

The story of autism research in Australia: A conversation with Cheryl Dissanayake

With the help of a generous benefactor, autism research in Australia is gathering critical mass.

25 July 2023 | by Brady Huggett

This transcript has been lightly edited for clarity.

Brady Huggett

Hi, I'm Brady Huggett, the enterprise editor at *Spectrum*. There has been a fair amount of documentation by now on how autism was first recognized as a condition, and how the research field grew from that initial diagnosis. And *Spectrum* has been part of documenting that, actually. Last year, we published a special report titled "The new history of autism," which looked at some underrecognized names from the field, but much of that documentation has focused on the United States and Europe, and less is known about other parts of the world.

So in this interview, I talk with Cheryl Dissanayake about autism research in Australia, where Cheryl is from. She is the Olga Tennison Endowed Chair in the Olga Tennison Autism Research Centre at La Trobe University in Melbourne, and she's a leading light in autism research not only in Australia but internationally. So that's the focus of this interview. Cheryl and I spent time talking about Australian autism research, Cheryl's path to the field, and what it means for Australia to host the INSAR annual conference in 2024.

And we also talked about just who Olga Tennison actually is. So I conducted this interview on June 20th, 2023, late in the evening for me on the East Coast of the United States, and mid-morning on June 21st for Cheryl in Melbourne. But before I start the recording, I should say that if you're listening to this on a podcast app, on spectrumnews.org, we have provided identifying links for the many historical names that Cheryl mentions in our conversation. OK, let's start here, where I'm asking Cheryl to take me through the history of autism research in Australia.

[transition music]

So there are — There are some good books, like Steve Silberman's very excellent "NeuroTribes," that sort of describe the history of autism, both the research and how it became known as a condition. But I really don't know how the condition came to be known in Australia, or the research, how the research grew up around it. And I'm interested in that history. And I'm wondering if you could maybe take me through that.

Cheryl Dissanayake

Yes, yes. Really, the person who would be the No. 1 researcher in Australia and who published the first paper, she's now passed, is Professor Margot Prior. Margot was awarded the Lifetime Achievement Award at INSAR in 2018. And she was a student at Monash University in the late '60s. And she decided to focus her first master's project, and then she went on to complete her Ph.D. at Monash University. And she focused on what was called sameness behaviors back then. And so that first publication would have come out in 1978, I think. And she ascribes the beginning of research to a GP. And he had a child who I believe was autistic, and sought some consultation with her, which is then what attracted her into studying

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this very unknown condition, and she then undertook her research in autism. So that's the first paper that was published in Australia.

Brady Huggett

But it was called sameness, is what you're telling me.

Cheryl Dissanayake

Just the behaviors that she decided to focus on was what we used to think about as the third symptom set. In the original DSM-III, we had the three classes of behaviors, which were derived from Michael Rutter's early work, um, his paper that was published in 1978. And so the behaviors which encompass repetitive behaviors was also known as the sameness behaviors. And we now have two classes of behavior that we use in DSM-5, which is sort of social communication and then repetitive behavior. So it would have been classed in what we would now say that the second, the second behavioral set of in DSM-5.

Brady Huggett

Yeah. But back then, those two were not linked in the minds of researchers. So she was sort of focused on this, what they termed sameness, these repetitive behaviors that we now know are one of the hallmarks of autism.

Cheryl Dissanayake

That's right. That's right. So that would have been the first paper published in Australia.

Brady Huggett

What was the paper itself? What was her paper? Just laying out these —

Cheryl Dissanayake

These behaviors and trying to understand them.

Brady Huggett

Yeah. OK.

Cheryl Dissanayake

So, you know, she was quite ahead of her time in really trying to understand this set of behaviors and, and how they manifest in children who were called back then, children who had early infantile autism, which was the name that Kanner first ascribed, um, to this set of behaviors that presented in his first 11 cases.

Brady Huggett

Yeah. After Margot, what happened to the field?

Cheryl Dissanayake

So I was an undergraduate at Monash University when Margot was doing her Ph.D. there. And she came

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into the field as what we call a mature-age student. She was a classical musician who had, um, whose husband drowned, while she and her three young children were sitting on a beach. She and her husband were classical musicians, um, part of the Brisbane Symphony Orchestra. And so her husband went out. They were having a picnic, and he went out to help some folk who had gotten into trouble. He saved these two people, but he drowned.

Brady Huggett

Oh, my God.

Cheryl Dissanayake

And so she then, originally being from Melbourne, brought her children back to Melbourne, and realized that her musical career could no longer be. Um, and so she decided to retrain and so went back to try and study, take up her studies in psychology, which, you know, was her first degree. She was accepted into Monash University as a postgraduate student. And so I then was an undergraduate student, but by the time I came to be a postgraduate student at Monash University and I chose the area of autism; this would have been in 1984.

And I then decided to study autism because it was introduced to me as in a lecture in my third year, which was in 1982. And so in 1983, I undertook my honors year, and then decided to focus on autism in 1984. By then, I mean, I was very new, obviously, into the field. And the other person who was working clinically here was someone, um, called Professor Bruce Tonge, and he was a child psychiatrist.

So really, in my mind, there was Margot Prior, who was, um, you know, a clinical researcher. There was Bruce Tonge, who was a child psychiatrist. But some early work had also been done by someone also at my university, at Monash University, by the name of Dr. Lawrie Bartak. And Lawrie undertook his Ph.D. with Michael Rutter in the 1960s, in the late '60s.

So Lawrie's work was really groundbreaking in charting this group of, really, children. We very much thought of this as, you know, a childhood condition. And Lawrie's work with Michael Rutter was so critical in showing that this wasn't a set of behaviors that people were talking about back in the '60s as an outcome of cold parenting, but rather, this was a cognitive difference. And so Lawrie and Michael basically charted these behaviors as, you know, really difficulties in communication and language. So they were undertaking that very early work.

Brady Huggett

I mean, maybe it was just because once the ball got rolling, people realized it and came in. But why was there such a center on Monash University? How were they drawing all this talent in autism research?

Cheryl Dissanayake

Well, Monash University established the first experimental psychology department in the country.

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Brady Huggett

I see.

Cheryl Dissanayake

And the person who was one of my mentors — I've had many mentors, certainly Margot was a key mentor. Lawrie was a mentor, and the man who set up this first experimental psychology department at Monash University was someone by the name of Professor Ross Day. And so he was the head of school.

Brady Huggett

Can I — So I want to back you up a second. Why were you interested in studying autism? What drew you to the field?

Cheryl Dissanayake

Well, two things. I saw as a teenager and an undergrad, I watched a film during my- my holidays, you know, university holidays, I think, and it was called "Son-Rise." And it was an American family, it was based on an American family, who had started working with their young autistic child, and had [developed a program around him](#), and they called this Son-Rise.

And watching that, um, film, it was on TV, sort of sparked my interest in this most unusual child, and this family, in the Kaufmans, this child who was spinning these plates and flapping. And he spent a lot of time doing this. There's a lot of information about that program. And it still, I understand, runs in the U.S. And that child was flapping and watching those plates spin, I understand, now runs a program and heads up that program in the U.S. But that triggered an interest in me. I'd always been interested in child development.

So seeing that most unusual child really sparked my interest. And in my third year of undergraduate psychology, another of my mentors, the woman who came to be my mentor, who was a lecturer, talked about early childhood autism. And I remembered that child. And so that really sparked my interest. And so that would have been in 1982. I knew that was what my focus was going to be.

And so when I came to undertake my Ph.D., I approached Professor Crossley about being my supervisor. And I approached her because there was no one working in autism at my university back then. And she had given me this lecture, but she was a behavioral geneticist. So she studied *Drosophila melanogaster*, the common fruit fly.

Brady Huggett

Yeah, yeah.

Cheryl Dissanayake

And so I very much had to become an expert myself. And so I sought out Lawrie Bartak, who was in the School of Education, because I knew he'd undertaken this work in autism for his Ph.D. And then I also

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sought out Professor Margot Prior, who now was at La Trobe University, and I was very interested in her work. So these two universities really became where the autism research was being undertaken.

Brady Huggett

In all of Australia?

Cheryl Dissanayake

Back then, in all of Australia, yes.

Brady Huggett

So you had this great wealth of mentors around you that you could sort of draw on to set you on your path. But I'm curious, what coming to UCLA was about? That was your-your postdoc, right? What made you do that?

Cheryl Dissanayake

That was my postdoc. Well, UCLA was about my, I guess, the choice of topic in my Ph.D. In working with Stella, Professor Crossley, she had an interest in attachment, how children developed attachments. And I undertook an attachment study for my honors thesis in typical child development, knowing that I wanted to focus on this in my studies in autism for my Ph.D. Because when I read the very early descriptions of Leo Kanner in that 1943 paper, he described a set of behaviors. He never talked about attachment, but that would indicate that autistic children are not attached to their parents.

And then clinical descriptions, in the absence of research, propagated this myth that autistic children didn't develop attachments in the usual way to their caregivers, but rather developed these attachments to things. And that really sparked my interest. And so when I came into the field in 1984, I didn't see any good studies on attachment. And I thought that would be very much of interest to undertake a detailed behavioral description of these children's relationships with those within the family home.

So while I was undertaking my Ph.D., there was a paper that was published. And that was by Marian Sigman and her group about attachment. So that just sparked my interest in her, and knowing that when I finished my Ph.D., that's really where I wanted to go. And her work was really some of the first work in autism that was taking a truly developmental approach.

Remembering, I was in a Department of Experimental Psychology, so I didn't see myself as a developmental psychologist, although I was interested in the development of attachment behaviors. That's really where when I finished my Ph.D., and like Marian's work, showed that autistic children do indeed develop attachments to their caregivers, and in fact, these attachments function in the same way as in children without autism. I was really driven to approach Marian, and I visited the U.S. in 1988, and I visited her lab at that time, and met her. I was still in the throes of completing my Ph.D. And so once I

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had submitted my Ph.D., I wrote to her and asked her if I could come and work with her. And in 1992, I got an invitation to do so.

Brady Huggett

So you came and returned to Australia. I think you went to La Trobe then, though, right? You took up a position there.

Cheryl Dissanayake

In '96, yes. So I worked with Marian in '93, '94, '95. I left UCLA in late '95 and returned to Australia to really interview for two positions. This was the key position that I wanted to get. And the reason I wanted to come to La Trobe University was that the two leaders who had just left had, and vacated some positions, were ideal for me in terms of their focus. One was Professor Beryl McKenzie, who was a developmental psychologist. And the other was Professor Margot Prior, who was a clinical psychologist working in autism.

And I knew that the infrastructure was already available at La Trobe University for me to hit the ground running. I knew the physical research space that was available for me that wasn't available at the other universities. So it was just a- a perfect environment for me to come into. And as luck would have it, another of my mentors was already here as an emeritus professor, and that was Professor Ross Day. So I interviewed for the position in November, and I began as a lecturer in psychology on the 8th of January, 1996. And I've been here since.

Brady Huggett

Yeah, I mean, there was probably some desire, I assume, just to return to your home country as well.

Cheryl Dissanayake

Oh, certainly. I traveled to America with my husband, and we were married then, but very much had made the decision to start a family. And that was really the decision that sort of drove us home. And, um, so, yeah, we came back, and-and that's indeed what we did.

Brady Huggett

Started your family, right? Can you tell me about OTARC, and how that came to be and how it was funded? I mean, I know obviously Olga Tennison was part of that, but can you just sort of take me through that center?

Cheryl Dissanayake

That's just a wonderful story for me. So I came back. I set up an autism lab here. I, you know, really ran my lab on the strength of very good research students. I say I ran my lab on the smell of an oily rag because the sorts of funds available for autism research was really nil, I would say, in comparison to the funds available in places like the U.S., you know.

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So in terms of being at Marian's lab, I mean, I felt I was in the center of the autism world there. You know, every key autism researcher came through her lab, and coming back to Australia was not like coming back to another country. It was like coming back to another planet. You know, we're very far away from the rest of the world, and certainly in terms of autism research, it was a-a huge change for me. I had been very longly in my Ph.D. studies. I went in my postdoctoral studies, and, you know, I was in the midst of everything there, and I came back again to Australia where there was more autism research by the time I came here, but it was still very distributed, you know, in different universities.

So when I came back, I approached the peak autism body in the state here, which was then called Autism Victoria, and the woman who was the executive officer of Autism Victoria had been the mother of one of the children in my Ph.D., and I asked her whether I could use the umbrella of Autism Victoria as a peak organization to set up an autism research group. She not only allowed me to do that but offered us secretarial support. So I started off a small group, which we call the Autism Research Reference Group. This was comprised of myself and other autism researchers at the other universities in our state of Victoria.

So we set up this group, we met, and then we established a yearly conference, so that our students could have a forum to present their work, and we could have a forum to present our work. And so it was the, you know, the first autism peak body in Australia to really start up a local conference.

Brady Huggett

So can I — can I ask, you know, you said the other researchers, what, what kind of numbers are we talking about here is, I mean, 50 or 10?

Cheryl Dissanayake

Um, they're pretty, they were pretty small. They were like a group. There must've been about five or six of us.

Brady Huggett

Uh-huh, yeah.

Cheryl Dissanayake

And but then, you know, we had our students and that's how autism research initially in our state started to grow. And Victoria really was punching above its weight. So Australia has six states and two territories. And there was really very little research going on that there was some research going on in Western Australia. Um, Professor Murray Maybery was undertaking some research. There was some research in Queensland, um, and occupational therapist Professor Sylvia Rodger was undertaking some research there. It was really fledgling, I would say, um, but La Trobe had research and, um, Monash University had research with Bruce Tonge and his team there.

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So it was starting to gather momentum, and then having this research conference, what we did, I convened this group, and what we did was invite, each year we invited a researcher from one of the other states to give a keynote.

Brady Huggett

But this—this idea that, as you said, Victoria was punching above its weight, that’s probably because it was relying, not relying, but it had been built off this earlier research, as you’re saying, Margot, uh, is that right?

Cheryl Dissanayake

I think so. Yes, yes. Yes. I certainly would think so. And then you asked me about the Olga Tennison Autism Research Centre, and I told you about the Autism Research Reference Group, which sounded like I wasn’t answering your question, but indeed I was, because it was in the context of this research reference group that we ran under the umbrella of Autism Victoria, that I first met Olga, because Olga had in 2007, had driven a straight line from her house to, um, she lived on the same street that the Autism Victoria was, was situated on just, you know, a few miles down the road and spoken to, um, Amanda Golding, who was the mother of, um, and the executive officer of Autism Victoria and the mother of the child, who participated in my Ph.D.. And Olga said to Amanda that she would like to fund autism research and wanted to know how to do that.

So that’s how I first met Olga, and we gave her various options of how she could fund autism research.

Brady Huggett

Well, let’s—let’s take one step back. So who—who was Olga, and why did she have the means to fund autism research like that?

Cheryl Dissanayake

Well, Olga was an octogenarian who had a grandchild who had had a diagnosis back then of Asperger’s syndrome. She felt — she was a community individual. She wasn’t an academic, but she felt that not enough was being done. Those were her words in terms of helping autistic people and their families in their day-to-day life. And she felt that research was the answer to this.

Brady Huggett

I mean, I’m assuming if she was, if she had money to spend on funding that she, she must have been of some means somehow. And this was her way of being benevolent. Is that correct?

Cheryl Dissanayake

Yes. But when I first met her, I had no idea, you know, about this person. I had no idea about her means. I had no idea about, you know, what she was interested in or, so we met her really as an introduction, and to tell her about autism research more generally, about autism research in Australia and how, you know, if

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she wanted to assist with autism research, the different various mechanisms and, you know, so when I met her in 2007, the only available funds for autism research was a small pool of funds called the Apex Trust for Autism. And in fact, as a Ph.D. student, I had received some funds from the Apex Trust for Autism. So I told her how very small that pool of money was. It was around 7,000 to \$10,000 a year. And that was the only dedicated funds for autism research in Australia in 2007.

And what I said to her then was what Australia did not have, and I was very aware of this, having spent my postdoc years in the U.S., was a research center dedicated to autism research. And if she wanted to really build autism research, it was to establish a center, and she was very keen on that idea. And it was at that point that I said, well, to build a research center, you know, I need to know how much money would be available.

And she then wrote us a check for \$500,000. And so my job then was to take that possibility to La Trobe University to see if the university would match those funds to build a research center. And La Trobe matched those funds. And a year later, we opened Australia's first research center at La Trobe University, the Olga Tennison Autism Research Centre. And unbeknownst to me, Olga came to the opening and gave me another check for another half a million dollars, which La Trobe matched on the spot at the opening. It's amazing. It's a lovely story.

Brady Huggett

Yeah. This is why the-the center is named after her. You're the Olga Tennison Endowed Chair, right? I mean, this is why her name is all over the university because of this sort of generosity.

Cheryl Dissanayake

I am, and I'd like to tell you, too, that she did not want the center named after her. And Amanda Golding, the executive officer of Autism Victoria, and I had to convince her that that would be important to advertise to other philanthropists what a difference they can make. And it was with that that she agreed to have the center named after her. She was a very modest, incredibly modest woman. And in her lifetime, she gave us each year a half a million dollars over a lifetime. She gave us six million. And then upon her death, she left us a bequest of \$45 million.

Brady Huggett

Oh, my God. Wow. I think she-she died in 2017. Is that right?

Cheryl Dissanayake

No, no. She passed in beginning of January 2021.

Brady Huggett

Uh-huh. OK.

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Cheryl Dissanayake

Yes. She left us this bequest, which we have now invested here in perpetuity, so that there will always be funds for autism research in Australia. And the funds are invested and the center partially operates off the earnings from those funds.

Brady Huggett

I mean, that is a — that is a huge change from when you first returned from UCLA. That has to have made all the difference in research in Australia. I mean, the funds are so key.

Cheryl Dissanayake

It's made all the difference in research in Australia. Something else that made the difference, and was that one of the first things we did when we established OTARC, that's the acronym, is that we — and this was an idea, we invited — when we established OTARC, we invited Margot Prior to be our inaugural advisory committee chair. And based on Margot's advice, we brought together all of the key Australasian autism researchers.

Remember, the Autism Research Reference Group was a small group where we worked pretty much in Victoria, really. And in 2009, there was another development in Australia where the Asia-Pacific Autism Conference was launched at a big meeting in Sydney. But we didn't have a solely research conference. So in 2009, in April, we brought together key Australasian autism researchers. There was about — I think we identified about 26 of us. And this was not just people dabbling in a little bit of autism research. We invited people where this was their focus in autism research. So it was about 26 people. And I think about 24 of them came on to our campus at La Trobe University, and we hosted a two-day meeting.

And out of that meeting, formed the Australasian Autism Research Collaboration, which ran from 2009 to 2011. And in those two years, we developed the Australasian Society for Autism Research. That now is our research society. We host a national conference, a biennial national conference. And in the alternate year, we host a state conference.

Brady Huggett

Well, that sort of leads me to my next question, is that in 2024, the INSAR, the International Society for Autism Research annual conference is going to be held in Australia. And you're-you're the conference chair for that. And I just wanted to ask about what you hope to highlight about Australia's research during that conference.

Cheryl Dissanayake

It's a wonderful platform, of course, for Australian research, but not just Australian research. What I'd really like to highlight is the work being undertaken in the Asia-Pacific region. So it's the first time INSAR will have been in the Asia-Pacific region. There was a regional meeting of INSAR in Shanghai, but INSAR has not been anywhere near Australia. And so it just is such a marvelous opportunity to have

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the conference in an area where the Asia-Pacific researchers will attend en masse. This region isn't, you know, Australia is the richest country in this region. And this region has a number of low- and middle-income countries. And so my hope for this meeting is that we'll have a large proportion of delegates who are from low- and middle-income countries, who can attend INSAR and whose research can be profiled here.

Because in terms of being a global society, INSAR really needs to be relevant to low- and middle-income countries. And the wonderful research that INSAR researchers undertake, needs to filter down into these countries so that best practice does not just sit in Western industrialized nations like ours. So Australia is a rich Western industrialized nation, but we sit in the Asia-Pacific. And so it's a great place to host INSAR and to really bring these Asia-Pacific autism researchers together.

Brady Huggett

Some of which may be attending INSAR for the first time?

Cheryl Dissanayake

Oh, absolutely. I would hope we would have a large percentage of attendees where this will be the first time they attend INSAR, and they will become INSAR members and reap the benefits of the INSAR membership. INSAR is such a wonderful research organization. It really is the, you know, the first meeting where the different World Health Organization regions will end up hosting INSAR. So a decision's now being made on the INSAR board to not, previously we used to have INSAR in North America, and every four years, it would go to Europe.

Now the decision is to have INSAR in North America, in Europe, and then in a Western — in one of the World Health Organization regions. And so, it's in the Western Pacific region this time. It will return next year to North America. And so it will be hosted once every three years in one of the World Health Organization regions. And hopefully in, you know, in regions where we, the research that we undertake can really filter down and impact, directly impact lives.

Brady Huggett

So I have one more thing I want to ask you. You mentioned earlier that, well, I think a little bit before you went to UCLA for your postdoc, but definitely afterward, that you felt a little lonely, almost, because all this research had been happening at UCLA, and there just was not that much in Australia when you returned. It probably does not feel like that anymore, right? I assume that it has grown a lot, and you're not lonely anymore.

Cheryl Dissanayake

It doesn't feel like at all because also in 2013, a group of researchers, well, actually not in 2013, I think we started working together in 2011. Australian autism researchers started working together, a group of us, working together to develop a bid for a cooperative research center. And in our first bid was a failed

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bid, but we were encouraged to reapply. And the Australian Cooperative Research Center for Living with Autism was launched in 2013, which was the first national autism research effort in this country and was funded by the federal government for eight years, from 2013 to 2021, and was extended because of COVID, um to 2022.

And so that also served to really sort of built a fire under autism research. And it just took off. And there's autism researchers right across Australia now, and many autism research groups and research centers. We were the first, but now, you know, there's so much really great autism research, and this is what we want to profile at INSAR in 2024.

Brady Huggett

Listen, thank you. I just wanna say thanks for taking the time to talk to me. It's been great.

Cheryl Dissanayake

Thank you. And I hope the quality of this is OK.

Brady Huggett

Well, we shall see. I'm sure it's good. Hold on one second. Let me pause this.

[ending music]