical disabilities could be challenging and rewarding
- Those who were heavily invested in the care of people with intellectual disability went above and beyond to give people their best lives from the earliest until the latest phases of their career



Where to from here?

- Today's data are preliminary
- Other aspects to explore from the data include:
 - Changes in provision of health care services over time
 - Access and equity then and now
 - Training
 - Ways of seeing the world

A way of seeing the world

Time to reflect on the past, contemplate the present and look to the future.

- *What is worth nurturing?*
- *How can we move forward in a way that promotes the best lives of people in this sector?*

Thank you

If you would like to get in touch,
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