

# Integrating scholarship and practice: A journey in disability advocacy and community empowerment



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## Introduction

This article reflects on the intersection of disability scholarship and practice by examining how the academic contributions of Leslie Swartz have shaped – and been extended by – the work of ChangeAbility, a community-based organisation in South Africa's Cape Winelands. Drawing on my dual role as disability activist and Chief Executive Officer (CEO), this article explores how ChangeAbility's initiatives operationalise Swartz's insights on systemic barriers, health inequality and participatory inclusion. It argues that non-profit organisations are not merely sites of implementation but are active contributors to theory, adapting and advancing academic frameworks in response to lived realities.

When one explores the work of Leslie Swartz on Google Scholar (2024), it is clear just how influential his scholarship is. His work is cited in 21 616 other sources, and he has a prolific publishing record. In 2024 alone, a search on him yields 116 results. His work is primarily in the disability field, where he explores a variety of topics. Swartz's work is also complemented and expanded on by other disability scholars from the developing world, such as Ghai's (2015) insightful study on disability in the Indian context, Botha's (2021) study on blindness and rehabilitation in South African non-profit organisations (NPOs) and Schneider's (2016) exploration of poverty and disability in South Africa.

Swartz's critical engagement with systemic barriers (e.g. lack of transport and cost-effective services, such as found for example by Eide et al. 2015), his advocacy for integrated health approaches (e.g. Van Rooy et al. 2012:761–775) and his emphasis on participatory models of inclusion (e.g. Swartz 2023:1–1) have shaped both my theoretical understanding and practical efforts in fostering disability rights and social change in the Cape Winelands of South Africa.

I am the CEO of ChangeAbility, a NPO based in Stellenbosch, South Africa. ChangeAbility serves over 400 beneficiaries with disabilities in five impoverished communities of the Cape Winelands. ChangeAbility provides health, awareness, community and skills support through a variety of projects (ChangeAbility n.d.).

I have served as CEO of ChangeAbility since completing my Doctorate, under the supervision of Swartz, in 2013. My dissertation explored disability employment attitudes and practices in South African companies (Wiggett-Barnard 2013). My role at ChangeAbility allows me to be a disability scholar, activist and non-profit leader. That being said, I will be remiss if I don't take Swartz' advice that:

[D]isability scholars need to appraise more carefully the investments of the more powerful (which includes us as non-disabled white South Africans) in how the less powerful are presented and called upon to participate in the production of knowledge on disability. (Swartz & Marchetti-Mercer 2018:485)

The following paragraph will reflect on my positionality.

As both the CEO of ChangeAbility and the author of this article, I occupy a dual position that offers unique insight but also presents the potential for bias. My close involvement in the organisation's strategy and operations inevitably shapes my interpretations of its successes and challenges. While this proximity enables a nuanced and informed analysis, it also necessitates critical self-awareness. I acknowledge that my position as a leader and advocate may influence how I frame the impact of our work. In line with Swartz's caution regarding the influence of powerful actors, I recognise the

**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.

responsibility to interrogate my own assumptions and to remain accountable to the voices and experiences of the communities we serve. This reflection is offered not to negate the value of insider knowledge but to show the importance of transparency, reflexivity, and humility in bridging scholarship and activism.

This article reflects on the work of Swartz and ChangeAbility, with specific reference to the intersection of addressing systemic barriers, promoting health and enabling participation and inclusion for people with disabilities. Insights for this article were gathered through a combination of donor reports, in-person interviews, and group observations. Donor reports provided valuable data on project outcomes, while interviews with staff, peer supporters and participants offered direct feedback on their experiences. Observations during group sessions and peer support meetings allowed me to see first-hand how our initiatives are implemented and how role players engage with them. This approach provided a clear and practical understanding of how ChangeAbility's work is shaping outcomes in the community.

## Addressing employment barriers

'People with disabilities experience barriers in the integration phase of employment' (McKinney & Swartz 2019:2298). The recommendations from this qualitative study on 72 people with disabilities includes ensuring that all phases of the employment process be accessible and appropriate for people with disabilities and that barriers to employment be addressed and acknowledged by human resources departments and employers.

Through ChangeAbility's awareness and sensitisation campaigns, we actively challenge these barriers, working to dismantle employer stigma and promote meaningful workplace inclusion. Our approach to sensitisation training, both with corporates and local government, adhere to the principle of 'Nothing About Us Without Us' (as explained by Charlton 1998). When we engage with employers, we guide them through the phases of employment similar to McKinney and Swartz (2019), by addressing job application forms, the interview protocol, selection and disclosure practices. We echo the conclusion that:

[I]n order to successfully recruit and select people with disabilities, it is important that those responsible for the phase of employment be aware of the barriers facing people with disabilities. In addition, they should have knowledge, skills and understanding relating to disability and people with disabilities. (p. 2314)

My own insights gained from my PhD (Wiggett-Barnard 2013), under the supervision of Swartz, informed us additionally on the employer perspective with regard to disability employment. With a clear understanding of opinions and attitudes from managers, the influence of company practices and policies and potential initiatives to enhance disability employment, as well as clear recommendation, research was able to inform the content of the sensitisation training performed by ChangeAbility. These

insights were also incorporated into ChangeAbility's latest online training offering to the hospitality industry, hosted on Sytème.io from September 2024.

In addition, our skills development programme has given people with disabilities skills and directly promoted employment opportunities while addressing the high levels of poverty and inequalities that Swartz highlight for this population. 'Disabled South Africans are, collectively, amongst the nation's poorest, even within a country characterised broadly by atrocious levels of economic inequality' (Swartz & Watermeyer 2006:1). Against this backdrop, ChangeAbility recruits, trains and employs people with disabilities as peer supporters. Over the past eight years, 23 people with disabilities have undergone accredited training, received a wage and gained work experience through this programme. These peer supporters are employed part-time to render support services to adults with disabilities and their families in the community in which they live and work.

ChangeAbility's peer support model equips individuals with disabilities to take on leadership roles and drive change within their communities. We use the World Health Organization's community-based rehabilitation (CBR) model of service delivery (ILO, UNESCO & WHO 2004). This model dictates that people with disabilities, their families, their communities and service providers should form partnerships to improve opportunities and social inclusion. As such, we recruit, train and employ unemployed people with disabilities as peer supporters. Each of these peer supporters is tasked with finding and performing needs analyses with people with disabilities in their own community. In just over three years, we have given peer-to-peer support to over a 1000 people with disabilities. We continue to provide ongoing training and guidance to our peer supporters, and they serve as our main community representatives.

Despite the success of our initiatives, there are challenges to the success in addressing employment barriers. One major barrier is the resistance and lack of motivation to change within some employers, where entrenched attitudes and misconceptions about disability slows progress. In addition, the ongoing need for resources to sustain our training and support for both employers and peer supporters remains a challenge. Finally, ensuring that our peer supporters can maintain their roles while balancing their own needs and responsibilities within the community also presents a constant logistical and training challenge. Nevertheless, we continue to adapt our approaches to overcome these barriers and drive meaningful change.

## Health promotion strategies

The following quote introduces the importance of promoting physical activity among marginalised groups, such as persons with disabilities:

Participation in regular physical activity promotes physical health and psychosocial well-being. Interventions are thus needed to promote physical activity, particularly among groups of individuals, such as persons with disability, who are marginalised from physical activity. (Conchar et al. 2016:152)

Swartz co-authored this qualitative study on factors that facilitate and hinder participation of 15 South African adolescents with Cerebral Palsy (CP) in physical activity. The study found four themes that influence physical activity participation. These were physiological factors (inherent to the individual's own body), intra-psychological factors (inherent to the individual's own thought processes), social factors (relationship influences) and macro-environmental factors (structural factors and environmental influences). The study concluded that:

'... the development of programmes to increase participation in physical activity will need to be innovative and take careful account of these realities if they are to be effective and sustainable.' (p. 162)

While this qualitative study was limited to youths with CP only and can thus not provide a comprehensive picture of all the barriers and facilitators that participation of physical activity can address, it did provide very similar findings from our own experiences at ChangeAbility.

ChangeAbility's weekly community-based exercise groups, which support individuals with disabilities in improving mobility, health and social connections, exemplify how integrated programmes can transform lives and communities. In 2024, we had 261 people with disabilities participating in our five community-based exercise groups. From the start, we realised that we would need to address the multiple challenges to exercise that people with disabilities face. If we compare our experience with the themes identified by Conchar et al. (2016), there is a very clear link between the research that Swartz contributed and our approach. In order to address the physiological factors, we partner with Stellenbosch University's Sport Science Department and conduct twice yearly health checks with exercise group participants. The Department's students also adapt the exercises to different abilities and take functional limitations into consideration. Our exercise groups are regular and consistent, giving participants the peace of mind and safe spaces to address intra-psychological concerns. The group setting and regular contact with peers, as well as involvement of significant others is often the main reason that participants attend our group exercise. And finally, the provision of free, disability-friendly transport and accessible venues address the macro-environmental factors.

In addition to the promotion of health, the work of Swartz and colleagues also call for strategies to address inaccessible healthcare for persons with disabilities (PWDs) (Eide et al. 2015, as well as Tomlinson et al. 2009). Among the barriers identified by Eide et al. (2015), a lack of transport and availability of health services was prominent. Eide et al. (2015:12) calls for an equitable health services, 'addressing the specific barriers that exist for different types of service users'. Watermeyer and Swartz (2023) also emphasised health discrimination and exclusion and that disability not only influences the quality of healthcare received but also that poor healthcare also causes disability.

Tomlinson et al. (2009), in their earlier study, also identified that barriers to accessing health services for people with

disabilities should be a research priority. In two rural South African studies by Swartz and colleagues (Vergunst et al. 2015, 2019), the researchers 'found that persons with disabilities have poorer health outcomes than persons with no disabilities' (2019:2676), and that better access to healthcare is needed in South Africa. The earlier study by Vergunst et al. (2015) emphasised that both practical and attitudinal barriers to accessing healthcare in South Africa must be addressed.

A good illustration of how this can be achieved in practice took place in our Macassar service area. Our social workers and peer supporters were instrumental in identifying the barriers' experiences by our beneficiaries at the local healthcare facility. They then went about building relationships with the health care facility manager in addressing these barriers, especially for wheelchair users. This led to the subsequent adoption by the local healthcare facility of a new protocol for health service delivery to wheelchair users specifically. This protocol was reviewed by the Macassar Disability Forum and ChangeAbility staff and have been in place for the past two years.

These initiatives mirror Swartz's argument that health interventions must address both individual and societal dimensions.

## Enabling participation and inclusion

In a co-authored article (Mji et al. 2011), an 'African way of networking around disability' is explored. The article reports on the successes and challenges of the African Network for Evidence-to-Action on Disability (AfriNEAD) network and applies the concept of Ubuntu to encourage collaboration. The AfriNEAD was created to translate research to real-world positive changes for PWDs in Africa by providing networking and collaboration opportunities among all stakeholders (Stellenbosch University 2025).

From the creation of AfriNEAD in 2007, it became clear 'that integral to the process of developing sustainable networks within an African cosmology is the need to pay close attention to the relationships amongst participants' (i.e. all relevant stakeholders, from researchers to activists and those living with a disability themselves) (Mji et al. 2011: 366). Later in the article, the challenges for AfriNEAD are mentioned, of which one is the central role that persons with disabilities themselves should play, both in informing research, but also in bringing about change in their communities.

When one compares the work performed by Swartz and colleagues in establishing AfriNEAD, there are clear parallels with the work that ChangeAbility does via its Awareness project. From the time that we established the Awareness project at ChangeAbility in 2014, I was cognisant of the fact that we need to strengthen the voices of people with disabilities themselves, as well as form a collective voice for Disabled Persons Organisations (DPOs) in the Cape

Winelands. The first network of this nature that we consequently established was the Stellenbosch Disability Network (SDN).

The SDN is a civil network and was established in October 2014. It is an open network for any organisation and members of the public and interested parties wishing to share information, raise awareness and ensure the inclusion of disability in local planning and service delivery in greater Stellenbosch. The SDN works to advance the full inclusion of, and opportunities for, people with disabilities in all aspects of development, planning, learning, working and living. The SDN envisions a Stellenbosch where all people with disabilities are acknowledged and enabled to thrive and participate fully in all aspects of public and private life.

In 2018, ChangeAbility also established a similar network in the Helderberg area, situated to the near south of Stellenbosch. The Helderberg Disability Network (HDN) was established to: share information and build a database on disability-related services and organisations, identify and record challenges faced by the disability sector and people with disabilities, ensure the inclusion of disability in local planning and services, avoid duplication of services and maximise the use of limited resources, raise awareness and sensitise the public on disability-related themes, build capacity within organisations to increase their efficacy and success and share responsibility for the betterment of people with disabilities in the community.

In order to make information more readily available to those who work and live in the Stellenbosch and Helderberg area, ChangeAbility created a website to share the details of local DPOs during 2020–2021 (Mapping Disability n.d.). It is crucial that when one does research for disability, even something as simple as gathering information from existing organisations, that it becomes readily accessible and available for all stakeholders to use.

In addition to the SDN and HDN, ChangeAbility facilitated four forums for people with disabilities in the communities of Macassar (City of Cape Town), Groendal (Franschhoek), Cloeteville and Kayamandi (Stellenbosch). Our main outcome for the forums was to create a system of collaboration and networking to identify needs and do creative problem solving for and by people with disabilities in their own communities. In the past year, we facilitated 16 forum meetings (one meeting per community per quarter).

The ultimate goal of ChangeAbility's Awareness project is to promote inclusive planning, service delivery and recognition of people with disabilities in the communities that we serve, as well as developing the skills of people with disabilities to become activists themselves. This resonates with the work that Swartz and colleagues have done via AfriNEAD and beyond.

In addition to advocacy and networking efforts towards disability inclusion, it is also stated that 'persons with disabilities

require a range of supports to be integrated into their communities, to participate in activities and to have access, on an equal basis to persons without disabilities' (Hunt et al. 2022:8269). Again, Swartz co-authored this scoping review on community support services in low- and middle-income countries. Important topics covered by this scoping review, combining peer reviewed and grey literature, found key support structures needed under each ecological level (individual, family, community and policy and/or environmental level).

The work of ChangeAbility reflects such a multi-level approach to community support for our beneficiaries. We have one-on-one support from trained social workers and peer supporters to address support needs on the individual and family level. We have community-based support and exercise groups, as well as partnerships with local service providers to address disability-related needs on a community level. Finally, with our forums and our work on tender with Stellenbosch municipality, we address the policy and environmental level of support.

Swartz's commitment to participatory approaches is reflected in another co-authored article that explored the partnerships between academia and Disabled Persons' Organisations (Kett et al. 2019). The article discusses how capacity is built, the advantages and disadvantages of collaboration, as well as the long-term outcomes of disability-inclusive research. ChangeAbility's involvement with academia mirrors the findings for this article. We have people from academia on our volunteer management committee, as partners in our exercise groups and as researchers into our community work.

From the Kett et al. (2019) article, DPO members suggested:

'... that one key learning provided through partnership with a DPO is the training they can provide around disability'. This benefit was also highlighted in another study by Swartz and colleagues (Rohleder et al. 2008). This study confirmed that the 'community work' that students do 'achieve a broadening awareness among students from different backgrounds about the notion of community' (p. 253)

We have found this to be the case, especially in our work with students from Stellenbosch University's Sport Science Department. We have also been able to, as the article found, be a bridge between researchers looking for participants and identifying potential participants, especially where there is a clear benefit to the community. Finally, we have also found that our beneficiaries with disabilities welcome being photographed as part of our reporting and marketing, but that their dignity should be protected at all costs. This is similar to the findings of Swartz and colleagues (Mji et al. 2014) on whether people with disabilities in rural South Africa mind being photographed in research.

## Conclusion

This article reflected how Swartz's theoretical insights have shaped ChangeAbility's practical work. It reflected on the work of Swartz and ChangeAbility, with specific reference to

three areas, namely addressing employment barriers, promoting health and enabling participation and inclusion for people with disabilities. As far as addressing employment barriers, ChangeAbility's peer support programme has provided skills training and employment opportunities for previously unemployed adults with disabilities while also engaging with employers and hospitality professionals. Health promotion is also a priority for ChangeAbility and through our weekly exercise groups and collaboration with Stellenbosch University, we systematically address the barriers to accessing healthcare that Eide et al. (2015) and Watermeyer and Swartz (2023) highlighted. Finally, our organisation is enabling participation and inclusion through the establishment and facilitation of the SDN and HDN, as well as a crucial online resource that share the details of local DPOs. This echoes the work performed by Swartz and colleagues in establishing AfriNEAD.

This article highlighted the intersection of academic scholarship and community work, demonstrating how the integration of both approaches can be instrumental in addressing the complex barriers that people with disabilities face. This synergy contributes to the ongoing efforts to create a more inclusive and equitable society. This commitment to disability activism is clearly stated by Swartz (2018) as follows:

I view my work on the African Journal of Disability as a form of academic activism; I believe I am playing a role in assisting a number of people who would not otherwise publish to express and disseminate their thoughts and experiences. (p. 124)

The emphasis on participatory models of inclusion is promoted by Swartz, as illustrated by the following quote: 'The focus for disability inclusion should not be solely or primarily on bodily impairments but on barriers to participation' (Swartz 2023:1). He also calls on science to be more inclusive, not only in being included as a topic on social justice but also to become more accessible to people with disabilities themselves. As an activist leading ChangeAbility, I believe we showcase how the marriage between academic research and practical interventions can work.

Looking to the future, the integration of Swartz's theoretical insights with ChangeAbility's community-based practice provides concrete opportunities for transforming how disability inclusion is approached in policy, research and service delivery. Specifically, the model demonstrates that combining academic frameworks with practical interventions can lead to more sustainable employment for people with disabilities, improved access to health promotion activities and stronger, community-driven support systems. This suggests that inclusive development efforts must prioritise not only service provision but also the empowerment of people with disabilities as leaders and knowledge producers. Swartz's call for science to become more accessible underscores the importance of creating academic spaces where people with disabilities can actively participate – not just as subjects, but as co-researchers and contributors.

Finally, to further advance disability service-delivery goals, there is also a need for more formal, evidence-based research to be undertaken in collaboration with NPOs such as ChangeAbility, whose impact is often supported by anecdotal evidence, rather than systematically collected data. Documenting and analysing the work of NPOs could produce better and more systematic outcomes, inform inclusive programme design across sectors and ensure that effective disability service delivery is embedded within broader national development strategies and policies.

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