Discussing Ableism in Fundraising:

Making disability a priority in the fundraising sector

Alison Hughes

The AFP Foundation for Philanthropy – Canada launched the **national expansion of the Fellowship in Inclusion and Philanthropy Program**, with funding from Heritage Canada. The Fellowship provides dedicated education, professional development and mentorship to 20 mid-level and emerging non-profit professionals from across Canada, representing a wide range of cultural backgrounds and interests. The goal of this program is to build the capacity of emerging fundraising leaders that reflect the diversity of our communities.

About the Author

Alison Hughes is a fundraising professional and Development Officer at Holland Bloorview Kids Rehabilitation Hospital Foundation. Born paraplegic, Alison received care at the hospital throughout her childhood. As a teen, she was an ambassador for the hospital's Foundation and spoke at numerous fundraising events. She also supported Variety Village and Track3 as an ambassador at various fundraising events while remaining active, playing wheelchair basketball and learning to mono-ski. After graduating from McMaster University, she returned to the Foundation to begin her career as a fundraiser. Alison has worked for Holland Bloorview for nine years supporting many different teams in the Foundation and is currently the Senior Officer, Philanthropy. Throughout her time with the organization, Alison has sat on the Accessibility Committee and was part of a group that developed Holland Bloorview's Equity, Diversity and Inclusion committee many years ago. This fellowship will further her opportunities to make inclusion a focus in the non-profit sector and within her organization.

Project Scope

The original intent of this project was to develop a lens or toolkit for fundraisers to use specifically around language. It became clear through my discussions and research that there is no general consensus and disability identity and the language individuals prefer is deeply personal and complex. I would be far out of my depth to suggest I have the right answers or can give direction. What became clear is that the sector needs to be reflective and have open dialogue about ableism in order to be more inclusive to all disabled persons.

What is ableism?

ableism (also ablism) noun

Discrimination in favour of able-bodied people.

Ableism is alive and well, much to disdain of disabled folk all around the globe. As a community, we lack equal access to many public spaces, transport, have inequitable access to education, are under employed and often undervalued. There are systemic barriers that attribute to the lack of progress and disability stigma plays a huge part as well. Though progress has been made- it was only a few short decades ago when institutionalization was commonplace- we still have a very long way to go.

The disabled community is far reaching and encompasses people with many different types of visible and invisible disabilities. In the podcast Overcoming Ableism with Liz Chornenki, Liz describes a disability as anything that can impact a person's physical or mental functioning in society. This includes but is not limited to people who use wheelchairs or mobility devices, are hard of hearing or deaf, have vision loss, mental illness or chronic pain. The list of conditions is long and many different people identify as having a disability.

Holland Bloorview Kids Rehabilitation launched #<u>DearEverybody</u> in 2017 to create conversation, share the realities of what disability means for youth and children in Canada and to help end stigma.

What does this have to do with fundraising?

As Liz candidly points out in her <u>op-ed with Hilborn</u>, "Fundraising has an Ableism Problem". The challenges in the sector are deeply engrained from disability being absent from discussions around diversity at major conferences and workshops, lack of disabled representation on boards and within fundraising organizations, lack of accessibility at fundraising events and in the language that is used in direct marketing materials. Disability stigma and ableism continue to perpetuate myths and negative stereotypes which create systemic and societal barriers for true inclusion.

Many non-profits support disabled people either directly as their sole mission or as part of a larger group. The disabled community ought to be every charities target audience – as many of us have been grateful recipients of charity we can be a very giving group in return. Disability is often an intersection of many other diverse groups- we are many races, genders, identities. Whether or not you think you are speaking to or for us, you likely are. But it's important not to speak for us, but with us if you truly want to make a difference. If inclusion and diversity are a priority at your organization, disability should not be an afterthought.

Language matters.

In fundraising, we know that compelling story telling is the key to fundraising success. We want to elicit specific reactions and emotions that create a sense of urgency and express need. Storytelling related to disability can often fall to two extremes- pity and sadness or heroism and inspiration. Sharing a story that tugs at the heart strings or uplifts our audience can translate to raising incredible funds for our cause. For many reasons, both can be damaging to disabled individuals and language can play a big role in this. Whose voice are we speaking in? Are we sharing in a way that reduces stigma or are we perpetuating it? Is raising a dollar more important than helping to reduce stigma and create real change for disabled people everywhere? How can we be authentic and inclusive in our fundraising?

Recently, a major hospital foundation found themselves in the hot seat when many disabled advocates spoke out about a campaign ad pairing a visual of a disabled woman and her child with language that was arguably ableist. The foundation responded swiftly with a very public apology and removed that ad from the campaign. It is time for organizations to dig a little deeper and do right by disabled people. These mistakes are avoidable with proper insight and consultation.

Louise Kinross shares her thoughts on the recent SickKids VS campaign in an article on BLOOM blog. The narrative of fighting against illness and disability with and end goal of being victorious leaves out and diminishes the story of those who will live with disability permanently. Should we feel less than when we will live our lives in bodies that are not viewed as perfect? It is no surprise that ads like this are successful and raise lots of money for a very worthy and important cause. But at what cost to the very people it supports?

Imani Barbarin expresses the danger of sharing stories that also cast disabled people in a heroic or inspirational light in her recent article featured on Bustle. The term widely used in the disabled community is inspiration porn. Imani points out the problem that many disabled people face when we are seen and showcased and made to look like we are included, like her experience dancing as a young child, but not taken seriously or challenged in the same way as our able bodied peers. Sensationalizing otherwise trivial activities and not giving praise on merit can create a confusing sense of self for young disabled people.

Though no clear consensus on specific language rules will exist, and I am not one to suggest I have the latest up to date, politically correct vocabulary, everyone agrees- ask the person you are speaking about what language they prefer. This is especially true when considering person first (person with a disability) versus identity first (disabled person) language. It is very lively debate amongst those who are disabled, are family members and those who work with disabled people. Many organizations with suggest using person first language as a default, when in doubt. If an individual feels strongly about using identify first, respect that choice, understand why and use that in storytelling.

Meaningful discussions on disability and ableism.

In order to learn more about how to address ableism and specifically language, I found some great discussions happening on Twitter. Many disabled individuals naturally find themselves falling into an advocacy or activist role- though it's important to note that being a self-advocate does not a great disability advocate make. Since the start of this fellowship I have stopped using that word to describe myself. Rather, I feel a new responsibility to turn to those doing it well and amplify their voices. I have found it helpful to find individuals with a mix of lived experience, education related to disability and who either work in social justice or fundraising as a profession including paid work and bloggers.

I found compelling and helpful content from Liz Chornenki, Development Officer at YWCA Toronto, Imani Barbarin, Director of Communications and Outreach at Disability Rights Network Pennsylvania and Creator of Crutches and Spice Blog, Louise Kinross, BLOOM Editor and Special Projects Manager at Holland Bloorview Kids Rehabilitation Hospital, and Ingrid Tischer, Creator of Tales from the Crip.

What can fundraising organizations and the fundraising sector do better?

Is your fundraising ableist?

Ingrid Tischer highlights some important insights to identify if your fundraising is ableist on the Tales from the Crip Twitter account.



Tales From the Crip @IngridTischer · Apr 25

2 More Top #CripTips for Spotting #Ableism in Your #Philanthropy

- 4. Per @hwatkins927: Disabled persons don't hold exec/decision-making roles and board seats. #WholsInformingYall
- 5. You perpetuate the myth of the ideal worker in assuming PT #disabled workers = lesser. #NCG2019



Tales From the Crip @IngridTischer · Apr 25

My Top 3 #CripTips for Spotting #Ableism in Your #Philanthropy You conflate #disability with #healthcare.

- 2. The words #disabled and #ableism don't show up in keyword searches on your website.
- 3. Your focus is on #ADA compliance more than how
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Check your unconscious bias.

There are many surveys and training tools your organization can use to check unconscious bias. It's not uncommon for most people to have biases, even despite being well meaning or making efforts to be inclusive. These biases are often influenced by the stories we read, videos we share and portrayals of disability in mass media. We can all know and agree that representation matters, though the disability community if often portrayed by able bodied actors with storylines created by able bodied writers. It's not uncommon for storylines to end with assisted suicide. What does that say about the value of a disabled life? Identifying these biases, acknowledging them and owning them can be a great first step to creating change.

Listen to disabled voices.

In order to better understand disabled people's lived experience, views on language and ableism, it is important to listen to disabled voices. Read Liz's Op-Ed and listen to her podcast. The following hashtags provide great insight into the barriers faced, views on language and social justice that many disabled people are engaging in on Twitter. Listen, let it sink in, validate and amplify voices.

#ableism #saytheword #ThingsDisabledPeopleKnow #DisTheOscars #ActuallyAutistic
#WhyDisabledPeopleDropOut
#DisabilityTooWhite
#DisabledInDevelopment

Talk about disability. Disabled is not a dirty word.

Part of the challenge in the sector is the lack of discussion. Disability is sometimes an afterthought which makes it harder to appropriately accommodate disabled fundraisers and donors and share stories that are compelling and create urgency without perpetuating stereotypes and reinforcing stigma. At the most recent AFP Congress, I attended a number of sessions that aimed to tackle diversity and inclusion and none had a focus on or really addressed disability. Accessibility at these conferences is also a barrier to meaningful inclusion. We need to seek out disabled voices and make sure to give them an appropriate platform.

Assess your people power.

Disabled people are significantly underrepresented in the sector. How does your organization include disabled voices?

- Have disability representation at board level.
- Create an accessible and inclusive environment for disabled fundraisers.
- Find your disabled donors and ask them how they would like to be included in your work. Ask them what you can do better. Then do it.

Watch your language.

- Take the lead from the person or group you are speaking about.
- Hire disabled consultants to train staff on ableism and how to avoid it in marketing.
- Hire disabled consultants to vet your campaign materials.

Accessibility

- Hire a disabled consultant to make sure your website is accessible to everyone
- Use tools like <u>this event guide</u> to make sure your events are accessible to everyone

Where to go from here?

If your organization is already making it a priority to address ableism and truly make disability a priority from the top down, great work. Share what you are doing and speak about it publicly.

If you aren't sure where to start, engage in meaningful discussions and listen to disabled people. Find your disabled donors or funding recipients and ask for their feedback. Hire a consultant to discuss disability with your team so that it can be woven into the fabric of your organizations work.

Most importantly be open, listen, learn and work towards a more inclusive fundraising mission.

Resources

Accessibility Directorate of Ontario, Ministry of Economic Development, Employment and Infrastructure. <u>Planning Accessible Events</u>. (2016). Access Ontario https://accessontario.com/wp-content/uploads/2016/06/Planning-Accessible-Events-May-2016.pdf

<u>Definition of ableism.</u> Oxfordfor University Press.

2019 https://en.oxforddictionaries.com/definition/ableism

Holland Bloorview Kids Rehabilitation Hospital. <u>Dear Everybody Position Paper</u> (2017) http://deareverybody.hollandbloorview.ca/wp-content/uploads/2017/08/Dear-Everybody-Position-Paper FA.pdf

Imani Barbarin. <u>All My Life, People Have Told Me I'm "An Inspiration." Here's Why It's So Harmful.</u> (2019). Bustle.

https://www.bustle.com/p/all-my-life-people-have-told-me-im-inspiration-heres-why-its-so-harmful-

 $\underline{17004612?utm_source=facebook\&utm_medium=owned\&utm_campaign=feminismbustl} \ \underline{e}$

Liz Chornenki, *Op-Ed | <u>Fundraising has an ableism problem.</u>* (April 2018) Hilborn Charity eNews, https://www.charityinfo.ca/articles/OpEDFundraisingAbleism

Liz Chornenki, <u>Overcoming Ableism with Liz Chornenki</u> (April 2019), The Small Nonprofi Podcast, Charity Village

https://charityvillage.com/cms/content/topic/the_small_nonprofit_podcast_overcoming_ableism_with_liz_chornenki/last/232#.XMeuiKZ7kWo

Louise Kinross, *Why I can't be 'for' the "SickKids vs" ad.*(October 2016), BLOOM. Holland Bloorview Kids Rehabilitation Hopsital.

http://bloom-parentingkidswithdisabilities.blogspot.com/2016/10/why-i-cant-be-for-sickkids-vs.html