

# The Universitas 21 Disability Inclusion Policy Mapping Report

Partnering globally to champion change

**Part Two: Disability inclusion and the research and  
innovation ecosystem**

June 2025

*Image illustrates the global collaboration of U21 and this project - the image on the title page is a map of the world with orange circle symbols of each member university appearing on the city where they are based.*





Fudan University



Korea University



KU Leuven



Lund University



McMaster University



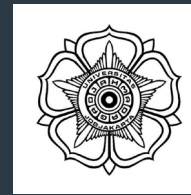
National University of Singapore



Pontificia Universidad Católica de Chile



Shanghai Jiao Tong University



Universitas Gadjah Mada



Tecnológico de Monterrey



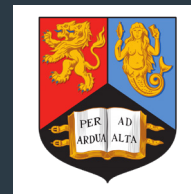
UC Davis



University of Amsterdam



The University of Auckland



University of Birmingham



University College Dublin



University of Connecticut



University of Delhi



The University of Edinburgh



University of Glasgow



The University of Hong Kong



University of Johannesburg



University of Maryland



The University of Melbourne



University of Nottingham



University of Illinois Urbana-Champaign



The University of Queensland



The University of Sydney



University of Zurich



UNSW Sydney



Waseda University

# Background

Throughout 2023 and 2024, the Universitas 21 Equity, Diversity, and Inclusion (EDI) Working Group undertook the development of a Network-wide framework to guide EDI efforts across member institutions.

As part of this process, the U21 Disability Community of Practice (COP) was consulted during the drafting of the U21 Framework for Equitable and Inclusive Global Engagement. Recognising the value of this Framework, the Disability COP sought to support and enhance the leadership of U21 universities in advancing EDI, particularly in the area of disability inclusion.

Building on this momentum, the Disability COP proposed the U21 Disability Policy Mapping Initiative. This initiative invited university leadership to submit all relevant public documents pertaining to the inclusion of persons with disabilities. Each institution was also asked to nominate a contact person to facilitate the provision of these policies and to participate actively in the Disability COP.

Professor Paul Harpur OAM, as co-lead of the Disability COP and with established funding and strong backing from U21, offered to lead a Comparative Interpretive Policy Analysis (CIPA) of the collected documents. This analysis aimed to identify common commitments and best practices across the network, culminating in recommendations for a U21 Disability Inclusion Policy Mapping Report.

In April 2024, the U21 Senior Leaders' Group formally adopted the U21 Framework for Equitable and Inclusive Global Engagement and endorsed the U21 Disability Inclusion Policy Mapping Initiative. Throughout 2024, the Disability COP received substantial support from the U21 secretariat in finalising and distributing a survey to all thirty universities within the network. The survey was completed, and relevant documents were collected. Additional data collection and analysis were required following the inclusion of the University of Illinois at Urbana-Champaign in the U21 Network. A dedicated team of staff and students from across the U21 Network contributed to data collection, analysis, and the drafting of this report, with a full list of contributors included in the attached document.

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The above table of contents lists the parts and chapters of the report. Each chapter is authored by staff from across the U21 Network, who may use variations of inclusive language as best matches their experience.

# Introduction to the U21 Disability Inclusion Policy Mapping Report

**Professor Paul Harpur OAM**

## Introduction

In this introductory chapter I want to share my personal vision, as well as the vision of many colleagues involved in this journey of change.

I believe universities are a force for good in society. University education opens opportunities to individuals and provides our nations with the workforces they need for economic growth. Universities employ thought leaders who produce research and innovation which grows economies, enhances policy responses, and leads to transformational scientific discoveries.

Discoveries which have strengthened food security, the environment, health, modelling and other benefits to society. Highly visible benefits of such research include the development of vaccines, such as for COVID-19 and the HPV viruses, GPS technology, and web browsers.

The universities who feature in this report, the 30 member universities of the Universitas 21 (U21) Network, individually and collectively are enriching, empowering, and enabling the communities they serve. Those communities are stretched over 20 countries, collectively including 1.3 million students, over 220,000 staff, have approaching 2.5 million alumni, and stretch their positive impact into towns, cities and across the globe.

Those of us privileged to work in a U21 Network university, work in an institution that is committed to positive change. For many of us who want to have a positive impact upon the world, when we advance our personal visions, we find we are aligned to the vision of our university. The energy of those involved, along with the support for this report, has already led to impact and to the successful completion of this report.

## Structure of this report

In addition to this introductory part, this report has 5 parts. The parts of this report groups chapters according to most universities' organisational structures. Accordingly, Part 1 addresses university-wide governance on disability inclusion and Part 2 groups chapters concerning key priority of research-intensive universities: research. These chapters introduce new norms pertaining to disability inclusive research and analyse how U21 Network universities are responding. The Report then turns to policies supporting students with disabilities. This part includes chapters where universities are responding to the profound shifts in norms and laws pertaining to disability inclusion. In an often-overlooked area, Part 4 addresses how universities can and should be supporting their staff with disabilities. Finally in Part 5, this report includes chapters on digital, physical, and library services that are used by students, staff, and the wider community. In addition to mapping out policies, each chapter makes recommendations to enhance the impact of this report.



**Although reports generally do not have impact until they are published, the process of producing *this* report has already led to positive impact.**

## Impact

Impactful change occurs when top down and bottom-up inclusion initiatives intersect. This is the reality on disability inclusion in the U21 Network.

The reality is that many of our universities are leading on inclusion, but many others operate in regulatory ecosystems where inclusion is less supported. The U21 Senior Leaders' Group has recognised and responded to the challenges by adopting in April 2024 the U21 Framework for Equitable and Inclusive Global Engagement.

In addition to adopting the U21 Framework for Equitable and Inclusive Global Engagement in April 2024, the U21 Senior Leaders' Group agreed to support the U21 Disability Inclusion Policy Mapping Initiative. When considering whether they should support this initiative, the U21 Senior Leaders' Group would have been aware that strategic, policy, and practical efforts on disability inclusion in higher education can be mixed. Despite the risk of adverse findings, the U21 Senior Leaders' Group decided to support this initiative and send a message that there is high-level commitment to identifying ways of doing better on disability inclusion.

By supporting the gathering of data from 30 member universities, the U21 Senior Leaders' Group have both sent a message across our communities that disability inclusion matters, plus provided tangible support to the gathering of data which has enabled this overview of current disability inclusion policies to be produced.

This top-down support was heard by people working in U21 Network member universities and has contributed to bottom-up efforts to respond to this opportunity and build lasting collaborations. Therefore, this report acknowledges the PhD staff members who contributed to authoring a thematic chapter.

The thematic groups that have come together have recognised the value in collaborating and thematic sub-groups of the U21 Disability Community of Practice have been proposed.

Already this report is contributing to lasting change.

Lasting change in the policy delivery space has been created by providing examples of workable solutions that exist in U21 Network universities. The U21 Network provides an avenue where universities with identified best practices, can share their experiences directly with other member universities, and thus build stronger responses to inclusion across the U21 Network.

With respect to informing responses, the professional and academic staff involved in this analysis have drawn upon their expertise when analysing the data to help generate a large list of recommendations. The recommendations called for by the authors in this report would profoundly shift the teaching, staffing, service delivery, and research ecosystems in our institutions. Transformation of this magnitude does not occur in the short term; however, reports of this nature occur infrequently, thus some recommendations might be adopted in the short-term, whereas others will take more time.

Often recommendations are grouped by what is possible in the short, medium, and long term. The different situations of universities across the U21 Network, caused by differences in cultures and regulatory environments across over 20 countries and by universities themselves, means that segmenting recommendations by implementation timeframes is not viable. Instead, recommendations are grouped by the domains in the report so that those reviewing their position can more easily identify the recommendations most relevant to their needs.

## Conclusion

To support the U21 Network and its university members to become disability champions of change, this report underscores the transformative potential of universities in fostering disability inclusion. By leveraging the collective strength of the U21 Network, we can drive significant advancements in creating inclusive educational, work and research and innovation eco-systems. This report not only highlights the current state of disability inclusion policies but also provides actionable recommendations to enhance these efforts.

The commitment from both top-down leadership and grassroots initiatives within our universities is crucial for sustained progress. As we continue to share best practices and collaborate across institutions, we can make meaningful strides towards a more inclusive society.

The work presented here is a testament to the power of commitment by those working in U21 Network universities and the U21 secretariat action and the dedication to improving how our universities operate and the lives of persons with disabilities. On disability, our universities train students with and without disabilities, employ staff with and without disabilities and produce research and innovation which can create a more inclusive world.

U21 is a place where we can come together to share, learn, and enhance our collective responses. Those responses will impact upon our universities, our U21 Network, to over 20 countries where our universities are situated and more broadly across the globe.

**// Changing the world for the better starts with a single step. I believe this report is such a step.**

Professor Paul Harpur OAM

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# Executive summary

**Between 15% and 20% of the world has a disability and in many of our universities more than 10% of our communities live with a disability.**

Universities train the disability leaders of tomorrow, employ the disability leaders of today, and produces research and innovation that leads to a better and more inclusive world. Drawing upon existing policies and practices from Universitas 21 (U21) Network member universities, this report provides a pathway for our universities, separately and collectively through the U21 Network, to more effectively and efficiently realise our missions, and through this, do better at what we do best: **Create and share knowledge for the betterment of all.**

This report was made possible following the adoption of the U21 Framework for Equitable and Inclusive Global Engagement and the support from the U21 Senior Leaders' Group to support this initiative. With over 100 U21 staff volunteering, this report involved 30 member universities across over 20 countries, resulting in a comprehensive analysis of disability inclusion within the U21 Network. This report, led by Professor Paul Harpur, aims to support U21 universities in advancing equity, diversity, and inclusion (EDI) in the disability space.

This report contains 5 main parts, each focusing on a different aspect of disability inclusion in the university setting. While these standalone parts like this one are available for convenience, readers seeking further context and detailed recommendations should refer to the complete report. A consolidated list of recommendations is provided after the Executive Summary.

## Part 1: Disability Governance Norms

This part explores the establishment of new norms on disability governance within the U21 Network. It emphasises the importance of fostering equitable partnerships among member universities and ensuring disability representation in governance structures. The report highlights the need for clear leadership roles, strategic integration, continuous improvement, and adequate funding to support disability inclusion initiatives. Additionally, it addresses the intersectionality of disability with other marginalised identities, such as Indigenous, LGBTQIA+, and age-conscious frameworks.

## Part 2: Disability Inclusion and the Research and Innovation Ecosystem

Part 2 examines how U21 universities can align their research and innovation practices with the United Nations Convention on the Rights of Persons with Disabilities (CRPD). It underscores the importance of integrating CRPD norms into ethics and grant review processes, enhancing data collection, and implementing co-design methodologies. It also discusses the role of university research groups in championing disability inclusion and the need for comprehensive disability inclusion research and innovation, drawing from the best model at plans of inclusive practices. It calls for increased representation of people with disabilities in research leadership roles and the establishment of formal benchmarks within institutional disability policies. For the sake of this report, the CRPD describes disability in Article 1 to **“include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”**

## Part 3: Creating an Inclusive Community for Students with Disabilities

This part focuses on the transition from reasonable accommodations to universal design and universal design for learning (UDL). It advocates for a proactive approach to designing inclusive educational environments that anticipate and remove barriers to learning. The report highlights the importance of enhanced outreach programs, pre-orientation and orientation programs, and accessible housing options for students with disabilities. Additionally, it addresses the need for clear access to disability support information for international and exchange students and the importance of tailored career counselling and work-integrated learning opportunities to support students with disabilities in their transition to employment.

## Part 4: Universities Support for Staff with Disabilities

Examining the measures adopted by U21 universities to create disability-inclusive workplaces, this part discusses proactive measures to promote the recruitment and retention of staff with disabilities, the implementation of universal design, and the streamlining of reasonable accommodation processes. Part 4 also addresses the challenges faced by staff with disabilities who travel for work and recommends central funding for disability-related travel expenses, mechanisms for non-disclosure, and internal booking systems with accessibility information. Furthermore, it highlights the importance of awareness-raising activities, including mandatory training, inclusive events, and the development of comprehensive resources to support ongoing education and awareness efforts.

## Part 5: University Services and Disability Inclusion

Part 5 explores the role of university services, including libraries and digital and physical spaces, in promoting disability inclusion. It emphasises the importance of integrating accessibility into all library policies and strategic planning, developing physical spaces and assistive technology, and providing ongoing training for library staff. The report also discusses the need for capacity building across university staff to ensure understanding and implementation of digital accessibility standards. It advocates for the development of digital inclusion roadmaps, publicising compliance and monitoring metrics, and partnering with other universities and software vendors to enhance digital accessibility. Additionally, it addresses the importance of establishing design guides and capital works plans for the built environment and creating dedicated positions, such as Campus Accessibility Officers, to oversee accessibility and inclusion initiatives.

# Part 2: Report recommendations

The following consolidated list of recommendations is drawn from and referenced in the chapters of this report.

## Part 2: Disability inclusion and the research and innovation ecosystem

### Chapter 2.1. Understanding when university research and innovation is and is not compliant with disability human rights norms

- a) **Integrate disability norms into ethics and grant review processes:** Universities should incorporate CRPD norms into their internal ethics and grant review processes to ensure that all research proposals are evaluated for compliance with disability human rights standards.
- b) **Enhance data collection:** Universities should systematically collect data on the representation of persons with disabilities across the research and innovation ecosystem. This includes tracking their roles in leadership positions, research projects, and specific disability-related research.
- c) **Implement co-design methodologies:** Universities should encourage the use of co-design methodologies in research projects to ensure that persons with disabilities are actively involved in all stages of the research process. This approach not only aligns with CRPD norms but also enhances the quality and relevance of research outcomes.

### Chapter 2.2. University research groupings as champions of disability inclusion

- a) **Support the operation of disability research groups:** The CRPD has shifted how research on disability is performed. To reflect new norms, and the opportunities it presents, universities should support the formation and operation of groups of researchers to form disability research groups.
- b) **Make disability research groups more visible:** The U21 Disability Inclusion Policy Mapping Report was supported by U21 universities and involved academics scanning websites to identify disability research groups. Despite these resources, it was challenging to identify all disability research groupings and disability led research for this chapter. Difficulty in identifying disability research groups and leaders hindered collaboration and research commissioning efforts. The challenges encountered when people sought to report on the disability research groupings and disability led research within their own university and across the U21 Network, illustrates a need to provide additional resources to coordinate and facilitate profiling of what activities are currently being undertaken across the U21 Network.
- c) **Universities should listen to their own disability inclusion expertise:** An analysis of the existing research groupings illustrates the benefits where universities harness their own research expertise to improve how they operate. To expand such benefits, it is recommended that university administrators should harness the disability inclusive expertise that research groups based in their universities contain. To harness this potential, processes to enable university researchers to inform operations and policies should go beyond ad hoc projects and should instead be formalised. This formalisation process should include administrative support, institutional commitment to support research which spans academic and operational groupings and recognising these activities in academic and professional workload allocations.

### Chapter 2.3. The power of university-wide research plans to champion disability inclusion

- a) **Adopt comprehensive disability inclusion research and innovation plans:** Universities should develop and implement comprehensive disability inclusion research and innovation plans that align with their overall strategy. These plans should include clear institutional commitments to change and be integrated into the university's broader research ecosystem.
- b) **Monitoring and KPIs:** Establish KPIs to monitor progress and ensure accountability. Regularly review and report on these KPIs to track the effectiveness of disability inclusion initiatives.
- c) **Capacity building:** Invest in capacity building for researchers with disabilities. This includes providing training, resources, and support to enable them to engage in research on an equitable basis with their peers.
- d) **Resourcing and support:** Allocate sufficient resources to support disability inclusion initiatives. This includes funding for reasonable accommodations, accessible infrastructure, and support services for researchers with disabilities.
- e) **Leadership and representation:** Increase representation of people with disabilities in research and innovation leadership roles within the university generally as well as supporting their collective activities through a research community of practice, group or network. This helps address power imbalances and ensures that the voices of people with disabilities are heard and valued in decision-making processes.



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## Individual acknowledgements

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## First Nations Acknowledgment

We recognise that due to the impacts of colonisation, Indigenous peoples are more likely to be living with disability and / or chronic illness compared to the wider population. This Review acknowledges the Traditional Owners of the lands and waters on which the 30 U21 Network universities are situated, and pays respects to their Elders, past and present.

The status of traditional owners of lands differs across the footprints of the U21 Network's 30 universities, and the lead author Professor Paul Harpur OAM is based at The University of Queensland (UQ) and thus will provide an acknowledgement which is more reflective of the traditional lands on which he and many authors work.

We would like to acknowledge the Traditional Owners and their custodianship of the lands on which UQ operates. We pay our respects to their Ancestors and their descendants, who continue cultural and spiritual connections to Country. We recognise their valuable contributions to Australian and global society.

The traditional owners acknowledged here include all those who are the traditional owners of the lands on which UQ operates. The UQ main campuses include 3 campuses in or around Brisbane city, being St Lucia, Dutton Park and Herston, as well as a campus at Gatton in the Lockyer Valley. The UQ geographical footprint includes off-campus sites with the Translational Research Institute, marine research stations at Heron and Stradbroke Islands, mineral research centre, seismograph station, veterinary and agricultural science teaching and research centres at Gatton, UQ Business School Brisbane City, social science research at Long Pocket, and teaching hospitals, health centres and other medical research facilities. The University's overseas establishments include UQ's North America office in Washington D.C., and the UQ-Ochsner Clinical School in Louisiana, United States of America.

Most students and staff are based in Brisbane city, which for tens of thousands of years was known by its traditional name, Meeanjin, which means "the place of the blue water lilies." Brisbane is the traditional home of the Turrbal and Yuggera peoples. UQ has geographic footprints on the lands of other traditional owners, and thus we also acknowledge:

- Bundaberg Rural Clinical School: Bailai, Gooreng Gooreng, Gurang and Taribelang Bunda peoples
- Gatton campus: Yuggera peoples
- Heron Island Research Station: Bailai, Gooreng Gooreng, Gurang and Taribelang Bunda peoples
- Hervey Bay: Butchulla people
- Meadowbrook - Yugambah Speaking Peoples
- Moreton Bay Research Station and Redland Hospital - Quandamooka people
- Rockhampton Rural Clinical School - Darumbal People
- Veterinary Practice Dayboro - Kabi Kabi people

# Method and approach

## Paul Harpur and Brooke Szucs

### Planning phase

This report has been made possible by the support of the U21 Secretariat and disability inclusion support within member universities. Efforts to build and strengthen collaboration on disability Inclusion was formalised in 2023 with the establishment of the U21 Disability Community of Practice.

When the U21 Senior Leaders' Group was developing the U21 Framework for Equitable and Inclusive Global Engagement they consulted with the U21 Disability Community of Practice. As part of this process, Professor Harpur proposed to the U21 Disability Community of Practice that he led a policy mapping initiative to advance the U21 Framework for Equitable and Inclusive Global Engagement. After consulting with the U21 Disability Community of Practice, as well as colleagues across the network, it was decided to seek support from the U21 Senior Leaders' Group in their April 2024 meeting in Hong Kong for a U21 Disability Inclusion Policy Mapping Initiative.

In their April 2024 meeting, the Senior Leaders' Group reiterated their commitment to advancing equity, diversity, and inclusion by adopting the U21 Framework for Equitable and Inclusive Global Engagement and by agreeing to support the U21 Disability Inclusion Policy Mapping Initiative to be led by Professor Paul Harpur.

Following approval by the U21 Senior Leaders' Group, Professor Paul Harpur reached out to Mr Paul Sheeran to benefit from his project management expertise. Paul Sheeran formed

an Oversight Project Management Group which provided valuable support to this report's success. In particular, the Oversight Project Management Group assisted in the development of a project management plan to manage a project across 30 universities situated in over 20 countries, spread across all inhabited continents, with language barriers and multiple work groups at each university.

A draft of the project management plan was shared with the U21 Disability Community of Practice, as well as key groups within to gain feedback, including the Disability Collaboratory, the Disability Inclusion Group, and the Disability Inclusion and Advocacy Network. After implementing suggested changes, the project management plan was adopted.

The project management plan called for data to be collected via a survey and through a manual document collection process. To facilitate this, existing networks were used to gather U21 staff members to support in finalising the research tools, and to participate in the data gathering, analysis and writing of this report.

In addition to the Oversight Project Management Group, staff were sorted into teams aligned with the thematic chapters in this report. During the process some staff withdrew, and new staff joined the project. Those who made a substantive contribution to thematic chapters have been named as authors.

## Data collection

### The U21 Disability Policy Mapping survey

A literature review was performed by the project team to identify key themes. Drawing upon this, as well as decades of academic and professional experience, the research team co-designed the U21 Disability Inclusion Policy Mapping survey. The survey was piloted tested at and several questions were added which addressed policy questions confronting those who delivered disability inclusion interventions.

The U21 Disability Policy Mapping survey aimed to gather information on disability inclusion policies and practices across the U21 Network of universities. The survey contained 30 questions covering various aspects of disability inclusion. Topics covered included:

1. **Governance:** Structure and evaluation of disability inclusion efforts.
2. **Strategies:** University-wide strategic plans and specific disability inclusion plans.
3. **Research:** Disability inclusion research groups and strategies.
4. **Courses:** Availability of disability studies programs.
5. **Training:** Disability awareness training for students and staff.
6. **Data Collection:** Collection of data on students and staff with disabilities.
7. **Accommodations:** Policies for making accommodations for students and staff.
8. **Support Services:** Support provided by libraries, IT services, and facilities.
9. **Innovative Initiatives:** Examples of innovative disability inclusion initiatives.
10. **Contacts:** Points of contact for sharing findings and participating in the U21 Disability Community of Practice.

The survey sort qualitative responses and relevant documents to inform shared insights and public resources aimed at enhancing disability inclusion across the U21 Network.

Ethical clearance for this project was obtained from UQ under reference number 2024/HE001229. After ethics approval was secured, an invitation to participate in the U21 Disability Inclusion Policy Mapping Initiative was shared across the U21 Network along with invitations to complete the survey being emailed by the U21 Secretariat to their contacts within member universities. In addition, the survey was distributed by members of the U21 Disability Community of Practice to colleagues they knew, at their university and others in the U21 Network, who would be well-equipped to respond.

### Manual searching

During the drafting of the survey tool, it was anticipated that the fragmented nature of disability inclusion policies across universities would result in incomplete responses. As anticipated, the fragmented nature of disability inclusion in universities made it challenging for staff members to provide full responses in all areas of the survey. Thusly, researchers from the thematic teams agreed to perform manual searches to ensure the data set was representative.

Often those working on the thematic chapters had engaged in policy searches of university websites for academic or professional purposes and thus were familiar with search protocols. Where this was not the case, the project lead was able to provide support.

In addition to relying upon staff assigned to thematic chapters, efforts were made to reduce challenges created by culture and language across the U21 Network. Professor Harpur used his ARC Future Fellowship funds to retain Ms Brooke Szucs, who speaks Japanese, German and Spanish, and Mr Nick Yao, who speaks all Chinese languages, to analyse documents and make direct contacts with U21 Network universities where these languages were the primary language of communication to elicit additional data.

## Data collected

A total of 22 universities submitted to the survey, contributing data that formed the foundation of the analysis. The data provided in the survey included qualitative responses along with documents that were uploaded to the survey and in other cases links to policy and websites. Where websites were provided, the documents were downloaded. This process elicited over 300 policy artifacts - policy documents and websites that explains processes.

The survey data was gathered and distributed to the teams working on thematic chapters. A preliminary analysis of the data was performed and gaps identified. To fill the gaps identified, manual data was collected from university websites, as well as requesting staff of target universities support in the provision of data.

## Data analysis

With the exceptions of chapters 1.2 and 2.1 which provide analysis of developing disability norms, and of chapter 1.5, on intersectionality, the approach to data analysis was the same in all other chapters. Even though the methods of chapters 1.2, 1.4 align with the method in this method chapter, the authors of those chapters desired to explain their methods in their chapters and thus those chapters include a method section.

The data was shared with the teams and support was provided to help narrow which

documents were most relevant to each thematic team.

To understand how different universities approached disability inclusion in each area, and to help identify innovative and best practices, each team engaged in a comparative policy analysis over the documents. This involved examining how different universities address accessibility and support based upon the qualitative data provided in the survey, as well as in the policies and websites gathered. Those involved in the analysis drew from their personal expertise working in the relevant policy area, as well as drawing upon scholarship and disability norms. Through this process, recommendations were developed for each chapter.

The involvement of multiple authors resulted in some variation of language, due to differing theoretical perspectives, and some slight variation in how chapters are structured. We fundamentally believe that diversity is a strength and decided that these slight variations strengthened the report.

Progress was monitored through regular communications. Ultimately all the thematic chapters were placed in a single document and shared across those who co-authored chapters for comment and updating of their own thematic chapters. This process resulted in this final report that will be presented to the U21 Senior Leaders' Group in May 2025.

## Part 2:

# Disability inclusion and the research and innovation ecosystem

**Chapter 2.1.**      **Understanding when university research and innovation is and is not compliant with disability human rights norm**

*Paul Harpur*

**Chapter 2.2.**      **University research groupings as champions of disability inclusion**

*Jennifer Smith-Merry and Paul Harpur*

**Chapter 2.3.**      **The power of university-wide research plans to champion disability inclusion**

*Paul Harpur, Helen Connick, Sarah Brown, Jean McBain, and Michelle King*

## Chapter 2.1.

# Understanding when university research and innovation is and is not compliant with disability human rights norm

Paul Harpur

### Introduction

This part of the report maps how U21 universities are researching disability and uses the UN Convention on the Rights of Persons with Disabilities (CRPD),<sup>1</sup> as well as the jurisprudence from the UN body charged with interpreting the CRPD, the CRPD Committee, as a benchmark to help inform best practice in disability research. In addition to calling for data collection, policy evaluations, and research in areas including architecture, business, engineering, health, law, policy, psychology, technology, and more, the CRPD transforms how research on disability should occur. This chapter builds upon the analysis of CRPD norms in Chapter 1.1 of this report and applies those norms to research and innovation. This chapter analyses when university research and innovation is compliant with new disability human rights norms.

The CRPD has profoundly altered disability norms and practices.<sup>2</sup> <sup>3</sup>This paradigm shift has transformed how States and higher education providers should perform disability related research.<sup>4</sup> Thus to be compliant with international norms, researchers and research ecosystems should follow a disability human rights-based disability research methodology.<sup>5</sup> A failure to understand these new norms can create reputational risks and could jeopardise ongoing funding.

U21 universities have recognised the importance of the CRPD and reference this convention as a guide. This can be seen in university-wide disability action plans at the University of NSW,<sup>6</sup> The University of Melbourne,<sup>7</sup> The University of Queensland,<sup>8</sup> and The University of Sydney,<sup>9</sup> as well in university equity plans, such as the plan at the University of Zurich.<sup>10</sup> The CRPD also features as a normative guide in university-wide research plans, such as Champions of Change Disability Inclusion Research and Innovation Plan,<sup>11</sup> as well as being used to set research directions at the University of Birmingham's Disability, Sport and Social Activism program,<sup>12</sup> the University of

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1 UN General Assembly. (2006). *Convention on the rights of persons with disabilities and optional protocol*. United Nations.

2 Harpur, P., & Stein, M. A. (2018). Universities as disability rights change agents. *Northeastern University Law Journal*, 10, 542.

3 Nilsson, A., & Broström, L. (2019). *Participation in research and the CRPD*. *International Journal of Mental Health and Capacity Law*, 25, 3-25.

4 Durham, J., Brolan, C. E., & Mukandi, B. (2014). The convention on the rights of persons with disabilities: A foundation for ethical disability and health research in developing countries. *American Journal of Public Health*, 104(11), 2037-2043. <https://ajph.aphapublications.org/doi/10.2105/AJPH.2014.302006>

5 Arstein-Kerslake, A., Maker, Y., Flynn, E., Ward, O., Bell, R., & Degener, T. (2020). Introducing a human rights-based disability research methodology. *Human Rights Law Review*, 20(3), 412-432.

6 University of NSW (2022). *Disability inclusion action plan 2022-2025*. <https://www.unsw.edu.au/edi/disability-inclusion-action-plan>

7 University of Melbourne. (2023). *Disability inclusion action plan 2023-2026*. <https://about.unimelb.edu.au/diversity-inclusion/disability-inclusion>

8 University of Queensland. (2023). *Disability action plan 2023-2025*. <https://research.uq.edu.au/strategy/disability-inclusion>

9 University of Sydney. (2019). *Disability inclusion action plan 2019-2024*. <https://www.sydney.edu.au/vision-and-values/diversity/disability-action-plan.html>

10 University of Zurich. (n.d.). *Equality for people with disabilities at the University of Zurich*. <https://www.uzh.ch/en/explore/basics/responsibility/disability.html>

11 The University of Queensland. (2024). *Champions of change: The university of Queensland disability inclusion research and innovation plan 2024-2026*. chrome-extension://efaidnbnmnnbpcjpcgclcfndmkaj/https://research.uq.edu.au/sites/default/files/2024-09/disability-inclusion-research-innovation-plan-design-version.pdf

12 University of Birmingham, School of Sport, Exercise and Rehabilitation Sciences. (n.d.). *Disability, Sport and Social Activism: Developing social justice through sport*.

Nottingham's Mental disability and law group,<sup>13</sup> The University of Sydney's Centre for Disability Studies<sup>14</sup> and The University of Melbourne's Melbourne Disability Institute.<sup>15</sup>

The first 2 parts of this chapter will analyse CRPD norms on disability research and apply them to U21 university practices. The CRPD has introduced new terminology, expectations and methodologies. Part 3 will shift from research methods which advance disability human rights, to analyse where the CRPD defines certain research methodologies as violating human rights.

## **Part 1. The roles of persons with disabilities, their families, and allies in research under new disability human rights norms**

The CRPD fundamentally alters the role of persons with disabilities in society – including their role in research.<sup>16</sup> For most of human history persons with disabilities had their voices discounted and had their lives controlled by family members, experts or the State. Consequently, persons with disabilities were subjects of research but rarely if ever leading the research or research ecosystems or having their names appearing on publications or grants. The disempowerment of persons with disabilities led to advocacy and the catch cry of “nothing about us, without us”.<sup>17</sup> The CRPD has enshrined the “nothing about us, without us” paradigm in articles 4(3) and 33(3) and through its implementation.<sup>18</sup>

The CRPD has altered the role of persons with disabilities in society and in research. From its drafting into the convention and in its implementation, the CRPD process empowers persons with disabilities to speak for themselves. In addition to requiring the support and empowerment of disability led groups to represent disability communities, discussed in this report at Chapter 2.2, and the formation of plans to make this happen, discussed in Chapter 2.3 of this report, the CRPD explains how disability should be approached.

In addition to ensuring the structures empower persons with disabilities to participate and that they are remunerated for their efforts, the CRPD requires equal representation, which translates to roles as researchers, as leaders of that research, on research committees, leading research groups and in formal roles, such as deans of research.

Data collection is critical throughout this process. CRPD article 31 creates a requirement and framework for counting who has lived experience. Persons with disabilities for this count are described in article 1 to “include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

Even though family members and allies cannot claim to have lived experience of disability, they have valuable experiences and roles that can contribute to creating a more inclusive world. For example, parents of children with disabilities bring lived experience as parents of children with disabilities.<sup>19</sup> Best practice is to recognise the important role of persons with disabilities and carers / parents. For

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13 University of Nottingham. (n.d.). Mental disability and law. <https://www.nottingham.ac.uk/diversity-and-inclusion-research-hub/mental-disability-and-law.aspx>

14 Centre for Disability Studies. (n.d.). [About CDS](#).

15 University of Melbourne. (2019). Melbourne Disability Institute: Building the evidence for transformation strategic plan 2019-2021. <https://disability.unimelb.edu.au/about>

16 Harpur, P., & Stein, M. A. (2017). The convention on the rights of persons with disabilities as a global tipping point for the participation of persons with disabilities. *Oxford Research Encyclopedia of Politics*.

17 Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. University of California Press.

18 Harpur, P., & Stein, M. A. (2022). The UN Convention on the Rights of Persons with Disabilities and the global south. *Yale Journal of International Law*, 47, 75.

19 Committee on the Rights of Persons with Disabilities. (2018). *General comment No. 7(2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention (UN Doc. CRPD/C/GC/7)*. United Nations.

<https://digitallibrary.un.org/record.pdf>

illustration, as there is a Disability Inclusion Advocacy Network<sup>20</sup> and a Network for carers of children with special needs and / or serious chronic illnesses.<sup>21</sup> Similarly, allyship is important to advancing the disability research agenda and should be supported. See for an example of this allyship resources at the Disability Resources and Educational Services, the University of Illinois Urbana-Champaign.<sup>22</sup>

## Part 2. Close consultation, active participation, and the “nothing about us, without us” paradigm

Although persons with disabilities should be included in decision-making processes around research and innovation ecosystems, the CRPD process ensures those who are asked to represent the disability community are able to represent that community. Thus, the CRPD includes both requirements to include persons with disabilities in policies and practices and mandates that frameworks are in place to make this happen. Reflecting this position, the CRPD Committee stated in General Comment No. 7, that if “participation is to be effective and meaningful, it needs to be understood as a process, not as an individual one-time event”.<sup>23</sup>

In addition to ensuring that disability representation is a formalised process, to ensure the effective participation of persons with disabilities, the CRPD ensures that those who are called upon to speak for the disability community, can in fact speak for that community. Beyond including persons with disabilities, the CRPD requires that those persons with disabilities are connected to their communities they purport to represent and have relevant expertise to speak on the subject matter. Thus, articles 4(3) and 33(3) require the participation of disability person representative organisations, which are both disability-led, and funded, so that those represented and representing are appropriately informed, benefit from capacity building activities, and administrative support to ensure a sustained collective group on an ongoing basis.

Developing disability representative expertise within universities is critical to advancing disability inclusive research and innovation ecosystems and projects. The need for internal disability expertise is illustrated by considering how U21 Network universities engage in co-design processes. Co-design involves the inclusion of persons with disabilities across the entire research and innovation process, including through conceptualising, designing, implementing, reviewing and benefiting (both in terms of financially and recognition as authors). Co-design is used by universities, such as in the development of its strategic plan to include all stakeholders,<sup>24</sup> and McMaster University<sup>25</sup> and the University of Auckland to target all diversity groups.<sup>26</sup> Most relevantly for this chapter, disability specific co-design is advanced in the research and innovation eco-systems at U21 universities, including at The University of Melbourne,<sup>27</sup> <sup>28</sup> and The University of Sydney.<sup>29</sup> Beyond

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20 The University of Queensland. (n.d.). Disability - Current staff. <https://staff.uq.edu.au/information-and-services/human-resources/diversity/disability>

21 The University of Queensland. (n.d.). [Work and caring responsibilities - Current staff](#).

22 University of Illinois. (n.d.). [Disability allyship resources](#).

23 Committee on the Rights of Persons with Disabilities. (2018). *General comment No. 7(2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention (CRPD/C/GC/7)*. United Nations. <https://digitallibrary.un.org/>

24 The University of Queensland. (2024). *Toward 2032: UQ Strategic Plan 2022-2025*. <https://www.uq.edu.au/UQStrategicPlan2022-2025.pdf>

25 McMaster University. (n.d.). [Home - Co-Design VP Hub](#).

26 University of Auckland. (n.d.). [Auckland Co-design Lab](#).

27 University of Melbourne. (n.d.). [Faculty of Education Disability Research Collaboration](#).

28 The University of Queensland. (2024). [Champions of Change Disability Inclusion Research and Innovation Plan 2024-2026](#).

29 Centre for Disability Studies. (n.d.). [About CDS - Centre for Disability Studies](#).

being best practice, using co-design is arguably a necessary part of disability inclusive methodologies.<sup>30</sup>

The CRPD Committee has explained that the co-design process must involve those who can represent the disability community.<sup>31</sup> Universities seeking to use co-design can sometimes include representatives from external charities; however, managing and funding such involvement can create challenges. Beyond the risks inherent in creating research and innovation strengths in external actors, universities generally prefer to build internal research strengths rather than constantly renumerating external providers. Instead of outsourcing disability expertise, universities can utilise their own research and innovation expertise and build disability research groups and plans. The operation of disability research groups and research and innovation plans is the subject of the next 2 chapters of this report.

### Part 3. When is disability research opposed by the CRPD

The imperative to strengthen internal disability research and innovation expertise and practices is intensified by CRPD article 15. CRPD article 15(1) provides that medical and scientific experimentation, without appropriate consent, constitutes a violation of the right to be free from torture or to cruel, inhuman or degrading treatment or punishment. To ensure, inter alia, persons with disabilities are giving their “free consent to medical or scientific experimentation”, CRPD article 15(2) requires States Parties to take all effective legislative, administrative, judicial or other measures.

States have not always taken appropriate measures. For illustration, the CRPD Committee in its Concluding Observation on the Netherlands raised concerns how the regulatory framework did not appropriately protect persons with disabilities to medical or scientific experimentation without their consent.<sup>32</sup> To redress similar concerns in the Concluding Observation on Israel, the CRPD Committee recommended the establishment of procedures to ensure that persons with disabilities under guardianship express their free and informed personal consent concerning medical treatment and medical or scientific experimentation, with appropriate accessible information and support for decision-making.<sup>33</sup> The CRPD Committee went further in its Concluding Observation on Malawi, and recommended that engaging in medical, scientific or social experiments on persons with disabilities without their consent should amount to a criminal offense.<sup>34</sup>

An additional challenge for States and universities is that the CRPD process has altered what is meant by free consent and alters the process for determining systems. The concept of consent and who can give it, was considerably altered by CRPD article 12. The importance of capacity is reflected by the fact article 12 formed the basis of the CRPD Committee’s first General Comment<sup>35</sup> and has attracted considerable normative attention by the CRPD Committee, law makers, ethicists and scholars.

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30 Strnadová, I., Dowse, L., & Garcia-Lee, B. (2022). Doing research inclusively: Co-production in action. Disability Innovation Institute, UNSW Sydney. [www.disabilityinnovation.unsw.edu.au/UNSW\\_DIIU\\_CoProductionInAction\\_FA\\_Web.pdf](http://www.disabilityinnovation.unsw.edu.au/UNSW_DIIU_CoProductionInAction_FA_Web.pdf)

31 Committee on the Rights of Persons with Disabilities. (2022). Concluding observations on the combined second and third periodic reports of New Zealand (UN doc CRPD/C/NZL/CO/2-3, 26 September 2022, Para. 18(d)). United Nations. <https://digitallibrary.un.org>

32 Committee on the Rights of Persons with Disabilities. (2024). Concluding observations on the initial report of the Kingdom of the Netherlands (CRPD/C/NLD/1, 12 August–5 September 2024, Para. 35(a)). United Nations. <https://digitallibrary.un.org>

33 Committee on the Rights of Persons with Disabilities. (2023). Concluding observations on the initial report of Israel (CRPD/C/ISR/CO/1, CRPD/C/ISR/CO/1, 9 October 2023, Para. 35(d)). United Nations. <https://digitallibrary.un.org>

34 Committee on the Rights of Persons with Disabilities. (2023). Concluding observations on the combined initial and second periodic reports of Malawi (CRPD/C/MWI/CO/1-2, 5 October 2023, Para. 32(b)). United Nations. <https://digitallibrary.un.org>

35 Committee on the Rights of Persons with Disabilities. (2014). General Comment No. 1 (2014): Article 12: Equal Recognition Before the Law (11th sess, UN Doc CRPD/C/GC/1, 19 May 2014). United Nations. <https://www.ohchr.org/en/no-1-article-12-equal-recognition-1>

This can lead to a situation where universities may violate human rights even though they are complying with local laws and their internal policies. Thus, universities could be compliant with national laws and practices yet still find their medical and scientific research impugned as violating human rights norms. Rather than seeking regulatory compliance, universities should ensure that their practices align with disability human rights norms.

## Recommendations

- a) **Integrate Disability Norms into ethics and Grant Review Processes:** Universities should incorporate CRPD norms into their internal ethics and grant review processes to ensure that all research proposals are evaluated for compliance with disability human rights standards.
- b) **Enhance Data Collection:** Universities should systematically collect data on the representation of persons with disabilities across the research and innovation ecosystem. This includes tracking their roles in leadership positions, research projects, and specific disability-related research.
- c) **Implement Co-Design Methodologies:** Universities should encourage the use of co-design methodologies in research projects to ensure that persons with disabilities are actively involved in all stages of the research process. This approach not only aligns with CRPD norms but also enhances the quality and relevance of research outcomes.

## Conclusion

The CRPD has fundamentally transformed the landscape of disability research and innovation, setting new norms and expectations for how research is conducted. This chapter has highlighted the importance of universities setting their policies to ensure their research and innovation ecosystem adheres to these norms. The involvement of persons with disabilities in research processes, the emphasis on co-design, and the need for proper consent mechanisms are critical components of this new paradigm. Failure to align with these norms not only poses reputational risks but also jeopardises ongoing funding and reputation of providers.



## Chapter 2.2.

### University research groupings as champions of disability inclusion

Jennifer Smith-Merry and Paul Harpur

#### Introduction

Disability research groups represent a powerful means to both advance disability involvement and leadership in research and research on the needs of persons with disabilities. Further, disability research groups represent a means through which States and universities can advance their obligations under the CRPD. In addition to doing research in accordance with disability human rights norms, the CRPD sets the norm that persons with disabilities must be producers of research as well as the subjects of its aims.<sup>36 37</sup> This includes Article 4(1), which emphasises the need to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind. It includes the obligation to undertake or promote research and development of universally designed goods, services, equipment, and facilities. This includes research and research environments, including universities. Disability research itself is also integral to the goals of the CRPD. Illustratively, CRPD Article 31 mandates the collection of appropriate information, including statistical and research data, to enable the formulation and implementation of policies to give effect to the Convention.

In 3 parts this chapter will reflect on current practices and unpack the potential of disability inclusion research groups located within universities to benefit society. The lead author of this chapter is Jennifer Smith-Merry, former Director of the Centre for Disability Research and Policy at The University of Sydney (2018-2024) and reflections on the place of this centre are included in the chapter as an example of current practice.

#### Part 1. Data from the survey responses km

In the survey we asked the following questions of the U21 members:

*Please list the research groups which focus on disability inclusion / rights with the following information:*

1. *A few lines explaining the nature of the group/s;*
2. *Whether those groups reflect the 'nothing about us without us' paradigm and have persons with disabilities in their leadership team;*
3. *Are there measures to help promote the research careers of persons with disabilities within the group;*
4. *Provide a link to the research group's website or other profiles.*

U21 Universities not referenced below either did not respond to the survey or provided no information in response to the question. A brief summary of the information provided by each of the other universities is provided in the table below, with a focus on universities where there was a dedicated research centre or research grouping focused on disability.

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36 Ellem, K., Harpur, P., Hardy, F., Stein, M. A., & Schormans, A. F. (2024). Young people with cognitive disability in transition to adulthood: Stories of survival, aspiration and systemic failures. Cambridge University Press. <https://doi.org/10.1017/9781009408721>

37 Nilsson, A., & Broström, L. (2019). Participation in research and the CRPD. *International Journal of Mental Health and Capacity Law*, 25, 3-25. <https://portal.research.lu.se/>

Table 1. This table shows the universities where there was a dedicated research centre or research grouping focused on disability.

Name of University	Summary of response
<b>McMaster University</b>	<ol style="list-style-type: none"> <li>1. No research centre.</li> <li>2. Large research project: Inclusive Design for Employment Access (IDEA) Social Innovation Laboratory</li> <li>3. Individual researchers working in disability</li> <li>4. Did not respond about promoting research careers or research leadership.</li> </ol>
<b>Lund University</b>	<p>Disability research centre: Certec – Rehabilitation Engineering and Design research centre.</p> <p>Did not provide any other information about promoting research careers or research leadership.</p>
<b>University of Birmingham</b>	<p>Several disability-focused research centres:</p> <ul style="list-style-type: none"> <li>• The Autism Centre for Education and Research (ACER)</li> <li>• Vision Impairment Centre for Teaching And Research (VICTAR)</li> <li>• Disability Inclusion and Special Needs (DISN)</li> <li>• Institute for Mental Health</li> <li>• U21 Autism Research Network led by Dr Sophie Sowden-Carvalho (the Network involves researchers from several universities across several countries)</li> </ul> <p>Also provided a list of individual researchers working in the field.</p> <p>Did not provide information about promoting research careers or research leadership.</p>
<b>University of Nottingham</b>	<p>Only responded in relation to the question about promoting research careers. Stated there are no targeted programs but have processes to ensure that internal calls have proportional numbers of disabled staff.</p>
<b>The University of Sydney</b>	<p>Several disability-focused research centres:</p> <ul style="list-style-type: none"> <li>• The Centre for Disability Research and Policy</li> <li>• The Centre for Disability Studies</li> <li>• The Brain and Mind Centre</li> </ul> <p>There are also other initiatives and schools mentioned that don't directly focus on disability.</p> <p>The Centre for Disability Research and Policy prioritises lived experience of disability in all of its researcher recruitment. Did not discuss university wide programs about promoting research careers or research leadership.</p>
<b>The University of Queensland</b>	<p>Informal research grouping: Disability Community of Practice, which is disability led. The UQ's Champion of Change Disability Inclusion Research and Innovation Plan, launched in September 2024, commits UQ to forming a university-wide research network to facilitate and coordinate disability related research.<sup>38</sup></p> <p>No measures to help promote the research careers of persons with disabilities or research leadership.</p>
<b>Pontificia Universidad Católica de Chile.</b>	<p>States that the answer to these questions is 'not known'.</p> <p>Provides link to the profiles of some researchers working in inclusion however the link focuses more on inclusion at the university not research on inclusion / disability.</p> <p>They did not respond to the question about promoting the careers of researchers with disability or research leadership.</p>
<b>University College Dublin</b>	<p>Lists several disability-related research centres / groupings:</p> <ul style="list-style-type: none"> <li>• Centre for Disability Studies</li> <li>• Inclusive Design Research Centre</li> <li>• Interdisciplinary Research and Teaching Group on Neurodiversity</li> </ul>
<b>University of Connecticut</b>	<p>Provides a link to the 'Collaborative on Postsecondary Education and Disability'. This is both a research centre and an education provider for people with disability through the Postsecondary Disability Training Institute.</p>
<b>University of Glasgow</b>	<p>Their research centre is the 'Centre for Disability Research'. It is both a research and teaching centre.</p> <p>They did not respond to the question about promoting the careers of researchers with disability or research leadership.</p>
<b>The University of Edinburgh</b>	<p>Interdisciplinary research group on disability called 'Disability Research Edinburgh'. They have a focus on career development, but this looks to be for everyone, and not specifically for researchers with disability. Did not discuss research leadership.</p>

<sup>38</sup> The University of Queensland. (2024). [Champions of change disability inclusion research and innovation plan 2024-2026](#).

Name of University	Summary of response
KU Leuven	The response provides a link to 'Disability studies: <i>Research into the history of persons with disabilities</i> '; however, this appears to not be a research centre, but a single researcher with a research team working with them. They did not respond to the question about promoting the careers of researchers with disability or research leadership.
The University of Hong Kong	They have a 'Disability Rights Resource Network' which is a research grouping. It does not employ any people with disability. There is also a research grouping focused on disability within the Department of Social Work and Social Administration. There are no specific practices that promote the research careers of researchers with disability or leadership in research.

As can be seen in the responses in the table above, most responses did not provide the required information, with a majority of respondents only partially responding to each of the questions. This may be because there was no way for central university to understand whether there were any research groups or career development within the university focusing on disability rather than there not being any. This is a finding that shows that disability research is not prioritised within most U21 universities.

Eight universities had dedicated research centres or research groups focusing on disability. These were split between general research centres or groups and those that focused on specific programs of work, for example in research related to design or education. Other research tended to focus on the work of individual researchers and their research teams. This is a less stable way of ensuring disability as a research priority because it can just fall away if that researcher leaves the university or moves on to other priorities.

Only one university commented on prioritising researchers with disability within research positions (discussed further below in example from The University of Sydney 'Centre for Disability Research and Policy'). No universities responded to whether the research groups reflect the 'nothing about us without us' paradigm and have persons with disabilities in their leadership team.

## Part 2. Drawing on additional information to reflect on disability research groups

Additional information was gathered from university websites and provided by universities on request. Combined with the data gathered from the survey, the range of disability research centres across universities more broadly fit into the following categories:

- **General focus on disability** – such as the 'Centre for Disability Research' at the University of Glasgow, which engages with disabled people and their organisations to carry out research that is relevant to the lives of people with a range of impairments and advances the rights of disabled people.<sup>39</sup> Some of these research groupings, such as The University of Melbourne's 'Melbourne Disability Institute',<sup>40</sup> focus on all aspects of disability, whereas some, such as The University of Melbourne's 'Centre of Research Excellence in Disability and Health',<sup>41</sup> focuses upon one aspect of the disability experience – in this case health.
- **Focus on a single area impacting on disability inclusion** – such as The University of Melbourne's 'Faculty of Education Disability Research Collaboration', which works to transform the lifelong educational experiences of people with disability through collaborative co-designed research.<sup>42</sup>

<sup>39</sup> University of Glasgow. (n.d.). Centre for Disability Research. <https://www.gla.ac.uk/research/az/centrefordisabilityresearch/>

<sup>40</sup> The University of Melbourne. (n.d.). Melbourne Disability Institute. <https://disability.unimelb.edu.au/>

<sup>41</sup> The University of Melbourne. (n.d.). CRE-DH – Centre of Research Excellence in Disability and Health. <https://credh.org.au/>

<sup>42</sup> The University of Melbourne. (n.d.). [Faculty of Education Disability Research Collaboration](#).

- **Focus on an aspect of disability inclusion but not broadly disability focused** – such as the ‘Disability, Sport and Social Activism’ Birmingham<sup>43</sup> and The Queensland ‘Centre for Olympic and Paralympic Studies’<sup>44</sup> which both includes a focus on the Paralympics but has a wider focus beyond disability. Similarly, the University of Nottingham’s ‘Diversity and Inclusion Research Hub’ focuses on projects impacting various minority groups and includes disability specific projects within this wider mandate.<sup>45</sup>
- **A point of focus within or across universities bringing together everyone focusing on disability for shared projects** – examples include the Collaborations in the Advancement of Research on Disability<sup>46</sup> and (dis)Ability Design Studio at the University of Illinois Urbana-Champaign which supports interdisciplinary design research centered around the lived experiences of people with disabilities<sup>47</sup> and the UC Davis and Yale Disability Collaboratory which brings together academics and collaborators from across communities, all to consider the intersection of research and advocacy concerning disability and chronic illness.<sup>48</sup>

Are centred around a particular large funding grant, for example:

- IDEA grant – the Canadian Government funded grant, at McMaster University, which works as a central hub for disability research at the university because of the funding available and activity that flows from the funding.<sup>49</sup> The IDEA project brings in researchers from other universities locally and internationally as well, for example being connected with the Centre for Disability Research and Policy at The University of Sydney and the Melbourne Disability Institute at The University of Melbourne.
- The Australian Research Council University of Queensland funded project ‘Normalising Ability Diversity through Career Transitions: Disability at Work’.<sup>50</sup> This project, because of its topic, also highlights the employment of people with disability within universities.
- While most projects focus on disability generally, some will focus particular attention on 1 type of disability. Many of these are long established and grew out of advocacy around particular disability types. Examples of this include the Down Syndrome Research Program within The University of Queensland’s School of Education which has been running since the 1970s<sup>51</sup> and the Centre for Disability Studies at The University of Sydney, which focuses on intellectual disability and has been running since 1997.<sup>52</sup>

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43 University of Birmingham, School of Sport, Exercise and Rehabilitation Sciences. (n.d.). Disability, sport and social activism: Developing social justice through sport.

44 The University of Queensland, School of Human Movement and Nutrition Sciences. (n.d.). Research Networks | The Queensland Centre for Olympic and Paralympic Studies. <https://hmns.uq.edu.au/qcops/research>

45 University of Nottingham. (n.d.). Diversity and inclusion research hub. <https://www.nottingham.ac.uk/research/diversity-and-inclusion-research-hub.aspx>

46 University of Illinois. (n.d.). Collaborative Working Group – Collaborations in the Advancement of Research on Disability. <https://card.ahs.illinois.edu/collaborative-working-group/>

47 University of Illinois Urbana-Champaign, College of Applied Health Sciences. (n.d.). Beckman, Dres Collaboration Launches (Dis)Ability Design Studio. <https://ahs.illinois.edu/2023-mf-bleakney>

48 Rogers, N. (2024). Communal knowledge: an experiential understanding of chronic illness. Yale News. <https://news.yale.edu/2024/02/01/communal-knowledge-experiential-understanding-chronic-illness>

49 McMaster University, MacPherson Institute. (n.d.). IDEAS grant (inclusion, diversity, equity, accessibility and sustainability).

50 The University of Queensland. (n.d.). Normalising ability diversity through career transitions: Disability at work.

51 The University of Queensland, School of Education. (n.d.). Down Syndrome research program.

52 Centre for Disability Studies. (n.d.). About CDS - Centre for disability studies. <https://cgs.org.au/>

### Part 3. U21 University case study – the Centre for Disability Research and Policy at The University of Sydney

The Centre for Disability Research and Policy was established in 2013 under the initiative of Professor Gwynnyth Llewellyn who was previously Dean of the Faculty of Medicine and Health and who was the first Director of the Centre until 2018. Since 2021 the Centre has received ongoing core funding for administration and a small operational budget from the Faculty of Medicine and Health who have prioritised the Centre as one of its 'Impact Centres' which are funded as areas of existing research strength.

The Centre has always had 3 core intertwined foci:

1. Disability focused research
2. Impacting policy and practice design within Australia
3. Improving disability inclusion at The University of Sydney

It is the latter goal here that separates it from many of the other research centres described above, but it is this goal that is probably the most important from the perspective of institutional change within the sector. This goal enables the Centre leadership to become involved in strategies such as the University's Disability Inclusion Action Plan<sup>53</sup> and its implementation and through this disability research is in turn recognised and supported by the University executive. This deals with the problem of a lack of visibility of disability research to the University, noted in our reflections on the survey responses above.

The Centre focuses on lived experience of disability in all facets of its research and leadership. This is enabled through the following strategies:

- Career development post-doctoral positions which fund researchers with disability. They have the aim of enabling the establishment of academic careers given the difficulties that many disabled researchers have in being competitive for early-career grants.
- Performance indicators that are linked to the numbers of staff employed with disability, the number of people with disability included in research teams and the number of publications that include authors with disability.
- A recruitment strategy in collaboration with the broader School of Health Sciences which prioritises the employment of people with disability in academic continuing positions, thereby boosting the number of people with disability employed in the school more broadly.

Over a number of years this has enabled a strong leadership team to emerge which is inclusive of people with disability as this was recognised as a gap in the Centre. In 2024 Professor Smith-Merry stepped down as Centre Director and Associate Professor Shane Clifton was appointed as the new Centre Director. Shane has lived experience of disability, and the Centre is now led by someone with disability for the first time. This was the culmination of many years of strategic work to ensure disability leadership and a supportive environment for that to happen.

### Recommendations

- **Support the operation of disability research groups:** The CRPD has shifted how research on disability is performed. To reflect new norms, and the opportunities it presents, universities should support the formation and operation of groups of researchers to form disability research groups.

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<sup>53</sup> The University of Sydney. (2019). Disability inclusion action plan 2019-24. <https://www.sydney.edu.au/about-us/vision-and-values/diversity/disability-action-plan.html>

- **Make disability research groups more visible:** the U21 Disability Inclusion Policy Mapping Report had support from those within U21 universities and had academics scanning websites. Despite these resources, it was challenging to identify all disability research groupings and disability led research for this chapter. The difficulties in identifying disability research groups and disability leaders reduces the ability of those keen to collaborate or commission research to do so. The challenges encountered when people sort to report on the disability research groupings and disability led research within their own university and across the U21 Network, illustrates a need to provide additional resources to coordinate and facilitate profiling of what activities are currently being undertaken across the U21 Network.
- **Universities should listen to their own disability inclusion expertise:** An analysis of the existing research groupings illustrates the benefits where universities harness their own research expertise to improve how they operate. To expand such benefits, universities should harness their disability inclusion expertise. This includes academics, research on disability inclusion, professional staff, who provide services but may not be in a specific equity role, and all staff and students, who may have experience with a disability or family member with a disability or some other connection within the disability community.
- **This formalisation process should include administrative support, institutional commitment to support research** which spans academic and operational groupings and recognising these activities in academic and professional workload allocations.

## Conclusion

The CRPD has transformed how universities should engage in research on disability. This includes in supporting disability leadership and facilitating research which advances disability rights. Although some of the disability research groupings referenced in this chapter reflect the disability human rights research paradigm, this is not uniform, and it appears not all universities are supporting disability research groups or disability leadership in those groups.

It is recommended that universities take steps to ensure their research activities align to the new disability human rights paradigm.

## Chapter 2.3.

### The power of university-wide research plans to champion disability inclusion

Paul Harpur, Helen Connick, Sarah Brown, Jean McBain, and Michelle King

#### Introduction

The undertaking of research that leads to new knowledge and original creative endeavour, along with research training, represents a fundamental and defining feature of universities.<sup>54</sup> In Australia, universities must comply with the *Higher Education Standards Framework (Threshold Standards) 2021* (Cth).<sup>55</sup> The Higher Education Standards Framework, created under section 58(1) of the *Tertiary Education Quality and Standards Agency Act 2011* (Cth), requires that universities engage in research. Specifically, to maintain status as a university, the institution must deliver doctoral degrees, demonstrates systematic support for scholarship and demonstrates scholarly activities and outcomes. The Threshold Framework requires that these research activities are conducted in accordance with a research policy framework that is designed to achieve ethical conduct of research and responsible research practices.

Even though universities have a sustained history of promoting research and innovation ecosystems, these ecosystems are not commonly disability inclusive. Persons with disabilities have been *subjects* of research, but rarely have they been research *producers*. These power imbalances in university research mean those *without disabilities* have decided what research questions are asked: leading, designing, publishing and financially benefiting from research about those with disabilities.

The United Nations *Convention on the Rights of Persons with Disabilities* (CRPD)<sup>56</sup> has responded to the disempowerment of persons with disabilities and swept in a disability inclusive research paradigm which requires States and other actors, including universities, to take strategic measures to transform how research is performed. This transformation includes how researchers with disabilities can be trained and employed as researchers and leaders of research, how research questions are determined, as well as how research is designed, implemented and published.

In 2 parts, this chapter analyses how the U21 Network universities are transforming their research and innovation ecosystems to become disability inclusive. Universities are championing the importance of disability inclusion research, and researchers living with disability, within their overall research endeavours. Part 1 illustrates how these changes in university practices reflect shifting norms in society and human rights. Part 2 advocates for university-wide inclusive research and uses the Disability and Inclusion Action Plan as a case study. The chapter concludes with recommendations to help champion transformative change for inclusive university research.

#### Part 1. Universities promoting a disability inclusive research environment

U21 Network universities have adopted a range of measures to create a more disability inclusive research and innovation environment. Some universities adopt measures which address one aspect of the research endeavour, for example, KU Leuven's focus on encouraging research on the

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<sup>54</sup> TEQSA. (2004). [Guidance note: Research requirements for Australian universities](#).

<sup>55</sup> Department of Education, Australian Government. (n.d.). [Higher Education Standards Framework](#).

<sup>56</sup> Convention on the Rights of Persons with Disabilities. (2007). *Human rights, 2515 U.N.T.S 3, entered into force generally May 3, 2008*. United Nations. <https://treaties.un.org/>

disablement of persons with disabilities.<sup>57</sup> Universities also seek to reduce the disabling impact of research environments through providing reasonable accommodations / adjustments. The University of Glasgow's Equality and Diversity Policy, for example, applies to research and requires Heads of School, Directors of Research Institutes or Heads of Service, with support from the appropriate Human Resources Manager, to ensure that reasonable adjustments are made for disabled employees.<sup>58</sup>

However, more comprehensive responses are required. The University of Melbourne's Disability Inclusion Action Plan 2023 – 2026, for example, includes a commitment to develop "an approach to support researchers, graduate researchers and staff with disability to engage in research on an equitable basis with their peers".<sup>59</sup> Similarly, The University of Sydney's Centre for Disability Research and Policy and Faculty of Medicine and Health Impact Centre, supported by The University of Sydney Disability Inclusion Action Plan presented the first university-wide forum on Lived Experience-led Research.<sup>60</sup> The resulting Call to Action - Lived Experience-led Research at The University of Sydney includes calls for increased attention to enabling academics and staff members with disabilities to produce lived experience-led research, and to address the lack of opportunities for academics, staff, and students with lived experience of disability in educational and research institutions. Similarly, participants in a University of New South Wales Public Service Research Group workshop identified that changes to university systems, structures and processes are necessary to realise disability inclusive research.<sup>61</sup> Participants identified needs for building effective system-wide disability research capacity that include:

- The need for senior champions and sponsors within universities, who advocate, and provide opportunities for people with disability. For example, appointing a Pro or Deputy Vice-Chancellor (PVC) Disability, responsible for overseeing the education and engagement of people with disability (similar to the appointment of PVC Indigenous Engagement).
- The need for greater disability representation in leadership roles, particularly to help address inherent power imbalances.
- The need for greater accessibility, including physical accessibility to buildings and workstations; accessible information technology such as screen readers, captioning services, accessible websites and databases, and facilitating participation in seminars, tutorials, meetings, etc on applications such as Zoom or Teams; and other reasonable adjustments to enable performance.
- The need for psychological safety for students and researchers with disability.
- The need for affirmative action measures, such as quotas.
- The need for dialogue regarding ableism in universities and how it manifests, such as in performance expectations regarding funding and publications, collegial attitudes and perceptions of research quality.

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57 KU Leuven. (n.d.). *Research unit education, culture and society*. <https://ppw.kuleuven.be/ecs/english>

58 University of Glasgow. (2019). *Equality and diversity policy*. <https://www.gla.ac.uk/media/Media.pdf>

59 The University of Melbourne. (2023). *Disability Inclusion Action Plan 2023 – 2026*.

60 The University of Sydney. (2023). *Call to action - Lived experience led research at the university of Sydney*. [https://www.sydney.edu.au/faculty-of-medicine-and-health/centres-institutes-groups/centre-for-disability-research-and-policy-calls\\_to\\_action\\_lived\\_experience\\_research.pdf](https://www.sydney.edu.au/faculty-of-medicine-and-health/centres-institutes-groups/centre-for-disability-research-and-policy-calls_to_action_lived_experience_research.pdf)

61 University of New South Wales Public Service Research Group. (2022). *Building effective system-wide disability research capacity in Australia*. <https://unsworks.unsw.edu.au/>

- The need to facilitate “crip time” for researchers with disability: this involves accepting and supporting researchers with disability to operate within the limits of what their minds and body can do.
- The need for more disability specific PhD scholarships and postdoctoral fellowships, with top-ups available if required, to provide sufficient time to complete research (i.e. 3-5 years).
- The need for unconventional and non-traditional career pathways that enable people with disability to enter, and remain in, academia. This would enable more representation of people with disability in research teams.

The need to actively include persons with disabilities can also be found in documents approved by university leadership. For example, The University of Melbourne’s Disability Inclusion Action Plan 2023–2026 has been approved by the university executive (2023). Clause 3.5 of this plan calls upon the university to facilitate expert advice on university projects. A Community of Practice was recommended as one measure to facilitate collaboration. This Community of Practice is intended to enable internal disability experts to promote innovation and lead practice across the university and assist in developing a university-wide culture of inclusive research.

## Part 2. The adoption of a university-wide research and innovation plan: Champions of Change – Disability Inclusion Research and Innovation Plan 2024-2026

The University of Queensland (UQ) *Disability Action Plan 2018-2021* contained a commitment that the University would support disability inclusion research which advanced its disability inclusion initiatives.<sup>62</sup> UQ’s *Disability Action Plan 2018-2021 End of DAP Report*<sup>63</sup> identified that UQ should expand its efforts to promote disability inclusive research and should, *inter alia*, create a disability inclusion research community of practice.

UQ’s *Disability Action Plan 2022-2025* contains a commitment to create a university-wide research plan and university-wide disability research group to help advance this agenda.<sup>64</sup> To meet these commitments, UQ is co-designing a university-wide comprehensive disability inclusion research plan: the *Champions of Change Disability Inclusion Research and Innovation Plan*.<sup>65</sup>

The *Champions of Change Disability Inclusion Research and Innovation Plan* is a blueprint for enabling disability research, and researchers, across the University. It includes 24 actions aimed at supporting researchers with disabilities, enabling partnerships to support disability research, and driving research excellence. The measures in the Plan include commitments on specific actors in the university to achieve outcomes. In addition to a disability-led disability research network supporting the Plan, the Plan includes reporting through the University’s standard key performance indicators for research initiatives. This includes providing additional support to postgraduate research degree students and staff with disabilities, such as promoting universal design, and improving support for researchers with disability in evidencing research achievements in grants applications. The Plan also deals with how knowledge is created in the University. It includes a commitment to promote best-practice in co-design and co-production of knowledge. These (and other) measures aim to transform the University’s entire research and innovation endeavour to one

62 The University of Queensland. (2018). *Disability action plan 2018-2021*. <https://www.capa.edu.au/libraryfile/university-queensland-disability-action-plan-2018-2021/>

63 The University of Queensland. (2022). *Disability action plan 2018-2021 end of DAP report*. <https://staff.uq.edu.au/disability-action-plan-2018-2021-end-of-DAP-report.pdf>

64 The University of Queensland. (2023). *Disability action plan 2022-2025*. <https://staff.uq.edu.au/DisabilityActionPlan.pdf>

65 The University of Queensland. (2024). *Champions of change: The University of Queensland disability inclusion research and innovation plan 2024-2026*. [disability-inclusion-research-innovation-plan-design-version.pdf](https://staff.uq.edu.au/disability-inclusion-research-innovation-plan-design-version.pdf)

that champions disability inclusion and realises the vision set out in the CRPD's disability inclusive research paradigm.

To support the facilitation and growth of cross-disciplinary collaborations, the *Champions of Change Disability Inclusion Research and Innovation Plan* commits the University to establish a disability inclusion research network. Resources were provided to support staff and students with disabilities, those with disabilities in their families, and disability allies to come together to co-design a research network. Between October 2024 and January 2025, over 100 staff and students explored how this research network should be structured and branded to use the University's research and innovation strengths to help create a more disability inclusive world.

## Recommendations

- a) **Adopt Comprehensive disability inclusion research and innovation plans:** Universities should develop and implement comprehensive disability inclusion research and innovation plans that align with their overall strategy. These plans should include clear institutional commitments to change and be integrated into the University's broader research ecosystem.
- b) **Monitoring and KPIs:** Establish key performance indicators (KPIs) to monitor progress and ensure accountability. Regularly review and report on these KPIs to track the effectiveness of disability inclusion initiatives.
- c) **Capacity Building:** Invest in capacity building for researchers with disabilities. This includes providing training, resources, and support to enable them to engage in research on an equitable basis with their peers.
- d) **Resourcing and Support:** Allocate sufficient resources to support disability inclusion initiatives. This includes funding for reasonable accommodations, accessible infrastructure, and support services for researchers with disabilities.
- e) **Leadership and Representation:** Increase representation of people with disabilities in research and innovation leadership roles within the University generally as well as supporting their collective activities through a research community of practice, group or network. This helps address power imbalances and ensures that the voices of people with disabilities are heard and valued in decision-making processes.

## Conclusion

**Universities should produce the research and innovation which promotes and enables the creation of a more disability inclusive world. To realise this vision, university research cultures and systems must embrace the CRPD's disability inclusive paradigm to truly champion transformative change. Ad hoc and disjointed measures will not suffice in delivering the capacity for universities to be leaders in disability inclusive research. Comprehensive and strategic approaches are essential to ensure that research and innovation ecosystems are inclusive, equitable, and supportive of researchers with disabilities.**



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