# Themes of AANM Discussion #1: Coming Out as a Disabled or d/Deaf Artist with Alexia Vassos

Summary by Sara Arenson

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This session was held on Monday, Dec 4, 2023 at 6:30 pm CST via Zoom. Jenel Shaw and Sacha Kopelow were present, along with presenter/facilitator Alexia Vassos and discussion participants.

At the beginning of the session, after Jenel made a land acknowledgement, Alexia introduced herself. She is an actor and writer based in Toronto. A graduate of the University of Toronto and Sheridan College, she has appeared on both stage and screen including commercial campaigns and TV/film ventures. She works as the Digital Marketing and Communications Coordinator for Creative Connector, researching and delivering accessibility opportunities and disability cultural events to subscribers across Canada. She is also a little person.

The general topic of the evening was, in Alexia's words, "disclosing disability". She opened the session with a qualifier:

"I want to preface this session with the understanding that disclosing disability is very much a personal choice and this webinar is by no means an attempt at providing a sort of how and when to disclose in a three easy steps formula, because that it is not, it is very much different and person specific."

With that said, Alexia provided the context for disclosure, the reasons for disclosure, talked about her own experiences and feelings around disclosure, gave some general advice, made some remarks about barriers to disclosure, then facilitated a discussion with attendees. Participants provided numerous examples from their own lives, covering areas like having to prove disabilities, disappointment with organizations, institutional barriers, the hierarchy of disability, aesthetics of the art world, tokenism, underrepresentation, and how to affect change. They also discussed an article that had been circulated before the session, "Life is Too Short For Someone Else's Shame" by Amanda Leduc.

Below is a non-chronological summary of the themes that were discussed.

## Context: What is disclosure?

Alexia defined disclosure as the act of sharing with an organization, institution, person, etc. that you are a disabled individual, for the purpose of getting your access needs met. That is, it is "requesting essential resources or accommodations that someone needs to take part in the workplace and do their job."

If you don't disclose, you have to mask, or pretend you don't have a disability, which is exhausting.

But even if you have an apparent disability, you're not really disclosing that you have a disability, you're asking for accommodation. For example, Alexia recently told someone via e-mail that she needed a step stool so she could reach things in a theatre space where she had a workshop gig, but when she meets people for the first time in person she doesn't necessarily have to disclose.

For a lot of people, disclosure happens before they even enter the workforce, within schools.

Alexia said that there are many different feelings around disclosure. Personally, she sometimes thinks of disclosure "as a sort of favour that disabled folks do for nondisabled people", and other times thinks about a world where access is the default and no disclosure would be necessary. No one discloses to *her* whether someone in a space she is entering is ableist or has never spoken to or known a disabled person before.

## What makes disclosure hard?

Alexia shared that in 2022, the Canadian Survey on Disability showed that 27% of Canadians aged 15 or older identified as having a disability or being disabled. Yet she shared that despite over a quarter of the population identifying this way, it is still "very frustrating" that there are no measures in place to make disclosure safer for people. Here are some reasons disclosure is so hard, as discussed by Alexia and others:

***Fear of career death:*** Fears of being harassed and passed over for opportunities and new roles, e.g. "sort of stuck in a static position without any growth in terms of salary and in terms opportunities".

***Administrative work involved in disclosure:*** Having to obtain professional assessments and come up with documentation to "prove" a disability, according to the medical model.

- Alexia shared that one U.S. survey found that 76% of students didn't reveal they had a learning disability because they were held back by the time and cost of professional assessments and the fear or reality of professors not honouring requests they had made.
- Jenel spoke about having to reapply as a disability student every year and get a letter from her psychiatrist and go to appointments.
- Another participant pointed out that even *with* these proofs, it can be like, do you really need it, though?

***Emotional labour:*** Participants spoke about grappling with fear, shame, pessimism and fatigue in making the decision to disclose.

- One participant talked about a positive "vibe" in workplaces, where either there are lots of other people with disabilities, lots of diversity and open-mindedness, or else another vibe "of like, nope". "And I've seen it repeated over and over again."
- Another spoke about not wanting to disclose when in a workplace where they like the people they are working with, so as not to be "disappointed". They've had many experiences of being "profoundly disappointed."
- A third pointed out how they recently applied for a residency grant and realized that their accessibility needs were more than their project needs. "Imagine what they will say when they see that." As they went through the process, they found themselves negotiating. And this was even with organizations that are talking about how they are trying to be inclusive.

***The hierarchy of disability:*** One of the topics that came up many times in this discussion was the non-disabled world's idea that some disabilities are easier to mask and/or accommodate, and how this leads to a "hierarchy of disability"[1] that harms everyone.

- In her opening remarks, Alexia said sometimes people think that non-apparent disabilities are easier, because you can mask, which means you are not blocked by social stigmas or obvious physical access needs that have to be immediately accommodated for you to get a job, or by the perception that you simply cannot do certain tasks. This ability to mask and act non-disabled can cause people to hide both before and after being hired, due to fears of discrimination. She spoke about a writer she knows who has ADHD who is just now able to talk about his neurodivergence, because "disability pride" has been "blossoming" the past few years.
- Later in the discussion, a participant said that "some disabilities will garner you a lot of support and there is structure in place to help you and people will understand it more". And pointed out how with mental illness, there is ableist language that is not taboo, and if you reveal you have it, "you will be harmed. And harmed and harmed and harmed. Overtly, publicly, structurally, in every way." So it's not that easy to just disclose, because you'll be "judged and shot down".
- Another participant talked about how in Ontario "even talking about the type of legal protections that [people with mental illness/neurodivergence] have and our right to be considered disabled at all is very new". This isn't to say it's "about this notion of trying to compare disabilities but just saying that just historically, we're kind of a little bit behind where some other folks are".

***Institutional attitudes:*** Old attitudes of ableism, patriarchy, and colonialism that ignore diversity and access needs.

- A participant pointed out that their institution, a university, was not good at meeting accessibility needs because it is seen as very inconvenient. "And university should be a place where accommodation is met more readily than other spaces," they said.
- Another participant spoke about how there were discussions at the WKP Kennedy Gallery / Capitol Center last September, between the Disability Collective, the public and artists

[1] Hierarchy of disability: where the more non-disabled someone seems, the more acceptable and less stigmatized they become to non-disabled people.

about how arts organizations can do better, including their experiences with the gallery there, and yet no actions resulted. They described a colonial, patriarchal perspective on the aesthetics of art galleries, where access and inclusion needs aren't being considered, i.e. the need to hang art for wheelchairs, or have chairs instead of benches. (A "doctrine aesthetic" that comes from the "cannon" of the "patriarch of everything".) They spoke about how they told a gallery all about what an accessible chair looks like, but when they went to an opening "the chairs they added couldn't even fit my ass in", and when they went to another opening, there weren't even any chairs. They concluded by commenting on the sparsity of art by women and black artists in galleries, imagining that the representation of disabled artists "would be next to zero".

- Another participant spoke about how, as a visually impaired artist, they have assistants that become pushy and tell them what to do, and then after the show, say "You're an inspiration."
- Alexia pointed out that part of the problem is that the person for "ministry of disability and et cetera, et cetera is a nondisabled older man" and "our experiences and our stories and perspectives aren't found in sort of any level except for entry level". And the problem isn't that the disability community isn't willing to share their knowledge, it's that these folks are not willing to listen our take our advice, advice given out freely and without charge.

***Fear of tokenism:*** The concern that once you are hired, you will become the symbol of and expert on "diversity" in your organization.

- Alexia spoke about how being tokenized has put her in an uncomfortable position due to organizations' self-congratulatory attitudes ("Oh, we have one of them. Look at us go. Aren't we great?"), monolithic view of disability, and hypocrisy. Once she was asked to appear on an organization's website, even though they didn't even have an elevator, and after she had been working there long enough that they needed her more than she needed them, she asked for the page to be taken down.
- Another participant talked about how they were asked to provide disability "expertise" in ways that went beyond their job description. They said while they love looking over people's stuff, "I also have mixed feelings about it. That's not really my job. And maybe you should get somebody and pay them to do this. I feel like I'm taking opportunities away from other people by doing that." They were angry at not being credited for work they did, but then when they were credited, they felt "weird", because they never actually set up the project and were not an equal partner, but a "late-stage addition". They were "proud" to see their name on the report but "also felt like oh, my God, no, I don't want to be associated with this. Because there is so much about this that I don't agree with... I feel like this makes me look bad in the community. But then I don't want them to take my name off of it because I did all the work."

## Alexia's advice for disclosure

Although she didn't offer a 1-2-3 formula for disclosure, Alexia did provide a few points of advice at different points:

***Less is more.*** "Never feel obligated to give the exact condition." The curiosity of non-disabled people is not your responsibility. You only have to tell them what accommodations you require, never a diagnosis or any medical history. "That is not for the employer or collaborator or institution to know." They are not even supposed to ask.

***Have someone in your corner.*** It is helpful to have somebody you trust to fight for you, e.g. someone in your friend group, job group, HR, the manager who hired you. Alexia has an agent who knows about her disability and can fight and advocate for her, but also can't choose not to disclose, because film and video is a very visual medium and people can see that she's disabled.

## Disability pride and voice

Much of the discussion also centered around unpacking ableism, validating our access rights, and celebrating our identity.

Before the session, participants read an article by disabled artist Amanda Leduc, entitled "Life is Too Short For Someone Else's Shame"[2]. They had a very positive response to this article, which they found validating and also challenging to internalized ableism. Specifically, they discussed two major points in this article:

***We all deserve access***: The idea that there is no "hierarchy of disability" when it comes to getting our needs met. No disability should be considered better or less, or easier to accommodate than another.

- Alexia said that this idea of one disability being more convenient or better than another has "been put on us" by non-disabled people, not dictated by our community.
- Another participant found this aspect of the article "affirming" of their right to have their needs met.

***Disability pride:*** The idea of disability as positive identity and a source of culture pride.

- Several participants, including Alexia, spoke about taking a journey to identify as a "disabled artist" rather than "artist with a disability", because this is a huge part of ourselves and informs our work. Alexia spoke about how some have started capitalizing Disabled like Deaf, as culture identity.

## Working for change

As well as discussing the challenges and frustrations around disclosure, participants talked about how we can work together for change.

***Strength in numbers.***

[2] https://disabilityvisibilityproject.com/2020/09/16/life-is-too-short-for-someone-elses-shame/

- One participant asked, “How do we put their feet to the flame now?” How do we fight the “big organizations that don’t accommodate?” How do you go there with a complaint or a request or an issue? They suggested that the change is made “by coming forth and making ourselves known that there are lots of us and then taking steps to put the feet to the flame of the system”.

***Disclosing for the people who come after you:*** How some of us are coming forward and starting the conversation to pave the way for others who will follow.

- Sacha, who finds herself disclosing “more and more and more”, said: “Every time another disabled person in your circle hears you disclose it makes it safer for them. And it makes it more of a community for them.” She talked about how being on CPP disability makes it easier for her to disclose, because she doesn’t have to worry about where her next paycheque is coming from. But she also talked about a paradox where on one hand you have to prove that you’re really disabled and on the other hand you have to show people that you can participate in the world.
- Alexia mentioned that as a white woman, she can use her privilege to come forward and ask for these changes. “Because the repercussions of that are less than someone who is not a white woman.” She spoke about coming forward to create a world where disclosure would be unnecessary since access needs were just built into everything, and, for example, “Your employer will know to send out in their confirmation e-mail in an interview, this is a list of access supports we have. If anything you need is not available, please mention it. It won’t have to be a prompt from us. It won’t have to be something we beg and scream and cry for. So it is a reason why I do it. And I hope that it becomes a standard.”

***The importance of spaces like this one.***

- One participant pointed out how spaces like the ones AANM provide offer an opportunity for people to feel less alone and more supported, to get their voices together and heard.
- Alexia talked about how she feels most like herself in spaces like the disability community or her family, unlike in public where everyone stares at her, there are questions, or she gets “accosted at the grocery store”.

***Caveat: Self-care is also necessary.***

- One participant one mentioned how they can’t always expend the energy to be advocating, that they also have to think about survival, and another concurred that people just get tired and can’t take anymore.

## Final thought: The drive to be “undeniable”

Towards the end of the session, Jenel invited one of the participants to offer a last comment.

They talked about Peter Owusu-Ansah’s ideas about the “drive” disabled artists have “to do something that is undeniable”, the idea of disability art having to be “ambitious” and “so good”, “the standard of having to be so far up here just to be acknowledged.” They spoke of the

disappointment that comes from this lack of acknowledgement. “Disability arts is so just like, beyond,” they said. “It is so beautiful. And special. And at the end of the day for a lot of people, it still doesn’t even really matter.”

Alexia pointed out that the art of non-disabled artists can be terrible and still get displayed and produced, and told the participants that “any art you make is great art”. “So be kind to yourself. Meet yourself wherever you’re at. And when you can find your community because that’s how we’re making waves.” She pointed out that her work has led to theatre companies and other places slowly integrating access “because there was a demand because we are demanding it”.

“So be loud when you can. Take rest when you need it. And just know that you have a support system within this community.”