

## **International Research Symposium: Equitable Health Services for People with Disabilities with a Focus on Low and Middle Income Countries**

Co-organised by the London School of Hygiene & Tropical Medicine (LSHTM) and the World Health Organisation (WHO)

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### **Closing Keynote Address By Myroslava Tataryn**

I am grateful to the LSHTM, the WHO, and all of you here today, for this opportunity to speak with you today.

I hope to use this privileged position of speaking at the end of the day without powerpoint, graphs, or charts, to take a step back and reflect not so much on what we're doing – which has taken up much of our day – but rather on why we do what we do.

I have spent 5 years working on disability rights issues in the field of HIV/AIDS as well as other projects related to disability rights in international development projects and, most recently as you just heard, humanitarian interventions...I feel extremely fortunate to be working in this field at such an exciting time. As an intern with Disabled Peoples International in 2005 I was translating daily press briefings from the negotiations towards the Convention on the Rights of Persons with Disabilities and three years later as Advisor on Disability with AIDS-Free World I celebrated the entry into force of the Convention and immediately began using it as a tool for our advocacy work calling for greater inclusion of people with disabilities in AIDS discourse, policy and programming. By 2009, I was invited to speak at the launch of the UNAIDS Policy Brief on AIDS and Disability. It was actually during this same visit to Geneva that I first met Alana and Tom was briefed on the upcoming World Report and two years later I have a copy on my desk at the LSHTM. It is important, I think, to remember and celebrate all of these major accomplishments that have been achieved in a relatively short period of time. It is truly exciting. But in this excitement of being in the midst of a rapidly expanding field I think we feel we don't have the time – or we don't take the time – to consider the underlying motivations for our work. To remember what brought us here. Why do we do what we do? What do we want to be doing and how? Not just patting our backs about what we've already done (though, of course that's nice to do too...).

So, I would like us to stop and momentarily consider why are we here today? What different factors have brought each of us here? Why have you been sitting through a day of discussions about disability and people with disabilities and access to health services? Why do you care? Why bother to talk about disability in particular when there are so many needs out there?

The answers in this room will be many: Perhaps you have been working in the field for decades, perhaps this is the first time you're exposed to the issues. Perhaps you were required to attend because of your work or studies. There are no wrong answers to this questions.

But, actually, before I go any further I would like you to turn to the person sitting beside you and ask them how they first came to the field of disability and health – whether the first exposure was today or 10 or 20 years ago. I know this is not a conventional exercise during a keynote address but, please, go ahead – just two minutes.

Thank you.

I hope that you learned something that you didn't know before, even if you're sitting beside a colleague you see every day.

We have spent this day together discussing aspects of *building equitable health services* and through several presentations today we've seen that it's not only about treating the "right people" and ensuring our quotas are met but also to tackle systemic issues impeding access.

(Though, of course, gathering data about who accesses our services and how that compares to who we expect to be treating is also important).

I want us to challenge ourselves to thinking beyond quotas and ticky-boxes on equal opportunity forms. We need to look at the social systems putting up barriers and how through the virtue of our gendered or racialised or other privileged positions we reinforce certain barriers. I think that, given the tremendous gains we have seen on the international disability "scene" over the past decade we are at a point where we can stop and reflect.

In order to try and give you an idea of WHY i believe this is important, I'd like to tell you a part of my own story of how I have come to work on disability issues and access health services.

Yes, I was born with most my joints dislocated, spent the majority of my first 4 years in hospital, started walking when I was 7 and used a wheelchair for long-distances until I was 20. But I was lucky to be born in Canada with accessible medical and surgical services and to parents who treated me just as anyone else and fought to get me enrolled in my local neighbourhood school when I turned 6. Now it seems unbelievable to me, but they were put under a lot of pressure to keep me at a segregated school, but my parents are unbelievably and gorgeously determined and I remained in mainstream schooling throughout my education.

From a young age, my sisters and I were raised to consider the privileges we enjoyed growing up and in many ways grew to appreciate all the benefits we derived from a good education, enough to eat and a comfortable home, but also to work towards challenging the systems that kept some people better off than others.

Yet, despite the appreciation instilled in me of my Canadian context, I grew up despising physiotherapy appointments and annual x-ray appointments. I didn't like to be singled out. Being told what to do, being expected to conform to the demands of clinical professionals. My aunt gave me a Sesame Street t-shirt with Oscar the Grouch on it saying "everyone has a right to be a grouch." I wore deliberately to medical appointments. I enjoyed swimming and weekly ballet lessons, I did not feel it necessary to sit alone in some room doing some exercise or other.

Some years later, while already in University, I agreed to have a few occupational students "shadow me" in University as they were meant to "meet a disabled person and learn about their daily life." They seemed a bit disappointed during their meeting. They admitted that, well, I was just another student like them. Why should this be surprising? Because they expected all their subjects to be hospital patients?

I guess that in some ways my critique of rehabilitation services was only possible due to my privileged access to health services as a Canadian, but also, it made me think that our access can lull us into a false sense of security. It can obscure the social factors of disability – the ways that people's attitudes disable or enable us. Especially as children growing up with visible disabilities. Having

surgery can help us to fit our foot into a shoe, or to be able to sit up better, but it does not make us necessarily accepted as “normal.”

In any case, I played wheelchair sports, got quite good at cross-country sit-skiing in long Canadian winters. And thanks to the regular interactions with fellow athletes with disabilities, I did see my experience of disability as part of a larger phenomenon, rather than just an individual physical frustration but I was adamant about the fact that just because I have lived experience with a disability didn't mean that I had to take that on as my social cause. Just as even if I identify as a feminist, as much as that pushes me to try to ensure that my work does not re-enforce sexist paradigms, I do not have to necessarily devote myself only to women's issues.

With time, I could articulate this in terms of intersecting prejudices after reading a book in my undergraduate years by Canadian scholar, Sherene Razak called “Looking White People in the Eye” I became more comfortable articulating how different prejudices, whether it's racism or sexism or homophobia, feed off of each other. One can never truly be addressed without tackling another; but reading that book came a few years later and I've digressed from my story, sorry.

I began my University studies in the year 2000 at Queen's University, in Canada. Having been raised with a strong sense of social justice, I appreciated the critical nature of the Development Studies programme that I found there and combined this with my degree in Environmental Science due to my extensive involvement with environmental activism at the time. For my third year of studies, I had the opportunity to travel to Ghana for a full-year of study in Accra and Tamale. I was expecting...hoping...to explore questions around traditional healers, herbalists, traditional knowledge.

But, in my first month there what shocked me was that the only people with disabilities I saw were begging on the street – it took me three weeks before I found a group of musicians practicing under a tree, one of which was disabled and so we started to chat. I was constantly being reminded of the visibility of my own disability when Ghanaians would walk by and comment “ah, look at that white girl! What happened to her legs!?” To be fair, the whole comment was said in Twi but I lived with 2 young girls who were very faithful translators and language instructors so the comments didn't escape me.

Questions about my positionality as a white, disabled person started forming in my head. I started asking more questions, finding out about treatment and attitudes. With time, I was brought to the Tamale Resource Centre for Persons with Disabilities where I was introduced to Madam Mercy Apoe, a blind woman about my mother's age who took me under her wing. She instilled in me the sense that, as an educated, relatively wealthy, disabled woman I not only had a role to play but I had the responsibility to speak out for the cause of women with disabilities, many of whom due to poverty and prejudice did not have the education and mobility that allowed for the voice that I could have.

I spent a lot of time at the Resource Centre, just chatting. Sharing stories. Talking about families, relationships, men, sex, marriage... This is why I stayed. I liked the gossip. Actually, seriously, probably the most common question I get asked across countries and contexts is about marriage and relationships. Not about funding or available surgeries.

Many of the people dropping into the centre from nearby villages commented that I was the first “white disabled” that they ever saw. Now this is not so long ago, yes Tamale is not Accra and is quite rural, but still it surprised me and made me stop and think. How many of our young student

volunteers, interns, and others conform to the expected image of wealthy foreigner: usually white, probably blonde, and not disabled.

So during my time in Tamale people took the opportunity to ask me about my own experience of relationships, and also education, and childcare and a whole range of really down-to earth topics. I was inspired and excited by the way they framed their issues as a social struggle. As a question of challenging assumptions and pushing for inclusion in social and political systems – regardless of how they walked or talked. I was refreshed by the diversity of bodies and ways of moving around that I was surrounded by in the resource centre. I was inspired by peoples perspective on the issues and humbled by the fact that they were asking me to be an ally in their struggle. They invited me to take part.

That is how I got onto the path I am now.

Positionality IS important. But it is not about essentialising someone's experience based on their label. My sister, Anastasia, is at times a much stronger disability advocate than I am! She has grown up with me and our youngest sister who has a neurodegenerative condition and requires constant care, and Anastasia is often more ready to be vocal about our rights to access this or that; or to challenge peoples offensive behaviour than I am. She is as involved in shifting societal perspectives of who does and doesn't belong.

I bring up this point because I think that often we want to quickly put people in boxes of who does and doesn't belong here or there. Within the disability movement we're starting to talk about the need to dismantle "hierarchy of disability." In other words, prioritising some people's voice by virtue of their disability. I think this is unhelpful, dangerous even as we draw divisions rather than cultivating alliances. And that can happen both within and outside of the disability movement.

A while back when I was chatting with Prof. Nora Groce, who's guidance I have been grateful for since the earliest day of my career, but when Nora and I were speaking a few months ago, I remember Nora marvelling 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?

Sometimes even within the disability movement we try to determine who does and doesn't belong rather than valuing different experience. Of course, we must be wary of thinking that a caregivers perspective is the same as, or a proxy for, that of a person with a disability. But, then again, these categories are definitely not as rigid as we may like them to be either. In certain times and places I also find myself as a primary care giver just as much as a disabled person myself. Just as I am simultaneously a disabled person and a researcher.

I remember once being toured around a new hospital site where the managers were very proud of the fact that the clinic was entirely accessible: space between beds, accessible toilets, everything. But then we had to climb up the stairs to get to the office. The management area of the hospital was not accessible at all. No one ever imagined that managers or clinicians would ever need a lift or accessible toilets!

In some ways that is what critical feminist disability scholarship gets to...it challenges the binaries of us and them, disabled/non-disabled, carer and cared for. We can be both oppressed and oppressors in different situations.

The more integrated schools we have, the more professionals and politicians with disabilities we see the more our movement will grow. Not because disabled people will intrinsically be better at their studies or at their jobs but because we would all be more and more exposed to different ways of communicating and interacting with difference and that in turn enhances our openness and inclusivity in our social and professional interactions.

Sadly, it's impossible to prescribe a universally applicable way of ensuring access or true inclusion. Disability is too multifarious, too historically, culturally and contextually contingent to permit a cookie-cutter approach. A clear set of 10-steps for accessibility isn't realistic because to ensure access because inaccessibility and exclusion is based on deeply entrenched notions of normality that we have grown up with. This needs to be challenged in order to dismantle barriers to access.

This large scope may seem very disheartening and it does seem like an insurmountable task on one hand, but very exciting on another because we each have a part to play: medical doctors and physiotherapists, yes, but also teachers and lawyers, shop-owners and parents.

And because each one of us plays a part in it, it is also important to both reflect on our participation – our complacency in the system and what opportunities we have to change it.

One of my favourite projects to talk about as a positive example is LVCT in Kenya. LVCT had been running mainstream voluntary HIV counselling and testing services for several years when it decided to address the gap in services available to Deaf people. So they trained Deaf people as VCT counsellors and employed them in Deaf VCT clinics in Nairobi, Kisumu, and Mombassa. The programmes were so well received and so successful that soon people with different disabilities who were hearing started coming to the clinic and LVCT had to hire interpreters to translate from the Deaf interpreters to the hearing clients. It was an unexpected but fantastic inversion of the norm but at the same time as it challenged perceptions, the project was also delivering solid services and the Deaf programme has since expanded into a larger disability VCT project.

Our consideration of equitable access through a lens of disability gives us the tremendous opportunity to challenge the way we see our patients, our clinics, or professional and personal roles. Considering disability as a peoples social and physical reality – a reality that anyone of us can experience at any point in time due to an injury, illness, or trick of genetics - give us the impetus to challenge our way of perceiving others and of building systems and structures to welcome a whole variety of people and bodies that do not conform to the unrealistic expectations that all our bodies are of a strong, white, heterosexual man.

Working towards accessible services will enhance access for people far beyond those we currently perceive as disabled. It will help open up our offices, clinics and services to single parents with young children, elderly people, caregivers requiring more flexible work hours....and many more people who may currently find it difficult to "conform" to what is perceived as normal.

It is one more strand in the many elements that feed into inclusive communities and community structures, including health services.

I think that still, too often, our minds jump to the specialised services – such as orthopaedic surgery and/or physiotherapy that people with certain disabilities may require. And as true and real as these concerns are. We also heard today from our colleagues whose work highlights the barriers that people with disabilities may face is accessing primary health care. Are babies born with congenital impairments accessing childhood immunizations at the same rate as children not diagnosed with any impairments?

I conducted a series of 100 interviews with women with disabilities in Uganda and Canada from late 2008 – 2009 asking about their experiences with sexual and reproductive health care services. I expected... but I found that the experience with the health care worker was just as likely to be positive as it was to be negative. We heard from Tom this morning that empirical evidence shows that actually women do face greater chance of mistreatment at the hands of healthcare workers than non-disabled women, but at the time it was a 50/50 chance in both countries. But what was much more likely to discourage them was a lack of transportation options to arrive at the clinic, and discriminatory comments from people in their home-village or in the queue at the clinic itself. Questioning why they should need to attend an HIV test centre or to attend pre-natal care. I remember hearing a story from one woman using a wheelchair who had no one to accompany her to the health centre when she was about to give birth, so someone's brother who was around at the time accompanied her. He faced so many derogatory comments while sitting in the waiting room "ei, you, how could you do that to her? Isn't her life difficult enough?" Not knowing, first of all, that he was the father but, secondly, never considering once that that woman may have in fact wanted to have that child and that that could be a positive experience for her!

I remember another story from a disabled woman who had to spend a few days in hospital after giving birth and the nurses warned that she won't be able to cope. That she'll struggle to cope at home when she couldn't even get in and out of her hospital bed with her new baby. She had to try to explain over and over again that at home everything would be fine. Things were set up for her, the counters were lower, her bed was at the right height and in the right position that she knew she would not encounter the daily frustrations she faced at the hospital.

Although in these stories the people did manage to access the health services, they still highlight the role of attitudes and perception and that ensuring equitable access to health care services is about so much more than just ramps or Braille.

So much exclusion and discouragement happens long before someone makes it to the front doors of a health care centre.

It is crucially important that we don't assume that we know too quickly the needs of others. We need to listen to peoples experiences. This is why individuals with disabilities and Disabled Peoples Organisations need to be part of the process of planning and implementing services. We have committed to this on paper, but how often is this actually happening?

I think that in our policy documents we've achieved this goal, just as on paper we have committed to including disabled people in our work, we have committed to cross-sectoral collaboration: working in partnership with organisations on the ground, valuing the experiences of activists and programme staff.

Thanks to gatherings such as today, we have the chance to take advantage of opportunities arising from different research methodologies, different ways of acquiring and presenting information and knowledge.

Thankfully we see this pattern developing in various contexts.

I have presented papers at 4 International AIDS Conferences of the past 6 years and I have seen the ways in which people living with AIDS are able to sit side-by side with microbiologists in the plenary session and present their own experiences of setting up community-based programs, establishing

relationships with scientists and researchers. The synergy between perspectives of users, policy makers, and scientists are increasingly respected.

This is not to devalue scientific knowledge but to value the different knowledge that is derived from different kinds of experiences and using this to deepen and strengthen – rather than to weaken and dilute our work.

Attitude towards knowledge affects how we use knowledge.

But true interdisciplinarity does not come just from hiring an anthropologist to join a team of epidemiologists or making sure that a few statistics are thrown into a series of case-studies.

Just as including disabled people and disabled peoples organisations (or DPOs) should not be done as simply a token gesture.

Yes, it can be difficult to work with DPOs. Collaborating with many community based organisations in low-resources settings across geographical, linguistic, technological and cultural barriers can be extremely frustrating. I have heard DPOs in the Caribbean referred to as “very weak partners” and had first hand experience with organisations in Africa mismanaging grants completely where their funding had to be withdrawn because it was simply being “eaten” so to speak.

Yet, before we write-off collaboration entirely OR before we agree to work with dysfunctional organisations at an arms length simply to satisfy inclusion criteria we should be looking at the underlying causes of these organisational weaknesses: lack of resources; lack of experience amongst staff; grants, money coming in chunks too large with time-lines too tight. Could we embed more shadowing? More training opportunities and partnerships within the projects we are funding or proposing to be funded? What about facilitating partnerships between disabled peoples organisations and other social movements and civil society organisations within the home city or community that our potential partner is engaged in? How can the capacity of these weaker organisations be built up in the course of the project?

When I was working in South Africa...Although I was based at DPSA I worked closely with colleagues at the Treatment Action Campaign that some of you may be familiar with. Colleagues from TAC were not very familiar with the needs of disabled people. They did have some members with disabilities but it was not, at the time, by conscious effort. In fact, the first time a friend at TAC was called to facilitate a 2-week training of trainers with a group of youth with disabilities from the townships he complained to his friends about how boring the coming fortnight was going to be – he was about to spend it with a bunch of disabled kids after all. But after 2 weeks of running the workshop his eyes has been opened up to disability issues just as much as the eyes of the participants were opened to HIV issues. He subsequently invited these and other youth with disabilities to each training, party, radio programme he was involved with through TAC because he was suddenly aware of the systemic exclusion these young people were facing for no good reason.

. We need more of this. This was not an expert coming in and teaching. It was more about listening, creating links, and enabling reciprocal exchange of info and expertise.

We need to reflect upon, recognize and take advantage of the strength of others. This can seem to lead to a trite statement about “everyone’s abilities vs disability” but I don’t mean it like that. Rather, I think that this can extend our conversation into a consideration of the multi-disciplinarity we see in this room today and how, as much as it can be difficult to work with people moulded in different paradigms, we can also celebrate the multi-disciplinarity in this room and try to approach

other ways of knowing and gaining knowledge as a strength rather than something to be measured out and placed on an epistemological hierarchy.

This includes activists appreciating the time and, yes, money that it takes to produce rigorous research, and to appreciate the immense benefits that they can derive from having robust data at their disposal after months or years of intensive research by qualified researchers. I think that in the NGO world we're not always good at appreciating this.

Yes, we must certainly do our best to ensure that there are ramps and facilities to accommodate people with various impairments in our health care centres, educational institutions and so on. But at the risk of sounding very cliché, I do believe that accessibility really is first and foremost a question of attitudes. Parents attitudes, extended family, teachers, bosses. Yes, legislation is important as is th UN Convention. But it is a tool. Only as useful as its masters, so to speak. It is up to people to use the legislative and other tools to affect change.

As I mentioned before, I don't think that there is a cookie-cutter approach. If there was, all of our jobs would be much easier! We'd just need to get the WHO to publish our 10-steps of disability inclusion and we'd be set.

But in my experience so much of access has to do with individuals. With communities. Yes, with laws and structures, but with the acting-out of them.

Disability teaches us that our bodies are diverse; that we interact in our environments in different ways. I truly believe that if we are open, creative, and genuinely fascinated and appreciative of this diversity then that will enable all of us to live healthier lives – which includes getting access to the health services we all need.