Disabled Honi



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ACKNOWLEDGEMENT OF COUNTRY

The SRC Disabilities Collective and SUPRA Disability and Inclusion Network recognise that our activism, advocacy and work happens on stolen, unceded Gadigal Land of the people of the Eora Nations who have, for countless generations, been the custodians of this Land. Indigenous peoples have had to endure significant injustices, despite being one of the oldest living cultures in the world. We are particularly indebted to disabled First Nations activists who fought and continues to fight against. We are committed to raising Treaty and Truth-telling within our activism as pillars of Indigenous justice going forward.

In our activism and work, we will uplift the perspective, voice and experiences of First Nations peoples in order to dismantle the colonial and ableist systems of oppression that plague every aspect of this colonial state for these systems of oppressions are intertwined.

Always was, Always will be Aboriginal Land.

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EDITOR IN-CHIEF

Khanh Tran, Gemma Lucy Smart and Jack Scanlan.

EDITORS

Hūhana Jade Barclay, Simar Batra, Iggy Boyd, Gian Ellis-Gannell, Sandra Kallarakkal, Annabel Li, Jack Scanlan, Gemma Lucy Smart, Khanh Tran, Victor Zhang.

WRITERS

Jade Barclay, Simar Batra, Gian EllisGannell, Lisa Gronich, Sandra Kallarakkal, Suhaila Mahafza, Jack Scanlan, Gemma Lucy Smart, Khanh Tran, Theodore Tsolakis, Victor Zhang, Kate Zhang.

ARTISTS

Hūhana Jade Barclay. **COVER ARTIST**

Bipasha Chakraborty.

BACKCOVER ARTIST

National Tertiary Education Union.

GET IN TOUCH

This publication was made possible by a collaboration between the Students' Representative Council (SRC) and Sydney University Postgraduate Students' Association (SUPRA). Get in touch with us via email at:

SRC: disabilities.officers@src.usyd.edu.au **SUPRA:** disability@supra.usyd.edu.au

EDITORIAL

By Khanh Tran, Gemma Lucy Smart and Jack Scanlan.

It has been an incredibly tough year for disability justice in Australia with the recent release of the final report of the Disability Royal Commission and relative dearth consideration of for disabled tertiary students in Labor's flagship Universities Accords. At the same time, it's also been a year when disability has been thrust into the spotlight, at the University and across the nation. It feels like finally disability matters are getting some of the attention they deserve.

The SRC Disabilities Collective and SUPRA Disability and Inclusion Network have been working hard with the opening of the disability space at the end of this year bringing a lot of hope for the future of the collective and network, and building a large and diverse generation of disabled

Tran, activists and a growing disabled community on campus. Disability Inclusion Week 2023 was the best we've seen yet, and we're super proud to bring you our first jointly funded and produced Disabled Honi.

We thank our amazing contributors for their tireless work, thought and care for the edition. There are many articles to highlight but we think that you will enjoy Lisa Gronich and Sandra Kallarakkal's investigation disability inclusion at our campus, Jade exposition **Barclay**'s of what genuinely inclusive research looks methodology like, and Theodore Tsolakis' explainer on person-first versus identity-first language to get you thinking about disability pride.

Activism does not stop when the year comes to an end. Through collective organising, we can tear down the disabling barriers we face.

What is Disability?

People with disabilities are defined as those "who have long-term physical, mental, intellectal or sensory impairments which in interaction with various barriers may hinder their full and effective participation in osciety on an equal basis with others". as per the *United Nations Conventions on the Rights of Persons with Disabilities*. A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).

Disability can be permanent or temporary, visible or invisible. And in the context of higher education it's important to appreciate that having a disability does not mean one is less suited to be a university student, it just means that one might need accommodations and support to achieve academically.

Discrimination on the basis of disability is prohibited by the federal *Disability Discrimination Act 1992* and the *Disability Standards for Education 2005*, these laws enshrine in law the rights of disabled studens to access education "on the same basis" as non-disabled students.

You have the right to:

- Use an assistive device or mobility aid
- Be accompanied by a carer, interpreter, reader, or an assistant
- Be accompanied by a guide or hearing dog or other trained assistant animal
- Access reasonable adjustments for lectures, tutorials and assessments so that you are not disadvantaged by your disability
- Access lecture materials in a format that you can understand
- Seek redress for abuse or harassment on the basis of disability

Inclusion and Disability Services (IDS)

IDS is the main point of contact for accessing disability accommodations during your study. Some of the adjustments they can arrange include:

- Assessment and exam adjustments, including extra time, smaller exam rooms and use of a computer.
- Timetable adjustments
- Alternative formatting
- Access to assistive technology
- Lecture support

Contact Inclusion and Disability Services:

Phone: +61 2 8627 8422

Email: disability.services@sydney.edu.au

Fax: +61 2 8627 8482

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Leading disabled scholar appointed to School of Health Sciences

Khanh Tran reports.

Former Assistant Policy and Commission Shane Cliton speaks on his four years in role and future work at the University of Sydney.

Associate Professor Shane Clifton has been appointed to an associate professorship at the Faculty of Health and Medicine. In 2010, Clifton had a spinal cord injury leading to incomplete quadriplegia.

Prior to his appointment, Clifton spent four years as a researcher and Policy Director at the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability or the Disability Royal Commission.

Clifton's ties with Sydney University dates back to 2013 when he joined the University's Centre for Disability Research and Policy as an honorary associate to write *Crippled Grace: Disability, Virtue Ethics and the Good Life.* He was also interviewed by Disabled Honi last year in an article on virtue ethics and disability.

Talking to *Honi*, Clifton is frank about the lack of justice for disabled people in Australia, with ableism, "paternalistic and dehumanising attitudes" driving violence and abuse on disabled people.

"What has stood out to me most in my four years at the Commission has been the strength and resilience of people with disability and their families. This was apparent in the courage needed to share difficult stories with the Commissioners and the countless ways they have fought against the violence, abuse, neglect and exploitation perpetrated against them," he said.

"The nature extent of maltreatment is shocking, as is the segregation and exclusion of people disability with too much mainstream Australian life."

Clifton is also noted for his campaign for academic freedom and support for LGBTQ+ inclusion in the evangelical Pentecostal Church when he resigned in 2018 after a protracted

battle. Clifton was formerly Dean of Alphacrucis College, the theological seminary for the Australian Christian Churches and Assemblies of God, including Hillsong.

In the aftermath of the Disability Royal Commission, he urged governments, both state and federal, to implement its recommendations, especially with regards to the call for a disability rights act.

"Governments need to grapple with the report and implement its recommendations, and I hope they take the bold step of enacting a disability rights act."

According to Dr David Roy in *The Conversation*, a disability rights act differs from the existing disability discrimination laws in that it reverses the burden of proof in alleged discrimination from complainants to the defendant.

This includes changing how reasonable adjustment is structured



so that alleged perpetrators of disability discrimination take on the onus to prove that they did not discriminate. One major criticism of the existing reasonable adjustment regime from the Disability Royal Commission is that it creates "little incentive for employers, schools, service providers and other duty-holders to take active measures to prevent disability discrimination".

"Governments need to grapple with the report and implement its recommendations, and I hope they take the bold step of enacting a disability rights act."

Now, at the University of Sydney, Clifton wants to focus on the "happiness, strength and wellbeing of people with disability" in his research, including "strategies for attitudinal change and promoting an inclusive society".

"Disability studies is about life and its meanings, vulnerabilities and strengths and thus stimulates rich classroom conversation."

Sydney Law School establishes two scholarships for disabled students

Khanh Tran reports.

Edisabled in recognition of two renowned disabled legal academics, the first cohort of David Benjafield Scholarship and Ron McCallum Interns will commence in early 2024.

Following the launch of a lecture series, the University of Sydney Law School has announced two scholarship programs for disabled law students. The two programs will offer paid work experience in the legal profession and students will get a chance to work in an organisation that helps marginalised and disadvantaged communities.

The David Benjafield Scholarship, named after Professor David Benjafield (1919-1980) who was a founding member of the New South Wales Law Reform Commission, he also presided as Dean and taught at Sydney Law School for more than twenty years. The Scholarship is open to both undergraduate and postgraduate students in the Law School.

"The goal is to help students navigate and challenge structural inequalities and lack of accessibility for disabled students in the legal field,"

Another program, the Ron McCallum Internship Program, takes its name after Emeritus Professor Ron McCallum. Both provide an opportunity for a disabled law student to work with organisations, including community legal centres such as the Public Interest Advocacy Centre (PIAC).

McCallum is the first totally blind academic to secure a full professorship at any university in Australia or New Zealand when he was appointed as the inaugural Blake Dawson Waldron Professor of Industrial Law in 1993. He also served as Dean of Sydney Law School for five years between 2002 and 2007 and was a special advisor to the Disability Royal Commission.

Established in 1982, PIAC is a renowned community legal centre offering free legal advice to people who are homeless or at risk of homelessness. The body also provides legal support for public interest cases, including reforms to strengthen disability anti-discrimination laws.



Speaking to *Honi*, Sydney University Law Society (SULS) Disabilities Officer Lucas Kao said that the impetus behind the scholarship and internship programs were to represent and combat obstacles in the legal profession facing students with disabilities.

"The goal is to help students navigate and challenge structural inequalities and lack of accessibility for disabled students in the legal field," said Kao.

"In inspiration of their careers and the impact they have made, the two programs were made to honour them whilst hoping to build support for current and future generations of law students."

The organisation also has strong ties to student unions on campus, notably assisting the Students' Representative Council (SRC) in a successful case against the University of Sydney on HIV discrimination between 1993 to 1996 soon after the Disability Discrimination Act came into force. The case ended in a settlement and the University retracted its previous position of effectively barring students who tested positive to HIV, Hepatitis B or Hepatitis C from graduating.

Expression of interest for the two programs will open in late October or early November this year. The first cohort of David Benjafield and Ron McCallum interns will take their positions in the first half of 2024.

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The Hidden Disability Flower and what it means

Gemma Lucy Smart reports.

You may have noticed folks on campus wearing some interesting green lanyards with yellow sunflowers on them. These are not just a pretty accessory, they are a sign that someone has a hidden, invisible or non-visible disability. It's all part of the Hidden Disability Sunflower Initiative, which the University has decided to formally partner with from 2023

Certain disabilities, medical conditions, or chronic illnesses may not be readily apparent. This lack of immediate visibility can pose a challenge when it comes to comprehending and acknowledging the legitimate need for support in individuals with "invisible" conditions, as the disability remains hidden from view.

Hidden Disabilities Australia describes The Hidden Disabilities Sunflower as "a simple tool for you to voluntarily share that you have a disability or condition that may not be immediately apparent – and that you may need a helping hand, understanding, or more time in shops, at work, on transport, or in public spaces".

Daniel Smith, Project Manager, Disability Inclusion Action Plan (DIAP), at the University of Sydney explains why the University decided to join the Hidden Disability Sunflower Initiative:

"We're proud to join the growing number of workplaces and institutions that support the Hidden Disability Sunflower Initiative in Australia. Supporting this initiative is part of our commitment to students, staff and visitors with disability outlined in our Disability Inclusion Action Plan. We want members of our community with hidden disabilities to feel supported during their time at the University – the Sunflower Lanyard is a great way for people with disability to identify themselves should they need a little extra help, understanding, or more time."

Individuals with non-visible disabilities make an autonomous choice to wear the sunflower as a way to communicate with those around them that they may have access needs. Student disability advocates were central in securing the University's commitment to the initiative.

Rosie Bogs, Faculty of Medicine and Health (FMH) student and the DIAP Implementation Committee's Postgraduate Coursework Representative shares why they were keen to get the University on board with the initiative:

"Wearing a sunflower lanyard gives me the extra confidence to ask for help when I need it from people who recognise its significance. It's important to me that they were recognised on campus because uni is a big part of my life - and so are my disabilities. It gives me a sense of community, too."

So, what do you do if you encounter someone wearing a Sunflower Lanyard? It depends on context. If you're simply passing someone in a public area or sitting next to them in a lecture hall, you probably don't need to do anything. If you're in a service role, teaching, or running an event, reach out to folks wearing the lanyard.

"We want members of our community with hidden disabilities to feel supported during their time at the University - the Sunflower Lanyard is a great way for people with disability to identify themselves should they need a little extra help."

A respectful and effective approach when initiating a conversation with someone is to say, "Hello, I noticed you're wearing a sunflower lanyard. Is there anything I can do to assist you today?"

Pay close attention and take cues from them regarding the support they require. Avoid inquiring about their specific disability or making assumptions about their abilities or needs. Instead, focus on offering solutions (if they want them) and being considerate. If the person has a caregiver present, address the individual with the disability directly.

Respect and kindness go a long way.

Where can I get a sunflower lanyard?

Sunflower lanyards are provided free of charge to the University community.

Students can get a lanyard through the University's Inclusion and Disability Services team, the SRC, or SUPRA.

Staff can get a lanyard by emailing the Diversity and Inclusion team:

diversity.inclusion@sydney.edu.au.

National Institutes of Health designates people with disability as a population with 'health disparities'

Hūhana Jade Barclay reports.

On 26th September 2023 the National Institutes of Health (NIH) officially designated people with disabilities as a population with health disparities. The NIH is the largest funder of medical research in the world, and specifically monitors minority health and health disparities research, but until now the organisationy has not included funding or monitoring for the health disparities, discrimination, or intersectional barriers faced by disabled people.

It seems that acknowledging and researching health disparities comes as a natural consequence for groups that fight for civil rights, and this delay is no surprise as disability rights are a long way behind the rights of BIPOC, gender, and LGBTQAI+ communities.

This new designation comes with two bonuses:

- (1) New funding opportunities for research into understanding and addressing the intersecting impact of disability, race and ethnicity, and socioeconomic status on healthcare access and outcomes.; and
- (2) Revising the NIH's mission statement to remove the phrase "reduce illness and disability". As we don't say "reduce gender" or "reduce race", this will be more inclusive of the disability community who have raised concerns about the eugenicist undertones of the old phrasing.

Public consultation is open now until 24 November 2023 to suggest more inclusive updates to the NIH mission statement.

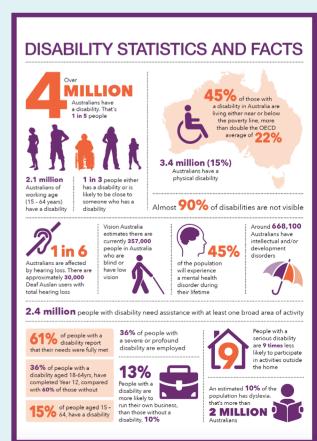
"The NIH now acknowledges that people like me exist, that we face health disparities, and that our health and lives are worth living in. While it may seem like a formality, as a disabled First Nations women in STEM, living with and researching disability and health disparities. [I've seen the] blind spots and data deserts."

The NIH now officially acknowledges that people like me exist, that we face health disparities, and that our health and our lives are worth investing in. While it may seem like a formality, as a disabled First Nations woman in STEM, living with and researching disability and health disparities, I have directly seen how this lack of designation has led to blind spots and data deserts in medical research and healthcare



services.

This development news is freeing, and brings relief and hope. It frees up people like us to be a little bolder, speak a little louder, and stop wasting precious time and energy constantly justifying things that are obvious to those who live and work in those intersectional blind spots.



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Do You Even Accessible?

Gemma Lucy Smart ranks the best and worst buildings for accessibility.

"They've got enough money for a meditation room, but not for a lift that works. I've complained so many times."

Isaac, Sex Education Season 4.

Sound familiar? Season 4 of the glorious TV series 'Sex Education' brought us some well earned disability representation - including the deep and consistent frustration with the lack of building accessibility at a rich and outwardly inclusive institution. So after swearing at a broken lift yet again I decided our buildings needed a thorough and seriously satirical investigation to rank them. Because who doesn't love a hypercompetitive critical academic lens applied to inanimate objects that can't defend themselves?

So here they are, our best and our worst as voted by vou dear readers *drum roll please*

BEST

Abercrombie Building (ABS)

Lush staircase AND working lifts? What a dreamboat. Leading the charge for the best buildings on campus is the signature social media ready home of the Business School. The ramp to the front of this one is as inviting as, well, a really good ramp and decidedly worth the bumpy trip TO it. All the rooms have accessible features and if you're lucky you even get to have a class in one of the trial multifunctional teaching spaces that have diverse seating options and a funky layout. ABS, you sexy thing. In case you've not found this treasure yet, ABS can be found on the corner of Abercrombie Street and Codrington Street, and she has a cafe inside so it's worth a visit.

9/10

Sydney College of the Arts (SCA, Old Teachers College)

A bit of a dark horse entry, for one of the older buildings on campus SCA punches above its accessibility weight. It gives you the world class aesthetics of a heritage venue we all know we partly went to this University for, and if you can work out the entrance (why are there ramps to the stairs? Where is the main ramp?). The lifts are turtles, not hares – but they work, there are hearing loops in most rooms, and the accessible bathrooms have automatic doors!



'The look of love': USU Board Doyenne Alexander Poirier

As former SRC Disabilities and Carers Officer Robin Eames tells me the fact that they announce when you're using them is ... less than ideal but hey I don't know maybe you like everyone knowing you're about to pee I don't judge.

The Conservatorium of Music

The Conservatorium of Music gets a special mention 3.5/10 for being 100% accessible which means between SCA and the Con our artistic and musical colleagues are onto a good thing here. Only drawback is I've been by Conservatorium Students' Association President Alexander Poirier that the lifts take 10294720842037 hours to move one floor because they also have to move pianos. All the signage in the building has tactile braille though, even the Students' Association, so the Conservatorium gets a free pass for having to move big delicate objects and not just disabled students. Turns our it's a symphony of accessibility in there. 7.5/10

Honourable Mention: The Charles Perkins Centre: what can we say, we like our grand staircases at the University of Sydney. Pair them with working lifts made of glass and you have another case of delightfulitis. Plus they do cool interdisciplinary work to improve global health in that building, always a bonus. Close to RPA, sporting accessible features and a concierge... meow what a catch.

WORST

Wentworth Building

Taking out the crown for worst building on campus is the home of the SRC, the Wentworth Building. As Disabilities and Carers officer Khanh Tran quotes: "As much as I hold the Langford Office and the SRC very close to my heart, the serial lack of windows, crumbling ceiling and dangling wires is a hazard waiting to pounce. This is before mentioning the woefully unreliable old lifts at the back of the building. Meanwhile, the maze inside the second floor is almost as if I'm in a game of Pacman." I've also been known to swear at the lifts in this building, and the sushi place deserves an accessible entrance dammit.

3/10

The Quadrangle

She may be pretty, but once you scratch the surface it's a hot mess. Ah the beautiful but inaccessible Quad. Jewel of Camperdown and nightmare for those of us with mobility issues, or needing an accessible bathroom, or like, basically human. Some rooms on the ground floor have been made accessible and props to the University for this, but there are large parts of the building that cannot be accessed except by the most spritely and able-bodied among us, and the room numbering is a nightmare. Perhaps some of the Engineering buildings or Wallace should be taking this spot, but the Quad is in our promo material, and

we deserve better.

The Chemistry Building

Old, hot, stinky. Do we even like Chemistry anyway? Just kidding, I love my chemistry colleagues and reckon they deserve better than a confusing rabbit den of a building with a temperature regulation problem. As Disability Inclusion Action Plan Postgraduate Representative Rosie Bogs quips: "What is with that gigantic bottom step? and why is the 'warning' label on one side only? you can see it on the way up but not the way down. It's also painful to find the lifts in that place." I know I've spent more time than I would have liked walking round in circles in that building!

Dishonourable Mention:

The Holme Building houses many things including SUPRA and while it is definitely a cut above the home of the SRC, its accessible features are often lacking or broken. The Courtyard Cafe gets a tick for good food, but time in the naughty corner for consistently blocking a clear path to the tiny lift.

4.5/10



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Inaccessible Institutions?

Sandra Kallarakkal and Lisa Gronich investigate the barriers to disability inclusion in universities.

Universities view themselves as places for 'highly gifted' members of society. Getting a degree is commonly viewed as the outcome of passing a series of academic obstacles, often many at once, under intense stress and scrutiny. Being able to pull off these hardships, fulfil them, and exit the other side unscathed is what a good student is expected to have done by the end of their time in university. Completion and acquisition of a degree is thereby an acknowledgement of their ability to survive this tough environment and emerge victorious on the other side. When a student does not meet these expectations set out by the university, it is seen as a defect of the student, rather than of the institution or system itself.

In Australia, universities are bound by the federal Disability Discrimination Act 1992 (DDA) and Disability Standards for Education 2005 (DSE) to ensure higher education is accessible to disabled students. Universities are legally required to provide reasonable adjustments for disabled students to remove barriers and make tertiary study as accessible as it is to their non-disabled peers. However, there is a lack of structural and institutional support afforded to ensure such adjustments and accommodations are implemented - much of the onus in ensuring access to these adjustments is placed on the shoulders of disabled students themselves.

Universities base their support of a student's disability through student registration with the university's accessibility and disability services. Within this context, registration is evidenced by a clinical diagnosis. This already poses many problems for students trying to access support. Getting a diagnosis is often an incredibly time-consuming and sometimes very expensive process, and is therefore not readily available to

everyone who requires it.

Diagnoses, especially for chronic and mental illnesses, often also cannot be given instantaneously, as they require a person to be experiencing difficulty over a long period of time in order to qualify. Whilst there are valid reasons that the system of diagnosing a condition is set up this way, in a university context it leaves those struggling from an undiagnosed disability unsupported, often for years at a time.

If a student is unable to seek a formal diagnosis, either due to essential commitments, cost, lack of disability awareness or because of how taxing the process inherently is, then they are left to rely on simple extensions and the kindness of lecturers to attempt to support them throughout the semester. A formal diagnosis can unlock a world of potential adjustments and accommodations for a student, and can be the difference between passing or failing a course, a semester, or a whole degree.

After acquiring a diagnosis and registering for accessibility accommodations, the next step is a meeting between university support staff and the student affected to figure out what accommodations are needed. This meeting is important in understanding how a condition uniquely affects a student, however, in practice, this meeting can easily become one of the student trying to prove how their disability affects their ability to participate in university to the support worker. This often involves having to put on a persona that emphasises their disability and having to view past experiences through a medicalised lens of disability in order to justify the request for

accommodations.

This process removes a large degree of agency from the student experiencing difficulty, and their whole journey to accessing support for their disability is mediated by others in a way that neglects their self-determination. They must receive a diagnosis from doctors, be validated in their struggles by university support staff, and receive adjustments ultimately decided on by the university itself.

Moreover, the effectiveness of adjustments available to disabled students depend heavily on what students' needs are. Gemma Lucy Smart, Sessional Academic at the University of Sydney and SUPRA's Disabilities Equity Officer, explained that the system is straightforward if students' access needs are.

"For instance, if a student requires assistive technology and it's standard then they will get access to that no issue and it's wonderful."

Theodore Tsolakis' experience reflected this. As a blind Law student at USyd in his first year of a JD, Theodore is able to use his own assistive technology customised to his preferences for exams, with his academic plan (AP) requiring he receive readings as accessible Word documents and lecture slides as PowerPoint slides. He noted that these adjustments, as well as exam accommodations, were usually "very easy to arrange".

More complex situations and needs require further support. However, a majority of adjustments available for students tend to be generic blanket provisions, and not always inherently geared toward the individual. For example, assessment extensions are a common adjustment available through APs. While this adjustment can be helpful if a student needs extra time to complete tasks due to health reasons or carer commitments, if a student has trouble initiating

initiate tasks, and oftentimes it can approved. As Robin Eames, PhD result in putting off tasks for longer.

Hannah Rose, a third-year Arts student, noted that while Inclusion and Disability Services (IDS) can easily facilitate extension adjustments, other barriers, such as attendance requirements, are harder accommodate.

APs can mention that a student's attendance may be disrupted due to their disability, and that this should not be taken as a student showing disinterest or lack of commitment in the unit. Depending on the supporting medical documentation, the AP may advise university staff to 'take this into consideration when reviewing their attendance record' or to apply 'relaxed attendance requirements'. However, this does not guarantee any directly actionable adjustments. An adjustment like this can easily be missed by staff – it only informs them

candidate and former casual staff member at USvd, explained "disability services and special considerations run on separate systems and aren't built with fluctuating or episodic disabilities in mind.

"I've had a special cons application rejected because an emergency ward discharge report for a dislocated shoulder didn't specify a period of debility."

These complex overlays of multiple different systems also mean that information about a student's disability and the accommodations required does not always find their way to the people who need to implement these accommodations.

Theodore also noted that he has had to often justify his requested adjustments in receiving hard copy exam papers in Braille.

tasks, extra time doesn't help them that special considerations will be Sydney Medical School was removed from his position as a Unit of Study coordinator due to a dispute over disability exam adjustments, where he maintained that access to these adjustments granted to students meant that those students did not meet Australian Health Practitioner Regulation Agency's (AHPRA) accreditation guidelines. Similar sentiments exist in other professional and prestigious degrees with attached accreditation boards, such as Law and Engineering, although it is likely such sentiments fly under the radar.

> Smart notes that while an optional Disability Confidence Training is available to staff, it is often booked out. She highlighted that a new training module is currently in development for staff to ensure they are equipped with the necessary knowledge to navigate disability adjustment systems and understand their formal policy obligations. Hopefully, this helps curb

Universities are legally required to provide reasonable adjustments for disabled students to remove barriers and make tertiary study as accessible as it is to their non-disabled peers. However, there is a lack of structural and institutional support afforded to ensure such adjustments and accommodations are implemented.

of the issue, rather than enforcing any solution to this problem that has already been identified due to a student's disability. Rose's experience reflected this.

"[Attendance is] particularly tough with classes that [also] have a participation mark as part of the overall grade of the subject. Because when I can attend, sometimes being able to speak up in class can be physically as well as mentally challenging. So then the teacher would mark my participation poorly, assuming I wasn't trying. I feel like I shouldn't have to explain that my flare ups or exacerbations of my disability which make it difficult for me to attend class are unpredictable and I can't plan them," she explains.

As Rose's experience highlights, disability adjustments are also often based on a static view of students' conditions. If it is not static, students are referred to special considerations. However, there is no certainty

"I've gotten the question "do you really need that?" on more than one occasion to which I've had to reply "yes, I do [for reasons depending on the particular unit], my AP says I'm entitled to it, and I've requested it far enough in advance that there should be adequate time to prepare it," he said.

Inconsistent levels of staff understanding disability on adjustments is a problem endemic at the University. Smart notes that some staff view APs as optional, rather than a necessity for disabled students because they do not "fully understand their obligations under University policy and the DDA". This lack of understanding speaks to a larger issue surrounding disability adjustments the myth of a 'disability con'.

The presumption that people are 'faking' disabilities to gain unfair advantages, 'disability con' can undermine the implementation of disability adjustments in APs, even after being approved. Just last year, an Associate Professor at the University of

'disability con' conceptions.

Despite the many misconceptions about the needs of disabled students, the silver lining is that Disabilities Officers working at Inclusion and Disability Services genuinely care about their work and do their best to advocate for provisions to help disabled students. The problem lies not with them, but more so in the rigid structure that disability accommodations must follow, and the flawed administrative systems in place to deal with disability. Hopefully, by following the lead of frontline staff and respecting the self-determination of those with disability, we can work to eradicate some of the barriers that disabled students face in accessing accommodations that help them participate in university life.

12 | LANGUAGE LANGUAGE | 13

Disability, Disabled, Different: Demystifying the Disarray

Theodore Tsolakis dissects the differences between identity-first language (PFL) and person-first language (PFL).

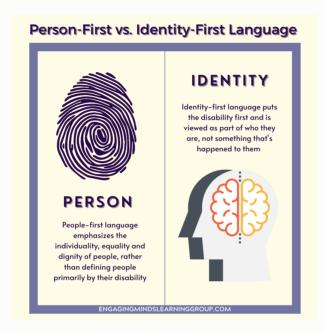
There are — in general — two ways of referring to **I** people with disability. Why isn't there consensus, and which method should vou use?

One approach, which is called person-first language (PFL), involves using phrasing such as "people with disability" and "person who is blind". Its most vocal proponents include governments and some organisations that provide advocacy for people with disability. they say that it reduces the stigma surrounding disability by avoiding objectifying language so that people with disability are viewed as individuals who are first and foremost people who "just happen to have" a disability.

"I believe that the optimal strategy when communicating about disabled people is to use the language that the particular person or group prefers; and in cases where there is a lack of consensus, it is best to include a mix of PFL and IFL."

Academics have argued that this framing will lead to people who do not have disability having a more positive impression of those who do. Supporters of PFL also claim that focusing on personhood will ensure that people with disability are not viewed as a homogenous group. Finally, they suggest that this phrasing may result in people with disability having a more optimistic attitude towards society and their place within it.





Person-first vs. Identity-first language

PFL is contrasted with identity-first language (IFL), which involves phrasing such as "disabled people" and "blind person". Its proponents, who are largely disabled people and advocacy organisations led by disabled people, point to the lack of evidence that PFL reduces stigma and the recent suggestion that it might actually have started intensifying stigma. They also claim that a double standard has been created because PFL is only used to refer to disabilities and medical conditions, while IFL—with the notable exception of "people of colour"—is used to refer to all manner of identity characteristics.

For example, contrast the phrasing "child with brown hair" with "brown-haired child", "woman who is pregnant" with "pregnant woman" and "man who is

> middle-aged" with "middle-aged man"; the latter is undoubtedly much more frequent. Finally, opponents of PFL also point to the repetitiveness and clumsiness brought about by additional words.

> Several groups of people with disability began to use PFL in the second half of the twentieth century of which the most famous is probably the PeopleFirst movement, which emerged in the 1970s,

but its rise to prominence occurred in the 1990s when simplistic arguments which are riddled with logical some government publications and academic journals mandated that it be used and that IFL be avoided. I, a disabled person, only became aware of the controversy when a nondisabled person reproached me for referring to someone using their preferred language. It seems that PFL has reached a level of saturation in the academic community that its use today is to an extent motivated by political correctness and conformity, with some people thereby committing the ad populum fallacy. The issue with mandating PFL is that it does not account for the possibility that—just as with other movements to modernise language—it is not universally endorsed by those concerned. There are large communities of disabled people who oppose it, the most vocal of which are the d/Deaf and autistic communities, but there are also individuals with other disabilities who eschew it.

The University's Inclusive Language Guide warns that it is "critical to avoid" IFL, but it seems appropriate to wonder whether forcing PFL despite its persistent internet search for any of these terms would yield and widespread opposition is the most inclusive approach that could be taken. Some publications note the controversy around PFL but advise that it should continue to be used despite its opposition using

Illustration courtesy of the NSW Department of Family and Community Services.



fallacies.

In addition to PFL and IFL, euphemisms for disability in general and specific disabilities abound. While many such terms are no longer socially acceptable, some, such as differently abled, special needs, challenged and handicapable continue to be used by nondisabled people, even though a cursory

"I, a disabled person, only became aware of the controversy when a non-disabled person reproached me for referring to someone using their preferred language. It seems that PFL has reached a level of saturation in the academic community that its use today is to an extent motivated by political correctness and conformity."

many articles decrying them.

These terms either inflate or downplay a disabled person's needs and abilities, when in fact no two people—disabled and nondisabled alike—have the same needs and abilities, and people with certain disabilities would have far fewer needs in a world that is more accessible. There is also a small—but growing—segment of the disability community who have reclaimed euphemisms such as crip and mad, primarily to express pride and resilience with members of a like-minded community, but as with all other euphemisms, it is generally inappropriate for people who are not part of these groups to use them.

So, what language should you use? I believe that the optimal strategy when communicating about disabled people is to use the language that the particular person or group prefers; and in cases where there is a lack of consensus, it is best to include a mix of PFL and IFL. A media guide published by the Sydney University Law Society uses this approach, and some style guides produced by other organisations are also adapting to respect individual and community preferences.

Both PFL and IFL have an important role to play in increasing the social acceptance of people with disability, but the language we use to talk about disabled people is only one small piece of the puzzle.

The Promise and the Pain

words by Hūhana Jade Barclay

every day is a trade-off
between risking and reaching
speaking up or staying safe
living between the promise and
the pain

when our very existence is exhausting is contested is paradoxical is unreliable, invalidated, disbelieved

when our health disparities are so obvious and real yet so unseen, undocumented, dismissed

when we live between worlds the kingdom of the sick the kingdom of the well invisibly in both but not fully in any

when the burden of proof the burden of education the burden of paperwork
the burden of illness
the burden of existing
the burden of inaccessible
support
and unavailable accessibility
a thousand extra miles to crawl
before the starting line is in
reach

when this life, this world this perspective and all it brings the curiosity, the complexity the insight, the oracles the comfort with uncertainty the systemic and unspoken is obvious in our bones but oblivious in our books

this precious life
this precious voice
this precious paradox
nestled between the promise
and the pain

Always Something

words by Gemma Lucy Smart

PART I

"It's always something with you" Always sick

You injured yourself again

Just an excuse, eh?

It's getting old,

If I'm honest

You're going to have to

Get over it

Grow up

Maybe this isn't for you?

Not 'cut out' for it

Don't bother me

No more

With your pain

If it's real?

Cause let's be real

It's always something with you

PART II

"It's always something with you"

I see the judgement

I make you uncomfortable?

With my illness

With my difference

With my ... disability?

Good

Get over it

Grow up

My body is human like yours

Vulnerable and physical

Interdependent not individual

Don't bother me

No more

With your ableism?

Cause let's be real

It's always something with you

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Painting the Pain

Composed by **Hūhana Jade Barclay** at the Art Gallery of New South Wales, 2019



"Warzones"





18 | JUSTICE ACCESSIBILITY | 19

Beyond the Royal Commission

Jack Scanlan examines what will happen after the royal commission.

Above me as I write this is a book shelf, and on that getting all of these policies implemented and fighting me is the 12-volume, 15 books, and over 6,000 pages making up the final report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (or the Disability Royal Commission) with 222 recommendations and dark purple spines staring down at me.

This royal commission was four years in the making, and it has brought alot of pain but with its release there is hope in the disability community; hope for change, for justice, for a better tomorrow for disabled Australians everywhere. While the royal commission is dense and filled with thorough recommendations, the volume that interests me the most is the last one, Volume 12: Beyond the Royal Commission (Yes, I did shamelessly steal the name).

While this volume is more filled with recommendations on how the government should measure the effectiveness of policy implemented, the

"The question all disabled activists and allies might be asking is: "What is beyond the royal commission?" and all that can be said is plenty of fighting ableism and winning the hearts of minds of the public and politicians for material change in the conditions of disabled Australians.

one part of this volume that gets skipped over is making sure these recommendations get implemented. This volume can go on and on about implementation but that's assuming the government even tries.

The Royal Commission is filled with recommendations, and as it says on the tin these are only recommendations to the government. From the Commission's, the media, and most of the public the job of disability rights is done. The stories have been told, recommendations printed, and the government has launched a working group. The job is done, it's time to pop the champagne.

But as any disabled activist will tell you: 'this is just the start'. The Royal Commission is ONLY the first step, and is luckily the least political. The real fight is in

shelf in my peripheral vision is this purple blur. Above every politician in the way to get our justice and rights. This is the largest challenge we find, because what these recommendations do not talk about is the roadblocks, the price tag, the political capital, and the continual fight that is still needed.

> Activists will start the fight for this but parliament is where these battles must happen and must be won. Parliament and the Government have primacy over the judiciary meaning if these reforms pass here the entire legal system will be shaped around this. If disability rights laws are proactive and not reactive we will have a government and a legal system that will provide the services, protections, and rights all disabled Australians deserve.

> Already there has been push back, with politicians like Pauline Hanson and One Nations pushing back on NDIS funding and services offered describing the NDIS as a "scam" and a "rort". None of the major parties (Labor, Coalition, Greens) have policies on a disability rights act, and the Greens are the only major political party pushing for desegregation of schooling and implementing all of the UN's Convention on the Rights of Persons with Disabilities; but only by 2030.

> The Albanese government's policy has been more about stopping waste and fraud in the NDIS and NDIA which is needed but very little has been commented on what Labor will do other disability rights issues outside of the NDIS/NDIA.

> The question all disabled activists and allies might be asking is: "What is beyond the royal commission?" and all that can be said is plenty of fighting ableism and winning the hearts of minds of the public and politicians for material change in the conditions of disabled Australians.

> We have given our advice and told our stories. It is time for change, it is time to ramp up political pressure until change is seen. Until we have desegregated schools, a disability rights act, and see material change in the conditions and lives of all disabled Australians.

Accessible Thesis

Kia ora from Te Ao Meomeoa, The Land of the Dreaming. I am Hūhana Jade Barclay. I am Ngāi Tahu.

I humbly acknowledge the diverse knowledges and sovereignty of all First Nations and displaced people and pay respects to the patients, scholars, healers, friends, and disability communities that have supported me throughout my PhD, and to elders past, present, and emerging.

To play a small part in creating a more accessible and just world, I choose to make my research accessible, open, and community-informed, and use open scholarship, and to share Kaupapa Māori research methodologies, and universal design principles wherever possible.

While academics and governments are starting to see the value in funding "lived experience" research and expertise in recent years, Kaupapa has a long history of putting community expertise and inclusion first in activism and research for both disabled and First Nations communities. Including and transcending co-design and the lived experience lens, Kaupapa Māori methodology adds an experiential aspect to knowledge generation and in essence is a combination of "nothing about us without us" and "with community, by community, and for community" and "Mō tātou, ā, mō kā uri ā muri ake nei" "for us and our children after us."

Here are a few ways we can bring an inclusive, sustainable, equity-driven spirit to all levels of research design and development, and how it has shaped my approach to my PhD research and teaching in practice:

Inclusive education, reflexive practice, universal design — reflect on positionality, power, implicit bias, and epistemic injustice, elevate erased or silenced voices from all forms of evidence, learn how to teach well and communicate effectively for CALD and neuro-inclusion.

Clinically-representative research sample aim to include knowledge from diverse cultures and the most severely affected and mobilitylimited participants who have been arbitrarily erased or excluded from traditional on-site single-disease research studies.

Person-centred gestalt design — consider the invisible sample: "who is centred, who is represented, who gets to speak, who is silenced, missing, or erased" from medical literature, clinical studies, population health, research samples, follow-up, and knowledge sharing.

Equity-driven data collection — prioritise the accessibility needs, culture, language, and convenience of the patient community over the convenience of the institution or research team.

Co-design, co-analyse, co-produced research — radically interdisciplinary collaboration with previously silenced or erased voices, prioritising community and researchers with relevant lived experience. Ensure each stage of the research is community-guided. This include literature and involvement from disabled, BIPOC, neurodivergent, queer and intersectional authors, patient-scholars, healers, analysts, artists, students, community connectors, and data scientists.

Share accessible resources — speak like a real person, write for real people. Communicate discoveries clearly to scientists, health professionals, leaders, and intersectional patient communities. Use tools that make it effortless to read, watch, listen, remix, share, and translate.

Accessible knowledge generation, not just



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LOVE KNOWS NO BOUNDARIES ON THE SPECTRUM



Suhaila Mahafza sits down and watches 'Love on the Spectrum'.

The autistic community are frequently infantilised **I** within discourse and pop culture, facing a stereotype of being "loveless" due to the burden of their disability. In addition to decades of poorly conducted research, this has contributed to a major taboo surrounding autistic romance and sexuality. Common phrases you may have heard thrown around include descriptions of neurodivergent people as 'cold and lacking emotion', 'too honest to sustain a relationship' or 'too self absorbed to consider others around them'. Popular characters, such as Sheldon from US sitcom 'The Big Bang Theory' associate autistic people with immaturity and a lack of empathy.

However, just as television can perpetuate false narratives about the autistic community, it has recently shown its potential to offer genuine insight into autistic lives. The reality TV series 'Love On the Spectrum' offers a unique insight into dating and relationships amongst autistic people. The documentary series follows the experiences of autistic young adults in the dating world: setting them up on blind dates in hopes of connecting them in loving romantic relationships. It is my opinion that Love on the Spectrum lovingly confronts the challenges which many autistic individuals encounter, such as lacking an understanding of the nuance of romantic relationships, developing the confidence to leave their comfort zones, and offering unfamiliar people a deep insight into their world.

The show effectively breaks down "loveless" stereotypes about autistic individuals, embracing the personality and interests of its cast, and not attempting to suppress their character or autistic traits. It allows for autistic people who have struggled to form meaningful relationships to meet others who share their experiences, and find a partner (that may or may not end up as romantic). It amplifies the love and respect that autistic people convey to those around them, even if it may not be in a conventional form. Critically, Love on the Spectrum provides reflections of autistic people as loving adults; a wholesome and educational depiction that we sorely need more of.

However, Love On The Spectrum has been met with criticism in regards to its lack of diversity and an inadvertent reinforcement of stereotypes. While the show makes an effort to portray autistic relationships through the eves of each individual, unfortunately, the show often falls short. Episode narratives tend to direct attention towards their families and friends, and seem to include at least one highlight reel of a family member talking about their experience 'having to deal with' the negative moments in the lives of their autistic loved one. This promotes the outdated thinking associated with "Autism Awareness", which problematises the behaviours of autistic people that are 'burdensome' to others in their lives. By viewing autism through the eves of those who have to endure it in others, autistic individuals are deprived of agency. 'Awareness' implies neither listening or understanding. And while there is no denying that being a caretaker is not easy work, it is in this misguided focus that Love on the Spectrum does not always represent the autistic community in a supportive or accepting way.

Further, the series has been criticised for its undertones of "inspiration porn". The show can unintentionally objectify autistic people into something more of a creature in the wild, rather than a human individual. It shouldn't have to be such a massive deal for autistic people to form connections and express feelings of romantic love, sexual desire and even human respect no matter where they exist in the multidimensional spectrum. Many autistic individuals are already able to embody these concepts – it may not appear conventional, but the show must be careful not to sensationalise the experience they are attempting to normalise.

Ultimately, Love on the Spectrum serves as a valuable reminder that love knows no boundaries, and provides a valuable platform for the autistic community to share their perspectives. The show encourages us to approach neurodivergent experiences with care and authenticity. Its sensitive and informative portraval of autistic individuals invites viewers to see beyond labels and misconceptions to appreciate the beauty of genuine human connections, regardless of neurological differences.

Migraine, more than just a headache

Simar Batra journeys through chronic pain.

Twas first diagnosed with chronic migraine at Ltwenty-two. Onset was sudden and debilitating. I'd wake up with an intense, throbbing pain that seemed to consume my entire head, making it impossible to get out of bed. Light and sound were unbearable. I often vomited from the pain. It felt like a vice grip was slowly squeezing my skull. But to the outside world, I looked perfectly fine. My friends, coworkers, and even some family members couldn't comprehend the sheer torment I was enduring. This invisibility made it easy for them to question the validity of my pain.

Migraines, characterized by throbbing head pain, are more than just debilitating headaches. They encompass a spectrum of diverse subtypes, each with its own unique features and complexities. Understanding the distinctions between these migraine subtypes is essential for proper diagnosis, effective management, and providing support to those affected. In this exploration, we delve into the world of hemiplegic migraine, classic migraine, complex migraine, the common migraine, and vestibular migraine, shedding light on the wide array of symptoms and challenges that individuals living with these conditions face. From the transient paralysis of hemiplegic migraine to the disorienting vertigo of vestibular migraine, these variations offer a glimpse into the multifaceted nature of this often misunderstood neurological disorder.

This migraine's sudden and unpredictable nature can lead to frequent work absences, reduced productivity, and difficulty maintaining a consistent work schedule. The symptoms, especially the aura in hemiplegic migraine and dizziness in vestibular migraine, can make it nearly impossible to concentrate on tasks. This migraine often leads to the cancellation of plans, impacting personal relationships and overall quality of life. Frequent medical appointments and the cost of medications can place a significant financial burden on individuals and their families.

The unpredictability and severity of this migraine may lead to job loss, as employers may not be able to accommodate frequent absences and reduced productivity. Individuals living with this migraine may struggle to secure new employment, especially in roles that require regular attendance and focus. Many people with hemiplegic and vestibular migraine are forced to change careers to accommodate their

health limitations.

In the broader spectrum of society, misconceptions still shroud the silent agony of migraine. I remained burdened with the responsibility of proving the legitimacy of my suffering. In my unwavering resolve to bridge the chasm between chronic migraine and societal comprehension, I became an advocate for

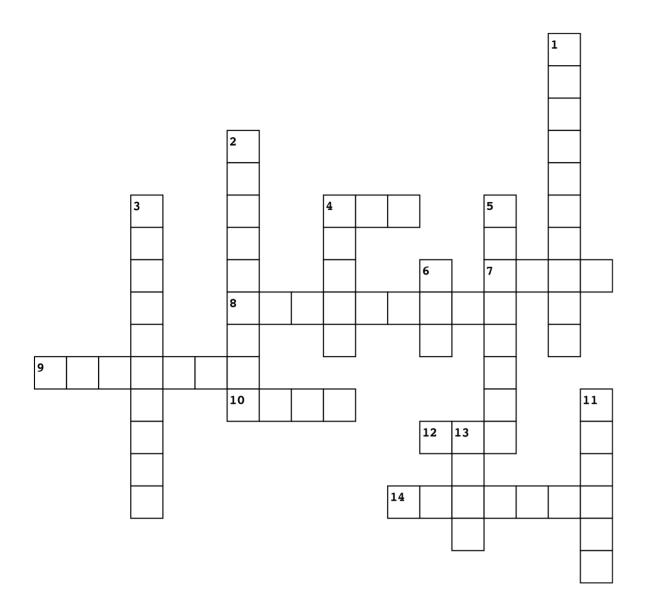
I participated in support groups like Migraine & Headache Australia, shared my story on social platforms, and engaged in advocacy, striving to bring about change. My journey has revealed that, within chronic pain, the human spirit possesses a rare and resilient strength. Understanding, compassion, and the fortitude to battle invisible torment have become essential allies in the ongoing struggle.

Being a student with migraines often left me feeling isolated from society. The unpredictable nature of these debilitating headaches meant that I frequently had to miss school, social events, and even family gatherings. The fear of an impending migraine attack made it challenging to commit to plans or engage in extracurricular activities, leaving me on the sidelines while my peers enjoyed their experiences. The physical and emotional toll of migraines, coupled with the difficulty of explaining their intensity to others, further isolated me. It became a lonely journey, marked by canceled plans and the constant struggle to catch up academically. As I grappled with the pain and exhaustion, the sense of isolation grew, making me feel like an outsider in the bustling world of student life.

Life can be unpredictable and challenging, and for those of us living with chronic classic and complex migraine, it's a journey fraught with emotional upheaval. Classic and complex migraine arrived unexpectedly, robbing me of vitality and turning life upside down. However, I've learned that resilience is a human strength. I continue seeking understanding, support, and effective treatments while forging a renewed sense of self and discovering that life can still be vibrant and meaningful.

Migraine may endure, but so does my commitment to shine a light on the hidden suffering within life. As I continue to tell my story and advocate for migraine awareness, I aspire to instill empathy, understanding, and a profound acceptance. This journey has unveiled the profound value of compassion, the intricate dance of emotions, and the enduring strength of the human spirit in the face of chronic pain.

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Across

- 4. Student union responsible for undergraduates
- 7. Condition where a person is unable to hear to a significant extent
- 8. Number of years since the Disability Discrimination Act was passed
- 9. Adjective describing raised or textured platforms for access
- 10. Universal scheme for adjustments for disabled people
- 12. Acronym for concept that there are more than one way of learning
- 14. Language developed by a blind French educator

Down

- 1. Item that is used to assist mobilityimpaired people for transport
- 2. Percentage of disabled people who have a Bachelor's degree
- 3. Concept involving making changes so that people can participate equitably
- 4. Student union responsible for postgraduates
- 5. Sultry, smoking gal mascot steeped in goss
- 6. Animal often used to assist people
- 11. Type of bird often found in urban areas
- 13. Strategic plan required by state law at every public institution on disability inclusion

Stand With Niko Statement

We, the Students' Representative trade, think the University of New Council (SRC) Disabilities Collective England with its flagship distance and Sydney University Postgraduate education programs. This includes Students' Disability & Inclusion Network, for-profit \$13,700 coding bootcamp condemn the University of Sydney and delivered entirely online and an School of Psychology terminating Dr entire suite of premium online-only Niko Tiliopoulos' employment on the postgraduate degrees released this year. basis of his disability and ill health.

Dr Niko Tiliopoulos has been working at Sydney University for more than How can the University claim that 16 years. If Dr Tiliopulous contracts it cannot accommodate Dr Niko's COVID-19, the condition represents conditions being a matter of life and an extreme risk for his health. For death when it offers online-only and more than three years, he has been partially online degrees? successfully teaching remotely due to his conditions.

A University spokesperson told Honi Soit that Dr Niko's circumstances do not fall within its disability accommodations.

a disability to perform the inherent spirit that drives DIAP. requirements of their position."

university community.

Many other universities deliver In solidarity, education, some with decades in the Jack Scanlan

Association (SUPRA) the University of Sydney itself with a

It is hypocrisy of the highest order.

Staff with disabilities do not deserve to be treated this way. Dr Niko does not deserve to be treated this way.

The University of Sydney says that it is committed to the Disabilities Inclusion Action Plan (DIAP) which is required "Unfortunately, in some cases it is by state law. However, the termination not possible for an employee with of Dr Niko's contract betrays the very

We stand in solidarity with Dr Niko We at the SRC and SUPRA say that this Tiliopoulos and wholeheartedly is a disgraceful and shameful statement. support the National Tertiary It is blatantly discriminatory. The Education Union's (NTEU) campaign University is effectively offering either and petition demanding the University death or loss of employment to a of Sydney to reverse its decision and longstanding, beloved member of our allow Dr Niko to continue teaching remotely immediately.

rigorous and high-quality online Khanh Tran, Gemma Lucy Smart and



Dr. Niko Tiliopoulos faces being fired for his disability. The University is refusing to allow Niko to teach remotely. If Niko catches COVID-19, his health is at extreme risk.

betteruniversities.work/ stand-with-niko



SCAN TO SIGN HERE!

Dr. Niko Tiliopoulos has been teaching at the University of Sydney School of Psychology for sixteen years. Beloved by students, since 2020, he has been shielding from COVID-19.

We demand that Sydney University immediately reverse its refusal to accommodate Dr Niko and respect staff with disability.



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