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Integration of a Disability Lens as Prerequisite for Inclusive Higher Education

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Abstract

PURPOSE. Occidental higher education often approaches disability as a disparate issue, failing to recognize that it is part of human diversity. Such an approach hinders inclusive education because it overlooks how disability is intertwined with other identities and concepts of exclusion. The overarching aim of this paper is to enhance understanding of (intersecting) disabling processes within education policy and practice and the impact thereof on students; and to raise educators' awareness about how integration of knowledge from Disability Studies within pedagogy and their daily interaction with students, can positively influence disabled students' wellbeing, their study opportunities and aid the overall process of inclusion.

APPROACH. This paper offers a disability lens by (1) presenting a literature overview from a Disability Studies (DS) perspective about disability and exclusionary phenomena, in particular disablism and ableism; (2) substantiating how a current focus on accessibility hinders actual inclusion; (3) analysing a case-study through the presented perspective with attention to Dutch contextual factors. For the case-study, the first author and 'Tess' engaged in regular conversations during a year in which Tess shared her experiences as a student of higher education. In this paper, a selection of these experiences is presented from a reflexive perspective and with application of the presented frameworks. With this, the complex impact of exclusionary processes on interactions between students, educators and on the organization of university involved (social) events is illustrated.

FINDINGS. The lack of nuanced, fluid and intersectional approaches to disability within mainstream education hinders the recognition of (epistemic) injustices. Exclusionary processes and practices in higher education remain unacknowledged, although they negatively impact disabled students and block their epistemic contribution. Moreover, the continued focus on accessibility hinders implementation of the international convention on the rights of persons with disabilities and deflects attention from the fact that inclusive education requires systemic change and a multi-layered approach.

KEY MESSAGE. The current trajectory of disability inclusion is counterproductive without true systemic change. Integration of the presented disability lens is imperative for truly intersectional approaches to inclusion and offers educators a way to positively influence students' wellbeing and identity development, even when policy changes are not yet achieved.

Keywords: disability, higher education, disablism, ableism, pedagogy

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Points of interest:

- Knowledge and attitudes about disability in higher education systems, in policies and practice, often do not portray disability from the perspective of disabled people themselves. There is also a lack of understanding how disability is part of human diversity and is intertwined with other identity aspects.
- Because higher education often focusses on including disabled people in existing systems by way of individual accommodations rather than on changing the design of the system, disabled students experience various forms of exclusion, varying from opportunities to study to the way they are approached by educators, that effect their wellbeing.
- The usefulness of disability studies theory is illustrated by applying them to the experiences of ‘Tess’, demonstrating how her personal and professional life was influenced by them.
- We argue that policies need to change and that educators themselves can work on true inclusion by recognising disability as diversity and by integrating up-to-date knowledge from the perspective of disabled people themselves in their approaches.

Introduction

Inclusive and equitable quality education is recognized to offer a key entry point for inclusive societies (UNESCO, 2015). As part of the global vision for education, the Sustainable Development Goal (SDG) 4 relates to the social justice argument for equal opportunities for every child and young person, irrespective of who they are and where they are from (Biesta, 2020a; UNESCO, 2020). Disabled people have long been excluded from (mainstream) education. The *United Nations Convention of Rights of Persons with Disabilities* (CRPD)—addressing the universal human rights of people with disabilities across the world—also explicates the right to education within regular educational settings (United Nations, 2006). The Netherlands ratified the CRPD in 2016, as one of the two last European countries to do so (Oomen, 2018).

Absence of inclusive policies negatively affects access to education for disabled people across all regions and income groups (UNESCO, 2021). However, truly inclusive policy development proves to be difficult; Harrington (2019) argues that occidental mainstream education often adheres to “normalizing notions of inclusion/exclusion” (p. 395) which is contingent on the premise that “being a typical student is the ideal state of being” (p. 394). With regard to disability, the focus often lies on accessibility by way of (individual) accommodation-provisions which reveals an underlying ‘deficiency perspective’ and requires disclosure and medical diagnosis of physical, mental, intellectual or sensory impairments. Literature shows such policies may reinforce disability stereotypes and influence pedagogical interactions between educators and students, negatively impacting disabled students (Daniels, 2020; Järkestig Berggren et al., 2016; Osborne, 2019; Van Hove et al., 2014). This counter-productive approach also incorrectly rationalizes that disabled people are inherently different with fundamentally different needs than non-disabled people. Furthermore, rather than markedly improving equity for historically marginalized students, the focus on accessibility has reconfigured mechanisms for inequity (Indar, 2018). Truly working on inclusion entails changing the system as a whole, rather than designing interventions to ‘include’ marginalized groups into existing (mainstream) systems which uphold unsustainable normative (often Euro-American) standards (Dirth & Adams, 2019). Additionally, especially concerning social and psychological inclusion, pedagogical skills and reflexivity of educators are important (Spaan & Rosalina, 2021).

UNESCO argues that obtaining progress in education for everyone requires questioning the assumptions and arrangements which led to exclusions and oppressions (UNESCO, 2021). The multi-disciplinary field of Disability Studies (DS) does just that and has many insights to offer. However, there is a continued divide between knowledge from DS and other scholarly fields which upholds certain marginalization principles by using disability to argue against equality and by justifying the marginalization of all minority groups (e.g., Baynton, 2001; Collins et al., 2016). Even now,

overrepresentation of different marginalized groups in referrals to ‘special education’ systems implies that disability serves as an over-all exclusionary mechanism; differences get labelled as deficient and on this basis students of marginalized groups are disproportionately excluded from mainstream education (e.g., Collins et al., 2016).

As the importance of a disability lens for the process of inclusive education is often under-estimated, this paper presents empirical examples to illustrate how the lack thereof has a tangible negative impact on disabled students’ lives. With this, this paper aims to enhance understanding of disabling processes and to emphasize how educators can positively affect (daily) educational practices by incorporating a disability lens. To do so, this paper’s approach is threefold: (1) presenting an overview of international literature about disability, disabling processes and exclusionary phenomena, in particular disablism and ableism as a background for the case study; (2) providing a theoretical substantiation of why the current focus on accessibility has not led to inclusive education; (3) presenting a case study from the Netherlands in which the presented frameworks are applied and contextual influences are discussed.

Methods

This paper is part of a larger research project with the working title ‘Disability identity in young disabled persons in relation to higher education.’ The study design is rooted in the ideology of what has been called ‘emancipatory research’ (Barnes, 2001; Oliver, 1997) which is based on fundamentals of reciprocity, gain and empowerment (Oliver, 1992). This approach acknowledges the personal positionality of the researcher; the first author identifies as a disabled, Dutch, white woman. She has a background in social work and currently works as a lecturer at a university of applied sciences in the Netherlands. This study has been approved by the ethical committee of the University of Humanistic Studies, Utrecht, the Netherlands.

Literature Overview

The presented literature overview aims to situate the case study within a DS perspective; presenting state-of-the-art theoretical frameworks in relation to disability and current occidental higher education (HE) policy and practice.

Case Study

Over a period of a year, the researcher engaged in regular communication with ‘Tess’ (pseudonym) about her experiences with disability and HE. Using a reciprocal approach meant that data collection did not entail ‘typical’ interviews but comprised of extensive conversations. The first conversations addressed Tess’s personal experiences with disability and provided room for her to ask questions, resulting in an exchange of experiences. Differences and similarities were explored and later on, the researcher introduced knowledge from DS as a lens for reflection.

During the research period, Tess shared former experiences (retrospective data), current experiences, previously written blogs with documented experiences and documents from her study (prospective data). Tess and the first author reflected on these together from multiple perspectives, including that of DS. Regular ‘member checking’ ensured correct interpretation and representation of data. Tess has read and approved publication of this paper. Quotations are translated from Dutch to English.

Literature Overview: A DS Perspective on Disability, Exclusionary Concepts and Education

Modelling Disability

Central to occidental disability activism and DS has been the distinction between two models of disability: the individual or medical model and the social model. These models have been intensively discussed, debated and critiqued (Van Hove et al., 2016) and can be considered an important basis for understanding western discourses on disability. On a rudimental level, the individual model assumes that, what the CRPD calls “long-term physical, mental, intellectual or sensory impairments” (United Nations, 2006, art. 1) within a person are the cause of disability—suggesting that disability is a horrible event, occurring randomly and by chance to unfortunate individuals (Oliver, 1990, 2013). This ‘personal tragedy’ classification of disability perceives people with ‘impairments’ as victims of their circumstances (Hoppe et al., 2011; Morris, 1991). This is in itself disabling by denying disabled people’s “experiences of a disabling society, their enjoyment of life, and their identity and self-awareness as disabled people” (French & Swain, 2004, p. 39). In contrast, the social model locates disability within society which is organized in a way which systematically does not consider the needs of disabled people or provide appropriate services for them (Oliver, 1990, 2013). The social model considers disabled people as a group, from a macro level (Altman, 2001).

One of the contended issues with the social model has been the lack of acknowledgement of influences of individual and ‘impairment’ factors within the concept of disability. However, Thomas (2008) in line with early disability activists, argues that the social model refers to disability as something ‘imposed on top’ of impairments; “disabled individuals live lives shaped both by impairment effects and by the effects of disablist social factors” (Thomas, 2008, p. 17). Furthermore, marginalization of disabled people takes place in relation to the dominant culture and is intertwined with e.g., race, gender, sexual identity, and class (Goodley, 2017). Consequently, the social model should not be considered as ‘racially neutral’ and aim to analyse disability in relation to other influences (Dunham et al., 2015), as well as take into account the dominant knowledge bases and ways of being of the society it refers to (Dirth & Adams, 2019). In the past, a lack of doing so has led to e.g. insufficient recognition of diversity of Indigenous perspectives and failure of acknowledging instances when large overburdens of impairment are maintained by poverty within and between nations (Hollinsworth, 2013). Overall, there is not just one explanatory theory or approach to addressing marginalization of disabled people (Goodley, 2017).

Beyond Modelling

A move away from ‘modelling disability’ has led to more “nuanced understandings of disability in relation to cultural difference and situated experience” (Barker & Murray, 2013, p. 67). To understand disability, experiences with e.g., chronic illness (Wendell, 2001) as well as influences of specific cultural, environmental and historical meanings (Barker & Murray, 2013) need to be recognized and included. Additionally, it is important to recognize that disability as a concept has historically been used to justify inequality for other minority groups by attributing disability to them, e.g., denying women voting rights and forbidding entry to immigrants due to ‘feeble-mindedness’ (Baynton, 2001) and that disability epistemologies and disciplines, including DS, have also been impacted by colonialism (Grech, 2015). Current consensus is that disability needs to be understood as a complex, fluid, multidimensional concept, and an identity marker which is critically impacted by and enmeshed with other constructs such as race, ethnicity and gender as well as nationhood, immigration, settler colonialism etc. (Altman, 2001; Ben-Moshe & Magaña, 2014; Grue, 2011; Linton, 1998; Loutzenheiser & Erevelles, 2019; Mollow, 2017; Reeve, 2002).

Disability is closely related to the construction of normalcy: when the concept of the norm is in use, disabled people are thought of as deviant, abnormal, ‘other’ and less human (e.g., Davis, 2013a;

Goodley et al., 2014; Goodley & Runswick-Cole, 2016). Ben-Moshe et al. (2012) argue that “one is always dis/abled in relation to the context in which one is put” (p. 211). A heuristic device is provided by the so-called dis/ability complex, an intersectional framework (Goodley, 2018) which recognizes that people occupy different places on a continuum, e.g., between dependent and autonomous. Within this framework, the binary of dis/ability (opposites on either end of the /) attends to “the very definite way in which humanity works through and against preferred and othered claimed and abandoned, majoritarian and minoritarian positions” (Goodley, 2018, p. 8).

Disablism and Ableism

In order to address barriers to inclusive education, we believe two concepts are particularly relevant: disablism and ableism. Although often used interchangeably, they are very much different concepts (Campbell, 2008a, 2009).

Disablism

Disablism concerns the exclusion or unequal treatment of people by a set of (conscious or unconscious) assumptions and practices because of actual or presumed disabilities (Campbell, 2009), or sensory, physical, mental or intellectual impairments. It is understood as a form of social oppression in contemporary society and is manifested in institutionalized and other socio-structural forms, as well as in person-to-person interactions (Thomas, 2012). Reeve (2012a,b) has explicated this as (1) structural disablism in the form of e.g., physical barriers or inaccessible information and (2) psycho-emotional disablism, in the form of e.g. hurtful comments, stigmatizing actions of others and internalized oppression. Disablism is often experienced on (almost) a daily basis and is interconnected with other aspects of identity and culture as well as life experiences. It can have long lasting effects on someone’s self-esteem and self-confidence (Reeve, 2006).

Disabled people find different ways of resisting disablism which in itself can have emotional and physical effects (Goodley et al., 2018; Reeve, 2006, 2012b, 2014). Moreover, experiences of disablism are often not recognized by other people, or maybe even by disabled people themselves, which can create a psychological environment in which one’s worth or self-identity is difficult to hold on to (Watermeyer & Swartz, 2016).

Ableism

The term ableism stems from grassroots activism of disabled lesbian feminists (Campbell, 2020). Studies in ableism have shifted the lens from what disability entails, to what the study of disability unveils about the production of abled-ness and the maintenance of the able, able-bodied and non-disabled identity (Campbell, 2008b; 2012). The notion of ableism draws on various theoretical approaches, including traditions from the global south (Campbell, 2019), and is useful in thinking about disability as well as other forms of difference resulting in marginality or disadvantage (Campbell, 2012).

Ableism is a [open] system of causal relations about the order of life that produces processes and systems of entitlement and exclusion. This causality fosters conditions of microaggression, internalized ableism and, in their jostling, notions of (un)encumbrance. A system of dividing practices, ableism institutes the reification and classification of populations. Ableist systems involve the differentiation, ranking, negation, notification and prioritization of sentient life. (Campbell, 2017, pp. 287–288)

Overall, ableism strives after ‘sameness’ (Campbell, 2008b) and rejects ‘variations of being’ (Wolbring, 2008). Ableism “remains a deeply entrenched structuring force in society”, leaving

“alternate conceptions” of disability as “subjugated knowledges” (Jain, 2020, p. 2). In occidental society, ableism can be recognized in the general acceptance of judgement based on abilities, often leaving subsequent processes of exclusion of those deemed ‘not able enough’ unquestioned and even unnoticed (Wolbring, 2008). Importantly, ableism need not refer to disability at all; it affects everyone, impacting people in different ways (Campbell, 2021).

As (occidental) ableist processes also make use of “critiques of idealized discourses associated with whiteness, masculinity, entrepreneurship, independence, labor, adulthood and accountability” (Van Hove et al., 2014, p. 22), it intersects with other ‘isms’ and forms of discrimination, including racism, nationalism, sanism and anti-fat prejudice (Dunham et al., 2015; Mollow, 2017; Wolbring, 2008). These different forms of ‘ism’ and discrimination can become deeply intertwined and operate in insidious ways, producing double binds (Dunham et al., 2015; Mollow, 2017).

When positioned against disabled people, ableism rejects the social model of disability; rather than accepting and accommodating disabled people, it focusses on ‘fixing’ individuals (Wolbring, 2008), perceiving disability as inherently negative (Campbell, 2009). Moreover, ableism reproduces disablism (Goodley, 2018).

Dis/ability and Occidental Education

From a DS perspective, HE often leaves little room for nuanced and complex understandings of disability. Much of the knowledge about disability within policy, curriculum and pedagogy, has been acquired from sources which pathologized and ‘othered’ disabled people while simultaneously individualizing their experience (Goodley & Runswick-Cole, 2012). Also, disability has historically been largely left out of pedagogy and the philosophy of education (Podlucká, 2020; Taylor, 2015). This influences perception and understandings of the experiences of disabled people; it can block them from contributing to epistemic resources (Dohmen, 2016), and from communicating their embodied knowledge (Catala, 2020). When left unchallenged, it can form a ‘hidden curriculum’ which is harmful to disabled learners and educators (Ressa, 2021).

Disablist and ableist processes and practices are ingrained in higher education systems: from mandatory attendance to inflexible forms of information and testing, architecture, lack of rest-spaces and so on (Daniels, 2020; Dolmage, 2017). Furthermore, in contrast to the aforementioned complex understandings of disability, dichotomized or linear definitions of disability are often deemed necessary for the acquirement of certain rights (Bart & Maier, 2016). This hinders intersectional frameworks and leaves undiscussed that e.g., disability and race have been shown to intersect with an ideology of evolutionary hierarchy (Baynton, 2001). Moreover, pigeonholing students in more than one ‘category’ leads to compounded experiences and impacts exclusionary mechanisms (Annamma et al., 2018; Collins et al., 2016; Dolmage, 2017).

Overall, incorporation of a disability lens can contribute to a more socially just education system and a transformative approach to inclusion (Jain, 2020). Assessing (existing) curricula through a dis/ability framework with the aim of presenting accurate disability information and depictions is called ‘cripping the curriculum.’ Such approaches should involve deconstructing negative representation and meanings of disability, accepting disability as an integral part of human variation (Connor, 2014) while allowing room for the emotion work involved in revaluations of disability (Wechuli, 2022). Importantly, knowledges from the global south should be included to prevent further (epistemological) injustice and to ensure just understandings of the complexities of disability and intersectionality (e.g., Campbell, 2020; Grech, 2015; Iqtadar et al., 2021; Nguyen, 2018).

Accessibility ≠ Inclusion

The continual perception of students with impairments as a qualitatively distinct category often leaves exclusionary practices interpreted as just (Reid & Knight, 2006) and the nature of institutions unquestioned (Baker, 2002). For example, policies offering accommodations for disabled students are widely accepted despite their aim to “temporarily even the playing field” and to achieve around, against, or despite of disability rather than with it (Dolmage, 2017, p. 70). Dolmage (2017) calls this retrofit:

The retrofit is one way in which we address structural ableism (for instance an inaccessible space) with means that simply highlight and accentuate and invite disablism—for instance, singling out the body that needs to ask for access. (p. 70)

From a DS perspective, retrofit is unjust; the often-required identification of disabled students has many consequences since the social identity of ‘disabled’ comes with a considerable amount of stigma, prejudice and even loss of personal autonomy (Grue, 2011, 2016). A person can distance themselves from the abnormality perceived with disablement, often referred to as ‘passing’ or ‘passing as normal’ (Campbell, 2009; Linton, 1998; Morris, 1991). ‘Passing’ can be done both voluntary and involuntary and although advantages may be avoidance of prejudices and discrimination (Wendell, 2001), it can also form a serious threat to selfhood (Campbell, 2009; Linton, 1998; Morris, 1991). Moreover, as only a fragment of people with disabilities identifies themselves as such (Bogart et al., 2017), such policies may not even reach the intended audience.

Moreover, retrofit can reproduce and reinforce certain stereotypes, assumptions and attitudes toward disability (Baker, 2002; Dolmage, 2017; Van Hove et al., 2014) and lacks room for intersectionality (Nieminen, 2023). This in turn leads to more exclusionary mechanisms on an inter- and intrapersonal level. For example: having to adapt regular inaccessible curricula per student reinforces ideas about disabled students ‘costing effort’, draining time/resources etc. (Matthews, 2009; Tobin & Behling, 2018).

Accepting impairment—or technically, a *diagnosis* of impairment—as a prerequisite for access to accommodations can also reinforce beliefs about ‘impairments’ constituting something objective and a ‘natural characteristic’ of an individual, even though this is not necessarily so (Davis, 2013; Tremain, 2018). Implicitly, it communicates that medical professionals’ perspectives are more valid and knowledgeable about an individual’s situation and needs than the disabled person themselves, referring ‘power’ to the (medical) professionals (Tremain, 2001, 2018). Similarly, HEIs transfer power to disability-officers who, although usually non-medical professionals themselves, ‘award’ (student) accommodations on the basis of said medical diagnosis. Such policies also leave unaddressed that there are dis/abled students who do not (yet) have a diagnosis or cannot attain one due to e.g., the cost or energy involved, impairments not meeting certain thresholds of, or not being recognized by current diagnostic criteria. Furthermore, mandatory disclosure is problematic because self-disclosure strategies are a mechanism for managing one’s identity in relation to disability and integration thereof in a ‘broader sense of self’ (Evans, 2019). Lastly, non-disabled students with different access requirements than the institutional norm are also impacted.

Accommodations for flexible testing are often guarded to prevent unfair advantage and protect quality, even though more flexible tests can be more valid and reliable (Hilberink et al., 2018). Additionally, traditional metrics used in assessing student excellence are more evidence of sustained privilege and group advantage rather than quality (Taylor & Shallish, 2019). And even when accommodations have been provided through stringent processes, both students and educators can still hold beliefs about ‘unfair advantage’ (Daniels, 2020; Dolmage, 2017; Osborne, 2019). Disabled students are stuck between risking stigmatization or risking education without sufficient support by not disclosing (Van Hove et al., 2014). Langørgen and Magnus (2018) found that such oppressive mechanisms may not be obvious to either students or staff due to efforts to fit disabled students into the ‘normality frame’ of academia: “[t]he more successfully they coped with their studies, the greater the chance that the

inadequacy of the system would not be visible, and the greater their expenditure of effort to compensate” (p. 612).

Overall, policies aimed at identifying disabled students are not actually inclusive when not simultaneously improving the system to ensure greater general accessibility (Van Hove et al., 2014; Schoonheim, 2016). Osborne (2019) argues how this can be considered a social (in)justice issue: “the dynamics of disability, and whether a student considers themselves disabled, whether a student is comfortable disclosing their disability, or whether the institution accepts that a student has a disability, can itself become a barrier” (p. 246).

Literature on Students’ Experiences

Institutional contexts shape disabled students’ experiences and their opportunities for access and equal participation in education (Järkestig Berggren et al., 2016). Higher risks of ‘dropping out’ and low study success in comparison to their non-disabled peers have been linked to the persistent and higher levels of academic, social and personal adjustment challenges disabled students face (Baker, 2002; Langørgen & Magnus, 2018; Lipka et al., 2020; Osborne, 2019). Frequent encounters with stigma and the navigation thereof negatively impacts access to support and accommodations as well as identity development and sense of belonging (Carette et al., 2018; Järkestig Berggren et al., 2016; Lipka et al., 2020; Osborne, 2019; Van Hove et al., 2014). Importantly, barriers comprise of complex interactions and an accumulation of such experiences (Langørgen & Magnus, 2018; Rath, 2022).

While accommodations are often perceived as helpful by disabled students, they are simultaneously ‘othering’ and connected to experiences of e.g., embarrassment and shame (Nieminen, 2023). Marshak et al. (2010) identified five thematic categories of student-defined barriers to the use of disability services: identity issues; desire to avoid negative social reactions; insufficient knowledge; perceived quality and usefulness of services; and negative experiences with professors. Notably, available or awarded accommodations do not always meet disabled students’ needs which can lead to e.g. feelings of failure, personal incapacity and worthlessness (Daniels, 2020; Hamilton et al., 2023; Järkestig Berggren et al., 2016).

Disabled students regularly encounter disbelief, a lack of understanding about the realities of living with disability and inhospitable environments which do not consider them as participators (Osborne, 2019). Unwillingness or unsureness from educational professionals to provide appropriate accommodations influences disabled students’ options to participate and can negatively impact their health (Francis et al., 2019; Hamilton et al., 2023). Moreover, disabled students experience ‘policing’ of accommodations, especially when the students do not fit into pre-specified boxes of what disability entails (Hamilton et al., 2023; Lane, 2017; Osborne, 2019).

Accommodations regularly focus on curricular access, testing and classroom-participation. However, a lack of disability awareness among tutors, academic staff, peers and a failure to use universal design techniques within teaching also negatively impact group work and class social engagement which can lead to lower academic participation as well as social isolation (Hamilton et al., 2023; Rath, 2022). Moreover, engaging in educationally beneficial activities leads to expending “disproportionate amounts of time and personal effort to overcome a range of systemic barriers” which comes at the expense of disabled students’ social engagement and wider sense of belonging (Rath, 2022, p. 8).

Overall, expectations of disabled students to assert their rights much exceeds those placed on traditional students, draining their personal resources (Rath, 2022). Importantly, disabled students provide insight in how the social-psychological environment within HEIs is at least as important as physical infrastructure for the process of inclusive education; even within exclusionary systems, (individual) educators as well as students’ peers can have beneficial impact on disabled students’ wellbeing and how they feel supported (Francis et al., 2019; Lane, 2017; Langørgen & Magnus, 2018; Nieminen, 2023).

Disability and Education in the Netherlands—A Disability Lens

Before introducing the case study, we present a brief description of the Dutch context.

Legislation and Historical Context

Dutch law or policy does not explicitly secure the goal of an inclusive educational system (Schoonheim & Smits, 2019). There are however some legislative frameworks pertaining to accessible education such as the CRPD, the Law on Higher Education and Scientific Research, the Law on Equal Treatment on the basis of Disability or Chronic illness (WGBH/CZ), as well as accreditation frameworks and norms for digital accessibility (Expert centre in inclusive education [ECIO], 2023). The right to education is also explicated in the Dutch government program “Onbeperkt meedoen!” (Unlimited participation!). However, The Netherlands Institute for Human Rights (NifHR) argues that the goal of inclusive education is too vaguely defined, leaving it (too) dependent on individual persons and hindering monitoring and progress with regards to the CRPD (Schoonheim & Smits, 2019; NifHR, 2020).

Disability as possible grounds for discrimination was left out of the general law on equal treatment in 1994 (Van Trigt, 2019) and has only recently been included in legislative frameworks. The WGBH/CZ, which entered into force in 2003, was adapted to include disability and to cover the entire field of education in 2016 (Goudsmit, 2016). However, during the process of ratification of the CRPD, the notion of accessibility was narrowed by defining ‘reasonable accommodation’ as ‘simple adaptations’ (Oomen, 2018). In January 2023, the Dutch constitution was amended to include both disability and sexual identity as explicit grounds on which discrimination is prohibited (Government of the Netherlands, 2023).

The consequences of centuries of segregated ‘special education’ in the Netherlands are still palpable. In 1994, 15 forms of special education were provided, serving almost 5% of all primary group aged children (Brants et al., 2018). In 2014, ‘fitting/suitable education’ was written into law which entailed collaboration between regular and special education to provide educational care based on students’ ‘needs.’ Currently, the educational divide continues: in 2020, (segregated) ‘special education provisions’ and ‘rugzakjes’ (the proverbial equivalence of baggage)—a (financial) provision aimed at enabling students with ‘special needs’ to attend mainstream education—increased (Van Yperen et al., 2020). Reports show that relatively more students from “cultural minority groups” have been referred to special education and that overall, males are overrepresented within special education provisions (Smeets, 2007; Smeets et al., 2009). Also, many disabled children and young people, especially those with intellectual disabilities or with mental distress, are placed outside of the regular education system (NifHR, 2022). Current financing systems and regulations are considered to hinder actual inclusive education (Schoonheim, 2016; Schoonheim & Smits, 2019). Moreover, inclusive education is regularly portrayed as charity rather than a right: e.g., charitable campaigns requesting donations so that disabled children ‘can attend schools within their own neighborhoods and make friends there’ (Stichting het gehandicapt kind, n.d.).

Higher Education and CRPD Goals

Students with disabilities at Dutch HEIs have reported higher rates of dropping out as well as study delays (Schoonheim & Smits, 2019). Nonetheless, the CRPD goals are becoming more visible in policy; some HEIs signed an intention-declaration to implement the CRPD (ECIO, 2021) and the ‘Dutch strategic agenda for HE and research’ explicates that inclusive education entails that students: (1) experience a sense of belonging; (2) have role-models with whom they can identify; (3) perceive

attention for increasing diversity and the necessary accommodation that comes with it (Ministry of Education, Culture & Science [EC&S], 2019).

Definitions of what constitutes disability and impairments as well as policy and practice with regards to (disability) inclusion vary between HEIs, as it does through governmental institutions. Some HEIs integrate policy on disabled students within general organisational policies or try to minimize separate policies all together; others have specific policies aimed at disabled students (Van Veen et al., 2021). Van Veen et al. (2021) argue that the extent and manner of CRPD implementation within HEIs are influenced by previous history with regards to inclusive education; the amount of (registered) students; organisational structure; type of education; governmental support; staff efforts and thought-paradigm; financial resources and expertise/information sources.

In practice, students are often urged to disclose their disability to the education implementation service (DUO) which is part of the ministry of EC&S and at the specific HEI at enrolment. Qualifying for accommodation then involves disclosing disability, personal circumstances and experienced barriers to student support officers or the equivalent thereof. Regularly, there are ‘standard’ accommodations geared toward specific impairments (such as extended exam-time for students with proof of diagnosis of dyslexia) and more individualized accommodations (such as rostering accommodations when not all classrooms are wheelchair-accessible). When eligible, disabled students can apply for financial compensatory accommodations through HEIs, DUO, and the municipality where students are registered (ECIO, 2020). As the Netherlands are a decentralized unitary state, policies and practices differ per municipality with regards to the qualification procedures and available (financial) support.

Notwithstanding many initiatives, structural embedment of the CRPD and a social model of disability within HE is still in the beginning stage (Pollaert et al., 2021). Moreover, Pollaert et al. (2021) found that the CRPD is often interpreted to be more about accessibility than disability inclusive curricula, and that disability and accessibility are often thought of as extra difficult, burdensome and expensive (p. 6). Paradoxically, actions aimed at implementing the CRPD may unintentionally lead to reinforcement of existing barriers. For example, as students were often unaware of their accommodation-options, the Ministry of Education, Culture and Science (EC&S) requested ECIO to establish a website clustering information (Van Veen, 2021). This website, named ‘higher education accessible’, is designed for students with ‘support needs’ or ‘support questions.’ It focusses mostly on retrofit and presents mixed discourses, revealing underlying assumptions of individual/medical models of disability, e.g.: impairment (in Dutch: functional impairment) is described as function-disorders which *cause* barriers and delays in the study process (a definition similar to that used in national student-surveys) and is explained to be a more neutral synonym of disability. Functional impairment is also argued *not* to be a medical classification (ECIO, n.d., FAQ section, para 1-2). However, in practice students need proof of medical diagnosis for eligibility for accommodations. This causes another (often unconsidered) barrier as in the Netherlands, physicians are not allowed to provide their patients with medical certificates (KNMG, 2018). This leaves students with the following choices: trying to attain notes from their physicians anyway, providing copies of their private medical files (which by law they can access) or obtaining ‘proof’ through an ‘objective third party.’

Presentation of Case Study: ‘Tess’

Inevitably, the mixed discourses on disability and focus on retrofit influence pedagogy and negatively impact disabled students’ lives. This paragraph applies the aforementioned theories to empirical examples from the Netherlands.

‘Tess’ is a young white woman (early twenties) who recently completed a bachelor degree in a socially oriented profession in the Netherlands. Previously, disablism led her to change course twice on her chosen profession: once influenced by physical inaccessibility and experiences of requests for accommodations not being taken seriously, which then disturbed her relationship with educational staff in such a way that it led her to leave. Another time when attending an open day of the study art-therapy: the organizers immediately referred her, different from visitors who were perceived as non-disabled, to a disability officer without concertation. During the (mostly one-way) conversation with

the disability officer and lecturer that followed, the focus lay on advice based on the options they projected for Tess. Without checking, they stated that “of course, Tess wouldn’t be able to play guitar with her hands” but maybe using her feet was an option. In response, Tess clarified that “she has no feet.” The lack of reciprocity continued and within a short time span it became clear that they did not envision Tess at this faculty, nor did they consider adaptations to play instruments a viable option. The fact that Tess is now happy with her current bachelor degree and loves this profession does not negate the fact that her study and consequently her career choices have been heavily influenced by disablism and ableism. Moreover, these concepts also impacted her during the study she completed.

Experiences with Psycho-Emotional Disablism

Tess described that she had been “working on conveying her physical boundaries.” At the root of this situation lay her experience of the outside world often perceiving her as a disabled person. Moreover, people’s view and behaviour towards her change when she describes what she needs to do ‘differently.’ Throughout her life, she noticed that when she clarifies what she cannot do, or what is difficult for her, people get the impression that these ‘boundaries’ apply to every situation rather than a specific situation:

They [boundaries] get generalized and somehow people then have the impression that if you can’t do something what may be simple for them, you can probably not do most ‘simple things’. Before you know it, they think of everything I cannot do rather than recognize what I can do.

This makes Tess cautious and apprehensive as she really doesn’t want people to stop ‘seeing her for who she really is.’

When discussing where this ‘fear’ may stem from, Tess explained that she often ended up saying to people “please do not see me as someone with impairments, I am me and more than my impairments” (in Dutch synonymous with ‘restrictions’). Paradoxically, she let her ‘impairments’ play a bigger role for herself: “it means that I cannot do certain things, or that I do not say that I cannot or should not do something.” As not articulating these boundaries often meant she needed to do a lot of extra work (preparation, checking accessibility etc.) which costs more physical and emotional energy, she wanted to work on changing this. This seemed the only way to stop and prevent getting over-exhausted all the time. Moreover, although this started during encounters and experiences with strangers, it had now also become an issue in her personal life. Even though she ‘knows’ she would still be accepted and “seen for who she is” by her friends and family if she would explain that she couldn’t do something.

Realistically speaking, Tess’s boundaries may often be related to structural disablism as, when she is outside, she often uses prosthetic legs and occasionally a wheelchair. However, the responses from other people when she points out inaccessibility have mostly been based on (stereotypical) assumptions such as disabled people not being able to participate in regular activities. When asked if a desire to “be normal” could play a role in her ‘boundary setting issue’ she explained that it didn’t:

If a doctor would call me and tell me that all my limbs could now be grown back, I would say give that to someone else. This is my life and I know how to live like this. I know the positive sides of it [disability] and I am living my life. [laughing] I bet I would have to go to physical rehabilitation all over again to learn how to walk with ‘real’ legs.

After the afore mentioned reflections had been discussed, Tess encountered a situation in which she put her intentions into practice and clearly communicated her physical boundaries. The way this was responded to illustrated another form of psycho-emotional disablism, her lecturer dismissed her knowledge about her dis/abilities and challenged her to ‘overcome’ them:

During an online class, Tess's lecturer argued that it would be good for students to meet up in person and go outside together. It had snowed and as this makes venturing outside unsafe for Tess, she briefly explained that this would not be an option for her at that moment. Her lecturer's response (in the presence of other students) was: "oh come-on, Paralympians pull themselves through the snow all the time." With this one comment, Tess's explanation of where her physical boundaries lay was rejected and the stereotype of supercrip was evoked: Tess should equate the performance of Paralympic athletes rather than let such a thing as snow keep her from doing what was proposed.

When another, similar, situation occurred with the same lecturer, Tess tried to address it. In a private conversation, Tess shared her feelings about these experiences. In response, the lecturer explained to "not mean anything by it" and suggested Tess should "take a look in the mirror" to figure out why these remarks had made her feel uncomfortable. This response places the 'issue' within Tess and takes away responsibility from the educator. Moreover, it suggests her lecturer may think that Tess's feelings were due to e.g., a lack of 'acceptance' of her disabilities rather than a response to disablism.

Experiences with Ableism

A straightforward example of (institutionalized) ableism reproducing disablism is that when Tess enrolled at the university of applied sciences, the disability office required her to provide a doctor's note to 'prove' that she e.g., has trouble writing for longer periods of time using a pen (assumed to be normal ability). She was then awarded the special accommodation of using a laptop for exams etc. (retrofit). In practice, utilizing this accommodation meant extra work for Tess as she had to submit a laptop request a few weeks before every written exam.

Tess also encountered other, more complex, forms of ableism: at the start of a study-year, an introduction-week was organized by students in cooperation with multiple local HEIs in which Tess wanted to participate. The promoted goal was for new students to get to know the town, the different HEIs, student-organizations etc. As enrolment involved a request to disclose disabilities, Tess specifically inquired ahead of time if she could indeed participate and disclosed specifics of her disabilities. After confirmation that she would be able to participate, she confirmed enrolment and paid for the program.

Tess enjoyed meeting 'her group' and liked her fellow students. However, the first day entailed a great deal of walking which caused her physical discomfort and pain. Also, one of the student associations they went to visit was located in a building with many stairs. This meant Tess couldn't join the group and waited outside, accompanied by a group-mentor, while the other students went inside. After that day she realized that she had developed blisters which prevented her from using her prosthetic legs for a week. Consequently, she had to forgo the rest of the voluntary program and attended the mandatory "study block" with the use of a wheelchair (which in itself can influence disablism experiences). Although Tess inquired about a partial refund afterwards, as she hadn't been able to participate in a substantial part of the week, she never received a response.

Tess and I reflected on the above experiences through the lens of ableism: the fact that being able to walk, and walk for long distances was assumed to be 'normal ability' for every student greatly impacted her experience. Additionally, as organizers had convinced Tess ahead of time that the event would be accessible to her—it put her in a difficult situation of having to either stop midst activity and disclose to everyone else there, or risk over-exertion and injury. It is also important to realize that Tess was not the only student affected that day; there may have been other students experiencing difficulties with walking great distances and as Tess wasn't able to participate with the entire program, she was excluded from contributing to the intended goals of the event.

In the blog Tess wrote at that time, we recognized the influence ableism had on her. For example, Tess had written that the blisters had been "entirely her own fault" as she "should have practiced walking longer distances before this week"; that she should have explained to the mentor that it was too much walking before she had developed so much pain; that she should have left earlier etc. She also

explicated how this was one of those moments which made her wonder why she can't just do "what everybody else can" and that maybe she would accept 'donor legs' in order not to be disabled. This illustrates how, especially when ableism goes unrecognized, it tends to get internalized and that it can influence e.g. self-perception, sense of worth and disability identity. Signs of resisting ableism were also present: she wrote that this situation had taught her to "listen to her body better" and that these are "just moments." Tess also explained that after a while, experiences like this fade away and then she wouldn't want these donor-legs anymore, she'd be fine with her disabilities again and accept who she is.

Discussion

Case Study Tess

We illustrated how ableism and disablism, recognisable in policy and practice, greatly impacted Tess's studies, career and personal life. Importantly, this paper only presented a fraction of Tess's experiences as a student. She shared many more experiences, with different educators, in which various barriers remained unacknowledged. Overall, educators focused on individual 'disability acceptance', thus promoting internalization rather than reflexivity. Additionally, educators would comment on her doing day to day things, e.g., a lecturer publicly praising her for peeling a mandarin. For Tess, her family and social network, playing sports etc. have aided her in coping with disablism and ableism but this does not negate negative influences.

As Tess's study pertained to the social domain, she was taught different forms of (professional) reflection regarding curriculum taught knowledge and her internship experiences; she also participated in professional supervision. However, these often involved an individual deficit approach of disability framing her experiences without recognition of disablement, thus reinforcing dominant discourse and discounting her embodied knowledge. These curriculum and pedagogical approaches fostered feelings of not wanting to stand out, self-doubt and not being understood. Moreover, not acknowledging the complexities of disability blocked Tess from disability knowledge contribution and exchange.

The key role of education systems in working on inclusive societies is also apparent: throughout Tess's life, medical professionals, social workers and psychologists had not discussed DS perspectives during treatment/rehabilitation, nor was it introduced during her own study. This illustrates a vicious circle in which certain stereotypes and paradigms about disability are reinforced and reproduced.

Shifting Paradigms

Arguably, Biesta's three 'domains of purpose' for education; qualification, socialization (to which identity is connected) and subjectification (Biesta, 2020b; Biesta & Stengel, 2016) cannot be achieved without changing the dominant paradigm. Qualitatively good education therefore needs a transformative approach incorporating more diverse, intersectional and complex interpretations of disability. Due to e.g. interactions between barriers and contextual influences, there is no clear 'roadmap' but this paper contributes to some of the directions needed.

Translation of international agreements into national policies and practices are one of the most challenging aspects of the process of inclusive education (Kamenopoulou et al., 2023). The Netherlands lacks a comprehensive (legal) framework and goal formulation for inclusive (higher) education and CRPD implementation (NifHR, 2020; Schoonheim & Smits, 2019); however, Kelly et al. (2022) argue that despite having a sound policy framework in South Africa, disability inclusion within education still lacks. In practice, educators who are motivated to teach inclusively are often constrained by complex realities of their institutions and the context of limited resources; their training should empower them to become "key-agents" (Kelly et al., 2022, p. 3). In order to do so, integration of knowledge about inclusive education and a DS perspective in teacher-training is essential (Bunbury, 2020; Jain, 2020; Kelly et al., 2022; Podlucká, 2020). Additionally, literature shows that disability as diversity needs to be part of all other aspects of education including the philosophy of education,

curriculum (including learning assessment approaches), and pedagogy (Connor, 2014; Dohmen, 2016; Grech, 2015; Iqtadar et al., 2021; Kelly et al., 2022; Nieminen, 2023; Podlucká, 2020; Taylor, 2015). True (academic) disability inclusion also requires interdependence and social epistemologies (Nieminen, 2023).

Over all, integration of a DS lens in mainstream HE can aid development of the needed paradigm; it provides room to acknowledge differences with appreciation. It also influences the social-psychological environment as it can aid educators, peers and disabled students themselves in reflexivity. Furthermore, such an approach recognizes disabled students as knowledge bearers- and producers and helps counter (internalization of) disablism and ableism as well as aid in (disability) identity development as illustrated by the case of Tess. For her, a DS lens has, among other things, offered new ‘language’ to describe and discuss experiences. During our conversations she argued that it has helped her realize that “it’s not just in my head.”

However, a note of warning is also important: Tess was introduced to the first author by an educator who recognized processes of internalization. Tess recalled that they described the first author as someone who was of the opinion that “everybody else and society should change to accommodate disabled people.” This description actually deterred Tess from getting in touch: it triggered her own disability stereotypes of, to put it crudely, people who don’t reflect on themselves or their own agency and as Tess called it “the idea that everybody should adjust for disabled people.” This highlights the importance of acknowledging the nuances and complexities of dis/ability when shifting paradigms.

Lack of a Disability Lens within Dutch Higher Education

The continued policies of mandatory disclosure and (medical) labelling of students in the Netherlands has historical and contextual roots and continues to regard disability as a disparate and care-issue. This in part explains the lack of questioning institutional norms and persistent focus on retrofit. Additionally, it hinders intersectional approaches to inclusion and enables continuation of the use of disability as a concept for rationalizing injustices in relation to students from other marginalized communities. This observation about the Dutch situation corresponds to what is described in literature about occidental HE in other countries.

We recognize that a true paradigm shift proves complex and needs constant evaluation. However, we argue that there are some very specific changes needed within the Dutch context; those HEIs specifying medical diagnosis as prerequisite for accommodations should change their policy. There have been decades of recording the negative impact of such policies on individual students and the process of inclusive education as a whole. These seem to remain unacknowledged in mainstream education. Our recommendation can be considered in line with the CRPD’s “General comment No. 4 (2016) on the right to inclusive education” which states that “[p]rovision of reasonable accommodation may not be conditional on a medical diagnosis of impairment and should be based instead on the evaluation of social barriers to education” (CRPD-Committee, 2016, p. 9). Simultaneously, plans for systemic change and general accessibility should be formulated with incorporation of intersectional and local complexities. Such an approach should dramatically reduce the need for individual accommodations and improve access and inclusion for all students. Information about which similar accommodations are awarded to a multitude of students could be used to locate some of the systematic exclusionary practices. Additionally, a critical discourse analysis of Dutch legislation and HEI policies may provide extra insight into barriers for systemic change.

Situating Knowledge

Occidental theories and methodologies have been problematically transported to other global locations, insufficiently recognizing the influence of specific cultural, environmental and historical meanings (Barker & Murray, 2013). This critique extends to formulation of the CRPD and the SDG’s, e.g.; prioritizing understandings of disability from the global North; focussing on productivity and

individual autonomy (neoliberalism) and a lack of diverse understandings of dis/ability within the CRPD (Iqtadar et al., 2021) and a lack of pluralist-participatory discourse within the goals and targets of the SDG's, separating processes of change from history, time, place and social actors (Cummings et al., 2018).

The authors therefore explicate that although this paper presented an international literature overview, frameworks were then applied as a lens to reflect on (the lack of) disability inclusion in Dutch HE. We encourage readers to explore the extent to which these findings can be generalized to other countries, taking into account specific contextual factors while simultaneously providing room for intersectionality.

Method: Strengths and Limitations

Empirical data were acquired and presented differently from more conventional qualitative interviews or coded analysis. We argue that by doing so, we illustrate the complexities of disability and HE. Additionally, presented examples are less 'isolated' and address the interactional context (Silverman, 2017) as well as reciprocity. Repeated member checking ensured correct representation of Tess's experiences. As memories can change over time, this paper presented reflections on prospective data, supplemented with retrospective data.

As mentioned, Tess encountered many more barriers than have been presented in this paper. A limitation of this study may be that we have not reported and categorized all barriers. Within a Dutch context however, there is a tendency to explore and quantify barriers to then address them by accommodations without disrupting existing approaches, reinforcing individual models of disability. The choice of introducing a case study from a reflexive perspective was made, aiming to enhance understandings of disabling processes as well as emphasize how educators can positively affect (daily) educational practices by incorporating a disability lens. With this, it adds to literature about the interaction of different barriers, how these relate to disablism and ableism, and the complex influence thereof on the daily experiences of students.

There is a vast amount of literature available on the dynamic complexity of disabling processes and current understandings of disability; this paper presented a selection thereof, influenced by a focus on connections between literature, policy and practice. Moreover, although we provided separate examples for disablist and ableist experiences, in practice (and in theory), separation of these concepts isn't always straightforward: "disablism is almost always wrapped into, and sometimes hidden within, ableism" (Dolmage, 2017, p. 70).

Furthermore, HE often involves work-experience or internships. Tess, like other disabled students (Büscher-Touwen et al., 2018; Hamilton et al., 2023; Nieminen, 2023), also encountered barriers with regards to this part of her education. Exploration thereof lies beyond the scope of this paper but we recognize and emphasize the importance of more research on this subject.

Ethical Considerations

The aim for transformative (research) paradigms and the contentious past of research about disability brings up the complicated question: who benefits from this research (Barnes, 2001; Oliver, 1997)?

This paper has situated itself within the process of the 'emancipatory research paradigm' seeking to contribute to understandings of disability and evoke change in dominant paradigms which sustain disability at various micro and macro levels (Barnes, 2001). On a personal level, there have been mutual benefits for the first author as well as Tess; a furthered understanding and shared experiences of disability and the personal connection which these bring. From an academic standpoint however, the authors are the first beneficiaries (Oliver, 1997).

The role of the first author comprised of conceptualization, methodology, investigation, resources and writing (original draft, review and editing). Both the second and third author were involved with conceptualization, writing (review and editing), and supervision. Tess's provision of data and

continuous engagement in joined reflexivity with the first author, leading up to publication, warrants authorship. However, that would entail giving up anonymity. While Tess finds it important that her experiences are shared in a way which furthers the process of inclusive education, she also wants to maintain control of who she chooses to share her experiences and reflections with in her personal and professional life. Therefore, Tess has chosen to remain anonymous and forgo authorship.

Conclusion

A perspective on disability that addresses its fluidity and contextuality is ineffectually incorporated in educational policy, curriculum and pedagogy. The continued focus on retrofit, rather than general accessibility and inclusion, reveals underlying assumptions of individual models and medicalized beliefs of disability. These assumptions are also woven through curricula and pedagogy and hinder an overall paradigm shift. Consequently, ableism, disablism and other exclusionary phenomena are reinforced and reproduced, leading to (epistemic) injustices which remain unrecognized. This negatively impacts students' well-being, negates their embodied knowledge and denies their agency. Exclusionary phenomena form an intricate web woven through all aspects of education; we therefore reiterate the necessity for systemic changes from governmental to local organizational approaches. Rather than 'singling out disability', applying a disability lens enables intersectional approaches by revealing how disability is concurrently intertwined with many other constructs and forms of marginalization. Therefore, when addressing knowledge hierarchies in curricula, this should also entail 'cripping the curriculum.'

When addressing normative inclusion, contextual influences are important as we have shown in our Dutch case study. In part due to historical legacies and societal discourse on disability, the euphemism of students with 'support needs' has been introduced in the Netherlands and seems widely accepted within governmental and institutional discourse. With this, intentions to implement the CRPD have paradoxically perpetuated the focus on identification and labelling of those students not meeting 'educational norms', again placing the onus on individual students. The prerequisite of 'proof' of disability subjugates alternative understandings of disability and transfers students' power to professionals. Within the Dutch context such policies also ignore professional physician guidelines, creating extra barriers for students.

The complex and very tangible impact of failing to incorporate a disability lens in inclusion processes was illustrated by Tess's experiences: it affects personal and professional spheres and reveals the vicious cycle whereby the formal and informal 'gatekeeping' by educators and educational systems perpetuate and reinforce stereotypical perceptions of disability and humanness, which in turn make work-places and societies as a whole less inclusive. Importantly, Tess's case also exemplifies that educators can actively contribute to positive change and inclusion. This can aid in breaking the vicious cycle by way of pedagogy and interactions with students, even while systemic changes are not yet achieved. In order to do so, more nuanced, dynamic and complex understandings of disability as well as knowledge of disablism and ableism and how these intersect with other exclusionary processes should become part of educators' knowledge base. This will help provide 'language' to communicate, support knowledge contribution, and acknowledge en-abling and disabling experiences for all students. Additionally, it will help prevent internalization of negative feelings for students and improve sense of belonging, as well as encourage reflexivity for both students and educators.

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