



THE UNIVERSITY OF  
SYDNEY

## Call-to-action: *lived-experience-led research at the University of Sydney*

IT'S IMPORTANT  
that research  
is done  
INCLUDING  
US!

COME UP WITH  
better  
ways  
TO TELL THE  
STORIES  
OF PEOPLE WITH  
DISABILITIES

LEARN FROM  
THOSE WHO **KNOW** the most

IT'S IMPORTANT  
that research  
is done  
INCLUDING  
US!

WE NEED MORE  
ABORIGINAL  
SCHOLARS  
in this space

"REST"  
IS ABOUT  
Survival  
— FOR —  
MARGINALISE  
ACADEMIC

CREATE A SAFE SPACE  
for the research to happen

WITH the RIGHT VOICES

OUR STRENGTH & DIVERSITY  
IS AN **ADVANTAGE!**

IT'S IMPORTANT  
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This document is produced by lived experience academics and is based on the presentations and participant engagement at the Forum to further lived-experience-led research at the University, held 27th April 2023. Authorship is shared, and special note is made of our presenters: Ellen Fraser-Barbour from Flinders University, John Gilroy, Susan Collings, Damian Mellifont, Annmaree Watharow, Alex Beckett, Jemma Chao from the Centre for Disability Research and Policy, the University of Sydney, Paul Newman from the Matilda Centre, the University of Sydney, Amanda Tattersall from Sydney Policy Lab, the University of Sydney, Rodney Adams from the University of Newcastle and Melanie Nolan, Suzie Jessep and Sarah Butler of the Inclusive Research Network from the Centre for Disability Studies.

We recognise and pay respect to the Elders and communities – past, present, and emerging – of the lands that the University of Sydney's campuses stand on. For thousands of years they have shared and exchanged knowledges across innumerable generations for the benefit of all.



The images used to illustrate the calls to action presented in this document are extracted from illustrations by Ben Crothers. The drawings were produced by Ben during the forum and highlight the major points discussed during the event.

[www.bencrothers.com](http://www.bencrothers.com)

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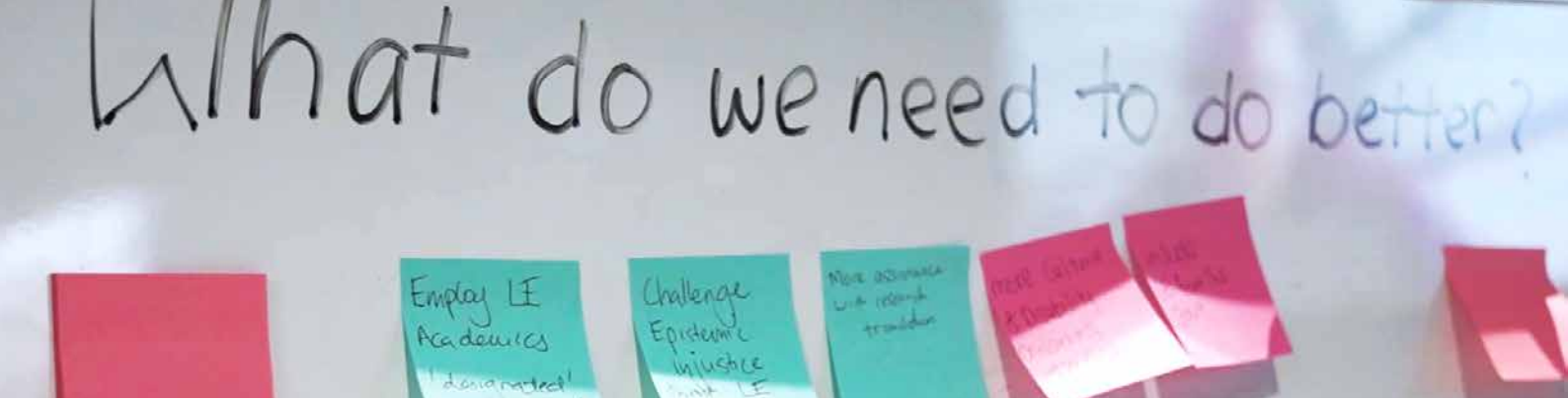
# Call-to-action: *lived-experience-led research at the University of Sydney*

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In 2023 the Centre for Disability Research and Policy (CDRP), Faculty of Medicine and Health impact centre, supported by the University of Sydney Disability Inclusion Action Plan (DIAP), presented the first University-wide forum on Lived-Experience-Led Research.

From this event we present *calls to action* for academics and staff members to further lived experience-led research at the University and address the lack of opportunities for academics, staff, and students with lived experience of disability in educational and research institutions.





## Impetus: nothing about us without us

as part of the 2023 Strategy the University aspires to develop a whole-of-institution governance structure that will deliver initiatives to improve the representation of marginalised groups, including people with disability. Supported by the DIAP, the University aims to be a world leader in terms of disability employment, student participation, and disability research. To meaningfully engage with the strategic aims of the university we must create a supportive environment where it is safe for people with disability actively contribute, while upholding the rights of all people with disability in our community. This document outlines some of the challenges and opportunities identified in the context of the University, and **calls to action** that arise from them.

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## Definitions

The terms 'disabled people' and 'people with disability' will be used interchangeably in this report but recognise that some people prefer one type of language over the other. We also recognise that some communities such as parts of the Deaf community prefer not to use the language of disability at all but are subject to the same or similar challenges as those who do.

Lived-experience researchers use their lived-experience of disability to inform, strengthen and direct research. Lived-experience can operate as a form of expertise alongside traditional forms of academic expertise. Lived-experience-led research centres the lives of those with disability in all stages of the research process.

## The current picture

The University excels in some areas of disability inclusion and research. The CDRP along with others across the University produce high quality lived-experience-led research. Both autonomous and University run disability networks exist and flourish for staff and students, and we have an enviable disability events program calendar catering to both the disability and wider community.

There remain extensive opportunities for the University to explore existing lived-experience-led research projects across disciplines, highlighting how lived-expertise enhances research quality, and to identify gaps in existing research. The following **calls to action** define actionable steps towards promoting lived-experience-led research within the University.

# Calls to action

## Culture

Fundamentally, changing the culture of the University to be safe and supportive for staff and students with disability requires challenging the status quo of academia and acknowledging that it has been a place of privilege, oppression, and harm for marginalised academics. This is now shifting, and there is room for these communities to come to the forefront of academia as part of social justice, progress, and learning.

### Calls to action

- 1 The time for greater investment in disability research, participation, and inclusion is now. We call for greater involvement from those with lived experience at all levels of the university, to challenge the structural and lived inequalities that still exist for people with disability.
- 2 That the university meaningfully engage with the 'wicked problems' that disability presents. This will require funding, affirmative action, and cultural change.

Working with staff and students with disability requires mutual trust. For the University to be a safe place for the lived experience of disability, particularly in the context of disclosure, we need to ensure that stigma and discrimination are not the likely consequences of disability. Greater work must be done to create a two-way street with the university for disability disclosure.

### Calls to action

- 3 Create clear safeguards for protection of rights for staff and students who disclose their disability and/or their experiences with disability.
- 4 Reasons to disclose require clarification and communication – reasons to disclose are clear for coursework students, but not necessarily in the case of staff and/or research students.

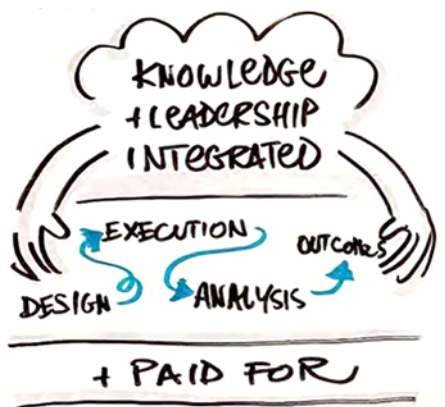


## Systems and processes

Unfortunately, institutions like the University routinely put lived-experience researchers in positions of precarity, instability, and sometimes/ultimately exploitation. Unspoken power inequities in the way that our institutions are run prevent meaningful systemic changes to processes that entrench this exploitation. Building a disability confident workplace takes expertise and tacit knowledge built over time. It is only by mobilising the resources of lived-experience experts that we can enable researchers and the research community to advance in disability research.

### Calls to action

- 5 Create clearer career pathways for those with lived-experience.
- 6 Create more, and sustainable job opportunities for those with lived-experience.
- 7 Work with respect and reciprocity, not exploitation.
- 8 Make it easier to employ lived-experience research associates as experts, regardless of their formal education background.
- 9 Make authorship pathways easier for lived-experience researchers.
- 10 Make it easier to pay lived-experience researchers through our systems and processes. This will require creative and imaginative solutions to the technical barriers that currently exist.



Accessibility should be built into systems, rather than requested as a part of 'reasonable adjustments' after systems are formalised. Ultimately, we need a better understanding that accessibility begins with unconditional positive regard, not a document wall.

TRULY INCLUSIVE  
WORK ENVIRONMENTS  
don't happen  
by chance

THEY'RE SHAPED  
BY PEOPLE WITH  
DISABILITY, +  
THEIR ALLIES

### Calls to action

- 11 We need Universal Design Principles used and accessibility options on all systems across the University, for both staff and students.
- 12 We need better recruitment processes and payment systems that are suited to a disability positive workforce.
- 13 We must remember that there is no such thing as 'full accessibility'. Accessibility requires responsiveness to the needs of the people who use systems.
- 14 Meetings present a particular challenge for accessibility, and we should develop strategies to make them inclusive through flexible guidelines and processes.



## Representation

The disability community is incredibly diverse. No one disabled person speaks for all. Disability representation is more than having a ‘disabled person in the room.’

### Calls to action

- 15 We need more (diverse) lived-experience in leadership roles, academic roles & other positions right across the University.
- 16 We call for affirmative action in the form of disability employment quotas.



Identifying as a lived-experience researcher allows space for others to identify and talk about their experience. This can be empowering, both for the researcher, and for those they encounter. However, it does mean that they may their service role(s) outnumber their peers, and much of this work can and does go unnoticed or unrewarded within University metrics.

### Calls to action

- 17 We need more lived-experience academics across all disciplines, in all roles.
- 18 We must take service more seriously in metrics using a systematic approach.
- 19 We need more appropriate workload management that takes service role(s) and lived-experience into genuine consideration.
- 20 Lived experience-focused research and/or teaching focused positions which value the experience of disability and the way this knowledge adds to our research and teaching.



Disability research is situated within a wider community, beyond the university. While it can be difficult to balance the relationships and needs of community with the norms and expectations of academia, partnerships with consumer organisations represent a growing opportunity for research at the University. Opportunities exists for academics to do outreach in the community, and to build a constituency.

### Calls to action

- 21 More funding for consumer led research that is grounded within the broader disability community.
- 22 More funding for partnerships with community organisations.
- 23 More funding for outreach work – and acknowledgment of that work within metrics.
- 24 More money for ‘slow’ research – short funding cycles do not work for this kind of research. Genuine co-design and co-production takes time, especially when working with people with disability.
- 25 A call for a cultural shift – to no longer underestimate people and their ability to participate because of their disability.



## Research and study

Research on or with people with disability takes time. Disability comes with an unavoidable emotional workload. It can and does take longer because of the challenges that disability presents. The playing field is not level between disabled and able-bodied academics. Burnout is a reality for many working in this space. Productivity metrics within university structures are not well suited to a disabled workforce and reflect abelist norms.

### Calls to action

- 26 Rest and recovery need to be built into the structure of the University system to facilitate participation by people with disability.
- 27 Productivity measures and measures of merit need to shift to reflect the diversity of our workforce.
- 28 Reasonable expectations of performance are needed to suit the diversity of our community. Positionality statements may assist with this, and we should encourage their use by all academics in all research contexts.



Lived experience-led research needs to include lived experience at all stages of the research process – from design to dissemination. It needs to embrace the inherent complexity of and tension between the disability community and academia, as well as respect forms of knowledge making that go beyond traditional academic research methodology. It requires an open mind, and time. Tokenism is rife in disability research.

### Calls to action

- 29 We call on researchers and the systems that support them to ensure that research design, analysis and outcomes are inclusive and embedded in lived-experience.
- 30 We ask researchers to be intentional about how we source original work – to understand the emotional component of knowledge making, and to tackle abelist norms and structures within our institution that prevent meaningful engagement.
- 31 We ask that data collection is carried out in ways that are empathetic and encourage trust among study participants.
- 32 We want knowledge translation and dissemination that is meaningful for the disability community, not just for academic metrics. This will include non-traditional outputs available in the public domain. For these to be viable to create they need to be supported through funding and metrics.



Despite improvements, stigma and stereotypes of disability remain entrenched at all levels of our institutional structure. It will take active engagement with our wider university community to dispel them.

#### Calls to action

- 33 We need more cultural and awareness training for all staff and students to equip them with a nuanced view of disability beyond simplistic frameworks like a deficit-based model of disability.
- 34 We ask that Human Ethics and the Research Office be trained to support staff engaging in lived experience research.

## OUR STRENGTH & DIVERSITY IS AN ADVANTAGE!

Higher Degree by Research (HDR) programs are currently prohibitive for many students with disability, or for carers of people with disability. At present there are a limited number of scholarships available for students who are disabled or carers, but none of these

offer the flexibility required in the context of disability. Government Scholarships through the Research Training Program (RTP) are taxed only when students move to a Part Time basis, further disadvantaging students who require additional time to complete. Opportunities for continuing work in the same geographical area post-completion are limited due to the culture of academia, which is a challenge for students with complex medical care and support needs.

#### Calls to action

- 35 We call for systemic change through the newly formed Graduate School that facilitates more suitable and flexible HDR programs for students with disability and/or carers.
- 36 We ask for the University to offer flexible scholarships suited to HDRs with disability and/or carers.
- 37 We would like to see the Graduate School work with HDRs to bridge more disability support services for research students with disabilities, and carers.
- 38 We call on the University to offer opportunities for continuing research positions to students with disabilities from our geographical area post-completion, across all disciplines and faculties.



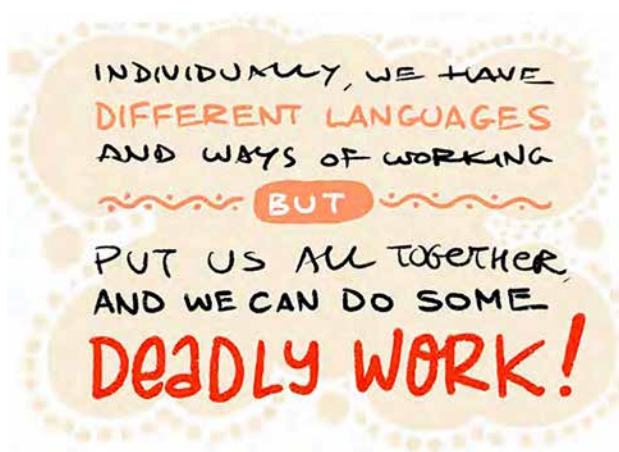
## Aboriginal and Torres Strait Islander peoples with disability

There exist large gaps in quality lived-experience-led disability research in the context of Aboriginal and Torres Strait Islander Peoples. Engaging in work in this space requires researchers to enter into research in good faith, to work in partnership with Indigenous scholars, and to question assumptions in the current literature that may entrench biases produced by research that is not lived-experience-led.

**WE NEED MORE  
ABORIGINAL  
SCHOLARS  
in this space**

### Calls to action

- 39 We call for more Indigenous scholars to be supported by the University in this space.
- 40 We call for more consistent funding, to create sustainable careers for scholars (both emerging and established) in this space.
- 41 We ask that researchers don't do standard systematic reviews on disability and Aboriginal and Torres Strait Islander Peoples, because they entrench bias.
- 42 We call on non-Indigenous researchers working in this space to take time, work in partnership, and engage in good faith research with community. Don't do work on disabled Indigenous people without disabled Indigenous people.
- 43 We demand that the University de-colonise our research, our assumptions, our practices.

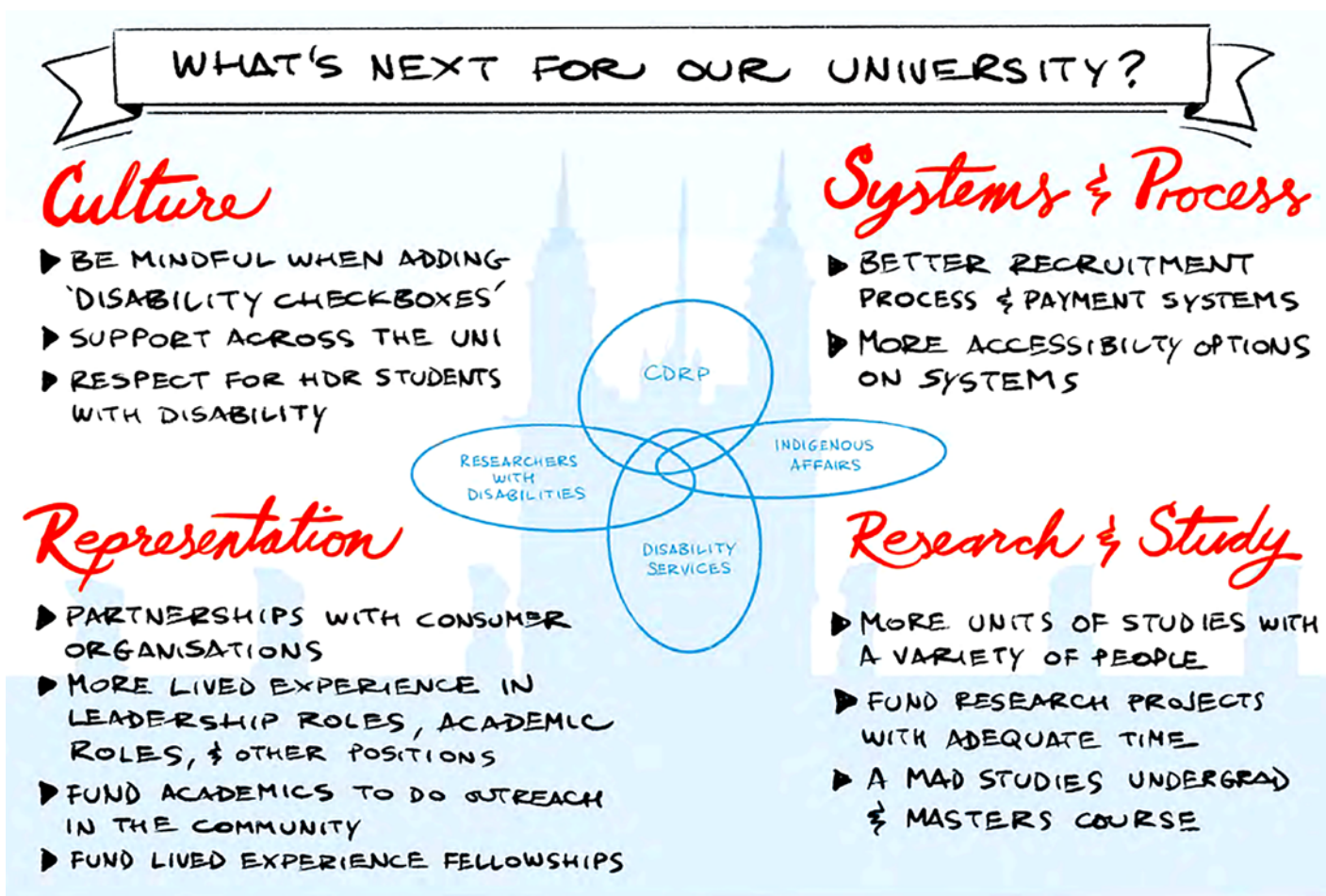




## What's next

There are extensive opportunities for the University to explore existing lived-experience-led research projects across disciplines, and to identify gaps in existing research. We need greater funding for lived-experience-led research, substantive investment in community partnerships, more lived-experience in leadership roles and positions across all areas of the University through Fellowships and employment opportunities.

We also need a cultural shift towards respect, accessibility and inclusion which is reflected in our systems, our processes, and our attitudes. Lived-expertise enhances research quality, as well as the educational and workplace experience for students and staff. These **calls to action** reflect the changes required for the University to genuinely become a world leader in terms of disability employment, student participation, and disability research.



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[centres/centre-for-disability-research-and-policy.html](https://sydney.edu.au/medicine-health/our-research/research-centres/centre-for-disability-research-and-policy.html)

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