

Ethics Protocols

Disability Arts & Activism Archives

Current state: FINAL DRAFT, revisions complete

Last update: June 27th, 2022

Project Summary

The Disability Arts & Activism Archive (hereby “DAAA”) is a research creation project documenting the disability organizing history and disability arts history across what is colonially called British Columbia.

The project will use one-on-one interviews with marginalized¹ disabled/crip/Mad/ill² organizers and artists who have substantial experience in disability arts and activism in BC (hereby called “Interviewees”); engaging marginalized disabled/crip/Mad/ill artists (hereby called “Artists”) to create multi-media Interpretations³ of these interviews; and presenting the collected data, interviews, and Interpretations, as well as a timeline detailing dates of interest regarding disability activism and arts shared by Interviewees, as an archive on a publicly accessible website.

This initial iteration of the DAAA will start September 1st, 2021 and conclude April 30th, 2023 during which all data collection and processing, and engaging Artists will be complete, culminating with the publication of the DAAA website accompanied by a launch event spotlighting the Interviewees and Artists. Should the DAAA website not be ready for publication by April 30th, 2023, a launch event will still be held, and to finish building the website a supplemental grant will be obtained to fund the website’s completion.

Much of documentation, research and presentation of disability activism is connected to academic institutions, centering cisgender, white, disabled men and therefore lacks the nuances of disability activism led by people living in poverty and existing in multiply marginalized communities. The DAAA aims to create a living archive of disability activism and arts history through a “ground-up” historical approach (i.e. archival work done through a critical lens) by fellow marginalized disabled/crip/Mad/ill people for the empowerment of marginalized disabled/crip/Mad/ill people, and the knowledge translation to the larger communities and relevant stakeholders, that will be developed by and accountable to the community that it endeavors to represent.

General Information

This project is funded by the Canada Council of the Arts and supported institutionally through Kickstart Disability Arts & Culture: (hello@kickstartdisability.ca), 604-343-9141

The Disability Arts & Activism Archive project can be contacted at Disability.Arts.Activism.Archive@gmail.com.

Research will be conducted by Quin (Q) Lawrence, who can be contacted directly at QuinEliLawrence@gmail.com.

¹ See Rationale and Background Information for the DAAA’s definition of marginalized.

² See Rationale and Background Information for the DAAA’s definition of disabled/crip/Mad/ill.

³ An Interpretation is an artwork created in response to an interview, in any medium that can be digitized or documented and therefore presented on the DAAA website archive (e.g. painting, poetry, music, photography, mixed media, installation, textile, ephemeral art, etc.).

Rationale and Background Information

Marginalized disabled/crip/Mad/ill organizing and artwork is largely ignored and erased, and in the times that it is recognized it is rarely recorded by fellow marginalized disabled/crip/Mad/ill people. While disability activism has historically been led by people living in poverty and existing in multiply marginalized communities, much of the documentation, research and presentation of disability activism is connected to academic institutions⁴. Historically this has meant the centering of cisgender, white, disabled men within accounts of disability activist efforts and has resulted in the erasure of the nuances of disability activism that is led by those with no access to academia⁵. This project matters now, as many on-the-ground activists are seeing this moment in time to be a pivotal shift in disability activism. Throughout the pandemic disability activists have come together to protect each other through efforts such as: #300toLive BC campaign, Disability Filibuster against Bill C-7, and the ongoing fight for vaccine access. The creation of a living archive of disability activist history in BC is a way to learn from past movements such as: efforts against sterilization, activism against institutionalization and incarceration, demands for access to school, and activism regarding healthcare. As new movements arise, looking to the past and engaging with the living archive will help contemporary disabled activists to learn about cross-disability and cross-movement solidarity work. This project opens up a vantage point that, unlike disability activism studied and presented by academic researchers, is developed by and accountable to the community that it endeavors to represent.

This erasure of organizing and artwork is in part largely due to institutional and systemic ableism. The DAAA recognizes Talila A. Lewis' working definition of ableism as of 2022:

"A system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism, and capitalism. This systemic oppression that leads to people and society determining people's value based on their culture, age, language, appearance, religion, birth or living place, "health/wellness", and/or their ability to satisfactorily re/produce, "excel" and "behave." You do not have to be disabled to experience ableism."

The DAAA aims to create an archive of these artworks and organizing for the empowerment of marginalized disabled/crip/Mad/ill people and the knowledge translation to the larger communities and relevant stakeholders.

In order to best understand the community based knowledge foundational to this work, below are the central ideas that situate the context of this work:

The DAAA defines marginalized as those excluded from mainstream social, economic, educational, and/or cultural life, including but not limited to disabled people who are Indigenous, Black, and racialized; living in poverty; queer, trans, 2SLGBTQIA+, Indigiqueer; fat; incarcerated

⁴ Kelly, C., & Orsini, M. (2016). *Bodies in Translation*. Bodies in Translation. <https://bodiesintranslation.ca>

⁵ Shakespeare, T. (2006). *Disability Rights and Wrongs*. Routledge.

or formerly incarcerated; houseless or formerly houseless; immigrants; non-citizens; seniors (recognized as a self-identifier defined by cultural contexts of race, class, gender, numerical and experiential age, and so forth, as well as Canada's definition of a person 65 years of age or older); people with intellectual/cognitive disabilities; drug users; and people at multiple axes of these experiences. While the DAAA considers these experiences potentially marginalizing, Interviewees & Artists may not frame their experiences as such for many reasons including the context of living in what is colonially known as "Canada" and "British Columbia"; there is room for prospective Interviewees or Artists whose experiences are reflected above but do not identify as marginalized. The intention of this definition and its inclusion in this project's selection criteria is to aid in prioritizing people who are not often represented in or given the opportunity to be involved in a project of this nature.

The DAAA defines disabled/crip/Mad/ill as: experiences of or identification with Madness, mental illness, chronic illness, chronic pain, neurodivergence, limb and facial difference, physical disability, sensory disability, d/Deaf or hard of hearing; with the understanding that claiming Disabled as an identifier is complicated for many for community, cultural, or individual reasons. This definition is neither exhaustive nor prescriptive, nor does it encompass the full breadth of every cultural and community expression of body-mind difference. Individual experiences of disability vary as does the language one uses. There is room for prospective Interviewees or Artists who recognize their experiences as disability/disabled without necessarily using any of the language in the DAAA's definition.

The DAAA uses the phrase "lived expertise" in lieu of the more common phrase "lived experience" to emphasize that marginalized disabled/crip/Mad/ill people's experiences "[inform their perspectives], what [they] look at and questions [they] ask...[that] someone else might overlook and fail to grasp the significance of"⁶, and that these perspectives are comparable to the expertise one may develop through formal academic education.

The DAAA defines accessibility as a dynamic and ongoing practice of interdependent support towards a goal of meeting the needs of everyone involved in the project, including participants and the Researcher & Project Team. The DAAA will collaborate with participants to craft access specific to each individual, striving to cultivate an environment of access intimacy⁷ to move "the work of access out of the realm of only logistics and into the realm of relationships"⁸ where possible. The DAAA draws on existing frameworks including Disability Justice and Open Access to inform its approach to access as "a creative...process"⁹, understanding that "all [bodyminds]

⁶ Peters, G. [@mssinenomine] (2021, January 16). *My lived expertise informs my perspective, what I look at and questions I ask. It is not a product I* [Tweet]. Twitter.

<https://twitter.com/mssinenomine/status/1350449210110345218>

⁷ Access intimacy is a term coined by Mia Mingus on her blog Leaving Evidence to describe the sense of comfort and ease of one's access needs and disabled self being wholly recognized and welcome. Mingus is clear that while she gave the experience a name, she did not create it nor was she the first to discuss it.

⁸ Mingus, M. (2017, April 12). *Access Intimacy, Interdependence and Disability Justice*. Leaving Evidence. <https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/>

⁹ Papalia, C. (2018, January 2). *An Accessibility Manifesto for the Arts*. Canadian Art. <https://canadianart.ca/essays/access-revived/>

have strengths and needs that must be met...[and are] confined by ability, race, gender, sexuality, class, nation state, religion, and more”¹⁰ that cannot be separated.

The DAAA considers accessibility in the public dissemination of this research creation project in both where the data is held and how it is presented as an online archive. The online archive will be publicly accessible and low-barrier, only requiring internet access. It will observe and strive to exceed the accessibility standards laid out by the World Wide Web Consortium (hereby “W3C”) Recommendations¹¹ in its design, including but not limited to formatting for screenreaders, openly available transcriptions of video and audio files, and captions on video files.

¹⁰ *What is Disability Justice?* (2020, June 16). Sins Invalid.
<https://www.sinsinvalid.org/news-1/2020/6/16/what-is-disability-justice>

¹¹ <https://www.w3.org/WAI/standards-guidelines/>

Goals and Objectives

- Explore artwork made and being made by marginalized disabled/crip/Mad/ill people about their/our experiences.
- Document how marginalized disabled/crip/Mad/ill people have been organizing and mobilizing in response to or for the advancement of their/our social conditions, community, and material livelihood.
- Curate artwork Interpretations of interviews from marginalized disabled/crip/Mad/ill artists, to publish alongside interviews on a publicly accessible archive website.
- Create a publicly accessible archive website containing an interactive multi-media timeline of dates of organizing and artworks, linking to artwork Interpretations and interviews of marginalized disabled/crip/Mad/ill organizers and artists presented in part or whole by the following or some combination of: email text, audio, transcribed audio, transcribed video.
- Provide accessible, empowering information and artwork of marginalized disabled/crip/Mad/ill arts and activism for disabled people toward their personal education and advancement, community engagement and mobilization, and broadly in academic and institutional spaces for positive change.

Project design

Conduct one-on-one interviews with seven (7) marginalized disabled/crip/Mad/ill Interviewees. Interviews will be recorded solely for the purpose of data processing¹² (hereby “Data Processing”) and used by Artists for Interpretations, and will be deleted by 5pm PST Friday, January 27th, 2023. Recordings will not appear publicly in part or full.

Raw data¹³ will be processed in order to create and populate the archive timeline and to present the interviews on the website in the form of text and audio, as well as generate the following informative texts for the archive: Interviewee & Artist bios, Explanatory Text¹⁴, interview content outlines, and event summaries.

Solicit seven (7) Artists to each create an Interpretation of the processed data of a one-on-one interview. Artists also have the option to include an Artist Statement¹⁵ that will appear alongside the Interpretation on the DAAA website.

Build and publish a website to present interviews and Interpretations alongside a timeline documenting dates of interest in disability activism and arts shared by Interviewees, as a publicly accessible archive.

¹² Data Processing is the preparation of interview content for public dissemination, including but not limited to: removal of content according to Interviewee consent and requests; production of transcripts, captions, and recorded reading of interviews; and creation of content notes—in collaboration with Interviewees on what is included and its media format.

¹³ Raw data is interview recordings and transcripts.

¹⁴ Explanatory Text is a brief extended bio that for Interviewees contextualizes their role in disability activism and arts, and for Artists explains their artistic practice and connection to disability activism and arts.

¹⁵ Artist Statement is an explanation of the Artists’ process and their connection to disability activism and arts as pertains to their interview Interpretation.

Methodology

1) Kickstart and the Researcher will use mixed method sampling, with a combination of an open-call through the Kickstart ListServe and snowball sampling, to solicit potential Interviewees, with consideration of meeting an intersectional scope in a small amount of participants. The open-call will ask marginalized disabled/crip/Mad/ill organizers and artists in BC with experience in disabled arts and activism to apply through a google form or by contacting the DAAA project email for plain text or voice recording application. The information the Researcher & Project Team will request by google form or email will include but is not limited to: are they applying as an organizer, artist, or both; what experiences do they propose to discuss; what dates of importance in disabled arts and activism history were they involved in that they propose be added to the archive; how do they identify (e.g. sexuality, gender, race, disability, citizenship, class, size, etc.); what communities are they a part of; when were they active as an organizer and/or artist; how long were they active as an organizer and/or artist; what roles did they take in disabled arts and activism (e.g. event planner, attendee, access coordinator, mutual aid provider, etc); who has informed their understanding of disabled arts and activism; why do they want to be involved in the DAAA.

2) Seven (7) Interviewees will be selected from the Interviewee open-call respondents and snowball sampling. Selection will be made by the Researcher & Project Team based on the following factors which are included in the open-call and the information requested of respondents: to what extent do the respondents' identities appear in media of this subject and theme; what depth of lived expertise in disabled arts and activism do respondents demonstrate; what depth and breadth of understanding of disabled arts and activism do respondents demonstrate; does a respondent have a life-limiting illness or otherwise demonstrate they have or have had few to no prior opportunities to share their lived expertise in disabled arts and activism. In the event of a potential Interviewee opting out of the project, or an Interviewee opting out of the project in full, the Researcher & Project Team will contact the next Interviewee open-call respondent(s) selected to be an Interviewee.

3) Following selection, potential Interviewees will be sent a consent form for their involvement in the project. The consent form will include but is not limited to: Interviewee agreements regarding what identifying information of the Interviewee can be published, if the Interviewee is open to a conversation with the Artist interpreting their interview, and if the Researcher can contact the Interviewee about future research and/or project expansion; and informing the Interviewee that their interview will be recorded, they can opt out of the project in part or full at any time, they have control over what language is used to refer to them and their experiences in the project, they may review the processed data from their interview before publication, they may review the Interpretation made from their interview and request changes or revoke consent to publish the Interpretation. Once potential Interviewees submit their signed consent form, they are engaged as Interviewees.

4) Interviews will be scheduled and conducted by the Researcher & Project Team in the communication method of the participants' choosing, with available options being email, audio call, video call, or in-person should the Interviewee be unable to participate in an alternative remote communication option and the Researcher is able to travel to the Interviewee. In the event of an in-person interview, all possible and applicable COVID safety measures will be taken; they are as follows: N95 or equivalent masks for Interviewee, Researcher and any accompanying persons; ventilation or an outdoor location; air purification system in place; testing for Interviewee, Researcher and any accompanying persons before and after interview; and any measures requested by Interviewee or accompanying persons. Interviewees will have full autonomy over subjects of discussion and disclosure of information. Each one-on-one interview will be unique to the history of the Interviewee and what they choose to disclose.

5) Kickstart and the Researcher will use mixed method sampling, with a combination of an open-call through the Kickstart ListServe and snowball sampling, to solicit potential Artists to create Interpretations of Interviewee interviews, with consideration of meeting an intersectional scope in a small amount of participants. The open-call will ask marginalized disabled/crip/Mad/ill artists in BC to apply through a google form or by contacting the DAAA project email. The information the Researcher & Project Team will request by google form or email will include but is not limited to: how do they identify (e.g. sexuality, gender, race, disability, citizenship, class, size, etc.); what communities are they a part of; what is their artistic medium(s) (e.g. painting, poetry, music, photography, mixed media, installation, textile, ephemeral art, etc.); what medium(s) are they proposing for their Interpretation; a link to their portfolio or previous work; who has informed their understanding of disability; how does disability affect their opportunities as an artist; why do they want to be involved in the DAAA.

6) Upon completion of the interviews, data processing begins (see below specifics of data processing). Once data processing has begun on all the interviews already conducted, if an Interviewee opts out of the project, the Researcher & Project Team will not contact any further open-call respondents for this iteration of the project. Once data processing is complete, Interviewees will review the processed data in a method that is accessible to them for any corrections, redactions, and addendums prior to the release of processed data to Artists.

7) Seven (7) Artists will be selected from the Artist open-call respondents and snowball sampling. Selection will be made by the Researcher & Project Team based on the following factors which are included in the open-call and the information requested of respondents: demonstrated completion of previous work; few to no prior paid artistic opportunities (in part due to marginalization); demonstrated political understanding of disability; to what extent do the respondents' identities appear in existing disability art projects. In the event of an Artist opting out of the project, the Researcher & Project Team will contact the next Artist open-call respondent(s) selected to be an Artist.

8) Following selection, potential Artists will be sent a consent form for their involvement in the project. The consent form will include but is not limited to: Artist agreements regarding

what identifying information of the Artist can be published, if they will write the visual and/or audio description of their Interpretation or consent to the Researcher & Project Team writing the visual and/or audio description, and if the Researcher can contact the Artist about future research and/or project expansion; and informing the Artist that their Interpretation and artist statement, if they choose to provide one, will appear publicly available on the DAAA website, they can opt out of the project in part or full at any time, they have control over what language is used to refer to them and their experiences in the project, they will use the language that the Interviewee uses in their Interpretation and artist statement, Interviewees will be given the opportunity to review the Interpretation and request changes within reason or revoke consent to publish the Interpretation, it is their decision if they will make changes to the Interpretation with the understanding that the Interviewee may revoke consent to publish the Interpretation in the event none or only some of the requested changes are made, and they may review the Interpretation, artist statement, and their bio as it will appear on the DAAA website before publication. Once potential Artists submit their signed consent form, they are engaged as Artists.

9) Artists will receive Interviewee bios and brief outlines of the interview contents from the Researcher & Project Team, and will respond with a ranked list of each interview in order of preference where they can include reasoning for their choices. The Researcher & Project Team will assign an interview for each Artist, respecting the Artists' preferences as much as possible.

10) Artists will develop and produce their Interpretation, write an artist statement if they choose to provide one, and write the audio and/or visual description of their Interpretation if they chose to write the description themselves. While developing their Interpretation, Artists can request: a recorded reading of the interview in part or full; a conversation with the Researcher and/or Interviewee in a communication method accessible for all participants (see available options in Project Design) for guidance, soundboarding, clarification, and additional details or background. Artists will submit their Interpretation and completed written material(s) by an agreed upon deadline. Once all Artists have begun producing their Interpretation and forward, if an Artist opts out of the project, the Researcher & Project Team will not contact any further open-call respondents for this iteration of the project.

11) The Researcher & Project Team will prepare a brief outline of each Interpretation's contents to include with each Interpretation for the Interviewee reviews.

12) Interviewees will have an opportunity to review their interview's Interpretation, and may accept the Interpretation, request changes within reason, or revoke consent to publish the Interpretation.

13) DAAA website development will coincide with the interview and Interpretation process, during which the website's design and interface will be constructed. The website will be populated with processed data and Artist Interpretations after Interviewee reviews. The website contents will then be proofed by the Researcher & Project Team, followed by an Access Review

by an Access Consultant, with all content and design changes made prior to a final review by the Researcher, Project Team, Interviewees, and Artists. Interviewees and Artists in particular will have the opportunity to review the presentation of their interviews and Interpretations, and may accept, request changes within reason, or revoke consent to publish their interviews and Interpretations. The DAAA website will be published upon completion of final review changes.

14) Interviewees and Artists will be notified of the DAAA website's publication by their indicated preferred communication method prior to the website going live.

Data Processing Specifics

1) Interviews will be transcribed word-for-word in full into plain text documents.

2) Each interview plain text document will undergo revisions according to Interviewee consent, including but not limited to: anonymizing names and locations; language corrections; fact-checking; addendums.

3) Revised full text of each interview will be sorted into timeline entries for chronological ordering, categorization for reference and archive searchability (see below categories), and to generate additional text materials (see point 4).

Events

- Interviewee (name or pseudonym)
- Date(s), time(s)
- Place(s)
- Form (protest, mutual aid network, solidarity or coalition building event, a memorial, commemoration, etc.)
- Motivating factors (social or political issues, or community needs)
- Who was involved in organizing/planning
- Organizations involved
- Message of event
- Marginalization, disability, community
- Impact and/or outcome
- Themes (for content outline)
- Notable attendees (groups, individuals)

Artwork

- Interviewee (name or pseudonym)
- Date(s), time(s)
- Place(s)
- Form (protest, community building, memorial, commemoration, personal processing etc.)
- Motivating factors (response to personal or social event(s))
- Who was involved in organizing/planning
- Organizations involved
- Message of artwork
- Marginalization, disability, community
- Impact and/or outcome
- Themes (for content outline)
- Inspiration and/or in conversation with
- Medium

4) The following texts will be generated from revised interview text for the Artist Interpretation process and to appear on site. The Interviewee bio, Explanatory Text, and revised interview full text will be reviewed by the Interviewee after data processing, in a method that is accessible to the Interviewee, before releasing to Artists.

- Interviewee bios
- Explanatory Texts
- Revised interview full text
- Interview content outlines
- Event summaries
- Captions for video interviews
- Timestamps for audio and video formats
- Estimated reading time (by the metric of 200 words per minute)

In addition to the accessibility measures listed in point four (4) of Data Processing, voice actors will be hired to record voice files of interviews, artist statements, bios, explanatory texts, content outlines, and event summaries to include on the DAAA website once the text to be recorded has undergone its final review as indicated by the applicable Interviewee or Artist.

Interviewee Guide

The following is a guide for the Researcher conducting interviews, to assist them in gathering details necessary for the DAAA website archive timeline, as well as to expand on the direction of discussion as led by the Interviewee. Interviewees are not required to answer any or all of these questions in full or part.

General to each Interviewee:

For Bios

- What was your role [artist/organizer/artist-organizer]
- How do you describe yourself:
 - date of birth
 - where do you call home; where have you lived that's important to you; where were you born; where are you currently
 - visual description
 - personal identities
 - personal definition of "community"
 - roles/identity in community
 - communities you belong to
 - communities you were/are involved in
 - any further descriptions you wish to add
- When were you active in this role
- Where were/are you active in this role

For Explanatory Text

- What were/are your formative experiences in organizing and/or arts
- When did you come to disabled arts and activism

- How did you come to disabled arts and activism (e.g. newly disabled, experiences of hardship, introduced by another organizer/artist, etc)
- Who was/is integral to your understanding of disability and disabled arts and activism (formal and informal connections, learning, resources, etc)

For Timeline Entries on organizing

- What form did the organizing take; was it a protest, a mutual aid network, a solidarity or coalition building event, a memorial, a commemoration, etc.
- Who else was involved in the planning and the execution of the organizing (individuals, organizations, collectives, etc); how were they involved (supporting, planning, event management, resource acquisition, etc)
- When did organizing take place; was it a single event, series of events, or a range of time
- Where did organizing take place (e.g. online, at a location of significance, occupying streets or building, etc)
- What social or political issues or community needs were you organizing for or against
- Who was the messaging of this action targeted towards
- How did your disability(ies) (and those of the other organizers if any) shape the planning and execution of the organizing in form, timeline, resources needed, acquired, and supplied, or other ways
- Was this organizing intended to engage a broader participation (e.g. protest, memorial letter writing campaign, etc.); who did you intend to invite/engage; who showed up and participated
- How were your communities, the general public, and/or political individuals or bodies intended to respond to the organizing; how did they in reality
- What were the results of organizing (e.g. policy changes, keeping community members housed and fed and medicated, accessibility improvements, etc)
- What were your thoughts and feelings when you were organizing
- What are your thoughts and feelings on the organizing looking back at it now
- How does community involvement in the organizing—the community's involvement in inspiring and shaping the organizing, the planning and execution of the organizing, the community's response and engagement afterward—show the significance of disabled arts and disabled activism
- What access offerings were considered in the planning and execution of the organizing
- What conflicting access needs were present in the planning and execution of the organizing; how or were they addressed (by organizers, community, involved organizations and collectives)
- Did you and/or other organizers account for sustainable practices, burnout, fatigue, and/or individual and collective information security in the planning and execution of organizing
- Did you experience burnout, fatigue, and/or breaks in individual and collective information security in the planning and execution of organizing; how did that present itself and affect this and future organizing

For Timeline Entries on artwork

- What is the artwork: its medium, topic, intended purpose, intended audience
- How did your disability(ies) shape the medium, method, creation process and timeline, how the artwork is in conversation with your own or other artists' work, and/or presentation of the artwork
- What personal or social event was this artwork created in response to
- How is the audience intended to engage with the artwork (viewing, interactive, tactile etc.)
- Where was the artwork made; where was it presented
- When was the artwork made; when was it presented
- Who was involved in the creation of the artwork; who was involved in the presentation of the artwork
- What was the response to this artwork from your communities, the general public, and/or political individuals or bodies
- At the time and following its creation and/or presentation, what were your thoughts and feelings on the effect the artwork had on your communities, the general public, political individuals or bodies and/or the decisions they made, and/or your experiences of the social climate
- What are your thoughts and feelings on the artwork looking back at it now
- What were your thoughts and feelings when you were making the artwork
- How does community involvement in this artwork—the community's involvement in inspiring and shaping the artwork, the creation and presentation of the artwork, the community's response and engagement afterward—show the significance of disabled arts and disabled activism
- What access offerings were considered in the creation and presentation of the artwork
- What conflicting access needs were present in the creation and presentation of the artwork; how or were they addressed (by artist, community, audiences)

Artists Guide

The following is a guide for the Researcher conducting conversations or communications with Artists, to assist them in gathering details necessary for the DAAA Artist bios and explanatory texts. Artists are not required to answer any or all of these questions in full or part.

General questions for each Artist

For Bios

- What is your medium(s) in art; how do you describe yourself as an "artist"
- How do you describe yourself:
 - date of birth
 - where do you call home; where have you lived that's important to you; where were you born; where are you currently
 - visual description

- personal identities
- personal definition of “community”
- roles/identity in community
- communities you belong to
- communities you were/are involved in
- any further descriptions you wish to add
- How long have you been creating; how long have you been making art in this medium/style
- Where do you create art (geographical location); what is your environment when you create (e.g. studio, outdoors, bed, etc)

For Explanatory Text

- What were/are your formative experiences in organizing and/or arts
- When did you come to disabled arts and activism
- How did you come to disabled arts and activism (e.g. newly disabled, experiences of hardship, introduced by another organizer/artist, etc)
- Who was/is integral to your understanding of disability and disabled arts and activism (formal and informal connections, learning, resources, etc)

Safety Considerations

Digital Communication and Storage Practices

The DAAA will undertake the following safety considerations regarding digital communication and local, cloud, and web data storage:

- Confidentiality of information shared over private digital communications (i.e. emails and direct messages on social media platforms) cannot be guaranteed in the event of a third party gaining access to participants' accounts or DAAA-affiliated accounts experiencing a breach in security.
- Surveys, interviews, and Conversations held over email will be backed up onto OneDrive and a password protected external harddrive. Emails containing this and other sensitive information will be deleted by April 7th, 2023, or by project end date. All email history with individual participants will be deleted based on the security decisions of the participant made in their consent form and in further discussion. The DAAA recommends participants' delete their own email history containing sensitive information in the event of a third party gaining access to participants' accounts.
- The Researcher & Project Team will use the preferred communication platform of the participants' choosing, however the Researcher & Project Team will inform participants of the above security considerations and recommend using email for further communication.
- The open-call application forms and informed consent forms will be generated in Google Drive for participants' accessibility, and forms filled out by participants using Google Forms and Google Docs will initially be stored in the DAAA's Google Drive. As forms are submitted, they will be exported to OneDrive and a password protected external harddrive, and deleted from Google Drive within a week of their submission.
- The DAAA will use Otter (otter.ai) for automatic transcription, Zoom (zoom.us) for virtual meetings (i.e. interviews and conversations), and OneDrive (onedrive.live.com) for cloud-based data storage, as well as a password protected physical external harddrive for local data storage that will be stored in the Researcher's home.
- Upon completion of transcription including any necessary editing process, content uploaded to Otter will be permanently deleted from its service by the Researcher & Project Team. This will be done by 5pm PST Friday, January 27th, 2023.
- Upon transfer to a separate storage service, recordings of meetings hosted on Zoom will be permanently deleted from Zoom's servers by the Researcher & Project Team. This

will be done by 5pm PST Friday, January 27th, 2023.

- The Researcher & Project Team will always apply the most secure sharing permissions possible to files and folders while allowing the best practical use of the OneDrive service for the project. Information about this will be transparently communicated to participants at solicitation and engagement, and upon request.
- The Researcher & Access Coordinator will back up data stored on OneDrive onto a password protected external harddrive stored at the Researcher's home, that only the Researcher & Access Coordinator will have physical access to.
- Raw data stored on OneDrive will be deleted by April 7th. Surveys and consent forms stored on OneDrive will be deleted by the latter of either the project end date or the launch of the archive website. Processed data will continue to be stored on OneDrive indefinitely for future expansions of the DAAA and will be updated alongside the archive website upon requested revisions.
- Raw data stored on the password protected external harddrive will be deleted based on the security decisions of the participant made in their consent form and in further discussion. Surveys, consent forms, and processed data will continue to be stored on the password protected external harddrive indefinitely.

Privacy Statement Summaries:

For Google Drive:

- Google Drive, including Google Forms and Google Docs, is covered by the Google Terms of Service, Google Privacy Policy, and Google Drive Additional Terms of Service.
- Google collects personal information including browser, device, and location details, and information users disclose upon making a Google account. This personal information may be used by third parties for targeted advertising.
- Contents of documents and forms made or completed in Google Drive are not used for targeted advertising.
- Google ensures that upon deletion, data is safely and completely removed from their servers or retained only in anonymized form.
- Contents of documents and forms made or completed in Google Drive are not retained upon completion of Google's safe deletion process, which may take up to two months.

Google's full Terms of Service, Privacy Policy, and Google Drive Additional Terms of Service can be read here: [Terms of Service](#) . [Privacy Policy](#) . [Google Drive Additional Terms of Service](#)

For Otter:

- Otter does not have any ownership claims to any content stored & processed by Otter.

- Otter does not guarantee that content stored on its cloud-based service is secure. Otter does make all reasonable attempts to maintain its security through commercially available means.
- Otter does not retain the content generated by the transcription service after its permanent deletion by the Researcher.
- Otter may use aggregated and deidentified data or content stored on its service for machine learning, marketing, or other business-related purposes. Any data or content used by Otter in this way will not identify you.

Otter's full Terms of Service and Privacy Policy can be read here: [Terms of Service](#) . [Privacy Policy](#)

For Zoom:

- Zoom does not guarantee the security of meetings held on its platform or recordings made of meetings.
- Personal data such as your name, contact information, user ID associated with your account may be collected and/or processed by Zoom in the course of a meeting.
- Personal data may be used by Zoom for product research and development; marketing, promotions, and third-party advertising; as well as legal, safety, and security purposes as detailed in its full Privacy Statement.
- Zoom employees do not access meeting, webinar, or messaging content (specifically, audio, video, files, and messages) unless directed by an account owner, or as required for legal, safety, or security reasons as detailed in its full Privacy Statement.
- Zoom does not use meeting, webinar, or messaging content for marketing, promotions, or third-party advertising purposes.

Zoom's full Terms of Service and Privacy Statement can be read here: [Terms of Service](#) . [Privacy Statement](#)

For OneDrive:

- OneDrive is a Microsoft product and therefore controlled by the Microsoft Terms of Use and Privacy Statement.
- Microsoft collects data about product users, contacts, and the content of communications in order to protect, improve, and provide services as applicable to the application.
- Data collected for use of OneDrive includes but is not limited to contact information; product user device information; contents of image, video, and audio files.

Microsoft's full Terms of Use and Privacy Statement can be read here: [Terms of Use](#) . [Privacy Statement](#)

Trauma-Responsive Practices

The DAAA recognizes that trauma is common in society and marginalized disabled/crip/Mad/ill communities in particular, and that the project may include discussion and engagement with experiences of trauma. The DAAA is therefore applying a trauma-responsive approach for the benefit and wellbeing of everyone involved in the project (i.e. Interviewees & Artists, Researcher, Project Team, and consultants). A trauma-responsive approach is the awareness of the prevalence of trauma; an understanding of the impact of trauma on physical, emotional, and mental health; enacting measures to avoid re-traumatizing anyone in the project; and providing care in the event of introducing trauma or recreating some conditions of a persons' previous trauma causing them to relive their trauma.

For Interviewees & Artists

- Active Listeners are available upon request before, during, and after all stages of the project (interviews, Interpretation process, reviews, publication event) until project completion to provide emotional support and assurance
 - Active Listeners are individuals with formal or informal training in listening attentively and without judgement, in order to provide support in the event of an emotional or trauma response contracted under a confidentiality agreement
 - Active Listeners will be assigned by their relevant background and experience and availability; and Interviewees & Artists can request a specific active listener or a change of active listener
- The Researcher is educated in how trauma responses can present and will conduct interviews and conversations with this in mind, including:
 - Offering an informal meeting with participants prior to interviews and conversations to establish trust, safety, rapport, boundaries, and needs
 - Opening interviews and conversations by establishing boundaries and needs of participants, including how the participant wants the Researcher to respond to potential trauma responses
 - Checking in with participants throughout interviews and conversations to re-establish and adapt to potential changes in boundaries and needs
 - Checking in with participants if and when trauma responses appear to present themselves and proceeding in ways the participant has requested during an informal meeting or at the start of the interview or conversation
- The Researcher will implement cognitive empathy practices of matching the energy that a participant is exhibiting where appropriate
- The Researcher will use the participants' language to refer to them and their experiences throughout the project and on the DAAA website
- Interviewees & Artists will have full autonomy over subjects of discussion and disclosure of information including the amount of detail provided
- Review of processed data and materials, in part or full, by Interviewees and Artists is optional
- Interviewees may dictate which portions of their interview if any will not be the focus of or included in the Artist Interpretation

- Prior to reviewing Interpretations, Interviewees will receive a brief outline of the contents of the Interpretation of their interview prepared by the Researcher & Project Team
- Interviewees have full control over what does and does not appear on the DAAA website and may revoke consent at any time by contacting the project
- When considering the Interviewees Artists may select for their Interpretation, Artists will receive a brief outline of the contents of the interviews prepared by the Researcher & Project Team
- Artists whose Interpretation is included on the DAAA website have full control over what does and does not appear on the DAAA website

For Researcher & Project Team

- The Researcher & Project Team are working from a Disability Justice-based perspective, meaning that the full and complex humanity of everyone involved is recognized and prioritized
 - Prioritizing the health and wellbeing of the Researcher & Project Team over project deadlines and workload
 - Allowing and providing time for slow practices, such as processing, discussion, and debriefing, at the pace set by the cumulative needs of the team
 - Time spent working on the project includes labour not traditionally defined as “work”, including preparing a workspace, recovering from intellectual and emotional labour, and taking breaks during billed hours
 - Accepting and embracing the ways our full and complex humanity affects how we are present in a work environment without judgement, e.g. emotional appearance, lack of on-camera presence, brain fog and other cognitive occurrences such as migraines
 - Adapting to new or changing access needs
- The Researcher & Project Team, while maintaining a culture of rolling check-ins regarding the workload and working practices, will formally re-evaluate working conditions, safety, and work culture monthly by meeting, email, or other preferred communication method.
- The Researcher has access to community-based therapy and resources that are aware of the nature of the project and are prepared to provide support
- Active Listeners are available upon request before, during, and after all stages of the project until project completion
- The Researcher & Project Team may delegate a task to another member of the Project Team in the event they are incapable of completing the task
- The Researcher and Admin Assistant will contract a temporary team member in the event that a Project Team member requires time off

Follow-up

After the completion of this project, the Researcher and/or Kickstart will notify Interviewees & Artists in the event of any of the following, by the communication method of their preference:

- The DAAA website's publication, prior to the website going live
- Further publication of processed data and/or Interpretations for exhibits by the Researcher and/or Kickstart
- Future iterations of this project that would expand the DAAA
- Further research projects by or in collaboration with the Researcher that make use of the processed data and/or Interpretations of this project
- Any use and reference to the DAAA website or any research collaboration the Researcher is made aware of

Interviewees & Artists will only be contacted regarding the above as they have indicated on their consent forms.

Expected outcomes

With the creation of a public archive of disability arts and activism created by and for marginalized disabled/crip/Mad/ill people, the DAAA expects the following outcomes:

- Empowerment of marginalized disabled/crip/Mad/ill individuals and communities to access resources and mutual aid, including insight into how they can organize themselves and with others
- Bolstering of grassroots efforts regarding disability justice, including increasing disability income assistance rates, changing policies around public demonstrations, and improving public access and accessibility
- Policy and cultural changes regarding the prevalence and accessibility of disability arts in art galleries and other institutions
- Employee policy changes and training initiatives regarding engaging with disabled people in art galleries and other institutions
- Policy; syllabus, curriculum, and research subject matter; and physical and digital access changes in academic spaces and institutions

Dissemination of Results & Publication Policy

Results of the project will be presented on a publicly accessible archive website in the form of an interactive timeline of dates of interest and the full text of interviews alongside Artist Interpretations. The website will be accessible and low-barrier, observing and striving to exceed the accessibility standards laid out by the W3C and only requiring internet access.

Announcement of these results will be made by the DAAA launch event; the Kickstart ListServe; a press release and interviews with the Project Team; Kickstart, the Researcher, and the project's social media; and word of mouth. Interviewees & Artists will be informed of the website's publication prior to the website going live, by their preferred communication method.

Acknowledgements will be made on the DAAA archive website of the Interviewees & Artists, Project Team, supporting individuals, and supporting organizations (Kickstart and Canada Council for the Arts).

Publication Longevity

The DAAA aims to be an accessible and publicly available archive that persists and develops continuously, and encompasses a broad and detailed range of geographical area, time span, and subject matter regarding disability arts and activism in "BC", with the possibility of expanding within "Canada". While the longevity of the DAAA is uncertain, it is considered and established through Kickstart overseeing and hosting this project as well as the archive website as an organization rather than a single individual. Therein, the archive website has funds allocated for long term hosting, and the Researcher and Kickstart plan to expand the archive in the future through further grant-funded projects. In the event of both the Researcher's death and Kickstart's dissolution, the archive website may deprecate, in which case future researchers are welcome to take inspiration in part or whole to document disability arts and activism history.

Artist Interpretation Publication Policy

Artist Interpretations will be published on the website archive alongside the full text of their relative interview, credited by name and with written bio. Artists can link to their Interpretation on their personal portfolio with use of an excerpt or preview of the Interpretation. Due to the personal and sensitive nature of information within the interviews, work in progress documentation and the final Interpretation cannot be published independently by the Artist, including on social media and their personal website.

Interviewees may revoke consent for the DAAA to publish the Interpretation of their interview after its publication, at which point the relevant Artist will be notified to remove the excerpt or preview of the Interpretation from their portfolio, but the Artist can still detail their involvement in the project. Upon the Interpretation's removal from the archive website, an Interviewee may consent to the Artist posting the Interpretation independently, at which point conversations of publication consent are solely between the Artist and the Interviewee.

Duration of the Project

September 1st, 2021 to April 30th, 2023.

Should the DAAA website not be ready for publication by April 30th, 2023, a launch event will still be held, and to finish building the website a supplemental grant will be obtained to fund the website's completion.

Anticipated Problems & Risks

The Researcher & Project Team considers the following anticipated problems and risks in conducting the project:

- Due to the potential for interviews, full interview text, and conversations to disclose and describe subjects and events of or relating to experiences of trauma, active listeners are available upon request before, during, and after all stages of the project until project completion.
- Due to the inherent risk of publishing sensitive information and names in relation to sensitive information, the use of a pseudonym or redaction of name by Interviewees & Artists is accepted at any point in the project and will be reflected both on the archive website and in the processed data; generalization and/or redaction of details including location names is also accepted and may be advised upon by the Researcher & Project Team to the Interviewees & Artists in the event such information is deemed sensitive. In addition, in the case of an Interviewee or Artist opting out of the project, their data will be eliminated from the project.
- Due to the inherent risk of publishing names in relation to sensitive information, the use of pseudonyms or redaction of names mentioned in interviews is accepted and may be advised upon by the Researcher & Project Team to the Interviewee in the event such information is deemed sensitive.
- If there are scheduling delays and conflicts with Interviewees, interviews will continue to be scheduled up until a week before the projected end of Data Processing.
- In the event that the access support workers as needed by the Interviewee and Researcher (including active listeners, ASL interpreters, etc) are unavailable for the date and time the interview is scheduled then the interview will be rescheduled until all access needs are met and all necessary access support workers are available. If the Researcher is unable to schedule the necessary access support workers to meet the Interviewee's access needs for their preferred communication method within the allotted interview scheduling time period, scheduling an interview can take place as late as Friday, September 16th, 2022. If barriers to scheduling the preferred communication method for an interview persist, scheduling an interview in an alternative communication method can take place as late as Friday, September 23rd, 2022, at which point the Interviewee will no longer be engaged in the project.
- In the event of a potential Interviewee opting out of the project, or an Interviewee opting out of the project in full, the Researcher & Project Team will contact the next Interviewee open-call respondent(s) selected to be an Interviewee. Once data processing has begun on all of the interviews already conducted, no further Interviewee open-call

respondent(s) will be contacted to fulfil the proposal of seven (7) total Interviewees for this iteration of the project.

- If there are scheduling delays and conflicts between Artists and Interviewees and/or the Researcher, conversations will continue to be scheduled up until a week before the projected submission deadline of Interpretations.
- In the event that the access support workers as needed by the Artist and Interviewee and/or Researcher (including active listeners, ASL interpreters, etc) are unavailable for the date and time the conversation(s) is scheduled then the conversation(s) will be rescheduled until all access needs are met and all necessary access support workers are available. If the Researcher is unable to schedule the necessary access support workers to meet the Artist and/or Interviewee's access needs for their preferred communication method within the allotted conversation scheduling time period, scheduling a conversation(s) can take place as late as Friday, December 16th, 2022, at which point, if the conversation(s) cannot be scheduled, the Artist will be advised to finish their Interpretation without the conversation(s).
- If an Artist is unable to meet the deadline for submitting their Interpretation for Interviewee review, Interpretations can be submitted by Friday, Dec 30th 2022 to be included in the review process and website publication in time for the website's launch event. Interpretations submitted later than December 30th will still be accepted for review and publication, provided the Interviewee is available for the review process, up until Monday, January 23rd, 2023 at which point the Interpretation cannot be included in the project.
- If an Artist is unable to meet the deadline for submitting their revised Interpretation, revised Interpretations can be submitted by Monday, January 30th, 2023 to be included in the final review and website publication in time for the website's launch event. Revised Interpretations submitted later than January 30th will still be accepted for final review and publication, provided the Interviewee is available for the final review, up until Friday, February 3rd, 2023 at which point the Interpretation cannot be included in the project.
- In the event of an Artist opting out of the project, the Researcher & Project Team will contact the next Artist open-call respondent(s) selected to be an Artist. Once all Artists have begun producing their Interpretation and forward, if an Artist opts out of the project, no further Artist open-call respondent(s) will be contacted for this iteration of the project.
- If the projected completion date is later than the project end date, a launch event will still be held, and to finish building the website a supplemental grant will be obtained to fund the website's completion.

Project Management

The DAAA Project Team consists of:

- Q Lawrence, Researcher: develop digital archive, engaging Interviewees & Artists, conducting interviews, directing Project Team.
- Fenrir Cerebellion, Access Coordinator: managing communications, coordinating scheduling, formatting documents, transcribing interviews and other non-written communication.
- Jenna Reid, Admin Assistant, Kickstart Disability Arts & Culture: administrative support and guidance, and liaison between Kickstart and the Project Team.

In addition, the following team members will join for access support and web development as required through independent contracts:

- Access Support Worker(s): active listener(s), ASL interpreter(s), captioner(s)
- Data Processing Assistant: assist the Researcher in data processing
- Voice Actor(s): narration of full text interviews
- Taz Soleil, Lead Web Developer: archive website development and publication
 - Additional web developer
- Accessibility Consultant(s): access review and audit of the archive website

Ethics Protocols

These ethics protocols are approved by Kickstart Disability Arts & Culture (hereby “Kickstart”). Kickstart is acting as the ethics review board for this project.

1) Before beginning this project and at listed points of development specified in Project Design, Q Lawrence (hereby “Researcher”) and Project Team including but not limited to Access Coordinator, Admin Assistant, web developers (hereby “Project Team”) and organizations involved (hereby “Organizations”) will carefully consider whether the project can cause potential harm to anyone involved. If any potential harm is identified, the Researcher, Project Team, and Organizations will seek and implement the best approach to minimize and/or eliminate these harms.

2) The Researcher will always provide sufficient information to Project Team & Organizations and Interviewees & Artists to fully comprehend the scope of the project. Interviewees & Artists will be fully informed of the purpose and approach of the research. Data collection and processing will be explained fully. The Researcher will make their contact details available to Interviewees & Artists for any complaints or ethical issues that may arise during the project, and these issues will be addressed through ethical review with Kickstart.

3) The Researcher will always obtain informed consent from Project Team and Interviewees & Artists individually prior to engaging them in the project. This will include but is not limited to: full disclosure of any Anticipated Problems & Risks to Interviewees & Artists; full detail of honoraria; if and how to name Interviewees & Artists in disseminating information publicly; specifying identifiers they wish to include or exclude; language in the project will reflect language used by Interviewees & Artists; Interviewees will have full autonomy over subjects of discussion and disclosure of information; communication will be held in the Interviewees’ & Artists preferred form (email, video call with captions and interpretation, voice call, in-person); full and early disclosure that interviews will be recorded.

4) Requests for consent will always include the possibility of opting out of the project. Interviewees & Artists have the option to opt out of the project at any point, including after completion. In the case of opting out of the project, data will be eliminated for Interviewees & Artists. In the event of an Interviewee opting out of the project after completion of an Artist Interpretation, there will be a discussion between the Researcher, the Interviewee and the Artist about whether the art will still be presented, in which the Interviewee has final say.

5) The Researcher & Project Team and Interviewees & Artists will be recognized in their full and complex humanity. Steps to achieve this include but are not limited to: access needs will be established and prioritized; Active Listeners are available upon request; a thorough communication and consent agreement will be signed by Project Team and Interviewees & Artists prior to engagement; interactions with the Researcher & Project Team & Organizations

and Interviewees & Artists are trauma-responsive, with space for grief, processing, and breaks at any time for any duration.

6) Any corrections, redactions, and addendums of Interviewee & Artist bios, Explanatory Texts, interviews, Artist Statements, and event summaries, including the addition or removal of provided images, can be made by the respective Interviewee or Artist at any point of the project including after public dissemination by request to the Researcher by way of the project email.

7) In gathering personal data from the Interviewees & Artists, data will not be used for any purpose outside of the project. All data including personal will be carefully organized and managed to ensure that no unauthorized use is made of it. Data collected that will not appear publicly, as dictated by consent and the parameters of the project, is only viewable by Researcher & Project Team.

8) Access to the raw data collected by the Researcher will not be provided to parties outside the named Project Team, which includes but is not limited to captioners and interpreters. In the event future researchers and outside organizations request data, Interviewees will be contacted individually for specific consent according to their consent form, on a case-by-case basis.

9) Raw data from Interviewees will be processed before Artists are engaged for the Artist Interpretations. “Processed” includes but is not limited to: names and locations anonymized where requested; identifiers they wish to include or exclude; language used by Interviewee and the Researcher reflects language preferred by Interviewee, adherent to Interviewees provided consent, including post-interview review of data. Artists will only have access to Processed Data.

10) Honoraria for Interviewees is paid upon completion of interview, regardless of if the Interviewee opts out of the project at a later date.

11) Honoraria for Artists is paid upon completion of Artist Interpretation, regardless of if the Artist opts out of the project at a later date.

12) Final presentation of processed data on the DAAA website will be subject to a final review by Interviewees & Artists prior to publication for any corrections, redactions, and addendums to the bios, Explanatory Texts, interviews, Artist Statements, and event summaries, and notes alongside presented media that is unable to be edited (e.g. visual media such as provided images and Artist Interpretations).

13) In the event of a future iteration or expansion to the DAAA, the Researcher will inform the Interviewees & Artists by the contact method stated on their individual consent forms.

14) If the Researcher is made aware of use and reference to the DAAA website or any research collaboration, they will inform the Interviewees & Artists by the contact method stated on their individual consent forms.

15) In the case of any research collaboration, regardless if the Researcher or a member of the Project Team is the lead researcher or not, Interviewees & Artists will be contacted according to their consent form to provide or withhold further consent for the outcomes of the research collaboration.

16) In the case of any research collaboration in which the Researcher or a member of the Project Team is the lead researcher, the Ethics Protocols/Statements of all the organizations and/or countries involved in collecting and handling the data will be studied. Explicit protocols concerning collection and treatment of data as well as use of data for public dissemination will be elaborated to cover as many of the ethical requirements of the organizations and/or countries as possible. However, compliance to the ethical considerations concerning the collection and handling of data in each organization and/or country will be the direct responsibility of the collaborating researcher in that organization and/or country.

Communication Guidelines

The DAAA recognizes that much of the language referring to disability is colloquially used in derogatory and oppressive ways; the Researcher & Project Team are resolved to use language that is non-discriminatory and anti-oppressive in order to not replicate societal biases and harms. The DAAA also recognizes that many of these words are used by disabled individuals in reclamation, and so when participants use language in this way to refer to themselves, their experiences, and/or their communities the Researcher & Project Team will ask participants whether that language should be used by the Researcher, throughout the project and/or on the DAAA website or only when the participant is using that language themselves.

The Researcher & Project Team will use the preferred communication platform of the participants' choosing, however if using direct messages on social media platforms the Researcher & Project Team will request to use email for further communication.

Confidentiality statement within DAAA email signature:

This message may contain confidential information and is intended only for the individual named. If you are not the named addressee or a support person, you should not disseminate, distribute or copy this email. Please notify the sender immediately by email if you have received this email by mistake, and delete this email from your system.

Prompt guide for Artist Statements

- What medium did you create the Interpretation in
- What was your creative process for developing (e.g. creating mental maps, brainstorming, having conversations, sketching, drafting, being outdoors, etc.) and producing (e.g. creating multiple iterations, using digital tools, renting equipment, collecting materials, etc.) this Interpretation
- Did you conduct any research in developing this Interpretation; if so, what form did your research take; if you made use of resources publicly available online please provide links
- How did/do you make your art practice accessible to you
- What access offerings did you consider in the creation of the Interpretation
- What are your thoughts and feelings on the interview you chose and/or the DAAA
- Why did you want to create an Interpretation in response to the interview you chose
 - Did you relate to the Interviewee in similar experiences of marginalization and/or disability, a geographical location, a community, an artistic medium; in shared life experiences (e.g. education, attending/participating in an event(s), etc.); in understandings and definitions of community; in how you came to disabled arts and activism; in who shaped your understanding of disability and disabled arts and activism
- Why did you choose this medium/materials/methods for the Interpretation
- What were your thoughts and feelings when engaging with the interview

- If you had a conversation(s) with the Researcher and/or Interviewee, how did that impact you personally; how did it change your initial understanding or perception of the interview and/or the Interviewee; how did it influence your creative process;
- What were your thoughts and feelings creating the Interpretation
- Who did you consider would be the primary audience of the Interpretation while you were creating it; who were you “speaking” or creating to or for
- Is there a message to DAAA website visitors in your Interpretation that you would like to share

Informed Consent Form

Disability Arts & Activism Archive

Disability.Arts.Activism.Archive@gmail.com

INFORMED CONSENT

Project Title: The Disability Arts & Activism Archive: Digital Documentation of Disability Activism History of BC

Researcher: Q Lawrence

Thank you for your interest in taking part in this project. This is a research creation project documenting the disability organizing history and disability arts history across what is colonially known as “British Columbia”. If you have any questions about the project, safety concerns, and/or accessibility considerations, please ask the researcher before you decide whether to join in. The researcher and project team also welcome these questions at any point in the project. Feel free to keep this Consent Form and refer to it at any time.

This project is funded by the Canada Council of the Arts and supported institutionally through Kickstart Disability Arts & Culture.

Interviewee Statement

GENERAL

- I agree that the research creation project named above has been explained to me to my satisfaction and I agree to take part in this project.
- I understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researcher and project team involved and withdraw immediately, at which point my data will be eliminated.
- I understand that I have full control over what language is used to refer to me and my experiences by myself, the researcher and project team, and on the archive website, by informing the researcher and project team of my preferences and identities in communications and the interview, and by taking part in review processes.
- I understand that the information I share in my interview will be included in a digital archive that will be publicly accessible in the form of a website, and that every effort will be made by the researcher, project team, and/or Kickstart Disability Arts & Culture to implement any changes that I request during and following the project, including corrections, redactions, and addendums.
- I understand that the information I share will be stored on OneDrive under the Disability Arts & Activism Archive’s Microsoft Account, and backed up onto a password protected external harddrive that only the researcher and access coordinator will have physical access to, and that every effort will be made to ensure confidentiality but I accept that

the researcher cannot take ultimate responsibility for this.

- I understand that the DAAA will delete the history of any emails that contain sensitive information pertaining to me, such as interview contents, mentions of personal or identifying information. In addition, I understand that the DAAA also considers personal email addresses as potentially sensitive information, as they may be identifying as well.

I wish for all my emails with the DAAA to be deleted upon project completion.

Yes No Ask me later
☐ ☐ ☐

- I understand that the DAAA recommends that I delete my own email history containing sensitive information in the event of a third party gaining access to my accounts.
- I understand that I will be paid an honorarium of \$500.00 CAD by cheque issued by Kickstart Disability Arts & Culture upon completion of my interview regardless of if I withdraw from the project at a later date. In addition, I understand that if my interview cannot be scheduled by September 23rd, 2022, an interview will not take place.
- I understand that automated captioning, live captioning (CART), and ASL interpreters are available as access support for my interview, upon request to the researcher.
- I understand that I have full autonomy over subjects of discussion and disclosure of information including the amount of detail provided, and the ability to decline questions and avenues of discussion from the researcher in my interview.
- I understand that the project may entail subjects of discussion relating to experiences of trauma or that are otherwise emotionally charged, therefore the researcher and project team have active listeners available upon request before, during, and after all stages of the project until project completion.

INTERVIEW PROCESS

- I understand that my interview will be recorded and that the transcript of this recording will be published on the archive website after it has been edited to my expressed language preferences, any requested changes (corrections, redactions, and addendums), and, if I choose to do so, reviewed by me upon completion of data processing and/or as it appears on the archive website prior to publication.

I wish to participate in review processes at:

Completion of data processing. Yes No Ask me later
☐ ☐ ☐

Completion of website construction. Yes No Ask me later
☐ ☐ ☐

- I understand that an audio recording of the edited transcript of my interview will be produced with voice actors and published on the archive website alongside my interview text for accessibility, and that changes to the transcript after the audio

recording has been produced are limited to removing portions of audio and/or including corrections and addendums as text.

- I understand that any images I volunteer to include on the archive website will be made publicly available, and that in the event that I wish to disclude any or all provided image(s) during or after the project, every effort will be made by the researcher, project team, and/or Kickstart Disability Arts & Culture to remove the image(s) from the archive website.
- I understand that the processed data of my interview—interview text as it will appear on the archive website and timeline entries generated from my interview—will be stored indefinitely on OneDrive and a password protected external harddrive. In addition, any changes I request to my information as it appears on the archive website will be changed as well on the OneDrive and password protected external harddrive.
- I understand that the DAAA will use Otter for automatic transcription of my interview, and that this transcript will be deleted from Otter's service by January 27th, 2023.
- I understand that the DAAA will use Zoom for video interviews, and that, if I choose to conduct my interview over video call, the recording will be deleted from Zoom's servers by January 27th, 2023.
- I understand that the raw data of my interview—the transcript prior to editing and the recording—is only viewable by the researcher and project team, and will be eliminated from the project OneDrive by April 7th, 2023.
- I understand that the raw data of my interview will be stored on a password protected external harddrive indefinitely unless I request that it be deleted.

I wish for my raw data to be deleted from the password protected external harddrive upon project completion.	Yes	No	Ask me later
	☐	☐	☐

INTERPRETATION PROCESS

- I understand that the researcher and project team will select an artist to create an artwork interpretation in response to my interview that will appear on the archive website alongside my interview text.
- I understand that the publishing of the artwork interpretation in response to my interview relies on my consent, and, if I choose to do so, will be reviewed by me prior to publication during which I may request revisions. In addition, I understand that I may withdraw my consent after publication in which case the researcher and project team will remove the artwork interpretation from the archive website.

I'm open to having a conversation with the artist assigned to create an artwork interpretation in response to my interview.	Yes	No	Ask me later
	☐	☐	☐

I wish to participate in the review process of the artwork interpretation in response to my interview.

Yes No Ask me later
☐ ☐ ☐

LAUNCH EVENT

A virtual launch event for the website will take place at the end of this project, in April 2023.

I wish to participate in the launch event.

Yes No Ask me later
☐ ☐ ☐

FOLLOW UP

- I understand that the researcher and project team will inform me of when the archive website will be going live.
- I understand that future researchers and outside organizations may request processed data from the project and that the researcher and project team will not release my processed data to future researchers or outside organizations without further, specified consent from me.

I'm open to being contacted for consent regarding future researchers and outside organizations requesting processed data.

Yes No Ask me later
☐ ☐ ☐

- I understand that the researcher and project team will not release any raw data—the transcript prior to editing and the recording—to future researchers or outside organizations.
- I understand that the researcher and Kickstart Disability Arts & Culture may use quotes from my interview, images I volunteer to include in the project, and/or excerpts from the artwork interpretation in response to my interview, in promotional material for the project.
- I understand that the researcher and Kickstart Disability Arts & Culture will not use my processed data or the artwork interpretation in response to my interview for presentations of this project outside of the archive website, or potential future projects without my further, specified consent.

I'm open to being contacted for consent regarding further research projects by or in collaboration with the researcher that make use of the processed data and/or artwork interpretations of this project.

Yes No
☐ ☐

I'm open to being contacted for consent regarding presentations of this project alternative to the archive website or potential future projects.	Yes ☐	No ☐
I wish to be contacted about future iterations of this project that would expand the DAAA.	Yes ☐	No ☐
I wish to be contacted about any use or reference to the DAAA website that the researcher and project team becomes aware of (e.g. news articles, academic paper, art projects).	Yes ☐	No ☐

PERSONAL INFORMATION	
Legal Name:	
Name:	
Name as you'd like it to appear in the project if different from above:	

Signature: Date: