Disability Matters

Online Symposium

Sydney - 22 August 2024

Hosted by the Disability Innovation Institute UNSW

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UNSW Disability Innovation Institute

Disability Matters

Acknowledgement of Country

We would like to acknowledge that we are hosting this symposium from the lands of the Bedegal People (Kensington campus).

We also acknowledge the Traditional Custodians of the various lands on which we all meet today and pay respects to Elders past and present and celebrate the diversity of Aboriginal peoples and their ongoing cultures and connections to the lands and waters of NSW.

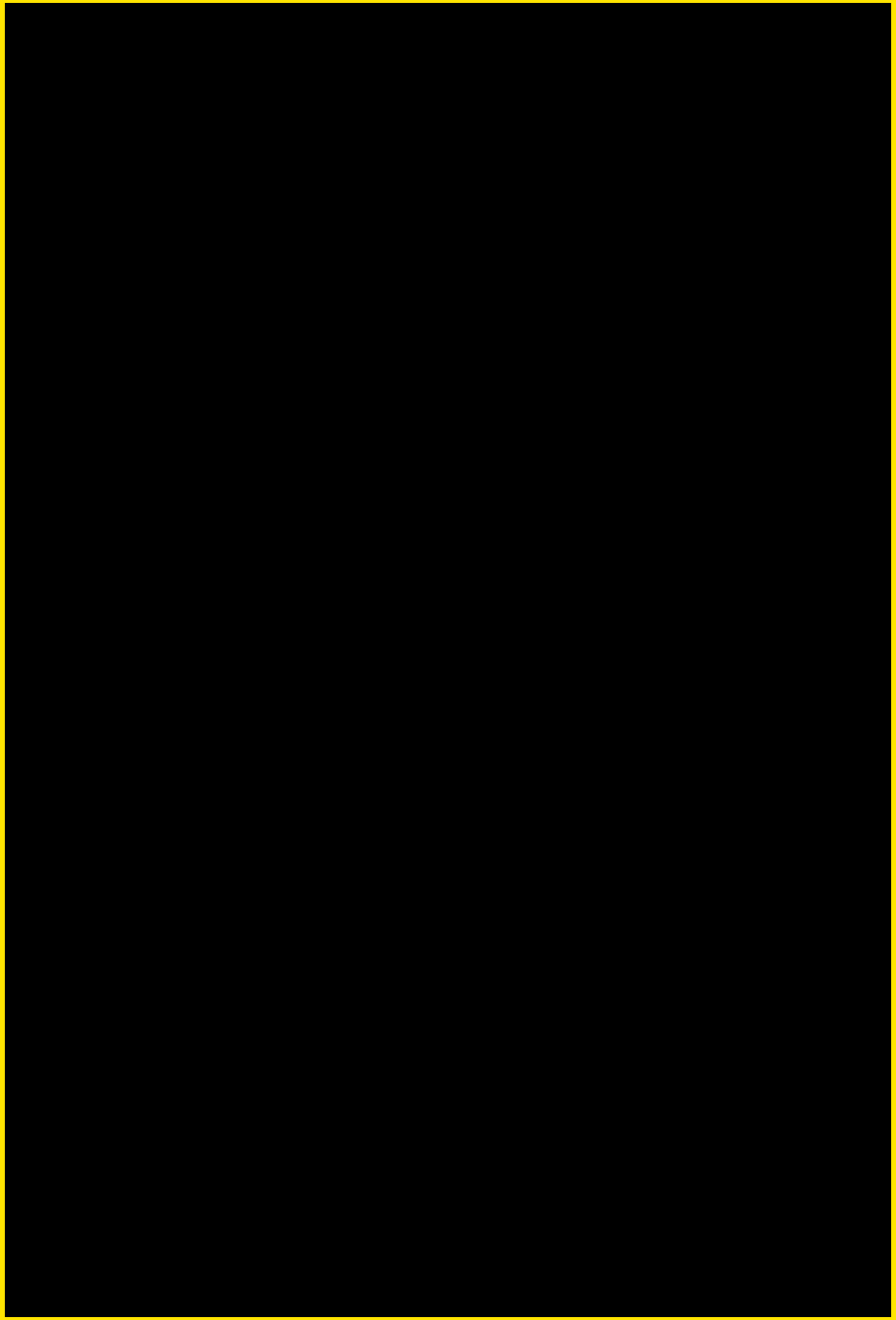
Format

- A video message from Project Lead, Dan Goodley
- Introduction by DIIU Director, Professor Jackie Leach Scully
- Our speakers:
    1. Dr Ellen Fraser Barbour
    2. Dr Michelle Tso
    3. Professor Sally Robinson
- 5 minute comfort break
- Questions from the audience
- Close and thank you

Housekeeping

- Having cameras on is completely optional
- If you wish to access English live captioning, you can turn this on by clicking the Live Transcription option in the meeting toolbar below
- The symposium will be recorded and made available on the Disability Matters website
- All papers, materials and a copy of this PowerPoint will be made available on the website
- Please direct questions to the Q&A box in the toolbar below, these will then be read out loud later on
- If you feel you need to leave the session at any point for any reason you are free to do so

A message from Dan Goodley



About the DIIU

The UNSW Disability Innovation Institute is a world first initiative, focusing on disability research, education and knowledge exchange. Its team members take pride in undertaking work that's radically inclusive, and that crosses disciplinary boundaries. The Institute's approach is to see disability not as a problem to be solved, but an integral part of the human condition to be encountered and engaged with rather than feared.

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Dr Ellen Fraser-Barbour

Lived experience leadership in inclusive research methods

Dr. Ellen Fraser-Barbour (She/her)

Independent researcher

Flinders University

Acknowledgement Of Lands We Are On:

I pay my respects to the **Gadigal people of the Eora Nation** on whose lands we meet on today.

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Lived experience knowledge honoured in inclusive research methodology

- Note that 'lived experience led research' is a spectrum of methodologies which typically includes co-researchers, co-design or co-production:

  - Genuinely led by people with lived experience
  - Their knowledge and leadership is integrated and paid for throughout, not only as subjects to be mined for data – but also honoured in the design of research, but also in analysis and outcomes.

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Academia as a historical site of oppression and harm

- Academia has deeply entrenched roots in colonialism as well as violence and oppression against anyone identified as 'Other' or as a 'minority' identity.

- Historically men produced research about women. Similarly now, disability research is mostly produced by those who do not have lived experience.

- Research has done a lot of harm against marginalized communities and this must be acknowledged as part of the context that we continue to navigate.

Academia as a site for social justice and progress:

- Academia has been a place where marginalised scholars think and communicate deeply about the issues of social justice.

- I have benefitted enormously from connecting with and reading through the lens of various scholars with lived experience. I know personally, it has helped me to stay the course in my own academic journey.

(art by Ruby Allegra)

Tensions in inclusive research spaces for those with lived experience

Risk of exploitation

Whose viewpoint are we hearing in disability research?

Emotion work undervalued in lived experience leadership

Burn out: emotional work for lived experience researchers

- Disabled lived experience researchers
  combat microaggression in the form of the daily grind of:
  - Inaccessible environments
  - Ignorance and stereotype
  - Attempting to keep up with ableist norms

- The personal is political for lived experience researchers.

"No amount of smiling at a flight of stairs has ever made it turn into a ramp"

– Stella Young (former Australian disability activist, journalist and writer).

The idea of solidarity in inclusive research spaces

- Question and acknowledge privilege
- Question who gets to analyze and interpret our contributions to knowledge
- Recognise the risk of burn out and query what help us to sustain and remain resilient:
  - Embeddedness in community
  - The need to rest survival for marginalized academics
- Be intentional about sourcing original creative works by disabled people and honor these ideas.

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References

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- Hersey, T. (2022). *Rest is Resistance: A Manifesto*. Hachette UK.
- Hochschild, A. R. (2012). *The managed heart : Commercialization of human feeling*. University of California Press.
- Kafai, S. (2021). *Crip kinship: The disability justice and art activism of Sins Invalid*. arsenal pulp press.
- Piepzna-Samarasinha, L L (2021) "Still Dreaming Wild Disability Justice Dreams at the End of the World," *Disability Visibility: First-Person Stories from the 21st Century (Ed. Wong, A)*
- Price, M. (2011). *Mad at school: Rhetorics of mental disability and academic life*. University of Michigan Press.

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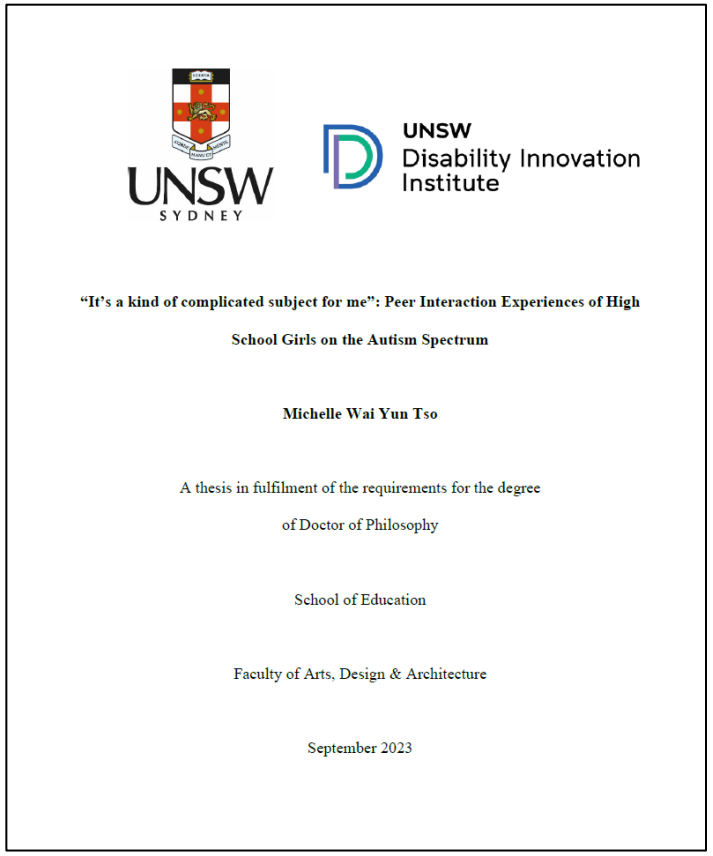
Questions?

Dr Michelle Tso



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"It's a kind of complicated subject for me": Peer Interaction Experiences of High School Girls on the Autism Spectrum

Michelle Wai Yun Tso

A thesis in fulfilment of the requirements for the degree of Doctor of Philosophy

School of Education

Faculty of Arts, Design & Architecture

September 2023

Front page of PhD thesis about peer interaction experiences of high school girls on the autism spectrum

A group of people with intellectual disability listening to academic researchers and co-researchers with intellectual disability presenting at a co-production workshop for GeneEQUAL project

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People with disability involvement

Community

control

Community-led

Co-producing

Engaging

Consulting

Informing

Educating

Coercing

Academic researcher involvement

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Figure about different levels of involvement from people with disability in inclusive research adapted from den Houting (2021)

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Original question: Have you ever felt lonely or excluded from a group?

Revised question: Have you had negative experiences at school?

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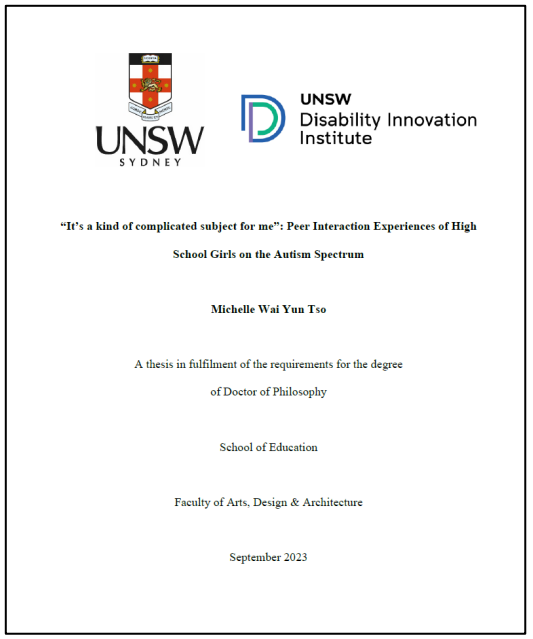

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What high school girls on the autism spectrum said

These were the 4 main findings from what the girls told us

The first finding was about what the girls thought about friendship

The girls had friends in and outside of school such as

- family friends, online friends, and friends in the community

4 girls thought that friends were people

- that they could talk to comfortably

The girls also thought friends were people

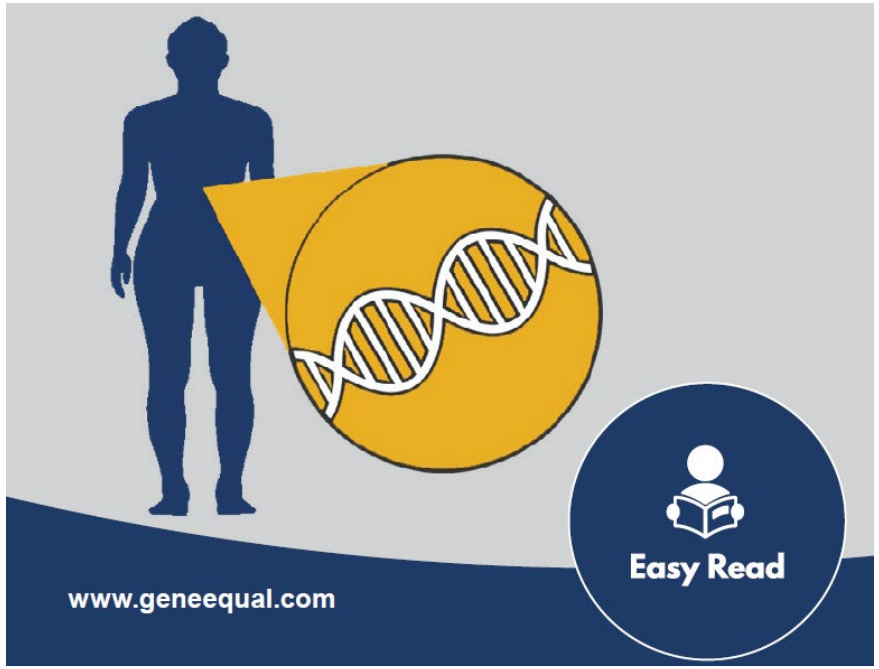
- that they supported

Savi shared a story about her friend

"Jane had never stayed over somewhere, and so she wanted to go home, but …I just stayed with her the whole time, and the teacher came up to me asking if I wanted to go to bed, and I said I wanted to stay with Jane …"

Plain English findings of what high school girls on the autism spectrum said about their friendships

A group of people with intellectual disability listening to academic researchers and co-researchers with intellectual disability presenting at a co-production workshop for GeneEQUAL project



Easy Read booklet with tips about genetic health care

A group of people with intellectual disability listening to academic researchers and co-researchers with intellectual disability presenting at a co-production workshop for GeneEQUAL project

Support to make a complaint

There are lots of ways to get support to make a complaint about the genetic clinic.

You can ask someone you trust to help you make a complaint.

This might be

- Someone from your family
- A friend
- Your support worker.

cid Council for Intellectual Disability

Council for Intellectual Disability has information about how to make complaints.

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Page inside Easy Read booklet with tips about ways to get support to make a complaint about health care

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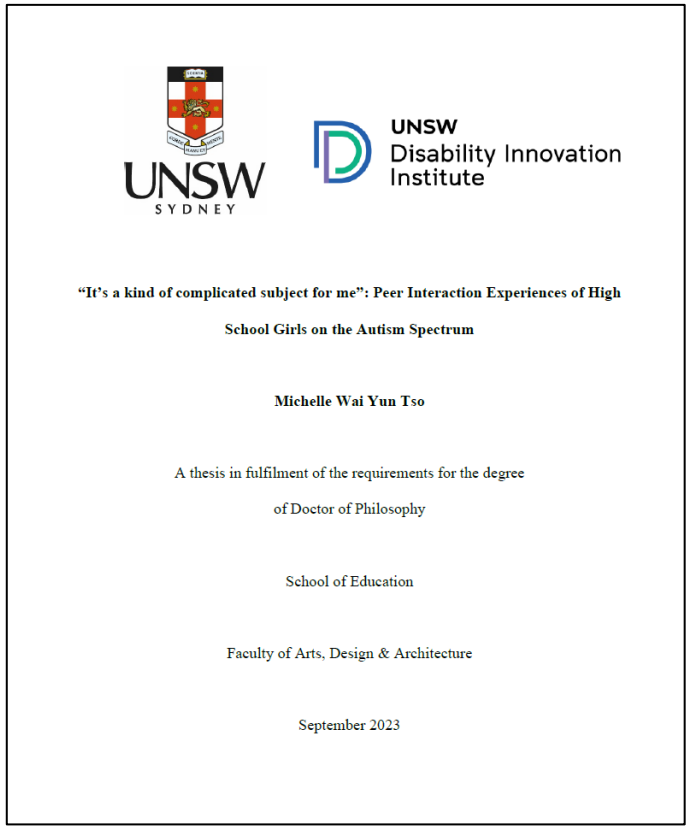

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Advisor's drawing of themselves in high school wearing a uniform with representations of self-harm

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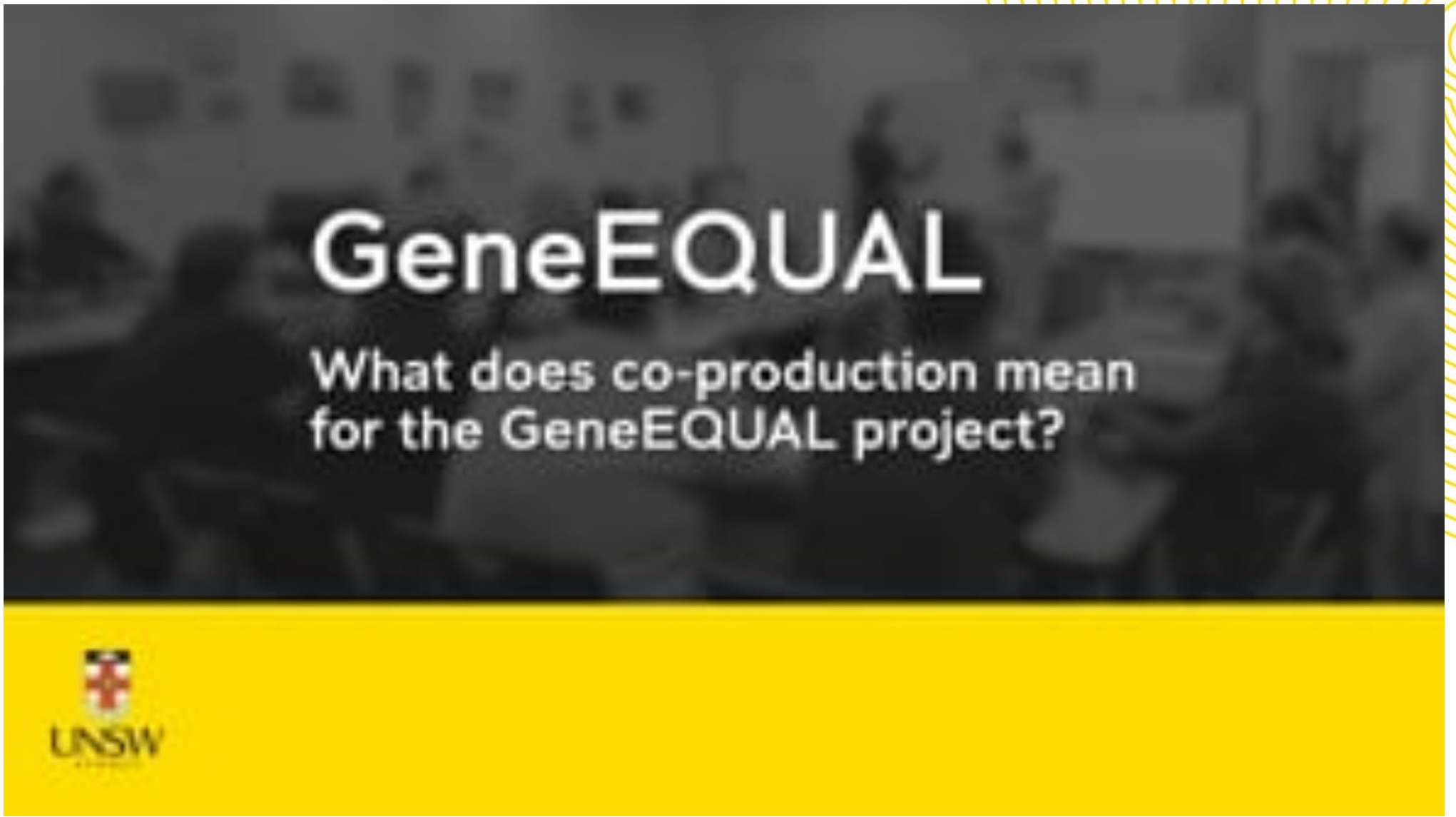
GeneEQUAL
What does co-production mean for the GeneEQUAL project?
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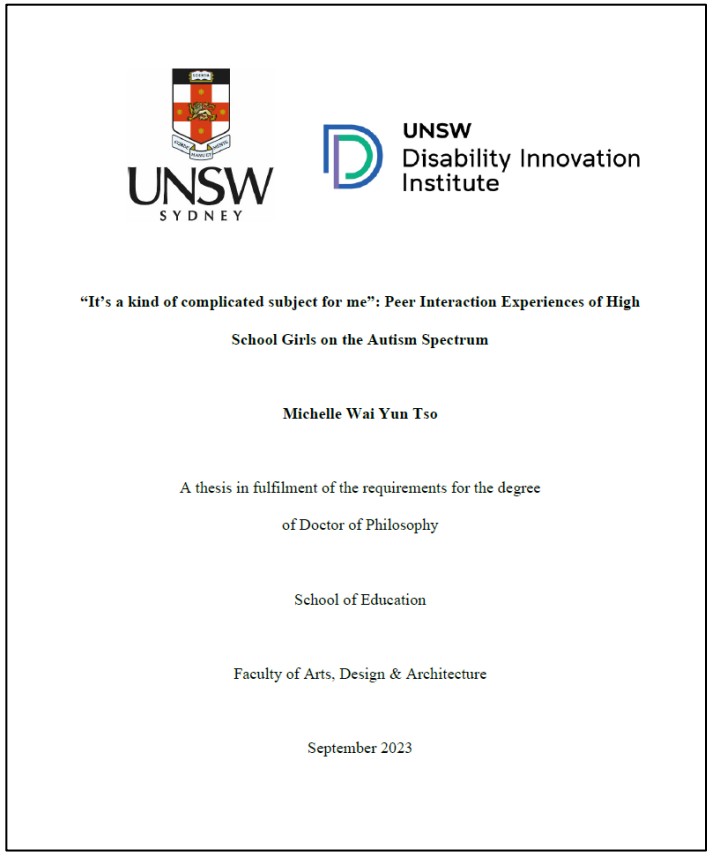

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Questions?

Professor Sally Robinson

with Professor Karen Fisher

Everyday steps to prevent everyday harm

Preliminary findings from fieldwork with young people with intellectual disability and their support workers

ARC Linkage Grant
LP210200536
All images CID conversation cards

RDCI Research in Disability & Community Inclusion
Flinders University
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SPRC Social Policy Research Centre

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Understanding everyday harm

- Consequence of interaction received as hurtful or harmful
- may cause people to feel insulted, degraded, excluded, rejected, threatened, silenced
- intentional or unintentional
- can have cumulative negative effect
- shaped and influenced by organisational policies, practices, rules, culture and wider social attitudes and norms

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Why use the term everyday harm?

- Accessible language for daily use
- Reframes microaggression, emotional and psychological abuse to people who find the broader theories inaccessible
- Informed by recognition theory, focus on interpersonal harm and effect on quality of relationships, in organisational contexts
- Opens opportunities for exploring repair and prevention of further harm in the relationship

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Preventing everyday harm

Young people and support workers:

- Look at each other's **body language, listen** carefully and notice if they or another person is upset or has become silent
- **Ask each other** if they feel upset about something
- **Work together to understand** what has happened, what to do to make things better and how to prevent harm from happening again

Managers and organisations:

- Explain **clear rules** about good practice to prevent harm
- Create an **open culture** that sets a good tone in the way people work together
- Allow time and opportunities for young people and support workers to **practise everyday steps**
- Support young people and support workers to **resolve harm they notice**

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Addressing everyday harm

Notice harm to self and others

- Check in and observe: listen and pay attention to body language, ask how people feel, take time to build trust and communicate openly with each other

Acknowledge that harm has occurred to yourself or someone else

Address harm

- Talk openly about what happened
- Encourage people in and out of the support relationship to work together to find ways to make things better
- Check during the process that the way of making things better is okay with people involved
- Check how organisational rules and culture might have caused harm. Can these be changed?

Making the future better

- Addressing harm through the above steps also contributes to better practice for the future
- People learn to check in with each other, care, respect and appreciate each other

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Organisational practice to prevent and address harm

Organisational practice is guided by:

- **rules** of the organisation – policies, laws and guidelines
- **culture** of the organisation – informal expectations about how things are done and how people work together

Good rules encourage and facilitate everyday steps

- When people understand the reasons for rules and see them as consistent with good culture, they are more likely to follow them
- Organisations check how rules impact people. They change rules that cause harm.

Good culture encourages and facilitates everyday steps

- Everyone helps create good culture in different ways
- Good culture means being open to improving and doing things differently
- Good culture encourages people to use everyday steps and speak up respectfully about poor practice

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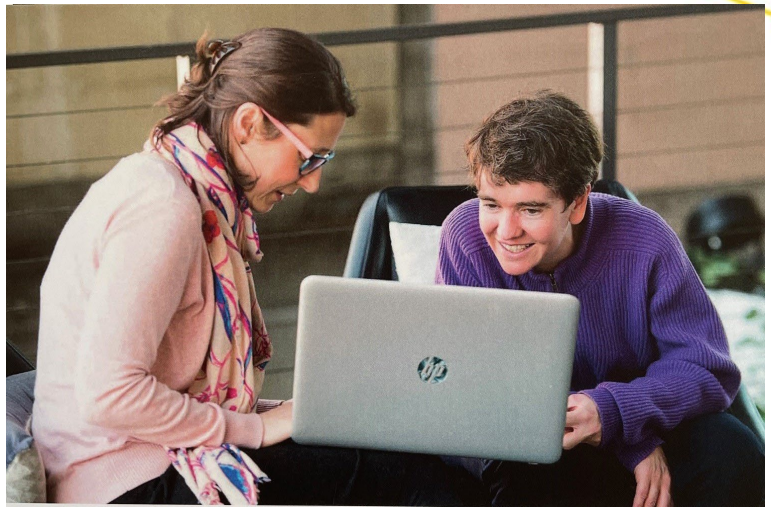
Next steps

Interviews with managers and board members

- How is everyday harm acknowledged in policy, gaps in practice
- What resources do they need to prevent and address everyday harm

Resources for everyday steps

- Academic and public summaries about everyday harm – understanding, preventing, addressing and organisational practice
- Guides and resources for everyday steps



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Our team

ARC Linkage Project LP210200536

Organisation	People
Flinders University	Sally Robinson, Jan Idle, Rachel High, Ruby Nankivell, Raffaella Cresciani, Eleanor Watson, Su Su Tun
UNSW Sydney	Karen Fisher, Heikki Ikaheimo, Ciara Smyth, Anna Jones
Northcott Community Researchers	Hannah Ogden, Tyra Buteux, Emma Wood
Partner Organisations	NDIS Quality and Safeguards Commission, SA Department of Human Services, Northcott, Mable, Bedford, Novita, GenU, VACRO, Purple Orange, DANA.

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Information about the project

https://www.researchdci.flinders.edu.au/projects/everyday-steps-to-prevent-everyday-harms-of-people-with-disability

https://www.unsw.edu.au/research/sprc/our-projects/everyday-steps-to-prevent-everyday-harm-of-people-with-disability

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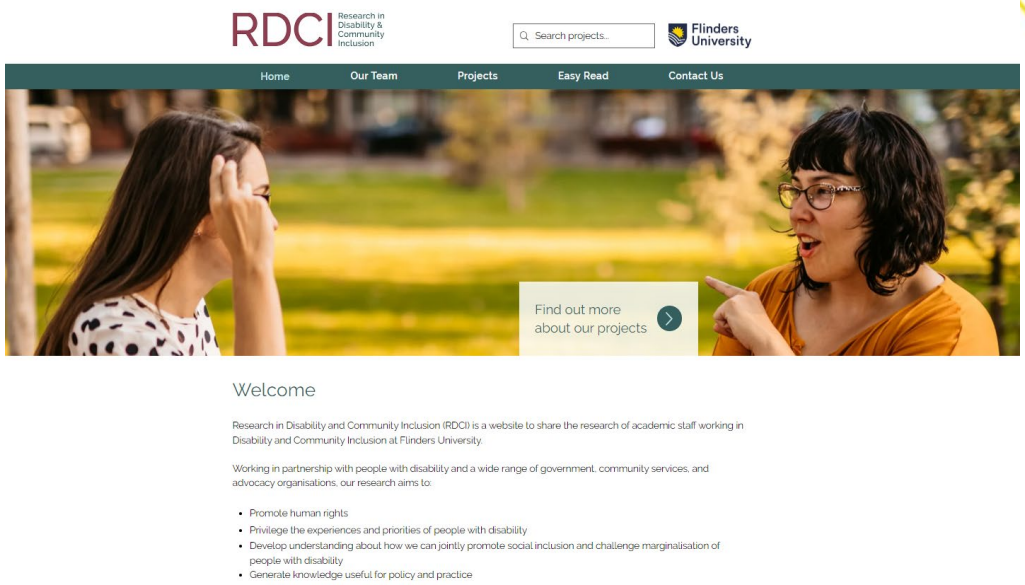

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Questions?

Thank you

Stay in touch

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