# The need for the Universities ACCORD to expressly recognise the educational and work rights of persons with cognitive disabilities

Submission by:

Associate Professor Paul Harpur, TC Beirne School of Law, the University of Queensland, ARC Future Fellow, and Affiliated with the Harvard Law School Project on Disability.

Dr Kathy Ellem, School of Nursing, Midwifery and Social Work, the University of Queensland.

Dr Fotina Hardy, School of Nursing, Midwifery and Social Work, the University of Queensland.

Professor Michael Ashley Stein, Harvard Law School, Harvard Law School Project on Disability.

Professor Ann Fudge Schormans, School of Social Work, McMaster University.

## Recommendations

The Universities Accord should create more opportunities for persons with cognitive disabilities in higher education. We recommend this is achieved by:

**Recommendation 1**: Setting diversity targets, require reporting and accountability against those targets and link this to funding to ensure that persons with disabilities are studying and working in the sector, on an equal basis as others. An equal basis requires that students with a disability are present and visible at all levels of study. In work, that persons with disabilities are present in academic, professional, and administrative roles in numbers which reflects their proportion in society.

**Recommendation 2:** Universities and regulators should create flexible courses which can accommodate more flexible learning paths. This should include micro and flexible learning options. This should include the opportunity to participate in part or all of certain courses at the university level, without the requirement to complete an entire program/degree.

**Recommendation 3:** Develop measures to create a feeling of belonging for staff and students who have disabilities. This should include having visible disability cohorts of staff and students in all areas and levels of university life.

**Recommendation 4:** Mandate that the built environment protects the psychological safety of all members of the community. For those with cognitive disabilities, such as those with autism and other psychosocial disabilities, they can have needs that differ from other disabilities or the wider community. These could include, but are not limited to, the need for access to quiet rooms and the ability to access appropriate disability expert counselling.

**Recommendation 5:** Champion a culture change from tolerating difference to embracing diversity. This can be achieved by openly celebrating universities and groups which adopt strengths based approaches to creating a sector which is open and welcoming to all – whether or not a person lives with a range of abilities labelled as a disability.

# Our submission

The Universities Accord Discussion Paper contains 49 questions. Our submission is especially relevant to these questions in the discussion paper:

*Q22 What role do tertiary entrance and admissions systems play in matching learners to pathways and supporting a sustained increase in participation and tertiary success?*

*Q28 What is needed to increase the number of people from under-represented groups applying to and prepared for higher education, both from school and from other pathways?*

*Q30 How can governments, institutions and employers assist students, widen opportunities and remove barriers to higher education?*

*Q38 How can the Accord support higher education providers to adopt sector-leading employment practices?*

*Q39 What reforms are needed to ensure that all students have a quality student experience?*

*Q40 What changes are needed to ensure all students are physically and culturally safe while studying?*

We illustrate below how helping those with various disability categories succeed in university study and work will positively impact on answering the above questions.

# Language

In this submission we utilise the term “cognitive disability” as an umbrella term to describe several diagnostic conditions, that is, intellectual disability, acquired brain injury, and autism spectrum disorder. It is important to note that these diagnostic labels are not always the terms used by those in the community to define themselves. Other possible terminology includes neurodiversity and psychosocial disabilities. We recognise language in the disability space is highly contested.

# The problem of exclusion and a way forward to inclusion

Universities can become disability champions of change (Harpur and Stein, 2018).

The Universities Accord sits within a comprehensive educational reform agenda, which includes a focus on early childhood, grades 1 through to 12, and on higher education. Focusing on the entire educational pipeline enables comprehensive measures to be adopted. This is a positive measure which will help improve the experiences of learners in Australia.

Particular work is required for disability categories where people are more excluded. For example, there are very few people or opportunities for people with cognitive disabilities in university study or work (Smith and Stein, 2020).

By challenging the concept of the normal and the expectations that flow from that concept it is possible to craft responses that do not reinforce existing inequalities (Karpin and O'Connell, 2015). In Australia, persons with disabilities have been treated as “abnormal” and forced into separate and inferior tracks of schooling (Disability Royal Commission, 2019a), been told higher education is not for them (Uditsky and Hughson, 2012), encountered disabling barriers at work (Harpur, 2019), and even been locked in institutions rather than being able to participate in society (Disability Royal Commission, 2019b). The human and economic cost of this exclusion has been, and continues to be, significant.

Lawmakers have enacted anti-discrimination laws and other responses to reduce the negative impact of these inequalities (Gaze and Smith, 2016). For many in the disability community, these changes have been remarkable. For example, blindness no longer leads to segregated and substandard school and sheltered workshops with sub-standard pay, as was the case in the mid-twentieth century (Gill, 2005). Deinstitutionalization, the National Disability Insurance Scheme, the on-going Disability Royal Commission and a normative shift in society has increased education options for a greater range of persons with disabilities, with these students increasingly seeking to enter the workplace and progress to becoming industry leaders, who happen to have a disability. However, entrenched ableism in society is still frustrating the aspirations of persons with disabilities seeking to transition through a career, and often limiting them to sub-standard work opportunities (Harpur and Stein, 2018).

Persons with cognitive disabilities represent one group of persons with a disability, who are increasingly less excluded from society, and are now seeking to exercise their human rights to education and work on an equal basis as the rest of the community. Supporting this transition, the deinstitutionalization movement has slowly enabled thousands to move into the community (Gooding, 2016) and the promotion of universal legal capacity and supported decision making are giving people a voice who have previously been silent (Bigby et al, 2015). People with profound disabilities are now exercising their rights and demanding equality to rights (Shogren et al, 2018); this includes rights to education, and through education, to work (Moore and Schelling, 2015). As persons with more complex disabilities and different vulnerabilities seek access to higher education (Smith and Stein, 2020), it is vitally important to ensure that education systems are reformed and made inclusive (Thoma, 2013), and that there is increased focus on ensuring students can transition from education to work, and then through the different stages of their careers. The Universities Accord process can and should play a transformational role in this process.

When considering, developing, implementing, and monitoring initiatives to increase the inclusion of persons with cognitive disabilities, all parties should ensure the full and effective participation of members of this group. To this end, the Universities Accord should empower the disability voice.

The participatory justice paradigm in the United Nations Convention of the Rights of Persons with Disabilities (CRPD) requires that persons with disabilities advocate on their own behalf and represent their communities (Harpur and Stein, 2022). This includes those with a cognitive disability – as demonstrated by the UN CRPD Committee including a member on its decision making body with an intellectual disability. Key to this advocacy is ensuring that persons with disabilities are in leadership positions in governance structures that effect their equal participation across all aspects of society.

The participatory paradigm is not limited to States simply offering persons with disabilities leadership positions. Instead, it requires States to ensure that persons with disabilities are able to take up those leadership positions. As a group in society, persons with disabilities are only able to take up leadership positions when they have benefited from education, have their economic rights to work and employment protected, their right to engage in public affairs acknowledged and supported and can exercise their other human rights which empowers them to be full and equal actors in society. The participatory paradigm therefore forms part of an interconnected framework which is focused upon enabling persons with disabilities to operate as full and equal citizens.

# Primary research on young people with a cognitive disability in Australia

We will be publishing the findings we discuss below in full in a Cambridge University Press Book entitled:

Kathy Ellem, Paul Harpur, Fotina Hardy, Michael Ashley Stein, and Ann Fudge Schormans, *Young People with Cognitive Disability in Transition to Adulthood: Stories of Aspiration, Opportunity and System Failures* (2024)*.*

## Data collected by Ellem, Harpur, Hardy, Stein, and Fudge Schormans for their book

We call in this submission for reforms to enable persons with cognitive disabilities to exercise their education and work rights in the higher education sector. To support these claims we present primary data that demonstrates the hopes, desires and challenges people in this community are experiencing.

We collected data through semi-structured interviews including:

* Nineteen accounts of young people with cognitive disability (aged 16 to 30 years) are included in the research.
* Twenty-seven practitioners participated in the research from a diverse range of organisations, including disability specific services, advocacy services, children and young people services, legal services, Aboriginal and Torres Strait Islander services and services for people who are culturally and linguistically diverse.

The sample included people with a mix of intersecting attributes, including Aboriginality, sexuality, regional location, and participants from lower SES.

Data collection was undertaken in urban, regional, and rural regions.

**The Data shows that primary and secondary schools are failing to get students with cognitive disability ready for universities now – it is up to the Universities Accord to provide a bridge.**

## Young people with cognitive disability and the education system

Education is a key system that all young people interact with, and it plays an important part in a young person’s transition into adulthood and their opportunities to participate in higher education. For many of the young people, family members, and practitioners, their experiences highlighted challenges, barriers, discrimination, abuse, and neglect within the education system. Despite having an interest in education, and indeed higher education, only one participant was able to attend a university. Most of the participants identified a lack of support and challenges through earlier secondary schooling education which automatically created barriers for any further educational opportunities.

## Not being understood

 Hilde[[1]](#footnote-1) (aged 18, neurodiverse, pronouns she/her), was the only participant who had entered university. While Hilde identified some positive and supportive teachers, overwhelmingly her experiences across multiple schools during her primary and secondary education journey were discriminatory and abusive. She discussed her experiences of being in an oppressive system which failed to understand her neurodiversity. She reported experiencing abuse from an early age:

*I used to get in so much trouble. When I was in Prep I’d be sent to timeout, which was abusive actually. … And I’d sort of be out there for five minutes. The teacher would come and say, “Are you sorry?” I’d say, “No.” Come back in five minutes, “Are you sorry?” “No.” “Are you sorry?” “No.” It was like, “When are you going to say you’re sorry?” So I ended up spending big chunks of time out there, because why would I lie?*

Hilde acknowledged that she did do some wrong things, however this did not justify the punishment, highlighting that she was behaving in a way consistent with her autism. According to Hilde she experienced abuse by about 50% of her teachers, but also highlighted that it was not always intentional. Hilde emphasised that “well meaning” people who “think they are helping us, are the ones who do the most harm usually”.

Hilde discussed the importance of the system changing to support the young person with a cognitive disability. In order for the education system to truly understand the young person, it needed ‘…to break down the harmful power structures and make everything, absolutely everything, not about people having things decided for them, but about people being supported to make their own decisions…..’.

Hilde identified resisting authority and abusive practices in school from the age of 6, where she supported other students, speaking out for them when teachers were teaching incorrectly, and challenging them when they exercised their authority in discriminatory and harmful ways. Hilde recalled one teacher who was neurodiverse who was “incredible” and that “…it was just astounding the difference it makes to have a teacher who actually says, ’I want you to challenge me. If you think I’m wrong, don’t…’”. This teacher welcomed input from young people, and perhaps had greater understanding of what it was like to be neurodiverse.

Other young people also desired to have their disability understood and to be listened to by school authorities. Amy (aged 30, pronouns she/her) described getting into trouble at high school and never having anyone listen to her side of things. Cody (aged 22, pronouns he/him) identified that his OCD was not understood at school which meant not receiving appropriate support to help with his assignments, or assessments. Cody identified experiencing panic attacks and reported being blamed, laughed at, and punished and spending copious time in detention. Cody described school being:

*…designed for the person who’s spotlight average. If you’re above average in some areas and below in others, pfft. Completely below average, pfft. They might have some people who are completely disabled. They don’t really have anything when people who are in between.*

These stories highlight the need for support early in the education journey for all persons with disabilities to be able to access higher education.

## Getting the right support

The university sector needs to consider alternative learning styles and notions of who belongs in higher education as a student or staff. Similar changes are required throughout the education journey from Kindergarten to Year 12 (K-12). Our research found that there were mixed accounts as to whether the school system made appropriate adjustments and accommodations for young people’s learning styles. Becky (aged 25) identified struggling at school because of her dyslexia and dyspraxia. She reported not being able to be in a big class because she thought people were talking about her. Becky identified the importance of schools helping people who are struggling with their learning but said this support was not readily available to her. She explained her desire for teaching staff to reach out:

*“Can you please stay after class today? I need to talk to you.” Doesn’t mean you’re getting in trouble. You’ve got to ask them, “Do you need to be… Because I will help you. After all school hours are done, I will come in and I will help you with what you need help with”.*

Becky’s discussion suggested that teachers needed to adopt a less authoritative approach, and more one that focused on genuine inquiry and concern for the young person. Unfortunately, Becky’s memories of school involved some regret: “If I’d got that extra help, I probably could’ve passed with flying colours. But I couldn’t because nobody offered it to me. I even asked for it, and they said no.”

Similarly, Rod, an occupational therapist reported systemic neglect of young people with autism by educational bodies, where they failed to provide appropriate educational adjustments to facilitate young people’s learning and young people would leave school in year nine or ten. He spoke of the detrimental effects on the young person’s self-esteem when “… your school has given up on you, everyone else is probably going to give up on you”. “I don’t want to talk to someone who could help me because school’s given up on me””.

Flexibility in support was crucial for some young people with cognitive disability. David, a young person with non-verbal autism (aged 21, pronouns he/him) attended a special school for all his formal education. As David matured into young adulthood, the changes associated with puberty affected him and he experienced a turbulent time emotionally. David’s mother reported that the school was able to be flexible with David’s reduced hours of attendance, which assisted David to have a great final year. Educational environments must have mechanisms to ensure that people can ask for support; that allowances are made regarding flexible enrolment for courses; and other mechanisms are available for someone who has complex communicative needs.

#### Feeling like you don’t belong

If you do not feel like you belong in K-12 education, what are the chances people believe they belong in higher education? If we want to create a feeling of belonging in higher education, we need as a society to ensure students with disabilities feel like they belong in K-12 education. This cannot be achieved when the system treats students with disabilities as difficulties and especially not when bullying, discrimination and exclusion is not firmly stamped out.

Not all young people achieved a sense of belonging at school. There were numerous examples of bullying of young people with cognitive disability by their peers. This could reach a crisis point for young people, which could lead to school disengagement. For example, Goldie, a First Nations young person (aged 22) attended 8 different schools, experienced bullying, and teachers not caring or protecting her. Goldie left school at the end of year 10 and then attended a flexible education centre. Her experiences at school resulted in feeling shame, and Goldie described ”hating herself” because of these experiences. As these experiences occur in the educational setting, places of education can become places of trauma.

This sense of not belonging could penetrate deeply, affecting the young person’s sense of self. Becky (aged 25, LGBTIQ+) talked about the impact of experiencing bullying, and physical and emotional abuse at school from other students which made her feel miserable. These included experiences such as:

*Nudging me on the shoulder, calling me a loser, that I was worthless, nudging me on the shoulder, as I already said, getting their shoulder up and hitting me on the chin. Just pushing me around pretty much and just calling me names. Names that make you feel like you’re actually worth nothing.*

It was problematic for Becky when she was told by her mother to ”just ignore it” which she could not do and so reached a ”breaking point” where she could no longer handle things. She pleaded with school authorities that they should do something to address the issue:

*… if someone’s bullying someone, trying to set them on fire or whatever, because it’s happened to me, suspend them, tell what happened to the parents, do something. Because it is not right. What’s happening in these schools right now is not right. But we do need to get these counsellors trained in at least the basic form of people who are trying to transition or the people who are gay or the people who are straight and they don’t know who they are. We need counsellors who are actually trained in that.*

Educational environments must be flexible. They must recognise the important aspect of education is socialisation. That education needs to be reframed to be more than achieving educational outcomes but also promoting a sense of belonging. This must be achieved across the education continuum, from K-12 through adult learning in higher education.

## Young people’s early experiences of the education system and its influence on their participation in higher education

Safe, secure, inclusive, and appropriately responsive education can create a strong protective support system to scaffold the young person with cognitive disability. Likewise, where this is lacking, it can create additional risk factors for abuse and discrimination. The findings of our research reflects both supportive and harmful practices within schools. Young people with cognitive disability felt supported when they were recognised as students who deserved the opportunity to learn, make and maintain friendships, and be listened to. A sense of belonging in school, something that is fundamental to learning, was not always present for young people. Responses from the educational system could lead to cumulative disadvantage, disconnect from same age peers, social isolation and poor educational trajectories.

Where a person is not equipped for university, but has the potential, outreach and bridging programs should be in place to support people into a higher education sector which is flexible and focuses on the attainment of education and work outputs, and less upon unnecessary conformity on how those outputs are achieved.

# References

Bigby, C., Douglas, J., Carney, T., Then, S. N., Wiesel, I., & Smith, E. (2017). Delivering decision making support to people with cognitive disability: What has been learned from pilot programs in Australia from 2010 to 2015. *Australian Journal of Social Issues, 52*(3), 222-240.

Birtha, M. (2020). Implementation of Article 19 of the CRPD in Hungary and Its Impact on the Deinstitutionalization Process So Far. In *Recognising Human Rights in Different Cultural Contexts* (pp. 227-256). Palgrave Macmillan, Singapore.

Disability Royal Commission. (2019a). *Education and Learning, Issues paper*.

Disability Royal Commission. (2019b). *Group Homes, Issues paper*.

Ellem, K., Harpur, P., Hardy, F., Stein, M. A. & Fudge Schormans, A. (In press). *Young people with cognitive disability in transition to adulthood: Stories of aspiration, opportunity and system failures.* Cambridge University Press.

Gaze, B., & Smith, B. (2016). *Equality and discrimination law in Australia: An introduction*. Cambridge University Press.

Gill, M. (2005). The myth of transition: Contractualizing disability in the sheltered workshop. *Disability & Society, 20*(6), 613-623.

Gooding, P. (2016). From deinstitutionalisation to consumer empowerment: Mental health policy, neoliberal restructuring and the closure of the ‘Big bins’ in Victoria*. Health Sociology Review, 25*(1), 33-47.

Harpur, P. (2019). *Ableism at work: disablement and hierarchies of impairments.* Cambridge University Press.

Harpur, P., & Stein, M. A. (2018). Universities as disability rights change agents. *NEULJ, 10,* 542.

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.

Karpin, I., & O'Connell, K. (2015). Stigmatising the normal: The legal regulation of behaviour as a disability. *UNSWLJ, 38,* 1461.

Moore, E. J. & Schelling, A. (2015). Postsecondary Inclusion for Individuals with an Intellectual Disability and its Effects on Employment. *Journal of Intellectual Disabilities, 19*(2), 130–148.

Smith, M. S., & Stein, M. A. (2020). Combating the exclusion and marginalisation of persons with intellectual disabilities in higher education in the United States. *A Better Future: The Role of Higher Education for Displaced and Marginalised People*, 268.

Thoma, C. A. (2013). Postsecondary education for students with intellectual disability (id): Complex layers, *Journal of Postsecondary Education and Disability*.

Shogren, K. A., Wehmeyer, M. L., Martinis, J., & Blanck, P. (2018). *Supported Decision-Making.* Cambridge University Press.

Uditsky, B. & Hughson, E. (2012). Inclusive postsecondary education: An evidence-based moral imperative. *Journal of Policy and Practice in Intellectual Disabilities, 9(*4), 298–302.

1. All participants were allocated pseudonyms to protect confidentiality [↑](#footnote-ref-1)