OUR STORIES: (RE)IMAGINING DISABILITY FUTURES THROUGH AUTOBIOGRAPHICAL PERFORMANCE BY NEURODIVERSE ARTISTS

BECKY LAUREN GOLD

A DISSERTATION SUBMITTED TO
THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFULLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

GRADUATE PROGRAM IN THEATRE AND PERFORMANCE STUDIES
YORK UNIVERSITY
TORONTO, ON

August 2023

ABSTRACT

In response to the lack of neurodivergent (self)representation on Canadian stages, this dissertation explores autobiographical performance as a vehicle for self-advocacy and imagining disability futures differently. Over seven months in 2021, during the height of the COVID-19 pandemic, I brought four neurodivergent artists together on Zoom to co-create a performance piece about their lived experience. What emerged was *Our Stories*, a presentation of autobiographical storytelling that uses song, dance, poetry, and theatrical monologue to reflect upon and respond to these artists' past and present experiences, as well as their goals for the future. Shaped methodologically by performance ethnography, this project illustrates the significance of the in-between moments and the learning that can emerge through the process of devising and creating new work with an interabled team.

Each chapter of this dissertation illuminates the process of co-creating *Our Stories* while contextualizing the themes and findings that emerged in relation to existing scholarly discourse. Chapter 1 offers an overview of the interdisciplinary fields of research that informed this project and highlights the most salient scholarship. Chapter 2 explores the process of creating *Our Stories* and reflects upon accessible co-creation strategies and working within non-normative temporalities and structures. Chapter 3 engages in depth with the completed work and serves as a kind of script analysis, offering further context for the creative decisions made and highlights themes of representation, autonomy, and authorship. Chapter 4 discusses what happened after the presentation of *Our Stories*, how care and relations were maintained even after the formal research project had concluded and what this means in the context of public allyship and interabled friendship.

This dissertation contributes to the currently limited scholarship around neurodivergent self-representation on stage and highlights the value of upholding practices of care and interdependence in interabled artist collaborations and the significance of performing and (re)imagining disability futures.

ACKNOWLEDGEMENTS

I would like to first thank my supervisor Magdalena Kazubowski-Houston, as well as my committee members Jenn Stephenson and Mary Bunch for their support, generosity, and guidance throughout the process of navigating the writing of this dissertation.

I am also deeply grateful to Carrie Sandahl and nancy viva davis halifax for serving on my dissertation examining committee and for contributing such valuable insights.

I extend my deepest gratitude to my collaborators on this project, Joey Gamulin, Catherine Anderson, Lindsey Chalmers, and James Brown for sharing their stories and always being down for a laugh and a dance.

I am grateful for the financial support that I received from the Social Sciences and Research Council of Canada as well as from the Sylff Association.

To the faculty and staff of York's Theatre and Performance Studies department who helped to shape my experience over the last five years, namely Belarie Zatzman, Marlis Schweitzer, Ian Garrett, Susanna Talanca, Mary Pecchia and Julia Kenny, thank you!

Big thanks to Katy Peplin of Thrive PhD for being the most wonderful coach and cheerleader, particularly in this last year of writing.

I would like to thank my disability arts colleagues and friends for the hours of generative conversation, support, and care: Alex Bulmer, Jessica Watkin, Megan Johnson, Drea Flyne, Ash McAskill, Niall McNeil, Eliza Chandler, Carrie Hage, Cheryl Zinyk, Kelsie Acton, Sarah Pickthall, and Catherine Bourgeois. Special thanks to Ben Clement for consulting on the plain language summary of this dissertation.

To my dear friends Kira Meyers-Guiden, Chelsea Dab Hilke, and Tara Gallagher Harris, I’m so glad that our academic pursuits brought us together and am forever thankful to have you three fabulous women in my corner.

I am grateful to my brother Aaron Gold for always being on my team and to my mother Anne Crozier for encouraging me to pursue work that “puts fire in my belly.”

Last, but not least, I am forever grateful to my partner Ryan Downey for his unwavering support and unconditional love throughout this process and every day. Thank you.

TABLE OF CONTENTS

LIST OF FIGURES

INTRODUCTION

Social justice advocate Patti Digh writes, “The shortest distance between two people is a story.” Storytelling is deeply engrained within the human condition and is grounded in forming connections and creating understanding between ourselves and others. As a vehicle for (self) representation, when performed live for an audience, stories have potential to become sources of pedagogical engagement or calls to action as well as create opportunity for self-exploration and discovery. The above quote from Digh inspired me to consider the following questions that would drive my dissertation research: Whose stories are not being performed? Who does not have an opportunity to share their stories publicly? What is at risk when certain life stories and experiences are privileged while others are silenced?

According to the 2017 Canadian Survey on Disability (new survey coming later in 2023), an estimated one in five or 6.2 million Canadians identify as having one or more disabilities. This statistic, which demonstrates a nearly fifty percent increase from the survey conducted in 2012, suggests that Canada’s disability population is continuing to grow. Despite these staggering numbers, the experiences of disabled artists, particularly those who are neurodivergent, are still significantly underrepresented as performers on Canadian stages. Working with neurodivergent artists as a theatre facilitator for many years, I have found that the stories that reflect the first-hand lived experiences of my students and their community seldom appear on Canadian stages and are rarely discussed in academic performance studies discourse.

In response to this notable lack of neurodivergent artists performing their own stories, I was drawn to explore how autobiographical storytelling might serve as a valuable form of self-representation, advocacy, and community activism for members of Canada’s disability community, specifically those who are neurodivergent. I ask: Can the act of collaborative advocacy through devising and performing personal stories offer neurodivergent artists opportunities for empowerment and creative exploration? And can exploring poignant narratives grounded in the artists' lived experience of disability prompt reimaginings of disability futures?

To address these questions, I developed a collaboratively created performance piece called *Our Stories* as the centre point upon which this dissertation revolves. Created with four neurodivergent adults, *Our Stories* uses autobiographical storytelling, dance, song, and poetry to reflect upon and respond to their past, present, and future experiences. This dissertation explores the process of creating this work from start to finish, highlighting poignant moments of discussion and reflection, the significance of upholding an accessible practice, and the value of care and relation-building in conducting research with marginalized participants.

Situating Myself

As this project is a collaborative account of people's experiences of disability, it is pertinent to my role as researcher that I situate myself within this collaboration. At the time of writing this dissertation, in the spring of 2023, I do not self-identify as having a disability. However, disability and health-related differences have always been a part of my life.

My father, who passed away in 2011, was diagnosed with Multiple Sclerosis in 1991 – the same year that I was born. Throughout my childhood and adolescence, I witnessed my father's mobility shift with the changes in weather and decline over time. I watched as he required a cane, then a walker and finally a wheelchair to move through space. Toward the end of his life, as the symptoms of his disability worsened, he began having issues with his memory and eventually lost his ability to communicate verbally. Despite the twenty years of experiencing my father's evolving symptoms and increased access needs, it took many years for me to recognize that he was a disabled man. To me, he was just always 'Dad.'

My mother also instilled in me the value of connecting across different life experiences. As a child, I spent many school PA days at Sick Kids Hospital in Toronto where my mom worked as a paediatric nurse practitioner for 10 years. While I would spend time playing on the computer in her office while she had meetings and did her rounds, I would often be introduced to patients in the hallways and, at times, spend time with them in their rooms playing as kids do – always focussed on connecting and making friends, rather than on their illness.

While I am sure these life experiences impacted the connection I feel to the disability community, my more formal foray into working with neurodivergent artists began in 2013. Over the past ten years, I have had the privilege of working with neurodivergent artists across the country. My practice has primarily revolved around providing arts-based programming or support to neurodivergent artists, working as a theatre instructor with various companies and organizations. My practice within disability arts has also included working collaboratively with blind artist Alex Bulmer and providing audio description services for theatre and video projects to enhance access for blind and low vision audiences. Despite the differing disability experiences, my care-centred and relation-focussed approach to artistic collaboration and support is applicable to all contexts of my practice.

As an emerging scholar, I have published several articles on the topic of neurodivergent theatre artists in Canada highlighting this community's often unique approach to the creative process, the impact of working with nondisabled collaborators and the value this community offers to disability arts and culture in Canada. While I do not presently identify as disabled, I feel deeply connected to this community through my allyship, advocacy and ongoing and ever evolving relations with members of the disability community.

A Note on Language

Language is messy and can hold significant weight and power. In choosing to use specific terms over others, one can find oneself aligned with certain groups and distanced from others. I offer this note on language not necessarily to justify my choices, but rather to explain them as part of a wider conversation.

Perhaps the most significant choice I have made regarding language in this dissertation is my use of the label ‘neurodivergent’ to describe my research participants and collaborators. I use neurodivergent as an umbrella term to describe minds that function in ways that diverge from dominant societal standards of what is perceived as ‘normal.’ The language of neurodivergence exists in contrast to that of ‘neurotypical’ or ‘neuroconforming’ which is used to describe minds that function in ways that meet conventional societal standards (Gold 2021; Walker 2014). In line with this understanding, neurodivergent can therefore be used to describe a range of diagnoses and lived experiences including Down syndrome, autism, learning disabilities, acquired brain injuries, ADHD, etc.

In a Canadian context, the group of participants with whom I collaborated might be labelled as having intellectual/developmental disabilities (IDD) or cognitive disabilities. It is also worth noting here that this language differs based on location. For example, those labelled under the intellectual/developmental disability category in Canada, would be labelled as individuals with learning disabilities in the United Kingdom. In Canada, however, the label learning disabilities has a different meaning. Throughout this dissertation, I cite scholars who live and research both inside and outside of Canada – it is therefore pertinent to highlight that despite differences in language, the community of artists we are writing about is the same.

With my decision to use the term neurodivergent to describe the lived experience of the artists I worked with for this project, I hope to embrace the commonalities between the lived experience and access needs of someone with Down syndrome to someone with ADHD, and in doing so, minimize the hierarchy between various experiences of neurodivergence. This language choice works to align various experiences of moving through and encountering the world differently rather than privileging certain experiences over others.

Finally, in discussing terminology to use when describing disability, it is ultimately best practice to ask the individual how they self-identify and to use their preferred label(s). In the group of artists involved in this project, three identify as having Down syndrome and one identifies as having learning and physical disabilities. As the cast of *Our Stories* does not all share the same diagnosis, I have used neurodivergence to be able to speak about the group collectively.

Another term that is used throughout this dissertation is ‘interabled.’ It is common for neurodivergent artists to work collaboratively or alongside nondisabled artists. To account for the difference of experience in these collaborative relationships, I have chosen to use the word interabled. This term is used as an alternative to the sometimes seen ‘mixed ability.’ Though not the context for this project, interabled is sometimes used when describing romantic relationships in which one person has a disability and the other does not. This use of language is therefore aligned with terms such as interfaith or intercultural to describe individuals coming together across different life experiences to develop meaningful relations or to pursue a shared focus or goal. As a nondisabled artist working collaboratively with neurodivergent artists, having a term to properly describe the context of our working relationship was significant and central to the overarching methodology of this project.

Methodology

This research project exists at the intersections of theatre and performance studies, disability studies, and autobiographical studies and is shaped methodologically by performance and imaginative ethnography– a practice of research that engages with the everyday through the use of the creative arts (Culhane 2017, 3). While ethnography broadly emerges from an anthropological discipline which as a field has been critiqued for its historical othering and pathologizing practices, performance and imaginative ethnography lends itself well to this interdisciplinary project due to its emphasis on creative practice as a method of inquiry and exploration, the prioritization of building meaningful relationships, and encouraging researchers to embrace practices of self-reflexivity. As collaboration, care and accessibility practices were central to this project, I also recognize creative and care-driven support methods as well as friendship as method as being integral to the development and dissemination of this work.

Methods

While the theoretical and methodological scope of performance and imaginative ethnography helps to contain this project, it is the methods of practice, the 'how' of the work that demonstrates innovation and new ways of working. *Our Stories* was collaboratively created over seven months. Together we utilized various methods of devising new work and explored a range of performance strategies to communicate the performers' autobiographical stories. These practiced-based methods are discussed in more depth in Chapters 2 and 3.

Care and Relation-Building as Method

From the outset of this project, collaboration, interdependence, care, accessibility, and relation building were pillars of the practice. These values are what connect all elements of the work together, from the co-creation of *Our Stories* to my critical analysis and reflection as researcher in how I write about the work now.

To minimize the traditional hierarchy of power between nondisabled researcher and disabled participants, I approached this work within the framework of interabled collaboration. I conceive of this framework as a vehicle for challenging expectations, breaking down barriers and exploring innovative ways of working across lived experience and ability. Embracing this idea of interabled collaboration between me and my research participants set us up for a way of working that prioritized accessibility and care at every stage of the process.

Methods of providing and upholding access were varied and evolved over the duration of devising and rehearsing *Our Stories*. While the specific approaches to access and support are discussed in depth throughout the chapters of this dissertation, it is worth acknowledging that the methods were emergent – discovered and developed over the course of the seven-month research process. It was through the act of collaboration and spending time together that the most accessible ways of working together and supporting each other were made clear. Throughout all facets of this dissertation project, methods of care and relation building were prioritized.

In addition to highlighting voices and stories from those who are not often heard from on Canadian stages, this project works to amplify the value of interdependence in collaborative creation processes. Embracing this perspective led me to Lisa M. Tillmann-Healy's concept of 'friendship as method.' She explains that 'friendship as method' is a model of qualitative inquiry that involves "researching with the practices, at the pace, in the natural contexts, and with an ethic of friendship" (2003, 730). Tillmann-Healy's writing on friendship as method offers language and scholarly insight into the interpersonal dynamics and flexible pacing and approach of this work. I hope that my own research and the creative approaches to interabled collaboration explored in this dissertation will contribute to scholarly discourse around relation-building and care in academic research. [1]

Critical Reflections and Room for Emotions

In writing this dissertation, I draw from ethnographic approaches to writing including reference to field notes and researcher reflection. In line with the practices outlined above around self-reflexivity, I offer personal reflections alongside critical analysis. These reflections illuminate the practices and processes of navigating this research project, as well as emphasizing the importance of recognizing one's positionality, impact, and insight throughout. In the spirit of reflexivity, radical relatedness, and practices of care, it would not be possible to reflect upon this process without carving out space for the emotions and feelings that came up throughout the process.[2] While the inclusion of researcher's emotions in scholarship has been devalued and critiqued in certain fields, I embrace it as a key part of the embodied and epistemological knowledge (Jaggar 1989) generated through this collaborative project. Veronika Kisfalvi (2006) argues that ethnographic research is "an inherently subjective and emotionally charged method of inquiry given the sustained contact and the particular closeness that is developed between researchers and informants. While these elements can easily become a source of bias if they are defensively denied or otherwise unexamined, both subjectivity and emotions can also become valuable sources of insight if they are acknowledged and explored" (118). Further, the role of

---

[1] Care as a concept can feel subjective and intangible. As it can take a variety of forms, it is hard to define within an academic or research-based context. Care however is foundational within disability justice, politics, and artistic practice. Some disability artists/scholars who have engaged with the complex and multifaceted topic of care include Dave Calvert (2020), James Thompson (2020), Leah Lakshmi Piepzna-Samarasinha (2018) and Mia Mingus (2017).

[2] While much discourse around the inclusion of emotions in research is rooted in feminist theory and women and gender studies (two fields with which I do not formally engage in this dissertation), as a relational practice, including emotional language feels well-aligned with this project as one shaped by interdependence, accessibility, care, and relation-building. In embracing emotion as beneficial to the development of new knowledges rather than adverse, I suggest that we can come to understand these physical and cognitive responses as ways to engage actively and ethically in the present moment as well as help shape desired futures.

sensory ethnography, which prioritizes one's external and internal senses as a means of building knowledge (Pink 2009) carves out space for nonverbal communication, emotional intelligence, and alternative forms of connecting as valuable within research spaces.

Ethics, Consent, and Recruitment

In seeking a community partner for this project, I connected with the Accessibility and Inclusion department (now the Wagner Green Centre for Access and Inclusion) at the Miles Nadal Jewish Community Centre (MNJCC) in Toronto. I had a pre-existing relationship with the MNJCC as a teacher of arts-based classes within their Accessibility and Inclusion Department which caters to young adults with developmental disabilities or autism. In addition to arts-based programming, this A&I department also facilitates social programming and programs that engage with social responsibility and self-advocacy. As a result of my pre-existing relationship with the department and their community of program participants, they agreed to assist me in my recruitment for this project by facilitating preliminary communications between myself and several potential neurodivergent collaborators.

Ethics and Consent

The process of ethics review is extensive and was an essential step to take before this project could begin. Through the process of completing the ethics approval documents, I was able to reflect and think critically about the project and how it would be framed and explained to prospective participants. Completing the ethics review process was, for me, truly an exercise in intention. What was I hoping to accomplish with this project and how would I do this in a way that ensured the safety and comfort of all involved throughout the process?

A key aspect of the required protocols asks how one will ethically acquire informed consent from one's research participants. In navigating the various ethics review forms, I was confronted with a question around whether my prospective participants would be deemed (by the university ethics board) as having ‘the capacity to consent.’ While there may be cases in which individuals with disabilities are unable to offer informed consent on their own behalf and a substitute decision-maker is necessary, within the context of this relatively risk-free study in which the benefits outweigh the risks, I did not believe this to be the case. [3]As part of my ethics protocol, I therefore presented a justification for embracing supported rather than substitute decision-making. Supported decision-making focuses on access and creating understanding so that individuals can choose to consent or not on their own behalf (Stainton 2016). This practice is in line with Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) that asserts that “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” and that parties shall “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity” (10). As this project is about speaking for and about oneself and maintaining autonomy over one’s lived experience, it was important to me that my participants had the opportunity to consent on their own behalf and that I honour their ‘capacity’ to do so. It would therefore be my responsibility to make the consent process as accessible as possible. [4]

Both the invitation to participate and the consent form itself were written in plain language.[5] The consent form explained the purpose of the research and offered a non-academic explanation of performance ethnography and what a doctoral dissertation entails. It also outlined

---

[3] Embracing supported decision-making was the most appropriate approach for this project, however, I acknowledge that it may not be appropriate in all situations. The approach chosen to obtain informed consent must be dependent on the particular scope and details of the project as well as the specific people involved.

[4] In my correspondence with prospective participants, I made myself available to answer any questions they had about the project before signing the consent forms. I was also provided with parent contact information for some of the participants. With this I was able to ‘cc’ parents in the distribution of consent forms so that they could review the form with their son/daughter and offer support in the decision making process.

[5] Plain language (sometimes also referred to as ‘easy read’) is a way of writing that makes text more accessible to a greater number of people (Aden 2021).

what would be asked of the participants, any risks (recognizing that sensitive subject matter could come up in sharing personal stories), my perceived benefits of the project, and participants' ability to withdraw from the project at any time. In line with standard research practices, I had initially made the decision that pseudonyms would be used in all writing about the project to maintain a level of confidentiality for the participants. However, after completing the research project, I pursued an amendment to my ethics protocol to allow participants to choose whether their real names would be used – again, allowing the participants the opportunity to decide for themselves whether they wanted to be publicly recognized for their contribution to this project or not. After thinking about the value authorship and ownership over one's own stories, I felt strongly that the decision should be theirs to make. This amendment was approved by the research ethics board and the updated forms were redistributed to my four collaborators. After reviewing the amendment, all participants consented to have their real names used in this dissertation and any other writing published thereafter.

This approach to consent and ongoing negotiation aligns with what Dara Culhane (2011) calls 'ethical engagement.' Culhane argues that ethical engagement embraces fluidity in the research practice and leaves space for constant renegotiation in accordance with the needs of the group. In reflecting upon this turning point in the project and revisiting the parameters of informed consent after its conclusion, I am mindful that the request to waive anonymity during the initial request for informed consent may not have been deemed ethical or appropriate. Rather, having the participants revisit the protocols of consent after having completed the project, with the knowledge of what they shared for the final product, was a demonstration of ongoing ethical engagement and an act of care.

Recruitment

As mentioned above, the community outreach and recruitment process for this project was achieved through a partnership with the Miles Nadal JCC. Initially, I had intended to recruit six participants to take part in this project. However, after reaching out to several community members with varying degrees of interest or availability, I ended up with a slightly smaller, yet excellent participant group of four – Joey, Lindsey, Catherine, and James.

Impact of the Pandemic

Consideration of the specific context and circumstances in which *Our Stories* was created is imperative to understanding how our ensemble worked together. While I had originally envisioned that this project would take place in-person in an environment that would allow my participants and me to connect face-to-face in shared space, the COVID-19 pandemic necessitated a shift in this plan. Instead of being together in a rehearsal hall, the *Our Stories* ensemble and I met weekly on Zoom.

At the time of beginning this project, we were nearly one year into the COVID-19 pandemic, and I had been teaching a weekly drama games class to groups of ten to fifteen neurodivergent young adults over Zoom through the Miles Nadal Jewish Community Centre (MNJCC). Through this online programming, I witnessed the impact of mandatory social distancing on members of this community and was happy to offer some respite from the isolation and opportunity for creativity and connection across distance. The four performers that I recruited through this project were all involved in this online programming.

The context in which this project developed was in many ways informed by the complex circumstances that we were navigating both as a global society and individually. I could speculate on the various ways in which the outcomes of this project may have differed if not impacted by a global pandemic, but rather, I choose to celebrate this project not only for the ways in which it engaged critically with performance and the neurodivergent experience, but also for how the participants and I worked to create a digital space for meaningful connection and collaboration when opportunities for this were scarce.

Chapter Breakdown

This dissertation takes readers on a journey through the entire process of creating and performing *Our Stories*. To situate the work within the fields of disability studies and autobiographical performance, Chapter 1 offers an overview of the literature that helped to shape my thinking going into this project. The literature review demonstrates the gap in existing scholarship that the dissertation addresses. This chapter positions *Our Stories* as offering something new to the field artistically as well as epistemologically and theoretically in how the work was conceived, devised, and performed.

Chapter Two reflects on the creation process – from preliminary interviews through the development of the script and rehearsals up until the evening of the project screening. This chapter illuminates how our group worked collaboratively and offers insight into the discussions that took place in devising this project. It also offers insights into the relationships that were being built and the significance of temporality in the creation process. This chapter concludes with discussions of integrated accessibility for both performers and audiences, emphasizing how this ultimately shaped the final performance product.

Chapter Three focuses on the final performance – a recorded and edited Zoom performance piece. It begins with a discussion of how the work was presented to an online audience and then offers a kind of script analysis, engaging further with the written content of the work. This chapter can be read as a companion to the full script included in Appendix A.

Concluding this chapter is a partial transcript from the post-show question-and-answer period with the audience, as well as my own reflections on the work written one year later.

Chapter Four brings into conversation what happens to research-based relationships once the project concludes. Informed by ethics of care and relation building, this chapter discusses my continued connection with the *Our Stories* performers after the research project had formally concluded. This chapter brings to the fore critical discussions of how researchers can offer care to our research participants and demonstrates what can be learned from maintaining some form of connection and working from a method of friendship.

I conclude this dissertation with a brief final chapter that aims to tie this project's research together, highlighting the value of interabled working relationships and the power of autobiographical performance and disability narratives as a vehicle for reimagining disability futures. In addition to the *Our Stories* script, a plain language summary of each chapter can also be found in Appendix B.

CHAPTER 1: SETTING THE STAGE, UNDERSTANDING THE FIELD

Introduction

To date, there has been a notable lack of theatrical opportunity for neurodivergent artists in Canada to create and share stories about their own lived experience – a discrepancy in Canadian disability arts practice that has been underserved by contemporary scholarship. Engaging with diverse approaches to autobiographical storytelling, *Our Stories* addresses this dearth of representation while highlighting the potential of this work as a vehicle for self-advocacy and community activism. This chapter situates *Our Stories* within the current scholarly discourse by unpacking and contextualizing the project through an interdisciplinary lens and highlighting the specific methods through which the project emerged. Shaped by performance ethnography as the method of inquiry, this project sits at the intersections of autobiographical performance and disability studies. In the following pages, I will introduce both fields of study and practice and then bring them into conversation with each other to further demonstrate how they collectively informed this project. I will then present a detailed summary of the project's methodological framework.

Autobiography

The literary field of autobiography seeks to invite the public to experience the personal. As defined by Phillipe Lejeune in *Le pacte autobiographique*, autobiography can be understood as a "retrospective prose narrative" written about one's own existence with a focus on one's individual life story and particularly, the "story of [one's] personality" (1989, 4). Lejeune's early, yet influential writing on autobiography brings forward various aspects of autobiographical storytelling that he believes are essential, including the ontological relationship between the author, narrator and protagonist and the contract between the author and the reader –

what he refers to as the autobiographical pact. The autobiographical pact is the implicit understanding that in literary autobiography the author, the first-person narrator, and the story's protagonist are all the same person (5). This pact, therefore, serves as a kind of unspoken and assumed contract between the author and reader that sets the ground rules – that the person's name on the title page of the text is the same person sharing their story. While Lejeune's writing offers a starting point for understanding autobiography as a literary genre grounded in true, real-life experiences, the writers who follow him have worked to expand upon and complicate his theories, and push against the rigidity and limitations of his autobiographical pact. More specifically, scholars have questioned Lejeune's concept of 'autobiographical truth' and determined trust in the autobiographical author (Stephenson 2013; Eakin 1985) as well as his lack of attention toward the potential collaborative nature of autobiography (Egan 1999).

In *Fictions in Autobiography: Studies in the Art of Self-Invention* (1985) Paul John Eakin argues that "autobiographical truth is not a fixed but evolving content, what we call fact and fiction being rather slippery variables in an intricate process of self-discovery" (17). Eakin frames autobiography as an 'art of memory' as well as an 'art of imagination' highlighting the elusiveness of capital 'T' truth in autobiographical works. Drawing from the thinking of writer and critic Mary McCarthy, Eakin asserts that "fiction can have for the autobiographer the status of remembered fact" (7). This idea shifts the notion that in autobiography, fiction is an un-truth or falsification of facts. Rather it suggests that regardless of how factually accurate, an author's particular recollection of a moment can remain *their* truth. Through Eakin's broadening of how we might redefine and understand autobiography, he grants permission for a flexible understanding of truth and emphasizes that truth can change over time as an individual does. Eakin's critique of autobiographical truth also prompts consideration of autobiography and first-person narration as representations of the truth (Jackson & Mazzei 2008). As Stephenson (2013) asserts, the act of presenting representations of lived experience through writing or performing autobiography distances the narrative from the first-hand, real-world experience. She uses the concept of ‘worlds’ to distinguish the various layers of representation at play,

> In the process of creating autobiography, the original subject is necessarily split into several ontologically distinct versions: The real-world subject residing in world^{a} – the actual world occupied by you and me – decides to become an author and in an act of divine performative creation gives birth to a performer-narrator resident in world^{b} who in her turn engenders the character-protagonist citizen of the nested world^{c}. In this chain of increasingly fictional [or representational] characters, only the primary subject of autobiography is rooted in world^{a}. For every subsequent version, the likeness to the subject is diluted, as each creator makes choices about what to include, what to omit, what to emphasize or ignore, and in what order events are to be related. (12)

Stephenson’s approach to understandings the complex layers of representation inherent in all forms of autobiography further problematizes Lejeune’s understanding of the autobiographical pact and the complexities of how we think of truth within the genre.

Shifting from discussions of the author’s truth and representation in the construction of autobiography, in *Mirror Talk: Genres of Crisis in Contemporary Autobiography* (1999), Susanna Egan invites consideration of the external factors that impact the development and production of autobiographical works and how these factors may also shape the truth of the work. She points to the influence of (inter)subjectivity in the creation of (auto)biography, particularly as it relates to the first-person storyteller and the often dialogic or collaborative nature of contemporary self-stories between subject and storyteller. Within the context of theatre and film in particular, Egan emphasizes that because these artistic practices “involve so many people in their making, and because their traditional genres deploy both technological interventions and competing subjectivities, the autobiographical subject in these genres lacks even that degree of control that the writer enjoys and may well fear an unfriendly merger” (85). Egan highlights autobiographical works are often a team effort which informs the execution and content of the final product. In moving from understanding autobiography strictly as a literary genre to that of live performance, discussions of autonomy, truth, privilege, and memory become even more complex as the autobiographical storyteller shifts from text on the page to a human embodying the words on stage.

Performing Autobiography

As both a field of artistic practice and subject of scholarly research, autobiographical performance, being an embodied practice, further complicates the relationship between truth and fiction, agency and justice, and the temporality of one’s lived experience. Drawing from the second-wave feminist credo of ‘the personal is political,’ autobiographical performance is an act of claiming and holding space for diverse stories and experiences, recognizing the potential for these stories to have real world impact. As a foundational text in the field, Deirdre Heddon’s book *Autobiography and Performance* (2008) emphasizes the value of autobiographical performance not only as a means of holding a mirror up to reflect all corners of society, but also as a vehicle to analyze, question, and reflect upon our immediate social environments and how engaging with these sometimes-limiting environments can impact how we perceive and understand our world. With a strong emphasis on the draw of autobiographical performance for marginalized community members she asserts that this genre of performance creation “can capitalise on theatre’s unique temporality, its here and nowness, while always keeping an eye on the future [... and] can engage with the pressing matters of the present which relate to equality, to justice, to citizenship, to human rights" (2). In viewing autobiographical performance as a reflection of the past and present, Heddon sees this work as a kind of 'performance of possibility;' a vehicle to imagine futures differently and contribute to ongoing societal growth and cultural transformation. In using autobiographical performance to (re)imagine futures, it is unsurprising that this genre of performance attracts those whose stories and experiences may be segregated to the margins.

In *Performing Autobiography: Contemporary Canadian Drama* (2013), Jenn Stephenson explores various techniques employed by 'dramatic autobiographers.' Through her analysis of various case studies, she questions what these techniques or approaches to performing self-stories *do* for the field of autobiographical studies. Stephenson also reflects upon the role of fiction in autobiography and engages critically with how performing fictionalized aspects of oneself can prompt real-world effects. In looking to the real-world potential for autobiography, Stephenson recognizes autobiographical performance not only as a vehicle for individuals to engage and reflect upon their personal pasts "but also as a catalyst to a newly imagined future" (11). In addition to her multi-faceted theorization of performance and autobiography, in her second book, *Insecurity: Perils and Products of Theatres of the Real* (2019), Stephenson again engages with several case studies including *RARE*, an autobiographical play about a group of young adults with Down syndrome. Her writing on this piece has impacted my own understanding of autonomy and ownership in autobiographical works that include neurodivergent artists. I will engage in further conversation with Stephenson and her writing on *RARE* in more depth later in this chapter.

While autobiographical performance can be an outlet or vehicle of meaningful expression for performers, it can also have a significant impact on audiences. Autobiographical performance has the potential to bring marginalized experience to the fore, and by doing so educate and change minds of those who bear witness to those stories. It can convey a message or present a future world more equitable than the one in which we currently live. These features of autobiography make it a valuable creative genre for members of the disability community "to talk out, talk back, talk otherwise" (Heddon 2008, 3). For a community that has historically been spoken for and has been framed in both literature and performance either as victims or villains (Lewis 2006), or more broadly used as a metaphorical device or symbol which David T. Mitchell and Sharon L. Snyder (2000) have termed 'narrative prosthesis,' the sharing of self-stories therefore provides an opportunity to rewrite disability narratives and in doing so to imagine disability futures differently. As articulated by disability activist and author, Alice Wong in the in the introduction of *Disability Visibility* (2020), "Collectively, through our stories, our connections, and our actions disabled people will continue to confront and transform the status quo. It's who we are" (xxii).

Disability Arts

Emerging from the disability rights movement of the 1970s and 80s, disability arts in Canada continues to evolve as a creative practice, a vehicle for activism, a field of scholarly research, and a diverse cultural community. Over the years, this growth has been fostered and celebrated through national symposia such as the National Arts Centre's Deaf, disability and Mad Arts Cycle (2016-17), various iterations of the Republic of Inclusion (2015; 2017), and most recently the publication of Jessica Watkin's *Interdependent Magic*, the first published anthology of plays by disabled Canadians (2022). Even with this recent expansion of the discourse surrounding the future of disability arts in Canada, there remains a scarcity of attention given to neurodivergent artists in comparison to artists with physical or sensory disabilities[6] – both on stage and in scholarship. While there are several reasons why this may be the case (Gold 2021), [7] I agree with New Zealand-based scholar Tony McCaffrey that "theatre involving people with intellectual disabilities is a theatre whose time has come" (2018, 1). Though writing and researching from a geographical context that is different from my own, McCaffrey recognizes a shift beginning in how theatre involving people who are neurodivergent is perceived – no longer understood as just a form of art therapy, but as innovative artistic work with cultural merit and social value, deserving of scholarly exploration and public engagement.

Coming Together in Conversation: Autobiography and Disability

While there have been many autobiographies, memoirs and personal essays written by individuals with disabilities,[8] there remains a lack of those written by individuals who have been diagnosed with intellectual or developmental disabilities. Rather, when the stories of these individuals do surface, they are commonly written by and through the lens of a parent or primary caregiver – highlighting the voices of those who experience 'disability by proxy' (Hadley 2020).

These works, which G. Thomas Couser (2004) refers to as 'parental memoirs,' have been criticized for the ways in which they remove the first-hand disability experience from the

---

[6] In using the language of sensory disabilities, I am referring to experiences of blindness or low vision as well as the experience of being Deaf or hard-of-hearing.

[7] In my article titled "Neurodivergency and Interdependent Creation: Breaking into Canadian Disability Arts," I suggest that this lack of representation may be due in part to the perception that disability arts must be led exclusively by disabled artists, and that neurodivergent artists often work and create with artists who are nondisabled. Further, there is a complex history in surrounding nondisabled people's involvement in the work of disabled artists (e.g. outsider art, art brut) which further complicates these dynamics and how they are perceived by the greater community.

[8] Some contemporary examples of autobiographical works written by people with disabilities include: *Deaf Utopia* (2022) by Nyle DiMarco, *Disability Visibility* (2021) edited by Alice Wong, Being Heumann (2020) by Judith Heumann, *The Pretty One* (2019) by Keah Brown, *Dirty* River (2016) by Leah Lakshmi Piepzna-Samarasinha, Look *Me in the Eye* (2007) by John Elder Robinson, and *The Reason I Jump* (2007) by Naoki Higashida.

narrative and instead offer a *representation* of disability experience from the perspective of the nondisabled parent or caregiver. While these texts may have a valuable place as resources for parents of children with disabilities, or to offer more awareness to the disability experience more broadly, these works are ultimately limited by their lack of what Gérard Genette describes as the 'autodiegetic narrative voice' – the first-person narration found in most autobiographical works (Lejeune 1989, 5). The voice of the person with lived experience of disability is ultimately missing from the conversation.

Couser unpacks the ethics of relations and representations of life writing when the author and subject are not the same. He writes, "ideally, the subject of life writing should have the opportunity to exercise some degree of control over what happens to their stories, including secrets and private information. Thus, over-writing their stories – imposing an alien shape on them – would constitute a violation of their autonomy, an overriding of their rights, an appropriation of their literary, moral and economic property" (2004, 19). In the case of the parental memoir where one might encounter (auto)biographical narratives about people who are neurodivergent, there is inherently a distance created between the disabled subject and the audience experiencing their story through the intermediary lens of a parent or caregiver. This connects back to Egan's theorization about the complex and collaborative nature of what she explicitly calls (auto)biographical works and how its dialogical nature has a significant impact on the final product. One must therefore approach these parental memoirs with the understanding that the descriptions of the neurodivergent experience are being translated through a specific filter; one that likely does not have first-hand or lived experience of disability.

In further unpacking these life writing narratives with neurodivergence as its subject, it is also valuable to consider how these texts can inform audience understandings of the neurodivergent experience. Sarah Kanake (2018) writes about what she refers to as the ‘Down Syndrome Novel.’ This genre of writing explores the experience of Down syndrome through the eyes of a parental figure, she writes that these works impose “narrative limitations of characters with Down syndrome when they are viewed exclusively through the mother’s point of view, particularly as they relate to agency, narrative inclusion and adulthood” (62). While a parent’s perspective on raising a child with Down syndrome may be valuable to community discourse, it is not guaranteed to represent the interests, growth, and perspectives of the disabled subject. “There continues to be a culture of low expectations around people with Down syndrome, and what are often seen as natural limits for people with Down syndrome are reinforced again and again by fictional representations of their lives and experiences” (Kanake 2018, 71-72).

In discussions about representation, we may consider Linda Alcoff’s arguments about the ‘crisis of representation.’ In her article “The Problem of Speaking for Others” (1991) Alcoff does not entirely reject the premise of speaking for others but emphasizes the importance of recognizing one’s positionality and privilege when doing so. She asserts that one should “strive to create wherever possible the conditions for dialogue and the practice of speaking with and to rather than speaking for others” (23). Further, Alcoff argues that in circumstances in which it may appear challenging to engage in ‘dialogic encounters’ that such spaces must be transformed to do so. Engaging in such dialogic encounters not only mitigates the issue of speaking for others but works against the possibility of essentializing a particular lived experience, and rather carves out space for a wider and more dynamic framework of understanding. In acknowledging the limits of (auto)biographical works that include neurodivergent subjects, we can explore new ways of working and sharing these stories that work toward an ‘ethical ideal’ – one that involves “optimising the autonomy of subjects, not merely ‘respecting it’” (Couser 2004, 23).

Couser's thoughts on optimising autonomy is particularly valuable to consider within the parameters of this project. This dissertation, as an academic text informed by stringent institutional requirements and guidelines, likely could not have been written by any of my research collaborators. Therefore, I am sharing my own experience, as well as theirs through my own lens. To mitigate the degree to which I am 'speaking for,' I have included direct quotes from my collaborators extensively throughout this written work– bringing their voices forward in conversation with my own to privilege their voices as equally valuable.

Performing the Self: An Analysis of Canadian Neurodivergent Self-Stories

Shifting from literary examples of (auto)biography and the neurodivergent experience, I will now draw attention to some recent examples in the field of disability, autobiography, and performance. At the time of writing this dissertation, there have been two significant professional theatrical productions produced in Canada that explore the neurodivergent experience (specifically Down syndrome). Judith Thompson's *RARE* and Niall McNeil and Marcus Youssef's *King Arthur's Night* are recognized for bringing stories of Down syndrome to the fore while including performers and storytellers with lived experience.

While on surface level, these productions may appear to have similar objectives in bringing the stories of artists with Down syndrome to mainstream stages, they take differing approaches to autobiographical performance. In what follows, I will offer a brief overview of each production, highlighting how they were received by both the media and scholars while noting points of similarity and departure in the process of creating these works. I draw attention to these examples to set the stage for the field at this moment in time and use them as a springboard for discussions of authorship and truth within the genre and the complexities of power dynamics within interabled collaboration.

RARE

RARE[9] premiered as a part of the 2012 Toronto Fringe Festival where it received recognition in its selection as 'Best of Fringe' and 'Patron's Pick.' It was then remounted the following year at the Young Centre for the Performing Arts. As described on the RARE Theatre webpage, "*RARE* featured nine theatre artists with Down syndrome, composed almost entirely of their words and their stories. Judith and the ensemble of nine crafted a production that used the actors' life experiences, thoughts and feelings to reveal their sorrows, frustrations, hopes and ambitions." This production was ground-breaking at a time when it was unprecedented in Canada for neurodivergent adults, specifically those living with Down syndrome, to be involved in mainstream theatre programming. While one can recognize what this production did for increasing the visibility of neurodivergent performing artists in Canada, *RARE* is not without its complications.

Before highlighting some key moments from the production's script, I'd like to draw attention to the ways in which the show was marketed and framed for the public and how this subsequently 'set the stage' for how audiences were encouraged to approach the production. Perhaps the most apparent aspect is the positioning by media of Judith Thompson as the owner of the piece. Nearly all headlines promoting the production focused on the lauded Canadian playwright over the marginalized individuals whose stories served as the play's content. In doing an initial search of "RARE by Judith Thompson" the following headlines appear.

"The actors in this Judith Thompson play are rare" (*The Globe and Mail* 2012)

---

[9] It is worth noting that *RARE* was the third production of a sequence of applied theatre work directed by Thompson that engaged with populations who experience marginalization or discrimination. Preceding *RARE* Thompson produced *Body & Soul* (2008-2010) and *Sick* (2009). Following *RARE* Thompson continued this theme of production with *Borne* (2013-2014), *Wildfire* (2017), and *After the Blackout* (2018). All of these productions with the exception of *Body and Soul* engage exclusively with disability themes and include disabled performers.

> "Theatre review: Judith Thompson's *RARE* makes the familiar strange" (*National Post* 2013)
>
> "Judith Thompson play 'RARE' gives voice to Canadian actors with Down Syndrome" (*Global News* 2013)

The possessive descriptions and attribution of the play to Thompson alone positions her in particular relationship to the work. [10] What I intend to demonstrate in drawing attention to these headlines is the recognition that Thompson receives for the work *she* did with and for this group of disabled actors, rather than the focus being on the talents and contributions of the performers themselves. Even the title page of the digital script reads "RARE by Judith Thompson" with a secondary title page reading "RARE by Judith Thompson and ensemble." Nowhere in this script are the performer-collaborators credited by name, despite the work being comprised of their own stories and words. While some of the reviews found online reference the performers by name, the work is still ultimately framed as Thompson's. The sticking point for me here is that the subjects of the work were not only involved as collaborators and devisers, but also as the performers – some even with lengthy professional acting resumés (though this is never acknowledged). If Thompson had gone into the community, consensually collected stories, written the script, and published it or had it performed by others (similar to the approach of creating the script for The Laramie Project[11] and other verbatim documentary works), then perhaps Thompson's primary ownership of the scripted work might be more warranted. However, as this was not the case, I would argue that in offering their personal stories to this

---

[10] Even in removing Thompson's name from the search, the media still highlights *RARE* as 'Judith Thompson's new play,' emphasizing her position not only as the 'writer and director' but also as the creator of the work (CBC News 2013; CTV News 2012).

[11] *The Laramie Project* is a verbatim theatre piece created by Tectonic Theater Project (TTP) surrounding the homophobia-driven murder of twenty-one-year-old Matthew Shepard in Laramie, Wyoming in 1998. The material for the script was sourced from the over 200 interviews that members of TTP conducted with the citizens of Laramie with varying degrees of connection to the case. The play which premiered in 2000 and has since been seen by over thirty million people worldwide. The text and structure of this play is used often as an example or verbatim or interview-based theatre.

project, these performers as creative collaborators and autobiographers should have received more credit.

Unfortunately, this problematic relation between the playwright/director and the performers is also present in the dramaturgy of the work. While much of the script's content is clearly autobiographical in nature, there are additional elements such as poetry or excerpts from European classic literature and music that offer an at times jarring contrast to the performers' own words. In reading the script, I found myself questioning the intentions behind the inclusion of works by classic high-culture figures such as Shakespeare, Yeats, Blake, Dickinson, and Tchaikovsky. Jenn Stephenson (2019) problematizes these dramaturgical choices as presenting a kind of "cliché of faux intellectual sophistication" as if the performers (or perhaps the playwright) are trying to prove to the audience "that they can participate in canonical literary culture at the 'highest' levels" (73). Having these words (taken from often inaccessible literary forms) spoken by artists with Down syndrome feels artificial and performative, and further, expresses a perceived need to prove something to the audience. In doing so, an 'us' vs. 'them' binary is established between the performers and the audience – solidifying and emphasizing a perceived difference. Perpetuating this dynamic also asserts an assumed and limited audience demographic. To use philosopher Louis Althusser's (1970) language, the audience is 'interpellated' or 'hailed' by the content of the work as subjects who are neither disabled nor have any connection to the disability experience.

This assumed positionality is solidified in moments of direct address by the performers to the audience including statements such as "You think I'm retarded? Please look at yourself!" as well as a monologue that begins with "Dear Pregnant Ladies" – a call for pregnant women who have found that their baby has Down syndrome via prenatal testing to reconsider pursuing abortion. While these politically charged words are valid and need to be heard, they do not account for the potential diversity of an audience's lived experience. Rather than calling audience members in to enhance understanding, or considering the possibility of disabled audience members, these pointed and at times unnecessarily aggressive assertions seem to further isolate and distance the audience from the performers, again solidifying an oppressive 'us' vs. 'them' binary.

In concluding this brief overview of *RARE* as an example of (auto)biographical performance including neurodivergent artists, I emphasize the need for further interrogation of this work particularly regarding ethics, agency, and authorship. Some questions worthy of consideration include: Whose words are being spoken aloud? Who is making the final creative choices? Who takes ownership over these stories? What are the ethical implications of these blurred lines of authorship and creative decision making? While *RARE* has been explicitly framed as Judith Thompson's play, the style of the script and the performance in many ways points to the performers as co-creators, regardless of how their words were altered or edited. Ultimately, there is a lack of transparency about the process of creation, which I believe undermines the ability and insights of the performers who gave their stories to this project.

To offer a different approach to interabled collaboration between a neurotypical playwright and artists with Down syndrome, I will present an overview of *King Arthur's Night*, highlighting how the creative process celebrated disability and new ways of working and performing interdependently and with an interabled cast.

King Arthur's Night

King Arthur's Night reimagines the medieval story of King Arthur, Guinevere and the Knights of the Round Table through Niall McNeil's eyes and weaves elements of his lived experience of

Down syndrome and unique worldview throughout. *King Arthur's Night* first premiered at Toronto's Luminato Festival in 2017 and in the following three years was staged in Ottawa, Vancouver, and Hong Kong. While *King Arthur's Night* and *RARE* both engage in interabled creative partnership, the methods of collaboration as well as how the productions have been marketed and reviewed are notably different.

In contrast to the framing of *RARE* as being written and directed by Thompson, *King Arthur's Night* has always had both McNeil and Youssef credited as equals (with McNeil's name always appearing first). Like Judith Thompson, Marcus Youssef is a well-regarded playwright, but his acclaim and prestige were never the primary draw of this project. Rather, McNeil, an actor and playwright with Down syndrome with over thirty years of theatre experience was the highlight of discourse surrounding this production. Centring McNeil as a lead artist was also reflected in how the media was writing about this new work with article titles including:

> "*This artist living with Down syndrome co-created a new King Arthur play, and here's why that rules*" (*CBC* 2017)
>
> *"King Arthur's Night opens the door to new worlds"* (Colin Thomas 2018)
>
> *"Camelot, chromosomally enriched"* (*Vancouver Observer* 2018)

In contrast to *RARE*, the language used in marketing and reviews of *King Arthur's Night* focussed more on the production's unique and collaborative approach and celebration of disability more so than the prestige of names connected to it.

While the story of *King Arthur's Night* is set in an already established and well-known fictional world, the inclusion of the autobiographical elements embedded throughout is what makes this production truly innovative and unique. This dramaturgical choice not only brings McNeil's experience into conversation with this classic story, but also enhances the overall aesthetic of the production, highlighting parallels that McNeil would draw from between his own experience and that of the original story's characters. In her article about the access and aesthetics of *King Arthur's Night,* Megan Johnson (2018) writes,

> While script development strategies are normally hidden from the audience, *King Arthur's Night* brings the process onto the stage in the first moments of the performance. Opening the show, Youssef and McNeil present the audience with a series of photographs that explain the collaborative working process by which they developed the script. During this prologue, we learn how key moments in McNeil's life (from his memories of the steam at BC's Harrison Hot Springs Resort, to his appreciation for the character of Gollum in the Lord of the Rings, to a slightly traumatic childhood run-in with a head-butting goat) were integrated into the narrative and the overall aesthetic of the show. (104)

As Johnson notes, this is a unique approach, not often highlighted in performance itself. However, as interabled collaboration and McNeil's interpretation of the original text was essential to the work, inviting the audience to look behind the metaphorical curtain offers a deeper insight into this unique creative process. I would argue that it was the weaving of McNeil's unique world view and lived experience into the classical tale of King Arthur that made this work so successful. This bridging of the real and the fictional, as Carol Martin suggests, "lead[s] to splendid unplanned harmonies in the service of the creation of meaning" (2012, 10). In addition to McNeil's experience of Down syndrome informing the production, the team also hired three additional actors with Down syndrome who they met through their work with the Down Syndrome Research Foundation (DSRF). Casting actors with Down syndrome in the roles of Guinevere, Magwitch and Saxon further informed how the work was staged and performed – working with these artists in ways that celebrated their unique ways of moving through the world, just as they had with McNeil.

In addition to being programmed nationally and internationally, the script for *King Arthur's Night* was published in 2018 as part of a two-play collection, *King Arthur's Night and Peter Panties: A Collaboration Across Perceptions of Cognitive Difference*. In the introduction to the collection, Youssef writes about how he and McNeil work together as well as the methods they use for exploring and devising a new play script. Youssef recognizes McNeil as a "gifted associator who makes links between characters and stories that defy traditional characterizations like 'fictional' and 'real'" (xvii). In highlighting McNeil's abilities to reimagine and create meaningful connections between seemingly unrelated themes, Youssef both celebrates the talent of his disabled collaborator, and establishes their interabled collaborative relationship as one that is truly interdependent and reciprocal. McNeil and Youssef have, through the development of these works, contributed to challenging hierarchies between disabled and nondisabled artists while breaking down barriers and challenging assumptions about who can or should be invited to create professional theatre.

I highlight these two productions as formative examples of Canadian theatre co-created and starring neurodivergent artists. I suggest that *RARE* and *King Arthur's Night,* while taking noticeably different approaches to collaboration and artistic authority, serve as the baseline from which future interabled works can be created – learning from the shortcomings and successes of these previously performed works. What I wish to demonstrate in briefly discussing these productions is that there is no textbook for working interdependently across ability, and no definitive answers for how to honour disability experience or support disabled artists while still leaving room for autonomy and ownership of their self-expression. These productions therefore provide a starting point for artists working within the Canadian disability theatre sector to explore further and innovate new best practices, methodologies, and frameworks for interabled collaboration with neurodivergent artists.

Unpacking the Practice

With the above artistic examples in mind, I further unpack the dynamics of working within an interabled collaborative framework, as well as the implications of these practices for the future of neurodivergent performance nationally and internationally. It is imperative to note, however, that presently there is a dearth of Canadian scholarship on the topic of neurodivergent performing artists and neurodivergent-informed artistic practice – a gap I have been working to address in my own publications. To remedy this, much of the literature I have consulted for this dissertation comes from scholars abroad – particularly those in Europe, the United Kingdom and Australasia, where the work of neurodivergent theatre artists seems to be more prevalent.[12] I bring into conversation several key themes explored in the literature that resonate with the intricacies of neurodivergent theatre practice and informed my thinking going into *Our Stories*. These themes include: the complexities of interabled collaboration, accessible performance practice and artistic support, as well disability-centred ways of knowing and sharing knowledge and how this can contribute positively to the development of new artistic forms and critical discourse.

---

[12] I can speculate that this work is able to thrive in these other parts of the world due to better systems of support and resources for disabled artists. For example, the UK's *Access to Work* is "a government-run program that equips citizens of the United Kingdom with the resources to enhance their access at work" in ways that are self-directed (Gold & Bulmer 2022). Australia has Arts Access Australia which established in 1992, serves as a national body for arts and disability and "work[s] for increase national and international opportunities and access to the arts for people with disability as artists, arts-workers, participants and audiences" (About Arts Access Australia). These resources and systems of structural support make it possible for people with disabilities to work and survive as full-time artists.

Interabled and Interdependent Collaboration

An under-theorised and yet key element of disability arts practice is the nuance and complexity of what I refer to as interabled collaboration. It is essential to keep in mind that theatre involving neurodivergent individuals has been, and in many cases still is, facilitated or guided by practitioners who do not identify as being disabled (Gold 2021; McCaffrey 2018; Perring 2005). With that said, I conceive of interabled collaboration as distinct from art therapy programs or arts-based services in which there is a clearly defined relationship of an obvious provider and receiver. Rather, I imagine collaborative, interabled artistic relationships as being fundamentally collegial, interdependent, and intentional in nature – where traditional hierarchies between disabled and nondisabled can be challenged and broken down. To reimagine and innovate new ways of working, it is necessary to first engage and reflect upon practices of the past – to not only consider the artistic development and output from such collaborations, but to be mindful of how power and traditional hierarchical positioning can impact such a practice. Particularly within the context of interabled collaborations between neurodivergent and nondisabled practitioners, it is essential to confront and question the discrepancy of privilege in such spaces.

In his book *Incapacity and Theatricality* (2018), New Zealand scholar and Artistic Director of Different Light Theatre[13] Tony McCaffrey asserts, "Even those contemporary theatrical practices that seek to emancipate or give autonomy to people with intellectual disabilities by means of performance are, however, forced to confront the complex nexus of intersubjectivity that characterizes the relationships between people with and without disabilities" (2). McCaffrey highlights the true complexities of these interabled relationships – noting that they can come with layers of unconscious, socioculturally-informed biases and

---

[13] Different Light Theatre is a mixed ability theatre company based in Christchurch, New Zealand.

ableism. This idea of ‘emanicpat[ing]’ or ‘giving autonomy’ to people with disabilities however, suggests that members of this community are unable to advocate for themselves and in turn positions nondisabled collaborators in some way as saviours or do-gooders, instead of focusing on the skills and talents of the disabled artists themselves. This perspective aligns narratives of Western saviourism (Kazubowski-Houston 2017; Schuller 2014), as well as oppressive colonial and imperial views of disability (Lovern 2021; Grech & Soldatic 2015).

This critique of the language used by nondisabled artists working with people who are neurodivergent demonstrates that there is much work to be done in theorizing these truly complex relationships; even nondisabled collaborators with ‘good intentions’ need to be reflexive and look deeply and critically at their own practice. For practitioners, taking the time to reflect on one’s own biases or preconceived notions of ability and working toward dismantling socioculturally informed hierarchies of power in one’s practice will ultimately improve interabled relations and facilitate the advancement of these creative dynamics. In terms of scholarship, these creative working relationships need further research and critical engagement. In noting the successes and shortcomings of these interabled creative relationships, I suggest that disability performance theory can be further developed and in turn inform how practitioners reflect upon and reimagine their own collaborative practice.

Access and Support

Accessibility is an essential element of disability arts as it pertains to artists as well as audiences. While providing accessibility measures can ensure certain levels of autonomy in participation, I believe it is the structures of support and appreciation for interdependent over independent art practice that grounds disability arts as both an art form and a cultural practice.

Before moving on, it may be pertinent to briefly outline here the distinctions between accessibility measures, access aesthetics and interabled artistic practice.

Accessibility measures are protocols, structures, or hired personnel used to enhance accessibility for people with disabilities. These measures may include the hiring of sign-language interpreters for those who are d/Deaf or hard-of-hearing, audio describers and sighted guides for those who are blind or have low vision, scent-free spaces for those who experience scent sensitivities, or plain language versions of complex documents for those with cognitive or learning disabilities. Ultimately, the list of possible access measures is infinite and determining the most appropriate measures for a production or event is best done in consultation with members of the disability community.

Access aesthetics in some ways bring accessibility measures into the artistic realm. Access aesthetics look for ways in which accessibility measures or practices can be intentionally and creatively integrated into artistic works, rather than included secondarily. For example, set design that incorporates ramps rather than stairs would enable performers with limited mobility to move around the performing space with greater ease. Another example might be casting a sighted actor in a role that shares scenes with a blind actor to create opportunity for integrated sighted guiding as part of the blocking. Along this same line, playwrights can engage in access aesthetics by integrating more visual descriptions into their writing, to enhance access for blind and low vision audiences. Access aesthetics may also look like line-feeding for actors who have difficulty with memorization and working to do so in ways that allows these prompts to function not only practically but creatively within the performance.

As for interabled artistic practice, I think of it as more than just disabled and nondisabled artists working together, though by definition this would still be accurate. Rather, I view interabled artistic practice as a way of working that is intentionally collaborative and interdependent. Interabled artistic practice can integrate access measures and aesthetics into the work, but the foundation of the practice is much more about collaboration and the mutual benefits of disabled and nondisabled artists working together. Regarding neurodivergent performers, these relational supports, while at times nuanced and complex, are often the most valuable in terms of enhancing access.

What I wish to highlight in this section is how support for neurodivergent artists may differ from artists with physical or sensory disabilities and the various forms that such support can take. A significant difference in supporting neurodivergent artists in contrast to those with other disabilities is often its invisibility to those outside of the creative practice. As Matt Hargrave (2015) notes, a "physically disabled performer may reveal the supportive infrastructure of prostheses, chairs or crutches; a [neurodivergent] actor, however, may depend on invisible support structures such as the extended time required to memorise the text" (100). Support for neurodivergent artists is in many ways intangible, with time and interpersonal relations being what I believe to be the most valuable resources.

Time as resource

Within the field of disability studies, the concept of time and the often-rigid parameters of timelines, schedules, and deadlines imposed by late-capitalism have been critiqued and reframed. The term most often used to highlight alternative frameworks of time in this context is 'crip time.'[14] This oft cited definition comes from disabled scholar Alison Kafer who writes that crip

---

[14] I wish to note here that 'crip' while once perceived strictly as a slur or term of oppression has been reclaimed by some members of the disability community. However, it is also important to recognize that "crip [is] a term which has much currency in disability activism and culture but still might seem harsh to those outside those communities" (Kafer 2013, 15).

time “requires reimagining our notions of what can and should happen in time or recognizing how expectations of ‘how long things take’ are based on very particular minds and bodies” (2013, 27).

She goes on to explain that while disability accommodations (particularly within the academy) are understood as the need for ‘extra’ time, crip time is not simply about providing *more* time. Rather, there is room for time available and the way it is organized to flex and shift. “Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds” (Kafer 27). In understanding time as a key resource for neurodivergent artists, one can appreciate how traditional eight-hour rehearsal days or intensive performance schedules may not be feasible. By embracing crip time, disabled artists are actively resisting capitalist and neoliberal ideologies that value speed and production over care and personhood. They instead aim to carve out working structures that are more conducive to their diverse needs and those of their community. Later in this dissertation, I return to the concept of crip time within the specific framework of the *Our Stories* project – further highlighting the nuance and flexibility of this temporal practice for the specific artists involved.

Relations as Resource

In conceiving of relations of support for neurodivergent artists, it is important to understand that the degrees of support required can exist on a spectrum. Ultimately, the specific needs of the disabled artist(s) will inform what support structures are necessary. The unique relationships between disabled artists and their (often nondisabled) collaborators or support personnel have received more scholarly attention in recent years. A range of terminology and labels have emerged that are attributed to the various roles held and degrees of support provided.

In 2014, Michael Achtman wrote a short 'Dispatch' article for *alt.theatre* magazine in which he describes the role of a 'creative enabler'[15] – a support-based position invented by Alex Bulmer, Michael Achtman and Claire Saddleton as part of their work at Graeae Theatre Company in the UK. Achtman describes the working definition of a creative enabler as "a support worker with skills and experience in the area practised by the disabled artist. The artist can call on the creative enabler to assist in ways that they could not ask of a general access support worker or personal assistant" (36). While this role was originally created in response to the needs of a particular artist employed by Graeae at the time, it names an incredibly valuable role within disability arts practice. In naming this role, Achtman demonstrates both the value of having one-on-one access support for disabled artists who require it, and how receiving support from someone who is also an artist and understands the disabled artist's field of practice can be greatly beneficial in imagining innovative and accessible ways of working collaboratively and interdependently in artistic spaces.

Despite the creative enabler having an artistic background, the degree to which they contribute artistically varies from project to project. At times, the creative enabler will only be asked to engage with access support, working to enable the disabled artist to engage fully in their artistic practice. Achtman notes that this approach to creative enabling can be one of the most challenging aspects of the creative enabler role. "[I]t is easy to become invested in the [artistic] outcome and sometimes difficult to suppress your own creative ideas. But the access support aspect of the role asks that you hold back" (36). In this context the creative enabler is distanced from the artistic development of the work. He gives the following example, "as an interpreter you would not add your own thoughts when repeating someone's speech; as a playwright's

---

[15] While the language of enabling in some contexts can be viewed as problematic or harmful, in this case, the language of 'enabling' is used as an antonym of 'disabling.'

scribe you would not suggest ideas for scenes or characters" (36). With that said, one could argue that any amount of artistic support could have an impact on the disabled artist as well as the development and execution of the work.

Through my own experience working as a creative enabler, I suggest a broadening of this term is needed to be more malleable to the specific needs of the project and the disabled artist(s) involved. There are times when it is appropriate or even required for a creative enabler to be actively involved in the artistic process. For example, a creative enabler may be cast as a character in a play's story – bringing the role of support to the fore and contributing to a kind of access aesthetic within the work itself (Gold & Bulmer 2022). A creative enabler may also, when required, work collaboratively with the artist they are supporting as well as the production team to problem solve or find creative solutions for embedding accessibility into the work in ways that will best serve the goals and access needs of the artist that they are supporting.

While the role of a creative enabler is ultimately to provide support and 'enable' the disabled artist in their artistic practice, the parameters of this practice of support can and should evolve with the specific needs of the disabled artist and the creative project. In this way, the language of 'creative enabling' could be synonymous with creative access support or a creative assistant. The language or label itself is less important than the relationship between artist and their creative enabler, which differs from that of a general access support worker. The relationship should be deeper and more interdependent – with a strong understanding of the artist as a person as imperative to this working relationship.

Expanding further on this idea of artistic support for disabled artists, in "Towards a new directional turn? Directors with cognitive disabilities" (2017), Yvonne Schmidt presents what she calls a 'Spectrum of Collaboration.' The Spectrum of Collaboration outlines five unique roles that utilize varying degrees of support and artistic contribution within an interabled artistic practice. These designations not only present five different approaches to working with an interabled team, but also offer language for how we may speak about these unique roles.

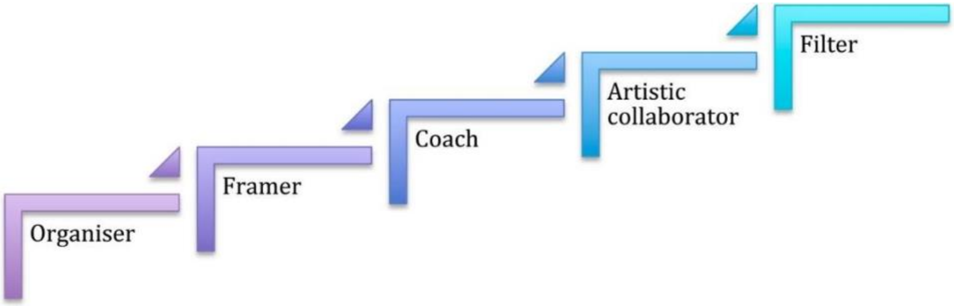


Figure 1: Spectrum of Collaboration (Schmidt 2017, 450)

On one end of the spectrum is the 'Organiser.' The organiser may take on more administrative duties, organising rehearsal or workspaces, rehearsal schedules, etc. and is not required to have an artistic background or contribute to the creative work. The next role is the 'Framer.' The Framer simply provides a specific artistic framework or structure so that the disabled artist is guided to create their work within particular parameters. An example of this might be an instructor of a studio-based class in which disabled artists are creating within a certain performance genre or artistic medium but still have artistic freedom to create what they want. Following the 'Framer' is the 'Coach.' The Coach role is more of an advisory position, which Schmidt notes may be congruent with the role of a dramaturge. The next role is that of the 'Artistic Collaborator.' This role brings together artists "on the same level" and does not position one as more or less of a leader/artist than the other. The final role in Schmidt's 'Spectrum of Collaboration' is the 'Filter' which she recognizes as perhaps the most common in theatre with neurodivergent artists. In a manner similar to the traditional process of devised theatre, the Filter, often also a director/playwright, will have the disabled artists improvise and explore but will ultimately be the one to shape or filter what is presented on stage (450).

Throughout her writing about the Spectrum of Collaboration, Schmidt offers terminology for various creative working relationships while recognizing that the boundaries of these roles can be flexible and that roles at times may overlap. My role within *Our Stories* arguably sat somewhere between ‘Artistic Collaborator’ and ‘Filter’ – aiming to find a balance between collaborative and non-hierarchical practices, while also offering some dramaturgical suggestions and directorial guidance.

In acknowledging that neurodivergent artists often work collaboratively with or under the direction of nondisabled artists, Schmidt’s Spectrum of Collaboration emphasizes the importance of reflexivity and transparency in developing interabled working relationships while remaining mindful of the implications of nondisabled authorship and ownership of artistic output. These interabled artistic relationships may also benefit from having a heightened level of interpersonal knowledge and awareness between collaborators, as well as establishing clearly defined roles and responsibilities at the outset of a project.

Understanding best practices and access needs for individual artists can take time but is key to building meaningful interdependent and collaborative relations (Gold & Bulmer 2022). This shared experience of developing meaningful understandings across difference aligns with what Mia Mingus calls ‘access intimacy.’ Access intimacy is a fluid term that can be both expansive and specific in its understanding and application. Mingus describes access intimacy as “that elusive, hard to describe feeling when someone else ‘gets’ your access needs […] Sometimes it can happen with complete strangers, disabled or not, or sometimes it can be built over years” (Mingus 2011). For collaborators of neurodivergent artists, it is important to understand that addressing access needs will not be as straightforward as ensuring there is a ramp in the rehearsal space or braille on elevator buttons – it will likely emerge from trial and error –

experimenting with time and technology, reframing language, understanding triggers or fixations, and embracing alternative methods of communication. It is through this enhanced level of understanding as well as taking the time to meaningfully develop these relations grounded in access and support that the most successful interabled collaborations can emerge. There is also great value in embracing lived experience of disability as a way of informing the artistic practice rather than as an afterthought or merely a reason for accommodation. Amplifying the activist and disability rights mantra of "Nothing About Us Without Us,"[16] I suggest that work that includes disabled artists should lead from a point of access and embracing disability-informed ways of working and creating together.

Embodied Knowledge and Disability Expertise

In working toward effective methods of interabled and interdependent collaboration, I suggest that there needs to be an understanding for nondisabled collaborators not only about their collaborators' disability experience, but additionally, how their experience of disability can inform the ways that they move through the world and by extension approach their art. Originally coined by Merri Lisa Johnson, the term cripistemology (crip + epistemology) offers language to the idea of navigating the world through the experience of disability. Johnson and McRuer (2014) explain the concept of cripistemologies as the "making and unmaking [of] disability epistemologies, and the importance of challenging subjects who confidently 'know' about 'disability,' as though it could be a thoroughly comprehended object of knowledge […and] questioning, in other words, what we think we know about disability, and how we know around and through it" (130).

---

[16] The phrase 'Nothing About Us Without Us' has been a staple of disability rights activism since the 1990s. It's history, however, precedes North American disability rights movement, and originated from 16th century political movements in Poland (Khedr and Etmanski, 2021). As a slogan of democracy, 'Nothing About Us Without Us' continues to offer meaningful language to marginalized communities resisting systemic oppression.

McCaffrey (2018) recognizes the significance of cripistemologies within the context of theatre with neurodivergent performers, “as it suggests incapacity as much as capacity in the project of knowledge” (4). While I am not keen on McCaffrey’s language choice of capacity vs. incapacity, the core of his statement draws attention to the crux of this work: that the neurodivergent experience can offer new knowledges, understandings and perspectives that can meaningfully contribute to the practice of and discourse around disability theatre. Within the cripistemological context, it is not just the more “normate” aspects of a neurodivergent artist that deserve attention and celebration, but all parts: the whole individual with all facets of their unique life experience.

Extending upon this notion of cripistemologies, Cassandra Hartblay (2020) offers the term “disability expertise.” Drawing from the work of Aimi Hamraie and Kelly Fritsch (2019) who assert that “disabled people are experts and designers of everyday life” (2), Hartblay frames disability expertise within the “domain of human practice” and defines it as “enacted knowledge specific to disabled people, acquired through life experience in non-normative bodyminds” (S27). This concept further emphasizes the fact that disabled individuals are the ultimate experts of their own individual experience. While practices of support and interdependence can work to illuminate new methods of access or collaboration, it is ultimately the disabled individual that holds the embodied knowledge of disability experience that informs the way they may move through the world.[17] Within the context of disability theatre and performance, embracing disability expertise allows artists and their collaborators to tap into ways of knowing and working that are informed by disability experience – a method that I believe can serve artistic projects both in terms of accessibility and aesthetics.

---

[17] I do not suggest that every disabled person is an expert of *all* disability experience, but rather that there is a level of expertise developed through one’s particular disability ‘embodiment/enmindment’ (Kuppers 2014, 43-44).

In thinking about utilizing disability expertise in performance, there are two productions that skillfully illustrate this work in creative practice. The first is *May I Take Your Arm?* which was first produced by ReDefine Arts (formerly Red Dress Productions) in 2018. Created in collaboration with blind artist Alex Bulmer, *May I Take Your Arm?* is theatre production that emerged from Bulmer's genuine need to orient herself to a new space. As Bulmer explains in a blog post on the ReDefine Arts website,

> In 2018, I moved back to Toronto after living in the UK for 15 years. While away, I'd become completely blind. Instead of a return to familiar landscapes and buildings, I came back to a void – endless space. Without sight, a new territory has no here-versus-there, no this-versus-that. "May I take your arm?" is a question I asked several people living in my new Toronto neighbourhood in an attempt to understand where in the world I had landed – to turn space into place into home.

To familiarize herself with her new neighbourhood, Bulmer went out on walks with locals. As they walked and explored various landmarks of the neighbourhood, their conversations were recorded. These recorded conversations and stories shared between strangers became the soundscape of the production. Bulmer's pursuit of stories and descriptions to assist her in orienting herself in her new neighbourhood served the work in bringing access and dramaturgy together. The elements of disability expertise best highlighted by this production take place during the actual performance. The set is made up of several small-scale replicas of the various locations that Bulmer visited on her recorded walks. These replicas or 'miniature worlds' were created by Anna Camilleri and were intended to serve not only as a unique visual element, but also as a tactile element that Bulmer and her audience could engage with throughout the performance. As the soundscape of Bulmer's conversations play through speakers placed around the room, she asks her audience to help her move between the miniature worlds so that she can engage physically with the space that matches the recorded conversations being played. To achieve this, Bulmer calls out to the audience with the request to guide her to a new location. “May I take an arm to Allen Gardens?” “May I take an arm to Riverdale Farm?” “Can someone guide me to the Necropolis?” Audience members are invited into Bulmer’s world, to offer their arm and provide sighted guide to various locations in the playing space – in this moment of interaction providing access becomes an aesthetic of the production. As the expert of her own needs, Bulmer engages in self-advocacy in asking for assistance and in doing so retains complete control of the performance while offering audience members the chance to support her. Though the sighted audience member is responsible for guiding Bulmer to her requested location, her expertise in vocalizing her needs from moment-to-moment allows her retain autonomy in this space.

Looking at disability expertise from more of a dramaturgical perspective, I would again highlight Niall McNeil and Marcus Youssef’s *King Arthur’s Night,* particularly for the ways that they embrace less conventional ways of navigating the writing process. As noted by Youssef in the introduction of their play collection, his and McNeil’s playwriting process is quite unique. Youssef notes that during their sessions working together he records everything. He writes, “I made the decision early on to record everything Niall and I did together. We hang out, talk, jam, improvise, write lines, talk about characters and story, joke, and argue. Sometimes we talk about the story we’re working on. Other times we talk about his life, and friends. Usually it’s both, simultaneously” (2018, xvi). This loose structure allows the creative work to unfold in ways that work best for McNeil, recognizing that valuable content for the play could emerge at any time.

Part of what makes McNeil's writing so evocative is his talent for making unexpected associations. "In the worlds of *Peter Panties* and *King Arthur's Night* there are permeable boundaries between the source material, popular culture, and Niall's own world. He is a gifted associator who makes links between characters and stories that defy traditional characterization like 'fictional' and 'real'" (Youssef 2018, xvii). For example, the character of Mordred in original King Arthur lore is Arthur's illegitimate son/nephew who rebelled and posed a threat to Arthur and his throne. In McNeil and Youssef's retelling, Mordred is portrayed as having been born with goat horns. In the play's prologue, McNeil (as King Arthur) describes a traumatic childhood experience that he had with a goat (McNeill & Youssef 2018, 13). Though McNeil, possibly breaking out of character for a moment, assures Merlin (played by Youssef) that he was not scared of the goat, there is an interesting parallel being made between the potentially threatening nature of this McNeil's childhood experience and the horned Mordred's threat to Arthur's kingdom.

McNeill's experience of navigating the world as a man with Down syndrome informs the way that he approaches his art and embeds his unique world view into his writing. Youssef therefore encourages McNeil's expertise about how he works best and recognizes that embracing these non-normative practices benefit the art that they create together. In centring disability expertise as a key element of collaborative, interabled artistic creation, the work becomes better situated to be more accessible for the disabled artists involved, as well as centring disability narratives as understood by those with lived experience.

The approaches to interabled support and collaboration outlined in this section deeply informed how I navigated this project. With an emphasis on centring the needs and goals of disabled artists as well as an encouragement to remain reflexive of one's positionality within an interabled project, these methods of collaboration offer myriad ways of working that uplift the disability experience rather than attempting to mold it to fit more traditional theatre practices. In the following section, I discuss performance ethnography as my chosen methodology, highlight pertinent literature, and further contextualize the project within the field.

Performing Self-Stories and Performance Ethnography

Traditional ethnographic research relies heavily on observation and verbal expression. Performance ethnography, however, uses embodied and multimodal methods of exploration as a form of participant observation and representation whereby the researcher addresses their research questions through the act of co-creating a theatrical work with participants (Kazubowski-Houston 2010, 14). This research methodology does not use performance as the secondary product of the research, but rather it holistically examines the entire process of creating and staging a performance (from first meeting through the run of the show). This approach uses both creative performance generation and staging as well as everyday performativity to inform the research. It emphasizes what can be gleaned through a collaborative creative process over strictly using a performance as the vehicle for the dissemination the field research.

For this project, I was drawn to performance ethnography for the way that it celebrates the potential of performance to communicate and inform. Norman Denzin, a key scholar of performance ethnography, recognizes performance as a form of public pedagogy – “an act of intervention, a method of resistance, a form of criticism, [and] a way of revealing agency” (2003, 9). This perspective resonates with my own understanding of the potential of theatre and performance as a vehicle for connecting across difference. Bringing people with diverse backgrounds and lived experiences together to collectively witness a story can have significant real-world impact. Further, I suggest that the experience of an audience does not end when they leave the theatre. Rather, they take their experience with them, share it with friends and family who may then choose to experience the work themselves, engage in discourse, or just reflect on their own. Through these second-hand experiences of an artistic work, a rhizomatic effect can take place where one audience member has the potential to inform others through their singular experience. For the purposes of this project, the focus was less on audience reception of the work and more about the impact on the performers – how their experience of writing and sharing their stories impacted their understandings of theatre's potential for enacting advocacy for themselves as well as their community.

Forming Relations

Building and fostering relationships is another key component of the performance ethnography methodology. These relationships are essential to the development of a creative work and are key to reimagining how researchers and participants can work collaboratively in ways that serve the project as well as the individuals involved. Clifford Geertz (1998) described his approach to field work as "deep hanging out" – emphasizing a more participatory approach to anthropological engagement over distanced observation. While this notion of deep hanging out infers a heightened level of camaraderie, it also positions this ethnographic practice as an exchange, putting value on understandings that may emerge from simply spending time together. "We listen to people telling stories about themselves, their families, their neighbours […and] share stories of our own" (Culhane 2017, 4). With this, the practice of performance ethnography is active and engaged, rather than passive and merely observational. To use Barbara Tedlock's term, we are shifting away from participant observation to 'observant participation' which "indicates a critique of theories that position researchers as active, observing subjects and research participants as passive, observed objects. Tedlock's reformulation also recognizes the growing number of 'insiders' conducting ethnography within what they identify as their own communities, networks, and organizations" (Culhane 2017, 10-11). This shift in language works to break down the binary of participant and researcher and highlights how these roles can intersect and overlap in meaningful ways. Johannes Fabian (1990) articulates this shift in language and practice further by proposing ethnography to be a co-performance in which the ethnographer and research participants collaboratively co-perform ethnographic knowledge. In this research approach, the ethnographer works with, not on the people with whom they interact (19).

Responsibility of the Researcher

When building these collaborative relationships, researchers must remain cognizant of disparate positions of power between themselves and their participants. Researchers have a responsibility to their participants who are giving their time and trust to a project. A key responsibility for those engaging in ethnographic research is to remain critically reflexive at all stages of the project, challenging conscious or unconscious biases, recognizing and addressing mistakes or misunderstandings, and being open to learning and relearning from one's research participants throughout the process. Within the context of ethnographic practice, critical reflexivity "demands we challenge, more than claim, ethnographic authority and calls upon us to critique 'values and ideas that have been incorporated into the self'" (Haddad 2003 qtd. in Culhane 2011, 258). Further, engaging in critical reflexivity promotes a cognizance of relations and structures of power and privilege within the research dynamics. In doing so, researchers may be forced "into the open with all our insecurities, blemishes, weaknesses. It challenges us to reveal ourselves and reflect upon ourselves" (Kazubowski-Houston 2010, 17). Not only does engaging in a practice of reflexivity serve the researcher and the project, but it also facilitates a level of accountability to one's participants in maintaining a creative space grounded in care and support.

D. Soyini Madison engages with these care-full research environments through what she calls an "ethics of attention." In an interview with Magdalena Kazubowski-Houston and Virginie Magnat (2018), Madison explains that an ethics of attention "entails being still, being quiet, to focus and attend to that which is present before you and that surrounds you in the here and now of the field" (458). What I find particularly striking about this is that Madison emphasizes the value of being present and truly paying attention to everything taking place in the moment. It is through engaging in such a practice that moments that might typically be brushed over or missed, can be embraced, and highlighted as key moments of understanding. "We need to be still, we need to keep quiet, we need to stand in love, and we need to pay attention – to fully attend to the feelings, sense, meanings and stories that emanate from the sights, sounds, and motion of engaged and imaginative fieldwork" (Madison 2018, 485). Embracing this active level of attunement and finding value in what is expressed out loud as well as in moments of silence is key (Kazubowski-Houston 2017). This practice of intentional presence and attunement is something that I strive to uphold in my work with neurodivergent artists – a practice that became far more challenging during the pandemic when connecting through screens. Because of this enforced and necessary distancing, maintaining an ethics of attention became even more imperative to this process in ensuring that everyone felt cared for and held, that their time and perspectives mattered.

Art has the potential to bring forward stories and experiences that may exist outside of the 'mainstream.' Stories inaccessible or typically out of sight for the general public can be brought to the fore, using performance is a meaningful way to understand experiences and perspectives that may differ to varying degrees from one’s own. As Denzin notes, “We cannot study experience directly. We study it through and in its performative representations” (2003, 12). Recognizing that we can never fully put ourselves into the shoes of another, engaging with performance in some cases may be as close as we can get to truly understanding experiences outside of our own. These experiences also present an opportunity for audiences to also look inward, not only to reflect upon what they witness on stage, but to also unpack how we may relate to the people and stories which we witness.

Engaging with poignant literature and theories from disability studies, theatre and performance studies, autobiography studies and performance ethnography, this project, by virtue of its interdisciplinary nature, works to bring these fields together in meaningful conversation. The following two chapters demonstrate how these theoretical and methodological practices emerged in the creation process of *Our Stories.*

CHAPTER 2: THE CREATION PROCESS

This chapter offers insight into the creation process of *Our Stories* from preliminary interviews to our final rehearsal before the invited screening. It contributes to the discourse surrounding collaborative methods of devised theatre, accessible theatre creation methodologies, working within non-normative temporalities and well as my multi-faceted role within the project.

Interviews

> Becky: Lindsey, how would you describe your disability?
>
> Lindsey: Hmmm.. how would I describe my disability… amazing! Amazing and special.

> Becky: Are you familiar with the term self-advocacy?
>
> Joey: [nods] Yeah.
>
> Becky: Yeah? What does that mean to you?
>
> Joey: So, to me that's where you speak up for yourself or if you need something […] I've had challenges with that too when I was younger and still kinda now too because you know, I don't like speaking up that much. But I feel like it's important to have self-advocacy because if you don't get heard then maybe someone won't know how to help you to get what you need.

Prior to our first meeting as a group, I conducted a brief one-on-one interview with each participant. During these interviews, I hoped to gain some preliminary information about their lived experience of disability, what they wish others understood about people with disabilities, significant life moments, and how they like to express themselves creatively. These interviews presented the first of many moments that challenged how I was thinking about this project in terms of my role as researcher/artistic collaborator as well as how I would be able to conduct this research in ways that would be equally accessible and meaningful to all participants. Despite all the preparation I had done, beginning this project still felt very much like diving into unknown waters and I quickly recognized that this research project was going to be an ongoing process of learning and unlearning. Jumping in first with these interviews granted me the opportunity to get my bearings and connect one-on-one with each participant. Engaging in these preliminary interviews also unsettled some assumptions I had made in the preparatory phase of this project. The following is an excerpt from one of my first field note entries:

> *These interviews have offered reminders about structure/format. It doesn't necessarily work/may not serve the group. Went into interviews with set questions – reminded that this is not the best way to connect/learn. Hoping that this project can be a good opportunity to relinquish control, to embrace uncertainty and everything/anything that might come up […] Remember: access may mean slowing down/being flexible, the best stuff will come out naturally without driving prompts, trust the process/trust the group/trust yourself […] Savour the uncertainty and get excited to witness the art emerge.*

While these interviews did not provide me with the kind of concrete data that I had imagined, they instead prompted me to actively reflect and reimagine my role as the researcher within the project's specific interabled and collaborative framework. I recognized that we were all bringing something unique to the table. For me, it was a scholarly knowledge base, theatre expertise (stage management, sound design, dramaturgy) and practical experience in supporting and facilitating programming for artists with disabilities. My collaborators were coming into this project not only with a range of creative talents (music, dance, creative writing) but also with their own 'disability expertise.'

As the instigator of this project, I cannot claim that this project was exclusively disability-led. However, each step of the process was disability-informed and embraced a cripistemological foundation that held space for meaningful artistic experimentation and collaborative creation. These moments of reflexivity and feelings of uncertainty would continue to ebb and flow over the next number of months – encouraging me to constantly reimagine and renegotiate our collective and interdependent artistic practice.

The First Meeting

Two weeks after completing the interviews, we scheduled a time for our first group meeting on Zoom. After imagining and preparing for months, I was excited (though slightly nervous) to get started and dive into this project headfirst. Upon opening the Zoom room and seeing the four boxes containing my collaborators pop up, I recall feeling more at ease and the excitement took over for my nerves. It was wonderful to see all four of the participants together – calling in from their bedrooms and living rooms across the Greater Toronto Area. Seeing them in their own spaces presented a kind of intimacy, but simultaneously served as a reminder of the physical distancing that we would have to maintain throughout this project.

As mentioned in the previous chapter, I had worked with all four of my collaborators before, but in varying capacities through programming offered at the MNJCC where I have worked as a performing arts instructor and workshop facilitator since early 2020. I was pleased to find that most of the participants also already knew each other, either through the JCC or through other disability-centred programming in Toronto. For example, Lindsey shared during this first meeting that a few days before, she had seen James at an online bingo event through the Down Syndrome Association of Toronto (DSAT). I believe the level of familiarity offered through these pre-existing relationships minimized barriers in developing our connection as collaborators and helped build rapport.

We began our first Zoom gathering with a check-in. This is something that I always try to make time for when teaching a class or workshop. I find that allowing time for people to ease into the space and share something, not only lets me know how everyone is feeling in the moment, but also instills the notion that their thoughts and feelings matter and that as a group we are interested and will hold that information. I adamantly resist the deep-seated theatre school or rehearsal hall mantra of "leave your shit at the door." This sentiment suggests that only the 'good' or 'healthy' parts of oneself are welcome in the space and that anything outside of a positive and eager mindset is unwelcome. This mentality is not only ableist and patriarchal, but also, as noted by Anishinaabe-South Asian playwright and performer Yolanda Bonnell, a harmful colonial practice. In a 2020 interview with Toronto theatre magazine *Intermission*, Bonnell states,

> This idea in the professional theatre industry world of leaving your shit at the door is just not real. It's not an actual thing you can do. And so, rather than that, let's talk about where you are at today. So that we are in space with each other… we can respect each other, and where our bodies are at. (Sur 2020)

It is important to recognize the diverse ways people may need to access and participate comfortably in a space. Traditional artistic spaces are commonly rigid in nature which could result in harm or exclusion for some artists. By considering creative spaces as both a physical and cultural environment, accommodations can be made to ensure the space is able to flex and shift to meet the needs of the group. This mindset is even more significant when working in spaces with members of the disability community. Accessibility, flexibility, and care are key to establishing an environment that is conducive to artistic collaborators who may have different and at times conflicting access needs.

In *Building Access: Universal Design and the Politics of Disability* (2017) Aimi Hamraie unpacks the fraught concept of ‘Universal Design,’ a term that frames itself as holistically accessible for everyone, but in doing so takes disability out of the conversations surrounding accessibility and design. Hamraie asserts that the claim of ‘accessible for everyone’ is misleading as it does not unpack what ‘everyone’ means in a world that does not value all bodies and minds equally. In response, she offers the term “access knowledge” which she presents as a vehicle for knowing and making access. Rather than working toward a universal design, access knowledge centres learning and understanding the myriad ways in which diverse bodyminds function in space. Ensuring that disabled voices are central in developing accessibility adaptations or accommodations is the only way to work toward designing environments that can be accessible to the greatest number of people regardless of whether they live with a disability, or not.

Comedian, writer, and mad activist Jan (JD) Derbyshire has also been vocal about the short comings of framing spaces as being inclusive and accessible for all. Derbyshire is often quoted for her assertation that when it comes to accessibility, ultimately “one size fits one” (2016, 265). This statement highlights that an environment (either social or physical) that might be accessible for one person, may not be accessible and comfortable for another regardless of a shared diagnosis or lived experience. Therefore, creating a space that is universally inclusive and accessible is incredibly challenging and rare.

While keeping ‘one size fits one’ in mind and actively pursuing ‘access knowledge,’ I worked to remain cognizant and aware of how each of my collaborators were feeling at any given time – always striving to maintain the most accessible environment possible. A practice that was maintained throughout our creative process was a pre-session check-in, which gave us the opportunity to connect and allowed me to gauge how everyone was feeling at the start of our time together.

While I approached our first session with an open, flexible, and caring mindset full of positive intentions I cringe as I watch back our very first group check-in. Excited to jump into the project and to engage my collaborators in giving meaningful or constructive responses, my ask for this first group check-in was to share “one good thing from last week and something that was hard.” While I am sure that my past self was thinking that this was a holistic way to check-in, to determine if anyone was navigating any challenges that I should be aware of, I now feel deeply uncomfortable with having asked my collaborators to respond to this. Why did I feel the need to prompt in this way? What was I mining for with this prescriptive prompt? Was offering space to share *anything* not enough? In reflecting critically upon this choice, I believe this instance presented another moment of needing to unpack and renegotiate the dual roles that I held for this project. I was feeling pulled in one direction by my role as researcher with the desire to be efficient with my time and to gather information succinctly and pulled in an opposing direction by my role as artistic collaborator looking to meaningfully connect with members of the group by offering them a space to share their feelings and thoughts and to be heard. Navigating these two roles and finding ways to blend them and have them merge into one was something I quickly realized would be necessary in this performance ethnography project.

Watching back the video recordings from our seven months of group meetings, I note that this was the only time our check-ins were framed by the binary of good and bad. Moving forward, our check-ins were framed broadly, I encouraged each participant to offer a few moments that were significant to them from the week previous – no prescriptive prompting, no moment too big or too small. We began every weekly meeting right up until the day of our performance with a check-in. This ongoing and consistent practice allowed us all to ease into the space at our own pace, to share something meaningful and to be present in listening and responding to each other. These check-ins also carved out time in our collaborative process for building rapport and personal connection – presenting a weekly opportunity to celebrate each other's accomplishments or offer support during challenging times, to sing happy birthday or to hear about what people baked with their parents over the weekend. It also allowed us the opportunity to get to know each other as individuals with hobbies, jobs, and passions outside of the project, which I believe fostered a strong foundation for us to come together as an ensemble and to create a piece of theatre that grew from a place of meaningful connection and lived experience.

Ensemble Agreement

Another practice that I brought to this project from my previous work as a drama instructor was the idea of a 'community agreement,' or in this case, what we called an 'ensemble agreement.' The use of community agreements for meetings or collaborative spaces are quite commonplace and I have found collectively crafting such an agreement to be a particularly valuable practice in my work with neurodivergent artists as a vehicle for accountability and keeping everyone on the same page. Our ensemble agreement was to be a living document that could be added to or adjusted at any time, leaving space for feelings and comfort levels to shift and change over the course of the project.

I began our process of collectively creating this agreement by asking the group if anyone knew what an ensemble was. Most shook their heads no, but Lindsey raised her and offered, "I think […] musicals have it?" Exactly! I went on to explain the concept of an ensemble as a group of people working together, like a team or a cast. I continued and suggested that together *we* were becoming an ensemble and that this agreement was not intended to be a list of rules, but rather a list of things that we would all agree on about how we would like to work together as a group over the next seven months.

Together we began crafting our agreement, beginning with some basics:

1. Be on time.
2. Support one another – be patient, encourage each other, be a team.
3. Take turns/raise your hand.

The last time that I had created an agreement in a class with neurodivergent artists, I offered the idea of 'advocating for what you need' which led to a more in-depth discussion about advocacy for people with disabilities on a macro level, as well as what it could look like on a more micro level for our class. I presented this as our potential fourth agreement item and asked our emerging ensemble if anyone knew what the word 'advocate' means. Most of the group shook their heads, but Joey's hand went up. He clearly articulated, "I know this one because I've personally worked on this a lot in my life… in my teens and stuff, and even now. I'm much better at it. So basically, what advocate means [is] speaking up for yourself and things like what you need."

I nodded affirmatively and then offered some specific examples that may be relevant within the circumstances of our online meetings. The first example was bathroom breaks – telling us that you need to step away for a moment. The next example I presented stemmed from a previous experience that I had with James while teaching an online improv class that he was a part of the year prior. During a particular activity, I asked James to provide the group with a prompt to help facilitate the next part of the game we were playing. He paused in thought and after a couple moments of silence said, “I’m just going to take my time.” Crip time in action. James articulated his need to ‘bend the clock’ (to use Kafer’s term) in a way that would work best for him. This moment for me as a facilitator was and continues to be incredibly impactful – he not only advocated for the time he needed to get to get his thoughts together, but in this moment, he also demonstrated for his peers what an act of self-advocacy looks like.

I reminded James of this moment and told him that it was one of the things I enjoyed most about working with him – that he is always willing to speak up and advocate for the time he needs. I am unsure whether he remembered this moment, as it just seems so natural for him, but it is an anecdote from my practice that I hold onto, as it keeps me accountable to have patience for my collaborators as well as myself. We continued along this line of self-advocacy, brainstorming other examples of advocating for what you need including asking people to slow down their speech, to repeat or clarify what they had said, etc. After our collective discussion on what advocacy might look like within the parameters of our online collaboration we added it to our list,

4. Advocate for what you need.

James suggested our fifth agreement item:

5. No swearing.

The 6th item came from Catherine:

6. Helping each other.

When I asked what ‘helping each other’ might look like, Catherine expanded on her point, “well, that is what friends are for.” She went on to explain that she sometimes needs help with her stutter. When prompted for further elaboration, she explained that she may need help with her speech because of her stutter and may also need support to keep calm when she stutters and gets flustered or frustrated with herself – another moment of self-advocacy.

Joey had a suggestion for number seven. He recognized that at times he finds it easy to get distracted by his phone during online meetings and suggested that we all try to stay focussed and present during our short time together each week. Everyone agreed and we added:

7. Focus on the group.

Catherine then offered another, "be confident." I recognized the value of Catherine's sentiment but noted for the group that it can be hard to feel confident *all* the time. Catherine quickly responded with a cheeky smile, "not for me!" The group, appreciating Catherine's to-the-point response laughed knowingly – Catherine *is* incredibly confident, no one could argue with that. I suggested that this idea was great, and that Catherine could use her confidence to support and encourage others when they might be struggling. She agreed and suggested a perfect reframing: "have courage." After allowing the others to chime in, we added our 8th agreement point:

8. Be brave (believe in yourself).

Lindsey added our 9th and final agreement item that had no dispute:

9. Be positive.

In line with the perspective that everyone is welcome to 'come as they are' to each meeting, there was never an expectation for unwavering positivity, but rather as a group, we determined that this was the goal or intention we wanted to set for our space.

Our ensemble agreement was complete. We determined together the practices that we wanted to uphold to ensure that we would be able to work together in ways that were conducive to the needs of the group and the interests of the project. In creating this agreement collaboratively, rather than me providing a set of rules or protocols for us all to follow, the ensemble was given space to offer agreement items that resonated and felt important to them and that they felt able to uphold individually and collectively. Instilling this idea of ensemble into the foundation of our work together proved meaningful not only in developing a collaborative and interdependent creation process, but also as a means of making ourselves accountable to one another. This notion of ensemble remained significant throughout our entire process – it informed the performers' camaraderie, the ways we learned to how to best support one another and our shared ability to connect and feel comfortable being silly and playful. The ways in which I conceived of our ensemble resonates with Suzi Gablick's concept of 'radical relatedness.' Radical relatedness as a practice of collaboration and relation building "calls for a priority valuation of intersubjective coexistence with others, the environment, the community and the world. It challenges us to move beyond an isolated modernist paradigm and to shift toward an interrelational attunement of mutual respect and care" (Bickel et al. 2011, 87). In this way, fostering an ensemble grounded by connection and radical relatedness meaningfully positioned us as collaborators to approach this potentially intimate project with care, empathy, and mutual respect.

Beyond the context of this research project, it became apparent within our first few Zoom meetings, the impact that being part of an ensemble was having on participants. I found that our weekly meetings and rehearsals were not only an occasion to explore and create new artistic work, but also presented opportunity for meaningful connection across distance; a chance to see friends, to socialize and catch up. The impact that the pandemic has had on members of the disability community has been well documented over the last few years. For individuals who had previously relied on in-person school, jobs, day programs, or other social programs for fulfilling and fostering meaningful community connections, mandatory social distancing and isolation had proven to be incredibly taxing (Schormans, et al. 2021). In a time of great uncertainty, remoteness, and seclusion, I believe that for our ensemble, our weekly meetings offered some respite and consistency. The development of this ensemble grounded in practices of interdependence, care and connection was truly the backbone of the new work yet to develop. With our ensemble established, committed, and connected, we were ready to begin exploring our stories.

Creative Explorations

I knew from the beginning of this process that exploring self-stories through a variety of mediums would be essential to maintaining accessibility as well as honouring the diverse creative interests of the ensemble. During our first meeting I explained to the ensemble what autobiography means, what it could look like in context of performance and that the theatre piece we were creating together would be based on *their* lived experience as people with disabilities. We established early on that our cumulative performance piece had the potential to take on a range of forms beyond more traditional storytelling including poetry, dance, and song. With freedom of form in mind, the first step in our process was to determine the topics and themes that the ensemble would be interested in exploring in this performance piece.

Methods of collectively creating a new piece of theatre can take a myriad of forms. During the years of physical distancing and working through screens, we were forced to reimagine the techniques and approaches that we may have once used for in-person collective creation to better suit our pandemic-informed reality. As this new work was going to be emerging from a place of autobiography, the process of gathering these self-stories began with ensemble members responding orally or through writing to prompts or questions about their lived experience. Our first writing activity was to create vision boards. For the purposes of this project, we expanded upon the traditional intention of a vision board used to highlight one's aspirations or goals for the future. Instead, we used the vision board format for ensemble members to reflect upon significant moments from their pasts, key moments from the present, as well as dreams for the future – creating an individual vision board for each. The goal with this activity was to see what came up for each person – what moments or experiences felt significant to them? What topics from their lived experience would they be interested in performing about? While this was our very first writing activity, many of the themes, topics, and ideas explored during this creative exploration were held onto and included in the final performance piece.

Another brainstorming activity that proved fruitful was imagining what one would want to speak about if invited to present a TED Talk.[18] To offer further context for ensemble members unfamiliar with the format of TED Talks, I played for the group a 2019 talk by Matthew Schwab titled, "How I Know Including People with Down Syndrome is a Good Thing." In his talk, Schwab, a young adult with Down syndrome, donning a t-shirt (his own merchandise) with the word 'INCLUDE' printed across his chest speaks passionately about the impact of employment for adults with Down syndrome and the value adults with Down syndrome can bring to the employment sector. An engaging and confident speaker, Schwab not only fosters a connection with the audience throughout his speech, but also offers statistics, cheekily sharing, "but don't take my word for it … there's even a study, so just google it!"[19] His words are well thought out

---

[18] As described on the TED Talks website, "TED is a non-profit devoted to spreading ideas, usually in the form of short, powerful talks (18 minutes or less). TED began in 1984 as a conference where Technology, Entertainment and Design converged, and today covers almost all topics — from science to business to global issues — in more than 100 languages. Meanwhile, independently run TEDx events help share ideas in communities around the world." (TED, n.d.)

[19] Assis, Vicente et al. "The value that employees with Down syndrome can add to organizations." *McKinsey & Company*, 1 March 2014, https://www.mckinsey.com/industries/public-and-social-sector/our-insights/the-value-that-employees-with-down-syndrome-can-add-to-organizations.

and clear, his approach charming while a little tongue in cheek, and the effect of his presentation impactful.

It was valuable for me to witness the ensemble's reactions to this talk. As I was sharing my screen through Zoom, I was able to simultaneously watch the video along with the ensemble, as well as witness their reactions. Throughout the nearly six-minute video, the ensemble showed deep engagement – listening closely, smiling, and laughing out loud at Schwab's jokes. When the video ended, I asked everyone what they thought. The first response came from Lindsey, "Wow!" James followed, "It was good!" We discussed what the talk was about and what Matthew was trying to explain to the audience – his Down syndrome and the value of inclusion. I then asked the group if *they* were going to give a TED Talk about something in their life, what might they want to speak about? This question prompted further consideration about the kinds of stories the ensemble members might want to explore in our performance. I then offered several follow up questions: What kinds of stories would you want to share with an audience? What do you want people to understand about you and your lived experience? What is something that you are an expert in that you could speak to an audience about?

Several ideas emerged in response to these questions including lived experience of Down syndrome, mental illness, the desire to get married, and wearing leg braces. From here, I asked each performer to write a brief "TED Talk" about their chosen topic. After agreeing on how much time would be needed to complete the exercise, the group took about fifteen minutes to work independently and write their talk. After each of the collaborators had completed their writing, I invited everyone to share. This sharing was incredibly informative and highlighted the diverse interests of the group. Catherine's approach to this writing prompt was less of a speech and more of a short theatrical monologue or poem. While this piece did not end up in the final production, it was an incredibly affective piece of writing to hear spoken aloud, so I am including it here:

I love helping you with your problems
And with your illness that you have
You can always lean on me
And I will be there for you

When I asked Catherine who she was thinking about or speaking to when she wrote this piece, inquiring if she perhaps had a friend in mind that she was writing to, she replied "everybody." Having only had the opportunity to work with Catherine in larger class settings, I am grateful this project allowed us to connect on a more personal level. As was the case with the rest of the ensemble members, over our months of working together, I was afforded the chance to learn not only about their interests and creative passions, but about values, personal priorities, histories, and goals.

For those who had written more of a traditional speech, I then posed an invitation to come up with a creative response to their TED Talk, suggesting that this could be done through poetry, music, dance, etc. Lindsey's initial piece of writing focused primarily on her experience as a woman living with Down syndrome, her love of family and her passion for independence. For her creative response to her written work, she opted to dance. Lindsey has been a dancer for many years. She is passionate about expressing herself through movement and this is evident when you watch her perform. She decided to perform a dance to the song "This is Me"[20] from the 2017 movie musical, *The Greatest Showman*. The music and lyrics of this song are powerful and affective and celebrate themes of self-love, acceptance, and thriving against the odds.

---

[20] 'This is Me' was written by Benj Pasek and Justin Paul and performed by Keala Settle and the ensemble of *The Greatest Showman*.

Lindsey performed this dance number for us on Zoom – entirely improvised and bursting with feeling. After Lindsey sat back down in front of her computer, took a sip of water, and caught her breath, I asked her if she could share what she was thinking about while she was dancing. She replied,

> I feel joy and happiness to be Down syndrome and also when some people are teasing you and bugging you a lot […] that's not good. But this song in *The Greatest Showman* has different sizes and also they are short or the female has a beard… Some people are teasing them, but that female actress sings that song in *The Greatest Showman*, "This is Me." This is me, I have Down syndrome. This is me, I am different. So it's that.

Catherine agreed, "Being different is a good thing!"

It was evident from Lindsey's performance and motivation, that this creative expression would have to be included in our final performance piece.

This TED Talk exploration also illuminated for me that while all members of the ensemble share a lived experience of disability, that their disabilities were not necessarily what they were most interested in speaking about. When I initially conceived of this project, I imagined that this work would be about four individuals preforming stories about their experiences of disability and reflecting on how they navigate the world as people who are neurodivergent. Over our first few weeks of working together however, it became abundantly clear to me that there was going to be so much more to explore in this project.

Over the next several months, we would continue to explore themes and ideas that felt meaningful and exciting to the performers. These discussions at times included themes around disability, but often not. It became clear that while disability was the lens through which these performers navigate their lived experience, it was not always the most significant part.

Throughout the process of devising and script development, I continued to encourage methods of expression and storytelling that deviated from more traditional methods of orating one's lived experience. Our performance piece therefore took the form of interwoven vignettes of solo and group performance which in addition to more traditional storytelling, also included poetry, song, and dance. In broadening our methods of storytelling, we were able to dismantle the idea of verbal communication or text-based storytelling as superior to non-verbal methods. Engaging with self-stories in new and creative ways allowed the ensemble members to communicate their stories via their chosen medium(s), celebrating their unique abilities, creative interests, and strengths.

Cripping the Script

I knew from the outset of our creation process (both from an ethnographic and creative standpoint) that I wanted the stories shared by performers to not only be based in their own lived experience, but also to sound like them – the way Joey, Lindsey, James and Catherine speak every day. As mentioned in the previous chapter, so often (auto)biographical work surrounding the lived experiences of neurodivergent individuals has been written by parents/caregivers, or filtered and/or edited by someone neurotypical to make it 'easier to understand' or more palatable for mainstream audiences. For this performance, I wanted to ensure that the words being spoken by the performers were truly their own. In line with Egan's understanding of the dialogical nature of autobiography, as a collaborator (or as she might label me, a biographer) I would at times offer dramaturgical suggestions and direction, but did little to no editing of the script text itself. As the intention of this work was to serve as a vehicle for these performers to share their personal stories, it was important to me that their voices in both spoken and written form remained authentic. I therefore made the intentional choice to embrace the ensemble's words exactly as they wrote or dictated them. With this, I did not correct grammar, nor did I put value on correct pronunciation or clear diction. As a performance piece centring autobiographical storytelling by neurodivergent artists, it was important to me, as both a neurotypical collaborator and researcher, that I not actively attempt to disguise or detach the disability experience from the stories being told. This choice was intended to not only maintain the authenticity of the work, but also to put the responsibility on the audience to do the work to understand ensemble members with non-traditional speaking patterns and to commit to their role as active and engaged witnesses of these often-overlooked stories.

As someone who has worked with the neurodivergent community for over a decade, the notion of "cleaning up" or clarifying language for neurodivergent artists is something that has been a sticking point for me or quite some time. A few years back, I began using the term 'able-washing'[21] for this exact issue. I conceive of able-washing as this idea that the disabled parts of an individual need to be hidden or fixed; edited or masked for mainstream palatability. I think of this practice particularly within the context of play scripts, performances, interviews, etc. In contrast to the idea of having another person speak for a disabled person, able-washing draws attention to the practice of neurotypical support personnel or collaborators feeling the need to rephrase, edit or clarify for their neurodivergent counterparts to make them 'easier to understand.' But why? For a community of people that have had to work to adapt, to try to fit in,

---

[21] The language of [blank]-washing has been used in a variety of contexts. For example, pinkwashing describes companies that present themselves as being invested in breast cancer research by promoting 'pink ribbon products' while simultaneously producing or promoting products that contain chemicals linked to the disease (Breast Cancer Action). Greenwashing is used to describe companies that perform or market themselves as being more eco-consciousness than they actually are. In line with disability discourse, Stacey Milbern (2020) writes about 'access washing' which explores how accessibility can at times be oppressive to multiply marginalized groups. An example of this could be implementing anti-homelessness/anti-encampment measures as a gesture of enhancing sidewalk accessibility without recognizing that many of those losing their public spaces are actually people living with disabilities. In a theatrical context, we often hear the language of white-washing which speaks to a lack of diversity in casting and on-stage representation. The term able-washing is best aligned with this final term, as it is used to erase difference or diversity of (dis)ability experience.

and to participate in a society that so often misunderstands and underestimates them, why in a creative process, should the ways in which they express themselves have to be washed of what makes their lived experience unique? Choosing to preserve and embrace each ensemble member's unique linguistic approach to telling their stories was, I believe, an essential choice in not only maintaining a disability-informed practice, but also in encouraging the artists to embrace self-representation by crafting their stories in their own words.

In-Between Moments

Our weekly sessions always proved to be generative and meaningful – the group showed up to each Zoom call engaged, eager to share and to collaborate. During one particularly intensive writing session, we reached a point where it was obvious that the group had 'tapped out.' They had given as much as they could that day – they were yawning, rubbing their eyes, and were clearly distracted – it was apparent to me that our work for the day was done. I suggested that instead of trying to push through to the end of our ninety minutes, that my collaborators could continue working on their in-progress writing on their own time and that we could review it together the following week. Before ending the Zoom call, I offered the option for us to move our bodies together until our scheduled time was up – "should we do a little two-minute dance party?" I asked.

"Yeah!" the group agreed, and I watched as their eyes lit up and their bodies re-engaged.

"Do we have any song requests?"

"My butt is hurting," Lindsey shared.

"Is that a song title?" I joked.

"No, it's not!" Lindsey threw her head back in laughter and Catherine squealed with amusement.

This exchange was typical of our dynamic, we joked together and laughed a lot. Joey and Catherine each chose a song, and together we danced. I watched as my collaborators regained energy through this offer to let loose. Each of us was dancing around alone in our rooms, but in that moment, there was a strong sense of togetherness as we watched one another dancing, laughing, and singing along. Joey even put on his colourful DJ lights, enhancing the party atmosphere as the final song came to an end and we all struck a final pose.

"Great work today, everyone! I'll see you all next week!"

We all said goodbye, Catherine said, "Au revoir!" and we concluded another session.

From here on, dancing and moving together became part of our collective creation practice. It served as a way for us to connect to one another, to our own bodies, to let go and be free. Recognizing the joy that the ensemble expressed through this moment, from then on, I concluded every devising session or rehearsal with an invitation to dance together.

I am grateful for the camaraderie that our ensemble was able to build so early in our collaborative process. Investing in the relationships we were forming with each other helped to establish a safe and creative space for authenticity and play to thrive. In addition to working toward an artistic product, it was important to me that our time together be fun, that ensemble members be excited to attend our weekly sessions, and that through being silly and playful together, feelings of hierarchy between me and the performers could be diminished. During our sessions, we laughed a lot, sometimes even to the point of tears. Aligned with the energy and desires of the group, this sense of fun and camaraderie that we built and maintained throughout the creative process not only helped to shape the content and overall aesthetic of the final production but also proved incredibly significant to understanding and thinking through our methods of creating an accessible interabled collaborative practice.

Integration and Politics of Access

In reflecting on the moment above where we cut our writing session short to dance, I can look back and recognize it as one of many enactments of crip time that occurred during this project. While crip time is often referenced in disability spaces as a practice of flexible scheduling or timelines, I would suggest that it can also serve as a lens through which disabled artists and their collaborators can approach their creative practice. Alison Kafer (2013) writes in detail about the more expansive impact of crip time:

> Crip time is flex time not just expanded but exploded; it requires reimagining our notions of what can and should happen in time, or recognizing how expectations of 'how long things take' are based on very particular minds and bodies. We can then understand the flexibility of crip time as being not only an accommodation to those who need 'more' time but also, and perhaps especially, a challenge to normative and normalizing expectations of pace and scheduling. Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds. (27)

While crip time is often used by those with physical disabilities or chronic illness as a means of navigating the temporal expectations of daily life, there are scholars that are working to expand its definition to be more applicable to the diverse bodyminds that make up the disability community. As author Jenny Odell writes in her book *Saving Time: Discovering a Life Beyond the Clock* (2023), "Besides offering a different set of values, crip time also offers an intuitive way to see time as a social fabric, in part because it flies in the face of dominant liberal concepts of independence, freedom, and dignity" (239). Odell's articulation of time as social fabric resonates deeply with how I feel the ensemble and I navigated our work together.

While discussions around crip time typically focus on “bending the clock” to allow more time if needed, this sole understanding of crip time is not always conducive to the needs of every disabled person. For example, many people who are neurodivergent benefit from developing and sticking to a schedule. In contrast to the standard understanding of crip time where start or end times can be flexible, for some, ending on time may be an important access measure to minimize feelings of anxiety or stress. During our time working together, I joked that Lindsey was my timekeeper. She would often send me private messages in the Zoom chat giving me an incremental countdown of how many minutes were left before our scheduled end of session – ten minutes left, eight minutes left, five, four, three, two. This was Lindsey’s way of expressing to me that keeping to a schedule is something that is important to her. A gesture that may have initially seemed like an eagerness to get off the call, I reframed for myself to be a demonstration of Lindsey advocating for what she needed. In this way, our crip time took on two contrasting forms. There were moments in our process when we embraced flexibility and the bendability of time and others when we worked within more conventional parameters of timelines and schedule.

Exploring further the idea of diverse disability-informed temporalities, I am drawn to Sarah E. Stevens’s writing on ‘care time’ which she describes as “the liminal place between crip time and abled time” (2018). In her article, “Care Time” Stevens describes her experience of existing in two different timelines – one in her role as a professor and scholar and the other as a caregiver to her disabled husband. She describes this movement between temporalities as “a complex, unpredictable dance” (Stevens 2018). For Stevens, care time means focussing on the present and being attuned to what is required moment to moment. In some circumstances, a rigidity of schedule might be necessary and in others flexibility and adjusted expectations might be required. Shifting how we think about disability-informed temporalities from strictly a place of access and accommodation to that of care allows timelines to adapt and shift day-to-day, moment-to-moment to best serve all involved.

This decision to put a hold on writing and instead dance together could have felt unproductive or irrelevant to our work, but in fact as an act of care, it was incredibly generative and meaningful for this project. For me, embracing more of a care time framework allowed us to find an accessible balance for everyone. Through taking our time in the creation process, we still pushed against the neoliberal pressures for timely production, but in response to the specific needs of the group, we also upheld a respect for schedules and working only within our allotted time together.

In addition to the integration of accessibility and flexibility in our collaborative creation process, it was important to me that we work to provide access to our audience as well. The first scene of *Our Stories* introduces the performers to the audience through direct address, offering what Jenn Stephenson refers to as a "mini autobiographical portrait" (2019, 71). These introductions welcome the audience into the world of the performance and gives them a sense of each performer before hearing any of their stories. This introductory scene begins with each performer introducing themselves by name, stating their age at the time of the performance, their favourite colour, hobbies, how they would describe themselves and how they would describe the ensemble.

I recognized in the process of crafting this container for the performers to introduce themselves that this structure of self-introduction (described in greater detail in the next chapter) would also lend itself well to providing visual descriptions as an accessibility feature for blind and low vision audience members. [22] As someone who has worked with members of the blind and low vision community for several years, it felt important to include physical descriptions of each performer in our script. I also recognized this as an opportunity to teach the ensemble about visual descriptions – to explain what they are, who they are for, and why they are important. I explained, "A visual description is what you might use to let somebody who can't see know what you look like […] So if there are people who come to our show, there's a lot of storytelling, so lots of auditory [information] – things people can listen to. We want people to have a sense of who you are as performers. So, in the introductions we are going to add in visual descriptions." I then offered an example of what this might look like by sharing a visual description of myself. The ensemble was entirely on board and with minimal support was able to articulate their own descriptions which I transcribed into our script.

> Lindsey: I am a lady with Down syndrome. I have white skin, brown eyes and long brown hair with bangs. I am wearing a hairband and also have glasses.
>
> James: I am a man with Down syndrome. I have light skin, with blue eyes and short light brown hair.
>
> Joey: I am a young man, with light skin, with dark brown hair and hazel eyes.
> Catherine: I am a lady with fair skin and blue eyes and Irish brown hair like Yentl.[23] Also, I have Down syndrome.

---

[22] Visual descriptions are used as a method of enhancing access for members of the blind and low vision community. When people introduce themselves at the beginning of a meeting or presentation, sighted people have access to a lot of visual information about the person without it having to be explicitly defined (VocalEyes, 2021). People who are blind or experience limited vision, therefore, are excluded from this information. Offering visual descriptions is a practice of describing some basic physical characteristics about oneself to enhance access for those who are not engaging with these presentations through sight.

[23] Catherine has a deep fondness of Barbra Streisand and a particular love of her 1983 film, *Yentl*. In this film, the title character cuts her hair short and disguises herself as a boy so that she can have access to her chosen education path. Catherine has aimed to emulate this short haircut for herself.

In the current moment, there are discussions taking place within the audio description (AD) community (both by providers and users) regarding how best to describe race, gender, and disability in ways that are accurate, relevant, and respectful of the performers (Hutchinson et al.). In 2022, VocalEyes, a UK-based organization that works to enhance access to arts and culture for blind and low vision community members partnered with blind scholar and professor Hannah Thompson from Royal Holloway (University of London) on a project titled Inclusive Description for Equality and Access (IDEA).[24] This project consisted of a series of workshops and events "to explore how AD can address diversity in inclusive and ethical ways" as well as offering practical resources for audio describers and theatres. In a video created about the project, Vicky Ackroyd, a VocalEyes describer shared the following,

> Many audio describers look a little bit like me. So white, middle aged, female […] There's sometimes some difficulty and some challenge around describing somebody who might look different to me. Because I might get anxious, or I might be worried that I'm going to be… say something offensive, get something wrong…

In the same video, Thompson addresses this concern directly, asserting that "if [audio describers] don't have the words or they don't feel confident, they tend just to not mention anything and that is in itself unethical because it means that difference is erased." This stress or uncertainty of 'getting something wrong' that both Ackroyd and Thompson speak about leads to the point that it is ultimately best practice for audio describers to connect with the actors and consult on how they would like to be described.

---

[24] IDEA was intended to extend and expand upon a project from 2020 called Describing Diversity. The report from this project offers an extensive look into discussions and recommended practices in describing race, gender, disability etc. when providing audio description for live theatre. The full report can be found on the VocalEyes website under 'Research': https://vocaleyes.co.uk/research/.

Our Stories is billed as an autobiographical theatre piece by neurodivergent artists – indicating that all ensemble members experience some kind of cognitive disability. In our initial discussion about how to describe oneself, I suggested to the group that if they wanted to note their disability in their description as something they would want blind and low vision audience members to know about them, that they could do that. While many cognitive disability diagnoses do not have physical traits attributed to them, others like Down syndrome do. As three of the four *Our Stories* ensemble members have Down syndrome, they possess phenotypes or physical characteristics that make their disability identifiable to sighted people. At a time when conversations about the importance of diverse representation on stage are plentiful, being aware of moments when this kind of representation is taking place is important and this information should be made equally accessible to members of the blind and low vision community.

As both a director and collaborator of this piece, choosing to incorporate something as simple as physical descriptions demonstrated the importance of considering accessibility in devising new work. In taking the time to explain what these descriptions are and why we should include them, the performers were given the chance to reconsider how they think about providing accessibility for others and to actively contribute to enhancing the accessibility of their performance. Accessibility for the performers as well as for the anticipated audience of this work deeply informed the way that the final version of this piece was constructed and produced.

Recording and Editing

The process of generating content for the final performance concluded faster than anticipated. We had our first group meeting on February 2, 2021 and had script completed by May 18. We then began the process of rehearsing. I recognized very early on in our process that performing this work live and online was, for several reasons, not going to work for us. Potential issues including inconsistent internet connections, navigating muting and unmuting, challenges with memorization, and lack of in-person support solidified for me the need to pre-record this work. By creating a piece of theatre that would be pre-recorded and shared asynchronously, we would be affording ourselves the opportunity to play with and incorporate certain production features that would not have been possible (or at least as seamless) if we were going to perform the piece live over Zoom.

The recording process was a practice of trial and error for me as collaborator/dramaturge. As the performers were not expected to have their lines memorized, we aimed to record the scenes in ways that allowed performers to read their lines off their computer screens, tablets, or printed scripts while also maintaining a level of performativity and engagement with our imagined audience. A challenge that we encountered with the choice to have the performers read their lines, rather than attempt to memorize them, was the way that their gaze would often be pulled from the camera. For those who were working with printed scripts or had their script on a separate screen or external device (e.g. iPad), it proved particularly challenging for them to look at their lines, absorb them and then look to the camera to recite them. To disguise the fact that the performers were reading lines, we tried a couple of different techniques – some more successful than others. We first tried having me share my screen with the script until I remembered that my screen would be recorded along with the performers' videos. We also tried having the performers repeat their lines after me – knowing that I would have to edit myself out of the final recording. The most successful technique that we discovered and implemented to support the performers' ability to maintain eye contact with the camera while reading their lines was through line-feeding via the Zoom chat. This technique served as a kind of makeshift teleprompter, allowing the performers to read their lines but to also keep their gaze in line with the camera. Overall, this strategy proved to be very successful and took some of the pressure off the performers in how they would read and perform at the same time (more on this in Chapter 3).

As highlighted previously, dancing together was a significant aspect of our collaborative practice. Recognizing this, I suggested that we use the recordings of our weekly 'dance parties' as transitions in between the scripted vignettes. Not only would these transitions provide flow within the piece, but including these recordings would bring to the fore elements of our creative process; giving the audience the opportunity to witness these moments of play and connection that occurred 'behind the scenes.' Given the nature of the vignettes, these dance transitions also ended up being the only moments in the piece that had the full ensemble (including me) on screen at the same time highlighting the ways that we were able to meaningfully connect without ever being in the same physical space.

We recorded the entire piece over three months. After each week's recording session, I would spend the rest of that week editing the freshly recorded pieces together. During the following week's session, I would share the edits with the ensemble to ensure they were pleased with how the piece was looking and sounding. It was important to me that they felt happy with their work and proud of what was going to be shared. One of the first scenes that was recorded was Lindsey's dance number – the one she improvised in response to her TED Talk. This scene featured Lindsey dancing to one of her favourite songs with a recorded voice over of her speaking about what the song means to her (this is discussed in more detail in Chapter 3). This was one of the first vignettes that I had to edit together, and I worked to perfectly time Lindsey's voiceover in between the lyrics of the song. I was eager to get her reaction and to hear the responses from the rest of the ensemble. As I played the edited piece for the ensemble during our next meeting, I watched them as they experienced the video – leaning in, listening, and watching closely. Toward the end, Lindsey (watching her own performance) began dancing, smiling, and singing along. When the piece finished, James was the first to speak up,

"Wow! That's amazing!"

I then asked Lindsey what she thought. Beaming with her face in her hands either in shock or awe shared,

"Wow! I can't believe I watched myself […] It's really cool when I did the sound over" – referring to her recorded voiceover.

I explained that I would be doing some more minor tweaks to the audio levels to make sure that we could hear her voice more clearly over the music and asked if that sounded ok to her. She agreed. I told Lindsey,

"I'm glad that you're happy with it!"

"I'm so happy with it!" she quickly replied.

This process of recording, editing, and sharing continued right up until our last group session, three days before the final screening.

For me personally, the process of editing this piece was simultaneously challenging and grounding. I had to learn to use a video editing software which I had no previous experience with while maintaining a mindfulness around how my editing choices could impact and potentially alter the overall aesthetic and experience of the work. Due to the nature of our performance being pre-recorded for online sharing, there were elements of candidness captured during the recording process that felt important to preserve in the final edit of the work. For example, some of the performers at times have difficulties with their speech – stutters, repetition, slower pacing, or challenges with articulation. While these features of their speech could have been edited out or their number of lines reduced or shortened to present a more smooth or normative way of performing text, it was important for me to preserve the unique intricacies of their speech.

During the recording process, it became clear to me that spending time working on speech patterns or diction would not serve the performers or the final product. Instead, I embraced their unique and natural ways of speaking and performing, which in some ways made the final product feel more real and personal – bringing us as close to liveness as we could be. As with the process of not editing the performers' language choices or grammatical inconsistencies in the written script, I applied the same perspective to the video editing. As outlined in more depth in Chapter 1, neurodivergent individuals and more specifically those identified as having intellectual or developmental disabilities have often been spoken about or spoken for by caregivers. In this project, I wanted to create a space where these four performers could speak for themselves, in their own words. This choice for me went beyond maintaining a sense of 'realness,' and rather aimed to put value on their individual voices and unique choice of language in sharing their stories without imposing a neurotypical idealized version of language onto them. Ultimately, I wanted the final product to sound like the performers, and working to minimize aspects of their voices by clarifying or correcting them would go against the intentions of this project.

While I was constantly checking in and sharing my edits and video construction with the ensemble, the one aspect of the editing process that I navigated independently was incorporating open captions into the video. My intention with including captions was primarily about making our work accessible for any d/Deaf or hard-of-hearing audience members, while recognizing that individuals outside of this community also benefit from the inclusion of closed captioning. Through the process of listening back to the audio of our work and editing in the closed captions, I realized that these captions would also enhance access or clarity for audience members who might struggle to understand the unique speech patterns of some of the performers. When I first began meeting with the ensemble, there were times where even I struggled to understand what was being said, but through our seven months of working together, I became more attuned to some of their speech patterns and my ability to follow their lines of thought improved. Recognizing that many audience members would be hearing the performers' voices for the first time, the decision to include captions added an extra element that could be beneficial to anyone experiencing the work.

I also chose to caption the piece myself, instead of outsourcing the work to an external company. This allowed for more flexibility and a reimagining of traditional captioning practices to better serve the goals of the project. Traditional closed captioning follows a somewhat standardized format for film and TV. This formatting style indicates how many words should appear on the screen at a time, how sentences should be broken up, how the captions align with the characters speaking, etc. (Making Accessible Media). As I researched and familiarized myself with industry standards for captioning, I felt that captioning our work in this traditional way would not serve the piece or reflect the performers' unique paces and patterns of speech. With this realization, there were two main choices that I made in reimagining and adapting the integration of captions for our video:

The first was that I would caption the performers' words exactly as they were said. This choice connects back to my decision to not edit the performers words or "fix" sentence structure in the script, but to ensure that the text remained true to the performers and how they speak. The captions, therefore, would have to reflect that – if a word choice was perhaps out of place or spoken in a grammatically incorrect tense, that was reflected in the captions as that was what was spoken by the performers in the recording and would therefore be heard by hearing audience members. I intentionally did not use the captions to correct or clarify what was being said, but to be an authentic reflection of the auditory elements of the work including speech, sound, and music.

The other intentional choice I made in captioning the piece was related to the pace at which the words would appear. Traditionally, captions appear as full sentences on screen, or the sentences are broken up into multi-word, line-long captions. This method of captioning however was not going to be conducive for our project. Catherine, for example, has a stutter and speaks at a slower pace so that she can get her words out more clearly. Captioning in full sentences would show the audience what Catherine was going to say before she had finished speaking. I did not want to the audience to feel that they were waiting for her to get her words out, as they would already know what she was planning to say via the captions on screen. Additionally, this pace of captioning (if following traditional practices) would not match the audio or visuals of Catherine speaking.

With this realization, I made the decision to caption the words in time with the performers' pace of speaking. This approach to captioning language is reminiscent of surtitling[25] or supertitling for opera, where the pacing of the translated text must align with the music being sung. Adopting this approach for *Our Stories*, unintentional though it may have been at the time, embraced the musicality of non-normative speech patterns.

This meant that occasionally the captions would appear on screen as only one or two words at a time. While this is not a traditional method of captioning, it was a more authentic

---

[25] SURTITLES™ were developed by the Canadian Opera Company in the early 1980s. As described on their website, "SURTITLES™ projections are a capsulized translation of an opera's libretto, projected on a screen hung from the proscenium arch of the stage during a live performance."

representation of the speech patterns of these specific performers, giving audiences who could not hear their voices the opportunity to still have a sense of how they speak and communicate. The process of recording and editing this work was at times arduous (mainly due to my lack of previous experience with the editing software), but well worth every minute. The ensemble was fully invested in this project and committed to presenting something that we could all feel proud of. I am grateful for the ways that this project prompted me to pause, reflect, reimagine and rework traditional methods of recording and editing, and in doing so, we were able to create a performance that we thought was truly representative of the *Our Stories* ensemble.

More Than Marketing

Despite making the decision to pre-record and share *Our Stories* asynchronously on Zoom, I still wanted this presentation to feel special for the performers. I decided to put some thought and resources into creating a show poster – something we could use to market the show but could also be an object of significance for the performers, a kind of added formality to our digital performance.

When initially conceiving of what the poster might look like, I knew that I wanted to include the performers' headshots. As the stories being told would be autobiographical, it only made sense that a representation of their physical presence be included. Rather than using photographs, I wanted to contract a disabled artist to illustrate the ensemble's headshots, transforming them into something more animated. In discussing this idea with the ensemble, they were all excited about the idea of having their faces on a show poster. At this point, I had a local disabled artist in mind and shared some examples of their work with the ensemble. I shared their Instagram page with the ensemble, highlighting some examples of what their animated headshots might look like. The responses were lukewarm and I could sense hesitation.

The consensus was that they wanted to look less “cartoon-like” and more realistic. With this feedback in mind, I reached out to Cristal Buemi. Cristal is a disabled visual artist and animator with whom I had worked on a film project in 2020. I explained the project to Cristal, why I thought having a poster would be significant, and the aesthetic that we were thinking for these animated headshots. During our conversation about style and form, Cristal suggested that we could also make a trailer for the show. Cristal specializes in stop-motion animation and explained how she could use a technique called rotoscoping to transform a video of our group dancing together into a line-drawn moving animation. This excited me! Trailers have become a mainstream marketing tool in theatre and this seemed like another opportunity to really celebrate this new work. As someone who does not identify as a visual artist, I put my trust in Cristal despite not having an entirely clear idea of what I was signing up for.

After a couple of weeks, the headshots were done. Visually, they appeared so simple – drawn with grey pencil, and yet captured each ensemble member perfectly. At the end of our next rehearsal, I shared the images with the ensemble. Before sharing my screen with the illustrated portraits, we counted down, “three, two, one!”

Joey: Oh my gosh!

Lindsey: Wow! That’s me!

As the ensemble members all moved their faces closer to their respective screens to get a better look, I zoomed in one each individual photo so that they could see the detail of each portrait. Upon looking at his image, James shared “It’s like a movie!”

After going through each portrait, I asked the others what they thought.

Joey: Very nice!

James: I love it!

Catherine: I love it!

Lindsey: I have lots of hair! (Noting that her hair was much longer in the reference photo that was shared than it was at the time of us meeting).

I explained that I would be using these images in the creation of the poster for our screening. I then shared that we were also in the process of putting together a trailer and explained the concept that Cristal and I had discussed with the rotoscope technique. The group giggled with excitement.

Over the next week, I created a digital poster which included the performers' new hand drawn headshots and names as well as the date and time of the screening and a link to register. I shared the poster draft with the ensemble during our next meeting, welcoming thoughts and feedback. James offered two big thumbs up. Lindsey was excited to see that her portrait was at the top and exclaimed,

"I am first! […] That's very cool!"

I zoomed in on the top part of the poster and read out loud for the group the tagline below the *Our Stories* title: "A presentation of autobiographical stories by disabled adults exploring past, present, and future." I told the group that I wanted to check in with them about the tagline and asked how it sounded to them. "Love that!" said Lindsey. I asked, "is everyone okay with that?" I wanted to ensure that everyone felt good about the language being used to advertise the project. The response was a resounding yes – I was thrilled that the group was happy with what I had put together and that they felt well-represented.

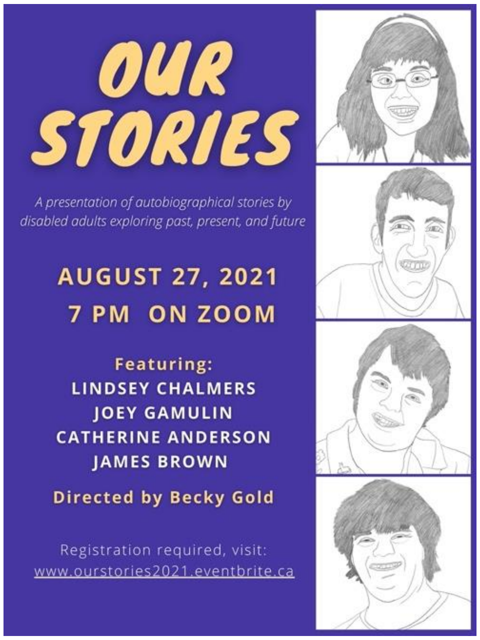


Figure 2: Our Stories poster designed by Becky Gold. Illustrated portraits by Cristal Buemi.

With the poster approved, we began inviting friends and family – sharing the poster via email and social media. I created an event on Eventbrite where interested audience members could register to receive the Zoom link. Our online performance would be free to attend, but this registration process would allow me to keep an eye on numbers and avoid the possibility of Zoom bombing during the show.

Shortly after sharing the poster online, I received the rotoscoped dancing clip from Cristal. In our email exchange about the trailer, Cristal informed me that she had hand-drawn ninety-six individual frames to capture the group's dancing in stop-motion. Before sharing the trailer with the ensemble, I added some title cards to introduce the piece, used the portraits from the poster to highlight the performers and included the registration info for the screening. Before finalizing and posting the trailer online, I shared a draft with the ensemble. Again, the responses were very positive.

"Wow!" said Catherine.

"I love it – so good!" said James.

At this point, we were about three weeks away from the screening date and our ensemble continued to gather weekly. Together, we would review my edits of the recorded scenes, the ensemble would offer notes, and we would re-record anything that we didn't feel was working. During these meetings, I would also update the group on audience registration for our online presentation. I was expecting a small handful of close family and friends to register to attend, and so I was pleasantly surprised to see the registration numbers continue to rise in the weeks leading up to the digital screening. By the day of our screening, we had eighty individuals registered for our event – a clear demonstration that these stories are ones that an audience would want to hear.

Conclusion

Thinking back to January 2021, at the outset of this project, I remember that my impulse was to plan and be as prepared as possible as the 'leader' of the group. I wanted our time together to be as productive as possible and to gather as much from each meeting as I could. As a result of working with and getting to know the four amazingly unique ensemble members, my perspective changed. I began reimagining this project not in terms of productivity and checking boxes, but rather in terms of meaningful moments and heartfelt conversations. Our collaborative process, while often playful and engaging, was not without moments of struggle. Given the nature of working collaboratively online and calling in from various locations, we encountered the occasional connection issue, glitchy video or frozen face. Together we enacted mutual support and collective care during times when performers experienced moments of stress or anxiety – always rallying for each other and wishing we could be together in person. Over our months of getting to know each other, telling stories, dancing, and creating, this piece of theatre evolved into so much more than I think any of us had imagined. It represented a consistent and safe place to gather, to celebrate each other, to connect and share. The value of our time together, not only for the performers, but also for me, as someone who was navigating feelings of isolation during the pandemic, was truly immeasurable. The process of creating *Our Stories* was so multi-faceted and dynamic, and I believe this made for a piece of performance that welcomed audiences in and highlighted the value of connection across distance – both in terms of physical space and in differences of lived experience. After seven months of weekly online gatherings, brainstorming ideas, co-writing a script, rehearsing, and editing it all together, we were finally ready to share our work with an audience.

CHAPTER 3: THE PERFORMANCE

Highlighting the relationship between the content of the stories and how they were executed in the performance, this chapter analyzes themes of representation, autonomy, and authorship in works by neurodivergent artists. This chapter begins with the night of the invited screening and moves into an analysis of the written work, acting as a companion to the script and recorded piece. It offers context to the creative decisions made and illuminates the conversations that helped to shape those decisions. I conclude the chapter with excerpts from a post-show question-and-answer period with the online audience as well as my own critical reflections of my role within the work, highlighting some best practices developed that will shape my future collaborations with neurodivergent artists.

Show Day

On the day of the screening, the ensemble and I gathered for one last check-in before opening the virtual house to audience members. The energy of the group felt full of excitement but simultaneously at ease. I explained how the evening would unfold – we would let the audience in to the Zoom room, I would give a brief introduction to the piece, we would watch it, take a quick break, and then have a question-and-answer period with the audience. I then shared with the ensemble how proud I was of them, of what we had created together, and joked (kind of) that my one goal for the evening was not to cry. We were ready – we had worked together for months and created something that we all truly believed in. It was finally time to share *Our Stories*.

Shortly before our scheduled 7pm start time, I began letting audience members into the Zoom room. Without any prompting from me, the ensemble began greeting their friends and family – beaming with excitement and gratitude for their support and attendance. Once everyone had received a virtual wave and greeting, we were ready to begin. I unmuted myself and thanked everyone for joining us. I briefly explained the project, the intention of the work and how our collective process had unfolded. With that, we were ready to hit play and begin the screening of *Our Stories*. I remember my heart racing, feeling anxious about whether Zoom would cooperate or if there would be any lagging or glitches with the video. I took a deep breath and pressed play. After letting in a couple of late-comers, I sat quietly with my partner Ryan and watched the piece that the ensemble and I had spent months devising, recording, and editing – the reach of *Our Stories* now extending beyond the eyes and ears of our group of five to over sixty audience members.

The experience of presenting a new work on Zoom is peculiar for many reasons. Most poignant in my experience with *Our Stories*, is the incommunicability of the audience. As audience members were asked to mute their audio and turn off their videos, I was unable to see or hear their reactions or responses as they witnessed the work, missing entirely the simple act of the audience 'audiencing,' succinctly described by Matthew Reason (2019) as "the doing of spectating." To witness audiencing is to perceive audience members "reflecting, engaging and responding to their own experience" (100). Due to the nature of our online presentation, I was unable to experience this process that often feels so essential to live performance. I was unable to hear laughter, witness smiling, the wiping away of tears, movements of discomfort, or whispers between those seated together. Instead, I had to sit in the discomfort of not knowing for the thirty-minute duration of the work and allow my own confidence in what we had created to sustain me.

To offer more in-depth engagement with the specific themes explored in *Our Stories*, the next section of this chapter presents a kind of script analysis. This analysis illuminates some of the behind-the-scenes aspects of the writing and creation process and offers further context to *how* certain creative decisions were made. In addition to my own researcher reflections, I have also included excerpts and quotes from the performers as a means of bringing their voices forward and in dialogue with my own in this critical engagement.

Script Analysis

Introductions

The introductory scene of *Our Stories* was crafted to give the performers an opportunity to introduce themselves to the audience. We set the stage through direct address, with the aim to acknowledge the audience as witness and invite them in. This introduction was created after we had already devised most of the individual vignettes and were beginning the process of assembling everything into a script. To structure our introduction, I devised a list of questions or fill-in-the-blanks for the performers to answer – presenting the audience with information about the performers that you might gather upon meeting someone for the first time.

The questions provided were as follows:

> Name:
> [Visual description]
> The year is 2021 and I am:
> My favourite colour is:
> In my spare time I like to:
> I would describe myself in three words as:
> Together we are:

Once each performer had answered the introduction questions, which I transcribed during one of our weekly meetings, I recorded their answers. I then edited their responses together so that each question presented was answered in succession– bringing their individual voices together in conversation with one another. The format worked as follows:

Catherine: My favourite colour is pink.

Lindsey: Red

James: Yellow

Joey: Blue

Not only did this scene offer space for the ensemble to introduce themselves to the audience, but it also situated the piece within a specific moment in time. By explicitly drawing attention to the fact that these recordings were made in the year 2021, we were prefacing the reality of the work as ephemeral. As Paul John Eakin (1985) notes, “autobiographical truth is not a fixed but evolving content in an intricate process of self-discovery and self-creation” (3). Drawing from Eakin’s work, one can understand that while often pulling from personal histories, autobiographical works can hold varying degrees of truth as time moves on. In this case, beginning the performance with these introductions highlights the work as an ‘autobiography of the moment’ recognizing that the ensemble members’ favourite colours or hobbies could change in the weeks, months, years to follow. With this understanding, I suggest that *Our Stories* as a piece of recorded performance also functions as an archive or time capsule, preserving in some way an insight into who these four ensemble members were in 2021during a time of individual and collective uncertainty shaped by a global pandemic.

As this dissertation has emerged from a place of interdisciplinarity, I want to acknowledge the slipperiness of viewing this work as an archive of a past moment in time. I recognize that from an ethnographic standpoint there is a complex history of positioning one’s interlocutors as ‘relics of the past’ without acknowledging the ongoing evolution of self and culture (Kazubowski-Houston 2010, 21). However, in my understanding of this work as an archive I perceive the autobiographical elements of this work strictly as truths of the moment, not necessarily indefinite truths. I recognize and celebrate the fact that identities can shift overtime with "new versions of the past evolv[ing] to meet the constantly changing requirements of the self in each successive present" (Eakin 1985, 36). There is value in preserving and being able to return to collective and recorded moments from one's past. As Carol Martin suggests, "Archiving 'real life' – what people do and say – keeps alive as primary data what previously had a life only as a memory" (Martin 2012, 175). Additionally, *Our Stories* could also be read as a vehicle for archiving futures. This reframes the concept of archive as not only looking backward, but also as a means of preserving imaginings and desires for one's life yet to happen.

Pain and Gain

During my initial interview with Joey, he shared with me that he had a physical disability. The online program where I had first met Joey is "designed for young adults 18-35 with ASD and/or developmental disabilities" (Miles Nadal JCC) and so while I knew that he was neurodivergent based on his enrollment in the program, having only ever seen him from the chest up in a tiny square on Zoom, I was less aware of his physical and sensory disabilities. During this one-on-one meeting, Joey described his "physical challenges" as well as his experience of low vision. He also shared with me an event from his childhood that has been particularly significant to him: travelling to Montreal as a child for a spinal fusion surgery. He was able to recount the details of his trip vividly – how excited he felt about travelling by train, the subsequent anxiety of being in the hospital, and the recovery process which led to him no longer having to wear a back brace. In his words,

"That chapter was over!"

During the TED Talk writing exercise described in Chapter 2, when I asked each ensemble member what they would like to share if given the opportunity to give a TED Talk as part of our performance, Joey returned to the topic of his physical disability and more specifically his experience of "wearing braces on [his] body." He was also interested in talking about his experience as a DJ. In our initial writing session for this exercise, Joey wrote a short piece about starting his DJ career and what it is like being a DJ with a disability. The next week however, he returned with a new piece, focused more on his experience with disability in general, touching on his diagnoses, surgeries, and wearing braces.

The piece he crafted is below:

> *Hello! My name is Joey. I am 22 years old; I live in Toronto and oh yeah, I have a disability, in fact, I have multiple disabilities as you can see from my leg braces. Growing up with a disability wasn't smooth sailing. It was difficult having to wear braces and go through surgeries to correct my conditions. The hardest part of dealing with my disability was wearing a back brace. I had a condition called Kyphosis and Scoliosis that affected my spine. This condition affected my life the most because wearing a back brace was very uncomfortable and sometimes it would hurt. Whenever the brace needed to be adjusted, I would go to the Shriners hospital in Montreal. They also made my back braces because they did a better job at crafting and designing it while at Sick Kids, they were unsuccessful. The only fun part about all this was taking the train to Montreal. I would go about at least once a year to get my back brace checked. I would have to wear my back brace for several years until I was about 13. That's when it was decided I would have a spinal fusion to correct my Kyphosis and Scoliosis. I never had a major surgery like that before and I was quite scared. I remember clutching on to my iPad for comfort. Yes, I*

> *know… anything in the world and I was clutching my iPad. I was in the hospital for about a month recovering. I had to learn how to sit up, walk and move again. In a matter of no time, I was running marathons! Just kidding. My life improved drastically, and I have the wonderful surgeons and nurses to thank for helping me.*

One week before the screening of *Our Stories*, as we prepared to record the above monologue during one of our Tuesday sessions, Joey shared that he no longer felt good about the piece he had written and was feeling stressed about the recording process. His anxiety about this was palpable. Through the screen I could see that his breathing was becoming heavy, his head in his hands. I did my best to calm him down from afar – to reassure him that this was okay, we would figure it out. I let a few days pass after our group meeting and sent him an email, inviting him to a one-on-one meeting to chat about how we might reimagine the piece in a way that felt good to him. In the email I wrote,

> *I don't want you to feel any stress about this, but I do want to make sure that you have another piece in the show that you can feel proud of and excited to share! If that's the TED Talk, let's figure out a way to make it work, if it's something else, we can chat about that too. At the end of the day, this show is about YOUR stories – whatever you want to share.*

He replied quickly, eager to chat and we met on Zoom later that day. Before diving into a full reworking of his original piece, I wanted to better understand what it was about the piece he was feeling "iffy" about. He explained that he was happy with the content of the piece he had written but was feeling embarrassed about having to look down to read his lines. As Joey experiences low vision, in order to read he has to be quite close to the written material either on paper or screen. The length of the monologue and the challenge of reading the lines was proving stressful for him. While I assured Joey that he did not have to be embarrassed about this, I also presented the option of reworking the existing text into a shorter piece while emphasizing to him that I would be happy with whatever he wanted to do. I offered that turning his longer TED Talk monologue into a poem might be a good way to work with shorter lines, and therefore be easier for him to recite. “I actually like that idea!” he replied enthusiastically.

With a new vision for his work, we planned to meet again the next day to workshop his monologue into a short poem. Before logging off the call, Joey reflected, “a little revision… that’s ok, that happens in theatre.” I agreed adding, “and sometimes it happens at the very last second. It’s totally normal!” Happy with this new plan, Joey’s anxiety about this last-minute change was dissolving.

The next afternoon, we met again on Zoom. I transcribed as Joey dictated, pulling out portions of his original text and rearticulating them more concisely and with poetic nuance. After about forty-five minutes, Joey had transformed his original monologue into a twelve-line poem which he titled, “Pain and Gain.” He was able to maintain the sentiment of the original work (including the humour) but had transformed it into something that he felt more comfortable presenting:

Summer of 2012
On the train to Montréal
Going to have surgery
No more need for a back brace
Leaving that behind me
Having family by my side
Through the pain, I gained a couple of inches and iron

I had to learn how to sit up, walk and move again
9 years later, telling my story
Sharing my experience with friends
Now, I can run marathons…
Just kidding!

After we finished recording this new, shorter piece, I watched the tension disappear from Joey's shoulders as he let out a big sigh. "I feel a lot better about this," he said. I was thrilled – with less than six days before our presentation date, this was the final piece to be recorded. The text length felt more manageable and Joey was able to preserve the moments of humour that he valued so much in his original writing. In allowing space for flexibility and last-minute accommodation, we were able to ensure that this piece, which holds such deep personal significance for Joey, felt like something he was excited to share.

This experience exemplified the importance of pushing back against strict and rigid schedules in service of care. Joey and I were able to come up with a solution that put his feelings above our shared timeline in finalizing this work, bridging practices of crip time (by embracing the concept of a flexible timeline) with cripistemological approaches to collaboration. Ultimately, the result was not only a more poetic interpretation of Joey's story, but one that honoured his needs and abilities at the time.

Down Syndrome Poems

It was unplanned that three of the four ensemble members cast in *Our Stories* have Down syndrome. The casting for this project was based on the pool of individuals already involved in JCC programming and then narrowed down by those interested in participating in this project. During our initial conversations, Lindsey, James, and Catherine had all mentioned Down syndrome as something that they would be interested in exploring as part of this performance project. As its own topic however, Down syndrome sat on the back burner for some time – overshadowed by other themes and subjects. With that said, Lindsey included Down syndrome and her pride in her diagnosis in several pieces that she had written – demonstrating that for her, Down syndrome is a significant aspect of her identity and deeply informs her sense of self. For James and Catherine, Down syndrome was less of a focus and more so a secondary theme that would arise occasionally in conjunction with other topics of interest. For example, in a conversation about who he would invite to his wedding, James spoke at length about the Down syndrome community, naming specific friends (including Lindsey and Catherine) and highlighting the importance of different programs that he has taken part in as a member of the Down syndrome community in Toronto. Catherine, in response to Lindsey sharing a piece about Down syndrome, spoke about her own Down syndrome being “pure and delicate” – a poetic statement that she had also shared during our initial interview. It became apparent over our months of working together that although these three artists share a diagnosis, their relationships to and understandings of what it means to have Down syndrome are varied and unique.

During one session, Lindsey had already completed her writing response and so I invited her to write another poem while the other participants were completing their work. To help avoid the overwhelm of having infinite options, I offered a couple of writing prompts for her to choose from: her love of dancing or her experience as a woman living with Down syndrome. She chose the latter and wrote:

My Down syndrome life is outstanding
I do love being down syndrome is a blessing
I can do everything I want to do of my own!

I won award for dancing and my break-dancing
Thank you to my parents to raise me perfect daughter I am
To have outstanding life with my amazing disability

While this writing prompt was intended to serve more as an exploratory exercise than an intentional written piece for the show, Lindsey's writing prompted an idea to also invite James and Catherine to speak individually about their own experiences and feelings about Down syndrome. In bringing their three unique voices together, I hoped that this scene would showcase for the audience that despite all three of them sharing a diagnosis that they are still individuals with diverse interests, personalities, and relationships to their disability. By presenting what Dierdre Heddon (2008) refers to as a "multiplicity of truths" these three pieces work in a reciprocal dialogue while actively resisting an essentialized Down syndrome identity. This concept of an essentialized identity is further problematized by Owen Barden and Steven J. Walden (2021) in their co-written chapter titled "The Metanarrative of Learning Disability." Barden and Walden describe a metanarrative as "a cloud of a story that displaces personal narratives and knowledges with overarching ones derived from dominant, etic discourses" (1). This concept of the metanarrative can be problematic in reinforcing certain stereotypes or perpetuating the idea that because you may know one person with a certain lived experience, that you can now understand or know about everyone with that same experience. Barden and Walden discuss and challenge the metanarratives of learning disability which ultimately positions neurodivergent people as Other and perpetuates both distanciation and marginalization of this community (2021, 78). In some ways, these Down syndrome poems and *Our Stories* as a whole could be read as a response to, and reframing of, these projected metanarratives.

During the following week’s session, I invited James and Catherine into a Zoom breakout room, so that I could support them in crafting their own poems to be performed in conversation with Lindsey’s. I suggested that they speak their poems aloud and that I would transcribe them. We began with Catherine and as a prompt, I reminded her of her previous sharing about her Down syndrome being “pure and delicate.” I emphasized my love for this statement, and suggested she begin there. “Ah, yes!” she replied enthusiastically. Speaking aloud for me to transcribe, Catherine infused her poem with affective language, references to Shakespeare and her own unique lived experience:

My Down syndrome is pure and delicate
Emotional like Juliet
Some people with Down syndrome can have mental illnesses
Sometimes it’s hard – stuttering
My Down syndrome makes me feel tender
Sweet
Fairer than a red rose

After months of working with James, I recognized that he benefits from very clear and concise instructions. I explained that we were going to write six lines about having Down syndrome. He quickly began speaking about his desire to get married to his girlfriend. I gently reminded him that we already had two scenes about him proposing and getting married (discussed in the following section) and so we were trying something new here. I reframed, “how does Down syndrome make you feel?” I asked him about the Down syndrome community and what he would want others to know about people with Down syndrome. He spoke his answers aloud into the following poem:

My Down syndrome makes me feel happy
Community – lots of good people
A lot of kids have Down syndrome
Down syndrome is going to be nice people and good people
Sweet
Sweetheart

Both Catherine and James created unique pieces of writing about how they think about Down syndrome; how it makes them feel and how it informs their relationship to others both in and outside of the Down syndrome community.

While I have briefly outlined some reasons as to why these poems added value to the overall narrative of *Our Stories* above, I will elaborate further on the choice to include a diagnosis-specific piece within the work while addressing why I believe the benefits of this topic outweigh the risks. While I had not planned to structure an entire scene around Down syndrome, the significance of this lived experience for the three ensemble members who share this diagnosis was apparent (often coming up in conversation) and called for an intentional and specific moment of self-representation. Rather than viewing these Down syndrome poems as pathologizing or medicalizing the artistic work of these artists, their writing demonstrated a pride in their Down syndrome diagnosis and an opportunity for self-reflection and representation. Through being invited to share their own thoughts and feelings about their experience of Down syndrome, Lindsey, Catherine and James spoke to and perhaps against an audience's potential preconceived notions or assumptions about their experience.

While public displays of self-advocacy and self-representation for neurodivergent adults, including those with Down syndrome, have become more common in recent years, there is a long history in which this community has been spoken for or about – most often by parents and caregivers who only “experience disability by proxy” (Hadley 2020). Author Sarah Kanake, who has a brother with Down syndrome, problematizes this history of neurodivergent people being spoken for within the specific context of what she terms ‘the Down Syndrome novel.’ Putting an emphasis on parent/child relations over inclusive representations of Down syndrome, Kanake suggests that these texts can present a very limited view of the Down syndrome experience, particularly as they relate to agency, narrative inclusion, and adulthood (2018, 62). While parent/caregiver understandings of Down syndrome may be limited in that they are unable to speak to first-hand experience, I suggest that their experience is not less valuable, but rather offers a different perspective. Again, this brings into the conversation the idea of speaking with rather than for others. Literature that is so deeply enmeshed in a specific life experience, but written from a second-hand perspective can potentially be walking that fine line.

With a focus on literary representations, Kanake (2016) also notes that Down syndrome is at times used as a plot device, a challenge or obstacle for the nondisabled narrator or protagonist to accept or overcome. In working toward more inclusive representation, it is no longer enough for a character with Down syndrome to be included in media. Kanake argues for more dynamic and complex representation for people with Down syndrome, “The marginalisation of the character with Down syndrome in narrative fiction is not [just] about appearing in a novel, but having a voice and agency within the narrative.”

Moving from the page to the (digital) stage, *Our Stories* invited these artists with Down syndrome to not only write about their own experience, but to also speak for themselves, to share in their own voices about their community, their passions and dreams for the future. As evidenced by these three unique poems, Lindsey, Catherine and James each have a distinct relationship to their diagnosis. They make it clear that to them, Down syndrome is more than a diagnosis or label – it brings people together in community, creates opportunity for meaningful self-discovery and can be seen as a beautiful thing to be celebrated rather than ignored or overcome.

James's Dream Wedding

Throughout our time working and collaborating on this project, James regularly expressed interest in talking and writing about marrying his girlfriend. Early in our process of devising the individual vignettes for the performance, I suggested that perhaps we could create a scene in which James could describe his "dream wedding." In response, I watched James's face light up and asked him how he felt about this idea. He quickly replied,

"I feel happy!"

His eyes shrinking into squints as a large smile grew across his face. As a jumping off point for engaging with this topic in more depth, I asked James some basic questions about what he wanted to wear on this wedding day, where the wedding would be, what would the cake look like? etc. He enthusiastically and confidently answered each of my questions, demonstrating (or at least convincing me) that he had spent a lot of time thinking about these things already. During this initial brainstorming phase, we also looked at photos online that represented the answers James was giving – allowing him to pick the images that he was drawn to and felt best reflected his wants and wishes for his dream wedding.

In recognizing James's comfort with working collaboratively in a more structured question-and-answer format, I began thinking about how we might construct a scene for exploring James's dream wedding that would be more accessible and interesting than him simply reciting a list of his wants. I suggested that James and Joey might collaborate on this piece – Joey could play a wedding planner, and James, the eager and impressively decisive client. With this structure, Joey's character could prompt James to describe each element of how he imagined his wedding and assist with the flow of the scene.

With this new scene structure in mind, I booked an additional session outside of our weekly scheduled meeting to work with James and Joey on their script. I shared with Joey the original list of questions that I had asked James in order to guide the conversation. Joey completely embraced the role of charismatic wedding planner which offered the perfect container for James to simply answer the questions he was being asked. With the guiding questions in hand, Joey and James began playing out their scene – Joey asking questions (with some additional improvised flair) and James giving his responses. As the conversation unfolded, I transcribed the lines as they were being spoken, jumping in at times to remind James about a thought he had shared earlier or to clarify what was being asked. With the script completed, we were ready to record the next week.

As briefly referenced in Chapter 2, one of the techniques that proved helpful for the ensemble in the recording process was for me to copy and paste their lines into the Zoom chat. This offered the performers some freedom in not having to look down at their paper copies of the script, and instead utilize this makeshift teleprompter and read their lines as they appeared in time with the flow of the scene. James found this prompting technique particularly helpful and requested that we use it for recording this scene. This approach allowed him to stay present in the scene and to not have to worry about losing his spot in the script.

During the process of recording this scene, we also found ways of making the process more accessible and comfortable for Joey. As noted earlier in this chapter, Joey experiences low vision which requires him to physically get quite close to whatever he is reading. For this scene, Joey was reading his lines from his tablet which was resting on his desk. This resulted in him having to look down often. When we first started recording, Joey took out a pen from his desk, “I’m pretending to write here, so it looks like I’m in an office.” Joey’s choice for his character to have a pen in hand gave me an idea. I suggested that he could be more dramatic with his pen, exaggerate the act of ‘writing notes’ which could disguise the fact that he was having to look down to read his script.

To further emphasize the idea that Joey’s character was looking down to take hand-written notes during this wedding consultation with James, I also incorporated this into the final edit of the recording. After watching several YouTube tutorials and a lot of trial and error, I was able to create the illusion of a notebook with ‘live’ handwriting that would appear below James and Joey’s Zoom squares. This not only added an additional aesthetic element to the scene, but also provided a visual interpretation of James’s answers as Joey’s character took them in. Having very little experience with video editing, this effect felt like a triumph, and I was happy to contribute creatively to the scene in a way that further brought the moment to life.

Figure 3 Screen shot from James's Dream Wedding scene in Our Stories. James describes wanting a single layer cake for his wedding as Joey the wedding planner 'takes notes'.

This scene, aptly referred to in the script as “Dream Wedding” was the only scene in the show with dialogue and direct interaction with another ensemble member. Though James and Joey were playing characters that in the world of the scene had never met before, their chemistry and comfort in working together was a joy to watch. I really value the ways that they supported each other in the development, rehearsal and recording of this scene and believe that their interdependent relationship shone through in the final product.

The scene, while generally upbeat in nature, with humorous moments including James’s desire to serve sushi and pizza at his wedding and his uncertainty about hiring Joey as the DJ for his special day, concludes in a way that may call for further engagement and explanation. After James answers questions including “how many people are you going to have at the wedding?” and “what kind of music would you like?” the scene concludes with the following:

Joey: So, tell me… last question – why is getting married important to you?

James: That’s a good question!

While this may seem like an odd way to conclude this scene – with a big question left unanswered – it was reflective of James’s mindset in that moment, and I would argue creates space for further consideration about the institution of marriage as it applies (or does not) for adults diagnosed with an ‘intellectual disability.’[26]

“That’s a good question” was a common response from James in most conversations. This statement would often preface a lengthy response, though often not explicitly answering the

---

[26] According to Article 23 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), “The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouse is recognized.” However, there is a significant lack of literature and resources around marriage for those with intellectual disabilities in Canada. While people with Down syndrome can get married, there may be increased barriers regarding perceived capacity in the eyes of the law and/or their legal guardians.

question that was being asked. During our initial discussion about his dream wedding, when I had asked James why getting married is important to him, he replied with "that's a good question" and proceeded to talk about how he imagined marrying his girlfriend, but never quite giving a clear answer about *why* the act of marriage felt important to him. I reflected on this initial response, which could be read as James responding with some tongue in cheek humour, but simultaneously highlights the simple fact that this is not a question that would commonly be asked of nondisabled adults. With this, using James's go-to response of "that's a good question" without providing any further elaboration felt like an invitation for the audience to reflect upon their own biases or understandings about relationships for neurodivergent adults as well as their right to marry.

In further unpacking the weight of this question and answer, I must also be self-reflexive about my decision to ask this question of James in the first place. While I had a genuine curiosity at the time of first making this inquiry, by the time we were ready to write and record this scene, I had worked closely with James for several months, heard his stories and his passion for love and his desire to have a wedding, I no longer felt that I needed an answer. It is crystal clear that James has a deep love for his girlfriend, and if marriage is something that they both want to pursue, as he says, "when [they're] older," then that's a beautiful thing that requires no further justification to anyone.

This scene put into practice the idea of autobiographical performance not only as a means of reflecting on the past but also as a way of imagining and articulating futures differently (Stephenson 2013). Through James's in-depth discussion with Joey about his dream wedding, he is performing a moment in life still to happen, yet performed into existence through this project.

Confidence in Me

In my preliminary interview for this project with Catherine, I asked her what she would want others to know about her and her life as someone living with Down syndrome. “Well,” she replied,

“It’s like *The Sound of Music* song, which is called ‘Confidence in Me.’ [27]

Having not watched *The Sound of Music* in some time, I had to look up this song as it was clear that this musical number held great significance for Catherine. She confirmed that *The Sound of Music* was her favourite musical and shared,

“I always wanted to be Maria since I was nine.”

Catherine and confidence might as well be synonyms. She always presents as self-assured and is not afraid to speak up and share her mind. Highlighting confidence as a key aspect of her personality and her desire for others to also feel confident, she wrote and recited the following poem which was included in the final production. The piece was underscored by an instrumental recording of “I Have Confidence” from *The Sound of Music:*

Confidence is freedom
I am an Angel
Special
Relieved
Confidence is caring
I am Friendly
Equal and
Romantic

---

[27] The true title of this song is ‘I Have Confidence.’ However, “I have confidence in me” is a recurring line throughout the song.

Confidence is Tender

I am lovable,

Classic and romantic

When I put on The Sound of Music

It makes me feel free

Like a bird in the blue sky

Catherine is someone who truly exudes confidence. Throughout our time working together, I witnessed how her self-assured energy shone even brighter when singing a song that she loves – fully immersed in the lyrics and music, dancing like nobody (or everybody) is watching. Clearly influenced by her love of music and musical theatre, Catherine was adamant that she also wanted to sing a song as part of her contribution to this performance piece. To preface her vocal performance, I invited Catherine to share in writing why she loves singing. She wrote,

I was born to be a singer

Singing makes me feel love

When I sing I am an elected artist

It also helps me with my speech

I don't stutter when I sing

Because it makes my vocal words clear and soft

What I found particularly interesting about this poem, was the attention that Catherine gave to the fact that music has always been a part of her life, as well as the connections she drew between her experience with music and her disability, specifically her stutter. She recognizes and shares that she does not stutter when she sings and there appears to be a sense of pride for her in this. Throughout our time working together there were moments when Catherine would become frustrated with the ways that her stutter at times impeded her ability to make her point or, in slowing her down, meant that at times she would be spoken over or interrupted. This recognition of the freedom she feels in singing, making her words "clear and soft," highlights that for Catherine, her love of singing is multifaceted.

Due to the challenges of recording singing on Zoom, I coordinated with Catherine's parents to record her singing at home to ensure that the audio quality would be as clear as possible. The video included in the final production shows Catherine standing in front of her bed in her bedroom; a large *Dirty Dancing* film poster hanging on the wall behind her. She looks directly at the camera and sings along to "My Favourite Things" from *The Sound of Music*, smiling the whole way through. She does not miss a word and sings her heart out – holding the final note for its full length before taking a gentle bow.

The power and confidence that Catherine finds in her own voice, even though her vocal characteristics may be perceived as what Rosemarie Garland Thomson (1997) would call "non-normate," is truly wonderful to witness. While she is self-aware of the limitations of her speech, she owns it. Catherine presents confidence in taking the time she needs to get her words out and does not accept others speaking over her. This level of self-assuredness for disabled women has not historically been depicted on Western stages, though this is beginning to change. In challenging the trope of disability experience as one overshadowed by hardship and barriers, I suggest that both of Catherine's creative sharings shine a light on the beauty of disability in all its forms; shifting the focus from the perspective of overcoming challenges to celebrating the ways in which people with disabilities can thrive personally and creatively. Through the act of 'self-storying' Catherine performs this most powerful version of herself, one that takes control of her own narrative and how she wants to be perceived by others.

Both of Catherine's performance pieces in *Our Stories* are demonstrations of #DisabledJoy. #DisabledJoy began as a Twitter hashtag used by disabled writer, Andrew Farkash. In October 2018, Farkash tweeted "There's a common misconception that you can't be Disabled and happy. That you can't express joy, and if you do, you must not be hurting or Disabled anymore. I propose a new hashtag to empower us and show people otherwise: #DisabledJoy" (Russo 2018). Since the publishing of this first tweet, the hashtag has been shared thousands of times, with some referring to it not just as a viral sensation, but a movement that emphasizes that "being happy and being disabled are not mutually exclusive qualities" (Russo 2018). Through her performance, Catherine exemplifies the intention of this hashtag – that not every day is easy, but that she finds joy and confidence in herself, particularly when she sings.

This is Me

As discussed in the previous chapter, one of Lindsey's key scenes was her improvised dance performance to the song "This is Me" from *The Greatest Showman.* This dance piece emerged as a creative response to the TED Talk writing activity for which Lindsey wrote about her experience as a woman with Down syndrome. While Lindsey's dancing is undoubtedly powerful enough to stand on its own, I invited her to write a short piece about what she feels and thinks about while dancing to "This is Me" – illuminating her connection to the lyrics and sentiment of the song. To combine Lindsey's writing into her dance performance, I recorded her reading her reflective piece and embedded it into the audio track of the song – bringing her voice into conversation with the music and lyrics of the song that she was dancing to. Below is an excerpt from "This is Me" followed by Lindsey's writing which was deconstructed and integrated into the music that she was dancing to:

I am not a stranger to the dark

Hide away, they say

'Cause we don't want your broken parts

I've learned to be ashamed of all my scars

Run away, they say

No one'll love you as you are

But I won't let them break me down to dust

I know that there's a place for us

For we are glorious

When the sharpest words wanna cut me down

I'm gonna send a flood, gonna drown 'em out

I am brave, I am bruised

I am who I'm meant to be, this is me

Look out 'cause here I come

And I'm marching on to the beat I drum

I'm not scared to be seen

I make no apologies, this is me

- - -

When I am dancing to the song "This Is Me" from The Greatest Showman I am feeling happy! The song makes me feel brave and proud to have Down Syndrome. I am different but that doesn't mean I can't do hard things. "Look out cause here I come" makes me feel like I can do anything I want. I can follow my dreams of starting my own coffee shop and I am not scared to be seen as a person with disabilities. In fact, I am *proud to have Down Syndrome.*

This is Me!

"This is Me" in and of itself is an autobiographical statement. In the context of this song, it serves as a kind of war cry, an anthem against discrimination and oppression. Listening to Lindsey's voice in dialogue with the impactful lyrics and watching her interpret the song through movement made for a powerful concluding scene for *Our Stories*. In many ways, this final piece was not only an expression of Lindsey's perspective about her own experience with disability, but it also resonated with the other ensemble members, speaking to how each of them challenges expectations of neurodivergency through their own creative and personal accomplishments.

Finale

Our Stories ended with the ensemble members thanking their audience:

Lindsey: *Thank you for watching us.*

James: *Thank you for your patience.*

Catherine: *Thank you for listening to us*

Joey: *We thank you for experiencing…*

All: *Our Stories!*

The thank yous were followed by one last collective dance number, leading into the rolling credits. The final song, "Fight Song" by Rachel Platten (2015) was selected and agreed upon by all four ensemble members. The lyrics of this song seem incredibly relevant to the themes explored in the performance and worked well as final words to be heard by the audience. The following is an excerpt from the song:

And all those things I didn't say

Wrecking balls inside my brain

I will scream them loud tonight
Can you hear my voice this time?
This is my fight song
Take back my life song
Prove I'm alright song
My power's turned on
Starting right now I'll be strong
I'll play my fight song
And I don't really care if nobody else believes
'Cause I've still got a lot of fight left in me

"Fight Song" calls out to listeners, asking to be heard, similar in many ways to the message of "This is Me." As another example of autobiographically-informed lyrics, this song exemplifies self-advocacy and self-determination in the face of adversity. Though the implications of this song within the greater context of the project were never discussed, this choice of song to conclude the performance of *Our Stories* is poignant.

Audience Responses and Q&A

When the credits finished rolling, the audience unmuted their microphones and applauded the performers. We then took a short break so that everyone could get some water, use the bathroom, etc. before beginning the Q&A session. When we reconvened, I invited our audience to give another round of applause to the performers – they cheered aloud, applauding, with clapping hand emojis popping up in the corners of their Zoom boxes. We then began the question-and-answer period – inviting audience members to offer responses or ask questions of the ensemble by posting in the Zoom chat. As our performance presentation was pre-recorded, I wanted to ensure that there was an element of ‘liveness’ to this event. This post-show engagement afforded us the opportunity to share elements of our creative process with the audience, answer questions, as well as receive feedback or comments. For me, as a researcher, carving out time and space for audience engagement was also illuminating in understanding the impact of the work on this particular audience. What follows is a selection of questions that were asked and the ensemble’s responses to them.

How did you come up with the topics that you explored in the show?

Joey: Back in the early stages of this project, Becky had us each come up and write about past experiences and what we want to share and what we felt we needed to share with everyone about our journeys and ups and downs and… it just took off from there.

What was it like collaborating on Zoom, what did you like and not like?

Becky: For me, there were definitely challenges to working on Zoom - primarily not being about to move around space together. So, everything that we kind of created had to be done in a way that was kind of from the chest up and that's the way we found would work best for us. I just miss being in physical space with other people. Like I said earlier, I've never been in the same room as most of these lovely people, so, that was a bit of a challenge or something I wasn't a big fan of.

Lindsey: I like Zoom a lot and to get to know everyone in my friends on Zoom and also it is one thing I don't like the most is the WIFI connection at my cottage. I am so proud I went to my mom's best friend’s house to have better connection.

Becky: We had some trouble recording Lindsey because her cottage WIFI wasn't always strong - but we made it work, right Lindsey?

Lindsey: That's right, Becky!

Joey: I found working on Zoom was… well, not the same as working with you guys in person - I would have preferred that because honestly now it feels like some of you don't even exist. All I see is you on the screen, but you are real, but sometimes I feel like 'oh they're not real' or they're somewhere across the world but they're in Toronto. But you know, it's better than nothing, you know - at least I get to see them. Yeah, I enjoyed it.

Are you going to miss getting together on Tuesdays?

[responses given simultaneously]

Lindsey: Oh yes, of course!

Joey: Yes, definitely

Catherine: Yes

James: The same, everybody the same!

Joey: I think we can all agree on that.

Lindsey: I will miss excitement and fun with James and Catherine and Joey and also the amazing producer, Becky. Becky, you are so talented, and I will see you on Sunday for the cast party thing. And I should miss you to meet on Zoom every Tuesday. We had amazing moments together!

What would you normally begin our rehearsals with? Would you begin with a warmup, tell a story?

Joey: When we would log-on on Tuesday afternoons to the meeting, we'd share individually. Each of us have a moment to chat about our week, how we've been doing, what's new in our lives, and yeah, we'd just go from there - share with each other.

James: I agree with Joey - what he's saying.

Lindsey: I think we did a vocal warm up sometimes and also we […] always danced together.

Becky: So that was kind of the inspiration behind having those transitions was that we spent a lot of time dancing together as either a warmup or warm down for our meetings.

What feedback would the amazing performers like to give Becky about their experience?

Catherine: Well, I want to thank Becky… well, to make me feel like a star … and to make my dreams coming true to be an actress.

Becky: Thank you, Catherine. Does anyone else have feedback?

Lindsey: Becky is outstanding person because she's an amazing producer for this production we are doing today. And you taught me so well and you're a really good leader and teacher and also most important thing is like multitasking stuff [*laughter from* *the group*] and I do enjoy your energy and fun and most of all, to make me a better dancer and I want to say thank you to Becky to put this video together.

Becky: Thank you Lindsey. You did all the dancing by yourself, I didn't help you with any of your dancing!

James: I would say the same as well about Becky as she was saying about drama and Everyday Friends.[28]

Joey: Okay, well, since I'm the last one to speak here […] Okay Becky, um, as you know I love drama, I love acting, I have since high school and doing this whole thing here this show and stuff, kind of made me feel like I was back […] This has been kind of like a gift to me. Becky asked me to do this, and I was like 'yeah, I want to do this. This will be fun.' And Becky's awesome - she helped me stay calm when I was like nervous about something and saying 'it's ok don't worry, we'll try something new.' Like she always found new ways to solve a problem when it was a little tough. So, I just want to give props to Becky - great job, great job.

Lindsey: I will agree with Joey about that.

Catherine: And, me too… I have something to add. Becky is also kind and also thoughtful and she also cares about how we all feel inside and we all love her for it.

---

[28] Everyday Friends is a social group run out of the MNJCC. There is significant overlap between members of that group and those who attend my drama classes.

Becky: Thank you, Catherine. What was the one thing when we met earlier today that I said I didn't want to do tonight?

Joey: Cry.

Becky: You guys are not making it easy on me!

Lindsey: I want to say something to parents and families - thank you for watching us tonight and also you are an amazing group of people and … mostly thank you to my mom as well because she emailed a lot to Becky to make it happen for me and I will appreciate that so much and thank you for coming tonight.

James: Thank you to my girlfriend who came today - I love her so much.

Before ending the Zoom call, we gave the performers one final round of applause. I thanked our audience for attending and being present to witness and celebrate the work that had been created. The ensemble echoed my thanks, waved, and said goodbye.

Impact on the Audience

In reflecting upon the audience feedback and engagement, it is relevant to highlight that our audience was comprised primarily of friends and family; people with already established buy-in to the performers and/or the project as a whole. I can speculate how responses and questions may have differed from a more diverse public audience, perhaps less familiar with members of the neurodivergent community. As a community that is often infantilized, I have witnessed the way audience members often describe performances by artists with Down syndrome or other forms of cognitive disability as ‘sweet’ or ‘cute.’ Not only is this language disrespectful, particularly to adult performers, but it diminishes the artistic work as being substantial or complex. Further, there is significant discourse within disability arts communities that rejects the idea of disability art as inherently ‘inspirational’ or ‘educational’ – particularly in works that include autobiographical themes. *Our Stories* was not created as a tool to educate or inspire, but rather as a platform for the ensemble members to perform about and through their lived experience – “to talk back and talk otherwise” (Heddon 2008, 3). In the context of this project, despite working toward the creation of a final product, the process of exploration and creation felt more important than how the work would be perceived by an audience. Ultimately, the piece is reflective of the goals, interests, and aspirations of the ensemble. They created something that they felt proud to share.

After the conclusion of the Q&A and signing off from Zoom, I remember standing up from my desk and releasing a deep exhale of relief – this night was the culmination of seven months of creative collaboration, and just like that, it was over. My partner Ryan who was watching the Q&A in separate room came in with a bouquet of flowers and words of congratulations. He had seen me through all the ups and downs of this project, navigating the difficulties of collaborating through Zoom, problem solving with editing software and more. While I knew that the conclusion of this evening was an ending of sorts, I also recognized it as a significant benchmark in preparation for the work yet to come.

Unpacking my Role

The role of the ethnographer, particularly in performance ethnography is to work collaboratively and alongside one’s research participants. While this was the case in our creative process, I made the conscious choice to have a minimal visual presence within the final performance product aside from the dance vignettes which offered a behind-the-scenes look into our process and highlighted my involvement as active participant rather than outside observer. My intention from the outset of this project was to provide these four artists with a supportive container in which their stories could evolve and be shared in creative ways that felt meaningful to them. My lack of presence on screen was therefore not an attempt to minimize my role or influence on the project, but rather was an intentional choice to have the four neurodivergent ensemble members be the stars of the show – for their voices to stand on their own, without me taking up space.

Throughout the entire process of developing *Our Stories* with Joey, Catherine, James, and Lindsey, I worked to remain self-reflective and cognizant of my own positionality within the project, as well as my influence (whether intentional or not) on the ensemble and the work that they were creating. While *Our Stories* is a work of autobiography, the creation process could not have happened independently; rather the entire process was dialogical, collaborative, and interdependent. The stories emerged from conversations and explorations, from finding ways of relating to one another and recognizing how the performers exist in and are perceived by the outside world. I understood my role as carving out a space for these explorations to take place, and to offer support, guidance, and feedback throughout the creative process.

While the cast emphasized my role behind the scenes to our audience during the post-screening Q&A session, framing me as the leader under the labels of director or producer, I did not come into this process with a clear creative vision. Rather, I came into the *Our Stories* project with questions and an eagerness to explore and learn alongside the ensemble members. Over our seven months of working together I opened myself up to learning new methods for working collaboratively, particularly within an interabled group. I am so grateful for this collaborative and interdependent experience as it has had a significant impact on the development of my accessible creative practice. Some key takeaways from this experience regarding my own artistic practice within interabled collaboration include the need to resist ‘normative’ timelines and frameworks, prioritizing cripistemology and disability expertise at all stages, and embracing opportunities for creative problem solving.

As already discussed, crip time in its various forms offers new ways of thinking about progress and efficiency in working creatively within disability-centred spaces. For me, embracing ways of working that pushed against the confines of rigid timelines and allowed for emergent conversations and explorations proved incredibly valuable. In terms of the creation process for *Our Stories*, I worked to strike a balance between keeping to task and allowing our work together to be guided by the needs of the group, session to session and minute to minute. I found this looser approach to be challenging at first, as I was navigating each session with a specific plan in mind. After the first few weeks however, I recognized the restrictiveness of this approach and allowed myself to give up some of that control, creating space for us to collectively find collaborative flow.

The idea of embracing disability expertise and ways of knowing goes hand-in-hand with upholding crip time. For me, honouring disability expertise is imperative in interabled collaborations. While I can offer suggestions and support, each of my disabled collaborators is the expert of their own access needs and ways of working that make the most sense to them. Although I have been a practitioner working with neurodivergent artists for the past ten years, it is through respecting expertise of each new artist that I work with that makes this collaborative work meaningful. In being open to learning new ways of working and reimagining ways of adapting the more traditional approaches to creation, new methods and aesthetics can emerge.

Finally, one of the most exciting aspects of this collaborative process was exploring creative problem solving. Much of the problem solving for this project was the result of trial and error, but ultimately presented opportunity for innovative approaches to interabled collaboration. In Chapter 2, I mentioned how we utilized the zoom chat as a kind of teleprompter to assist with the performers ability to deliver their lines to the camera. This technique was not something that I had predetermined and developed as a strategy, but rather it emerged through our work together, as we experimented with different ways of reading lines (off paper, tablets, etc.) I view this discovery as a meaningful example of how interabled collaboration creates opportunities to work in new and innovative ways. My work with Lindsey, Catherine, Joey and James has informed how I aim to develop interdependent relations and navigate time and access in my creative practice. These strategies may not be universally applicable but can offer a meaningful starting point for determining new working practices in any future collaborations.

Reflecting One Year Later

Throughout writing this dissertation, I have watched our recorded Zoom meetings, performance video and recorded Q&A session several times; often noticing things that I had not perceived in the moment. As I rewatch the *Our Stories* performance video, I reflect with fondness about the time that the ensemble and I spent together on this project, an archive of a creative process conducted during a strange and unprecedented time. In watching the performance video with a keen eye, one can observe changes in haircuts, varied layers of clothing reflecting the changing of seasons, and a range of Zoom backdrops and locations (resulting at times in variable levels of video quality) in which the different scenes were filmed. These small observations not only highlight the passage of time, but also offer an intimate look into the spaces in which each of us spent our time during phases of pandemic-driven isolation.

I also appreciate how the energy and unique personality of each performer shines through. Even in this prerecorded, digital presentation, each ensemble member was able to take up space to speak for themselves, and share their past and present experiences, as well as their dreams for the future. As individual performers, they demonstrate the wonderful diversity of the neurodivergent experience, but as an ensemble, they highlight the power of community and friendship across shared experience. I find myself getting emotional each time I watch the performance video. I am so proud of each ensemble member and moved by their honesty, vulnerability, and their desire to share their victories, challenges and dreams through spoken word, song, and dance.

In thinking through the self-representation, self-advocacy and #DisabledJoy displayed throughout *Our Stories*, I would be remiss to not acknowledge more intentionally the significance of the ensemble writing and performing these stories in a Canadian context. As a country with a long history of institutionalization and forced sterilization for people with disabilities as well as the current discourse around the potential routinization of non-invasive prenatal testing (NIPT) and selective termination (Ravitsky et al. 2021),[29] the sharing of these stories by young adults with disabilities (in particular those with Down syndrome) demonstrating independence, well-developed personal relationships, professional goals, as well as disability pride is truly significant. In celebrating these stories and carving out space for this collaboratively created project to be shared in an artistic and scholarly context, one can envision

---

[29] The current discourse around NIPT in Canada and internationally is quite extensive. Recent studies bring into question the potential social, political and ethical implications of making these tests a routine practice of antenatal care (Perrot & Horn 2022; Ravitsky et al. 2021). NIPTs mainly target the detection of Down syndrome (Trisomy 21), Patau syndrome (Trisomy 13) and Edwards syndrome (Trisomy 18). The articles I reference bring up ethical concerns regarding the potential pressure for women to accept such testing if it becomes routine, the possible impact on the populations of people with disabilities (particularly Down syndrome) and how this could impact resources for individuals and families. These conversations of course are also navigating the importance of honouring women's reproductive and ultimate right to choose.

the potential of works like this to prompt new ways of thinking about disability futures in Canada and internationally.

Conclusion

There is something so emotional about closing a show – an experience many theatre practitioners have had. In a typical production, one may have spent three to four weeks with a cast during rehearsals and the run of the show, with no guarantee or obligation to maintain those relationships after closing night. While our 'show' was technically over as of the evening of August 27, 2021, it was important to me that the ensemble and I remain connected. Our group had spent seven months collaborating, consistently spending time together each week. To simply cut off these ties would not only be challenging for the performers, but for me as well. It was important to me to facilitate opportunities for continued connection over the coming months and to maintain relations with the participants who I had grown to consider both collaborators and friends. The final chapter outlines this continued relation-building and its significance within ethos of the project.

CHAPTER 4: CONTINUING CONNECTIONS AND FRIENDSHIP AS METHOD

This chapter explores what happened after the screening event concluded; after the project in many ways had been completed. In this chapter, I discuss my choice to continue spending time and fostering relations with the *Our Stories* ensemble. I will not be analyzing these gatherings as a form of research data, but instead aim to emphasize the significance of offering and maintaining relations with one's collaborators, particularly within the context of care-informed research practices, friendship as method, and the sociopolitical implications of public allyship and interabled relations.

The Cast Party

Our Stories was screened on a Friday evening, and I had organized with the ensemble members that we would get together for a cast party two days later, on the Sunday. During our final ensemble meeting before the screening, the cast expressed great excitement for this post-show gathering. In line with the goals of creating a show poster and trailer for our online screening, to celebrate the work, it felt important to offer the ensemble members the experience of having a post-show party. This cast party was also going to be the first time that our ensemble would be gathering in person, face-to-face, after seven months of online engagement.

As we were still in a time of recommended social distancing and masking indoors, it was imperative that we find a way to gather safely. We planned to meet for a picnic in High Park, a large park in the west-end of Toronto located right on the subway line, but unfortunately, the forecast was calling for rain. Rather than cancelling or trying to reschedule, I instead relocated our cast party to the front porch of my apartment building about fifteen minutes away.

With Ryan's help, I brought my IKEA kitchen table down from our apartment, covered it with a cheery orange tablecloth, set up several folding chairs and set out some snacks and drinks, paper plates and plastic cutlery along with a large bottle of hand sanitizer (truly an object of the time). After all the amazing work these performers had done, I wanted this cast party to really feel like a celebration, at least as much of a celebration as I could fit on my 6x10 front porch.

The first person to arrive was Joey. He arrived by taxi with his mother. He greeted me with a cheery, “Hi Becky!” and I watched as he gingerly yet eagerly stepped out of the cab and walked up the front steps of my house. It was amazing to finally meet him in person and I remember thinking that for someone with such a big personality, he was shorter than I had imagined. As he reached the porch, he took a quick look around and promptly picked a seat at the table. As any young man in his early twenties might, after a few minutes of chatting and settling in, he shooed his mother off to her own get together at a friend’s house around the corner.

Lindsey arrived next. Lindsey and I have known each other for a few years and had worked together prior to this project. However, after only seeing her online for many months, it was wonderful to experience her smile and the joy that radiates from her. She had just finished a shift at Starbucks and expressed as much excitement as I felt in finally getting to see Joey in person.

Next to arrive was James. He had walked up from the subway with his mom, wearing extra-large gaming headphones and carrying a large pot of yellow flowers. He walked up to the house and appeared a little bit overwhelmed in seeing me and the others in person after engaging through a screen for months. I came down from the porch, meeting him and his mom on the sidewalk. James was quiet, looking around and taking it all in. He then handed me the flowers and as I thanked him, he carefully walked up the front steps before joining his friends and taking a seat at the table.

As I was getting everyone settled in, pouring cups of water, and offering snacks, Catherine and her mom arrived. Catherine, like James, seemed a little bit astonished to see us all in person.

She joined us at the table, sitting between Joey and Lindsey and leaned over to give Lindsey a big hug. We were all met, settled, and sitting together at one table. When everyone had a drink in hand, Ryan made a toast - remarking on what a great job everyone did, offering recognition for the ensemble's hard work and how wonderful their performance was.

Over the next two hours, we just hung out. We discussed how family and friends felt about the screening, we played games, sang along to music and of course, laughed a lot. Sitting together with my collaborators was truly magical - to be in physical space with them, sharing food and reflecting on our work together. As the end of our cast party was drawing near, I handed each ensemble member a box containing a token of my appreciation for all their incredible work. I gifted each of them a mug that I had customized with an image from the show poster on one side and their digitally illustrated headshots on the other. Before all going our separate ways, we took a group photo - a document of our work together as collaborators, as creative colleagues, and friends bound by a piece of art that we created together.

Figure 4: Photo of Becky and the Our Stories ensemble after their cast party. They stand front of a hedge on a residential street, each ensemble member holds up their custom mug.

The cast party was a wonderful experience. It was great to connect and spend time together in the same physical space, no longer separated by screens and distance. There is something so profound about creating a piece of theatre with others – it binds you together through your shared creative and at times vulnerable experience. We will forever be connected by *Our Stories*, our seven months of collective creative work and time spent together. While the cast party was a celebration of the cumulation of months of creative work and the sharing of a final product, it also marked a moment of transition. Our relationships with each other were shifting from that of creative collaborators bound by a project and timeline, to one of friendship.

Continuing the Connection

For the next number of months, I continued to plan monthly gatherings for the ensemble. We found opportunities to come together either online or in person – always being mindful of the current health and safety guidelines in place. Continuing to foster connection and relationships with one's 'research participants' may be perceived as out of the ordinary or unconventional in some research contexts, however, it felt imperative to the ethos of this project that these relationships did not dissolve after our final presentation. I wanted to offer occasions for the five of us to stay in touch and maintain some of the connection that we had built during the process of developing *Our Stories*. Sometimes these meetings took place on Zoom, a casual opportunity to check in, share what was new in our lives and maybe do a bit of dancing together – a call back to our creative time together. While these moments of coming together digitally were valuable, the times we were able to gather in person allowed us to connect more meaningfully. In what follows, I will describe a few of our get-togethers, both in person and online and offer reflections on the experience.

Fall

Our first in-person get together after our cast party took place in October 2021.

I organized a group outing to a board game café in Toronto. The group was excited for another opportunity to connect in person and to have an evening out with friends. Lindsey, Joey, Catherine and I coordinated to meet at the subway and travel together, while James would be walking down to meet us. Once we arrived, we settled into a booth in a quiet corner of the café, picked out some games and ordered food and drinks. I remember how accommodating and patient all the servers were with our group. While this should be a given, I was appreciative, nonetheless.

After a couple hours of enjoying our meals and playing games, our evening was coming to an end. I ordered Catherine an Uber and James set out on his short walk home. Lindsey, Joey, and I had planned to travel home together on the subway again. As we started making our way to the nearest subway station, a quick five-minute walk away, we experienced something that will stick with me for a very long time. I knew then that this moment, while challenging to recount, would be important to capture and to include in this dissertation. In writing about this moment, I want to share the events as they occurred as well as offer reflections on how this incident made me feel both in the moment and at the time of this writing. The following excerpt is adapted from a note I wrote after arriving home that night:

> *Bloor Street on a Sunday night was surprisingly busy.*
>
> *Passing by groups of people I heard a sound that caught my ear… at first, I brushed it off, assuming I had misheard. Then I heard it again a little bit louder…. A cough. "Retards!" Another cough. "Retards!" A final cough.*

I felt rage and nausea at once. I turned around to look at the man spewing such hate. All I could muster in response was "are you okay?!" I really wanted to ask what the [expletive] is your problem!? The woman he was with told me he was drunk, but also didn't call him out. The man yelled back, "I sneezed!" Stepping closer to us, "gesundheit!!"

I turned away and shifted my focus toward Joey and Lindsey. As we walked away together, I put an arm around each of them protectively and asked if they were ok. They both brushed it off, "just ignore him … it's not worth it."

I wanted to cry and scream and defend. In 2021, this still happens.

In recalling and writing about this incident, I do not feel that my words can adequately encapsulate the heaviness of this moment as we felt it that evening. While this singular event does not overshadow the many moments of joy and lightheartedness I experienced with my collaborators, it feels important to include here as a reminder that ignorance and the abuse of people with disabilities, and particularly those with visible disabilities, is not an issue of the past.

The use of 'the R word' whether referring to people with disabilities or not is incredibly harmful and holds a history of abuse and discrimination. What made me most upset about this night is how little this altercation seemed to impact Lindsey and Joey (at least outwardly) – they were telling *me* not to worry about it. I have thought a lot about this evening and my own lack of preparedness for how to best handle this situation. In the moment, I was caught somewhere between fight and flight. To not address and speak up against this person's outwardly discriminatory behaviour would not have sat right with me, but at the same time, it was important to know when to step away. The safety of my collaborators and friends had to be my priority. This altercation highlighted for me that despite the meaningful relationships and interdependence I had developed with my collaborators, I will never be able to fully understand what it feels like to be visibly disabled and be the target of this kind of abuse. No matter how much I advocate for the community, at the end of the day, I hold a level of privilege and invisibility when I walk down the street. I reflect on this evening with a deep respect for Lindsey and Joey's strength and wisdom in how they handled the situation. This moment was not about advocacy or activism, but about safety; they demonstrated for me the power of walking away and knowing when the fight might not be 'worth it.' Luckily, we had many more positive gatherings to come.

Winter

In December, I offered to host a small holiday get together for the cast with cookie decorating and festive music. Unfortunately, the COVID-19 numbers were rising and so I made the decision to move our gathering online. While we were all disappointed to not be able to celebrate the holidays together, there was a collective understanding that everyone's safety was more important. In moving this event online, I encouraged everyone to join the Zoom meeting with some festive snacks and that we would watch a movie together. Once everyone had logged on, some wearing festive clothing, we began with our usual catch up and shared our plans for the holidays. We danced together to a playlist of Christmas music that we had created together during our online November get together and watched *Elf*. While it wasn't the ideal circumstance to have our holiday party over Zoom, I was still grateful that we were able to connect and spend time together.

Spring

In the spring, the COVID cases had gone down once again, and I organized another in-person get together. We planned to meet for a potluck picnic in the park – still doing our best to ensure each other’s safety during this time of uncertainty by gathering outdoors. It was a warm afternoon in May, and we all gathered outside the front entrance of High Park. We found a shady spot on the grass to set up, I laid out a picnic blanket and we all sat down together. We shared food and drinks, told stories, gave life updates, listened and danced to music playing out of a small Bluetooth speaker, and as usual, we laughed a lot.

These gatherings offered opportunity for continued engagement and connection, further demonstrating the interdependent nature of our relationships. I was not spending time with my collaborators to continue collecting data, nor did I view these social outings as acts of service or a way of “giving back to the community,” though this mindset is a staple of ethnographic research (Kazubowski-Houston 2017, 3). Rather, these moments of continued connection were the result of months of fostering genuine and meaningful relations, sharing and learning from one another and imagining futures where opportunities for individuals with disabilities are equal to those without.

Within the context of this dissertation, relationships and forming connections across lived experience are central. While interabled artistic relationships were discussed in Chapter 1, it is worth revisiting the implications of these relationships within the context of scholarly and community-engaged research. It is important to recognize that not all interabled relations (both inside and outside of the arts) function equally and that understandings and practices or performances of allyship can be fraught. As Bree Hadley notes, “In a context where the aesthetic practices of disabled artists are an increasingly fashionable and fundable component of the contemporary arts landscape, tensions around non-disabled artists appropriation of disabled artists’ bodies, stories, or theatrical styles regularly arise” (2017; 2020, 179). As a nondisabled theatre practitioner and researcher working with disabled artists, I remain mindful of the privilege I hold in certain spaces as well as the implications of fostering genuine relationships with my collaborators.

Working in the field for over ten years, I have witnessed performative allyship by nondisabled artists who work with members of the neurodivergent community. Whether realized through hushed sidebar conversations or made explicit through the framing of theatrical productions, these interabled relations perpetuate an ingroup/outgroup dynamic. It is this dynamic of division that leads to the accolades being received by a nondisabled director or facilitator for simply working with disabled artists, rather than celebrating the disabled artists themselves. While this depiction of performative allyship may not be explicitly harmful to the community, these actions can be seen as contributing to the status or public image of the ‘ally’ rather than taking action to intentionally uplift and support the marginalized group with which they are connected (Kutlaca & Radke, 2023)

Friendship as Method – Where Research, Care and Allyship Unite

Through an active rejection of an us vs. them, ingroup/outgroup binary, relations across difference can evolve from a foundation of care and friendship. As I reflected on the unique relationships that I had fostered with my collaborators for this project, I encountered Lisa M. Tillmann-Healy’s concept of ‘friendship as method.’ She explains that friendship as method is a model of qualitative inquiry that involves "researching with the practices, at the pace, in the natural contexts, and with an ethic of friendship” (2003, 730). Emerging from ethnographic research practices, friendship as method is grounded in experiences of the everyday, building relationships, engaging in deep hanging out and being responsive to participants’ shifting needs. The pace at which the research is conducted is also integral to this method. In line with ethnographers’ often lengthy fieldwork timelines, friendship as method puts emphasis on time as the only way for relationships and findings to emerge organically. As Tillmann-Healy notes, “The unfolding path of the relationships becomes the path of the project” (735). Working within a pace of friendship connects to the way crip time was embraced throughout the creation of *Our Stories* – working with the specific needs of the group and being flexible and adaptive if or when those needs shift overtime.

Considering the context of *Our Stories* within the framework of friendship as method is interesting given that we were collaborating digitally as was mandated by public health guidelines. Typically, the context of this work would have the researcher going to where the participants are – working in public or private spaces, locations where the participants would have familiarity and comfort. If we had had the opportunity to meet in person, we likely would have secured a room at the MNJCC – a community space that has proven itself welcoming and inclusive to the disability community and a place where each of the participants have a pre-existing connection. However, as we were working together remotely, the context of our collaborations (in some ways) ended up being even more intimate as we Zoomed in from our bedrooms, kitchens, living rooms, etc. Rather than meeting out in the community, we were invited into each other’s homes and personal spaces. I would argue that this intimacy heighted our ability to connect not only as collaborators, but as friends.

Tillmann-Healy’s last key element of engaging with friendship as method revolves around the ethics of the research practice. She asserts that “Friendship as method is neither a program nor guise strategically aimed at gaining further access. It is a level of investment in participants’ lives that puts fieldwork relationships on par with the project” (735). Working within an ethics of friendship grounds the research in interdependence, breaking down hierarchies and upholding practices of radical reciprocity. This privileging of relations also aligns deeply with Indigenous research methods which prioritizes relational accountability, respect, responsibility, and reciprocity in one's work (Wilson 2008, 77). Putting value on the relations fostered through one's research can, as suggested by Linda Tuhiwai Smith, be "foundational to decolonizing theory and praxis"(xiii).

In line with the ethics of this research method, friendship as method emphasizes the importance of one's findings and writings being shared with the community. The ethics of this aligns with my decision to craft a plain language summary of this dissertation; recognizing that the main dissertation requires an approach to writing and analysis that may be challenging for those outside of academia or research fields to understand. As an ongoing commitment to my collaborators and upholding an ethics of friendship, it felt pertinent to ensure that they would be able to engage with the final written product of the research. The provided summaries will offer access to this.

It must be noted however that not every research project will be well-served by friendship as method. In certain situations the blurring of researcher-friend relations could prove problematic for both researchers and participants and could also present issues for the project itself. The complexities of navigating power imbalances, boundaries, ongoing consent, and upholding an ethics of reciprocity (Owton & Allen-Collison 2014; Hall 2009) emphasize the importance of making an informed decision and working with such a method only if everyone involved is comfortable and find benefits in such relationships. In the case of this project, I did not enter the research process with the goal of establishing friendships with my collaborators, but also had no intention of taking the approach of 'drop in, get the data, and get out.' As G. Derrick Hodge (2013) notes, such a research ethic "indicates a commitment to the *data,* but not to the *people*. A commitment to the well-being of the people with whom we work is not merely a side effect of long-term ethnographic presence, but should be incorporated *as a core of the anthropological ideal*" (292, emphasis in original).

I remain cognizant of the fact that the friendships developed throughout this project can not diminish the power dynamics at play. Though I worked to facilitate a collaborative creative environment, I was still involved in this project as a researcher with particular goals and questions in mind and the ensemble members were consenting participants helping to explore and unpack those questions through performance. While there are potential obstacles or challenges to friendships born out of research projects, as Sarah Marie Hall notes it "does not make these friendships any less enjoyable; it just requires a little more patience, consideration and perhaps a lot more understanding" (2009, 270).

Friendship as method resonates with the ethos of my own research practice in embracing ways of engaging in research that prioritize care and relations not in addition to the critical research, but as an essential part of it. It is worth noting that in embracing friendship as method Tillmann-Healy is not resistant to conventional research methodologies, but rather prioritizes care and collective wellbeing as paramount for all involved. She writes, "Researching with the practices of friendship means that although we employ traditional forms of data gathering (e.g., participant observation, systematic note taking, and informal and formal interviewing), our primary procedures are those we use to build and sustain friendship: conversation, everyday involvement, compassion, giving, and vulnerability" (734). I assert that this methodology should not be discounted for lack of academic rigour, but rather celebrated for how it works to reframe and adapt more traditional research frameworks in ways that privilege human-to-human interaction and connection. From a place of activism and allyship, embracing such a methodology offers opportunity to create meaningful difference beyond one's scholarly output. To quote Tillman-Healy once more,

> When friendships do develop across social groups, the bonds take on political dimensions. Opportunities exist for dual consciousness-raising and for members of dominant groups […] to serve as advocates for friends in target groups. As a result, those who are 'just friends' can become *just* friends, interpersonal and political allies who seek personal growth, meaningful relationships and social justice." (731, emphasis in original)

To Tillmann-Healy's articulation of friends as advocates, I would also add that these friendships can also work to enable or support those in these 'target groups' to advocate for themselves. As evidenced throughout this dissertation, and this chapter specifically, care and relation-building has been essential to the creation of this work. It not only informed the final production of *Our Stories*, but also the process of creation and reflection.

Final Thoughts

The goal of this chapter was to further illuminate the value of fostering meaningful relations and even friendships with those involved in one's research. My choice to maintain connection and relationships with my collaborators was a decision that felt in line with my values not only as a researcher but as an ally and advocate for members of the disability community.

Moving on to the concluding chapter of this dissertation, I will offer further consideration to the value of these research relationships that embrace interdependence, care, and everyday acts of accessibility. Drawing from May Chazan's (2023) writing, we may ask ourselves as researchers how honouring interdependence and reciprocity in one's work with marginalized community members can be a key factor to our "collective reworlding processes" (12). In concluding this dissertation, I will focus on the potential of autobiographical theatre and collaborative performance creation to explore and imagine disability futures differently.

CONCLUSION

Dara Culhane (2011) writes, "One of the greatest premises of ethnography is its capacity to surprise. So, we pause, rather than conclude, at the end of specific research projects, more often than not with new questions rather than definitive answers" (266). The conclusion to this dissertation begins with a return to the research questions that prompted this project, highlighting prominent themes and findings that emerged throughout the process of creating *Our Stories*. In line with Culhane's suggestion to pause, rather than claiming definitive conclusions, I consider the implications of this work as it pertains to imagining disability futures differently. In doing so, I reflect on this project and look toward future opportunities for continued scholarly and community-driven engagement that celebrates neurodivergent artists and their stories as potential catalysts for emergent, real-world change.

This research project emerged from the gap I had noticed within Canada's disability arts and culture sector – one that seemed to highlight and celebrate artists with physical or sensory disabilities more so than those with cognitive disabilities. I explore this topic in depth in my article, "Neurodivergency and Interdependent Creation: Breaking into Disability Arts" (2021) which considers the implications of interabled collaboration and how the direct involvement of nondisabled collaborators can have an exclusionary impact on how art by neurodivergent or cognitively disabled artists is received by the broader disability arts community.

Produced on a small-scale and during a global pandemic, *Our Stories* was created as a response to the disparity of neurodivergent self-representation on Canadian stages. *Our Stories* worked to privilege neurodivergent experiences and self-stories through a collaboratively created performance piece. The process of creating this work, for me as researcher/collaborator, prompted further consideration of power and privilege in interabled creative spaces, the dialogic nature of autobiography and the ways in which accessible practices can inform aesthetic and creative outcomes.

This performance ethnography project presented an opportunity to engage first-hand in an interabled creation process and find ways of working that would serve the goals of the participants personally and creatively. Centring neurodivergent voices and using the framework of autobiographical performance, the artists included in this project were able to write and perform their own self-stories driven by past and present experiences as well as their dreams and hopes for their futures.

The questions initially posed at the outset of this project focussed on whose stories are not being performed, whose voices are privileged on stage and what is the risk of privileging certain life stories and experiences over others. More specifically, I was curious to explore how collective creation could serve as a vehicle for self-advocacy and community activism and how exploring narratives grounded in lived experience of disability might contribute to (re)imagining disability futures.

While conversations surrounding self-advocacy took place as part of our creative exploration, it was through the process of devising and collaborating that more nuanced themes emerged and became in some ways even more central to the project. Over the seven months of meeting and creating together online, *Our Stories* became less about storytelling as activism, and more about the intricate dynamics of collaborative and interabled creation processes, relationality, care, interdependence, and the power of sharing one's story. As the creation process for this work was emergent and informed by the ensemble, accommodations to traditional creation practices were made and renegotiated during every session. This process of ongoing negotiation of the various access needs present in our virtual rehearsal room prompted further consideration of what might be gained in giving equal attention to the process and final product, and how one might influence the other. Further to this, one of the most illuminating findings in developing and co-creating *Our Stories* was that despite the ensemble's shared lived experience of neurodivergence, 'disability' was in many cases a secondary plot point in the stories shared. Rather, the topics explored in *Our Stories* showcased the performers relationships to their hobbies, employment, family, friends, and the performing arts. Through developing this work, writing and performing about past and present experiences, we were able to look forward and imagine potential futures for these specific performers as well as for members of the wider neurodivergent community. The next part of this concluding chapter will offer further engagement with the idea of (re)imagining disability futures and world building through performance as well as sharing potential next steps for this work.

(Re)imagining Disability Futures

As an example of autobiographical performance, *Our Stories* engages with four neurodivergent performers' past and present-day experiences as a way of looking toward the futures they dream of. This dreaming together of ideal futures connects with what Jill Dolan (2005) refers to as 'utopian performatives.' Dolan describes utopian performatives as "small but profound moments in which performance calls the attention of the audience in a way that lifts everyone slightly above the present, into a hopeful feeling of what the world might look like if every moment of our lives were as emotionally voluminous, generous, aesthetically striking, and intersubjectively intense" (5). Perhaps the most obvious example of this occurring in *Our Stories* is James describing his dream wedding. As a kind of utopian performative, James performs this dream into existence and indirectly asks the audience to think of a world where marriage might be commonplace for adults with Down syndrome. Expanding on the impact of utopian performatives, Dolan asks, "instead of art imitating life, how might we bend life to imitate theatre" (90). The narrative of *Our Stories* pushes against the perception that those who live with a disability are constantly struggling, that they are limited and should be targets of pity. Instead, *Our Stories* emphasizes the beauty of disability joy, disability ambition, and disability friendships.

The implications of using autobiographical performance in the present to imagine futures differently are twofold – there is the impact on the co-creators/performers as well as the audience members who witness the work. For those performing their stories, this project served as an opportunity to imagine a desired future and to perform that future into existence.
As Kazubowski-Houston notes in her chapter in *Anthropologies and Futures* (2017), "storytelling the future means to search for it, courageously and stubbornly, in a world that systematically and consistently takes that future away" (221). By performing their desired futures, the *Our Stories* ensemble demonstrated ownership over their futures, vocalizing their goals and ambitions for others to hear. In doing so, these performers push against society's ableist expectations of what might be achievable for them – perhaps this is where the activism truly sits in this work.

From the perspective of the audience as witness of this work, these autobiographical stories may prompt a different way of thinking and shed a light on the importance of carving out space for conversations about disability futures. While *Our Stories* was not intended to be an educational tool, I do hope that it prompted reflection and perhaps challenged some preconceived notions of the neurodivergent experience. As Alison Kafer (2013) writes, "How one understands disability in the present determines how one imagines disability in the future; one's assumptions about the experience of disability create one's conception of a better future" (2). I suggest that this quote from Kafer is applicable both to those with lived experience of disability as well as those without. As Kafer emphasizes, there is a power in how we speak, perform, and write about disability experience. Whether sharing autobiographical truths of the present moment, or imagined futures, these sharings can have real-world impact. In her writing about imagining disability futures specifically, Kafer shares a quote from Judith Butler, “Changing our imaginations allows us to change our situations. Fantasy carries a ‘critical promise’ allow[ing] us to image ourselves and others otherwise” (qtd. in Kafer 2013, 46). Understanding the wider implications of autobiographical performance as a vehicle to reflect, but also to look forward, adds strength to this work in its potential for real-world impact.

Building New Worlds and Embracing Disability Narratives

Aligned with the idea of reimagining disability futures, Rosemarie Garland-Thomson (2017) writes about disability world building. Moving beyond the stage of imagining, Garland-Thomson explains, “The premise of world building is that the shape of the material world we design, build, and use together both expresses and determines who inhabits it and how we use it to exercise the duties and privileges of citizenship within that world” (52). This notion of world building therefore explores and confronts ways of being and navigating the world and recognizing the gaps, barriers, and discrepancy of privilege. She contrasts what she calls ‘inclusive world building’ with ‘eugenic world building.’ While the latter perpetuates ableism, segregation, and restrictive environments for disabled people, the former “seeks to integrate people with disabilities into the public world by creating an accessible, barrier-free material environment. Inclusive world building frames disability as valued social diversity and supports the civil and human rights-based understanding of disability” (52). In looking toward more supported and valued disability futures, it is essential to recognize and highlight what the disabled experience contributes to the world – “its generative potential rather than its restrictive potential” (Garland-Thomson 2017, 54). I suggest that autobiographical performance is a valuable vehicle for accomplishing this.

Drawing from the writing of Sharon Snyder and David Mitchell (2006) Garland-Thomson claims that disability narratives can counteract ‘social disqualification’ highlighting the significance of self-representation in building a more equitable world. She further explores the potential of disability narratives by engaging with Arthur W. Frank’s writing on the topic in his book *The Wounded Storyteller: Body, Illness, and Ethics* (1995) in which he makes an argument for disability, specifically disability self-stories as a ‘narrative resource.’ Viewing disability narratives as productive rather than compensatory resources, Garland-Thomson aligns her thinking with Frank’s in recognizing how disability narratives can contribute to self-understanding, identity formation, and I would also add community connection. Garland-Thomson recognizes the potential for the generative work of disability narratives in producing new knowledges which can have significant real-world impact and serve as an epistemic resource. She writes, “the material experience of navigating a world built for the majority while living with the minority form of embodiment like disability can produce a politicised consciousness or epistemic epiphany regarding the relativity of exclusions that the status quo explains as natural or essentializes as inherent inferiority” (56). Garland-Thomson’s writing on this subject further illuminates the cyclical relationship between narrative and epistemologies. Engaging with disability narratives through autobiographical performance, we approached each session prioritizing disability-informed ways of knowing, or cripistemologies. These ways of knowing shifted and developed over time and ultimately helped to inform the stories that were told.

Through developing and performing disability narratives that engaged with the performers' collective and individual pasts, presents, and imagined futures, *Our Stories* offered an opportunity to explore and celebrate dynamic and varied experiences of disability. Using autobiographical performance, this work calls for a future that is more inclusive, equitable and recognizes the value that disability experience brings to the world.

Final Reflections and Thinking Forward

This dissertation has engaged with a variety of themes and concepts pertaining to neurodivergent performing artists, interabled collaboration, and autobiographical theatre. As an interdisciplinary project engaging with performance ethnography, autobiographical theatre creation and disability arts practice, *Our Stories* served as a creative vehicle through which to address pertinent questions surrounding the ethics of interabled collaboration and accessible creation methodologies, care work in research, and the power of theatre as a catalyst for reimagining disability futures.

For me, as a practitioner, the eight months of devising and collaborating with Joey, James, Catherine, and Lindsey on this project prompted me to reflect on my own accessible theatre practices as well as how my power and privilege as a nondisabled facilitator can influence the creative process.

While this dissertation aimed to address some of the complexities of interabled working relationships, I suggest that there remains room for more scholarly research on this topic. In line with Culhane's assertion that in concluding research projects, we may be left with new questions, I offer the following as a call for further engagement and consideration around the themes of this dissertation: What is the role of allyship in interabled creation practices? How might nondisabled allies mobilize their privilege without impeding disabled artists ability to self-advocate? In what ways might fostering practices of care and friendship in devising new theatrical work impact the culture in the room as well as the final production or performance product?

I conclude this dissertation with a deep gratitude for having the opportunity to facilitate this research project, to consider more deeply the implications of interabled collaboration and the potential for autobiographical work by disabled artists to prompt reimaginings of disability futures. My hope is that this dissertation has illuminated the need for more neurodivergent representation on Canadian stages and demonstrated how fostering interabled relationships both within and outside of artistic practice can contribute to creating a more equitable world today and in the future.

WORKS CITED

Achtman, Michael. 2014. "How Creative Is the Creative Enabler?" *alt.theatre* 11, no. 3: 36.

Aden, Bashir. 2021. "The Call for Plain Language: A Q&A with Disability Studies Professor Rebecca Monteleone." *Centre for Journalism Ethics*. Accessed November 4, 2022. https://ethics.journalism.wisc.edu/2021/05/11/the-call-for-plain-language-a-q-a-with-disability-studies-professor-rebecca-monteleone/.

Ahearn, Victoria. 2013. "Judith Thompson play 'RARE' gives voice to Canadian actors with Down Syndrome." *Global News*, January 23, 2013. https://globalnews.ca/news/382758/judith-thompson-play-rare-gives-voice-to-canadian-actors-with-down-syndrome/.

Althusser, Louis. 1970. *Lenin and Philosophy and Other Essays*. Translated by Ben Brewster. New York: Monthly Review Press.

Amirkhani, Emily. 2018. "Ontario Superior Court Rules on the Capacity to Marry." *British Columbia Law Institute*. Accessed June 11, 2022. https://www.bcli.org/ontario-superior-court-rules-on-the-capacity-to-marry/.

Arts Access Australia. "About Us." Accessed April 12, 2023. https://artsaccessaustralia.org/about-us/.

Assis, Vincente et al. 2014. "The value that employees with Down syndrome can add to organizations." *McKinsey & Company*, March 1, 2014. https://www.mckinsey.com/industries/public-and-social-sector/our-insights/the-value-that-employees-with-down-syndrome-can-add-to-organizations.

Barden, Owen & Steven J. Walden. 2021. "Metanarratives of Learning Disability." In *Metanarratives of Disability: Culture, Assumed Authority, and the Normative Social Order*, edited by David Bolt, 77-93. Milton: Taylor and Francis.

Breast Cancer Action. n.d. "What is Pinkwashing?" Accessed May 13, 2023. https://www.bcaction.org/pink-ribbon-marketing-culture/what-is-pinkwashing/.

Bulmer, Alex. 2021. "From The Artists: May I Take Your Arm?" *ReDefine Arts*. Accessed June 20, 2022. https://redefinearts.ca/blog/from-the-artists-may-i-take-your-arm.

Calvert, Dave. 2020. "Convivial theatre: care and debility in collaborations between non-disabled and learning disabled theatre makers." In *Performing Care: New Perspectives on Socially Engaged Performance*, edited by Amanda Stuart Fisher & James Thompson, 85-102. Manchester: Manchester University Press.

Canadian Down Syndrome Association. n.d. “Down Syndrome Answers.” Accessed June 13, 2023. https://cdss.ca/awareness/down-syndrome-answers/.

CBC News. “Down syndrome cast members provide the spark in RARE.” *CTV News Entertainment*, January 30, 2013. https://www.cbc.ca/news/entertainment/down-syndrome-cast-members-provide-the-spark-in-rare-1.1333041.

Chazan, May. 2023. “Crip Time and Radical Care in/as Artful Politics.” *Social Sciences* 12, no. 3: 99. https://doi.org/10.3390/socsci12020099.

Couser, G. Thomas. 2004. *Vulnerable Subjects: Ethics and Life Writing*. Ithaca: Cornell University Press.

CTV News. 2012. “Canadian play features actors with Down syndrome.” *CTV*, July 31, 2012. https://www.ctvnews.ca/canadian-play-features-actors-with-down-syndrome-1.898956.

Culhane, Dara. 2017. “Introduction.” In *A Different Kind of Ethnography: Imaginative Practices and Creative Methodologies*, edited by Denielle Elliott & Dara Culhane, 1-21. Toronto: University of Toronto Press.

Cushman, Robert. 2013. “Theatre review: Judith Thompson’s *RARE* makes the familiar strange.” *National Post*, February 2, 2013. https://nationalpost.com/entertainment/theatre/theatre-review-judith-thompsons-rare-makes-the-familiar-strange.

Denzin, Norman. 2003. *Performance Ethnography*. Thousand Oaks: SAGE Publications.

Derbyshire, Jan. 2016. "Infrequently Asked Questions, or: How to Kickstart Conversations Around Inclusion and Accessibility in Canadian Theatre and Why it Might be Good for Everybody." *Theatre Research in Canada* 37, no. 2: 263-269. https://doi.org/10.3138/tric.37.2.263.

Eakin, Paul John. 1985. *Fictions in Autobiography: Studies in the Art of Self-Invention*. Princeton University Press, 1985.

Egan, Kelly. 2019. “Egan: ‘I should have the right to marry and life my life’ – Ontario guardian stops wedding of disabled woman.” *Ottawa Citizen*, December 6, 2019. https://ottawacitizen.com/news/local-news/egan-i-should-have-the-right-to-marry-and-live-my-life-ontario-guardian-stops-wedding-of-disabled-woman.

Egan, Susanna. 1999. *Mirror Talk: Genres of Crisis in Contemporary Autobiography*. Chapel Hill: University of North Carolina Press.

Frank, Arthur W. 1995. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press.

Garland-Thomson, Rosemarie. 1997. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press.

Garland-Thomson, Rosemarie. 2017. "Building a World with Disability in It." In *Culture – Theory – Disability: Encounters Between Disability Studies and Cultural Studies*, edited by Anne Waldschmidt, Hanjo Berressem and Moritz Ingwersen, 51-62. New York: Columbia University Press.

Geertz, Clifford. 1998. "Deep Hanging Out." *New York Review of Books* 45, no. 16: 69.

Gold, Becky. 2021."Neurodivergency and Interdependent Creation: Breaking into Canadian Disability Arts." *Studies in Social Justice* 15, no. 2: 209–229. https://doi.org/10.26522/ssj.v15i2.2434.

Gold, Becky and Alex Bulmer. 2022. "Creative Enabling: Relations and Structures of Support for Disabled Artists." *Canadian Theatre Review* 190: 19–23. https://doi.org/10.3138/ctr.190.004.

Grech, Shaun and Karen Soldatic. 2015. "Disability and colonialism: (dis)encounters and anxious intersectionalities." *Social Identities* 21, no. 1: 1-5. https://doi.org/10.1080/13504630.2014.995394.

Hadley, Bree. 2020. "Allyship in Disability Arts: Roles, Relationships, and Practices." *Research in Drama Education* 25, no. 2: 178–194. https://doi.org/10.1080/13569783.2020.1729716.

Hall, Sarah Marie. 2009. "'Private life' and 'work life': difficulties and dilemmas when making and maintaining friendships with ethnographic participants." *Area* 41, no. 3: 263-272. https://doi.org/10.1111/j.1475-4762.2009.00880.x.

Hamraie, Aimi and Kelly Fritsch. 2019. "Crip Technoscience Manifesto." *Catalyst* 5, no. 1: 1-33. https://doi.org/10.28968/cftt.v5i1.29607.

Hargrave, Matt. 2015. *Theatres of Learning Disability: Good, Bad, or Plain Ugly?* London: Palgrave Macmillan.

Hartblay, Cassandra. 2020."Disability Expertise Claiming Disability Anthropology." *Current Anthropology* 61, no. S2: S26–S36. https://doi.org/10.1086/705781.

Heddon, Deirdre. 2008. *Autobiography and Performance*. New York: Palgrave Macmillan.

Hodge, G. Derrick. 2013. "The Problem with Ethics." *Political and Legal Anthropology Review* 36, no. 2: 286-297. https://doi.org/10.1111/plar.12028.

Hutchinson, Rachel et al. 2020. “Describing Diversity: an exploration of the description of human characteristics and appearance within the practice of theatre audio description.” *VocalEyes*, Accessed May 17, 2023. https://vocaleyes.co.uk/research/describing-diversity/.

Jaggar, Alison M. 1989. “Love and knowledge: Emotion in feminist epistemology.” *Inquiry* 32, no. 2: 151-176. https://doi.org/10.1080/00201748908602185.

Johnson, Megan. 2018. “Integrating Accessibility and Aesthetics Onstage in Neworld Theatre’s King Arthur’s Night.” *Canadian Theatre Review* 176: 102–106. https://doi.org/10.3138/ctr.176.019.

Johnson, Merri Lisa, and Robert McRuer. 2014.“Cripistemologies: Introduction.” *Journal of Literary & Cultural Disability Studies* 8, no. 2: 127–147. Project MUSE.

Kafer, Alison. 2013. *Feminist, Queer, Crip*. Bloomington: Indiana University Press.

Kanake, Sarah. 2016. “Friday essay: on telling the stories of characters with Down syndrome.” *The Conversation*. Last modified April 21, 2016. https://theconversation.com/friday-essay-on-telling-the-stories-of-characters-with-down-syndrome-56436.

Kanake, Sarah. 2019. “The Down Syndrome Novel: A Microcosm for Inclusion or Parental Trauma Narrative.” In *The Routledge Handbook of Disability Arts, Culture, and Media*, edited by Bree Hadley & Donna McDonald, 62–73. London: Routledge.

Kaye, Lincoln. 2018. “Camelot, chromosomally enriched.” *Vancouver Observer*. Last modified February 2, 018. https://www.vancouverobserver.com/culture/theatre/camelot-chromosomally-enriched.

Kazubowski-Houston, Magdalena. 2010. *Staging Strife Lessons from Performing Ethnography with Polish Roma Women*. Montréal: McGill-Queen’s University Press.

Kazubowski-Houston, Magdalena. 2017. “quiet theater: The Radical Politics of Silence.” *Cultural studies, Critical methodologies* 18, no. 6: 410–422. https://doi.org/10.1177/1532708617744577.

Keung, Nicholas. 2021. “Court sides with mentally disabled man after immigration hearing questions legitimacy of his marriage.” *Toronto Star*, January 31, 2021. https://www.thestar.com/news/canada/2021/01/31/court-sides-with-mentally-disabled-man-after-immigration-hearing-questions-legitimacy-of-his-marriage.html.

Kisfalvi, Veronika. 2006. “Subjectivity and Emotions as Sources of Insight in Ethnographic Case Study: A Tale of the Field.” *M@n@gement* 9, no. 3: 117-135.

Kuppers, Petra. 2014. *Studing Disability Arts and Culture: an introduction.* Basingstoke: Palgrave Macmillan.

Kutlaca, Maja and Helena R.M. Radke. “Towards an Understanding of Performative Allyship: Definition, Antecedents and Consequences.” *Social and Personality Psychology Compass* 17, no. 2. https://doi.org/10.1111/spc3.12724.

Lejeune, Phillip. 1989. *On Autobiography*. Ed. Paul John Eakin. Translated by Katherine Leary. Minneapolis: University of Minnesota Press.

Lewis, Victoria Ann, ed. 2006. *Beyond Victims and Villains: Contemporary Plays by Disabled Playwrights*. New York: Theatre Communications Group.

Lovern, Lavonna L. 2021. “Indigenous Concepts of Difference: an alternative to Western Disability labeling.” *Disability Studies Quarterly* 41, no. 4. https://doi.org/10.18061/dsq.v41i4.8468.

Madison, D. Soyini, Magdalena Kazubowski-Houston, and Virginie Magnat. 2018. “The Imaginative Ethnographer as Vagabond Bricoleur: Being Still, Being Quiet, Standing in Love and Paying Attention.” *Anthropologica* 60, no. 2: 457–466.

Martin, Carol. 2012. *Theatre of the Real*. London: Palgrave Macmillan.

McCaffrey, Tony. 2019. *Incapacity and Theatricality: Politics and Aesthetics in Theatre Involving Actors with Intellectual Disabilities*. Milton: Routledge.

McNeil, Niall, and Marcus Youssef. 2018. *King Arthur’s Night and Peter Panties: a Collaboration Across Perceptions of Cognitive Difference*. Vancouver: Talonbooks.

Mercanti, March. 2017. “This artist living with Down syndrome co-created a new King Arthur play, and here's why that rules.” *CBC Arts*, June 16, 2017. https://www.cbc.ca/arts/exhibitionists/this-artist-living-with-down-syndrome-co-created-a-new-king-arthur-play-and-here-s-why-that-rules-1.4164174#:~:text=Niall%20McNeil%20has%20brought%20his,any%20we've%20ever%20seen.

Milbern, Stacey. 2020. “Notes on ‘Access Washing.’ *Disability Justice Network of Ontario*. Last modified April 25, 2020. https://www.djno.ca/post/notes-on-access-washing.

Miles Nadal JCC. “Accessibility and Inclusion.” Accessed 14 July 2022. https://www.mnjcc.org/access.

Mingus, Mia. 2011. “Access Intimacy: The Missing Link”. *Leaving Evidence*, May 5, 2011. https://leavingevidence.wordpress.com/2011/05/05/access-intimacy-the-missing-link/.

Mingus, Mia. 2017. “Access Intimacy, Interdependence and Disability Justice.” *Leaving Evidence*, April 12, 2017. https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/.

Mitchell, David T. and Sharon L. Snyder .2000. *Narrative Prosthesis: Disability and the Dependencies of Discourse.* Ann Arbor: University of Michigan Press.

Owton, Helen and Jacquelyn Allen-Collinson. 2014. "Close But Not Too Close: Friendship as Method(ology) in Ethnographic Research Encounters." *Journal of Contemporary Ethnography* 43, no. 3: 282-205. https://doi.org/10.1177/0891241613495410.

Perring, Giles. 2009. "The Facilitation of Learning-Disabled Arts: A Cultural Perspective." In *Bodies in Commotion*, edited by Carrie Sandahl and Philip Auslander, 175–189. Ann Arbor: University of Michigan Press.

Perrot, Adeline and Ruth Horn. 2022. "Preserving women's reproductive autonomy while promoting the rights of people with disabilities?: the case of Heidi Crowter and Maire Lea-Wilson in the light of NIPT debates in England, France and Germany." *Journal of Medical Ethics* 49, no. 7: 471-473. http://doi:10.1136/medethics-2021-107912.

Piepzna-Samarasinha, Leah Lakshmi. 2018. *Care Work: Dreaming Disability Justice*. Vancouver: Arsenal Pulp Press.

Pink, Sarah. 2009. *Doing Sensory Ethnography*. London: SAGE Publications.

Platten, Rachel. 2016. "Fight Song." Track 5 on *Wildfire*, Columbia Records, Spotify.

RARE Theatre Company. n.d. "Productions: RARE" Accessed September 29, 2022. http://www.raretheatre.org/productions.

Ravitsky et al. 2021. "Noninvasive Prenatal Testing: Views of Canadian Pregnant Women and Their Partners Regarding Pressure and Societal Concerns." *AJOB Empirical Bioethics* 12, no. 1: 53-62. https://doi.org/10.1080/23294515.2020.1829173.

Reason, Matthew. 2019. "Participatory audiencing and the committed return." In *Staging Spectators in Immersive Performances: Commit Yourself*, edited by Kolesch et al., 88-101. London: Routledge.

Russo, Gianluca. 2018. "People are sharing photos proving that you can be 'disabled and happy' – and the internet is loving it." *Insider,* October 17, 2018. https://www.insider.com/disabled-joy-hashtag-photos-2018-3.

Schmidt, Yvonne. 2017. "Towards a New Directional Turn? Directors with Cognitive Disabilities." *Research in Drama Education* 22, no. 3: 446–459. https://doi.org/10.1080/13569783.2017.1329653.

Schormans et al. 2021. "Social isolation continued: COVID-19 shines a light on what self-advocates know too well." *Qualitative Social Work* 20, no.1-2: 83-89. https://doi.org/10.1177/1473325020981755.

Schuller, Mark. 2014. “Being an Insider Without: Activist Anthropological Engagement in Haiti after the Earthquake.” *American Anthropologist* 116, no. 2: 409-412. https://doi.org/10.1111/aman.12111.

Schwab, Matthew. 2020. “How I Know Including People with Down Syndrome is a Good Thing.” TEDx Talks. January 10, 2020. Video, 5:46, https://youtu.be/yKNftrna8B4.

Settle, Keala and The Greatest Showman Ensemble. 2017. “This is Me.” Track 7 on *The Greatest Showman: Original Motion Picture Soundtrack*, Atlantic Records, Spotify.

Stainton, Tim. 2016. “Supported Decision-Making in Canada: Principles, Policy, and Practice.” *Research and Practice in Intellectual and Developmental Disabilities* 3, no. 1: 1–11. https://doi.org/10.1080/23297018.2015.1063447.

Stephenson, Jenn. 2013. *Performing Autobiography: Contemporary Canadian Drama*. Toronto: University of Toronto Press.

Stephenson, Jenn. 2019. *Insecurity: Perils and Products of Theatres of the Real*. Toronto: University of Toronto Press.

Stevens, Sarah E. 2018. “Care Time.” *Disability Studies Quarterly* 38, no. 4. https://doi.org/10.18061/dsq.v38i4.6090.

Sur, Sanchari. 2020. “Decolonizing Theatre Practice as a Playwright and Performer: A Conversation with Yolanda Bonnell.” *Intermission* Magazine, February 24 2020. https://www.intermissionmagazine.ca/features/decolonizing-theatre-practice-as-a-playwright-and-performer-a-conversation-with-yolanda-bonnell/.

Surtitles. “Who We Are & What We Do.” Accessed April 13, 2023. https://surtitles.com/.

Tectonic Theatre Project. “The Laramie Project.” Accessed April 13, 2023. https://www.tectonictheaterproject.org/?avada_portfolio=laramie&portfolioCats=4

TED. n.d. “About: Our Organization.” Accessed March 15, 2022. https://www.ted.com/about/our-organization.

Thomas, Colin. 2018. “King Arthur’s Night opens the door to new worlds.” *Mapping the Intuitive*, February 18, 2018. https://colinthomas.ca/2018/02/01/king-arthurs-night.

Thompson, James. 2020. “Towards and aesthetics of care.” In *Performing Care: New Perspectives on Socially Engaged Performance*, edited by Amanda Stuart Fisher & James Thompson, 36-48. Manchester: Manchester University Press.

Thompson, Judith. 2012. *RARE.* Toronto: Playwrights Guild of Canada.

Tillmann-Healy, Lisa M. 2003. “Friendship as Method.” *Qualitative Inquiry* 9, no. 5: 729-749. https://doi.org/10.1177/1077800403254894.

Timson, Judith. 2012. “The actors in this Judith Thompson play are rare.” *The Globe and Mail,* July 5, 2012. https://www.theglobeandmail.com/life/the-actors-in-this-judith-thompson-play-are-rare/article4392909/.

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). 2006. “Article 12 – Equal recognition before the law.” Accessed October 14, 2020. https://www.un.org/development/desa/disabilities/convention- on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with- disabilities-2.html

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). 2006. “Article 23 – Respect for home and the family.” Accessed June 11, 2023.

VocalEyes. 2021. “Self-description for inclusive meetings.” *IDEA Inclusive AD Forum.* Royal Holloway University of London and VocalEyes. Last modified May 12, 2021. http://vocalEyes.co.uk/services/resources/self-description-for-inclusive-meetings.

Walker, Nick. 2014. “Neurodiversity: Some Basic Terms & Definitions.” *Neuroqueer*. Accessed August 8, 2020. https://neuroqueer.com/neurodiversity-terms-and-definitions/.

Watkin, Jessica, ed. 2022. *Interdependent Magic: Disability Performance in Canada*. Toronto: Playwrights Canada Press.

APPENDICES

APPENDIX A: OUR STORIES SCRIPT

Scene 1 – Introductions

JOEY: Welcome

CATHERINE: To

JAMES: Our

LINDSEY: Stories!

LINDSEY: Hello, my name is Lindsey.
I am a lady with Down syndrome. I have white skin, brown eyes and long brown hair with bangs. I am wearing a hairband and also wear glasses.
The year is 2021 and I am 29.
My favourite colour is: Red
In my spare time I like to: Dance.
I would describe myself in three words as: independent, sensitive, and good looking.
Together we are: Friends.

JAMES: My name is James
I am a man with Down syndrome. I have light skin, blue eyes and short, light brown hair.
The year is 2021 and I am 23.
My favourite colour is: Yellow.
In my spare time I like to: Play guitar.
I would describe myself in three words as: gentleman, handsome, and nice.
Together we are: Flowers.

JOEY: My name is Joey
I am a young man with light skin, with dark brown hair and hazel eyes.
The year is 2021 and I am 22 years old.
My favourite colour is: Blue.
In my spare time I like to: Play the piano and play video games.
I would describe myself in three words as: funny, talented, and determined.
Together we are: Wild and crazy!

CATHERINE: My name is Catherine
I am a lady with fair skin and blue eyes and Irish brown hair like Yentl. Also, I have Down syndrome.
The year is 2021 and I am 37.
My favourite colour is: Pink.
In my spare time I like to: Sing like a diva.

I would describe myself in three words as: romantic, Orthodox Catholic and handsome.
Together we are: Kindred spirits.

Scene 2 – Pain and Gain

JOEY: Summer of 2012
On the train to Montréal
Going to have surgery
No more need for a back brace
Leaving that behind me
Having family by my side
Through the pain, I gained a couple of inches and iron
I had to learn how to sit up, walk and move again
9 years later, telling my story
Sharing my experience with friends
Now, I can run marathons…
Just kidding!

[Dance Transition: "Waving Through a Window" from Dear Evan Hansen]

Scene 3 – Employment

LINDSEY's voice is heard over top of a video of her making a drink at Starbucks.

LINDSEY: So many people has disabilities can have employment and job opportunities at different places you can find on Internet on your computers and laptops.
Employment means to me because I have to become better employee at my job at Starbucks in Downtown, Toronto.

I felt so happy and joy working at Starbucks so much. I am so comfortable and feeling so blessed and enjoy working in Starbucks. I do enjoy and love making coffees so much.

I felt so excited and happy when I talk to wonderful customers at Starbucks so much.

Starbucks means a lot to me.
I have amazing job I do love so much and I have an amazing manager.

Actually, I enjoy loving working at Starbucks! Of course, I am creative to make coffee art on many coffees.

[*Dance Transition: "Nine to Five" by Dolly Parton*]

Scene 4 – Soundscape Poems

Confidence

An instrumental recording of "I Have Confidence" from The Sound of Music underscores.

CATHERINE: Confidence is freedom
I am an Angel
Special
Relieved

Confidence is caring
I am Friendly
Equal and
Romantic

Confidence is Tender
I am lovable,
Classic and romantic
When I put on the Sound of Music
It makes me feel free
Like a bird in the sky

[*music fades out and transitions into next scene*]

Marriage

JAMES on the phone

JAMES: Hey honey!
I think we're gonna get married when we get older…

[*Mendelssohn's Wedding March fades in*]

Invite all of my friends with Down syndrome…
When we get older.
Snacks and food and drinks go in the backyard
Going to get married in a church
Nice flowers
A ring
Husband and wife

Sounds good?

[*music fades out and transitions into next scene*]

Independence

A soundscape is played under the monologue. Sounds include TTC door chimes, jazzy coffeehouse music/chatter and a piano instrumental track of "Cabaret" from the musical Cabaret.

LINDSEY: Independence means freedom.
Going on the subway by myself.
Stopping to buy a chocolate bar at a stand.
Chatting with customers at my job at Starbucks.
Dancing and acting in my classes.
Singing my favourite Broadway Musicals as loud as I want.
Independence means freedom.

[*music fades out and transitions into next scene*]

Music

A soft piano melody underscores the monologue, images of JOEY DJing are inserted into the video.

JOEY: I believe music has a way of letting emotions run free in you.
These emotions can make you feel happy, sad, love or anger.
I want people to feel happy when I DJ.
To help them have a good time and forget about their worries.
To be able to wash their fears away with the music.
DJing takes effort and skills to learn and if you do it right, big things can happen.
Three, two, one!

A techno beat drops and JOEY dances along.

[Dance Transition: "Happy" by Pharrell Williams]

Scene 5 – My Down Syndrome…

Each performer recites their poem to the camera.

JAMES: My Down syndrome makes me feel happy
Community – lots of good people
A lot of kids have Down syndrome
Down syndrome is going to be nice people and good people
Sweet
Sweetheart

CATHERINE: My Down syndrome is pure and delicate
Emotional like Juliet
Some people with Down syndrome can have mental illnesses
Sometimes it's hard – stuttering
My Down syndrome makes me feel tender
Sweet
Fairer than a red rose

LINDSEY: My Down syndrome life is outstanding
I do love being Down syndrome is a blessing
I can do everything I want to do of my own!
I won award for dancing and my break-dancing
Thank you to my parents to raise me perfect daughter I am
To have outstanding life with my amazing disability

[Dance Transition: "Firework" by Katy Perry]

Scene 6 – Dream Wedding

JOEY on screen writing something in a notebook. JAMES knocks on the door of Joey's Wedding Parlour.

JOEY: Open!

JAMES enters

JAMES: Hello Joey! I need your help planning my wedding!

JOEY: Well, my friend, you've come to the wrong place… just kidding!
Don't worry my friend, I'm here to help you!

JAMES: I'm so excited!

JOEY: Awesome, So have you gone over any ideas of what you might want for the wedding?

JAMES: Yes!

JOEY: Oh, I like the sound of that! So, tell me, who's the lucky lady?

JAMES: Tamarah!

JOEY: Tell me more about her.

JAMES: She has Down syndrome and she's wonderful!

JOEY: Aw, so sweet that you two found each other – I'm really happy for you. Alright, now let's get down to the business, partner.

JAMES: Yes!

JOEY: So where do you plan on having your wedding?

JAMES: In my parents' backyard in Toronto.

JOEY: Ok… What time of year are we having this wedding?

JAMES: In the summer!

JOEY: That's the best time of year to get married… in my *professional* opinion of course. How many guests will be attending this wedding?

JAMES: Fifteen… I think?

JOEY: Ok… I'll put that down. So James, what are you thinking of for decorations for this wedding?

JAMES: Pink and purple flowers – I want nice decorations for my wedding.

JOEY: Can do, can do… So James, what do you plan on wearing for this wedding?

JAMES: I will wear fancy clothes – black and white. A black tie, a white shirt, black pants and shoes. Maybe a suit jacket, but not if it's gonna get warm!

JOEY: Ok so we've got that covered. Now let's go on to the food!

JAMES: For dinner, we want sushi and pizza, and healthy snacks are going to be carrots, celery and broccoli and cauliflower. And drinks we will have juice and pop, and for dessert, cookies and two kinds of smoothies: strawberry banana and blackberries – pink and purple!

JOEY: Wow James, very on theme! Ok… will you be having a wedding cake?

JAMES: That's a good question! Alright, the wedding cake is going to be one layer, the inside is going to be rainbow-coloured and taste like chocolate. Tamarah wants the outside to be pink and purple with a little bride and groom on top.

JOEY: Are you going to have any entertainment for your wedding?

JAMES: Yes!

JOEY: So James, are you thinking a band or a DJ?

JAMES: DJ!

JOEY: Nice! So, do you have anyone in mind?

JOEY holds his DJ business card up to the camera.

JAMES: Hmm not yet…

JOEY is disappointed. He swiftly tosses his business card over his shoulder and sighs.

JOEY: Ok… ok… next question… So, what kind of music or artists do you like?

JAMES: Justin Bieber, Elvis, Bruno Mars, and love songs.

JOEY: (*wipes a tear*) You're gonna make me cry, bro! That's so sweet, they're awesome.

JAMES: Don't be sad, you're fine, Joey!

JOEY: Thanks James. So tell me, last question…why is getting married important to you?

JAMES: That's a good question! *[James smiles at the camera]*

[*Dance Transition: "Marry You" by Bruno Mars*]

Scene 7 – Born to Be a Singer

CATHERINE: I was born to be a singer
Singing makes me feel love
When I sing I am an elected artist
It also helps me with my speech
I don't stutter when I sing
Because it makes my vocal words clear and soft

CATHERINE sings part of "My Favourite Things" from The Sound of Music.

[*Dance Transition: "Proud Mary" by Tina Turner*]

Scene 8 – This Is Me

LINDSEY dances to "This is Me" from The Greatest Showman. The monologue below is inserted as a voiceover in between the lyrics of the song.

LINDSEY: When I am dancing to the song "This Is Me" from *The Greatest Showman* I am feeling happy.

> The song makes me feel brave and proud to have Down Syndrome. I am different but that doesn't mean I can't do hard things.
>
> "Look out cause here I come" makes me feel like I can do anything I want. I can follow my dreams of starting my own coffee shop.
>
> And I'm not scared to be seen as a person with disabilities. In fact, I am proud to have Down Syndrome.
>
> This is Me!

[*Dance Transition: "Brave" by Sara Bareilles*]

Scene 9 – FINALE

LINDSEY: We thank you for watching us.

JAMES: Thank you for your patience.

CATHERINE: Thank you for listening to us.

JOEY: We thank you for experiencing…

LINDSEY: *Our Stories!*

CATHERINE: *Our Stories!*

JOEY: *Our Stories!*

JAMES: *Our Stories!*

[*Final dance transition: "Fight song" by Rachel Platten*]

Credits Roll

End.

APPENDIX B: PLAIN LANGUAGE SUMMARY

About the Plain Language Summary

The document which this summary is a part of is called a dissertation. A dissertation is a large essay about a certain research topic. Writing a dissertation is a big step in someone completing their PhD or doctorate degree.

This dissertation was written by Becky Gold.

In this dissertation, Becky writes about the process of creating an autobiographical performance called *Our Stories* with four disabled artists, Joey, Catherine, James, and Lindsey.

Some of this dissertation has been written in complicated words that might be hard for people who are not university researchers to understand. This part of the dissertation will summarize the main ideas that Becky has written about to make it easier for those who are not university researchers as well as those with learning or cognitive disabilities to understand. Becky consulted with disabled artist/educator Ben Clement on the language used in this summary with the goal of making the writing as accessible as possible to those who were not directly involved with the project.

Becky was inspired to create this plain language summary because of a writer/researcher from the United Kingdom named Matt Hargrave. In 2015, Matt and another writer/researcher named Ruth Townsley created an ‘easy read summary’ for Matt’s book called *Theatres of Learning Disability: Good, Bad, or Plain Ugly?* Because Matt works with performers with learning disabilities and wrote about them in his book, he wanted to make sure that his ideas could be made accessible to them. Some other researchers who have done this include Bree Hadley and Donna McDonald. Bree and

Donna wrote a plain language summary of their book, *The Routledge Handbook of Disability Arts, Culture and Media*. This book was published in 2018 and includes chapters written by different artists and researchers all about disability arts. They also wanted to make sure that their book would be more accessible.

This plain language summary will tell you about some of the main ideas that Becky has written about in her dissertation. This summary can not cover everything discussed in the dissertation (as it would be far too long) but covers the main ideas from each chapter. You may not agree with everything Becky says in this summary and that is OK! This dissertation is meant to spark conversation about the way things have been done and how they might improve in the future.

Key terms

In the introduction, Becky explains two terms that she uses throughout her dissertation. The first term is 'neurodivergent.' Becky uses this term to describe the group of artists that she works with. Neurodivergent is a way to describe people who have disabilities related to how they think and process information. Some diagnoses that could be included as neurodivergent include ADHD, autism, dyslexia, Down syndrome, intellectual or developmental disabilities, etc. Because the four performers that Becky worked with for this project do not all have the same diagnosis, she uses the term neurodivergent to be inclusive of how they experience disability.

Another term that Becky uses is 'interabled.' She uses this word to describe the relationships of nondisabled artists working with disabled artists. You may have heard the term 'interfaith' or 'intercultural' to describe people of different religious or cultural experiences coming together. Interabled therefore can describe people with different experiences (disabled and nondisabled) connecting and working together.

Chapter Summaries

Introduction

In the introduction, Becky explains what inspired her to create this project. While Becky does not identify as disabled, she has worked with disabled artists to create theatre for more than ten years. What she noticed though, was that there were not many examples of neurodivergent artists telling their own stories on stage in Canada.

Becky was curious to explore how performing about your own lived experience could connect with the idea of self-advocacy and make people think differently about the future for people with disabilities.

To do this Becky connected with four artists who she met while teaching drama classes at the Miles Nadal Jewish Community Centre (MNJCC) in Toronto. Together they worked to create an online performance about their past and present experiences as well as their goals for the future. The four artists used poetry, singing and dancing to express their ideas. Becky explains that the reason that this performance was created online is because it was 2021 and during the COVID-19 pandemic. This meant that Becky and the performers could not meet in person.

Chapter 1

In Chapter 1 Becky writes about some of the main themes of the dissertation and highlights other researchers who have also written on these topics. She discusses autobiography which is a style of writing where a person writes about their own lived experience. She also writes about autobiographical performance – what it looks like when people perform their lived experience on stage. Becky also mentions about disability arts. This term is often used to describe art created by disabled artists about their experience of disability.

Becky brings together the ideas of autobiographical performance and disability arts and discusses two examples of theatre productions where neurodivergent artists include parts their lived experience in their performance: *RARE* by Judith Thompson and *King Arthur's Night* by Niall McNeil and Marcus Youssef. She explains that these two productions take different approaches to autobiographical performance.

RARE is a play that was created by a playwright named Judith Thompson and nine actors with Down syndrome. This play invited the performers to talk about what it is like to have Down syndrome and to share their thoughts and experiences with the audience.

RARE was first performed in 2012 as part of the Toronto Fringe Festival. Becky says that this play was ground-breaking, that it was doing something new and exciting. In Becky's research she found that when reviewers or people who write for newspapers or magazines talk about *RARE*, they give more attention to Judith than to the performers with Down syndrome. Becky thinks that the performers with Down syndrome should have received more recognition for their work on the play because it was about *their* lived experiences and stories.

Another play created by a neurodivergent artist that includes autobiographical elements is *King Arthur's Night*. This play was created by Niall McNeill and Marcus Youssef and was first performed as part of the Luminato Festival in 2017. Niall is a playwright and actor with Down syndrome from Vancouver. Marcus is a nondisabled playwright and actor who has worked with Niall for many years. *King Arthur's Night* has toured nationally and internationally and was even published in a book along with Niall and Marcus's other play, *Peter Panties.*

King Arthur's Night tells the story of King Arthur and the Knights of the Round Table but has been adapted based on Niall's unique understanding of the story. Even though Niall plays the part of King Arthur in the play, in the script there are elements of Niall's own experience that he included to add something new to the story. In contrast to *RARE*, *King Arthur's Night* was celebrated by reviewers and audiences for the fact that it was written by an artist with Down syndrome.

Becky notes that it is very common for neurodivergent artists to work with nondisabled collaborators and that there is not just one way or a 'right way' for disabled and nondisabled artists to work together. However, Becky thinks that when personal stories are being shared as part of creating a new piece of theatre, that everyone who contributed to the script's development should be given credit as an author/playwright.

Becky recognizes both of these plays as examples of interabled collaboration in theatre. She understands interabled collaboration as different from art therapy or facilitated arts programs. This approach to collaboration should try to keep everyone, disabled or nondisabled as equally important to the project.

In this chapter, Becky also writes about the importance of understanding access and support when creating theatre with neurodivergent artists. In her research as well as her work as an accessible drama instructor, Becky has noticed a few things that are helpful to keep in mind when participating in interabled artistic collaborations. Two things that Becky finds are key to this work are time and relationships.

Becky explains that it is important to understand how time works for different people – some people need extra time and others might need to stick to a schedule. In terms of relationships between collaborators, Becky writes about the importance of different kinds of support that people can offer to their disabled collaborators and that there are many ways that support can exist depending on the needs of the artists involved. Sometimes an artist might need lots of support throughout the artistic process and sometimes they might just need help with administrative and organizational tasks.

Becky says that when nondisabled artists are collaborating with disabled artists, it is important that they encourage and celebrate ways of working that serve the disabled artists' access needs and creative vision. She also emphasizes that it is important to recognize that disabled people are experts of their own experience. In embracing ways of working that celebrate the experience of having a disability, exciting opportunities for creating theatre can come about. This idea helped Becky in how she thought about co-creating *Our Stories*.

Chapter 2

Chapter 2 reviews the process of creating *Our Stories* from start to finish. The entire process took seven months from February to August 2021.

During the first meeting, Becky, Lindsey, Joey, James, and Catherine created something called an ensemble agreement. An ensemble is what you call a group of people who perform together, like a cast. This agreement was a list of things to help shape how the group wanted to work together and make sure everyone was on the same page.

Becky and the ensemble came up with the following list of agreement items:

1. Be on time.
2. Support one another – be patient, encourage each other, be a team.
3. Take turns/raise your hand.
4. Advocate for what you need.
5. No swearing.
6. Helping each other.
7. Focus on the group.
8. Be brave (believe in yourself).
9. Be positive.

Over the next few months, Becky and the ensemble of performers used different writing exercises to explore autobiographical storytelling. They wrote speeches, poems, and even created dances to perform about their lived experience.

In putting the script together, Becky explains that she did not edit the performers' written work. Because their writing was autobiographical, she wanted to make sure that the words that the performers would be saying would sound like how they speak in their daily lives.

Once the script was written, Becky recorded the performers doing each of their parts on Zoom and then edited it together into a short film. The recording process was interesting because the performers were not required to memorize their lines. Instead, they had their scripts either printed out or on their computers or tablets. Becky recognized that it was sometimes hard for the performers to read their lines and still look at the camera. She problem solved this by typing the performers' lines into the Zoom chat so that it worked like a teleprompter – a system that TV hosts use so that they can read their lines and look toward the camera at the same time. This technique worked very well.

Becky wanted to make sure that *Our Stories* could be accessible to lots of different people. One of the ways that this was done was through captioning the video. This made the short film accessible to people who are deaf or hard-of-hearing, as well as others who like being able to read what is being said. Another way of enhancing access was through something called visual descriptions. Becky introduced this idea to the ensemble and explained that it is helpful for people who are blind or experience low vision to know what each of the performers looks like.

Below are the visual descriptions that the four performers wrote:

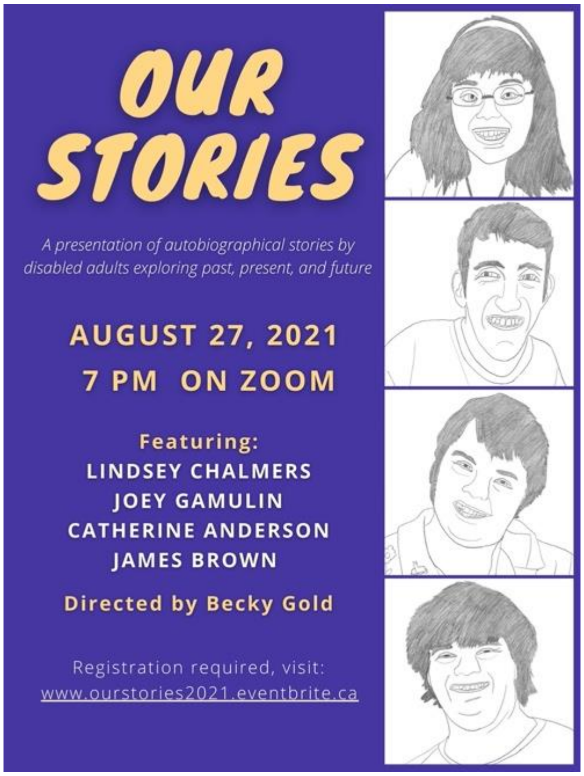
Lindsey: I am a lady with Down syndrome. I have white skin, brown eyes, and long brown hair with bangs. I am wearing a hairband and also have glasses.

James: I am a man with Down syndrome. I have light skin, with blue eyes and short light brown hair.

Joey: I am a young man, with light skin, with dark brown hair and hazel eyes.

Catherine: I am a lady with fair skin and blue eyes and Irish brown hair like Yentl. Also, I have Down syndrome.

Even though the performance was happening online. Becky wanted to make sure that the sharing of this project felt special for the whole group. She worked with a local disabled artist named Cristal Buemi to help create illustrated headshots of the performers as well as a video trailer for the performance. Becky took the headshots that Cristal drew and used them as part of a poster for the screening event.



OUR STORIES

A presentation of autobiographical stories by disabled adults exploring past, present, and future

AUGUST 27, 2021
7 PM ON ZOOM

Featuring:
LINDSEY CHALMERS
JOEY GAMULIN
CATHERINE ANDERSON
JAMES BROWN

Directed by Becky Gold

Registration required, visit:
www.ourstories2021.eventbrite.ca

Becky ends this chapter by writing about how this project made her think differently about productivity and timelines. She also explains that everyone in the project did a really good job of supporting one another and that the seven months it took to create

Our Stories was meaningful, especially during a time when many of us were feeling isolated during the pandemic.

Chapter 3

Chapter 3 talks about the day of the screening and goes through the *Our Stories* script, looking at some of the individual scenes in more detail. Becky has chosen a few to discuss in this summary. Following the screening, Becky and the ensemble participated in a question-and-answer period with the online audience. The full script of *Our Stories* is included in Appendix A and a partial transcript of the Q&A that followed the screening can be found on pages 116-120 in the main part of the dissertation.

Our Stories was screened on Zoom on August 27, 2021. Becky explains that the screening experience was strange because the audience had to be muted and stay off camera. This meant that Becky and the performers could not see or hear the audience's responses as they were watching. However, Becky and the performers were all very excited to finally be able to share their work.

Our Stories begins with each of the performers introducing themselves. To help with the introductions, Becky asked each of the performers to complete the following sentences:

My name is:
The year is 2021 and I am ______ years old
My favourite colour is:
In my spare time I like to:
I would describe myself in three words as:
Together we are:

Having the performers complete these sentences not only helped to introduce them to the audience, but it also positioned *Our Stories* as a kind of archive or time capsule, preserving this particular moment in time. Becky writes about how the performers' answers to the above prompts were true when they wrote them in 2021, but that their responses are likely to change as they get older. It is interesting to be able to look back and see what their hobbies were or how they would describe themselves during that particular year.

"Pain and Gain" by Joey

Joey wrote a piece for *Our Stories* called "Pain and Gain." This piece was originally created as part of the speech-writing exercise that the ensemble did. Joey wrote a monologue about his experience with his disability – having to wear a back brace and then getting a spinal fusion surgery. About a week before the screening, Joey shared that he was not feeling great about what he had written and that reading such a long piece made him feel uneasy. Becky and Joey met to discuss and figure out a plan to make Joey more comfortable with his piece. They decided that Joey could transform his longer monologue into a shorter poem. This would allow him to still get the message of his story across but would have fewer lines and be presented more artistically.

“Pain and Gain” can be found in the *Our Stories* script on page 158.

“Dream Wedding” by James

James collaborated with Joey to create a scene about how he imagines his future wedding. In this scene, Joey plays the role of a wedding planner and asks James many questions about the different things he wants for his wedding. Some of these questions include where James wants the wedding to take place, what kind of decorations he wants, what kinds of food would be served to guests, and whether or not he wants to hire a band or DJ to play at his wedding.

The final question Joey the wedding planner asked James is “why is getting married important to you?” to which James replies, “That’s a good question!”

Becky writes about the significance of this final question. When James had first mentioned wanting to get married, this is a question that Becky had asked him. However, after going through the whole process of co-creating this performance with the ensemble, Becky reflected and realized that this was a silly question. She notes that people who are not disabled would not be asked this question and that even though James has Down syndrome, he does not need a special reason to want to get married. "Dream Wedding" can be found in the *Our Stories* script on pages 161-163.

"Born to be a Singer" by Catherine

Catherine is a talented poet and wrote several poems for *Our Stories.* One of the poems she wrote was about her love of singing and how she does not stutter when she sings (see page 163). Throughout our time working together, Catherine would sometimes get frustrated if she was having trouble getting her words out. However, when she would sing, she was always very confident. As part of the final production, Catherine sang part of the song “My Favourite Things” from *The Sound of Music* which is one of Catherine’s favourite musicals.

“This is Me” by Lindsey

The final scene of *Our Stories* was of Lindsey dancing to the song “This is Me” from the movie musical, *The Greatest Showman.* This is one of Lindsey’s favourite songs and she improvised a dance number to it. As a writing exercise, Becky asked Lindsey to write about how it feels to dance to this song. The short monologue that Lindsey wrote is about how proud she is to have Down syndrome and that even though she has a disability, it does not mean that she can not do hard things. Lindsey’s monologue was recorded and edited into her dance video as a voice over that could be heard between the lyrics of the song. Lindsey’s monologue can be found in the *Our Stories* script on pages 163-164.

At the end of this chapter, Becky writes about what she learned from this process. She recognizes the significance of this project in bringing a group of people together to create a piece of theatre during a time when we were all being forced to isolate and not gather in groups. She writes about why it is important that Joey, Lindsey, James, and Catherine have the opportunity to tell their own stories and perform about their past and present experiences as well as their dreams for the future.

Chapter 4

Chapter 4 is all about what happened after the screening of *Our Stories*. Becky felt that because of the relationships that she had developed with Joey, Lindsey, James, and Catherine that it was important they keep in touch.

To celebrate the ensemble's hard work, Becky hosted a cast party. This was the first time that the group was able to gather together in person. As the Ontario government was still encouraging that groups of people avoid gathering indoors at this time, Becky hosted the cast party on the front porch of her apartment building. The group had snacks and drinks and they sang and danced together. It was a really special time. As a thank you for all their hard work, Becky gifted each ensemble member a mug with one of the show posters on one side and their illustrated headshots on the other. Below is a photo of Becky and the *Our Stories* ensemble holding their mugs.

Over the next number of months Becky continued planning in-person and online hang outs with the ensemble. In the fall, they went out to a boardgame café. In the winter, they had a virtual holiday party where they watched *Elf* on Zoom and danced to holiday music. In the spring, they had a picnic together in High Park.

Becky explains why it was important to continue spending time together and the role of friendship and care in this project. She explains that over the course of their time working together, she formed friendships with her collaborators. This is not always the case in research projects. However, because this project was about theatre and collaboration, it became easy to develop friendships. These relationships and the care and support that the whole group offered each other helped to shape the way that Becky and the ensemble worked and created together.

Conclusion

The conclusion to this dissertation reflects upon the inspiration behind this project: the lack of opportunity for neurodivergent artists to share about their own experiences on Canadian stages and how that might impact the way society views this community.

Becky writes that when disabled people share their lived experiences and their dreams for the future, like the four *Our Stories* artists did, this creates opportunities for imagining disability futures differently. We can use theatre to demonstrate the best and most inclusive world we can imagine – this might be a world where everyone has equal rights and equal opportunity to do what they love whether or not they have a disability. Becky believes that theatre has the ability to make change in the real world and hopes that *Our Stories* maybe encouraged some audience members to think differently about what people who are neurodivergent can accomplish.

While Becky learned a lot through the process of co-creating *Our Stories* with Joey, Lindsey, James, and Catherine and also through the process of writing this dissertation, she recognizes that there is always room to grow and learn more. She feels very grateful for the opportunity to have facilitated this project and hopes that it might make a difference in how people see those with disabilities on and off stage.

APPENDIX C: PARTICIPANT CONSENT FORM & ETHICS APPROVAL

Informed Consent Form

Date:

Study Name: (En)Acting Self Advocacy: Reimagining Disability Futures Through Autobiographical Performance by Neurodiverse Artists

Researcher name: Becky Gold, Theatre and Performance Studies (Doctorate), York University
Principal Investigator
Contact: blgold@yorku.ca

Purpose of the Research:

- To learn about how performing stories based on your lived experience can be used as a form of self-advocacy and can teach audiences about different experiences of disability.
- This research project will use a method called Performance Ethnography. This means that we will use performance and acting as a way of exploring what it means to live with a disability.
- This project will result in a final theatre production as well as a dissertation. A dissertation is a very large essay that is written about a research project (like this one) and is a significant part of finishing my doctorate degree.

What You Will Be Asked to Do in the Research:

- Participants will be asked to attend weekly writing sessions and rehearsals from January – August 2021.
- Before our weekly meetings begin, we will do an interview together to discuss what topics you might be interested in exploring through this project.
- You will be responsible for attending these writing and sessions, as well as doing some additional writing on your own.
- As we will be writing a play to be performed, this performance will take place in September 2021. We will decide as a group if the play will be open to the public, or just family and friends.
- After the performance, we will do a final interview together about your experience with the project.
- The entire project will take place over the course of nine months (if our meeting time overlaps with holidays or other significant events, meetings may be cancelled, and makeup sessions scheduled).
- As a result of COVID-19, meetings and rehearsals will take place over Zoom. This may only change if/when the government says it is safe to work in-person. Participant safety is a priority, and all research activities will abide by the health and safety rules and regulations outlined by the province of Ontario.

Risks and Discomforts:

- As we will be talking and writing about your own personal experiences, there may be times where discussing certain things may feel uncomfortable. You will never be pressured to talk about anything that you do not want to, and you will be able to take breaks as needed. I am here to support you throughout this project and want to make sure that you feel comfortable.

Benefits of the Research and Benefits to You:

- Currently, there has not been very much written about artists with cognitive disabilities in Canada. I hope that this project will fill that gap and draw attention to the value of performing personal stories for members of the disability community.

- I believe that this experience will also be beneficial to you in in learning about the process of writing about and performing your own lived experience, learning about the experiences of your peers, as well as being involved as collaborators in a research project.

Voluntary Participation and Withdrawal:
Your choice to participate in this project would be completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer, to stop participating, or to refuse to answer particular questions will not influence the nature of your relationship with me (Becky) or anyone else assisting with this project. It will also have no effect the nature of your relationship with York University either now, or in the future.

If you decide at any point that you no longer wish to be involved in this project, all of your personal information and writing will be removed from the project and any digital recordings will be deleted.

Confidentiality:

- Throughout the research process, I will be taking notes about our work together. I will also, at times, record audio of our online writing sessions and rehearsals. Photos and videos may be taken during rehearsals and the final performance.
- All information will be stored securely. My notes and any recordings will be stored on a password protected laptop.
- All of the information gathered for this project will be kept for three years following the end of the project – August 2024. At this time, all electronic documents will be deleted and wiped from the computer and external hard drive backup.

All information you supply during the research will be held in confidence. Unless otherwise indicated below, your name will not appear in any report or publication of the research, and instead pseudonyms (fake names) will be used. Data will be collected using handwritten or typed notes, as well as audio and video recording. All hard copies of my notes will be transcribed or scanned onto a password protected laptop, after which the original copies will be shredded. All digital recordings of meetings and rehearsals will also be kept on a password protected laptop/hard drive. Only I will have access to this information. The data will be stored until August 2024, after which time it will be deleted permanently. Confidentiality will be provided to the fullest extent possible by law.

Additional Online Protocols:

- This study will use Zoom to collect data, which is an externally hosted cloud-based service. When information is transmitted over the internet privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g., government agencies, hackers). Further, while York University researchers will not collect or use IP address or other information which could link your participation to your computer or electronic devices without informing you, there is a small risk with any platform such as this of data that is collected on external servers falling outside the control of the research team. If you are concerned about this, please contact me for further information.
- Recordings (audio/video) will be saved in a password protected file to my personal computer, not the cloud-based service.
- Please note that it is the expectation that participants agree not to make any unauthorized recordings of the content of a meeting / data collection session.

Questions About the Research?
If you have questions about the research in general or about your role in the study, please feel free to contact me at blgold@yorku.ca or my supervisor, Dr. Magdalena Kazubowski-Houston at mkazubow@yorku.ca and/or 416-736-2100 ext. 22257. You may also contact the Graduate Program in Theatre and Performance Studies at gradthea@yorku.ca and/or 416-736-5785.

This research has received ethics review and approval by the Delegated Ethics Review Committee, which is delegated authority to review research ethics protocols by the Human Participants Review Sub-

Committee, York University's Ethics Review Board, and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, Kaneff Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca).

Legal Rights and Signatures:

I____________________________, consent to participate in (En)Acting Self Advocacy: Reimagining Disability Futures Through Autobiographical Performance by Neurodiverse artists conducted by Becky Gold. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

__________________________ __________________________
Participant Signature Date

________________________________ __________________________
Principal Investigator Signature Date

Additional consent (where applicable)

1. **Audio recording**

☐ I consent to the recording of writing sessions/rehearsals and post-production interviews.

2. **Video recording or use of photographs**

I ____________________ consent to the use of images of me (including photographs, video and other moving images), my environment and property in the following ways (please check all that apply):

In academic articles	☐ N	☐ Y
In print, digital and slide form	☐ N	☐ Y
In academic presentations	☐ N	☐ Y
In media	☐ N	☐ Y
In thesis materials	☐ N	☐ Y

3. **<u>Preferred naming</u>**

I __________________________ choose to waive my anonymity as a participant and have my real name used in all publications related to this project including thesis materials, academic articles, etc.

☐ Y ☐ N

If you selected N (no) Becky will choose a pseudonym for you to be used in all writing, presentations and media related to this project.

______________________________ __________________________
Participant Signature Date