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PETER TORRES FREMLIN

Maintain grassroots authenticity

Challenges of leadership renewal and other insights from the mailbag

Dear Debriefers,

This edition opens the Debrief mailbag to find insights on organising, the Olympics, and saving oneself.

Readers discuss the challenges faced by the disability movement, barriers to leadership renewal, and what can be done about them.

Discussions of ableism throw a new light on attitudes that hold disabled people back, and correct me on language that I used.

All this and much more in wide-ranging responses to recent reporting and what Debrief readers are busy with, from falling over to hip hop.

Reader support [makes the Debrief possible](#). Thanks to Say for a new contribution.

Maintain grassroots authenticity

The reporting I did on [what went wrong](#) at the International Disability Alliance (IDA) was challenging in itself and also scary for me to publish. Thanks to the many readers who welcomed it.

Among them was Kate Swaffer of Dementia Alliance International, an observer member of IDA. Kate [sees](#) a lack of transparency around the crisis as “unacceptable”:

“The way to advance the rights of all people with disabilities, is to include us all, to be transparent, and to ensure the advocacy is not corrupt.”

Many readers pointed to the broader context of challenges within advocacy organisations. In Disability Thinking Weekly, Andrew Pulrang considered the [questions](#) that the crisis raises for disability organisations of all sizes:

“How do disability organizations maintain grassroots authenticity, a strong advocacy edge, and a humane personal responsiveness — while at the same time acting professionally, meticulously following businesslike steps in planning and administrative approval processes, and responsibly managing and growing the funds necessary to pursue their missions?”

Andrew goes on to show the tensions that can occur:

“Being grassroots and professional aren’t mutually exclusive of course. But they are often viewed as opposite priorities, which I think does contribute to — and sometimes cynically excuse — dysfunction in disability organizations. And then of course there’s a more pessimistic interpretation which we should never completely dismiss. It’s always possible that a disability organization might become merely a vehicle for a few disabled people to make a comfortable living in socially prestigious positions.”

Indeed, the discussion of governance challenges led different readers to reflect on how their own organisations were run. One reader on the board of an international organisation of persons with disabilities shared:

“What you wrote about the capacity of the Board members really resonated with me because I also don't think all of us on our Board, including myself, have the capacity to fully understand and monitor all aspects of spending. True, we do ask questions and we receive thorough explanations from the Secretariat and the Finance officer who attends all Board meetings but if something like this happens would we be able to recognise it and pick it up? Maybe yes, maybe no.”

Why new leadership doesn't come?

My own reporting led me to call for a [renewal of disability leadership](#).

One reader, writing from a South Asian country, found “lots of similarities” between the challenges faced by IDA and their national umbrella organisations representing disabled people. Answering “why new leadership doesn't come?” the reader sees the continuities of leadership in member organisations, who then elect the same leadership each time. In his view, if we hope for renewal then we need to work from the grassroots and build up from there.

Yuliia Sachuk, co-founder and president of Fight For Right in Ukraine, shared this desire for an organic movement development for grassroots organisations. And

she pointed to its challenge: “We are ready for more transparent activism, but where is the platform?”

One reader thinking about community organising is Bailey Grey. She recognises many organisations of persons with disabilities are well-run, but sees commonalities when there is a crisis, “challenges that go beyond financial mismanagement and bullying”. Bailey sees three areas that need work:

“1) Trauma-informed approaches to deal with the trauma in the sector. 2) NGO management tools to fill knowledge gaps. 3) Sector-wide discourse on the power dynamics of community organising – how we can empower and build leadership of EVERYONE to truly transform power dynamics? We must drive towards the model that sees power as limitless, expanding, shared, supportive, cooperative, and collective and less confrontational, linear, self-interested, and competitive.”

In her work, Bailey has seen trauma coming not just from individual experiences of disability but also dynamics within the sector itself. Given the disempowerment and isolation that persons with disabilities face, she finds “cooperative models of shared leadership work best”:

“Support structures for all built within [organisations of persons with disabilities] and a culture of collective care are very appealing aspects of certain types of community organising models. These concepts transcend culture, gender, age, type of disability, etc, and can be adapted to a specific context. But it requires us to stop focusing attention on who can be the loudest and instead to learn to become facilitators, turning the attention from ‘me’ to the wider ‘you’ (or more correctly, you all).”

Another reader thinking about the future of the movement is Shikuku Obosi who explores [rebuilding trust in the disability movement](#). Shikuku asks if there are alternatives to Western models of governance, ways to respond to trauma, and how to bridge the gaps between leadership and grassroots.

Pressure not to quit

Speaking of leadership renewal, interesting discussions came out of my piece on [ageism and ableism](#) in the US Presidential Election. Readers wrestled with the line between what might be a legitimate requirement for President of the United States and what would be an ableist criteria.

For example, friend and historian Emile Chabal wrote:

“I would have thought that a degenerative mental illness raises different questions to a degenerative physical illness? Mental acuity and mental fitness are clearly prerequisites for public-facing political roles - and, indeed, for many intellectual activities. To what extent are criticisms of Biden on those grounds ‘ableist’?”

I agree that I didn't tackle the specific implications of potential cognitive change as directly as I could have. But the main points of the piece apply: the need for competency-based assessment and adaptations. I'm not sure what an alternative looks like. And, as Emile also pointed out, a requirement of some level of coherency would rule out many existing political leaders.

I asked a reader who advises businesses on disability inclusion what they would recommend for an executive experiencing cognitive decline. They told me that it would be critical that the executive themselves was open to the discussion about a possible transition. And that for me is one of the key reflections from the episode – that Biden and his team didn't make space for more constructive discussion than the binary of “fit” or “unfit” to be President.

Andrew Pulrang – whose thoughtful reactions I have come to count on – [reflected](#) that a pressure not to quit is also a way that ableism can manifest. Going beyond the case of the President, Andrew sees this pressure particularly on disabled people who feel pressure not to give in to a supposed weakness:

‘We are made to feel that we have to “soldier on” because to step back, even for our own physical and mental wellbeing, would “let down” the disabled community, and do harm to non-disabled people’s perceptions of disability.’

Beyond disability stigma

Another interesting reaction to the piece on the US Presidency came from Mark Carew, who related it to a paper he's written with Tom Shakespeare, [Beyond Disability Stigma](#):

‘As you said in that Debrief, we should always “reject outright prejudice.” before we engage with the merits of the arguments leftover. What we argue in this article is that the leftover non-prejudicial arguments to oppose disability issues can be defined specifically as “intolerance”. My hope is that this article stimulates some work in the area, since I think cases of unjustified intolerance may be “sticky” and not able to be addressed by prejudice/stigma reduction efforts. We need something else in the toolbox...’

An example that they give to illustrate is a taxi driver who refuses to take passengers with assistance dogs. This might be because of prejudice against disabled people, but it might be a lack of tolerance towards dogs, unrelated to disability.

I agree with the authors that we need to study attitudes in a more nuanced way, going beyond “stigma”. Their distinction is useful although I wonder how much the concept of ableism might speak to both dimensions. I appreciate their provocation and hope others will join me in thinking further.

Tensions in the Olympics and Paralympics

Ahead of this summer's Olympics, I shared a [darker side](#) to the Games that some called “social cleansing”. From Japan, Yoshiko Miwa shared a similarly ominous history of the 1964 Games:

“Before Tokyo Olympic/Paralympic games were held in 1964, as one of the preparations, people with problems (not only psychiatric ones, for example, poverty) were hospitalized in psychiatric hospitals with easy procedures. Local governments that made someone being hospitalized were rewarded. This policy contributed to stabilizing the management of psychiatric hospitals, but [some] of those patients spent their lives in the wards until death.”

Yoshiko tells me that activists with psycho-social disabilities were worried this might occur again in the Tokyo games of 2020. The covid pandemic meant the Games didn't take place with the same crowds but, as elsewhere, the awful conditions of pandemic response did go towards exposing the [harrowing stories](#) of psychiatric hospitals.

As for this year's Games, many felt the tensions John Loeppky described in [Paralympic Paradoxes](#). One quote from John's piece that several readers highlighted was:

“Some of the tensions between disability rights and the Paralympics are built into the Paralympics themselves. Disability rights are about levelling the playing field without any exceptions. Sports are about fairness of competition that leads to winners and losers.”

Correcting my language

Back in June I [wrote](#) about the tragic murder of Asimwe Novath in Tanzania. Annabahati Gwacha from the Africa Albinism Network (AAN) wrote to welcome

the reporting and to alert me to the language I'd used. I'd referred to the “albino community”. Annabahati told me why I should avoid the first word:

“As with many other disability constituencies, using person-first language acknowledges that albinism is just one aspect of who we are, rather than defining us solely by our genetic condition.

The term ‘albino’ has historically been used in derogatory and dehumanizing ways, reducing individuals to a condition and stripping us of our identity and individuality.

Advocacy organizations, such as the United Nations and various human rights groups, recommend using ‘person with albinism’ as part of a broader effort to promote human rights and combat discrimination”.

I apologise for using a derogatory term, and I've updated it on the web version of that article. Thanks to Annabahati and AAN for correcting me.

As well as the correction, AAN shared their petition calling on the World Health Organization (WHO) to [re-add Sunscreen](#) to the List of Essential Medicines, a vital step to protect people with albinism from skin cancer.

Friends in falling

Many readers resonated with the explorations of lived experience of disability on the Debrief.

Saving oneself. Lea Labaki's essay from the [other side of the glass wall](#) was, for Áine Kelly-Costello, a:

“Raw, powerful essay with probably the most grounded personal critique I've come across of the complex and too frequently flattened notion of community”

For Catherine Hyde Townsend, Lea's piece was “gorgeous writing” and:

“A reminder that collective care has always been needed and that stepping out of disability rights work is not abandoning a community, but sometimes saving oneself.”

What we experience. Anna Maria's piece on [Working to Work](#) focussed on experiences of disabled people in urban India, but readers as far apart as the United States, Kenya and Tunisia said it resonated with them. For Paul Mugambi in Kenya:

“A beautiful piece reflecting what we experience as persons with disabilities. It seems we share similar tribulations!”

It moved a lot of things. My poetic auto-biography [Fall with Me](#) brought out many fellow fallers in the Debrief audience. Thanks to those who showed me it is much a poem about getting back up as it is about falling. And for Virginia Ossana:

“I could see my own life in your words. I don't think I was prepared for it. It moved a lot of things. I had a little cry too.”

More from Debriefers

Readers have been sharing the many and varied initiatives they're involved with...

Disability hip-hop. Chad Harper shared [Ability](#), a music video recorded in Sierra Leone and performed by artists with disabilities.

Disability board game. Tanzila Khan told me about [Woopie Town](#), a board game where players build a city and explore accessibility, including by suing each other.

My name is Yedia. Louis Bickford told me about this [new children's book](#) by Coumba Toure, shining “a much-needed spotlight on women and girls with disabilities in Senegal”.

Barrier Free Finance. With a group of fellow-advocates, Paul Surreaux started the [Barrier-Free Finance Initiative \(BFFI\)](#) for improved access to financial services. He encourages folk to get in touch to be involved.

That's all for today. Do stay in touch and until next time,

Peter

Please share this with friends, as that's how people find the Debrief. On socials we're on [Linkedin](#), twitter at [@DisDebrief](#) and I'm [@desibility](#). And hit reply to say hello!

Acknowledgements

Many thanks to my correspondents for such a varied range of insights and provocations. And, of course, to the individuals and organizations whose [support](#) makes the Debrief possible.



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