PERSPECTIVES IN REHABILITATION

Power, politics and rehabilitation in sub-Saharan Africa: from the personal to the political

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Abstract

This article discusses the complexities of facilitating community-based rehabilitation in resource-poor contexts in Sub-Saharan Africa. It does so through a reflection on the book Able-Bodied: Scenes from a Curious Life, written by Leslie Swartz, a South African expert on disability in the context of international development. Swartz uses his own personal experiences as son of a disabled father as a springboard for reflections on his long involvement in the often-fraught areas of disability research and activism. He pays particular attention to the way in which emotions shape the struggles around expertise and power that bedevil disability identity politics. In particular, his work highlights how the complex dynamics of race, class and disability undermine the effectiveness of the movement.

Keywords: Africa, politics, community-based rehabilitation

It is well established that rehabilitation needs are the greatest in regions of the world where there are scarce resources. There is a reciprocal relationship between disability and poverty, with each reinforcing the other. Paradoxically, though, it is precisely in the regions where there is greatest need that there are the scarcest resources and the smallest evidence base on which to build appropriate interventions. One such region is sub-Saharan Africa, a region beset with many challenges, including endemic poverty, poor infrastructure and communications networks, widespread social disruption through war and civil unrest, governance challenges, epidemics (including HIV/AIDS) lack of health facilities and a brain drain of skilled health and rehabilitation personnel to wealthier countries.

Despite the challenges that exist, there is also increasing evidence that it is possible in sub-Saharan Africa to innovate in the field of rehabilitation and in community-based rehabilitation in particular. Though it would be a mistake to be too romantic about what has been and still can be achieved, vibrant community-based models do exist and are being developed. At the heart of almost all such initiatives are partnerships between those with more skills in the conventional sense of the word, and those who have local skills and knowledges. Pragmatism and flexibility have to be the order of the day, with boundaries breaking down between traditional roles, and professionals and non-professionals working side by side, not in prescribed roles, but in a spirit of needing to get things done.

For these initiatives to work, though, it is essential that relationships amongst all parties are good, that there is mutual respect and a lack of hostility and suspicion amongst parties. Depictions of such relationships in the literature are often very positive (at times glowing), but this depiction may mask another side of work in resource poor contexts. Community-based rehabilitation projects, like many other community-based projects in Africa and elsewhere, may face challenges of burnout, high staff turnover, internal conflicts and struggles for power and resources. Competing sets of ethics may apply— for example, one person’s nepotism may be another’s ethical imperative to find work and resources for
Leslie Swartz, author of *Able-Bodied: Scenes from a Curious Life*, is uniquely placed to comment on these difficult issues. Swartz is a clinical psychologist well known for his work in the mental health and disability field. He is well published in the academic and professional literature and enjoys an international reputation as a key player in disability, mental health and development literature. Research by Swartz and his colleagues has been reported in high impact international journals, and he has been successful at attracting research funding. At the same time, though, Swartz is a white, able-bodied South African man employed at an institution (Stellenbosch University) which though in the throes of some very impressive reforms, was formerly the intellectual home of apartheid. Indeed, the department in which he works was formerly associated with none other than Hendrik Verwoerd, the South African prime minister who was key in the development and entrenchment of the most brutal apartheid policies. If there is anyone who has visceral experience of the ambiguities and contradictions of identity politics in the disability and development field in sub-Saharan Africa, then, it is Leslie Swartz.

In *Able-Bodied* (an appropriately ironic title if there ever was one), Swartz abandons his more accustomed voice of the dispassionate academic, the formal researcher, the contributor to randomised controlled trials and to large-scale surveys, for a much more personal, often humorous tone. Part of Swartz’s avowed intention in his role as both academic and self-described activist for the rights of disabled people is to open the issue of disability and disability rights to a wider and more general audience: to be, in a word much prized in disability activism, accessible. Alongside producing academic collections such as the recent *Disability and International Development* [1] co-edited with Malcolm MacLachlan, for example, Swartz et al. have worked with Angela Buckland, a photographer who has a disabled child, to produce a text, intriguingly entitled *Zip zip my brain harts* [2], which is visually very appealing and which speaks to parents and professionals in such a way as to engage the emotions – this is an activism of personal engagement. *Able-Bodied* takes this trend in Swartz’s work further – it is at once a popular book in the currently fashionable mode of personal memoir (complete with delightful family pictures), and a book which helps the reader to engage deeply and personally with disability and development issues [3].

The fact that the book is simply a good read, and interesting and fun book to engage with, would be enough to recommend it highly, but beneath the surface of often hilarious and at times very moving anecdote, there is a serious purpose to this unique piece of activism. Not only is Swartz doing what we are all called on to do with our professional and research work – to make the findings and the lessons more widely understood and more widely available – he is at the same time making a more subtle, but no less important point. He is not simply popularising, he is also embodying through his work his firm belief, based on years of experience in the development and rehabilitation fields, that emotions matter. The
difficult personal emotions which come into play in this work are not for Swartz simply epiphenomena which need to be managed or even got rid of – they are, for him at the heart of the work. Central to his understanding of disability politics in his part of the world and, indeed, elsewhere, is his view that the enormous personal investments we all have in issues of disability, the feelings we have about brokenness, exclusion and experiences of humiliation, are at the heart of much disability politics. For Swartz, it is these keenly felt experiences of shame, disgust, envy and confusion which not only are occasioned by disability politics but also, in part, constitute and shape disability politics themselves.

Given this view of Swartz, in his book *Able-Bodied* he does the logical (some would say brave, some would say foolhardy) thing – in this work he writes not primarily from the head but from the heart. He tells his family’s fascinating tales, both to entertain and draw the reader in (and the book is every bit as entertaining as a good novel) ans to show, using his own life as an exemplar, how important and central the personal is to professional and political work. We read, therefore, with interest, about the troubled relationship Swartz had with his own father, who was disabled, and with the powerful role played in the family by two formidable but knockabout characters – Swartz’s ‘large Wagnerian grandmother’ whose life, she felt, was blighted by her producing disabled children, and her sister known as ‘the Buchenwald Chicken’, a bitter, angry woman who felt the world owed her better. The poignant and funny stories Swartz tells about these characters, these family secrets, layer on to a lifetime’s work as a scholar and activist. When Swartz, for example, discusses his confrontation an obnoxious and all too familiar disability activist from Europe at a meeting held in a very hot tent in an African city, he shows how his own behaviour in this very public and political arena, though politically well founded, gains its impetus from his own personal experiences of disability in his family.

Swartz is not afraid to confront difficult issues, but he does this in a unique way. He describes in some detail, for example, how a process of developing a large scale research project in the disability field becomes derailed not through difficult relationships between disabled and able-bodied people but through something more sinister. He describes working with an able-bodied researcher who has replaced academic and research rigour (viewing this rigour as elitist and exclusionary) with a commitment to participation and development which is not in fact thought through. The researcher produces sub-standard work but refuses to engage with questions of the academic merit of the work, retreating instead into rehashing slogans about the importance of issues of participation in research processes. Quite chillingly, Swartz argues that disabled people are not uncommonly given a raw deal by able-bodied researcher activists – they are given work which scores high on participation and low on rigour and usefulness. This happens, Swartz argues further, not as an unfortunate byproduct of disability work, but because of the nature of the work itself. Because of our own uncomfortable and commonly unacknowledged struggles with disability and difference, Swartz suggests, we may enter into collusive relationships between disabled and non-disabled people in which we pretend that our difference and our feelings do not matter. A byproduct of this collusion, Swartz suggests, may be that it is easier to do work which does not lead to any change, because change will expose the differences and difficulties which make us all feel so uncomfortable.

*Able-Bodied* is a very unusual book, and a book which resists convention and pigeon-holing. It is a good read, the sort of book you could give to a friend for Christmas. At the same time though, it uses very accessible methods to engage with deeply serious issues, issues which are of key concern to all those wishing to improve the lives of disabled people in Africa and beyond.

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**References**