INTERNATIONAL STUDIES IN WIDENING PARTICIPATION

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RESEARCH PAPER

Listening to other voices: Building inclusion of higher education students with disability from the ground up

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This paper examines the discord that exists between the institutional rhetoric of inclusion in higher education and the complex realities of being a student with a disability. Findings are drawn from a small-scale qualitative study of 28 students with disability studying at a regional university in Queensland, Australia, who reflected on their experiences and views about key aspects of university life, including admissions processes, university services (including disability support), academic engagement, and specific academic policies and processes. Emerging themes present a disparate picture. The biggest barriers faced by students with disability were not physical or based on a lack of access to resources, but, rather, reflected narrow attitudinal and cultural understandings of disability within institutions. Participants also identified student disability services as a key support in navigating wider institution practices that reinforced stigma, inequitable power structures and dominant normative discourses. The paper positions the voices of students with disability as central to critical reflection on policies and practices of inclusion at university. It builds on previous work that has challenged the way in which universities reinforce deficit views of people with disability, arguing for a more unified and socially just framework in which student self-determination rather than deficits are valued.

Keywords: disability; inclusion; higher education; student equity; access; student voice

Introduction

In its landmark 1990 social justice paper, *A Fair Chance for All*, the Australian Federal Government identified people with disability as one of six groups that are significantly underrepresented in higher education (Department of Employment, Education and Training, 1990). The paper set out for the first time, a coherent set of national objectives, targets and strategies for ensuring that the benefits of higher education are spread to as much of the Australian population as possible, regardless of people's background. This agenda included an articulation of the responsibilities of both the Commonwealth and higher education institutions, and a framework for measuring and reporting progress, with the aim of keeping the achievement of equity objectives at the forefront of institutional activity. At that time, it was rightly perceived that a major barrier to the participation of people with disabilities was the lack of appropriate equipment and facilities in higher education institutions. This political will, coupled with the Australian *Disability Discrimination Act 1992* and the subsequent Disability Standards for

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Education 2005, provided an overarching framework of accountability within the sector, and universities "were required to anticipate and plan for the inclusion of students with disability, make responsible adjustments and provide support services" (Kilpatrick et al., 2016, p. 2).

Over the last decade, government and institutional policy and program frameworks around widening educational access and participation of students from disadvantaged backgrounds has maintained a focus on addressing patterns of inequality in higher education. The emphasis on widening, rather than simply increasing, access to and participation in higher education places focus on those groups who have been traditionally excluded or under/misrepresented in higher education (Burke, 2013). The positioning of students with disability as 'disadvantaged' has highlighted the complex interplay between social background, life circumstances, access to education, academic achievement and inequality. But in many ways, the widening participation agenda has not challenged traditional assumptions about students who are 'problematised' because of their background and/or circumstances. Instead, this agenda has to some degree reinforced deficit orientations through the maintenance of stereotypes, inequitable power structures, cultures of exclusion and marginalising practices. For university students with disability, this includes the necessity of disclosing a disability or medical condition in order to receive individualised support, having to provide medical documentation to 'confirm' a diagnosis, and needing to navigate through various academic and administrative layers to receive reasonable education adjustments. Beauchamp-Pryor (2010) argues that one of the significant ways in which students with disability experience disempowerment in higher education is through lack of control and non-involvement in decision-making. This can be both subtle and direct, evident most commonly where students with disability are not involved in the development or review of disability specific policies or evaluation of disability support services, even though they are the primary users. It can also be witnessed in the ways in which students with disability are rarely given opportunity to share their experiences of living with disability in a meaningful way, thus sending a message that this is not valued, and reinforcing the view that university is not for them.

Despite the simplicity of its message, *inclusion* is a contestable term. University rhetoric about inclusion is often aspirational rather than based on an understanding or connection to the circumstances and lived experiences of students with disability and how these shape identity and academic progression. The inclusion narrative can be simplistic and misrepresented if it is focusses on "…ways of doing that relocate students with disability into dominant institutional culture rather than interrogating how institutions reinforce inequity through hegemonic practices" (Gibson, 2015, p. 878). Widening participation policies, programs and processes fail to make universities more inclusive if they don't challenge underlying power structures that reproduce inequality. These superficial efforts risk becoming only bureaucratic exercises to demonstrate compliance, rather than genuine, institutionally holistic reform. Thus, a misunderstood and misrepresented form of 'inclusion' is practiced in education. Inclusion becomes about attempts to induct that which is 'different' into already established forms and dominant institutional cultures (Gibson, 2015). Yet, rarely are universities ever held to account or challenged about their 'inclusion credentials'.

This paper explores how inclusion (or exclusion) is *experienced* by students with disability regardless of how it may be defined or presented by an institution. Through a qualitative design, the study set out to understand how students with disability navigate what Madriaga, Hanson, Kay, and Walker (2011, pp. 901-902) term "normative educational contexts" which reinforce traditionally deficit views of people with disability through positioning them as problematic. Using quotes from study participants, the paper aims to connect the reader to the personal experiences of students living with disability and a more nuanced appreciation of their circumstances. Importantly, it argues that knowledge and awareness of the lived experiences of students with disability are essential to a credible interrogation of institutional values and practices of inclusion. This is particularly important in challenging the assumption that personal 'struggle' is a consequence of living with a disability, rather than the imposition of institutional barriers. Before describing the research methodology, the paper briefly introduces some of the ways in which the conceptualisation of disability as impairment or difference creates barriers that prevent people with disability from exercising choice and control.

Background

'Disabalism' is an umbrella term referring to a range of barriers experienced by people with disability. It is used to describe everyday practices that (unwittingly) perpetuate oppressive structures and deficit perspectives of people with disability (Madriaga, 2007). The positioning of students with disability as 'different' or 'problematic' is reflected in the ways in which universities tend to identify and separate the needs of students with disability from those of the general student population through, for example, the establishment of specialised units and teams who are responsible for supporting these students and negotiating with other stakeholders on their behalf. These practices are generally carried out under the banner of inclusion whereby non-traditional students are welcomed to the university, but their 'difference' or 'otherness' renders them incomplete, or not full participants. This acknowledgment of difference underpins the way power is distributed and how social relationships are constructed. Madriaga et al. (2011) refer to this as the 'pervasiveness of normalcy', in which "normalcy is equated with everyday eugenics, which heralds a non-disabled person without defects or impairments as the ideal norm…reproducing thinking that non-traditional students are non-white, working class and/or disabled" (p. 901).

Approximately 6% of domestic students in Australian universities indicate they have a disability, impairment or long-term medical condition (Department of Education and Training, 2016); however, the retention rate of this group falls short of the rate of other domestic students (78.46% and 81.56% respectively). While the reasons are complex, a recent study in Australian universities found that the monitoring (of retention and success) of students with disability "was either not being done or not being done well" (Kilpatrick et al., 2017, p. 9). In examining why this is the case, it would be simplistic to draw parallels between lower overall retention among students with disability and a reduced capability or capacity to achieve, rather than consider how institutions may "fail to engage with the complexity of the relationship between social inequalities, academic achievement, educational choice and life chances" (Burke, 2013, p. 110).

The risk here is that without research and deeper analysis to unpack the experiences of students with disability in tertiary institutions and their impact on retention and success, individualising and deficit arguments linking lower overall retention and completion of students with disability to a reduced capability or capacity to achieve will prevail. This misrepresentation also means that institutions will not be held to account for the ways in which they reproduce 'disabalism' by failing to engage with the complexity of relationships between disability, agency, academic achievement and inequality. Therefore, an institution's 'inclusion' policies and practices must be examined, not through the lens of its own beliefs and assumptions, but through the experiences of inclusion, narrated by the students themselves. There is a subtle power redistribution when dominant cultural views about the needs of students with disability are held up for comparison to the articulated experiences and needs shared by that group. Valuing the voices of students with disability affirms the importance of their lived experiences and the insight and credibility this brings to any institutional understanding of inclusion. This reinforces the value of diversity within the institution and gives authority to interrogate the efficacy of services for students with disability and inclusive practices in the learning and teaching space.

Research methodology

This study was conducted at a regional Australian university which typically attracts a high proportion of mature age students from low socio economic status (SES) backgrounds, undertaking a significant proportion of their studies online. While the focus of this research is on students with a disability or a health/medical condition, it is acknowledged that personal identity is shaped by the full spectrum of human experience and circumstance which is cumulative. Living with disability cannot be quarantined from other aspects of identity. As Threadgold, Burke and Bunn (2018) note, “students’ backgrounds are not shed as they enter university or adulthood, but instead influence their views and what they see as plausible and meaningful opportunities” (p. 8).

In this study, conducted in 2017, approximately 335 students who registered and received support with disability services were emailed and invited to participate in a semi-structured phone interview via the Customer Relationship Management System. Interested students were encouraged to contact a university research assistant directly, rather than via the disability support unit. Participation was voluntary and no incentives were offered. All data emerging from the interviews was de-identified. Twenty-eight students agreed to participate in interviews which were recorded. All of the students had registered for support due to the impact of their disability or ongoing medical condition and had been studying at the university, either full or part time for at least 12 months. The majority of the participants were female reflecting a wider higher education sector trend of greater representation of women in tertiary studies (over 60% at the undergraduate level). It is also important to note that of the total number of students who indicated that they have a disability when they enrolled at the university where the research was undertaken, only about half went on to register for support with disability support services. Future studies on the relationship between disability, identity and disclosure would likely shed more light on the reasons. In the current study, all participants had made the decision to seek support although they were not asked to talk about the process of disclosure as part of the research.

Advice and assistance from disability services staff was sought on the content and structuring of interview questions which covered key areas of admissions, disability support and other services and learning and teaching practices. The semi-structured interview methodology was considered the most appropriate for students to share their personal narratives and raise issues of relevance with the interviewer. It was a deliberate choice to represent the voices of students with disability meaningfully. The interviews were then transcribed, and a thematic analysis of transcripts was undertaken by members of the research team. All feedback and comments quoted in the discussion below are identified by fictitious names assigned to participants.

Findings

Emerging themes present a disparate picture in which the biggest barriers faced by students with disability were not physical or based on a lack of access to resources, but instead were attitudinal and cultural, reflecting a narrow and often misunderstood view of the students. Study participants also identified student disability services as a key support in navigating wider institutional practices that reinforced stigma, inequitable power structures and dominant normative discourses. The discussion below follows the major themes emerging from the data which challenge taken-for-granted assumptions about inclusion, raising questions about who writes the narrative about students with disability and how it is interpreted throughout the institution.

Finding timely support

Study participants shared experiences of frustration and confusion when commencing university. While some of the respondents said they learned about disability support services via orientation activities, most stated that it was hard to find information about disability services online. Students said they struggled with knowing the correct terms for online searches, as terminology varied widely (for example, disability, equity, accessibility or inclusion service). Others did not learn about the service until well into their courses or after failing units, despite direct questions about disability being asked as part of the enrolment process. For the students, this lack of information or guidance was frustrating and impacted how they managed challenges in their studies before receiving support.

Jess, who is in her first year, spoke of her frustration at the length of time it took to find out information about disability services:

> *I just went straight from grade 12 to university. My father and I had to find a way to navigate through the website to find what we wanted…it took us several tries before we were able to find what we wanted…We had to make a lot of calls too, to figure out how to do certain things.*

This sentiment was echoed by Ellen, a third-year student with a mental health condition, who thought disability services needed to be more proactive, "*not just leaving it for the students to stumble around to try and find*". A number of students were unaware of the additional support they could receive. Lorraine, a mature aged student studying by distance who returned to study after a break, recalled:

> *I didn't know anything about the disability process in the first couple of years. I wish I did, because I had a problem with exam anxiety. If I'd known about that a bit earlier, I probably would have tackled it – because I sort of – I took a break out of my degree because of that reason, because of the anxiety with exams.*

Any ambiguity in how the university presents information about disability services or how it can be accessed can create a barrier for and directly challenge notions of inclusivity. It was clear from many participant narratives that information about disability support services is not communicated well or consistently throughout the university. However, some heard about the service from fellow students or were referred by academic staff. A strong theme within the interviews was the need to educate more staff about the services and what support can be offered. Furthermore, messaging needed to be continuous, not just during Orientation events at the start of the academic calendar as was the case.

Having safe and supportive conversational spaces

Participants spoke about the time, trust and emotional investment required to share information about their individual circumstances and the impact of their disability. For many, though not all participants, these discussions often happened with disability support staff where there was a prevailing attitude of acceptance and non-judgement regardless of the type of disability or level of disclosure. This acknowledgement was explicit, despite the fact that the institutional support system is based on the provision of medical documentation to confirm a diagnosis in order to receive support. Jonathon, who has Attention Deficit Disorder (ADD), depression and anxiety, explains, "*…if not for them [disability services], I wouldn't be here because they enabled me to realise that I belong here and have the right to be here like anyone else*". Jonathon spoke about feeling very isolated prior to a chance encounter with a counsellor who helped him to understand the impact of ADD on his educational goals and introduced him to specific disability supports. Up until that point, he did not know what services were available to support him.

While acknowledging the important role of disability services, confining safe and supportive conversational spaces to a specific service area risks reinforcing normative views of the academic space in which difference cannot be engaged with. Jennifer, a distance student who lives with an autoimmune disease, shared:

> *I'm quite capable. But, managing a health condition is hard, so there's no way I would have been able to study without being given that level of support, and they [the disability staff]…never kind of questioned me [my story], because sometimes you can have an invisible illness and people will [make a judgement about your ability].*

For Nicole, who has been studying for over 10 years while managing a chronic health condition and Post Traumatic Stress Disorder, conversations about disability outside of specific support services are difficult and often prove frustrating:

> *I think it's hard for some people [such as Faculty staff] because they don't have that experience. They haven't lived with somebody with a disability, or had family members with a disability, so it's extremely hard for them to actually understand what others go through…some were completely clueless, just absolutely knew nothing.*

Nicole believes that the lack of awareness around issues for students with disability reinforces their feelings of being different. Thus, although disability support services provided important emotional and practical supports, some students with disability felt very alienated within the broader higher education space.

Overall, students reported a lack of consistency in terms of approachability and knowledge about disability among teaching and academic support staff. Some students recalled experiences in which teaching staff had been supportive and non-judgemental when considering learning adjustments. Others recalled negative experiences of staff making assumptions about their individual capacity or displaying reluctance to implement reasonable adjustments, based on academic integrity. For all students however, the notion of being judged as capable was connected in some way to having a disability. Sandy, a mature aged student, recounted an interaction with her lecturer in which she asked for an assignment extension due to a number of setbacks at the time relating to her health. According to Sandy, the lecturer advised her to pull out of the unit as she "*had too many problems*" and said he could help her with that process. Sandy felt "*really devastated*" by the advice because she didn't want to pull out at all, just get an assignment extension to help her through, and believed that the assumption that she had too many problems was based on a narrow view of her capability. Fear of such experiences led some students to feel intimidated at approaching academic staff for support. Margie, a student with an acquired brain injury, spoke of her deep reluctance in reaching out to her lecturer for help because of her academic track record (absences and some fails). Margie's overriding concern being that her ability would be judged in relation to her disability. She said, "*I'm just literally too scared to go back to the lecturer…because it so undermines my confidence*".

Gibson (2015) uses the term ‘cultures of difference’ to explain the divide that exists within tertiary education when it comes to disability, whereby inclusion becomes about attempts to “induct that which is different into already established forms and dominant institutional cultures” (p. 878). Without training or guidance for staff about how best to support students with disability or respond to their circumstances, as was the case at the study institution, institutional rhetoric around inclusion becomes lip service if the significant cultural investment needed to move from the aspirational to grounded practices embedded throughout the university is not undertaken.

For students with disability this superficial commitment to inclusion in university can reflect broader feelings of exclusion experienced in the wider community more generally. For Mike, a distance student living with an ongoing medical condition, judgement on the basis of disability was a routine occurrence:

> *I think anyone with a medical condition as a general rule is afraid of being judged, and I think that’s general life, not necessarily at uni even…and also because you can’t see my issue…I just feel like I have to cover it up a bit more sometimes.*

Despite the institutional rhetoric of inclusion, Mike’s comments point to no discernible difference between the ways people with disability may be viewed internally or externally in wider society. Rather, the experience of students with disability in and out of higher education is experienced as a continuum of the sense of always being marked out as different. Hence, the desire to disclose disability competes with a desire to develop a ‘normal identity’ free of the disability label and the choice to progress alone, without support (Grimes, Southgate, Scevak, & Buchanan, 2018, p. 12).

Reaching out to overcome self-doubt

In this study, students articulated clear benefits of both peer support and engagement with student services, in order to mitigate feelings of inadequacy or negative learning experiences. Kilpatrick et al. (2016) argue that good relationships contribute to the success and retention of students with disability, particularly in smaller institutions that can provide a more personalised approach. In general, interview participants had a good awareness of support services, such as counselling, library and academic assistance, and reported positive experiences, particularly if they had been referred. However, these experiences of reaching out for library or academic assistance often came *after* fail grades or stressful experiences completing assignments. Moreover, these services often required individual students to self-diagnose study problems. If they did not know the nature of the problems they faced, these services only offered ambivalence. Reflecting on an initial lack of engagement with academic support services, Jonathon said, “*I didn’t know what to ask for, and if you don’t know what to ask for, people don’t know what to give you*”.

Participants who accessed academic support services spoke about feeling empowered by that support, rather than seeing it as a reflection of a deficit in their capabilities. Although, it is the case that students without disability also seek out such services. Participants in their early years of study spoke about increased feelings of autonomy and self-efficacy in navigating the academic terrain which had previously felt unknown, particularly for mature aged students who had returned to study. As Mark, a mature aged distance student reflected: “*It is purely because I do have that academic support that I am still here. If I hadn't had that level of support in my first year of undergrad, I would have been gone*.”

Learning how to advocate

The importance of disability services staff acting as student advocates was reflected in a number of narratives shared by students, particularly if they faced difficult conversations with academic staff or had to participate in specific academic processes such as a review of grade. For a number of study participants, having a university representative who could understand and represent their interests was a way to mediate the inequitable power structures inherent in these interactions. While students felt supported by having disability advisers providing this role, there was no indication in the responses that any of the students felt empowered to self-advocate, and although well-intentioned, support staff need to reflect on their role in contributing to negative discourses about people with disability. A study by Fossey et al. (2017) concluded that disability staff need to adopt more of an enabling role rather than one of acting on behalf. This approach is needed to ensure that students "develop the necessary knowledge and skills, increase their awareness of disability rights and power so they can effectively negotiate the implementation of reasonable adjustments with teaching staff" (Fossey et al., 2017, p. 830). Fundamentally, this can only be done in an institution in which self-determination is viewed as part of the learning experience for all students, not just those who fit the norm.

Discussion

A traditional view of university sees the student journey as linear, with learners commencing their studies with the requisite experience, knowledge, skills and cultural capital to negotiate, progress, achieve and meet academic milestones in discrete timeframes. Yet, the experiences of students with disability who participated in this research don't conform to this trajectory. Rather, the research points to a gap between inclusive policies and rhetoric and actual practices at the study university that have consequences for students with disability and their educational success. At worst, they reinforce inequality, stigma and dominant normative discourses. Of course, it is important to note that the students who agreed to be interviewed may have had negative experiences which motivated them to participate in the study. The significant barriers faced by students with disability as revealed in interviews are attitudinal and cultural, less about individual issues that students may have with particular staff and policies in the university, and more about avoidance by the institution to fully engage in understanding how inclusion is experienced by people with disability. In this way, the inclusion narrative can be simplistic and misrepresented, focused on "…ways of doing that relocate students with disability into dominant institutional culture rather than interrogating how institutions reinforce inequality" (Gibson, 2015, p. 878).

While pervading deficit attitudes towards people with disability are not exclusive to higher education but to society at large, they point to a failure within the institutional setting to break traditional barriers to university for people with disability and other equity groups. While government policy has stimulated greater demand for higher education, this agenda has not yet succeeded in challenging the inequitable structures, marginalising practices and cultures of exclusion that permeate tertiary institutions. Unless challenged, the retention rates of students with disability will continue to remain below those of other students with little interrogation of the statistics or reasons, beyond stereotypes, to explain why.

In this research, participants spoke about feelings of frustration, fear and judgement being part of their everyday experiences at university. But there was also a clear validation of disability services for these students, and its role as an intermediary between themselves and the wider institution. While acknowledging the important role of disability services, the danger here is that disability issues and their resolution remain confined to 'disability specialists' rather than making the whole institution more accountable. Importantly, students with disability who reach out for assistance to other services, such as academic support and the library, reported stronger feelings of self-efficacy and empowerment. While students with disability often don't draw on discourses of entitlement to navigate challenges, advocacy skills training and an increased awareness of disability rights can be a way forward (Fossey et al., 2017). In the same way, greater investment by universities in ongoing staff training about inclusive practices and disability awareness is needed to build inclusion from the ground up. Universities need to provide opportunities for teaching staff to interrogate and/or challenge assumptions about disability as part of grassroots strategies to embed inclusive support practices.

Importantly, from the thematic analysis discussed in the sections above we see that meaningful inclusion requires a more comprehensive integration of disability policy, academic practices and support services within educational institutions. An underlying message was the need for greater involvement of students with disability in the planning and review of both disability services and inclusive teaching and learning practices in order for the institution to maintain a high level of responsiveness to the needs of such students and thereby provide a more objective measure of inclusion based on their lived experiences. Personal struggle with university study is not a consequence of living with disability, rather it is the imposition of institutional barriers which make it hard for students with disability to navigate.

Conclusion

The research discussed in this paper demonstrates that an institutional rhetoric of inclusion does not translate into inclusive experiences or increased involvement of students with disability in the development and evaluation of services, policy development and service planning. As noted above, the lack of control and non-involvement in decision-making and review of relevant services and policies can contribute to further experiences of disempowerment. It is imperative that inclusion is built from the ground up, based on an understanding and validation of the experiences of students with disability and from other equity groups rather than their misrecognition in the reproduction of inequality.

The study positions the voice of students as central to critical reflection on inclusive policies and practices. Significantly, inclusion is 'experienced' in relational spaces between students and staff. As Sayer (2011, cited in Vehmas & Watson, 2011) notes, "…the surrounding community, society and ideological environment necessarily affects the subjective experiences of disablement" (p. 14). The research identified key themes which highlight the ways in which universities reinforce deficit views of people with disability. Universities, as so-called places of learning and progress, diversity and tolerance, need to create opportunities for meaningful engagement with students living with disability, to make connections between lived experiences and what it means to be inclusive. University leaders also need to be mindful of ensuring that support services are evaluated on the basis of their purpose, value and response to need. Without spaces to analyse our assumptions and practices, we are not always aware of the insidious hold of misrecognitions and exclusions in education.

Study participants highlighted insights and experiences that can only be gleaned from an enquiring methodology that provides space and opportunity to share individual realities and experiences. Through the student narratives, we see examples of deficit and disabalism which highlight the discord that exists between institutional inclusive rhetoric and the complex realities of being a student with a disability. Going forward, it is critical that students with disability participate in the development, implementation and review of policies and practices to ensure that their perspectives are present within the structures and processes that shape their experiences of higher education.

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