

Excerpts from:

Rosemary Kayess interviewed by Kim Rubenstein in the Trailblazing women and the law oral history project, 6535/25, National Library of Australia (*Sydney, Australia, 1–3 January 2015*).

Sound files from the interview can be searched and listened to at:

<http://catalogue.nla.gov.au/Record/6774757>

Rosemary is profiled on The Australian Women's Register at:

<http://www.womenaustralia.info/biogs/AWE5718b.htm>

A Reflections on aspects of diversity and equality

1A

Session 4: 1 hour, 13 Mins

Rosemary Kayess: Um well again it's the frustration because of the level of um resources that are available. And that's always going to be um a problem. And I just don't think we've got to the point where we can have, it's still really hard to get people beyond care, protection and treatment. And this is going to be the measure of the success of the Convention I think. The, the point that we can get people past care and protection and treatment and you know to truly recognise disability as part of human diversity. And it, it's tricky. It's about making some quantum leaps. I mean when you talk about it in terms of unfit to plead. I mean I gave um the Matt Laffan um ...

Rosemary Kayess: oration, lecture, whatever they call it. I gave the Matt Laffan oration this year, last year.

Kim Rubenstein: That's right, it was when you were the ... [ill]

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Rosemary Kayess: The first couple weeks, the first couple of weeks of January is a nightmare.

DELETED – Section on Unfit to plead

Rosemary Kayess: Um so I gave them that I-, the 2014 Matt Laffan oration. Um and I was saying that the experience with people with disability is one of separated and segregated. And that is generally as w-, you know as the, that that's, that comes about not just, it comes about even when we're trying to include. So parking pl-, spaces, there's separate little parking spaces off the side and separate for people with disability. So disability is you know, you know identified and segregated as other over there with the blue spots.

Kim Rubenstein: Yep.

Rosemary Kayess: Whereas everybody could benefit from having slightly wider spaces, with there being a designated space between every second car. You know it, everybody would benefit—aged people, people with prams, people with small kids—everybody would benefit. You would have a far more accessible you know car park ...

Kim Rubenstein: Environment.

Rosemary Kayess: for everybody. You wouldn't have to segregate people in terms of their characteristics. Mums with prams, people with disabilities, aged people it's, you know. It, it that's not what inclusion is about. That's, that's the minority politics you know, minority identity um accommodation, tolerance type stuff. It's not about inclusion.

Kim Rubenstein: Yeah.

2A

Session 5, 1 hr, 4 minutes

Rosemary Kayess: ... this is why I see inclusive research as so important because without the voice of people with disability, without people with disability engaging in the policy discourse which incorporates the legal discourse as well, the law reform discourse as well ...

Rosemary Kayess: You know people with disability have been locked away from that conversation for so long. And so we're not in academia. We're not, we're not in the public service, embarrassingly so. Worse and worse figures every year. We're just getting further and further behind. So we're not in the senior levels of public service. We have one person with disability in the South Australian state parliament. And so research then becomes, if the voice of people with disability isn't coming through in the research, how do you build capacity with the decision makers not to be prejudiced?

Rosemary Kayess: How do you influence the judiciary not to be prejudiced?

Kim Rubenstein: Yep, yep.

Rosemary Kayess: Not to be ignorant of the experience of disability. And you see in judgements that they are incredibly ignorant and misunderstand what disability is all about.

Kim Rubenstein: That makes me think Rosemary, you know there's the National Judicial College where they, and I know that historically they've had gender training. Has there been any move to have some ...

Rosemary Kayess: No but it, God it needs doing.

Kim Rubenstein: Yeah that might be something ...

Rosemary Kayess: It really doing.

Kim Rubenstein: really worth investigating M'mm particularly in light of your comments on various decisions of the courts and the lack of understanding of ...

Rosemary Kayess: Yeah, yeah.

Kim Rubenstein: those issues that if, if the courts are one avenue for asserting rights you need the court to be, the judges. Which adds into the notion of the experience of disability adding into the life experience of judges. I mean you need judges with disabilities too, to be able to ...

Rosemary Kayess: And you need to be able to embrace. I mean and you need to helicopter people in I believe. Because it's a bit like what I was saying before about um legal capacity. p. 256/ In 50 years' time this will all be a different situation because people will have gone to mainstream education. They will have grown up in the community. They will have much stronger social support networks. They will be much more engaged in the community. They will go and, through to university. They will be academics. They will be judges. So down the track it's not a problem but now we have to deal with that transition to that.

Rosemary Kayess: And so I think there's value for a bit of um affirmative action and helicoptic, helicoptering people in to build um you know ...

Kim Rubenstein: That understanding.

Rosemary Kayess: Yeah build that understanding to build capacity.

3A

Rosemary Kayess: The disability sector—like all sectors—is not a homogenous sector. Um I'm sure look there are parents, parent groups that are in ministers' ears daily about congregate care facilities. They want them. They have fear about what's going to happen to their children once they're gone. The fact that their child may now be a forty year old adult. Um there are people that believe we should still have sheltered workshops.

Kim Rubenstein: So it's also then about educating, working out ways to educate those sectors to the more ideal scenario.

Rosemary Kayess: Yeah, yeah. And I mean the lawyer in me really, ah I mean NDIS is not perfect. Please don't get me wrong. And I mean there are elements of the legislation that are downright frightening. I mean ...

Kim Rubenstein: Can you, yeah can you give us an example?

Rosemary Kayess: Well it really hasn't embraced, I mean it's embraced CRPD and the ideology of giving people choice and control and um ...

Kim Rubenstein: And RPD stands for?

Rosemary Kayess: Oh sorry CRPD is the Convention on the Rights of Persons with Disabilities. Um but they completely ignore the level of capacity stuff and they just for p-, they say that you know if people lack decision making capabilities they will appoint you know a substitute decision maker. Well no. You know we're supposed to be moving away from the best interests type concept and substitute decision making. Trying to centralise people in their own decision making processes. Um the Australian Law Reform Commission um released a report just before Christmas that I was um part of. I was on the advisory group for it and it was looking at disability um capacity and quality.

Rosemary Kayess: And basically what they're saying is that we need to turn the concept around and not focus on whether someone has capacity or lacks capacity. We need to be focussing on what supports are available and are the supports adequate to meet um the requirement for legal trust. And I mean that's what it's about—legal trust. Can we trust that decision in a legal way?

Kim Rubenstein: Yep and in that report um is, are there mechanisms suggested for, for that to happen? Can you give us an example?

Rosemary Kayess: Yep, yep. Um well they've set out a series of um decision making princ-, ah principles around supported decision making. They've emph-, emphasised the fact of supportive decision making, that people um, that ah, that the default position that people have capacity um is maintained, yeah.

4A

TS 245

Violence suffered by women with disabilities

Rosemary Kayess: ... Violence, violence for people with disability in general is a huge concern for women. It's twice as you know, it's nearly twice as bad. Um the figures, and the fact that we haven't got good figures is a worry.

Rosemary Kayess: Um in terms of sexual assault and in terms of domestic violence and if we broaden out the way we understand domestic violence and include within that scope violence within congregate care, ah women with disability are incredibly vulnerable to violence. And experience it you know three times, four times more than the general population. We've tried and tried and tried to embed disability in the national focus that's happening on violence against women but it's been so hard. The last government wouldn't, didn't appoint a person

with disability to the council. Julie Bishop I believe will raise it as one of the issues of concern when um Australia goes for election to the Human Rights Council.

5A Disability and discrimination

TS 171

Kim Rubenstein: ... um your identity in terms of it being, a disabled person has been a strong sort of theme in, in the way we've, I've engaged you in your discussion. But what about in terms of any, of your experience as a woman in terms of sexism or discrimination along the way on top of that. Have there been particular ...

Rosemary Kayess: It's hard to separate the two. You know it, ah am I being overlooked because I'm a woman or because I'm a person with a disability? Who knows. But I also don't have a lot of the um, the characteristics that lots of women experience discrimination ... I don't have um dependant family, I'm not um a married, I'm yeah so I don't have that caring responsibilities.

...

Rosemary Kayess: That, that put me in line for a lot of that indirect discrimination.

6A Disability Loss of Identity

Session 5, 46 minutes, 27 seconds. *Transcript pp241-243*

Rosemary Kayess: ... I mean basically what's so exciting, ah that whole inspirational thing, I remember being in London, remember being in London and I'd come downstairs to the um café area where they had breakfast. It was in this little hotel in Hampstead. And I'd come down for breakfast and I came around and I'd spoken to my brother and I went over to the buffet area.

Rosemary Kayess: I hadn't said anything at this stage and there was this woman beside me and she said, she turned around and she you know gushingly told me what, you know, 'I think you're such an inspiration.' Now at this stage I hadn't said a word so she didn't know I was Australian, so she didn't know that I was 9000 miles, 1200 kilometres you know away from home. She didn't know that I'd been you know the last two weeks in Ireland teaching a summer school on international human rights law and the Convention on the Rights of People with Disabilities. So she didn't know any of that stuff so my immediate reaction is to say, 'What because I'm considering the baked beans?' It, it just came out of nowhere.

Rosemary Kayess: I mean I wouldn't have minded so much if she was suggested you know, 'I'm really impressed with your work or what you do.' Or anything, but she didn't know any of that. She was just inspired that I was sitting at the buffet thinking will I have baked beans. Because you know when you're travelling you always go to have your baked beans every now and then or whether I'd have a poached egg.

Kim Rubenstein: So the fact ...

Rosemary Kayess: It's not overtly inspirational.

Kim Rubenstein: But is it, but the notion of being able to live a regular life as a person who isn't fully abled, you find pat-, it's patronising to be ...

Rosemary Kayess: It's incredibly patronising. She didn't, look the thing about this hotel is it's right around the hos-, right around the corner from the Free Hospital. And you got to get in quick to get a room there because it's one of the you know really rare, really accessible hotels in um London because oh bloody English and their bathrooms.

Kim Rubenstein: Yeah.

Rosemary Kayess: But anyway um I digress. You know and you got to get in really quick because the ho-, the hospital books out the rooms so overflow of the people ...

Kim Rubenstein: Ah visiting or ...

Rosemary Kayess: you know need, well no were coming in from outer areas.

Kim Rubenstein: Oh yes.

Rosemary Kayess: And so they come in the night before and then they go that, you know go into the hospital the next day. Um yeah so she, I, I could have been a patient or ... It just, it's ...

Kim Rubenstein: Yeah.

Rosemary Kayess: It's incredibly patronising.

Kim Rubenstein: M'mm yeah and on that level we, we started really in terms of that, just the ways in which you deal with that either with humour or with, yeah.

Rosemary Kayess: Well but it also belittles other people that are doing significant stuff. So if everybody in a wheelchair's inspirational well what do you say to the people that do, do you know fabulous stuff. What, what do you say about Stella Young?

Kim Rubenstein: Yeah, yeah.

Rosemary Kayess: It just becomes so trite and meaningless.

Kim Rubenstein: Yeah.

Rosemary Kayess: And a bit insulting. So yeah sorry.

Kim Rubenstein: No it's absolutely fine.

Rosemary Kayess: Humour yes, humour definitely.

Kim Rubenstein: Is a key, yeah.

Rosemary Kayess: You have to. Well for me it is, yeah.

B Reflections on the challenges Rosemary has experienced in this context &

1B TS 131-132. Challenges of travel in general and to NY in 2003

Kim Rubenstein: How does it work with you Rosemary in terms of your chair when you go onto ...

Rosemary Kayess: Oh I've got to transfer into the seat and I watch my chair go off into the hold and pray to God that it comes out in one piece. So I try and tape it up and fold it up and neaten it up so nobody can do anything stupid. But oh ...

Kim Rubenstein: It's not fun.

Rosemary Kayess: Air travel M'mm anyways so we did, we did the big jaunt to New York and it had been a hell of a flight just because it was economy class and it, it is such a long haul into New York. And we got to New York and of course we had all these great assumptions about New York, didn't we? We thought New York was going to be you know the biggest, the best, the ... And um we get there and there is no way for us to get into Manhattan. And it took us nearly six hours to get from JFK to get some form of accessible transport we could use to get into Manhattan. So then we get into Manhattan and the hotel's given, given away to somebody our accessible, my accessible room. So at one o'clock in the morning I've got this you know until, one o'clock in the morning this inaccessible room.

DELETED SECTION

Rosemary Kayess: And because I really needed sleep. My day had been about 44 hours long by that stage. So anyway Phillip said to me, um Phillip and Darren said well you know, 'You sleep in. Come down when you can.' Because it was like three o'clock before I got into bed.

Rosemary Kayess: And then of course the um power transformer on my mattress wasn't working so my air mattress—my pressure care mattress—wasn't working properly. So I was sinking into this stupid mattress and really uncomfortable and really tired.

2B

TS 144; 144-145 Travel with 2 carers

Kim Rubenstein: And you had a, ah did you have a um, a single carer or a group of carers with you on that trip?

Rosemary Kayess: Um well what I t-, who I travel with and what I was travelling with then was my nephew who was at university at the time. I'd been, I'd been the source of financial funds for my nieces and nephews going through university for a period of time now. My um nephew Lyndon, um he and I are good mates and um he ...

DELETION

144-145

Rosemary Kayess: Um and so Lyndon travelled with me and I took a carer with me um to shower me and dress me and be available to me overnight. So I, I, I travel with someone that basically does from nine o'clock in the evening through until nine o'clock in the morning. So someone that puts me to bed, um is available if I need anything during the night. Gets me up, showers me, dresses me, sends me on my way. And then someone that's with me during the day when I'm doing whatever I'm doing.

Rosemary Kayess: Most of the time that second person tends to be um one of my brothers or one of my nephews because it's really good to have someone that can pick you up out of an aeroplane seat if there's any issues, can rebuild your wheelchair if it comes out of a hold and it's not looking like it should. Um and can you know do any running repairs so yeah, um drive you from Galway to London in one day um those sorts of things.

3B TS 220

How she uses her laptop

Kim Rubenstein: Yeah and you, do you have a lap-, ah do you use a laptop?

Rosemary Kayess: I have a laptop yeah ... [I have a laptop.]

Kim Rubenstein: So that's by your bed, always by your bed so you're able to really keep yourself ...

Rosemary Kayess: Yeah I was able to set it up on a you know one of those tables on wheels over my bed. And, and I was able to manipulate it with my mouth stick. I mean it wasn't easy but you know the internet gave me access to and ...

Kim Rubenstein: Yeah, yeah the world came to you through the internet.

C Reflections on the successes she has experienced

1C

TS 140-143 *Rosemary's chairing skills in the drafting of the UN Convention*

Rosemary Kayess: Yeah, yeah that draft, drafting process. What had happened at the end of the first ad hoc committee that I went to was, there was to be a drafting group. And so I was asked to chair the second last day of the caucus meeting which was what the steering committee did. You know we took turns in chairing um the caucus which was all the NGOs that were at the meeting. And what we had to decide was how the NGOs would be represented on the small working group to draft text. And I ah for whether it's good or bad chaired that meeting, chaired that day. Now the governments were in—the sorry, member states—were in what they call informals basically all of the day.

Rosemary Kayess: So we were basically in caucus all of the day trying to hash out how we would, what we would put forward to the member states in terms of um representation on the

drafting group. Now I don't know if you could conceive this but it's probably a room about the size of my lounge, dining, kitchen?

Kim Rubenstein: Yes which is um for the, I mean I know that because I've been into your lounge, dining, kitchen but we're talking ...

Rosemary Kayess: It's probably about six metres by about, the room would have been about 6 metres by about 15 metres. My, my lounge room's 5.5 metres by 12 metres. So just slightly larger but not much and you've got about 80 people in there.

Kim Rubenstein: Gee.

Rosemary Kayess: Of these 80 people you've got in one corner a group of young Korean girls and in the other corner a group of young Japanese girls and they've all got little translator things. And so they're translating what you're saying into Japanese and Korean for the delegates that are in the room that are Japanese or Korean with the various ear pieces in. You then have people kneeling beside people in wheelchairs whispering in Spanish and Arabic and um people who are beside people who are blind whispering in Spanish and Arabic what I'm saying or what anybody else is saying from English to Arabic or English to Spanish. You've got an American sign language interpreter, a Finnish sign language interpreter, a deaf blind interpreter, um an AUS-, no we didn't have an AUSLAN interpreter for that.

Rosemary Kayess: Um and oh sorry and a court reporter person doing CART um real time captioning as well for what I was saying. So I've got all this interpretation going on. I've got people putting their hands up, people who are blind um just jumping in in the middle of everything and it was just absolute chaos and absolute pandemonium.

Kim Rubenstein: And you're chairing?

Rosemary Kayess: And I was chairing. And we came, we came to a conclusion. We, we said we wanted ten spots on the, that we'd have five for the IDA group and five for the regions.

Kim Rubenstein: And IDA is the ...

Rosemary Kayess: Ah International Disability Alliance so it's those intern-, you know World Federation of the Deaf, World Blind Union, It-, Inclusion International, the ones that I mentioned before.

Kim Rubenstein: Yeah.

Rosemary Kayess: Um and so that was going to be our proposal. Now that took us all bloody day to get agreement on that. And anyway um so that was the proposal we were going to take to um the ad hoc committee.

Kim Rubenstein: And can I ask you just before you move on there, in your, your chairing, is there any formality to the chairing or is it literally your choice as to how you conduct and manage?

Rosemary Kayess: Oh it was just the way I conducted it and managed it. And for my sins or ah maybe, I don't know maybe not for my sins—I don't know that I did anything special but at the end of that day people stood and applauded. The first people to stand and applaud were the interpreters.

Kim Rubenstein: Wow.

Rosemary Kayess: And everybody just asked me if I'd come back and chair tomorrow.

Kim Rubenstein: Fantastic.

Rosemary Kayess: So I did. I don't, I don't know if I've got particularly good chairing skills. I don't know if it's because I'm reasonably articulate. I don't know, I really don't know what was behind it. I obviously impressed people. People still to this day turn to me about that meeting and are in, so in awe of my chairing of that meeting. I don't think, I personally don't think I did anything special. It was a hard, long day but we got through it. And ...

DELETION

Kim Rubenstein: Yeah M'mm and were you exhausted by the end of the day?

Rosemary Kayess: Oh God yes.

Kim Rubenstein: And did you have a ...

Rosemary Kayess: And kind of exhilarated too but um, and I mean that's the exciting thing about New York. It's that thinking on your feet that's always such fun.

Kim Rubenstein: Yeah, yeah.

2C

TS 134-135 *Rosemary's unique input into setting the international legal standards for disability: advocacy for a 'non-deficit' construct of disability.*

Rosemary Kayess: DELETION... And so we were engaged in a lot of corridor conversation with the Australian um delegation. And it was in one corridor conversation standing outside the men's toilets ...

[Laughs]

Rosemary Kayess: Why we were standing down there, I don't know. But anyway um and I was saying to them that you know what you're failing to understand is, you're wanting to annex those two instr—so the two declarations, the '71 and '75 Declarations on Mental Retardation and Disabled Persons—were part of the problem. You know they, they were the paternalistic, institutionalised construction of disability that we needed to move on from. And what you want them to do is annex them to the International Bill of Human Rights. And it was just, it's like this dawning realisation to them that M'mm okay. I said, 'Go back. Have a look at those declarations. See what they say to you. Is that what you want to embed as the international norms and standards, legal standards for people with disability in the 2000s?'

Kim Rubenstein: And Rosemary do you think all that work that you've done during your honours had sort of given you the foundation to such solid um engagement with all of these issues? Now I guess the fact that you've been working in the areas obviously and your life experience, but do you think that that sort of academic foundation sort of gave you the strength and then you're, you're there as a law student?

Rosemary Kayess: Well yeah I mean there are several skills that I suppose that I've gathered along the way—(a) the language of um what's the best way of doing it, best way of saying it? The discipline around a social theory of disability. I don't believe there's a, a theory, social theory of disability but there is you know, the social model—for the want of a, a better label—um a social perspective, a human rights perspective, whichever way you want to label it, having the language behind that, um having an appreciation of how the law and legal construction works. And yeah the role of legal construction um and, and over-weaning logic as my niece ah, 'Oh gee Rosemary are you being logical again?'

Rosemary Kayess: And I do it. I have ah, things have to be logical for me. Not that I find the law always logical. I don't find the judiciary always logical ...

[Coughs]

Rosemary Kayess: But there are elements of the law that can be very logical. And so I'm about trying to find logical solutions that I'm happy with. If things aren't logical they don't, you saw me get on my you know, about the um purpose decision. There's nothing logical about that decision so it frustrates me. And ah it, the fact that they can't see it just sort of gets me ...

Kim Rubenstein: Yeah, yeah totally agitated.

Rosemary Kayess: It, yeah. It, yeah so um I have this social science background. I had the law background and I had the personal experience. And so it was the combination of those three things that sort of put me in the right place at the right time.

3C

TS 167-168 *Rosemary's unique input into setting the international legal standards for disability: advocacy for an inclusive construct of disability.*

Rosemary Kayess: ... once we got closer and closer and closer to finalising the convention all of a sudden these countries came out of the woodwork that just wanted the traditional disabilities, traditional disabilities. What are the traditional disabilities?

Rosemary Kayess: Oh you know people in wheelchairs, the deaf and the blind. Oh so yeah huge gap in terms of intellectual disability and psychosocial disability. And they were quite upfront about that, you know using terms like traditional disabilities like that is God. So um what we did—and this was a particular stroke of genius of Matt Minogue's. I was always impressed with Matt. He was very, very good. Um he proposed that we incorporate um a scoping of the people covered by the convention in the purpose of the convention. So in article one there's just um a, a sort of, an indication of who's covered. And so between that and the preamble you, you get a, a definition by default but there is no binding definition.

Kim Rubenstein: Definition, M'mm. And so that ah, in essence even though um you're reasonably happy with it, that was something that was not originally on your plan in the terms ...

Rosemary Kayess: No, no it wasn't on our plan but you know um we were happy to move with that because we were able to come up with a, a solution to the problem. And I gave my all to um that process because it, it, it's in people with disability and you know about seven thirty on the Thursday night, I turn around to Ben Wallace. I said, 'Oh I think this might work better if we stuck it 'all' in there.' So I said, 'Look.' I said to the meeting, 'Um I think at the p.168 second paragraph should have, where it's got people with disability, all people with disability just to reemphasise the fact that it's a non-exhaustive list.' And so I gave my all to the convention.

[Laughs]

Kim Rubenstein: Oh, oh very nice, very nice Rosemary.

[Laughs]

4C

TS 149-150 *Nomination as NGO representative on the Australian government delegation*

Rosemary Kayess: ... when we got back everyone said, 'We've got to get you on the Australian government delegation. And you were well placed because you were the only Australian on the drafting.' And so I was nominated to um be the NGO representative on the Australian government delegation.

TS 164

Kim Rubenstein: And your, you actually completed your law degree at the end of 2003.

Rosemary Kayess: Yeah mid 2-, yeah.

Kim Rubenstein: Or mid 2003. So you'd started this process and then you ...

Rosemary Kayess: Yep at the same time as finishing my law degree.

Kim Rubenstein: Law degree and how did you logistically do that? You were just basically ...

Rosemary Kayess: Stupid. [Laughs]

Kim Rubenstein: You just had subjects and assessment you had to hand in while you were still doing this work?

Rosemary Kayess: Yup, yep, yep. I don't think my discrimination law mark is all that sp-, special which is really quite embarrassing since I teach discrimination law.