

VOICES FROM THE FIELD

My ‘disability and development’ journey: reflections*

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In this reflective paper I will be talking about relationships. AIDS, Power, Politics...dealing with each of these and all of these boils down to relationships. In order to explain how, I would like to share a bit of my own history with you. I would like to tell you a bit about my first experience living outside Canada. I did not spend a gap-year in Europe...rather, as a student of development studies and environmental science I embarked on a year of studying abroad in Ghana.

I was not a disability activist. I was an environmental activist – committed to student organising throughout secondary school and into my undergraduate years. Yes, I had a congenital condition that meant I had lived with a disability all my life. I trained and competed in wheelchair sports throughout secondary school and spoke out about issues of injustice, inappropriate language, exclusion but I didn't see myself a disability activist. I was an environmentalist (and would love to continue to be, but with the amount of carbon miles I've incurred in the past few years, I'm afraid I can't really claim that label).

In any case, I arrived in Ghana for the beginning of my 3rd year of undergraduate studies. I moved in with a Ghanaian family upon my arrival and was determined to listen and to learn that year. I was interested in traditional medicine, herbalists and village healers. Or so I thought...but what struck me was that in the first couple of weeks the only disabled people I saw were on the side of the road begging. So, sure, in the day time in lectures I was pondering community projects and post-colonial theories but on my way home I was wondering if that's the corner I would be sitting on if I had been born in Ghana. Was begging the only option? Before too long, I met some musicians practicing under a tree outside the gates of the University of Legon (in Accra). I loved the music and would sit under a nearby tree listening to them on my way home from lectures. Many of the musicians seemed to be more or less my age, and one of them had a visible mobility impairment, having had polio at a young age. This was my first glimpse...that, no, even here begging was not the only option...

So, months went by and I moved up to Tamale in Northern Ghana where we were to begin a

*Paper previously presented at the Disability and the Majority World Conference Manchester Metropolitan University, 8 July, 2011

sort of 4-month volunteer placement or work-experience after which we would write a paper and present on our experiences to gain credit for this portion of the course. I wasn't planning on working on disability rights. But, during my course-work, I had come across the Resource Centre for People with Disabilities in Tamale (which, at the time, was funded by UK-based Action on Disability and Development). I was surprised and delighted when the chairperson of the resource centre asked if I would spend my 4-months with them. Of course I agreed! My other Canadian classmates had to almost beg to be accepted at other agencies and here I was being invited. I was grateful.

Soon upon my arrival at the Centre, the people who worked and spent time at the resource centre told me that they had never met a "white disabled" before. Now, I bring this up not to make my Ghanaian colleagues at the Centre seem backwards or uneducated but rather to just remind us of who it is that we (in the west) usually send on international placements. Where I was in Tamale was far from the capital, a city but in a very rural region. Goats and cattle in the streets with bicycles weaving between. The Canadians (and other foreigners) that show up there from overseas are, for the most part: young, white, well-educated, non-disabled. Not quite representative of the cultural, linguistic, racial and other diversity that I encounter in Canadian towns and cities.

To be honest, when I started coming to the Resource Centre on a daily basis, I felt I didn't do much *real work* – sure I helped refine some funding proposals, helped plan a few events, went to pick up the post...but mostly I just had long conversations. People wanted to know what it was like being disabled where I came from. Probably the most common question was if I was married and if...in our place, it was also difficult for a disabled woman to find a husband. We talked about husbands, wives, boyfriends and children...you see? Relationships! We talked about the struggles families with disabled children face.

I told them the story of Tracey Latimer...

They were horrified at the very thought at a father could do such a thing and that he wouldn't be justly punished in a country such as Canada.

Maybe the name of Tracey Latimer is not familiar to all of you: Tracey was a teenager with CP in rural Canada who was killed by her father in the late 90s. Her father put her into their car, connected a tube from the exhaust into the window, turned on the ignition, left the garage and killed his daughter by carbon monoxide poisoning. Frighteningly, his trial produced an outburst of sympathy for him, and not a cry of outrage against the murder. Somehow, the public bought his argument that he was doing this out of "love" because she was "suffering and in pain." The disability rights movement in the province of Saskatchewan and the Country trembled with fear at the implications of this public opinion and proceeded to mount significant protest. Finally, despite a frightening amount of indecision in the courts, the

Canadian Supreme Court ruled that the minimum sentence of 10 years for 2nd degree murder should be upheld. But the Latimer Case continues to be an emotive one in Canada. Latimer's name is still in the media and to this day he has never expressed any remorse and he continues to enjoy massive public support.

Like Shaun mentioned in his keynote yesterday, too often we just talk about the Africans who kill disabled children at birth. As if similar incidents don't happen in Canada, or the UK. As if there are not loving, generous African parents who will walk for miles with their child in their arms, to see if any basic rehabilitation assistance could be provided in town.

But seeing as I was only 20 at the time, we were talking a bit more about relationships that about children.

I was impressed with how the friends and colleagues I found at the resource centre spoke of disability in terms of social exclusion: "He won't marry me because his family thinks I can't cook." About how societal perception disables them based on physical difference and perception of inability.

The chairperson of the resource centre, named Madam Mercy Apoe, took me under her wing and instilled in me the sense that as educated disabled people we had a responsibility to work tirelessly for the improvement of the situation of our other disabled brothers and sisters who did not have the access to education and sense of empowerment as we did.

Growing up, I was instilled with a sense of social justice and need to speak out against injustice and discrimination but I had not really come across disabled people that framed their struggle in that way growing up in Canada.

I now know that they are there too...but at the time I was more inspired by environmental activism and the movement against corporate globalisation, protests in Seattle and Quebec City than disability politics.

But Madam Mercy, my adopted Ghanaian mother, had planted a seed and was watering it... I started asking myself, as an educated Canadian with the freedom to speak, write, and travel; am I in a unique position to work for the promotion of disability rights internationally?

There was one conversation I remember that I could say set me on the track that I continue to follow today. Madam Mercy often pointed out examples of so-called mainstream development organisations working with women's groups, micro-finance and so on who came into communities where there were groups of disabled people but yet they failed entirely to include these people into the cohort of their beneficiaries.

But there was one conversation when Madame Mercy felt particularly frustrated by their struggle to get funding or attract attention from the NGOs that seemed omnipresent in Tamale. She said, “Everyone is coming in to do HIV now, but no one will come to us. What? They think that we’re not also at risk? Don’t they see we also have children? How do they think that happens?”

The seed was planted and watered earlier, and now she had just fertilised it.

The academic year ended, I returned to Canada and soon found myself back in lectures at Queen’s University for my final year of studies. I continued in my Critical Development Studies programme but tried to insert a disability perspective into my work at every opportunity. I took a module on social drivers of HIV and AIDS and this resulted in a research paper focused on the risk factors disabled people faced in regards to HIV/AIDS: invisibility, perception of asexuality and evidence of widespread vulnerability to sexual abuse. This was 2003, Nora Groce’s landmark World Bank Global Survey on AIDS and Disability had just been launched.

We were facing a situation where, in some countries in Southern Africa 1 out of every 4 people were infected with HIV. Amongst black youth in South Africa, it could be said to be as high as 1 in 3. Inevitably, amongst disabled people the same ratio would exist, if not a higher one because disabled people faced consistent barriers to prevention messages and accessing testing centres. Yet, the majority of AIDS-service organisations were entirely ignorant of the fact that disabled people should be within their target audience.

So, in the summer of 2004, I presented my paper at the inaugural meeting of the Canadian Association of Disability Studies, and through the relationships developed there, I was offered an internship with DPI (Disabled Peoples International) and Disabled People South Africa to assist with the development of an HIV/AIDS strategy and programming for DPSA members.

Around the same time, the results Nora’s World Bank/Yale University Survey were published in *The Lancet* and, finally, we could quote a reputable source saying “People with Disabilities are at an equal or greater risk of every known risk factor to HIV/AIDS.” At long last, there was a concerted call for cooperation between AIDS activists and the disability movement.

I hope that these background stories are giving a bit of a sense of the history and motivation for my work at the intersection of AIDS and disability...I was pushed by the critical perspectives offered me by my foundations in critical development studies and inspired by my conversations with colleagues in Ghana and beyond as my networks expanded from Canada.

So, in 2005, I travelled to Cape Town and lived and worked there for 6 months.

South Africa was a completely different experience from Ghana. I lived in Cape Town, the biggest city I'd ever lived in my life, definitely no goats or sheep crossing my path on my way to work! And I was placed at the largest DPO-umbrella organisation in the country. I was at the national office, in a multi-story office building, minutes away from the houses of parliament and St. George's Cathedral. I had to spend more time in front of a computer than I had in Ghana, or previous jobs, but I still found enough opportunities for long conversations with staff – both disabled and non-disabled. And I took every opportunity I could to visit member organisations in Khayelitsha, Gugulethu and other townships surrounding the city.

But, sadly, it was during this contract, while based at a DPO and working on issues related to HIV and AIDS, that I became acutely aware of the dynamics of power and abuse of power that exist – even in an organisation that ostensibly works to dismantle systems of oppression and marginalisation in society.

If nothing else, the global AIDS pandemic teaches us about the pernicious ways that social marginalisation on the basis of gender, monetary wealth, education, race, access to media and resources can fuel an epidemic. Yes, HIV is a virus, a purely physical, biological reality; but the pathways it follows as it wreaks havoc amongst communities is largely contingent on social, inter-personal realities. Relationships – husbands and wives, uncles and school girls, gay men and fundamentalist Christians, rape victims and legal services, disabled people and their carers. Each of these relationships of power differentials fuel the pandemic. And just as much as we need to fight for access to services, to medicines and so on we need to work to understand and then dismantle the underlying structures of power and inequality that allow exclusion to continue.

Similarly, we acknowledge that it is social structures and prejudicial attitudes that turn common physical realities whether it be speech impairments or hearing impairments, albinism or epilepsy, into severely alienating disabilities.

After decades of struggle against HIV and AIDS, in the last few years the AIDS movement is acknowledging the need to frontally address homophobia, hegemonic masculinity, and gendered socio-economic disparity - if it is to turn the tide of the AIDS pandemic. But we have not yet adequately acknowledged this within the international disability movement.

Let me take you back a bit again...Shortly after returning to Canada from Ghana, I read a book by Canadian sociologist Sherene Razak called *Looking White People in the Eye*. The book explores racism, sexism and ableism in Canadian courtrooms and classrooms. She writes about interlocking oppressions how each form of oppression re-enforces and augments the other. And how, even though she is often in a marginalized position as a black, muslim,

woman...she must also recognise how in other social interactions she may actually be the one exerting power as an educated, non-aboriginal, non-disabled Canadian citizen. In order to combat ableism in our society it is crucial that we also combat sexism and racism and other forms of oppression within our own movement, our organisations, and institutions.

In South Africa, we know of the epidemic of rape rampant throughout the country. But how many disabled peoples organisations or disability-focused agencies are doing anything about sexual violence? I may be wrong, but I can't even name one. Yes, our representatives may speak about disabled women's increased vulnerability to rape but what are we actually doing to respond? Do we offer legal services and counseling services to victims within our communities? Are we engaging with underlying factors of masculinity, power and control with each other? With staff, volunteers, members of our organisations and their families?

But this is not just about South Africa, how many of us working in northern and southern-based disability-related organisations take time to think critically about what we mean by the very notion of development? What do we really mean by inclusion? Are we continuing to perpetuate the sexist hierarchies that fuel ableism in society? Do we allow prejudices based on class or appearance or mother-tongue affect who has a voice within our organisations?

If we are continue to challenge the exclusion and marginalisation in broader society we must also simultaneously address it within our own work as activists and academics.

As cliché as it may sound, I firmly believe in the Ghandian proverb that we must be the change we wish to see in the world.

So, there are the dynamics of AIDS, of Power, and now to Politics...

In 2008 I moved to Kampala, Uganda, where I was based for a year and a half working as an Advisor on Disability and AIDS for the American-based advocacy organisation, AIDS-Free World.

Uganda was chosen as our first base because of its vibrant disability movement, strong representation of disabled people in parliament, and excellent reputation in responding actively to the AIDS pandemic. I arrived in Kampala just in time for the 3rd Meeting of African Campaign on Disability and AIDS. This was an initiative that ran from December 2006 until December 2009 co-sponsored by Handicap International and the Secretariat of the African Decade of the Disabled. Uganda's national DPO umbrella, NUDIPU, had recently launched a multi-year AIDS and Disability initiatives. With all of these important projects around, it seemed like the ideal location for a new AIDS advocacy organisation, founded only in 2007, to conduct some field-research and start building networks of colleagues and comrades.

While in Uganda, I admired the progress made in the recognition of disabled people and disability rights in parliament and policies at all levels of government. It was during my time in the country that Uganda ratified the UN CRPD. Men and women with disabilities are at the table from the Government House in Kampala to the Local Councils at village level. These achievements were accomplished by the Ugandan disability movement itself through decades of dedicated advocacy. Now, we not only see MPs representing disabled people but also a female MP who was first appointed as a representative for disabled women in the North now sits as an elected representative in the House.

Such representation means that there is acknowledgement of the need to have policies in governmental and non-governmental organisations that include people with disabilities. But, we still see very little ideas or resources for implementation.

And, in the field of HIV/AIDS we continue to hear people repeating the same stories about the daily barriers encounter:

“You know Blind people they can’t see, so they can’t read the poster about condoms in the health clinic...” and “Deaf people, they are afraid to go for HIV testing because their interpreter may tell others...”

This is the reality. But repeating this refrain is not enough...just providing information in Braille or training Deaf people as counsellors, it’s important but that does not make for an accessible society!

Have we stopped to question the underlying dynamics that make for an ableist society? The fact that what will make us inclusive is if we speak to each other in whatever languages we can find – that we help each other to learn, yes through Braille, but also a multitude of other formats.

The other day I was reading through a paper by David Hulme, who spoke yesterday. He wrote it a few years ago, I’m sorry I don’t remember the exact date...but in it he discusses Amartya Sen’s work and claims that pressures to view people as homogenous groups can both weaken analysis and distort policy.

I think a similar warning against homogenisation was echoed in Shaun’s and Ray’s presentations yesterday too.

Yes, we must be happy and proud of the political progress we made over the past 5, 10, 15 years but we cannot forget that the daily struggles faced by disabled people in townships, villages and slums continue daily in very tangible ways.

We must stop ignoring the “hierarchies of disabilities” we have allowed to crop up in our organisations. To help illustrate what I mean by this, I’d like to share an anecdote I heard from Nora Groce (at UCL) recently. She was marveling at how many meetings she has attended of mental health activists who were saying “Yes, we may have some problems but we’re not stupid...” and then soon after she’d find herself in a meeting of people with learning disabilities and they’d say “Sure, we may have trouble understanding things sometimes but we’re not crazy...”

Where does *that* leave us?

The Convention is making progress...slowly but surely...and we must continue to lobby governmental and non-governmental organisations to integrate disability rights policies into AIDS policies and programmes as well as a multitude of other sectors including education, urban planning, public health, legal structures...But we cannot just point fingers to what *they* should do. What about our own relationships?

We must recognise our own complicity and our role in perpetuating the structures of inequality and marginalisation that oppress us. Let’s build relationships across hierarchies, across structures and across movements – like we start to see when engaging with the struggle against HIV and AIDS.

So, as we call for social change, we must continually self-reflect on our own relationships and the relationships we facilitate in our organisations so that we actually come to embody the change we’re calling for out there.