# BEYOND 'IF' TO 'HOW': DISABILITY INCLUSION IN HIGHER EDUCATION

UNIVERSITY OF CAPE TOWN CASE STUDY

SERIES NO. 4

BEYOND 'IF' TO 'HOW':

DISABILITY INCLUSION IN HIGHER EDUCATION

UNIVERSITY OF CAPE TOWN CASE STUDY

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AFFIRM   ADVOCATE   ACCOUNT

ACKNOWLEDGEMENTS

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AIMS AND INTENTIONS OF DISABILITY CATALYST AFRICA

The situation of disabled people calls for a catalyst to prompt the changes and shifts to the status quo that will ensure their participation as active citizens. Disability Catalyst Africa intends to create spaces for dialogue, debate and action among different players in higher education institutions, civil society organisations and government, particularly local government. It also intends to generate awareness on disability-inclusive development and facilitate self-representation of disabled people in academic and public forums.

The pillars are **affirmation**, **advocacy** and **accountability**. The series of Disability Catalyst Africa should appeal to those at every level who are able to influence disability inclusion in their institutions to make a difference in the lives of disabled people, their families and communities.

FOREWORD BY VICE-CHANCELLOR, UNIVERSITY OF CAPE TOWN

Higher education institutions provide leadership for societal and technological development. We should aspire to make this true of disability issues too. This publication is an example of how the various aspects of an higher education institution can (and should) be engaged in the quest to understand and operationalise insights about disability. This engagement of higher education institutions with issues of disability is demonstrated here at UCT by:

Dr Max Price

- The research on disability inclusion in the curricula and on access to higher education for adults with intellectual disability carried out in the Faculty of Health Sciences;

- Curriculum modifications carried out to educate students in the Faculty of Engineering and Built Environment about the transportation needs of the disabled;

- The information technology and computer system applications that are being developed in collaboration with disabled users in Faculties of Commerce and Science;

- The quest for deeper understanding of disability being attempted by mapping the intersection of disability, gender and identity construction, in the Faculty of Humanities; and

- Research on issues of consent and credibility in the case of legal proceedings involving disabled victims, being carried out in the Faculty of Law.

The chapters included here from UCT's six academic faculties highlight the complexity and diversity of disability through the lenses of different disciplines and faculties. In the process, the publication encourages reflection that each faculty (and indeed the broader society) may employ to further their own understanding of and engagement with disability issues.

In higher education institutions, active engagement with disability issues is
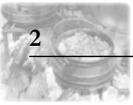
more than just the recognition of the medical and social aspects of disability and the need for inclusive policies. This engagement is also fundamentally analytical and critical where the conceptual, theoretical, explanatory and practical dimensions involved are perceived to be of central importance. By re-aligning itself to the needs of everyone (disabled or otherwise), the university plays a leading role in correcting existing misconceptions about difference and disability in society. Ultimately, the issue of disability is an issue of transformation. This publication is therefore a demonstration of our deep commitment to the values of transformation.

Dr Max Price

Vice–Chancellor

CONTRIBUTORS

Theresa Lorenzo

Theresa Lorenzo, Associate Professor in the University of Cape Town's Disability Studies and Occupational Therapy department, gained experience in community-based disability and development programmes in the rural communities of Limpopo and Mpumalanga. She joined UCT's occupational therapy department in 1996 and has worked with the SACLA Health Project in building students' capacity to work with civil society organisations in addressing the needs of disabled people and their families. She initiated the Disability Studies Postgraduate Programme at UCT in 2003 to bridge the gap between activism and scholarship.

Chioma Ohajunwa

Chioma Ohajunwa is a lecturer in the Disability Studies Programme in the Department of Health and Rehabilitation Sciences at UCT. Chioma has a B.Ed in special education, and an MPhil in Disability Studies. Her special area of interest is intellectual disability and higher education and, as the researcher in the DIRECT project, was able to explore different perspectives on higher education curricula and disability.

Judith Mckenzie

From 1998 to 2008 Dr Judith Mckenzie taught at Rhodes University and the University of Fort Hare in inclusive education. In 2009 she was awarded the UNESCO/Emir Jaber al-Ahmad al-Jaber al-Sabah Prize for promoting quality education for persons with intellectual disability. She is a lecturer in the Disability Studies division of UCT's School of Health and Rehabilitation Sciences. In 1993 her youngest child was born with Down Syndrome.

Adelene Africa

Dr Adelene Africa is a clinical psychologist who lectures undergraduate and postgraduate students in Gender Studies at the University of Cape Town.
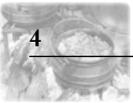
She convenes the first-year undergraduate course and her teaching focuses on introducing students to foundational concepts integral to the study of gender. She convenes one of the core courses at Honours level in which students are encouraged to critically engage and develop the theoretical ideas gained during their undergraduate studies. She also participates in undergraduate and postgraduate teaching in research methodology and contributes to postgraduate supervision. She has a keen interest in feminist disability studies and integrates this into the first-year programme as well as encouraging postgraduate research in this area.
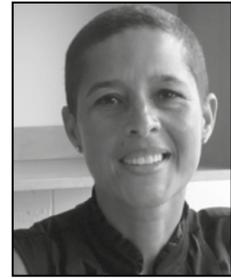
Edwin Blake

Edwin Blake is a professor in Computer Science at the University of Cape Town. His work focuses on the relations of people to computers in the context of a developing country. His schooling and undergraduate education was obtained in South Africa. He read for a PhD in Computer Science at Queen Mary College, London University. He was subsequently senior researcher in the Department of Interactive Systems at the Centre for Mathematics and Computer Science (CWI) in Amsterdam, the Netherlands. His main research focus has been on Information and Communications Technology for Development. He also works on User Experience as applied to Games and Virtual Environments. His research outputs range from reflections on policy issues to methods for Community-Based Co-Design.
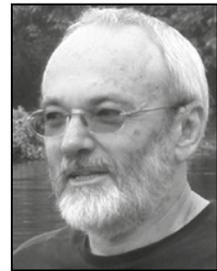
Kevin Johnston

Kevin Johnston is an Associate Professor in the Department of Information Systems at the University of Cape Town. He worked for 24 years for companies such as De Beers, Liberty Life, Legal & General and BoE. Kevin's main areas of research are ICT Management, Project Management, IS educational issues and Open Source Software.

Meryl Glaser

Meryl Glaser is a researcher and facilitator consulting on Deaf issues in education, language and literacy. She studied Audiology at the University of Cape Town and subsequently trained as a teacher, completing an

MSc in Human Communication (specialising in Deaf people) from the City University, London. She has many years of experience in Higher education, both at University College, London and at UCT. She is the co-ordinator of the Adult Literacy Project for Deaf Community of Cape Town, a nongovernmental organisation. She is a member of the Ministerial Curriculum Management Team tasked to implement South African Sign Language (SASL) as a subject in all schools for Deaf learners. She collaborates on various ICT4D projects with the Computer Science departments at both UCT and the University of the Western Cape.

Roger Behrens

Roger Behrens is an Associate Professor in UCT's Department of Civil Engineering, Director of the Centre for Transport Studies, and Director of the African Centre of Excellence for Studies in Public and Non-motorised Transport. He graduated with a Masters degree in City and Regional Planning (with distinction) from UCT in 1991 and with a PhD in 2002. His current research relates to three fields. The first is the regulation and improvement of para-transit, and its interface with integrated, planned public transport systems. The second is the analysis of the dynamics of changing travel behaviour, and the implications this has for the management of travel demand. Third is the analysis of the use of transport systems by pedestrians and the quality of pedestrian infrastructure and environments, and the identification of frameworks through which improvements can be made.

Iain Low

Iain Low is a professor at UCT where he convenes postgraduate programmes in architecture. He was a Fulbright scholar and visiting scholar at the American Academy in Rome. As a practitioner, he was Project Architect for the World Bank/GoL where he designed schools for the Training for Self-Reliance Project throughout Lesotho, and he designed the award-winning reinstallation of Iziko's San Rock Art at the SA Museum in Cape Town. Currently his research area is 'space and transformation' and spatialisation in the contemporary (post-apartheid) city. He is published in a number of local and international journals and is editor of the Digest of South African Architecture.
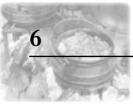
Gerard M. Samuel

Gerard M. Samuel has been a senior lecturer and Director of the UCT School of Dance since 2008. He is a pioneer of disability arts and integrated arts projects in South Africa, and established the Left-feetFIRST Dance theatre group. Gerard's choreographies include neoclassical ballet – *Prabhati*, contemporary dance – *Milky Tears*, and children's theatre – *Who says, The Ugly Duckling?*, which has toured Hungary, Denmark and South Africa. His made-for-dance film *Place of Grace* was supported by the prestigious Creative Arts Award of the Gordon Institute for Performing and Creative Arts in 2010. Gerard is a PhD candidate exploring the nexus of ageism, disability and otherness in dance.

Dee Smythe

Dr Dee Smythe is Director of the UCT Law Faculty's Centre for Law and Society and an Associate Professor in the Department of Public Law. She holds a BA and LLB from UCT and JSM and JSD degrees from Stanford University, where she was a Fulbright Fellow. Her research spans a range of areas at the intersection of law, policy and social justice. She is an expert on state responses to gender-based violence, with a specific focus on sexual offences, and has a particular interest in the regulation of criminal justice agencies. She teaches in the areas of sexual offences, law and society and criminal procedure.

Rachel Weiss

After having worked as a medical doctor in the public and private sector for many years, Dr Rachel Weiss returned to academia to teach medical students at the University of Cape Town. She completed an MPhil in Education in 2008 and currently oversees the Faculty of Health Science's skills training programmes as Director of the Clinical Skills Centre. Her PhD research mainly draws on applied linguistics, multimodal social semiotics and discourse analysis to interrogate relationships of power and access in health profession education. She has a particular interest in professional identity and pedagogic approaches that encourage patient-centred communication practices amongst medical students.

Preface by Deputy Vice-Chancellor

The human rights of disabled people have been historically denied and, although various policies have been put in place to address this marginalisation, the implementation of these policies has been a challenge (Reiter, 2008; Karr, 2011). The World Health Organisation has noted the capacity of higher education institutions (HEIs) to implement changes that could transform society, and mandated HEIs to support initiatives that impact on the disadvantaged members of society (Blumenthal & Boelen, 2001).

Prof Sandra Klopper

The *Disability Catalyst Africa* (DCA) series responds to this challenge by stimulating discussions and debates on disability, in a bid to address issues related to disabled people, who represent a minority group. Various studies have been done related to the accommodation of disabled people in higher education institutions (Tagayuna et al., 2005; Murray et al., 2009; Konur, 2006), but the current DCA is focused on disability inclusion in the curriculum. The interrogation of a transdisciplinary disability studies and what that might mean for higher education curriculum is advocated (Lubet 2008).

The contributors to the DCA are academic staff from all six faculties at the University of Cape Town (UCT) who include disability in their teaching, showcasing the interdisciplinary nature of disability. The contributors discuss strategies used to include disability and the enriching impact on the classroom as a collective.

The chapters of the DCA come from a variety of experiences and perspectives that not only present the successes and challenges of inclusion, but reveal the creativity, tenacity, negotiations and commitment of academic staff who have achieved disability inclusion in their teaching. Although these are documented experiences from academic staff who practiced these strategies, the strategies are not presented as a recommendation, but simply as evidence of good practice so as to encourage other lecturers and academic curriculum committees to do likewise.

Although disability inclusion is a nuanced and ongoing process with its

particular complexities, it is happening at the University of Cape Town, and the relevance of engaging in this discourse needs to be garnered so that further progress can be made and support can be provided within and beyond the institution.

The DCA posits disability as an issue of diversity, and argues that disability should feature in the curriculum like race and gender. The University of Cape Town through its Vice Chancellor's Strategic Goals (UCT, 2009) has shown leadership in seeking to create and promote an inclusive institutional culture that is mutually respectful and welcoming of diversity.

Professor Sandra Klopper

Deputy Vice–Chancellor

Executive Summary

Monitoring disability-inclusive research enabling curriculum transformation

Institutions of higher education are called to integrate disability as a social justice and diversity issue rather than merely a medical problem. Equal opportunities aim to make all systems in society, including activities, services, information and documents, available to everyone in society (UN, 1982). As such, transformation of curricula is required rather than focusing only on admission and reasonable accommodation of disabled students and staff. The South African and other African governments have signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the Optional Protocol. This obliges them to report every five years to the Office of the Human Rights Commission in Geneva. South Africa's Constitution also promotes and protects the rights of persons with disabilities and seeks to address violations through Chapter Nine institutions. Developing a three-year cycle to evaluate the impact of disability inclusion for institutional change would build capacity for reporting on the UNCRPD nationally and internationally.

The aim of research reported in series four of the *Disability Catalyst Africa* was to determine the extent and nature of disability inclusion in teaching and research in curricula at the University of Cape Town. Chapter One provides a detailed methodology and the two-pronged approach of identifying teaching and research that focused on impairments as well as environmental factors influencing participation and inclusion.

The chapters in this series of the *Disability Catalyst Africa* present case studies across six faculties to elicit the experiences of disability inclusion in teaching and research at UCT. The capacity to empower disabled people's organisations to monitoring disability inclusion and social change opens up relevant opportunities for collaboration with other higher education institutions, communities as well as the business sector.
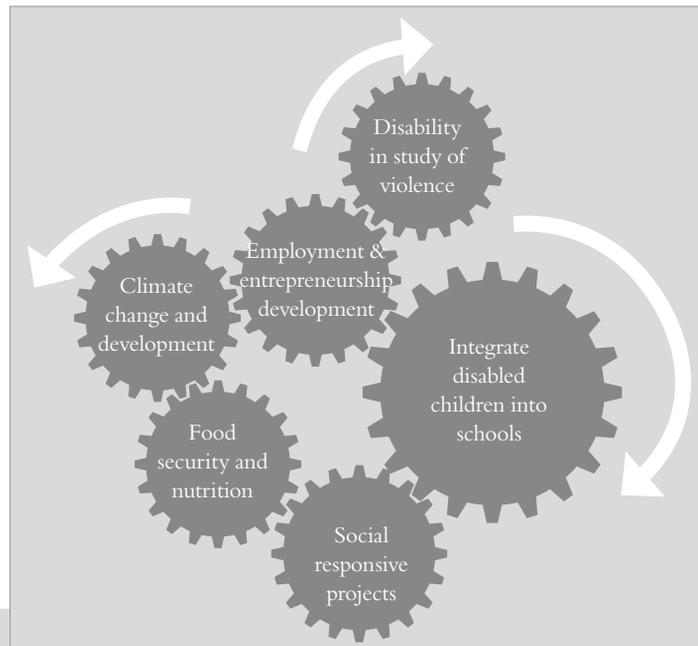
Higher Education Disability Services Association (HEDSA) and the transformation offices at institutions of higher education could play a critically relevant facilitatory role.

Many of the VC's Strategic Initiatives have the potential to integrate disability inclusion into the projects so that academic staff and students become competent in disaggregating disability as an issue of social justice and identity politics.

Disability should be seen as an issue of social justice and identity politics and not just a medical or health issue, particularly for those with intellectual and psycho-social impairment as they experience greater marginalisation and stigma. Researching disability provides multiple opportunities for interdisciplinary collaborations. The challenge remains for DIRECT (Disability-Inclusive Research Enabling Curriculum Transformation) to explore ways in which disability contributes to South Africa's and Africa's development challenges and global citizenship.

Associate Professor Theresa Lorenzo

Series Editor

Topics

Mental Health
Intellectual impairment
Inclusive education
Space and environment
Accessibility and reasonable
accommodation
Models of disability
CBR and advocacy
Disability prevention
Disability assessment for occupational health

Focus

Individual impairments
Primary health care
Socio-cultural aspects of disability
Socio-economic issues
Intersectionality
Family context
Development practice
Environmental effects
Legislation
Community issues
Programme
management

**Teaching
strategies**

Lectures
Participatory methods e.g.
discussion groups, video discussions
Seminars
Tutorials
Journal articles
Media articles
Masters by full dissertation
Case study approach
Life history approach

**Learning
strategies**

Experiential learning
Practical experiences
Clinical practice
South African Sign Language
courses e.g. strategy for making
health care services accessible for
Deaf persons and their families

Introduction

Chioma Ohajunwa and Judith Mckenzie

The *World Report on Disability*, which provides the most comprehensive global picture of disability to date, paints a picture of social exclusion and poverty of disabled people and their families (World Health Organisation, 2011). The problem is simply stated:

> "Persons with disabilities experience worse educational and labour market outcomes and are more likely to be poor than persons without disabilities" (p.39).

In terms of numbers, the UN estimates that there are over 650 million persons with disabilities worldwide, 80% of whom live in developing countries. Less than 10% of disabled African children attend school and less than 5% of disabled people on the continent have access to necessary rehabilitation services (Kett, Lang & Trani, 2009). People with disabilities are more likely to experience physical and sexual violence than the general population, with disabled women experiencing gender–based violence and sexual abuse at extraordinarily high levels (Baladerian, 2004, Elman, 2005, Mall & Swartz, 2012).

Disabled children are equally vulnerable to violence and abuse for many reasons, which include lack of knowledge, understanding of disability and negative beliefs and cultural practices to name a few (UNICEF, 2013). Furthermore, it is not only the disabled person that is affected by disability but their families as well. An international advocacy organisation, Inclusion International, makes clear the enormous impact on the family of providing ongoing care to family members with intellectual disability (Inclusion International, 2006). The aging population also contributes to increasing disability rates in developed contexts and requires consideration of their needs. Thus the issue of disability is not a relatively obscure and minor medical issue but it affects individuals in multiple ways: by having a disability; by having a family member with a disability; by facing the pros-pect of disability in aging; and in a concern with social justice and equity. The current *Disability Catalyst Africa* addresses disability inclusion in the curriculum by presenting a brief overview of research on the topic at the University of Cape Town and examining experiences of inclusion by UCT academics.

WHY IS DISABILITY EXCLUDED?

Disability has been primarily classified as a medical issue relating to bodily impairment rather than to the socio–political and environmental causative and maintaining factors of disability and given over to the 'expert' hands of health professionals. These professionals have operated within a medical model that looks on the social exclusion associated with disability as directly caused by the impairment of the individual. Whatever barriers that the disabled person experiences are attributed to that impairment (Hammell, 2006). The concept of autonomy in decision making is one such example. Disabled people are often not involved, consulted or given voice, even regarding issues that concern them. Often parents, siblings, caregivers and doctors become the 'experts' and the disabled person is on the receiving end of the outcome of their decisions. Thus the way to deal with disability, in the medical frame, is to treat the impairment as far as possible, since the amelioration of the health condition is seen as the pathway to social and economic inclusion. When the limits of treatment (and therefore of participation) have been reached then a welfare model of care and protection becomes the practice.

Disabled people have argued for the realisation that their disablement arises to a greater extent from the way that social systems stigmatise and exclude them than from the physical impairment (Brisenden, 1986). This oppression has created a network of exclusive systems in the areas of health, education, employment and social participation to mention a few (Karr, 2011). A social model of disability has been developed as the lens through which disability can be viewed.

The social model of disability is based on the premise that inaccessible physical structures and systems, and lack of reasonable accommodation exclude disabled people from equal participation in society, not their impairment. This social model has repositioned disability within a socio–political framework (Dewsbury, Clarke, Randall, Rouncefield & Sommerville, 2004) and has influenced a number of policies that have focused not just on impairments, but more on the role of society in creating disability for the individual with impairment.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, UN 2006) is one such policy and came into existence to address these issues of marginalisation, exclusion and oppression and to enhance equal participation as a right of disabled people. The UNCRPD asserts that disability is "an evolving concept, and arises from the interaction between persons with impairments and attitudinal and environmental barriers that inhibit their full and effective participation in society on an

equal basis with others" (UN, 2006). In relation to higher education the Convention has this to say:

> "States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities" (United Nations, 2006; Article 24:5).

However, it would be misleading in the light of the pervasive effects of disability within society to consider this educational inclusion as the sole contribution of higher education. There is a further contribution to be made in terms of seeing disability as an issue of social justice as outlined in the Convention. This requires a much bigger systemic change that relates to the way diversity is viewed in society. Experiences with race and gender have highlighted the ways in which diversity is exploited as a means of exclusion and the grounds for assertion of dominance of one group over another. The recognition that the difference that disability brings as an element of diversity that is used to certain effects in power relations has been masked by a medical understanding of the issues and it is this unmasking that needs to occur within the curriculum, much as has been done for race, gender and class.

DISABILITY AND HIGHER EDUCATION INSTITUTIONS

The World Health Organisation (WHO) has mandated higher education institutions (HEIs) to develop programmes that address developmental challenges that impact on the disadvantaged members of society, rather than focusing on medical intervention mainly. WHO states that HEIs are uniquely positioned to influence change. University initiatives that affect economics, employment, education and social issues (Blumenthal & Boelen, 2001) will have a great impact on the alleviation of societal challenges and aid transformation. These initiatives will impact on issues of access for disabled people at all levels of societal endeavour.

The accessibility of higher education for disabled people has been made possible through the collaborative work of international disability movements and the academy. Disability Studies as an academic field began in the 1970s in the United Kingdom and United States. Currently, there are disability studies programmes in countries in Asia, Europe and Africa

(Mason, 2010). In the United States alone, there are over 60 disability studies programmes in various HEIs. One evident similarity among these programmes is the involvement in social and political activism to influence change in the way society perceives disabled people (Mason, 2010). The shift in understanding of disability as a social justice and human rights issue across the curriculum continues as many higher education institutions struggle to make their institutional space more inclusive of disabled people. While there might be no 'magic' formula to eradicate discrimination against disabled people, inclusion of disability in the curriculum is one way of reaching for an equitable inclusion for disabled people by creating awareness and addressing societal ignorance regarding disability through the curriculum.

Disability can be included in the curriculum in a variety of ways because of its evolving and multi-faceted nature. It has been argued that disabled people form a culture unique in their own right (Couser, 2011; Garland-Thompson & Stoddard-Holmes, 2005), so disability can be introduced into the curriculum from the discussions on culture. Disability is equally an issue of diversity (Olkin, 2002) and can be included in the curriculum in the same way as race, gender and sexuality. Disability is also perceived as a construct of society (Anderson, 2009). This view emphasises the fact that disability in the curriculum could also help us interrogate what influences our thinking, our making meaning of our world and how we perceive it. Our personal biases influence how we interact with disabled people and disability in the curriculum helps us examine these biases and influences (Strauss & Sales, 2010; Guzman & Balcazar, 2010). Disability is also seen as an issue of human rights, equity and social justice (UN, 2006) and so is included as part of discussions on human rights and policies on human rights. Disability, in effect, is interdisciplinary (Campbell, 2009; Lubet, 2009), and disability studies that will appeal to all disciplines is advocated.

Regarding disability debates, and especially inclusion of disability in the curriculum generally, Ware (2008) insists that educators be encouraged to probe further into the ways they have come to understand disability in their own lives without any self-recrimination. This can aid the acceptance of the complexity in understanding the disability experience as varied and layered. This understanding can equally be "awakened and invoked as a resource to integrate more disability-related content" into the curriculum (Ware, 2008: 577). The understanding one has about disability influences the manner in which it is included in the curriculum, and this is evident in the various disciplinary approaches used when teaching on disability.

In the light of this ongoing discussion on disability inclusion, the Disability Studies Programme within the Department of Health and Rehabilitation

Science undertook a project called Disability in Research Enhancing Curriculum Transformation (DIRECT) (Lorenzo, 2010), which is linked to the fifth and sixth Strategic Goals of the University Cape Town: *Enhancing the quality and profile of UCT's graduates* and *Expanding and enhancing UCT's contribution to South Africa's development challenges* (UCT Strategic Plan, 2009). This study was funded by the Vice-Chancellor's Strategic Fund. The methods and detailed findings of the study are reported elsewhere (Ohajunwa et al, 2013, Ohajunwa, 2012) but a summary of the findings is presented below.

RESEARCH FINDINGS OF THE DIRECT PROJECT

The DIRECT research was aimed at discovering whether disability is included in the curriculum and how it is included in the curriculum of all six faculties at UCT. An audit of the faculties of Health sciences, Humanities, Law, Engineering and the Built Environment, Commerce, Sciences and CHED was carried out. The expectation that there would be no disability inclusion was not met in the results of the study but inclusion remained patchy and incomplete (Ohajunwa, 2013). The picture across faculties is presented below.

Faculty of Health Sciences

Eight departments out of 11 in the Faculty of Health Sciences include disability either as an impairment issue and/or as a social construct. This means that while some departments focused the curriculum on how to 'treat' the impairment and help the disabled person 'fit' into society (medical framework), other departments explore how societal attitudes, issues of access, culture and beliefs, resources, environmental and politically oppressive structures create disability (social framework). The Departments of Health and Rehabilitation Sciences, Clinical Skills and Psychiatry explore the environmental influences of disability. The Disability Studies Academic Programme and the Division of Occupational Therapy also situate disability within the Community-Based Rehabilitation framework. The major area of disability inclusion in the curriculum is through practice learning.

Faculty of Humanities

The Faculty of Humanities had the widest perspective on disability, of all the faculties that participated in the study. Out of 18 departments, eight

responded that they include disability in the curriculum. Disability was understood to be an issue of diversity intersecting with gender by the African Gender Institute, and Social Development includes disability as an issue of development and teaches on mental illness and its impact on the family. Psychology focuses on intellectual disability and is beginning to look at the impact of a lack of access to resources on disabled people. The Department of Dance taught on disability by focusing on capacity and ability of the body, rather than disability and incapacity. Diversity Studies introduces disability as an issue of diversity, and the Department of Education teaches a module that simulates an inclusive classroom.

Faculty of Engineering and the Built Environment

Five out of six departments included disability in their curricula. The departments were Civil Engineering (Transport Division), Chemical Engineering, Architecture, Mechanical Engineering and the African Centre for Cities. Disability was introduced into the curriculum through discussions on the creation or adaptation of assistive devices for disabled people in mechanical engineering. Although disability was included from a legislative framework which emphasises universal design principles, Architecture also examines how space is constructed in the city as a disabling factor. Chemical Engineering had previously worked with disabled students only, but was interested in looking at the relevance of disability in the Chemical Engineering curriculum.

Faculty of Science

There was only one example of disability inclusion in the 12 departments of the Faculty of Science within the Computer Science department. This was linked to research being done in collaboration with the Deaf community on how computer technology could enhance communication for Deaf people.

Faculty of Commerce

Three departments out of six in the Faculty of Commerce include disability in their teaching. They are: Organisational Psychology, Information Sciences and Economics. Organisational Psychology taught on workplace injury that leads to an impairment and its implications regarding the Employment Equity Act. Information Sciences draws attention to stereotyping as a form of disability and invites disabled people to classroom discussions with students, while the Department of Economics introduces disability as it relates to the economics of HIV.

Faculty of Law

Two departments (Public Law and Commercial Law) out of three include disability in their curriculum. Public Law includes disability in discussions around intent and capacity to commit a sexual offence, and so there is a lot of focus on mainly intellectual disability.

What became apparent from the above study was that although disability inclusion is still in its early phases it is indeed happening across a wide range of disciplines. The researchers therefore put out a call to those academics who had begun on this pathway to share their experiences and build knowledge and capacity in this relatively new area by reflecting on their own work and the place of disability in this. These are the reflections contained in this volume.

Pathways to inclusion at UCT

The inclusion of disability in the curriculum is a complex process as shown by the outcomes of DIRECT project, and often disciplinary considerations and the understanding or framework guiding the lecturer influences the practice of inclusion. However, beyond being the 'transferer' of knowledge and 'shaper' of the curriculum, the participants' teaching practices can be related to some personal theories of teaching that influence their engagement with the concept of disability, and the strategies they choose. The influence of the developed theories of teaching is evident when examined in light of disability inclusion strategies employed by the participants (Fox, 1983).

Twelve academic staff who participated in the study were asked to contribute to this publication. At least one participant from each faculty who participated in the DIRECT project has chronicled their experiences of including disability in their curriculum. The participants also reflected on theories that could support or inform inclusion of disability within their discipline.

As editors we have found these contributions to be fascinating reading both for the commonalities between the different disciplines and the differences. All of these teachers have moved beyond an understanding of impairment alone as the cause for social exclusion. They note that lack of empathy, physical barriers and rigid power relationships are some of the barriers that operate within society and create disability. There is a move away from the notion of disability as a fixed category and growing recognition of the nature of disability as a porous concept varying across contexts, ages and

environmental supports. Instead of viewing "the disabled" as an homoge-
neous category, these teachers are beginning to highlight the diversity that
exists within the category of disability itself, notwithstanding needs and
rights that are common across different forms of impairment.

Perhaps the most surprising aspect of the understanding reflected by these
academics is that disability is seen as a resource within the teaching environ-
ment. In Gender Studies, disability is a form of diversity that helps students
to understand what they take for granted and assume as biological necessity
rather than as a product of social structure. In the teaching of clinical skills,
interaction with people with disabilities provides an opportunity for students
to learn from their patients rather than from doctors. For dance and archi-
tecture, disability challenges the students to be creative and to innovate.
In this sense, disability is drawn upon as a teaching tool that extends and
challenges students in ways that they might not have encountered before. In
so doing, they become not only more aware of disability but more effective
thinkers and practitioners overall.

The multiple strategies used by these teachers include using film and media,
engaging with and listening to the experiences and expertise of disabled
people and the use of stories and cases. All of these develop the empathy and
imagination of students with regard to disabled people. Two main teaching
strategies are experiential learning and the use of projects. Through engaging
with disabled people and experiencing some of the problems that they
face, students come up with viable solutions through project work. This
learning then extends beyond the disability context into a problem-solving,
open-minded approach that is informed by an empathic understanding of
another's positionality.

The contributions are outlined below.

Faculty of Humanities

There are two contributors from Humanities, one from the School of Dance
and the other from the Africa Gender Institute (AGI). Gerard Samuels from
dance explores the need to educate dance teachers for an inclusive education
system where they will be working with different physicalities. He gives a
background to his engagement with disability dance and outlines how he
has taught in this area at UCT. A consequence of inclusion of disability
within the Dance curriculum is a heightened awareness around accessibility
of the Dance School buildings and the message that this conveys of who
belongs and who does not within these walls. Adelene Africa from the
African Gender Institute outlines how disability forms an integral part of
her first-year course on understanding gender. Her article illustrates the use

of disability as a lens through which to understand diversity and highlights the intersections of gender and disability in the construction of identities, and the role of media in reinforcing dominant perspectives of normalcy, while disability becomes the abnormal.

Faculty of Law

Dee Smythe offers a vivid description of her often surprising interactions with students in her teaching on mental disability and sexual offences. She uses case law and discussions to address everyday stereotypes that are hardened into law and underpin attitudes of prosecuting officers and other government officials towards women with intellectual and psycho-social disabilities. She argues for an understanding of these disabilities that is differentiated according to individuals' capacity and the demands of the context in which they function. She further proposes that it is relevant for Law students to be made aware that intellectually-disabled women have agency and the capability for autonomy and choice, which is their right, and cautions against a situation where protection becomes negation of their sexuality.

Faculty of Commerce

Kevin Johnston from Information Systems posits the building of relation-ships with disabled people as a way to understand disability, and shows how this understanding has impacted on his teaching. He encourages his students to adopt the perspective of disabled people, "walking in their shoes", when considering how they use their ICT skills. His students are exposed to experiences and stories that show that disability is not a fixed entity but rather varies across time and context and cannot be as easily categorised as taken-for-granted ideas would have it.

Faculty of Engineering and the Built Environment

The focus of the article from the Centre of Transport Studies in the Civil Engineering Department is on the introduction of a universal disability audit for transport planning systems based on students' experiential learning on disability. Roger Behrens describes how the experience of navigating inaccessible routes in a wheelchair provides an unforgettable awareness of the role that environmental barriers play in creating disability. The exercise is effective in bringing students to an understanding of the exclusionary impact of inaccessible environments. Iain Low from architecture uses a similar disability experience to form a background for a student project on urban spaces. He highlights the absurdities of access, where the Disability

Services Unit is less accessible than the Robert Leslie Social Science Building. In concluding this section he asks that we look not only at what architecture can give to disability but also at what disability can give architecture. Disability integrated into design, as an element amongst others, becomes a "generator(s) of architectural space".

Faculty of Health Sciences

Rachel Weiss from Clinical Skills department writes on experiences of medical students during an assignment on community engagement with disabled people. She makes the claim from the start that her focus on disability is not so much about disability per se but rather about engaging students in an interaction where their notion of doctor identity is destabilised and they are impelled to "read the patient as text" rather than relying on doctor-centric learning. The writer shows how the students not only 'give' to the disabled person, but the disabled person equally 'gives' back by allowing the students experience their world. The patients become the 'text' that the students read to gain understanding of the context.

There are two articles from the Disability Studies Academic Programme. The first article is an introduction of the DCA focusing on disability and higher education curriculum, and this brief introduction of the chapters that follow. The second article discusses the link between disability inclusion in the curriculum and current research looking at access to higher education for disabled adults (Access to Higher Education for Adults with Intellectual Disability (AHEAiD). Emphasising the link between the AHEAiD project and the UCT's Strategic goals, the relevance of creating a pathway for intellectually disabled adults to access tertiary education is presented. Judith McKenzie discusses the outcomes of a pilot course that integrated intellectually disabled adults and mainstream students at UCT, outlining the benefits of an integrated, rather than a segregated educational setting. While this chapter deals with inclusion of disabled students, the argument is made that these students can bring about curriculum change by virtue of the diversity and varied life experiences that they bring to the learning environment.

Faculty of Science

The contributors are from Computer Science and discuss a current ongoing research with the Deaf Community in Cape Town exploring the concept of universal design for deaf cell phone users. The research is community based and was co- designed by UCT, and the relevant disadvantaged communities. The research carried out showcases the unique understanding of

'partnering' with the community and all the negotiations involved in this process.

Conclusion

The range of contributions presented here gives an indication of future directions. Firstly, it is abundantly clear that disability is trans- disciplinary, and does not relate in totality to any one discipline. As an issue of diversity, it should be included in the curriculum same as race and sexuality. Interesting opportunities present themselves, such as for example Transport Studies and Architecture students working together in finding a route across the campus in their wheelchairs. What would they come up with together? Issues of access are largely focused on the needs of wheelchair users and it seems that the particular topography of UCT will ensure that this remains a cause of concern for some time to come. While the process of inclusion can be a challenging and ongoing process for institutions (Tressou, Mitakidou & Karagianni, 2007) the University of Cape Town has demonstrated the possibility of disability inclusion in the curriculum by these examples of good practices. Disability inclusion has far-reaching impact on students as they graduate with attributes that prepare them to deal with a global issue like disability (Bryen & Shapiro, 1996).

The UCT Strategic Goals also aim to address South Africa's developmental challenges and produce graduates who have knowledge beyond their discipline and who can work in a globalised work environment (UCT Strategic Plan, 2009). The inclusion of disability in the curriculum will increase the knowledge of UCT graduates beyond their field of expertise and, since disability is a global issue that relates to social justice, the graduates will gain valuable insight into a global issue that impact on the workplace. The graduates will be equally empowered to contribute positively to South Africa's developmental challenges as disabled people are one of the most marginalised groups.

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Chapter One

Including students with intellectual disability in higher education: Implications for curriculum

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The Disability Studies programme at UCT initiated the Disability Inclusion in Research Enabling Curriculum Transformation (DIRECT) project in 2010 in response to a call by the Vice-Chancellor for projects that would enhance the university's capacity to address the stated strategic goals of the university (see Ohajunwa, this publication). The focus of this chapter is a description of the activities within DIRECT relating to people with intellectual disability – defined as impaired cognitive and adaptive functioning present from birth or soon after birth (American Association on Intellectual and Developmental Disabilities, 2008). These individuals comprise a substantial (estimates vary from 2% to 3%) proportion of the population in South Africa (McKenzie, McConkey, & Adnams, 2013). As a group the nature of their impairment necessitates ongoing support through the life span. Currently this support is framed within a care model with the departments of Health and Social Development providing minimal support and the family providing the bulk of it.

However, with the advent of a human rights perspective on disability as expressed within the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006), these individuals and their families are questioning the marginalised position that they occupy

within society and claiming their rights to full participation in community life. A critical element of participation is retention through the education system to ensure personal growth and skills development for employability.

With these thoughts in mind the DIRECT initiative entered into a project with service providers, the University of the Western Cape, family members and educators in accessing higher education for people with intellectual disabilities, known as the AHEAiD project. While this *Disability Catalyst Africa* makes the distinction between including disabled students and disability inclusion in the curriculum, this initiative is presented in this volume as an instance where both aims come together. The argument is made that inclusion of students with intellectual disability is a vehicle toward disability inclusion in the curriculum.

ACCESSING HIGHER EDUCATION FOR ADULTS WITH INTELLECTUAL DISABILITY

Currently in South Africa, young people with intellectual disability are accommodated in special and mainstream schools, normally finishing school between 18 and 20 years. However, they are slower learners and research indicates that their learning maturity peaks in their twenties (Brown, 2010). Adults with intellectual disability would therefore benefit from higher education in a transition period between school and work. However, there are virtually no programmes available in South Africa to support and develop young adults with intellectual disabilities as they make transitions towards independence, lifelong learning and employment. The issues that need to be taken into account when considering the role of the university in responding to this challenge are access, the degree of inclusion and determining appropriate outcomes.

ACCESS

The first issue of access in the South African situation relates to the historical exclusion of people on the grounds of race and class from university education. The need for historical redress is a politically charged issue and given its contested nature claiming access for those who are clearly not able to follow the accepted route from university through to professional employment is problematic on the face of it. However, considering the socio-economic reasons for greater access, there are good grounds for making a claim on

behalf of people with intellectual disability. They have been traditionally excluded and remain invisible in the tertiary sector, affecting not only their own personal growth but also the nature of the services that they can expect to receive in their lifelong need for ongoing support from professionals who are being trained at these very institutions. The message that regular students are currently getting is that people with intellectual disability require special and separate care by virtue of their biological incapacity. By the same token they are not deemed to have a claim to equal participation in community life

The second issue relates to why higher education for adults with intellectual disability should be placed within a university environment as opposed to the further education and training (FET) sector. Currently, access to FET is very difficult for learners with intellectual disability because they are not certified within the National Qualifications Framework for entry into FET on completion of their schooling. This affects a number of young people, not only those with intellectual disability, and excludes them from seeking qualifications for employment. Thus, while FET might ultimately be a feasible option, the capacity of the university as a research institution should be brought to bear on examining the access to and nature of such FET programmes.

DEGREE OF INCLUSION

The history of disability in general and intellectual disability in particular is one of social exclusion. Segregated settings for schooling, employment and living as adults have often been developed with the stated aim of providing for specific needs. However, there is an ever-growing movement toward facilitating normal developmental pathways and life experiences as a quality-of-life issue. Uditsky and Hughson (2012) warn against segregated programmes at universities from this perspective but note that often parents are so happy to see their children given access to the university that they do not demand the same levels of inclusion that they might have in school. In Alberta, Canada, programmes are inclusive in the following ways:

- Students with intellectual disability audit courses as fully participating students.

- They have full access to campus facilities, same courses, field trips, labs etc.

- They participate in all aspects of curriculum – group projects, assignments and exams, which are modified as required.

- They receive a certificate of completion and a personal portfolio of completed work and references.

(Uditsky & Hughson, 2012).

Courses offered in Canada, the United States and Australia begin from the premise that access to tertiary education is part of an inclusive process that enables people with intellectual disabilities to participate in all aspects of society (Grigal & Hart, 2012). It is a process that requires support and awareness amongst all of those involved and, as Brown (2010) states, the pathways that they follow through this sector appear to be as varied as that of more typical students. However, the pervasive low expectations about their capabilities tend to restrict and determine the type of courses and learning that they are assumed to need (Grigal & Hart, 2012).

A concern about inclusive learning programmes is that they might result in a physical presence in the classroom but an intellectual absence. Such a situation would not serve anyone well. In addressing this it is useful to consider the guidelines on responding to learner diversity developed by the Department of Basic Education in South Africa (DBE, 2011). These guidelines promote the inclusion of learners with a range of abilities in one curriculum by means of differentiating the curriculum. This involves adapting methods of presentation, student engagement and assessment in such a manner that different ability levels can engage in the same activity. This principle is widely accepted for students with other forms of disability where the medium of presentation is adapted to be accessible to learners with visual or hearing impairment. The DBE argues that the same principle can be applied to curriculum content where the level of abstractness and the volume of information can be differentiated to accommodate differing ability levels.

DESIRED OUTCOMES

Previously, the focus on postsecondary education for adults with intellectual disability has been vocational and geared toward doing a job. However, education is about much more than preparation for the marketplace. This remains true for people with intellectual disability. Brown (2010) provides a description of educational outcomes relevant at a postsecondary level that can enhance the quality of life of people with intellectual disability. These include basic social and adaptive skills, employment readiness, dealing with relationships and sexuality, working with information technology and making use of leisure and recreational activities as well as artistic expression. Thus education is about more than employment and encompasses social

skills as well as self-expression. Within inclusive learning programmes it is the differentiation of learning outcomes in terms of the level of achievement that would be key.

AHEAiD PROJECT

A principal of a special school dealing with learners with mild to moderate intellectual disability in the Western Cape recently noted that of the 100 school leavers from his school per year, fewer than 10 have found employment. Despite learners acquiring useful skills at school, such as bricklaying, office management and hairdressing amongst others, they lack the entrepreneurial ability to make use of their skills. Furthermore, they do not meet the entry requirements for FET as these skills are not certificated within the SA National Qualifications Framework (Faleni, personal communication, 2013). One response to this situation has been to develop supported employment options. Work4U is one such organisation that provides employment preparation, placement and support. The success of this model has led to reconsideration of what adults with intellectual disability are able to achieve. An occupational therapist from Work4U expressed the concern that parents and service providers may have low expectations that limit the potential success of these young people. Her work has revealed that expectations are exceeded at every step with adults showing maturation of competencies between the ages of 18 and 25 (Newby, personal communication, 2012). It was with the motivation of enhancing learning potential at a postsecondary level that a group of parents, academics and service providers came together to discuss the need for further education for these young adults forming the project, Access to Higher Education for Adults with Intellectual Disability (AHEAiD).

Access was then framed in terms of a human rights issue of inclusion and a research priority. Members of AHEAiD from the University of Cape Town and the University of the Western Cape agreed in principle to collaborate on the project. In addition, we made links with Trinity College in Dublin, Ireland, and with a network of universities in Australia that are exploring access to postsecondary education in their own context. We recognised that the full inclusion route could not happen in the short term, but that our efforts should be in this direction. We realised that an inclusive process is more difficult than a segregated one but we believe that it is worth the effort. The group also adopted a broad view of education as lifelong learning rather than just preparing for employment.

Process

The first step in the development of a programme of higher education was to draw on the international experience. The Certificate in Contemporary Living at Trinity College Dublin served as an initial model. This is a two-year course that aims "… to promote the full inclusion of individuals with intellectual disabilities and facilitate their lifelong learning, providing them with the strategic skills to become independent self-reliant adults and giving them the potential to contribute fully in society"(O'Brien et al., 2008, p21). This course consists of 10 modules, which aim primarily to promote personal growth, develop literacy and numeracy, encourage expressive skills such as art and dance and to provide work placements for future career development.

The initial idea of AHEAiD was to develop a course along the lines of that offered by Trinity College, Dublin. Like this course we envisaged a two-year fulltime programme with modules such as computer skills, literacy and communication, financial management, social and life skills, supported employment, independent living skills and elective subjects in the creative arts and humanities. The course would be open to all adults with intellectual disabilities, ranging from those with Down Syndrome to those with Foetal Alcohol Syndrome, who meet the entry requirements. However, the financial implications of such a programme as well as the shift in attitude that it would require amongst various stakeholders persuaded the project members to adopt a gradualist approach to higher education. Recognising that people with intellectual disability have historically been subject to low expectations, we have adopted an action research approach to setting up such a higher education programme, which is described below.

Campus visits

We tested the waters with a visit to UCT's Upper Campus. Since some young people in the AHEAiD group had been in inclusive schools they were able to meet old school friends and we noted the pleasure with which fellow students greeted their old classmates. Students with intellectual disability had been included at school but their peers were surprised that this could happen on campus. The regular UCT students were thus challenged to look at their stereotypical views of people with intellectual disability.

Pilot module on the certificate in disability practice

The next step was a pilot course integrated with the Rehabilitation Care Workers' (RCWs) training programme, the Higher Certificate in Disability

Practice. This programme is undertaken by a consortium of higher education institutions (HEI) in the Western Cape under contract to the Western Cape Department of Health. It addresses the need for upgrading the skills and employability of home-based carers currently employed by non-governmental organisations (NGOs) in the province in rehabilitation skills.

While the RCWs' training encompasses a range of skills, it was decided to include the adults with intellectual disability in just one of the courses titled Inclusive Development and Agency. The course has the aim of enabling participants to promote the rights of people with disabilities and implement strategies and actions to enable participation.

Specific learning outcomes for the RCWs include:

- Defining the concepts of disability, inclusion development, identity, agency and power.
- Discussing selected disability rights policies.
- Identifying barriers to participation across sectors.
- Identifying strategies to enable participation and access to services across sectors.
- Mobilising local resources and consult relevant expertise and stakeholders.

Students with intellectual disability were included in the second block of the course and fully integrated in the learning and teaching of the group of 35 RCWs. The facilitators were, for the most part, aware of their participation and took care to make use of teaching strategies for all students that were not dependent on literacy. These included the following:

- Drawing pictures.
- Using video material.
- Presenting information through role play and drama.
- Making use of pictures.
- Asking one student to read to another one.
- Verbal presentations.

The module outcomes for the students with intellectual disability were not differently specified as the purpose of this pilot was to observe their capabilities without being restricted by low expectations. At the end of the module they demonstrated the following capabilities that were not evident when they started:

- Preparing a task for homework using visual representation and literacy support from parents.

- Presenting a poster before a class of more than 35 people.

- Finding their way independently to the venue and back again, despite changes every day.

- One student learned to make use of public transport as she was so keen to get to class every day and her mother was unable to bring her.

- Understanding that disabled people have rights.

- Understanding that disabled people can make a contribution and care for others.

At the end of the module facilitators, students and parents of students with intellectual disability were asked to reflect on their experiences of inclusive learning.

The facilitators observed that all of the RCW students were very accommodating, interested, respectful, kind and inclusive all class members. Some of the students interacted with jokes and chatter whilst the others were less forthcoming. It seemed that the presence of the intellectually disabled adults had a positive effect on the way the RCWs learnt about disability through their interaction and sharing of experiences. However, the facilitators felt that they needed to be better prepared in terms of teaching and assessment strategies to accommodate the wide range of learning needs in the classroom. They also need to know what is expected of them in terms of engagement and outcomes of their programme.

The RCWs evaluation comments showed that they generally enjoyed being in the same class with the intellectually disabled students (who came to be known as self-advocates) as they had an opportunity to learn from each other. They stated that their understanding and knowledge about disabled people, their feelings and how they want to be treated improved. The RCWs felt that being in the same class with the self-advocates was a privilege and interesting in the sense that they were given an opportunity to learn, work and participate together through sharing different stories and experiences. It gave them a new perspective on how to promote inclusion of disabled people to the extent that they feel empowered to go back to their respective communities and educate people on how to handle and treat disabled people the same and equally to others. Lastly, it became clear to them that disabled people also have needs like any other human being.

Parents reported that they had noted a marked difference in their sons' or daughter's development during the course. One young woman started to use public transport for the first time. These students did homework

exercises with diligence and perseverance to an extent that surprised their parents.

The self-advocates stated that they really enjoyed the course especially the fact that they were part of the larger class. Their learning appeared to be more in the area of social participation but they also seemed to benefit from engagement with course content.

The pilot module appears to contribute to potential graduates gaining an awareness of social injustice that people with intellectual disability face. The self-advocates were able to share their personal experiences and to expose what they felt had been unfair treatment. As the RCWs related to these young people in a respectful manner and appreciated their worth they could better appreciate how social injustice affected them.

RECYCLING AND MENTORING

On the basis of the RCW pilot and with input from the young people with intellectual disability, the AHEAiD team has decided to run a course on recycling waste. Many people with intellectual disability are engaged in this type of work, contributing to better waste management. We were fortunate in making contact with the Transformation desk of the UCT students' representative council (SRC), which has taken up disability as a major issue for the current term. They in turn made the link between the AHEAiD project and the Ubunye student society, which is engaged in mentoring, career guidance and debating in disadvantaged schools in Cape Town. We partnered this group with Lathi Tha School of Skills in Khayelitsha and asked them, through their mentoring programme, to recruit young people for the upcoming module. The mentoring programme of Ubunye students' association will host a series of workshops at Lathi Tha with staff and students. They follow a 'set' mentoring programme and focus on soft skills that will help students plan activities following school. It is anticipated that the mentoring programme will both prepare and give ongoing support to learners who attend the recycling course. The SRC representative saw this development as important in the transformation agenda of the University of Cape Town and the Green Campus Initiative is interested in not only contributing to the module but also to working with the school around environmental issues. We are currently working on linking the recycling course to standard units recognised by the South African Qualification Authority with the aim of certificating students in recognition of their skills. We are also linking with large recycling companies to find out more about the skills that they require and employment prospects for these young

people. In 2014 we anticipate offering a course on sports coaching as well as linking up with the University of the Western Cape in a research-driven module on information and communications technology.

FUTURE DEVELOPMENT

In addition to providing opportunities and benefits to these young adults, we believe that the AHEAiD programme is in line with and supports the achievement of the strategic plan of UCT. This plan identifies the current situation of UCT and lays out interventions that need to be made by 2014 in order to meet the challenges facing higher education in the South African and global context (University of Cape Town, 2009). The interventions are expressed within strategic goals that are supported by specific strategies. Goals Two, Five and Six are particularly pertinent to the inclusion of students with intellectual disability.

Strategic Goal Two: *Transformation of UCT Towards Non-Racialism - Redress, Diversity, Inclusiveness and the Recognition of African Voices* will be achieved once "we no longer hold stereotypical views of others based on their gender, race or disability. Such stereotypes may be dissolved because we have consciously overcome them and because the generalisations no longer apply"(University of Cape Town, 2009). This outcome is supported when people with intellectual impairment are no longer subject to harmful stereotypes. These stereotypes range from barely acknowledging the humanity of such individuals through to viewing them as fundamentally and qualitatively different from those without this impairment (Carlson, 2010). This notion of difference constructs people with intellectual disability as not having lives worth living and requiring care rather than personal growth and development. However, these stereotypes are beginning to be rolled back through inclusive education in schools and universities (Grigal & Hart, 2012). As UCT graduates are exposed to the life experiences of people with intellectual disability they are developing what Nussbaum (2002, p. 299) terms the: "'narrative imagination', the ability to imagine what it would be like to be in the position of someone very different from oneself". This is an element of education that Nussbaum argues is critical for global citizenship.

Goal Five: *Enhancing the Quality and Profile of UCT's Graduates* speaks to the production of graduates who are not merely prepared for the marketplace but who also have the capacity "to compete in a globalised workplace; who will have a spirit of critical enquiry through research-led teaching; and who will have an understanding of the role they can play in addressing social justice issues." (University of Cape Town, 2009). The issue of disability has

largely been seen as a personal tragedy that requires medical intervention as far as possible and then care and support. However, disability activists have brought to light the social construction of disability as a stigmatised social identity that condemns its bearers to exclusion and injustice (Oliver, 1996). For UCT graduates to address social injustice related to disability, they need to recognise that a political and social response is required.

With Goal Six: *Expanding and Enhancing UCT's Contribution to South Africa's Development Challenges,* the University commits to "strengthen UCT's role in addressing key development challenges facing our society through engaged research, policy and advocacy, strategic partnerships and expanding opportunities for students to become involved in community-engaged education programmes"(University of Cape Town, 2009). It has been convincingly argued that disability constitutes a development challenge as disability and poverty are closely related in a range of causal and maintaining factors (Yeo & Moore, 2003). Approximately 10% of the world's population are persons with disabilities (over 650 million persons) of whom approximately 80% live in developing countries. Thus attempts to address developmental challenges are likely to be incomplete if they do not seriously tackle disability issues. International advocacy organisation Inclusion International describes the situation thus:

> There are 130 million people with intellectual disabilities and their families around the world and the vast majority live in poverty. Regardless of where they live...they tell a remarkably similar story. People are excluded from education, employment, health care and other services, and from belonging in their communities. Parents and siblings face barriers to employment, adequate income, community services and community acceptance. People find their rights are denied. They feel invisible in development and poverty reduction strategies (Inclusion International, 2006, p. 4).

More specifically, future benefits for the university include:

• Developing a more inclusive university for the benefit for all students and staff (e.g. sharing experiences with education and health sciences students who begin to understand better their role in teaching or working with learners with intellectual disabilities; working with information technology students on ways in which technology can improve information access for disabled people).

• Promoting innovative teaching and learning methodologies inclusive of entry criteria, assessment and supports for the students.

• Redressing the discrimination of the past.

CONCLUSION

The DIRECT project specifically addresses curriculum issues relating to disability rather than the inclusion of disabled students. However, we have argued that the inclusion of students with intellectual disability can have a profound impact on the type of graduates UCT produces. We have framed this contribution in terms of the strategic goals and made the claim that their inclusion is as much of benefit to UCT as it is to the individuals with intellectual disability and their families.

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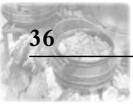
Chapter Two

Patients as text: Collaborative knowledge construction in the context of disability

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I have vivid memories of my first home visit as a doctor almost 20 years ago. It was to see a pretty young girl of 11, suffering from a rare neuromuscular disease that left her paralysed, incontinent and unable to communicate with anyone except her mother. After years of medical study, internship and working in government hospitals, I had just started my own private practice. I was seen as bright, articulate, professional and 'a good doctor'. However, I soon realised that my training had not prepared me for this case. The problem wasn't that she required specialised care – mostly check-ups and antibiotics for urinary tract infections, really. It was that, for the first time, I experienced the devastating impact of disability on a family: a marriage falling apart, siblings being neglected, a mother's anguish and descent into depression. My armour of professional optimism and empathy gradually crumbled under the disempowering realization that nothing I could do would truly make anyone in this family better. I started to question the legitimacy of being their doctor. Over the years, they had researched this disease, and knew much more about the condition and its impact than I did with my theoretical knowledge. Furthermore, my authority felt diminished because my patients required care rather than medicine. Doing home visits removed the comforting paraphernalia that traditionally signify

the emotional and physical divide between patient and doctor. They had become 'people with problems' rather than 'patients with disease'. I felt resentment, then guilt, anger and hopelessness. Gradually, I had to learn to let go of my preconceived ideas of what constitutes care, to be available and willing to just hold someone's hand. I learnt through experience that when the doctor listened to their complaints, it signified something more than when the neighbour next door did exactly the same thing. It took years to understand and accept that it was my identity as a doctor that was significant to this family, rather than any 'medical thing' that I did or said.

INTRODUCTION

This chapter explores the theoretical constructs of patient-centredness and describes a specific curriculum activity that aims at foregrounding the role of patients with disabilities as primary source of learning. By reflecting on my personal experience as a young clinician 20 years ago in the current context of my work in teaching and curriculum design, I hope to stimulate discussion of the reasons for and the challenges and potential gains in exploring new ways of learning. As part of a wider research focus on doctor–patient communication, I am interested in the ways in which patient-centredness (Illingworth 2010) are realised in the undergraduate medical curriculum, and in how particular types of patient-student interaction contribute to students' awareness of their role and identity as doctors. Even though the learning activity I describe takes place in a rehabilitation environment, my aim is not primarily to 'teach students about disability'. Rather, I draw on disability as an aspect of social diversity. I see disability as a lens or a way of looking at the world and how people position themselves in that world. In other words, by partnering my students with spinal injury patients in a rehabilitation context, I attempt to foreground a social framework of health care rather than the medical or 'technical' aspects of caring for patients with disabilities.

PATIENT-CENTREDNESS IN THE MEDICAL CURRICULUM

The concept of patient-centredness is well described in literature as a 'philosophy of care' that is realised primarily in doctor–patient interaction as 'discovering the patient's perspective' and 'sharing control over decision-making' (Illingworth 2010). This philosophy is commonly operationalised

in medical education through an emphasis on particular communication strategies such as the use of open-ended questions (Fletscher 1988) and an emphasis on the patient's social and environmental context. In South Africa, these concepts form the philosophical underpinning of a new biopsychosocial model of care that replaced the traditional biomedical, doctor-centred model of health care (MacDonald 2002). The term doctor-centred refers to attitudes that are more paternalistic and less attuned to psychosocial issues (Krupat et al 1999) and that are associated with a 'cure-oriented' rather than a 'care-orientated' approach to medicine (Valck et al 2001). Subsequent reforms towards patient-centredness in our medical curriculum include first and second year students being taught explicit 'interviewing techniques' that foreground cultural beliefs and socio-economic factors and engaging with topics on human rights, disability and the Primary Health Care philosophy.

PATIENT-CENTREDNESS IN THE CLINICAL SETTING

Despite these endeavours, aspects of the biomedical model nevertheless persist in the clinical training environment. A study amongst our third and fourth year medical students showed that students perceived a dichotomy between what was taught in class about patients' rights and what they experienced in ward rounds and bed-side tutorials (Draper et al 2012). While the task of inculcating patient-centred attitudes seems to be addressed in the curriculum's theoretical content, the greater challenge seems to lie with operationalising the theories in real patient contact. The clinical platform presents serious challenges in that the overwhelming burden of disease and understaffed facilities contribute to a culture of managing patients' 'primary presenting problems' rather than pursuing a holistic approach to the patient's state of health. In other words, in getting on with the business of service delivery in a challenging environment, clinicians may not always be aware what practices and attitudes towards patients they role-model. Bower and Mead (2007) add another dimension to patient-centredness: recognising the influence of the bond between doctor and patient and the influence of the doctor's personal qualities and subjectivity in the consultation.

Bower and Mead's model encourages students to become meta-aware of how their emerging professional identities manifest in their interaction with patients. This focus on the doctor's identity is shared by Tracy and Naughton, who define identity as "self in situation…constructed, maintained, and challenged by self's and interlocutor's communicative practices" (1994: 281). Therefore, claiming identity reflects lived experiences

and social memberships (Gergen 1991). However, researchers suggest that medical education and the authoritative 'voice of medicine' (Mishler 1984) construct a professional identity that actually impedes doctor–patient communication, clashing with the 'voice of the lifeworld' experienced by patients and eroding students' ability to develop effective social relationships with patients (Hafferty & Franks 1994, Weston & Brown 1995). For this reason, it is essential that patient–centred curriculum activities explicitly foreground the patient's 'voice' and 'lifeworld' in ways that are not just merely philosophical (for example, talking about disability in class) but practical and grounded in real social contexts (for example, working with patients with disabilities in their communities).

Bleakley and Bligh (2008) go further in pursuing a working model of patient-centredness, positing the notion of patient-centredness as a type of behaviour or praxis instead of an attitude or value set learnt from doctors as role-models and reinforced by medical educational input. In fact, they reason that in the philosophical model "patient-centredness is then, para-doxically, not learned from patients" (2008:92). This certainly seems to be the case with our students. Draper et al (2010) confirmed that third- and fourth-year medical students preferred learning activities that centred on the doctor as resource, and while they placed high value on patient contact, they saw the interaction more as an opportunity to practice their skills, rather than a primary source of learning. Bleakley and Bligh suggest that the way to counter the development of these doctor-centred behaviours is to engage students in explicit, mutually-beneficial 'collaborative knowledge production' (2008) with patients, where educators "explicitly register their intent to provide a resource supporting student learning, not shaping it" (2008:93).

Explicit foregrounding of the patient as primary source of knowledge may require different learning contexts than what is currently the norm. Patients themselves are encultured into more passive roles within hospital settings (Draper et al 2012); therefore, empowering patients as teachers may be more achievable when the learning activity is shifted outside of the usual consultation or ward setting with its traditional power structures. The design of the activity should limit students' recourse to the authoritative 'voice of medicine' and instead encourage listening to the patient's version of what is important or relevant. There is certainly a place for learning communication skills as 'pre-designed' questions aimed at gathering information; however, the real challenge lies not in learning how to ask but in how to listen, and how to accept that sometimes listening is all that is required. This is especially relevant when dealing with permanently disabled patients, such as in paraplegia, where prescribing treatment for a 'primary presenting problem' such as urinary tract infection does not 'heal' the patient nor necessarily address the patient's most urgent need.

INTRODUCING PATIENTS AS 'TEXT'

An opportunity arose for an activity that speaks to Bleakley and Bligh's behavioural model. Third-year medical students are sent to the Western Cape Rehabilitation Centre (WCRC) for a day accompanied by an experienced nurse educator, who pairs them with selected wheelchair-using patients. These patients are sent to the WCRC for rehabilitative therapy after being discharged from the hospitals where the acute phase of spinal cord injury was managed.

By usual academic standards, these students are relatively unprepared for the visit. At this stage of their education, they are adept at 'taking a history' and 'performing' a medical examination. However, they have little content knowledge of spinal anatomy, physiology, pathologies and the clinical examination of the neurological system, and their understanding of multidisciplinary team work is purely theoretical. Their learning instructions are deliberately simple: they are to follow the patient around on their daily activities, and to get to know the patient's story (as opposed to 'taking a history'). This means that students wait when the patient waits, assist nursing staff with physical moving around as necessary and spend a considerable time observing the patient as he or she goes about ordinary activities like having a cup of tea, or navigating from one venue to the next. Of course, students also see various aspects of the multidisciplinary team in action, depending on which rehabilitation activities their patient is attending on that specific day. Most importantly, though, they are asked to talk to their patient and get to know their patient as a 'person' – someone who, before life took a drastic turn, had certain dreams, plans, expectations, maybe a girlfriend or perhaps a job opportunity; someone who had now lost what we may take for granted; someone who, in a few weeks' time, has to re-enter a predominantly able-bodied society as a 'disabled person'. The activity is designed in such a way as to displace students from their role as clinicians; they are relatively disempowered not only by their lack of clinical knowledge but also by their inexperience with wheelchairs. They cannot hide for long behind formal interview techniques, or offer advice, or do something 'medical' to distract themselves from the situation. All they can do is to listen, and ask the patient to show them what to do. They have to confront the physicality of 'dead space' around a wheelchair and the awkwardness of different eye level heights and social embarrassments; dilemmas such as: "do I kneel down, or pull a chair closer? Is it okay to offer help with the tea cup, or is that considered patronising?"

This activity typifies what Bleakley and Bligh call a knowledge-generating dialogue between patients and students (2008), where the student 'reads'

the patient as primary text. Framing the patient as text implies that the student becomes a 'close reader' of not only what is said but also of the gaps, silences and contradictions. An important component of this encounter is students' lack of medical preparedness. No pre-reading is prescribed, and they have very little scientific and clinical background knowledge in this area. The patient's version of the story takes full stage; the student does not have predetermined questions or diagnostic bias to guide or to filter what the patients says. In other words, the patient determines 'what counts as knowledge' based on his or her view of health and social context. Students start to see that a bedsore is more than a wound; it is a threat to what little mobility the patient may still enjoy in being able to sit up in a wheelchair. Framing the patient as text also acknowledges that "the text is always greater than both its author and reader, offering a 'surplus' that remains beyond interpretation… This places the reader, such as the student, in a position of uncertainty that must be tolerated, involving a level of 'unknowing'". Students have to suspend the desire to 'master' the text and learn to tolerate "the ambiguity of not knowing" (Bleakley & Bligh 2008: 103).

In the first year that we ran with this activity, students came back from their visits expressing a desire to show their appreciation to patients for sharing what was, for most, an intensely emotional and humbling experience. As a result, a second activity evolved where students organise social events at the WCRC. It usually takes the form of a Fun Day that may include crafts, card games, music and entertainment; in the first year students organised a blow-dart competition involving community members and league players. Students do all the planning, fund-raising and work associated with the event on the day. The activity has had several consequences. Fundraising efforts often result in members of the public pledging their support in building a more inclusive society; for example, a school built a ramp at their own sports centre after realising that it prevented them from hosting wheelchair basketball games. For patients, it is a welcome distraction and for some, the first opportunity after their accident to socialise with their families. The high point is always when one of the students makes a speech at the end, explicitly acknowledging their patients as having been their 'teachers' for one day and for helping them to understand their role as one of service to the community – whether addressing a clinical or a more social need. It is very significant that at every event, without fail, patients then reciprocate enthusiastically and agree that they have much to offer students in learning how to be good doctors.

It is obvious that whereas the first activity required no preparation, arranging the social event requires many hours of work, and includes fundraising by talking to sponsors, careful planning of what types of food would be suitable, and how to set up activities so that patients are able to participate

fully. Again, this notion of patient-centredness is enacted behaviour rather than a philosophical principle or value set. The Fun Day is not intended or framed as a charity event; students and lecturing staff reiterate that this is about giving back for what they have received from their patients. The act of publicly acknowledging patients as teachers is paramount and anchors the Fun Day in the minds of students and patients as a reciprocal rather than charitable gesture. The patients speak with great pride about their contribution to 'educating young doctors' about the needs of patients with disabilities. This is in stark contrast to the passive submission Draper (2012) found with disabled in-hospital patients. Even when they were reluctant to be examined yet again by third-year medical students, these patients usually consented and downplayed their own rights because 'students have to learn'.

STUDENT AND PATIENT FEEDBACK

At the end of their rotation, students are asked to write notes on what they have learnt from patients, and to comment on whether the 'lived experience' amongst patients with disability may have influenced the way they imagine practicing medicine one day. The task is required but not assessed or read by staff, as it was intended as an opportunity for private reflection. In conversations with students it seems that, for the most part, students value the experience as unique and necessary for their personal development. After the blow-dart day, one student summed up his thoughts:

> I don't think we understand how important the little things are and we tend to glance over the 'minor' complaints and difficulties patients have, such as getting changed, or being embarrassed about their incontinence. It is important for doctors to take time to discuss the problems that are bothering that particular patient as every patient is unique.

Another student told me about her internal struggle and suppressed hostility because she really did not want to socialise with her patient. She saw the idea of the social event as an act of charity and thought that it was patronising. It was not until she heard her patient speak up at the social event that she understood what it meant to him to be acknowledged and to be 'served by young doctors' whom he (and others) described as being 'socially superior'. She understood that, while unintended, her distant attitude had probably contributed to his perception of their social roles. It was her lack of insight that made her feel patronising. The whole experience had for her been a profoundly humbling and enriching one. One patient wrote to me after that event and commented that:

"Everybody started smiling and laughing and for the first time they were able to socialise with the student doctors and just be themselves not a patient… it was so nice to see their 'masks' come off. I sincerely hope that every student would have the opportunity to be part of this type of event so that they can realise that we are sensitive social human beings who sometimes just need a little bit of love."

Of course, not all students are willing to experiment with this relational shift in power, and some either miss or dismiss the ideological objective and design of the WCRC activity. In their feedback, there are always a few that suggest that the WCRC visit would be more valuable if it coincided with their neurology teaching, rather than preceding it, so that they could "maximise the time by asking the right questions". Even though they believe themselves to be patient-centred, they don't realise that these comments and others like "organising social events is not part of medicine" are in fact characteristic of the biomedical practices of 'busy' doctors with heavy workloads related to 'real medicine' – the very model that that we are trying to change.

PROBLEMATISING THE WAY FORWARD

It is clear that the way in which patient-centredness is defined is central to a biopsychosocial curriculum model. Reading Bleakley and Bligh and Bower and Mead's models together provide theoretical underpinning of what I came to believe as a clinician: that patient-centredness is behaving in a way that serves the patient's need, while constantly reflecting on and adapting one's own understanding of what it means to be someone's doctor. Operationalising this view requires curriculum activities that prioritise 'collaborative knowledge production' centred on the patient's needs and contexts and that position the teacher more peripherally as facilitator and support. The WCRC may well be such an activity; however, academic rigour in curriculum design demands clear objectives as well as evidence that these objectives have been met, and this is where the challenge lies in designing for new ways of learning. Influencing behaviour and attitude, and developing patient-centred professional identities are long-term goals. These are also difficult to measure; for example, should the act of assessing students on whether they met the goals of 'patient-centredness' not then reside with patients within their specific contexts? There are also other challenges. Contrary to common perception, this type of activity needs more (rather than less) contact time with experienced clinicians as some students

may experience emotional trauma on exposure to the tragedy of permanent disability. How do we ensure that students are accessing mentoring that supports them in becoming mature and reflective practitioners?

CONCLUSION

This chapter describes a learning activity within the MBChB curriculum that, based on theories of patient–centredness, creates deliberate power shifts in the conventional doctor–patient relationship in order to explore patient–centredness as a function of patient-orientated behaviour rather than a value set. There are clearly gains and losses; however, the design and subsequent evolution of this activity highlights a tension between espoused ways of thinking about curriculum and the need to develop authentic patient-centred learning opportunities. The medical curriculum has no shortage of clinical and scientific content. However, in my own journey I have come to realise that it is not enough. By positioning the students to 'read' their patients as text without the conditioning filters of medical knowledge, we hope to create awareness that there are other types of knowledge that you can only learn directly from your patient.

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Chapter Three

Intersecting gender and disability: Lessons from Gender Studies

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Feminist disability studies seeks to theorise the intersections between feminist theory and disability studies such that it 'augment(s) the terms and confront(s) the limits of the ways we understand human diversity, the materiality of the body, multiculturalism, and the social formations that interpret bodily differences' (Garland-Thompson, 2002, p. 3). Consequently, the first-year undergraduate programme in Gender Studies at UCT focuses on disability as a 'category of analysis and a system of representation' (Garland-Thompson, 2002, p. 3) which can broaden students' analyses of gender and other systems of oppression.

The focus on diversity is at the heart of teaching within the discipline and many of the challenges faced by disability studies scholars are also faced by gender studies scholars. The need to integrate disability into the higher education curriculum is mirrored by the need to integrate issues of race, gender, class and sexual orientation – all of which speak to the range of experiences of people who are often constructed as 'Other'.

Understanding Gender is a first-year course open to any undergraduate student at UCT. While it forms the foundation course for a major in Gender Studies in the Faculty of Humanities, this course, which bears 18 credits, is also taken as an elective by students from a wide range of disciplinary backgrounds. Currently the course has an annual intake of approximately 300 students and introduces them to critical ways of analysing gender in African and other contexts. Lectures, tutorials and online forums provide students with the opportunity to engage critically with the subject material,

grapple with their personal standpoints and experiences and discuss the challenges presented by the course. Thus the course provides an academic framework within which they can understand and analyse their particular personal experiences. The course aims to challenge students at academic and personal levels. With regard to the academic requirements, students are assessed in terms of their conceptual knowledge and the degree to which they have assimilated an analytical stance towards the study of gender. They are required to submit tutorial response papers that are comprehensive analyses of particular prescribed readings. These tasks assess the extent to which they have understood and critically analysed the material. In addition, they are also required to submit two course essays, which assess their ability to integrate and analyse the material covered in the course. The final examination focuses on the assessment of conceptual knowledge and the ability to structure coherent, lucid arguments pertaining to particular essay topics.

This chapter reviews the didactic process within the first-year undergraduate programme by discussing the aims and objectives of the course, the theoretical framework underpinning our approach and the strategies and techniques which we use to engage debate around disability. I also consider some of the challenges which we face in foregrounding disability in our teaching within Gender Studies.

Understanding gender

The Understanding Gender programme aims to introduce students to Gender Studies by providing analyses of various aspects of social life from a feminist standpoint. It therefore aims to critically examine basic gender concepts, debates and concerns within Africa and abroad. It encourages students to examine the construction of identities within various contexts and to develop critical understandings of the intersections of gender, race, class, sexual orientation and disability. The course encourages students to question taken-for-granted assumptions about the world such that their worldviews are challenged and hopefully transformed. Drawing from a wide range of empirical and theoretical literature, the course encourages students to deconstruct concepts such as gender, sex and sexuality by examining how they have come to be entrenched in deterministic discourses of biology. Teaching an undergraduate course in Gender Studies is both challenging and exciting. On one hand, it presents us with the opportunity to introduce students to thinking critically about the world. On the other hand, it is challenges us to present the material in an accessible yet thought-provoking manner.

At the outset of the course, students are introduced to basic 'units' of analysis such as gender, sex, masculinity and femininity. Given that most people are socialised into accepting biological and other forms of predetermination, the subtext of my teaching is 'deconstructing reality/normality'. Thus gender and other social systems are critically explored by providing students with readings and case studies that challenge mainstream academic theory and empirical research. A variety of strategies are used to convey the feminist framework which underpins our analyses. These include analyses of biographical narratives, popular media, film and music videos. These strategies illustrate how particular discourses about gender become entrenched within society such that they are accepted as 'normal' and 'real'.

GENDER AND DISABILITY THROUGH THE LENS OF INTERSEX

One of the ways in which the course begins to critically analyse the relationship between sex and gender, is by examining how intersexuality disrupts the notion of two sexes. The purpose of this is two-fold: firstly, by exploring the possibility of 'other' sexes, students are encouraged to think beyond the male-female binary. Secondly, they are also encouraged to question the belief that intersex is a disability which needs to be cured. The course explores how ambiguous genitalia are seen to be indicative of a disabled body which cannot be classified into the discrete categories of male and female. Parallels are drawn with other disabilities so as to show how intersexed bodies are viewed as abnormal.

To foster critical thinking, the course focuses on the life narratives of intersexed people who successfully navigate both masculine and feminine 'worlds' – this encourages students to interrogate the inherent relationship between sex and gender and to question whether genitalia determine gender identity. We explore the impact of corrective surgery on people's lives and question why intersex is viewed as needing correction. By exploring the stories of intersexed people whose 'conditions' were medically corrected, students are prompted to question the political utility of such actions. The course requires them to examine their own ideas and prejudices and how these are shaped by dominant discourses of sex and gender. Underpinning this kind of analysis is the idea that 'normality' itself should be questioned. Students are encouraged to question who defines the parameters between normal and abnormal and for what gain. Thus the course challenges students on various levels as it provides strong academic evidence for our critical stance while encouraging them to question how commonly-held ideas function to maintain particular hierarchies within society.

Teaching strategy: Print media

Magazine articles and advertisements are used to illustrate how institutions such as the media perpetuate and reinforce dominant discourses of masculinity, femininity and heteronormativity. For example, I use a collection of South African magazine covers to explore dominant constructions of femininity so as to encourage students to examine how the female body is portrayed by popular media. Some magazines portray images of white, heterosexual, skinny, able-bodied women thereby conveying strong ideas as to a particular feminine ideal. Other magazines posit beauty ideals for black women that include a focus on a well-groomed appearance and success within the public and private spheres. These images posit normative ideals for white and black women thus strongly marginalising (or even negating) the disabled body. We explore a range of images of disabled women so as to explore how these bodies are relegated to the sidelines and are constructed as abnormal, ugly, asexual and undesirable. We also explore how the female body is imbued with racialised meanings thereby entrenching discourses about race and gender.

In further exploring the relationship between race and the gendered body, we draw links between femininity and the intersexed body. In particular we explore how race and intersex are dealt with in particular instances in South African society. For example, the course explores the experiences of Caster Semenya, who is intersexed but who self-identifies as a woman. I have found that a focus on topical issues, such as the global outcry caused by the gender verification testing of this world-class athlete, is useful in explicating challenging concepts to students. The image of someone gendered as a woman but who is intersexed challenges students to think about the relationship between gender and sex and the male-female binary. It also encourages them to focus on society's construction of intersex as a medical abnormality thus giving rise to discussion on what constitutes a disability. Given the predominant construction of intersexuality as a condition in need of surgical correction (Kessler, 1990), the course explores how the intersexed body destabilises traditional constructions of the inherent relationship between sex and gender. Thus we engage in discussions of various attempts (both medical and social) at correcting these biological anomalies such that unruly bodies conform to the male-female binary.

Students were shown magazine portrayals of Caster Semenya and encouraged to question the purpose of her 'transformation' from 'power girl' to 'glamour girl'. They were challenged to analyse how a magazine using Semeya on its cover had appropriated the athlete's body and made it conform to traditional conceptions of femininity. We explored how normality is

constructed (and entrenched) by refashioning the intersexed body. Thus some media pictures portray her as a 'hard' somewhat 'masculinised' athlete while the magazine cover portrayed her as 'soft' and feminine. Students were encouraged to think about how her difference (genital ambiguity) is hidden such that she presents as a 'normal' woman. In this way we explore traditional conceptions of normality, who constitutes the boundaries and for what purpose.

INTERSECTIONALITY

As can be seen from the above, the teaching of various constructs does not occur within isolation of each other. Students are shown how multiple locations interlink and intersect so as to position individuals in particular ways. For this purpose our work draws heavily on intersectionality (Collins, 2000; 2007) which is an "analysis claiming that systems of race, social class, gender, sexuality, ethnicity, nation, and age form mutually constructing features of social organisation" (Collins, 2000, p. 299) which shape people's experiences. While Collins primarily foregrounds the experiences of black women in the United States of America, her work is critical to any analysis of gender. In terms of an intersectional approach, disability is another location that shapes individuals' lives. In the Understanding Gender course, gender, race, class, sexual orientation and disability are seen to intersect such that it "creates different kinds of lived experiences and social realities" (Collins, 2007, p.8).

It is within this critical context that disability is taught. While feminist work has often been criticised for marginalising disability as a site of oppression, there is a growing body of knowledge in this arena. Drawing on Garland-Thompson's work (2002; 2005), the course examines how traditional discourses of disability as defective and pathological (amongst others) entrench the normal–abnormal binary which in turn creates particular lived experiences for women and men with disabilities. The course therefore explores the societal meanings attributed to disabled bodies rather than examining the specifics of impairment. We also seek to show how particular power hierarchies are maintained by reinforcing constructions of people with disabilities as collectively defective and in need of correction. Thus disability is viewed as a category of analysis which enables us to explore and understand particular locations and experiences within society. Given that an intersectional approach is pertinent to the analysis of gender, disability is then also viewed as another axis of analysis along with race, class and sexual orientation. We are therefore concerned with exploring how these particular locations impact, shape and influence individuals'

life experiences. Implicit in this approach is the critique that universalist assumptions about gender, disability and other social systems are essentially flawed and that these need to be challenged. Consequently, the course also has a strong focus on how identities are constructed. The meaning that people imbue in their own identities and the ways in which these identities are constructed then become the foci of analysis. The course explores how prevailing discourses shape this process and examines the multiplicity of ways in which people take up or oppose these stereotypically gendered discourses.

TEACHING STRATEGY: FILM

While the ability-disability (normal–abnormal) dichotomy is questioned from the outset of the course, we do pay particular attention to disability within the context of intersectionality. Since the primary focus of our work is on the social meanings of 'disabled bodies' and 'disabled identities' we challenge students to think critically about significance of these constructions. We introduce the construct of the disabled body by screening a story called *La Petite Vendeuse de Soleil* (The Little Girl Who Sold the Sun) by Djibril Diop Mambety. This Senegalese film revolves around Sili, a little girl between 10 and 13 years old who makes her way to the city to earn money for her impoverished family. She moves with crutches as her legs cannot support her since she has had polio. She tries to get close to the young boys who sell newspapers, but they taunt her and push her around. Undeterred she decides to take her destiny in her own hands by selling newspapers. In some instances people choose to buy their newspapers from her while in others she has to compete with the boys to get her papers sold. At times they cruelly frustrate her attempts at earning a living. However, she finds ways of dealing with them and also befriends a boy who seems to take a liking to her.

In exploring the themes of the story, we encourage students to think about how structural forces such as poverty, shape Sili's experience. We also explore how she is stigmatised and taunted by the newspaper boys because she is a girl with a disability. Thus we highlight how class, gender and disability intersect to locate Sili in particular ways. We can therefore gain insight into her particular experiences by paying attention to these subject positions as they are portrayed in the story. Given that disabled bodies are often constructed as asexual and genderless, the story also explores ideas around budding sexuality. Sili's friendship with a boy hints at a heterosexual attraction thus causing us to consider her as a sexual being. This construction is pertinent as it challenges students to question the limits and
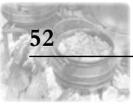
societal constraints placed on the disabled body as far as sexual intimacy is concerned.

This film provides the platform for further discussions of the experiences of women with disabilities. For example, we draw on the work of Meekosha (2004) and Grobbelaar-du-Plessis (2007) to analyse how some disabled women are marginalised and socio-economically disadvantaged within particular contexts. Thus we explore the social locations of these women and examine how disadvantage is perpetuated and reinforced by social systems that discriminate against them.

In essence we examine disability by utilising strategies that enable various levels of analysis. Print and film media present us with the opportunity to analyse popular constructions of gender and disability. These mechanisms have proven to be useful in fostering critical thinking within our discipline. Coupled with critical academic texts, these approaches forward alternative ways of analysing and understanding the world.

Student engagement

Having taught this course for the past three years I have found that students generally experience the work as challenging, thought-provoking and at times frustrating. The feedback with regard to the content broadly focuses on the ways in which it challenges their personal beliefs about the world. Discussions about oppression are never easy and I have found that students struggle with the ways in which the course material challenges their personal convictions, values and beliefs. While some students are resistant to discussions about difference and hold deeply conservative world-views, I have found that they are prepared to voice their opinions in class thereby stimulating lively debate.

The focus on critical thinking and deconstruction also encourages different ways of conceptualising the world. My aim is to equip students with skills and knowledge which extend beyond the academic curriculum such that they are aware of how stereotypes and the resultant behaviour entrench various oppressions. On the whole the course has received positive feedback as we aim to locate our theoretical work within 'real-life' situations. However, some students struggle with this as they feel that a focus on life experience or life narratives does not constitute academic knowledge. This I would argue is one of the major challenges of our work- to encourage students to think about epistemology in different ways such that the outcomes of the knowledge-production process are useful in bringing about social change.

Since the course uses intersectionality as a theoretical framework, the focus on disability is crucial. As I have stated above, the course material challenges students on various levels thus the inclusion of disability does not pose any additional challenge. The manner in which is taught (as a level of intersectional analysis) coheres with the way in which other systems of oppression are taught – thus its inclusion is imperative. In this way, the course also addresses the lacuna which often occurs within feminist analyses of oppression.

POSTGRADUATE RESEARCH

Opportunities for research within a feminist disability studies framework are provided at the postgraduate level. Since we approach gender disability from a critical feminist perspective we encourage students to frame their projects within this framework. We have found that where students have pursued their interests in this field, their decisions have been motivated by personal or familial experiences of disability. For example, an Honours project focused on the meanings that carers attach to their work with disabled children, while a Masters project explored visually-impaired women's experiences of intimacy. Our students predominantly work within a qualitative paradigm so as to explore meaning-making, identity construction and life experiences of women and men with disabilities in greater depth. The challenge we face is to encourage more students to engage in empirical work within the field.

My aim is to strengthen the disability lens within the first-year programme and to collaborate with my colleagues so as to find ways in which it can be integrated into the second- and third-year programmes. I think that as we develop our focus at undergraduate level, we will be able to attract more students to postgraduate research in the area.

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Chapter Four

From the coalface: Teaching disability through dance

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Where this journey began...

The word 'coalface' in the title of this article may suggest that the introduction of Disability through the discipline of Dance Studies at the University of Cape Town's (UCT) School of Dance was a struggle. On the contrary, I have found my journey relatively easy given my confidence at having taught similar modules for the University of KwaZulu-Natal and that, as new Head of the School of Dance, I was able to introduce new aspects to the UCT curriculum unopposed. This chapter intends to clarify some of the strategies and practices used to achieve a goal of inclusion of disability into an existing academic programme of dance. What can be learnt, extended about Dance and Performance theory through disabled people who dance? It will illuminate key impressions of the first generation of students (and staff) who were exposed via a series of lectures (undertaken by me), workshops and performances in dance by disabled people from 2009 to date. The article suggests how dance could be a pedagogic vehicle of disability given its unique multi-discursive placement and engagement with body. Many Dance and Performance scholars including Sally Banes, Susan Leigh Foster, Merce Cunningham, Simone Forti, and others closer to home: Juanita Finestone, Lliane Loots, Sylvia Glasser and Sharon Friedman, have argued for the power of the dancing body. This chapter extends such discourse through its reportage – from the coalface – of contextual shifts in UCT School of Dance, Cape Town.

SNAPSHOT OF AN HISTORICAL OVERVIEW OF THE SCHOOL OF DANCE

The study of Dance at a tertiary level has a proud episteme at the UCT School of Dance that can be traced to 1934. The School's founder, Dulcie Howes, and her successors including Emeritus Professor Elizabeth Triegaardt are recognised by many as driving forces in the Southern African region for the study of the art form – Dance, especially classical ballet. With the advent of contemporary dance as a new area of scholarly investigation, the 1980s saw a period of further review of teaching methods that were previously aligned with ballet.

The much-anticipated Education, White Paper 6 (Department of Education, 2001) on the need for inclusive education finally situated dance for all South African learners – disabled and able-bodied – as part of a human rights culture, one which was attempting to address key issues like quality education for all. But the challenges remained – who will teach such dance for all body types? Further, what aspects of dance should form part of a curriculum for disabled learners? These issues continue to plague policy makers, directors, school principals, parents and the many stakeholders who have a vested interest in the delivery and sustainability of high quality education for disabled (and able-bodied) learners.

Lliane Loots, lecturer in Movement Studies at the University of KwaZulu-Natal (UKZN), confirmed her passion for Dance in Education courses as early as 1995. By 2000, Loots's course had included disability arts. I was a guest lecturer and undertook some aspects of that work in conjunction with fellow young dance academic Linda Peyters, who had just returned to Durban from furthering her studies in New York. Loots continues to teach in Durban and at UKZN remarked that her teaching includes:

> "a full module on disability arts and dance in my Honours Dance in Education course here at UKZN. This involved four seminars and a practical module done with Flatfoot Dance Company and our programme called LeftFeetFIRST with the Open Air School. The module culminates in a long essay that is a combination of theory and praxis-led research" (2013).

Loots and my intertwining is made more complex as the youth dance group – LeftFeetFIRST – mentioned above was established by me in 2000 and is now entrusted to her Flatfoot Dance Company.

A significant part of my experience in working with young disabled people

and developing integrated strategies to bring disabled and non–disabled dancers together stems from these fluid encounters and a series of community–based dance projects of The Playhouse Company between 1995 and 2000. My position as Dance Co–ordinator at the time allowed me to develop and lead programmes of inclusivity and contemporaneity. A highlight was *Journeys in Dance*, which I co–choreographed and directed in 1998. This innovative project led Loots to comment:

> "...he is beginning to profoundly challenge audience assumptions of what constitutes a dancing body. Dance as an art form defines itself on the use of fit, able performers and has often excluded the possibility of challenging the elitism of a dance world which demands perfect bodies" (Loots, 1998).

I also have gained invaluable experience teaching disabled children in Denmark, which in itself is a useful comparative space for further writings of this relatively unchartered field.

DEVELOPMENTS AT UCT

As the school's newest director in 2008, I was able to begin a module – Introduction to Dance in Special Education in Dance Teaching Methods course (DTM) for third–year students in 2009. The course carries 36 credits at HEQF level 6 and has several modules all of which must be passed. These include Theories of Education; Planning and Time Management of the Curriculum; and Practical Teaching in Schools. This new module carries 5% of the year mark. In 2010 I had seven students – a mixed bag of some Dance Teachers' Diploma students and BMus (Dance) pedagogue stream students. In 2011, the number increased to 10 students, and in 2012 that doubled to 20 students. It is important to note that the upward trend is a reflection also of a generally increased number of dance students at the School of Dance. For some, these numbers might appear to be only a handful. Even if this is so, one would need to be mindful that the total registration for full–time dance students at the third–year level figures was between 8 and 22 for this period. Therefore, registration for this module is more than 90% of the third–year class. This is significant, especially if one could project what exposure would come from 90% of registered students of, for example, accounting courses at UCT completing such a module as the one in the dance department. Further, I am suggesting that the impact of disability issues could reach a wider audience within the university through the introduction of short courses/modules.

I have had the privilege of learning about applications in Creative Dance and principles of modern dance education from pioneers of the disability

arts and integrated arts fields such as Jasmine Pasch (Pasch, 1996) and Adam Benjamin (Benjamin, 2002), both from the UK. Benjamin was key to the Tshwarangano dance project supported by The British Council in 2000. The project was hosted in Johannesburg and brought together dancers from various provinces including Gladys Agulhas, Nicola Visser and Malcolm Black.

Malcolm Black and Gerard Samuel during the Tshwarangano workshop in 2000.   *Photograph: John Hogg*

To Jurg Koch, Edward Salt, Catherine Cole and other innovators who travelled to this country shortly after the heady start of democracy, much is due.

In 2009, I was urged by Friedman to develop appropriate lecture material for senior students who were likely to encounter disabled learners given the rapidly shifting contexts and discussion of integration and mainstreaming by the Western Cape Education Department (WCED). Part of this brief was to address the complex issue of not only whose dance do we teach but how to provision WCED schools adequately with suitably qualified teachers of dance?

An extract from the course outlines clarifies my central position for the task that lay ahead. I wrote:

> This short series of lectures will examine work in dance by, with and for disabled learners and is introductory in nature. It is offered in the context of the holistic learning and teaching environments where a range of ability of all learners is present.

The broad topic of (dis)ability will be discussed to suggest a theoretical construct and socio-cultural phenomenon. The position and label of 'useless', 'nonproductive' and thereby' un-imaginative' for persons with handicaps/disabilities /mixed abilities/ differently abled will be explored to investigate an artistic contribution with culture (Samuel G., 2012).

Students were provided with seminal text, and DVDs of choreographic work emanating from both South Africa and elsewhere were shown. In each year I have shown the work of Candoco – a London-based Dance Company founded by Celeste Dandeker and Adam Benjamin. For many students, the rationale behind the use of contemporary dance as the corner-stone of dance by disabled people has become clearer. The porous nature of the art form facilitates inclusion of a range of movement expressions and thus its adaptability and deconstruction of hegemonies comprise a fertile space for dancer and choreographers alike. My teaching tools and resource packs include photographs of performances that are interrogated to elicit context and content of the work, style of movement, choreographic and scenographic elements.

A scene from *Silent love* by LeftFeetFIRST Dance Theatre Company at the JOMBA festival in 2003.   *Photograph: Val Adamson*

Rudimentary exercises in Sign language were also explored, such as greet-ings, learning how to say 'Thank you', 'Stop', 'From the top' (in dance this usually means from the very beginning), 'Slow down'. The importance of
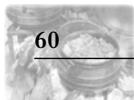
working with a sign language interpreter was discussed. One of the unique aspects of the class was a review of either a workshop or performance by the local integrated Remix Dance Company. Most students were able to participate in a creative choreographic workshop or view the company's most recent work, *Lovaffair*. One student noted:

> Studying these various different environments in which disabled people have contributed to dance has given me a greater understanding and appreciation for the potential of individual movement language.

Environments that inspire this coherent way of creating dance are not aimed at evoking sympathy, but rather inspiring and encouraging people to break down barriers between people of different physicalities. They also contribute to the development of personal confidence and the breaking down of one's personal limits, if disabled.

Another student wrote:

> When viewing physical integration works, one can really appreciate the artistic value and expression...What I also noticed is that the difficult part of physical integration is not the creative movement but is remaining an active partner in all the moves. At Remix one of the dancers was hearing-impaired. He had to feel the music through the vibration of the floor. Yet he was still able to move freely.

The effect of the module, however brief, and the limited period under review in this chapter suggests a very strong shift in the mindsets of UCT students of the abilities and artistic contributions of disabled persons. Yet another student noted that the module was "intellectually stimulating...comprehensive and relevant". Of significance too (even if from such a small sample) is the response to the question: Have you any desire to follow this course with relevant postgraduate study? Respondents indicated a firm YES.

WHAT MAY LIE AHEAD?

Whilst this grouping may appear overwhelmingly keen to have been exposed to issues of disability, the following physical barriers bear mention. The premises of the School of Dance has an imposing staircase as its entrance. In 2009 I began a petition to have various wheelchair ramps installed and corridors made more deliberately accessible for all users at the School of Dance. The students and I were also engaged for a lengthy period during

the filming of *Place of Grace*, a short made-for-film dance project, with well-known film-maker Shelley Barry. Also our Director of Photography, Barry's magnetic presence and unapologetic use of all dance studios for our work could be read as a further leveler.

These issues for me were strategic as I am of the firm view that issues of access should be both physical, infra-structural, as well as intellectual and philosophical. The vision for the School of Dance, which I have publicly expressed to be a hub for dance, cannot be realised if whole segments of our population are unable to even meet with the student dancers and myself! This may explain why my choreo-activist approach comes to the fore.

Not only do we need proper toilet facilities for disabled persons who may wish to rehearse in such venues, but their dignity, privacy and especially their creative spirits need room to equally soar. We need to examine what absences, blockages and stale irrelevances we as academics cling to. UCT in my view is in a unique and vulnerable position to lead. With our coal-blackened faces we need to share our findings and open the dialogue of what can be achieved by teaching disability through dance.

Photograph: Tania Scott, Remix Dance Company

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Chapter Five

South Africa: [Enabling space | Enabling people]

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Since the advent of settlement, space and its counterpoint, built form, represent two significant phenomena in the regulation of humankind and the organisation of societies that have a profound effect on an individual's ability to participate in the affairs of everyday and celebratory life. The configuration of space is reflective of the dialectic between the socius, or our lived experience, and the constructed, the material world. As such, space has become a necessary mediator in human interrelations and its configuration is reflective of power relations, and its evolution, that of societal change. In South Africa, where the manipulation of space has served as a primary tool of dispossession, discriminatory policies as applied to land and human settlement, continue to be primary obstacles to universal access in a quest for a more equitable society.

The triumph of democracy over apartheid in South Africa has been accompanied with vast expectation of radical change. This is particularly relevant in the case of previously marginalised communities to enable them to freely participate in all dimensions of human life. To a large extent this aspiration has been met by varying levels of 'service delivery' by a bureaucratic state. Discriminatory legislation has been repealed and new enabling laws have been enacted. The new government has 'delivered' houses, electricity, water and sanitation as well as social amenities across the breadth and depth of the country, in parallel with a host of empowerment legislation and related regulatory frameworks. Nevertheless, the spatial legacy of apartheid endures, most spectacularly through its practice of spatial segregation, a practice that constructed one of the most unequal societies of its era.

The predominant post-apartheid discourse around space resides in questions of human rights and social justice. This has focused in land and its redistribution as well as the provision of shelter or housing and basic services. However, when conceptualised as a consideration of spatial justice, space needs to be (re-)conceptualised in terms of access and equal opportunity. The restitutive aspects of change require a more nuanced and qualitative consideration; the impossibility of reversing the spatial effects of 300 years of accretive colonial rule requires us to think more imaginatively.

The University of Cape Town is a South African institution of higher learning whose current leadership takes enormous pride in its perceived status as the leading university in South Africa and indeed on the African continent. Located on the slopes of Table Mountain, the campus enjoys an unparalleled setting. Yet, it is this setting where the difficulty of access and building design find both failure and accomplishment. Within the dual dilemma of its remote location and steep topography, the prospect of establishing an inclusive 'urban' campus has proven to be a major impediment for designers of the built environment.

Architecture is possibly one of the most difficult disciplines to master. Not only does one need to gain insight into foundational and core knowledge, but one requires a level of knowledge, ranging from familiarity to that of expertise, across a multiplicity of related fields. The architect is subsequently required to interpret this knowledge, through design thinking, in an integrative and synthetic manner, in relation to a dynamic and constantly evolving terrain.[1] Due to the breadth and scope of the knowledge field required for architectural practice, it is not possible within the university curriculum to develop full expertise across all aspects of the discipline. Many Schools of Architecture, including the University of Cape Town, prioritise design above all else. A consequence of this is that, despite offering a MArch (Prof) degree, certain dimensions of professional knowledge become marginalised, and even ignored.

One of the areas often overlooked is in the domain of the regulatory environment. The recently introduced SANS 10400 standards promulgated by national government through the South African Bureau of Standards (SABS) are intended to regulate, inter alia, interventions in the built environment. Part S of these standards, is entitled "Facilities for persons with disabilities". These provide the basis for appropriate regulation in addressing both qualitative and quantitative dimensions of access, with scientific and 'deemed to satisfy' criteria for measuring compliance.

Notwithstanding the above, issues relating to the needs of persons with disabilities do become incorporated in the design studio investigation through a number of formal and less planned ways. At UCT several sites of

learning present themselves; the university campus as a built environment affording opportunity for testing disability access and subsequent reflective assessment; the university's Disability Unit (providing both expertise and human resources for accessing and interpretation of policy); functional need and an understanding of the lived experience of people with disabilities;[2] the Built Environment library with its reference and the database sections; and finally the synthetic design studio as the primary site for a student's active integration of learning and discovery.

During the course of their Completing the Freeways[3] design studio inquiry, the current cohort of BAS (Hons) architecture students were challenged with the task of 'representing absence'[4] on Cape Town's Foreshore. The analysis and site interrogation was directed at interpreting information for the design of an urban intervention that sought to provide opportunities for incorporating previously marginalised communities and individuals, as residents, into the City of Cape Town. Many student projects focused on the introduction of Gap Housing[5] into the Foreshore to establish a viable precinct where living, working, learning and recreating could be integrated; in other words a living inner city neighbourhood.

During the course of this investigation a particular exercise was negotiated with the UCT disability unit whereby time was set aside for the exposure of students to a cross-section of spatial and related experiential considerations deemed relevant informants to the design of the environment.

Scenario: [Un-]Learning from the campus

Located beyond the urban edge, against the eastern slopes of Devil's Peak in Cape Town, the UCT upper campus enjoys a privileged position by virtue of both its relation to nature and its overview of the city and environs. This privilege comes with severe spatial limitations. On the one hand it is difficult to negotiate the campus, given the steep incline across its section, combined with the autonomy of the siting of most of its buildings, and the general remoteness from the city fabric. Despite that Jammie complex, as the first campus intervention, established a series of urban platforms for integrating related groups of buildings, the subsequent additions have all adopted a modern approach to their siting, thereby establishing a fragmented experience for users. The buildings remain unintegrated within the campus fabric. This fragmentation results in a significant problem for physically disabled users. Not only are buildings themselves inaccessible, but traversing through and across and between them is almost impossible.

This was the experience and conclusion of the group of architecture students who were fortunate enough to experience a UCT disability workshop. Located at the interface between theory and practice, this workshop enabled students to acquire practical knowledge, but perhaps most significantly, to 'approximate disability'. In complementing exposure to the literature and experience of disability on our campus, an exercise of role-playing enabled students to directly experience the lived reality of a typical 'day in the life of'. The exercise of moving from the architecture design studio, located in the Centlivres building, at the south extreme of the University Avenue on the upper campus, to the disability unit, in the Steve Biko student union building, exposed design students to the levels of friction and difficulty confronting those with disabilities, particularly for those who are wheelchair users, in negotiating movement across the campus.

The contour of University Avenue provided for an unimpaired and swift passage across campus, apart from the presence of motor vehicles on the avenue which present an obstacle to all. However, upon entering the Otto Beit building,[6] a labyrinth of difficult spatial negotiations commenced. The primary problem rests in the location of the disability unit. Their address is in the middle of the Steve Biko student union building on University Avenue level plus 3. Consequently, it is necessary for those in wheelchairs to struggle with three separate elevators. This incurs calling and waiting for elevators; the negotiation of spaces designed according to minimal space standards, that is cramped space; utilising a different elevator for each level change (and having to traverse lateral space, at times outside, in order to locate the next elevator); and having to negotiate a student commons before entering the disability unit. This does not reflect on the other associated problems such as power outages and inclement weather, which are compounded for those living with disability.

Poorly integrated environment renders conflicts between vehicles, bicycles, pedestrians and the disabled.

The disability map provided by the university is apparently prepared by an able-bodied person, with possibly little, if any, consultation with disabled/wheel-chair-using students. Despite the fact that the map identifies buildings with elevators, the disability access map fails to communicate the complexity associated with level changes, with lift changes etc., which will be encountered at the interior of the buildings. The cumulative frustration experienced by able-bodied architecture students, temporarily confined to

Architecture students navigating their way around UCT's campus.

wheelchairs, lead some of them to attempt alternative routes. This brash-ness can be associated with both their inherent spatial imagination, as well as with their embodied knowledge of the campus and its layout and spaces, acquired as abled-bodied students capable of freely moving around the campus.

The consequence of the above scenario was that, despite the frustration for those following the map, and the ordeal of taking over 20 minutes for what should be a 5-7 minute journey, the first group, that is those following the direct route, arrived 30 minutes ahead of the 'rogue group', those who had elected to chart their own alternative route across campus. This delay impacted on the final group discussion session, held in the disability unit seminar room. Not only were the rogue group denied the in-house tour of the disability unit, but they also were only able to participate in the tail end of the wrap-up discussion.

In this sense, what constituted a different but shared experience for this group was the added sense of alienation experienced by disabled people, who are frequently further marginalised through an application of regulatory

University Avenue – tree as obstacle or landmark?

frameworks in a perfunctory and add-on manner. The fact is that discrimination engenders a subset of marginalisation thereby compounding the exclusion experienced by people with disabilities.

A further exercise was undertaken whereby the campus was evaluated for its degree of accessibility by means of an unstructured and collective experience of 'movement and mobility'. In addition to University Avenue, two other domains were identified for affording what are considered to be successful environments, that is where abled and disabled comfortably might co-exist; first, the route through the Sports Centre up from lower campus and the student residences, and second, the Robert Leslie social sciences building. These two buildings were designed and implemented in the mid-1970s at a time when the 'Uytenbogaardt school of thought' was prevalent.[7] What is enlightening is that, although disability regulations were not then enforced, as in the current global building environment, these buildings, most notably the Robert Leslie, provided built environments that are user friendly toward wheelchairs. We are all subjected to the force of gravity and as a species lived grounded existences. Recognition of the ground plane as a democratic leveler of human experiences has permitted the designer of this building to interweave a series of overlapping routes into a well configured terrain whereby disabled are inclusive to the whole. This marks a decidedly different attitude to the so-called 'problem' of disability through strategic design thinking.

This attitude represents a phenomenon recognised by two respected design theorists in the built environment; on the one hand Juhani Pallasmaa has made a plea for the decentring of the tyranny of the eye (Pallasmaa, 2005), and the associated singular 'perspectival thinking' that it fosters. Whilst his project is for an architecture that is more phenomenologically responsive (i.e. responding to the senses), this form of thinking can also be considered within the concerns of disability. For many disabled persons, particularly those blind or using wheelchairs, the issue of independence and individual freedom, in relation to personal movement and mobility, is a consideration that occupies much of their realities. In this respect, Alex Wall's[8] thesis on the 'programmable urban surface' (Wall, 1999), which refers to issues of infrastructure and mobility at the urban scale, holds relevance for inter-relating disability with (architectural) space. If we think of the surface of the earth as a text, then we could use the analogy of braille for 'preparing ground' for the legibility of universal access. In comprehending the needs of those with limited ability, we can anticipate trajectories of flows and delays, and thereby create a fieldwork wherein disabled and abled-bodied individuals find comfortable coexistence. More importantly, this might include for active social programming, as opposed to merely being a utilitarian response[9] as in the case of the Robert Leslie.

The challenge for inclusiveness is central to the post-apartheid project. The necessary redress of apartheid planning and the damage instigated by the Native Land Act of 1913, resides in the possibility of achieving a democratic society wherein restitution is accompanied with respect as due to all who dwell therein. The current interpretation of this challenge resides in 'land restitution', implying a predominantly technical and legal exercise, and is lacking in the spatial and social–economic attributes necessary for complete healing and societal transformation. Reimagining the ground plane as a surface prepared for interaction provides a constructive trope through which to re-imagine the techno–regulatory. It is predicated on a desire to give life to the forms[10] that govern our human relations, be they institutional or material.

In the subsequent address of disability through the studio environment, two factors emerged; firstly, a number of students individually and spontane-ously declared that the exercise constituted one of if, not the most, enjoy-able learning experiences of their architectural education and, secondly, that the experience had contributed a new strand of research in respect of active role-playing and post-occupancy evaluation. Thus, despite the frustration experienced during the task, the 'approximation of disability' exercise, whereby students traversed the campus from Centlivres building across to the disability unit, was iteratively referred to by students regarding the power and impact of the learning experience. The value of role-playing, in a hierarchically prejudiced society, cannot be underplayed, particularly in disciplines that are responsible for the design of the environment.

The students' application of their learning experience revealed itself in the Foreshore studio project where the 're-presencing of absence' Gap Housing project presented opportunity for exploring the ground plane at the scale of the city. Investigations to activate the urban surface produced a series of provocative speculations on the future of the city, in the form of a series of urban armatures that co–privileged the pedestrian and disabled together. Public interiors as place-links, public open space as theatre and commu-nity facilities as social programme, emerged as three strategies intended to produce a robust and recombinant urbanism,[11] situated within the prob-lematic of our local context. These design solutions were heavily premiated by the earlier exposure to the non–technocratic approach to design research that the disability role-playing workshop had facilitated. Engagement with the experiential exigencies disability directly assisted students in thinking from the social toward the spatial, as opposed to the common default of resorting to form-making.

So what is it that architecture can offer disability?

If the task of architecture is the (re-)configuration of worlds in order that humans can dwell in comfort, then our responsibility is to attend to and respond constructively to the needs of all its inhabitants. Located at the interface of scientific and artistic disciplinary bias, architectural practice requires extraordinary skill in mediating the complex differences that characterise contemporary cultural conditions. Consequently, the interpretation of user desires and their subsequent translation into built form requires enormous intellectual and imaginary capacity to realise our strategic speculation. This can be uniquely accomplished through the architect's mode of 'design thinking', reflecting a manner of reflective working that is best practiced in the studio environment. As such it is capable of connecting seemingly disparate concerns and achieving coherent spatial ordering.

When approached through this practice, disability would never be conceived of as an additional or separate concern. Rather, it would necessarily be located firmly within the realm of the architectural inquiry to the extent that its 'problematic' could easily become unknowingly construed as a design opportunity or prompt for architectural imagination. The case of the Robert Leslie social sciences building on the south end of University Avenue on the upper campus of UCT demonstrates this principle admirably. Having successfully contested the autonomy of the individual building, it reconnects with Solomon's initial practice that was established with the original Jameson Hall complex development at UCT (Low, 2013).

This strategy foresees the preparation of the ground plane as addressing human purposefulness. It is therefore equally important, if not more so, to the task of space making and enclosure associated with the more functional aspects of a building. As such it represents a countercurrent to the predominant 'creative problem solving' approach that is favoured by governments and bureaucratic institutions which have become increasingly driven by managerial considerations.

Simultaneously responding to disability needs, whilst attending to the ordinary requirements of everyday users, can bend those involved toward creative co-production. It is imperative for designers to have this approach validated and encouraged in foundational instruction. Herein lays an urgent task for academia; to locate disability studies as integral to the everyday, rather than in the realm of the regulatory and its 'minimum standards' approach. We should foster 'design thinking' as a means of developing

integration in the built environment; sustainability, disability, heritage, and the plethora of additional dimensions that have been 'added-to' the architectural curriculum, could become generators of architectural space. When conceived of as integral to design, disability requirements will cease to be prefigured as prosthetic to the architectural body, but rather, complementary to the poetics of thoughtful practice and the task of architecture.

ENDNOTES

1   Architecture is located at the interface between the arts and sciences. The resulting ambiguity enables its scholars to mediate the divide between extremes of our professional practice. Design action demands the application of legal, regulatory, spatial, economic, aesthetic, material, structural and constructional as well as socio-anthropologic knowledge fields in its thinking and subsequent representation. In 'drawing outlines' we necessarily discriminate. Consequently this application requires conceptual clarity and theoretical intentionality in order to effect representations that are imaginative and purposeful whilst appropriately responsive to a host of users.

2   The registration of a student living with disability presents a unique opportunity for cross learning and specialised research; currently Hiten Bawa is an MArch [prof] thesis student in the school whose dissertation is focused in a particular dimension of disability (hearing impairment) and its relation to the built environment.

3   This is the topic of a joint research agenda signed between Alderman Patricia de Lille, Executive Mayor of Cape Town and Professor Francis Peterson, Dean of the Faculty of Engineering and the Built Environment (EBE) at UCT at the end of 2012.

4   The full title of the studio was 'Ikapa Yethu Fo Sho – Re-Presencing Absence, Careful Urban Renewal and Restructuring on the Foreshore' and was offered as an elective studio under the PG programme's apg4042f design inquiry. Unpublished document: School of Architecture, Planning and Geomatics, UCT; Cape Town, 2013.

5   In terms of the current Breaking New Ground (BNG) policy of the Department of Human Settlements (DoHS), Gap Housing is directed at persons earning above R3 500pm yet below R15 000. Specifically these individuals do not qualify for a housing subsidy (less than R3 500), whilst they would not qualify for a housing mortgage either, hence the name Gap housing (http://www.dhs.gov.za/uploads/human_settlements_programmes_and_subsidies.pdf. http://www.dhs.gov.za/uploads/housing_project_process_guide.pdf).

6   The Otto Beit is a building in the original Jammie Complex, and occupies a strategic position in the lower RH corner on University Avenue. Today it acts as a significant entry into the student facilities complex, bridging University Avenue and the upper reaches of the campus.

7   The late Roelof Uytenbogaardt was an academic at the University of Cape Town and generally considered to be the leading architectural figure in South Africa at the time. His oeuvre of built and project work includes the UCT Sports Centre and Werdmuller Centre, two controversial projects that were 'unloved' by client and user

communities alike. Whilst not without their controversies, this disrespect resulted in their neglect and compromise from an early period. The Werdmuller Centre is slated for demolition and stands behind hoardings today, whilst the UCT Sports Centre is undergoing maintenance of its facades that disrespects the original idea of the building.

8   Alex Wall is one of the original members of Rem Koolhaas's Office of Metropolitan Architecture – OMA, where he is recognised predominantly for his urban imagination.

9   For a deeper discussion on the benefits of friction and delay in the design of space for human experience see Fardjadi & Mostafavi, 1996.

10   The Life of Forms was the topic of the 2013 Johannesburg Workshop on Theory and Criticism (JWTC) at the Wits Institute for Social and Economic research (WISER). See also Focillon, 1992.

11   Recombinant Urbanism represents an approach urban design in the context of the contemporary urban complexity associated with the global age; see Shane, 2005.

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Chapter Six

Disability inclusion in transport studies

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INTRODUCTION

The Transport Studies Programme was established in 2002 as a cross–disci-plinary home for postgraduate teaching within the field of urban passenger transport in the Faculty of Engineering and the Built Environment. Two taught master degrees are offered: a Master of Philosophy (MPhil) degree which attracts a range of students from a variety of undergraduate back-grounds, typically employed in the transport departments of different spheres of government; and a Master of Engineering (MEng) degree which attracts engineering graduates, typically employed in consulting practices, public transport operating companies and road agencies. Staff in the Depart-ment of Civil Engineering convene the programme's courses.

This chapter describes the experiences of one of the programme's courses – dealing with local area transport planning, management and design (END5036Z) – with respect to disability. Its aim is to reflect critically upon the modest inclusion of disability considerations in the course's content, and upon the impact this has had on students. The course is available to both MPhil and MEng students for the purposes of acquiring elective coursework credits.

The chapter first briefly discusses the degree to which disability consider-ations have been included in transport planning practices, both abroad and locally. It then describes how disability considerations have been included in the above–mentioned course on local area transport planning, largely in the form of a universal access audit assignment, and discusses, in qualitative terms, the feedback from students with respect to its impact. The chapter

concludes with some tentative reflections on the challenges and dilemmas associated with improving the inclusion of disability in the Transport Studies Programme.

INCLUSION OF DISABILITY IN TRANSPORT PLANNING PROCESSES

To provide some background on the extent to which disability considerations have been included in transport planning practices, this section presents a brief discussion on the development of the conventional transport planning process, and on the emerging recognition disability has received in contemporary South African transport planning, design and funding processes.

Disability critiques of the conventional transport planning process

The so-called 'conventional urban transport planning process' through which city-wide transportation systems are installed emerged in the 1950s in the United States, largely in response to accelerated private motor car use. The availability of unprecedented quantities of federal funding for road construction, and the advent of computers capable of manipulating relatively large quantities of data, were particularly influential in the development of the planning practices that emerged at the time (Pas 1995, Weiner 2008). It was believed that if certain relationships between land use, population and travel could be measured, these relationships could be used as a means to predict future travel. Computers enabled the use of mathematical equations describing these relationships to calculate large quantities of data, and enabled the examination of travel patterns across large geographical areas. The early computer models were developed in a milieu of positivism and 'rational comprehensiveness', in which it was believed the earlier 20th century successes in the natural sciences would extend to the social sciences, and into the planning of urban settlements more specifically.

The first applications of the 'conventional urban transport planning process' were undertaken in Detroit and Chicago in the 1950s (Weiner 2008). The 1953 Detroit Metropolitan Area Traffic Study (DMATS) assembled the elements of an urban transportation study for the first time. It developed a procedure for collecting data; forecasting travel demand; preparing road network proposals; and testing and evaluating these proposals (Creighton

1970). The 1955 Chicago Area Transportation Study (CATS) extended these practices by developing computation procedures to forecast trip patterns, known as the 'four-stage' model (Pas 1995). These practices diffused to elsewhere in the world, including to South Africa (Behrens & Wilkinson 2001).

The emphasis in the DMATS and CATS studies was on planning a road network that could cater for the large increases in private motor car travel in urban areas that were forecast in their models. Both the natural and financial resources necessary to achieve this were seen to be abundant. The resulting plans were therefore heavily oriented toward long-term, capital-intensive expansions of transport system capacities. The planners were concerned primarily with technical questions of how to link trip origins and destinations with an optimum road network: the alignment and capacity of arterials and freeways were therefore the foci of planning and improvement. It was assumed that the continued increase in the ownership and utilisation of private motor cars was both inevitable and sustainable. As a result, public and non–motorised transport modes received little attention.

The pioneering transport planning studies also tended to analyse trips, rather than the people who make them. The analytical methods developed provided little insight into the travel needs and behaviour of different kinds of individuals. This led to the emergence in the 1970s of a series of critiques that argued that certain groups were being overlooked and ignored, and that the transport systems that were being developed were inherently inequitable (Denmark 1998). The overlooked (and often overlapping) groups identified in the seminal critiques of the time included 'the young', 'the elderly', 'the poor' and 'the handicapped' (Falcocchio & Cantilli 1974, Taebel & Cornehls 1977). Falcocchio and Cantilli (1974:4) referred to these groups as the 'transportation disadvantaged', while Taebel and Cornehls (1977:98) referred to them as the 'outsiders'.

An important contribution of these seminal critiques was the creation of awareness in the transport planning discipline of the, hitherto unrecognised, extent of the urban passenger population that was either permanently or temporarily unable to access transport services. They demonstrated that disabled passengers ran into several millions, and they provided quantitative insight into the extent of latent travel demand amongst these groups, and the causes of their immobility. Thus early transport planning practices do not include disability considerations in any systematic way.

Emerging recognition of disability in contemporary South African transport planning processes

As a result the above critiques, attention has turned in recent decades to the development of more disability inclusive practices. In South Africa, more specifically, disability has been recognised in local street design, and in public transport systems planning. In the case of the former, the Department of Transport, for instance, included the design dimensions of persons with visual impairments and in wheelchairs, and provided guidance on how the gradient, clearance, turning and surfacing needs of road users with mobility impairments should be accommodated in road design, in its Engineering manual to plan and design Safe pedestrian and bicycle facilities published in 2003 (DoT 2003:A.5, B.7, C.3). In the case of the latter, the Department of Transport's conditions associated with municipal funding applications to the Public Transport Infrastructure and Systems Grant – a grant established by the National Treasury to fund the construction of 'integrated rapid public transport networks' in major cities – stipulate the following universal access requirements: all trunk stations must be universally accessible (including wheelchair access through at least some fare gates); all stations and stops must include the provision of tactile ground surface indicators both inside stations and along major pedestrian routes leading to stops; all newly procured vehicles must meet universal access standards (including the provision of wheelchair bays and designated seating inside vehicles; and an 'access auditor' must be appointed to ensure accessibility requirements are achieved (DoT 2011:17). With respect to rail systems, the South African Rail Commuter Corporation (now the Passenger Rail Agency of South Africa) drafted a national policy in 2003 to guide the implementation of universal access requirements in the planning and provision of rail services (Stanbury & Scott 2005).

INCLUSION OF DISABILITY IN THE TRANSPORT STUDIES PROGRAMME

It is against this backdrop of neglect in the conventional transport planning process, and emergence of requirements for disability inclusion in South African practices, that the Transport Studies Programme incorporated universal access auditing and design methods in its course on Local area transport planning, management and design (END5036Z). The course was offered for the first time in 2003. It contributes 20 (11%) of the required 180 credits for a master degree. Between 2003 and 2012, 142 students regis-tered for the course, with an average class size of 20 students. This section

describes how the course has dealt with disability, and discusses its impact on students.

Universal access audit assignment

The inclusion of disability in the course centres on a group assignment that runs over a week. A series of videos and lectures by experienced practitioners are presented to prepare the students for the assignment. To develop awareness of disability and its misconceptions and complexities, a video titled *Talk* (produced by the UK Disability Rights Commission) is screened, and the students are presented a lecture on the mobility problems experienced by persons with physical, sensory and intellectual disabilities. In the past this lecture has been presented by Jeremy Opperman of Jeremy Opperman and Associates. To develop skills in universal access auditing, a video titled *Access Audits* (produced by the Centre for Accessible Environments) is screened, and the students are presented a lecture on disability audit and infrastructure retrofit practices in South Africa. In the past this lecture has been presented by Guy Davies of Disability Solutions. Both of these lecturers are themselves disabled.

The students are then presented with the following hypothetical brief relating to the University of Cape Town's (UCT) campuses:

> It is the intention of the Physical Planning Unit of UCT's Properties and Services Department to make the University's six campuses universally accessible so that no person could be excluded from study, employment or visiting opportunities on the grounds of movement disability (inclusive of all physical, visual and aural disabilities). To achieve this goal a comprehensive universal access audit of the University's buildings, movement infrastructure, and staff and student transport system has been proposed.
>
> You are a consultancy appointed to design the universal access audit method and process. Your brief is to design a method and process through which the nature and extent of existing and potential disability needs can be established, and the adequacy of existing buildings, movement infrastructure, and the staff and student transport system can be assessed against specified criteria. The timeframe for the universal access audit process is 12 months. The audit will inform subsequent phases which will involve the preparation of a detailed and fully-costed retrofit plan, and the roll out of a ten year investment programme to implement the retrofit plan.

As part of this assignment you will be required to test the audit method you develop specifically for wheelchair users on selected routes of the Upper Campus. For the purposes of undertaking the wheelchair access audit each group member will be issued with a wheelchair.

In undertaking this project, the questions that you will need to give consideration to include the following:

- What does 'disability' mean, what forms does disability take, and what does it mean for infrastructure to be 'universally accessible'?

- How should the universal access audit be structured, what assessment criteria should be included for different forms of disability identified?

- How should audit data be collected (e.g. should only people with the particular disability in question collect the audit data, or can able-bodied persons perform this role as well, and if so, how)?

- How should the accessibility status of the campuses be monitored and maintained over time, particularly with respect to building and infrastructure renovation and construction?

With respect to the wheelchair access audit more specifically:

- What assessment criteria should be included in a wheelchair access audit?

- What physical barriers (e.g. widths, gradients, surfaces, obstacles, etc.) to wheelchair access are there along the selected study route, and what difficulties (e.g. route information, signage, rest areas, access to toilet facilities, etc.) do wheelchair users experience in navigating the selected study route?

Impact on students

From the students' perspective, qualitative feedback and course evaluations indicate that the assignment is a powerful learning experience. Because the fieldwork component of the assignment brief is focused on wheelchair accessibility, it is this part of the assignment that students have typically devoted greatest attention to. The development of access audit criteria for a broader range of disabilities has tended to be less developed.

With respect to the wheelchair access audit component of the brief, the typical approach adopted by students has been to develop a checklist that

itemises the potential access barriers that wheelchair users might encounter, and indicates standards against which measured gradient, clearance, turning radii and width dimensions can be compared. An example of such an audit checklist is presented in Figure 1. These checklists are then used in field-work to systematically record the nature of access barriers observed, and where they are located along the assigned study route. Figure 2 presents an example of an assigned audit route (and access barrier locations identified in fieldwork) on the UCT upper campus.

FIGURE 1: EXAMPLE OF A WHEELCHAIR ACCESS AUDIT INSTRUMENT		
	Criteria	Comments
1.	No obstacles	examples: parked vehicles street poles, hawkers and advertisement boards, service covers
2.	Steepness of gradient	ideal: 5% > 5% a resting place every 10m
3.	Adequate resting place	no clear guidelines
4.	Simple route	minimise crossing, changes in slope, and cross-falls
5.	Adequate signage and warnings	
6.	Level and smooth surface	minimise undulations and corrugation, and loose material. preferred option: all-weather material (e.g. asphalt, concrete)
7.	Clear separation from vehicular traffic	
8.	Minimise height of vertical disruption	no clear guidelines, approx. 10mm
9.	Vertical clearance	>=2.1m for pedestrians
10.	Horizontal clearance	>=1.5 m (sufficient for 2 chairs to pass each other)
11.	Accommodate wheelchair passenger eye level	facilities i.e. communication utilities
12.	Maintenance of route	check surfacing conditions, obstacle free including vegetation
13.	Street lighting	
14.	Street works	deliberate measures to alert people with special needs
15.	Kerb ramps perpendicular to kerb	
16.	Step-free paths between different levels	including ramps
17.	Minimise crossfall	< 2.5%
18.	Turning radius	minimum 1.5 m
19.	Landing	≥1.5 m wide
20.	Consistent patterns	includes amenities, textures and visual queues
21.	Flush connection between ramp and roadway	
22.	Avoid abrupt changes in gradient	algebraic difference ≤11%
23.	Street crossings	incorporate traffic calming measures at crossings should be safe, accessible and reliable
Source: Gqwabe et al (2005)		

FIGURE 2: EXAMPLE OF A WHEELCHAIR ACCESS AUDIT ROUTE, SHOWING BARRIER LOCATIONS

Source: Kolman et al (2007)

Undertaking the fieldwork in a wheelchair has proven important in ensuring that students are forced to experience the barriers they observe and measure (see Figure 3[a–b]). A further benefit is that they gain first-hand appreciation of the absolute nature of inaccessibility: they find that even the smallest barrier renders an entire route inaccessible. The students are encouraged to record systematically the access barriers they encounter in route sections, and to record them photographically (see Figure 3[c–h]) for examples of some of the barriers that have been recorded in this way).

The access audit assignment therefore develops skills in universal design and access auditing through a form of experiential learning, and from a pedagogical perspective the assignment appears to serve this purpose well. However, student feedback has revealed that the most powerful learning experience has been less to do with the development of auditing skills, and

more to do with the creation of a different level of awareness of the worlds they live in. In course evaluations, students often report that the assignment opened their minds to a way of perceiving the infrastructure around them in a way that they had never been able to do before. They report noticing gradients, steps, textures and colour contrasts that they would never previously have taken note of.

FIGURE 3: WHEELCHAIR ACCESS AUDIT FIELDWORK

(a) Ramp gradient measurement[5]

(b) Footway width measurement[2]

(c) Insufficient effective footway width[5]

(d) Public furniture obstacles[3]

(e) Intractable surfaces[4]

(f) Missing crossing facility kerb drops[6]

(g) Inaccessible bus entrances[1]

(h) Unreachable emergency services[2]

Sources: 1 Booi et al (2011); 2 Engelbrecht et al (2006); 3 Gqwabe et al (2005); 4 Grey et al (2011); 5 Jennings et al (2007); 6 Kolman et al (2007)

Linked to this development of awareness is a development of, what for many is, a different way of viewing the cause of disability. The students exit the course with an understanding (or at least exposure to the view) that disability is caused as much, if not more, by the nature of infrastructure design as it is by the physical condition of the user. In this regard, the paradigm of disability presented to students in the course is the 'social', as opposed to 'medical', model. The students are taught that the social model views disability as a consequence of environmental and attitudinal barriers that prevent people with mobility impairments from full participation in society. What follows logically from this model, and forms the base rationale for the access auditing assignment, is a view that the mitigation of disability lies in changing the environment and societal attitudes. The students are taught that, in contrast, the 'medical model' holds that disability results from an individual's physical or mental limitations, and that what follows logically is a view that the mitigation of disability lies primarily in the treatment of the individual.

CONCLUSION

To conclude, the experience of including disability in the Transport Studies Programme has resulted in an essential and powerful learning experience. A limitation of the universal access auditing assignment around which this inclusion has revolved, however, is its focus on wheelchair access. The learning experience and associated skills development would be improved by giving greater attention to other mobility impairments. More specifically, scope exists to extend the assignment by including sight and hearing

disabilities in the access audit fieldwork. To maintain the experiential learning nature of the assignment – which has proved so effective in the past – students auditing infrastructure from the perspective of the sight and hearing impaired would need to have these senses blocked by blindfolds and earmuffs.

A further potential improvement to the inclusion of disability in the programme would be an exploration of the more contentious, realpolitik issues associated with pursuing policies of universal access in the arena of public transport provision, in the context of the hard fiscal resource constraints prevalent in the Global South. Equipping students with the skills required to negotiate the depth versus breadth trade-offs between, on the one hand, making small parts of the system fully accessible, and, on the other, making the whole system partially accessible, is more fraught and contested than equipping them with the skills required to audit transport system infrastructure. This would require exposure to debates in moral philosophy and disability theory, and a departure from the disciplinary comfort zones of most of the students who enter the programme.

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Chapter Seven

Computer Science students learning co-design with a Deaf community

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INFORMATION AND COMMUNICATIONS TECHNOLOGY FOR DEVELOPMENT

Information and Communications Technology for Development (ICT4D) is a new sub-discipline within Computer Science that focuses on the impact that computing related technologies can have on issues of socio-economic underdevelopment. ICT4D departs from the rest of Computer Science in terms of the context of the users who are its domain of concern and also in the methods employed in artefact design. ICT4D typically targets users in under-resourced communities in developing countries.

ICT4D aims at digital inclusion, ensuring that all people have access to ICTs and the skills to use them; this is often called "bridging the digital divide". This notion of digital divide has been extensively problematised but is useful as an initial concept for students to work with. It signifies the gap between the current state of a society and the envisaged desired outcome of the digital revolution as an Information Society where knowledge resources are equitably distributed. The digital divide is the disparity in access and use of ICT between various groups of people, mirroring and exacerbating existing disparities such as:

- gaps in education (for example, illiteracy)

- location (rural–urban)

- gender

- race

- income level

- personal physical impairment

The South African digital divide arises from our history of division and historical backlogs for large groups of people. The digital divide also arises from global circumstances that apply to all developing countries. Apart from having poor access to digital infrastructure and equipment, another consequence is that people use applications and digital contents with an inappropriate cultural bias.

The need for specific ICT4D research and training is driven by the high failure rate of ICT projects in the developing world (Benjamin, 2002) (Heeks, 2002) . This has led to an approach that had to abandon traditional methods of design in computer science (found in software engineering and human–computer interaction). The engineering perspective is one of creating systems that are 'fit for purpose' but this implicitly depends on users who are able to state their needs clearly in terms that can be understood by technologists. It has become apparent that uncovering the specific purpose for which a new artefact is needed is problematic. Methods that deal with 'customers' are not adequate to encompass ICT4D. This is because such approaches assume customers are similarly educated and from the same culture and can express their needs in a language that Computer Science practitioners understand.

We now realise such notions of the aims of design have to be challenged. Designers have to work with users as co-designers and together identify the problem that needs to be addressed, the means of tackling the issues and then together decide on measures of success.

Having described the new field of ICT4D we shall sketch our involvement in a specific project briefly in the next section. This is with a Deaf community in Cape Town. On the basis of this relationship we were able to offer our fourth-year students a unique learning experience. We describe the course objectives and then describe the course and our experience in more detail. In our conclusion we highlight the fact that our course had a profound effect on our students' views on disability even though this was not the prime purpose of the course.

LONG-TERM ENGAGEMENT WITH THE DEAF COMMUNITY OF CAPE TOWN

Academic researchers from the Computer Science departments at both UCT and UWC have sustained an involvement over many years with a grassroots NGO, DCCT (Deaf Community of Cape Town) which is staffed almost entirely by Deaf people and serves the needs of the larger Deaf community in the Western Cape. It was founded by members of the community in response to a dearth of services and support from mainstream and official sources. Most Deaf adults are semi-literate, at best, due to disadvantageous educational practices at schools for deaf learners. Many are unemployed, but those who are employed are often underemployed in menial jobs. This adversely affects the socio-economic level of the community as a whole. The Deaf community is underdeveloped in terms of ICT access and participation. In general we believe that ICT can be an enabling technology that supports development and empowerment. Thus this group might benefit from ICT interventions.

It is a common experience of designers that one may design artefacts very carefully for a given purpose but when such artefacts are deployed they get put to uses that the designers never intended and could not have anticipated. This is referred to as appropriation. ICT lends itself to this since the technology is malleable and adaptable and can easily be shaped for different purposes. A well-known example of this is the Short Message Service (SMS) of mobile phones that was intended for telephony control purposes but was appropriated for private communications. This leads to the idea that one designs to enable appropriation by creating systems that can be adapted by their users. An extreme form of this would be to create tools with which users can create their own artefacts.

In the Deaf community our initial intent was to support remote communication between Deaf people and hearing people, Deaf to Deaf and Deaf to officialdom. While this has been achieved to a certain extent, of equal interest has been the way the original computer systems have been appropriated. This relates to the unexpected uptake in the use of the computers for general access to information and social networking, e.g., the prolific use of Facebook. Included in these spin-off uses was the demand by the community for the training Deaf people in ICT literacy. We facilitated by the introduction of the internationally accredited ICDL programme . In addition a Deaf person was trained to maintain the computers at DCCT. We gave access to hardware and software and network and in time the system has been adapted for advocacy and empowerment.

This has all been enabled by the ongoing presence of students and academic staff from UWC and UCT. One of the funding bodies, South Africa Netherlands Research Programme on Alternatives in Development (SANPAD), required collaboration with a Dutch researcher and thus we worked extensively with Dr Adinda Freudenthal from the Technical University of Delft. An outcome of this has been the publication of a case study in a leading Computer Science textbook (Blake, Tucker, Glaser, & Freudenthal, 2011). This case study of our ongoing work in the Deaf community illustrates our method of Community-Based Co-Design and shows how it grew out of a synthesis of participatory design and action research. 'Community-Based' conveys the fact that we deal with groups of people rather than individuals (in the developed world computers are geared to individual requirements — PC stands for Personal Computer). 'Co-design' derives from the application of the action research paradigm in a design setting: both the computer experts and the community members are designers on an equal footing and work co-operatively.

There is a well-known tradition in Computer Science of tackling hard problems as a way of driving research by looking at extreme cases. In ICT4D work we viewed the work with DCCT as precisely such a challenge that would lead us to new insights with wider application. We did not consider it very distinct from other developmental and empowerment challenges faced in our field, at most it differed by a matter of degree. There was no explicit notion of tackling disability. We did of course adapt the design process and deliverables to take into account impairments which impact on functioning. We shall see below that this disinterested view is not necessarily the case with the students who took our courses.

Following international convention DCCT describes themselves as Deaf with a capital D thereby denoting membership of a cultural, linguistic group which uses in this case South African Sign Language (SASL) as their preferred language. This is as opposed to deaf with a small d which refers to a medical condition, i.e., loss of hearing. In the latter case the emphasis is only on the impairment. This self-identification as a community moves the discussion beyond disability to one of digital exclusion in a disadvantaged community. When we discuss our experience below we will occasionally distinguish between general lessons which would apply in any related community-based course and specific examples that depend on the fact that we were dealing with a Deaf community.

EDUCATIONAL OUTCOMES

In our role as educators we train students in ICT4D, following on from the role of a university in moving research results into the curriculum. The essence of the course is to train the students in working with and learning from communities who are very different from their own and to teach a form of design thinking where design decisions are held in abeyance until the participant users are able to contribute equally.

Community-based

Computer science can be characterised as a discipline where students are trained in the uses of abstractions and to become fluent in working at different levels of abstraction as the need arises. The essence is one of moving from detailed concrete descriptions to higher level concepts that encompass many details behind the abstract description. Students have not been trained to the same extent in involving people in their work. A detailed example of adding people into network abstractions can be found in the notion of a Softbridge Stack (Tucker, 2009).

Upon this valuable technical training we now set out to sensitise students to major cultural differences and help them develop ways of entering into design conversations with people who do not have these skills but who are knowledgeable on their own needs. Students have to realise too that there is no 'one' community with whom we work. In every design situation there are many communities: elders, youth, women, migrants, people with disabilities, and so on. Each has to be given a voice in design. For that to happen students have to be trained to recognise groups of stakeholders, identify gatekeepers and consider how all the diverse needs might be investigated.

Co-design

Once stakeholders have been identified, a common language (or metaphor as it is sometimes called in computing; like the ubiquitous desktop metaphor of office computing) has to be developed. With sophisticated users this language can be based on crude mock-ups of a computer interface since such people can readily imagine how this might work in an ICT artefact. Where a common understanding of technology does not exist, co-designers have to be given insight into the possibilities offered by the technology by means of approximations implemented using technology.

A key feature of co-design training is for the students to learn to keep their own design decisions in abeyance. It is a serious mistake to commit (psychologically) to a design solution before the co-designers have found their voice.
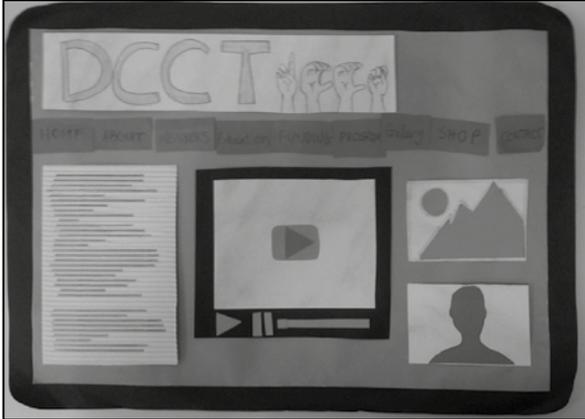
Figure 1. Mock-up of a display. Components can easily be altered. Some find it difficult to imagine the dynamic aspects of a system in a paper version and must be shown active prototypes running on a machine.

Fieldwork

Our solution was to design an Honours (fourth year) module that exposed students to field work. This is an unusual step in that Computer Science students have had little direct training in working outside the computer laboratory. We attempt to scaffold their understanding by appealing to their previous experience in software engineering and human-computer interaction . It is necessary to provide support since students are anxious about this unusual activity and we also have to ensure that students behave ethically with respect to the targeted community.

NEW COMPUTER SCIENCE HONOURS MODULE

The South African Bachelor's degree often has a fourth year course where students specialise in a particular subject (called Honours and based on the Scottish system). In Computer Science the year comprises 160 credits (of which 60 credits are for a major project) and this module, called

Community–Based Co–Design, counted 10 credits under this scheme. The advantage of the honours year is that most of the modules offered are elective and attract only interested students and academics can experiment with different offerings more closely tied to their research interests. Almost all modules, and this one is no exception, require students to create computing artefacts as part of the module. In this case the requirements were driven by the community involved and it was up to the students to design and build a (prototype) system that satisfied their needs. As it turned out in this case it was a content–driven website.

The course started with an exercise to identify which students were really interested in working in the module and then to split them into groups of four students. We only wanted fully committed students who would not abuse our good name in the Deaf community. After the introductory sessions students undertook action research design and implementation cycles involving the DCCT community.

Introductory lectures

The module included two mornings of introductory lectures and group exercises. The lectures introduced ICT4D and associated qualitative research methods (action research). The construct of Deafness was introduced along with ways of interacting that are appropriate to Deaf culture; including interacting with SASL interpreters, appropriate seating, the importance of lighting and so forth. The more practical material continued with a review of design principles and process and the elicitation of user requirements by means of expert interview, focus groups, ICT requirements interviews and paper prototyping.

Cycles of fieldwork

The introduction was immediately followed by practical work in the community.

This started with an expert (key informant) interview (jointly conducted by students and facilitator). Generally speaking the purpose of a key informant served to give the students detailed information to help them build an understanding of the community and to develop cultural sensitivity. Specifically in this case the interview served to problematise the relations of Deaf–Deaf and Deaf–hearing. The central role of a signed language in Deaf culture was emphasised.

Subsequently the students engaged in reflection and preparation for the focus group on the next day. Each group started working on materials for

the paper prototype (see Figure 1). They also drew a mind map of their current understanding of the key stakeholders and their relationships. This mind map served to highlight any gaps in their understanding that could be addressed in the meeting.

A focus group with staff members of DCCT was conducted by means of questions from the students. The general aim was to discover community needs and wishes and to identify types of ICT applications that might empower or support the community. They were exposed to the ethics of video recording interactions. Specifically they experienced the actual practice of working through an interpreter, seeing that two interpreters swapped over because of the demanding nature of the task and how the interpreters conveyed more than just content but also nuances and affect.

The focus group session was followed by a process of facilitated reflection where the facilitator and students reflected on the outcome of the discussion and attempted to identify possible ICT applications and prepare for the next cycle of enquiry. This was important because in these sessions the overall theme and aim of the class was decided and the themes and roles of the groups arranged.

The next day the students engaged in structured requirements elicitation by following up the reflection with further engagement with Deaf members of staff in small groups to investigate needs and design in more detail. Reflection and subsequent design of an executable prototype was followed by implementation as the action for this next cycle. One group had to set up the framework for the other groups to work within. Groups could send representatives to selected informants to gather further information or materials.

Presentation of the first version of the prototype to Deaf co-designers and the evaluation by Deaf users was done ten days after the focus group. The initial response from DCCT was positive and encouraging. They engaged constructively in a discussion on aspects they liked and features they wanted changed. Interestingly, there were many spelling errors, which immediately subverted any perceived power arising from the students' superior education while the fact that such errors could easily be corrected, demonstrated the flexibility of the design. It encouraged the DCCT staff to suggest other changes.

The student groups then prepared a one-page summary of their reflections on the reception of the prototype. This served as an explicit opportunity to engage in the reflective phase of action research and also to encourage students to commit their observations to writing. They tend to find this difficult but it was well done across the board.

The preparation of a final prototype, the first deliverable to the community, followed and this also included further work on back-end systems that were not immediately visible to the users. One meeting of the class was set up after a week to report back on progress with the actions. This was to monitor developments and assuage the uncertainties of the facilitators, given the novel nature of this course and process.

The formal presentation of the final prototype to DCCT staff was made about one month after the start of the module. During this session the groups demonstrated the changes and additions they had made based on previous feedback. It also provided a final opportunity for the students and the community members to reflect not only on the product but also on the process of this co-design. It was clear from this last meeting that the extended engagement was mutually beneficial and valued.

Deliverables from students for the course

A university course requires formal assessment. This is partly made up of group deliverables but also has to include individual elements. For this course the requirements were:

Group deliverables

1. Report on the design process (including highlighting roles and contributions of individual students), only this report was formally assessed;

2. First prototype;

3. One-page reflection after the first prototype; and

4. Final prototype.

Individual deliverable: Reflective essay by students.

This paper was the final (summative) assessment in the module. Students had been encouraged to keep notes and other source documents to provide material for this paper. Marks were based on insight into the impact of the module. Our students would not normally have had such a task before and therefore detailed guidelines were provided on what is meant by reflection on an experience.

They were asked to address the extent to which the objectives of the course, using headings such as 'community-based' and 'co-design', were realised in their case. This was probably one of their first experiences of doing design in a real situation. The impact of the (Deaf) culture they worked with and

the group response to the situation were also important topics for reflection. Ethical and professional issues had been emphasised and they were asked to consider those as well as sustainability of the project after the end of their course. Finally they were invited to look at their own growth as professionals and the impact of the lecturers in this course.

Our reflections on the course

While we anticipated that students would be anxious when confronted with such a departure from their normal type of course, we as lecturers also experienced trepidation in the lead up. This was a new pedagogic approach for Computer Science and we did not know how the process and the relationship with the community would unfold.

As far as the teaching was concerned, we dealt with the uncertainty by calling in outside expertise to assist in the form of a colleague from an established design faculty in the Technical University of Delft (in the Netherlands). She has extensive experience in such field work in technology, albeit not directly with teaching Computer Science. This relationship had been built up via our research projects over the years. In this sense this was a successful exercise in skills transfer that empowered the local facilitators with the confidence to run the course in future.

In negotiating access and expectations with the community we relied on previous trust and relationships built in the years of collaborative work with this community. We knew the people we worked with and knew how to get skilled facilitators such as SASL interpreters. It was important to maintain a relationship of beneficial reciprocity.

We structured the course to facilitate conveying an action research based method (namely our community-based co-design method) to the students. In parallel with their cyclical build-up of reflection upon action we were able to develop our own growing understanding of the pedagogic necessities. We also had to ensure that effective deliverables were produced.

We were apprehensive of taking Computer Science students, with their focus on abstraction rather than people, into a learning experience more usual in the social sciences. It turned out there was a very significant advantage associated with the skills of our students. Central to our field is the need for practical work that produces a usable deliverable at the end. This practical, and we hoped usable artefact, as the output of the students' work facilitated a reciprocal relationship with the community.

As far as co-design was concerned, it was clear that the paper prototypes

(mock-ups) presented at the initial design session worked well only with the more sophisticated staff members of DCCT. Once we had a working prototype however, everyone felt able to engage and suggest improvements (especially after the Computer Science students demonstrated their own ineptitude with English spelling). Their suggestions included: placing greater emphasis on their traditions and history on the homepage of their website, showcasing the people involved in creating the craftwork that is made and sold by them and showing the front of their building instead of the back entrance. They were also concerned about intellectual property, but agreed to safeguarding their ideas via watermarking of photos of the craftware.

Students' reflections on the course

Many students had never had contact with Deaf people. Many expressed fear of this unknown. They were unaware of SASL as a language in its own right. They had never considered the issue of low-literacy and the access issues that arise for Deaf people.

It is clear from the reflective essays that the students presented that participating in this course and their active engagement with members of DDCT resulted in significant shifts in their understanding of, and attitudes towards, Deaf people.

There was a strong realisation that language/communication, poor education and access to technology were the barriers rather than deafness or disability per se.

> "I had my stereotypes of that culture torn down as I realised the truth that deafness is far, far less a disability than signing is the language of that community. Deafness is not what hampered the co-design process; the difference in our and their computer literacy is what had the most negative effect."

Another student commented that there were more similarities between the Deaf community members and themselves, with language used being the primary difference. Negative preconceptions were shifted: "I was surprised to discover that most of the staff at DCCT were Deaf, I could not believe it at the time". Another student expressed surprise at how extensive the list of services on offer at DCCT was. In addition they realised that "the absence of verbal language did not imply the absence of other cognitive features". There was a noted change in attitude to Sign Language, which was originally thought to be slow and more limited but with exposure understood it to be "diverse and effective".

One of the students commented,

> "It was an eye-opening experience working within the Deaf community and learning about their culture from observing their interactions. It was interesting to note how they were all comfortable with each other and not in any way disabled."

The students expressed interest in understanding the mores of Deaf culture including the use of sign names, lights used as alerts and providing adequate lighting for seeing the facial expressions used in sign language. For many students this was their first experience of working through interpreters, specifically, SASL interpreters. Many commented on the skill of these professionals in making the communication seamless. It was awkward at first but with the interpreters "the longer we spent there, the more normal and comfortable it became".

It was evidently a challenge for all the students to avoid technical terms and jargon. This was important for two reasons: the Deaf did not understand these terms and nor did the interpreters. They learnt the importance of using video and pictures rather than text.

Students commented that Deaf people have a positive outlook despite challenges and have the same goals and aspirations as everyone else.

> "I figured the Deaf people were exactly that; PEOPLE!"

CONCLUSION

We see our primary achievement as that of giving Computer Science students an opportunity for direct engagement with a community where the students could deploy and refine their design skills. Students commented favourably that they dealt directly with real users, which was precisely the reason they had chosen this module.

The people with whom we worked commended our students on their approach; they felt that the people of DCCT were treated with respect and dignity. We believe this is partly due to the humility inherent in the approach of co-design where the people we work with are not so much seen as 'users' but rather as collaborators whose views are important in the enterprise of building a satisfying outcome. The community felt listened to and not patronised. During the final meeting they responded with a spontaneous gesture of offering the students a T-shirt reflecting their pride in their language and institution (see Figure 2).

Figure 2: Students, lecturer and DCCT staff. Students are wearing the T-shirts they were given after the final prototype demonstration.

This course came about because of a fundamental belief in a new way of working in Computer Science together with a number of seemingly fortuitous factors that depended on our network of connections and the history of our collaboration. The following insights may serve as a template of requirements.

1. The community involved will have to accept invasion by a class of students. Such a relationship is probably established over a long time in a reciprocal relationship. The course must fit into and build on such a partnership. The academics benefit from being able to offer a high quality learning experience and the community must see some benefit.

2. This kind of course requires funding to pay for materials, interpreters and expert consultants where necessary. In the ideal situation this would be part of general departmental funding but realistically these resources will probably have to be found in research funding.

3. The course involves risks and so will only work in a situation where risks are tolerated: an honours year offers this. The students may regard a situation where assessment is qualitative as risky for them if they have been used to high achievement in quantitatively-assessed well-determined courses. The planners of the course also cannot predict the exact events

and have to be comfortable with a skeleton schedule that is populated as the action research cycles unfold.

4. A course like this requires interdisciplinary expertise and input. In our case, we had the benefit of a long collaboration across a number of disciplines, but would suggest that networking (both within and beyond the university) to set up these collaborations is necessary.

5. In genera, a university may not support interdisciplinary teaching and so the resources, people, and space in the curriculum has to be found in spite of the structures present.

6. While the specific access needs and requirements for Deaf users, e.g., language access via SASL interpreters and cultural sensitivity, were addressed in this project, the principles and process are generalisable to working with other communities of users with other impairments and other development challenges.

7. Experience for Honours Computer Science students of working with the Deaf community has revealed lessons for including disability into the curriculum for ICT4D and related research and practical projects.

This course has been an opportunity to put into practice the dynamic interplay between research, pedagogy and practice in Computer Science.

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Chapter Eight

Bringing the personal to the professional in Information Systems

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The purpose of this chapter is to relate some anecdotes of my personal experiences of disability, and the way I have tried to make meaning of these experiences, both for myself and others within my role as an Information Systems (IS) professional. The focus of the chapter is on bringing the personal to the professional.

PERSONAL REFLECTIONS

I am seen as an able–bodied person, yet I have a minor permanent disability, and have had short periods of being temporarily disabled. I believe that almost no adult is always fully able; that all people experience periods when for one or more reasons they are unable to perform optimally. There are many forms of disability, some relatively minor such as faulty eyesight and some permanent and major such as total loss of sight; some headaches can be momentary and comparatively minor, while others can be temporary but severely disabling.

I believe that there is not a single category or type of ability, but that people have a wide range of abilities. Take the ability of sight as an example; the range from 20/20 vision to 100% sight loss is huge. I believe that people should not be broadly categorised as able or disabled, as a person might have many abilities (each ability at a different level on a broad spectrum), and many disabilities (each again at a different level). No two people are alike,

no two people have identical abilities and disabilities.

In 1994 I was privileged to meet Dr Geoff Busby who was born with cerebral palsy. Dr Busby cannot walk or use his hands, and has speech impairments, yet he earned a PhD in Computer Science. Dr Busby told me that many people are denied simple freedoms, such as freedom of choice, the freedom to choose when to go to the toilet, when to go to bed, the freedom to say thank you, or to select a TV channel. Many people are denied freedom of access and movement, such as the freedom to enter public buildings, to use public transport, and to travel.

According to the United Nations, approximately 10 percent of the world's population have a disability of some kind. In pure numerical terms that amounts to 650 million people, 4,5 million of them in South Africa. The United Nations says that disabled people are the world's largest minority, who are effectively denied many freedoms.

Professional implications

In order to bring my personal reflections into the teaching of information systems, I employ a range of strategies.

Exposing students to firsthand accounts of disability

Barry Blomkamp became a professional public/motivational speaker after he was blinded in a car crash, and over the years I have invited him to speak to my students on many occasions. As Barry is a friend of mine, I introduce him as such, and I am able to brief him and negotiate his contribution to the class. The students realise that although a person might have one disability, they have many abilities. As a user of ICT tools, Barry provides a useful and humorous account of how technology can provide much needed support for his participation in society. Barry's definition of technology is, "Technology is absolutely anything that improves and/or simplifies one's life. eg, A hat can be described as technology as it prevents one's skull from getting cooked by the sun!" In Barry's words, the technology he uses in his daily life includes:

- *Talking calculator:* A standard stand–alone device that is the same as any calculator, except it has an in-built voice which "speaks" out every key stroke and the result of the calculation. Essential in working out my overdraft!

- *Talking cellphone:* Currently, this is a Nokia C5. A standard phone used by millions all over the world. The only difference being that mine is converted to "talking" mode by the addition of special software. This software allows me to operate the phone completely independently like finding contacts in the number directory, typing and reading SMS and emails, amongst many other functions. I have a fully-sighted friend who is that dyslectic he can't read his phone's screen and uses this technology to program the phones talking software to tell him who is calling.

- *Talking computer:* These days virtually any computer can be converted to "talking" by the simple addition of specialised "Screen Reading" software. The two top and popular developers in this regard are JAWS and GW Micro's Window-Eyes. Again the expense of this software is prohibitive to the average South African blind person.

- *Talking CD book reader:* I use a device specially designed to read books on CD. Called a Daisy reader (Digital access information system), this is supplied to the "Print handicapped" in South Africa by the Library for the Blind in Grahamstown, free of charge, who also supply the books on CD.

- *Talking spouse:* Not a device for all blind persons but in some cases, a necessity. I use mine to great effect and enjoy this technology immensely. Julie version 1.only, is an asset in my life with many and varied functions, far too many to be mentioned here.

Highlighting how ICT tools and techniques can be used to assist people with disabilities

Many more choices could be extended to people by empowering them with Information and Communication Technology (ICT). Mankind has created numerous aids to help people, and ICT has been used to extended these many aids in various ways. These aids range from the everyday such as the capacity to increase font sizes in most Information Systems (IS) applications, to applications such as 'Light Talker' a voice synthesizer, which is used by quadriplegics such as Professor Stephen Hawkins to communicate. ICT companies such as Apple and Microsoft offer a range of assistive technology products, which are according to Microsoft "specialty hardware and software products (such as screen readers and voice recognition products) that provide essential accessibility to computers for those with significant vision, hearing, dexterity and mobility, language and communication, or learning needs." Interestingly, Apple has included assistive technology in its products as standard features at no additional cost. I believe that IS students should be aware of these important and interesting developments.

Sharing my personal stories and experiences

I suffer from cluster headaches, and when I have such a headache I am incapacitated. I suffer what to me is intense pain. The right hand side of my head including my eye and jaw are extremely sensitive and painful, and I believe I look rather strange. The pain is exacerbated by warmth, light and noise. What I need is a cold, dark and quiet place with an ice pack on my head. The headaches usually only last for 1-3 hours. In 2011, I had such an attack in the air as the plane was approaching Heathrow airport. The cabin crew were alarmed by my appearance, but luckily my wife was with me and explained the situation to them. On landing, I was escorted off the plane and put into a wheelchair. Although in pain, I was aware of what was going on, and could hear every word spoken. Being pushed in a wheelchair through a crowded venue such as Heathrow is not a pleasant experience. I felt as if I was in a moving cylinder as all I could see were the bottoms and stomachs of people swarming around me. No one apart from my wife ever spoke to me or listened to anything I had to say. The staff at Heathrow treated me like a package as they discussed me, and moved me through customs and immigration. Sharing stories such as these stimulates discussion amongst students.

Giving lectures on social inclusion and social exclusion

The intent here is to challenge students to consider how ICT can help or hinder social inclusion. The impact of such lectures is indicated in the quote below from one such student:

> "The lecture on disability and social exclusion triggered me to think about the opportunity and even responsibility that comes with being an IS professional, to socially include the 'socially excluded'. With the knowledge of social inclusion/exclusion, I think that information systems can and should absolutely be used to socially include the ones that are in some way or another socially-excluded. I inherently believe that society is becoming increasingly aware and active in socially including people, who in some way or another are socially excluded, and that incentives to do so are on the increase.

> "The discussion in these lectures also triggered me to revisit the concept of developing my own information system that links those who want to donate money or to volunteer, to non-profit organisations that provide relief to those who are socially-excluded, and who require the funding and volunteers

to make a positive impact on society. Furthermore, this system could 'create' incentives, in terms of allowing individuals and business to earn online 'points of goodness', share these points on social networks (to create more awareness), and to potentially receive free products/services or discounts on these based on these earned points."

I ask students how many use the ramps in the building rather than the stairs, and point out why the ramps were constructed. In a similar vein I point out that the computer mouse was originally seen as an aid for people who found it difficult to use a keyboard. I use this to illustrate how many devices, originally developed for 'disabled' people are then used by many able people.

Research interests

I have done very little research in the area, but did do some research on Lighttalker several years ago for a friend. I wrote and presented a paper on the use of ICT for social inclusion and or exclusion in 2008. I have recently done some work co-designing a website with my friend Barry, and asked him to assist me with research topics, and projects to assist disabled people. I feel that more could and should be done in terms of researching what and how ICT and IS can be used to assist all people.

Conclusion

We all know somebody whose freedom of choice has been limited by disability, and we can make a difference through our actions, research, and by simply creating awareness through our interactions with others.

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Chapter Nine

Consent, capacity and credibility: Incorporating mental disability into teaching on sexual offences and the law

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INTRODUCTION

Studies have illustrated the particular vulnerability to sexual violence both of women with cognitive impairment and those with mental health issues (Goodfellow & Camilleri, 2003) and the difficulties that they face in being understood by the law and accessing the criminal justice system (Pillay & Sargent 2000; Dickman & Roux, 2005). The competence of mentally impaired people to credibly recount their victimisation in court is likely to be challenged (Cooke & Davies, 2001; Green, 2001) and they are almost invariably seen as lacking credibility, embodying for many the stereotypical crazy woman who fantasises and lies about being raped.

In this chapter I reflect on the inclusion of mental disability, including in this context both cognitive impairment and mental health issues, in the

Masters course I teach on Sexual Offences and the Law. The course covers laws and procedures relating to sexual offences, as well as what we know about criminal justice practice. In teaching the course I draw on my own experience of participating in South Africa's rape law reform process and of doing empirical research on the management of rape complaints by police and prosecutors. The examples I provide below, of cases involving women living with mental disabilities, are drawn from police dockets in the Western Cape, and form a tangible basis for class discussions about vulnerability, capacity and credibility. I am fortunate that the course generally attracts an even mix of postgraduate law (LLM) and social science (MPhil) students, which enriches my own experience of the course and their interactions with each other, through a more nuanced engagement with social realities. The course is evaluated by means of a long paper and a service learning component, in which students working in groups partnered with the Rape Crisis Cape Town Trust to address the need for accessible training and information materials on the law and legal process. While the student papers often make reference to disability as an aspect of vulnerability, none have yet grappled fully with the complexities of disability in the context of sexual offences and the law.

Students come into the course knowing that South Africa has high levels of gender-based violence, particularly directed at women. Inevitably they are still shocked to learn quite how extensive and how violent sexual aggression is in this country. There is no rigorous data collected in South Africa on the sexual victimisation of persons with disabilities. We know from international studies that people with mental disability are more vulnerable to abuse than the general population (Brown, Stein & Turk, 1995; McCarthy & Thompson, 1997; Hughes et al, 2012) and often less able to manage their potential victimisation through the kinds of protective routines around which women ordinarily organise their lives (Nedelsky, 2011). Studies report that rates of sexual violence for adults affected by cognitive impairments range between 25% and 67% (Beail & Warden, 1995; Masuda, 1995; McCabe, 1994; Stromsness, 1993). Among women with disabilities, reported rates of sexual violence rise to between 51% and 79% (Masuda, 1995; Stromsness, 1993). Where disability intersects with poverty, disorganised communities and families at risk, the vulnerability is compounded and the ability to seek recourse even further curtailed.

Criminal law views people as victims and perpetrators. In the context of sexual offences (which is taught as a specific criminal offence), the focus on victimisation is particularly pronounced. Whenever one teaches about this type of violence, which is so dehumanising, it is important to guard against creating our own stereotypes that treat people only as "victims". This is particularly true when focusing on the extreme vulnerability and

challenges facing women with disabilities, where one has to guard against the maternalistic instinct to equate their position to that of children, in need of protection from others and themselves, lacking agency and devoid of sexual autonomy. It is therefore also important that students recognise that people with mental impairments also have sexual rights, including a right under section 12(2) of the Constitution to make decisions regarding reproduction and to security in and control over their bodies, characterised by autonomy, choice and mutuality. With that proviso in mind, I discuss below the key concepts of capacity, consent and credibility as they arise in this context.

Capacity and consent

The concept of "mental capacity" is central to the law. Without it you cannot enter into a contract, you cannot marry, you cannot be held criminally liable and, if you lack mental capacity at the time of the trial, you cannot be tried. I deal with the latter two examples in my LLB course on criminal procedure, where mental capacity is generally understood to have a cognitive aspect, in the ability to distinguish right from wrong, and a conative aspect, in the ability to be able to act in accordance with that understanding. Students are always shocked to learn that it is a judge and not a psychiatrist who decides on this question.

The Criminal Law (Sexual Offences and Related Matters) Amendment Act 32 of 2007 (SORMA) deals with sexual offences against "persons who are mentally disabled" and students are asked to read Helene Combrinck's analysis of the SORMA provisions in the Sexual Offences Commentary (Smythe & Pithey, 2011) to gain an understanding of the architecture of these provisions, their utility and their limitations. The Act picks up on the issue of mental capacity in relation to that person's ability to consent to sexual activities. Circumscribing consent is critical, because rape is the only crime in which consent (or rather, a lack of consent) is part of the definition of the offence. This means that the prosecution must prove beyond a reasonable doubt that the complainant did not genuinely consent, showing that she was coerced through violence or the threat of violence, or that consent was obtained by fraudulent means, or that the victim lacked the mental capacity to consent. SORMA therefore specifies in s57(2) that: Notwithstanding anything to the contrary in any law contained, a person who is mentally disabled is incapable of consenting to a sexual act [s57(2)].

This provision appears to prohibit any person living with a mental disability from engaging in any sexual activity. I raise this point to a confounded

silence in class: students initially find it difficult to understand why a blanket prohibition on having sex with "mentally retarded people" would be anything but protective of their psychological and bodily integrity. When conversely framed as a prohibition on "mentally retarded people" living with cognitive impairments having sex at all, or even engaging in other sexual acts, this certainty starts to break down, as the distinction between the policy basis for prohibiting protecting children from having sex and prohibiting people living with mental disabilities from choosing to having sex becomes more clearly divergent.

It is an important discussion to have with students, but largely moot when it comes to the law, as the Act does not in fact entail such a broad prohibition. The key to this provision lies this particular law's definition of a "person who is mentally disabled" as someone who, at the time the offence was committed, was unable to appreciate the nature and reasonably foreseeable consequences of a sexual act, unable to resist the commission of or to communicate their unwillingness to participate in the act, or able to appreciate the nature and reasonably foreseeable consequences but unable to act in accordance with that appreciation. It is important that the assessment relates to capacity at the time that the offence was committed, because psychiatric disabilities "do not always follow a regular pattern, making it difficult to predict when symptoms and functioning will worsen… These variations may impact on the person's capacity at different times to give consent to sexual intercourse" (Combrinck, 2011, 5).

We discuss in class what we all understand to be the "foreseeable consequences" of consenting to sexual activity. And we tend to disagree. As Combrinck asks, in the context of women living with disabilities: "…do they have to know that a woman can become pregnant? That both men and women can contract sexually transmitted diseases? Must they know the names of the diseases? Should they be able to explain why people have sex? Should they be able to tell us who are the 'right' partners to have sex with?" (Combrinck 2011,7; Denno 1997). This links back to the concept of consent and what kinds of mistaken beliefs as to the nature of the sexual act, or the person with whom it is committed, should be allowed to negate consent. Case law tells us that being led to believe that sexual intercourse is a gynaecological examination negates consent, but the belief misrepresentation that engaging in sexual intercourse will improve your singing voice does not. Nor does the belief that your sexual partner is Bill Gates, when actually he's Joe Blogs (although in Israel, believing your partner to be Jewish, when he is actually Muslim, has been found by the courts to vitiate consent). Not disclosing a sexually transmissible disease is considered by most students to be an absolute basis for negating consent, but not by the law, where that debate has raged for over a century, from syphilis (then

incurable) through HIV. A small minority think that if you don't ask, you have only yourself to blame.

Through our readings and class discussion, students begin to think about people living with mental disabilities in differentiated terms, and their experiences of sexuality and of sexual victimisation as contextual, rather than as an immutable category of presumptive victims, who are all incapable of giving consent.

CREDIBILITY

In our discussions about the recourse provided by the criminal justice system, I draw substantially on my own research into the processing of rape cases. The cases we look at illustrate the centrality of victim credibility, and the complex relationship between the rules of evidence and procedure that frame what is to be believed and the rules of practice that often put some victims with mental disabilities "beyond belief" (Goodfellow & Camilleri, 2003). We focus particularly on who is believed and how this is evaluated.

For centuries the State's response to rape has been based on the premise that women lie about their sexual victimisation. Wigmore conveys this view in the following passage, which has often been cited with approval by our courts well into the late 1980s as justification for treating rape complaints with particular scepticism (Wigmore, in J.H. Chadbourn revn, 1970, para 924A at 736):

> Modern psychiatrists have amply studied the behaviour of errant young girls and women coming before the court in all sorts of cases. Their psychic complexes are multifarious, distorted partly by inherent defect, partly by diseased derangements or abnormal instincts, partly by bad social environment, partly by temporary physiological or emotional conditions. One form taken by these complexes is that of contriving false charges of sexual offences by men. The unchaste…mentality finds incidental but direct expression in the narrations of imaginary sex incidents of which the narrator is the heroine or victim. On the surface the narration is straightforward and convincing. The real victim however, too often in such cases is the innocent man; for the respect and sympathy naturally felt by any tribunal for a wronged female helps to give easy credit to such a plausible lie.

The system is shaped around the deeply embedded assumption that all rape complaints are suspect. We are told that there is a delusional state called pseudologia phantastica, in which "the complainant truly believes that she had been raped although no rape, and perhaps no sexual contact of any kind, had taken place" (Kanin, 1994, 81), and there have been suggestions that all rape complainants should be subject to psychiatric evaluation or lie detector tests (Legrand, 1973). At the same time, the credibility of complainants actually living with mental or psychiatric disabilities is particularly questionable, precisely because of their disability (Kelly, 2002), with "mental health problems" invariably raised as one of the primary motivators behind false rape complaints (Jordan, 2004).

It is difficult for any victim to provide a sufficiently coherent and credible account of her victimisation to found a valid claim worthy of investigation. The challenges for a woman with mental disability are amply reflected in a case involving a 41-year-old woman who went missing overnight. Her mother reported that when she found her daughter:

> She was wandering and she was dirty. I noticed that the whole set of teeth was missing. She was in a state of devastation. I asked where she was and she started crying. She told me she had been raped by five men on the field…

She took her daughter home and then to a doctor, who was not available. His secretary told her to go to the police station. The detective on duty refused to take a statement from the victim, telling her, according to the mother's statement, that she hadn't been raped. He told her that she was "just a naughty child" and instructed her mother to take her home and give her a bath. While bathing her daughter, the mother found that her panties were covered in blood. She took her back to the doctor. This time the doctor told her that he could not examine her daughter without permission from the police. She called the police station again and was told to bring her daughter in the following day, which she did. A different police officer took the complainant to see the district surgeon, where she was finally examined. The doctor concluded that her injuries were "not incompatible with an allegation of a sexual assault as alleged" (doctors use this tortured language structure because they have been told that only judges can determine if someone has been raped). Her demeanour was recorded as being "overwrought, tearful and unable to answer questions". The doctor also noted that she was schizophrenic and had been hospitalised on several occasions.

Reflecting on stereotypes of mad and hysterical women, we talk about why the police (or prosecutors or judges, for that matter) find it so difficult to believe claims of rape, but perversely easy to accept the recantation of a rape

complaint by a women who is mentally impaired. In this case the detective notes in the docket:

> Complainant won't say if she was raped. She is not deaf, dumb, stupid or retarded (in Afrikaans: "doof, dom, stom of gestrem") and just refuses to speak. She stated after a while that she was not raped and just slept out.

On this basis he drafted a withdrawal statement on her behalf saying:

> [The victim] denies she was raped and was just afraid because she slept out.

Goodfellow & Camilleri summarise the point well, writing in the Australian context: "…when some victim/survivors with cognitive impairment disclosed that they had been sexually assaulted to someone, they were not believed, whether the person was their support worker, a police officer, or a friend or family member. Whilst this is a common experience for many victim/survivors, this lack of belief where women with cognitive impairment are concerned, rests on myths and assumptions about disability – developed over time into core attitudes and values…when a person has a cognitive impairment they can be perceived as not knowing, not remembering and not being truthful." (Goodfellow & Camilleri, 2003, 52).

Evaluating capacity and providing support

While we talk a lot in class about the ways in which stereotypes become scripted into criminal justice practice, we also talk about the challenges facing people who work in the criminal justice system. It is difficult for ordinary detectives, even those specialised in sexual offences, to function effectively without the support of mental health professionals. They fret about "how do we know she is telling the truth?" Some insist that they cannot proceed without a mental health assessment to determine whether she is capable of distinguishing "what is right and what is wrong". This support is largely unavailable, notwithstanding the fact that there are pockets of excellent services available (Dickman et al, 2006). Non-governmental service providers and forensic social workers are stretched to capacity and police investigation diaries routinely record that it will take more than ten months to get an appointment to have a complainant assessed. Detectives are frustrated at this delay:

> Don't get me wrong, they [forensic social workers] are doing a good job, but I am not happy with them. I had a case of a 12-year-old mentally handicapped child who was raped by some guy that the mother knew… I sent a fax to the [social

workers] explaining the circumstances that the child was living under, with an alcoholic mother who was never there, and the child prey to anyone … That was more than two years ago and no response.

There are very few cases referencing mental health problems that show a referral was made for psychiatric support and evaluation.

Complainants with mental health problems are more vulnerable to sexual assault and more vulnerable to police ineptitude. In the following case the complainant's mental health status was obviously considered to be an important factor. The complainant had returned home at midday, where a man known to her by sight followed her into her shack and raped her. He threatened that he would kill her if she told anyone. The medical examination recorded soft tissue injuries to her neck, as well as recent tears, bruises and bleeding in and around her vagina and perineum. It also recorded that she was schizophrenic and epileptic, specifically mentioning that she was not psychotic at the time of the examination. Six weeks later the detective visited the complainant, who told him that the suspect had run away. He gave her a "point out note", which effectively instructs her to find the perpetrator and call the police when she has done so. Nothing was done on the case for a further two months and no effort was made to find the perpetrator, before the case was closed. The first entries in the investigation diary do not, as they typically would, contain the details of the rape, and of the suspect. Instead they read:

1. Complainant was interviewed.

2. Complainant is schizophrenic.

The lack of attention given to this case leads one to the conclusion that the complainant's mental health status was determinant of the outcome.

Protective measures

Finally, for the few cases that do make it to trial, it is important to consider that protective measures are available to complainants. SORMA introduced for the first time, by an amendment to section 170A of the Criminal Procedure Act, the possibility of intermediaries for witnesses below the biological or mental age of 18 years, where the court is of the view that they will be exposed to "undue mental stress or suffering" as a result of testifying in open court. While both the victim's mental age and the potential impact of testifying will require expert testimony, this is an important recognition of

how terrifying it can be to engage with the criminal justice system, to sit in court with the person who violated you and be cross-examined in their presence on your version of events.

CONCLUSION

I try to teach all of my courses in a way that surfaces the social context within which the law operates. In this article I have focused specifically on the inclusion of disability in my Masters course on Sexual Offences and the Law, and in doing so I have inevitably endowed this important issue with more coherency than it has actually had in my teaching. At the same time, this process has created its own coherence and made my thinking about these issues more explicit, which allows for a more purposeful approach to the future inclusion of disability.

In my course, students learn that sexual victimisation of women with disabilities is compounded by stigma, social isolation, dependency and a lack of skills in the criminal justice response, which results in them not being believed, or in cases not being properly pursued. The result is that victims are not afforded protection by the State and that they are therefore put at further risk, often being returned to contexts that are at least neglectful of their welfare, if not overtly abusive. They learn that questions of consent, capacity and credibility are deeply contextual and profoundly bound up with normative scripts enacted in everyday criminal justice practice. It is important for students to understand the law as it relates to people with disabilities who are victims of sexual offences, the institutional barriers that they face in gaining recourse, and the stereotypes that feed poor criminal justice outcomes. But these are not explicit learning outcomes. Instead my intention is that students should gain a more nuanced understanding of key legal concepts and the criminal justice process, with the inclusion of disability supporting that outcome. The next step is to think about how one assesses the extent to which students have shifted their own understandings of law and disability through this course as a learning outcome.

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Ultimately, the issue of disability is an issue of transformation. This publication is a demonstration of our deep commitment to the values of transformation.

Higher education institutions provide leadership for societal and technological development. We should aspire to make this true of disability issues too.

Dr Max Price
Vice-Chancellor
University of Cape Town

Beyond 'If' to 'How': Disability Inclusion in Higher Education

Disability should be seen as an issue of social justice and identity politics and not simply a medical or health issue, particularly for those with intellectual and psycho-social impairment who experience greater marginalisation and stigma. Researching disability provides multiple opportunities for interdisciplinary collaborations. The challenge remains for academics and researchers to explore ways in which disability can be addressed in teaching and learning. This is essential as institutions of higher learning strive to meet the development challenges of South Africa and Africa, as well as contribute to global citizenship.

This publication highlights success stories of how disability is being addressed in a variety of ways across disciplines at the University of Cape Town. The authors, all innovative leaders in their fields, provide inspiration and show what can be achieved with courage and foresight.

Affirm   Advocate   Account