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Students with Disabilities in Higher Education

Editors

Geert Van Hove, Minne Bakker and Alice Schippers

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Academic Editors
Geert Van Hove (Ghent University, Belgium/VU Amsterdam, The Netherlands)
Minne Bakker (VU Amsterdam, The Netherlands)
Alice Schippers (Disability Studies in the Netherlands/VU Amsterdam, The Netherlands)

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Editorial

Editorial: Students with Disabilities in Higher Education

Geert Van Hove [1,2,*], Alice Schippers [2,3] and Minne Bakker [2]

[1] Department of Special Needs Education, Ghent University, 9000 Ghent, Belgium; E-Mail: geert.vanhove@ugent.be
[2] Department of Medical Humanities, VU University Medical Centre/Amsterdam Public Health, 1081 BT Amsterdam, The Netherlands; E-Mail: mi.bakker@vumc.nl
[3] Disability Studies in the Netherlands, 3811 HR Amersfoort, The Netherlands; E-Mail: aliceschippers@disbilitystudies.nl

* Corresponding author

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Abstract
This editorial will at first present the thirteen different articles published in the issue. On a second level, we will focus on "overarching themes". Those themes should be understood as links between the different articles in this volume.

Keywords
Disability Studies; higher education; students

Issue
This editorial is part of the issue "Students with Disabilities in Higher Education", edited by Geert Van Hove (Ghent University, Belgium/VU Amsterdam, The Netherlands), Minne Bakker (VU Amsterdam, The Netherlands) and Alice Schippers (Disability Studies in the Netherlands/VU Amsterdam, The Netherlands).

1. Introduction

This issue of Social Inclusion contains a collection of thirteen articles concerning students with disabilities in higher education. We firmly believe this collection opens up some new perspectives on the "problematic intersection", dixit Margaret Price (2011, p. 5), between (mental) "disability" and "the most important common topoi of academe". The latter include: rationality, criticality, presence, participation, resistance, productivity, collegiality, security, coherence, truth and independence.

Our articles are linked with Austria, Belgium, Egypt, Germany, Israel, Norway, South Africa, the Netherlands, the US and the UK. We are convinced the presented collection can help us get better insights into the above mentioned problematic intersection, and this across countries, labels/diagnostic categories—from a large sample of "all students with a label" in Austria over to specific groups like hard of hearing students, Deaf students, students with bipolar disorder, students with lived experiences of mental health problems, students with visual impairments and students with physical impairments—but also beyond a specific "category of actors" within the field of higher education institutions such as administrative staff, lectors and professors, students with and without label, HR-experts within the labour market, etc.

This editorial will at first present the thirteen different articles. On a second level we will focus on "overarching themes". Those themes should be understood as links between the different articles in this volume.

2. Short Presentation of the Articles

In a very personal article by Jonathan Harvey, "Contemporary Social Theory as a Tool to Understand the Experiences of Disabled Students in Higher Education", we can observe how the introduction of contemporary social theoretical frameworks (Foucault, Derrida, Deleuze and Guattari, Braidotti) can help demystify the experience of disabled students (Harvey, 2018). This text is a wake-up call to stop the excessive use of practical-technical solutions and to balance one-size-fits-all solutions with solid theory.

In the article by Roth, Pure, Rabinowitz and Kauffman-Scarborough (2018) we get a presentation of a Disability Awareness Training and Empowerment program as developed in/for one campus. The authors are showing how they combined a literature review to construct the program in close cooperation with all stakeholders while using a kind of action research plan. At the end of the article we are confronted with a nice new discussion opening up the question of whether it is necessary to offer such training packages also to students without labels.

We learn from Robert Aust (2018), in his article "Disability in Higher Education: Explanations and Legitimisation from Teachers at Leipzig University", that an analysis of the perspectives of staff members of an institution of higher education vis à vis students with disabilities shows that a lot of the medical/individual perspective on disability is still a reality. The author is introducing the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD) as a tool to remove barriers connected with this medical model thinking, replacing them for more human rights based practices.

In "Learning Experiences of Students Who Are Hard of Hearing in Higher Education: Case Study of a South African University", Bell and Swart (2018) show us that students who are hard of hearing in South Africa (as in a lot of other countries) are accepted but, once there, don't get the necessary support based on the framework of "reasonable accommodations". Analysis of lived experiences of students themselves are leading to recommendations for teaching and learning as well for curricula transformation.

The article by Büscher-Touwen, De Groot and Van Hal (2018), "Mind the Gap Between Higher Education and the Labour Market for Students with a Disability in the Netherlands", reveals that those who finish higher education are confronted with a gap in the transition to the regular labour market. Several factors seem quintessential to understand this phenomenon: it seems there are no stable data and nobody organizes a follow up about the transition; it seems different policy makers don't see this group of young adults as their chore business, and that the regular labour market shows the same attitudinal prejudices as the higher education sector.

In Kermit and Holiman (2018) we learn that downgrading social aspects of the inclusion of Deaf students, due to heavily focusing on the academic chapter of the study trajectory, leads to little interaction with hearing students. Central to this diagnostic group is the knowledge of teachers regarding intercultural communication and visually oriented instruction.

In "Designing a Model for Facilitating the Inclusion of Higher Education", du Toit (2018) defends the statement that, as students with special needs in higher education are seen as real students, they should get the opportunity to go through an international experience. An in-depth analysis of the South African situation shows how many different role players are involved and could be—if they worked together—for incoming and outgoing students with special needs in pre-departure, study and return phase.

Zaussinger and Terzieva (2018) describe a large scale research project in Austria. The large data set is combined with a contemporary interpretation of stigma theory. We learn what factors lead to fear for stigmatisation, but also what characteristics of a program play a role in self-identification of students and their willingness to speak openly about their needs and necessary accommodations.

In "Barriers to Higher Education for Students with Bipolar Disorder: A Critical Social Model Perspective", authors Kruse and Oswal (2018) are making use of the critical social model framework to analyse the lived experience of one of the authors with the label of bipolar disorder. This analysis shows the (hidden) ableist assumptions and the parallel oppression experienced by the students. This paper also brings in a lot of practical recommendations to solve certain problems.

In Carette, Van Hove and De Schauwer (2018), the authors try to introduce the experiences of "mad students" and their attempts to disclose their mental health problems. Worldwide initiatives of psycho-education and information about mental illness seem to fail if they don't install/give support to simple communication about the expectations and needs of mad students. While young students just want help, Higher Education institutions keep a naïve belief that providing information about psychological well-being and mental health can be seen as a solution for several problems.

Research by Almog (2018) reveals a lot about "identity constructions" of students in higher education as both being disabled and being a student. The costs and the benefits related to the chosen positions are balanced in an article that depends heavily on the lived experiences and expertise of the students themselves.

Lord and Stein (2018) introduce Egypt as an in-depth case study to confront the realities of developing countries with the framework of the UNCRPD. As we can expect, an enormous amount of barriers are observed and a human rights-inspired way of working is presented to move the agenda on micro, meso- and macro level. It can be seen that problems as described here can also be found in so called developed countries.

The commentary by Benjamin Ostiguy, "The Inherent Value of Disability in Higher Education", introduces the philosophy of Arne Naess and his framework of Deep Ecology to improve our capacity to understand, value and to give support to students with disabilities. The Deep Ecology framework destabilizes the existing structures and ideology of "normalcy" on a campus.

3. Overarching Themes

When we analyse the different articles presented here more in depth we can find several themes and bridges between them.

We know from historians working in Disability Studies (Stiker, 2000) that persons with a label always have been silenced and marginalized. It is remarkable that we could build a collection of articles where the voices of students with special needs are so prominent. A lot of the authors based (part of) their research on the lived experiences of these students, and we think we may say that they really followed the basic principle of the Disability Studies field: "nothing about us without us".

With the exception of one article using large numbers of participants, most authors in this volume are using qualitative research methodologies (Hammarberg, Kirkman, & de Lacey, 2016). Most of the time qualitative research methods are used to answer questions about experiences, meaning and perspectives, from the standpoint of the participant. It is clear that in this journal the "voice" of the students helps us learning about the way they experience learning/living trajectories in higher education institutions.

It is good to see that some of our colleagues feel the need to rely on theoretical frameworks and concepts, like the work of Foucault, Derrida, Deleuze and Guattari, Braidotti, the Stigma theory, the framework of Critical Social Model, Deep Ecology of Naess, ideas coming from Mad Studies, the Social Identity Theory, the Explanatory-Legitimacy-Theory, the Ableism framework and more. These theoretical frameworks guide them through a critical analysis of different realities. In this way these articles are following authors like Siebers (2008) who are introducing theory to show the complex nature of disability and the inadequacy of a one-size-fits-all theorizing of the phenomenon.

To think about inclusion of students with disabilities in higher education goes hand in hand with thinking about a broader spectrum of themes. It (also) has to do with curricula, the transition to the labour market, identity construction, international study experiences, etc. It shows how the study of this phenomenon "can lead to the identification of novel veins of inquiry, bolster critical analyses, and help facilitate meaningful change in uncertain times" (Ostiguy, 2018, p. 241).

4. Conclusion

Although we can rely on existing binding international legal frameworks, like the UNCRPD, this does not necessarily lead to a human rights-based practices. In the era of neo-liberalism, students are still seen as individually responsible and are heavily dependent on the goodwill of individual lecturers.

We hope the readers can enjoy the different papers and will feel encouraged to confront their own practices in Higher Education with the analysis and insights of our articles.

Conflict of Interests

The authors declare no conflict of interests.

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About the Authors

Geert Van Hove, Prof. Dr., works at Ghent University and at the VUmc in Amsterdam, in the field of Disability Studies.

Alice Schippers, Dr., is Executive Director at Disability Studies in the Netherlands and Researcher at the VUmc, Department of Medical Humanities.

Minne Bakker, Dr., works as Postdoc Researcher at the VUmc, Department of Medical Humanities.

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Article

Contemporary Social Theory as a Tool to Understand the Experiences of Disabled Students in Higher Education

Jonathan Harvey

Institute of Education, Plymouth Marjon University, Derriford, PL6 8BH, UK; E-Mail: jharvey@marjon.ac.uk

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Abstract
This is a conceptual article which seeks to consider the use of contemporary social theory to help understand the experience of disabled students in higher education. The use of social theoretical insights has been criticised by many as demonstrating a lack of engagement with the everyday experiences of disabled people. Work which strives to embed theoretical insights into the study of disability has also been criticised for lacking engagement with the 'reality' of impairment. In this article I intend to address some of these criticisms by suggesting some ways in which the use of contemporary social theory may provide an explanatory tool which disentangles confusion regarding the journey undertaken by the disabled student. I will discuss how the writings of several social theorists may be helpful in making sense of disabled student journeys. I will begin by discussing why the work of Jacques Derrida can be useful in this regard. These writings will be considered alongside a debate which draws on the writings of Michel Foucault on the use of power in contemporary higher education institutions. I will critically discuss the theoretical insights of Deleuze and Guattari and their offerings on the notion of 'becoming'. I will then critically interrogate the work of Rosi Braidotti and apply these to a re-imagining of the disabled student journey. The writings of these important theorists have been used before to explore the experiences of disabled people. However, this article is unique in that it proposes that these writings can be used to demystify the experiences of disabled students in higher education. I suggest some ways the work of Derrida, Foucault, Deleuze and Guattari and Braidotti enable a greater understanding of my personal student journey. I suggest that they could be used to make sense of a far wider range of student journeys. I conclude the article by offering a model which utilises some important aspects of these theoretical insights.

Keywords
contemporary social theory; disability; higher education; postsecondary education; Social Security Disability Insurance; student; Supplemental Security Income

Issue
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1. Introduction

The study of disability and impairment provides the opportunity to apply theoretical insights to lived experiences. The study of disability and impairment is quite rightly underpinned by the experiences of disabled people. However, it has been noted that when lived experiences remain on the outside of the realms of theoretical analysis, they are less mobile and lack the ability to resonate with the lives of others (Goodley, Hughes, & Davis, 2012; Goodley, Lawthom, & Runswick Cole, 2014; Roets & Braidotti, 2012; Van Trigt, Kool, & Schippers, 2016; Vandekinderen & Roets, 2016). In contrast, there are authors who cite the complexities that are generated by the use of theory in aiding understanding of the experiences of disabled people (Vehmas & Watson, 2014; Watson, 2012). Furthermore, it has been stated that the journey through higher education—whether it be concerning disabled or non-disabled people—is under theorised and relies on taken for granted 'truths' rather than sophisticated theoretical ideas to aid understanding of student journeys (Strom, 2018; Taylor & Harris-Evans, 2018; Wang, 2015). Consequently, it would be beneficial to generate discussion regarding the usefulness of social theory in the analysis of the journey of the disabled student.

In this article, I seek to contribute to the debate surrounding the use of social theory to explain the experience of disabled people by suggesting some ways in which the experience of disabled students may benefit from a robust analysis from contemporary social theory. I will apply these theoretical ideas and critically discuss the ways in which they may make those experiences more understandable. In suggesting theory may enhance the understanding of disabled students' experiences, I aim to make the process of attending university as a disabled person easier for others in the future.

In what follows I use the theoretical writings of Derrida, Foucault, Deleuze and Guattari and Rosi Braidotti to question discourses of disability that present opposition to the application of theory to aid understanding the experiences of disabled people (Watson, 2012). Following Goodley et al. (2012), I make no excuses for the use of 'intellectual plunder' (p. 315) as I seek to explore how theoretical ideas can help demystify the student experience of higher education and I take the view that:

> Any intellectual system or social theory is fair game when it comes to building a case for emancipation or for sharpening the tools that are of value in opposing discrimination, exclusion and oppression. (Goodley et al., 2012, pp. 315–316)

I am a disabled person who has navigated the higher education system. Thus, I feel I am well-placed to interrogate the process from the perspective of the disabled student, person interested in the journeys of disabled students, and as a lecturer in special educational needs and disability studies. I have stated elsewhere that having more than one perspective on a subject increases the epistemological authority of the assertions one can make (Harvey, 2017; Letherby, Scott, & Williams, 2012).

The situation regarding funding is ever-changing and this is exemplified through recent changes in the system (Student Loans Company, 2018). Additionally, any 'group' of people such as disabled students, should not be considered a singular, homogenous entity. The ever-changing social landscape of student funding, together with the vast differences in student needs, dictates that a firm grasp of contemporary social theory is important in reaching a sophisticated understanding of student experiences. I begin by detailing my journey through higher education before returning to my personal experiences once again at the end of the article to demonstrate what viewing experiences of higher education through the lens of these theorists can offer.

2. My Journey through the Higher Education System

My first encounter with university came when I was 19 years old when I went to university to study physiotherapy (a three-year course in the UK). However, at the age of 21 (2003), I sustained a severe traumatic brain injury which left me physically unable to complete the course. I have written about my rehabilitation experiences elsewhere in more detail (Harvey, 2018). In 2007, I returned to university as a disabled student. I completed an undergraduate degree (health and social care studies), Master of Science degree (social research), and a PhD (a sociological approach to acquired brain injury and identity). Throughout my journey, I received fantastic support from both university staff and my peers. Reflecting on my experiences with the help of social theory has made the process of gaining meaning from and understanding my journey, far easier. Through exploring various theoretical viewpoints and relating them to some of the difficulties that disabled students may encounter, I hope to make this journey smoother for others in the future. I will now discuss how the writings of Jacques Derrida can relate to the presence of disabled students in higher education.

3. The Insights of Jacques Derrida

Jacques Derrida was a French philosopher born in 1930. He is most well-known for the idea of deconstruction, which is essentially stripping a concept back to its constituent parts to allow close inspection of each part (Stocker, 2006). I feel it is important to analyse disabled student journeys through a Derridan lens as the term 'deconstruction' aligns well with an exploration of disabled people's experiences. Deconstruction also entails a rejection of common-sense 'truths', something that is at the heart of much contemporary disability studies writings (Goodley et al., 2012; Harvey, 2017, 2018). Indeed, although Derrida did not refer to disability specifically, it can be said that his opposition of dualism can be said to be at the core of the contemporary view that no longer sees *disability* as a polar opposite of *ability* (Harpur, 2012). Furthermore, Derrida would suggest that the very notion of 'inclusion' reinforces the divide that exists between disabled and non-disabled students. Perhaps it would be better to reconceptualise higher education as a space where 'the student' is classified as the heterogeneous entity that is engaged with the gaining of knowledge amidst an environment of reciprocity, interdependence and affirmation. This will be discussed more when reference is provided to the work of Rosi Braidotti.

Derrida's criticism of the 'dishonest pursuit of certainty that shapes reason' (Corker & Shakespeare, 2002) is, I would argue, an interesting way of theorising the presence of disabled students in higher education. Many disabled students who pass through university have resisted the power of common-sense understandings of life which would state that a university education is not a 'realistic' option. Due in part to the much-cited fluidity of the contemporary world, the landscape is ever-changing for disabled individuals who are interested in pursuing a university education.

For example, technological advances have dictated that students—who would have once found it difficult to attend university—can now purchase specific items of assistive technology that are designed to support the learning of disabled students in higher education institutions (Seale, Georgeson, Mamas, & Swain, 2015). Furthermore, it has been argued that technology has developed to such an extent that 'mainstream' electronic devices (smartphones, MP3 players, and computers) perform similar functions to items that were once 'reserved' for the disabled person (Tripathi, 2012). Indeed, it is likely that Derrida would have seen little need for labels such as 'disabled student' which arguably merely serves to mark out differences between disabled students and their non-disabled peers. This view is counterbalanced by one that suggests the importance of gaining access to services (such as the disabled students allowance in the UK) which is gained through the use of such labels.

Then, applying a framework that draws on the writings of Derrida to make sense of the experiences of disabled students would focus on an ethical approach to higher education. This ethical approach would embrace the most slippery divide between disabled and non-disabled bodies (Price & Shildrick, 2002). Such an approach would classify learners as just that, rather than 'disabled learners' or 'non-disabled learners'. All students would be on a journey which is concerned with education notwithstanding the corporeal features of the individual student.

The use of labels for disabled people is very much entangled with the debate surrounding power. Therefore, the work of Michel Foucault demands a particularly robust consideration in this debate regarding disabled students in higher education.

4. Michael Foucault

Foucault was also a French philosopher. Much of Foucault's work sought to examine the way power is used in social practice (Lemke, 2015; Tremain, 2015). The writings of Foucault have been used to make sense of a host of disabled people's experiences (Goodley et al., 2012; Tremain, 2015). It would therefore seem sensible to explore the lives of disabled students through a Foucauldian lens. In this discussion, I seek not to highlight the ways in which power is seen as a merely repressive concept in the lives of disabled students, but rather the way the use of power subtly dictates the lives of students on an everyday basis:

> The most effective exercise of power, according to Foucault, consists in guiding possibilities of conduct and putting in order the possible outcomes. The concealment of these practices, these *limits* of possible conduct, allows the discursive formation in which they circulate to be naturalised and legitimised. That is to say, the production of these seeming acts of choice (these *limits* of possible conduct) on the everyday level of the subject makes possible the consolidation of more hegemonic structures. (Tremain, 2015, p. 8)

In terms of disabled students then, Foucault's work could be very useful in determining the way impairment may restrict the choice of the disabled student. Reflecting on my own experience of being a disabled student in higher education, this idea resonates with me greatly. During the process of choosing an appropriate course to study, I was immediately put off by any course which contained a significant amount of examinations as the mode of assessment. This was because of my impairment and the way that I would need someone to write my answers for me. It would be interesting to establish the proportion of students who make similar choices. Arguably this establishes the way that social theoretical insights can be used at the everyday level to explain the way that impairment can and does create added complexities for disabled people. However, it has been suggested that a Foucauldian analysis limits the attribution of agency to the choices disabled people make (Hughes, 2005).

In response to this criticism, I must stress that I do not wish to categorise the way impairment dictates certain decisions in a purely 'melancholic' way (Roets & Braidotti, 2012). It is important that there is recognition of the capacity of the disabled student to acknowledge the presence of these complexities and integrate them into the choices they make. Interestingly, there is literature that highlights the way that disabled and non-disabled students face similar challenges when negotiating assessments in higher education (Madriaga et al., 2010). Therefore, when stating the capacity of the disabled student to make an informed choice, it is not simply a case of the disabled student 'overcoming' impairment that has been much criticised in British social model disability studies literature (Oliver, 2013). Rather, it is the demonstration of the way disabled people can and do rise up to the challenges that a disabling society offers (Campbell, 2009; Goodley, 2014), together with an appreciation of the way that identity is a wholly fluid concept which is highly changeable amongst disabled and non-disabled people alike.

A contemporary development in the higher educational landscape is the growing influence of neoliberalism, subjecting higher education to market forces. Indeed, stark warnings have been given regarding the role of universities within the knowledge economy particularly around assessment practices and governance (Torrance, 2017). Assessments such as the research excellence framework (REF) and the National Student Survey (NSS) are now hugely influential in determining the level of funding universities receive. This development has been widely criticised (Bessant, Robinson, & Ormerod, 2015; Nixon, Scullion, & Hearn, 2018; Olssen, 2016) particularly in the way that it prevents academics from having the ability to shape their own institutions. The increasing classification of students as 'consumers' of university resources, may have severe consequences for disabled students as they seek to learn in an environment which promotes the importance of notions such as self-determination and independence (Mitchell, 2017). For these reasons, I believe situating student experiences within a theoretical landscape such as the one provided by Michel Foucault is, I would argue, very useful in reaching a sophisticated understanding of the experiences of disabled students in higher education. I now move on to discuss some ways in which the philosophical writings of Deleuze and Guattari can relate to the journey of disabled students through higher education.

5. Deleuze and Guattari

Deleuze and Guattari provide a blend of philosophy which also seeks to stray far away from common-sense understandings of life. In their text *A Thousand Plateus* (Deleuze & Guattari, 1987) the concepts of the rhizome and the nomad provide a way of viewing life 'as if it were not a linear, pre-determined entity with a definite 'end in sight', but instead as a journey with unforeseen checkpoints along the way' (Harvey, 2018, p. 95). The writings of Deleuze and Guattari have been used to explore the experiences of disabled people before (Goodley, 2014, 2016; Goodley et al., 2012; Madriaga & Goodley, 2010). Therefore, I consider these insights to be most suitable to investigate the lives of disabled students. Indeed, when commenting on the use of the work of Deleuzue and Guattari to explore the experiences, Strom (2018) criticises the way that the writings of Deleuze and Guattari are all too often dismissed as being inaccessible and are not used in a sophisticated analysis of higher education. Strom (2018) provides an analysis of her own educational journey through a framework devised in conjunction with the writings of Deleuze and Guattari. In her account Strom (2018) highlights the nonlinearity of her journey. It is stated that:

> Reflecting on my own non-linear journey from a teacher who had no use for theory or philosophy, to one whose career (at least in part) hinges on it, I believe now that both the inaccessibility of language and the discourses surrounding these bodies of thought probably played a part in my initial resistance to engaging with them. (Strom, 2018, p. 112)

The idea that life is not a linear and predetermined entity also resonates with my own journey through education and appears to represent the way that many students would feel that their path to higher education has taken. I suggest that an approach to higher education that views the journey as not a fixed, predetermined entity with inevitable hierarchical results is helpful. Such classifications of student journeys (both disabled and non-disabled) would celebrate the unknowable and unforeseen benefits of such a journey which is characterised by the gaining of experience, rather than the acquisition of a qualification.

Another useful metaphor offered by Deleuze and Guattari is that of the map. A map highlights the way there are many ways to arrive at a checkpoint. A map can also be 'torn, reversed, adapted to any kind of mounting, reworked by any individual, group, or social formation' (Deleuze & Guattari, 1987, pp. 13–14). When related to the presence of disabled students at higher education institutions, this indicates that there is no single 'correct' way to navigate higher education, but rather there are many different ways. According to the philosophy of Deleuze and Guattari, a journey through higher education is not the end of a journey. Indeed, I would suggest that attendance in higher education is seen as a stepping stone in life rather than the final destination. The extent to which this is considered the case for disabled students as well as non-disabled students is arguable. The way universities attract students using a systematic approach based around statements, study objectives, learning activities, curriculum materials, assessment, and learning outcomes is termed curriculum mapping (Wang, 2015). The concept of curriculum mapping in higher education has been criticised (Wang, 2015) for its failure to sufficiently engage with the myriad possibilities attending university can provide. Rather, curriculum mapping (in its current form) is said to be akin to tracing, whereby creativity is stifled at the expense of linear development. Higher education institutions produce homogenous, predictable students who have the tools to be economically successful but are unable to live truly fulfilling lives. Wang (2015) concludes by stating that:

> By knowing the world, students open their minds and expand their lives. Students should not only be successful in *tracing* an entrepreneurial self; receiving a higher education has the potential to free them from a pre-designed self by *mapping* the self in other ways. Therefore, the purpose of curriculum mapping is to educate a cartographer to create his or her new life. (Wang, 2015, p. 1558, emphasis in original)

The transition in life that attendance at higher education represents has been marked as being an under theorised concept which is plagued by common-sense and taken-for-granted assumptions regarding what this transition actually means (Gale & Parker, 2014; Taylor & Harris-Evans, 2018). It is stated that far too often transition is a concept that is thought of in a linear way, as a pathway from school to higher education. However, in practice this is often not the case (Gale & Parker, 2014) and it would seem sensible to suggest that disabled students do not always take the 'typical' pathway to university. Indeed, if a framework that enables greater understanding of the importance of experience in the transition to higher education were used to make sense of student journeys, this would arguably allow greater space for the celebration of the gaining of experience in the non-traditional spheres of education.

When discussing the contribution of the work of Deleuze and Guattari to disability studies, Roets and Braidotti (2012) call for a celebration of the diversity of bodies and minds. In their view:

> This produces a significant shift from the notion of an oppositional and split disabled/non-disabled dichotomy to an open-ended, relational vision of interdependent subjects. (Roets & Braidotti, 2012, p. 175)

In relation to higher education, a significant departure from a disabled/non-disabled split, would produce a very different environment for the disabled student. It has been argued (Madriaga & Goodley, 2010) that a higher education system that moves away from these dichotomies which focus on so-called deficits and instead towards a system which embraces the uncertain desires of students would be a useful development. Following this, then, it would seem sensible to suggest that the reflections of disabled students are a vital source of information in creating a truly inclusive higher education system. I now go on to explore the theoretical insights of Rosi Braidotti which are very much a continuation and an extension of the ideas of Deleuze and Guattari.

6. Rosi Braidotti

Braidotti is a contemporary social theorist, who has many interesting concepts that relate to both disability and in particular the disabled student. Most well known for her recent book *The Posthuman* (Braidotti, 2013), Braidotti extends the notions of 'the rhizome' and 'the nomad' that were first introduced by Deleuze and Guattari. Braidotti draws upon the concepts of the rhizome and the nomad in her questioning of the relevance of independence, and the call for the recognition of reciprocal interdependence in a framework which highlights the importance of positivity when talking about disability. Braidotti's work is being employed increasingly to make sense of the phenomenon of disability (Goodley et al., 2012.; Goodley et al., 2014; Harvey, 2017, 2018; Vandekinderen & Roets, 2016). Braidotti's theorisation aligns well with an analysis of the student journey, as I will outline below.

For Braidotti, the disabled subject is a subject who is 'ever moving and becoming' (Roets & Braidotti, 2012, p. 168). Therefore, this is:

> An appeal for the re-conceptualisation of the nature of impaired bodies-and-minds as always in process, always in becoming and in relation to the collective. (Roets & Braidotti, 2012, p. 165)

This is a powerful statement that is important for several reasons. Firstly, this conceptualisation highlights the way that viewing 'bodies-and-minds as always in process' necessitates less reliance on the things that disabled students might find difficult and instead places more focus on what the student might be capable of. Another way that this conceptualisation is useful is the focus it has upon the unsteady and unpredictable nature of the future. I argue this allows the period of higher education to be contextualised in the overall living of a life. Finally, this quotation states the importance of 'becoming in relation to the collective'. The notion of interdependence is a concept that has been used when analysing many aspects of disabled people's lives including; rehabilitation (Harvey, 2017, 2018), self-advocacy (Roets & Goodley, 2008) and mental health problems (Vandekinderen & Roets, 2016). I would suggest that a theorisation which leaves space for a view that does not position the subject as a singular and independent being is very useful when considering the educational journey of disabled students. Firstly, let us consider non-living 'objects'.

Increasingly, technological devices are playing a vital role in education. From just a cursory glance at a lecture theatre in the university in which I currently work, devices such as computers, over-head projectors, lecture-recording equipment and 'check-in' codes to ensure attendance data is correct can be found. This, together with the heavy reliance upon the student to be computer literate in order to access online tutorials, etc., highlights the changing landscape of higher education. When considering disabled students, the need to use technological devices in the form of dictaphones, mobile phones and cameras may be even greater. When added to the impact that walking aids can have on disabled people and especially on their sense of identity (Harvey, 2017), it is clear that a theorisation which acknowledges the importance of these nonhuman objects is important in reaching a thorough understanding of the disabled student journey.

The importance of human interdependence and companionship is also included in Braidotti's visualisation of contemporary life. Arguably, this is very relevant to the journey of disabled students. Certainly, during my journey through higher education, I found the support of my peers (both in lectures and in my every day negotiation of the university environment) to be very important. The university environment provided a space where I could socially interact with like-minded people. The importance of friendship and the formation of lasting social bonds demands mention. This may be especially important when considering the lives of people who may not have great opportunities to form such bonds, due in part to the stifling impact of disablism and ableism (Goodley, 2014).

A conceptualisation of the disabled student which acknowledges the 'always in process' and 'always in becoming' nature of the disabled person has important implications. Higher education institutions are increasingly seen as commercial organisation where education is a commodity that can be bought and sold (Altbach, 2015). It has been stated that disabled people have become disadvantaged in the application of market forces in welfare and social care (Dodd, 2016). Given this, it would be sensible to suggest that disabled students may well struggle to a larger degree than their non-disabled peers in coming to terms with higher education that is governed by a 'neoliberal worldview' (Lawson, Sanders, & Smith, 2015, p. 1182). However, if the disabled student was considered as a person who is 'in becoming', then arguably this turns the focus away from the 'acquisition' of higher education as a transactional and economic purchase, whereby value-for-money is demonstrated by assessment results. Under an 'always in becoming' framework, close attention is paid to the experience of attending university and the way it is contextualised into an overall life journey with a focus upon the benefits that it can give, which are arguably far more than economic.

Braidotti guides us towards a vision of disability and impairment which is wholly affirmative and strays far away from referring to disability as an 'individualised phenomenon (which) implies negativities, including pathology, pathos, social death, inertia, lack, limitation, loss, deficit and/or tragedy' (Roets & Braidotti, 2012, p. 161). This notion of reconsidering disability as an affirmative identity is also relevant to the presence of disabled students in higher education institutions. Attending university is an important part of the life of any person (Newton & McCunn, 2015) whether the person is disabled or not. Braidotti's affirmative conceptualisation of life enables a dynamic view of our education which sheds light on the most productive elements of attending university as a disabled student.

7. Theorising the Disabled Student Journey

Throughout this article I have critically explored the usefulness of social theory in making sense of the disabled student journey. I would suggest that social theory does indeed play a useful role in demystifying the student journey.

I have found social theory to be very useful when analysing my own journey through higher education. In particular, the non-linearity of my journey and the way I had to start university, withdraw from my course, and then start again a few years later seems to align well with the non-linearity of life that these theorists cite. Though I accept my experience of acquiring an impairment during my 20's is not typical of the experiences of many, I still believe that, whatever the cause, this non-linearity is common. This is confirmed in the research of others (Gale & Parker, 2014; Madriaga et al., 2010; Nixon et al., 2018). Furthermore, the way that social theory allows us to stray away from taken-for-granted assumptions was very helpful. Reliance upon such assumptions would arguably lead to a lack of appreciation of the way that disabled learners could rise up against the restrictive barriers that seek to confine disabled people within limited spaces provided by a disablist society (Goodley, 2014; Watermeyer & Swartz, 2016). I was very aware that my longstanding presence at university was unusual. Indeed, being in a position of (relative) authority in being the course lead for a university degree is also unusual and places me in a position of being able to challenge some of the restrictive barriers mentioned above. I suggest that analysing the experiences of disabled students through lenses such as those that query dualism; those that emphasise the use of power in society; and those that see life as the accumulation of experience would result in highly sophisticated analyses that are capable of being resonant to the lives of many.

Throughout this article, I have engaged with theoretical insights that were not intended to be used to increase understanding of the disabled student journey. However, I contended that theoretical insights come alive and are both hugely relevant and powerful when related to everyday situations and used as a tool for social change (Goodley et al., 2012). This is further exemplified by Steven Seidman (2016, p. ix) when he states in the preface to his book *Contested Knowledge: Social Theory Today*, that:

> Sociological theory has all too often, especially in the last two decades, become isolated from public life and has chased the idol of science to a point of its own obscurity. Much sociological theory has abandoned a moral and political intention to engage the world as a medium of critical analysis and change. (Seidman, 2016, p. ix)

Following Seidman, I have sought to engage social theory, seeking to apply it as a medium of critical analysis and social change. I make no apologies for applying various theoretical ideas to interpret disabled students lives. Further, it has been stated that disability is the human condition which can shed light on a host of political, practical and social issues (Goodley, 2016). In this article, I have mobilised theoretical insights to establish how the equity of higher education may be examined from the perspective of disabled students.

In conclusion, I offer a simple model below (Figure 1) which is designed to demonstrate some of the ways that social theory can be used in the analysis of disabled student journeys. It is very much my hope that this model is of some use to disabled students as they seek to make their way through education.

Figure 1 is intended to underline the importance of acknowledging the influence of taken-for-granted assumptions; reflecting upon the importance of the influence of power in shaping disabled student journeys; and the importance of situating the experience of higher education into a life-course. I suggest that employing a social theoretical approach can be extremely helpful in reaching toward a sophisticated understanding of the disabled student journey.

The way that student journeys through higher education have been said to be simplified by analysis which involves social theory (Gale & Parker, 2014; Strom, 2018;

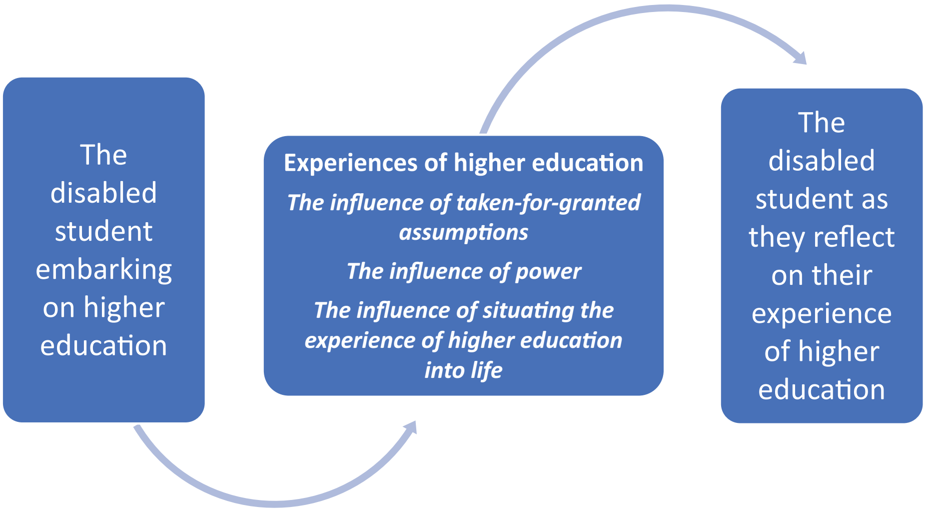

Figure 1. The way social theory can be used to understand a disabled student journey.

Taylor & Harris-Evans, 2018; Wang, 2015) is important in the creation of this model. Consequently, I would suggest that a social-theory-inspired analysis of all student journeys would provide a healthy source of inspiration to those interested in undertaking such a journey in the future.

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Conflict of Interests

The author declares no conflict of interests.

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About the Author

Jonathan Harvey (PhD) is a Lecturer in Education at Plymouth Marjon University and leads the BA (Hons) Special Educational Needs and Disability Studies course. His research has been conducted primarily with disabled people. His published research includes work which explores identity and disability; narrative methods; and the daily lives of chronically ill and disabled people. He is currently researching the complexities for disabled people who navigate the higher education system.

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Article

Disability Awareness, Training, and Empowerment: A New Paradigm for Raising Disability Awareness on a University Campus for Faculty, Staff, and Students

Dana Roth [1,*], Timothy Pure [2], Samuel Rabinowitz [3] and Carol Kaufman-Scarborough [3]

[1] Disability Services (Ross Center), University of Massachusetts, Boston, MA 02125, USA; E-Mail: dana.roth@umb.edu
[2] Learning Skills Program, Solebury School, New Hope, PA 18938, USA; E-Mail: tpure@solebury.org
[3] School of Business, Rutgers University-Camden, Camden, NJ 08102, USA; E-Mails: rabinowi@camden.rutgers.edu (S.R.), ckaufman@camden.rutgers.edu (C.K.-S.)

* Corresponding author

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Abstract
A select committee of faculty, staff, administrators and students collaborated to create and implement the Disability Awareness, Training, and Empowerment (DATE) program on the campus of a midsize public state institution in the Northeastern United States. Based on studies of existing literature in the field, as well as campus climate information, the committee created a unique training program that has, to date, seen the training of over 350 faculty members, staff and administrators. This article will explore the literature that was surveyed to form the philosophical underpinnings of the program. The starting place for the training was *No Pity: People with Disabilities Forging a New Civil Rights Movement* (Shapiro, 1993), as well as the research of Cole and Cawthon (2015), Hehir and Schifter (2015), and Oliver (1990). After surveying this supporting literature, the article will then explore the evolution and facilitation of the training program, including the various iterations of the training as it took its final form. The article will conclude with an exploration of possible new directions for disability awareness training programs on university campuses. The discussion also includes an expansion to the student body and a corresponding fulfillment of the university's civic engagement course requirements.

Keywords
accessibility; accommodation; disability; disability awareness; disability rights; empowerment; faculty; higher education; student; training; university

Issue
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1. Introduction

In recent years, college and university campuses have sought a stronger understanding of the needs of students with disabilities, and the ways to offer support to this traditionally underserved student population (Lombardi, Murray, & Kowitt, 2016; Murray, Flannery, & Wren, 2008; Murray, Wren, Stevens, & Keys, 2009). Both academic and practical studies have examined general issues such as facilities upgrades through program-specific needs including service learning, athletic programs, and career services for students with disabilities.

This article will describe the development of a university campus training program on a midsize public university campus in the Northeastern United States. The program grew from the recognition by university faculty and staff that there were numbers of campus community members who lacked information about how to work effectively and proactively with students with disabilities. The relevance of creating greater awareness of how to confront issues surrounding students with disabilities resulted from a report presented by the University Senate, a representative body of faculty, staff, administrators, students, and alumni, of a midsize North American university. One of the recommendations was to offer disability awareness training opportunities in order to help faculty and staff better serve students with disabilities. With this recognized need in mind, the chancellor of one of the university's campuses created a Disabilities Advisory Council, and a number of subcommittees to examine all aspects of the experience of students with disabilities. One of the subcommittees formed through the Disabilities Awareness Council centered on Disability Awareness Training and Empowerment (DATE subcommittee).

Working in concert with university leadership, the subcommittee was tasked with creating a time-sensitive and time-efficient training program that sought to educate faculty, staff, administrators, and students on the needs of students with disabilities, best practices related to relevant legislation, and recommendations to support these students across campus. Planning for the training sessions commenced in the fall semester, with a piloted series of workshop and subsequent feedback sessions occurring the following spring.

This article will articulate the need for the Disability Awareness, Training, and Empowerment (DATE) program, the supporting literature, including a brief discussion of approaches to disability studies, a description of the DATE program, and feedback collected. It will conclude with recommendations for future training and education initiatives.

2. Context and Initial Considerations

2.1. Problem Statement

Examinations of student success indicate that persons with disabilities can thrive in an environment where they are expected and understood (Bellman, Burgstahler, & Ladner, 2014; Simonson, Glick, & Nobe, 2013). College campuses are no exception. However, it is also common that faculty and staff are unclear how to work with and support students with disabilities, especially in activities designed for the entire student body. It was clear that, on a campus which advocates a mission of diversity and inclusivity, a proactive approach to education and training was needed (Evans, Herriott, & Myers, 2009; Lombardi & Lalor, 2017). As Lombardi, Murray and Dallas (2013) note, collaboration is critical for successful university stakeholders and staff disability awareness training programs.

2.2. Call for Awareness Training from University Stakeholders

The University Senate, made up of faculty, staff, administrators, alumni, and students, presented a report to university leadership, noting a lack of understanding of issues related to success for students with disabilities. In an effort to improve understanding of this, often invisible, minority, the University campus's chancellor worked to establish the Disabilities Advisory Council, which included faculty and staff from several parts of the campus. The Council created a number of working groups related to success initiatives for students with disabilities and charged the DATE subcommittee with creating a pilot program for faculty, staff, and administrators. The subcommittee was comprised of faculty from the department of Fine Arts and the School of Business, as well as staff and administrators from the Division of Student Life and the Center for Learning and Student Success. The primary aim of this program was to increase and improve familiarity with the needs of students with disabilities, with the overarching goal of supporting, retaining, and graduating students with disabilities in a more effective and timely manner.

3. Literature Underpinning the Program

3.1. Disability Rights and Equal Access

The philosophy behind the disability rights movement, beginning in the 1960s, served as the starting place for the creation of a training program for faculty and staff in higher education. *No Pity: People with Disabilities Forging a New Civil Rights Movement* (Shapiro, 1993, henceforth referenced as *No Pity*) was chosen as a common resource providing insights into the creation of laws such as the Americans with Disabilities Act of 1990 and Section 504 of the US Rehabilitation Act of 1973. In the case of higher education, the primary focus centers on institutional barriers that deny access to students with disabilities. As Judy Heumann states, quoted in *No Pity*, "disability only becomes a tragedy for me when society fails to provide the things we need to lead our lives—job opportunities or barrier free buildings" (Shapiro, 1993, p. 20).

3.2. Institutional Barriers from the Student Perspective

Institutional barriers can take many forms, from inaccessible classroom buildings, paper-only textbooks, and PowerPoint slideshows that lack alt-tagging, to videos that are uncaptioned. Such challenges are often cited by students as significant barriers to their access to academic curriculum and courses. Stigma of disability can present one such barrier, when students may perceive that the disclosure of a disability, along with requesting of accommodations, will be treated negatively by faculty. Cole and Cawthon (2015), in a survey of students with disabilities at a large public university, found that a number of students did not disclose their disability to faculty. The power of stigma looms large. In a qualitative analysis of students with disabilities at Harvard University, one of the participants offers the following statement, after a poor experience disclosing her disability to a faculty member:

> Whether the professor did actually tie my grades to assumptions about my disability, I perceived it that way. For the rest of my college experience, I did not volunteer to have conversations with my professors about my disability. (Hehir & Schifter, 2015, p. 165)

What's more, in one survey of undergraduate students, approximately one third of student respondents reported feeling hesitant or fearful of approaching a professor regarding accommodation requests (Baker, Boland, & Nowik, 2012).

3.3. Training for Faculty and Staff

Research also points to a knowledge gap between faculty responsibilities and appropriate training. Again, Cole and Cawthon (2015, p. 176) note: "[Students with learning disabilities] reported that, when they approached faculty with their accommodation letters, professors often did not seem to know what to do". As Baker et al. (2012) found in a survey of 400 undergraduate students and faculty, faculty understand the concept of disability, but do not always understand the laws that govern services for students with disabilities. In the survey, approximately one third of faculty respondents strongly disagreed or disagreed with the notion that they are familiar with the ADA and Section 504.

Significantly, once provided with information regarding both legal compliance and also pedagogical training, studies have shown that faculty are able to provide improved support for students with disabilities. For example, after attending a three-day summer institute, faculty felt better equipped to provide accommodations and academic support for students with disabilities in their courses during the following semester (Park, Roberts, & Stodden, 2012). A study of disability training programs at two universities indicates that "faculty attitudes could improve if a variety of training opportunities [were] available" (Lombardi et al., 2013, p. 230). Taking this a step further, we observe that faculty who participate in training and awareness programs are better equipped to support students with disabilities (Lombardi & Murray, 2011; Lombardi, Murray, & Gerdes, 2011; Murray et al., 2009).

Additionally, as Murray et al. (2008) and Evans et al. (2009) note, student affairs professionals do not receive explicit training in or possess awareness of the needs of college students with disabilities. In order to effectively support the needs of these students both in and out of the classroom setting, it is imperative that staff and administrators develop the tools to help students access college curriculum and co-curricular endeavors (Lombardi & Lalor, 2017). Participating in disability awareness training programs develops staff and administrators' understanding of student needs and develops more positive attitudes toward working with students with disabilities (Murray, Lombardi, & Wren, 2011). With these demonstrated needs and impacts in mind, it is evident that a training program that serves the interests of staff and faculty alike will be beneficial to constituents across the college campus.

3.4. Approaches to Disability Studies

Early academics considered persons with disabilities to have "spoiled" lives that would "never" accomplish their life's purpose. Many viewed persons with disabilities as not belonging in society, feeling that these individuals might best be served by being hidden away in institutions. As sociologist Erving Goffman (1963) suggested, they would live their lives apart from society as people to be avoided, feared, and protected from contact. As a result, they were unlikely to be considered when mainstream educational systems were designed. Scholars such as Chouinard (1997), Imrie (1999), and Oliver (1990) framed the experience of disability through two classic models: the medical model and the social model. The medical model, as its name implies, assumes that the actual disability causes the person to become isolated from society (Llewellyn & Hogan, 2000). Hence, it focuses on identifying ways to "fix" the individual so that they might participate in the environment of able-bodied persons (Chouinard, 1997). This perspective is based on ableism, the expectation that one must be able-bodied to participate, which tends to create privileged access for persons who do not have disabilities.

In contrast, the social model assumes that the environment should be changed or "fixed" to provide access to persons with disabilities. In essence, the social model identifies problems that should be adapted in a society so that access is available for all persons. Thus, workplaces, schools, shops, religious institutions, and entertainment venues can all "disable" persons who might otherwise function comfortably and effectively (Oliver, 1990). Such "disabling" can occur when infrastructure is built that overlooks the necessity to include persons with disabilities (Paar & Butler, 1999). As a result, classrooms may be built without proper access, while online education systems may fail to provide closed-captioning or transcripts of lectures. However, more recent works criticize the social model as outdated and needing expansion (Shakespeare & Watson, 2001) to correct its simplified picture of the real world (Owens, 2015).

4. Program Features

The DATE program seeks to go beyond the traditional social model in solely considering campus environmental problems to be corrected. Instead, this program takes a broader perspective in examining the activities, attitudes, myths, misunderstandings, technologies, and pedagogical practices that can limit inclusion in the university setting. The article will now explore the evolution of the training program, including the various iterations of the training as it took its final form.

4.1. Description of Practice

In order to represent touch points with the entire spectrum of student life, the subcommittee members created a hybrid process to be delivered through advance online readings and two videos, plus an in-person 90-minute interactive presentation, lunch, and a collaborative learning exercise organized in campus workshop format. This approach ensured that the training would be delivered in a time-effective manner. The presentation itself was divided into two sections. The first half employed a lecture format and covered the following topics:

- Americans with Disabilities Act of 1990, Americans with Disabilities Amendments Act of 2008, and Section 504 of the Rehabilitation Act of 1973, coupled with the impact on students and higher education institutions alike;
- The need for maintaining confidentiality related to a student's disclosure of a disability diagnosis;
- A review of appropriate disability documentation, and how decisions related to disability status and accommodations are made at the institution;
- The process for requesting and receiving academic accommodations at the institution, including the request and approval process, notifying faculty of accommodations through a Forecast Memo and Letter of Accommodation, and providing updated documentation as needed to provide accommodations throughout a student's tenure at the institution;
- A discussion of possible accommodations available to students;
- A discussion of "unfair advantage" and the aims of accommodations leveling the playing field for students with disabilities, which included an overview of the underrepresentation of students with disabilities on college and university campuses and in the workforce;
- An overview of self-advocacy, and its impact on student success.

The second half of the session involved attendees discussing scenarios (further details follow below).

4.2. Scenario Development

The DATE subcommittee first collaborated to brainstorm situations that they or their colleagues had observed. A concerted effort was made to identify barriers to inclusion from various aspects of the lives of SWDs. For example, representatives from student life were able to consider campus social events while information technology and learning staff provided instances of technology barriers. Short, real-life discussion scenarios were chosen as the mode of collaborative learning for the training sessions. Each scenario was written to be read easily within five minutes, and was followed by a discussion of questions including: "What is the problem? What should have happened? What could have prevented the problem? What can be done to prevent this situation from happening again?" The desired outcome was that participants learned to predict and diagnose a possible problem, and to implement changes to prevent it from recurring. After initial sessions were completed, the subcommittee fine-tuned these cases in order to represent a variety of general themes of how to address disabilities within the student body. These cases were later presented to training session participants for small and large group discussion.

A typical scenario featured a classroom, campus, or event situation in which a faculty or staff member interacted with a person with a disability. Other persons may have appeared in the scenario, but their role was incidental to the main point. Within the scenario, something occurred that was a violation or misunderstanding of the rights of the person with disabilities. The situation was rich enough that multiple interpretations were possible. Table 1, "Examples of Scenarios", is presented below:

Table 1. Examples of Scenarios.

Scenario Description	Possible Outcomes of Discussion
Scenario 1: At a workshop on Professionalism and Ethics attended by various faculty and undergraduate students, a guest lecturer, a distinguished professor from another university, is giving a presentation. Danielle, a student with a hearing impairment who receives captioning accommodations through the Office of Disability Services (captioning allows a hearing-impaired student to read from a computer screen as a stenographer captures what is being spoken), is seated in the front row, her laptop open in front of her so that she can follow along. The guest lecturer is animatedly gesturing to Danielle to close the laptop and pay attention to the lecture. Question 1: If you were Danielle, how would you handle the situation? Question 2: If you were a faculty member in the audience, how would you respond?	Discussion of the student's role in self-advocacy, with an acknowledgement that this places the student in a highly uncomfortable position. Discussion of the faculty member perhaps intervening to assist student. Understanding that this was a failure of planning on the part of the organizer of the workshop, that issues of access and accommodations should be dealt with proactively (i.e., letting the guest lecturer know he/she should speak to a designated faculty member or school representative if he/she has any questions).

Table 1. (Cont.) Examples of Scenarios.

Scenario Description	Possible Outcomes of Discussion
Scenario 2: You are a professor of physics at a major university in the northeastern United States. One of the students in your class, Peter, approaches you and says, “Hi, Professor. I’m Peter, and I have ADHD. My other professors have all given me extended time on tests, and I would really appreciate it if you would do the same”. You ask to see his letter of accommodation from the Disability Resources Office, and he says that he does not have one, but it should not be a big deal. After all, Peter says, “It’s just a little extra time. And all of my other professors have done this for me. I’d really appreciate it”. While you want to be helpful, you have an uncertain feeling about the request. Question: What do you do?	Discussion of the processes and procedures for requesting accommodations. Additional discussion of the resources available to faculty to assist them in supporting students with disabilities in their classroom work.
Scenario 3: You are a disability services officer at a public university in New Jersey. A student on file with your office, Lora, has approached you regarding an issue she is having with an online course. Lora’s letter of accommodation specifies that she is eligible for extended time of 150% on all in-class and/or online tests, quizzes, and exams. A professor for one of her courses has told her that he believes it is an unfair advantage for her to get extended time, so to be fair to everyone, instead of an hour, the entire class will receive an hour and a half. Lora states that this seems to be unfair to her. Question 1: What is your response to Lora? Question 2: What is your response to the professor?	Discussion of the topic of “unfair advantage”, especially as it pertains to classroom accommodations. Discussion of the role of a disability services office in mediating this situation on behalf of the student, as well as a discussion of faculty roles and responsibilities.
Scenario 4: You are a psychology professor at a small university. Grace, a student who uses a wheelchair, is in your introductory lecture and lab. At the beginning of the semester, the student discloses that she will need to use an assistive technology software, such as Dragon Naturally Speaking, in order to write in your class (Dragon Naturally Speaking allows a student to speak to a computer, which then transcribes the spoken word into text on a word processing program). What’s more, this student reports transportation issues and sudden illnesses, which may make class attendance a challenge. Question: How do you proceed with this student’s requests?	Discussion of the use of assistive technology to support students with disabilities in the classroom. Exploration of the issues regarding absences for medical conditions and how faculty can best work with the student and the disability services office to support a student in their class. Importance of referral to the disability services office on campus.
Scenario 5: You and your son are visiting the campus of a major university, as your son is attempting to choose which school he will attend for his BS in Engineering. You have toured the campus, your son has fallen in love with the school, and he is already talking about his interest in a potential internship with a major aeronautics firm located nearby. At the end of the day, you and your son visit the Office of Disability Services. Your son has dysgraphia, a learning disability that interferes with his ability to produce written material. He utilized a computer program, Dragon Naturally Speaking, to aid him in writing his papers in high school, and is quite proficient in its use. Upon your son explaining his disability to the disability services officer, the staff member replies, ”Oh, dysgraphia. I’ve never heard of that before. That’s a form of blindness, right? We don’t really do a good job helping people who can’t see. This might not be the school for you”. Question: What do you do?	Discussion of the role of parents in the academic lives of students with disabilities, and an exploration of how to handle a poor interaction with an office that facilitates disability accommodations on campus. Discussion of the parent’s perspective on this situation.

4.3. Pilot Study and Revisions

For the pilot of the DATE program, the initiative leaders presented three 90-minute sessions to the campus community in the beginning of the spring semester. Sessions included the following components:

- Prior to the in-person training sessions, the subcommittee asked participants to register to attend a session online, view two online videos, and read a short, one-page compilation of excerpts from *No Pity*;
- PowerPoint Presentation, detailing legal issues and responsibilities surrounding college students with disabilities, materials that the Office of Disability Services provides to faculty (i.e., Letter of Accommodation, Forecast Memo), and common misconceptions of college students with disabilities;
- Small group discussion of one of four cases, along with questions provided to groups;
- Larger group discussion of findings from each group's case;
- Wrap-up and inform participants of follow-up feedback session dates.

4.4. Participants

After the training was developed, the DATE initiative opened the pilot study to participation from a cross-section of the campus. DATE representatives reached out to four divisions of the university campus: School of Business, Division of Student Life, Department of Fine Arts, and the Center for Learning and Student Success. Members of these four divisions were invited to participate in the training sessions. From these divisions, 60 faculty, staff, and administrators attended one of three 90-minute training sessions.

5. Anecdotal Program Feedback

Following the three initial training sessions, participants were solicited for their feedback from their experience later in the spring semester. In addition, the subcommittee members were interested to learn the participants' reactions and suggestions, as well as whether their learning was consistent with expectations.

Seven follow-up debriefing sessions were offered for participants to attend, after the DATE subcommittee delivered the three 90-minute workshops. Thirty-eight faculty and staff attended these follow-up sessions. During the follow-up sessions, participants' feedback on their feelings of workshop structure, content, and overall message, as well as recommendations to make future workshops more beneficial for their coworkers were solicited. Faculty and staff overarchingly agreed that the training should be required for all faculty members moving forward, and that new faculty members should attend this workshop during their orientation. To this end, outreach to Human Resources to coordinate this training was recommended. Faculty and staff agreed that training would be beneficial for staff, though the training should be adjusted, to include cases that highlight student interactions with staff, in addition to their interactions with faculty.

Participants also remarked that while one training is helpful, it would be preferable to have the option of ongoing trainings throughout the year and throughout their tenure with the University. Accordingly, one suggestion was to require all staff and faculty to attend the overview session, which currently includes cases for faculty and staff, and offer special interest training sessions throughout the year. The special interest training sessions could focus on specific disabilities that are increasing in number at the University, including Autism Spectrum Disorder, Posttraumatic Stress Disorder, and Traumatic Brain Injury; sessions could also highlight areas such as, "how can we make our office more accommodating to student employees with a disability", or "how can academic and career advisors work more effectively with students with a disability".

6. Post-Pilot Training

Following the piloted training program, the subcommittee began growing the DATE program. Using the suggestions from original participants' feedback, the subcommittee members created a total of 17 scenarios to draw from and discuss in various training sessions. Additionally, sessions were tailor-made for specific schools and majors to incorporate specifically-requested situations. For instance, the School of Nursing had particular travel and clinical issues to cover that are not common across the general campus. As of the current time, the DATE program has had more than 350 faculty, staff, and administrator participants representing all parts of the campus.

Participants also shared that in the future, they wish to see an increased online presence for disability services. This increase would focus on specific resources to guide staff and faculty knowledge of disability-related issues and serve as another means to inform their interactions with students.

6.1. Post-Pilot Resources for Participants

For example, participants requested a glossary of disability-related terms, which could break down materials and services that Disability Services provide and promote (i.e., Forecast Memo, Letter of Accommodation, Assistive Technology, Universal Design for Learning; definitions of various disabilities, i.e., dyslexia and ADHD; and types of Assistive Technology, i.e., Dragon Naturally Speaking, LiveScribe SmartPen, etc.). Another online resource that participants requested was a list of frequently asked questions and answers, in conjunction with sample cases that Disability Services has overseen.

Additionally, participants requested broader access to a Disability Manual, which Disability Services maintains and updates periodically. After consulting a variety of postsecondary institutions' websites, the subcommittee members observed that many schools provide a link to their Disability Manual on the Disability Services website, and the campus is looking into following suit. Moreover, participants noted that they wish the Disability Services website was easier to find, and that it provided links to information such as best practices, the Association on Higher Education and Disability, and explanations of legislation. The authors will consider this feedback moving forward, as well.

In addition to these recommendations, faculty participants have requested a disability statement to include in their syllabi and have encouraged the subcommittee to consider providing evening training sessions, in order to accommodate part-time lecturers. Moving forward, the subcommittee will consider how to provide trainings both in-person and in an online format.

7. Recommendations

This article concludes with an exploration of possible new directions for disability awareness training programs on university campuses. The discussion also includes an expansion to the student body and a corresponding fulfillment of the university's civic engagement course requirements.

These observations can apply broadly to college and university campuses that seek to offer or require professional development opportunities for faculty, staff, and administrators, in order to cultivate understanding of the needs of students with disabilities. As prior empirical research suggests (Murray et al., 2008, 2009, 2011), growing staff and faculty awareness of the needs of students with disabilities leads to more positive attitudes, greater willingness to support students with disabilities, and more positive student experiences and student success. By continuing to offer trainings such as this, particularly in relation to key areas of exploration on individual campuses, faculty, staff, and administrators will be better equipped to serve their students.

7.1. Training Includes All Points of Contact on and off Campus

The authors learned the importance of gaining the support and participation of those who interact with students with disabilities in all facets of their college experience. While other approaches may focus on the experiences of students with faculty in their courses, the DATE subcommittee members believe that access limitations and misunderstandings may also occur when interacting with staff and administration. Awareness and sensitivity to issues that impact on this part of the student population will move the University towards greater inclusiveness. Session participants also indicated that advance planning must precede off-campus activities, such as those encountered when students go on field trips, participate in internships, and work in academic cooperatives.

7.2. Educational Access Beyond the Physical Setting through Online Training and Online Education

In many academic settings, faculty, staff, and administration may find difficulty in attending training during their work days on campus. Instead, building an online training program is a logical next step in order to engage faculty who cannot come to on-campus training sessions. Online training also offers the opportunity to review training materials at later dates, to view video discussions of other scenarios, and potentially to engage in discussion forums with the training session leaders.

Additionally, colleges and universities continue to grow programs offered in a variety of online formats ranging from hybrid courses to fully-online degree programs. The educational community indicates that both similar as well as unique barriers can be found, ranging from registration issues such as non-accessible tables, and activity posts that lack accessibility information, to the lack of accurate closed-captioning, presentation scripts, and alt-tagged photos. Educating faculty, staff, and administration to these issues can make a significant difference in the accessibility that students can experience. A similar method can be followed in developing representative scenarios that capture the realities of the online students' experiences.

7.3. Training for Students without Disabilities

Beyond the participation of the faculty, staff, and administration, the authors would recommend creating greater awareness among students without disabilities with a training program emphasizing student to student scenarios. For example, students who lead campus organizations could be coached in planning activities that welcome all students to participate and attend, or at least attempt to minimize barriers to access. As a potential incentive, campus administration can require student organizations to include a simple request for accessibility needs as a routine part of their publicity. Colleges can also require that off-campus activities be held at locations that are accessible to all students.

Students can also gain insights into accessibility by participating in selected public activities and forums. For instance, civic engagement activities and internships involving interactions with local schools who educate students with disabilities might add to such awareness.

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Conflict of Interests

The authors declare no conflict of interests.

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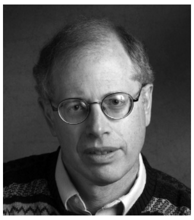
About the Authors

Dana Roth is the Assistant Director of Disability Services at the University of Massachusetts Boston. She has focused her professional experience on student access and success initiatives, including disability services and academic support. In her current role, she provides academic accommodations to undergraduate, graduate, and professional students with disabilities, and consults with faculty to provide trainings on disability-related issues.

Timothy Pure was the Assistant Director of the Rutgers-Camden Learning Center and the Coordinator of Disability Services at Rutgers University, Camden, during the time of this study. His professional experiences involve providing academic accommodations to undergraduate, graduate, and professional students with disabilities, developing accessible course materials, and providing training on disability-related issues to faculty and staff. He has also taught a psychology course on the history of disability, the disability rights movement, the laws protecting the rights of students with disabilities, and an in-depth exploration of physical, psychological, learning, and developmental disabilities.



Samuel Rabinowitz is a Professor of Management and Area Head for Organizational Behavior, Human Resource Management and Marketing at the Rutgers School of Business, Camden. His academic work and interests center on career and life stage issues, job attitudes, and disability-related applications in the workplace.

Carol Kaufman-Scarborough is a Professor of Marketing and the Director of the RSBC Business Leader Development Program. Much of her academic work investigates the marketing, retail, and legal aspects of accessibility for shoppers with disabilities. Her studies have included shopping access by persons with mobility disabilities, online access for persons with visual impairments, and in-store experiences of persons with cognitive impairments. She has presented various professional and academic seminars on the effectiveness of the Americans with Disabilities Act and has been active in disabilities access both at Rutgers and within the community.

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Article

Disability in Higher Education: Explanations and Legitimisation from Teachers at Leipzig University

Robert Aust

Equal Opportunity Office, Leipzig University, 04109 Leipzig, Germany; E-Mail: robert.aust@uni-leipzig.de

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Abstract
In 2009, Germany ratified the UN Convention on the Rights of Persons with Disabilities (UN-CRPD) and committed itself to allow for “the full and effective participation [of people with disabilities] in society” (United Nations, 2006, §3), especially in education (United Nations, 2016, §24). The present article addresses the necessary follow-up question: which patterns of perception university teachers have of students with disabilities? A first project-based qualitative analysis of data from the EU-project “European Action on Disability within Higher Education” has been conducted on the grounds that disability can be described as a constructed sociocultural phenomenon (Tremain, 2005), showing that heterogenous concepts of disability can be reconstructed from the interviews (Aust, Trommler, & Drinck, 2015). In an adaptation of theoretical sampling according to Grounded Theory (Glaser & Strauss, 2010), interviews with teachers were selected for this article. The Explanatory Legitimacy Theory Model by DePoy and Gilson (2004, 2010) served as a pool of ideas for analysis. The four main areas of, 1) effective power of symbols or iconic figures, 2) performativity of attributions of disability, 3) dimension of time for concepts addressed, and 4) perpetuation of the medicine model can be reconstructed. The analysis indicates that the medicine model remains the dominant reference when teachers in higher education speak about disability. In conclusion, conditions that impede the proper implementation of the UN-CRPD in higher education must be identified so that higher education institutions can be further developed as multicultural organisations (Schein, 1984).

Keywords
disability; Explanatory Legitimacy Theory; Grounded Theory; higher education; medicine model; qualitative research

Issue
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1. Introduction

With the adoption of the UN Convention on the Rights of Persons with Disabilities (UN-CRPD) and its ratification by the German parliament (Bundesministerium für Arbeit und Soziales [BMAS], 2011), the German state committed itself to establishing an inclusive education system. So far, most of the research and political efforts in social practice in the German educational system have been focused on the primary, secondary or pre-school system (Tippelt & Schmidt-Hertha, 2013). However, given that higher education is also part of the education system (Knauf, 2015), there is a wider field of research desiderates concerning disability in higher education in general (Knauf, 2013; Tippelt & Schmidt-Hertha, 2013) and students with disabilities specifically.

The EU project “European Action on Disability within Higher Education” (EADHE) was established by seven universities—Aarhus (Denmark), Bologna (Italy), Coimbra (Portugal), Crakow (Poland), Ghent (Belgium), Gothenburg (Sweden) and Leipzig (Germany)[1]—to close this gap in knowledge about the situation of students with disabilities and about studying with disabilities in higher education in Europe (Aust, Cao, Drinck, & Chattat,

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[1] For a project overview visit www.eadhe.eu

2014). The main focus was on extracting and processing data on the disabling effects higher education structures have on students with disabilities or on studying with disabilities and to then identify best practices of dealing with the needs of students with disabilities. One product of this project is a database of needs of students with disabilities and the requirements for studying with impairments, as well as best practices that could be used to support these students. To complete project tasks and to establish a database[2] of best practices, the project partners collected data by: 1) interviewing employees of universities, and 2) surveying, with an online questionnaire, students who identified themselves as disabled. The interviews with employees where selected on the grounds of their experience with students with impairments or with studying with impairments (Aust et al., 2014, p. 39).

During the process of analysing the interviews conducted at Leipzig University, it became evident that there is no one consistent definition used by employees speaking about disability or students with disabilities. Rather, the interviewees used a lot of different words and concepts to speak about disability (Aust, Trommler, & Drinck, 2015, pp. 8–9). As differences in social meaning and construction of reality were not at the focus of the EADHE project at the outset, such a detailed analysis had not been conducted before. But in order to identify appropriate measures for inclusion, to raise awareness for students and for studying with disabilities and to develop higher education institutions as multicultural organisations (Krell, 2008; Schein, 1984), it is essential to reconstruct the subjective patterns of interpretation and categorisation, the beliefs and conceptual approaches of institutional actors in higher education (von Karsdorff, 2013, pp. 615–618). Only if these aspects are taken into account, social practices in higher education such as teaching, guidance and research can be improved (Schein, 1984, p. 14) and effective measures initiated (Krell, 2008, pp. 14; Bohnsack, 2008, pp. 188ff.).

This article aims to provide an outline of reconstructive approaches to find out about disability concepts employees in higher education have.[3] Given that disability can be defined as a socially constructed phenomenon (Tremain, 2005), the concept of the "Explanatory-Legitimacy-Theory" (ELT) by DePoy and Gilson (2004, 2010) will be used to analyse interviews from the EADHE project in an explorative way. Starting with a short description of the theoretical framework and current research in Germany within higher education and disability, the theoretical perspectives of ELT and its methodological approaches will be defined in a second step. This will be followed by a description of the data sample and data research strategies as well as the analysing processes. Finally, I will highlight first impressions from the analysed material and then, with regard to the research question, discuss the results within the reconstructed concepts of disabilities.[4]

2. General Framework

2.1. Conceptualising Disability—A Short Description

The social and scientific perspectives on disability have changed over the last 20 years (Waldschmidt, 2012, pp. 731–732). Various national and international contributions to the question of "what is disability?" have been discussed in recent years (Albrecht, Seelman, & Bury, 2001; Cloerkes, 2007; Davis, 2006; Dederich, 2007; Degener, 2003; DePoy & Gilson, 2010; Goodley, 2011; Hermes & Rohrmann, 2006; Kastl, 2010; Mitchell, 2009; Priestley, 2010; Swain & French, 2000; Tremain, 2005; Waldschmidt, 2005; Waldschmidt & Schneider, 2007). The focus is no longer just on a person's impairment(s) or disability, as in the medicine model proposed. The social (cultural) model (of disability) considers it inappropriate to attribute disability to a person on the basis of health condition categories alone (Goodley, 2011, pp. 11–12; Swain & French, 2000, p. 570). Such concepts do not address the social human being as a whole. It defines a person exclusively by their disadvantages, deficiencies, problems and impairments. The medicine model distinguishes between the disabled and the non-disabled, a perspective that is not helpful either. Swain and French (2000, pp. 570–571) argue that, by choosing two contrasting, interdependent categories such as disabled and non-disabled, virtually nothing is said about the individual, and that such categorisations are therefore insufficient. Like the "iconic turn" was a shift towards an interdisciplinary perspective on language and communication (Maar, 2007, pp. 11–12), the social (or sociocultural) model is a shift from perspectives of the medicine or clinical model, which was primarily used to address and describe disability on the basis of individual impairments (Berger, 2013, p. 26; Goodley, 2011, p. 11), to addressing disability in society towards a model that describes disability and impairment as a socially constructed category and phenomenon. With that said, disability remains a socially constructed phenomenon, a category defined by power and knowledge (Tremain, 2005, pp. 1–2). The shift in language is about persons "having an impairment", understood as a person-first terminology which aims to characterise a person as more than his or her disabilities (Jaeger & Bowman, 2005, p. 4).

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[2] For the database see www.eadhe.eu/index.php/toolbox

[3] The use of the ELT model and first impressions from analysis were first presented at the II International Congress of University and Disability (CIUD) in Madrid, between 24th and 27th November 2014, under the title "Subjective Theories and Constructions of Disability in Higher Education. First Impressions of a Study on Lecturers from the University of Leipzig about Descriptions, Explanations and Legitimacies" together with Friederike Trommler and Barbara Drinck. For the conference paper see Aust et al. (2015).

[4] Aspects of this article are part of my PhD thesis *The Administration of Disability in Higher Education. A Comparative Discourse Analysis amongst Five European Universities* (Working Title), supervised by Prof. Justin Powell at the University of Luxemburg and Prof. Vera Moser at Humboldt University of Berlin.

This new perspective "disassociates impairment from disability" (Swain & French, 2000, p. 571).[5] Through this lens, showing that it is no longer the person who is disabled or has a disability, the focal point of addressing disability is now society, the social, economic, political processes and geographic conditions that disable people so that they are impaired (Berger, 2013, pp. 27–28; DePoy & Gilson, 2004, p. 53). This has replaced the deficiency perspective of human beings (medicine model) with a perspective of their capabilities. In the scientific community of disability studies, a lot of differentiations of various impairments have been addressed (Swain & French, 2000, p. 571), focused on extending the social model. It could be argued that this process moves back to individual perspectives and to attributing the impairment/disability to the persons concerned. This article focuses on the social perspective of disabilities. Addressing individual attributes as a communicative act is different.

2.2. The Situation in Germany: Higher Education and Disability

In the United Nations (UN) report about the implementation of the UN-CRPD for Germany (UN, 2015), the Committee on the Rights of Persons with Disabilities expresses concern over a negative overall situation concerning inclusive societal development, especially in the education system. The Committee recommends that Germany "[i]mmediately develop[s] a strategy, action plan, timeline and targets to provide access to a high-quality, inclusive education system across all Länder [i.e., federal states], including the required financial resources and personnel at all levels" (UN, 2015, p. 8).

Even though the legal framework for an inclusive higher education system in Germany has been improved in recent years, the fact remains that research and practical approaches towards a more inclusive higher education system are lagging behind the transformational and developmental processes in legislation. Although research about disability in higher education in Germany is only in its beginnings (Döbert & Weishaupt, 2013; Knauf, 2014; Tippelt & Schmidt-Hertha, 2013), a considerable number of studies about the group of students concerned in general (Deutsches Studentenwerk [DSW], 2011[6]; Ebersold, Schmitt, & Priestley, 2011; Middendorff, Apolinarski, Poskowsky, Kandulla, & Netz, 2012; Powell, Edelstein, & Blanck, 2015; Powell & Solga, 2011)[7], or sub-groups of disability (Lenz, Otto, & Pelz, 2013; Schramek, 2012; Smith, 2010; Stange, 2014; Zaussinger, Laimer, Wejwar, & Unger, 2012), and teachers and questions about their professionalisation (Bender, Schmidbaur, & Wolde, 2013; Busch, 2014; Dannenbeck, Dorrance, Moldenhauer, Oehme, & Platte, 2016; Klein, 2016; Klein & Heitzmann, 2012; Knauf, 2014; Schuppener, Bernhardt, Hauser, & Poppe, 2014) have been published in recent years. Also, political actors and (research) networks in Germany (Autorengruppe Bildungsberichterstattung, 2014, S119–S138; Hochschulrektorenkonferenz [HRK], 2009, 2013) or Europe (Crosier & Parveva, 2013; Hartl, Thaler, & Unger, 2014; Organisation for Economic Co-Operation and Development [OECD], 2003; Quinn, 2013; Riddell, 2012) have disseminated reports in recent years.

However, a widespread approach towards reconstructive perspectives is missing in this scientific field in Germany.[8] If disability is social constructed research has to focus on research designs and data that documents these social processes. Qualitative research designs with various instruments and analysis strategies is able to reconstruct social processes, like the construction of disability. As a common instrument of qualitative research (Deppermann, 2013) interviews can provide such opportunity, because interviews "purpose is to gather descriptions of the life-world of the interviewee" (Opdenakker, 2006) and it documents the interaction process between two or more persons about a specific topic or time courses.

2.3. Purpose of the Study

Project-based data analyses at Leipzig University revealed that, 1) a large variety of narrations of impairments could be described, and 2) several, individual, subjective concepts and constructions were linked with these narrations (Aust et al., 2014). This comes as no surprise, knowing that in order to communicate and understand concepts, individual interpretations and theoretical adoptions are required (Bohnsack, 2008, pp. 57–59; Brüsenmeister, 2008, pp. 39–45; Marotzki, 2013, pp. 178–181). But to understand the habitualised perspectives on disability held by a group of subjects that could be defined as major actors in higher educa-

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[5] Tremain (2005) criticizes the social model: while the social model distinguishes between disability and impairment, it remains a chimera and "renders the impaired body the exclusive jurisdiction and medical interpretation" (Tremain, 2006, p. 187) and thus withhold "body" towards medical regulations and juridification, for example, intersex people "do not seem to count as "disabled" (Tremain, 2005, p. 10).

[6] It was the first time that empirical data for a large group of students, and for all of Germany, were made available (DSW, 2011). This provided a first insight into examples of the students' socio-economic situation, their access to social life and higher education, the accessibility of buildings and the variety of disabilities addressed. A second similar study has been conducted in 2016–2017. The results will be presented in October 2018 (for more information, visit the German National Association for Student Affairs' website, www.studentenwerke.de/de/content/ibs-fachtagung).

[7] Several other quantitative studies conducted in Germany might provide information about the areas of higher education, of disability or impairment and inclusion, like the SOEP-Panel (www.diw.de/en/soep), the Federal Government Participation Report about Persons with Disabilities (BMAS, 2013) or several previous studies about the socio-economic situation of German students (the last one is from 2012, cf. Middendorff et al., 2012). All of these studies present results about people with impairments or a group of stakeholders in higher education, but not specifically within the field of studying with impairments in higher education.

[8] Grounded in Bourdieu's habitus concept, Schmitt (2010) discussed conflicts students experienced while studying. Other authors examine transmission into higher education by using biographic, narrative research designs (Bargel, 2006; Bülow-Schramm, 2009; Heine, 2010).

tion (Deutscher Hochschulverband [DHV], 2015; Knauf, 2016), it is necessary to further analyse these narrations in a specified, qualitative way. This is consistent with the previously stated perspective that, in order to enhance the awareness and sensitivity of academic staff and to improve inclusion in higher education, it is necessary to identify and reconstruct the personal concepts of these actors (Bohnsack, 2008, p. 191f; Marotzki, 2013, pp. 181–185).

This article is using the perspective of the Explanatory Legitimacy Theory (ELT; DePoy & Gilson, 2004, 2010) to identify disability in interview data from the EADHE project to provide an idea of how the desiderate in the German scientific field of higher education and disability studies can be filled. On the grounds that disability can be described as a constructed sociocultural phenomenon (Tremain, 2005), the ELT framework is used to analyse interviews with teachers from Leipzig University. In an adaptation of the theoretical sampling from Grounded Theory (Glaser & Strauss, 2010), interviews were selected to identify procedures that configure teachers' language about students and studying with disability in higher education. The ELT model offered a pool of ideas (Glaser & Strauss, 2010) for analysis.

On the basis of these assumptions, I used the following main research question to analyse the interview sample from Leipzig University: which explanations and legitimisations can be reconstructed from the subjective approaches of teachers and researchers at Leipzig University for the concepts of disabilities? The importance of knowledge about teachers understanding of disability is, that those reconstructions and empirical evidences can provide an idea whom and how universities can start actions towards a more inclusive higher education. The identification of such attitudinal and social structure barriers would help to develop training programs for the professionalisation of university teachers (Powell & Solga, 2011, pp. 157–158, 176–178).

3. The ELT as a Methodological Approach

The ELT views disability as one of the many phenomena of human diversity, comprising three mutually influential elements: description, explanation and legitimacy. ELT attributes the categorisation of human appearance and behaviour to established value systems that are context-dependent (Aust et al., 2015, pp. 5–6; DePoy & Gilson, 2004, p. 53).

DePoy and Gilson (2010, p. 3) refer to ELT as the "language" to analyse disability with. To apply these theoretical assumptions in research practice they distinguish three main areas: description, explanation and legitimacy. These elements of description and explanation are an expression of human diversity and as such, they do not suffice to legitimise disability yet. Only if certain context-dependent value systems are applied, will the limits of diversity be determined and everything else be defined as disability. Categorisation is carried out on the basis of value systems applied to descriptions and explanations (DePoy & Gilson, 2010, pp. 86–87).

DePoy and Gilson distinguish between descriptions based on "observables" and those based on "reportables". Descriptions of "observables" refer to people's outward appearance, i.e., how they are perceived by others, and to their behaviour with respect to what they do (activities) and how they do it (way of behaving). Individual experiences, on the other hand, are not directly observable by others but can be expressed by those who underwent them. They are "reportables".

Descriptions of attributes of disability correlate the typical with the atypical and contrast them to each other. The way these distinctions are made depends on various factors (DePoy & Gilson, 2004, p. 59). There are different explanations that reproduce and substantiate the distinction of the typical from the atypical (DePoy & Gilson, 2004, p. 70).

DePoy and Gilson (2004, p. 70) recommend considering description and explanation as independent, yet mutually influential, elements. According to authors, retrospective theories (such as Sigmund Freud's or Jean Piaget's) and behaviouristic approaches have shaped what is considered typical or atypical today. There are also explanations which do not only consider features/attributes primarily linked to impairments but also contextual factors such as race, ethnicity and gender so that the atypical can be distinguished from cultural non-affiliation (DePoy & Gilson, 2004, pp. 60f). In conclusion, DePoy and Gilson distinguish two sets of explanations—medical-diagnostic explanations and constructed explanations (DePoy & Gilson, 2004, pp. 70–75). The latter further differentiate explanations within a social, political or cultural line of argumentation. Medical-diagnostic explanations specify typical and atypical phenomena and explain their occurrence in a biomedical way. Medical approaches focus solely on medical findings whereas rehabilitative approaches also take into account any barriers that might result from these findings or conditions (DePoy & Gilson, 2004, pp. 70–73). Constructed explanations do not consider disability a physiological phenomenon. Constructed explanation approaches reject the categories of normal or abnormal and instead perceive humans as individually different. Thus, perceptions and definitions of what is typical or atypical are connected to context-dependent interactions of individuals with their environment (and vice versa; DePoy & Gilson, 2004, pp. 75f.).

Within this model, I seek to identify processes of conceptualisation of disability within the sampled interviews. In its methodological descriptions, the ELT model proves to be capable of reconstructing, in social interactions, the processes that bring about disabilities. The three key areas of description, explanation and legitimacy provide a standardised but flexible and dynamic toolbox facilitating the identification of the concepts communicated or addressed. The ELT model by DePoy & Gilson (2004, 2010) served as a pool of ideas to analyse the interviews (Herfter, 2014, p. 142; Strauss & Corbin, 1996).

4. Interview Sample and Research Process

To collect the project data for the EADHE project, an interview guideline modelled on the Problem-Centred Interview (PCI; Witzel, 2000) was developed. Following the two guiding principles of a PCI, the narrative and the dialogical approach, allowed us to gather data about a) the field of inclusion, disabilities and impairments in higher education and b) an individual perspective (Hopf, 2013, p. 350) on every-day life social practices and experiences of academic staff members. As a qualitative research instrument, the interview allowed for the collection, extraction and reconstruction of information about daily routines, practices and experiences in the context of studying with disability, along with personal attitudes and behaviours of students with disability (Hopf, 2013, pp. 350f.).

4.1. The Interview Sample

At Leipzig University, 36 interviews with employees were conducted (Aust et al., 2014). Within the EADHE research design, three types of employees were defined: teacher, administration and student support services. The sample was selected through an email invitation, sent to all employee email addresses by the Leipzig University central computing centre. The invitation email included a general description of the EADHE project, its aims and objectives and an invitation to an individual, face-to-face interview. Contact information was provided, and a document summarising all relevant information was attached. The whole interview sample from the EADHE project indicated that there are more than the assumed three types. For example, there might be a "mix" of two or three types in one, there are differences within teacher types (professor, researcher with different amount of teaching percentage) and also types, where the status of being an employee is combined with that of a student.

For the purpose of this article, I focussed on interviews with the "teacher" type (sample size: 16 interviews). The hypothesis was that there are different terms of speaking about disability,[9] related to their work tasks (teaching), their position within the university hierarchy and their assumed practical experience and level of knowledge in working with students with disabilities. Also, the importance of teachers for (higher) educational success is addressed in the centre as one of the core criteria for an inclusive university (Plate, 2016; Powell & Pfahl, 2018). This methodologic decision facilitated a short but concrete analysis and discussion of the interpreted results.

The interviews were chosen through an adapted theoretical sampling process (Glaeser & Strauss, 2010, pp. 148f; Schroeter, 2014, pp. 113f.). The sampling strategy consisted of two main categories: 1) the status of the interviewee inside the university (professor versus teacher) and 2) years of teaching experience. Both variables were collected in the pre-inquiry questionnaire, which is part of the PCI (Witzel, 2000). Both categories relate to each other, but also have their own premises. Thus, the status professor is not only linked to a longer teaching experience, but also to a possibly different kind of speaking due to the higher status within the university. This methodological approach allowed for 1) the use of data material which had been collected in a different setting and context and offers different kind of "speaking about disability", and 2) to establish and stabilise a kind of explorative view on the material, to maintain sensitivity and to keep track of the interviewees' narrations (Schroeder, 2014, p. 114).

Using qualitative interviews to identify and reconstruct subjective theories and concepts about disability in higher education made it possible to analyse and understand the issues of studying with disabilities in higher education in a more detailed way. To gain an understanding of the interviewees' perspectives, they were asked one question as a narrative prompt: "what is your definition, your personal understanding, of impairment?" This question served as the narrative-activating question, enabling the interviewee to start talking about disability in general as well as their own personal views. This question had an activating momentum for their own concepts and beliefs, but not specifically in their field of work or higher education alone. It was meant to help the interviewee to get into a rhythm of speaking, to adapt to the situation and feel safe and comfortable in the interview situation (Witzel, 2000). For our research, I analysed the narrative sequence following this first prompt.

4.2. Analysing the Interviews

By adopting the ELT framework of descriptions, explanations and legitimacy, I used a sequential analysis to identify different categories of statements about students and/or studying with disability in the interviews. In a first step, all such statements were collected in a coding chart. In a second step, these statements were differentiated into descriptions, explanations and processes of legitimisation according to the ELT framework.

5. Results

With the three following quotes from interviews, serving as exemplary quotes for all teacher interviews, the methodological approach of the ELT model will be

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[9] Within my PhD thesis, this hypothesis about different types of statements, related to these proposed three different types of employees in the discourse on disabled students, is part of the analytical work. The question is if there are different statements/manifestations and, if so, whether they are related to: 1) different hierarchical positions at university level, 2) locality, and/or 3) cultural and/or national frameworks (such as legal rights, welfare state, etc.). For this article, I will focus on one type only.

demonstrated. In the next step, four main areas reconstructed from interviews are described, followed by a summary of the results. This second step is a conclusion of the analytical process and does not focus on each individual interview.

5.1. Descriptions, Explanations and Legitimacy of Disability in Higher Education

> This isn't just about physical impairments, like deafness or blindness or whatever, old school etc. but also, well, about psychological disorders, social anxiety and so on. (EPwp2_20; 24–26)[10]

> But for me, limitations are what you would generally call disabilities, even though there are others, too, right? the way I see it, everybody is somehow impaired, add to that the mental ones that often come to my attention, me being their course advisor. (EPwp2_05; 65–69)

> That, to me, is the spectrum at a school. when you talk about it at a university or in an academic context, it's more about any kind of physical disability that is visible or…maybe disabilities like neuroses or let's say other psychological conditions that don't impact you mentally in the sense of intellectually but rather in the sense of stress or something like that. (EPwp2_16; 24–30)

Descriptions of disability are performed by using physical and psychological criteria. Those get specified by establishing subcategories like deafness and blindness, "mental ones" or neuroses. Teachers do so by referring to both reportable and observable descriptions of disability. The first type describes visible (observable), physical impairments, for example sensory impairments labelled as "old school" (EPwp2_20, 25), i.e., classic or familiar. The second type, comprising mental impairments and psychological disorders, is invisible at body level, but reportable by the students concerned or can be assumed from their behaviour and may get "my attention, me being their course advisor" (EPwp2_05, 68–69). This means that disability can either be visible on the body level or in the way people appear, i.e. be subject-related, or, they can be invisible and of a cognitive or psychological quality. The latter can only be reported by the person concerned (student) or assumed by others, in this case, the teacher. Also, a generality of impairment in all people[11] is used to include psychological aspects in descriptions of disability (EPwp2_05, 66–67). The field of descriptions of disability differs between several relations of opposite meanings: visible-invisible, classic-new, personal-property of others.

The explanations for using these categories are: 1) naturalistic explanations, 2) observed differences, and 3) generalisations or equating disability for all. It appears as a natural logic that there are different types because it "isn't just about" one type of disability. The invisible types of disability are observable and stating so is related to the experience and the attention and awareness of teachers. Differences between educational levels of school and higher education are used as well to explain the differences in speaking about disability. The argument of physical impairment is described as an "old school" category different from other fields of impairment/disability, as a non-physical. The explanation here is a stated difference of physical vs. non-physical, something that is natural and something that is a developed one. In conclusion, these explanations, together with described differences, are combined to legitimise disability.

Through the performed descriptions and explanations, the legitimatization for labelling somebody as disabled is executed. And these authorisations, as a legitimacy, are explained by individual experiences and understanding of the teachers.

5.2. First Notes on Discourse Areas: Symbols, Performativity and the Medicine Model

Four major areas of speaking about disabilities addressed in the context of higher education can be described (Aust et al., 2015, p. 9): 1) effective power of symbols or iconic figures, 2) performativity of attributions of disability, 3) dimension of time for concepts addressed, and 4) perpetuation of the medicine model.

To figurate disability, the interviewees refer to established symbols or icons (1). These references mean they produce separations most often between physically visible and/or long-term limitations on the one hand, and psychological phenomena on the other. Most of the time, these psychological phenomena are seen as impairments, not disability, and framed as a temporary issue, a solvable challenge for the individual. Also, impairment is separated from disability. By referring to iconic figures and symbols, the interviewees try to establish common ground with the interviewer when speaking about disability. Referring to figures which are well-established and consolidated by and in society it seems easier to speak about disability, to hide personal opinions behind these figures, and to speak less about own behaviours beside established norms and figures. Those tensions interviewed persons experience while navigating between an established, "common" ground of disability, their own perspectives and the sensitivity to talk about disability could be seen in figurations with symbols and their neces-

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[10] The codes refer to the numbering for the anonymization of the transcript and to the line numbering.

[11] The performance of depicting all as being (more or less) disabled, the notion that we are all equal and, thus, are all impaired in one way or another, seems to contradict the legitimisations of disability. Within my dissertation analysis comparing interviews from five different European universities, I labelled this as the "discourse for all" where disabled and non-disabled persons are equalised. The discursive strategy is to de-specialize one group (disabled students) and equate them to the others in order to get support or extra help (non-disabled students) for example. More on this discourse strategy will be described in my dissertation.

sity of establishing their own manner of speaking, their own language to talk about disability. But by (re)using those figures, their power and their hegemonic status is continued or re-established and consolidated, becoming (more) powerful. Which leads to the performative aspect (2).

By (re)using those established figures, their normativity aspect becomes relevant. Due to this normativity, the individual perspective on students disappears while a kind of general template to speak about those "to be disabled" addressed students is (re-)established. This means that those generalisations provide a way of seeing and speaking about students that "fulfil" these figures and symbols. But at the same time, other students that "lack" these normative symbols are left out. This means an exclusive area of speaking and thinking about how they see those students is established. Even if the statements in the interviews describe this in interpersonal relationship "templates", a normative agenda gets established. By doing so, and interdependent process can be reconstructed: the power of medical perspectives remains and shows in those outspoken beliefs about students with disabilities and, vice versa, performs and prefigurates the way of speaking about them.

Another interesting aspect, time (3), is established through the interviewees' line of argument. Depending on the duration of certain limitations, they are categorised as disability if they are long-term limitations, or as impairments, which are framed as temporary or transient. Two major issues emerge from this area of speaking: First, the link between time and disability/impairment refers to administration and its categorisations and instruments to certify disability. This means such processes of speaking reconstruct the administrative aspect of disability, the need to administrate disability, whether in higher education or in other areas of education or politics. Secondly, it refers to the role of science—its involvement in producing and consolidating disability. While the "concept" of impairment is introduced through the interviewer, the interviewees try to take up this information, using this concept or integrating it into their way of speaking about disability. This means they try to fulfil the requirements of a different language used in science while using the time category to solve this challenge. So, by forcing the interviewees to "use" this "concept" of impairment and position themselves towards it, the involvement of science in consolidating and re-establishing the medicine model becomes visible.

Of all four areas, the perpetuation of the medicine model (4) seems most salient. It appears impossible for any of the participants to think "outside the box". By using established symbols and icons, through the performative effect of these figures, and by trying to use "other" words and concepts and link them to a time concept, the medicine model is or gets established, consolidated and reified.

6. Conclusions

The utilization of the ELT model (DePoy & Gilson, 2004, 2010) seems an appropriate way to identify and reconstruct strategies to perform disability. As shown in the short description and explanation with three interview statements, the concept makes it possible to reconstruct observed and reported descriptions that are used to explain processes to legitimize disability. The interviewees refer to medical or constructed explanations. These medical references specifically consolidate and reify the medicine model of disability.

As a first conclusion, it can be stated that these four main areas have in common that they refer to a low visibility or narrative embeddedness of the social (or sociocultural) model within (narrated) social practices in higher education. The medicine model seems to be the perpetual, consolidating and reifying narrative framework shaping the interviewees' beliefs. There are variations and shifts of reconstructable concepts of disability in the narrative processes of description, explanation and, finally, (addressed) legitimatisations. But, first, all concepts refer to the subject as being responsible for being addressed for—and being the addresser of—disability, none of the concepts addresses any kind of functional system within higher education or the educational system or society in general and, finally, most of the narrations do not refer to the person speaking as a subject of interaction in the fields of higher education and studying/students with disabilities. All relevant items addressed, variables or examples put students with impairments at the centre.

With all these descriptions and reconstructions of the social negotiation for disability it becomes clear that the majority of employees describe disability with medical and psychological characteristics and problems and thus support arguments that disability is individual, naturally adherent. It seems that the changes around the term disability, which have been pointed out, found only a marginal space in university speaking.

But an analysis of the whole sample of interviews is needed in order to verify or further develop the four major areas identified in our study and to develop a theoretical map of the disability concepts of higher education teachers. It would be important to compare these analyses and interpretations with the other EADHE project partners and their interview data and to identify similarities and differences. It also seems necessary to interview employees of universities that identify themselves as "persons without any experience in supporting students with impairments" and, more importantly, students with or without impairments about "your definition, your personal understanding, of impairments". And last but not least, the involvement and entanglements of science and scientists need to be put under scrutiny. Their way of preparing the "space for speaking about disability" is important to think about. The question is "why" and "how" teachers are speaking in the way they speak.

A first idea is that they are reusing governance frameworks of administration, management and evaluation in higher education.

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Conflict of Interests

The author declares no conflict of interests.

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About the Author

Robert Aust holds a state exam in Teacher Education and is Research Assistant at the University Leipzig, currently at the Equal Opportunity Office. He is a PhD candidate at the Luxemburg University and Humboldt-University of Berlin and holds a scholarship from the Heinrich-Böll Stiftung. His research interests are discourse research and analysis, disability studies and comparative education sciences, along with interests in higher education research, media literacy, especially computer and video games, and youth culture.

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Article

Learning Experiences of Students Who Are Hard of Hearing in Higher Education: Case Study of a South African University

Diane Bell [1,]* and Estelle Swart [2]

[1] Business School, Stellenbosch University, 7602 Stellenbosch, South Africa; E-Mail: diane.bell@usb-ed.com
[2] Educational Psychology, Stellenbosch University, 7602 Stellenbosch, South Africa; E-Mail: estelle@sun.ac.za

* Corresponding author

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Abstract
Students who are hard of hearing (HOH) are being granted access to university increasingly, yet they remain significantly under-represented and under-supported, often resulting in poor academic outcomes with elevated levels of attrition. This situation places a growing obligation on universities to improve the support provided to these students in order to have a positive influence on their overall academic experience and eventual economic independence. This trend is relevant to South Africa, where Higher Education Institutions (HEIs) are accepting and registering students with a hearing loss but are not providing adequate academic support and inclusive curricula. Furthermore, in South Africa, almost no research has been conducted concerning students who are HOH in higher education regarding their teaching and learning needs or the coping strategies which they use to survive academically. However, what is known is that, of those HOH students who do enter higher education, many do not graduate successfully (up to 75%) and, of those that do graduate, many continue to be excluded from professions. The aims of this article were to report on the teaching and learning experiences of students who are HOH at a South African university, who prefer to make use of spoken language, to share the daily barriers with which they are faced, and to provide recommendations for teaching and learning, as well as curricula transformation. This study adds to the existing body of knowledge on this topic in South Africa and could be relevant in similar contexts.

Keywords
deaf; disability; hard of hearing; higher education; inclusive curricula; hearing impairment; South Africa; teaching; university

Issue
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1. Introduction

Students who are hard of hearing (HOH)[1] are increasingly being granted access to university in both developed and developing countries, yet they remain significantly under-represented and under-supported in higher education, often resulting in poor academic outcomes with high levels of attrition (low persistence) (Rawlings, Karchmer, DeCaro, & Allen, 1991; Stinson & Walter, 1997). This situation places a growing obligation on uni-

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[1] Terminology in deaf education is often derived from two paradigms. Firstly, the socio-cultural-linguistic view which associates deaf people with sign language and a culture. The second paradigm is characterised by the medical-audiology perspective, which encompasses ear and hearing health, diagnostics, rehabilitation and auditory assistive technology (Lomas, Andrews, & Shaw, 2011). These two paradigms often influence the identity of learners with hearing loss. In this article, which falls within the latter paradigm, the term has been used to refer to people who present with varying degrees of hearing loss and who choose to make use of spoken language in conjunction with auditory assistive technology.

versities to improve the overall teaching and learning support provided for these students in order to have a positive influence on their overall academic experience and eventual economic independence. This is of relevance in South Africa, where Higher Education Institutions (HEIs) are accepting and registering students with a mild, moderate, severe or profound hearing loss, but are failing to provide the necessary academic support, and accessible and inclusive curricula (Department of Higher Education and Training [DHET], 2018; Foundation of Tertiary Institutes of the Northern Metropolis [FOTIM], 2011).

Hearing loss is the fourth highest cause of disability globally. Disabling hearing loss can be defined as a loss greater than 40 dB in adults and 30 dB in children (World Health Organization [WHO], 2018). According to the WHO, it is estimated that there are currently 466 million people with a 'disabling' hearing loss globally, projected to be 630 million by 2030. Globally, hearing loss is also the most common congenital anomaly found in newborns, occurring in approximately two to four infants per 1000 (Delaney, 2015). Of the 466 million people worldwide who have some form of hearing loss, two thirds live in low- and middle-income countries (WHO, 2018). In South Africa people with disabilities make up 7.5% of the total population (Statistics South Africa, 2011). The data reveal that 0.1% of the population 'cannot hear at all', 0.5% experiences 'a lot of difficulty', 2.9% experiences 'some difficulty' and the balance, 96.4%, has 'no difficulty' in hearing. These figures show clearly that people with hearing loss make up the largest, single disability grouping in the country. Approximately 16 to 17 babies are born every day in South Africa with a hearing loss and many of them remain undiagnosed and untreated (Swanepoel, Storbeck, & Friedland, 2009).

The 2015–2016 figures for the global prevalence rate of students with disabilities from the Higher Education Statistical Agency (HESA, 2017) showed that, in the United Kingdom, 11.7% of registered students, at all levels of study, have some form of disability. Of this overall figure, 2.33% disclosed being Deaf or HOH (HESA, 2017). In Australia, the number of students with disabilities has also increased annually (Brett, 2010) with an overall participation rate of 4.3% in 2013, with students with a hearing loss comprising approximately 10% of disability disclosures (DET, 2013). From the available data, it is thus evident that, despite increasing participation rates, students with disabilities, including students who are Deaf or HOH, are still under-represented in higher education, not only in developing countries such as South Africa, but also in the developed world. This is a matter for concern since participation in higher education should result in access to better-paid occupations and professions (Branine, 2015; Ndlovu & Walton, 2016). Furthermore, according to Richardson (2001), the low numbers of students with hearing loss (Deaf and HOH) in higher education affects both the individual as there is a personal cost and, indirectly, the economy.

Globally, literature concerning how Deaf and HOH students experience higher education is limited (Schroedel, Watson, & Ashmore, 2003), with much of the existing research focusing on children and not considering the implication for their capabilities as adults (Richardson, MacLeod-Gallinger, McKee, & Long, 2000). A body of knowledge about the characteristics of obstacles faced exists but much less is known about potential solutions to the problem or the effectiveness of support services such as note-taking and real-time captioning for Deaf students (Lang, 2002; Stinson, Elliot, & Kelly, 2017). However, what is known is that, many of those students who do enter higher education, do not graduate successfully and many of those who do graduate, continue to be excluded from professions, especially when the high demands of theory and practice in preparation for specific professions pose particular challenges (Ndlovu & Walton, 2016). According to Rawlings, Karchmer, DeCaro and Allen (1991), up to 75% of Deaf and HOH students do not graduate from post-secondary educational institutions.

These global trends are also relevant in South Africa where HEIs are accepting and registering students with mild, moderate, severe or profound hearing loss, but are failing to provide the necessary academic support, and accessible and inclusive curricula (Department of Education–South Africa [DOE–SA], 1997, 1998; DHET, 2018; FOTIM, 2011). Generally, there is a lack of research on Deaf students in tertiary institutions in South Africa (Moloi & Motaung, 2014). Similarly, research concerning students who are HOH and who make use of spoken language is extremely limited so very little is known about their educational experiences and/or the teaching and learning support provided to them.

In South Africa, almost no research has been conducted regarding the teaching and learning needs of HOH students who are in higher education or the coping strategies they employ in order to survive academically (FOTIM, 2011). The studies that have been undertaken are mostly focused on training teachers of the Deaf, early hearing detection and intervention, development of Deaf identity, Sign Language and Deaf adults' views on Deaf Education in South Africa (Storbeck, 1998).

After two decades of democracy, university enrolments in South Africa have increased radically, but racial and other discrepancies remain (DHET, 2013, 2018). The South African Bill of Human Rights is the cornerstone in the Constitution of the Republic of South Africa of 1996 (Republic of South Africa [RSA], 1996, act 108). The Constitution states clearly that: "Everyone is equal before the law and has the right to equal protection and benefit of the law. Equality includes the full and equal enjoyment of all rights and freedoms" (RSA, 1996, article 9). The Constitution protects and supports the principles of human rights that inform all legislation, regulations and policies developed since 1996. Therefore, higher education policies spell out clearly the need to redress historical inequalities, transform the higher education system to serve a new social order better, improve the quality of life for all citizens and free their potential, respond to new realities and opportunities as well as increase university participation rates through the ‘massification’ of higher education (DHET, 2013; DOE–SA, 2001a; RSA, 1996). Access is almost universal today, but there is still a need to create equity, i.e., where people with disabilities can participate fully, feel that they fully belong and are set up for success.

Clearer norms and standards for the inclusion and success of students and staff with disabilities in the post-school sector were only given recently in the form of the White Paper on Post-School Education and Training (DHET, 2013) and, more specifically, the Strategic Policy Framework on Disability for the Post-School Education and Training System (DHET, 2018). The DHET’s approach to disability and education was informed by landmark, international treaties and protocols ratified by South Africa, including the Universal Declaration of Human Rights (United Nations [UN], 1948), the United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol to the Convention (UN, 2006), the United Nations 2030 Agenda for Sustainable Development (UN, 2015), and the Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Persons with Disabilities in Africa (African Commission on Human and People’s Rights, 2016). Furthermore, relevant South African legislation, policy and regulations were developed for education and disability, including the White Paper on Integrated National Disability Strategy (INDS) (Office of the Deputy President, 1997), the reworked INDS now called the White Paper on the Rights of People with Disabilities (Department of Social Development, 2015), the National Plan for Higher Education (DOE–SA, 2001b), and the Education White Paper 6 on Special Education: Building an Inclusive Education and Training System (DOE–SA, 2001a).

With regards to teaching and learning, the Strategic Policy Framework on Disability for the Post-School Education and Training System states that:

> Teaching and learning practices as well as the pedagogical design of curricula should reflect the context of social inclusion in institutions. This Strategic Policy Framework on Disability calls for critical engagement and improvement of current teaching and learning practices as well as pedagogical design of curricula in the context of inclusion of people with disabilities. (DHET, 2018, p. 57)

The infrastructure and support for teaching and learning should be based on universal design principles. In the higher education environment in South Africa, statistics regarding the numbers of university students who have disclosed disabilities, and more specifically hearing loss, are not readily available owing to factors such as differing definitions of disability, misinterpretation of disability codes on university application forms and stigma associated with disclosure of a disability (Bell, 2013). Students often elect not to disclose their disability status, as their self-identity is that of a ‘non-disabled’ person and they see no social benefit to be gained from being identified as disabled (Mutanga, 2013). However, a study conducted by the FOTIM (2011), involving 15 South African universities, reported the following statistics concerning students with disabilities:

- The proportion of students with disabilities as a percentage of the total student population was less than 1%;
- Disability units support between 21 and 400 students per year on average; and
- Very few disability units provide support services for students who are HOH and even less so for Deaf students who make use of Sign Language.

In 2012, the National Student Financial Aid Scheme (NSFAS), which funds needy but capable students in higher learning, allocated R45.5 million in bursaries to 1,368 students with disabilities. This was increased to R69.9 million in 2014, benefiting 1,383 students as from 12 February 2015. Ndlovu and Walton (2016) purport that this funding might not be adequate for studying professional degrees in higher learning with limited extended support being provided to students with disabilities during their fieldwork. Furthermore, according to the Higher Education Management Information System (HEMIS) data, the number of enrolled students with disabilities increased from 5,856 in 2011 to 7,110 in 2013 and, over the period of 2010 to 2015, the increase was from 5,357 to 7,379 (DHET, 2018). It is thus clear that the number of students with disabilities accessing higher learning is increasing every year. HEMIS (2010) data obtained from the DHET for the period between 2003 and 2010 indicated that the number of students with hearing impairment registered at HEIs in South Africa increased from only 155 in 2003 to 326 in 2010. Without current statistics being available in South Africa, it can be assumed from the aforementioned figures that the increase in the overall number of students with disabilities attending university would include students who might be Deaf or HOH.

The aims of this article were to report on the teaching and learning experiences of HOH students who prefer to make use of spoken language to share the daily barriers with which they are faced, and to provide recommendations for teaching and learning, as well as curricula transformation.

The following sections are focused on a review of the literature and the empirical study. The background theory emphasizes: 1) the conceptualisation of inclusive education in South Africa and its effectiveness; 2) inclusion within higher education; 3) the potential effect of hearing loss on learning; and 4) types of support services for HOH students; and the barriers experienced by these students.

2. Review of the Literature

2.1. Conceptualising Inclusive Education

Inclusive education is generally viewed as an 'overall principle that should guide all educational policies and practices; building on the premise that education is a basic human right and the foundation for a more equal and just society' (UNESCO, 2009, p. 8). Being 'inclusive', as argued by Thomas and O'Hanlon (2004, p. xi), involves more than simple integration or mainstreaming as it is deeply entrenched in a wide range of social, political, psychological and educational contexts. The philosophy of inclusion is concerned with creating and developing a system in which both equity and diversity are the goals and are truly welcomed. However, inclusion can be interpreted very differently depending on the specific context (Yssel, Engelbrecht, Oswald, Eloff, & Swart, 2007).

In the South African educational system, inclusive education is defined primarily as a 'learning environment that promotes full personal, academic and professional development of all learners irrespective of race, class, gender, disability, religion, culture, sexual preference, learning style or language' (DOE–SA, 2001a, p. 16). The decision by the government to follow international trends regarding inclusion, i.e., to embark on a process to provide a more just, unified and equitable system for all, was a critical step for education in South Africa. However, inclusion cannot be achieved without the provision of relevant and adequate resources and support to ensure effective implementation across all levels of education (Swart & Pettipher, 2018). As argued by Howell and Lazarus (2003), change to accommodate students with disabilities needs to take place at a discursive level, as well as at the level of institutional organisation and practice.

Various researchers have investigated the influence and effectiveness of inclusive practices on students' educational experiences. In their review of the literature on inclusion, Salend and Duhaney (1999) concluded that the benefits of inclusion for students with disabilities might include gains in academic achievement, increased peer acceptance and richer friendship networks, higher self-esteem, avoidance of stigma, and possible lifetime benefits such as higher salaries and independent living. Inclusive education has the potential to bring about equalisation of opportunity with regards to education and social life, particularly in countries where it has been well organised (Abosi & Koay, 2008, p. 2). However, in South Africa, this situation of equalisation of opportunity is yet to be realised fully with the United Nations Convention on the Rights of Persons with Disabilities (UN, 2006) not having been properly domesticated yet (Human Rights Watch, 2015). Evidence clearly suggests that, although policy frameworks promote inclusive education within the ambit of 'education for all', a different reality of 'exclusive' education is revealed in practice (Armstrong, 2003; Booth, 2000). A recent monitoring report of the Convention on the Rights of the Child acknowledged that 'the challenges faced by children with disabilities in realizing their right to education remain profound' and that they are 'one of the most marginalized and excluded groups in respect of education' (UNICEF, 2013). The Human Rights Watch (2015) also revealed South Africa's dismal failure to provide inclusive education for children with disabilities.

2.2. Inclusion within Higher Education

Inclusive education is both a global imperative (UN, 2006) and a national priority in South Africa, which has a strong legislative framework (DHET, 2013; DOE–SA, 2001a) that provides guiding principles and parameters for implementation. Despite this progressive legislative and policy framework, students with disabilities, especially in higher education, continue to face a multitude of barriers—physical, social and attitudinal (FOTIM, 2011; Ndlovu & Walton, 2016). Presenters at the 2009 African Network on Evidence-to-Action in Disability (AfriNEAD, 2009) conference highlighted infrastructural, institutional and environmental barriers faced by students with disabilities in higher education, including 'inaccessible environments, lack of reasonable accommodation, negative attitudes, discriminatory application and admission procedures and lack of disability policies and resources that unnecessarily disadvantage disabled students' (Lyner-Cleophas, Swart, & Bell, 2009). Although there has been a considerable increase in graduates with disabilities in the system (984 graduates in 2011 to 1,294 in 2013), the attrition rate is still significantly high (SA News, 2015). Furthermore, evidence clearly shows that very few people with disabilities acquire professional degrees and, even those that do, are often excluded from professional jobs (Ndlovu & Walton, 2016).

In essence, it is clear that, despite the progressive legislative framework in South Africa and the noble commitment to right the wrongs of the past, students with disabilities in higher education still remain marginalised and insufficiently supported. Those who are fortunate enough to gain access to higher education still face many barriers which not only impinge on their human rights but also affect the quality of their experience of education, which has a direct effect on their educational outcomes.

2.3. Potential Effect of Hearing Loss on Learning

The effect of the loss of functional hearing depends primarily on the type, extent and timing of the hearing loss. According to Tucci, Merson and Wilson (2009), mild to moderate hearing loss in children might lead to delays in the development of spoken language, whilst profound hearing loss could lead to significant delays in speech and language development. These delays often result in individuals with a hearing loss who prefer spoken language, being unable to acquire adequate oral communication skills. Without audiological and speech interventions, HOH children might never develop speech and language or any ability to communicate effectively. Moreover, a significant hearing loss might inhibit the social interaction of students and, if they communicate using speech, articulation problems sometimes make it difficult to understand them (Lewis & Doorlag, 1999). Some HOH students in higher education might exhibit some or all of the following traits (Sheffield Hallam University [SHU], n.d.):

- Difficulty producing discussion elements of an assignment, particularly where these depend on abstract thinking rather than practical observation;
- Taking longer to read, understand and absorb information;
- Relying heavily on dictionaries, references and tutors to check their understanding; and
- Often having low self-confidence regarding their academic work.

The fact that these consequences of the hearing loss are completely independent of the intellectual ability or potential of a student who is HOH has been highlighted by Burke (2010). Luckner and Bowen (2006) assert that even though students with hearing disabilities are able to master the academic content, their ability to demonstrate academic performance is compromised because of delays in developing communication, language, reading and writing skills.

2.4. Types of (Internal) Support Services for HOH Students in Higher Education

At university level, the responsibility to request support services lies with the student (Boutin, 2008; Gardner, Barr, & Lachs, 2001). However, when a student with an identified disability is admitted, it is the university's responsibility to provide reasonable accommodations that will provide equity of access to the physical as well as the teaching and learning environment. Support services available to HOH students vary greatly between universities in terms of quality of delivery and availability. Cawthon, Nichols and Collier (2009) maintain that the services that address the communication needs of HOH students might be an important predictor of these students' success at enrolling for, and completing, a degree. The types of support services available to HOH students could include: manual note-taking by human note-takers, academic tutors, instructional and curricula adaptations, language modification (e.g., of assessments to simplify the language), extra time, induction loop systems, real-time captioning and assistive devices, for example, personal FM-systems and vibrating alert devices.

2.5. Barriers Experienced by HOH Students in Higher Education

Students with varying degrees of hearing loss face a multitude of barriers in higher education. In the researchers' opinion, there could be many reasons why these barriers exist, such as: lack of support; lack of awareness of the accommodation needs of these students; the 'invisibility' and uniqueness of their hearing loss and thus complex support needs; teaching staff ignoring calls to attend disability-related, professional development courses; attitudinal barriers of faculty members; and lack of financial and human resources. This array of factors could make it unattractive to universities to admit students who are HOH, resulting in under-representation in higher education. The subsequent barriers, as reported by Howell (2006), have a profound and sustained effect on the psycho-social well-being and functioning of the students. In general, students with disabilities, who have managed to attend HEIs, argue that the energy, emotional resources and levels of stress involved in dealing with the wide range of barriers they are confronted with undermine them and place them at an ongoing disadvantage in relation to other students. If they are unable to deal with these issues, the prevailing attitudes and prejudices towards their abilities are reinforced. Reindal (1995) argues that students with sensory disabilities encounter so many practical difficulties that their ability to study can be undermined, which often results in attrition or lack of persistence in higher education.

2.6. Attrition, Persistence and Academic Outcomes

As previously mentioned, the participation figures of students with a hearing loss in higher education are very low and, of those students who do enter higher education, many do not graduate successfully owing to a variety of factors such as lack of support. The gap in academic achievement between students who hear and those with a hearing loss is often reported (Marschark, 2006; Moores, 2003).

Attrition refers to the gradual decline in the number of registered students (Tinto, 1987). The highest rate of attrition commonly occurs during the first year of study at university. The same truth applies to students who are HOH. According to Allen (1986), almost 75% of students with hearing loss do not graduate from post-secondary educational institutions (including colleges and universities). In a later study, Stinson and Walter (1997) also found that the two- and four-year college retention rates for students with hearing loss were considerably lower than those for students who can hear.

Tinto (1987) explains that persistence means to remain in college until graduating whether multiple institutions of higher education are attended or not and, in a later study, he found that persistence is particularly important during the first year of college since most attrition occurs at this time (Tinto, 1998). In post-secondary institutions in the United States, according to a study by Albertini, Kelly and Matchett (2012), only approximately 35% of deaf (Deaf and HOH) students graduate from two-year programmes, compared with approximately 40% of their hearing peers; and according to Marschark, Lang and Albertini (2002), approximately 30% of Deaf students graduate from four-year programmes compared with approximately 70% of their hearing peers.

Tinto (1987) argues that it is important to monitor the progress of deaf and HOH students, particularly during the most vulnerable first 10 weeks of study since, generally, attrition is highest during this period (Boutin, 2008). A central aspect of Boutin's persistence model is that students need to be integrated into both the academic as well as the social systems of the university (Boutin, 2008). Research conducted with degree-level students showed that Deaf students do not feel as much a part of the 'university family' as their hearing peers, which could influence their educational success (Foster, Long, & Snell, 1999).

In the next section, the context of this case study and participants' details are provided and the method used is described.

3. Method, Participants and Context

A qualitative approach was used, and interviews were conducted with students who were HOH and were attending the university in South Africa at which this case study was carried out. The case study was descriptive in nature, adopting a constructivist paradigm to explore and describe the lived and subjective learning experiences shared by the students studying at a 'hearing' university. Using both the participants' and the researchers' understanding, the participants' social worlds were explored (Ritchie & Lewis, 2003). The main research goal of this study was to explore and describe the academic teaching and learning experiences of students with hearing impairments, using the oral method of communication, at the university participating in the study.

The university involved was chosen because, at the time of the study, it had the highest enrolment of students who were HOH and thus it was presumed to have accrued experience in supporting these students. Only students with a hearing loss who preferred to use spoken language were selected for this study as they were given access to HEIs in South Africa more readily than Deaf students at the time. More recently Deaf students have been admitted and provided with Sign Language interpreters.

3.1. The Case Study Institution

This research was undertaken at one of the public universities in South Africa. The student body in 2014 comprised approximately 29,000 students with an equal distribution of male and female students. The university had a disability unit, a policy for students with disabilities, which subscribed to the social model of disability (Oliver, 2004) and defined the term 'disability' as referring to 'a verifiable physical, non-visible and/or psychological limitation/s which negatively affects [a student's] daily activities in a specific way.[2] Although the study corps was relatively diverse in terms of ethnicity, culture and language, only 1.7% of the total student population disclosed having a disability on their application forms.

3.2. Selecting and Describing the Participants

Typical of case study methodology, a purposeful sampling procedure was used (Silverman, 2010). The criteria for inclusion of students in the study were that they:

- Had to have a hearing loss, regardless of type, degree or age of onset;
- Needed to be registered students at the case study university; and
- Had to make use of spoken language as their primary mode of communication, i.e., not Sign Language.

Students who had disclosed their hearing loss to the disability unit were invited by email to participate in the study. Seven out of a possible thirteen students responded positively as shown in Table 1.

3.3. Data Generation Methods

Qualitative data were generated by conducting individual, in-depth interviews, lasting approximately 1.5 hours each, having received prior consent. Preceding each interview, the participants were requested to complete a biographical questionnaire which provided background data (see Table 1). All the interviews were held in a quiet environment to facilitate barrier-free communication, were conducted in English and were digitally recorded. A printed copy of the interview guide was provided to the participants, so they could read the questions as well as listen to them being posed.

3.4. Data Analysis and Ethical Considerations

ATLAS.ti (version 6) was used to code the transcribed interviews, to develop categories and themes and to build various network views (Charmaz, 2006). The grounded theory coding process involving the initial phase, focused/selective phase and the theoretical coding phase, as explained by Charmaz (2006), was used. The measures used to ensure trustworthiness of the data were crystallisation (Richardson, 2000), member checks (Holloway, 1997), peer review (Merriam & Tisdell, 2016) and an audit trail (Silverman, 2010). The following ethical arrangements were taken into consideration in this study: informed consent, anonymity and confidentiality, and protecting the participants from any harm.

4. Findings and Discussion

The results have been presented in terms of four key themes:

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[2] No reference is provided to protect the anonymity of the institution.

Table 1. Biographical data for each student participant.

Participant Pseudonyms	Age	Gender	Year of study	Onset	Degree of hearing impairment	Audiological devices	First language	Ethnicity
Barry	23	Male	3rd	Birth (L & R)	Profound implant (R)	Cochlear	English	White
Merle	21	Female	3rd	Birth	Moderate (L & R)	None	Afrikaans	White
Paul	24	Male	3rd	Birth	Profound (R)	BTE* hearing aid (R)	Afrikaans	White
Astrid	24 6	Female	4th R = 8 yr	L = 4 yr (L & R)	Profound implant (R)	Cochlear	English	White
Colin	20	Male	1st	Birth	Moderate (L & R)	BTE hearing aid (R)	Afrikaans	White
Stewart	20	Male	1st	Birth	Severe (L & R)	BA*** hearing aid (L & R)	Afrikaans	White
Noelene	19	Female	1st	L = 2 yr R = 10 yr	Profound (L & R)	Cochlear implant (R)	English	White

Notes: *L = left and R = right; **Behind-the-ear; ***Bone-anchored

4.1. Inclusive Teaching Practices and Curriculum Accessibility

Teaching practices at the university were not inclusive and those practices that students with a hearing loss found useful, such as the provision of electronic notes and the use of electronic calendars were not deliberate attempts to be inclusive but were typical for post-modern universities in a technological age. The use of microphones was also not specifically intended to accommodate students who were HOH but was rather an attempt to enhance audibility for large classes. One useful practice was the provision of preferential seating in large classrooms. Unfortunately, without enforcement by the lecturer, these rows of seats would be occupied quickly and be unavailable to those who needed to be seated in the front to be able to hear and lip-read. One student shared her negative experiences in this regard:

> There is space, like the first row, for students who have disabilities, but many times other students go sit there as well....Lecturers should also say to the other students that they shouldn't sit there as this is reserved for the students with disabilities. (Merle)

It was also found that curricula were largely inflexible with little transformation having taken place at the university in order to accommodate HOH students. Existing curricula did not adhere to the principles of accessibility, flexibility or universal learning design and thus were not responsive to the needs of the students. Two students shared their experiences:

> Well, the real barrier is communication and to overcome it I usually use my fellow students....They really help....When a lecturer is explaining something it is frustrating because you can't always hear so I really do rely on the PowerPoint notes that they have on WebCT [online learning management system] as it explains the stuff to you. It is just frustrating because it is not like you can ask for the PowerPoint notes. If I could have heard what he said, maybe I could have seen that I don't understand and ask him, but I don't know what to ask because I can't hear what he is saying. (Colin)

> Yes, some of the lecturer's notes are hard to find because they are not all on WebCT. They have their own website somewhere else, so you have to google search for it....[It's] very frustrating and I can't hear the lecturer, so that is also frustrating. (Noelene)

It was noted that similar findings regarding inaccessible teaching practices and curricula have been reported since 1998 at universities in South Africa yet the practices continue to prevail (Council on Higher Education [CHE], 2005; DHET, 2018; DOE–SA, 2005; FOTIM, 2011; Howell, 2006, p. 168). Based on their research, Cummings, Dyson and Millward (2003) reported that the focus of inclusive education was on organisational characteristics instead of important issues such as pedagogy, curriculum and educational outcomes. The findings from the present study were similar, indicating a need for real change. In research by McLean, Heagney and Gardner (2003), it was found that the lack of curriculum flexibility and the barriers to curriculum access developed because of the ways in which learning support services for students with disabilities had been conceptualised. Similarly, at the case study university, the conceptualisation of support was still based on the deficit model of disability (Oliver, 1989), which had an effect on student learning.

4.2. Reasonable Academic Adjustments

Reasonable academic adjustments refer to strategies that minimise or eliminate the effect of a disability, enabling the individual to gain access to, and have equal opportunity to participate in, the university's courses, programmes, assessments, services and activities (Brinckerhoff, Shaw, & McGuire, 1992; UN, 2006). Limited, reasonable academic adjustments had been made for students who were HOH at the university. However, only one of the participants had requested and received permission to make use of additional time for assessments: 'For the tests/exam I have extra time. I get 10 minutes per hour' (Paul). Generally, the participants were unaware of any academic adjustments (reasonable accommodations) available to them and either they felt that it was not necessary or that it would be an unfair advantage for them or they did not want to be subjected to the application procedure and be required to declare their disability. Colin shared his lack of awareness by stating: 'Not at all; I never even knew there was a support system for the students'.

4.3. Learning Support

At the time of this research, support services offered by the case study university to students who were HOH were largely inadequate. This included both human and technical support. Participants were mostly unaware of the availability of support services and thus the uptake of learning support was low. The only available learning support included academic tutoring, mentoring, extra time for assessments and the use of peers for taking notes or sharing their notes with the HOH students. In a recent study by Stinson et al. (2017) it was found that students rated the printed or electronic file text (part of the speech-to-text service), which they used for study after class, as being more useful than notes from a note taker. It was also important to note that both tutoring and mentoring were available to all university students.

One participant who made use of the note-taking service did not find it helpful as he struggled to interpret the notes taken, as they reflected someone else's filtering of the information based on their prior knowledge and context. Another student shared his feelings of discomfort having to rely on someone else for support in class:

> In the Maths class the note taker will take the notes and I will just sit and try to listen to what the professor is saying….I feel a bit uncomfortable to rely on somebody else, because you want to do everything by yourself. (Barry)

There was a need for increased learning support at the case study university, such as academic one-to-one tutoring, as the teaching venues made learning inaccessible to students who were HOH owing to the unavailability of audio induction loop systems and other, well-functioning audio equipment such as public address (PA) systems using high-quality speakers or microphones. The learning support that was most urgently required, especially for students with a profound hearing loss, was real-time speech-to-text captioning.

4.4. Barriers to Learning

All of the participants experienced a significant number of barriers related to learning. These barriers were associated mostly with communication, teaching practices and assessment. The students' experiences varied, depending on the severity and age of onset of their hearing loss. The major barriers faced by HOH students related specifically to the audibility and accessibility of their primary (oral) mode of communication. Examples of typical barriers shared by the participants were:

- Inability to hear or lip-read the lecturer, especially when switching between two languages without warning;
- Difficulty following class discussions, high levels of background noise and poor acoustics, especially in large venues;
- Inaccessible teaching practices, such as the lecturer talking whilst writing on the board, and videos without subtitles;
- Poor lighting when using a data/video projector as HOH students were not able to lip-read; and
- Lecturers not making use of audio equipment or the equipment being in a state of disrepair or not available at all.

Three students share their 'lived' experiences:

> [Following class discussions] If a student is sitting in front of me then it can be quite a problem because the sound is away from you and you are not able to lip-read…that is a problem. I can't always follow because some lecturers don't repeat the question, they just answer, and I don't know what was asked. (Paul)
>
> But sometimes I will ask them to speak, like, many lecturers don't like to use the microphone, but the class will ask them to use it, and they will be like, 'I will just do this [speak louder without the microphone]', but it doesn't really help, like, them standing in front or trying to talk louder…it doesn't help. It is very frustrating. (Merle)

Another participant expressed experiencing severe frustration when he could not hear during class because of a lecturer speaking indistinctly. This created a communication barrier, not only for him, but even for all the 'hearing' students in the class: 'The frustrating thing is that the lecturer doesn't really speak very clearly. My friends with normal hearing even struggle to hear the lecturer' (Colin).

It seemed that the common thread throughout this discussion was that students who were HOH were not aware of available learning support, albeit insufficient, which precluded them from accessing it. This, in turn, resulted in these students experiencing many barriers and having to devise their own personal coping strategies. At the time of the study, HOH students at the case study university faced many barriers. These barriers, including attitudinal, pedagogical, communication, assessment practices and environmental barriers have the potential to affect the students' educational experience and their academic attainment negatively.

5. Conclusion and Recommendations

The purpose of this study was to explore the learning experiences of HOH students at a South African university. Various exclusionary practices were identified, which resulted in these students facing significant barriers to learning. The barriers they shared were based on their lived experience. While some attempts had been made by the case study university to be more inclusive, these students were inadequately supported in terms of their unique learning and communication needs.

The participants made a number of recommendations regarding curriculum flexibility and transformation in order to reduce the learning barriers experienced:

- Lecturers should:
    - Learn and apply the principles of universal learning design in their curriculum design, chosen materials and delivery methods;
    - Attend staff development workshops to increase their knowledge and raise their awareness of how to provide adequate support for students who are HOH in their classes;
    - Ensure that they are aware of the needs of each individual student and his/her specific needs by collaborating with the disability support services;
    - Make glossaries of new and complex terminology available prior to it being taught in class and provide electronic copies of detailed notes well in advance to allow for prereading of materials;
    - Be available to meet with the students one-to-one, and their primary mode of general, 'out-of-class' communication should be by email;
    - Insist that the first one or two rows in a large venue be kept open for students with special communication needs, e.g., students who are HOH, and make use of specialised audio equipment;
    - Repeat questions asked and answered in class by other students and ensure that all audio-visual materials have subtitles.
- Interaction amongst Deaf or HOH peers should be encouraged as this might help with some of the issues raised, e.g., sharing of knowledge/notes, etc.;
- Support and access must be made available to all HOH or Deaf university students regardless of their communication preference;
- Any support provided should be tailored to address individualised needs;
- Large teaching venues should be fitted with good-quality, audio equipment which is well maintained;
- Additionally, as suggested by Chataika, McKenzie, Swart and Lyner-Cleophas (2012), a compulsory module on diversity, disability and inclusion should be implemented for every university student, and lecturers should be included, to produce future leaders and policy makers who are sensitive to disabilities.

While acknowledging that the university involved in the case study provided some support, it has been argued that this was insufficient to meet the real and unique needs of each student with hearing loss who preferred to use spoken language to communicate. It is therefore the researchers' contention that, unless strategies are put into place to support students who are HOH in higher education better, they will continue to experience significant barriers to learning that will have a potentially negative effect on their educational experience as well as their academic attainment. Upon accepting and registering students with disabilities, it is incumbent upon universities to provide adequate and appropriate support to ensure that these students have equitable access to learning and thus fair opportunity for educational success. A call to action is required for university administrators, lecturers and students to support and participate in awareness workshops.

This also implies that there is a need for cultural change towards understanding and support within universities for them to become truly inclusive for all.

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Conflict of Interests

The authors declare no conflict of interests.

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About the Authors

Diane Bell currently serves as the Director of the Carel du Toit Trust. In her previous positions she worked as a member of the Global Cooperation on Assistive Technology (GATE) team at the World Health Organization (WHO) in Geneva and served as the Academic Director at the University of Stellenbosch Business School Executive Development (USB-ED). She is a mother of a daughter born with a profound hearing impairment. Diane's doctoral thesis focused on students with hearing impairment in higher education and she has authored several journal articles and a book chapter on this topic. She also serves as a member of the Presidential Working Group on Disability in South Africa and currently consults for WHO in the area of assistive technology.

Estelle Swart is a Professor in the Department of Educational Psychology at Stellenbosch University, which she chaired for several years. She is a National Reseach Foundation rated researcher with an interest in disability in education, professional learning and support practices in inclusive education. Estelle is the co-editor of two books, *Addressing Barriers to Learning* (2016) and *Understanding Educational Psychology* (2018), and authored and co-authored chapters and articles in scholarly journals. She is a registered educational psychologist, was a member of the Health Professions Council of South Africa Board for Psychology and chaired of the Psychological Society of South Africa Division for Educational Psychology.

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Article

Mind the Gap Between Higher Education and the Labour Market for Students with a Disability in the Netherlands: A Research Agenda

Marjolein Büscher-Touwen [1,2,*], Marian de Groot [1,2] and Lineke van Hal [3]

[1] Expert Centre Handicap + Studie, 5211 AP s-Hertogenbosch, The Netherlands; E-Mails: marjolein.buscher@handicap-studie.nl (M. B.-T.), marian.degroot@handicap-studie.nl (M.d.G.)
[2] CINOP, 5211 AP s-Hertogenbosch, The Netherlands
[3] Verwey-Jonker Institute, 3512 HG Utrecht, The Netherlands; E-Mail: LvanHal@verwey-jonker.nl

* Corresponding author

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Abstract
The transition from higher education to the labour market is experienced as difficult by students with a disability. This gap between higher education and the labour market has tangible consequences for the participation of (young) people with a disability. Research shows that these students have a higher unemployment rate. This article addresses this gap by studying existing research data and by exploring experiences of students with a disability and other stakeholders as collected by the Dutch expert centre Handicap + Studie. We focus on the perspectives and responsibilities of the different parties involved: educational institutions, employers, municipalities, ministries and students with a disability. With this exercise, we want to contribute to putting this ‘gap’ and its stakeholders on the research agenda, arguing that more in-depth research on the transition from higher education to the labour market for students with a disability is needed. We will therefore conclude with themes that need to be researched in order to gain more knowledge for reducing the gap.

Keywords
disability; higher education; labour market transition; stakeholders; unemployment

Issue
This article is part of the issue “Students with Disabilities in Higher Education”, edited by Geert Van Hove (Ghent University, Belgium/VU Amsterdam, The Netherlands), Minne Bakker (VU Amsterdam, The Netherlands) and Alice Schippers (Disability Studies in the Netherlands/VU Amsterdam, The Netherlands).

1. Introduction

Work is an important way to participate in society, to be economically self-sufficient and to give one’s life a sense of purpose. However, participation in the labour market turns out to be more difficult if you have to deal with disabilities such as a chronic illness, physical disability, autism or Attention Deficit Hyperactivity Disorder (ADHD). This holds true even if you are young and have a good educational qualification (university, university of applied sciences). Indeed, highly educated young people with a disability experience obstacles in their transition from studying to employment. This has two consequences: on the one hand young people do not receive the opportunities they need, and on the other hand society takes measures that do not really contribute to a solution. How should we understand this gap between higher education and the labour market? And what should be done to bridge this gap? These are the questions we want to discuss. More specifically, we concentrate on setting a research agenda focussed on the transition from higher education to the labour market for young people with a disability aged 18 to 27.

2. Approach

This article is based on an explorative study of perspectives and experiences of different stakeholders involved in the transition from education to the labour market. The exploration is based on individual interviews and group discussions held by the Dutch expert centre Handicap + Studie. Participants were large municipalities (7); the Ministry of Education, Culture and Science (OCW); the Ministry of Social Affairs and Employment (SZW); educational institutions (10 universities, 15 universities of applied sciences); students and alumni with a disability (30); specialised intermediary agencies for young people with a disability (4); trade unions (2); National Think Tank 2017; politicians (5); and interest groups (5). From all interviews and group discussions, reports were made and shared with the informants.

The exploration started in 2014 with interviewing the Employee Insurance Agency (UWV), representatives of educational institutions, municipalities, specialised vocational rehabilitation agencies and employers. The goal of these conversations was to detect issues and bottlenecks regarding the transition from higher education to the labour market of students with disabilities. These issues were validated and further explored during group discussions in 2015 around the theme of internship and work of students with disabilities. In these well-visited meetings (135 participants), there was a shared recognition of bottlenecks. Subsequently, the exploration was deepened by interviewing labour unions, a group of students with disabilities and national ministries. In this process, bottlenecks were validated and insight grew in the (possible) roles and positions of various stakeholders.

In 2017 the reports of aforementioned meetings were thematically categorised within a project group, with experts on (higher) education and disability, quality of labour participation and sustainable employment. Categorisations were based on common types of bottlenecks and roles and responsibilities of stakeholders. The preliminary categorisation was presented to various stakeholders from which the educational institutions, alumni with a disability, student trade unions and labour unions confirmed the analyses of bottlenecks and stakeholder responsibilities. In 2018 new group discussions were held in order to explore changes in transitions issues, to deepen our understanding of existing bottlenecks and to explore possible solutions. In these meetings (3) the categorised bottlenecks were discussed and broadly recognised by the (150) participants.

Based on the aforementioned practical explorations, in this article we describe the roles of the various stakeholders, the categorisation of bottlenecks and relevant issues for further research. The roles and bottlenecks are illustrated by quotes from individual interviews and group discussions.

3. Dutch Context

Thirty percent of all students in Dutch higher education state that they themselves study with a disability, and 10% of all students experience obstacles as a result (Van den Broek, Muskens, & Winkels, 2013). At the same time, the employment rate of people with a disability in the Netherlands is twice as low as that of people without a disability (Statistics Netherlands [CBS], 2015, 2016). Recent figures from CBS on the Dutch labour market indicate that 15% of all employees feel slightly impeded in carrying out their work by a long-term illness, affliction or handicap and 3% feel strongly impeded in their work. However, employees aged 18 to 27, who are the focus of this article, feel less impeded by a disability than older employees aged 55 to 65. Women experience impediments more often than men and this difference is even more marked among younger employees (Van den Berg, Dirven, & Souren, 2018).

"The Europe 2020 strategy objective aims at reaching 75% employment rate in the European Union (EU) for people with a disability" (European Disability Forum, 2018). However, the employment rate of people with basic activity difficulties and/or longstanding health problems in the EU-28 was 47.3%, almost twenty percentage points below that of people without such difficulties. At country level, the highest gaps in employment rate were observed in the Netherlands (43% and 80% respectively) and Hungary (24% and 61%), with differences of more than thirty seven percentage points between the groups. This contrasts sharply with the situation in Luxembourg, where the smallest variation (two percentage points) was observed (Eurostat, 2011).

These figures show that the Netherlands, in comparison to other countries, is falling behind in terms of the employment rate of people with a disability and this is a cause for concern.

4. Patterns and Gaps in the Netherlands

There is currently not enough information available about the situation of more highly educated young people with a disability who are transitioning from higher education to the labour market. The first indications of difficult access to the labour market can already been seen during their studies. Some of the students with a disability, for instance, do not manage to find suitable internships. This is often due to two causes: 1) conversations with students and supervisors show that students often find it difficult to communicate their disability, for instance because they fear not being accepted for the internship; 2) furthermore, employers still struggle to see the person behind the disability, do not know how to respond to this issue and therefore offer only limited support. Various organisations that provide work-related support to people with a disability confirm this problem and aim to tackle it. In cases where completing an internship constitutes part of the final attainment level of the degree programme and it proves impossible to complete this component, this means that these students leave the programme without a degree certificate, which makes it difficult to find a job. Sometimes students manage to graduate without an internship or other work experience. Due to a limited ability to handle workloads, it is not always possible to combine work and studies. However, work experience is often an important element on the curriculum vitae (CV) presented to employers in order to have a better chance of a job.

In the Netherlands, the education process culminates in a degree certificate. After completion of the degree programme, the education system ceases to provide support. Once they have a degree certificate in their pocket, young people are left to their own devices. This includes those young people who require support in finding their niche in the labour market. Paradoxically enough, the fact that they stand alone seems to be related to the large number of involved parties who play a role regarding the education, work and income of young people with a disability: all of these parties work along separate tracks.

5. Stakeholders

Various parties are involved in the transition of young people with a disability from education to the labour market. The various parties and their roles and responsibilities are set out below, together with their perspectives on the issue.

5.1. Higher Education Institutions

The higher education institutions are responsible for their students until they have completed their degree programme with a degree certificate. Generally speaking, the educational institutions assume that students take steps towards and into the labour market independently. The institutions put their focus on a good education and on supplying qualified, independent and responsible students to a certain specialist field. This is revealed by conversations conducted by Handicap + Studie with the OCW and the experiences of professionals at the educational institutions. As a consequence, there is no structural attention given to preparing young people with a disability for the labour market and helping them make the transition.

5.2. Municipalities

The basic principle applied by the Dutch government is full participation: everyone takes part. This means that no person should be left behind, that people help each other, and support is offered to vulnerable people so that they can as much as possible participate in society as well. However, the municipalities that put this principle into practice are currently placing their main focus on youth unemployment among less well-educated young people with a disability and not, or less, on more highly educated young people with a disability. This is revealed by conversations with seven large municipalities. The alderman for economic affairs and education from Rotterdam stated: “We have to deal with scarce resources and our emphasis in policy is on young people without a basic qualification in the poor neighbourhoods”. A policy advisor from Eindhoven underlined this vision: “Our focus is on youth employment and especially on young people without a basic qualification”.

5.3. Ministries

The OCW states that the higher education system is responsible for a good education up to and including the degree certificate. Its policies devote little or no attention to preparing for and transitioning to the labour market. As the head of policy advisors in Higher Education expressed: “The transition to the labour market for students with a disability should have more attention. That is according to us the responsibility of the Ministry of Social Affairs and Employment”. In 2017, a number of young people’s organisations found that too many students feel insufficiently prepared for the labour market (ROA, 2017).

The SZW is responsible for employment, integration, reintegration and participation. Young people with a disability first need to be without work before a safety net comes into operation. These persons can then apply to the municipality for social benefit payments. The municipality must also help job seekers find work and prepare themselves accordingly. People who are expected never to be able to earn the minimum wage due to their illness or handicap are entitled to invalidity benefits. The Social Affairs and Employment Inspectorate has conducted research into the support offered by municipalities to young people with a work-limiting disability. One of the conclusions is that some of the young people are not on the radar of the municipalities. This principally involves young people who do not (yet) receive any benefit payments and young people who lose their job. A total of 6% of all municipalities state that they do not have a clear picture of this group (Social Affairs and Employment Inspectorate, 2016).

The Ministry of Health, Welfare and Sport is the umbrella ministry for disability policy and therefore also for the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This was ratified in the Netherlands in 2016 and states:

> States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. (United Nations [UN], 2016)

The UNCRPD is based on inclusion, personal autonomy and full participation. It requires organisations to think proactively about the inclusion of people with a disability so that they can participate in all areas of society and in all processes.

5.4. Employers

Some employers take on people with a disability and have a corresponding policy. They are required to carry out appropriate adjustments in line with the Equal Treatment of Disabled and Chronically Ill People Act. To provide some examples, many employers operate inclusive policies for employing and retaining people with a disability, such as Philips, Shell, ABN-AMRO, PWC and many companies in the small and medium enterprises (SME) sector. However, many employers remain reluctant to take on employees with a disability or state that they are unable to offer any suitable jobs (National Think Tank, 2017). For example: employers are afraid that young people from this target group, because of their vulnerable health, will fall out sooner by sickness and that they have to pay them for two years because of legislation. Employers also see practical barriers like difficulties in extra guidance. There is ignorance about how to get in contact with young people with work limitations. Moreover, employers are hindered by the procedures hassle (National Think Tank, 2017, p. 15). See also the paragraph on changed legislation and regulations in section 5.

5.5. Students with a Disability

In addition to the responsibilities of organisations, students with a disability also bear their own responsibility to prepare for and transition to the labour market. These young people themselves need to state that they experience obstacles and require support. It is also important that they participate actively in offered activities, such as job application workshops, in order to prepare as thoroughly as possible for the transition to the labour market.

What do young people with a disability themselves say about their preparation for—and access to—the labour market? A few quotes from a meeting, in October 2017, between Handicap + Studie and the trade union CNV Jongeren follow:

> As a disabled employee, I have to work harder.
>
> I need to prove myself more.
>
> My degree programme should have devoted more attention to career orientation with a disability.
>
> Due to my functional disability, I experience additional stress about entering the labour market.

These quotes show that young people with a disability experience more difficulties in preparing for and accessing the labour market than young people without a disability. They indicate that they have the feeling they need to prove themselves more by working harder, and also that they feel insufficiently equipped for entering the labour market with disabilities. Research by Gerritsen, Van Hal, Meesters, Van Bodegom and Verharen (2018) shows that young people with a disability want to be seen as ‘normal’, but they realise that they require support to a certain extent. They appreciate support persons who put themselves in the other person’s shoes in practical terms and who see both disabilities and possibilities. However, young people are often unsure about their prospects, including those on the labour market, and this in turn influences the expectations they have of themselves. The transition from education to work is experienced as difficult.

What are the explanations for this difficult transition as described above?

6. Possible Causes of the Low Labour Force Participation Rate

6.1. Changed Legislation and Regulations

The principle of the Participation Act is for as many people as possible to work in normal jobs for normal employers. Since 1st January 2015, municipalities are responsible for people with a functional disability who are able to work (people with an ability to work). As a result, young persons with a disability but also an ability to work have been barred from the WAJONG—the Disability Act for young people—benefit payment system as of 1st January 2015. This has made it all the more important for them to find work, but not all jobs are suitable for more highly educated young people with a disability.

Employers, too, are reluctant to take on employees with a disability. The majority of the more highly educated young people with a disability do not come under the definition of the target group register, a national register containing everyone who comes under the Jobs Agreement. The Jobs Agreement between the government and employers means that both parties have an obligation to create jobs for people with an illness or disability. A person receives an indication for the Jobs Agreement (and thus inclusion in the target group register) if they are unable to earn the minimum wage due to an illness or disability (UWV, 2018).

This means that in terms of the Jobs Agreement, they do not offer any added value to employers. It is attractive for employers to employ persons from the target group register because they can take advantages of schemes such as wage subsidies, a no-risk insurance policy and a job coach. In addition, these employees count towards the total laid down in the Jobs Agreement. Due to their level of education, more highly educated young people with a disability can be considered for higher and better-paid positions. As a result, they are usually not eligible for an indication unless they have a very serious disability. However, this means that the great majority of the more highly educated fall between two stools in this respect.

6.2. No Policy or Monitoring Regarding the Transition to Work

Most higher education institutions do not have a policy on helping students with a disability to get internships and jobs. Handicap + Studie carried out interviews at 25 universities and universities of applied sciences, asking whether attention is given to preparing students with a disability for the labour market. This reveals that the institutions devote limited and incidental attention to (specific) preparation for the internship and the labour market. As a student counsellor stated:

> The priority in my work is on a good start of the study and the first couple of years of the student with a disability. Our university offers career guidance, but there is a lack of knowledge about the transition to the labour market for students with a disability.

Limited or incidental attention often involves ad-hoc activities at a programme or faculty level on the initiative of individual staff members. Examples include job application and networking workshops, buddy projects for students with autism and a priority internship for students with a disability (see section 6.4 on good practices below). Students with a disability are not monitored following completion of their studies or if they drop out before graduation. As a result, higher education institutions have no accurate picture of how these students are doing, nor do they have solid figures. Once the students have completed their studies, the institutions lose contact with them. In this respect, they have now fallen into the 'gap' as well.

These young people require appropriate support during the move from education to the labour market. In this important transitional phase (the final year of studies and the first year after graduation) the main issues are finding an internship, graduating, seeking a job, applying and then starting work and holding on to your job. In conclusion, the education sector often devotes no attention to what comes after the completion of the degree programme. However, the education sector is already familiar with these young people and their studies are actually the time when attention should already be given to facilitating the next step after graduation. Young people can also indicate in the annual National Student Survey (NSE) how they feel about how their institution has prepared them for their further professional career. There are no specific figures available for students with a disability, but the figures for all students (Holzmann & Berger, 2017) for 2017 show that the average satisfaction score for preparations for a professional career was 3.52 (on a five-point scale), but this differs widely between institutions: students at universities of applied sciences are more satisfied than students at research universities. Within this theme, they are least satisfied with the contact with the professional field (3.43). The theme of internships as part of the programme is assigned the second-worst score: students are dissatisfied with how their institutions prepare them for the internship (3.14), while they are a little more positive about support and supervision during the internship (3.35). They are much more positive about the experience gained during internships (3.94).

6.3. No Ownership of the Problem

Consultations with the OCW, the SZW and UWV's Social Medical Affairs division (SMZ) have made clear that there is currently not enough collaboration between educational institutions, municipalities and employers to prevent young people with a disability from falling through the net and/or becoming unemployed. No single party has assumed ownership of the problem—it seems that the responsibility of the education system stops when students leave the institution and the responsibility of the SZW and of the municipality only begins when a person is sitting at home and applies for a benefit. As an employee of the Ministry of OCW expressed: "Transition to the labour market is an important issue. In our opinion this is the responsibility of the SZW and the municipalities". Quotation of a policy advisor of a municipality: "We have to prioritize. Therefore, our focus is on the young people with very little chances in life. So, we cannot give attention to high-educated young people with a disability". There are no incentives provided to employers, they are simply appealed to in moral terms. There is no legislation regarding support and integration in the labour market for more highly educated young people.

6.4. Stigmatisation and Prejudices

People with a work-limiting disability need to draw attention to their limitations in order to be eligible for support by society. On the other hand, processes of integration in the labour market often devote little attention to finding and retaining work when you have a disability.

Previous research into labour market reintegration of adults with work-limiting disabilities (Van Hal, Meershoek, Nijhuis, & Horstman, 2012, 2013) shows that support schemes often devote attention exclusively to possibilities. As a result, it is insufficiently clear to both job seekers with a disability and to employers how someone can best work on the basis of both their possibilities and their disability.

Many employers (49%) state that they have no suitable jobs for people with a work-limiting disability. Moreover, they often have prejudices about employees with a disability (Netherlands Institute for Human Rights, 2013), for instance that these employees are more frequently absent, require a lot of support, and are burdensome and expensive. This is also due to unfamiliarity with the target group and the lack of support possibilities. Consequently, they are reluctant to take on young people with a disability. One of the employers explained:

> I didn't realise that we also can hire high-educated young people with a disability. Our focus is on the target group register, but we also need high-educated young people with a disability, so this is a new opportunity for us.

Another employer mentioned:

> Every time an employee with a new disability (for example, autism, a physical disability or an hearing impairment) start working at our company, the employee faces all kinds of problems and we need time to make adjustments to the working procedures to include the employee.

The social costs of attention, interventions and extra efforts on the part of the parties involved should however be weighed up against the benefits for society when young people enter work, pay taxes and no longer require social benefit payments (Bureau Doet, 2017). Participation promotes the sense of inclusion and leads to improved health. As the UN formulated it:

> Although there is no universally agreed definition or benchmark for social exclusion, lack of participation in society is at the heart of nearly all definitions put forth by scholars, government bodies, non-governmental organizations and others. Overall, social exclusion describes a state in which individuals are unable to participate fully in economic, social, political and cultural life, as well as the process leading to and sustaining such a state. (UN, 2016)

Some educational institutions that do devote specific intention to preparing young people with a disability for the labour market have launched initiatives to help them make the transition. These can be regarded as good practices:

- Each year, Radboud University Nijmegen organises a career week in which a workshop for students with a disability is a standard part of the programme.
- Fontys University of Applied Sciences started a pilot with job coaches to support 15 students with (characteristics of) autism from their internship up to and including the start of their first job. By taking part in the pilot, students were less likely to fall behind, and they found a more suitable job. The pilot was conducted in cooperation with the municipality of Eindhoven, job coaches from 'Autismepunt' and employers. They gained insights into the success and failure factors of the method (qualitative) and funding options for an integrated approach.
- Hanze University of Applied Sciences' School of Nursing started priority internships for students with a disability. The career centre ensures that these students are given priority at one of the internship addresses. Corresponding agreements have been made with the care institutions in question.
- The executive Board of Fontys University of Applied Sciences indicated at a meeting on the transition from higher education to employment that her university feels responsibility for their students and alumni until they are landed on the labour market or in further education.
- Delft University of Technology offers a Job Search workshop for students with an Autism Spectrum Disorder. They offer: a preliminary interview with a student career advisor; four theme-related meetings of 2.5 hours each in a group with a maximum of six students (theme 1: self-analysis, qualities and interests; theme 2: CV guidelines; theme 3: motivation letter guidelines; theme 4: preparation for the job application interview); concluding interview and follow-up steps, possibly with external parties such as a job coach from the municipality.
- The University of Groningen organised a workshop for students with a disability about job applications and drawing up a job application letter. They also provided this workshop to staff of the Student Service Centre and of Career Services. These staff members advise students on job applications. The programme was organised by two student counsellors and two student employees of Career Services. The training was provided by an alumnus with practical expertise in the field who also provides similar training sessions to the Eye Association Netherlands (a patient association for people with a visual disability). The training was widely advertised, with an announcement being sent to all students who indicated when enrolling for the first year that they had a functional disability and would like to receive information about specific events for students with a functional disability. It was also posted on the Facebook page for students with a functional disability, and the student advisors were informed about the event.

7. Conclusions

This article explains how the labour market participation of more highly educated young people with a disability in the Netherlands is lagging behind compared to the participation of young people without a disability and why they often fall into the 'gap' between education and the labour market. The changing legislation and regulations do not work in favour of the more highly educated and of educational institutions and there is no policy on the transition to work for young people with a disability or for monitoring these young people. Furthermore, employers often have prejudices about taking on young people with a disability and see it as difficult to provide them with support. Results of the study by Nevala, Pehkonen, Koskela, Ruusuvuori and Anttila (2015) show that the key facilitators and barriers of employment were self-advocacy, support of the employer and community, amount of training and counselling, and flexibility of work schedules and work organisation. These topics should be taken into account when preparing students with a disability for the labour market. One final important conclusion is that there are many parties involved in the transition from education to the labour market for young people with a disability and (currently) insufficient collaboration between these parties; no party has taken ownership of the problem.

All these factors have consequences for the young people with a disability themselves, as well as for society. How can the gap between education and the labour market for these young people be closed? This requires further research on various themes.

7.1. Themes for Further Research

On the basis of the (limited) available research data and available experiences of students and other stakeholders, we recommend further research on the following themes:

7.1.1. Preparation for the Labour Market in an International Context

- What approach is taken in countries with a high level of participation by young people with a disability?
- What are the experiences of these young people themselves and of other stakeholders?
- How does this approach affect the transition of young people with a disability from education to the labour market?

According to Beyer and Beyer (2016, p. 68), the effectivity of employment support should be investigated. The conclusion of this review is that disabled people, governments, and taxpayers, are likely to benefit financially in the long-term from greater investment in inclusive employment:

> When taken with the data on the gap in employment rates between disabled and non-disabled citizens, and the generally high levels of unemployment experienced by young people across the E.U., it seems clear that savings to taxpayers may be available if we invested in employment support that had evidence that it worked.

The Netherlands could learn from the United Kingdom in working towards inclusive higher education and using their suggestions for an inclusive approach (see Figure 1 below; Disabled Students Sector Leadership Group, 2017). This inclusive approach enables students with a disability to deliver to their full potential. It will also make a difference for employers and the society. It is an opportunity for higher education institutions to work in partnership with employers to improve the transition from education to the labour market.

7.1.2. Responsibilities of Stakeholders

- How do stakeholders see their responsibilities?
- What are the experiences of young people with a disability with regard to the various stakeholders?
- What is necessary for parties to work together on the basis of a shared responsibility to close the gap between education and the labour market for more highly educated young people with a disability?

Jordan, Schwartz and Mc-Gie-Richmond (2009) stated in their study about preparing teachers for inclusive classrooms:

> We provide evidence to suggest that teachers' beliefs about disability and about their responsibilities for their students with disabilities and special educational needs may be part of a broader set of attitudes and beliefs about the nature of ability and about the nature of knowledge, knowing and how learning proceeds; that is, epistemological beliefs. The implications for these findings are considerable for teacher training and development. Little is known about how skills for effective inclusion are developed, or about how changes in teachers' beliefs about disability, ability and their epistemological beliefs may be reflected in changes in their practices.

How can beliefs about and attitudes of teachers towards students with disabilities be changed? How can skills for effective inclusion in education be developed?

7.1.3. Further Insight into the Situation of More Highly Educated Young People with a Disability in the Netherlands

- What is the size and composition of the group of more highly educated young people with a disability and what is the situation as regards their labour market participation?
- What are the experiences and needs of the young people themselves?
- What are success factors for labour market participation?

Once the proposed research has provided more knowledge, this could serve as basis for investigating the social costs and benefits of best practices that focus on bridging the transition from education to work.

With this article, the authors aim to help put the 'gap' and the various stakeholders on the research agenda and propose stones for bridging this gap. This has been done by arguing that more in-depth research into the transi-

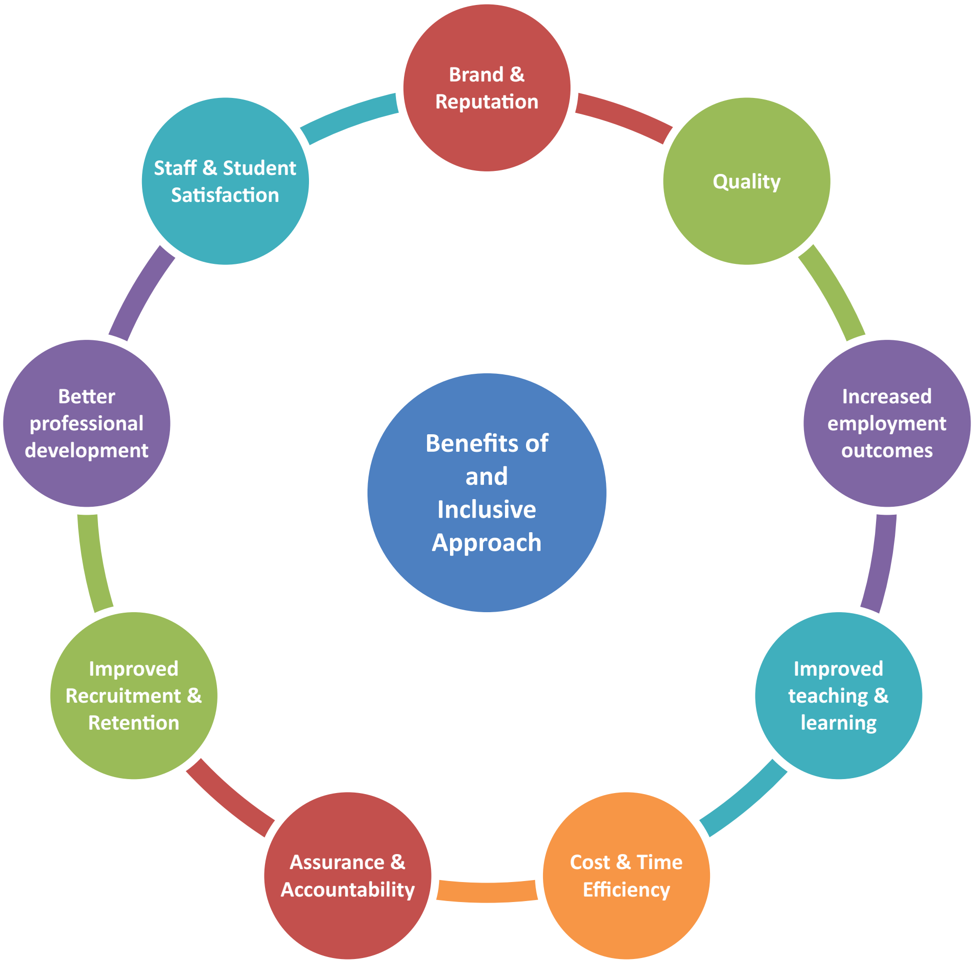

Figure 1. Benefits of an inclusive approach.

tion from education to the labour market for young people is required in order to narrow the 'gap'. Narrowing this 'gap' will benefit both the young people themselves and society as a whole.

Conflict of Interests

The authors declare no conflict of interests.

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About the Authors

Marjolein Büscher-Touwen is consultant at Expert Centre Handicap + Studie. She stimulates and supports educational institutions in the development of inclusive education. She graduated as a communication scientist and worked at the central counselling department of the VU University Amsterdam for several years having different roles: disability advisor, career counsellor and project manager. She also lived in Mozambique and was involved in projects of Handicap International and a local literacy organisation for children.

Marian de Groot is Director of the Dutch Expert Centre Handicap + Studie. She studied psychology and managing of change in organisations. The focus in her work is on inclusion of students with a disability in (higher) education and the labour market.

Lineke van Hal, PhD, is a Senior Researcher at the Verwey-Jonker Institute, the Netherlands. Trained as a medical anthropologist, she conducts scientific research on social issues such as participation, work and youth (care). In her work she pays attention to perspectives of citizens, 'clients' and professionals to study from a multiple perspective what happens in practice.

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Article

Inclusion in Norwegian Higher Education: Deaf Students' Experiences with Lecturers

Patrick Stefan Kermit [1,2,]* and Sidsel Holiman [3,4]

[1] Department of Social Work, Norwegian University of Science and Technology, 7491 Trondheim, Norway;
E-Mail: patrick.kermit@ntnu.no
[2] NTNU Social Research, 7491 Trondheim, Norway
[3] Statped, Norwegian National Service for Special Needs Education, Norway; E-Mail: sidsel.holiman@statped.no
[4] Department of Education and Lifelong Learning, Norwegian University of Science and Technology,
7491 Trondheim, Norway

* Corresponding author

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Abstract
Nordic research concerning disabled higher education students has suggested that inclusion often simply means placement among non-disabled peers. Individual disabled students are the ones who must bridge the gap between which accommodations are offered and what their felt needs are. The study presented in this article is based on semi-structured qualitative interviews with five deaf Norwegian master's degree students. Teachers' knowledge regarding visually oriented instruction and intercultural communication was central to the students' perceived inclusion. The informants largely saw themselves as responsible for academic inclusion and would make demands for adjustments only when all other options were exhausted. Achieving results was given such priority and demanded so much effort that little energy was left for social activities and interaction with hearing peers. This article discusses the lack of experienced inclusion understood as a collective practice encompassing both academic and social aspects. Deaf students' own experiences are resources for improvement that remain untapped by Norwegian universities.

Keywords
academic inclusion; classroom accommodation; deafness; disability; higher education; intercultural communication; Norway; social integration

Issue
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1. Introduction

During the last two decades, there has been a change in Norway from a situation where few deaf people had access to and attended higher education to a situation where higher education is supposed to be routinely accessible. Norwegian universities are expected to facilitate inclusive education in line with Norway's commitments to, for example, the Salamanca Statement (UNESCO, 1994) and the United Nations Convention on the Rights of People with Disabilities (Utenriksdepartementet [UNCRPD], 2012). The number of deaf students attending universities has increased accordingly in Norway, as in many other countries, over the past 20 years (Hansen, 2005; Lang, 2002).

This article presents a small qualitative interview study with five deaf master's degree students. In general, there are few Nordic studies regarding deaf students in higher education, and, as far as we know, none focusing on master's degree students.

The main research question guiding the study is: what are the lived experiences of deaf Norwegian master's degree students in so-called inclusive teaching settings?

In this text, we focus particularly on the primary results of the analysis, which are concerned with notions of inclusion in general and the lecturer's role as the facilitator of inclusive practices in particular. In the following sections, we present research approaches to the study field, as well as the study's background and methodology. From there we move to the results and their analysis before concluding the article by discussing its most important findings.

2. Intertwined Notions of d/Deafness

In the field of Deaf studies, many scholars have followed the custom of differentiating between the medical condition of being deaf (which is written with a lowercase 'd') and being a member of a signing community (in which case Deaf is written with a capital 'D'; see, for example, Markowicz & Woodward, 1978; Padden & Humphries, 1988; Woodward, 1972).

For the purposes of this study, we propose that it might be fruitful to approach d/Deafness in a way that encompasses perspectives derived from both sign language and Deaf studies and disability studies. The former perspective approaches interactions between Deaf and typical hearing people in terms of language and culture, and here we can also draw on research concerning intercultural communication. The latter perspective links the matter at hand with general research on disabled students in higher education. Furthermore, disability studies traditionally distinguish between bodily impairment and disability. The latter is a social phenomenon that manifests when a person with an impairment encounters socially created barriers in his or her interaction with a social environment (Shakespeare, 2006).

A previous analysis performed by Kermit (2009) has pointed out that the distinction between deafness (as physical impairment) and Deafness (as lingual and cultural belonging) does not encompass this third notion of deafness as socially-created disability, which we find relevant to include. In what follows, we simply chose to use the term "deaf" in accordance with standard spelling rules, keeping in mind that this term is meant to encompass all three of these different and intertwined notions of d/Deafness: deafness as impairment, deafness as disability due to socially created barriers, often in the form of discrimination, and finally Deafness as lingual and cultural belonging.

The point here is not to suggest that one of these notions of d/Deafness should be ascribed ontological or epistemic superiority; rather, we suggest that these notions are intertwined in the lived experience of d/Deaf people.

3. Research Concerning Higher Education: Disabled Students in General and Deaf Students in Particular

There is a large body of international studies focused on disabled students in higher education. A recent publication by Langørgen, Kermit and Magnus (2018) has commented that many of these studies point in much the same direction. Even though all students are expected to struggle to achieve their educational goals, many disabled students face additional struggles that are often associated with lack of access, participation, and inclusion.

In 2002, Harry Lang published a review study on deaf students in higher education that highlighted several research priorities. Among other ideas, Lang has pointed out that much is known about the barriers deaf students face in higher education, but much less is known about what may lower these barriers and improve the academic achievement and retention of deaf students. One predictor of academic success is increased participation of deaf learners in the higher education classroom. Lang has pointed out the necessity of examining the relationship between deaf students' participation and academic achievement when the instruction is being given directly or via interpreters (Lang, 2002). The topics suggested by Lang have been addressed in more recent studies. Powell, Hyde and Punch (2014) have focused on communication barriers and access to interpreters as an important prerequisite for participation in higher education. Noble (2010) has pointed out the necessity of the lecturer being prepared to receive a deaf student into his or her classroom, and the environment being both physically and technologically adapted to accommodate the deaf student's needs. Ross and Yerrik (2015) have addressed the role of the lecturer, as Ross has described her own experiences as a deaf student and emphasised the importance of student-lecturer cooperation. In her experience, it is important that the lecturer asks the student about his or her needs rather than assuming that he or she knows what is best for the student.

4. Inclusion and Communication

Deaf people may be viewed as a lingual and cultural minority, and in accordance with this perspective, interpreters facilitate classroom communication between lecturer and student. The responsibility for the quality of the communication, however, lies with the lecturer and the student. Bilingual teaching can thus be seen as intercultural communication. A prerequisite for intercultural communication is intercultural competence. Spitzberg (2009) has pointed out that intercultural competence encompasses three distinct capacities: 1) attitudes, 2) knowledge, and 3) skills. In Spitzberg's words, attitudes "include awareness of cultural values, understanding and devaluing of ethnocentrism or discrimination and appreciation of the value of risk taking and cross-cultural interaction" (Spitzberg, 2009, p. 425). The second capacity, knowledge, "includes an awareness of self, and understanding of oppressions, and an appreciation of the nature of social change and the effects of cultural differences on communication” (Spitzberg, 2009, p. 425). Skills, the third capacity, “include an ability to engage in self-reflection, identify differences, take multiple perspectives in multiple contexts, and challenge discriminatory acts” (Spitzberg, 2009, p. 425). These perspectives emphasise an understanding of intercultural communication as vital for inclusive communication, and thus inclusive practises. The communicator is challenged to see the other from the inside, and to see oneself from the outside, which is indeed a demanding task (Rygg, 2014).

5. Methods and Material

The researchers involved in this study are interested in the phenomenon of inclusion, especially in connection with deafness. In order to explore inclusion in a higher education setting, five deaf master’s degree students were recruited to participate in an interview-based study. The study was reported to the Norwegian Centre for Research Data, and permission to conduct the study was granted.

The students were strategically selected because they had experience in master’s degree education both in terms of attending general courses and as members of a co-enrolled deaf group. It was thus an important goal to investigate the students’ experiences being taught by lecturers with varying levels of knowledge about deaf students in various teaching situations.

The university administration contacted the students by e-mail in order to ensure that no pressure would be felt if the researchers contacted them directly. A total of seven students were contacted, and five agreed to participate in the study. All of the informants were women between the ages of 35 and 55. They all had a minimum of preschool teacher or teacher education; three of the informants had additional undergraduate education. All informants therefore had significant work experience within a broad field of educational services. This meant that their perspectives on central topics such as inclusion were dealt with both as a question of personal experiences and as concepts they were familiar with professionally.

Four of the interviews were conducted at the informant’s place of work and one interview at the informant’s home, according to the informants’ wishes. According to the informants’ preferences, four of the interviews were conducted in Norwegian Sign Language and one in spoken Norwegian. The researchers themselves, both of whom are fluent in Norwegian Sign Language and spoken Norwegian, carried out all interviews. All interviews were also filmed. In preparation for the analysis of the collected data, one of the researchers translated the interviews into written Norwegian. When there was doubt concerning a phrase, the phrase would be viewed by both researchers. All of the filmed material was examined in this manner twice, and then both researchers reviewed the films and written translations a third time. The written translations were subsequently analysed using a phenomenological approach (Creswell, 1998), where our primary focus was on the informants’ experiences of inclusive and exclusive practices. The translations were coded according to topics, and these topics were ordered according to frequency and emphasis given by the informants. The topics were subsequently grouped in order to establish what underlying concepts they represented. Phenomenological analysis is thus based on qualitative and hermeneutical principles, but the overarching analytical goal is to get behind the mere descriptive understanding of the data, grasp the underlying meanings, and so explore the deeper structures of the students’ experiences.

Upon the conclusion of the analysis, the five informants were invited to a seminar where the researchers presented their analysis of the material. Three informants were able to attend and were invited to respond to the analysis, elaborate on the findings, and correct lingual or conceptual misinterpretations. Methodologically speaking, this is often referred to as respondent validation or member check (Creswell, 1994). This seminar was not filmed, but extensive notes were taken by one of the researchers.

6. Results and Analysis

All the informants were professionally engaged in pedagogical fields and were thus familiar with concepts such as inclusion and participation. When reflecting on these concepts during the interviews, however, none of them drew on their own professional experiences as teachers; instead, they focused solely on their experiences as students.

When asked about inclusion or the lack thereof, the informants all steered the conversation towards their different experiences with different lecturers. They identified the lecturer as the person with both the opportunity and the means to either promote or hinder inclusion. They emphasised that the lecturers’ knowledge of deafness and the accompanying practical teaching skills were crucial factors. At the same time, they indicated that knowledge and skills were not enough if the lecturers displayed disablist or audiocentric attitudes towards deaf students. The informants thus spontaneously pointed to the intercultural capacities introduced by Spitzberg (2009). By doing so, they also proposed that the cultural and lingual aspects of deafness were the ones they identified with most compared to the disability aspect.

Different lecturers’ level of competence and knowledge concerning deafness is the organising principle in the following text. Schematically, we can distinguish between three levels of competence among the lecturers described by the informants: 1) lecturers with no or little deaf competence, who had never met or taught deaf students, and who faced them and the interpreters for the first time; 2) lecturers with some deaf competence, ranging from those who had some prior experience teaching in bilingual settings with a sign language interpreter, to typically hearing lecturers who are proficient in sign language; and 3) lecturers with high deaf competence, who teach in sign language or in spoken Norwegian, but are conscious of the demands of visually oriented instruction (Hansen, 2005).

Before returning to the different levels of lecturer competence, some general aspects of the results and analysis are presented to clarify why the emphasis on the lecturers' competence seems analytically reasonable.

7. Central Aspects of the Informants' General Situation

7.1. Struggle for Inclusion and Participation

The informants described typical learning activities as attending lectures and working with other students in colloquiums, the latter mostly privately organised by students. It is noteworthy, that the informants had little to say about typically hearing, non-signing fellow students' roles in inclusion or exclusion. The informants did not give any examples where fellow non-signing students had acted in ways that promoted inclusive practices.

The emphasis on attending lectures is understandable because the Norwegian master's degree students are expected to study and work independently and to take responsibility for their own learning process. The lecture is thus the primary situation where students and university lecturers meet. When many students attend a course, the lecture might take place in a large lecture theatre, offering little opportunity for interaction between the lecturer and the students. Many master's degree courses, however, have only a small group of students, and these courses will often have a more interactional character where the lecturer and the students discuss the topic at hand and maintain a running dialogue. Our informants had experienced lectures in large groups, typically in courses on methodology (i.e., research methods and statistical methods). They had also attended lectures in smaller groups during courses specific to their subject matter. In the large groups, they had always been a minority. In the smaller groups, some of the students had attended courses where there was an even balance between deaf and typically hearing students. The informants' general expectations concerning learning outcomes was closely linked to attending lectures, since the lecture was the place where the course curriculum was presented and explained.

As indicated above, there might also be another reason why the lectures became a focal point in the interviews: the informants ascribed informal responsibility for inclusion to themselves and to their fellow hearing students; however, to them, the lecturers represented the face of the university and were the professionals who were formally responsible for its inclusive practices. To the informants, the inclusive practices established by the lecturer, or the lack thereof, influenced the way deaf and typically hearing, non-signing students would interact and cooperate both inside and outside the lecture theatre. Hence, the finding that the lecturer decisively influences the ways in which different learning practices become inclusive, is an important finding and one that has been supported by other studies (e.g., Antia & Stinson, 1999; Antia, Stinson, & Gaustad, 2002; Hansen, 2005; Ohna, 2005).

As suggested above (referencing Kermit, 2009), the respective notions of deafness as disability and as lingual and cultural belonging are intertwined, and they proved to be so in this study. As previously mentioned, the students' own focus rested firmly on the latter concept of deafness. Even though, in terms of disability, the students described experiences of outright discrimination and encounters with several socially constructed barriers, their own narratives and descriptions emphasised aspects of intercultural communication challenges. In compliance with the informants' preferred perspective on deafness and intercultural communication, we structured the results in accordance with different levels of lecturers' deaf competence.

7.2. Lecturers with Little or No Deaf Competence

The teaching style of lecturers who have never met or taught deaf students is best described as teaching solely on the terms of the typically hearing. These are generally lecturers who conduct their business as usual without regard for the presence of deaf students and interpreters in the group. This often means the absence of observable inclusive practices, which manifests itself in several examples offered by our informants. A lecturer who lacks a basic understanding of what it means to teach in a bilingual and visually orientated setting will seldom observe or appreciate that deaf students struggle when they must simultaneously direct their gaze at the interpreter and at other objects of interest such as the blackboard, the text of the PowerPoint presentation, or other artefacts used by the lecturer. If the lecturer maintains a running dialogue with the students during the lecture, he or she may not pay attention to the time lag between what is spoken and what the interpreter translates. The deaf student's ability to enter the conversation is therefore significantly decreased, and even keeping up visually with who is saying what can be a confusing struggle when fellow students engage in animated discussions and the deaf student must look at the interpreter and look around in order to identify who is talking.

This teaching style also encompasses other less easily observable aspects of exclusion. The lecturer may not be aware of the importance of offering either the interpreter or the deaf student preparation materials before lectures, a measure that can counter some of the challenges associated with taking notes while looking at the interpreter.

When faced with lecturers who have little or no deaf competence, deaf students must accept the primary responsibility of informing the lecturer of the minimum requirements for accessible teaching. The informants typically described this activity as "asking for adaptations". An informant recalls:

> I am older now, but it is still hard to ask [for adaptions] all the time. When I was younger, it was unpleasant to ask.…I eventually stopped asking. I chose to read afterwards and tried to understand on my own.

By choosing such words, the students indicated that this was a constant element of frustration they had repeatedly encountered throughout much of their education. When lecturers do not establish inclusive practices, deaf students must appeal to the lecturers' benevolence in order to obtain something they see as their self-evident right. None of the informants had, however, confronted their lecturers and pointed out that establishing inclusive practices should be the responsibility of the lecturers, not the deaf students. The informants' description resembles what disability researcher Donna Reeve has called psycho-emotional disablism: the non-disabled, often unthinkingly, convey the tacit signal that the disabled person always comes second compared to the non-disabled (Reeve, 2014). Reeve describes the effects of such treatment as internalised oppression. The deaf informants, however, all adamantly stated that they saw themselves as equal to their typically hearing student peers. This statement of equality was firmly anchored in their everyday experience of belonging to a lingual and cultural signing minority community. The understanding of deafness as lingual and cultural belonging thus demonstrates an important moral and practical advantage compared to the disability approach. The everyday experience of belonging to an interdependent signing community was the source of a moral conviction derived from practical experience, not a mere theoretical argument about equality.

The fact that deaf students' capacity for resilience is strengthened by their lingual and cultural belonging when facing discrimination is an important result that has been confirmed by other studies on deafness. Though the formulations vary, numerous studies have proposed the practical superiority of the lingual and cultural approach (Bauman, 2004; Bauman & Murray, 2014; Harris, 1995; Ladd, 2005; Ladd & Lane, 2013). Nevertheless, this study further describes deaf students' experiences of encountering or approaching lecturers with little or no prior knowledge of deafness. When the topic was raised, the different lecturers' attitudes were immediately identified as a crucial aspect with profound effects.

The informants distinguished between three different types of attitudes: 1) the stereotyping attitude that deaf students are in need of special education; 2) an indifferent attitude; and 3) an open and inquisitive attitude.

As for the first type of attitude, all of the informants shared the experience of a lecturer treating them as inferior to typically hearing students. In the context of higher education, this experience of discrimination, or being 'othered', was comprised of different elements, many of which are strongly linked to tacit attitudinal signals to deaf students. The general signal thus conveyed was that the lecturer though the deaf students should have been directed to some form of special needs education so that the lecturer would be spared the extra trouble of adjusting to the deaf students' needs. The feeling impressed on the deaf informants was that such adjustments were obstructing the effective teaching of the rest of the students. A frequent example of how this attitude played out was when lecturers indicated that efforts to prepare interpreters or adjust their lecturing style in order to accommodate for interpreting was a nuisance. An informant says:

> I didn't ask for much, only some consideration, but no. I didn't get PowerPoints before the lecture. Some gave them to me but told me not to share them with other [students]. I felt I was made special and I didn't want that. If the interpreter asked for a repetition, she was ignored. The lecturer just continued.

In the informants' opinions, this experience of being reduced to the hearing-impaired person in need of special treatment was the ultimate denigration and something that severely obstructed both access to participation and learning. Furthermore, when lecturers displayed this attitude it destroyed the informants' motivation to try to engage socially with typically hearing fellow students. This result from the analysis was explicitly presented to the informants present at the respondent validation seminar, and they confirmed the finding:

> Low [deaf] competence, that is as if there are no deaf people in the group, that's the most excluding way, might even be discrimination.…Deaf people's needs become individual or private, it's not *our* interpreter but *your* interpreter. [It's] tiresome, lonely, you lose information [and] the motivation to engage socially is reduced.

The second attitude, indifference, shares the main characteristics of the stereotyping attitude. The lecturer sees no reason why he or she cannot teach in his or her traditional fashion, that is, the fashion suitable for typically hearing students. Even though this attitude does not encompass the first attitude's elements of outright discrimination, the effects on the deaf students are quite similar: the informants experienced isolation and a lack of participation both during and outside of lectures. Their learning processes were reduced to what they could accomplish individually, and the informants generally felt that the lectures were barriers they had to scale rather than assets promoting participation in a learning community of peers. This lack of inclusive practices has been well described in research (Kermit, 2018) and is above all characterised by individualisation of the student’s responsibility. In terms of the classic disability study approach, this is what the “medical model of disability” (Shakespeare, 2006) means. The indifferent or unreflective attitude implies that since it is the student’s hearing impairment that causes all the extra challenges, it is the student who must carry all the responsibility for bridging the gap between what is offered and what is required in terms of accommodation. The interpreter, for example, is typically seen as the deaf student’s individual aid instead of as a professional who works with all parties present.

The informants reported that when they encountered the first two types of attitudes, being part of a co-enrolled group of deaf students was a great comfort. There is strength in numbers, and the informants said that the support they lent each other eased the burdens associated with being ‘othered’ by the lecturer. It did not, however, make contact with typically hearing peers any easier.

The third attitude, the open and inquisitive attitude, is perhaps the most interesting. In the context of disability research, the effects of discrimination are well known and have been described in similar ways to those above. Some of our informants emphasised that even a lecturer with no prior knowledge concerning deafness could promote inclusive practices as long as he or she was “open and inquisitive”. We interpret this in line with the previously mentioned research on intercultural communication. Instead of facing deaf students with premeditated stereotypical ideas about ‘them’, the open and inquisitive lecturer first and foremost signals that even though the deaf student might be different, he or she is not unequal or inferior. The informants who brought this to our attention indicated that the open inquisitiveness in many ways compensated for the lack of actual competence. This makes sense, especially when compared to the strong resentment the informants felt when they perceived that lecturers saw them as students in need of special educational measures. The simple attitudinal signal of equality was a source of motivation and an incentive to engage fellow hearing students and generally participate in activities inside and outside of lectures.

7.3. Lecturers with Some Deaf Competence

As mentioned above, these lecturers range from those who have some prior experience teaching in bilingual settings with a sign language interpreter, to typically hearing lecturers who are quite proficient in sign language. Significantly, they all make certain adaptations to their teaching style in order to facilitate both bilingual teaching situations and a visually orientated learning environment. This teaching style is nevertheless based on traditional models of teaching the typically hearing and therefore favours the typically hearing students at the expense of the deaf students. Examples of these lecturers’ adaptations range from routinely preparing interpreters to more thorough lecture planning. In the latter case, the lecturer would realise that the deaf students should be allowed to look at one object at a time and would, for example, routinely give all students time to read the PowerPoint slide before beginning to comment on its text. In the same fashion, the lecturer could organise a sitting arrangement where students were seated in a semicircle facing the blackboard so that all students could see who was talking or signing.

Understanding these lecturers’ attitudes is somewhat more complex compared to understanding the attitudes of the low-competence group of lecturers. Since these lecturers have a certain level of knowledge concerning deafness, visual communication, and visually organised classroom practices, it is not so much a question of whether or not they have dis/abling attitudes. It is more a question of how, and to what degree, they choose to act on their knowledge. One example offered by the informants was that of a lecturer who knew Norwegian Sign Language quite well but still chose to teach in spoken Norwegian. The lecturer facilitated visual access and prepared the interpreters, but the informants still felt that this lecturer would have sent a much more inclusive signal if she had chosen to sign instead. Another example frequently mentioned was that of lecturers who would excuse themselves for neglecting to prepare the interpreters or for not having sent the students handouts before the lecture. These were lecturers who would also ‘forget’ to observe the principles of visually organised teaching and, for example, simultaneously talk and show a slide with text. An Informant says: “I often remind them, but the lecturers forget. I don’t want to make a fuss, that is unpleasant. I remind them once, maybe twice, some forget anyway”.

This kind of unthinking audiocentrism affected students in much the same way as the indifferent low-competence lecturers mentioned above. The deaf students felt they were relegated to second place compared to their typically hearing peers. Also, their learning processes became less collective and more individual, though they would find the same strength in numbers as mentioned above.

7.4. Lecturers with High Deaf Competence

The high-competence lecturers would teach in sign language and let the interpreters translate to spoken Norwegian. Some of these lecturers were themselves deaf. When discussing these lecturers, the informants reported that they felt they were on an even footing with their typically hearing fellow students, because signing lecturers automatically observed and obeyed the demands of a visually oriented classroom. These lecturers would, for example, automatically pause for the audience to read bullet points on a slide. Turn-taking in discussions would also be visually structured. For example, the lecturer would visually identify any students who were called upon to sign or speak.

Even though this was the informants’ preferred way of being taught, they did acknowledge that hearing lecturers who were proficient in sign language but taught in spoken language also contributed to a sense of inclusion and equality. This, however, requires that the lecturer adheres to all the characteristics of a visually oriented classroom and simultaneously pays attention to the interpreter in order to monitor the translation. The latter could prove vital in enabling deaf students to make comments at the appropriate point during class discussions.

Teaching in sign language was thus reported to be the only instance where the informants felt that all barriers to learning and participation fell away, and the learning process became collective in ways that triggered both motivation and creativity. Such effects were particularly significant where there was an even number of deaf and hearing students. An Informant recalls:

> [The lecturer] signed at high speed and the interpreters had to work hard to voice her. The conversation was fun and animated, but I sensed that the hearing [students] became quieter and that we deaf kind of forgot them a bit.

When the researchers pressed the question about inclusive practices, the informants reflected on whether a signing lecturer represents a genuinely inclusive practice, or whether this is just a way of turning the table on the typically hearing students, excluding them in the same manner that the deaf students were often excluded.

8. Discussion

Our results are in accordance with findings in a 1999 study by Foster (referred to in Lang, 2002): according to the deaf students, effective lecturers have two unique characteristics. First of all, the deaf students preferred professors who understood deaf people and deafness as an educational condition, and secondly, students who use sign language valued lecturers who were able to communicate clearly in signs.

In terms of inclusion-related questions, these findings may require further qualification to actually contribute to an increased understanding of the challenges at hand. There is a particularly important distinction between individual and collective aspects of studying and learning in the material, and, similarly, a distinction between academic and social inclusion.

Our results and subsequent analysis suggest that for the informants, the question of inclusion is often reduced to an individual matter, where hearing impairment is seen as the main—and individual—problem. This reduction is systematic in the sense that it reflects the results of institutional factors and factors related to lecturers' professional conduct.

The overall impression given is that lectures with deaf students and interpreters present are conducted like any other lecture, even by lecturers with some deaf competence. The institutionalised idea of what a lecture is seems to be intrinsically connected to the idea of the student being typically hearing and speaking. In this manner, inclusion means little more than placement (Haug, 2016), and the overall absence of inclusive practices reflects the attitude that deaf students' presence is in itself sufficiently inclusive, but all other matters associated with deaf students' needs are reduced to their individual problems. This finding is in line with recent reports about hearing-impaired children and adolescents in so-called inclusive settings in Nordic kindergartens and schools (Kermit, 2018). Even though these institutions are legally required to be inclusive, since 2010 Nordic research has generally pointed out that in most kindergartens and schools it is (hearing) business as usual, and the hearing-impaired children and adolescents have to fend for themselves as best they can.

One effect of inclusion as placement is that deaf students become individually responsible for their inclusion and individually dependent on the good will of individual lecturers. Theoretically, when placement is confused with inclusion, it is only the fulfilment of a token right for deaf students to be formally equal to their classmates. In reality, placement is a form of discrimination because of the tacit signal conveyed to the deaf student that his or her needs are less important compared to the needs of other students. A lecturer is supposed to teach in a manner whereby he or she is both attentive and adaptive to the needs of the students in general. Even though many lecturers in higher education might be less observant when it comes to this professional responsibility, the usual lecture is at least in a crude sense accessible to typically hearing students. This way of reasoning leads to a more fundamental theoretical point concerning inclusion: it is not about adaptions in order for one individual to better fit in with the rest. There is an element of reciprocity to inclusion that negates an individualised understanding of the concept. Among traditions supporting this notion, neo-Hegelian philosophers promoting ideas about reciprocal recognition have formulated the idea that discrimination is not only a problem for the one who is discriminated, but also for the society at large wherein discrimination is taking place (Honneth, 1995; Taylor, 1992). Reciprocal recognition is thus a fundamental prerequisite for social justice and for the individual's access to authentic self-appreciation (Danermark & Gellerstedt, 2004). The implication of a token inclusion reduced to placement is that overlooking the needs of one group of students is a problem not only for this particular group but for all students, and ultimately for the society where such practices occur. In other words, the individualisation of deaf students' needs is a collective problem, because the lack of inclusive practices is a problem for everyone, not only those who suffer the most because of it. This is not just a theoretical statement; it is also practical. Haug (2016) has pointed out that in general, good teaching practices probably contribute more to inclusion than do special measures designed to assist the individual student who is "different". Along the same line of reasoning, one could suggest that inclusive practises designed to serve the collective community of students might have positive effects for all students. Finally, the collective approach to inclusive practices also rejects any notion of inclusion as some sort of good deed the "normal" choose to perform to accommodate the needs of those who are "different". On the contrary, inclusion is not something depending on someone's good will; it is a principle formulating what kind of organisation we have chosen for our educational systems and ultimately for our societies.

These deliberations regarding inclusive practices are not original but merely a summary of how inclusion is understood in, for example, the UNCRPD. Nevertheless, the present study sheds light on some important aspects of inclusion, or the lack thereof. In the context of inclusion as an individual or collective effort, the informants' distinction between academic and social inclusion is of interest. The informants largely saw themselves as solely responsible for academic inclusion and would ask for adjustments only when all other options were exhausted. Achieving academic results was thus given such priority and demanded so much effort that little energy was left for social activities and interaction with typically hearing peers.

In light of the above promotion of inclusion as a collective undertaking, the division between what is considered academic versus social should be critically examined. The informants clearly distinguished between the academic and the social, particularly when describing their experiences with token inclusion and placement. When describing signing lectures, on the other hand, they described their learning processes in collective terms as something they achieved as members of a community of learners (Antia et al., 2002). Again, this might not be a novel discovery, but the findings emphasise that individual approaches to inclusion cement a misunderstood and discarded notion of education as something you can get from books if you are so unfortunate as to be unable to achieve it with fellow peers (see, for example, Vygotsky, 1978, 1986).

In the context of higher education, it might very well still be a widespread truism among lecturers that their responsibilities as teachers are limited to the academic, whatever that might entail. The informants' identification of the lecturer as a key person when it comes to inclusion is an important finding in this context. Even though the informants addressed the lecturers' individual attitudes, they also saw the lecturer as the professional representative of the university and the one with the formal responsibility and the means to establish inclusive practices. This points not only to the individual lecturer but also to the university's responsibility, and again emphasises that inclusion involves questions of policies and organisation, perhaps to a larger extent than questions about attitudes. Universities should establish inclusive policies and formulate a clear mandate for all employees that inclusive practices are obligatory rather than individual options to be chosen or discarded according to preference or taste.

The above reflections on inclusion are not limited to deaf students. To point out what clearly does not work (the individual approach) and suggest a theoretical alternative (the collective approach) might not provide much guidance when someone asks what inclusive practices might look like. The focus on deafness in this study, however, involves aspects of inclusion as practice that are likely relevant to other contexts as well.

The informants' conviction of formal equality in spite of discrimination was a strong source of positive self-identification. This is a central result of this study: the students fought the stigma of deafness as disability not by admitting to it or accepting the role of victims of discrimination; rather, they turned the table and identified the problem as the lecturers' lack of competence and questionable attitudes, thus retaining positive self-identification. This can be interpreted in several ways. First, the cultural and lingual approach is both relevant and a source of positive self-identification (Honneth, 1995). This is an approach where strength in numbers is also helpful, because a group of deaf students can display both for themselves and for their typically hearing fellow students and lecturers that they constitute a lingual community rather than a group of disabled students. The three capacities of intercultural competence mentioned above (attitudes, knowledge, and skills) have been proven relevant in this study as key concepts when establishing intercultural communication. Building on these concepts in our analysis also allowed for a structured rendering of the different experiences of the informants, since they had faced lecturers with different levels of competence concerning deafness. The informants used strong words to describe the differences between being recognised as a signing person and being categorised as a "special education case". The former is the prerequisite for inclusion, whereas the latter nullifies all attempts at inclusion. This in itself might be an important part of the answer to how inclusive practices should be. Furthermore, it is noteworthy that the students did not consider it problematic if the lecturer had no prior experience with deafness/signing as long as he or she was open and inquisitive in a recognising manner and would ask the students about their preferences instead of just assuming something about them.

Secondly, by redefining the lack of inclusive practices as lack of intercultural communication skills, the informants highlighted a pathway to more inclusive practices. The nearest thing to inclusive practices identified in this study is when the teaching practices allow for visually oriented languages. This need not be happening only when the lecturer signs, but also when the open and inquisitive lecturer adapts to the demands of a visually oriented classroom. The list of requirements for a visually oriented classroom is not long, but the complexity involved should not be underestimated: making a teaching situation visibly accessible to all students may not require more than adjustments to the seating arrangement, obedience to simple rules of turn-taking, and an awareness of the necessity of a structure where one need only look at one thing at the time. The more complex matter regards the more profound question of how to achieve inclusive practices encompassing both deaf and typically hearing students. Since none of the deaf students' experiences could actually be said to represent such practices, this question has yet to be answered. We can only point out that the informants had never before been asked for their thoughts concerning teaching styles and inclusion. Lecturers should therefore not assume that they know what is best for the students or that they themselves can define when inclusion has been achieved. Lecturers should ask students like our informants how they think inclusive practices might be achieved and commit themselves to mutual cooperation with all of their students.

9. Conclusion

The informants' lack of experience with collective inclusive practices promoting an intertwined notion of academic and social achievements is problematic. Norwegian universities' formal obligation to promote inclusion must be regarded as any other legally imposed demand on higher education institutions and not as a mere appeal to the individual lecturer. The individualised model where social aspects of studying at a university are downgraded must be challenged. The division between what is academic and what is social is hardly productive for the deaf students, their fellow students, or, in the end, the university. Academic and social inclusion should be viewed as intertwined aspects of what being a student means for all students, not only those who are deaf or disabled. Without institutions accepting responsibility for promoting this notion of inclusion, there is little to be hoped for from the efforts of the individual lecturer, however competent some of them might be. It is further relevant to emphasise that this study also suggests that lecturers who maintain an open and inquisitive attitude and interact with students in order to discuss their needs and preferences can compensate for their lack of specific knowledge and skills with this attitude. If universities demand inclusive practices, this might not mean that their lecturers must acquire new formal, specialised skills. Instead, focusing on general aspects of what successful collective, inclusive practises entail involves principles of interaction between lecturers and students and high teaching standards, perhaps to a larger extent than specialised expertise.

Having highlighted these implications for policies and practice in Norway and other higher education contexts, we also want to point out some further implications for research. As a qualitative study, the possibility of making general claims about the state of Norwegian universities when it comes to inclusion is limited. Nevertheless, tapping into students' own experiences in a qualitative manner has highlighted important aspects of inclusion. In particular, the manner in which our informants struggle for recognition as equal peers, and the way they reject the notions of deaf students as a special needs education category, tell us much about the likely unintended yet profoundly felt effects of an education system labelling some students as different. An obvious challenge for research in this area is to be sensitive to the ethical aspect of education and take this into consideration when approaching different notions of inclusion.

Conflict of Interests

The authors declare no conflict of interests.

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About the Authors

Patrick Stefan Kermit is Professor of Disability Studies at the Norwegian University of Science and Technology (NTNU), Trondheim, Department of Social Work. Kermit's research interests centre around deafness, inclusion and ethics. He has published papers discussing ethical aspects related to cochlear implantation of pre-lingual deaf children, as well as challenges related to the education of deaf and hearing-impaired children and adolescents.

Sidsel Holiman has a master's degree in Educational sciences from the Norwegian University for Science and Technology and is currently a PhD student at the same university. She works at Statped, the Norwegian national service for special needs education as a senior adviser in the department for research and development. She has extensive work experience within the field of deaf education and sign language.

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Article

Designing a Model for Facilitating the Inclusion of Higher Education International Students with Disabilities in South Africa

Nina (HG) du Toit

Department of Research, Innovation and Partnerships, Faculty of Informatics and Design, Cape Peninsula University of Technology, 7535 Cape Town, South Africa; E-Mail: ninadutoit1@gmail.com

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Abstract

Higher education in South Africa is regulated by several policies, and the obligation of increased access and participation of persons with disabilities into higher education is recognized in legislation (Department of Education, 1997; Department of Higher Education and Training, 2013). However, research indicates that the proportion of students with disabilities in higher education and in study programmes abroad is still very low worldwide (Fazekas, 2017; Organisation for Economic Co-operation and Development, 2011). Study opportunities for these students in higher education institutions abroad, including South Africa, should therefore be increased to provide equal access and experience in an inclusive higher education environment. This study explores possible reasons for the low engagement of South African students with disabilities in international mobility programmes and the function of key role-players in supporting international students with disabilities studying in South Africa (incoming students) and South African students with disabilities studying abroad (outgoing students). This study also explores the ways by which the exchange process could be facilitated more effectively within the context of an inclusive higher education environment. Data on the support services offered to these students was obtained by means of questionnaires sent to the International Relations Offices and Disability Rights Units at higher education institutions in South Africa. The study culminated in the design of a model which specifies the roles of the various role-players in supporting international students with disabilities during their pre-departure, study and return phases.

Keywords

disability; higher education; international mobility programme; South Africa; student

Issue

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1. Introduction

During the last century, a considerable amount of education-related research focused on the influence of globalisation and internationalisation on the character and behaviour of higher education institutions (Altbach, 2002; Cross, Mhlanga, & Ojo, 2011; De Wit, 2011; Edwards, 2007; International Association of Universities [IAU], 2012; International Education Association of South Africa, 2014; Mavhungu, 2003; McLellan, 2008; Mitchell & Nielsen, 2012; Oxford University, 2017; Tadaki, 2013). This contributed to the increased focus on the internationalisation of higher education. Knight (2004, 2013) emphasises that internationalisation needs to be understood at the national as well as at the institutional level. She defines internationalisation of higher education as “the process of integrating an international, intercultural or global dimension into the purpose, functions or delivery of postsecondary education” (Knight, 2004, p. 11). This definition includes the teaching, research and service elements of an institution. Egron-Polak and Hudson (2014) emphasise that the internationalisation of higher education could be a central motor and integral part of an ongoing process of change. Waters (2009) also points out that institutions often borrow cross-national and international policies from each other. These policies are mostly linked to international political organisations, such as the European Union, World Bank and the United Nations Educational, Scientific and Cultural Organisation ([UNESCO], 2017).

The literature further indicates that higher education institutions could play a distinctive role in the internationalisation of higher education (De Wit, 2011; Lutabingwa, 2005; Mthembu, 2004). According to Van de Water, Green and Koch (2008) this could be done through different kinds of international collaborations and strategic partnerships such as the well-known European Union's Erasmus Mundus projects. Institutional strategic partnerships are mostly long-term, comprehensive collaborations between two or more institutions, based on principles of sustained reciprocity and mutual benefit.

At the institutional level, higher education institutions have developed their own strategies to internationalise their research and teaching. The IAU's 4th global survey (2014)[1] on internationalisation of higher education provides important information regarding these developments, together with challenges in internationalisation of higher education (Egron-Polak & Hudson, 2014). According to the IAU's Report, student learning and mobility could be one of the priorities of internationalisation, with the expected benefit of student knowledge and appreciation of international issues. The recruiting of all students, including students with disabilities, to participate in international mobility programmes[2] should, therefore, be one of the focus areas at higher education institutions.

In South Africa, several policies have been developed in recent years that regulate higher education in alignment with international developments. This includes the *Education White Paper 3* (Department of Education, 1997) and the *White Paper on Post-School Education and Training* (Department of Higher Education and Training [DHET], 2013). Values such as equity, non-discrimination, and humanity, which highlight the principle of social inclusion, are endorsed by the Constitution of the Republic of South Africa (1996). Regarding higher education, these policies promote increased access for previously disadvantaged students[3], including students with disabilities. As articulated in the *National Plan for Higher Education* (Department of Higher Education, 2001), the moral and educational responsibility rests with individual institutions to ensure effective access and success for all students.

However, higher education access and participation for students with disabilities should be broadened to include international exposure and experience in an inclusive environment, as well as the development of a student network of international partners. To achieve this, UNESCO (2017) stipulates that successful implementation of inclusion principles depends on an integrated working system, involving all role-players.

No national data or other information could be found regarding incoming and outgoing international students with disabilities[4] at higher education institutions in South Africa, although several policies and reports have already emphasised the need for a more comprehensive databank regarding students with disabilities in higher education (Department of Social Development, 2015; Howell, 2005). However, MacGregor (2014, p. 1) points out that "since 2007, the average growth rate of all international students has been 4.4% per annum, compared to the national average of 5.47%". Under these circumstances, the increase of numbers of all international students necessitates the need for identifying key role-players at higher education institutions to ensure that all international students benefit optimally from their international experience.

Rouhani (2007) distinguishes several key role-players in the broader framework of the internationalisation of higher education. These include international agencies, national governments, higher education institutions, staff, students, and the private sector. The aims of these key role-players may differ, overlap or complement each other. In the South African context, key role-players include government departments, the higher education sector, institutions, statutory bodies, professional associations, students and sponsors. According to Rouhani (2007) the interactions among the above key role-players lack coordination.[5] Rouhani (2007) also points out that no national policy on internationalisation in South African higher education has been finalised yet. However, on 8 May 2017, the DHET released a draft policy framework for the internationalisation of higher education for comment.

2. Access to International Higher Education Mobility Programmes for Students with Disabilities

As a human rights and development issue, disability is not an attribute of a person, but results from "the inter-

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[1] This report presents the largest and the most geographically comprehensive collection of primary data on internationalisation of higher education available today.

[2] In this study the term "mobility" refers to students who study abroad without a partnership or agreement between his/her home institution and a host institution. Most of these students register for a full degree at the host institution. The term "exchange" applies to Erasmus Mundus scholarships which runs from a minimum of one month to a maximum of one year. An exchange student lives temporarily in a foreign country and attends courses at a host institution but remains registered at his/her home institution. The host institution does not award degrees/diplomas to exchange students.

[3] The term "previously disadvantaged students" refers, amongst others, to "the difficulty experienced by disabled people in South Africa, especially disabled black people, who have been historically disadvantaged in a number of ways under the apartheid system, including substantial exclusion from all levels of education" (Howell, 2005, p. 18).

[4] The term "incoming International students with disabilities" refers to students coming to South Africa from countries outside South Africa, whereas "outgoing international students with disabilities" refers to students from South Africa studying at a higher education institution abroad.

[5] Fazekas and Ho (2014, p. 54) also highlight the "lack of adequate information or insufficient cooperation within and between Higher Education Institutions when it comes to supporting international students with disabilities".

action between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others" (United Nations, 2006, p. 3). The South African disability movement and government also approach disability from a social model perspective. Howell (2005, p. vi) states that "the response to disability in the social model is the restructuring of society for it to be able to deal appropriately with people with impairments". It also "enables people with disabilities to express their situation in terms of human rights and as an issue of equality" (Fazekas, 2017, p. 2).

According to the United Nations Convention on the Rights of Persons with Disabilities ([UNCRPD]; United Nations, 2006, p. 3), people with disabilities include "those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with other".[6] In order to curb the potentially devastating effects of these barriers, the international community has introduced legislative interventions, including the UNCRPD (United Nations, 2006) and the World Health Organisation's *World Report on Disability* (2011), which seek to entrench the human rights of individuals with disabilities. The UNCRPD addresses a variety of issues, including the rights of all forms and levels of education (United Nations, 2006, Article 24). In higher education, this means access for students with disabilities to all opportunities, facilities and services that are available to other students, enhancing their full participation in various university activities and embracing the social model of disability (Broderick, 2018; Fazekas, 2017).

There is an extensive literature worldwide in the field of international mobility programmes in higher education (for e.g., Daly & Barker, 2005; Dean & Jendzurski, 2013; Mitchell & Vandegrift, 2014), but limited information on international students with disabilities. However, the Association for Higher Education Access and Disability, the European Association on International Education: Access and Diversity Expert Community [EAIE: ADEC], the European Commission, and the European Disability Forum are useful resources on matters concerning students with disabilities' international involvement, experiences, as well as learning and access needs. The Support Centre for Inclusive Higher Education (SIHO, & LINK Network, 2012), as well as Fazekas and Ho (2014), and Fazekas (2017), undertook research projects on the international mobility of students with disabilities in European countries, whereas the European Action on Disability within Higher Education (2016) explored the mobility of all students in the light of diversity. In addition, Mitra (2006) developed a survey of daily routines of international students with disabilities, whereas Holben and Ozel (2015) focused on the mentoring of these students. The Erasmus Student Network in Europe ([ESN], 2017) recently finalised their research on the international experience of students with disabilities in international mobility programmes and launched their new MappED inclusive mobility platform in Brussels on 30 August 2017.

In 1995, with funding from the United States, Mobility International USA (MIUSA) launched the National Clearinghouse on Disability and Exchange to broaden the participation of people with disabilities in international exchange programs (MIUSA, 2017). MIUSA offers comprehensive information, referral services, and training for people with disabilities and exchange organisations (Brademas, Fulbright, & Sygall, 1997). Several other organisations also provide information and services on the international mobility of students with disabilities. These include, amongst others, the American Higher Education Association for the Disabled, as well as Emerging Horison.

According to the European Commission (2014), only 339 students with disabilities participated in international mobility (study) programmes during the academic year 2012–2013. Although an increase of 15% has been observed in comparison with previous years, the percentage of students with disabilities who participate in these programmes is still exceptionally low (Fazekas, 2017; Institution of Higher Education, 2016). MIUSA (2017), as well as Dessoff (2006), also highlight the lack of participation and the under-representation of students with disabilities in international mobility programmes.

3. Overview of the Study

The study was guided by the following three research questions: a) What are the reasons for the low engagement of students with disabilities in international mobility programmes? b) Who are the key role-players in facilitating the exchange experience of international students with disabilities in an inclusive higher education environment? c) What are the roles and responsibilities of the key role-players in supporting international students with disabilities in meeting their learning and access needs effectively?

As contextual framework for exploring the interdependence and roles of relevant role-players in supporting international students with disabilities, the ecological system theory of Bronfenbrenner (1979; Skinner, 2012) was utilised in an adapted format. The theory includes micro-, meso-, exo-, macro- and chron-systems. These systems are linked and influence one another. In this study, the micro-systems include the institutional non-academic and academic staff, the student population, international students with disabilities, as well as several external role-players. In the adapted format, the meso-system represents the interactions between the micro-systems (different role-players) in an inclusive higher education environment. The exco-system represents the host/home institution with its internal policies on internationalisation. All these systems influence each other's functionality and

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[6] In this study, the definition of people with disabilities also includes people with chronical illnesses.

operate within the overall macro-system of international higher education. Finally, a support services model is proposed that stipulates the functions of the different role-players in supporting international students with disabilities, and also indicates other aspects involved in the social inclusion of these students.

The data collection tools consisted of documents and questionnaires. Since the main purpose of the data collection process was to identify current tendencies regarding the research topic at the respondents' higher education institutions, the captured data was not analysed quantitatively. Due to the small number of respondents[7], the findings could not be generalised. Using the content analysis method, specific themes were identified. To ensure the validity and trustworthiness of the captured data, data was double-checked with the specific respondents.

Although South Africa has 26 public higher education institutions, only 22 of these complied with the selection criteria for respondents.[8] For institutions who met the criteria, comprehensive questionnaires were developed for their IROs and DRUs, respectively. Three IROs from three traditional higher education institutions and from urban areas, as well as two DRUs from rural and eight DRUs from urban areas respectively, responded. Six of the responding DRUs belong to traditional institutions, three to institutions of technology, and one to a comprehensive institution.

4. Data Analysis, Findings and Discussion

During the data analysis process, four main themes were identified, namely: a) policies, b) statistical data, c) institutional structure, and d) support of international students with disabilities. The last theme consisted of six sub-themes, namely: 1) the pre-departure, 2) study and 3) return phases, 4) the support services and 5) role-players, as well as 6) the challenges faced by the incoming and outgoing international students with disabilities. The themes and sub-themes should be viewed within the broader framework of the internationalisation of higher education institutions, which has an important and meaningful influence on the international mobility of students with disabilities.

4.1. Policies

The data indicated that currently South Africa does not have an explicit national strategy for the internationalisation of students with disabilities in higher education. Although institutional policies on internationalisation of students are in place at the respondent IROs, there are no specific references to international students with disabilities. It seems that they are included as part of the broader category of international students. However, it is important that reference should be made to their specific learning and access needs. Seven of the respondent DRUs indicated the existence of a policy on the support of international students with disabilities, whereas three respondents pointed out that support of these students was included in the main policy on support of local students with disabilities.

All the respondent institutions have internationalisation strategies in place which promote international ties with institutions abroad, including opportunities for professional staff and student development. However, no clear reference is made to staff and students with disabilities.

4.2. Statistical Data: International Students with Disabilities

The lack of accurate and reliable statistical data on international students with disabilities, both at the national and institutional levels in South Africa, was one of the main findings of the research. Although most of the respondent IROs were able to provide statistical data on current international students without disabilities, the information on outgoing and incoming international students with disabilities was inadequate. However, in one instance, the IRO, who works closely together with the DRU at the institution, was able to provide clear data. The lack of statistical data could be the result of the protection of data of personal nature, unwillingness on the part of international students with disabilities to disclose their disability, and insufficient communication between the relevant role-players.

The respondent DRUs, on the other hand, were able to provide statistical data on current students with disabilities. Six DRUs were aware of incoming international students with disabilities, although the number of these students, as captured by the DRUs, was low (2,3%).[9] Four DRUs indicated that they were not aware of any incoming international students with disabilities. As far as prospective outgoing students with disabilities are concerned, no respondent had any data.

4.3. Institutional Structure of Respondent IROs and DRUs

The data indicated that, although each of the 10 respondent institutions had an IRO, the designation of the of-

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[7] Only 10 institutions, out of a total of 22, responded to the questionnaires that were sent out.

[8] The selection criteria for respondent institutions were the following: a) presence of an International Relations Office (IRO) and/or Disability Rights Unit (DRU); b) a representative variety of institutions, including universities of technology, traditional universities and comprehensive universities; c) urban and rural institutions; d) no institutions established during the last three years; and e) no distance education institutions.

[9] A total of 64 incoming international students with disabilities out of a total of 2,750 students with disabilities were on the six DRUs' databases. 45 of these international students were from Africa. Rouhani (2007) points out that most sponsors prefer to send students from the rest of the African continent to South Africa rather than overseas for higher education and training. According to Teferra (2017, p. 244) the reason for this is that since "South Africa has a strong economic and highly developed higher education system compared to other African countries, it has become a destination of choice for most African students and scholars wanting to further their studies and career opportunities".

fices differed between the institutions. This was related to the line-function and location of the IRO within each institutional structure. The designation most commonly used was "International Relations Office", although "International Student Division", "Office of International Affairs" and "International Student Office" were also used in a few cases. Most of these offices report directly to the Deputy Vice Rector of the institution.

The designation "Disability Rights Unit" was used at most of the respondent institutions, although two units preferred the term "Disability Unit". Four of the DRUs function as independent units, but report to the Office of Student Affairs. Six respondent DRUs are part of Student Counselling, which also report to the Office of Student Affairs.

4.4. Support of International Students with Disabilities

During the data analysis process, it became clear that support services rendered to international students with disabilities could be grouped into three main phases, namely a pre-departure, study and return phase. The roles and responsibilities of the key support role-players in these phases could also be identified.

4.4.1. Pre-Departure Phase

Most of the respondents considered the pre-departure phase as the most important.[10] Respondent IROs and DRUs indicated that, for awareness and marketing purposes, websites were also available for incoming international and prospective outgoing students with disabilities. However, not all websites were accessible. The respondent IROs indicated that their websites provided information on international study opportunities, the application process and general information regarding their offices. The DRUs' websites focused mainly on specialised support services to all students with disabilities, including international students with disabilities.

Although awareness-raising regarding international exchange programmes was pointed out as one of the important roles of IROs, the data showed that, in practice, students with disabilities usually became aware of these opportunities through other sources like friends, class mates, family members and lecturers. These role-players were usually aware of international mobility programmes or had been involved in such programmes themselves. However, it became clear that awareness-raising and marketing initiatives regarding international mobility programmes for international students with disabilities needed more attention at most of the respondent institutions.

Two respondents mentioned that in the past, outgoing prospective students with disabilities used the IRO as a "first desk contact place" for application processes, information on study visas, clearance and immigration requirements, as well as financial issues. One DRU also assisted some students with the preparation of examination concession and accommodation documents before their departure to the host institution.

Most of the respondents indicated that only a very small percentage of incoming international students with disabilities personally contacted the IROs or DRUs at the host institution before leaving their home country. In cases where they did so, their administrative needs were attended to, but for their additional needs they were in most instances referred by the IRO to the DRU for advice and support.

The information needed by incoming international students with disabilities were in most cases related to application matters, academic programmes, support services, accessibility of buildings, as well as accessible accommodation (technically referred to as "reasonable accommodation"). Unfortunately, most of these students arrived at host institutions without any pre-departure communication with role-players at the host institution. This resulted in serious adjustment challenges for these students in many cases. The reasons for not contacting the host institution included insufficient information, a lack of awareness-raising and marketing of available support services at home and host institutions, the absence of an exchange agreement between the home and host institutions, a lack of communication between key role-players and prospective international students, and the preference of some of these students not to disclose his/her disability.

Two IROs and five DRUs indicated that online welcome guides/international student guides were available for all international students. Unfortunately, most of these guides did not provide any information (for e.g., contact numbers) regarding the learning and access support services that were available to international students with disabilities. It is important that role-players in the international mobility process, such as the home and host IROs, as well as the specialised support services and academic coordinators and academics, provide all the necessary information, advise and support to prospective international students with disabilities in their choices of available host institutions and study programmes (EAIE: ADEC, 2014; Soneson & Cordano, 2007).

60% of the respondents indicated that parents were likely to contact DRUs before their son or daughter arrives at the host institution. In most cases the communication related to the severity level of the student's disability, as well as the necessity of the exchange of important information in this regard. One respondent mentioned that their general preference was to work only with the students "because students are adults", but in the case of students with autism, the parents would be contacted.

It is important that, although pre-departure orientation sessions are the responsibility of IROs and DRUs, other role-players are also included, for e.g., travel agen-

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[10] In this regard it has been pointed out that this phase should start well in advance (EAIE: ADEC, 2014), since it could be time-consuming and needed planning.

cies, visiting international students from the host country/institution, returning international students with disabilities, as well as friends and family members who already visited the host country. During orientation sessions involving the institutional role-players, prospective outgoing international students with disabilities and parents, important and necessary information should be shared. Since most students with disabilities have a fear of the unknown and question their own ability to cope in new environments (Fazekas, 2017), these students, as well as their parents, would benefit from pre-departure orientation sessions. The EAIE: ADEC (2014, p. 1) also recommends that prospective outgoing international students "consider going on a preparatory study visit…to get a full picture of what to expect (living, learning, social life, etc.), and to get in touch with staff and other students".

4.4.2. Study Phase

Furthermore, the data showed that the IRO's level of involvement with incoming international students with disabilities during the study phase depended on the presence of a DRU on campus. If an efficient DRU was in place, the IRO would strongly rely on the DRU's relevant expertise and the support services rendered to students with disabilities.

Although general support services for local students at the respondent institutions were also available to incoming international students with disabilities, these students encounter additional barriers (Fazekas, 2017; Katz, Soneson, & Cordano, 2007) that have to be addressed. At most of the respondent institutions, financial support for international students was not included. With regard to personal assistance, there was limited support for incoming international students with disabilities. However, a buddy/peer system was available, which was mostly arranged by the DRU of the host institution. At one institution, a local student organisation, together with the DU, arranged the buddy-support for incoming international students with disabilities. Buddies could play an important role in helping and orientating such students in the new study environment. Unfortunately, no information was provided by the respondents on the general training of buddies and other role-players with respect to the learning and access needs of incoming international students with disabilities.

Regarding the availability of maps of the institution's campus(es) and surrounding areas, the data indicated that at most of the respondent institutions this information was lacking. Three institutions indicated that maps were available online. This could provide important information for incoming international students with disabilities (ESN, 2017). The respondents indicated that DRUs should be the first point of contact in cases where these students required information on learning and access needs. In most cases the DRUs also acted as coordinators of support services for these students, in close cooperation with relevant role-players from academic and non-academic departments.

The process of academic support to international students with disabilities differed slightly between the respondent institutions. Language proficiency was regarded by the respondents as the most important aspect for the inclusion or exclusion of incoming international students at the host institutions and in the new environment. However, the data showed that language requirements for these students differed between institutions, which could influence the teaching and learning experience of incoming international students with disabilities drastically.

Respondent institutions had their own social organisations which supported all students, including international students. Stafford (1984) highlights the importance of external role-players in building friendships and relationships, as well as by providing cultural orientation, in the social inclusion of incoming international students with disabilities. Although physical, academic, social and practical support are very important to these students, the data showed that emotional and mental support could be regarded as the most crucial aspect of a successful international experience.

4.4.3. Return Phase

Furthermore, the data showed that prior to the return phase some specific final administrative matters had to be attended to. In this regard, IROs could play a leading role in supporting returning international students with disabilities regarding the required procedures and travel arrangements. Gaw (2000) also draws attention to the reverse culture shock experienced by students returning from studying abroad and emphasises that they need a pre-return orientation session to prepare them emotionally for re-entering their home institution and country. This is due to the fact that experiences at the host institution and country often change the students' perceptions and world view. When back at their home institutions, returning international students with disabilities could contribute to awareness-raising, motivation and orientation sessions regarding international mobility programmes (EAIE: ADEC, 2014). Collaboration between the IRO, other relevant role-players and returning international students with disabilities should not be underestimated. The data showed that prospective outgoing international students preferred listening to the international mobility experiences of peers who have already visited host institutions.

4.4.4. Support Services

The data showed that incoming international students with disabilities were usually referred by IROs to DRUs for support services, as well as to Student Counselling and academic faculties, where necessary. Support services to incoming and outgoing international students with disabilities, which were identified by the respondents, include the following: accessible living (10), accessible learning environment (10), management of exchange scholarship matters (10), personal assistance (4), buddy/peer support (7), selection of modules and assistance in registration (8), additional language courses (6), specific academic support (10), academic support in and out of class (8), mentoring of international students (2), integrated sports, cultural and social activities (8), clinical services (10), counselling services (10), and transport of students with physical disabilities (6).[11] A high percentage of incoming international students with disabilities personally approached DRUs for support or were informed by friends regarding the latter's support services. Referrals from role-players at home institutions or referral information gained from websites accounted for only 10% of referrals to DRUs.

Three respondents indicated that they were uncertain about the availability of support services rendered by the DRU at their institution. At some institutions, two or more role-players were responsible for the same support services.[12] According to the data collected, not all support services were provided to incoming international students with disabilities at all the respondent institutions (for e.g., transport). One respondent indicated that all the support services available to other international students were also available to incoming international students with disabilities. This is in line with the important principle of inclusion.

All incoming international students studying at a host higher education institution need support before and during their stay, even more so in the case of international students with disabilities. These students need the same general support as other international students, which is mostly available at respondent higher education institutions, however, in the case of most international students with disabilities, additional support is needed to enable them to be successfully included in the host institution environment (EAIE: ADEC, 2014; Fazekas, 2017). A holistic approach in supporting these students at host institutions is of the utmost importance, and all key role-players should be involved.

4.4.5. Role-Players

Respondents identified 28 role-players that are involved in supporting incoming international students with disabilities. These role-players represent both the non-academic and academic institutional sectors, as reflected in Table 1.[13]

Role-players responsible for specific support services for incoming international students differed between institutions. At eight institutions the IROs were responsible for the management of exchange and mobility scholarship matters, whereas one institution indicated that their Department of Research, Innovation and Support handled these matters. One institution indicated that exchange scholarship matters were provided through their DRU. One IRO provided useful details about the different role-players in their Office and their responsibilities. This included the Manager, a Senior Administrative Officer (for matriculation exemptions), a Coordinator (for study abroad), an Administrator (for administering loans and scholarships), a Student Life and Finance, Programme Administrator (for study abroad) and a Help Desk Assistant (for clearance to register and with responsibility for student files). The data indicated that support of these students by friends, buddies and parents should also not be underestimated. In addition, private providers (e.g., community leaders, personal assistants, medical services, sponsors and host families), should be involved, if needed.

Role-players should be active in different areas of support, depending on their functions and responsibilities in their specific unit, office, department, organisation or external profession. Communication between role-players in meeting the learning and access needs of international students with disabilities is crucial. Unfortunately, the captured data showed a lack of communication and collaboration between specific role-players, as well as a lack of knowledge regarding the specific needs of incoming and outgoing international students with disabilities. Some role-players relied on other role-players to provide support in meeting these students' learning and access needs, such as mentoring. In other cases, more than one role-player regarded the same support service as their responsibility. This lack of collaboration often resulted in double provisions of the same support service.

The data showed that respondent DRUs were well-equipped and knowledgeable to support international students with disabilities, and that they mostly functioned as "umbrella" units in supporting incoming and outgoing international students with disabilities in their learning (academic) as well as access (academic and non-academic) needs. However, these students often experienced a feeling of exclusion in cases where DRUs took responsibility for all the support services. International students with disabilities could only experience real inclusion when all role-players took responsibility for supporting them in their particular field of expertise, for example, by offering of general orientation sessions, organising social and sports events on campus, etc.

4.4.6. Challenges

Most of the respondents were not aware of the challenges facing outgoing students with disabilities. One

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[11] The number of respondent higher education institutions which provided the specific support services are indicated in brackets.

[12] At the one respondent institution the Residence Department, Infrastructure Department and Disability Rights Unit worked together to provide accommodation access for incoming international students with disabilities.

[13] The designations of key role-players at the respondent institutions often differ. The different designations used are indicated in Table 1 by the forward slash (/) symbol.

Table 1. Role-players that support international students with disabilities at the respondent institutions.

Role-players	Institutional sector
International Relations Office (IRO)	Non-academic
Disability Rights Unit (DRU)	Non-academic
Admissions/Student Enrolment Centre/Administration	Non-academic
Financial Department	Non-academic
Infrastructure/Facilities Management	Non-academic
Examination Office/Assessment Office/Examination Division	Non-academic
Office of Student Affairs /Student Support and Services /Student Development	Non-academic
Campus Health and Wellness Centre/Campus Clinic/Student Health	Non-academic
Residence Department/ Residential Services /Housing services/Housing and Residence Affairs	Non-academic
Student Counselling/Centre for Student Counselling and Development/Counselling and Careers Development Unit	Non-academic
Sports Office/Sport and Recreation Unit	Non-academic
Social Justice and Transformation Unit	Non-academic
Development and Leadership Unit	Non-academic
Student Organisations/Student Representative Councils/House Committees	Non-academic
Buddy/Peer Support	Non-academic
Transport Services/Public Services	Non-academic
Private Providers/Sponsors/Host Families	Non-academic
Academic Faculties	Academic
Academic International coordinators/Academic International Managers	Academic
Lecturers	Academic
Centre for Teaching and Learning	Academic
Centre for Languages/Language Centre	Academic
Department of Research Innovation and Support	Academic
Centre for Academic Development	Academic
Library Services	Academic
Sign Language Interpreters	Academic
Academic Assistants	Academic
Tutors	Academic

respondent remarked that these students were essentially catered for by the IRO, and that the DRU had very little contact with them. The same respondent mentioned that very few incoming international students with disabilities at their institution had "high support" needs. These remarks showed a lack of knowledge and insight into the needs of these students. Another respondent highlighted a few main challenges for these students which included language, financial and transport issues, lack of information and orientation, inaccessible residences/buildings and inaccessible academic material. Another respondent mentioned personal challenges experienced by these students which include adapting to a different climate, cultural differences, changes in eating habits, interpersonal relations and concomitant misunderstandings, as well as academic and health difficulties (see also Fazekas & Ho, 2014; Fazekas, 2017). In addition, incoming international students with disabilities from Africa sometimes experienced a negative attitude from local students, which could be regarded as a form of xenophobia (Shindondola, 2002). Respondents also mentioned that the lack of in-depth preparation during the pre-departure phase could increase the challenges faced by these students in physical, cultural, political, social, academic, and safety areas. All these challenges could contribute to a feeling of loneliness and homesickness.

In summary, the data showed that the lack of communication and collaboration between role-players at most of the respondent higher education institutions could be regarded as the main barrier in supporting international students with disabilities effectively.

5. A Proposed Support Services Model for Facilitating the Inclusion of Higher Education Incoming International Students with Disabilities

The model proposed in this section was developed for structuring the support services for all incoming international students, including students with disabilities, within the broader framework of inclusive higher education. The model entails that all the general support services for international students which are rendered by different role-players, should also be made available and offered to incoming international students with disabilities. However, in cases where the incoming international students with disabilities need support for their learning and access needs, the support services also have to include specific units. The model briefly provides information on the specific roles and responsibilities of the relevant role-players. As will be indicated, it differs in this respect from the traditional view that IROs, among other things, are predominantly responsible for the preparation, reception, welcoming, orientation and inclusion of new incoming international students.

Within the proposed model, the IRO's main function is to develop policies, memoranda of understanding, partnerships and relationships with other international higher education institutions. However, marketing and awareness-raising regarding international exchange opportunities for all students, assistance with application and registration procedures, as well as financial issues, especially for students with disabilities, remains the responsibility of the IRO. The IRO has an administrative role and does not have responsibility for the practical inclusion of incoming international students in the host institution's environment. The practical inclusion of these students is the responsibility of the International Student Support Coordinator (ISSC), who supports these students during their pre-departure, study and return phases. However, when the ISSC needs data regarding incoming and outgoing international students and support with the application process for study permits, visas and the payment of international grants, if applicable, the ISSC will communicate and collaborate with the relevant IRO.

The ISSC forms part of the Office of Student Affairs, which has responsibility for all student affairs matters, including the academic and social inclusion of all international students. The ISSC acts as the key role-player and main coordinator of support services for all international students. As a staff member of the Office of Student Affairs, he/she works on a daily basis with the role-players and students as their first point of contact, and acts as coordinator of services that relate to the needs of all international students. During the pre-departure phase, the ISSC contacts prospective incoming and outgoing international students, after receiving information from the relevant IRO. With the support of the ISSC and other relevant role-players, these students are prepared for the study phase at the host university. Welcoming events, welcome guides and orientation sessions for all incoming international students are the responsibility of the ISSC. If incoming international students with disabilities need specific support, they are referred to the relevant role-players by the ISSC. One of the main responsibilities of the ISSC is to promote efficient collaboration and communication between all role-players regarding the holistic support of incoming international students with disabilities. This will ensure that all international student matters, including international students with disabilities, will be coordinated and monitored by the ISSC.

In cases where specific support is needed for incoming international students with disabilities, the DRU functions as the key role-player, and works in collaboration with the ISSC. The DRU is responsible for the specific academic support of these students and also works closely together with academic departments. Specific academic support services usually include the provision of adapted and accessible study material, training in the use of assistive devices, arrangements for examination concessions, as well as the use of peer assistants and sign language interpreters. Together with the academic departments, the DRU monitors the academic development of incoming international students with disabilities and provides learning and access support where necessary. The DRU also has the function to advise the ISSC regarding the access needs of incoming international students with disabilities.

Academic departments need to play an important role in the selection process of prospective incoming and outgoing international students with disabilities during the pre-departure phase. During the study phase, academics are responsible for assisting incoming international students with disabilities in their choice of modules and possibly additional language courses, where necessary, as well as the implementation of adapted teaching and assessment methods. The provision of tutors and academic assistants for incoming international students with disabilities, where needed, are also part of their responsibilities. Relevant departments are assisted by the DRU in supporting these students in the classroom environment.

Non-academic departments include the infrastructure, residence and student counselling departments. In collaboration with the ISSC, they are responsible for ensuring the accessibility of buildings, adapted transport, the provision of accessible accommodation (reasonable accommodation), and the emotional and mental support of incoming international students with disabilities. Furthermore, Student Counselling needs to give guidance regarding coping skills, as well as daily and study challenges, if needed.

Student organisations, sport and culture clubs are responsible, in collaboration with the ISSC, for the social inclusion of incoming international students with disabilities by means of social interaction. This includes exposure to a different culture experience, the provision of buddy support, and the promotion of inclusive sport and culture activities.

External role-players, especially host-families, play an important role in supporting incoming international students with disabilities with regard to their basic daily needs during their adaptation period. Other external role-players, which include community leaders, parents, sponsors and medical services, should also support these students emotionally, financially, physically and socially, when needed. The ISSC acts as coordinator of all these support services. Figure 1 presents a diagram of the proposed support services model.

6. Limitations of the Study

Although invitations were sent to 22 higher education institutions in South Africa to participate in the study,

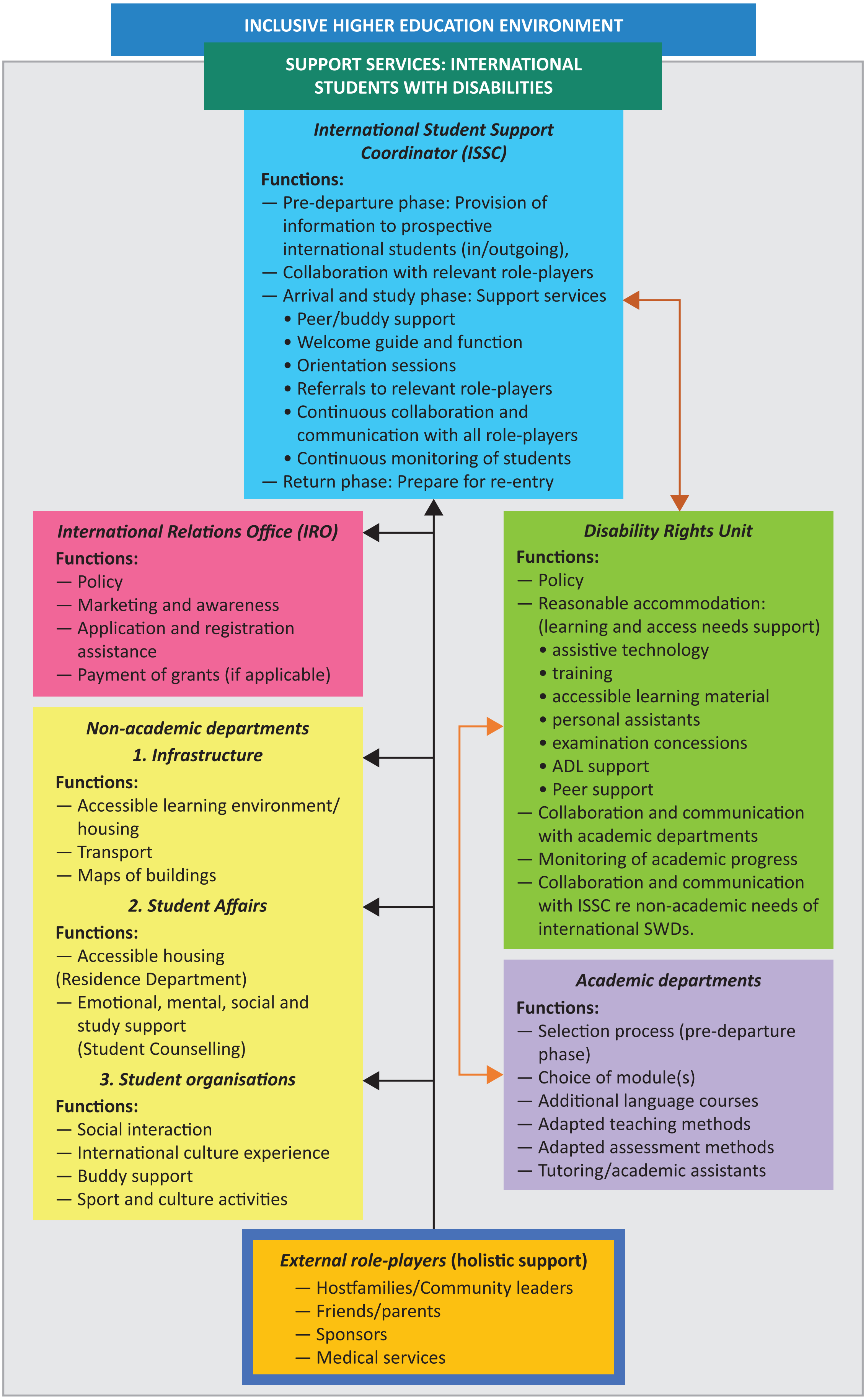

Figure 1. Facilitating the inclusion of higher education incoming international students with disabilities.

a low percentage of IROs responded. This could be attributed to a number of factors, for example, incorrect contact details and information provided on some websites regarding IROs at higher education institutions, the inability of role-players at higher education institutions to provide the requested information, due to a lack of statistic data on international students with disabilities on campus, protocol policies regarding sharing private information, or difficulties to complete the questionnaires within the time that was available. As a result, the findings have certain limitations, and are not presented as universally applicable.

7. Recommendations

Following the findings set out above, the following recommendations are made for facilitating the inclusion of higher education international students with disabilities in South Africa.

7.1. Investigation and Evaluation

a) A more comprehensive investigation should be undertaken of the broader framework for, and effect of, internationalisation and international higher education on the human rights of students with disabilities in South Africa. This should include the experiences of outgoing and incoming international students with disabilities;

b) The current institutional structures for the support of international students with disabilities should be evaluated.

7.2. Awareness-Raising and Marketing

a) More attention should be given to awareness-raising and the marketing of international exchange opportunities for students with disabilities which highlights the benefits of participating in such programmes;

b) Training and workshops should be offered to key role-players, as well as to the general student population, on the learning and access needs of international students with disabilities, and the challenges that they experience in a disabling environment;

c) An effective online network of international alumni should be created and maintained to support prospective and current international students with disabilities;

d) In cases where international study opportunities are not available, the principle of internationalisation at home (Beelen & Jones, 2015; EAIE: ADEC, 2014) should be promoted.

7.3. Role-Players

a) Role-players, both at the national and institutional levels, should be requested to prioritise the collection of accurate and reliable statistical data on students with disabilities and international students with disabilities by means of efficient data collection tools;

b) Dedicated collaboration and open communication between all the relevant role-players at home and at the host institutions are of the utmost importance. Regular interactions, which include meetings and workshops, could contribute in this regard;

c) Joint initiatives should be undertaken by key role-players to develop procedures for the support and referral of international students with disabilities to the appropriate role-players;

d) The roles and responsibilities of all relevant role-players should be clarified and implemented;

e) A dedicated role-player, namely the ISSC, should coordinate and monitor the support services rendered to all international students in an inclusive environment. This should take place in close cooperation with all the relevant role-players;

f) The national government has an obligation to financially support outgoing international students with disabilities, where necessary.

7.4. Social Inclusion of International Students with Disabilities

a) Opportunities for interaction between international students with disabilities and the student population at the host institution should be created at the beginning of the study phase;

b) Open contact groups and workshops could enable international students with disabilities to share their academic experiences with other students and create opportunities for extra support and help;

c) Community partners, for example host families, could contribute to the social and emotional support of international students with disabilities.

8. Conclusion

The scarcity, and sometimes lack, of accurate and reliable statistical data on international students with disabilities, both at the national and higher education institution levels in South Africa, was one of the main findings of the research. This could be due to a number factors, for example, the protection of data of a personal nature, unwillingness on the part of the students themselves to disclose their disability, or insufficient communication and sharing of relevant information between the role-players in this area. This points to the need for a comprehensive, accurate, and up to date data-bank on international students with disabilities in higher education, for purposes of future strategic planning, awareness-raising, and meeting the learning and access needs of these students.

Although policies on the internationalisation of students in general are in place at some higher education institutions, there is no specific reference to international students with disabilities. From a human rights' perspective, reference should be made to their specific learning and access needs. This would not only contribute to an awareness of these students in the institutional and public spheres, but also to insight and knowledge regarding their access needs.

The low engagement of students with disabilities in international mobility programmes could be ascribed mainly to insufficient awareness and marketing initiatives, among them and the institution at large, regarding the programmes. Other factors, such as fear of the unknown, inaccessible environments and financial constraints could contribute to this. The low engagement issue needs to be addressed to a much greater extent at most of the respondent institutions.

The data showed that DRUs were regarded by the respondent institutions as the main, and sometimes the only, role-player in supporting international students with disabilities during their crucial pre-departure, as well as study and return phases. However, this could contribute to the feeling of exclusion which is often experienced by these students. In this regard the appointment of a dedicated ISSC, who is located specifically in the Office of Student Affairs and works closely in cooperation with all role-players in different departments/units, is crucial for supporting international students with disabilities. This will assure an inclusive environment for these students.

The support roles and responsibilities of other key role-players, such as the IRO, DRU, academic and non-academic departments and external role-players, should be outlined more clearly than is the case at present, and should be redefined, where necessary, to promote efficiency and prevent the current overlap of functions. The support services model, which was developed during this study, offers several new perspectives on the support roles and responsibilities of the key role-players, and could contribute in this regard.

Finally, the study identified a lack of sufficient knowledge and insight amongst key role-players regarding the specific learning and access needs of incoming international students with disabilities. This is crucial for the success of all support efforts. Awareness-raising and training workshops on general disability issues would benefit all the role-players involved.

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Conflict of Interests

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About the Author

Nina (HG) du Toit (PhD) is a Research Fellow in the Department of Research, Innovation and Partnerships in the Faculty of Informatics and Design at the Cape Peninsula University of Technology, South Africa. She was Head of the Disability Rights Unit at the same university in 2008–2016 and served as vice-chairperson of the South African Higher Education Disability Services Association. Post-doctoral scholarships were awarded to her in 2011 and 2016 for research on disability issues at the Universities of Antwerp and Ghent in Belgium, as part of the Erasmus Mundus programme.

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Article

Fear of Stigmatisation among Students with Disabilities in Austria

Sarah Zaussinger * and Berta Terzieva

Higher Education Research Group, Institute for Advanced Studies, 1080 Vienna, Austria; E-Mails: zaussing@ihs.ac.at (S.Z.), terzieva@ihs.ac.at (B.T.)

* Corresponding author

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Abstract

In Austria, 12% of all students in higher education report a disability that, at least somewhat, limits their study activities. As they still face many barriers throughout their studies, support services play a key part in their academic success. However, data from the Austrian Student Social Survey demonstrate that every second student with a disability is reluctant to contact fellow students, lecturers, or institutional support in case of study-related difficulties. One in four students with disabilities does not seek any assistance because of stigmatisation fear. With respect to these tendencies, our article examines factors that promote or inhibit the reluctance of students with disabilities to seek support due to fear of stigmatisation. For this purpose, we construct a binary indicator of stigma fear, which encompasses items concerning social isolation or drawbacks to academic opportunities, inhibitions about contacting people or disclosing one's disability. In a regression model, we identify influential factors such as noticeability of disability and degree of study-related limitations as well as social factors like the feeling of anonymity and sense of belonging.

Keywords

Austria; disability; health impairment; higher education; stigma; student survey; support services

Issue

This article is part of the issue "Students with Disabilities in Higher Education", edited by Geert Van Hove (Ghent University, Belgium/VU Amsterdam, The Netherlands), Minne Bakker (VU Amsterdam, The Netherlands) and Alice Schippers (Disability Studies in the Netherlands/VU Amsterdam, The Netherlands).

1. Introduction

There is broad acceptance across multiple disciplines that disability is not just an individual health problem, but also a complex phenomenon, reflecting the reciprocal relation between naturalism and social constructivism, a person's body and the society one lives in (Kastl, 2010). This consensus is reflected in the definition of the World Health Organisation ([WHO], 2018) where disability is defined:

> As an umbrella term for impairments, activity limitations, and participation restrictions. Disability is the interaction between individuals with a health condition (e.g. cerebral palsy, Down syndrome, and depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports).

The intertwinement of individual and collective aspects of disability has also been taken into account at the national level. According to the Austrian Federal Disability Equality Act, disability (in German: *Behinderung*) is the effect of a non-temporary (i.e., lasting more than six months) physical, sensory, mental, or intellectual impairment that impedes participation in society (bmask—Federal Ministry of Labour, Social Affairs and Consumer Protection, 2010).

These are just two examples of the institutionalised social mindset change that has been taking place since the social model—"the bedrock of disability activism" (Shakespeare, 2012, p. 129)—became popular in the 1980s (Oliver, 1983). It distinguishes between *impairment*—mental or physical deficit—and *disability*—the social response to people with impairments (Shakespeare, 2012).

This article focuses on disability in the context of higher education. Using student-level information from the Austrian Student Social Survey, we define disability as any type of self-reported health impairment that, at least somewhat, limits students' study activities. Thus, our definition attempts to incorporate the social model of disability and to take students' individual perception and "sense of self-concept" (Kimball, Wells, Ostiguy, Manly, & Lauterbach, 2016, p. 97) into consideration.

According to the most recent report on students with disabilities (Terzieva, Dibiasi, Kulhanek, Zaussinger, & Unger, 2016), 12% of students in Austria have a health impairment which, at least somewhat, limits their study activities. Their most common problems are related to unexpected sickness absence episodes, but also to a rigid and inflexible study organisation, as well as problematic social interactions with peers and academic staff. As students with disabilities in Austria still face many barriers in the context of higher education, support services play a key role in their academic success. Terzieva et al. (2016) demonstrate, however, that students have limited knowledge of the support provided by their higher education institution (HEI). Every second student with a disability is reluctant to contact fellow students, lecturers, or institutional support in case of disability-related difficulties. Most students with disabilities are simply not aware that help is available (only 17% know about these offers); others question the benefit of such assistance or prefer to solve the problem on their own. Moreover, one in four students with disabilities does not seek any assistance because they fear social isolation or drawbacks to academic opportunities; they have inhibitions about contacting others or disclosing their disability. Fear of stigmatisation presents a significant barrier to help seeking. This is evident in all disability groups, especially among students with non-apparent disabilities such as mental health problems (Terzieva et al., 2016).

People with disabilities encounter stigma in their daily lives, regardless of whether their disability is apparent or not, disclosed or not. As this also applies to the context of higher education, we investigate both individual characteristics and environmental factors that prevent students from seeking assistance provided by the university or from contacting peers or lecturers in case of difficulties because of fear of stigmatisation.

This article addresses the following research question: which factors promote or inhibit the reluctance of students with disabilities to seek support due to fear of stigmatisation? We argue that a better understanding of the difficulties experienced by students with disabilities may enable HEIs to address and alleviate relevant issues or support students in tackling them.

The article is structured as follows: first, we focus on literature related to the experiences of students with disabilities. We define key concepts regarding disability and stigma and review relevant empirical literature. After briefly elaborating on our methodological choices, we present our findings. We conclude with a discussion of the central ideas and some recommendations that have emerged from our work.

2. Theoretical and Empirical Framework

2.1. Concept of Disability

There are many different theoretical approaches to disability, e.g., moral or social justice; however, it is the medical model and the social construction model that are most influential in both research and practice. The traditional medical model attributes disability solely to biological factors so that only medical treatment could allow a disabled person to participate fully in society. While this model problematises the individual, the social construction approach regards society as the problematic component in disability (Goering, 2015; Kimball, Vaccaro, & Vargas, 2016; Shakespeare, 2012; Waldschmidt, 2005). The social construction model distinguishes between the physical (impairment) and the social (disability) dimension, thus advocating for a shift in focus from "physical limitations of particular individuals to the way the physical and social environments impose limitations upon certain groups or categories of people" (Oliver, 1983, p. 23). These opposed conceptions of disability have been criticised for failing to address the complexity of the disability phenomenon, either by viewing disability as an individual medical problem (a bodily flaw from which social disadvantages derive) that needs to be treated, or by downplaying the health dimension of disabilities and considering social structures as the root cause of any disadvantages experienced (Kimball, Wells, et al., 2016; Shakespeare, 2012).

Disability is a multidimensional phenomenon that differs across cultural, societal and historical contexts. Approaches to measuring disability vary greatly depending on the aspects examined, their purpose and application. The ambiguity of the term might contribute to the major differences in the reported share of students with disabilities. According to the project EUROSTUDENT, though based on a standardised definition, the share of students indicating any type of health impairment or disability ranges from less than 10% in France, Georgia, Romania, Albania, and Serbia to more than 25% in Iceland, the Netherlands, and Sweden (Hauschildt, Vögtle, & Gwosc, 2018). Furthermore, it is evident that not all students with health impairment, chronic illness, mental disorder, or other long-standing health problems perceive themselves as *disabled*. Using appropriate terminology is fundamental to recognising the diversity and complexity of disability. Support services, however, often use very narrow terms, which might account for their inability to address the diverse demand of the student body (Terzieva et al., 2016).

Finally, our analyses focus on higher education students with self-reported health impairment that, at least somewhat, limits their study activities, regardless of the type of impairment. This definition attempts to take students' individual perception of their health condition into consideration and to avoid assigning them to categories with which they do not identify. In other words, if they do not perceive their impairment as a relevant aspect of their experiences on campus, they are not part of our target group.

2.2. Disability Stigma

Regardless of how disability is defined, there is widespread consensus (based on broad empirical evidence) that "people with disabilities constitute a stigmatised group and that disability stigma has a negative impact on students with disabilities in higher education settings", as pointed out by Kimball, Wells et al. (2016, p. 98).

Most closely associated with the work of Erving Goffman (1963), stigma refers to "an attribute that is deeply discrediting", perceived as "an undesired differentness from what we [the *normals*] had anticipated" (Goffman, 1963, p. 5). Goffman identifies three types of stigma: *physical stigma* (any physical deformity), *stigma of character traits* (e.g., unnatural passions, dishonesty, mental disorder, radical political behaviour), and *stigma of group identity* (e.g., race or religion) (Goffman, 1963, p. 5). Since a disability is often considered as stigma, people with disabilities are at risk to experience stigmatisation due to their physical appearance, behaviour, or the fact that they disclosed as disabled. Disability visibility does not automatically mean stigmatisation but may facilitate being stigmatised by others (Cloerkes, 2009). The extent to which individuals' disability is visible to others and possibly does not allow them to *pass for normal*, constitutes a key determinant of their experiences.

Stigma conceals a double perspective depending on whether the differentness is "evident on the spot" or "neither known about by those present nor immediately perceivable by them" (Goffman, 1963, p. 4). Those with a visible stigma—such as a physical disability—are discredited, whereas those with an invisible stigma—such as mental disease or learning disability—are discreditable, i.e., they are not automatically discredited, but face the risk of discredit. In their interaction with *normals*, the discreditable engage in a process of impression or information management with regard to their blemishes—they can decide "to display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where" (Goffman, 1963, p. 42). Hence, not only the stigma but also the effort to conceal it "become 'fixed' as part of personal identity" (Goffman, 1963, p. 42). This impression management occurs when individuals want to convey certain attributes that render them and conceal attributes that (might) stigmatise them (Waterfield & Whelan, 2017, p. 993).

Goffman's distinction between the discredited and the discreditable as well as the process of impression management are fundamental to understanding the significance of the social environment and the decision to conceal or disclose one's disability. In addition, the concepts of public stigma and self-stigma, i.e., the societal discrimination and the "self-imposed behaviours and responses…such as internalising negative social responses, which lead to feelings of rejection" (Corrigan & Kleinlein, 2005) emphasise the relevance of disclosure in reducing or enhancing the impact of stigma. According to these considerations, we do not only focus on students who have already experienced stigmatisation, but also consider the fear of stigmatisation as equally detrimental to individual identity.

2.3. Stigma Effects

Stigma does not remain without consequences. Martin (2010) describes stigma as "a socially constructed mark of disapproval, shame, or disgrace that causes significant disadvantage through the curtailment of opportunities" (Martin, 2010, p. 261). Many researchers acknowledge through various empirical studies that students with disabilities encounter significant stigma effects and attribute their difficulties to disability stigma (Kimball, Wells, et al., 2016; Markoulakis & Kirsh, 2013).

Students with disabilities struggle with fear of stigmatisation and are reluctant to disclose their difficulties on campus in order to protect their privacy and avoid discrimination (Markoulakis & Kirsh, 2013; Martin, 2010; Tinklin, Riddell, & Wilson, 2005). They fear diminished opportunities in their studies but also in future employment endeavours, and community interactions (Martin, 2010). According to Austrian and German survey data (Poskowsky, Heißenberg, Zaussinger, & Brenner, 2018; Terzieva et al., 2016) students with disabilities indicate that their peers, lecturers, and members of administration often have little familiarity with disabilities and do not know how to interact with someone with health impairment. Some believe that their peers hold negative attitudes towards them. Thus, some students choose to deal with their problems on their own and prefer as few people as possible to know about their health condition. Moreover, students with disabilities have troubles networking with fellow students, experience social isolation, and report insufficient study-related exchange (Poskowsky et al., 2018).

Consequences of (fear of) stigmatisation may be even more severe when considering that many students are in a vulnerable position since higher education may require many adjustments—living away from home, making new friends or dealing with financial difficulties (Tinklin et al., 2005, p. 510). Drawing on case studies of students with mental problems, Tinklin et al. (2005) indicate that "the nature of higher education had exacerbated and even created some of the students' difficulties" and that "lack of understanding among lecturers, a culture in which it was difficult to admit to having difficulties, a lack of support for learning and badly designed learning experiences had all contributed to the students' distress" (Tinklin et al., 2005, p. 510).

Disability stigma may induce a reluctance to disclose one's disability and to seek assistance or to use available services at the HEI (Denhart, 2008; Kranke, Jackson, Taylor, Anderson-Fye, & Floersch, 2013; Markoulakis & Kirsh, 2013; Weiner, 1999). However, research consistently shows that students who take advantage of support services perform better academically (Dong & Lucas, 2016; Kranke et al., 2013; Trammell & Hathaway, 2007; Trammell, 2003). Stigma can be seen as a "powerful force" in preventing students "from gaining access to appropriate support" (Martin, 2010, p. 259). Martin (2010) found that the majority of the students surveyed with mental health difficulties had not disclosed their health-related problems to university staff, even though they affected their studies. The prevalent reason is fear of discrimination and disadvantages (e.g., restricted opportunities at the university or in future employment) arising from the stigma of mental illness. Such negative experiences can leave students feeling "depersonalised, rejected, and disempowered" (Pilgrim, 2009, as cited in Martin, 2010, p. 261). In contrast, students who disclosed their mental health condition to university staff had improved outcomes and report receiving helpful assistance, primarily regarding submission deadlines (Martin, 2010, p. 261).

Kranke et al. (2013) identified three choices that students with non-apparent disabilities make regarding disclosure of their disability to faculty: 1) immediate disclosure, when the functional limitations compromise their success; 2) disclosure after some time, once the risks to their academic performance outweigh the fear of negative perceptions by professors; and 3) no disclosure—the driving force behind students' decision to not disclose is the significant fear of being stigmatised (Kranke et al., 2013, pp. 47–48).

Unlike students with hidden disabilities, those with apparent disabilities do not have the option of not disclosing in order to avoid stigma and prevent undue discrimination. Research shows that students with disabilities report that they do not "deserve" special consideration and do not want to disclose their disability to avoid being perceived as double-minded or as seeking unmerited privileges (Martin, 2010; Terzieva et al., 2016; Weiner, 1999). Some students are not aware that their disability qualified them for academic accommodations because they did not perceive themselves as disabled (Terzieva et al., 2016; Weiner, 1999).

The social environment and the personal contact with peers and faculty play a key role in the process of stigmatisation. Students without disabilities often feel uncomfortable or unsettled because they do not know how to interact with peers with health impairment (Terzieva et al., 2016). According to Fichten and Amsel (1986), stereotypes attributed by students without disabilities to their physically disabled peers can "interfere with the comfortable interaction between the two groups" (Fichten & Amsel, 1986, p. 423). "Able-bodied" students often described those with physical disabilities in negative terms, e.g., "aloof-introverted, lazy-submissive, and ingenuous-unassuming" (Fichten & Amsel, 1986, p. 423), they were attributed less socially desirable traits and perceived to be the opposite of people without disabilities.

3. Methodological Approach

3.1. Data

In the following analysis, we use data from the Austrian Student Social Survey (IHS—Institute for Advanced Studies Vienna, 2016). Designed as a complete student population survey, this cross-sectional study covers a wide spectrum of topics related to the social and economic situation of students. The survey has been carried out at regular intervals since the 1970s and is thus one of the most important sources of information for higher education policy in Austria.

For the purposes of this article, we use the most recent data available—spring semester 2015. The total target population at the time of survey amounts to approximately 318,000 students. More than 47,000 students (valid cases) of all types of HEIs participated in the online survey 2015; among them, 5,424 students reported having a disability that, at least somewhat, limits their study activities (Terzieva et al., 2016, p. 8).

The most recent report on students with disabilities in Austria (Terzieva et al., 2016) shows that the female prevalence of disability is nearly 20% higher than for males (12.5% versus 10.5%), though this gender gap decreases with age. With regard to age, disabled students are on average a year older than the general student population (28.6 years old versus 27.3 years old). These age differences are closely related to different transition patterns, more frequent (health-related) study interruptions, and slower study progress. Students with disabilities tend to transfer from upper-secondary to tertiary education with a delay or enter higher education via a non-traditional route (e.g., students who do not have an upper-secondary qualification, or obtained it later in life via evening classes, adult learning, etc.). They show a comparatively slower study progress due to health-related interruptions or study-related organisational and structural difficulties. Chronic diseases (36%) and mental health problems (33%) are the most often named limitations, followed by sensory impairments (vision and hearing), mobility impairments (10%), and learning disabilities (4%). 65% of students indicate a non-apparent disability, which is a key determinant of their experiences. Noticeability aside, more than half of the students with a disability report severe disability-related limitations in their study activities. Three in four students with disabilities, especially females, face some kind of disability-related difficulties in their studies: unexpected sickness absence episodes, exam-related barriers, rigid assessment methods, or inflexible study organisation, e.g., compulsory attendance, inflexible registration procedures, tightly arranged exam schedule, strict deadlines, etc. (Terzieva et al., 2016). 53% of students who indicate such difficulties do not seek support from others (lecturers, peers, or institutional support) to solve their issues. Those who seek help are more likely to have a noticeable disability and perceive greater support at their university; among others, every third student feels inadequately supported in their studies. In contrast, students who do not exploit support opportunities are slightly more likely to be male and to experience less disability-related limitations in their studies (Terzieva et al., 2016).

Due to the focus of our analysis, we only take disabled students who did not seek support in case of difficulties into consideration (1,919 valid cases). In order to increase the response rate, the completion time was reduced by introducing several thematic modules only visible for a random 50% of the respondents. Therefore, our logistic regression model is based on 475 cases.

3.2. Methods

We utilised a stepwise logistic regression analysis in order to investigate the determinants of stigmatisation among students with disabilities as a barrier to help seeking. The analysis restricted the sample to students with disabilities who indicate having disability-related difficulties in their studies but did not seek support (39% of all students with disabilities). These students were then asked to choose from a list of twelve motives those that explained their reluctance to seek support. These motives were grouped (ex-post, based on their content and correlations with one another) into *stigma-related* and *not stigma-related* motives (see Table 1): 47% gave at least one stigma-related reason while the remaining 53% named other reasons.

Consequently, our dependent dichotomous variable describes 0 = students with other (not stigma-related) reasons and 1 = students with a fear of stigmatisation (regardless of any additional concerns). Survey participants who did not respond to this question were excluded from the analysis. Since students seeking help were not asked about their motives, we can assume that their coping strategies regarding help seeking and disclosure (e.g., Kranke et al., 2013) may, for some, be related to a fear of stigmatisation (i.e., seeking support does not necessarily mean there is no fear of stigmatisation). Due to this missing information, they are not part of our target group, which allows a more reliable comparison.

Drawing on our theoretical and empirical discussion, the selection of the potential factors is based on the intertwinement of impairment and environment, which is fundamental to the fear of stigmatisation associated with the reluctance to seek support. In order to investigate this interplay between individual and environmental aspects, we take a closer look at its integral parts: disability-related characteristics reflect the individual aspects of impairment, while *objective* study-related and *subjective* well-being concepts account for the environmental factors (within and outside the higher education context). These key aspects of our model are illustrated in Figure 1 and will be described in detail below:

Following the control variables *gender* (0 = male, 1 = female) and age at time of survey (metric), we include specific disability characteristics in a second step: we operationalise the type of disability using two variables—*noticeability* (0 = noticeable immediately or after some time, 1 = not noticeable) and *degree of study-related limitation* (1 = low degree, 4 = high degree). We include the metric variable *size of the study programme*

Table 1. Motives for not seeking support in case of disability-related difficulties in one's studies. Source: Terzieva et al. (2016, p. 37).

	Students with disabilities who did not seek support
Stigma-related motives	
I didn't want to reveal my impairment.	33%
I had inhibitions about contacting people as a result of my impairment-related problems.	28%
Because I was afraid it would put me at a disadvantage in the rest of my studies.	10%
Because I was afraid other students would/will avoid me as a result.	7%
Not stigma-related motives	
I don't think that this would have changed my situation.	66%
It would have been too much effort.	11%
I want(ed) to resolve my problems on my own.	39%
Because nobody had been able to offer me adequate support the last time.	9%
I don't think that my problems give me the right to ask people for support.	28%
I didn't know of anyone I could contact for support/advice.	17%
I don't want to be given "special treatment".	35%
Other reasons	7%

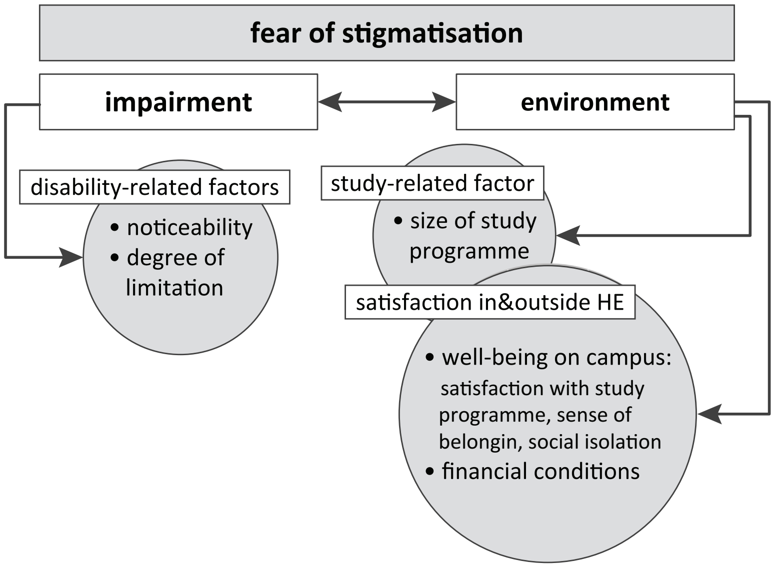

Figure 1. Determinants of fear of stigmatisation associated with the reluctance to seek help.

in step 3. This predictor is used as a proxy for the feeling of anonymity on campus, assuming that study programmes with large numbers of students are associated with a greater feeling of anonymity. When developing the model, we tested different study-related characteristics, e.g., type of HEI or field of study, but they were excluded due to non-significant results or an insufficient number of cases required for the proper performance of a regression analysis.

Finally, we assume that positive environmental conditions for studying have a beneficial effect, i.e., reduce the reluctance to seek help due to fear of stigmatisation. This last step of our model takes the following variables related to well-being on campus or in everyday life into account:

- The predictor *satisfaction with study programme and HEI* is a weighted index of four items: degree of identification with and recommendation of the study programme, fulfilment of expectations and overall satisfaction at the university. The index was built by applying a principal component analysis (revealing a single dimension) and using the factor loadings as weights;
- *A sense of belonging* at the university was measured using a five-point Likert scale (1 = strongly disagree to 5 = strongly agree);
- *A feeling of social isolation* at the university was measured using a five-point Likert scale (1 = strongly disagree to 5 = strongly agree);
- *Financial difficulties* were measured using a five-point Likert scale (1 = "not at all" to 5 = "very strongly") indicating to what extent students were facing financial difficulties at the time of the survey.

4. Results

Table 2 presents descriptive statistics regarding the motives that explained students' reluctance to seek support. Even though there are no significant gender or age differences between the two groups, students who are reluctant to seek help due to fear of stigmatisation are more likely to have severe disability-related limitations or a non-apparent disability. Three quarters report a (very) high degree of study-related limitations due to disability while this applies to half of the students with otherwise (not stigma-)motivated reluctance to help seeking. Furthermore, all variables regarding environmental factors differ significantly between the two groups: students who do not seek support due to fear of stigmatisation are less satisfied with their study programme/HEI, lack a sense of belonging or indicate social isolation. Moreover, they are significantly more likely to be affected by financial difficulties.

In a logistic regression, the dependent variable *fear of stigma* (yes or no) was regressed on a number of predictors. The values of the regression coefficients (βx) determine the direction of the relationship:

$$\begin{aligned} Y = \beta_0 + \beta_1 * gender + \beta_2 * age + \beta_3 * noticeability + \\ + \beta_4 * limitation + \beta_5 * size + \beta_6 * satisfaction + \\ + \beta_7 * belonging + \beta_8 * isolation + \beta_9 * financial \end{aligned}$$

Table 3 presents the odds ratios (Exp(β)): values above one indicate that higher values of the explanatory variable increase the predicted probability of the first (not seek assistance due to the fear of stigmatisation) relative to the second outcome (not seek assistance due to other, not stigma-related reasons). Coefficients less than one indicate the opposite. Thus, the ratio of 1,745 for the degree of limitation in the second step of the model indicates that the odds of not seeking assistance due to fear

Table 2. Predictor variables. Data source: Austrian Student Social Survey 2015 (IHS—Institute for Advanced Studies Vienna, 2016).

	Reluctance to seek support due to	
	other reasons	**stigma fear**
Gender [chi-square (1) = 0.162, p = 0.687]		
male	40%	39%
female	60%	61%
Age (*arithm. mean*) [t (1846.785) = −1.469, p = 0.142]	28.7y	28.1y
Noticeability of disability [chi-square (1) = 9.015, p = 0.003]		
noticeable	36%	30%
not noticeable	64%	70%
Degree of study-related limitation due to disability [chi-square (3) = 112.010, p = 0.000]		
low	16%	6%
medium	30%	20%
high	34%	38%
very high	20%	36%
Size of study programme *(arithm. mean)* (1 unit = 100 students) [t (1911.116) = −1.441, p = 0.150]	19.5	17.7
Satisfaction with study programme/HEI *(arithm. mean) (*1 = *very* 5 = *not at all)* [t (968.618) = −3.258, p = 0.001]	2,3	2,5
Lack of sense of belonging in HE [chi-square (4) = 34.725, p = 0.000]		
strongly disagree	29%	18%
disagree	25%	21%
partly	21%	20%
agree	15%	24%
strongly agree	10%	17%
Social isolation, contact difficulties [chi-square (4) = 44.724, p = 0.000]		
strongly disagree	41%	25%
disagree	20%	20%
partly	16%	16%
agree	15%	19%
strongly agree	8%	20%
Affected by financial difficulties [chi-square (4) = 39.094, p = 0.000]		
not at all	17%	12%
slightly	20%	15%
moderately	26%	23%
strongly	22%	27%
very strongly	15%	23%

of stigmatisation are 75% higher compared to not seeking assistance for other reasons, as the degree of limitation due to disability increases by one scale point.

The model achieves a Nagelkerke's Pseudo R^{2} of 20.8% according to Cohen's *f* (1992), this corresponds to a medium effect (effect size of $f = 0.21$). The Omnibus tests of model coefficients (chi-square (9) = 79.540, p = .000, n = 475) prove the soundness of the model.

The demographic characteristics age and gender (used as control variables in this model) are not significantly associated with the stigma of fear as a barrier to seeking support. In contrast, the influence of disability-related characteristics is substantial. An increased degree of limitation increases the odds of not seeking assistance due to fear of stigmatisation. Having a noticeable disability decreases the stigma-related reluctance to seeking help. These effects are significant in each step of the model; the effect strength fluctuates only moderately.

Adding the study programme size as a predictor reveals that an increase in the number of students decreases the relative odds of not seeking assistance due to the fear of stigmatisation.

Finally, the environmental factors added in the last step of the model prove to have a substantial effect on the fear of stigmatisation as a barrier to seeking support. Lacking a sense of belonging to higher education, feelings of social isolation and perceived financial difficulties

Table 3. Determinants of disabled students' reluctance to seek support due to fear of stigmatisation: results of a logistic regression (odds ratio). Data source: Austrian Student Social Survey 2015 (IHS—Institute for Advanced Studies Vienna, 2016).

	Step 1	**Step 2**	**Step 3**	**Step 4**
Demographic characteristics				
Gender: female (versus male)	1.299	1.211	1.258	1.329
Age	0.987	0.992	0.991	0.995
Disability-related variables				
Noticeability of disability				
not noticeable (versus noticeable)		1.652*	1.644*	1.784**
Degree of study-related limitation due to disability				
(high values = high degree of limitation)		1.745***	1.792***	1.605***
Study-related variables				
Size of study programme *(1 unit: 100 students)*			0.989**	0.986**
Satisfaction on campus				
(high values = low satisfaction)				
Satisfaction with study programme / HEI				1.129
Sense of belonging in HE				1.291**
Social isolation, contact difficulties				1.183*
Satisfaction in everyday life				
Financial difficulties *(high values = very serious difficulties)*				1.189*
Constant	1.027	0.134***	0.152***	0.025***
Nagelkerke Pseudo-R^2	0.01	0.102	0.123	0.208

Notes: n = 475; significance levels: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

are found to be significantly associated with the reluctance to seek support due to fear of stigmatisation. An increase in any of these predictors results in an increased probability of not seeking assistance due to fear of stigmatisation. In contrast, the index regarding satisfaction with the study programme and HEI has no significant influence on the dependent variable.

5. Discussion

This article highlights that the social environment on campus is a key factor in the experiences of students with disabilities and that the concept of stigma plays a decisive role. Students with disabilities are indisputably a stigmatised group and stigma has many negative effects—it upholds barriers to participation and may even exacerbate some of the students' difficulties (Kimball, Wells, et al., 2016; Tinklin et al., 2005). This is why stigma and fear of it prove to be fundamental to seeking support in case of difficulties and respectively to revealing one's health impairment.

This disclosure dilemma may put students' interactions with their social environment at risk. Revealing one's disability is often associated with difficulties regarding social contacts at the university (e.g., study groups or social networks for exchange) which are instrumental for academic success. A good student-faculty relationship is fundamental to receiving disability accommodations, e.g., modifications within courses, open discussion, and disclosure of disability. Similarly, administrative staff plays an important role in the support of students with disabilities. Nevertheless, some students have difficulties communicating with teachers or administrative staff, which can result in problems within courses, e.g., when learning materials are not usable for students, the course design makes it hard for them to participate or there is a lack of flexibility regarding the exam modes (Poskowsky et al., 2018). As our analysis reveals, increased social contact and a greater sense of belonging can decrease stigma-related reluctance to seek support and thus encourage students with disabilities to demand adequate assistance in case of difficulties. These factors prove to be more important than the satisfaction with the study programme. Furthermore, an increase in the study programme size (as a proxy for the feeling of anonymity) decreases the reluctance to contact others due to stigma fear in case of disability-related difficulties. Apart from study-related characteristics, it is the noticeability and the degree of study-related limitations that significantly influence the fear of stigmatisation as a barrier to help seeking—and thus, increase the risk of missing support opportunities. Therefore, non-apparent disabilities should be brought into focus; these are mental health problems, learning disabilities, as well as many chronic diseases.

The fear of stigmatisation regarding support seeking is also influenced by factors outside of the university. Our analysis shows that the financial condition, in particular, financial difficulties, increases the reluctance to seek help due to stigma fear. Here, a vicious cycle becomes apparent: the difficulties faced by students with disabilities go far beyond their study life. They are much more likely to be dissatisfied with their living conditions, have less well-paid jobs, struggle with financial problems, and tend to be less optimistic about their employment prospects on the labour market, compared to their colleagues without disabilities (e.g., Terzieva et al., 2016).

Nevertheless, there are limitations to this study, which should be noted. Like most studies using student-level data, the analysis relied on self-reported information which may be inaccurate for a variety of reasons (Kimball, Wells et al., 2016; Trammell, 2009). For instance, social desirability and the associated reluctance to disclose one's disability (even in an anonymous survey) may lead to measurement errors and limit the generalisation of the results. Furthermore, some types of disability are rather associated with social stigma, which might have a great influence on the willingness to disclose one's disability (in a questionnaire) and thus lead to their underrepresentation. Participants' self-classification can also be problematic due to the complexity of disability dynamics, especially when dealing with cross-sectional data, which refers only to a specific point in time (Burchardt, 2000). Beyond that, the operationalisation of our theoretical concepts has been inevitably shaped and, to a certain extent, constrained by the data available. For instance, the differentiation between stigma-related and not stigma-related motives is based on theoretical considerations as well as a data-driven exploratory approach, not on a validated instrument. Clearly, a larger number of cases would allow including other covariates, e.g., type of health impairment, and reveal new aspects concerning stigmatisation among students with disabilities.

6. Conclusion and Recommendations

Over the last few decades, the question of the social dimension of higher education has become an issue of great importance in the European Higher Education Area (EHEA). Member states have agreed on the shared goal that entering, participating, and completing higher education (at all levels) should reflect the diversity of the broader population (EHEA, 2007, p. 5). This common vision has been guiding the development and implementation of national and international strategies ever since. However, unlike gender, socioeconomic and ethnic background, disability appears to be less relevant in these documents. In 2017, the Austrian government released a national strategy on the social dimension of higher education (bmwfw—Federal Ministry of Science, Research and Economy 2017). In regard to students with disabilities (one of the target groups), the strategy aims to improve quality and accessibility of information materials and expand support mechanisms, quiet spaces and retreats (bmwfw—Federal Ministry of Science, Research and Economy 2017, pp. 4, 7). However, (probably) due to lack of data, no quantitative goal was set in these strategy documents.

Despite such documents and relevant legislation declaring inclusive aims, many students with disabilities still report unmet needs and unwillingness to seek institutional support, also because "difficulties go beyond the areas where support is conventionally offered" (Mortimore & Crozier, 2006, p. 247). Based on our results, we argue that addressing stigma is ultimately a cornerstone to a more inclusive higher education environment. Therefore, interventions at all levels and the involvement of all parties (policy makers, management, administration, faculty, and students) are needed. In order to ensure appropriate support for students with disabilities, it is important that HEIs promote a culture of openness and normalisation of disability more proactively, an appeal that has also been made by the participants in the Austrian Student Social Survey (Terzieva et al., 2016). Kendall (2016) calls for a cultural change and for institutions to "encourage students with a disability to disclose prior to the commencement of studies" (Kendall, 2016, p. 10). Mortimore and Crozier (2006) suggest that institutions should apply a more empowering and problem-solving model—acknowledge students' strengths, identify their difficulties and provide adequate support. However, even the best offers may be useless if they miss their target group: in Austria, for instance, an alarmingly high share of students with disabilities is not aware of the existence of support services on campus. Institutions are urged to provide more information about their support services.

Universities should provide teaching staff with "knowledge and resources to support students who may be experiencing difficulties due to their disability" (Padden & Ellis, 2015, p. 433). As suggested by Hopkins (2011), universities can introduce regular, compulsory training around disability awareness for all lecturers and actively encourage applications from disabled people for academic or other posts, especially mentors in disability support services (Hopkins, 2011, p. 724). An example of good practice comes from University College Dublin (UCD), Ireland, which has developed and implemented a communication and training strategy to improve disability awareness among academic staff (Padden & Ellis, 2015). Tips and strategies from the UCD include providing accessible learning materials, improving class delivery methods according to students' feedback, offering a choice of assessment methods, providing detailed assessment information, ensuring consistency of assessment methods, facilitating clear communication between students and faculty, etc. (Padden & Ellis, 2015, p. 443).

Organisational and structural flaws that may impede student progress should be tackled in order to improve learning conditions for both students with and without disabilities. Investigating students' experiences and identifying their needs are essential steps towards the adequate alleviation of barriers. Institutions should consider ways to improve the design of courses, introduce more flexibility in the learning environment, and address the rigidity of study requirements. Removing such barriers could not only prevent negative academic outcomes and decrease dropout rates but also help all students flourish both academically and socially. Creating a caring, supportive and welcoming environment is fundamental to the individual sense of belonging, particularly for students with disabilities, as emphasised by O'Keeffe (2013). On the one hand, "care overcomes the sense of isolation and separateness that a student with disabilities feels and gives him/herself the permission to nevertheless belong and succeed in a frightening and challenging college environment" (Graham-Smith & Lafayette, 2004, as cited in O'Keeffe, 2013, p. 608). On the other hand, university staff and faculty members who disregard the needs of students with disabilities may, by doing so, exacerbate the challenges students experience (O'Keeffe, 2013). Developing a sense of belonging (through good relationships between students and faculty, well-resourced support services and welcoming diversity and difference) is crucial to students' academic success and retention (O'Keeffe, 2013) and may reduce the fear of stigmatisation associated with reluctance to help seeking, as our analysis has shown.

In conclusion, this study and previous research show that despite relevant legislative and social endeavours, there are still many attitudinal and structural barriers for students in higher education. Given the diversity of the student body and the importance of enhancing the social dimension of higher education, it is crucial to respect the interplay of individual and environmental factors as instrumental to students' well-being and success, i.e., institutions should not address issues individually but recognise and consider their interaction. The ultimate goal is to create a more inclusive environment, a culture in which revealing a health problem, admitting having difficulties and seeking support is not associated with stigmatisation, discrimination, distress, or social isolation. Clearly, this is a societal concern not limited to the higher education context—and thus a very high aim.

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Conflict of Interests

The authors declare no conflict of interests.

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About the Authors

Sarah Zaussinger is a Researcher in the Higher Education Research Group at the Institute for Advanced Studies in Vienna and currently serves as Deputy Head of the research group. Her scholarly interests include social inequality in higher education, with a particular focus on the social situation of students, gender differences, and students with disabilities.

Berta Terzieva is a Researcher in the Higher Education Research Group at the Institute for Advanced Studies in Vienna. Her research focuses on the social and economic conditions of student life, with a particular focus on underrepresented groups, such as students with disabilities. Moreover, her research interests include discrimination and imbalances in international student mobility.

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Article

Barriers to Higher Education for Students with Bipolar Disorder: A Critical Social Model Perspective

Allison K. Kruse and Sushil K. Oswal *

School of Interdisciplinary Arts and Sciences, University of Washington, Tacoma, WA 98402, USA;
E-Mails: allisonkkruse@gmail.com (A.K.K.), oswal@u.washington.edu (S.K.O.)

* Corresponding author

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Abstract
Employing some of the features of participatory research methodology, a disabled faculty joins a student with mental health diagnosis to examine the factors that hinder or enable success for this group. The theoretical framework or scholarly bearings for the study comes from the critical social model of disability, disability services scholarship in the United States, and education theory literature on “student success”. With a particular focus on students with bipolar disorder, the article highlights the gaps in disability scholarship on this specific group while underscoring the oppression experienced by them through the inclusion of an autoethnographic segment by the primary author in this collaborative, scholarly work. The model of access, we propose, moves beyond accommodations—which are often retrofits or after the thought arrangements made by an institution—and asks for environmental support, social and institutional inclusion, and consideration for students with psychiatric health diagnosis. This article not only presents an array of problems in the United States academy but also a set of recommendations for solving these problems. Going beyond the regime of retrofit accommodations, we ask for an overhaul of institutional policies, infrastructures, and curricula so that the academy is inclusive of neurodiverse bodies and appreciates their difference.

Keywords
academic ableism; autoethnography; bipolar disorder; critical social model; disability; disability accommodations; disclosure in higher education; psychiatric health diagnosis; retrofits; student success; students with mental disabilities

Issue
This article is part of the issue “Students with Disabilities in Higher Education”, edited by Geert Van Hove (Ghent University, Belgium/VU Amsterdam, The Netherlands), Minne Bakker (VU Amsterdam, The Netherlands) and Alice Schippers (Disability Studies in the Netherlands/VU Amsterdam, The Netherlands).

1. Introduction: An Overview

This article examines the needs of students with mental health diagnosis in post-secondary education through the scope of bipolar disorder and suggests changes that may promote an accessible pedagogy and assist in the inclusion of students with mental disabilities in the academy. The focus on bipolar disorder is important because very little research has been published on this student group’s specific needs (Demery, Thirlaway, & Mercer, 2012; Donaldson, 2015). In doing so, this article advances several of the goals of this special issue by addressing mental disability, such as: 1) a student and an instructor taking the slogan, “nothing about us without us”, to heart by co-authoring a participatory research article to explicate the experiences of students with mental disabilities; 2) critique how faculty and staff in higher education view performance of students with and without disabilities from their privileged spaces and cultivate an unfriendly academic climate of ableism; and 3) expand the methodological toolkit within qualitative research by employing in an intersectional manner methods from Disability Studies including, a disability narrative, personal reflections, and the use of medical and critical social models of disability to frame this discussion that collectively make connections between lived experiences of disabled students and how they are restricted by social and physical structures, institutional policies, and ableist norms.

1.1. Critical Social Model of Disability

We employ the critical social model of disability as a lens for our discussion throughout this article, which is based on an earlier model of disability sometimes known as the social model of disability (Union of the Physically Impaired Against Segregation, 1976). Social model of disability, which bifurcated disability into two by separating biological condition or impairment from disability, was put forth to sever disability from the clutches of medical establishment and to draw political attention to the socio-economic barriers experienced by the individual. However, the social model ignored the demands of many physical and mental impairments on the body. It also overlooked the dependencies an impaired body might have on professionals for medicine, day-to-day care, and other survival functions (Crow, 1996; Morris, 1991). We find the reasoning of the critical social model, therefore, meaningful for several reasons in the context of mental disability in the academy. First of all, critical model questions the sharp division of “impairment” and “disability” by the social model and its recognition of dependencies. Impairment—temporary or permanent—resulting from a mental disorder is real and it cannot be separated from the social disability experienced by the individual due to the physical and societal barriers (Ghai, 2003; Priestley, 1995; Shakespeare & Watson, 2001). For example, a student with bipolar disorder can be dysfunctional during a difficult episode of illness or might need specific accommodations for the resulting impairment to function adequately in or outside the class. Impairment is of central concern for the student to survive in the highly competitive environment of the university. Individuals with mental disabilities also can’t distance themselves from the medical establishment to the extend the old social model did because they depend on medical professionals for their needs for medicine, therapy, and counseling. Under the neoliberal regimes of the recent decades, the welfare state has been diminishing in the industrialized countries and many students experience conditions of poverty, lack of adequate healthcare, and general depravation commonly associated with developing countries.

1.2. Unwelcoming Institutional Conditions for Students with Mental Health Diagnosis

We stress that institutional standards of accommodation and assistance for students with mental disabilities are in place, and have been in place for decades; however, students with mental disabilities still choose, in overwhelming numbers, to leave their mental disability in the closet. Further, the stigma attached to mental disabilities, lack of knowledge/training/experience among faculty and staff, and a difficult accommodations process deter students from living openly with their disability, thus setting them up for failure (for this neglect of disabled students in general in higher education see the extensive literature review by Kimball, Wells, Ostiguy, Manly, & Lauterbach, 2016; for a detailed treatment of the concept of “stigma”, see also Goffman, 1963/2009). This failure is shown by the excessive number of student dropouts with bipolar disorder even before they had a chance to apply their abilities in their studies. By exploring the experiences of a student with bipolar disorder, the ableist assumptions of our society, and gaps in the current support policies and processes, this article not only presents an array of problems but also a set of recommendations for tackling with these problems. The model of access, we propose, moves beyond accommodations—which are often retrofits or after the thought arrangements made by an institution—and asks for environmental support, social and institutional inclusion, and consideration for students with mental health diagnosis. The model of access we argue for demands an overhaul of institutional policies, infrastructures, and curricula so that the academy is inclusive of neurodiverse bodies and appreciates their difference. These changes can produce physical and learning environments in which disability accommodations are unnecessary or needed only infrequently. This model also advocates that the disabled person’s agency always remains intact when they have to avail of accommodations because of the persisting ableist institutional policies and structures. We want to point out that we intentionally avoid making a legal argument to make our case because the extensive literature on judicial decisions from the United States indicates that the courts might not be the best place for seeking support for students with psychiatric disabilities (Kiuhara & Huefner, 2008). Instead, we appeal to universities to make reasonable modifications in their rules, policies, structures, and practices to include the student needs and show concern for their well-being as full-fledged members of the academic community. We further ask educators to abandon the deficit view of students with mental disabilities and focus on the assets they bring to our classes through their neurodiversity, their persistence to succeed, and their real-world struggles as human beings (Dinishak, 2016).

We begin by defining the various assumptions about mental disability in higher education from the perspective of critical social model of disability and how these assumptions create and sustain stereotypes that prevent disabled students from achieving their academic, career, and social goals (Oswal, 2018). Working from this critique, we develop a discussion on how the very disclosure process that all disabled students must maneuver through to become eligible for accommodations and often erratic and sometimes unreliable implementation of these accommodations by faculty in the classroom pose barriers to receiving equal learning opportunity. After showing how the ableist assumptions about mental disability by medical and disability services professionals can contribute to the systemic oppression of students with mental disabilities, we make recommendations to university educators for removing these barriers that can prevent the learners with bipolar disorder from achieving their dream of a college degree. While our descriptions of mental disabilities and the discussion of the institutional and pedagogical barriers come from our lived experiences—the primary author is a student with a mental health diagnosis and the second author is a faculty with long-term experience of receiving and giving disability accommodations on six different campuses in the United States—the vast literature on disabled students in higher education documents that many of these issues also materialize in one or other form on college campuses around the globe (Kimball et al., 2016). Likewise, the variations of these issues have been documented in the experiences of disabled faculty in the United States and elsewhere although we limit our discussion here to the concerns of students with psychiatric health diagnosis (Kerschbaum et al., 2013). We also want to note that the disability-related terminology used throughout this article alternates among "students with mental disabilities", "students with mental health diagnosis", "mental illness", "mentally disabled students", and "disabled students" to reflect the prevalence of diverse labels in the published literature and the differing preferences students show for these labels.

2. Background Data

According to the National Institute of Mental Health (2006), approximately 25% of all Americans experience a diagnosable psychiatric disability each year. The self-reported data by college students match these national numbers (Sharpe, Bruininks, Blacklock, Benson, & Johnson, 2004). Out of all the students enrolled in colleges in the United States in 2011–2012, more than 11% had a disability, and out of this population of disabled students, almost every one in four had a mental disability (National Center for Education Statistics, 2016). According to an earlier National Survey of Campus Disability Services, up to 86% of students with mental disabilities may never finish their college degree (Collins & Mowbray, 2005).

3. Mental Disability and Academia

The onset of mental disability often occurs from ages 17 to 25, and so many students with mental disabilities are experiencing symptoms for the first time as they enter college (Collins & Mowbray, 2005; Mullins & Preyde, 2013). In order to receive accommodation for mental disability, students are required to disclose their disability, provide appropriate documentation, and then enter a negotiation process with their professors. However, the majority do not disclose and do not seek accommodation (Clark, 2006; Collins & Mowbray, 2005; Demery et al., 2012; Venville, Street, & Fossey, 2014). One specific deterrent to disclosure and seeking treatment is stigma, which is created by ableist assumptions that those with mental disabilities are violent, unstable, and unsuited for academic environment (Eisenberg, Downs, Golberstein, & Zivin, 2009; Price, 2011). The protected value of competition in academia also presents the barrier that a student may be accused of or believed to be lying about her disability in order to receive "extra help" over her peers, or even rejection on the grounds that accommodation for the disability creates an unfair advantage within the classroom. (Clark, 2006; Price, 2011).

4. Bipolar Disorder

Bipolar disorder (also termed bipolar affective disorder) is defined by the World Health Organization's (1992) International Classification of Diseases (ICD-10) as:

> Characterized by repeated (i.e., at least two) episodes in which the patient's mood and activity levels are significantly disturbed, this disturbance consisting on some occasions of an elevation of mood and increased energy and activity (mania or hypomania), and on others of a lowering of mood and decreased energy and activity (depression). Characteristically, recovery is usually complete between episodes, and the incidence in the two sexes is more nearly equal than in other mood disorders.

While little information has been collected on students with bipolar disorder, the symptoms have been documented. While we don't include the full range of symptoms that people with bipolar disorder experience, we include symptoms with needs that are not met by the current academic system. Most information from this section has been taken from Nitzburg et al. (2016) in their study "Coping Strategies and Real-World Functioning in Bipolar Disorder".

Students with bipolar disorder are at a high risk to respond to adversities—in this case, the disclosure, accommodation, and education process—with "maladaptive coping strategies", including dropping out, self-blame, and substance abuse, another common mental disability in post-secondary education with highly unmet needs for treatment (Blanco et al., 2008). The "giving up" coping strategy was seen throughout studies in which most bipolar students did not complete their education (Blanco et al., 2008; Venville et al., 2014). Verbal ability also can be impaired significantly by symptoms of bipolar disorder. Additionally, people with bipolar disorder are extremely affected by the conditions of their environment—particularly the ableist environment that enforces blame on the disabled person and not society.

5. "But There Are Already Places for the Mentally Disabled, Right?"

Most colleges today have some sort of student health center with resources for students who may have a mental disability. However available and accessible these centers are, a large number of students with mental disabilities will not seek help or treatment due to the perceived stigma. Rhetoric scholars of disability, however, remind us of the relevance of narrative genre for giving voice to those lacking authority "to speak against dominant perceptions of mental illness" (Pryal, 2010, p. 499). Our research design and analysis are further based on the understanding that the voices and lived experiences of those who are seen on the receiving end of services, education, and support can offer rarely recognized but equally crucial, on-the-ground knowledge (Roets, Kristiansen, Van Hove, & Vanderplasschen, 2007; Trivedi & Wykes, 2002). Likewise, feminist theorists have pointed out that when the "personal becomes political" the researchers can make better connections between personal narratives and historical, societal, and institutional structures of power (Thomas, 1999). Thus, personal narratives are a crucial tool for the process of self-empowerment (Barton, 1998, p. 37).

Here, one of us narrates our own experience of seeking help through our educational institution to demonstrate the unmet needs of students with mental disabilities when they may need help.

5.1. Personal Experience

In reaching the stage of receiving the actual help for my bipolar disorder, that is, my first session with a counselor, the student help center took nearly two months. My prolonged wait is only one example of many such experiences with every campus enrolling dozens and dozens of students with mental disabilities. Looking back, I realize that the extended period of time it may take to be seen for the first time can be just as debilitating for a student with bipolar disorder than no help at all.

I remember the receptionist being friendly, but I also remember distinctly the way that she looked at me: like I might throw myself out that fourth story window at any minute. The look alone made me want to turn around and leave. Many students with mental disabilities fear stigma the most out of all repercussions of disclosure, and I was looking stigma in the face before I even had the chance to disclose—in a way, my being there in the first place was disclosure enough, and assumptions had already been made. This, too, can act as a powerful deterrent to students with mental disabilities.

I explained to her that I wanted to be seen by one of the counselors, and she told me she would send me an email with a questionnaire. This was to determine if my mental state was more fragile and urgent than the unknown (but apparently large) number of students who had filled it out before me. I would then be called by one of the doctors within a few weeks to discuss some further questions. If a system put in place to help students tells those same students to "take a number" when they need help, the system may only strengthen the already-present feelings of self-deprecation and wanting to give up that the very system is put in place to fight. And there, as I was experiencing one of the most debilitating and intense depressions I had ever experienced, I was told to "take a number".

The day the doctor called, I was on my 30th hour in bed; I had spent 24 of them sleeping. I hadn't attended classes in nearly a week. I picked up on the very last ring, after internally talking myself out of the belief that it didn't matter, that they weren't going to help me; that I was beyond help. The doctor answered, verified my name, and then began this series of questions: have you seriously considered ending your own life in the past week? Have you made plans to end your own life in the past week? How often do you drink alcohol? Have you seriously considered harming yourself or others in the past week? This phone call itself embodied the issues of what Disability Studies scholars call the medical model of disability (Oswal, 2018). I was a piece of paper with checked boxes, determining whether or not I was mentally ill "enough" to be considered for assistance.

I tried to answer honestly, knowing that each checked or un-checked box was going to influence my chances of being helped. The anxiety had convinced me that I had failed one of my courses already due to my absences, my anxious and depressive states, and my inability to think of anything but my own hysteria in class. I just wanted help. But as I answered the questions to the monotone man on the other line, I felt less and less like a person.

My call was returned two weeks later, and they had decided I should be seen "immediately" but my appointment was set for two more weeks out. I wanted to be relieved or happy, my depression reminded me that the only reason I was getting help was because I was "sicker" than the rest of them. Additionally, I couldn't help but wonder how many students had to lose their opportunity for help just so I could get mine; how many students would never have their "number" called. The guilt followed me deeply during my depressive states and proved to be almost as debilitating as the shame that came with being considered "more mentally ill" than the rest.

The help that I received following this process was my own accommodation, and I was able to complete my academic year with the help of weekly sessions with a counselor. I share this narrative not to say that the system my school offered did not help students at all who needed help, rather that the system we have in place at my school (and many others) still has much room for improvement before it is truly for the mentally disabled.

5.2. Analysis: Stigma and Process as Deterrents for Seeking Help

Here, we would like to discuss two reasons that students do not approach these mental health centers for treatment: stigma surrounding mental illness, especially in college students, is extreme and unforgiving, and the process to be seen and helped is often extensive, impersonal, and lengthy, and during this process the students are evaluated to determine whether they are disabled "enough" to require care. The story here also shows the aforementioned processual barriers between mental disability and seeking care in academia: stigma, time, and seeking proof that someone is disabled "enough" (Goffman, 1963/2009).

The demeanor of the receptionist upon meeting and speaking with the student carried a few problematic assumptions about mental disability: that the student was perpetually on the edge of a violent outburst (toward her or others), that it was appropriate to express pity or sadness on her behalf, and that she was to be treated differently (with a softer voice or gentler words). This fear is an extreme deterrent particularly for students with disorders that affect their self-esteem or social capabilities. One of the biggest fears students have about seeking help for a mental disability is how stigma will affect the way they are treated, and without even being seen, diagnosed, or evaluated, the student was already being treated differently because she believed that she was mentally disabled. This is not to say that the receptionist was unkind or deliberately attempting to deter this student's quest for help: in fact, the student left the office angry not at the staff, but at the commonsense assumptions that it is appropriate (or best) to respond in that way.

Moreover, the six weeks that the student was required to wait before she even knew if she qualified for care is another extreme deterrent for many students with mental disabilities seeking care, particularly students with bipolar disorder. In the case of bipolar disorder, moreover, conditions and symptoms constantly change and can be unpredictable. A student willing to seek help one day may find an onset of symptoms the next day that prevents her from seeking help. In the primary author's case, the symptoms clearly almost prevented her from completing the application process midway due to an onset of a major episode of depression.

The series of impersonal and category-infested surveys students are required to fill out further demonstrate one of the most problematic assumptions about disabled people: that you must fit into a specific category and you must be in a fixed state of disability to receive help. The fact is that disability lives on a spectrum and people with bipolar disorder go through different experiences, feelings, emotional and mental barriers, successes in overcoming these hurdles, at different times in their day-to-day lives, and all or some of these might situate an individual somewhere at a different point on this spectrum that depicts from most extreme to some very mild states of impairment and disability. For example, a student with a mental disability may be suffering in all aspects of life on one day: her bipolar disorder might prevent her from attending class, participating in online group projects, or leaving her home to go to work, and this student may never experience violent thoughts in her life. Should she choose to seek help, she may have to face the assumption that her disability is not detrimental enough to require help, despite the fact that she is facing the loss of her academic career, job, etc. The point here is not limited to whether or not universities provide adequate help sooner or later, it is also about whether or not universities show an understanding of the experiences of a student with bipolar disorder and make an effort to match the delivery of their services to that experience. In practical terms, it could mean that the student would not only receive counseling when it is needed but also that the professor would say that the student doesn't have to submit that major assignment exactly on Friday midnight and its completion could wait until she can recover. When disability services offices and faculty insist on a set standard formula for additional time to complete an assignment as an accommodation, they fail to notice the nuances of bipolar disorder as a disability. They don't realize that a student with bipolar is not asking for additional time because it takes them longer to write in braille or typing on a keyboard because of their hand-motor disability; instead their time clock is tied to the onset and departure of an episode and while they are in the grip of it.

6. Implications of an Ableist Environment

Ableism is defined as the societal attitudes that devalue and disregard people with disabilities (Oswal, 2013). Others have described ableism as "denoting an attitude that devalues or differentiates disability through the valuation of able-bodiedness equated to normalcy" (Campbell, 2009, p. 5). Ableism has influenced the way we view accessibility by the belief that society should center around what a "normal" person is: entirely healthy and able-bodied. Because of this belief, equal access for those who are not considered "normal" is seen as excessive or unfair (Boys, 2014). Ableist society believes that those with disabilities can be (and should be) able to "overcome" the barriers of their disabilities and succeed by "normal" standards, regardless of the fact that the barriers they face are often created by society and not their disability (Chrisman, 2011; Oswal, 2018; Runswick-Cole & Goodley, 2013). Even in this second decade of the 21st century, university faculty can choose to play self-styled disability therapists in the face of all disability rights and can coerce disabled students to adapt to their ableist pedagogies For an example, see the heavy-handed treatment of a student with an invisible disability by a senior professor about giving accommodations in her class in an article by Hornstein (2017) in *The Chronicle of Higher Education*. For instance, when faculty members insist that all students must employ the same modality at the same pace, they are asking students with disabilities—who might possess a different body or mind—to perform on a rigid ableist scale and they forget that the same learning goals can be achieved using different means at a different pace. In the same vein, when university faculty enforce the mandatory attendance policy on all students as a universal requirement, they forget that a bipolar body and/or mind simply might not be in a shape to obey their edict on a particular day of class (for a comprehensive treatment of compulsory attendance policy and its implications for the disabled in the academy, see Nicolas, 2017).

More than anything, faculty need to be shown that well-meaning interactions often pose serious problems to students with disabilities and they need to work with disabled students and not work at them. Because of expectations to overcome and not resist, many disabled people choose to pass as "able" and endure the difficulties of their disability in private on top of the exhausting demand of constantly working to hide a disability (Boys, 2014; Price, Salzer, O'Shea, & Kerschbaum, 2017). In spite of the national disability laws in most industrialized countries for over a quarter century, colleges and universities continue to formulate policies that ignore the needs of disabled students, faculty, and staff, build inaccessible infrastructure, teach exclusionary curriculum using ableist pedagogies, and publish scholarship that either ignores disability, or exhibits ignorance about it (Grasgreen, 2014; Jones & Brown, 2012; Oswal, 2017).

6.1. Mental Disability in an Ableist Academia

In order to understand specific issues in regard to mental disability in academic life, it is important to understand that the overall issues regarding mental disability are no different in our larger society than in academia except that the university itself is an elite and exclusive institution. Critical social model of disability, that places equal emphasis on socially-constructed disability and individual's impairment, offers us a useful lens to study the physical needs of the students and the social context of receiving help (Oswal, 2018). Stigma, or shame associated with mental disability, is a common problem among mentally disabled students, as the common social stereotypes associated with mental disability work to marginalize the mentally disabled in society.

Some of the stereotypes regarding mental disability are: 1) the belief that one can only be abled or disabled, with no gray area or in-between; 2) disabled people are exempt from rules of appropriate social interaction or require pity, concern, help, etc., at all times; 3) disability can be categorized and cured accordingly, and these cures work universally for disabilities within a certain category; and 4) disability is an individual problem.

Mental disability is often overlooked or doubted in academia because of the unpredictability of symptoms. Disability has been framed as a box that is checked or un-checked and must be manifested at all times and in all circumstances in order to qualify as "disability" in the first place, despite the fact that mental disability is not so simple or clean-cut a state in lived experience.

Assumptions about the lives and feelings of disabled people have also created the added assumption that abled-disabled social interaction is governed by different rules than those of "normal" people (Silvers, 1994). "Invisible" disabilities, such as mental disabilities, are often kept invisible through passing due to the new and invasive rules of social interaction that further work to marginalize the student with a mental disability. In addition, the disabled person's right to privacy is assumed to dissolve with her disability, as a college staff member may offer invasive suggestions: "my sister was diagnosed with bipolar disorder, you should try this medication". By disregarding the respect that would be expected in a conversation with a non-disabled person. Such behaviors further marginalize mentally disabled people by inadvertently showing "they aren't normal, so they don't need to be treated that way".

Another problematic assumption in our ableist society is the belief that mental disability has been accurately broken down into scientific categories, and every disability has a medical fix. For many mental disabilities, pharmaceuticals dominate this belief system, despite a slew of more-disabling, known side effects. This becomes even more problematic when a person experiences more than one disability and is expected to take a large variety of medications.

Despite the ableist assumption that the disabled are helpless without the non-disabled, the ableist society further isolates disability by enforcing the belief that it is the disabled individual's responsibility to cope with their disability, seek help, pay for the cost of help, and live with their disability day by day, regardless of the reality that living with disability is problematic primarily due to the incorrect belief the all or most people are non-disabled or "normal". In other words, disability is only problematic because of its placement in a society designed by nondisabled people for other nondisabled people, but this ableism also governs the belief that disabled people must find a way to fit in instead of non-disabled people redefining problematic societal frameworks and infrastructures that shun or exclude disability.

At the root of these issues is also the ableist assumption that disability is over there, not here and that mental disability is a special circumstance requiring special care, not a part and parcel of everyday human life, and therefore, societal life. By creating a defining line between the so called "abled" and the "disabled", disability has been excluded from the qualifications of what constitutes "anyone". This "anyone" we are referring to here is the concept of our society that we will design, create, legislate, and live in ordinance with what "anyone" could and should do. While this marginalization may not be deliberate, it is deeply engrained into our commonsense belief systems, and is constantly working toward preventing the equality, success, and inclusion of disability in the academy.

6.2. Mental Disability inside the Classroom

In this section, we specifically address how the stereotypes about mental disability have transferred into legal accommodations for disabled students in post-secondary education, and then there are additional assumptions in academia that further marginalize disability. These include: 1) accommodations process as a problem and not a solution; 2) competition as a core value of academia; 3) lack of staff training; and 4) the belief that teachers must be objective and impersonal.

Most college courses include a syllabus, and in this syllabus is a (required) disability statement, which often states that a student requiring disability accommodations must speak to the professor, provide proper paperwork from the campus disability services, and negotiate the terms of accommodation. These boilerplated disability statements prove to be one of the many not-so-helpful “quick fixes” for several reasons.

First, disclosing one’s mental disability is a gamble in itself: once disclosed, this information is accessible to anyone in the academic world, and can become a problem during the student’s application for a graduate program or search for a career, among others. Students who have disclosed a mental disability in order to receive accommodation have experienced a variety of consequences including the belief of the faculty writing recommendation letters that the student will not be able to handle higher-level academic programs and jobs just upon knowing the student has a disability.

Second, proper medical documentation is expected which is extremely reliant on the belief that disability must be categorized. This requirement also proves to further marginalize underprivileged students with disabilities. If a student cannot afford to undergo extensive psychiatric examination to “prove” their disability, disability accommodations will not be available from the university. Readers might note that the process cannot be completed in a single visit to the doctor, as psychiatric evaluation is often based on a series of sessions with a psychiatrist.

Third, the negotiation process can prove to be grueling and oppressive for the mentally disabled student. Even with proper documentation, this process places the power of deciding whether a person is disabled “enough” in the hands of the creator of the curriculum, who is not likely to be trained with an understanding of mental disability and has only commonsense assumptions to help judge which accommodation is appropriate. Students with “invisible” disabilities like bipolar disorder may receive little to no help during this process, as the common belief that one is either obviously disabled or not disabled influences the educator’s decision.

Academia’s holding of competitiveness as a ee value in its community also works against mental disability in post-secondary education. Accommodations can often be refused on the grounds that giving a student more time or eliminating the requirement of attendance will give the student an “unfair advantage” over her peers, regardless of the fact that her bipolar disorder has already given her peers an unfair advantage over her. No doubt, the course curriculum and pedagogy for the class also has been designed for the nondisabled peers in the first place and not the students with disabilities.

The issue of competitiveness as a core value can also be seen in teacher’s skepticism to believe a student has an “invisible” disability at all. Skeptical responses by professors show that academia holds competition at such a high value in its community, teachers are led to believe that a student would sooner lie about being mentally disabled to gain an unfair advantage over her peers before she would likely be honest about having the disability. This belief, too, returns to the commonsense assumption that if a disability is not constant and obvious, it is non-existent.

Most of the conduct by professors to further marginalize mental disability in academia is due to lack of training and information about disability and disability studies

While K-12 educators are required some degree of training in child psychiatry—which still uses the problematic medical model of disability—college professors are not required any training in working with mentally disabled students. Despite the report that one of the biggest issues educators face in working with disabled students is not knowing how to work with them, they are still expected to teach disabled students all the same (Collins & Mowbray, 2005). This results in the extreme disconnect in their understandings of mentally disabled life, or what may result in their belief that a student’s inability to complete an assignment due to a manic episode is unbelievable.

Further on, academia fails to challenge its own ableist assumptions by enforcing the belief that teachers should be educators and educators alone which can have its own repercussions for a disabled student. In fact, the educational community discourages interpersonal relationships between teachers and students on the grounds that the “emotional burden” is not within the scope of the responsibilities of the teacher (Price, 2011). Despite this belief, a trend among successful students has been reported due to interpersonal and “friendly” relationships with their professors (Halawah, 2006).

A variety of factors attribute to the extreme stress that is placed on college students just by attending college (Davidovitch & Soen, 2006). With the added stress of adjusting in a highly competitive academic environment—completing homework with rigid deadlines, participating in graded class discussions, and attending class itself—mental disability can be seemingly an impossible state to cope with amidst an episode. For students with bipolar disorder, the distance created between students and teachers is effectively eliminating another possible support system that could make the difference of staying in or dropping out.

6.3. Additional Barriers for Students with Bipolar Disorder

As bipolar disorder is an “invisible” disability, it may also be met with disbelief and skepticism when the student chooses to disclose. The belief that one must be either abled or disabled prevents educators and faculty from understanding that, although the symptoms of bipolar disorder may be inconsistent and unpredictable, that student is still disabled and may require accommodation. It is assumed that because a student was not experiencing the symptoms of her bipolar disorder two weeks ago, she is not truly disabled.

The medical regime also threatens students with bipolar disorder with the pressure or requirement of medication, despite the fact that pharmaceuticals are only one option of many treatments. Students with bipolar disorder who do not seek pharmaceutical treatment may be subject to stigmatic repercussions by their educators, staff, and peers. Marginalization of disabled people is further cemented through the belief that those do not experience positive effects from the miraculous cures of these pharmaceuticals or methods should be cast out as the “incurable” or are then responsible for their own disability due to the refusal of pharmaceuticals or other methods, pushing them even farther from what Garland-Thompson (1997) calls the world of “normates”. Normates possess “the corporeal incarnation of culture’s collective, unmarked, normative characteristics” (Garland-Thompson, 1997, p. 8). In short, it is a standardized body imagined by a culture as perfect but never approximated by any mortal, let alone the people with disabilities.

7. Recommendations for Reconceiving the Student–Teacher Relationship

Students with mental disabilities are subject to the limiting structure of an academic system made by the abled, for the abled which to them appears no better than a black box whose inner mechanisms are invisible. While there are retrofit systems—systems that try to fix the problems of access after the fact, or as an add on—in place to assist students with mental health diagnosis, the disability services delivery processes themselves have flaws that are more likely to deter students from seeking accommodations. We make several recommendations for improving these processes and changing the campus climate for disabled students.

7.1. Rethinking the Academic Accommodations Process

When students are seeking accommodations for mental disabilities and a psychiatric evaluation is not immediately possible, the university should have an alternate plan in place. Here, we emphasize that we must begin this process with the belief that a disclosure of mental disability is not a ruse to earn more leniency in class. If a student is seeking an academic accommodation and needs psychiatric evaluation to support that accommodation, the student should be given the appropriate academic accommodations during the evaluation process. Additionally, psychiatrists should be provided for students expected to undergo evaluation that do not have appropriate medical care. While most college campuses have a student counseling center in place for students seeking psychiatric care, this office needs to work closely with the disability services office to provide psychiatric evaluation to those who cannot afford it otherwise.

Second, faculty involved in handling the accommodation process must be prepared to help students whose disabilities prevent from communicating in ways that we may believe “anyone” can communicate, such as surveys or the expectation that a student will know exactly what accommodations are best for them.

Third, it is important to ensure that the process in which a student seeks accommodations is not off-putting and does not contribute to the creation of stigma and marginalization of the mentally disabled. As seen in the experience of one of us seeking accommodation in the form of regular counseling and vouchsafed by published research, the process can often be impersonal, indifferent, and difficult in an already elitist college climate (Wilson, Getzel, & Brown, 2000). It is important to understand that many students with bipolar disorder may opt to taking lower grades, taking time off, or dropping out entirely in lieu of participating in this process, so the process itself must not be a deterrent.

Last, we also want to draw attention to the diversity among students with mental disabilities on our university campuses and their specific needs. We don’t believe that the traditional multicultural competency training offered to clinical counseling staff is sufficient to meet the needs of today’s university student populations (Hansen, Pepitone-Arreola-Rockwell, & Greene, 2000). To provide adequate support to these highly diverse student groups, including a significant percentage of international students, university counseling services will do better off staffing their services with experts possessing intersectional understanding of the needs of students with mental illness diagnosis who might have other disabilities, or belong to diverse racial, ethnic, and cultural groups (Harsh, 1993; Olkin, 1999). Scholars writing about the discipline of Psychiatry have also been asking for interdisciplinary and intersectional approaches to practice so that the knowledge and meaning-making processes of other disciplines could be availed by the field of counseling to make it less clinical and more human (Carel, 2012, 2017).

7.2. Training Staff and Educators: The Goal is Access

Post-secondary staff and educators need to have some training on working with disabled students from the perspective of critical social model of disability to actualize the inclusion of mentally disabled students in academic life. Critical social model asks for viewing disability as a social phenomenon beyond the tangible fact of physical or mental impairment. The ultimate goal in this model of disability is access through environmental support, inclusion, and consideration. The critical social model of disability we support interrogates separate arrangements for people with disabilities. In higher education setting, it demands an overhaul of institutional policies, infrastructure, and curriculum so that the academy is inclusive of neurodiverse bodies and appreciates their difference—the difference that has the potential of transforming the ableist university. Of course, the purpose of these changes is to produce physical and learning environments in which disability accommodations are unnecessary or needed only infrequently. It also demands that the disabled person's agency always remains intact when they have to avail of accommodations because of the inaccessible and ableist institutional policies and structures. This training is also imperative in the implementation process of accommodations, as teachers must be trained to understand that "Every time I've seen her, she's seemed 'normal'", is not appropriate reasoning for refusing accommodation. Rather, they should be trained to develop course management techniques, curricula and pedagogies that are natively accessible. Here, we would like to specifically address the importance of training educators on the concept of "crip time" from disability culture which takes a less rigid approach to normative time (Gill, 1995). Normative time's understanding is that classes are paced according to the expected amount of time a non-disabled student would be able to complete the coursework. However, this pace does not allow enough time for students with mental disabilities to complete the work should they be experiencing symptoms. By educating faculty about the meaning of "crip time", they may be better able to understand that pacing a class around "ability" is not equitable.

Besides, bipolar disorder may create great conflict in a student's ability to participate in and attend class. Researchers have pointed out that "we tend to view the inability of students to participate in certain aspects of university life...to not be a function of anything inherent to those individuals, but rather the way the university is set up" (Stout & Schwartz, 2014). Critical social model of disability also situates the educational barrier in the institutional policies and structures, not the student's body. By training educators in bipolar disorder and its symptoms, professors will better understand how this mental disability conflicts with common requirements of participation and attendance in any course. For instance, interacting with one's peers is an important part to expanding knowledge and learning content. However, a student with a bipolar disorder may not learn from the requirement to speak up during class discussions because of the heightened fear of judgement and backlash. A variety of unrelated responses or feelings may prevent them from speaking up at all. If they do speak up, they may be unable to retain any content from the discussion due to anxiety over the judgment of their peers and instructor. Ultimately, professors must know that the belief that the traditional attendance and participation are essential to the learning process is framed from an ableist perspective and alternate pedagogical methods exist to learn and to evaluate student learning. For example, class participation does not always have to happen orally; it can also happen through short, written comments from students on index cards which could then be circulated among small groups by the instructor for carrying on class-wide discussion.

7.3. Supported Education

Supported education is a "psychiatric rehabilitation intervention that provides assistance, preparation, and support to persons with mental illness in enrolling in and completing postsecondary educational programs" (Collins & Mowbray, 2005). Supported education can help mentally disabled students who are unable to attend or participate stay caught up in class, understand and complete material, and stay healthy while attending college. Supported education may also help faculty in interacting with and assisting students with mental disabilities to better understand which accommodations a student may need and why. Research and Innovation Center for Rehabilitation at the Hanze University of Applied Sciences in the Netherlands has published a supported education toolkit for helping academic units to start such programs (Hofstra & Korevaar, 2016).

7.4. Funding Student-Driven Self-Support Projects

Academic accommodations for students with disabilities have been often described as costly and requiring fundamental changes in curriculum and pedagogy. While we urge for these fundamental changes—and they are not as costly when instituted into the university policies than implemented as retrofits—, we also note that colleges also don't pay attention to student support systems which require little investment in new infrastructure or resources. Even the neoliberal universities of these times can easily afford to allot funds for constructing support for low-cost student communities. For example, so few colleges offer encouragement or support to disabled students for organizing their own online campus networks using listservs or other social media where current and prospective students would have safe spaces to exchange personal notes about their classroom experiences, ask questions on academic and social matters, and voice concerns about the campus life. By supporting and maintaining such virtual groups, colleges can not only let students with disabilities form self-supporting communities but also indirectly provide support to at risk students; thus, raising the critically low retention rates for disabled students in higher education.

We also advocate for special programs to mentor students with bipolar and other psychiatric diagnosis by experienced faculty with and without disabilities on the line of other diversity mentoring programs to break the circle of isolation, serve as a liaison between students and various services when an intervention is essential, offer emotional and social support at a personal level, and closely track their academic progress-related needs. As the mentoring literature reports again and again, students with diverse characteristics and critical needs can flourish in supportive mentoring relationships (Hastings, Griesen, Hoover, Creswell, & Dlugosh, 2015). Similarly, we also need faculty coaches with the knowledge of disability studies, event planning experience, and fundraising skills who could train students with mental disabilities to organize small, regional conferences which could function as venues for mingling with students from other colleges. Such conferences can provide opportunities for students to emerge from their disability closets; confront the stigmatizing aspects of their campus life with activism, policy change demands, and communal teach ins about disability hate and bias; form coalitions with other minority groups to strategize disability initiatives; and combine their academic and personal life goals into a purposeful and cohesive whole.

7.5. Interpersonal Student–Teacher Relationships

The taboo of interpersonal student-teacher relationships must be challenged as well. College students with disabilities are often experiencing a drastic change in their daily routine when they first move to a university campus. Some students are living without their parents for the first time in their lives, hundreds or thousands of miles away from friends and family that had been their support system before. Interpersonal relationships between students and teachers may prove to be a driving force in encouraging students to seek accommodation when accommodations are necessary. If educators are trained in understanding mental disability and are no longer institutionally steered away from interacting with their students on a personal level, educators can become helpers to students who require accommodations but feel discouraged from disclosing their mental disability for the usual reasons in seeking accommodations. While educators certainly aren't expected to adopt a parental role to their students, students with mental disabilities should be able to express the difficulties and realities of everyday life on campus about their disability to educators. Not only will this allow educators to better understand why a student may need certain accommodations, students are also far more likely to succeed without the invisible barrier between the educator and student.

7.6. Inclusive Research about Students with Bipolar Disorder

Finally, we call for more studies about students with bipolar disorder in post-secondary education and we urge disabled students to take a leadership role in undertaking such scholarly projects. We must conduct more research to understand how students with bipolar disorder are functioning in college and what their unmet needs are. Emancipatory and participatory models of research proposed by Disability Studies scholars are specifically suitable for such scholarly and activist undertakings to create a comprehensive picture of life with bipolar disorder in higher education (De Schauwer, Van Hove, Mortier, & Loots, 2009; O'Day & Killeen, 2002; Tew, 2006).

Besides the self-support projects discussed above, students and faculty, particularly those with disabilities, must take a lead in organizing small-scale, local and regional disability conferences and symposia on campus to make the university community aware of the mental disability issues, to help the overall student body understand disability rights of their peers, and form a "crip pride" campus community where disabled and nondisabled students could mingle and discuss disability issues.

8. Conclusion

These solutions, such as supported education through close mentoring by faculty with background in disability support, availability of small, regional conferences to assist students in coming out of their disability closets, staring social prejudices in the face through student activism to make the age-old stigmas bend down, campus-level disability education initiatives, and anti-ableist institutional policies, can turn the tide in favor of academic and social inclusivity for students with psychiatric health diagnosis. Our article enforces the relevance of participatory studies of institutional life that record detailed accounts of what students with mental disabilities feel they are missing from their higher education: knowledge of the human body, equitable resources, and an inclusive society. While our recommendations call for a fundamental shift in academic and institutional policies, physical and social structures, curricula and pedagogies, and faculty, staff, and student attitudes, they are essential for the success and well-being of students with mental disabilities, as well as, for transforming our universities into less ableist and more diverse places for learning and teaching.

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About the Authors

Allison K. Kruse is a graduate of the University of Washington's Technical Communication program in the School of Interdisciplinary Arts and Sciences which excels in accessible design, human-computer interaction design, and user experience (UX). Her interests include human-centered design, disability studies, and technical communication. Besides her scholarship in the area of disability studies and accessible design, Allison has also conducted field research in prototype design and usability testing at the University of Washington. She is presently looking for opportunities in the areas of content development and writing, technical communication, publishing and editing, and related research.

Sushil K. Oswal (Dr.) is an Associate Professor of HCI and Accessible Design in the School of Interdisciplinary Arts and Sciences and an affiliate faculty in Disability Studies at the University of Washington. His PhD research focused on the application of environmental science and environmental technologies in the research for innovative cosmetics formulations and corporate policy in a Japanese multinational corporation. His current interdisciplinary and international research deals with information and communication technology development's (ICTD) role in human health development projects, as well as, the impact of ICTD projects sponsored by the governments, international monetary institutions, and nongovernmental organizations of the global north on the rural women with disabilities in the global south. He is also working on a longitudinal study of interaction design of self-service digital kiosks in aviation and banking. His recent interdisciplinary accessible design and disability studies work is available at journals.sagepub.com/toc/bcqe/81/1

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Article

“Everywhere We Go, People Seem to Know”: Mad Students and Knowledge Construction of Mental Illness in Higher Education

Lieve Carette *, Elisabeth De Schauwer and Geert Van Hove

Department of Special Needs Education, Ghent University, 9000 Ghent, Belgium; E-Mails: lieve.carette@ugent.be (L.C.), elisabeth.deschauwer@ugent.be (E.D.S.), geert.vanhove@ugent.be (G.V.H.)

* Corresponding author

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Abstract

Psychological wellbeing has received attention from academics and policymakers worldwide. Initiatives to improve psychoeducation, campaigns to raise awareness, and charity projects have been established as part of efforts to change public attitudes and behaviors toward mental health problems. The common goal of these initiatives is the prevention of mental health problems in order to reduce the global burden of mental health disease. Some target groups have benefited from such initiatives. However, little attention has been paid to side effects—including harm—of widespread knowledge sharing that is not accompanied by appropriate action. Young adults may be less afraid than older adults to disclose mental health illness and share their lived experiences of mental health. Like older adults, students try to protect their autonomy and privacy in disclosing mental health problems and associated diagnoses. However, many young adults view self-disclosure as a request for help. Confronted with rising demand to support students’ psychological well-being, many higher education providers have launched initiatives to improve students’ knowledge about mental illness. Instead of making assumptions about what students need to know in order to improve their overall psychological wellbeing, we asked ‘Mad students’ (that is, students who identify as mentally ill) about their knowledge construction and management of mental illness. Analyzing this process highlights that mental health promotion is more complicated than sharing appropriate information or applying effective strategies. Knowledge sharing has improved public knowledge of mental illness. However, mental health promotion that omits simple communication about expectations and needs around mental health, to co-produce a shared knowledge base, may lead to misunderstanding and failure in meeting the needs of target groups.

Keywords

higher education; knowledge management; mad studies; mental disability; mental health; mental illness; mental support

Issue

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1. Introduction

1.1. Knowledge Management Life Cycle Model: What Are We Talking About?

In this article, we will examine how students in higher education acquire knowledge about psychological wellbeing, as well as factors that may influence how they present themselves within this setting. Based on Evans, Dalkir and Bidian (2015), the knowledge management life cycle model (KMLC), with its seven non-sequential phases, will be used to analyze how knowledge is processed and used (Figure 1).

Knowledge management models are used to improve organizations, including to enhance strategic and/or operational problem-solving, decision-making,

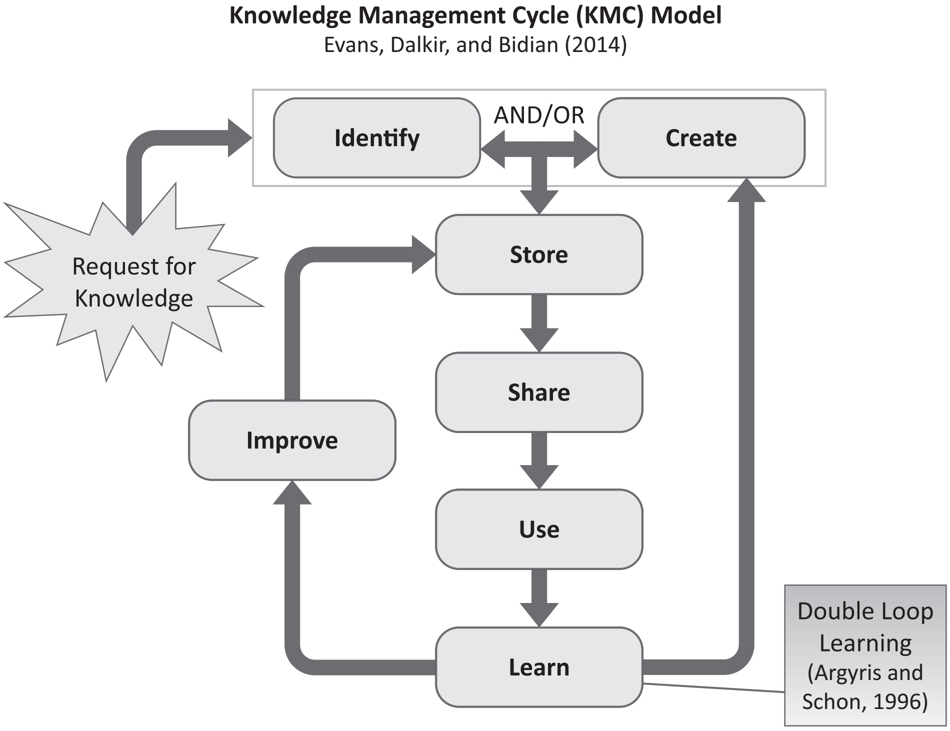

Figure 1. The KMLC. Source: Evans et al. (2015, p. 85).

knowledge gap analysis or innovation (Evans et al., 2015). In this article, the phases of the model are used to identify what students know about completing their studies while living with mental illness and what information they desire about mental health; how students find or retrieve about mental health; and how knowledge about mental health and wellbeing is shared and used within higher education. Knowledge gaps noticed by students reveal how students search for, retrieve or share new knowledge or where there is a need to create new knowledge around mental health and wellbeing.

Based on Evans et al.'s (2015) knowledge management life cycle, construction and processing of knowledge may seem simple and straightforward. However, the model does not address that different people may have different understandings of a phenomenon. In this article, we will investigate how differences are possible at various levels of the KMLC. To start with, people may have different knowledge of a phenomenon due to previous life experiences; different students may gather different knowledge from the same situation; real life and virtual encounters can produce different knowledge or influence the type of knowledge that is shared; in the 21st century, knowledge is stored in and accessed from different places on the worldwide web and can be interpreted differently; the use of the knowledge can differ due to personal motivation; and some students will work with existing knowledge, while others will need creative or innovative knowledge to solve a problem.

In this study, we listened to students to explore factors that affect students' knowledge about psychological wellbeing. We focused on effects of students' own experiences, as well as the influence of media campaigns set up with a special focus on young people's mental health and wellbeing.

2. Methodology

Students were invited via support officers and on social media to participate in semi-structured interviews. Each student who participated in our research identified as having mental health issues, but not all students possessed a medical diagnosis or were registered as having mental health issues in the database of their higher education institution. The umbrella term we use for this group of students is 'Mad students'—referring to Margaret Price's book *Mad at School: Rhetorics of Mental Disability and Academic Life* (2011):

> Many of us are mad at school. This includes not only those of us with mental disabilities who work and learn in academic settings; it also includes those who are mad at school in the other sense—frustrated, critical and concerned. (Price, 2011, p. 20)

As critical and concerned, we also refer to BeMSA Gent (2018). One student from this organization participated in this study to share her experiences and give voice to students who participated in the 'start to talk' meetings. These meetings were set up to enable Mad students to connect and exchange how they feel in a safe environment with peers.

In line with themes from Mad Studies (LeFrançois, Menzies, & Reaume, 2013) we sought Mad students' perspectives on knowledge production, psy-centered ways of thinking within higher education, opportunities for Mad activism in sharing lived experiences in relation to the context of higher education, and the impact of wellbeing promotion. Mad Studies is an area of education, scholarship, and analysis about the experiences, history, culture, political organizing, narratives, writings and most importantly, the people who identify as: Mad; psychiatric survivors; consumers; service users; mentally ill; patients, neuro-diverse; inmates; disabled (Costa, 2014). It is a project of inquiry, knowledge production, and political action devoted to the critique and transcendence of psy-centered ways of thinking, behaving, relating and being (Beresford, 2016; LeFrancois et al., 2013).

As an introduction, all students were invited to tell something about themselves and their motivation to participate in the study. Each participant explained why they decided to enroll in higher education, including reflecting on their experiences of mental health and wellbeing before and during their studies, as well as their expectations of their experiences in the future.

First, we explored how students learned about psychological wellbeing and how to pursue this during their studies. Next, we asked students about the possible influence of news, social, and other media on their knowledge of mental health and wellbeing. Most students in this study were not familiar with recent media campaigns on mental health. For this reason, we used 10 logos from campaigns circulating in different media channels in Flanders as prompts in interviews. These campaigns were selected because they aimed to reach young people with messages concerning mental health and wellbeing. Most students did not recognize the logos. Even so, the logos inspired students to discuss charity projects they were familiar with or had participated in.

The data retrieved from the introduction, the audio recorded and written notes from the semi structured interviews were analyzed to look for concepts and categories. Each manuscript was carefully read through several times and was subjected to a content analysis. For this analysis we followed the inductive and conceptual mapping procedures as suggested by Clarke (2005) and Charmaz (2006). Reoccurring themes, common patterns and key points were identified by the first author after coding the interviews (Bogdan & Biklen, 1998; Patton, 1990). The themes were examined for consistent patterns and exceptions. This approach was combined with the KMLC, the different stages of this model were used as a guide to distinguish categories in knowledge management.

3. Results and Reflections

3.1. Part One of the KMLC: Identifying the Sources Students Use in Knowledge Construction

Beginning with the concept of psychological wellbeing, students quickly separated the concept into two 'mental health' as opposite to 'wellbeing'. In discussing mental health, most students mentioned illness, pathology, and perceived difference as deficit. On the other hand, wellbeing related to their needs as an 'ordinary' student, not necessarily linked to their reported mental health problem (Titchkosky & Aubrecht, 2009, p. 183).

Instead of leaving the question very open from the beginning, we could have commenced interviews for this study by questioning students about assumed knowledge concerning mental illnesses that would be familiar to most adults in the general population. Dumesnil and Verger (2009) found three indicators to measure people's knowledge of mental illness. Applying the three indicators to the higher education context, we could have asked students if they knew about the prevalence of mental illnesses among students, about *symptoms* that signal when someone is in distress, and where to find *support* for mental illness, including treatments, or types and places of care.

Prevalence of mental illness denotes measurement and registration data. However, Rampazzo et al. (2015, p. 158) report that "not all the countries have national web-based health information systems containing epidemiological data, nor databases of effective mental health promotion interventions". In addition, higher education institutions do not maintain registers of all students with disabilities. As such, there is a lack of data showing how many students are living with a disability. This lack of data is compounded regarding mental health among students, considering mental health often is seen as a separate category than physical health. Without accurate databases on mental health among students and considering students do not always disclose mental illness in higher education contexts, we can only estimate the prevalence of mental illness among students. The question is whether data on prevalence is important knowledge for students: is it necessary for a student to know how many students have medical diagnoses similar or different to their own? In interviews for this research, students reported the benefits of knowing that their peers were experiencing similar mental health problems. However, students were more interested in how other students experienced mental health problems, and what kind of support had helped other students to succeed in their studies or careers. In sum, regarding prevalence of mental illness, students were interested in how their peers pursued psychological wellbeing. Participants stressed that students in the same degree program or with the same diagnosis would not necessarily need the same information or support.

Students who had experience with therapeutic counselling sometimes had prior knowledge concerning warning signals and strategies for handling their specific situation. Students for the first time confronted with mental health issues in higher education tended not to have this knowledge. Compared to their own experience of mental illnesses and prior knowledge based on that experience, students said it would be difficult to gather this knowledge for other mental illnesses without direct personal experience. Students claim: "When you have a lived experience, you gained knowledge by what others tell you and their reactions, but also by lived experience and 'doing your own research' to get answers to specific questions". Students reported that as a child they had tended to accept information from adults in their life. However, in adolescence and young adulthood they had become more critical of information and had access to more objective and professional information, equipping them to do their own research and reach their own conclusions about mental health. This process included to resist what others said about and for them. One student said he had a parent who reinforced the student's perceived disability by having low expectations of the student, limited to physical survival. Becoming a student meant making decisions for himself and pursuing psychological wellbeing in striving to accomplish his own dreams. However, when entering higher education, the student was confronted with a checklist and advice about the reasonable accommodations for his disability, making him feel stigmatized and oppressed again. Students said they mostly needed help with studying, and perhaps help to reach their academic and professional goals. Students want to be independent (De Schauwer, Van Hove, Mortier, & Loots, 2009). Some students said they didn't expect university staff to know much about their situation and how to handle with it as they themselves. However, they said staff could help them to access the correct information.

Students said it was difficult for them to find reliable and appropriate information about studying with mental illness. As such, they felt it was best to use several sources, starting with resources including recognizable narratives about mental illness that were not problematized or stigmatizing. When asked to provide examples of resources used as an initial point of reference, it was expected that students would mention support websites from mental health organizations or university services. Instead students with a prior history of mental illness said they consulted literature and media: autobiographic novels, fiction with recognizable characters, poems, movies, online narratives, blogs and vlogs. Students who reported that they had experienced emotional distress for the first time during their studies said they had sought support from someone who could help them with the perceived acuteness of their situation. Some students turned to local mental health support websites. Students with and without medical diagnoses said they sought recognition and understanding. They looked for information or persons to express or visualize feelings they struggled to explain. Students described finding this kind of information or connection as a relieve from feeling isolated and misunderstood.

Each student commences higher education with knowledge and information based on their own previous experiences. As such, it seems difficult to detect or record knowledge or information about mental health held by higher education students. Amid evolutions in dealing with big data, including tools to access data efficiently, it may be possible to work with students to identify and disclose information about mental health, facilitating knowledge sharing among future students. Making existing knowledge of mental health accessible and visible, for instance through websites with information about mental health support, continues to be a challenge for mental health providers and stakeholders. The important message is that the mental health knowledge students value most concerns lived experience, recognition and mutual understanding of mental health.

3.2. Part Two of the KMLC: Storage—Individual or Collective Memories?

In today's knowledge society, building an all-encompassing repository of knowledge about mental health and wellbeing in higher education may seem an effective mental health promotion measure. Some mental health providers and stakeholders view information gathering as the first step in mental health promotion, ahead of implementing strategies that draw on that knowledge to address the rise in mental health problems: "Much is now known about what works in mental health promotion, prevention, care and treatment. The challenge is now to implement this knowledge" (World Health Organization, 2018).

However, in spite of access to knowledge and information about mental health, students in this study reported that they had to search for appropriate and relevant resources to support their mental health and wellbeing in combination with studying. For students, a collection with information about psychological wellbeing shared by other students in higher education is not yet available. On an individual level, students reported that they stored literature or websites with information concerning their specific situation and connected with social networks, finding inspiration in the lived experiences of others. Students said it was not a random collection, but assembly of knowledge that gave them a feeling of not being alone anymore, understanding their own situation better, knowing how to handle it better. Students said they assembled this information alone or with their peers, but outside the control of support officers or other professionals. However, students' collective information about mental health and wellbeing contained some professional knowledge, or knowledge from mental health or medical organizations. Students said they knew where to find professional information concerning their diagnosis and prognosis. They mentioned a knowledge gap when seeking information relevant to young adult students. They said most information available is about adults, sometimes linked to employment or about children and young minors, sometimes linked to normal development or schooling. Students said they filled gaps in the information available to them by assembling fragments with information that could be used in the context of higher education (for example, procedures to apply for reasonable accommodations), sections and interpretations of professional information (for example, criteria from the *Diagnostical and Statistical Manual of Mental Disorders*), and information based on their own or other peoples' lived experiences (for example, how it felt to be in a certain situation and results of their actions).

However, as these sources of information include subjective or fictional information with personal interpretations and beliefs, it is possible they include false or incorrect information about mental health. For example, in interviews for this research, students reported their incorrect understanding that it was possible to postpone university exams if they were experiencing symptoms of a psychological illness.

It is a pity each student must build their knowledge of mental health and wellbeing from scratch and cannot build on their peers' searches for information, including material other students have identified as interesting. One potential strategy to create collective knowledge of mental health relevant to students is connecting Mad students in knowledge communities where they can share and collectively store their knowledge and lived experiences. The process of efficiently retrieving and accessing this shared knowledge could begin with recording why students individually or collectively value this knowledge.

3.3. Part Three of the KMLC: Sharing as a Form of Caring?

Students reported that they did not exchange much information about their mental health with friends or peers. Some students discussed their experiences of being admitted to psychiatric services, exchanging knowledge about experiences with other patients—for example, swapping stories about strategies they had used to misguide the nurse caring for them. In settings where students had been forced to disclose their mental health problems, for example through compulsory group counselling, it was easier to exchange information because they were all in the same situation as, for instance, other in-patients on the ward. Students reported their experience finding their place within the community of students was something different:

> You first have to be a normal student, meaning you first of all exchange information about the courses and how to study, about student friendly places to hang out, extracurricular activities….Students don't talk much about personal feelings and struggles, only once in a while about workload and psychosomatic stress when it has an impact on all of our wellbeing.

One student noted that students disliked talking with mental health support officers, but neither did talk to fellow students about personal struggles. In choosing a new project (BeMSA Gent, 2018) a medical student and her peers established 'start to talk' meetings. In groups, students were asked to share their experiences and feelings, including factors that made them feel safe to exchange information with others and express their thoughts, worries and strategies for pursuing psychological wellbeing. The goal of creating this connection between students and their peers was to make students feel supported and understood in order to facilitate discussion of their knowledge and lived experiences of mental illness.

Students participating in this study all wanted to share their story. This raises the problem of selection bias. Most participants said they hesitated for some time to disclose their mental illness, in part because they did not know how to share their story. Some were pushed by friends to disclose. Others took advantage of the opportunity to share the story anonymously through participating in this research. Others sought an opportunity to share their lived experiences of mental illness in order to benefit other people living with mental illness, having missed this kind of mentoring and support themselves. For some students, it was the first time they shared the whole story of their lived experience of mental illness, in what became their first step in seeking new ways to share their experiences and find allies who had similar experiences. Some students had come close to sharing their lived experiences of mental illness, ultimately deciding not to because they feared the consequences in terms of their perceived suitability as a student or employee. Students mentioned their desire to be accepted as different to support other people living with mental illness. At the same time, students felt they could not speak for other people living with mental illness because of the uniqueness of each person's lived experience. As mental health problems are invisible illnesses, students noted that they could choose whether to disclose.

Still, at the conclusion of interviews, each participant said they had felt safe to open up because they were listened to without judgement and felt a connection with the interviewer, who they viewed as trustworthy. Participants said the interview questions made them feel understood, as did the examples they provided in response. This suggests that self-disclosure of mental illness involves sharing invisible, sensitive and private pieces of oneself in addition to sharing knowledge about mental health and wellbeing.

In sum, information sharing between students with mental illness seems possible only through creation of safe spaces to facilitate disclosure. Students value existing knowledge that is available online, for example providing information on professional mental health support services. However, these repositories could be improved through cooperation with students. Online sharing is one strategy to give students the tools necessary to exchange personal knowledge, lived experiences and information about how to care for each other's' mental health. However, results of this study suggest that online sharing is less effective than knowledge production via dialogue or networks. Knowledge sharing about psychological wellbeing in higher education should focus not only on mental health issues but should try to grasp the complexity of student life in adding and combining assets about studying, psychosocial issues, and diversity. Narratives should be included in shared knowledge, because students first look for recognition of their mental health problems, which helps them feel less alone among their peer group. A step further than online exchange is real life exchange, where students find peers to connect with. Higher education institutions could promote peer-led actions to create safe spaces for students, instead of redirecting students to support courses and therapeutic offerings where knowledge is transferred instead of exchanged.

3.4. Part Four of the KMLC: What Happens with the Compiled Knowledge and How Is This Used by Students?

How knowledge is used depends primarily on perceptions of the need for that knowledge, along with challenges around, urgency and drive underlying implementation of knowledge-based changes. In higher education, students with disabilities first of all try to determine if it is possible for them to study the course that interests them. Students try to predict what they will need in order to pursue psychological wellbeing during their studies based on prior knowledge, experiences and strategies that were effective in previous situations. Students use this knowledge in an effort to situate themselves in relation to their learning environment and future career, including their expectations of support that may be necessary.

In interviews, students reported using their knowledge of mental illness to negotiate with educational staff, fellow students and their support network. It is for students to decide how much or how little information and knowledge about their mental health they wish to share. Some students reported sharing as little as possible about their mental health due to fear of the consequences. Other students expressed their hope that, in disclosing their mental illness, higher education staff would empathize with their situation. In many cases, students reported that sharing information about their mental health prompted higher education staff to consider whether special education needs were available to support their medical condition, instead of focusing on provision of support for their psychosocial wellbeing. Higher education students and staff members' knowledge and opinions of mental illness are constructed, their decisions made based on incomplete information. This is because students and staff have access to incomplete information about studying in higher education settings while living with mental illness. Social scientists use the information deficit model (Dickson, 2005). Information deficits may lead to skepticism about available knowledge or knowledge from unqualified sources being relied upon. Participants explained that, unlike visible disabilities, they sometimes had to explain their invisible condition to justify the support they sought:

> I couldn't negotiate about my accommodations until I disclosed my illness. Together with the disability officer we agreed on necessary accommodations for my case. When contacting the professor and although he didn't know my disability, he didn't agree. He answered there was no evidence-based argument to approve this, it would be positive discrimination and it wouldn't help me in my future career.

Unlike disclosing a physical disability, students felt that people who disclose mental illnesses may face questioning about whether their mental health problem caused problems in cognitive functioning or could pose a threat to fellow students or patients. Students felt there was a stigma around mental illness in public attitudes, such as media reporting on crime that conflated dangerous, confused, or crazy people. Students felt that higher education staff should strike a balance between trusting students to know what support they needed and encouraging students to take responsibility for meeting certain obligations in spite of their mental illness. Students confronted with stigmas around mental illness felt that higher education staff should show more willingness to listen to and learn from students with mental illness: "One professor was different, he really understood my struggle and took his time to ask questions and look for ways that could help me take the hurdle. He had a family member with similar problems".

3.5. The Never-Ending Loop in the KMLC: Learn, Improve, Create, Innovate, Restart

Knowledge is constructed in interaction. Each encounter holds opportunities to enhance existing knowledge. Students learn about mental illness in part through encounters with and reactions from higher education staff and the surrounding world. Positive and negative reactions show students how they are perceived by others, shaping their identity and counter-reactions. Depending how knowledge of mental illness is used, students may feel misunderstood or stigmatized as a result of disclosing their mental illness. As Mills (2018) argues, there are no universally agreed-upon definitions of mental health. This is a problem for people who live with mental illness:

> Definitions of mental health and distress do not only have implications for people's identities and the types of support they receive. They also shape attempts to quantify the burden of disease and the economic burden of mental disorder, not to mention shaping the idea that mental distress is a 'burden' in the first place. (Mills, 2018, p. 851)

Students reported learning how to behave as though they were mentally healthy in order to hide their mental illness lest they be viewed as a burden. On the other hand, students reported learning how to act in stereotypically mentally ill ways in order to receive necessary and desired support. Dynamics around mental illness left students responsible for using knowledge of mental illness to their benefit or not. However, students expressed their hope that knowledge they shared would change or improve higher education learning environments for students with mental illness.

In *Toward a Mad-Conscious Classroom*, Johnk (2016), who positions herself as a Mad student, describes how discussions with classmates about authentic disability and invalid bodyminds helped her to see that she was not crazy. Instead, Johnk argues that unnoticed dynamics of power within education settings had led her to view herself as mentally different and deficient. ‘Kairotic spaces’ is the term Price (2011, p. 63) uses to describe informal, often unnoticed, dynamics in academe where knowledge is produced, and power is exchanged:

> Despite their importance, kairotic spaces tend to be understudied. One reason for this is that it’s difficult to collect data in them. Another, more compelling reason is that their impact tends to be underestimated by those who move through them with relative ease.

Students learn that educational staff react differently to disclosures of mental illness. Not all higher education staff are up to date with procedures or possess adequate knowledge about studying with a disability. Some students argued that the responsibilities of education providers extend beyond transferring knowledge and skills. Instead, students felt educators should normalize students’ mental health problems in the classroom.

Students who manage their own knowledge about mental health can turn the vulnerability that comes from mental illness into a strength. Sharing and exchanging knowledge with peers who are living with mental illness helps students to devise and create new ways of perceiving and presenting themselves within the framework of students with mental health problems. Some students reported participating in initiatives to create shared knowledge systems, caring for fellow students by addressing a gap they perceived in support services. By using social networks, blogs and vlogs, these students hoped to reach other students who lacked adequate and relevant knowledge to maintain their mental health while studying.

3.6. Influencers and Breaking in on the Knowledge Construction

In interviews, few students could name examples of effective knowledge gathering to adequately respond to the needs of people with mental health problems in order to prevent suicides and reduce the economic burden of mental illness.

However, these instances may have a different perspective on mental health than people who are living with mental illness (Titchkosky & Aubrecht, 2009, p. 181). They may not understand the needs of people with mental illness and best practices in mental health from the perspective of people with illness. An example of a translating knowledge of mental illness into action in an education setting is the European Commission’s (2016) *Joint Action on Mental Health and Wellbeing*. One priority of the *Joint Action* was a project focused on mental health in schools, which resulted in a report with recommendations to improve mental health among students (Rampazzo et al., 2015). The report’s recommendations were to:

1. Strengthen information and research on mental health and well-being among children and adolescents;
2. Promote schools as a setting where health promotion and prevention of mental and behavioral disorders and early identification can reach all children and young people;
3. Enhance training for all school staff on mental health; and consider schools as part of a wider network with other stakeholders and institutions involved in mental health of children and adolescents in local communities.

These recommendations illustrate what organizations learn from compiled knowledge of mental health in schools. An avenue for potential future research is to connect knowledge from this report with relevant knowledge constructed by students. One step in this process would be asking students how they value knowledge in the report.

The public is exposed to educational information about mental health through mental health promotion campaigns. Mental health promotion campaigns emphasize prevention of mental illness, including through personal responsibility in acting on signs of mental illness and supporting people with mental illness, which extends to the education sector. Ecclestone and Hayes (2009) call this phenomenon “the dangerous rise of therapeutic education”. Similarly, Bazan (2018, p. 3) notes:

> The mental health crisis is gigantic, growing, systemic, generalized in the western society and largely spilling over from its proper field to adjacent fields such as work and school....Every age and every culture sees a flourishing of ‘fashionable’ psychopathologies, many of which do not stand the test of time....Another particularity of our age is the tendency to confound discomforts, difficulties and particularities with pathology, as a result of which, logically, anybody is a potential patient.

Trends in training of mental health support staff in higher education highlight an increase in new diagnoses, with student referrals to psychoeducation workshops based on ‘fear of failure’, ‘ineffective time management skills’, ‘lack of resilience’, ‘mindfulness’ (Doll & Lyon, 1998; Ecclestone & Hayes, 2009; The Guardian, 2018).

Applying these insights to students’ own knowledge constructions, including translating that knowledge in a people-centered way in line with the findings of this study, highlights the need to correct the lifecycle of knowledge management around mental health in higher education. A fine line exists between providing accurate knowledge and disqualifying knowledge based on lived experience or imposing knowledge that does not match knowledge produced by Mad students.

Trying to connect different repositories of knowledge about, and understandings of mental illness in higher education settings is easier said than done. Many mental health initiatives have used websites and public media to spread knowledge and reach a broader audience, including through social media. However, when asking students in this research about projects designed to raise awareness of wellbeing or mental health, including initiatives on television, social media, or in magazines, students reported that they had not seen such initiatives before. Many information-sharing initiatives were viewed by students in this research as charity projects, raising money for a good cause, instead of awareness-raising campaigns. One student in our study said she had stopped using social media because she felt overwhelmed by the array of reactions, opinions and tips about mental health and wellbeing. Other students had deleted their online profiles in an effort to ensure they could be contacted by family and real friends only. Other students said they were fed up with the seemingly happy and perfect lives depicted through other peoples' social media profiles and did not want to compare themselves anymore.

Students said they were not familiar with most mental health promotion initiatives. In interviews, students mentioned one exception, not recognizing the initiative as a longstanding program with new logo. This project was focused on a younger audience and previously had another name (which roughly translates in English to 'Children's Helpline') and logo. Working with volunteers, the program allows children in distress to call or chat online anonymously. In addition, children can find simple information on the program's website, including coping strategies. Children accessing the program are not put on a waiting list. Recently, 'children' has been omitted from the initiative's name, and adolescents and young adults seem to use the helpline as well now. Clark, Algoe and Green (2017) explain why this project may have been able to reach beyond its target group: although it uses social media, it fulfils children and young adults' needs for acceptance and belonging. In addition, the authors note two traditional pitfalls of social interaction frequently mentioned by students in distress: isolation and social comparison.

4. Conclusion: Puzzling to Get *a* Bigger Picture, Not the Whole Picture

This article has drawn on the foundational idea of Mad Studies: "listen to Mad people and look at madness from their points of view".

Listening to 12 Mad students, we sought to learn about their knowledge management regarding psychological wellbeing within higher education settings. Exchanging and learning about Mad students' private knowledge requires creating safe environments where interviewees feel understood and not judged. Understanding as a form of connection is not transferred but co-produced as part of a bigger picture, with an unending evolution of possibilities (Kelly, Dornan, & Ruparell, 2018).

Identifying the types of knowledge students seek may surprise creators of online knowledge or expertise centers that utilize information like indicators, prevalence figures, *Diagnostic and Statistical Manual of Mental Disorders* criteria, possible treatments, and treatment services. Before expert information can capture students' attention, and before obtaining an appropriate diagnosis, students look for recognition. Sometimes not consciously aware of their needs, students encounter familiar stories with recognizable feelings and experiences that reassure them that they are not deviant. Once they find this information, students can add expert knowledge that is applicable to their situation. This shared process of knowledge creation around mental illness is "[a] dynamic web, constantly rewoven. There are no absolute truths or certainties: the question and investigation remain open, transforming over time as part of a dialectic inter-relationship between self, world and other" (Kelly et al., 2018, p. 2). In the process of creating shared knowledge around mental illness, higher education students report that they value sharing lived experiences, narratives, literary work, movies, blogs and vlogs. Even if a collective memory to record and store this information is possible, it does not exist yet. Students are making their own repositories from their own lived experiences, interpreting and adapting available knowledge to their case, leaving space for different understandings or even false information.

Some students desire ways to share knowledge they have gathered because it could fill a gap they may have encountered when looking for information. What and how they want to share that information may be different again. Some students think about sharing information online. The use of media and technology can facilitate knowledge transmission, distribution and storage. However, as Fahey and Prusak (1998, p. 273) note, "it can never substitute for the rich inter-activity, communication, and learning that is inherent in dialogue". This sentiment speaks on behalf of peer-led initiatives that invite students to talk with each other and exchange lived experiences in community knowledge networks. However, it is possible that isolated students are less likely to join meetings of this kind. Using multiple social media channels with various sources of information could be an alternative for these students.

Students use knowledge in the first place to make sense of their own experiences, to understand how these experiences shape their interactions and how their behavior is perceived by their network. In the context of higher education, students use knowledge to support their arguments in negotiating support for their special education needs. Students with mental illnesses do not expect staff and fellow students know as much as they do about mental health, meaning students are in positions of power in using their knowledge. Decisions about meeting student requests for support are based on trust and partial knowledge. How others react to their request adds knowledge to students' personal lived experience, shaping how they will use this knowledge in the future. Although it is possible that other students with mental illness have different views on support services that are helpful or unhelpful, Mad students in this research reported that they preferred not to be mothered, patronized or oppressed. They did not want other people to decide what supports they needed or would be effective, disqualifying what they had learned about their mental health during the knowledge management process. Students said they wanted the opportunity to test support strategies, improve on them or find alternative solutions.

Looking for possible factors that influenced higher education students' knowledge of mental illness, it seemed limiting to analyze knowledge acquisition based on the KMLC. If mental health promotion is to have impact within higher education, mental health advocates could start their initiatives from the perspective of Mad students, questioning where there is a need to improve and what kind of knowledge is lacking in Mad students' view. It is possible that unknown or inaccessible knowledge networks are creating a demand for better knowledge exchange processes. Possibilities may exist for students to access necessary information autonomously instead of through therapeutic interventions.

This brings us back to the framework of knowledge management. Still too little is known about studying with mental health problems because we continue to fall into the paternalistic trap that disabilities should be segregated, managed and monitored for the good of all students. Fueled by public pressure, expectations over academic achievement, and medically-driven frameworks, higher education providers desire to control, cure and prevent the current mental health crisis. In the process, higher education providers have leapt into action without connecting existing knowledge and knowledge production from the perspective of students.

This is where education providers can effect a knowledge-based change in attitudes toward mental illness: higher education can try to link existing knowledge of mental illness to the knowledge students with mental illness consider important and facilitate sharing or creating this in cooperation with students. Higher education providers can set up in-person community knowledge networks that include students and staff. In addition, higher education providers can invite students to share their lived experiences of mental illness as role models, putting knowledge about pursuing psychological wellbeing in the right perspective. Higher education providers can invest in and support peer initiatives focusing on connecting students with mental illness parallel to existing courses and support. Students need safe study environments with equal opportunities, without stigma, oppressive advice or stereotyping. Higher education could follow the multi-dimensional approach Fredman (2016) proposes, requiring synthesis and compromise without prioritizing, "to redress disadvantage; address stigma, stereotyping, prejudice, and violence; enhance voice and participation; and accommodate difference and achieve structural change".

The educational community should invest in closing the gap in knowledge of mental illness among students. To this end, students can speak openly about their mental health, while staff can use previous experiences to learn about, improve on and share knowledge regarding mental health problems among students. Students and higher education staff could aim to become aware of their attitudes, use of language, and prejudices concerning mental health. Action should not be taken without participation from students. Instead, students should be invited to participate in research and practice relevant to mental health.

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Conflict of Interests

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About the Authors

Lieve Carette (MA) is a PhD student in Disability Studies, working on the topic of psychological wellbeing in higher education. Previously she worked as a psychological counselor at Ghent University. She is interested in the perspectives of students concerning disability, based on their past and present experiences and future prospective. Learning from students and their networks, she wants to get insight and raise awareness of simple measures that can make a difference in students' life.

Elisabeth De Schauwer (MA, PhD) works as a Visiting Professor in Disability Studies at Ghent University. She works closely together with children, parents and schools in inclusive education. As activism, research and teaching go hand in hand, following people and their stories is a never-ending source of inspiration for her research and daily life. Her research focusses on 'difference' and the influence on relationships. She is interested in strengthening interdisciplinary links between pedagogy and other disciplines like philosophy, feminism, anthropology, etc.

Geert Van Hove (MA, PhD) has a background in Educational Sciences. He is Professor in Disability Studies and Inclusive Education at Ghent University. His current research projects include, e.g., “Narratives of Fathers with Children with Disabilities”, “Inclusive Education in Uganda”, “Disabled People and the Labor Market” and “Arts Based Research Methods and Disability Studies”.

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Article

“Everyone Is Normal, and Everyone Has a Disability”: Narratives of University Students with Visual Impairment

Nitsan Almog [1,2]

[1] Department of Education and Societal Studies, Ono Academic College, 5545173 Kiryat Ono, Israel;
E-Mail: nitsanalmog@gmail.com
[2] Louis and Gabi Weisfeld School of Social Work, Bar-Ilan University, 5290002 Ramat Gan, Israel

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Abstract
University students with visual impairment in Israel and worldwide face multiple academic and social barriers and must develop techniques, strategies and skills to adjust to the university environment. The current article is based on a longitudinal qualitative study aimed at incorporating students’ voices and offers some insight into the ways students experience their academic journeys. The research method combined grounded theory with the emancipatory disability research paradigm, which draws explicitly from people with disabilities’ collective experience and thus directly challenges this group’s widespread social oppression. This combination allowed the researcher to focus on students’ initial experiences as subjectively perceived. Sixteen students all defined as legally blind, from four universities in Israel, were interviewed over a 2-year period of their studies. The findings present two complementary narratives the interviewees used while configuring their identities. The article will focus on findings that suggest that during their academic journeys, students needed to manage a process of integrating their identity both as disabled and as students, choosing when and where to perform each identity and determining what the implications of each choice were along with each one’s related costs and benefits. The study’s implications and recommendations can help professionals and support services improve inclusion and equality in higher education.

Keywords
disability studies; higher education; identity; students; visual impairment

Issue
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1. Introduction: Research Background

In the last three decades, the number of university students with disabilities in Israel and elsewhere has increased steadily (Bruder & Mogro-Wilson, 2010; Heiman, Almog, & Godder, 2006; Wisbey & Kalivoda, 2016). This increase resulted from policy changes that broaden access to higher education and from legislative processes ensuring the rights of people with disabilities (Riddell, Tinklin, & Wilson, 2005; Vickerman & Blundell, 2010), including ratification of the Convention on the Rights of People with Disabilities (CRPD), which mandates the right to higher education (Kanter, 2015) and from the implementation of Israel Equal Rights for People with Disabilities Law of 1998. Similar to the Americans with Disabilities Act (ADA), this Israeli law demands full inclusion for individuals with disabilities, declaring the right of people with disabilities to be equal members of society, treated with respect and support (Vilchinsky & Findler, 2004). Although the law’s regulations regarding the accessibility of higher education institutions were enacted in 2016, they were scheduled to take full effect by the end of 2018. In the meantime, Israeli higher education institutions continue to write disability provisions into their policies and are progressing in terms of accommodations and support services for students with disabilities.

People with disabilities have lower employment rates than the rest of the population does, no matter their qualification level. In Israel, only 51% of working-age persons with disabilities are employed compared with an employment rate of 79% for the rest of the population (Barlev, Admon-Rick, Keren-Abraham, & Haber, 2017). Nonetheless, the employment rate for people with disabilities with academic degrees was higher (74.3%; Berman & Naon, 2004; Pinto & Fass, 2014) but remains lower than that of nondisabled graduates (88.2%; Israeli Ministry of Economy, 2013). The situation of the legally blind population in Israel is even worse, as only 33% of those of working age (19–64) are employed (Monikendam-Givon, 2017). However, the employment rate among legally blind university graduates is extremely high at 68% but still 20% lower than that of the nondisabled university graduate population (Berman & Naon, 2004; Naon et al., 2012).

Despite the increase in the number of students with disabilities and the growing understanding of the importance of higher education for people with disabilities, empirical research on this group remains quite limited (Peña, 2014), and most of the literature concerning students with disabilities has focused on learning disabilities (Heiman & Precel, 2003; Kimball, Wells, Ostiguy, Manly, & Lauterbach, 2016). Only a few articles have explored university students with visual impairment (VI), such as Lewin-Jones and Hodgson (2004), Myers and Bastian (2010), Pfau (2007) and Wong (2014). Many reviewed assistive technology (Bishop & Rhind, 2011; Fichten, Asuncion, Barile, Ferraro, & Wolforth, 2009; Gurb, 2000; Phatthanan, Singha, & Chanboon, 2017; Wolffe, Candela, & Johnson, 2003) or student support services and accommodations (Heiman et al., 2006; Hewett, Douglas, McLinden, & Keil, 2017).

University students with VIs often face academic and social difficulties and thus develop their own means, methods, and skills to adjust to university life (Myers & Bastian, 2010). Many discover that they do not have the learning skills necessary to meet academic demands. Some choose the so-called easy departments or must repeat some courses several times or lengthen the period of learning in university into an additional semester or even added years (Gurb, 2000). In Israel, the number of university students with VI remains low: only 400 students who identify/are defined as legally blind were enrolled in higher education institutions both years (Avgar, 2014; Hess, 2015). Empirical data on those students remain lacking in general, and data on students with VI are particularly scant, as only a few studies have detailed their higher education experiences. Most examined it through a special education or rehabilitative approach, in other words, acquisition of foreign language among students with VI (Krisi, 2014) or transition to higher education (Machmud, 2008). The current research uses a disability studies approach, a relatively new field in Israel (Ziv, Mor, & Eichengreen, 2016) and thus focuses on various aspects of life in terms of disability, as socially understood, rather than in terms of living with a VI per se—in terms of medicalized discourse (Thomas, 1999). As of 2018, still no academic program for disability studies in Israel exists, which might be one of the reasons for the anachronistic perception of the status of PWD in Israel and for university students with disabilities in particular (Almog, 2018).

I examined the academic journey of university students with VI, specifically the ways in which they experience their adjustment to university both academically and socially. The study explicitly seeks to incorporate student voices and, using in-depth interviews, to offer insight into students' experiences of their academic journeys. The aim is to raise awareness about how students with VI experience higher education, to improve the understanding of obstacles and barriers, and to shed light on the strengths and inner resources these students discovered along the way.

1.1. The Emergence of Disability Identity

Historically, disability was viewed as a purely medical phenomenon and as a tragedy for the individual marked as deviant and as an object of pity and patronage (Michalko, 2002). The "medical model of disability" placed responsibility for disabled persons' poverty and exclusion at their own doors, viewing this social predicament as an unavoidable outcome of the body or mind's functional impairments (Kanter, 2011). Critics of this model pointed to its systemic ignorance of social factors that mediate the experience of disability, which was then viewed purely as a phenomenon of the disabled body. This critique led to the establishment of the disabled minority as a political movement. The movement demanded recompense because of this group's discrimination and exclusion, which lie at the core of the appalling social suffering of people with disabilities (Barnes, Oliver, & Barton, 2002). The new disability paradigm that has emerged in the 20th century describes disability as the product of the interaction between the individual and his or her environments. The model, also known as the social model of disability, "locates" disability in society and identifies social prejudices, inaccessible environments, discriminatory work arrangements, and segregated education as disabling societal elements (Oliver, 1996, pp. 32–33). The model stresses that specific problems experienced by people with disabilities result from the totality of disabling environments and cultures (Oliver, 2004). For example, visually impaired students are not disabled by their lack of sight but by the lack of accessible reading materials (i.e., Braille, audiobooks) and by stereotypical ideas about blindness.

Both the social model and the disability rights movement have empowered PWD by changing the way they think not only about themselves but also about society and the way they are included within. The body of knowledge that led to the emergence of the social model of disability is primarily concerned with both the "political project of emancipation" and the development of an "oppositional politics of identity" (Corker & Shakespeare, 2002, p. 3). This perspective discusses disability identity as something fixed and stable, as the identity is "hypostasized and turned positive against the negative descriptions used by the oppressors" (Davis, 2006b, p. 231). Later scholars have critiqued the social model, as it has become a "generic term for social inclusion" (Shakespeare, 2018, p. 130), occluding the complexity of disabled people's day-to-day experiences. These scholars have redefined disability as a complex and multidimensional phenomenon composed of the individual, society, and biology and discuss disability identity as more fluid changes between both contexts and in relation to other identities of the individual (Watson, 2002). Disability identity refers to possessing favorable and positive views toward one's disability and feelings connected to others from the disability community. A coherent disability identity is believed to help individuals adapt to disability and instructs them how to act in different situations in which disability issues arise (Dunn, 2014).

Nario-Redmond, Noel and Fern (2013) examined disability identification and its effect on personal and collective self-esteem and noted the tension between an individual fluid disability identity to a distinct collective and empowered disability identity. Dorfman (2017) studied the way in which disability models translate into disability identities and how self-identity perceptions of Social Security benefits claimants clash with the one they need to perform in front of state officials in order to be considered eligible for benefits. A similar conflict between the identity as perceived by the self and the one needed to be projected and performed exists in regard to accommodations in higher education.

1.2. Disability Identity Conflicts in Higher Education

The higher education environment confronts students with disabilities and students with VI in particular in multiple situations in which such students stand out by being unusual, different, and uncommon and consequently activates disability identity conflicts (Dunn, 2014). Many of the practical difficulties that students with disabilities experience are due to environmental barriers and obstacles that directly result from an inaccessible educational environment (Almog, 2018; Titchkosky, 2009; Wisbey & Kalivoda, 2016). This environment includes inaccessible learning materials, inequality in examination conditions, inadequate understanding of the students' needs, and lack of information about support services (Bishop & Rhind, 2011; Wong, 2014). University students with disabilities are aware of this construction of disability within higher education and described it as "negative, stigmatized, and associated with something that is not normal" (Vaccaro, Kimball, Moore, Newman, & Troiano, 2018, p. 46). Seale (2013) claimed that even the use of technology by students with disabilities is influenced by the academic pressure to be like other "normal" students.

The process of adjusting to campus life is a neutral phase in the individual's maturation process and represents the transition from dependence to interdependence/autonomy (McBroom, 1997). Because most students enter higher education while transferring from adolescence to young adulthood, they are also experiencing a "natural" maturation phase. Along with studying, the individual must leave the parents' home, find mutually satisfying relationships, and choose a profession. This is also the first time most students with disabilities must claim academic accommodation themselves, as during high school, this was the parents' responsibility. This requires self-advocacy and conflict resolution skills (Anctil, Ishikawa, & Scott, 2008) but above all confronts students with their disability identity.

Attending university has implications for the way in which students with disabilities construct their personal and social identity (Borland & James, 1999), as they are aware of the possible stigma associated with their impairment and seek to control others' perceptions to then be perceived as equals (Olney & Brockelman, 2003). Social stigma can also lead to closeting and not identifying as a person with disability, affecting the use of institutional support services (Grimes, Scevak, Southgate, & Buchanan, 2017) or making friends (Lourens & Swartz, 2016). Passing as nondisabled through ingenious ways that conceal their impairments is one of the strategies for managing identity of people with disabilities (Siebers, 2004). Shakespeare (1996) also claimed that people with disabilities may use the denial strategy to minimize the impairment's effect on their lives by concealing their disabled identity and claiming to be "really normal".

According to Tajfel's (1978) social identity theory (SIT), people in a minority group not identified with the mainstream will be forced to confront a negative social identity, especially when their in-group is considered inferior. This negative perception might create a conflict between the individual's belonging to his or her in-group and belonging to the group representing the dominant culture. SIT and other psychological research have examined variations of disability identity and its occurrence in various contexts. Nonetheless, in contrast to other social identities (race, class, gender, etc.), disability identity is a relatively new category and has not been researched adequately in the context of higher education (Kimball et al., 2016).

The current article addresses this gap in knowledge and presents various disability identity narratives of university students with VI as experienced by them during their academic journey. It is also the first study in Israel to explore the topic of disability identity within higher education.

2. Research Design and Methodology

The study was longitudinal and qualitative in design and examined university students with VI's academic journey during 2 years of their studies. Each student was interviewed four times within this period. I collected and analyzed the data based on grounded theory principles (Glaser & Strauss, 1967) and used an emancipatory research paradigm (Oliver, 1992), which draws explicitly on people with disabilities' collective experience and thus directly challenges this group's widespread social oppression. This paradigm affects the types of questions researchers ask and the way the answers to those questions are analyzed (O'Day & Killen, 2002). Moreover, it encourages the generation and production of meaningful knowledge about various structures that create and sustain the multiple deprivations people with disabilities encounter (Barnes, 2003). Oliver (1992) detailed three essential principles in an emancipatory methodology that influenced the research design and process.

The three principles are as follows:

i. Reciprocity: the relationship between the interviewer and interviewees can never be completely equalized. In the current study, three things made that even more difficult to accomplish. First, most of the interviewees were undergraduate students, whereas I was a doctoral student. Second, the participants knew that my experience includes serving as a coordinator for students with special needs at the Open University, and they at times solicited my advice as a learning counselor. Third, the participants knew that I also face difficulties as a student with VI and frequently asked questions that were directed toward learning from my own experience of overcoming shared barriers. I did endeavor where possible to build on this relationship and make it as equalized as it could be. The sharing of experience was important, as some participants had felt isolated and unable to share their experiences with anyone else;

ii. Gain: the study participants possessed my contact details, and some used them to share their experiences with me—whether it was about issues that had arisen in the interviews or other topics outside of the research. Some interviewees mentioned that it was a therapeutic experience for them and that they looked forward to our subsequent meetings. It should be noted that none of the participants dropped out of university during the research period. This is not a representative characteristic of the population of university students with VI and must be considered when the results are analyzed. After the research was completed, the study's implications and recommendations were shared with professionals and support service administrators during several training sessions that the Israeli National Insurance Institute conducted. The institute had initiated a program to address the problem of access to higher education for students with disabilities by allocating substantial government funding to develop centers to support students with disabilities. Ultimately, through the dissemination of the research findings, I hope that greater inclusion and equality will be achieved for students with VI;

iii. Empowerment: the imbalance of power between people with disabilities and nondisabled people is well known. People with disabilities have been discriminated against throughout modern history in many aspects. The decision to carry out a research study and to make the experiences of a minority oppressed group known is, in itself, a form of self-empowerment (Vernon, 1997). The fact that several participants in the study provided the researcher with other contacts to interview, as occurred in this current study, "is also evidence of the same self-empowerment" (Vernon, 1997, p. 172). In addition, Vernon claimed that treating participants as equals helps them increase their self-confidence and self-esteem. Moreover, the sharing of experiences can literally prove empowering for the participants (Vernon, 1997).

Oliver (1992) suggested that empowerment is not something that can be given to people: people must undertake specific actions to bring about their empowerment. According to Oliver's view, researchers should ask whether their work is contributing to this empowerment process. The findings and implications of the current study were presented to those working with support services in higher education institutes and as a means of assisting the participants and the community of people with VI.

2.1. Participants

Participants included 16 university students and graduates, six men and 10 women, all defined as legally blind. Eight of the students were completely blind (five from birth), and the other seven were visually impaired. Ten participants were studying for their BA and five for master's degrees, and one had graduated with his bachelor's degree. Students ranged in age from 20 to 35. Although some of the students have a visible disability and could be identified immediately upon entering a room (via use of a cane or guide dog or an unusual eye appearance), others have a hidden disability, allowing them to pass as nondisabled.

All participants were identified by pseudonyms. Other identifying details (university's name, department of study, etc.) were also changed to ensure anonymity.

2.2. Method

I collected data through in-depth, semi-structured interviews. This allowed participants to express the meanings they ascribe to the behavior, feelings, thoughts, and perceptions they and others hold in their own language and with their own concepts. During the interviews, participants were asked to describe their lives "from the perspective of being a university student with VI". All interviews were audio-recorded.

The interview structure was flexible and dynamic. I sought to allow the participants to share their stories in their own way. I tried not to interfere or give clear directions (e.g., where the story begins, what is important, and what is not) to allow participants to bring forth their personal narratives of being a student with VI. After the participants finished telling their stories, I reviewed the interview guide. If the following topics were not mentioned, participants were asked about them. These included the following: high school experience; military or national service (if it existed); choice of university and department; learning experiences; contact with tutors and lecturers; use of assistive technologies; contact with readers; orientation and mobility issues; accommodations, friendships, and social interactions; and perceptions of failure and success.

After three periods of interviews, a list of categories and themes had emerged from the data up until that point. The fourth interview was the only one conducted differently. It included a list of 10 questions regarding the themes that had emerged from the previous interview and that had been analyzed. The questions concerned a meta-cognitive analysis and introspection on the different periods of studying in university, screening of the support the students used, learning skills that were acquired, and so on. This interview purpose was to validate the findings with participants. After the fourth period of interviews had ended, I understood that the research had reached it saturation point—that point occurs when "gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of your core theoretical categories" (Charmaz, 2006, p. 113). The Ethics Committee of Bar Ilan University, Israel, granted study approval.

2.3. Procedure

I recruited students via snowball methods and through Internet forums and support services. Students were contacted by telephone and email and then provided general study information. I conducted all interviews. Most were carried out on campus and some in students' houses or in the dormitories. The interviews took from 90 minutes to three hours. I took steps to create a comfortable and accepting atmosphere in all the interviews. With the interviewees' written consent, interviews were audio-recorded and transcribed. Data constituted more than 650 single-spaced pages of text composed of transcripts and analytic memos. I analyzed the interview data according to themes (content analysis). Content analysis of the data created a grounded theory, which provides an overview of the academic journey of students with VI and meaningfully explains this journey's characteristics. The theory is constructed through a systematic process of repeatedly returning to the field to collect reams of data until a meaningful, rich theory has been constructed (Shkedi, 2003).

3. Research Findings & Discussion

When I called Tal, one study participant, to schedule a meeting, she asked: "Why are you researching students with VI? We are just like any other students". After a short conversation, I convinced her to meet me to discuss the meaning of being a student with VI. I stressed that the research intent was not to look for the differences between sighted students and students with VI but to incorporate students' voices, which might also demonstrate similarities between these two populations. The question Tal asked is one that students with VI confront every day. It is a question of identity. At that point, I assumed that Tal's statement reflects the fact that, for her, having a disability is merely one aspect of her identity and not the sum total of it. Like Tal, all the participants in the current study discussed similarities and differences between them and nondisabled students.

Seven distinct themes emerged from the data. The first, which is also the core category, presents two complementary narratives participants used while configuring their identities. The second relates to environmental barriers in the academic world. The third describes the tension between independence and dependence. The fourth relates to impairment effects (Thomas, 1999) and their interactions and effects on the experience of the research participants. The fifth presents different ways to create social interactions and their importance for students with VI. The sixth describe the process of self-disclosure, and the last theme describes internal and external forces that helped students with VI throughout their academic journeys. This article focuses on the "core category" of the theory that emerged from the interviews' data. The core category is the central phenomenon, through which all other categories can be organized and that occurs both as the phenomena's reason and as their result (Charmaz, 2006).

This category presented the question of constructing an identity of students with VI. Two answers to the question "Who am I?" were presented. Whereas the first answer is "I'm just like the others", the second one is "The others are just like me". These two answers are different sides of the same coin.

During the interviews, students mentioned in various ways that they are just like everyone else and that the others are just like them. Everyone has some kind of disability and has some level of dependence on others, visually impaired or not. This approach universalizes disability (Zola, 2005) and erases the boundaries between people with and without disabilities.

Students were aware of the perceptions society holds toward disabled people and try to fight them. Davis (2006a) claimed that every aspect of our life includes some idea of a norm, mean, or average that can be calculated (school tests, weight, salary, intelligence, etc.), and that people have an "inherent desire to compare themselves to others" (Davis, 2006a, p. 3). The study's participants adopted this view about normalcy and were busy locating themselves, but others too, on a continuum between disability and normalcy. The participants discussed two differing narratives that located them on this continuum. The first more common one emphasizes that they can do everything, just as sighted students can. The second makes sighted society into a disabled society one way or another. It seems that by using these complementary narratives, participants normalize their disability or disable normalcy. This situation is similar to the third stage of Gill's (1997) positive disability identity formation process. This stage, termed "coming together", concerns people with disabilities' understanding of being both part of nondisabled society and part of the disability community.

Using the two narratives, normalizing disability and disabling normalcy, is one way whereby people with disabilities might try to pass as nondisabled, though not in its classic sense of concealing disability but through decreasing the gaps between them and able-bodied others. Siebers (2004, p. 5) defined the "dominant social position simultaneously as normative and desirable". Through passing, people can improve their social status and increase chances for social acceptance. These two narratives will be presented in the following sections.

3.1. Normalizing the Disability: I Can Do It Just Like Everyone Else

Some of the students described their efforts to do things the way sighted students do. Adva for example told me about difficulties she had had in a certain course in her first year due to her impairment. When I asked her why she had not sought accommodations, she answered: "It doesn't look good to complain when you're a freshman". This means that Adva completely ignored the fact that the difficulty she had experienced resulted directly from her inability to see the learning material. Instead, she preferred to act as a sighted student, and for a first-year sighted student, complaining is a liability. In another situation, someone offered to call her a taxi, but she insisted on using the bus "just like everyone else". Racheli, an MA student who had lost her sight at 13, also stressed this idea by saying: "People do not know that we [blind people] are capable of doing everything; I say everything, and I mean it".

The influence of the social mechanism, which leads us to fit the criterion of being normal, is extremely common today in many facets of everyday life. Many wish to standardize our whole being toward what Garland-Thomson (1997, p. 8) has called the "normate", which represents the collective's culture with its normative characteristics. Though Garland-Thomson (2002) primarily described processes of normalizing the body (reconstructive procedures, plastic surgery, etc.) and suggested that these procedures' goal is to improve the patient's psychological well-being, I propose that normalizing other aspects of the disability identity is done to achieve the same goal. These findings align with Watson's (2002) findings, suggesting that for some individuals, both impairment and difference are not perceived as important to the sense of identity, and people with disabilities do not perceive themselves as different from the nondisabled. Dorfman (2017) defined this sub identity category as "quasi-normalization" because people who use it do not define themselves by their disability and reject its implications for their lives. As presented here:

> I'm a blind student, but let's say it's not primary but secondary, I will not present my blindness before anything else, only "by the way". I live with roommates at the dorms—you know, my life is ordinary. Sometimes the blindness makes it difficult, but it's not the central thing in life. That's it. (Dana)

> Many times I try not to mention my impairment or whine about it. I always try to submit papers on time and not to postpone things, but it doesn't work all the time, because I depend on others. (Orly)

Certain students use this approach, and its main idea is driven by the "people first" language, which stresses that persons come before the disabilities/impairments and that disability is something that accompanies people. As Nadav explained:

> There is the person and then the disability….I'm a person with blindness, and I must put myself up front with my abilities but also let people be angry at me…when you are a person with a disability, people just pity you…suddenly you are just a nice guy, and one of the things is not to be just a nice guy, to have your opinions, what you think, not to take on that attitude that I'm handicapped, but to be me, a person with a disability who feels and thinks.

It seems that this narrative of normalizing the disability occurs in different ways of thinking and in various levels of analysis in the participants' discourse. Eitan, an MA student with VI, tried to explain the rationale behind this way of thinking through his discussion of his childhood experience of being disabled:

> My tryout to be a normal kid and trying to integrate works in a logical/non-logical way, saying that if I hide it [the impairment], I will be like everyone else; if I'm like everyone else, I can fit in. You have this feeling of some kind of defect that you have and that you just want to hide it….[My] parents always allowed me to do everything. At bicycle age, I had one, everything—so what if I fall; so what? They always said, "So what?" Judo. So I did judo; so I always wanted to integrate, to fit in, and this is the way to do so.

Eitan, as many other persons with disabilities, was socialized into the understanding that a disability marks you as an outsider who cannot fit into the mainstream or integrate. The desire to be like everyone else, to normalize the disability, is very clear from the perspective of this socialization process. Throughout their lives, people with disabilities are "constantly bombarded with the values of the dominant culture" (Charlton, 2006, p. 222) and are required to be "like everybody else".

3.2. Disabling Normalcy: Everyone Has a Disability

The other way to understand the ambivalence of being a university student with VI is via making the sighted society into a disabled society. As Adva described it: "Everyone is normal, and everyone has a disability"; or in Rachely's words: "Everyone has his or her own package".

Some of the students described difficulties they face while studying. They know that every student faces difficulties when studying. Rebecca described her experience of getting to know people and places during the first semester of the first year as difficult due to her VI but then regretted this and said: "I couldn't understand that all the students here felt exactly the same as I did".

Trying to face the challenge of being disabled, some of the students claimed that, in some way, everyone is disabled, everyone faces difficulties stemming from studying at university, and other students may be occasionally dependent on others in some manner. By framing things this way, students transform being disabled or dependent into something ordinary.

> Now I'm helping others, and I say, "Hey, what's wrong here?" I thought I'm the one who needs help…but suddenly I saw that this student is just staring, and the other asks for summaries from the others, so I found out that it's a part of being a student, whether you are impaired or not. (Ayelet)

> No one understands anything during the first semester, and everyone thinks that the others do understand; it's really frustrating. During the first year, you just learn how to manage, and it has nothing to do with you. (Eitan)

> Statistics is so difficult…and who the lecturer is is so important; people suffer from it [this situation] whether visually impaired or not. (Rebecca)

It seems that sometimes by thinking of others as facing the same difficulties, students thus "normalize" their experience and present it as part of human diversity. This way of thinking is another way to reduce the gap between students with and without disabilities, and it can serve to bolster students' positive self-perception.

A critical look at this narrative exposes that the boundaries between disability and able-bodiedness are extremely fragile. In fact, as McRuer (2002, pp. 95–96) puts it:

> Everyone is virtually disabled, both in the sense that able-bodied norms are 'intrinsically impossible to embody' fully and in the sense that able-bodied status is always temporary, disability being the one identity category that all people will embody if they live long enough.

Moreover, some disability rights activists and disability studies scholars use the phrase "temporarily able-bodied" (TAB) as a reminder that many people will develop disabilities at some point in their lives due to accidents, illness, or aging.

Dvir referred to this concept when discussing his frustration about accessibility on campus:

> Why is it so difficult to install an accessible name plate (bold/large print/Braille), one that you can grab onto? It costs nothing….This opacity is so frustrating for me because you can go blind at any given moment. You can walk the street in Ashkelon and suddenly a missile falls and you are blind. But people do not understand this.

I do not claim that the participants were aware of this critical thinking, but it seems that they do hold a deep understanding of the fragility of life and that disability and able-bodiedness are concepts on a continuum rather than being dichotomous concepts. This understanding makes it easier for the participants to minimize the differences between them and members of nondisabled society who, through this lens, become formed as TAB.

3.3. Compulsory Able-Bodiedness and Disability Identity Conflicts

By using the two narratives presented above, study participants were simultaneously negotiating identities both as students and as persons with VI. McRuer (2002), inspired by Adrienne Rich's concept of "compulsory heterosexuality", coined the term "compulsory able-bodiedness" as an ethos that presents the able body as an ideological norm: a sign of beauty, strength, health, and power. As able-bodiedness is constructed as a norm, disability is an exception constructed to preserve it in the binary system in which the norm is defined and constructed as its opposite. Kafer (2003) claimed that one of the ways in which compulsory able-bodiedness works is through what Rich calls, "control of consciousness"—assume able-bodiedness unless otherwise stated. This last mechanism pushes people with invisible disabilities to pass as nondisabled and confronts them with the dilemma of identifying or avoiding their disability identity. For people with apparent disability, compulsory able-bodiedness brings forth the concept of cure and healing—because disability, satisfaction, and quality of life cannot all coexist. The system of compulsory able-bodiedness demands that people with disabilities respond affirmatively to the "unspoken question": "Wouldn't you rather be able-bodied?" (Kafer, 2003). This social mechanism justifies the desire of participants in the current study to identify as normal and able-bodied.

Disability is much more than the clinical medical definition of one's impairment. Compulsory able-bodiedness is a tool the mainstream culture uses to silence, erase, and exclude the disabled existence. It seems that the higher education environment constantly drowns us with a message that demands that students meet the normalcy criteria in order to "fit in".

Orly, a congenitally blind MA student, shared an event wherein the demand to be "like others" was used against her. Orly wanted to submit an application to split her first-year courses over two years:

> The head of my department just does not care whether I have enough readers or not. In her opinion, "You are like everybody else". It has already been said before: "You are like everybody else, a student like every other student, so try to be like everyone else". Well great! I try to be like everyone else, but for the record, I am not like everybody else.

This quote exemplifies how the "normalize the disability" narrative collapses due to the disabling environment. Even though the head of the department holds the same idea as the study participants do and tries to normalize Orly, Orly claims that she is not like the others. By presenting this disability identity, Orly indicates that academic accommodations are the base essential of creating inclusive higher education.

Dvir, a BA student with VI, described a similar event with one of the lecturers:

> I asked them to print the assignments in Infi [Infinitesimal calculus] instead of writing it because I cannot see. I went and talked with the teaching assistant, and he told me that there is nothing that could be done about it. I spoke with the lecturer, and what did she say to me? "There is nothing to be done; you should be able get along with it like everyone else! If you cannot see it, you do not know math.

Dvir's lecturer uses an abelistic approach in which you are not able to know math if you cannot see, a demand that reflects a naturalized perception of the able body. Being visually impaired is subordinated in an environment that values normalcy. Both Orly and Dvir must identify as disabled to obtain the accommodation that will allow them equal participation in higher education, but when they do so, they are confronted with derision and with significant feelings of inferiority. These sorts of reactions to students with disabilities are just a part of the attitudinal barriers these students face every day and significantly affect the students' experiences.

These events demonstrate the powerful meaning of normalcy that students with disabilities meet and just might stand at the base of the "normalize disability" narrative. It seems that by using this narrative, students demand others to see them as equal and as suitable for higher education. Jonathan, a first-year student, also explained how important it was for him to build his timetable all himself. He said:

> I made such an effort that I even fell down the stairs. I walked through places I don't know; no one helped me or accompanied me. I made it on my own. This is one of the most important things for a student.

It seems that Jonathan avoided the support he needed so he could gain a sense of independence and ability that makes him feel as though he is like all the other students. Study participants used this tool similarly, trying to integrate, fit in, and be accepted in the university environment. Only after the students can perceive themselves as having integrated, in their self-perception, can they demand their rights.

The use of compulsory able-bodiedness also explains why the "normalizing the disability" narrative was used more frequently than the "disabling normalcy" narrative was. The able-bodied institution allows the continued oppression of people with disabilities. Through the construction of normalcy, people with disabilities are excluded in multiple ways. Thus, the strategies that participants in the study used to gain access to the university environment are the means of declaring themselves disabled but normal, exactly like the other students, or alternatively, of claiming that others are also disabled, only in different ways.

4. Conclusions and Implications

The most significant issue participants dealt with during their academic journeys was their identity and its location on the continuum between disability and normalcy. However, this location changed throughout each of the research interviews and over time. When I asked participants to tell their stories of being a student with VI, students primarily discussed the similarities and the differences between them and sighted students, as presented in this article. The two complementary narratives, "normalizing disability" and "disabling normalcy", that the participants used stem from the struggle students with VI faced during their lives, while trying to fit in and be included in the mainstream, into nondisabled society. These struggles are even more powerful in the higher education institutional environment, in which able-bodiedness and normalcy are central requirements for participation, both socially and academically. The interchangeable use of these narratives regarding students' disability identity aligns with Siebers' (2008, p. 4) definition of disability identity as an "elastic social category".

One of the study's aims entails raising awareness of how students with VI experience higher education and improving the understanding of barriers and enablers these students discover along their academic journey. Faculty, staff, and university support services can make a profound difference for a student with VI. Whether through administrative assistance (i.e., helping students navigate the campus itself) or through academic accommodations (i.e., provide assignments in different accessible formats), support services are crucial. To facilitate such support, universities must promote an understanding of disability identity conflicts within higher education—among staff, faculty, and students with disabilities themselves. It also must be recognized how the compulsory able-bodiedness mechanism works within higher education and be acknowledged that making this environment inclusive demands a widespread cultural-organizational overhaul. This can be undertaken via training sessions for staff and faculty, which Israeli law requires of every higher education institution, and via joint working groups composed of people with and without disabilities seeking to promote an institutional inclusive environment. Israel's new regulations regarding accessibility of higher education institutions will take full effect in the near future (in November 2018), making this an opportune time to consider how dilemmas concerning disability identity can shape how we establish support services and provide them to students with disabilities. Although further empirical evidence would demonstrate the importance of these students' developing a positive disability identity, another question to be asked is how higher education can encourage the development of such. As issues of disability identity are part of the field of disability studies, it is important to develop an academic infrastructure/foundation for disability studies in Israel and throughout the world. The absence of such an infrastructure might be one reason that disability issues remain under-theorized. As Titchkosky (2009, p. 38) claimed, there is an intimate relationship between establishing disability studies "as a form of critical knowledge production within the university and creating accessible learning environments" where students with disabilities, but also faculty, staff, and support services, can succeed.

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Conflict of Interests

The author declares no conflict of interests.

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About the Author

Nitsan Almog serves as the head of the Inclusive Education program at Ono Academic College and is a Lecturer at the Rehabilitation and Health MA program at the School of Social Work, Bar-Ilan University. She is also the lead consultant to the Israeli National Insurance Institute for the "Revolution in Higher Education", an entrepreneurial project that has established 35 support centers for students with disabilities in universities and colleges across Israel. She co-edited a special issue of *Social Security* (Israeli social policy journal) regarding the employment of persons with disabilities, in 2017.

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Article

Pursuing Inclusive Higher Education in Egypt and Beyond through the Convention on the Rights of Persons with Disabilities

Janet E. Lord * and Michael Ashley Stein

Harvard Law School Project on Disability, Harvard Law School, Cambridge, MA 02138, USA; E-Mails: lord@american.edu (J.E.L.), mastein@law.harvard.edu (M.A.S.)

* Corresponding author

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Abstract
Inclusive higher education is elusive for students with disabilities, especially in developing countries. The adoption and rapid ratification of the Convention on the Rights of Persons with Disabilities (CRPD) provides, if applied as its drafters intended, a "whole of institution" framework for its realization (CRPD Committee, 2016). Myriad legal, attitudinal, physical, and communication-based barriers limit or exclude participation. The individual impact of such discrimination is clear and carries lifelong consequences. Equally endemic are the broad societal and pedagogical effects of this exclusion. To illustrate: preventing persons with disabilities from Teacher Education courses impacts inclusive education in primary and secondary education; barring people with disabilities from academic programs in the sciences stifles innovation in assistive technology, health, and rehabilitation; and limiting access to studying the humanities hampers the emergence of disability studies as a rightful discipline. This article presents a framework for inclusive higher education in developing countries as contemplated by the CRPD. In doing so, we draw on field work conducting the first assessment of the accessibility of Egyptian public higher education to students with disabilities. We outline lessons that can be learned and pitfalls to be avoided both in Egypt and indeed for other countries in the Global South.

Keywords
accessibility; Convention on the Rights of Persons with Disabilities; disability rights; Egypt; Global South; higher education; human rights; inclusive education; international development; students

Issue
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1. Introduction

Globally, students with disabilities face historic and deeply entrenched barriers relative to their non-disabled peers in accessing higher education at the university, graduate, or post-graduate level (Harpur & Stein, in press-a). This is particularly true in the context of the developing world where the exclusion of these students is predicated on several factors including stigma, prior exclusion from primary and secondary education, social isolation, and resource constraints (Harpur & Stein, in press-b). Ironically and deleteriously, precluding students with disabilities from advanced education dramatically increases their likelihood for experiencing poverty and their exclusion thus adds to the vast challenges experienced by persons with disabilities and their communities in the Global South (Heymann, Stein, & Moreno, 2014; Trani, Kett, Bakhshi, & Bailey, 2011).

The right of persons with disabilities to equally access higher education was implied by Article 23(3) of the United Nations Convention on the Rights of the Child (CRC), and subsequently affirmed in non-binding instruments (CRC, 1989; Standard Rules, 1993; UNESCO, 1994). The right to inclusive education was established unambiguously by Article 24 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) through its mandate for "an inclusive education system at all levels and lifelong learning" (CRPD, 2006) as an integral component of realizing other disability-related human rights. Article 24 accordingly prohibits disability discrimination at all levels and requires that reasonable accommodations be provided to facilitate full inclusion and quality education (CRPD, 2006). The framework sets out, for the first time in a legally binding instrument, a "whole of institution" approach to inclusive education for all levels of education (Ainscow & Florek, 1989; CRPD Committee, 2016). In doing so, it promotes a standpoint theory that privileges the voice, experience, and knowledge of persons with disabilities over all others while avoiding "the categorical authority" that seeks to sideline precisely the experience of others whose social and contextual standpoint as non-disabled are integral to addressing barriers (Shildrick, 2012, pp. 36–37). The provisions of the treaty, at various points across the text, call out for critical engagement with the discourses of exclusion, whether in education or any other realm.

The barrier-dismantling directive of the CRPD, accordingly, is to assess the entirety of the educational experience and environment in identifying and removing barriers for students with disabilities. The Committee on the Rights of Persons with Disabilities (CRPD Committee)—the treaty body tasked with interpreting, monitoring, and enforcing the CRPD—addressed accessibility within education in its General Comment No. 2. There it affirmed that "it is the entire process of inclusive education that must be accessible, not just buildings, but all information and communication, including ambient or FM assistive systems, support services and reasonable accommodation in schools" (CRPD Committee, 2014).

Accessibility as it is understood in Article 9 of the CRPD further reflects the notion that persons with different disabilities may require distinctive strategies and supports to enjoy equal opportunity via services offered by higher education institutions. These standards form the basis for assessing compliance with human rights-based inclusive education mandates. They are fleshed out in the CRPD Committee's General Comment No. 4 on inclusive education (CRPD Committee, 2016). Arising from Article 24 and General Comment No. 4 is the notion of "quality inclusive education", comprising those elements of education aligned with the CRPD's international human rights law framework. These include availability, accessibility (including non-discriminatory access and the provision of reasonable disability-related accommodations), acceptability, and adaptability, with the aim of full participation and inclusion, on an equal basis with others (CRPD, 2006, arts. 3, 5, 24, 30; CRPD Committee, 2016; de Beco, 2016).

Guidance contained in General Comment No. 2 and General Comment No. 4, underscore that Article 24 ensures equal access to students with disabilities in higher education even as its practical manifestations remain a work in progress. Indeed, most States ranging from Australia to the United States, and Uganda to South Africa, struggle to provide equal access for students with disabilities to State-based higher education (Foundation of Tertiary Institutions of the Northern Metropolis, 2011; Harpur & Stein, in press-a; Linder, Fontaine-Rainen, & Behling, 2015). Consequently, many obstacles remain to achieving the legally and socially required goal of inclusive higher education.

Yet, notwithstanding these barriers, significant factors raise hopeful prospects for global improvement. Persons with disabilities are now explicitly recognized as development stakeholders in international development programs and policies, including the nearly-universally ratified CRPD, the Sustainable Development Goals (SDGs), and the embrace of disability-inclusive development by bilateral and multilateral donors (CRPD, 2006, art. 32; UN Development Programme, 2016; World Bank Group, 2007). Hence, global drivers towards inclusive development may open up inclusive higher education for students with disabilities. Certainly, this promising and worldwide shift towards inclusivity in higher education policy has translated nationally in Egypt with the emergence of the 2014 Constitution, the 2030 Sustainable Development Strategy (SDS), and the 2018 Egyptian Disability Law. To illustrate: the eleven references to disability within the SDGs, which include the right to equally access higher education, were responded to by Egypt's SDS which confirmed these rights and introduced some inclusive measures.

This article draws on field work undertaken in 2017 on behalf of the US Agency of International Development (USAID) assessing multiple barriers faced by students with disabilities when accessing Egyptian universities and technical colleges. Following a review of our research methodology, Section 3 provides an overview of the legal and data barriers to inclusive higher education in Egypt. Next, Section 4 sets forth the bulk of our findings relating to educational hindrances to inclusive higher education in Egypt. Seeking to ameliorate such obstacles, Section 5 recommends steps to accelerate CRPD implementation as a means of promoting inclusive higher education in Egypt, as well as other Global South countries. Throughout, we maintain that the CRPD framework, when properly applied in its entirety and complexity, offers a legal template for advancing an inclusive "whole of institution" approach to inclusive higher education.

2. Research Methodology

The research project into the accessibility of students with disabilities to higher education in Egypt assessed, among other things, the needs of students currently enrolled in Egyptian public universities and technical colleges (collectively, public higher education institutions, or HEIs) and the barriers they experienced. We examined twenty-four public universities and eight technical colleges across Egypt (Lord, 2017) and utilized a mixed methods approach. Nineteen data collection tools were developed for the field work and included nine key informant interview protocols, three group discussion protocols, two paper and pencil surveys, two online surveys, a facility accessibility tool, and an online accessibility checklist for manual and automated audits. Components of the field work included key informant interviews (KIIs) with Egyptian governmental offices, donors, businesses, and site visits to HEIs. At each university site, KIIs were combined with the administration of structured survey instruments allowing students with disabilities, faculty, and staff to share their experiences via group discussions. during field visits. We also performed two accessibility audits, one of the built-environment at each HEI and another of the online environment. Ultimately, we reached a total of 825 stakeholders. Additionally, a desk review examined available data on the number of students with disabilities enrolled in HEIs.

Finally, and marking the first of its kind in a disability-inclusive development assessment of higher education, the tools were developed and mapped out against the CRPD. This was made possible by conducting a detailed legal analysis focused on assessing Egyptian commitments made in view of its CRPD ratification and probing deeply into the domestic indices of CRPD implementation which, like most domestic disability law frameworks, present not a single entry-point for analysis but rather a fragmented and often conflicting repository of legal provisions. Further, an accessibility audit was conducted of the physical environment of each HEI, utilizing a modified version of a protocol used to assess compliance with building standards under the Americans with Disabilities Act, the accessibility standards on which the Egyptian building code is based. An automated and manual online web accessibility audit was performed for those HEIs with an online presence. A major limitation of the research was that the assessment covered students with physical and sensory disabilities and not, overtly, students with learning, intellectual, or psychosocial disabilities. Currently, only students with physical and sensory disabilities are captured in existing data, and thus remain the focus of action by the Egyptian government in education. The resulting documentation detailing the assessment findings, conclusions and recommendations were set out in a comprehensive report and executive summary (Arabic and English) and also included accessible formats including an executive summary in Braille, and video in American Sign Language and Egyptian Sign Language (USAID, 2017).

3. Part I: Legal and Data Barriers

Beyond the purview of Egypt's higher education system, but nonetheless impacting directly upon its HEIs, the study revealed multiple legal as well as data barriers to inclusive education for Egyptian students with disabilities. Mapping the findings against the CRPD framework reveals gaps as well as entry points for advancing accessibility in HEI.

3.1. Legal Barriers

Egypt ratified the CRPD in 2008 and yet work underway to bring domestic legislation into alignment with the treaty were much delayed on account of political turmoil. The 2014 Egyptian Constitution does address the rights of persons with disabilities in nine specific provisions, providing a strong foundation for advancing disability rights, yet missing some helpful elements such as the requirement that reasonable accommodation be provided as a measure of meeting non-discrimination obligations (Constitution of Egypt, 2014). Still, the Constitution contains an explicit prohibition against disability-based discrimination and recognizes health, economic, social, cultural, entertainment, sporting, and education rights. Following the period of political turmoil, disability-specific legislation was adopted in 2018 and still requires detailed regulations to effectuate its provisions (Persons with Disabilities Act, 2018). Hence, there is ample opportunity to provide needed guidance for advancing the rights of persons with disabilities at all levels of education.

The 2013 Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired, or Otherwise Print Disabled is not yet ratified, such that Egyptian law does not require book publishers to provide accessible formats of books—including, notably, textbooks for students at HEIs (Marrakesh Treaty, 2013). A further problem which ratification and implementation of the Marrakesh Treaty would resolve is the practice of university professors creating their own materials and then refusing to share electronic copies on the basis of proprietary interest. Moreover, the absence of public procurement policies on ICT accessibility remains a significant gap in the legal framework. Although presently lacunae, each of these shortfalls likewise offers a promising avenue for change.

A greater shortcoming in the legal framework is the lack of a clearly prescribed and resource-supported legislative path from secondary school into higher education for students with disabilities. While this is suggested by the CRPD, it is a missing element in the Egyptian legal framework. Significantly, transition services to facilitate the move from secondary education to higher education are absent (Lord, 2017, pp. 10–11). Hence, students with disabilities are left without access to information on accessibility in HEIs or the skills required to self-advocate for needed accommodations.

Moreover, few university-wide policies exist for students with disabilities across Egyptian HEIs. This, too, is an element of CRPD implementation, via Article 4, yet largely missing from Egyptian HEI practice (CRPD, 2006, art. 4). Likewise, literature on advancing inclusive HEI is strongly suggestive of the need for clear and coherent policies for disability-inclusion (Emong, 2014; Reiser, 2012). Instead, the norm is ad hoc decision-making controlling the inclusion of students with various disabilities within specific HEIs and their individual faculties and departments, creating major (and inconsistent) barriers for these students to access programs of their choosing. The few efforts that have been made to address HEIs collectively have failed for lack of guidance or implementation (Lord, 2017, p. 15). While the Supreme Council of Universities (SCU) issued a decree allowing qualified students with disabilities to seek to enrol in any faculty they choose (SCU Decree, 2016), enrolment, however, remains subject to additional interviewing by individual faculty departments, with the possibility of appeal to the SCU where not approved. Further, the decree was not accompanied by guidelines on what support (including reasonable accommodations) students with disabilities should benefit from within HEIs. Thus, it is unclear if the SCU decree will impact access and improve selection and choice. The study also disclosed that when reasonable accommodations and other supports are provided, it is also highly discretionary within HEIs and often viewed as a gesture of good will rather than as a fulfilment of a duty (Lord, 2017, pp. 19–20).

3.2. Disability Data Collection Gaps

Literature abounds with evidence disclosing the lack of data and statistics on disability in education at any level, and where data exists it is unreliable (World Health Organization [WHO] & World Bank Group, 2011). In 2003, the OECD (2003, p. 23) reported on the global dearth of reliable data on students with disabilities and their higher education outcomes. Yet even following near-universal CRPD ratification, only a few institutions anywhere require such data collection; strikingly, few national-level requirements exist for data collection on students with disabilities at any level of education (OECD, 2003).

Estimates put forward by the Central Agency for Public Mobilization and Statistics in Egypt indicates that 10.7% of the population is disabled, or nearly 11 million persons (CAPMAS, 2017) This does not strongly contradict the estimated global disability prevalence of 15% provided in the 2011 World Report on Disability (WHO & World Bank Group, 2011). Disaggregated Egyptian data as to disability type is nevertheless hard to come by; a WHO household survey estimated 6% hearing loss, or some three million Egyptians (UNESCWA, 2015; WHO, 2015, p. 19). The WHO also estimated that there are one million blind Egyptians (WHO, 2015, p. 19).

Our research revealed, unsurprisingly, that the actual number of students with disabilities in HEIs is unknown (Lord, 2017, pp. 8–9). Those HEIs with data readily acknowledged the numbers were unreliable because students with disabilities were significantly underreported. The largest university in Egypt, for instance, has some 270,000 students and yet acknowledged that they were able to account for under 1,000 students with disabilities; those who could be counted were identified because they had specifically sought out assistance from disability support services (Lord, 2017). Students with disabilities, faculty, and administrators further explained that student non-disclosure of disability is due to stigma, fear of discrimination, and concurrent restrictions on choice of studies.

4. Part II: Educational Barriers

Two conceptual notions reflected in the CRPD are upheld in the educational barriers disclosed in the data. First, the barriers identified are evident in legal, policy, physical and online environments, and in information, communication, and attitudes (CRPD, 2006, preamble (e), art. 1). This is not surprising, but the point should not be missed that the CRPD’s conceptual framework responds to all dimensions of the social environment. Second, these realms of disadvantage are interdependent, interrelated, and indivisible in the manner that a rights-informed frame makes clear (CRPD, 2006, preamble).

The following themes emerged from an analysis of our data: (1) pre-higher education barriers; (2) admission, enrolment, and program choice barriers; (3) attitudinal barriers; (4) physical environment and transport barriers; (5) course curricula and material barriers; (6) examination barriers; and (7) online environment barriers.

These barriers map out against the provisions of the CRPD; yet understanding these barriers and then pegging them to the CRPD provisions presents a common framework that moves beyond the “wouldn’t it be nice” motivating factor into the more prescriptive law and policy realm. The discussions following in this and the subsequent section explain how this mandate may be implemented.

4.1. Pre-Higher Education Barriers

While the research focused primarily on the experience of students with disabilities currently enrolled in Egyptian HEIs, a recurrent theme across interviews with students was that pre-higher education barriers ultimately impacted their experience in HEI and, in many respects, set students with disabilities up for failure. First, students pointed out the problem of documentation on secondary school records that disclosed attendance in an “inclusive education” environment. This notation flagged disability status and resulted in limiting choice of studies in HEIs insofar as students were “outed” and thus marked for exclusion or restrictions by HEIs. Second, students noted the lack of information about the availability of support services in HEIs. Third, the students’ self-advocacy skills were often weak, thus compromising the navigation of barriers and assertion of accommodation needs. Additional barriers included shortcomings in their computer and technological skills, including assistive technology usage, and restrictions on access to taking certain courses that, in turn, impacted choices within HEI (Lord, 2017).

Differentiating among disability types, barriers experienced by students worked to disadvantage in various ways. Students identifying as blind emphasized limited opportunities for training at primary and secondary levels in the use of Braille and various assistive technologies needed to succeed at HEIs, thus emphasizing ongoing issues in accessing knowledge content. Deaf students indicated that there was limited access to quality education and restricted or no access to accommodations (e.g., Egyptian Sign Language) which hindered their ability to acquire needed reading and writing skills (Lord, 2017, pp. 19–20). Finally, students with physical disabilities noted physical and built environmental barriers such as reduced access to transportation to schools, classrooms on a higher floor without elevator access, and inaccessible bathrooms (Lord, 2017, pp. 17–18). The upshot of these findings was that students with physical disabilities stayed at home altogether or simply missed out on certain lectures and activities. These findings dovetail with research into the specific barriers experienced by children with disabilities at primary and secondary levels of education in developing countries (Danso, Owusu-Ansah, & Alorwu, 2012; Leonard Cheshire Disability, 2017).

The importance of the findings regarding experience prior to entry into university is that barriers existing in primary and secondary education may often have a knock-on effect at higher levels, diminishing opportunity and access. The foregoing also connects to the obligation in the CRPD that requires due attention to accessibility at all levels of education (CRPD, 2006, art. 24). Likewise, the CRPD recognizes that self-advocacy and awareness measures for teacher and administrators is one among many skill sets needed and required to address entrenched stigma and discrimination (CRPD, 2006, art. 8).

4.2. Admission, Enrolment, and Program Choice Barriers

Our assessment revealed significant barriers in HEI admission, enrolment, and program choices, and additional obstacles even after admission by individual departments within HEI faculties. To begin with, admission criteria for students with disabilities into HEIs are unclear or arbitrarily applied at the level of the faculty or individual department within a faculty (Lord, 2017, pp. 11–12). A typical reflection of this arbitrariness is the experience of a philosophy student with a physical disability: “The Faculty determines that we only join certain departments—they push us to join certain departments so not all are open to me” (Lord, 2017, p. 13). Likewise, another student explained: “I wished to study pharmacy, but they told me that they won’t accept me in the major. I was persuaded to change to diploma instead….I’m not allowed because of my physical disability” (Lord, 2017). Students with physical disabilities also face restrictions in joining their department of choice. For example, students with upper arm amputation were not allowed to enrol in faculties that require extensive writing or drawing, regardless of their qualifications. Similarly, students with physical disabilities were more often than not denied entry into any medical field (Lord, 2017).

Notably, deaf students experienced the greatest barriers to admission in HEIs. Even the recent SCU decree allowing students who are deaf permission to enrol into HEI faculties limits their enrolment to teacher training in the fields of music, arts education, home economics, and technology education (Lord, 2017). Likewise, students with visual impairments face severe restrictions in accessing their selected fields of study on account of both formal and informal exclusions (Lord, 2017, pp. 8–9). As one student noted: “After I became blind, while enrolled in the Faculty of Commerce, I was told I would need to switch faculties, which I did not want to do, so I left university” (Lord, 2017, p. 12). And some HEIs had put into place written policies excluding blind students from enrolling in certain faculties. For example, at one HEI, although the Faculty of Education supported admitting students with disabilities, a university-wide bylaw on admissions did not (Lord, 2017, pp. 15–16). At another HEI, blind students could not enrol in the computer information faculty, even though, paradoxically, that same faculty housed an assistive technology centre for persons with disabilities.

All too often, even in the absence of written policies, it was found that informal practices and “general understandings” worked to disadvantage students with disabilities. Thus, at one university, two students with visual impairment were admitted to the sociology department only to be told a few days before the exam that they were being transferred to another department (Lord, 2017, pp. 11–12). Subtle pressure was applied, sometimes by a single faculty member, to dissuade a student from pursing a course of study and solely on the basis of disability, irrespective of qualification. Another student who acquired a visual impairment during his course of study was thus told he would no longer be able to pursue his studies in commerce and would need to transfer to the arts faculty; he dropped out of university as a result (Lord, 2017, pp. 11-12). This arbitrariness in decision-making is precisely what the CRPD attempts to address in requiring States to create a legislative and—especially for higher education institutions that operate more autonomously than lower levels of education—regulative basis for non-discrimination (CRPD, 2006, art. 4).

4.3. Attitudinal Barriers

At eighteen of the twenty eight HEIs visited, attitudinal barriers were apparent among faculty and staff, non-disabled students, and students with disabilities themselves. These perceptions about disability were regarded as a major barrier to full participation and inclusion in HEIs (Lord, 2017, pp. 13–14). At the same time, upper level HEI management (i.e., university presidents, vice presidents, and deans) conveyed high levels of interest in supporting students with disabilities. A major theme of all focus group discussions held with students with disabilities was the understanding ascribed to disability within HEI culture. While both the social and individual/medical models were apparent, the latter was the predominant model among faculty, staff, and administrators (Lord, 2017).

Not surprisingly, the findings on disability awareness barriers lead to the conclusion that faculty are unfamiliar with the rights of students with disabilities, including their right to access HEIs on an equal basis with other students. Moreover, the failure to accommodate students with disabilities has a knock-on effect in terms of including faculty with disabilities in higher education which is shown to have a demonstrable (positive) impact on student attitudes about disability (Reiko & May, 2011). Creating a more enabling environment within which greater knowledge and understanding of how to identify and remove barriers must take place concurrently with specific provision for training and education on disability exclusion, consistent with articles 8 (awareness-raising) and 9 (accessibility) of the CRPD.

4.4. Physical Environment and Transport Barriers

Following the CRPD framework for environmental accessibility, the study assessed physical access prior to reaching an HEI campus, entry and egress onto the campus facilities, movement around the campus, and accessibility features inside facilities (CRPD, 2006, art. 9).

Barriers in physical infrastructure and transport were evident across all HEIs (Lord, 2017, pp. 17–18). Adopting the holistic approach required by the CRPD in Article 9, the assessment examined whether and how students with disabilities were reaching and benefitting from the all of the services offered, including lectures, library facilities, housing, sport and recreational events, and pathways across campus. Somewhat surprising given the low cost of basic barrier removal, physical barriers routinely prevented students with physical disabilities—especially wheelchair users, but also blind persons—from attending lectures and activities. Students, especially blind and physically disabled students, described the impact of multiple barriers in how such barriers impacted their getting to campus in the first place, and then restricted campus building entry and egress, and limited participation in field trips, extra-curricular activities and access to housing structures. Further, the results of accessibility audits uncovered barriers to water and sanitation facilities and inaccessible toilets in all campuses assessed. Somewhat disingenuously, resource limitations were cited as a major obstacle to ensuring physical access, especially to old buildings, by administrators, faculty, and engineering staff; old buildings in eighteen of the twenty eight HEIs visited were not physically accessible. Nonetheless, the appearance of a disabled parliamentarian at one university's concert hall resulted in the construction of a wooden ramp within thirty minutes.

Only eleven of the twenty eight institutions visited had accessibility plans and measures to monitor and evaluate accessibility of any kind and none that were effectively implemented to any significant degree (Lord, 2017, p. 18). Students were wholly reliant on the goodwill of other students or family members to mediate physical barriers inside and outside of campus buildings. Other hazards observed and reported by students included door thresholds; unlevelled, unpaved and rough walkways and roads around campus; and lack of safety railings in toilets or hallways. These physical barriers were found to limit students with disabilities' regular attendance at lectures and, inter alia, their access to education (Lord, 2017). Curiously, universities were not utilizing low cost solutions to address priority barrier removal, although a pilot program to assess and remove physical barriers in cooperation with a non-governmental organization at Cairo University offered some promise. Additional missed opportunities abounded for integrating barrier removal into academic programming, for instance by engaging with engineering faculties to provide students with campus-based academic and service learning opportunities. Finally, and underscoring the problems that arise when students with disabilities themselves are not consulted about resource allocation in barrier removal, 100 wheelchairs donated by a wealthy patron had no apparent distribution plan attached to it nor a needs assessment, and golf carts purchased for disabled students were ill-equipped for many and ill-coronated to facilitate timely transfers. Consultation as a precondition to decision-making, as required in Article 4(3) of the CRPD, assumes particular significance in a context where resources are limited and must be put to best use.

4.5. Course Material and Curricula Barriers

Difficulties in access course material and curricula were widely cited. A majority of students with visual impairment (72%) and hearing impairment (56%) reported barriers in obtaining course materials in an accessible format (Lord, 2017, pp. 19–20). As one blind student explained: "I have a printing problem there are legal issues related to copyright and it makes it hard to get what I need printed in Braille" (Lord, 2017, p. 20). A large minority of students with physical disabilities (44%) faced similar problems (ibid). In addition, HEIs are not facilitating the learning of Egyptian Sign language (ESL) or ensuring delivery of education in the most appropriate means for deaf students (CRPD, 2006, arts. 24, 30).

The results of the study disclosed that providing alternative formats (courses, exams) and accessible teaching modalities for the visually disabled (e.g., PDFs and PPTs) is all but unknown. Further, students and assistive technology staff explained that accessibility was seen as a measure of "good will" and not of "rights" (Lord, 2017, pp. 19–20). Hence, access to course materials in accessible formats is frequently dependent on the individual discretion of faculty members. Students, assistive technology staff, and library personnel similarly report delays in obtaining accessible formats of academic material (e.g., Braille, large print, audio recordings) due to resource constraints (Lord, 2017). In addition, assistive technology and library personnel report shortage of staffing, assistive technology, and technical know-how on up-to-date print access accommodations (e.g., Arabic language software). Unfortunately, in the absence of knowledge and understanding about the duty of HEIs to provide reasonable accommodations to facilitate access to course material and curricula, students engaged in surreptitious self-help strategies, as in secretly recording lectures on their cell phone to listen to later on (Lord, 2017).

4.6. Examination Barriers

Barriers to accessing needed accommodations during examinations and assessments were a major issue noted by many students. Student surveys revealed that 94% of deaf students reported barriers in taking course examinations (Lord, 2017). Students with visual and physical disabilities pointed to the problem of poorly qualified readers and writers assigned to them during the examination period. They also noted the faculty perception that providing them with qualified readers/writers would give them an unfair advantage or pave the way for cheating (Lord, 2017). This points to the need for educating teachers and administrators about reasonable accommodations in the specific context of assessment and, in addition, to the need for university-wide regulation and quality control.

Beyond putting in place uniform policies and procedures, in some instances HEIs had discriminatory processes in place according to which bylaws required readers and writers for students with disabilities to be younger and less qualified than the students they were assisting, apparently on the basis that this would prevent any unfair advantage. Students emphasized the need for by-laws that facilitated their access through qualified assistance. Many put forward their own solutions, pointing to the availability of computer technology that might allow students to have access to computer examinations to facilitate their access (Lord, 2017). Examples of desired accommodations noted by students with disabilities to achieve equal access to exams were diverse, and yet HEIs were seemingly unaware that a core element of the duty to provide reasonable accommodations in education is individualizing such accommodations (CRPD, 2006, art. 2). The measure of reasonableness allows for the circumstance that not all types of accommodations will be possible (e.g., on account of the need for resources to obtain, for instance, the latest screen reading software), yet many exist that are readily achievable.

4.7. Online Environment Barriers

Online accessibility is an increasingly important dimension of higher education. Accordingly, barriers were assessed in the online environment against globally accepted standards for web content accessibility, namely, the Web Content Accessibility Guidelines, version 2.0. Webpages were tested against twelve guidelines organized under four key principles: perceivable, operable, understandable, and robust. Stark results were revealed: every HEI website viewed showed significant degrees of inaccessibility (Lord, 2017, pp. 22–23). Manual checks were undertaken to confirm automated barriers and to assess barriers that cannot be captured by automation. For instance, websites were inaccessible for students with visual impairment, utilizing assistive technologies (e.g., JAWS, NVDA, and VoiceOver), preventing easy page navigation or quickly accessing the entirety of the website. The near total absence of captioning on videos made such content inaccessible to persons with hearing impairment. Page navigation across the entirety of the HEI websites would be difficult for persons with physical disabilities where mouse navigation is not an option. Further, the existing Egyptian law and policy framework was silent on the accessibility of web content, online learning, or other increasingly important modes of access to materials (Lord, 2017).

Finally, interviews with students and faculty members with disabilities disclosed other barriers such as inaccessible content on Facebook pages, a highly utilized medium within HEIs (and the primary online presence for seven of eight technical colleges), including no captioning on videos, no audio description for images, graphics. One faculty member noted the practice of informing faculty and staff across the university of upcoming events and meetings via PDF versions of xeroxed pages that were totally inaccessible even to his own screen reading technology (Lord, 2017). The Supreme Council on Higher Education conceded its lack of technical capability in making the growing online e-platform accessible but evidenced a strong interest in receiving such support. More than other areas of CRPD implementation, accessibility in the online environment was little understood notwithstanding explicit provision made for it in the treaty (CRPD, 2006, art. 9). The failure of HEIs to facilitate the entry of blind and Deaf students into information technology and computer science programs demonstrates the potentially far-reaching consequences of limiting program choice. It stands to reason that such restrictions will stifle innovation (Haddon et al., 2005; Miller, Paul, Parker, & Gillinson, 2004; Von Hippel, 2005).

5. Part III: Recommendations to Advance Inclusive Higher Education

It is one thing to catalogue obstacles to inclusion as the findings and conclusions of the USAID study highlight in comprehensive measure. It is quite another to tackle and dismantle these barriers, knowing in particular that local shortcomings align generally with findings in other developing countries where resource constraints create similar barriers for many, if not all students irrespective of disadvantage rooted in disability (Emong, 2014; Reiser, 2012).

The radical claim of the CRPD is that such hindrances are not inevitably determined on account of the absence of material capabilities to dismantle them. Granted, in some instances, resources will impose a certain temporality, a limitation on how quickly some barriers must be removed (CRPD, 2006, art. 4). And these elements are embedded in the human rights framework that renders social rights—including education—subject to progressive achievement, and indeed, the reasonable accommodation duty which sets up some parameters (reasonableness, undue hardship) for the imposition of that duty (CRPD, 2006, arts. 2, 5). But a whole of institution approach, as laid out in the legal framework of the CRPD, makes many components of barrier-removal immediately realizable. In fact, the claim of the CRPD is that there are numerous grounds for advancement and these hinge on recognition of the legal capacity and personhood of persons with disabilities. Further, that progress can be best achieved by engaging persons with disabilities in the processes of barrier identification and removal. Thus, CRPD Article 4(3) astutely requires that persons with disabilities must be active agents in assessing all policies, laws, and programs. Real inputs from stakeholders would expose the absurdity—beyond its inherent illegality—of pushing people into certain schools and careers based on disability-type.

Moreover, a close reading of the CRPD, combined with a "whole of institution approach" to accessibility in higher education, offers guidance on the interventions required to advance accessibility for students with disabilities into quality higher education both in Egypt and beyond Lord (CRPD Committee, 2016, para. 12). Within HEIs, six core priority interventions are needed to advance inclusive quality higher education in Egypt. These include: (1) dismantling barriers in pre-higher education; (2) addressing law/policy and data gaps; (3) tackling disability stigma; (4) advancing inclusive curricula, materials, and examinations; (5) creating barrier-free infrastructure; and (6) ensuring ICT accessibility. We underscore the iterative and interrelated nature of these recommendations. At the same time, we acknowledge that bringing about the change contemplated by the CRPD will be constrained by availability of resources that constrict inclusion for all students in developing country high education, disabled and non-disabled alike. Yet in all of the areas requiring measures to advance inclusion and accessibility, a pre-condition to the expenditure of resources in a sensible direction is the meaningful participation by persons with disabilities to prioritize and generate solutions.

5.1. Dismantling Barriers in Pre-Higher Education

Our study concluded that attention to the removal, or at least mitigation, of pre-higher education barriers was important for facilitating entry into HEIs for students with disabilities. Illustratively, instead of eliminating geometry and data-handling in math and science subjects in secondary school for blind and deaf students, inclusive education techniques must be employed, and accommodations provided within those courses (Lord, 2017, p. 20). Further, reforms in higher education can facilitate the removal of many barriers for students with disabilities in primary and secondary levels of education. Poignantly, teachers trained in inclusive education at HEIs can develop and disseminate expertise on assistive technology, occupational therapy, and sign language at secondary school levels (Lord, 2017).

5.2. Addressing Law/Policy and Data Gaps

Egypt can bring about the implementation of international disability standards by strengthening its legal and regulatory framework in the light of the CRPD and by ratifying the Marrakesh Treaty. Policy development is also fundamentally important to inclusive higher education at both the national and university level given the autonomy exercised by many HEIs in addressing disability inclusion (Lord, in press). There is a need for coherent university-wide policies on non-discriminatory enrolment and selection of academic courses, equal access to course material and curricula, the provision of reasonable accommodations, and grievance processes to address instances of discrimination—including failures to provide these supports (CRPD Committee, 2016, para. 63). Trenchantly, disability support services require specific policies, procedures, trainings, and authorization that apply specifically to all departments and teaching staff to enable their implementation (Lord, 2017, p. 20). Further, university-wide policies on making examinations accessible for students with disabilities can serve to eliminate discretionary decision-making by individual faculty members (Lord, 2017). Finally, uniform and expedient disability-inclusive HEI policies must extend to procurement policies, especially in relation to obtaining ICTs and equipment (e.g., software and computers) where the principle of user-testing should be reflected in policy (Haddon et al., 2005).

Measures must be undertaken at all levels of education regarding the participation of students with disabilities to address the persistent data gaps (Lord, 2017). Data on primary, secondary and higher education must capture and disaggregate on the basis of disability type, school enrolment, retention and advancement (CRPD Committee, 2016, para. 66). Gathering disability-specific data and statistics—admittedly challenging given the persistence of stigma and attendant reluctance to self-disclose—is crucial for informing HEI policy and programming on accommodating students with disabilities (CRPD, 2006, art. 31).

5.3. Tackling Disability Stigma

HEIs must address the causes of disability stigma and discrimination among faculty and staff, including misperceptions about disability accommodations conferring an unfair advantage (Riddell, 1999). Further, students with disabilities should be empowered to understand their rights and self-advocate, recognizing that cultural mores create internalized stigma and support the myth of accommodations being a “favour” rather than a required duty (Lord, 2017, p. 24).

To this end, HEIs can use CRPD Article 8’s awareness raising mandate to break down stigma and foment positive imagery (CRPD, 2006, art. 8). This could involve trainings for students, faculty, staff, and administrators, especially according to active learning principles that expose the fallacy of common stereotypes through dialogue between persons with disabilities and targeted participants. A practical element of enhancing such awareness is building knowledge about the duty of HEIs to provide reasonable accommodations to facilitate equal access to academic programming, including exams and course materials (Lord, 2017, p. 21). A precondition to understanding the duty to provide reasonable accommodation is imparting the sense that accommodations are equalizing measures and do not convey extra-advantage. Specifically, that extra time for handwriting exam answers or being able to conduct an exam in Braille are measures for providing meeting student needs equal access. Further, that they do not undermine or compromise the assessment needs of the faculty member. HEIs must likewise train faculty and staff on strategies for delivering content accessibly, or for modifications to provide better access to students, for example, allowing for students with hearing disabilities to sit up front, or describing images for students with visual disabilities (Lord, 2017, pp. 19–20).

5.4. Advancing Disability Inclusive Curricula, Materials, and Examinations

Inclusive education for students with disabilities requires access to course curricula, materials, and examinations and therefore requires their provision in accessible formats (CRPD, 2006, art. 24). Hence, HEIs must put into place a system for the timely distribution of accessible formats of materials to students with disabilities to prevent delayed access that compromises quality inclusive education. Failure to consult with students about their specific needs and, crucially, their suggested solutions is likely to result in wasted resources. Ensuring equal access to examinations for students with disabilities suggests not only the need for clear policies on equal access to examinations, but specific guidance and clear directives on accessibility to faculty on good practice with illustrative accommodations for students with different disabilities. This should include training for faculty and HEI administration on the duty to make examinations accessible, and the provision of accommodations that do not fundamentally alter the nature of the academic program (CRPD, 2006, art. 24).

Academic curriculum must be inclusive if a whole-of-institution approach is to take hold in HEIs. Disability-inclusive curricula and research agendas within HEIs can serve to incentivize the development of disability expertise within HEIs. as suggested by research in South Africa (Ohajunwa, McKenzie, & Lorenzo, 2015). Opportunities to develop disability-inclusive curricula can likewise help change attitudinal perceptions, and some of these approaches were beginning to emerge in some Egyptian HEIs (Lord, 2017, p. 13). Bringing these initiatives to scale and working to include in the curriculum courses on disability law, disability studies, inclusive education and accessibility in ICTs, among others, ought to be prioritized.

Finally, the value of disability-inclusive curricula is borne out by the emergence of disability studies as a discrete discipline within higher education in the United States, the United Kingdom, and elsewhere. Prioritisation could include developing disability studies in the humanities; sign language teaching and accreditation; inclusive education teacher training (e.g., including inclusive education training for new teachers, allowing students with disabilities entry into teacher training courses, and promoting university-sponsored workshops for training teachers); ICT accessibility (in relation to assistive technologies, e-learning accessibility, and accessible web content development) for specialized faculties (e.g., computer information, computer science); and disability law, and international and comparative disability law.

5.5. Creating Barrier-Free Infrastructure

Creating barrier-free infrastructure is fundamental to fostering an enabling environment for students, faculty, and staff with disabilities (Lord, 2017, p., 18). The two elements required are dismantling existing barriers in HEI infrastructure and ensuring that new building and infrastructure projects are made accessible to persons with disabilities. Consistent with the CRPD (and common sense) this must be conducted by government in consultation with persons with disabilities and their representative organizations. Such collaboration can develop guidelines and plan new infrastructure by efficaciously drawing on the knowledge and lived experiences of persons with disabilities in accessing their environments (CRPD, 2006, arts. 4, 9). Engagement with local disability rights groups can serve to: (1) identify, prioritize, and effectively plan for barrier removal; (2) effectively train HEI personnel responsible for infrastructure and accessibility; and (3) support innovative pilots utilizing HEI faculty and students, including students with disabilities, to integrate barrier removal into practical training and service learning under the aegis of relevant faculties, like engineering and architecture.

5.6. Ensuring ICT Accessibility

Training for HEI information and communications personnel on international standards and guidelines on web content accessibility and their application to HEIs is a priority to remove persistent barriers in the online environment (Simpson, 2009). Further, practical training of faculty on accessibility practices for PDFs, PPTs, and other modes of content delivery in-class, and support for development and piloting of online courses in accessible formats is an imperative given the increasing reliance on such materials in HEIs (Ziegler & Sloan, 2017). Guidance provided by CRPD Article 9 and *General Comment No. 2* on accessibility applies equally to information and communication technology, as it does for other elements of accessibility such as physical infrastructure (CRPD, 2006, art. 9; CRPD Committee, 2014).

6. Conclusion

The adoption of the CRPD in 2006 and its subsequent near universal ratification point to global recognition that the right to inclusive education for persons with disabilities at all levels of education is firmly embedded in human rights law. Currently this promise is unfulfilled at all levels of education worldwide, but progress is underway, spurred on by the CRPD's legal framework and its institutional arrangements. For countries like Egypt to make good on their legal commitments to inclusive education, international donors and their implementing partners must turn their attention to higher education. Ironically, but positively, the potential assets to advance inclusion in higher education and in primary and secondary education lie untapped within institutions of higher education yet close-by in local organizations of persons with disabilities.

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About the Authors

Janet E. Lord is an International Lawyer and Inclusive Development practitioner with more than 15 years of experience assessing, evaluating and monitoring development projects. She served as Team Leader for the QED Group resulting in USAID's first assessment on the accessibility of Egyptian universities to students with disabilities. A senior fellow at the Harvard Law School Project on Disability, she holds Law degrees from the George Washington University Law School (LLM) and the University of Edinburgh in Scotland (LLB & LLM).

Michael Ashley Stein is Visiting Professor of Law at the Harvard Law School and Executive Director of the Harvard Law School Project on Disability. He holds an Extraordinary Professorship at the University of Pretoria Faculty of Law, Centre for Human Rights and regularly consults with governments and disabled people organizations on disability law and policy. A leading scholar on the human rights of persons with disabilities, he holds degrees from the Harvard Law School (JD), Cambridge University (PhD) and New York University (BA).

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Commentary

The Inherent Value of Disability in Higher Education

Benjamin J. Ostiguy

Department of Educational Policy, Research, and Administration, University of Massachusetts, Amherst, MA 01003, USA; E-Mail: ostiguy@admin.umass.edu

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Abstract

Evidence suggests that college students with disabilities (SWDs) continue to encounter attitudinal and physical barriers while institutions endeavor to offer reasonable supports—mainly in the form of accommodations and modifications. In practice, disability is largely treated as something external and ancillary, with most colleges administering measured allowances, but otherwise managing to avoid change. However, as we proceed into the 21st century, very little seems assured, least of all the status quo. Under the dominant neoliberal regime, virtually everything and everyone is valued in proportion with their perceived economic utility. No longer is higher education widely embraced as a public good. Instead, there is increased scrutiny of the academe with an eye for "value added", and the returns students can expect with regard to careers and earning potential. Viewed through this narrow hegemonic lens, SWDs must assimilate or transcend their perceived impairments if they are to belong. In this commentary, I introduce key concepts from the environmental philosophy/theory of Deep Ecology to the scholarship of disability in higher education and assert that disability in academe has an "intrinsic value", irrespective of expected economic utility. I conclude by discussing ways that the deep valuing of disability can lead to the identification of novel veins of inquiry, bolster critical analyses, and help facilitate meaningful change in uncertain times.

Keywords

disability; Deep Ecology; higher education; neoliberalism

Issue

This commentary is part of the issue "Students with Disabilities in Higher Education", edited by Geert Van Hove (Ghent University, Belgium/VU Amsterdam, The Netherlands), Minne Bakker (VU Amsterdam, The Netherlands) and Alice Schippers (Disability Studies in the Netherlands/VU Amsterdam, The Netherlands).

1. Introduction

This commentary introduces the philosophy of Arne Naess and "Deep Ecology" to the disability in higher education research literature. Throughout this piece, I offer my thoughts on how research into the experiences of college students with disabilities (SWDs) can derive inspiration and direction from Naess and the Deep Ecology movement, improving our capacity to understand, value, and support college SWDs.

2. Arne Naess and Deep Ecology

Contemplative and rugged, Naess conceived and articulated a philosophy of Deep Ecology in nature, regularly trudging arduous miles of elevation to Tvergastein, his modest cottage on a slope of a mountain named Hallingskarvet. Naess' chosen ecosystem was alpine, involving organisms and interrelationships that are rather small and easily unnoticed by a distracted, casual observer. It was through his willingness to be present and attentive that Naess came to understand and articulate the value of all organisms, even the inanimate features of a landscape or place. Central to Naess' philosophy is a rejection of the assumption of humanity's primacy among living beings. This controversial idea is well captured in the first three of Naess' eight principles for Deep Ecology (Naess & Haukeland, 2002, p. 108):

1. All living beings have intrinsic value;

2. The richness and diversity of life has intrinsic value;
3. Except to satisfy vital needs, humans do not have the right to reduce this diversity and richness.

These deceptively simple assertions stand radically opposed to dominant neo-liberal views that assign value to the natural world proportionate with its potential to address *human* needs, wants, and interests; and contribute toward economic growth and the production of wealth. Naess proposes an ontology of "unity and diversity" (Naess, 2001, p. 4), one that unites all organisms through the recognition of their interplay of interdependence, without losing the sense of the inalienable dignity of each part.

3. The Need for a Deep Perspective

Similar to the external economic forces that inspired Deep Ecology in the environmental sciences, higher education is experiencing scrutiny and demand with respect to its ability to serve neoliberal agendas, such as infusing the workforce with competitive human capital. In this context, efforts to support college SWDs reflect a "power over life" (Foucault, 1990, p. 139), leveraged through the systematic application of law, policy, and administration. For instance, virtually all campuses in the United States require students who experience barriers to inclusion to seek a qualifying disability status by submitting third-party diagnostic documentation. Once qualified, SWDs must engage prescribed policies and procedures in order to request reasonable accommodations. Ironically, these structures—designed to protect and support SWDs—simultaneously stigmatize and differentiate (Loewen & Pollard, 2010; Markoulakis & Kirsh, 2013; Weiner, 1999). This reflects a largely unexamined, shallow view of disability on campus; one that allows for minimally responsive efforts (i.e., the least amount required to remain in compliance) with implications for domain specific research, including the scholarship of teaching and learning.

4. Toward a Deep Campus Ecology

"Deep Ecology is an invitation to thinking and presents challenging questions and dilemmas" (Devall & Sessions, 2007, p. x). Through Naess we are entreated to approach our work at the local level, with an awareness of our own incomplete knowing. Deep Ecology asks the observer to adapt and change their sense of self in relation to the environment, and not merely rely upon assumed modes of thinking, perceiving, and understanding—such as the neoliberal default orientation of today's university. Rather than simply asking or assessing if the student with a disability comports with conventional expectations, we should seek to perceive/know/appreciate how they belong in the larger context—contributing towards the comprehension of a bigger picture that may suggest novel veins of inquiry.

We must recognize the intrinsic value of SWDs. A deeper view of disability in higher education can begin with valuing SWDs, beyond their apparent potential to perform or thrive within existing academic or professional structures and domains. Unquestioned, the concept of disability supports unsubstantiated and often arbitrary standards of normalcy. For instance, when instructors design and implement a curriculum, it assumes a status of "normal", with required efforts to accommodate SWDs regarded as exceptions to the norm.

We must Consider what constitutes a "vital need". On occasion, efforts to include SWDs will contradict conventional practice. In response, Deep Ecology calls for a blend of "high level emotional maturity with sophisticated analytical and logical reasoning to draw attention to conflicts between our actions and our fundamental aims" (Glasser, 2002, p. xxi). Beginning at the individual level, in our respective roles, each of us can evaluate if the status quo truly constitutes a "vital need" for students, for the discipline, for the institution, and ultimately for society. If not, then the identification and adoption of inclusive options is suggested.

We can adopt deeply inclusive values and practices. The following items are adapted from a larger list of "Lifestyle Trends within the Deep Ecology Movement" (Naess, 2008, pp. 140–141):

1. Employ accessible and inclusive pedagogies, methods, technologies, and research instruments;
2. Avoid adherence to rigid standards and traditional practices absent of "intrinsic value" or unrelated to "fundamental goals";
3. Before adopting a new or trendy technology, method, or instrument, first consider if SWDs will find it accessible and inclusive;
4. Recognize and value the diverse identities, perspectives, strengths, and challenges represented among college SWDs; cultivate an awareness of intersectional oppressions (e.g., ableism and homophobia);
5. Understand that SWDs are a heterogeneous demographic with identities, priorities, expectations, opinions, and access requirements differing within and among specific disability "types". Note that perspectives on disability vary and evolve, so what is deemed appropriate or supportive may/will vary by generation, culture/ethnicity (e.g., international students), and social/historical context;
6. Employ the concept of universal design in all aspects of your work, including teaching, assessment, research, and service;
7. Develop research questions that account for SWDs and accurately represent/address their perspectives, needs, and sense of dignity;
8. When faced with apparent pedagogic/epistemological dilemmas, err on the side of accessibility and inclusion;
9. Speak out against campus policies, procedures,

and traditions that are not universally inclusive, or otherwise stigmatize SWDs;

10. Reject the idea that a student's value to a campus or academic discipline is proportional with their apparent potential to contribute toward the economy and the upward distribution of wealth.

5. Conclusion

Applied to a college campus, Deep Ecology destabilizes existing structures of normalcy, affording opportunities to promote a deeper approach to inclusion.

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Conflict of Interests

The author declares no conflict of interests.

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About the Author

Benjamin J. Ostiguy is a Doctoral student in Higher Education and Associate Director of Operations for disability services at the University of Massachusetts Amherst. As a practitioner-scholar, his areas of inquiry involve college students with disabilities and institutional practices designed to support their full inclusion. He lives in Northampton, MA, with his partner Carol and their daughters, Emma and Gigi.

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