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

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Abstract:

This paper 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.

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It is well established that rehabilitation needs are 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 nonprofessionals working side beside 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 poor-resourced 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 their family members when resources are scarce. This side of rehabilitation work and of development work in general is commonly glossed over especially because international agencies and funders are understandably concerned that their resources are best spent and used for the means for which they have been intended rather than to fuel internal squabbles and interventions which represent political compromises rather than the best that can be done. The issues at stake are simultaneously political, ethical, and personal, and it takes some courage to discuss them openly, in a critical but constructive manner.

Layered on to the politics which is a feature of all development work in sub-Saharan Africa and similar contexts is another level of politics which confronts all those wishing to work in the field of disability. This is the issue of disability identity politics, and the struggles around expertise and power which are a hallmark of disability-related work. Nobody who has worked in the rehabilitation field for any length of time in wealthier countries can fail to be aware of the importance of slogans such as “nothing about us without us” and with the widespread mistrust of professionals and the so-called “medical model” among activist groups, a mistrust which is well founded in a history in which professionals have failed to engage with or even to recognize the agency of disabled people themselves. This battle of disability politics is by no means over anywhere in the world, nor should it be, but it takes on a particular meaning and valence in sub-Saharan Africa, where disability politics interfaces with the struggles around development and community building which have been discussed earlier. If we are to sustain and develop good models of disability work in the development field in sub-Saharan Africa and elsewhere, we need to have a way of understanding the dynamics at play – of not avoiding them or glossing them over, of avoiding the alternative overly pessimistic (“Africa as basket case”) story of this world, but of engaging bravely and honestly with the issues at hand. We need to face them and to become more comfortable with them if we are to be able to address them adequately.

How do we do this? It is no easy task to achieve our goals in disability and development work, but an important and original new book takes an unusual route to providing us with just the help we need. 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 randomized 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* (Springer, 2009) co-edited with Malcolm MacLachlan, for example, Swartz and colleagues have worked with Angela Buckland, a photographer who has a disabled child, to produce a text, intriguingly entitled *Zip zip my brain harts* (HSRC Press, 2006), 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.

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 popularizing, 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) but 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 are engaging in themselves but Swartz uniquely shows how these personal stories, 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 nondisabled people in which we pretend that our difference and our feelings don’t 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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