

# Engaged scholarship, disability and the politics of the personal: Mentorship by Leslie Swartz



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## Dates:

Received: 31 July 2025

Accepted: 30 Aug. 2025

Published: 30 Nov. 2025

## How to cite this article:

Watermeyer, B., 2025, 'Engaged scholarship, disability and the politics of the personal: Mentorship by Leslie Swartz', *African Journal of Disability* 14(0), a1820. <https://doi.org/10.4102/ajod.v14i0.1820>

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## Introduction

Now a disability studies academic in my mid-fifties, my relationship with Leslie Swartz as supervisor, mentor and friend spans well over 30 years. This special issue celebrates Leslie's extraordinary contribution to disability studies as a discipline, as well as to awareness of disability as an issue of social justice in South Africa and across the continent. In the story of my mentorship by Leslie, this growth of intellectual discourse on disability takes place parallel to my own life as a university student with disability and later as activist, clinician and academic. It is a demonstration of how, for Leslie, the work of intellectual inquiry is embedded in an ethics of real life, which is curious about the human world in ways which transcend divides between personal, professional, scholarly and political realms. Observing Leslie's career is a study in the compassionate ethics of engaged scholarship which, as I shall explain, has empowered the breaking of oppressive silences in many lives, including my own.

## Starting out

As a young person living with severe visual impairment, my future was very uncertain. Born into the privilege of white suburban South Africa of the 1970s and 1980s, I battled through school in a mainstream setting, before being exceptionally fortunate to be admitted to university. Although the path was hard for me in many ways, because of apartheid's racist and ableist policies the vast majority of young South Africans with visual impairment had at that time not experienced the inside of a classroom, underscoring the inequalities that I benefitted from as a white, male and heterosexual South African. Undoing the silencing of the lives of those left out, and foregrounding how this mass exclusion continues to stain our democracy, is an ongoing motivation for my own research work (Watermeyer, McKenzie & Kelly 2024).

## Disability intersections with higher education

As an undergraduate I aspired to train as a clinical psychologist, but feared that this career path, like so many others, would be prohibited by my disability. It was a time when visually impaired persons in our country, if employed at all, were limited to an exceptionally narrow repertoire of occupations, headlined by switchboard operating and piano tuning. Growing up with the invisible, insidious reality of progressive vision loss, my well-meaning but ill-equipped family showed me that if I was to be accepted in the world, the only option was to appear as non-disabled as possible and certainly make no demands (Omansky 2011). As I was unable to access print in the usual way, my ageing but dedicated mother read an entire bachelor's curriculum to me, at a time when access support at South African universities for students with disabilities was in its stuttering infancy (Howell 2006). My university experience was coloured with insecurity and loneliness, as it seemed clear to me that, were I to disclose my disability to lecturers or administrative staff, the response would be to tell me that I had no place being there. And if that was true, then there appeared to be little possibility that I would be acceptable to a professional community in clinical psychology. Nevertheless, I completed my undergraduate programme with a distinction and went on to my honours year in psychology, where my research project was supervised by Prof Leslie Swartz. Still with no reliable access support, I endured periods of indescribable stress, as I scrambled to gather the means to perform my studies. I quickly became aware of Leslie's interest and concern for my situation, which was an unusual one, because students with visual impairment were, at that time and institution, rare.

**Note:** The manuscript is a contribution to the themed collection titled 'Growing disability studies on the African continent: The career contribution of Prof. Leslie Swartz' under the expert guidance of guest editors Prof. Brian Watermeyer and Prof. Lieketseng Ned.

During this period, I held a bursary for students with disability from a philanthropic organisation. To confirm that their money was well spent, the organisation required that an academic staff member from the university sign a document declaring that the profession to which I aspired would not be made unfeasible by my particular disability. Imagining this to be a routine procedure, I took the form to the professor in charge of the masters level professional training in clinical psychology, to ask for her signature. She abruptly refused the request, opining that it was impossible for someone living with visual impairment to train or work as a clinical psychologist and advising me to seek an alternative profession. Reflected here was the way in which ableism remains built into the foundations of the university as we know it, with narrow conceptions of achievement at its core (Dolmage 2017). I was shocked but also unsurprised by the professor's response, leaving me in a familiar place of insecurity, alienation and fear for the future. I had no grounds on which to argue and felt, familiarly, that there would probably be no place for me in the world of work, and that I was too damaged to be of any real use to society.

With no other choices, I nevertheless put in my application for the masters level clinical psychology training and was invited to a selection week of intense interviews and role-plays. This procedure was very anxiety provoking indeed for all applicants, but the apprehension was compounded for me by the resurgence of an archaic, deeply embedded feeling that I did not, could not, belong. My memories from those first interviews remain vivid, more than 30 years hence. At one point a professor on the panel, who was in charge of the internship placement in neuropsychology, confronted me brusquely with the following 'problem': 'How', she asked, 'am I supposed to deal with *you*? We run a very busy unit; I don't have time for problems'. I had no answer. Other questions reflected similar demands from the selection committee, that I offer some sort of a plan to deal with whatever access difficulties arose during the training. Of course, like any applicant, I had virtually no understanding of the day-to-day reality of a trainee or practitioner and so had barely any idea of the possible problems that may arise, let alone solutions. Looking back, what was in fact anxiety felt by trainers through being confronted with the awkward anomaly that was me, showed itself in simmering exasperation and resentment. This anxiety was evident just behind their congeniality. My application was turned down, with the feedback that I required more self-insight and life experience. This assessment was, in fact, accurate – a fact that is clear to me now after having selected and trained a large number of clinicians myself. Yet it was impossible for me to know how my disability had featured in the discussion. My hunch was that the door was very firmly and probably permanently closed to me, as a 'misfit' (Garland-Thomson 2011) to the profession and its gatekeepers. But while my reality was as new to him as anyone else, I sensed in Leslie a generous interest in me and the dilemmas which my presence raised for broader questions of inclusion and equity.

## Disability, ideology and the university

It is difficult to overstate the silence and invisibility of disability in higher education (and elsewhere) in South Africa in the mid-1990s – it was not part of the diversity agenda, instead occupying an awkward, marginal position shrouded in medicalisation and exclusion, which was seldom questioned (Watermeyer et al. 2006). It is in countless challenging circumstances such as this that I have, over decades, learned from Leslie's exceptional ability and courage to look beyond what is comfortable, to questions that seem obscure and overwhelming in the present, yet will all but define the future. Only very recently has debate in health sciences education literature begun to clearly voice the reality that, if we are to create services attuned to the life worlds of people with disability, it is essential that the disability community be well represented in the ranks of every health profession (Edelist et al. 2024; Iezzoni 2016). Thirty years ago, such an idea was barely thinkable. Still with no reliable present or future, Leslie's thoughtfulness began to provide me with a place to begin making sense of the bewildering world I had inhabited since early childhood.

Over the following 4 years I underwent 8 masters' selection processes across 5 South African universities, with the issue of my disability surfacing again and again, in varying ways. Some responses were, in today's terms at least, unashamedly discriminatory, amounting to an unspoken question, as in my first experience described above, of 'why are you wasting our time?' On other occasions, I was required to answer intrusive, sometimes mystifying questions about my disability, reflecting jarring ignorance regarding issues of identity and difference in general. If I chose to speak at length about my disability it was read as my having not yet 'come to terms' with it, and being stuck in some form of self-absorption. If I, in response to this view, chose to de-emphasise my disability, this was read as denial. But what was occurring over this period, with Leslie's ongoing support, advocacy and facilitation, was the development of a national debate in higher education over the question of training visually impaired psychologists in particular, and professionals with disability in health sciences and other fields in general. Undergoing selection interviews at our university three times over a 4-year period, I sensed a change in the engagement with me, perhaps as anxieties about the unknown were slowly replaced with the beginnings of critical thought on disability and diversity. Four years after my initial application I was accepted onto the programme. Notwithstanding what I have already said, I want to point out that the decision to accept me into training was an act of courage and faith on the part of my lecturers and supervisors – I certainly did not have all of the answers, but nor did they; we were all venturing into uncertain territory. Clinical work comprises a host of different skills, many of which rely heavily, in traditional ways of working, on vision. Leslie's ever-curious and intellectually bold example was a foundation for all of us during this time, with his tireless position of not asking whether we can do what is right, but rather how we will achieve it. While the path was difficult for me, I also cannot emphasise enough that without my

white, middle-class privilege and the social capital it afforded I would not have been able to begin this battle, let alone sustain and finally overcome it. Adjectives fail me as I try to describe the depth of silencing, the slammed door of exclusion, which confronts most South Africans living with severe forms of impairment.

### **Listening to oneself and one another**

Through the course of this period, and into my training years and beyond, my relationship with my disability, as well as with myself and the world, was undergoing seismic changes. If one begins with a deeply held assumption, as so many people with disability do, that it is entirely up to you to find a way to fit into a barrier-ridden and largely indifferent world, then the journey to some degree of solid, appropriately entitled ground is a long and non-linear one (Watermeyer & Swartz 2008). Simplistic social model thinking would have us believe that the answer to every disjuncture between the impaired body and the social world is a one-dimensional demand for material accommodations, flanked by the fantasy that such changes can solve any and all problems of access and participation (Thomas 2007). Of course, all identifiable and avoidable material barriers must be dealt with, but what emerges through this process is the social model's denial of relationship, complexity and the pivotal role of affect (Watermeyer 2013). Disability begins with human difference, which is hard enough for any of us, but then adds the reality of how diverse bodies intersect with material and cultural environments in a myriad ways. Without deliberately centralising relationship in the work of inclusion, the project has no hope (Kittay 2011). For me, and with Leslie's support and example, inclusion requires constant re-negotiation in the context of compassionate listening on all sides – what I have elsewhere referred to as a 'generosity of engagement' (Watermeyer 2013). This is not to suggest that people with disability should approach the world apologetically, not at all. But it does point to the reality that we are all products of segregation, and that disability difference is for most people both new and unsettling; it is possible to firmly advocate for inclusion while holding empathy for those grappling with change. It is likewise possible to protest vociferously without othering or dehumanising those we see as obstacles to transformation.

Later, supervising my master's research project, Leslie's incisive but always empathic thinking began to convince me that I might have something useful to say about disability in an unequal, excluding world. This is no small thing, as the invisibilisation of experience and the prohibition of expressions of emotion are centrepieces of the ableist world's response to the impaired body-mind (Ahmed 2010). Put simply, the social world endlessly reiterates, both discursively and in its material nature, that disability-related struggle is a shameful taboo and is not only unacceptable in social exchange, but even internally is best banished to the furthest reaches of one's awareness. This is true for both socially engendered adversity and difficulties

relating to embodiment. Establishing a clear dialogue with what one's experience as a person with disability is, as well as how one feels about it, is the first step towards disentangling the layers of othering, blame and shame which permeate the air around impairment. But the unrelenting invalidation experienced by so many people with disability can make this an insurmountable challenge. Successful social movements are those that care for the hearts and minds of their constituency, rather than only operating mechanistically at the level of the tangible. It is for this reason that I continue to be an ardent advocate of empowering, subversive mental health services, such as psychodynamic psychotherapy and group-based psychopolitical conscientisation for disabled people. After Fanon (1963), it is to me beyond doubt that the ways in which ableist ideology settles into the inner worlds of people with disability as internalised oppression must be recognised as a lynchpin which cements exclusion and inequality. Overcoming this is the ever-unfinished work of a lifetime. Thanks to Leslie and the extraordinary privilege of my education and career path, I have on my own journey been gifted with an artillery of intellectual tools, opportunities for growth, the supportive relationships of co-travelers and insights and knowledge from the research record in disability studies – in short, a world of ways to make sense of my own life. Yet, even with these resources, aspects of disability and ableism remain mysterious and obscure, gesturing towards human dilemmas which transcend time and circumstance. Inequality in access to knowledge on disability as an issue of social justice, as well as the humane, relational support needed to cultivate self-compassion in the face of a bewildering, obliterating world, is an absolutely central challenge to the cause of disability liberation.

### **Mentorship and being believed**

Through the course of my master's and later doctoral research, Leslie became not only an intellectual guiding light and mentor but also an academic colleague and dear friend. Going out on a limb, he was instrumental in my first appointment to an academic post, thereafter engaging with typical enthusiasm in dilemmas and struggles associated with securing reasonable accommodation. I cannot say for certain, but perhaps our work together in those early years was part of what sparked his growing interest in disability studies, leading to his prodigious later work in the field, as well as our many collaborations. Like so many people with disability, I had previously had little experience of that layer of my subjective life which pertains to disability being welcomed or believed, which is an essential precursor to internalising another's faith in oneself. Of course, one has to say something before one can be believed, and as I have said, so many lives with disability are shrouded in silence (Murphy 1987). Yet a relationship that allows the beginning of trust that one will be believed, showing itself in the growing internal sense that one's experiences are worthy of contemplation, is a rare gift. As reflected in the testimonies of many others in this collection, Leslie's ability to, first and

foremost, clearly affirm that one's understanding of and response to the world is legitimate and meaningful, no matter how strange or awkward it may be, is a precious gift. It reflects the heart of an intellectual driven not only by curiosity but also by a humble and honest compassion. The invitation posed to myself, as well as so many others privileged to have been mentored by Leslie is something like 'tell me who you are, what things are like for you. We have time, it's important, and I'm curious'. There could be no better example to young academics in the social sciences concerned with undoing injustice. After that comes the gift of faith that one might contribute something of value to the world, which, in my case as well as many others, I began to believe.

I understand relationships with mentors and role models – in our work, often positioned as research supervisors – as operating at a number of levels. Of course, there is the obvious and essential issue of intellectual guidance and the fostering of critical thought. More rarely discussed, though, is what occurs at the level of affect, at which – to put it simplistically – a relationship can release self-assurance and creativity or reaffirm conflicts with the self over adequacy, which can halt growth. I have alluded above to our human need to be listened to and understood by a kind and accepting other, who may also express some faith in our ability to accomplish things we aspire to. Without someone credible telling us that we can cope with what Vygotsky (1978) called the 'zone of proximal development', located just beyond the limits of our confidence and abilities, we literally have nothing to go on, no reason to believe that we can grow and develop. To be impactful, however, this message must come wrapped in an accurate, empathic understanding of who we are and what things are like for us. At play here is what the psychoanalyst Wilfred Bion (1962) called 'containment' – an experience of someone else welcoming and being able to hold our reality, in all of its complexity and messiness, while still having faith that we will, after all, be OK. The experience of being thought about by someone else in this steady, compassionate way builds inner security, allaying self-doubt and anxiety in a manner which opens the way to expressiveness and creativity, so important in our work as explorers of new knowledge. I have argued elsewhere that, because of the silencing and concealment so prevalent around disability, people with disability may to some extent be systemically deprived of this most important resource (Watermeyer 2013). As has been described in a range of identity markers, broader society generally does not want to know how members of oppressed groups feel, and exercises a range of prohibitions accordingly (Cheng 2000). In the lives of people with disability, often surrounded by human networks which encourage avoidance of the awkward topics of exclusion, discrimination and embodiment, this means a lack of experiences of feeling truly known, and hence having one's experience – not least of ableist oppression – validated. The purpose of this discussion is to describe the gravity of my experience of being met, in an existential sense, by Leslie as a supervisor with a deep understanding of these dynamics, as well as the moral insight to act upon them. Over decades

I have also had the privilege of observing Leslie's capacity to engage with the same gentle curiosity, as a white heterosexual, Jewish and middle-class professor, across other intersecting forms of difference, from race and gender identity to language, sexuality, socio-economic status and religion. Oppressive histories are disrupted and confounded along the way, but never denied. A host of testimonies demonstrating this are to be found in the pages of this publication, often showing how this action, at once personal and political, resonates with the liberating subversions of decoloniality, as epistemic hierarchies are disrupted to reveal new knowledges.

In my own work, I have been shown time and again how significant it is for students with visual impairment, or any form of disability, to be supervised by someone who shares the same identity. As a student, it would literally have meant the world to me to have access to a role model who was 'like me' who had managed to succeed in my chosen profession, as well as in the professional world in general. In my conversations with students with disability I have supervised, I see how my own life-world benefits greatly in my attempts to provide experiences of understanding and validation, which are typically a stark contrast to the signals from society received previously. But this cycle of mentorship had to begin somewhere, and without extensive personal experience of life with impairment to draw on, it was Leslie's exceptional foresight, empathy and courage which excavated a hidden but essential conversation. In my own role as mentor it is Leslie's example of compassionate curiosity which, even after many years, I continue to draw on.

### Being there

In any struggle to do with identity and exclusion, the first and most basic priority is presence – in other words, making the marginalised visible in domains which have excluded them, such as institutions. It is only through engaging daily across our differences that we can begin to confront all that divides us, from prejudice and paranoia to questions of access, equity and the cultivation of mutual understanding. In the disability arena universities have a pivotal role to play as environments that carry formative influence on the culture of our social institutions, as professionals reproduce what they have learned in both manifest and hidden curricula (Dolmage 2017). Universities that fail to include persons with a range of impairments as students and staff at all levels perpetuate societies built on an artificial and fallacious understanding of our shared humanity, reflecting a hierarchy of belonging in the human family. This is a harm not only to the disability community, but to all of us, as it upends the work of creating societies that welcome the vulnerability which we all ultimately share, despite our frantic appeals to the contrary. The history of structural segregation and cultural concealment means that disability is, in its many forms, a new and strange reality for most people to experience at close quarters – step one is to ensure that disability is in the room. We then have a place to begin.

## Conclusion

As the movement for social justice surrounding disability continues, an essential element is the nurturing of self-awareness and self-compassion among the disability community, to overcome the annihilating silence which ableism creates. Carefully listening to the voices of people with disability, not simply with a sense of solving problems of access – important though this is – but with consciousness of our shared vulnerability as part of the human family, moves us closer to this ideal. Across society, so many remain hoodwinked by the myth of some fundamental difference in the humanity of those designated as with disability and those not, supporting division, inequality and an alienation from self in all. Leslie's insight remains that disability struggle is not only continuous with human struggle, it is foundational to it. Consequently, an open-hearted engagement with our fears and assumptions about disability has much to teach us about overcoming human divides of all kinds, lighting the way to a more caring society. These learnings have powerful consequences on both the societal and internal plains; I thank Leslie for guiding us towards a more inclusive and humane future.

## Acknowledgements

### Competing interests

The author declares that no financial or personal relationships inappropriately influenced the writing of this article.

### Author's contributions

B.W. declares that they are the sole author of this research article.

### Funding information

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

### Data availability

Data sharing is not applicable to this article as no new data were created or analysed in this study.

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