“Disability on Stage”: The DisAbility Project (USA) and Graeae Theatre (UK) Theatre’s Impact on Disabled Actors: A Comparative Study

Dissertation

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ABSTRACT

Few opportunities and many challenges exist in professional theatre for performers who have disabilities in the United States and in the United Kingdom. Joan Lipkin leads a community theatre group in St. Louis, Missouri in the United States that provides opportunities for disabled actors to perform live theatre encompassing original material that is focused on bringing disabilities to the forefront of each production. Likewise, Jenny Sealey leads a professional theatrical company in London, England called The Graeae Theatre. Graeae hires disabled artists as actors, writers and producers. Graeae is leading the way in changing perceptions of non-disabled people and showing the world that disabled artists have important work to perform.

This dissertation examines the impact theatre has on the quality of lives of disabled actors and civil rights gains achieved for them by examining the history of disablity theatre in a comparison study of the DisAbility Project of the United States and Graeae Theatre of the United Kingdom. It covers work by disability scholars in a field that is in its beginning stages historically and shows how far this discussion has come since the passage of the ADA in the United States in 1990. My research delves into the perspectives of disabled actors in The DisAbility Project from St. Louis as well as representatives of The Graeae Theatre Company in London. These interviews include perspectives from Joan Lipkin and Jenny Sealey as each one circumnavigates the political climates of their respective countries as well as dealing with funding issues.

I also draw from scholarly works from Petra Kuppers, Bree Hadley, and Carrie Sandahl to illuminate where the research began and where it is heading as we move into a time in history where communication is instantaneous and lack of awareness is inexcusable. The continual evolution of media allows information to flow by a click of a button. I compare and contrast the work of Graeae and DisAbility Project and show how the work of the aforementioned scholars helps both companies attain more exposure and become well known in the world of theatre.

Dedication

To my family, friends, and colleagues who have supported me during this long journey and who never doubted me even when I doubted myself. To my wife Kellie Ann, my number one fan, and my children: Tony, Rachel, and Allison. To my grandchildren Charlie and Sam. To my brothers Danny, Kevin, and Matt. And to all disabled artists who strive to achieve equality in theatre. This is for you.

Acknowledgments

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I would like to also thank the Graduate School and the Department of Theatre at OSU for supporting this project with a travel grant to allow me to visit The Graeae Theatre and finish my research of the company.

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Chapter 1: Introduction

Disability theatre. What is disability theatre? This chapter will serve as an explanation of the term as well as a guide for people seeking to incorporate disabled artists in their companies. Information about this topic is relatively new as many theatrical organizations with disabled performers are just beginning to chronicle the works that have been staged by their companies.

Disability theatre encompasses every aspect of theatre, from writing to directing and all parts between. There are companies like Graeae Theatre in London, England that exclusively hire disabled artists. There are some like the DisAbility Project in St. Louis, Missouri that are made up of both disabled and non-disabled artists. There are companies that produce original works and others that produce established material while others produce a combination of both.

Any organization that works with disabled artists must decide on whether or not to bring its facilities up to date and meet the standards for accessibility. The only theaters that have such accommodations are newer buildings designed by people who had the foresight to plan with those standards in mind. The physical limitations of each theatre present unique difficulties for each disabled actor. Lack of an elevator will not prevent an actor with multiple sclerosis from getting on stage, but the steps that exist might prove extremely challenging and potentially could cause him or her harm while climbing up or down.

My work on this dissertation started in 2008 at Ohio State University in Columbus, Ohio. The origins of my work with disabled artists goes back much farther. The first time I met a disabled person was in 1974. In my hometown of New Lexington, Ohio we have a facility that houses disabled residents. It once served as a Catholic high school and included a gymnasium. While waiting for my ride home from basketball practice I met and started conversing with a resident named Jim. It is part of my upbringing to welcome anyone who wishes to become friends. We and I became friends shooting baskets and passing time until I had to go home.

Several years later I began my undergraduate work at Wright State University in Dayton, Ohio and was awarded one of two scholarships in the theatre program with an incoming class of 140. This was a tremendous honor and signaled that I had chosen the correct field. In April of the following Spring my mother passed away and it led me to rethink my choice of professions. I decided to leave the Acting program and pursue my education degree which led to dual certification in Social Studies and Theatre.

After graduation I worked as a substitute teacher for Beavercreek City Schools in Beavercreek, Ohio. I was one of the only substitutes who voluntarily filled in for the Special Needs classes which gave me the opportunity to work with many of our younger disabled students. I was hired full time that year as a social studies teacher. While working at Beavercreek High School in Beavercreek I continued to work with many community theatres until the supplemental position opened that allowed me to direct one play a year.

In 2002 one of the Special Needs teachers approached me about directing a group of disabled students in a play. Karen Morgan and I had worked well together with disabled students who had both of us as teachers. When she asked me to direct this show I immediately said yes. Morgan's question had actually been "Can this be done? I don't know how to direct, but if you can do that, I can make everything else happen that is needed to put on the show (sic)." Working with a group of over 15 students (the numbers varied based on which students showed up on a given day) with varying disabilities was unique but not impossible. I chose the script *Parcel* by David Campton. The parcel in this play is a reference to the Grandma who is old, silent, and almost immobile. Grandma is being passed from one relative to another as they take turns caring her. Her house is gone and her beloved piano is destroyed during the moving process. While being passed along the Grandma asserts her rights as an individual and disappears. After many years of preparation and groundwork, we successfully staged the show on June 10, 2006.

The process to bring this piece to fruition was hindered by lack of rehearsal space and finding a performance space that was accessible. At Beavercreek we have the good fortune to have an auditorium that was built in 1998 and opened in 1999 designed with consultation from Mark Shanda of Ohio State University. Mr. Shanda shared this information with me after I began my work at Ohio State. With this stage we were able to complete our work with all of the actors including Beth, a young lady who was hit by a drunk driver as a young teenager. Beth uses a computer to help her speak and is in a wheelchair for her daily activities. The role of Grandma only required a few lines and allowed Beth the ability to perform in front of an audience for the first time in her life.

There was no formal audition process. With the guidance of Karen Morgan and the other Special Needs teachers and aides the casting was completed before the rehearsals began. Most of the rehearsals took place in a gymnasium at the Lorry Center in Dayton, Ohio. The venue serves as a central meeting place for the students and their aides for activities that take place outside of regular school hours. Once or twice a month we gathered to explore the scripts which had been adapted for each person's needs to allow for clear understanding of the text. In some instances the words were enlarged for easier readability. Beth could not physically hold on to a script so she worked with her parents and her aide to memorize the entire play. Her lines were uploaded into her electronic speaking box and Beth would access each line by looking at a certain part of the box and blinking. At times the connection was not made and her aide would manually activate the button.

Other actors would hold their scripts in front of them while in rehearsal and during the final performance. An actor named Wes continued to get louder and louder as he grew more confident with his lines. Wes quickly became the leader of the group as he went around reminding the other actors to say their lines on time. This was never meant as a slight to their abilities. It did show everyone involved that Wes was serious about the play and wanted everyone to be at their best for the final performance. The set pieces were provided by the family members of the actors as they insisted on helping out with the show. Costumes were altered to fit each person and any devices needed to assist them in their movement. Beth's costume was strategically cut to fit her over her wheelchair. There were over 200 people who attended the performance during this afternoon performance. The afternoon time frame was chosen to accommodate the actors' personal schedules for personal care. There was a window of approximately 3 hours to get in costume and make up, perform, and set strike for a 45 minute show. The joy in the audience response as well as the family response was enough to convince me that I needed to continue this work in the next phase of my professional career.

Many of the actors thanked me after we closed *Parcel*. This showed me that this work could continue. The work just needed an advocate to bring additional opportunities to a part of our society that is tremendously underrepresented. I continue to add shows that vary from *Romeo and Juliet* to *Sleeping Beauty*. Each group I work with changes as students grow older and are moved on from the high school setting into the work force. I also encountered a major change in my personal life as my father passed away in 2007. This bookend of losing both of my parents led me to pursue my doctorate in theatre. Theatre has been my passion since high school and it seems logical that I finish my career with a degree that will allow me to be an advocate for disabled performers and see that additional opportunities continue to be afforded to all people who wish to work in this field.

There is an intrinsic satisfaction that comes from seeing people achieve things in the field they have a passion for and wish to pursue. Many of the young disabled actors I work with have not had an opportunity to express their creativity outside of the classroom setting. This is not to say any of them will go into the theatrical arts. Many of them will go into different post-secondary fields of study at college or university. I currently run the entire theatre program at Beavercreek High School. My responsibilities include teaching all of the Acting and Advanced Acting classes, directing the Fall and Winter plays, directing the Spring Musical, directing the Faculty/Staff play, and directing the Rolling Stock Players which is our disabled performing company. I make no assumptions that any of my students will pursue theatre after graduating from Beavercreek. I treat everyone the same and work to nurture their love for performance or technical theatre. My job is to provide opportunities to all. I have had several disabled students work onstage and behind the scenes. This is the crux of this dissertation. Opportunities should be made available to all people who wish to express themselves theatrically. It fulfills each of them in ways that other work does not. It increases their quality of life and opens the door to new work to be seen onstage. This is why I am pursuing my doctorate. I want to be a voice of change that will benefit disabled artists now and in the future.

This paper addresses issues faced by artists who wish to perform on stage and what measures have been taken to alleviate the problems that arise when productions begin the audition process and continue through rehearsal and performance. Disability theatre is not one dimensional. It is complex and has a background that has taken society from times of freak shows to disabled actors leading casts and winning Tony awards.

The importance of this paper is to bring to light the many works that are in progress that embrace using disabled actors in live theatrical performances and the process they have to go through in order to obtain those positions. There are many disabled artists throughout the world who do not have the same opportunities made available to non-disabled artists. This paper speaks to these artists’ experiences and the work that is currently underway that makes use of the talents of these performers. It is extremely important for disabled artists to have a voice in this discussion. Disability theatre is not new, but it is a topic that is finding its platform for all stakeholders to come together and discover ways to put it on the same level as other theatrical movements throughout history. It is unique in that many companies have not hired disabled actors to work in their theaters. At issue is the need for equal opportunities for disabled artists to work in the creative arts field, not only to tell their personal stories but to tell other people’s stories.

Chapter 2 focuses on the scholars of disability theatre and the work that has been done to document the progress of groups that have undertaken the work to bring more opportunities in the field to disabled artists. Carrie Sandahl, Petra Kuppers, and Bree Hadley are among the authors of works dealing with training, rehearsal, and performance of disabled actors. Sandahl's work covers deaf performances as well disability identity in live performance and film. She also explores the cultural significance of training and performance of disabled artists as is noted in her book *Bodies In Commotion: Disability and Performance*. Kuppers is known for her work in disability studies as well as theatre, poetry, and dance performances as they relate to disability theatre as she explores in her books *Disability and Contemporary Performance: Bodies on Edge* and *Disability Culture and Community Performance: Find a Strange and Twisted Shape*. She also discusses 'staring' and what it means in society as well as performance pieces. Hadley has worked to identify the construction of identity in contemporary, pop cultural and public space performance practices specifically as they relate to disability performance. This is discussed in her book *Disability, Public Space Performance and Spectatorship: Unconscious Performers*. Along with all of the literature by these disability scholars I will discuss perceptions of non-disabled audience members who attend productions with disabled performers and the choices being made to include more actors with disabilities on stage.

Chapter 3 considers the work of the DisAbility Project out of St. Louis, Missouri and its artistic director Joan Lipkin. Lipkin is based in St. Louis but much of her work takes place in international settings. The DisAbility Project is composed of amateur actors in a community theatre setting. This proves to be an incredible challenge as the group is often in need of accommodating rehearsal and performance spaces. Lipkin's company is made up of mostly disabled actors, but she does include non-disabled players as the need occurs to fill in for actor absences due to illness, personal challenges, or lack of transportation.

Chapter 4 focuses on the Graeae Theatre Company based in London, England. Current Artistic Director Jenny Sealey continues the work of this professional organization that hires disabled artists to write, direct and perform in its shows. Graeae has performed mainly in London but it has also broadened its scope to other cities in England and around the world. Graeae has performed in two Paralympic opening ceremonies and has influenced other theatre companies to hire disabled artists.

Chapter 5 concludes with a comparison and contrast between the DisAbility Project and Graeae Theatre Company. Changes that have occurred in this developing field are highlighted since my formal studies of disability theatre began in 2008, thus bringing my study full circle. There has been much progress in the opportunities that have been afforded to disabled artists and there is more awareness of the work that is being done by companies that hire them. This chapter focuses on the importance of continuing to stage shows with disabled actors in venues that encourage attendance of non-disabled audiences so that more of this work is looked at and hopefully appreciated. This paper contains several references to appropriate terminology used by disabled people. The following is a chart that provides a guide to the right words to use when discussing disabilities and disability theatre. [1]

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[1] *A Guide To Inclusive Teaching Practice In Theatre*. Graeae Theatre Company. September 2009. Copyright Graeae Theatre Company. Reg Charity no. 284589. Reg in England no. 1619794. This table is part of the guide for teachers, directors, practitioners and staff.

ACCEPTABLE TERMS	**UNACCEPTABLE TERMS**
DISABLED	HANDICAPPED, CRIPPLE, INVALID
DISABLED PEOPLE	THE DISABLED
HAS (AN IMPAIRMENT)	SUFFERS FROM…, VICTIM OF...
NON-DISABLED	NORMAL, HEALTHY
HAS LEARNING DIFFICULTIES/LEARNING DISABLED	MENTALLY DISABLED, RETARDED, BACKWARD
WHEELCHAIR USER	WHEELCHAIR BOUND, CONFINED TO A WHEELCHAIR, IN A WHEELCHAIR
DEAF, DEAFENED OR HARD OF HEARING PEOPLE	THE DEAF
DEAF SIGN LANGUAGE USER, BSL/ASL USER	DEAF AND DUMB, DEAF MUTE
BLIND OR PARTIALLY SIGHTED PEOPLE, VISUALLY IMPAIRED PEOPLE (VIP)	THE BLIND

HAS MENTAL HEALTH ISSUES, IS A MENTAL HEALTH SYSTEM USER OR SURVIVOR	MENTALLY ILL, INSANE, MAD, CRAZY
HAS CEREBRAL PALSY	SPASTIC
RESTRICTED GROWTH, SHORT STATURE	DWARF, MIDGET

This chart is provided by the Graeae Theatre Company as part of their educational package and includes many terms that are used by non-disabled people when discussing or describing disabled people. Joan Lipkin's DisAbility Project provides similar educational material to the schools it visits. The goal is to encourage questions from students who have not heard the terms or need clarification as to what they mean. The discussions that arise may be handled by the classroom teacher or the company after it performs for the school. The DisAbility Project guide delineates between physical disabilities (affect how people move, walk, or get around), sensory disabilities (affect the senses, especially sight and hearing), and cognitive disabilities (affect how a person thinks).[2]

Another term I reference is deaf. The term is an argumentative point in the deaf community. Big "D" Deaf refers to people who are born deaf to deaf parents and sign and live primarily with

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[2] *The DisAbility Project High School Study Guide*. That Uppity Theatre Company. St. Louis, Missouri. 2005. This is one of several guides. Each is specific to grade levels. The high school guide is being referenced due to its advanced nature that also applies to adults.

the deaf community. Lower case "d" deaf people are born hearing and become deaf but integrate with mainstream society in their primary living situations. This includes people who use cochlear implants and those who do not rely on sign language as their primary means of communication.[3]

The main issue that drives a wedge between Deaf (big "D") and deaf (small "d") communities is the definition of deaf as a disability. The Deaf community is in disagreement as to the designation and many do not want to be "fixed" as no problem exists. Those who choose to have their Deaf children go through the procedure to receive cochlear implants are looked at as disregarding the Deaf culture and not embracing the community. This paper does not take sides on the issue but is designed to provide information about the two views on the issue and an understanding about the terms as they appear throughout the study.

Appendix A contains interviews with the DisAbility Project team members. Appendices B and C contain scripts from the DisAbility Project that Joan Lipkin generously provided for inclusion in this paper so that the information the performance company shares with schools and community organizations is available to people who may not have the opportunity to see the actors in performance. Except for inclusion in abstracts and other written professional papers, the scripts have not been officially published. Like Graeae, the DisAbility Project promotes collaboration with outside organizations that wish to follow the path they have taken to incorporating disability theatre into communities.

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[3] Galloway, Terry. *Mean Little Deaf Queer*. Beacon Press. 2009. Galloway's memoir is look at her life as she found herself outside of both the Deaf and hearing communities.

Chapter 2: Disability Scholars and Changes Since the Adoption of the Americans with Disabilities Act of 1990

The topic of disability theatre encompasses a dynamic of theatre that has changed significantly in the last twenty to thirty years. The Americans with Disabilities Act (ADA) of 1990 in the United States was a culmination of work brought together by advocacy groups composed of parents of disabled children, congressional leaders who wrote the actual legislation, and people with disabilities fighting against exclusion and segregation. It provided the United States' first comprehensive civil rights law for disabled individuals. The 1990 legislation had ties to Section 504 of the Rehabilitation Act of 1973 which banned discrimination on the basis of disability for people to receive federal funds and classified disabled people as a minority group. Most of the initial work was to ensure fair housing standards, equal health benefits, and to prevent discrimination in the workforce.

From there the legislation continued into schools and led to changes in the Individuals with Disabilities Education Act (IDEA) standards that require differentiated instruction through the use of Individual Education Plans (IEPs) to accommodate different learning styles as well as 504 plans for students who are part of inclusive education settings who need extended testing time or adjustments to help them keep up with non-disabled students in the classroom. All of these legislative works have led to changes in work and training opportunities in all fields in order to comply with federal standards.

In the United Kingdom, a more recent piece of legislation sets the guidelines for disabled citizens. The Equality Act of 2010 (EA) defines disability as having a physical or mental impairment that has a substantial and long-term negative effect on one's ability to do normal daily activities. It protects disabled people from discrimination in the workplace and in wider society. The Equality Act placed all previous anti-discrimination laws into a single piece of legislation to strengthen its protections and make it easier to decipher when questions arise concerning the rights of disabled citizens. This included the Disability Discrimination Act (DDA) of 1995 which only affected relations between disabled and non-disabled citizens as it pertained to daily interactions in society and failure to make reasonable adjustments for disabled citizens. The EA replaced the vague ideas of the DDA with specific regulations in work, housing, and schools.

In both the United States and in the United Kingdom legislation has been introduced to bring about more opportunities and legal protections for disabled workers to train and find jobs in their fields of expertise. This paper focuses on changes since the passage of these two important pieces of legislation as they pertain to live theatre and the productions that have taken place during this time period.

There are many scholarly works dedicated to the subject written by university professors and professionals in the field of performing arts that have used case studies as well as individual research to bring a better understanding to non-disabled members of society. The themes highlighted include training and the opportunities for disabled actors to hone their craft, changes that have occurred in disability theatre since the passage of the ADA, and recent works that have included disabled performers. The scholars discussed will often reference each other as their studies have intersected during the course of their work. This strengthens the work that has been accomplished in a relatively new topic of research in disability theatre. Each professional writer has had the opportunity to observe work their contemporaries have undertaken and to learn from the experiences with either a combination of non-disabled and disabled actors or a strictly disabled troupe.

Training Opportunities for Disabled Performers

The first concern regarding theatre training opportunities for disabled performers is resolving a multitude of barriers such as ensuring that actors have transportation and can then safely and adequately move and have their physical needs met within rehearsal and performance spaces. The second biggest challenge is communication among all parties involved. This may encompass the use of sign language while speaking with deaf actors or simply listening more carefully to an actor with a unique speech pattern. The scholars I reference include Carrie Sandahl who has written extensively on disability studies and theatrical works, Paul Steven Miller who is a disability rights activist, and Stephanie Barton-Farcas who has designed a guide for people who would like to create a theatre production company for disabled performers. Each one has worked specifically with disabled actors and advocate for continued support for new productions that move the conversation and work of disabled actors forward by focusing on the needs of the actors and bridging the gap between non-disabled and disabled actor preparation.

Paul Steven Miller says ”It is our responsibility as disability scholars in the arts and humanities not only to educate the general populace about disability discrimination but to work outside legal frameworks to engender a sense of disabled peoples' humanity.”[4] Miller was the Henry M. Jackson Professor of Law at the University of Washington School of Law. Miller's statement encompasses the works that have been accomplished by Graeae, The DisAbility Project,

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[4] Sandahl p. 125. Paul Steven Miller (May 4, 1961 – October 19, 2010).

and Deaf West. Miller fought discrimination in the professional world as his short stature was the subject of discriminatory practices by his potential employers. Miller's work as an advocate for disability rights led to changes in hiring practices and the ability for disabled workers to advocate for their rights in a court of law. He served on the Obama Transition Team as a member of the U.S. Department of Labor and the U.S Equal Employment Opportunity Commission (EEOC) agency review teams.

From 2006 to 2009, Professor Miller was the director of the University of Washington's Disability Studies Program, an interdisciplinary program that examines the social, cultural, historical and personal experience of disability. Prior to joining the law faculty, Professor Miller had been one of the longest-serving commissioners at the Equal Employment Opportunity Commission. While there, Professor Miller spearheaded the development of the agency's successful mediation program. He also served in The White House as Liaison to the Disability Community. Miller's actions in working for disability rights led to avenues being opened for disabled performers to work through Equal Employment Opportunity Commission to ensure that fair hiring practices take place when hiring professional actors. Miller's statement gives us insight to what is needed to bring about the necessary changes to the process and allow for further exploration in the field of training for disabled performers. His words are similar to the mandates put in place by the legislators who wrote the ADA and EA.

Carrie Sandahl has brought together her own work and included many disability scholars and activists in her research. She has worked with Brenda Jo Brueggemann, Jim Ferris, Philip Auslander, and Petra Kuppers. Dr. Sandahl is an Associate Professor at the University of Illinois at Chicago in the Department of Disability and Human Development. She directs Chicago's Bodies of Work, an organization that supports the development of disability arts and culture, through festivals, advocacy, and an artist residency program. Her research and creative activity focus on disability identity in live performance and film. As a leading scholar in Disability Studies, Sandahl has pioneered a new look at disabled artists and the cultural significance of training and performance in her book *Bodies In Commotion*. The idea of 'commotion' as disturbance and unruliness is only one way of using the term as a description of disability theatre. Sandahl looks at commotion as people and things moving together which is why she brings costumes, props, and staging to her daily life activities and disrupts them. She encourages other disabled artists to welcome staring by others and seeks to bridge the worlds of non-disabled and disabled people. Sandahl notes that the word 'commotion' references disturbance and unruliness as well as moving together.[5]

Sandahl takes into consideration that staring occurs in typical interactions between disabled and non-disabled people in everyday interactions. Her goal is to have disabled artists actively put themselves in the view of non-disabled audiences with their art and invite staring. By opening this line of communication conversations can begin during the interactions that will open up both parties to understanding the relationship that has been established by that specific work of art. If verbal communication does not occur the work is still effective because the art is in view of the non-disabled audience and has an effect on that person. Sandahl posits: "How does the disabled body challenge theoretical notions of performativity?"[6] Sandahl's training of her actors has taken

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[5] Sandahl p. 10.

[6] Sandahl, Carrie and Philip Auslander. *Bodies In Commotion: Disability and Performance*. University of Michigan Press, 2005.

what started with the passing of the ADA in 1990 and brought what was in the background into the forefront of disability advocacy. Although she was not the first to advocate for professional training of disabled actors, Sandahl has created a body of work that invites other scholars and theatre professionals to follow up with their own works and creative processes.

Stephanie Barton-Farcas has gone beyond research on disabilities and has provided a practical manual for inclusion in the arts. Her book *Disability and Theatre* contains many case studies that show different theatre companies that have mounted productions that include disabled actors and the various difficulties each has encountered while producing their shows. As artistic director of Nicu's Spoon Theatre Company, she has faced similar issues as the companies she highlights and gives suggestions for overcoming the same problems for future companies that wish to begin similar work.

Barton-Farcas provides a subdivided list of disabilities for the layman: visual, hearing, mobility, cognitive/developmental, degenerative diseases, and general. All of these would classify under the term impaired and each presents its own needs when approaching the topic of acting on stage. Barton-Farcas advises first and foremost to include all details of the production in the audition process and to clarify all needs by the actors who will perform the roles. She also mentions that all the details from the performers need to be collected so communication is open and all parties concerned are on the same page. The production team is responsible for leading the changes in the production that are made for disabled actors to ensure success. She also points out that it is the responsibility of those working in disability and inclusive theatre to serve the disabled audiences as well as the artists.

In addition to the scholars that have focused on education and training are professionals in the theatre world who have had advanced training usually reserved for non-disabled performers. Bernard Bragg was trained at the New York School for the Deaf before enrolling at Gallaudet University for his actor training.[7] Bragg was a part of the big "D" Deaf community. Both of Bragg's parents were deaf. This led to his studying at Gallaudet which is a school for deaf students. He has since served as an artist in residence at Gallaudet as well as performing globally. The man who would co-found the National Theatre of the Deaf received training from schools specializing in working with deaf actors. This is an example of proper training being received and turned into a successful career. Bragg continued his individual training with Marcel Marceau in France and helped create theatrical works on stage and television. Bragg's career is an example of what can happen when professional training is disseminated to prospective performers.

Another deaf actor who has had success in her own work is Terry Galloway. Galloway has detailed her experiences in her memoir *Mean Little Deaf Queer*. In it, she tells about her life as a little "d" deaf artist growing up in a hearing community. As stated earlier, big "D" refers to people born to deaf parents who sign and live primarily with deaf communities. Lower case "d" people are born hearing and become deaf but integrate with mainstream society in their primary living situations. Galloway began to lose her hearing at the age of 9 due to an experimental antibiotic given to her mother when Galloway was in utero.[8] It was not until later in her career as a deaf performer that she decided to act out her own humorous interpretation of her life experiences. She

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[7] Bragg, Bernard. *Lessons in Laughter: the Autobiography of a Deaf Actor*. Gallaudet University Press, 2002.
[8] Galloway, Terry. *Mean Little Deaf Queer: a Memoir*. Beacon Press, 2009.

became a more vocal advocate for disabled artists. In 1986 Galloway performed her one person show *Out All Night & Lost My Shoes*. That same year she co-founded the Mickee Faust Club in Tallahassee, Florida and became its Artistic Director.[9] Both Galloway and Bragg have written their own material which aligns them with the goals of Graeae to promote the professional works of disabled artists.

Visibility and Hypervisibility

The subject of what is seen on stage is essential to the discussion of disability performance on stage. Disabled actors will be performing in roles that may or may not have originally been written as having disabilities. No matter what the origin of the fictional character the disabled actor will bring his or her specific disability into the role. Visibility is what we see as audience members when we attend the performance. Hypervisibility references specific attention given to the disability and the detail in making the audience members aware of the disability as it is played out on stage.

British Deaf Leader Paddy Ladd states: "We wish for the recognition of our right to exist as a linguistic minority group…labeling us as disabled demonstrates a failure to recognize we are not disabled in our own community."[10] This statement is in reference to the Deaf community and its view on the communication barrier that exists between itself and the hearing community. It is used as a catalyst for change and the need for attention from both communities to bridge the gap that exists between hearing and deaf people. Ladd's desire to be recognized as a part of a specific

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[9] www.theterrygalloway.com/terry-galloway.html.

[10] Sandahl, Carrie and Philip Auslander, editors. *Bodies In Commotion*: *Disability & Performance*. 2005. University of Michigan Press, p.44.

community references both uses of commotion with the desire to disturb the typical thoughts about deaf people while moving together, and hearing people acknowledging deaf people while working with them and recognizing their contributions to society.

The idea of community in this context is a reference to groups of people that interact on a regular basis. When varying communities come together and see differences between each community there will be questions about differences and why they are separated from each other. This blending of deaf and hearing communities while recognizing their uniqueness and what each brings to the table is part of the change that has occurred in theatrical works with deaf actors. Prior to the Americans With Disabilities Act (1990), deaf performers were relegated to work in industrial jobs that require little or no communication between employees. Deaf actors had to seek out or create their own works in order to be afforded the opportunity to perform on stage or screen. In the motion picture *The Miracle Worker* (1962) Patty Duke is neither blind nor deaf. Her portrayal of Helen Keller earned her a Best Supporting Actress Award as her work was seen by audiences as heroic and uplifting. When deaf actors appeared on television programs in the 1970s and 1980s, it would often be in supporting short term roles. This did not translate into live theatre until more recent endeavors by producers and directors willing to use Sandahl's definition of commotion and move the deaf and hearing communities together.

Tennessee Williams' *The Glass Menagerie* is a play that continues to be performed professionally and on amateur stages on a regular basis. Written by Williams in 1943 and first staged in 1944 in Chicago, the play centers around the Wingfield family. Mother Amanda depends on son Tom to bring in money for the household since her husband left. Daughter Laura has a limp due to a childhood illness. Laura has a collection of glass figurines that are the center of her life as she continues to withdraw from the outside world. Amanda is focused on having someone take care of Laura and pressures Tom to bring one of his co-workers to the house to meet Amanda.[11] The role of Laura is often portrayed by a non-disabled actor as she walks with a limp around the stage. Carrie Sandahl addresses the stereotyping and negativity of disability as it pertains to the stage in *Bodies In Commotion*. In the chapter entitled "The Tyranny of Neutral", Sandahl argues that Laura Wingfield's limp is a 'mark of shame' as it is used as an excuse for her depression and desire for male companionship.[12] This is one example of disability as negative. It also leads directors and producers to choose non-disabled performers even though there are disabled actors available to be cast. Sandahl argues that this inequality in casting has caused many disabled artists to avoid pursuing professional training in the arts to improve their craft. There is an assumption for beginning actors that they must prepare their bodies and minds by learning to strip away their personal idiosyncrasies and achieve a 'neutral' body. This does not make sense to a disabled actor who must embrace his or her disability and how it will be used in creating a character. Disabled actors' bodies may wobble, tremor, or be asymmetrical. The assertion is that an imperfect body cannot achieve neutrality and cannot create the correct character. This is yet another roadblock to disabled artists seeking proper training and eventual performance on stage.

A 2017 production of *The Glass Menagerie* starring Sally Field as Amanda at the Belasco Theatre in New York City also starred Madison Ferris in the role of Laura. Ferris has muscular dystrophy and is in a wheelchair. Director Sam Gold wished to bring more focus to the disability

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[11] Williams, Tennessee. *The Glass Menagerie*. New Directions, 1966. (Original published date 1943).

[12] Sandahl, Carrie and Philip Auslander, *Bodies In Commotion: Disability and Performance*. University of Michigan Press, 2005.

by making it more obvious to audiences. This example of a director casting a disabled actor to perform a role that has a different disability that demonstrates the creativity of choice and how a production can be used to bring more attention to another aspect of the written part. The draw for the show was Sally Field. The audience members who attended were confronted by the visualization of a disabled actor and the barriers she faced on stage that could be projected to her everyday life outside of the theatre. *Chicago Tribune* theatre critic Chris Jones applauded the choice by director Gold in his review.

Jones' critique spends most of its time complementing Gold and Field with a focus on the stage entrance of Amanda pushing Laura's wheelchair from the side of the theatre to make it onto the set on stage. His description of how Field should be commended for not receiving the normal adulation from the audience during her initial appearance in the play due to the work she is doing to help Ferris' character get to their house undermines the work of Ferris in her role and again champions the work of non-disabled actors working with disabled artists. He does not mention Ferris' performance at all but focuses on changes in the storyline that made the character of Tom seem selfish and evil for wanting to leave his sister as he seeks his independence from the household.[13]

In contrast to Jones' review is Ben Brantley's from *The New York Times*. Brantley gave each actor equitable time and space as he focused on the acting and not the celebrity of the stars. His take on Ferris' interpretation includes a description of an actor who emanates a no-nonsense spirit of independence and is the least pitiable Laura he had seen. She stood up to her mother in

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[13] Jones, Chris. "Sally Field Stars In A 'Glass Menagerie' That Breaks The Mold." *Chicago Tribune*. March 9, 2017.

conversation with the eye-rolling exasperation of a contemporary teenager and had an insolent beauty with a face that brought to mind a young Debbie Harry. She was not the willfully invisible, shyness-sickened girl recalled by the play's fourth character, Jim O'Connor who knew Laura when they were in high school. She showed an independence that challenged viewers to see her for more than her obvious disability.[14]

The difference between these two professional critics mirrors the difference in audience reactions to the same show. Neither is incorrect in what he saw. Each one chose to place emphasis on what he believed to be the stronger part of the performance. To Jones, the focus was on the visibility of Ferris' performance. She was a disabled actress performing a role on stage. Brantley alludes to hypervisibility as Ferris' disability is described as being very much in the sightlines of the audience. Ferris knew the role of Laura would bring her into the realm of hypervisibility and that her acting would bring a better awareness of disability performance to audience members.

This is a specific example of Carrie Sandahl's statement about hypervisibility and the importance of inviting staring from non-disabled audiences. By hiring an actress with a different disability than the character being portrayed, director Gold brought hypervisibility to the show and challenged non-disabled audience members to look at a disability in its true form and see it played out on stage.

Deaf West Theatre recently staged a production of Steven Slater and Duncan Sheik's musical adaptation of Frank Wedekind's play *Spring Awakening*. The 2015 production made history by having the first recorded casting of a wheelchair actor on a Broadway stage. It also used

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[14] Brantley, Ben. "Review: Dismantling 'The Glass Menagerie.'" *New York Times*. March 9, 2017.

deaf actors with non-disabled actors in the lead roles. American Sign Language (ASL) was used as well as captioning for audience members unfamiliar with ASL. This is an example of disabled actors taking on roles that were originally written as non-disabled. Director Michael Arden made a choice to use both non-disabled and disabled actors much like Joan Lipkin has done with her work with The DisAbility Project since 1995. The blending of the cast shows the work that can be done given proper rehearsal time and communication among the artists.[15]

Deaf actress Sandra Mae Frank portrayed Wendla Bergmann. Frank was shadowed by non-disabled actress Katie Boeck who carried a guitar as she spoke Frank's lines and sang her songs while Frank communicated with ASL. Alex Boniello did the same for deaf actor Daniel Durant in their shared role of Moritz Stiefel. The production served both hearing and deaf audiences as both types of communication were used. The use of multiple disabilities on a Broadway stage gave more credence to future productions that may not have been considered prior to this production. It also brought hypervisibility like was used in *The Glass Menagerie*.

At times when there was only ASL used, a translation was provided on a chalkboard for non-ASL users to understand. The show opened on Broadway in the Brooks Atkinson Theatre. This performance altered both the audio and visual perceptions of actors and audience members. The preparation had to take into account the work of the actors as well as the needs of the audiences who would be in attendance. It not only showed that this work can be accomplished but that it can be done at the highest level of theatre.

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[15] Ross, Ashley. "How Deaf Actors Are Breaking Boundaries On Broadway With Spring Awakening." *Time*. October 8, 2015.

One other nuance to *Spring Awakening* was the use of a disabled actress in a wheelchair. Ali Stroker danced, sang and acted with her non-disabled cast mates and had to learn ASL to complete her role. In an interview with the *New York Daily News*, she mentioned how difficult it was to learn ASL and how much work she put into communicating with the deaf actors in the cast.[16] Stroker's casting made history as the first recorded wheelchair performer on Broadway. Stroker's training will always differ from non-disabled actors as her 'neutral' position will begin and end in a wheelchair. Stroker's disability was acquired as she was in a car accident that left her paralyzed from the chest down.

Disabled artists in the performing arts have improved their quality of life by taking active parts in these shows. The opportunities for disabled actors to perform have increased since the passage of the ADA in America and more companies are being challenged to use disabled actors to perform disabled roles.

The use of multiple disabilities on stage in a Broadway show gives more credence to future productions that may not have been considered prior to this production. Non-disabled people are not used to seeing a disabled person in a wheelchair pop a wheelie as part of a dance. This was a choice made by the actor, director, and choreographer in the production of *Spring Awakening*. All parties were involved in creating this artistic movement to enhance the show.

Since the main concern of Deaf actors is communication, the Deaf community works on bringing attention to works performed by deaf actors or that have deaf actors in the cast. Kristy

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[16] Dziemianowicz, Joe. *'Spring Awakening' actress Ali Stroker Makes History As First Actor In A Wheelchair On Broadway*. New York Daily News. September 15, 2015.

Johnson references The Graeae Theatre's production of *Blood Wedding* in her book *Disability Theatre and Modern Drama*. In this piece, Kristy Johnson references that the character of Mother was deaf in this performance and that captions were used to help those who had trouble hearing the mother when she chose to speak.

Two concepts are critical in this choice by director Jenny Sealey. First, there is a misconception that deaf people cannot speak. The link of being deaf and being mute is based on stereotypes that are portrayed in the media and passed on to the hearing community that has no other frame of reference. Second, the audience members are taken into consideration for all Graeae productions. In this case, Sealey and Graeae made a decision to keep hearing and deaf audience members from misunderstanding what the mother was trying to communicate by using captions. This also helps when ASL or British Sign Language (BSL) is used to permit hearing audiences to better understand what is being said on stage.

Petra Kuppers states in her book *Disability And Contemporary Performance: Bodies On Edge*: "The physically impaired performer has to negotiate two areas of cultural meaning: invisibility as an active member of the public and hypervisibility and instant categorization as passive consumer and victim in the popular imagination."[17] Kuppers is relating to her own personal experience as a disabled artist and scholar. Many of her essays relate to the experiences she has encountered which make her work more grounded in the details necessary to bring a greater understanding of what a disabled artist faces in a world dominated by non-disabled performers.

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[17] Kuppers, Petra. *Disability and Contemporary Performance: Bodies On Edge*, Routledge, 2003.

The invisibility Kuppers references comes from the interactions disabled people have when out in society with the lack of disabled workers in retail or other businesses that mirrors the lack of disabled actors on stage. Hypervisibility references the need for society to fix the “broken” people with disabilities. In theatrical terms, it is a reference to my mention of the need for non-disabled audience members to see a non-disabled actor take on a disabled role and “rise” to the occasion and overcome the disability at the end when the bows are taken and the actor is able to see or walk. This is an instinct in non-disabled people to see disability as a negative aspect of life instead of accepting it as is. The need to ‘fix’ what is broken is another way to describe a non-disabled view of a disabled person. Non-disabled actors seem heroic when portraying a disability because they have convinced the audience that they truly had those disabilities. Kuppers and Sandahl have dedicated their work to moving past these perceptions about disability and see the work for its merit, not for the misrepresentation of disability as broken part of a person.

Kuppers posits this truism concerning disability performance: “The performance of disability relies on the understanding that disability is transparent, uni-vocal, easy to see, and wholly reproducible in theatre.”[18] This statement encompasses all aspects of disability in society as well as on stage. A disabled person will show his or her disability in all things that he or she does. Even if the disability is not visually obvious it will be a part of that person’s interactions with non-disabled members of society.

Mickey Rowe, an autistic actor chosen to perform the lead role in *The Curious Incident of the Dog In The Night-Time* that opened on September 17, 2017 at the Indiana Repertory Theatre,

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[18] Kuppers p. 54.

needs a script to go shopping or otherwise interact with people as he goes about his life. This is the same with disabled people who have epilepsy or Alzheimer's Disease as they negotiate everyday communication in typical settings. Each of these disabilities can be replicated on stage with actors who have these disabilities. Risa Brainin, director of the show, looked up Rowe's website after he auditioned for the role. One video clip showed Rowe juggling fire while riding a unicycle. This showed Brainin that Rowe had the physical ability to perform the role.

Colette Conroy has stated in her book *Theatre & The Body* that phenomenology is an important reference point for scholars and practitioners of disability theatre. "When we think about bodies as entities that see, feel and move in radically different ways, as in disability theatre, the idealized body becomes disparate bodies."[19] It is important to understand that the disabled actor will experience a completely different preparation for a role than a non-disabled actor. The process of developing that character will draw from the actor's own experience and it is the responsibility of the director to use this background and incorporate it into the role in order to bring out the best performance from the actor. The audio and visual aspects of the play will be altered as it pertains to the actor involved in the role.

Conroy also points out that we need to think about bodies as entities that see, feel, and move in radically different ways, as in disability theatre, and the idealized body becomes disparate bodies. The way a disabled actor in a wheelchair moves from place to place will be unique based on the position he or she needs to take during each scene. This will look odd to anyone who has

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[19] Conroy, Collette. *Theatre & The Body*. Palgrave Macmillan, 2010. P. 55-56. Colette Conroy is Lecturer in Drama at Royal Holloway, University of London, U.K. and editor of *Research in Drama Education's* themed issue: "Disability: Creative Tensions in Applied Theatre."

not been exposed to that disability. Conroy talks about the Graeae Theatre Company's 2006 production of Sarah Kane's *Blasted*. This production involved the actors vocalizing brief descriptions of their actions as they performed the show. There was also a projection on the backdrop with subtitles and signs for deaf audience members.

Roderick Random wrote a critique for the Graeae production and compared it to a German show he saw the year prior. Thomas Thieme, the actor playing the soldier in the German production is described as a slow-moving giant of a man with overpowering physicality. David Toole played the same role in the Graeae show. Toole has both legs amputated and move around the stage on his hands. Random applauded the power, emotion, and versatility of this actor but criticized the speaking of stage directions as taking away from the raw physicality of Kane's text.[20]

In this review, the critic falls into the same trap mentioned earlier about romanticizing disability by talking about how heroic David Toole's performance was in this show. His assertion is that the tall German actor's height brought more drama to that production. Random's critique is contradictory as he praises Toole's performance but shuts down the reading of stage directions by the same actor.

This critic's response to disability theatre is an example of what Conroy points out as a change that needs to occur in the relationship between non-disabled audience members and disabled actors. Every disabled performer uses his or her body in disparate ways to convey the message of the play or musical. Non-disabled critics should educate themselves about the actors

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[20] Random, Roderick. "Theatre Review: Blasted by Sarah Kane-Graeae Theatre Company-Soho Theatre." February 15, 2007. http://roderick-random.blogspot.com/2007/02/theatre-review-blasted-by-sarah-kane.html

and companies before placing their own viewpoints into their written pieces. Actors use critiques to understand the audience perspective on their work. A better critique would focus on the changes that have occurred because of the work of companies like Graeae which have allowed more disabled actors to perform on stage and make a living in the fine arts. The fact that Graeae chose to work with such a powerful and challenging script as Blasted shows how far theatre has come since the early part of the 1990s.

Bree Hadley, scholar at Brisbane University in Australia, investigates the construction of identity in contemporary, pop cultural and public space performance practices. She concentrates her research on the way spectators are positioned as co-performers in these practices. She views public performances by disabled artists as a challenge to audiences and their perceptions of what is to be expected and what is actually being shown by the individual or company. "What are you? What is wrong with you? How can you live that way?"[21] These questions are posed by people in clinical settings such as hospitals or medical care facilities. The same questions have been posed to disabled actors during talkbacks that are held after performances. Joan Lipkin and her DisAbility Project have heard similar questions in the many venues they work in and around St. Louis, Missouri. When opening the discussion of the performance up to questions most non-disabled audience members pose personal questions of the actors that sometimes have little or nothing to do with the content of the performance.

Hadley's point is that dry and clinical questioning used for purposes of science has shifted over to public performance as it becomes more prevalent in society. It is a part of the process of

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[21] Hadley, Bree. *Disability, Public Space Performance and Spectatorship: Unconscious Performers*, Palgrave Macmillan, 2014.

opening a conversation with both non-disabled and disabled people to increase awareness of the obstacles faced by actors who use their talents in a field that is adding more performances and performers each year. Hadley also points out that there is much more to do to progress the discussion. Hadley provides an example that centers on the character of Artie Adams on the television show *Glee*. The producers made a conscientious decision to have a non-disabled actor portray a disabled character in a wheelchair. Furthermore, when a dance is incorporated it is used in a functional manner without artistic sense for the number. As was mentioned previously in the staging of *Spring Awakening* by Deaf West Theatre, actress Ali Stroker danced with the non-wheelchair actors during the musical numbers. This included jumping with her chair and twirling around on stage in live performance. The work can be done. Producers and directors make choices that set back advancements that cannot be attributed to the limitations of the actors or the disability.

Cripping Up: Playing a Disability Instead of Living It

Non-disabled actors who perform disabled roles continue to be challenged. The term is referred to by scholars and disabled artists alike is ‘cripping up’ which specifically criticizes the awarding of non-disabled actors disabled roles because of how believable they are in playing those characters. This section looks deeper into the arguments for eliminating this practice and how it further inhibits disabled actors from obtaining roles in theatre.

Petra Kuppers is a professor at the University of Michigan who challenges existing assumptions about disability and artistic practice. Specifically, she explores the intersection where cultural knowledge about disability ends, and the lived experience of difference begins. An award-winning artist and theorist, Kuppers investigates the ways in which disabled performers challenge, change and work with current stereotypes. She explores freak show fantasies and medical theatre as well as live art, webwork, theatre, dance, and photographic installations. Kuppers casts an entirely new light on contemporary identity politics and aesthetics. Thus, Kuppers explores some of the most pressing issues in performance, cultural and disability studies today, writing as a leading practitioner and critic.

As a disabled artist Kuppers gives firsthand knowledge of the limitations imposed by non-disabled society on disabled performers. Kuppers has published several books along with her duties as Creative Director for The Olimpias. The Olimpias project series was set up in 1998 as a platform to investigate relationships between technologies, identity, and a holistic understanding of well-being and community arts. Participants of Olimpias include people in pain, disabled people, people with cancer, women's groups, professional dancers, visual artists, alternative health practitioners and members of community projects.

Petra Kuppers is an Associate Professor of English, Women's Studies and Theatre & Drama at the University of Michigan, who answers to many labels — professor, dancer and author, to name a few. However, she is also a wheelchair user and fully embraces the label of disabled, a label she has had all her life. In Kuppers’s lifestyle, her history, her classes, and her work, she embodies the phrase ‘New Traditions’. Kuppers states that writing from her cultural perspective has always been really important. The cultural movement related to disability is changing the world. Kuppers’s classes not only embrace the ideals of her University that requires inclusion and fulfill a requirement, but they aim to break down the walls of discrimination and open students' eyes to their own bodies.

Kuppers is an artist whose medium is available at any moment and in any form. She is a dancer, an author, a producer and a teacher who is amazed and moved by the beauty of the human body. Kuppers states that in our culture, thin bodies are sought after, but able bodies are expected. The body's limitations are constantly exposed and revealed, from diet crazes to medical imagery practices showing the terribly intricate spreading of cancer cells.

Kuppers was born disabled in Germany and has been a wheelchair user all her life. She has traveled the world and bridged gaps between disability culture and the body as an instrument for expression. Before becoming a tenured professor, Kuppers began her career performing poetry and engaging in the alternative and community dance scene. Her performances fuse video, poetry, and dance and encouraging audience participation. Aside from three academic books, Kuppers has co-authored a poetry book, *Cripple Poetics: A Love Story*. During a performance, they dance, touch and smile at each other while reading from the book. Written from the perspective of her lover recounting one of their shows, it details a shared, intimate moment: the melting and reshaping of two important worlds — bodies and passion. Kuppers states that the majority of responses are warm and positive and that many people speak to her about how empowering it was to them, to see someone speak about love and sexuality in the context of disability, and from a position of being involved in it, rather than analyzing it.

The book's title verges on taboo. The word 'cripple' holds negative connotations; it's a harsh word to the ears of many disabled people. Kuppers states: "I have chosen to use this word in this book not only because of its strong emotional impact…"[22] She uses the term because of its

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[22] Kuppers, Petra. *Disability Culture and Community Performance: Find a Strange and Twisted Shape*. Palgrave Macmillan, 2013.

poetic richness; there is much more heft, much more richness, much more weight, and so much more metaphorical density in the word ‘cripple’ than there is in ‘disability.’ She is very interested in the meanings of the word, how it sounds in the ear and how it ripples off her tongue. She restates her belief that disability culture depends on opening itself up to all connotations of disability.

However, disability culture is more than the rectification of discrimination. While the Americans with Disabilities Act of 1990 affords similar protections as those in the Civil Rights Act of 1964, Kuppers believes there are still plenty of places out there in the world that cannot be accessed. Internationally, many dance departments and theater departments are still inaccessible to wheelchair users. Kuppers still can’t get into the spaces. She could not do what she does anywhere else in the world that makes her very glad to be living in the U.S.

In keeping with her positive personality, she acknowledged that while discrimination and lack of access have been intimate features of her life, at the same time they’ve been the machines that always pushed her to create her art and shape a creative politics. Disability culture is about accepting and transforming the challenges that come with living in a discriminatory world and celebrating the richness of human responses to hardship.

Kuppers received a Ph.D. at an arts college in the United Kingdom. As an undergraduate performance studies major, Kuppers explained, that she was able to take classes, but the students usually had to be moved to other, more accessible buildings, and that was very awkward because it was always focused on her.[23] Thus began Kuppers' experience with hypervisibility as a disabled student in a primarily non-disabled world.

Kuppers describes her Disability Culture class as getting right to the center of the subject—there's no fluff. According to her, it's a class in which they talk about this emerging cultural form, the disability culture movement. The students look at a wide range of causes and look at the responses to those causes, given the kind of world they live in. And they consider how the world has changed, the discrimination that people have faced, and the significant creative opportunities that are emerging. Her work is about the depth of our culture, a wider and deeper experience that's not just about celebration and pride, but celebration and pride with an acknowledgment of pain.

When reflecting on her experiences, both scholarly and artistic, it's clear both are exposed in her written word as well as in her performances. Aside from personal work, Kuppers is also involved with research. It does not just spark a need for change or involvement within disability culture, it pushes, pulls and creates a desperate need for an awakening of personal experience, in connection with others' personal experiences. Understanding discrimination in all its facets is an important part of a liberal arts education. As students, we are often taught the important dates, the big movements, and the strides in society. We learn to sympathize and empathize. But with educators like Petra Kuppers, that is just not enough. Disability culture is a strong woman's tool for learning and teaching others about self and about the community. Kuppers believes that

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[23] "'U' Professor Petra Kuppers Dances With Her Disability." *The Michigan Daily,* https://www.michigandaily.com/content/petra-kuppers.

disability culture, in a sense, stems from a need to overcome obstacles and find community and that is really quite how all of us live our lives.

Kuppers challenges the work of scholars to move the conversation to one of disabled actor preparation and performance instead of lingering over past stereotypical reactions and continuation of the 'cripping up.' She states: "Similar to blackface actors, non-disabled people can prove the 'mastery' of their craft by acting disabled."[24] This bold statement from Kuppers may be seen as circumventing of racism and racist tropes if taken out of context. In the setting of theatre, it has a direct correlation to a distinct minority group, namely disabled performers. Kuppers insists on using the word 'cripple' at a time when the acceptable word is being changed to disabled for non-disabled people. She uses the word in the context of how things used to be to demonstrate how far society has come in its understanding of disabilities. In theatre, her use of an outmoded and unacceptable word prompts discussion to reflect on the past and to prompt the work that still needs to be done.

In her newer works Kuppers has faced criticism. Students and community members who have attended her performances have suggested her company needs to rehearse more to make the work better. This is not her goal. Such disapproval is part of myth-making which is an outcome of the expectations of non-disabled audience members. The audience members' response is a reaction to the imperfect bodies on stage taking longer to speak, move, and generally portray their parts. It is for the benefit of the audience that it is uncomfortable. The audience has suggested that the actors should "rehearse more."[25] This type of commentary does nothing to help with the

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[24] Kuppers p. 54.

[25] Kuppers p. 6.

understanding of disability theatre. Such criticism uses ‘standards’ of theatre as an excuse to dismiss disabled actors and the work they have accomplished. A more clear discussion between audience and actors would encompass theatre aesthetics and expectations of the performance. In this specific case both sides needed to communicate more clearly prior to the show what expectations they had with this piece of art. Both sides have to be in on the conversation in order to get the experience of a truly moving theatrical piece. Kuppers wanted to make the setting uncomfortable to welcome ‘staring’ an invite criticism to what was produced. The next steps are the most critical in inviting both sides to the discussion and creating an understanding of how important the work of artists like Kuppers is to disability theatre.

Kuppers makes a very strong statement in *Disability and Contemporary Performance: Bodies On Edge*. In it, she states “Disabled performers are often aware of the knowledges that have been erected around them: tragic, poor, helpless, heroic, struggling, etc.”[26] With this she is not speaking to non-disabled actors performing disabled roles. She is emphasizing that there is no barrier that cannot be overcome when placing a disabled actor on stage. Kuppers’ work with actors using her own style of rehearsal and performance is pushing expectations of theatre and introducing a new dynamic with disability theatre. Adaptations that are required to be made in homes and public buildings can be reproduced on a stage. It is the responsibility of the producers of the shows to make the physical changes necessary to accommodate the disabled performers.

Deaf West provided such changes with the dressing rooms and the stage entrances for *Spring Awakening*. Stroker’s ground floor dressing room was updated to meet the ADA standards

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[26] Kuppers p. 3.

that included handlebars in the restroom. A ramp was added to the set design for entrances and exits although Stroker would also use the set doors with the non-disabled actors. The final issue in the process is choosing the best actors for the roles that are cast. Opening casting calls to disabled actors will create a more inclusive process and people can be judged by their acting prowess. Taking away physical barriers literally and figuratively opens doors and allows for more opportunities for disabled artists to audition for parts. This removes the first part of the argument for more inclusiveness and moves the discussion on hiring disabled actors to perform in roles that have not been offered to them in the past.

Included in Kristy Johnson's *Disability Theatre and Modern Drama* is a discussion about a multimedia performance art piece with Terry Galloway and Carrie Sandahl concerning *Shattering The Glass Menagerie*. Amidst the showing of images from various productions of *The Glass Menagerie* by Tennessee Williams both Galloway and Sandahl discuss their interpretation of the character Laura from the viewpoints of two disabled artists. Both artists coveted the role of Laura at some point in their lives. Both felt that it was a role that fit them since the role is disabled with a limp. This leads to a discussion of disability as it is performed on stage and actors that are cast in those roles. Both rue the fact that they had never been cast in the role for various reasons. Sandahl because she was cast as the older curmudgeonly character of Amanda, Galloway because she was cast as the male characters of Tom and Jim in separate productions.[27] These slights made them begin to hate the character Laura and how she has been portrayed as someone needing to be saved due to her disability. Non-disabled actors are used to show the 'heroism' of their work.

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[27] Johnson, Kirsty. *Disability Theatre and Modern Drama: Recasting Modernism*. Bloomsbury Publishing Plc, 2016.

Sandahl and Galloway use this piece as an example of a systematic problem in the performing arts community in its use of non-disabled actors in disabled roles.

Kirsty Johnson also references Simi Linton whom is one of the top disability studies scholars. Linton and Sharon Jensen led a discussion of disabled artists and industry professionals in 2005 concerning the number of disabled actors featured in theatre, film, and television. A statement by Emily Perl Kingsley, a writer for *Sesame Street*, sums up their work succinctly: “The message has to get out to casting people with disabilities can be ordinary.”[28] The work of Sandahl and Linton among others cannot be progressed unless there is an open discussion with people like Kingsley who are involved with the everyday work of the performing arts.

. In my earlier example of the character of Laura in *The Glass Menagerie* these roles go to non-disabled performers who are given praise for how realistically they portray the disability. Once the curtain falls and the actors come forward without the disability they have enacted they are lauded as triumphing from the disability. Disabled playwright John Belluso stated in a similar panel discussion in 2001 that when a non-disabled actor takes a bow and is standing instead of remaining in his wheelchair the audience is let off the hook as the performance is artifice. When a disabled actor comes out for a bow, the audience must face and understand that the disability is real and is bigger than the topic of the play.

As stated earlier the 2017 production of *The Curious Incident of the Dog in the Night Time* staged by Syracuse Stage and starred the first autistic actor in the lead role of Christopher Boone who is autistic. Actor Mickey Rowe first performed the role at Indiana Rep before taking on the

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[28] Johnson, Kristy. *Theatre and Modern Drama*.

same part in New York. The Broadway production won a Tony Award for best play in 2015 with the role of Christopher portrayed by non-disabled actor Alex Sharp. The casting of Rowe is another step in giving an opportunity for a disabled performer to act in a disabled role. During an interview with *Playbill*, Magazine Rowe stated his case for being chosen to play the character of Christopher. "Being an actor comes naturally to me. I use scripting in my daily life."[29] His reference in the interview was to his interactions with people as he shops, studies, and generally interacts with others. Rowe has a script in his head that he has memorized when making purchases. If any part of the script is altered he does not have a way to improvise. He sticks to his script and moves on despite what other people may think of his words or actions.

I was first introduced to the novel which provides the source material for *The Curious Incident of the Dog in the Night Time* by my Disability Studies professor at Ohio State University. Professor Brenda Jo Brueggemann assigned it as reading material in 2009. At the time I did not see this as a potential play adaptation. Parents with autistic children can relate to the source material on a personal basis as they contend with the unique world their children live in and coping mechanisms they use to get through each day. Casting Rowe as Boone allows a more in-depth portrayal of the role and gives a bigger voice to the lives of autistic people.

Conclusion

Disabled artists have faced many barriers accessing the world of theatre as performers. Disability theatre continues to be an emerging topic because the work of professionals like

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[29] Rowe, Mickey. *The First Actor with Autism to Play Curious Incident's Autistic Lead Speaks Out*. http://www.playbill.com/article/the-first-actor-with-autism-to-play-curious-incidents-autistic-lead-speaks-out. March 13 2017.

Kuppers, Sandahl, Barton-Farcas, Conroy, and Hadley. New work opportunities for future productions have been created through the hard work of actors and theatre companies willing to make choices that will not necessarily translate into immediate monetary success due to the newness of the work being done and the response of audiences to these works. The use of disabled actors in theatrical performance continues to be proven successful in examples as noted. What then is holding back more theatres from making the choice to use disabled actors?

Since the ADA was enacted in 1990 opportunities for disabled actors to work in theatre have increased due to other aspects of life becoming more manageable and on par with non-disabled people. Transportation, residences, and workplaces have been updated to bring them up to code based on the mandates of the ADA. While owners of businesses argue that unfunded mandates put the economic burden solely on them it is more often referred to as reparations for past injustices at which time these services were not available to people with disabilities.

Petra Kuppers challenges conceptions of disabled performers and the use of harmful words in descriptions of disabled people in society. "When all buildings have ramps, when all work spaces have safe rooms, when all elevators talk, disability will disappear."[30] This statement brings everyone together with the position that removing the physical barriers from all people will lead to the removal of societal barriers imposed by the misunderstanding and often the non-recognition of disabled people in all aspects of life. The disability will not disappear. The artificial barriers will.

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[30] Kuppers p. 17.

Carrie Sandahl brings her work as a disability scholar to the theatrical world with many examples of successful productions but with a critical eye towards the history of disability portrayal in the written word as well as on stage. "Disability is considered out of the ordinary, separate from the everyday, a cause for pause and consideration."[31] It is this statement that links disability studies and disability performance. Both topics are driven by the demands of the onlooker upon the person he or she is looking at in a given circumstance. In theatre, it is a statement that culminates in a relationship between audience and cast that will bring questions and challenge preconceived notions of disability and how it is portrayed compared to the past experience the audience members may have with a disability.

Stephanie Barton-Farcas provides a practical guide to working with disabled actors using experiences from professional and community disability theatre groups. This guide is not meant to be condescending or as the answer to all questions that may come up during work with a theatre that features disabled actors. It is meant as a tool in an increasingly complex and a more complete list of works that are being written and staged for audiences as time has passed. Kristy Johnson and Collette Conroy have cited recent productions that have successfully used disabled actors to perform roles that have traditionally used non-disabled actors. Plays as different as Frederic Garcia Lorca's *Blood Wedding* and *Blasted* by Sarah Kane have moved the conversation forward from the traditional disability dramas such as *The Miracle Worker* (1957) by William Gibson and *Children of a Lesser God* (1979) by Mark Medoff, both which featured deaf female roles.

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[31] Sandahl, Carrie and Philip Auslander. *Bodies in Commotion: Disability and Performance*, University of Michigan Press, 2005.

Leonard Davis is one of the top disability scholars at the University of Illinois at Chicago. As Dr. Davis notes 15% of all Americans have a disability. These disabilities are by birth, accidentally acquired, or results of injury during a conflict. This percentage justifies the need for the ADA and the changes it inspired. Davis references disabled artists such as the writer James Thurber who lost an eye due to an early childhood accident and how Thurber did not let his disability prevent him from following his passion to become an author. Thurber did so without the benefit of ADA legislation. Educational institutions are now federally required to assist students and provide them with the least restrictive environments to accommodate the learning process. Students on Individual Education Plans (IEPs) has almost doubled since ADA growing from 31.7% to 62.2%. (National Center for Education Statistics 2017 data).[32]

The ADA was one step that opened a larger discussion about opportunities in the workforce for people with disabilities. The theatrical world is now involved with this same discussion as more companies are providing opportunities for actors who have disabilities to take the stage and perform for a living. In the following chapters, I highlight two specific companies that have taken steps to bring newer works not only performed by disabled actors but written by disabled playwrights. I discuss each company's significance in the big picture of disabled theatre and how its landscape has changed since the time of ADA.

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[32] Https://nces.edu.gov/fastfacts/display.asp?id=64.

The first is a discussion of the DisAbility Project in St. Louis, Missouri and the second focuses on the Graeae Theatre in London, England. Both have grown in performance and structure since the passage of ADA. I compare and contrast each company and examine their contributions to the field and discussion of the future of disability theatre.

Chapter Three: Joan Lipkin and the Formation of The DisAbility Project in St. Louis Missouri

"Our name reflects who we are: bold, brave, willing to step outside the status quo in order to instigate social change, promote civic dialogue and produce transformative theatrical art of the highest quality for people of all ages."[33] This mission statement of That Uppity Theatre Company reflects the specific objective of the mission statement of The DisAbility Project: namely it empowers individuals, honors their stories, sparks imaginations, fosters community, encourages civic dialogue, and enhances public awareness about disability through innovative theatre of the highest quality.[34]

Joan Lipkin created That Uppity Theatre Company in 1989 in St. Louis Missouri and serves as its producing artistic director. Lipkin was working as a guest artist in residence at Washington University in St. Louis when she decided to create the company. The focus was and continues to be to create commissioned work about social issues pairing amateur and seasoned actors. The group makes work about lives of underrepresented people including university students, at-risk youth, survivors of suicide, people with Alzheimer's and early onset of dementia, women with cancer, gay/lesbian/bisexual/transgender adults and youth, and people with disabilities.[35] Each focuses on the specific message of their division but allows for crossover to occur when possible. The DisAbility Project exists under the umbrella of That

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[33] www.uppityco.com. Mission statement from That Uppity Theatre Company. (Accessed 1 June 2019).
[34] www.disabilityproject.com. Mission statement from The DisAbility Project (Accessed 30 April 2015).
[35] www.uppityco.com. Wording comes directly from the company's web page.(Accessed 1 June 2019).

Uppity Theatre Company. Its members are of varying age, gender, ethnicity, and sexual orientation. The overall theme for the DisAbility Project is public awareness of disabilities and identifying stereotypes non-disabled people believe about disabilities.

The DisAbility Project is a community based company in St. Louis, Missouri. It is composed of actors, producers, and technical assistants with and without disabilities. In the following this chapter considers the origins of the company as well as its works through the years up to the present. It includes comparisons to contemporary companies that use disabled performers.

Joan Lipkin is a playwright, actor, director, teacher, and social activist. Her work encompasses all groups underrepresented by the mainstream theatre. In 1995 she co-founded The DisAbility Project with Fran Cohen, an occupational therapist. The Project has a season that runs from September through July and performs in Missouri and Illinois. Despite Fran's death in 2012 the group continues her work as the company enters its 23rd season in the fall of 2018. Vanessa Roman who joined in 2001 serves as an Artistic Associate which is necessary as Lipkin's work often takes her to New York City and beyond for lectures and other projects. Becky Galambos is the Arts Administrative Assistant and Lipkin's right-hand person in keeping all schedules in place for actors, directors, and audience members. The current choreographer is Jennifer Medina from the Common Thread Contemporary Dance Company.

Three specific points and time periods are considered during operation of The DisAbility Project as well as the history of its founding. Lipkin begins the work a few years after the passage of the Americans with Disabilities Act in 1991. Following is a focus on *The Assorted Short*

Adventures of Tom, Huck, and Becky that was the first major piece performed by the company. The next section moves to the early 2000s and work entitled *One World* that incorporated more movement and opportunities than previous productions. I close with current projects and changes faced by the company due to scheduling conflicts and health situations with specific members is the focus of the final section.

Fran Cohen and Joan Lipkin Found The DisAbility Project

Fran Cohen was working at Washington University in St. Louis as a faculty member in Occupational Therapy as well as coordinating the adult day care program for the Red Cross when she met Lipkin. Cohen's work with elderly disabled people at the university and as coordinator of the adult day care program for the American Red Cross sparked Cohen's interest in bringing disability theatre to St. Louis. As a student, Cohen had been an athlete at Washington University and became the first international women's racquetball singles champion in 1970.[36] This experience was crucial to her future career. Cohen wanted everyone to be able to move and live full lives no matter what physical condition they were experiencing.

Cohen and Lipkin began the project with the goal of bringing together people with and without disabilities to model the inclusion program that is used in public schools in the U.S. In this educational setting inclusion involves a disabled student or students taking part in a classroom that has nondisabled students with a regular classroom teacher. A special needs assistant follows each disabled student as he or she travels between classes and remains in the room during the class

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[36] Sorkin, Michael D. *Fran Cohen; Teacher, Therapist and Co-Founder of the DisAbility Project Acting Troupe*. Https://www.questia.com/newspaper/1P2-33555931/fran-cohen-teacher-therapist-and-co-founder-of-the.

period. The regular classroom teacher in tandem with the special needs assistant work cooperatively on lesson strategies to build a classroom experience. This focus makes sure that disabled students are able to work in the least restrictive environment and interact with the nondisabled students.

The DisAbility Project emulates this model by providing such an environment for its actors and by welcoming personal aids to rehearsals and performances when schedules permit. Since there is no specific home base of operations for the theatre company they rely on available space as it opens up that can accommodate the personal needs of the actors. Cohen's connections with local hospitals and rehabilitation services allowed for the initial use of these facilities. In recent years the company has been hard-pressed to find rehearsal space and have worked more as a nomadic tribe as they continue applying for state and federal funding to assist the continuation of their group's work.

Lipkin cannot point to one particular incident that inspired her interest in disability issues. Growing up in Chicago's Hyde Park, she was friendly with a one-armed fruit and vegetable seller. Much later, as an adult working with Uppity, she began to realize that disability was a natural outgrowth of feminism. Her reason for such a connection is that both women and disabled people are defined by their bodies. [37]

In 1996 Lipkin attended a workshop at the Atlanta Center for the Arts with the celebrated playwright and director Joseph Chaikin, who had written several experimental plays about

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[37] Levitt, Aimee. "Thespians On Wheels: Joan Lipkin's DisAbility Project Is On A Roll." *Riverfront Times*. 12 November 2009. This quote is part of interview Levitt did with Lipkin after The DisAbility Project's performance of *Tom Sawyer* for the Big Read Festival in St. Louis.

disability. Chaikin studied at Herbert Berghof Studio in New York City before joining The Living Theatre in 1959. He left The Living Theatre in 1963 and founded his own ensemble called The Open Theatre. After many successful years, he disbanded The Open Theatre in 1973 believing it had become too institutionalized. Chaiken said, "...I have learned that to study or to talk about the theatre is to come face to face with assumptions beyond those which I could see at first."[38]

Chaikin staged works in the Joseph Papp Public Theatre, Yale Repertory, Manhattan Theatre Club, and The Mark Taylor Forum. He collaborated with Samuel Beckett directing Beckett's *Endgame* in 1980 at The Manhattan Theatre Club. Chaikin also collaborated with Sam Shepard co-writing the plays *Tongues* and *Savage/Love* that he performed as the voice while Shepard played percussion in 1978. Both plays are monologues about romantic love and both closeness or distance between lovers. Chaikin suffered a stroke in 1984, which left him with aphasia, a language disorder. Lipkin remembered that his speech was difficult to follow, but Chaikin was an inspiring and amazing model of an artist she aspired to become. Despite his stroke, Chaiken continued to work in theatre and he continued his relationship with Shepard.

Lipkin would work with Chaiken as an associate director at the Atlantic Center for the Arts. She likened his process to Matisse making cutouts after he became ill and could not paint while standing.[39] Her belief is that if you want to be an artist you need to look at the world and uncover truths and dissect the world and put it back together in a different way. Lipkin believes that people

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[38] Chaikin, Joseph.*The Presence Of Theatre Pg. ix* (1972) part of the forward.

[39] Joan Lipkin interview Transcript #6 Appendix A. It is important to note that in an interview with Aimee Levitt (*Thespians On Wheels: Joan Lipkin's DisAbility Project is on a roll* 12 November 2009) Lipkin was quoted as saying "...Monet made cutouts after he started to go blind." My interview with Lipkin included this same anecdote except that the artist she referenced was Matisse. Matisse is the correct artist for this reference

have the drive to create and to be in the world and are adaptive. Chaiken made her look at disability in a new way that made her want to go back to her own community and do similar work.

Upon returning to St. Louis, Lipkin met Cohen for the first time after Cohen contacted her about her work with Chaiken in Atlanta. Cohen asked Lipkin to give a talk about her experience. Instead Lipkin suggested they both meet with leaders in the disability community in St. Louis and propose they establish a theatre troupe to perform work like Chaikin's. Cohen liked the idea and believed it would allow people with disabilities to advocate for themselves and would be very empowering. The meeting included Max Starkloff, the founder of Paraquad that is a privately funded independent Living Center for people with disabilities, and Jim Tuscher, Vice President of Public Policy at Paraquad. Tuscher was the Missouri field leader who advocated passage of the ADA and was on the White House lawn when President George H.W. Bush signed it into law in 1991.[40] Lipkin originally proposed the project for adults because children had more options for socializing in their school setting. Once everyone was in agreement that this new theatre company would work under the umbrella organization That Uppity Theatre Company and that Lipkin would serve as producing artistic director, the decision was made to begin meetings once a week with interested actors. Cohen used her connections in the Occupational Therapy school at Washington University to secure the use of the lobby of the school. Meetings took place on Saturday as the building was rarely occupied at that time. The DisAbility Project was the first group of its kind in St. Louis.

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[40] Sorkin, Michael D. *Fran Cohen; Teacher, Therapist and Co-Founder of the DisAbility Project Acting Troup.*Questia. https://www.questia.com/newspaper/1P2-33555931/fran-cohen-teacher-therapist-and-co-founder-of-the.

In the fall of 1996, Lipkin was diagnosed with breast cancer.[41] After she recovered, she began to work with her ensemble to create a repertoire of sketches. Lipkin found that this new company was attracting interest in younger people with disabilities and many of them joined as it was getting off the ground. This showed Lipkin that the need was just as significant for young people with disabilities even with the services they receive at school. Lipkin and Cohen initially focused on the process and not the product. 'Sharing circles' began each session that allowed people to talk about their lives. The actors were getting to know each other and to trust each other. These stories would become the basis for the first scripts used by the DisAbility Project.

The initial performances were held in the lobby of the Occupational Therapy building among family and friends. This was done to ease the group into acting in front of an audience while receiving feedback. As the performances continued invitations began coming in because of the connections Cohen had with organizations in the St. Louis area. The group gave its first public performance in the spring of 2000 at the downtown Marriott for 300 attendees of the International Post-Polio and Independent Living Conference. The company went out to the staging area and looked out at the sea of people. Some of the audience members were on ventilators. Lipkin suggested that the actors and audience should do some deep breathing and gentle stretching to begin the show. The audience looked at the actors with eyes wide with expectation as the stretching exercise began. Lipkin realized the power at that moment as the audience went along with the cast's movements. They were open to the first thing she suggested. Something was really starting

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[41] Levitt, Aimee. "Thespians on Wheels: Joan Lipkin's DisAbility Project Is on a Roll." *Riverfront Times*. 12 November 2009.

to happen. All future work would include at least one interactive component to actively involve bringing the spectators into the performance mode.

Lipkin told her actors, “Some of you did this with us and wanted to work on this, or wanted to work with me, and there’s no expectation that you continue, but I have a feeling that there’s something really special that happened here that can continue. I want to continue.”[42] Under Lipkin’s creative direction the company uses skits, songs, dance, stories, audience interaction, and question-and-answer sessions to communicate their message to their audiences. They have toured primarily through the states of Missouri and Illinois and have performed in front of more than 100,000 people in over 150 venues. The typical audience is a school ranging from kindergarten through high school although they have also reached out to businesses, colleges and universities, churches, and county fairs.

A production will typically focus on the disabilities of each of the actors. It then focuses on a recollection of a personal story about that actor and the situations he or she has faced in a real-life situation and how it affects future choices made by the actor when encountering a non-disabled person in a specific setting. Such autobiographical performances allows the company members to co-author new scripts and take on the additional role of the playwright for the performances. Lipkin takes the stories from the actors and incorporates them into a cohesive story that allows each person to be involved in a work’s creation.

One colleague of Lipkin’s is Ann Fox, a professor of English and gender studies at Davidson College in North Carolina. Fox specializes in 20th and 21st-century dramatic literature

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[42] Joan Lipkin interview Appendix A Page 205.

and disability studies. Dr. Fox has received many fellowships and has served on the executive board of the Society for Disability Studies and the MLA Executive Committee of the Division on Disability Studies. She lectures on the topic of disability and representation at universities and conferences around the world.[43]Fox describes The DisAbility Project as a community-based theatre. Fox was part of the ensemble when she taught at Washington University in St. Louis. She explains that the group comes out of the local community, for the local community, to answer questions it has about itself as a disabled theatre company.

In terms of process the performances could be compared to the work of Anna Deavere Smith. Such a comparison centers on using spoken text as the source for the scripts. Smith is an author, playwright, and actor celebrated for her one-woman plays in which she performs multiple characters. The work examines social issues linked to current events. Smith uses interviews with a variety of people whose personal stories become the source material for her work.[44] This is similar to Lipkin's work with The DisAbility Project on their *One World* production. Lipkin's actors relate their personal life experiences when they perform. Fox explains she can only think of only two other similar groups that use a similar process: Actual Lives in Austin and the Wry Crips in Berkeley. Every rehearsal begins with the sharing circle where cast members talk about their lives.[45] These discussions furnish the raw material for most of the group's productions.

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[43] https://www.davidson.edu/academics/english/faculty-and-staff/ann-m-fox. (Accessed 6 June 2019).

[44] Britannica.com/biography/Anna-Deavere-Smith. (Accessed 10 November 2019).

[45] Levitt, Aimee. "Thespians on Wheels: Joan Lipkin's DisAbility Project Is On a Roll." *Riverfront Times*, *Riverfront Times*, 14 Mar. 2019. Https://www.riverfronttime.com/stlouis/thespians-on-wheels-joan-lipkins-disability-project-is-on-a-roll/Content?oid=2482592.

Several years ago, Stuart Falk, an actor in the DisAbility Project who has multiple sclerosis, spent several weeks in and out of the hospital owing to a series of urinary-tract infections. He described his experience as a trip to a resort — not quite Club Med, but Club Medicine. In a potential breakthrough moment, Lipkin and Fox looked at each other and asked Falk to tell more but to stay within the metaphor of being at ‘Club Med’. Fox and Lipkin went home and typed it up which resulted in a five-minute monologue entitled *Club Med* and remains Falk's signature piece. In the piece, he finds himself in the back of a warm van with a woman in uniform. She says, 'What's your name?' and begins touching him in different places. She then asks “How does this feel? Here? Here? Now, do you have insurance?” which bursts that bubble. The piece starts as a look at a potential romantic encounter for Falk and transforms to a worrying clinical approach to hospitalizations and health insurance.

Fox and Lipkin wrote a paper for *Feminist Disability Studies In 2011*.[46] Their essay “Res(Crip)ting Feminist Theater Through Disability Theater Selections from the DisAbility Project” focuses on the literature that is available concerning perceptions of disabled people living in a ‘normal’ world from the vantage point of disabled authors. Similar to the early works of Graeae Theatre of London these plays focus on disability as the topic for the actors to discuss. This continues to be the focus of The DisAbility Project. The Fox and Lipkin paper emphasizes that The DisAbility Project is a group that is composed of amateur performers and has fewer resources than professional companies that work with disabled actors.

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[46] Fox, Ann M. and Joan Lipkin. “Res(Crip)ting Feminist Theater Through Disability Theater Selections from The DisAbility Project.” *Indiana University Press*. DOI: 10.1353/nwsa.2002.0004. This paper publishes three scripts from Joan Lipkin and The DisAbility Project: *Facts and Figures, Employment,* and *Go Figure*. They are listed as unpublished manuscripts as they have not been submitted to a company for public viewing.

There are about 25 short plays in the repertory that are rotated in and out of commission depending on the group's audience and who happens to be in the current ensemble. *Club Med,* for instance, would not be appropriate for an assembly of first-graders, particularly the part where the narrator bemoans his inconveniently timed erections, and most certainly wouldn't be as funny without Falk's New Jersey whine. The work is personalized by Falk and is focused on his life experiences. Like many new works created by playwrights Falk relies on what he knows to tell his story as a disabled artist.

Tom Sawyer **Revisited: A Modern Look at a Classic Literary Work**

One of the early pieces was a production entitled *The Assorted Short Huck, and Becky Adventures of Tom*. This musical was part of the Big Read project of St. Louis which selected *The Adventures of Tom Sawyer* as its highlighted novel for its libraries. In this production, most of the actors were in wheelchairs including the leading roles of Tom and Becky. The musical was co-written by Lipkin and Aarya Sara Locker, who was working as Associate Director of The DisAbility Project in 2010. Locker was a former clown with Cirque du Soleil before coming to St. Louis. Local songwriters and musicians Steve Givens and Mike Hall composed the score and wrote the lyrics. Felicia Scott served as a vocal coach. Scott worked with the St. Louis Symphony Orchestra and served as Executive Director of Wired Women, Inc., a production company that hosts women’s dances across the St. Louis Metropolitan area. J.T. Ricroft choreographed the dance numbers after working on the national tour of *A Christmas Carol* as well as Opryland USA and Busch gardens where he served as a performer and choreographer.

"We focus on what everybody can do and not get caught up in what they can't do," says Locker, the associate director, in a company interview in the *Riverfront Times*. "The hard part is not to assume what they can't do. It's easy to take people at face value, and everyone in the group is more than their face value."[47]The company wanted the opportunity to do theatre work other than works that reflected on them as disabled. Lipkin agrees: “Most of our work has been about the culture of disability, but why not stretch ourselves? Why can’t Tom Sawyer be played by someone in a wheelchair?”

For this production, the ensemble consisted of 15 active members with and without disabilities who were diverse in age, race, ethnicity, class, occupation, education, religion, sexual orientation, physical ability, and performance experience. The productions were free to audiences with reservations required due to limited seating. Challenging audience perspectives was a primary goal of the production. Casting Margaret Jorgensen as Tom opened discussions with audiences about role reversal and perceptions of characters that change from book to stage. Jorgensen has been in a manual wheelchair since 2001. Her diagnosis is degenerative joint disease and rheumatoid arthritis. Ana Jennings took on the role of Becky working with an electric wheelchair. Jennings has a spinal cord injury she acquired late in her life. She continues her work as an advocate for people with disabilities while working with The DisAbility Project.

One of the realities of the company is the need for every actor to know all of the parts of each piece. This includes songs, staging and choreography. The need did not come up that often for *The Assorted Short Adventures of Tom, Huck, and Becky*. But this mandate was significant as

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[47] Levitt, Aimee. “Thespians on Wheels: Joan Lipkin’s DisAbility Project is on a roll.” *Riverfront Times*. November12, 2009. https://www.riverfronttimes.com/stlouis/thespians-on-wheels-joan-lipkins-disability-project-is-on-a-roll/Content?oid=2482592

health or transportation issues were known to occasionally keep some cast members from attending booked performances. Since the need for transportation and preparation is fundamental to the success of each performance, each cast member is ready to step in and take on a role that was not originally assigned to them. Choreography for the dance numbers involves a mixture of non-disabled and disabled actors. The movements involve a blend of walking actors turning performers in wheelchairs while maintaining a physical connection by holding hands. Actor Bryan Jones has a limitation of how much weight he can lift due to Ehlers-Danlos Syndrome. Jones will often dance with a non-disabled actor while standing on the tops of that person's feet. This movement helps Jones with his confidence during the musical numbers while protecting the safety of both Jones and his dance partner.[48]

The *One World Project* and Common Thread Contemporary Dance Company

"...why I created original material, because when you devise, you can meet the needs of whoever is in the room, and not just the needs but the desires of whoever is in the room, right?"[49] Joan Lipkin, discussing the *One World* performance, explains in her interview for this project. Each member of the company was invited to give their specific connection to The DisAbility Project. The company's individual experiences are crucial information in understanding the work and its scope. Lipkin explains: "I was interested in the fact that I didn't see many people with disabilities in the audience, let alone on stage. It seemed to me that there was a crucial part of the

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[48] Jennifer Medina interview Appendix A Page 150.
[49] Joan Lipkin interview Appendix A Page 226.

contemporary experience that was being left out."[50] These words from Lipkin serve as a window into her thinking as she formulated her plan to work with Fran Cohen and create a project that would bring opportunities to a segment of society in St. Louis that did not exist to that point. Lipkin is not the first to notice this deficiency in the theatrical community as I have pointed out in my first chapter. It was, however, a defining moment in her motivation to bring about an activist theatre project that would go beyond the traditional productions of a company. She brought to the forefront a group that used their own disabilities as part of the production which normalized the use of disabled performers in productions.

As Lipkin explains, "We don't want to be tolerated, we want to be included."[51] This statement is at the crux of the argument that pervades the political and social aspect of disability studies. There is a misconception that tolerance is an acceptable term when varying groups of people encounter each other in unusual circumstances. Students in schools are taught to use the mantra 'teach tolerance'. This accepts the premise that some groups are not valuable to society. Lipkin fights against this premise with another educational tool: inclusion. I have witnessed both of these practices first hand as a high school educator. Inclusive education does more to help a range of different groups understand the struggles of each person who is not 'allowed' to be part of the other groups. Lipkin uses this premise as her backdrop in working with the various stories of each performer on their scripts. The productions become lessons in everyday interactions that the actors deal with on a regular basis. The scripts are not used as platforms for demeaning or

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[50] Baugher, David. *Inclusive Theatre Group Readies for JCC Performance*. https://www.stljewishlight.com/feature/arts_culture/inclusive-theater-group-readies-for-jcc-performance/article_6de7b9zz-4a83-11e0-bd3-001cc4c002e0.html.

[51] Lipkin, *The Journal*, Webster University, 2013.

talking down to audiences. They are used to transitioning the conversation from disassociation to empathizing with the actors.

Lipkin says: "Disability is an experience that crosses all categories of identity including race, gender, class, age, and sexual orientation. It is a club that any of us can join at any time."[52] Her reference here is to her own battle with breast cancer. Her conclusion brings forward a discussion on many people who will be temporarily disabled during the course of their lifetime due to injury or illness. It also allows Lipkin to speak from a disabled perspective as she did not anticipate being impacted personally by cancer. Lipkin moved from affecting change for her actors to being affected and relying on others to help her with her treatments.

The *One World* piece grew out of the need to tell each performer's story and relate their experiences from a global perspective. Once again Lipkin turned to a choreographer. Jennifer Medina and her Common Thread Contemporary Dance troupe are based in St. Louis. Medina worked with the actors using the music chosen by Lipkin and the company. The basic choreography remains in place but the need for each actor to learn everyone else's blocking and movement presents a challenge that is not limited to spacing. In some cases, a different placement means working with a different non-disabled dancer. This may be an easy adjustment for the Common Thread members but for the actor Bryan Jones, it is a change that can mean the difference between a successful performance and a bad experience. Jones has adjusted to these changes with varying success and would rather try a new dance partner than not perform at all. "It was exciting!

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[52] *Vital Voice*. January 3 2014. http://www.thevitalvoice.com/disability-project. This is one of the more recent articles about Lipkin and her work with the DisAbility Project.

It was different, and, well, I was kind of nervous at first. When we start new things I'm kind of like that. I get nervous when we start new things. But once we got into it, it wasn't bad."[53]

Bryan recalls his recent works as they are the freshest in his mind. The sketches *Three Little Pigs* and *People See Me* are pieces Bryan enjoys because rap is used. The biggest obstacle Bryan faces with the DisAbility Project is accessibility for the performers. He wants to continue to perform with the group and is hopeful that additional work will continue to be booked. My interview was short because Bryan communicates with very short and direct statements. I closed my questions by asking Bryan if he would like to see more people with disabilities on stage. After confirming he would like this I asked him why. His response sums up his view on the issue of disability theatre. "Because people with disabilities can do things that other people can do."[54]

In 2015 the company was invited by the St. Louis Museum of History to perform *One World* for the 25th anniversary of the ADA. The museum had many guest speakers and displays showing the history of this civil rights law. The DisAbility Project took the outdoor stage in between two of the speeches and provided the conference audience the opportunity to witness a contemporary performance group that embraces the ADA's ideals. This is the most recent production from The DisAbility Project. *One World* is a piece designed to inform audiences about the specific issues each cast member faces or faced while negotiating a society that has not been as open to assisting when needed or treating disabled people with respect. The work shares conversations between disabled and non-disabled people. Choreography is incorporated with non-disabled dancers from Jennifer Medina's Common Thread Contemporary Dance Company. Non-

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[53] Bryan Jones interview Appendix A Page 145.
[54] Bryan Jones interview Appendix A Page 153.

disabled Common Thread dancers and The DisAbility Project disabled dancers work in unison to connect both worlds on stage.

The stories that are incorporated into the *One World* production come from the backgrounds of the actors and speak to the specific disability each actor has and the reactions he or she has when encountering non-disabled people in everyday situations that range from a grocery store to hair salon. The performance focuses on educating the audience about prejudices the performers face and the presumptions that are made by non-disabled people about disability. The introduction allows each actor to illuminate the audience about his or her respective disabilities. The cast begins by entering the stage as the Lady Gaga song *Born This Way* plays on the sound system. Each actor moves forward at intervals and informs the audience about his or her disability and if he or she was born with it or acquired it. Ana Jennings moves downstage first and states: “I wasn’t born this way. I was 18 years old when I contracted tuberculosis of the spine and spinal meningitis. I walked into college at LSU at the age of 18, and at the age of 23, I rolled out with my degree.”[55]

It next turns to an empowering scene titled *I Am A Piece Of Art* and allows each actor to describe how he or she is a piece of art. Actor Margaret Jorgensen says “My name is Margaret and I am a piece of art because strength is art and my struggles only make me stronger” as she spins around in her wheelchair. In more intimate spaces the cast invites the audience members to take an active part in the production by stating how each of them is a piece of art. This allows for a

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[55] Script from *DP ”One World” Show*, Appendix C, revised October 16, 2014. Printed with permission from Joan Lipkin.

connection to develop between audience and performer and creates a sense of empathy to begin taking shape so that non-disabled members become a part of the show.

The transitional scenes incorporate monologues from each actor that specify a situation that the actors have encountered attempting to take part in activities that are more difficult to negotiate based on their disability and comments that have been made directly to them. A specific encounter concerns a fast food worker speaking extra loud and slow to communicate with an actor in a wheelchair when taking an order. The scene communicates clearly a demeaning and patronizing moment between the wheelchair user and the customer. Another startling instance is a non-disabled person using a disabled person's wheelchair as a coat rack while the person is in the wheelchair. Such real-life encounters help make the performance a work of social justice theatre with the goal of bringing understanding along with potential long-lasting change. It is also cathartic for the performers as they are able to express themselves and work through the issues they face on a daily basis. It increases the quality of their lives because they do not bottle up the hurt feelings they may have but instead express them in a theatrical production.

They wrap up with a series of poems by the actors giving advice to current and future friends about how to treat people with disabilities that breaks into *The DisAbility Project Rap* for its ending. The music and dance help the performers bring a rhythm and cadence to the performance while inviting the audience to experience an upbeat ending. The rap is used to modernize the material and allow an even flow of conversation between the players and the audience. Since most of the performances are in front of younger people it is important to The

DisAbility Project's process to connect with the students and relate the material in a way that produces further conversation on the topic of disability rights.

The personal interviews with cast members of the DisAbility Project bring a direct vantage point to the discussion. Each member has agreed to speak to the work of Joan Lipkin, how they came to be a part of the project, and how it has improved their quality of life. It is important to consider each actor's background. Each has a different disability. Some were natural born, some acquired through trauma, and some acquired through illness or disease. The company membership has been fluid as many actors have left due to illness, personal decisions to leave, or death. What must be noted is that each actor volunteered to join so he or she could be part of this project. It offered the opportunity to act on stage, something that had not been available to the performers before being involved with the project.

Lipkin's own work has been used in various incarnations of The DisAbility Project productions. *The Healing Ministry* was co-written by Sally Haywood, Edith Ritterband, Richard Scharf, Jim Tuscher, and Lipkin. It concerns the hypocritical attitudes of some religions towards people with disabilities. The central focus is how disability is perceived by non-disabled people. This is similar to the Graeae Theatre's early productions in that they both highlight disabilities that the actors have and how they negotiate daily interactions with non-disabled people. Lipkin's works take an approach of advocacy for awareness and societal change.

Lipkin's works are provocative and demand the audience look at all aspects of disability performance. *The Assorted Short Adventures of Tom, Huck, and Becky* references the original literature and includes music from folk musicians Steve Givens and Mike Hall. Co-written by

Aarya Sara Locker and Lipkin it includes disabled actors in the title roles. The piece incorporates local geography when referencing obstacles faced in the daily lives of the disabled performers. Choreography is also an integral part of the production, much like the choreography in Deaf West Theatre's *Spring Awakening*. Wheelchair-bound actors are able to move within the space they are given on stage and can jump and turn as needed depending on the type of chair they use. The choreography is adapted to the performers of the day as changes occur due to the availability of the actors and the schedule they keep.

Beyond *One World*: Perspectives on Future Works

"What interested me was that we would be equal parts education and entertainment and that we would help to change people's understanding and perception of disability and thus response and behavior towards people with disabilities through our work."[56]

These words speak to Lipkin's commitment to include people from all walks of life when she creates theatre. It is also what draws the performers to work with her in the various groups under the umbrella of That Uppity Theatre Company. Ana Jennings has been with The DisAbility Project longer than any other active member. Ana is an advocate for people with disabilities. She was attracted to it because of the entertainment value and the message it sends to people of all ages and educational backgrounds. Jennings believes that the company makes a statement in regards to what people with disabilities can and cannot do and provides a forum for displaying the abilities of people with disabilities. Initially invited in 2000 by a friend who was in the company to watch

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[56] Joan Lipkin interview Appendix A page 207.

a performance. Ana later approached Lipkin about joining. She was invited to a rehearsal and has been with them since.

A common practice in the structure of the group is the rotation of directors, producers, and choreographers. Jennings mentioned working with several different people who came from various locations in the U.S. This change in leadership is similar to the change in the performers in the company. The difference is the reason for leaving. The disabled performers leave for various health reasons. The directors leave for new opportunities in theatre. This dichotomy between people in the same company is a microcosm of the overall picture of disability theatre. Fewer options are available to disabled artists. Relocation is not a choice for actors who are dependent on personal aides or assistants to help them with daily functions such as travel, food preparation, and personal hygiene. An opportunity to perform in a city that requires uprooting the home structure is not easily accepted due to these constraints. This provides a more concise picture of roadblocks that exist for disabled artists but are not necessarily the same for non-disabled artists.

As noted previously, each venue is completely different in its approach to disabilities. Many are compliant with ADA codes, but older sites do not have access to the stage areas that are necessary for the actors to perform. Lipkin, her current artistic associate Vanessa Roman, and her administrative assistant Becky Galambos scout each site to make sure the needs of the actors can be met and the performance will be up to the company’s expectations. Lipkin initially managed all parts of The Uppity Theatre Company. As time passed and her presence was required at conferences both national and global events. Lipkin needed a person to manage the everyday workings of each subgroup. Galambos now manages the day to day details of The DisAbility

Project. This allows Lipkin to travel as needed and still have a system in place in St. Louis as a home base of operations for the company.

Becky Galambos joined the DisAbility Project in 1999 as a personal assistant to one of the actors in the group and helped some of the other performers who were dropped off at rehearsals by their attendants. Within two years Lipkin's personal assistant had left and Galambos was hired to manage the logistics of The DisAbility Project and its headquarters. Galambos' responsibilities include checking accessibility for each performance venue, sound and light options, and availability of power outlets for use by the actors with motorized wheelchairs. Accessibility takes on different meanings for each disability and requires preparation that does not allow for improvisation at the last minute. Due to Galambos' hard work ethic and the need to have a manager in charge of her home office, Lipkin hired Galambos to manage all parts of That Uppity Theatre Company. Interns are hired from local universities to assist Galambos in the daily upkeep of social media and marketing aspects of the job.

Galambos believes the most important issue involved with disability theatre is the portrayal of disability on stage and the actors chosen to play these roles. Galambos advocates for more representation of disabled actors when possible and for professional companies to take the lead in this advocacy. This also includes the use of non-disabled language when discussing disability issues. Part of the work of is to educate audience members about correct usage of language in its proper context when referencing people with disabilities and what language is considered offensive or insensitive. Galambos helps prepare each performance for each grade level if it is used in an educational setting. The messages remain the same but the delivery changes for each age level.

Galambos works with funds that come from the state of Missouri that support arts in education but has had the need to search for alternative paths such as crowdfunding to continue the work that was started by Cohen and Lipkin. Part of her responsibilities as manager of The Uppity Theatre Company is to keep all funding separate while maintaining a working balance for all of the groups under its umbrella. The DisAbility Project experiences fluctuations in government funding depending on the budgetary guidelines set by the political party in power. They are also reliant on local and federal funding. This reliance will often make the difference between being an active group that tours or holds performances on a regular schedule and being a group in name and rehearsal only. Galambos works from the home base in St. Louis to fulfill the needs of The DisAbility Project while maintaining a continual flow of funds for That Uppity Theatre Company as a whole.[57]

Needs include a managing director for each part of Uppity in order to delegate more responsibilities. This led to hiring of Vanessa Roman for The DisAbility Project. Roman was initially hired to direct a one-act play for Uppity and was offered the job with The DisAbility Project after the event. Roman has the role of director/actor/playwright for the group that fulfills the work Lipkin needs to be accomplished while she travels on her lecture circuit throughout the

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[57] "That Uppity Theatre Company." *That Uppity Theatre Company*, http://www.uppityco.com/.

world. Roman works with Galambos to do site visits and complete a comprehensive checklist of requirements from the venue that includes bathroom facilities that are accessible, green room space, and water. One organization that did not have accessible restrooms asked Roman if the actors could just ‘hold it’ for the performance. Roman turned down the offer as it would have set up a difficult situation for the actors.

This perspective from the people at this venue highlights the lack of understanding some non-disabled people have concerning disabilities. The irony is that part of each DisAbility Project performance focuses on the roadblocks the actors face in their everyday lives with public facilities and reactions from non-disabled people when confronting them in a public setting. Roman focuses on the positive reactions the company receives from audiences and the questions that arise from the material that is introduced to each new group. In the educational settings there are more revelations from staff members who tell Roman that they were unaware of the extent of the difficulties disabled people face in their everyday interactions..

Roman focuses on replacement of actors as the need arises for each performance. This will be the most important part of her job as director and will not change due to the dynamics of The DisAbility Project. The addition of music and dance provides another nuance to the shows and requires an expert choreographer. Jennifer Medina fills this role and works with Roman to bridge the blocking and movement portions of each scene. At times Roman will have to stop in for an actor who is ill so she herself must learn the choreography for all the parts. Medina cannot recall where they met but does remember wanting to work with disabled performers and especially with

Lipkin to flesh out her vision of disability performances. Medina's first work was during the Global Inclusion and Diversity Summit on February 28, 2013 held at Webster University.[58]

One of Medina's former students was born with only two fingers on one hand. The student moved to New York and began working with dancer Heidi Latsky. Latsky founded her own company in 2001 called Heidi Latsky Dance in New York City. This follows a career that includes being a principal dancer for the Bill T. Jones/Arnie Zane Dance Company, a commission from the Cannes International Dance Festival in 1993, and heading the Movement Department at the School for Film and Television. Latsky began working with Lisa Bufano who is a bilateral amputee that changed her focus to advocating for disability rights. [59] Medina sent her student to work with Latsky because she knew of the work she did and wanted her to work with the best. The networking between artists allows each one to find work situations that work out for both the artist and the company. Medina's professional connection with Latsky opens more doors for disabled artists to find such work.

Medina relies on Lipkin's personal knowledge of each actor to help her shape each move while finishing each scene. Medina's shaping references the optimal movement for each individual's disability. For Ana, one of the company members in a wheelchair, it focuses on the use of the chair as part of her movement. For Bryan, another company member, the focus is on having him dance on the feet of his dance partner so as to guide his movements and provide

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[58] Katelyn Gosik, "DisAbility Project demonstrates acceptance through performance", *Webster's Journal*, 5 March 2013.

[59] Http://heidilatskydance.org/heidi-latsky.

constant human contact. This alleviates Bryan's concern for the choreography and allows him to focus on his characterization.

Jennifer Medina describes what it was like to work with the DisAbility Project actors. She says: "Well my goal was to, as always, when I work with people who haven't danced before or very much, is to find shapes that they can achieve."[60] This statement from Medina extends beyond the Lipkin's work to all aspects of her choreography. Medina approaches all dancers with the same respect and set of expectations to have them perform at their highest level of professionalism. The most important part of her process is listening to the actors and working with their specific abilities and keeping communication open as they work together on each number. Medina sees each dancer she works with for the potential he or she has to perform at the highest level he or she wishes to attain. Their performance at the Missouri History Museum, discussed earlier, was the culmination of months of preparation and collaboration between The DisAbility Project and Common Thread Dance Company. They were prepared. The artists worked in extremely cold weather in an outdoor setting. This did not hinder them from giving their best during the performance.

The DisAbility Project serves as an example of amateur theatre managed by professionals that includes disabled actors, writers, dancers, and singers. They are not paid for their work yet they still pursue theatre as a means to express their artistic capabilities. I have given examples of professional training in dance and acting that provided to the players and the opportunities to perform for a range of people from a few dozen to thousands. The interest in their work is apparent. As Petra Kuppers states, "This performance work does not aim to only create beautiful products,

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[60] Interview with Jennifer Medina Appendix A Page 129.

but wishes to share a more accessible and respectful world for all of us, a world I can and wish to live in."[61] Kuppers references disabled actors who create live theatre for audiences to observe as opposed to other fine arts fields where works such as paintings or sculptures are on display without the presence of the artist. Joan Lipkin's work embodies this dynamic and works to bridge the communication gap between non-disabled and disabled people by presenting work that is provocative and informative.

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[61] Kuppers, *Disability Culture And Community Performances*, p. 4.

Chapter 4: Beginning of The Graeae Theatre of London, England, and their current work

"This disabled theatre company had given me the confidence to perform and a belief that I, as a disabled person, had equal value as an arts creative."[62] (Matt Fraser, Graeae actor)

The Creation of a Professional Theatre Company for Disabled Performers

In 1981 Richard Tomlinson and Nabil Shaban founded The Graeae Theatre Company. Actor, writer, film-maker and activist Shaban had attended Derwen College to become an actor. He had been rejected by several drama schools but was determined to pursue his craft. From Derwen, he moved on to Hereward College for the Disabled in Coventry where Tomlinson was a professor of history and English. Tomlinson interviewed Shaban during his application process. It was during this interaction that Tomlinson became aware of Shaban's interest in theatre.

Shaban was born in Amman, Jordan and was disabled by Osteogenesis Imperfecta, better known as brittle bone disease.[63] This disability led his parents to send him to England for medical care and his subsequent movement from hospital to hospital and eventually a series of residential homes. He had minimal contact with his family and decided to pursue an advanced educational degree at the university level. Shaban's professional partnership with Tomlinson would begin after Shaban graduated from the University of Surrey with a degree in Psychology and Philosophy. They soon created the Graeae Theatre Company**.**

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[62] Sealey, Jenny. 20 *Reasons To Be Graeae*, Oberon Books Ltd., 2018. Pg. 20.

[63] Shaban, Nabil. *Unfinished Histories: Recording the History of Alternative Theatre*. Https://unfinishedhistories.com/interviews/interviewees-r-z-3/nabil-shaban/.

Tomlinson was born in Glasgow and was educated at Cheltenham College. He pursued and obtained a history degree at London University, traveled to South Africa, then returned to England to teach history at the National Star Centre at Cheltenham before moving to the Sandford Centre in Cheltenham. Tomlinson became principal at the Thomas Delarue school for the disabled in Tonbridge from 1981-1989 where he brought in the Major Road Theatre Company to create site-specific work with his students. His work at Thomas Delarue coincided with his collaboration with Nabil Shaban to create The Graeae Theatre Company.

Tomlinson was a longtime worker for disabled people specifically in the field of education. He met Nabil Shaban at Hereward College for the Disabled in the early 1970s. Shaban was a student and Tomlison a lecturer. They first discussed forming a theatre company of physically disabled actors while they both were at Hereward. From Hereward College Tomlinson went to the University of Illinois in Chicago to obtain his MA in education with a specialization in child psychology. The first show he worked on was entitled *Ready Salted Crips* which would later be renamed *Sideshow*. He continued developing *Sideshow* with Shaban and first staged it at the University of Illinois in 1976. Tomlinson convinced Shaban that they should create a theatre company for disabled performers to continue building upon their initial work.

Tomlinson believed that disabled people had stories to tell about their experience and wanted to create a series of shows that told these stories. They toured *Sideshow* around Warwickshire and its success inspired them to create a theatre company that provided opportunities for disabled people to educate non-disabled people about their lives.[64] Their initial goals were the

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[64] Https://Graeae.org/about/our-history/. The website for the company has been redone since the beginning of my research and today reflects a more condensed version of its history. Both Tomlinson and Shaban are still credited with the founding of Graeae.

same as Joan Lipkin's DisAbility Project. Shaban agreed to create the company with Tomlinson if he could continue to act. His life had been spent proving his reliance on a wheelchair did not inhibit his ability to achieve his goals in life which included acting.

"Disabled people have the right to expect the same opportunities as anyone else. That isn't only a legal requirement, it's a moral imperative. (Jamie Bedard, Graeae actor)"[65] Tomlinson and Shaban wanted a name for the company tied to mythology and disability. Shaban wanted to use something from mythology to dispel the misconceptions and myths about disability and that idea became the name of what was to become a myth-breaking theatre company. Graeae is the Greek name of three sisters who shared one eye and one tooth. Perseus sought the Graeae to find the location of three magic items to aid in his killing the Gorgon Medusa. Perseus stole their eye and promised to give it back in exchange for the location of the three items he needed. Shaban and Tomlinson decided that would be the name of their new theatre company because of its reference to disability.

The year 1981 was designated the International Year of Disabled People so they worked to get Graeae up and running by that year.[66] To gain the attention of the theatrical world they applied to perform at the International Conference On Rehabilitation and Disability that was to be held in Winnipeg, Canada in 1980. After their application was accepted they brought their

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[65] *A Guide To Inclusive Teaching Practice In Theatre.* Graeae Theatre Company. September 2009. This quote is from an interview of Graeae actor Jamie Bedard and included in the DVD that comes with the guide. It gives support to the work Tomlinson and Shaban did to create Graeae and shows the commitment Bedard and other performers have in the company. Bedard currently works as co-artistic director of Extraordinary Bodies which is a partnership between Cirque Bijou and Diverse City at the National Theatre in London.

[66] *Nabil Shaban-Unfinished Histories*. https://www.unfinishedhistories.com/intervews/interviewees-r-z-3/nabil/shaban

production of *Sideshow* to the conference which led to a tour of the United States beginning at the University of Illinois. The duo performed twenty-seven shows in twenty-three days.

At this time Tomlinson and Shaban were simultaneously recruiting actors for *Sideshow*. The first troop consisted of people who were blind, in wheelchairs, had muscular dystrophy, and spina bifida. The only other abled bodied person besides Tomlinson was the assistant stage manager. The official start date of the company was May of 1981 with a premiere at Surrey University then a tour of the USA.

Shaban described the uneasy birth of the company: "Richard wasn't happy with the *Sideshow* script, felt it needed a better ending, so he was still writing it as he drove half the cast to our first performance at Surrey University. I was already at the venue, getting nervous and impatient, waiting for Richard to arrive with the other half of the company, having to make apologies to the organizers for the delay. Richard arrived, announcing that the script was completed and we had ten minutes to learn the new ending. Despite all this last-minute panic, I was stunned at the audience's enthusiastic reaction, laughing in all the right places, and giving us a standing ovation."[67]

The cast and crew were considered amateurs at the time so were limited to performances on the weekends. Professional companies performed during the week as well as the weekend. Their first paying venue was Oval House which paid the company 200 pounds for a single performance. The publicity from the company advertised the show as a comedy with burlesque and satire

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[67] Https://the-ndaca.org/resources/audio-described-gallery/graeae-theatre-company-poster-for-the-production-sideshow/. Quote from Nabil Shaban published by the National Disability Arts Collection for audio archive by Colin Hambrook in February of 2018.

featuring characters trapped in a fairground freak show under the control of their warden Uncle Sidney. Shaban had hoped to shock and outrage the audience only to receive loving responses from the people who saw the production. Oval House has a reputation as one of the most important centers for pioneer fringe theatre groups that dates back to the 1960s. Works that have been sponsored by Oval House include gay and lesbian plays, women's theatre, and new black and Asian productions.

The inclusion of disabled actors stretched the scope of productions sponsored by Oval House. Katie Milton, Development Director for Oval House at the time explained: "For the first time, wheelchair users will be able to access our whole building, in our current building wheelchair users have no access to the Upstairs Theatre and a large part of our seasonal programming. We need a theatre which is fully accessible to disabled artists, young people, audiences and staff." [68] Thus this production made a significant impact on theatre spaces in London.

Next Stage: Moving Towards National Recognition and Finding New Audiences

"These brilliant, skilled, funny, bright, knowledgeable people were just everything to me and I wanted to create the best theatre for them. And that meant taking risks." (Ewan Marshall, artistic director of Graeae).[69]

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[68] Https://ovalhouse.com/Ovalhouse-in-Brixton. 2019. Quote from Katie Milton Development Director of Ovalhouse in Brixton. This is one of the new approaches to bringing facilities up to date for disabled actors. Ovalhouse is working on this as part of the Somerleyton Road Project that includes new homes, health facilities, and this fully accessible modern theatre.

[69] Sealey, Jenny. *Reasons to be Greaeae*, Oberon Books Ltd. 2018. Pg. 38. Marshall served as Artistic Director of Graeae from 1992-1997.

Shaban would go on to work at the National Theatre. He continued to serve on the Board of Graeae through the 1980s and returned on stage as Volpone in *Flesh Fry* in 1994. Shaban continues to work in film and stage as well as co-devising with D.A.R.E. (Disabled Anarchists' Revolutionary Enclave). He received a commission from Graeae to create a new work in 1996 called *The First To Go* which looked at the Nazi treatment of disabled people. This play would be in development for several years while Shaban and Tomlinson toured *Sideshow* in Winnipeg, Canada and the University of Illinois in the United States. On May 23, 2008 Shaban premiered *The First To Go* at the Royal Lyceum Theatre in Edinburgh. The show takes place during the Nazi regime in the 1930s and 1940s. A review by Mark Fisher of *The Guardian* praised the work for reminding audiences of the atrocities of the Nazi experiments on disabled people while asking questions of the circumstances of different disabilities (being born with the disability or acquiring the disability) and how they are perceived by non-disabled people.[70] Although this was originally commissioned to be a Graeae production Shaban continued to develop it on his own after he left the company. This is an example of Graeae promoting continued works outside of its home base to increase the awareness of disability theatre.

Tomlinson would continue his work with disabled artists after leaving Graeae. He was a client services director with MacIntyre Care, a national consultancy for the learning disabled. After the death of his wife, he moved to Manchester and became chief executive of the Royal School for the Deaf and Communications Disorders which is located in Cheshire. Tomlinson died in May of 2006.[71]

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[70] Fisher, Mark. "The First To Go." June 3 2008. Https://theguardian.com/stage/2008/jun/03/theatre.

[71] *Nabil Shaban-Unfinished Histories*. https://www.unfinishedhistories.com/intervews/interviewees-r-z-3/nabil/shaban.

Upon Shaban and Tomlinson's departures, Graeae sought a new artistic director and found one with Ewan Marshall who took the helm from 1992-1997. His focus was to move Graeae beyond accessible theatres and open up performances in older theatrical spaces that were not built for disabled actors. This includes many of the mainstream theatres. Marshall's intent was to grow the company's audience so that more people would become aware of the work that was being done by Graeae and would potentially step outside their comfort zone and visit a theatre that is specifically designed to be accessible to audiences and casts. The 2012 production of *The Garden* was staged on the banks of the Thames during the Thames Festival in a non-traditional setting. The purpose of using this venue was to bring attention to the work being done by Graeae. Audience members who attended were given information about the Graeae studio and invited to attend future productions held at the Graeae studio as well as other venues where they would perform. Non-disabled audiences who take the time to visit the studio at Bradbury can then observe the work that can be accomplished in a setting that is accessible to disabled actors.

Marshall had been in an accident when he was eighteen while riding his motorcycle that resulted in the loss of an arm and took him months in rehab. He had wanted to be an actor and many people around him, including the nurses and doctors at the hospital, began advising him to look into professions that did not require much movement. While recovering in the hospital he watched a program called *Arena* that was profiling the Graeae Theatre Company. The opening for the Artistic Director came just as Marshall was looking for that type of work. The interview with Shaban inspired him to seek out Graeae. [72]

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[72] Sealey, Jenny. *Reasons to Be Graeae: A Work In Progress*. Oberon Books, Ltd., 2018.

The Graeae office was located in Bayham Street in Camden when Marshall began his work. It was a portacabin which is a portable office or warehouse space. The company had already selected a play entitled *Hound*, which was about the experience of blind people undergoing guide dog training and needed a director. Marshall had not been around other disabled actors as he was used to being the only disabled performer in a group. This led to his realization that there weren't many disabled actors around. This presumption was based on the few opportunities available to disabled actors and would become the focal point of growing the company.

"Well, it's a funny question really. It's like me asking you if you ever wish you could fly. You can't, though you might occasionally wonder what it's like and you know that some things in life would be made easier if you could, but you don't spend your whole life thinking about it." This quote is from *Hound* by Maria Oshodi. The character of Joe is blind and was asked if he ever wished he could see. Oshodi is a blind playwright and director and founder of Extant, a theatre company made up of blind and visually impaired actors.[73]

Hound was notable for its depth of characterization and innovative staging and establishing a new voice of disabled artists in British theatre. The play challenged the assumption that disability theatre was only worthy or appealing to the sympathy of its audience. Written by Maria Oshodi it concerns three blind people at a guide-dog training center. The arrival of a television documentary team forces them to confront the media and the intrusive questions asked by the team that airs their personal views for the world to hear. Graeae advertised the show as the first professional play to

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[73] *13 Questions: Maria Oshodi-BBC.* www.bbc.co.uk/ouch/interviews/13_questions_maria_oshodi.shtiml.

be written by a visually impaired playwright and performed by an actor who is also visually impaired.[74]

One of the first shows Marshall directed after the production of *Hound* was *The Trial of Ubu*, an abridged version of the original by French playwright Alfred Jarry and turned into a punk play written by Simon Stephens. It would be the first Graeae production to incorporate a sign language interpreter into the action. Vikki Gee Dare signed while wearing a birdcage over her head and the deaf audience members felt that the show was geared specifically towards them even though the hearing audience took what they wanted from the same performance.

Theatre critic Michael Billington said that he was not convinced that the headphone-wearing interpreters were ideal for the format of the show. Billington had attended the trial of Slobodan Milošević in The Hague and questioned the portrayal of what such a trial would have been like for the fictional Ubu during the time of its occurrence since a major political figure was being tried and suggested using the tribunal-theatre techniques used in current trials.

Billington commended the puppetry which opens the show with a portrayal of the original work by Alfred Jarry from 1896. He also commends the power of the words as being prophetic of future war atrocities and the subsequent public trials of the despots that were tried for war crimes. "Having attended the trial of Slobodan Milosevic in The Hague, I can vouch for the bizarre contrast between the dry legal formality and the hideous crimes under review. But I think Mitchell misses something by giving us a secondhand version of Ubu's trial: the irony of Stephen's idea would

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[74] Sealey, Jenny. *Reasons To Be Graeae*, Oberon Books Ltd. 2018. Pg. 36-37.

have been clearer if we had seen Tricycle tribunal-theatre techniques applied to a fictional archetype like Ubu."[75]

Billington vacillates between complementing the originality of Graeae and imposing his own views of current war crime activities and how the production should have reflected more upon present day political atrocities. Graeae's goal is always to bring more exposure to disability performance. Billington's critique is an example of how far Graeae has come since its inception in that it is now inviting discussion on the source material and receiving the same criticisms that a non-disabled cast would hear had they chosen the same type of staging.

Marshall's vision was to see Graeae established in the wider theatre circuit and to be the best theatre around. Ewan Marshall also recalls his efforts to hire a blind performer by following a blind woman to the Society for the Blind. He did not hire that woman for the role but she helped him find visually impaired artists. He does not mention where he specifically met the actors but he did notice future Graeae actor Jamie Beddard while walking on the Southbank and recognized him from his resume photo. Beddard would co-star in one of Jenney Sealey's first productions for Graeae entitled *Fittings: The Last Freak Show*.

"My other family just said 'You're sailing too close to the wind. This is too close. Too close,' and I said 'It has to be. If you don't sail close to the wind, what's the point?"[76] This quote is from actor Ray Harrison Graham after his family watched his performance in the play *Sympathy For The Devil*. The show is part of the first Graeae plays to be published.

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[75] Billington, Michael. "The Trial of Ubu-Review." *The Guardian*. January 25, 2012.

[76] Sealey, Jenny. *Reasons To Be Graeae*. Oberon Books Ltd. 2018. Pg. 47.

After producing a number of shows Graeae decided to publish their original works in *Graeae Plays 1* in 2002. As a professional company that specializes in staging new plays or updated versions of classic shows Graeae began and continues to lead in relation to publishing scripts for disabled actors. The intention is to showcase the originality of the playwrights and set an example for prospective writers who are looking for a place that will champion this type of work. Ray Harrison Graham was both author and lead actor for *Sympathy ForThe Devil*. The play concerns Graham's personal experience with his church and reactions to disabled people and the role of God and the Devil in their lives. This original piece was very personal to Graham and was noted by *The Guardian* as "…rare and rewarding to find a piece as dense and intelligent as this."[77]

The New Phase: Enter Jenny Sealey as CEO/Artistic Director in 1997

"But the disability arts movement sometimes sees Graeae as something separate because we also play to mainstream audiences in mainstream (accessible) theatres. I want everyone to know who Graeae is and see the talent within our community. Sometimes I feel like I'm caught between a rock and a hard place."[78] This is part of a group interview Sealey held with past Graeae members Sarah Scott, Ewan Marshall, and Ray Harrison Graham. Sealey is commenting on her frustration of being pigeonholed into serving only one community by outside observers. Sealey also notes that everyone cannot be satisfied and that this viewpoint drives her work with Graeae.

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[77] Sealey, Jenny. *Graeae Plays 1: New Plays Redefining Disabliity*. Aurora Metro Press, 2002.

[78] Sealey, Jenny. *Reasons To Be Graeae*. Pg. 49. Oberon Books Ltd. 2018.

Jenny Sealey became deaf when she was seven years old and spent her educational career as the only deaf person in her classes. A self-taught lip reader, Sealey felt as if she was playing catch up with everyone else. This is an often too common experience for deaf people who do not receive specialized services that are intended to provide the least restrictive environment for all students in an educational setting.

Sealey answered the audition notice Graeae placed for *A Private View* by Tasha Fairbanks and directed by Anna Furse in 1987. She was surrounded by people with a variety of disabilities including some who were deaf. This setting gave Sealey the confidence to win the role and go on tour with the company. She met several disabled people throughout her travels and gained exposure to inequality, marginalization, and discrimination that were faced by disabled people. She did not have an interpreter during this time which would inform her decision to have interpreters in future shows.

In 1997 Sealey saw an advertisement in *The Stage* for an artistic director for Graeae Theatre Company. She had been involved with Interplay Theatre which produced work with young people who had multiple disabilities as well as creating work for the D/deaf community in the Midlands. As part of her interview, the team asked Sealey to direct some Graeae actors using her own choice of text. She chose *Stepping Stones* by Mike Kenney which was written in the Haiku form and was originally a work commissioned for Interplay. Sealey was offered the job that night and has remained the Artistic Director to present.

Sealey's first directed production at Graeae was *Two* by Jim Cartwright in 1998. Vicki Gee Dare and Rob Chalk were brought in as sign language interpreters. During the rehearsal process, it was decided that actress Caroline Parker would also sign while Dare would provide the voice over. In Sealey's view, there were four performers instead of two so the collaboration became more intense for the interpreters as the production moved forward. Graeae received the rights to use British Sign Language (BSL) with this production which would lead to additional use in future productions. The rights were obtained so the author would accept this interpretation of his work. By being proactive Sealey was able to bring BSL into play for future productions performed but not written by Graeae members.

Criticism and the effect of words on disabled theatrical works

"It is presented by the Graeae Theatre Company, whose performers are all handicapped, and the actresses in peeling share their characters' disabilities. Beaty (Lisa Hammond) is four feet tall; Coral (Sophie Partridge) has tiny limbs and a torso about the same size as her head; Alfa (Caroline Parker) is Deaf."[79] This an excerpt from a critique of the show by Rhoda Koening.

This production of *peeling* by Kaite O'Reilly was performed in 2002 and is an updated version of Eurpides' *The Trojan Women*. A fine line is drawn at critical reviews if they encompass only physical attributes of performers as opposed to the performance itself. Sealey welcomes critiques as they bring acceptance of the theatre being produced by Graeae as it pertains to mainstream theatre. The above statement by Rhoda Koenig is an example of the language that is offensive and misdirected. Sealey penned a response to The Independent that outlined Graeae's expectation of equal treatment for its performers in critiquing theatre. Sealey specifically questioned the language that was used and the need for the publication to be educated on the appropriate terms used in reference to disabled people. The inaccurate stereotypes used by Koenig

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[79] Sealey, Jenny. *Reasons To Be Graeae*. Pg. 102.

work against the actors and make it more difficult for disabled people to be heard and treated equally in society.

Despite this negative reaction, there were many firsts accomplished by Graeae during the run of *peeling* that informed their work with writers, text, film and other media on stage since this production. It was the first time a play was created that was open about physical and communicative impairment. PowerPoint slides of the text were projected using different font and color for each actor. Short films were shown after each epic moment to show the essence of the text for audience members who could not easily read BSL. Each of these enhancements was intended to enrich the performance and take additional steps in bringing Graeae productions to a wider audience.

A Broader Audience: 2012 and the Paralympic Games Opening Ceremony

The public response to Graeae productions brought more attention nationally and an offer that would bring international attention to the company and the theatre it produced. In 2005 London had won the bid to host the 2012 Olympic and Paralympic Games. Funding initially came from Unlimited, the London 2012 Cultural Olympiad program which provides funds for D/deaf and disabled artists. Sealey was appointed an artistic advisor to the organization and the initial talks began soon after to develop a production for the opening and closing ceremonies for the 2012 Paralympic Games.

With the need for acrobatic and circus skills by the ceremony directors, Graeae began training in aerial skills. Funding paid for a small group of disabled people to be trained on sway poles, rope, hoop, and silk work through a partnership with Circus Space which is now known as the National Center for Circus Arts and Strange Fruit, a Melbourne-based performing arts company that produces and performs a remarkable style of work that fuses theatre, dance and circus, using a unique elevated medium. When funding dried up Circus Space and Graeae took on the costs so the training could be completed. This led to the first Graeae production that involved sway poles. Sway poles are tall poles usually made up of flexible but sturdy material such as PVC pipes that allow the user to remain in the air while performing yet are malleable so that the players can move back and forth as the action dictates. *The Garden* was written by Alex Bulmer and produced for the Unlimited Festival. This festival took place during the 2012 Paralympic Games from August 30 through September 9. Its premiere was held at the Greenwich & Docklands International Festival.

Bulmer’s association with Graeae began in 1991 while studying at the Central School of Speech and Drama as an international student visiting from Canada. She met Ewan Marshall at Interchange Studios and was offered a job as a tutor on a disabled youth theatre project led by visually disabled artist Ailsa Fairley. Bulmer returned to Canada to continue her writing and work with disability theatre before making a trip back to England in 2004. She met with Jenny Sealey and Jamie Beddard and began working with Graeae actors on voice work with a specific focus on actors with speech impediments. Between 2006 and 2010 she developed a department of new work and writing for Graeae. This program became known as the Play Lab and is a training ground for beginning disabled artists. The success of Play Lab led to the creation of the Write To Play program which focuses on the more technical aspects of playwriting and sponsors scholarships for new works by upcoming artists.

The story of *The Garden* centers around a group of story-keepers who share three stories of love, innocence, and hope. The Keeper of Dreams, Keeper of History, Keeper of Song, and Keeper of Names are dressed in long duster coats and begin sharing their ritual on top of sway poles located at the four corners of a raked stage. The role of the Keepers is to collect the stories of those who have died but are in limbo. By telling these stories the Keepers give them the ability to move on out of limbo. A small orchestra accompanies the narrator who is the only one who speaks through the performance. The story-keepers sway with the music but also add to and take away items from the stage. Each one is strapped in at the waist and continues the movement as the stories unfold before the audience. Other cast members act out their parts of each story which includes song and interaction with the Keepers. At the conclusion of each tale, one of the characters from the stage becomes a Keeper as he or she steps into a new role in the tale.

One of the requirements for Graeae was for the show to be transportable. The Unlimited commission provided the initial venue which was at The Riverside Terrace, Southbank Centre on the Thames during the Thames Festival from September 6-9 in 2012. I attended the performance on September 8 which was free to the public. Most of the audience members were strolling along the Thames prior to the beginning of the show. The area near the stage became quiet as the actors began their performance. People who watched were enraptured by the captivating story and gave the actors a standing ovation. What was most astounding was the capability of the people who were on the sway poles to keep their balance while dealing with the wind that swirled that evening on the banks of the Thames. Their work at this venue convinced Sealey that the show had the ability to travel.

Opening Ceremony 2012: *Spasticus Autisticus*

“I want people to see a great show and come out saying: 'Bloody hell, I never knew there were so many disabled people.' This is our chance not to be hidden anymore. And a chance to be naughty." This quote from Jenny Sealey sums up her view of the new exposure granted to Graeae with their opening to the 2012 Paralympic Games.

The goal of Sealey and her fellow artists was to bring disability theatre center stage during the opening ceremonies in 2012. The August 29 show was named *Enlightenment* and included disabled artists from different performing art forms. 80,000 people filled the Olympic Stadium for the event. Among the professional performers were 73 deaf and disabled actors and singers. Among the volunteers supporting the event were 68 people with disabilities. Before the official opening, a flyover was executed by members of Aerobility, a British charity training people with physical impairments to become pilots.

The concept, borrowed from William Shakespeare’s play *The Tempest* is that Prospero, portrayed in the play as a wise old man and the rightful Duke of Milan, teaches his daughter, Miranda, about the brave new world, detailing to her the advances humans have made technologically, but also socially, transporting her into the ‘present’ where she herself should act as an agent of progress. Sealey notes that the character "sees everybody but she doesn't judge. That is fundamental to our personal and political ethos. It is fundamental, you look without judging. It's about removing those attitudinal barriers.”[80]

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[80] Gardner, Lyn. “No More Teletubbies: Paralympics Opening Ceremony Director Speaks.” *The Guardian*, *Guardian News and Media*, 17 Oct. 2014.

Graeae then stepped in and sang Ian Dury's *Spasticus Autisticus* that had been banned from the radio by the BBC. Written by Dury in 1981 it was a protest against the Year of the Disabled. Dury's disability came from contracting polio at the age of seven from swallowing a mouthful of infected water. He believed the celebration in 1981 was patronizing to disabled people and felt the well-meaning liberals were naïve and arrogant. Dury was quoted as saying "Oh, I see, so in 1982 we'll all be all right!"[81] Dury chose the name Spasticus as a play on *Spartacus* one of his favorite movies. He believed all disabled people could shout individually that "I am Spasticus" to unite as one group with something in common. His music served as an introduction of the 2012 Paralympic Athletes from across the globe. "So place your hard-earned peanuts in my tin/ And thank the Creator you're not in the state I'm in/ So long have I been languished on the shelf/ I must give all proceedings to myself."[82] These are lyric's by Ian Drury for the song *Spasticus Autisticus* performed at the opening ceremony for the 2012 Paralympics.

"On a personal level, Graeae has given me some of the most amazing and fulfilling jobs in my career and has taught me so much about my skill and potential as an artist and a person. On a more general level, they have given me the capacity to also be an ambassador and to connect internationally with people who are fighting the same fights or who are just learning about the wonder and strength that is the disability community."[83] This quote from Amelia Cavallo explains her view on being included in Alex Bulmer's *The Garden* that was performed in Rio de Janeiro.

The company was invited to perform *The Garden* at the 2016 Paralympics in Rio de Janeiro, Brazil. This performance used multiple languages: British Sign Language (BSL), Brazilian Sign Language (Libras), spoken (and sung) English and Portuguese, and audio description (AD). Actress Amelia Cavallo worked on both shows and complimented the Brazilian actors who had only four days to rehearse the entire show for the first time. The international exposure that both Paralympic Games gave to Graeae and disability theatre is still being measured. It is an example of an opportunity being met with success as indicated by the invitation to perform at a second straight Paralympic Games.

***This Is Not For You*: A Tribute to the 100 Year Anniversary of the Great War 2014-2018**

"They just said 'Jen, it's better to come back dead than it is to come back disabled-you get more recognition, and the process of trying to adjust to the new you is so painful, and there's a real lack of support.' And that just stayed in my mind for ages and ages, and when the 14-18 NOW funding commission was announced I thought, 'this is my opportunity to tell the story that I think is so important. We need to remember the dead of course, but most importantly, please, respect and remember the living."[84] This is a quote from Jenny Sealey when asked what inspired her about speaking to injured veterans.

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[81] *The Day The BBC Banned Ian Dury*. Https://dangerousminds.net/comments/spasticus_autisticus_the_day_the_bbc_banned_ian_dury.

[82] Drury, Ian. Lyrics from *Spasticus Autisticus*. Located at website genius.com/Ian-dury-spasticus-autisticus-lyrics?scrlybrkr+d936c682.

[83] Cavallo, Amelia. *Swaying In Rio*. September 26 2016. Located at website www.graeae.org/swaying-in-rio/.

[84] *This Is Not For You-The Play About The Plight Of Injured Veterans*. August 9 2018. Located at website www.forces.net/news/not-you-play-about-plight-injured-veterans.

Graeae Theatre Company was co-commissioned by Blesma: The Limbless Veterans and 14-18 NOW, the UK's arts program for the First World War centenary and supported by Calouste Gulbenkian Foundation's UK Branch. The piece entitled *This Is Not For You* was written by Mike Kenny, choreographed by Tina Carter and Freddie Opoku-Addaie, and directed by Jenny Sealey. Original music was written by Oliver Vibrans. The production took place at the Greenwich-Docklands International Festival on June 30 and July 1, 2018, as well as the Stockton International Riverside Festival August 2 and 3, 2018.

As part of the preparation for this show, Graeae partnered with the National Centre For Circus Arts to create a training program for veterans across the UK. Over the course of 10 weeks, Blesma members learned how to use aerial equipment to build their strength and confidence in preparation for the show. The project had been four years in the making from its initial conception. Funding had become a major problem and many donors needed convincing that the project was worth their investment. I attended the June 30 performance that began at 3:00 in the afternoon.

The show utilizes both disabled and non-disabled performers. Sealey only had 2 weeks to fully rehearse the piece which was enormous and demanding from many who had not taken part in a theatrical production. The military background of most of the actors led to the expectation of a military type of exercise for rehearsals. Sealey wanted to show them that the process is messy while trying out new things and engaging in emotions, objectives, and subtext and that when the time came for performance it would become more disciplined.

"The military, on the other hand, is disciplined from the start but the aftermath of war is incredibly messy emotionally and psychologically etcetera."[85]

This quote from my interview with Sealey is a comment on her actors who had served in the military and how the rehearsal process for the show brought such emotional performances from people who had been to war and were injured or witnessed injuries during their tours of duty.

The show is designed for an arena type of setting although it could be adapted to an indoor stage. It is theatre in the round with audience members invited to sit on the ground floor at tables set up for the actors' use during the performance. Local choirs are located at both ends of the arena with a lead singer one level above on each side. Sealey wanted music to enhance Mike Kenny's script so she hired disabled musician Oliver Vibrans to write the songs that accompanied the show. In our discussion afterward, Jenny asked what I thought of that aspect of the performance. I found out that we both use music to bring a fuller story to our audiences and connect them to the spoken words and the characters. This choice brings even more opportunities for disabled people to express themselves through art. This specific set of performances faced a challenge that would not have occurred if it had been performed at an indoor facility. The heat index for the end of June and beginning of July included temperatures over 100 degrees Fahrenheit with no cloud cover. Sealey informed me after the performance I attended that an ambulance was waiting outside of the arena in case the need arose. Multiple actors had to be transported for heat-related symptoms. The rest of the cast filled in for the missing actors and finished the show. This is similar to the issues that arise with Joan Lipkin's DisAbility Project. Lipkin and her company must be prepared for last minute cancellations due to illnesses non-disabled people do not experience. Some are due to

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[85] Jenny Sealey Interview. Appendix B.

compromised immune systems while others, like the overbearing heat of the day, cannot be endured as easily so medical assistance is needed in these circumstances.

The cast and crew were housed in a building adjacent to the arena for their backstage preparation. The warehouse atmosphere did not provide a flow of air but did offer protection from the sun. Each actor had a personal assistant to help with costuming and makeup and most were the actors' own aides who did not have backgrounds in theatre. Those who did not have an aide with them worked with Graeae makeup and costume crew members.

Working against the company was a lack of funding beyond what was raised for the Greenwich and Docklands International Festival. Sealey was limited in her direct work with the actors to stage four performances in the middle of the summer. This did not prevent them from working with interpreters to sign the show for deaf audience members. The show was staged on Artillery Square in Woolwich and competed with other music performances that were playing at the same time.

Critic Kate Wyver noted the use of metal scaffolding for the set pieces and how one actor with a prosthetic lower leg removed it and handed it to another actor when he could not continue his climb then retrieved it on the other side.[86] Each metal unit was a framework of metal tubes that were used to represent uphill skirmishes on the battlefield as well as trenches the soldiers had to crawl through in order to get to the fighting. Wyver's main concern for the piece is that it did not explore in more detail the part detailing the need for some of the veterans to beg for food when

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[86] Wyver, Kate. "Greenwich Docklands International Festival Review-An Unreal Takeover of the Streets." *The Guardian*, *Guardian News and Media*, 23 June 2019 https://www.theguardian.com/stage/2019/jun/24/greenwich-docklands-international-festival-review.

they could not find work upon their return from war. Wyver did note the emotion that was expressed by the performers, specifically Royal Navy veteran Allan Long who stopped singing towards the end while fighting back tears. The message is clear that the soldiers have a deep connection to the source material and re-live many of the events depicted on stage in their everyday lives.

"In remembering their exercises, these ex-servicemen and women recall their old, uninjured selves. 'Don't feel sorry,' they say, 'Don't feel guilty. Just don't turn away."[87] This quote from critic Matt Trueman references the specific disabilities that each soldier displayed during the show. He mentions the uneven parade of soldiers who were not quite in step due to the loss of arms and legs that have been replaced by artificial limbs or not replaced at all. The march was still ingrained in each soldier as he or she had been trained at one point in preparation for the battles that were to be fought. Trueman also points out the powerful message during the segment when each soldier receives his or her compensation from the government after returning from war. The government agent shouts out the disabling injury and the amount each person will receive in benefits. Trueman emphasizes one of the main points of the show while pointing out the lack of restitution for the soldiers who have invisible injuries such as PTSD and shellshock. It is one of the messages Kenny and Sealey wanted to convey when writing and staging this show.

Carole King was a member of the Women's Royal Army Corp serving from 1983-1990. Raised by foster parents due to lack of care from her mother, King joined the Corp at the age of

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[87] Trueman, Matt. *Review: "*This Is Not For You (Greenwich and Docklands International Festival: Graeae team up with a group of veterans to celebrate those injured through war." July 2 2018. Located at website www.whatsonstage.com/london-theatre/reviews/this-is-not-for-you-greenwich-docklands-graeae_47001.html.

19 until an accident left her with a badly damaged leg and eventually an amputation of her left leg above the knee. This was the beginning of her work with Blesma, The Limbless Veterans. Blesma encouraged King to skydive, ski, scuba dive, and take part in several Remembrance Parades in London. When Blesma joined with Graeae to produce *This Is Not For You* they encouraged King to take part in the production.

King was able to strengthen her core and balance on her one leg because of the work required for the show. The training began in early April of 2018. She initially had difficulty with the work with ropes and the aerial hoop that was to be used by the actors. King questioned the need to do aerial work since there was no aerial part of the show. The production team's goal was to have all actors prepared for the physical portion of the show when working with the scaffolding equipment which would change shape and meaning throughout the show. The work progressed to trapeze work as each person pushed to prepare for the final product. By May the team turned to work with cubes which more closely resembled the set pieces they would be using for the show. Scripts were distributed on May 14, 2018, which was the first time the cast had seen the work and heard the words out loud. This would give the company a month to put words and actions together and put a final product that would fulfill the goals of Graeae and Blesma. King sums up her experience with this quote: "They pushed us out of our comfort zones. Especially for me having people very close and in my personal boundary space."[88]

Sealey and King were the only members of Graeae to respond to my interview requests. Their insights to the production of *This Is Not For You* provide a contrast between a professional

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[88] Carol King Interview Appendix B Pg. 295.

theatre artist who has worked on many productions and an actor taking part in her first production. Both share their dedication to this specific project and how important it was to bring it to fruition despite the roadblocks of funding, rehearsal space, and time. Graeae has provided many new performers a chance to tell stories that relate to the experiences of disabled people in society and the reactions from non-disabled people when both sides meet in social settings. Sealey has continued to build Graeae's resume and continues to promote more opportunities for disabled artists to produce work that is relevant and timely. Graeae is not the only company to work with disabled actors but it is leading the way for other companies that are contemplating producing similar works.

Graeae has originated pieces and put their own spin on existing pieces in accessible spaces, older theaters that are not up to date on building codes, and outdoor venues that grant them exposure to bigger audiences. Graeae is a professional company that has fought for every advancement it has made in the theatre world. This is one of the best examples of what can be done the right leadership and determination. This company is providing training and opportunities in theatre for disabled artists around the world. It is affecting other professional companies that are now looking at its model and planning to incorporate disabled performers in their seasons.

Chapter 5: Conclusion

Petra Kuppers in some ways sums up the aims of the research, the scholars who work and perform in this arena, and the actors and companies considered here: "This performance work does not aim to only create beautiful products, but wishes to share a more accessible and respectful world for all of us, a world I can and wish to live in."[89] Kuppers uses her position as performer and professor to fight for opportunities for disabled artists to be trained in their respective fields and continue with work in the professional world. Graeae and The DisAbility Project are two companies that follow that vision by providing training and work not only for the players of their organizations but educational opportunities for their audiences.

Kuppers is an articulate spokesperson of change and an example of an artist/scholar whose practiced-based research who demands progress. It is important that more opportunities for disabled artists are becoming available as this information is becoming more readily obtainable to the layman in the form of news articles and books. The most important part of bringing the facts to the forefront is performance includes-itself. Many are being exposed to this type of theatre for the first time. Graeae and The DisAbility Project are leading this movement by continuing their work in their respective parts of the world.

The actors from The DisAbility Project encompass a wide array of disabilities and are searching for the opportunity to perform in front of audiences that will see them as equals in both their work and in life.

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[89] *Disability Culture And Community Performance.* Kuppers. P. 6. 2011.

Joan Lipkin and Fran Cohen created a company that works to bridge these two worlds and question old norms by presenting truths that are uncomfortable for non-disabled people to confront and discuss on an intellectual level. Graeae does similar work but more so on a nationally in the United Kingdom. Since their funding comes primarily from the British government it is necessary for Graeae to have exposure that reaches as many people as possible and justifies Arts Council England's grant funding for their work. This includes an international awareness of Graeae. In Chapter 4 Graeae's inclusion in the 2016 Paralympics in Rio de Janeiro is a singular instance of their ongoing expansion of their reputation. Alex Bulmer's *The Garden* is an excellent example of work that transcends the political debate about whether disabled artists should be on stage and pursues the quality of the work being done.

Graeae does not take its responsibility to the disabled community lightly. The professionalism incorporated in the daily operations by Jenny Sealey and company has included a document for teachers, directors and other staff members who are looking to hire disabled performers or are looking to begin a similar type of organization.[90] This publication also includes a language section to help with acceptable language to use when referencing specific terms as they pertain to disabilities. It is an educational based document that focuses on inclusive practices in the performing arts. Likewise, The DisAbility Project has its own educational resources that are used by the schools the actors visit while in production. Both companies are steeped in the educational process and the work that needs to be done to bring this information to people who are uninformed or misinformed about disabilities and the artistic choices by disabled performers.

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[90] *A Guide To Inclusive Teaching Practice In Theatre*. Graeae Theatre Company. September 2009.

Perceptions by Nondisabled Artists and Audiences

"Disabled actors are told that their impairments would detract from the playwright's or director's intent for a nondisabled character" explains Carrie Sandahl."[91] This statement is at the crux of Sandahl's assertion that disabled actors face incredible odds vying for roles that typically go to non-disabled actors. She highlights the misperceptions by non-disabled artists when confronting disabled actors auditioning in her work. The assertion that a person with a disability will take away the focus of a character's motivations and intent for a scene belittles the capability of the disabled actors. Sandahl argues that the same concern is nonexistent when a non-disabled actor takes on the role of a disabled person. In this specific case, it is important to point out that there is a tremendous difference in disabilities as perceived by non-disabled people. The invisible disabilities are ones that do not show any outward signs of the disability such as early stages of multiple sclerosis, seizure disorder, or early stages of Parkinson's Disease. Visible disabilities such as Down Syndrome, amputations, or spina bifida are not able to be dismissed or ignored. Sandahl's assertion includes her own role as disabled and she knows that she and others can encompass the disability without losing its focus.

Jenny Sealey and Graeae have created work that has run in opposition to what Sandahl describes in relation to what happens to disabled actors during auditions, namely that they are being denied roles based on their visible disabilities. Graeae has staged mainstream shows such as Sarah Kane's *Blasted* (2006, 2019) and Federico Garcia Lorca's *Blood Wedding* (2001, 2015). In the first production of *Blasted* the actors gave voice to the dialogue as well as the stage directions

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[91] *Bodies In Commotion*, Carrie Sandahl, 2005 p.255.

while projection screens were used for the benefit of deaf audience members. [92] Sealey does not focus on critics. Her vision includes potential audience members and the needs they have when attending a theatrical performance. Similarly, Sealey and David Ireland used projection screens as well as BSL interpretation for the 2015 production of *Blood Wedding*. The ensemble included deaf and wheelchair performers. “The play features a number of disabled actors but is never defined by disability. The emphasis is on movement, emotion, light and sound.”[93] This quote from reviewer Sandra Ireland shows the complexity in Graeae’s work and how the interpretation of the source material by Sealey and David Ireland transformed the way audiences were able to enter into the world of Lorca and see things from multiple perspectives. Graeae still produces original works that focus on disability as a primary theme but they expanded-to include visions of works that do not include disability as a core part of the storyline.

Conversely, The DisAbility Project has moved from reinterpretations of classic works such as Mark Twain’s *Tom Sawyer* and has focused solely on works that center on disabilities and the interactions between disabled and non-disabled people. Their original productions of *The Healing Ministry* and *One World* focus on disabilities and how non-disabled people respond to disabled people during everyday interactions in society. Lipkin’s goal is to encourage discussion between the artists and audience members after each performance. Each scene is based on actual events that the ensemble encountered during their lives. Humor is instilled in the dialogue to allow the work to speak for itself and is not used as a soapbox to preach to the audience. This method opens up dialogue that is used to answer questions people may have about disabilities and stereotypes that

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[92] https://www.heraldscotland.com/news/12401246.blasted-tron-theatre-glasgow-45/.

[93] Sandra Ireland, *Dundee University Review of the Arts*, March 26 2015. Https://dura-dundee.org.uk/2015/03/10/blood-wedding.

have pervaded public perception about disabilities. The DisAbility Project also shows disabled actors actively working on stage to set an example to disabled people who might not think they have a chance at working in theatre.

Like Jenny Sealey, Joan Lipkin works on proper training of her actors and providing the least restrictive environment during rehearsals and performance. This aspect of disability theatre is the most important for the actors but is also the most time consuming due to the physical limitations of older buildings that are used for some companies. Lipkin's group does not have a home base and relies on the generosity of outside organizations to donate space and time that may be used for The DisAbility Project's productions. Sealey and Graeae worked for many years before obtaining the space they currently have at Bradbury Studios in London. The space is enough for rehearsal but is not designed for public performances. Graeae still relies on outside venues for their performances. Both companies are limited to facilities that are available and meet the basic standards of accessibility. The DisAbility Project will work in most venues that contract with them to perform because the actors are not paid and the mission of the organization is to increase awareness. Graeae contracts with companies that are willing partners in their productions and share space while working on their own seasons.

Training and Opportunities to Perform

"For people with disabilities, daily interactions in social situations, spaces, and places can feel like a series of performances in which their idiosyncrasies are, whether they like it or not, on show."[94] Bree Hadley makes an important point about what is on display when people with disabilities go out in society and interact with a world composed of mostly non-disabled people. This worldview is a broad stroke that can be used as a guideline to understanding what disabled actors face when seeking professional training in the performing arts. Advanced training instructors are not always versed in educational pedagogy that is required for work that involves disabled artists. This is more than a university policy that outlines the rights of disabled students or a mission statement from a theatrical company that states all potential clients will have equal opportunities as is listed by the United States Equal Employment Opportunity Commission (EEOC).[95] Advanced training classes that include instructors with certifications that will assist disabled artists prepare for professional work in the field of performing arts is not readily available in all communities.

As I pointed out in an earlier chapter physical roadblocks are already in place due to buildings that remain out of date on codes regarding accessibility. This disregard of federal law in the United States, as outlined by the ADA, prevents disabled artists from gaining access to audition

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[94] *Disability, public space performance and spectatorship.* Bree Hadley. P.1.

[95] https://www.eeoc.gov/employees/. This specific reference includes the following statements: Unfair treatment because of your race, color, religion, sex (including pregnancy, gender identity, and sexual orientation), national origin, age (40 or older), disability or genetic information. Denial of a reasonable workplace accommodation that you need because of your religious beliefs or disability. Both sections relate specifically to professional opportunities for disabled workers.

halls and in some cases classrooms. The action of attempting to enter a building becomes a public display as non-disabled people will either stop and stare at the situation or try to force help without asking if it is needed. Ana Jennings works as a performer for The DisAbility Project and has faced this situation. She has encountered people who talk very slowly to her as she continues to try to gain entrance into a building with her wheelchair when no ramp exists.[96] This personal account is incorporated into the original work *One World*. Jennings and her fellow actors request that they be asked directly if they need help as opposed to people assuming they need assistance. The slow speech pattern from people who believe they are helping is a misperception on the part of some non-disabled people who think that all disabled people have a mental disability that accompanies their physical disabilities. Both of these examples come directly from the actors in the DisAbility Project and show how much more work needs to be done to inform the public about stereotypes that still pervade society.

How Far We Have Come Since the Beginning of this Study

My work in this field began in the fall of 2008. There has been much headway made in disability theatre since that time. Although there is still much to do to bring more work to disabled artists, the progress is encouraging. Examples discussed here include Graeae Theatre's performance at the opening ceremonies for the Paralympics in London in 2012. A more recent event took place in January of 2019 when the Royal Shakespeare Company (RSC) announced that it plans to cast three disabled actors for its 2019-2020 season. Artistic Director Greg Doran hired Karina Jones who is visually impaired, Charlotte Arrowsmith who is deaf, and Amy Trigg who

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[96] Appendix B Page 346.

has spina bifida for three Shakespeare productions. Jones will portray the vicar (changed to Madame Olivia Martext) in *As You Like It*. Arrowsmith will take on the roles of Audrey in *As You Like It* and Curtis is in *The Taming of the Shrew*. Trigg has the roles of Biondella in *The Taming of the Shrew* and Juliet in *Measure for Measure*. [97]

The work of Graeae and similar theatres has not gone unnoticed by the RSC. According to Doran "It's also about working with the rest of society-not just, as it were, a white middle-class elite."[98] This decision by Doran will have a long-term effect on future work offered to disabled artists. Part of the goals set by Jenny Sealey while at Graeae was the need for more exposure for the work being accomplished by the company so that more people would become aware of Graeae and its artists. Doran's decision to open the RSC to more inclusive practices will bring more exposure to disabled performers in classic theatre roles. Doran also mentions that work needs to be done so it's a level playing field as far as casting goes for theatrical works.

At the 2019 Tony Awards ceremony history was made as best featured actress in a musical was given to Ali Stroker for her role as Ado Annie in *Oklahoma!* Stroker had already made history as the first actress in a wheelchair to perform on a Broadway stage during her run in *Spring Awakening*. The most telling part of the ceremony was that there was no ramp to the stage from the auditorium seats. Stroker had to enter the stage from the wings in order to receive her trophy. Stroker used her time in her speech to plead for changes in designs for theatres to include access for people with disabilities. This magnifies one of the main points of this dissertation. Although

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[97] "This is another crack in the glass ceiling: RSC casts disabled actors in new season." Dalya Alberge. *The Guardian*. Saturday 6 January 2019. Https://www.theguardian.com/stage/2019/jan/26/rsc-casts-disabled-actors-shakespeare-glass-ceiling.

[98] Https://www.theguardian.com/stage/2019/jan/26/rsc-casts-disabled-actors-shakespeare-glass-ceiling.

many inroads have been made hiring disabled artists, there is still much more work to be done with the physical environment of the theatrical world.

In 2017 Actor's Equity, the professional theatre union in the USA for stage actors and stage managers, released a study concerning hiring practices for all minority groups. The research revealed that only 219 members self-identified as disabled.[99] The study concludes that this number is most likely not representative of all disabled actors working with a professional Equity card as many have not identified themselves as disabled. There is no empirical evidence to prove this assertion, but the union has stated it will continue to work to be more inclusive in its membership and provide services for all members.

The hiring of Stroker in the first place represents an enormous step in the philosophy of Broadway casting that falls in line with what the Royal Shakespeare Company achieved. Yet to match the RSC's hiring of three actors, a Broadway company would need to commit to casting several disabled actors for a season and use the model provided by Graeae Theatre to ensure a successful run of shows that feature disabled actors.

Another example of advanced work in the field of disability theatre took place at the Laura Pels Black Box Theatre in New York City on March 1, 2018. *Amy and the Orphans* opened as part of the Roundabout Theatre Company's season. Written by Lindsey Ferrentino and starring Jamie Brewer in the role of Amy, the show centers on three siblings who reunite after their father's death. Brewer has Down Syndrome as does the character of Amy. Brewer and her understudy Edward

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[99] *Diversity & Inclusion: Actor's Equity Association*. Https://www.actorsequity.org/resources/diversity.

Barbanell are considered as the only known Down Syndrome performers to serve in the lead roles in a Broadway or Off Broadway production.[100]

Ferrentino had been working on the script with Brewer in mind as the lead role since 2015. Brewer received national recognition with her various roles in the television anthology *American Horror Story*. Ferrentino's draft notes of her script contains her requirement to have an actor with Down Syndrome in the role of Amy. The play is based on Ferrentino's aunt who had Downs and has since passed away. When understudy Barbanell is performing the production is retitled *Andy and the Orphans* at the request of the playwright. Ferrentino made her casting requirement clear when she stated: "Finding a talented actor with Down Syndrome isn't difficult. So please do it."[101] Ferrentino has created a body of work that seeks to explore the life of a person who happens to have a disability and how he or she copes with a family tragedy. This is an example of work being produced that employs disabled actors who are working professionally in the theatrical arts. It is a far step from where theatre was as recent as eleven years ago when this research began and gives a concrete example of success in staging similar productions in the future. This is how Ferrentino uses her influence as an author to reinforce the ideas of inclusive hiring practices in theatre.

This research is designed to present a comparison and contrast between two theatre companies. Graeae and The DisAbility Project serve as active, contemporary examples of organizations that seek to increase the opportunities for disabled artists to perform. It is through

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[100] Sopan, Deb. "A Barrier Breaks: An Actress With Down Syndrome Plays The Lead." *New York Times*. February 14, 2018. Http://www.nytimes.com/2018/02/14/theater/amy-and-the-orphans-down-syndrome-jamie-brewer.html.

[101] Sopan, Deb. "A Barrier Breaks: An Actress With Down Syndrome Plays The Lead." *New York Times*. February 14, 2018. Http://www.nytimes.com/2018/02/14/theater/amy-and-the-orphans-down-syndrome-jamie-brewere.html.

their work and the work of many other companies that these opportunities are expanding as the theater profession moves forward. The companies and the voices of their artists give credence to the precept that enabling disabled actors improves their quality of life. As Grayson Perry, a visual artist in the United Kingdom said: “Making and consuming art lifts our spirits and keeps us sane. Art, like science and religion, helps us make meaning from our lives, and to make meaning is to make us feel better.”[102]

Two aspects of this research gave me significant insights into this research. The first is the interviews with the two companies I compared. For The DisAbility Project I interviewed seven members of the company. The words of these artists provided insights and deeper understanding of what it means to be a disabled theatre artist. For the second company based in London I was only able to interview two members: Jenny Sealey and Carole King. Due to Graeae’s access to publishers, their books *Graeae Plays 1: New Plays Defining Disability* and *Reasons To Be Graeae: A Work In Progress* provided significant material from Jenny Sealey the artistic director.

A second crucial element was my ability to see actual performances by both companies. These included *One World* from The DisAbility Project. With partial funding from Department of Theatre and the Graduate School at Ohio State University I had the opportunity to see two of Graeae’s productions: *The Garden* and *This Is Not For You.* Finally, I also made an effort to see other productions such as Indiana Repertory’s *The Curious Incident of the Dog in the Nighttime* as well as the production at Ohio State University Department of Theatre’s in 2019. Both the

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[102] Brown, Mark. “Arts can help recovery from illness and keep people well, report says.” *The Guardian*. July 19 2017.

interviews and the performances provided me with the views of those working to create theatre for a disabled minority, many of who are themselves disabled.

Jenny Sealey and the Graeae team have included guidelines for new theatres who wish to follow their model for creating successful theatrical enterprises for any company with a vision of inclusive theatre. It is important to recognize that the United Kingdom has better funding support than the USA. This can be seen in this comparison between these two companies. Joan Lipkin and her team have focused on the educational aspect of disability theatre and continue to work from the ground level to inform non-disabled people about the realities of living a disabled life in a primarily non-disabled society. They use theatre to bring their stories to life and invite questions so that the doors of communication will be opened and future opportunities for disabled artists will be accessible. We are at the threshold of bringing disability theatre into mainstream society in a more viable way. The works of each writer, director, and actor mentioned in this paper will pave the way for more work that includes all artists and does not look at the disability and focuses on the artists and the stories they tell. They are leading the way to making this question redundant: What is disability theatre?

Appendix A: Interview Transcripts With DisAbility Project Artists

The following interviews took place in the Spring of 2017 in St. Louis, Missouri. All interviews were face to face except Jennifer Medina's and Vanessa Roman's which were done through FaceTime and Ana Jennings' which was conducted by phone. These interviews include the acting company as well as the production team. Accompanying me at the interviews was my wife Kellie Kochensparger. She will be notated in the interviews. They include each performer's time with the company as well as their recollections of past members who have left the group or have passed away. The DisAbility Project is in flux due to illnesses and work conflicts that prevent some members from continuing with the group. My recorded interviews include Joan Lipkin [co-founder and current producing artistic director], Jennifer Medina [choreographer], Vanessa Roman [artistic assistant], Becky Galambos [office manager], Bryan Jones, Ana Jennings [current actors], and Angie Schaeffer [past performer]. In Angie's case the interview had two parts to include additional information that she wished to convey for the purpose of this paper.

Interview with Jennifer Medina

Jennifer Medina is the Artistic Director of Common Thread Dance Company in St. Louis, Missouri. Medina is also an adjunct faculty member at Washington University in St. Louis while providing choreography for the DisAbility Project. This interview was conducted through FaceTime between St. Louis, Missouri and Dayton, Ohio on May 27, 2017.

Jennifer Medina: How are you doing, Jonathan?

Jonathan Kochensparger: I'm doing very well, thank you. What's been amazing is, I could not believe the response I got when I sent that out. I just went individually to everybody and I was just stunned because everybody's meeting with me at one point in time.

JM: Of course!

JK: No, that's very sweet, but I know how busy everybody's time is. I'm like, "Here I go, let's try this," and I have to wait till the end of the school year, but Kellie went ahead and organized our going to St. Louis and everything, and we just love going there. This is good.

JM: I'm so sad that I'm going to be gone when you're here!

JK: I know, I know.

JM: You're gonna come up and speak with some of the participants like Ana and Bryan?

JK: Yeah, they’re all great, and you know Ana, and you saw how Bryan posted about it on Facebook, which I thought was so sweet. He called me right away and he said, “Can we meet at the Magic House?” And I said, ”Whatever you need, Bryan, that’s perfectly fine,” and I said, “Well, what time?” And he said, “Well, how about noon?” And he’s talking to me directly, and I’m like, “That’s fantastic!” So, I don’t want to be in the middle of his work, and I’m like, “Oh my gosh, I’m afraid I’m going to be there while he’s working, but we’ll adjust to it as we need to.” But I definitely need to talk to the players, because that’s a big part of it, is to find out what their end of it is. And then for you and Vanessa and Becky and Joan, that’s the big part of the other end of it, how all this came together is really what I want to hear from all of you if that’s okay. The paper is basically a combine/contrast comparison to ours, to the DisAbility Project and the Graeae Theatre up in London, and what they do, because theirs is a professional theatre. So that’s what my professor wants me to do, is see all the differences between those two, and the similarities, because I’ve seen both. That’s the nice thing. I’ve been very fortunate. When I was up in London in 2012, I had to give a speech. Surprisingly enough, they asked me to give a speech. I didn’t expect that, but it was on the Worlds Together Shakespeare conference, and using it in the classroom, and working with raw Shakespeare, and I thought, “Wow, that’s kinda cool!” Kellie went with me, and then we got to see one of their performances called *The Garden,* and it was beautiful, and you would kill that. You would do so well with that. I asked the author, Alex Balmer, “Do you mind if we do this? How do I get the rights to this?” And she said, “That’s fine, that’ll be five thousand dollars,” and I said, “Oh my gosh.” And she wanted to come down and actually help them, and I understood that, but I said “Well, we’re a high school, and I was just wondering, and I understand,” but it was truly the most fabulous piece of work

I’ve ever seen in my life, and I was just stunned. And then I saw your work, on that day we came a few years ago, and I was like, “Well, we’ve topped that! What am I doing here in the middle of so much great artistic work?”

JM: I wish you had seen it when we did it in the theatre with the lights and all that stuff.

JK: Still, I take into account the venue and the weather, like it was when we were up there to see it.

JM: Crappy weather, when you guys were up here to see it.

JK: I know but it was still very … You’d really have to hate theater not to love what you saw. I really do mean that. It was just incredible. I thought, “Wow, everything. That was put together, and everybody’s working.” I just love that part of it. I just think it’s just fantastic to see everybody.

JM: It was actually, like, a truly collaborative effort. It wasn’t, like, like, I know Joan would say, probably, “She did this; she did that; she did this; she did that.” That’s just how Joan is. Vanessa and I honestly were there more, physically, and I think you’d find probably a similar response from Vanessa. It was, like, Joan would start to tell us what to do, and we would filter what we thought that meant. It was definitely not like a typical choreographic experience, where I just go and put stuff together for people. It was everyone’s contributions that made it special. I think that’s why it’s truly special. It’s really honest. It’s not just filtered through me. It’s like, “Those are Ana’s words; those are Bryan’s words. That’s what they said.”

JK: The music choice, was that Joan's music choice and then you worked with that, or how did that … ?

JM: I fought her on the Lady Gaga, because I thought it wasn't…I fought with Joan a lot. I'm more of a symbolic person and I think she's a literalist. I thought the Lady Gaga was too explicitly literalist, and I wanted an opening that was a little bit more, kind of a compositionally prepared dance piece, which would be not so much game-show, introduce-the-characters, but more like illuminating one at a time with the music only, and maybe music with some Beethoven or something. So that was one of my, "Okay, you know, you have to pick which hills to die on a lot in life."

JK: I love that, because my interpretation, when you say that you disagree, is that's how you collaborate because if you just have someone that agrees with you all the time, you're never going to move forward.

JM: Like with Donald Trump right now, I'm having to pick which hills to die on. I feel like everyone's obsessed with him and they're not obsessed with how their state governments are completely screwing them every day, and that troubles my soul. So right now, I'm very heavily working with people on Twitter that are working on hacking the vote through gerrymandering, voter activism, and then also with the resistance. It's, like, you gotta pick which hill to die on.

JK: I know, and I see what Joan does, and I thought, "Wow, that's amazing." It's a lot to have to choose, like what you said, statewide in Ohio. We have a similar thing, I think, to what you have, in Missouri. You've got to start locally or else it's not going to … You've got to move that way.

JM: Yeah! And then traumatized by espionage in the White House, and, like, oh, it’s horrible, oh my gosh.

JK: Oh my goodness.

JM: But at the same time, it’s, like, not practical to obsess over. I’m obsessed. I’ll stay up till three, four in the morning reading op-eds and stuff, so I’m on that end of the obsession. So I sound kinda funny but, like I said, like anything in life, you’ve got to go, “Okay, that’s the thing I’m gonna let go, that’s the thing I’m gonna hold on to, I’m gonna let go of this,” so in the process of that piece it was definitely, that was the thing. At one point I had different music for Bryan’s section and she said it sounded, how did she say it? She called in the morning, real blunt, like, “That just sounds bluhhh.” And I go, “Okay, well, you can use your nicer words, I won’t get pissed off if you’re nice about it.” So we ended up kind of talking about that. But I did agree with her. I felt it undermined his dignity. It was a little too juvenile, I guess, maybe. I don’t know. So we got to change it. I miss it, though. I miss the people. We haven’t done it since we saw you.

JK: That’s what I wondered.

JM: And I’m kinda bummed about that, but it’s hard because Joan’s not geographically here, and I feel like they’re not doing anything right now. So I’m opening, like, a brand-new facility and it’s accessible through the front door. If they want to come in they can park by the front door, so I’m hopeful that maybe we can reconvene after she officially decides that she’s done. I think it’s hard for her to decide that she’s done or not. I haven’t talked to her in a while, honestly.

JK: I just had a message with her, these huge messages she sends, I don't know how she has the time to write what she writes, these messages on Facebook, oh my lord. She writes very well and it's just a lot. I thought, "I don't have that capability, because I just, I can't write that well, first of all, but also I just don't have the physical time to, like you said, go in and answer and react, and there's a lot of other stuff I'm needed to do. And that doesn't excuse it. I just need to do more, I know. I need to find more time, but I'm stunned by how many people she's trying to reach out with nationwide, and I know that takes away from the local, and that's what I figured part of this was, is that she just hasn't been able, like you said, to physically be there with you. So I'm gonna start with this: How did you get started with them? I know when I met with them a couple of years before I actually came and saw you, I just met with the company, and they were busy going around to the schools and performing, and that wasn't something that I saw as part… I didn't think you were part of it then. If you were, I'm sorry, I just wanna make sure I get that correct.

JM: Well, I wasn't. I was familiar with Joan's work, but I didn't really join the DisAbility Project until we started this piece.

[beeping]

JM: Hello? Are you there?

JK: I’m still here. I’m sorry. My aunt called. I will tell you, I have two old Italian aunts, and they’re wonderful, and I love them, but when I call them they tend to say, “Oh, we’ve got a call on the other line,” and I go, “You’re talking to me!” And they just called, and I’m like, “What are you doing now?” They’re my mom’s two sisters and I love them unconditionally, but they’re funny. They don’t have a cell phone. They just have their regular phone, so it comes and goes when it has to, so, I’m sorry.

JM: It’s okay, it’s okay. I’m just trying to remember how this all manifested. I was talking to Joan about it.

JK: Well, you’ve been working in St. Louis for how long?

JM: Oh, six, seven years now, I guess. Okay, okay, and I think I came back around 2011 or 2010, something like that. I’d known Joan before that, because I was from here. I’d met her at some events. You know, a friend might say, “Oh, this is Joan Lipkin.” But I don’t remember how it came to pass that she asked me to do this. I don’t remember. Isn’t that sad?

JK: No, that’s fine; you’re so busy,

JM: I don’t remember.

JK: And if you’re as busy as you are, and that’s what I say with choreographers, I cannot picture that talent, because I don’t have that talent.

JM: It’s a very unique skill set.

JK: But I can remember details, like my wife says—Kellie’s gonna come out and say hi to you in a little bit—of things that are so minutiae. It’s just horrible.

JM: My sister's that way in weird ways. She remembers crazy details. I just remember being there. I think that we met and talked about it first, but it could have been through FaceTime. But we communicated after the fact once we got going. Her folks were still alive, so there was a lot of caretaking at that point, because her other sister's in Chicago and her brother's a world-famous CDC doctor, so he's quite busy. At that point we would do Skype. At that point she had Skype, so we would do Skype, and she's notoriously bad at technology, so it was funny. Then she'd come to town and we'd plan out the dates. When we first did it, if I'm not mistaken, it may have been a commission. She can tell you the details. I can't remember the details, like, how that all went down, but I know the first place we did it was for a human rights conference that was positioned on disability rights. It was at Webster University. It was in the fall of, I wanna say, maybe 2013. When did my gran die? 2013 or '14? Before that. It was the year before that. I'm terrible with dates, too. I do, like … very hazy world here up in the clouds. I have to get back down to earth sometimes to do taxes and shit; it's torture. We staged it quickly, within about four or five rehearsals for this event. Warren Rosenblum was hosting it at Webster. I think it's something he does annually with it, and then each year the conference is positioned on a different element, obviously of human rights. That's my understanding. I could be wrong. I can check that out. We did it in a conference room in front of some of the biggest leaders in disability rights in the world. Like Chen Guangcheng from China; he's blind and was kicked out of the country for demanding human rights, God forbid, you know. And then one of the writers of the ADA was there, a woman with long hair. Of course the [inaudible], and then groups from all over the world. We met Argentinians, Mexicans, it was crazy. It was crazy and it was the first time we tried it, so we did make some changes, then, after that first go-through, then we had quite a while until we did it again for my dance concert, and that's when I think it really was able to, the version you see was fleshed out better at that point. But I don't recall how Joan and I met, even?

JK: Okay.

JM: I know I met her before I went to conservatory, so I met her before 2004. So somewhere around in there, she talked me into doing this, and I just love to try things. I have a crazy compassionate heart, so it sounded like a kinda fun project, so I was like, "All right," but I ended up really working with Vanessa probably more than Joan, and Vanessa can also speak to that

JK: I think that speaks to part of … Joan's also putting off things. Vanessa's also been busy, just from what I see on Facebook, so.

JM: The movie thing? Trying maneuvers? Telling stories? I love Vanessa.

JK: I do, too. I think the combination is the reason why there just hasn't been as much communication. I know Bryan keeps on, Bryan Jones, dear love him, he just keeps on going, "I wish we could get back to her; I feel so bad when I reach out."

JM: I know. I know.

JK: About the piece itself, the entire piece, I think the people who I saw when we came for the ADA conference, was that the entire group you worked with? Or did you work with others and it changed, or how did that … ?

JM: Was Bryan … ? Oh god.

JK: Was it Angie?

JM: Angie was gone.

JK: She was gone at that time.

JM: There was another lovely man in a wheelchair; he just passed away.

JK: David.

JM: Was he there when you were there?

JK: He was not there. He had already passed, I think. I’m trying to remember that, but I believe he had passed, or else he was not with us and he passed very shortly after.

JM: He just passed very recently. He was hard to pin down, that one. He was hard to get, you know, consistently there, consistently performing. I loved him, though, he was hilarious, and a great little contribution to the piece, ‘cause he was gay, but, yeah, Angie was gone, so it was a smaller group that you saw live than what we did for the other show. Yeah.

JK: David, I think during our first conversation, because I met them, like I said, before that day, was about how difficult the transportation was for him. There was one example, he said, where he was at a school because they had scheduled to go to a school and the school did not tell them they were not in session that day, and he was stranded there at that school from his ride because he’d expected to be in there for a long period of time.

JK: They finally came back, I think it was Ana who came and got him, or Margaret, one of the two, and it was insanely rude and wrong because, you know, I work at a school, and I know how schedules work, and if I'm in charge of something, then I'm the key person and I'm constantly talking back and forth, and that frustrated me, listening to it, because I thought, "How dare they?"

JM: Yup! They deserve everything.

JK: I know. I know.

JM: [inaudible—bad connection]

JK: I'm sorry?

JM: My whole next year is already planned out. I mean it, like for shows and everything? It's insane.

JK: I know. I'm right with you. I'm scheduled all the way through next summer at the end, but we have to, because we can't just sit there and wait and say, "Oh, I'd like to do this." That's why I felt horrible about contacting you just a couple of days ago.

JM: Don't feel bad about that! We're all in this together, and it's important to make sure it gets documented properly, even at first, because then you take that and you use it for advocacy at the governmental level, and, I mean, it all is part of the puzzle of fighting fascism in the long run, hopefully.

JK: That's my plan. That's exactly why I'm doing this. I don't have time to sit around and do nothing. I just can't do that. I'm just not that type of person. So the piece you have that you put together? You have movement from both the disabled actors and then your dance troupe also, so when did you decide to include them, and how did they respond to that work?

JM: Like the initial? My company is already pretty focused on social justice issues, so the people that dance for me, when I interview them I have to know that, not to be funny, but I have to know that they're not going home and believing Rush Limbaugh, or believing Hannity. They have to be clear in what their purpose is on this planet as an artist, and if they want to be just entertainers, I have no judgement of that. I think that has a very important place. But if they want to do work that matters, if they want to get in and deal with things that are not pretty truths, then those are more the people I want to work with anyway, because that's who I am, so they're like an extension of myself, which sounds hella narcissistic but it makes for a more comfortable environment for me to be vulnerable in as I create stuff. So what I did was, I had, at that point, dancers who'd been with me quite a while. I knew this was gonna be a not-paying gig, which is always complicated, when you ask people to do things for free, so I assured some of the younger dancers who were new to me that had not done the homeless piece a couple years before. See, I had worked with, the year before, Peter and Paul Community Services has a rehabilitative two-year program for the chronically homeless and if they go through the program, they graduate the program, they get an apartment, social services, a job. It really is incredible.

JM: They only take eight at a time, and they were doing a documentary about the program … Sorry, that was my friend Renee calling, and I'll call her back. Anyway. So one of my dancers' parents were involved with the documentary and they asked if we wanted to be involved, and they were gonna do a simultaneous kind of showing of the documentary with a stage production at the history museum and they needed some choreography, and I said, "Yeah, I'll do it, of course!" But I sent months with the homeless community—in traditional housing. They weren't totally homeless. I'm sure you were wondering. So those dancers that had gone through that project, I asked them first if they wanted to do the DisAbility Project, and if the time permitted they would do it and then of course the newer dancers to me, especially Stephanie and Laura [inaudible]. Now Laura's going on to physical therapy school, so I think that kind of comports in with it as well, and then Sydney was working with me [inaudible] and needed some credit for a class she was taking, and I was like, "Well, this is going to be your credit, three hours on Saturday for a three hour course. That seems reasonable." And then that's how it kind of came to be.

JK: So how did you make the decision of who was going to dance with which of the DisAbility Project people? Was there a method to it or did it just … ?

JM: No. That's hella arbitrary. I'm just like, "You go left, you go right." My creative process is … I don't know what other people's is like, but it's hella mystical. Let's put it like that. 'Cause I don't think, and that's my favorite feeling in the world, to not have to think, cause I'm hella smart, and got ADD and all the things.

JM: My brains' a-cookin'. So when I'm doing that, the ADD takes a different place in my brain, and I can, like, hyper-focus on puzzle pieces. That's how I see it, like puzzle pieces, like constantly moving and reshaping a puzzle. So, yeah, it was totally arbitrary.

JK: That's fine. It's pretty much how I approach my directing of my shows. I don't have it pre-planned. I can't do that.

JM: I'm just like, "I'm not gonna plan," you know? I've gone on gigs before, where people have commissioned works from me for thousands of dollars, and they'll say, "What are you gonna do?" Like the night before, at dinner, when you've gotta go through all the food crap, and I'm, like, "I dunno." They always look, like, about to have a heart attack! And I'm, like, "Well, how am I supposed to know what I'm gonna freakin' do until … I haven't met the people! I brought five CDs, I got an iPod full of music, I have an 'ish' plan of songs I like, you know, but I have to look at their faces and see how they react!" Similarly, I did that with DisAbility Project for sure with the music choices, kind of like, "Do you like this one? I dunno. Do you like this one?" It was more important to me that they like it than Joan.

JK: I appreciate that. I have a kindred soul, because I think sometimes, when my students look at me:"It's a living breathing thing," I tell them. I say, "I don't know! That day it may look like this is better and the other day…" It just depends on what we're working on here and that to me is more of a … I just like to see it that way. It's more alive and they feel the energy, so I appreciate it. I will tell you that, firstly, I appreciate that

JM: I change my own work every time I perform it because I might look at the video for a few months and be like, “I can’t stand that arm on the upstage left girl on that phrase,” and then the next time I do it I’ll just change it.

JK: Exactly.

JM: You just gotta have some space from that shit to see if you like it still or not. Hi Kellie!

Kellie Kochensparger: Hi! How are you?

JK: [laughing]

JM: I’m better, now that I got my new shoes for my trip tomorrow! [laughing]

KK: Excellent! Congratulations on your new studio! I can’t wait to see all the pictures!

JM: I wish you guys could see it when you’re here, but we’re gonna be out of town with the kids. They’re performing in Tennessee next week, my babies, so I won’t be here. But oh my god, two years’ torture, more mansplaining than my mother and I ever want to endure ever again. A lot. But it’s almost done.

KK: Keep a good punch list!

JM: We’re gonna own the building. We’re one of the few businesses that gets approved by SBA!

JK: Good!

KK: Excellent!

JM: It’s a good loan. It means that even Donald Trump can’t mess up the loans.

KK: Yay!

JK: [laughing]

JM: Unless we get blown up by some North Koreans, but I'm not going there yet. [laughing]

JK: Well, that just means we're going to have to have another trip to go to St. Louis.

JM: You do! You do. The goal is, like I was saying earlier, hopefully, you know, I don't want to step on Joan's toes about it, but for instance, one of my former students was born with a hand deformity. She has two fingers, and she moved to New York. Beautiful dancer, but it's hard for her to find work in a classical company with a weird-shaped hand, and so she started working with Heidi Latsky two years ago. And if that's not on your radar, get it on your radar. It's one of the most amazing dance companies. Like, Dancing Wheels does great shit, but, like, Heidi's stuff is unbelievable. Like, she's got a dancer that has, like, cerebral palsy, and of course Elise is with her, so my goal is to get the DP back, reorganized under a different name, and start something a little different that's more on the fine-arts spectrum, a little bit. Dance theatre, perhaps, but I really have these dreams of them doing like, I don't know, Chekov plays, that I, like, rearrange, or just, like, not doing things necessarily about being disabled but just being disabled doing things.

JK: That's more where the narrative is, yes.

JM: And I know Joan’s work is definitely very bent on advocacy and education so of course then it becomes, you know, “This is what it’s like to be in a wheelchair,” but don’t you just want to see Ana with, like, angel wings on the back of that chair, and some dramatic headpiece and gorgeous dress? I want to take it to that space, I guess. It’s a ballet company so they’re more part of the ballet company, so they’re emerging as well with the dance and the theatre.

JK: That’s what we saw when we saw *The Garden* that I talked to you about, at the Graeae. They had giant poles on the … It was a square, but it was tilted a bit, a bit of a raked stage, but it had four bendable poles, and they climbed those poles. They had rehearsed that, every one of them had a disability and they were moving, and they would bounce back and forth between the center and bring a flower to the person in the center, or a [inaudible], and that’s exactly what we were talking about, and it was an amazing story.

KK: All different types of disabilities, and lots and lots of collaboration with the group. It was amazing to watch them perform. It was not at all about their disabilities.

JM: Do you feel like … ? Okay. My friend Jackie, she’s a woman of color. She’s one of my best friends, and we talk about this often. She’s a director and she’s directed Shakespeare plays here. She’s amazing, right? So when she acts, very frequently I always joke, “Okay, are you a slave this time? Are you a woman that works in the kitchen?” It’s always, like, a crapshoot whether she gets a part that’s just about being a person, a woman, or is it about being a black woman?

JM: She and I talk about this often, with the DisAbility Project, by saying, the problem we have with rights is just that people aren't represented as normal, you know what I mean? Even though this is part of life, so why isn't there someone in a wheelchair who's the lead actress on a TV show? You know what I mean?

JK: That's hard.

JM: But she's working in an office and it's a comedy or something, or it's serious, so that's where I'm at with it.

JK: When I worked—

JM: But I don't fight with Joan about it, you know? I don't want to be, like, "Are you done yet?"

JK: I think that's a part of what Joan wants. She just wants to expand to so many advocates. That's why she's so busy with everything, and you're right, but the kids I work with at my school, they have multiple disabilities. We have kids who cannot speak. We have kids who can't be there onstage too long because it's just too much for them, and we put them on the same stage. This past year, when we did our performance of *Snow White*, and it's just a simple thing, it's just enough, because the words are so difficult for some of them, but we had one person, she had her iPad that spoke for her. They had that programmed in, but she had to be the one to go ahead and it was amazing. She was stunning with it, but they all spoke at some point. That's what I wanted. I wanted them to each have a part and speak, and one of them, he wasn't going to perform, but then he realized that, you know, if he didn't, then he wouldn't be onstage, and then they opened the curtain and it changed completely, and he said his first line and he just shook his fist in the air, like, "I did it!" It was just the greatest.

KK: It was wonderful.

JK: Because he did it! And the rest, it brings tears to my eyes, of joy, not tears of sadness, because they are working, and that's what I want to do. That's my goal, so it's going to happen. I'm too old to say no.

JM: You've just got mad love for those humans.

JK: Oh my goodness.

JM: And you just know it's an important part, an important piece of their journey and their lives. That's what happens when you teach kids, it makes you really [inaudible]. I'm like … I was on the radio two days ago and the radio interviewer, she goes, "If you could say anything about your students, what would you say?" I was bawling. I was trying to talk like I was not, but literally just crying. They're good citizens of the world. These kids now, they're not like, I don't know. How old are you guys? I'm 45.

JK: I'm 52.

KK: 49.

JM: So we're around the same age, right? But the millennials, you know, I love the millennials. They are not here for any of this bullshit at all. Sometimes I will want to kill them because they ain't got no sense yet, 'cause they're still kids.

JK/KK: [laughing]

JM: But they are just so over it. They're, like, "Our whole lives have been screwed up by terrorism, so we are not here for this. No more. No more fighting about gay marriage and stuff like that." I feel that when you do what you do, and you love it, I always say, when you cry it's just love coming out your eyes.

Jon/Kellie/JM: [laughing]

JK: That's excellent. So when you worked with the people from the DisAbility Project and choreographing them, how much one-on-one was that? Or was it … because you talked about how you know your dance group, you know exactly what they need … Okay, I'm sorry, she's moving my phone here to make sure… What specifically with Ana, and Bryan too, because he has such definitive sensory needs. What was it like to work with them?

JM: Well, my goal was to, as always, when I work with people who haven't danced before or very much, is to find shapes that they can achieve. So, like, Margaret can only lift that one arm, you know, so we dealt with that right away. When we would do things with arms, I would say, "Just do the one arm, Margaret." Same impact, no big deal. Or Angie was non-disabled, and so she could do more in terms of the rap and stuff, when they were kind of dancing around, and she was a little more physical. Joan was good for me, though, because she knew her actors better. I didn't know them. Of course, I wasn't in the space of thinking about … I had heard years ago from someone like in a chair that they didn't like it when people touched their chair, and so I didn't want to be too physical. I'm a definite believer in autonomy, so I always ask people, "May I give you a hug?"

I'm not an arbitrary toucher, you know how it is, if you've been living around people with sensory issues. I have my own kind of sensory issues. I was abused when I was a child, by my father, so loud noises, loud men, there's things that definitely still make me triggery. I just didn't think about touch. I don't know. Joan came in one day and she said, "Well let's do a contact improvisation warmup," and I was, like, "Say what?" [laughing] I'm like, "They're in chairs and shit! What are you talking about?" And she's, like, "No, we do this all the time," and so then that brought us the middle. There's a middle section before … I should have watched the piece before I talked to you. There's a middle section before the end, kind of, where they do a contact improv section, and that was definitely Joan's doing. That was not my doing. I shaped it and kind of made it consistent, but she was the one that pushed that, and I was really grateful for that, because myself was thinking, like, too much fragile porcelain dolls and not, like, you know, humans that I can assume have more ability than I'm giving them credit for. Do you know what I mean? So for my own shit, I was, I guess, ableist in a way, you know what I mean? To think that way. So yeah. I guess I just mostly looked at shaping. I'm very good with patterns. I'm very good with moving groups around. That's something I've always been quite adept at, so moving them around, shaping each space for the next section, that might sound narcissistic or grand or something, but that's not that hard for me. What's hard is exactly what I faced, which was like, what is their capability space? I don't want to hurt anyone physically, but I also, you know, I was assuming too delicately, I think, initially, honestly. Bryan, you know, he loves to play. He loves to play. He's funny. So you just ask him, "Is it okay if she gives you a hug, or can you hold her hand?" He just says, "Oh sure!" He's just a gentleman. It was fun to work that whole section of him learning to walk. Joan said he wanted to see it and I tried it, I think, with her first. I tried it with her first, I believe, to kind of fiddle around with that. And then we both knew that was really awesome when we saw it. She was there that day when we did it. That's one of my favorite parts.

JK: I was going to say, why was the decision made to have Malia Wirtel, I believe, dance-walking with him? Why did you choose her as opposed to one of the other dancers? Since she's part of the DisAbility project, was that a purposeful choice, or was that just … ?

JM: Well, when we did it for the Amsel show, one of my dancers did do it, and then when we restaged it, that dancer couldn't be there anymore. So, knowing me, it probably had something to do with, like, geography, like if someone was already offstage, or she was closest to him, she would've been the one to … It probably was a geographical choice, honestly.

JK: I didn't know if there was any issue that came up with, like you said, with him. Some of my students are more comfortable with one person and if you make a change, that's some of them. I kinda get the sense from Bryan that that's what it was.

JM: It was just a restaging kind of moment, where we just found the space to do it. I think I had less dancers. Did I have four, when you saw it, or three?

JK: It was four. One came in late. She had to get there. She was trying to get there as fast as she could so she came in at the last minute, but I think it was four that you had that day.

JM: That's what we started with. That's what we usually … See, Destiny couldn't do it, so one of my high school kids did it, yeah. Yeah. Was Stephanie gone, too? I believe Stephanie was gone too. Boy, I need to take some ginkgo biloba or something. My brain. Wow.

JK: It's hard to get all the details, like I said.

JM: After forty, they say you start getting dumber. I feel it.

KK: [laughing]

JK: I don't know about that.

KK: We call it stress in our household.

JM: I tell my kids, when I sound stupid as a teacher, I say, "You know, I can only hold so many files, and I've gotta delete whole files."

JK: I'm with you. They changed our class to a semester from a full year, so I'm rushing to get to know these kids, and by the time I know them, it's the end of the semester and I've got a whole bunch of new ones. I'm, like, "You are kidding me here. I can't get this all down!" I'm way past that fifty time where I could just go ahead and remember everybody in the world. I tell the kids, if I see them outside, "If I say 'Hi, how are you,' I don't know your name. You've gotta tell me. If I say 'Hey you,' I don't know you. I know you by face, and I could tell you where you sat, in what class."

JM: I can remember my neighbors' dogs' names but not their names. How bad is that? That's bad.

JK: [laughing]

JM: I call my one neighbor "Milo's mommy," and I asked Robin, the other neighbor, "What's Milo's mommy's name?" And she goes, "I don't know," and I'm, like, "Dude, we need to find out! We keep talking to her like we know her name!" Anyway, so I guess that's how I chose …

JK: I'm now looking at the questions I had, which were my preset questions. I had to submit these to my IRB, which I'm trying to get used to. That's the International Review Board and that's important for dissertations, and you've answered everything which is so fantastic, and we don't have to worry about it.

JM: You can listen to it and rewind it right?

JK: Yeah, so what's going to happen is, my professor is Dr. Lesley Ferris. She's phenomenal. I don't know if you've ever met her. If you never do, then that's a loss, because she's just tremendous. She's just so patient with me and has helped me, guided me all the way through this, put me in touch, really, with Joan and Fox and so many people, and she said, you know, "Get this professionally transcribed so you don't have to do it yourself," and I go, "That's true, because I'm not…"

JM: That's good advice, yup.

JK: So I'm just gonna turn all these tapes over to that person, and I've got to keep them safe, in an actual safe. They'll physically stay with me until they direct me to destroy them, and everything will be destroyed. I'm just gonna use it, like I said, for the paper itself, so it helps tremendously, but like I said, you have everything. I have one last thing I think I need to … If you can name anything that has not been addressed as far as disability rights in performing arts, and explain why that's important. I mean, you've sort of addressed that.

JM: I touched on that a little bit, in terms of, I guess, how we are perceiving the embodied practice, like if it is … there is this show on TV, have you seen the show on TV? It's a comedy. Of course I don't know the name.

JK: The man in the wheelchair, right?

JM: And he had an aide, and … you know?

JK: Yes.

JM: And I'm appreciative of that show, but I feel like he's sort of not the center, but he is, but I feel like … I don't know what I think about that. I like it, but … What do you think about that show?

JK: As soon as they announced it, I was really happy to hear that, but I wasn't sure what they were doing with him. We watched a few episodes, but again, me and my schedule and rehearsal, I don't really get a lot of time and we don't have a DVR, so. You used to be able to record these on a VCR. I can't do that anymore, so I don't have the chance to keep up with it.

JM: I saw it on the Hulu, and that's how I watch TV. I don't have cable. I just pay like twenty bucks a month for the Netflix, and now Hulu has to be on boycott right now because they're still buying the ads on Hannity's show on FOX, so I'm cutting a long list of crap for that. So that kind of sucks because *Handmaid's Tale* is awesome. Anyway, I guess I just felt like, it's just so frickin' hard. It's like racism; it's hard because you're the white person, right? So when I intersect with people of color, how do I sit in that space and not take space and be not a "white guilt" person, but also be supportive of … I mean it's like … That's not as hard for me because I've always had black friends and I've always had, from the time I was quite young, very close friendships with black people, so that to me is not hard.

JM: I got together in the 90s with a whole bunch of black gay men when I was dancing with them, and we'd get in the car, and they'd say, "Whatever you do, don't speed, bitch," and I'm like, "Okay." Or like, "You don't got any weed in the car, do you?" "No, no." "Oh, okay, good because we're not trying to get in no trouble." I mean they just got me all the way together about cop violence from when I was eighteen, seventeen, so whenever Mike Brown got shot, it was kinda like, "Yeah, I know, that happens. It's horrifying." And then there's still people who argue about that.

JK: I know.

JM: So I feel like disability is like, so not on the radar. There's a woman I follow on Twitter who has lupus, who used to be a spy. She's a lawyer now, and she was heavily involved in the NSA for a while. She was getting vetted the other day because people were saying "Oh, you're not a lawyer anymore." Well, she had to stop being a lawyer because she got really sick, and they had to take her license, and so she started using the word "ableist" frequently on Twitter threads, and I don't know how many people said they had to look up ableist and what it meant! So, like, culturally, we're in a really interesting time, in my opinion, because I feel like whether it's the issues dealing with women's rights, race, religion, or disability advocacy, to me, disability is at the bottom of that list of concerns frequently. So as far as how we're perceiving people, I mean, you can turn on the TV and see Kerry Washington in the lead role on *Scandal*, love it! I'm here for it! I never miss a Shonda show. If Shonda Rhimes makes a show, I will watch it! To support that black director, I will watch it! But finding shows that are positioned on disability? I mean honestly, name two.

And I can't even remember the name of that bad sitcom with the kid in the chair. I guess what I would say is that I hope that this work you're doing is going to help. If we can get the arts, who are supposed to be these big rebels of the world and these big ball-bustin' change-the-world people to actually do something about it in terms of inclusion and perhaps that could start to translate to things that are more on TV, which then also which sounds nuts to say that you have to think about television being central to cultural discourse, but it is! 'Cause it's accessible.

JK: I know.

KK: I think the name of the show was *Speechless*.

JK: *Speechless*. That's right, Kellie.

JM: That's right! That sounds right! But the thing is, even when I watch it, I've watched several episodes, and I almost feel like it's more about the mother, and how she's reactive to situations that have to do with his disability, versus him having capers and fun with his friends and that being positioned at the center of the show. So it's curious to me that it's called Speechless, like he can't talk, but that's not true. He actually can talk, so even the title could be seen as sort of not appropriate in some way, because it's sort of like saying … Maybe that's why I blocked it out. Maybe it pissed me off. That sounds right. No, I was sitting here several months ago, it came on, and I was watching it. That's right. I blocked it out because I didn't think that was right. I was like, "Why would you take a risk, and then…?" I don't know. Because humans just have a hard time going all the way in. Some of us can do it and we're just, like, "No problem." I don't mind putting anyone on my stages.

JM: I did that piece for the DisAbility Project, and I put them in a dance concert. I sometimes wonder if that was a component of me eventually losing that job, because the dean that I had had this image of a dance department that was just very lily-white, cute, pretty blond girls, and I know she did. I could just tell from talking to her. She was from Texas. She was conservative. I just knew that was how she felt about it, and when I told her I was gonna have disabled people in the show, she said, "Isn't that interesting?" I mean, she didn't go all the way in with sounding super ableist and discriminatory, but you know how people sound when they're not there for that? I was like, "Screw it. I'm doing it anyway. I don't care." I put them in a dance concert, and everybody, I mean everyone, from the chancellor on down that saw the show—a lot of people came to that show—I got wonderful feedback but not from that dean. Not from that dean. And a year later, I lost my job, because I had hired a black guest teacher. I taught mostly black kids at that program! I mean, it was St. Louis! I was at a faculty retreat, and my guest teacher got harassed by the cops, and she came to campus to teach for me, for my class. And they fired me that afternoon. What did they say…I got a call from academic affairs, and they were like, "You need to vouch for this person!" And I said, "I sent my info in. I thought I put the contact correctly. I don't understand. What's going on here?" And they said, "We don't have any record of her and we don't know who she is." I said, "She has a master's degree from the Royal Academy in London!" And I said, "She's [inaudible] in Kansas City, and she's an incredible leader, and she's a high functioning autistic, so she's a genius. You're holding her in the campus cop office?" And they said, "Yeah," and I said that she needs to be let go immediately. So she has the case pending with the [inaudible], and they're still mad. And they let me go that afternoon, yeah. I just felt like that was just part and parcel to what the process is. If you are trying to advocate for anything in this world, if you're not in an environment that's conducive to it, you will find that people will hate you, and they'll think you're a rabble-rouser. At one point I thought about calling the ACLU and saying, "Are there cases of white people protecting black people where they lose their job? Is that a thing?" Because maybe more white people would be willing to stand up for black people if they didn't feel like their own lives would be compromised too. It's one thing for me to lose my job. I don't have kids. I live in an apartment that my parents have paid for for years because I work for my parents so it's just a trade-in. I don't have to worry about that. A lot of folks do. So it gives me space to be that way.

JK: That's an excellent point. I wonder if there are people who are afraid to go ahead and actually be advocates because they're just so worried about the response, like you just described.

JM: Exactly! I have had to hold my tongue for years in my business. I don't talk about politics. I don't post political things on my Facebook. My Twitter would make your toes curl.

Jon/KK: [laughing]

JM: It's the most political crap you've ever seen in your life. Bad language, you name it. But there's not one person in my professional life who's on my Twitter. Not one. I've got a hundred friends that are part of the resistance and that's it.

JK: One last thing about that show on TV … Brenda Brueggemann was my one teacher at Ohio State, a brilliant lady who is deaf, and she just did a fantastic job, she has hearing students and she introduced us to the book *The Curious Incident of the Dog at Night*, and all of a sudden that's a Broadway show. I read this for this class that was in 2008 or 2009, and I'm surprised she had me read that, but the lead actor is supposed to be autistic. Well, they just now hired an actor who has autism to play this damn role.

JM: I can't believe it.

JK: I'm like, "What took so long," you know?

JM: I can't believe it.

JK: I mean this is exactly the role and that's one of the things … I veered too far away from my paper, because Dr. Brueggemann was trying to keep me focused, to get it done, but there was a part of me that just wants to say, "Why is this acceptable that we're gonna have all these people play a disability when you have disabled actors who can play that role? They have that disability. Why wouldn't they even be considered?"

JM: Or play transgendered folks? That drives me bananas, when all these actors play transgendered folks. I'm quite confident there's transgendered actors. That's what I mean. We're culturally on very wide spaces on the spectrum right now, and I don't know why. I know y'all are similar in age to me, and we remember the 70s with Archie Bunker, and then Reagan came and everything got a little more superficial.

JK: Ugh.

JM: You know, pretty bows, and money started … I feel like the socioeconomic shift happened then, where more rich were getting richer, and the poor kinda stayed there, and then Bill Clinton and the Internet "pssh" thing, instant information. George W. had terrorism so everything kinda rolled back, and Obama happened, so now we got gay marriage, woohoo! First black president, yay! And now we got this shit, with this Donald Trump crap, I don't know where to put this crap. It's unbelievable. It's so restrictive and fascist, and so obviously fascist. So we're just on this weird … I told my kids, not long after Trump was inaugurated, the kids looked really depressed, and I could understand that, but being a good model and leader, I said, "Look at this way! If Obama was the result of the Bush administration, and Trump was the result of the Obama administration, imagine how expansive and wonderful the next administration is gonna be! Shoot, we're gonna have free food, free healthcare, free electricity, free everything! Keep your wits about you. It's on the way, you know. The world will get better. It's just a process. The work that we do is lonely and weird, because there's so few people that really understand that you have to learn through doing the work. It's not like I walked in to DisAbility Project with this advanced understanding of advocacy and ableist thinking. Many of these things I had to learn. This isn't my specialty. My specialty is ballet, but having an open mind and an open heart and being willing to hear someone say, "That's not what we do," and being open and not being a jerk about it. Just go, "Oh okay." Listening and believing people when they tell you that that's their life, that's the biggest part of it, I think, and continuing to show up, even if it's just to say, "Hope you feel better, Margaret," or, "How are you doing today, Ana?" Just as a friend, it's important to be part of people's lives. I think we're just on the cusp of … The cultural discourse is shifting. Post-Mike-Brown, that's my feelings on it. I felt, since that day, that so much has shifted and so much is changing so quickly that those of us who are willing to keep up with it … I think it's largely driven by millennials, I really do, by younger people that are growing up in a world that they didn't like looking at. They're in their 20s now, thinking about raising families and things, and maybe they don't want so much racism, and maybe they don't want so much environmental fear, and they don't to have kids that grow up on a planet that isn't going to exist anymore. I feel humble, I guess, to be a human being that's a part of making the world better for people that have had to suck up a whole lot of shit in their lives. Just to say I'm here for that, whatever form that takes.

JK: Thank you so much for your time. This is so generous of you. This is fantastic. I'm glad we got to catch up with you and we could actually talk for a while!

JM: It was sort of a little bit of both, like talk about what you need but just talk about stuff too, 'cause I'm sorry but when you've got a crazy president who's like King George, you have to be there for people, and you have to say, "It's gonna be okay, we're gonna make it, we just gotta keep fighting, stay strong, and take care of yourself where you can." You guys are welcome to call me anytime, just to talk about anything. I don't have much of a social life, so. I really am very antisocial.

JK: No, no, you're fantastic. I don't take anything for granted. Anyone who wants to spend time with me, I'm grateful, because I can be a chore.

JM: No! You care about people. It's a big deal. There's only so many caring people to go around.

JK: With my kids, like I said, my students have been more nervous, tense, whatever, after the election, and I'm trying to keep them calm and my fellow staff members calm, and I'm like, until something really bad happens, just keep doing what we do.

JM: Are you in a private school or in a public school? What's the situation?

JK: Public.

KK: He's in public, but I'm in a private school and I can't say anything to mine about anything.

JK: It's the best.

KK: Every day.

JK: Any time you want to call, for either of us, please do so. I'll send you Kellie's number, too.

JM: Aw, you guys are so sweet.

JK: We do have to come out and see you!

JM: Where are you in Ohio?

KK: We're in Dayton, Ohio.

JM: You're in Dayton? Aw, I have had so many friends pass through Dayton. So many beautiful people in Dayton. Mwah! Thanks so much, guys!

KK: Love you! Mwah! Best wishes with the new studio!

JM: Love you, Kellie! Mwah! Bye guys!

JK: Bye-bye. Take care.

Interview with Bryan Jones

Bryan Jones is a performer with the DisAbility Project. Bryan has worked with the company since 2003. The nature of his disability is Ethlers Danlos Syndrome, which is a genetic disorder of the connective tissues in his arms and legs and limits the weight he is able to lift. This interview took place at The Magic House in St. Louis, Missouri on June 1, 2017. Jones was on break from his work as a volunteer for this children's museum.

Jonathan Kochensparger: I know, because we have all this wonderful stuff that's going on here around us.

Bryan Jones: Yeah. The blues exhibit just opened up.

JK: So what's the blues exhibit? For the … [muffled] … ?

BJ: Yeah. Okay.

JK: So, Bryan, the first thing I need to know, actually, is, how did you, you yourself, get started with the DisAbility Project? How did that all begin, because I don't know the beginning of your part of it.

BJ: Well, it was in October 2003, and I was in the career training program at the zoo, and I was telling jokes and making everybody laugh. There was another student who was in the DisAbility Project, and the teacher suggested that I join her group, and I go, “Yeah, okay.” So she gave me the information, and I called Joan, and she set up a date to come to rehearsal, and the rest is history.

JK: Okay. So what was the first show that you worked on with Joan?

BJ: It was … Oh gosh. It was at Maryville University. That was my first show with them. It was back in February of 2004.

JK: Okay. Would you have known the name of the show? That was *Tom and Huck*, or not?

BJ: No, that was in 2010.

JK: Okay. So do you remember what the first show was?

BJ: It was the sketches that we did, all the sketches that we did.

JK: So you continued then, all the way through, and you’ve been with the active players? What kind of rehearsal schedule did they have? How often did you rehearse when you were working with them?

BJ: We rehearsed every Saturday at the OT school in Forest Park.

JK: I’ve got to remember everything. I’ve got a set of questions I have here, so I’m trying to remember everything as we go through it.

BJ: That’s all right, take your time!

JK: When Jennifer started working with you for the choreography, for dancing, how was that different from the other stuff you did?

BJ: It was exciting! It was different, and, well, I was kind of nervous at first. When we start new things I'm kind of like that. I get nervous when we start new things. But once we got into it, it wasn't so bad.

JK: That project, that part of it, was the one that I saw you perform in outside when it was cold, for the ADA Conference and Celebration.

BJ: Oh yeah, I remember!

JK: That was the last one I saw you in.

BJ: That was fun.

JK: And that was great, because you were dancing with Malia a little bit.

BJ: Malina.

JK: Malina, okay, and that's what … I know you had to rehearse with her and that was something unique because that part of the program, I believe, was you learning to walk, I believe?

BJ: Mmhmm, I was.

JK: How much of that was your story?

BJ: My mother told me that I was three and a half but I think I was four when I started … Well she had me up on her feet, and we took it little by little, and eventually I learned how to walk.

JK: Did Joan ask you to share that information?

BJ: Yes.

JK: So that was your big story?

BJ: Yeah.

JK: Was there anything else you added to that?

BJ: Not that I know of.

JK: The music they chose when you started working with the dancers, and I know that you worked with many of them …

BJ: That was good.

JK: That's what I was going to say, that was … I was stunned by that. It was amazing. We watched that, and the fact that it was so cold that day, I felt so bad for you.

BJ: That's okay.

JK: We were waiting for you to be able to go ahead and actually start, like, "What's going to go on here?" But did you perform that one more time? Margaret said something about the fact that you had one more performance after I saw you with that one, and I know you're pretty good about your details. That's why I was wondering.

BJ: Yeah, we did but I can't seem to remember.

JK: That's okay. I just was wondering. That next time, was that the last time that you worked together with the DisAbility Project?

BJ: Well, we did a show last November, in New Haven.

JK: Was that the same show?

BJ: No, it was *Sketches*.

JK: Okay, that was *Sketches*, going back to your first one. Can you tell me about *Sketches*? What's the sketch? Because I haven't seen you do the *Sketches*.

BJ: It was, um, gosh, it's been so long. We did a sketch called *Three Little Pigs*, about setting up an ice cream shop, and there's one where we do the rap, that was fun, and *Some People See Me As,* and pretty much I can remember …

JK: When you work with them, most of the time are you working with Joan? Vanessa? Becky? Who do you work with the most?

BJ: Vanessa and Becky.

JK: Because Joan's busy?

BJ: Yeah Joan's rarely there. She's usually out of town.

JK: I was going to say, because she has to go between California and New York.

BJ: I know.

JK: I know we walked through this. That's hard when you're traveling that much. What's Vanessa's role to you? What does she help you with?

BJ: She's like a mother to the group, the mothering type. She's amazing. She comes up with these great ideas for the DisAbility Project.

JK: Oh, excellent. And do you guys add in at the same time?

BJ: Mmhmm. We add in our own stories about our experiences with disabilities.

JK: And do you … I asked this also yesterday of Margaret … Do you have to know everybody else's part in case somebody cannot be there?

BJ: Yeah, I pretty much know everyone else's part.

JK: And have you had to do somebody else's part before? Because I know that's real hard to get to know everything, and you don't know 'til the day of. … We've answered the first five questions! I love this. This one I can ask, for you yourself, when's the first time you were involved with any theatre at all?

BJ: I took a lot of drama classes in high school and I was in the spring musical in my senior year.

JK: Which one was that?

BJ: It was called *Rags*. It's about immigration.

JK: Wonderful.

BJ: It was really good.

JK: Did you continue through high school and still do that, other shows?

BJ: That was it.

JK: That was it. Okay. And then very soon after that you got involved with the DisAbility Project?

BJ: Yeah. I've always wanted to act and perform for as long as I can remember.

JK: Well that's fantastic. You do a great job. I love watching, every time I get to see you guys perform.

BJ: I love doing it.

JK: What are the biggest obstacles you face when you work in a new place? I know a lot of times when you work with the DisAbility Project you have to get like this school, or that building. What's the biggest obstacle you have?

BJ: Seeing if it's accessible.

JK: And then you adapt or change to whatever the … ?

BJ: Mmhmm.

JK: Okay. What do you think could be done the best, or what changes could be done to a place when you go to it, to help you as a performer? What's the best situation? The best place to perform?

BJ: Usually in a gym, or if they have an auditorium.

JK: The auditorium is best out of all of them?

BJ: Yes.

JK: What's the reception you receive from the audience? What type of reactions do they have?

BJ: They love it. Usually we get a standing ovation at the end.

JK: Do you get a chance to talk to the kids or the audience members?

BJ: Mmhmm, they ask us a lot of questions.

JK: Do they ask you, specifically, questions?

BJ: No, just to the other ones. They go, “Why are you in a wheelchair?” And they ask, “Do you guys live nearby?”

JK: Really?

BJ: And about other things, yeah.

JK: That’s different for each of you, because you live close enough that you’re …

BJ: I live in Affton.

JK: Okay. So how far away is that from St. Louis?

BJ: Not too far. South County.

JK: Can you tell me one thing that you think has not been addressed as far as disability rights and performing arts?

BJ: Well, I’m not too sure.

JK: Is there anything you think could be done better for people who are disabled performers, to give you more opportunities? I guess that’s what I’m wondering.

BJ: To be more willing to perform, yeah.

JK: Would you like to continue on beyond just right now?

BJ: Oh yes.

JK: To continue this through?

BJ: I want to keep going with the DisAbility group.

JK: Okay, but if another acting group or company said they would like to have you?

BJ: I'd love to.

JK: So as long as there was an opportunity you would like to go ahead?

BJ: Yes.

JK: Excellent. Fantastic. You've answered everything, and very quickly! This is so much faster! This is great! When I saw you perform the first time, it was when you were in rehearsal, and you were all there, and David was there, and Angie was still there with him. That was a larger part of the group. Is that the largest amount of people you've had?

BJ: When I first started out it was like twelve or thirteen people with me, and then over the years they went on their own way.

JK: And you guys are still the core group, like Ana and you?

BJ: Yeah. Five or six.

JK: So twelve or thirteen? That's a lot.

BJ: Twelve or thirteen, yeah.

JK: Do you still maintain … like, we're in touch because of Facebook, which is fantastic. Are you still in touch with the rest of them?

BJ: Oh yeah, on Facebook and the telephone.

JK: Do you talk to them often and ask what they're doing?

BJ: Yeah, and I go, "I miss you guys a lot," and they go, "We miss you too!"

JK: Good. That's excellent. I see that, and I see some of that when you talk, and I saw the note you had with Joan, and I thought, "Wow, that is so cool." That's what I like Facebook for, so we can go ahead and go back and forth. I'm just trying to think if there's anything else, you've answered almost everything. That's why Kellie is here to help me. She's better at this than I am. Just a couple more things, I want to make sure I've covered everything.

Kellie Kochensparger: What advice would you give to someone who's setting up the theatre for folks for disabilities?

BJ: If you put your mind to it, you can do anything that you want to do. That's my advice to anybody starting out.

JK: I think we have everything. This is fantastic!

KK: Did he sign the paper?

JK: We'll have to do that here in a second. I've got a paper they want you to sign. What the purpose of this is, I've got to finish my actual dissertation, that's the big thing to get my doctorate.

And, as I told Joan and mentioned to some others, the next step is to start a group like the DisAbility Project in Dayton, Ohio, which makes it … Hopefully I can expand and add more and more, because I think that's something that has to happen. There's a … I don't know if you've ever heard of *The Curious Incident of the Dog at Night*.[103] It's a play on Broadway and it's about an autistic boy.

BJ: I don't think so.

JK: And he's solving mysteries, and they finally cast an autistic boy to play the part.

BJ: That sounds great!

JK: I know, and I couldn't believe it. I finally read that, and this was just, like, two weeks ago. It took them a long time; they've actually had this on Broadway for a while. Since you've just heard of that just now for the first time, and I'm not trying to lead you to say one thing or another, would you like to see more people with disabilities play parts on Broadway and other stages?

BJ: Yes, yes!

JK: Why would you like to see that?

BJ: Because people with disabilities can do things that other people can do.

JK: Do you think you convey that message when you talk to the kids and you see them?

BJ: Yeah.

JK: What's the largest crowd you've had to perform in front of? Joan said something about that.

BJ: 100,000 people, one time.

JK: 100,000? Gotcha.

BJ: That was at the Jones Dome.

JK: How did that feel, to perform in front of that many people?

BJ: It was amazing. It was a lot of fun, doing that.

JK: Did they have the same type of reaction to your group?

BJ: Yeah.

JK: Well, that's good. You didn't get the chance to talk to all of them, right?

BJ: No, of course not.

JK: I ask that because, 100,000 people? That'd be hard.

BJ: [laughing] It would have taken all day to talk to all of them.

JK: What did it feel like to have all those people?

BJ: It felt amazing.

JK: That's a lot of people coming to look at you

BJ: Yeah, I know.

JK: That's about it. Thank you for your time.

BJ: It's no problem!

Interview with Angie Schaeffer

Angie Schaeffer is a past performer with The DisAbility Project. Between my first introduction to Schaeffer in 2014 and this interview she had resigned from the group to work full time in her family's business which includes designing furniture and redesigning homes of people with disabilities. Angie's disabilities include epilepsy and bipolar disorder. This interview took place at the Coffee Cartel in St. Louis, Missouri on June 1, 2017.

Jonathan Kochensparger: I'm gonna let you hold it if that's okay, because I need to hear your words more. Bryan thought it was difficult, because he was a little nervous. Name and time and date, and all that?

AS: My name is Angie Schaeffer and today is June the 1st. And it's Schaeffer now. It was Bilyeu, but it's Schaeffer now, because I'm married. It's about twenty after seven.

JK: I typed in your name as Bilyeu, and I was like, "Why is it not showing up? Oh that's right it's Schaeffer." Can you tell me your first experience of your work with the DisAbility Project, how you became involved? Were you approached? Did they approach you?

AS: Actually, we have this website called STLauditions.com. Forgive me, I’m trying so hard to remember. I came across the website two days ago, and I hadn’t come across the website in probably three years since the DisAbility Project, honestly, because I didn’t need it anymore. It’s where all the local places put their postings of, “I need this actress, I need this actor,” and I saw something that looked like I could fit that shoe, something about people that are different, that have disabilities, and they stand up strong for what they believe in, and they can act independently. It hit me like a sack of rocks. And I was sitting at my office with my mom, my mom’s my boss, and I turned to her and said, “Mom, listen to this.” And she said, “Oh, Rose.” Rose is my middle name. She said, “Oh, Rose, I think that just sounds wonderful.” And I said, “Me too.” And so I messaged the unknown person and it turned out it was Joan, I believe, and Joan messaged me back and just said “Yeah, just come to rehearsal. Just join us for a Saturday. We meet every Saturday from 9 to 1,” or whatever it was. I was elated. I was nervous as heck, but I was excited, and I couldn’t wait to experience, you know, this was a real theatre company, That Uppity Theatre Company is a real theatre company, and I went to school for theatre, so, you know, acting is my passion. Acting is what I love to do. Acting is so much of me, and I was excited to have my first chance to get to go out there and join a company. I went to my first rehearsal, and we just had a blast. Everybody jived so well, and I was just in awe of the spirit of the whole thing. It was so neat. It just made me feel like I was doing something good, because I learned that the whole purpose is to just spread the word about equality. Everybody is just the same so just love people and treat them how they want to be treated. You know, the basic rule that we’ve all been taught our whole lives, but it was just so thrusted out through drama, and I loved it. So I joined immediately, and I was with them for three years, and we just had a blast. It was so much fun.

JK: Do you remember what your first production was with them?

AS: I don't remember my first one. I know the thing that makes the DisAbility Project so cool is that we pretty much wrote all of our own monologues, and that's what makes it so cool. In the beginning, they only knew bits and pieces of my story, because I didn't have the chance to really delve into it, and it wasn't until maybe about the third rehearsal or so, and then we had time for Angie's story. And I really got to go into everything, as far as the illnesses and overcoming them, and the journey through dealing with people, and coming out, and all of the stuff I've gone through. It was a process. I don't remember, exactly, the first production, but I remember it was enlightening and brilliant. It was for students, I remember that, and it was great.

JK: When you work with the group, and there's someone missing, this is what impressed me so much, is you just filled in for each other, which, I think Ana asked me, "How'd we do?" about the first rehearsal, the one I went to see for the first time. I don't know whether she thought it wasn't great. I'm sitting there and my mouth was dropping because I wish my students could do as well, because it was seamless, the transitions.

AS: It was.

JK: Did you have to learn other parts or other people's stories that you'd have to use?

AS: We just kind of ended up memorizing each other's parts, in all honesty, because of the repetition. We'd just do them all the time, and they're the same monologues all the time, so I could have just stood there and given you pretty much anybody's monologue.

JK: Did you ever have to do that in a performance?

AS: There's plenty of times where we had to ad-lib where somebody slipped a line or forgot where they were. Bryan, he's so cute, he would get stuck sometimes and he would get this look on his face of terror, and in my head, I'd be like, "Okay, we just have to gear him back to where he was," and we'd drop some line, and he'd be, like, "Oh yes, and then," and then he'd go back and do his story and be right back where he wanted to be. I love everybody in that group. That is a group of quality people, I mean, people who genuinely have the biggest hearts of anybody. My heart grew ten times the size of what it was and my love for people with disabilities grew so much through that, which works out because my day job is working with people with disabilities, helping them remodel their homes so they can stay there longer and live there at home and not have to go to a special home or something, so they can have their home as their home. And that group just influenced me tremendously.

JK: So you were working with your mom and her company before you even…?

AS: I was. My mom's company, I'm the fourth generation, actually. This is kinda cool. My great-grandpa started the company back in 1944, and it was a home building company, as well as a little commercial, and then my grandfather took over the company, and he built homes like crazy, like madness, and he expanded the company and it really became a large company.

AS: And then my mom, her passion was remodeling, and she did kitchens and bathroom additions and things like that, and then about ten years ago she started finding her true love in accessible design, so with people with wheelchairs. She just wanted to help them find a way to get in their house, get out of their house, be safe in their house, get around their house, just let their house be there house. We met so many people that were either born with their disability or ran into it, unfortunately, and it's so neat when these people come to you, because they have a need, and you can fill that need and it feels so good. My job's absolutely fulfilling, 100%, because I have a talent and a skill, and they have a deficit, and I can fill that deficit and we both come out on top. I love my job too.

JK: Along that line, because I ask this with everyone, also, when you had to go to the different venues because they were so different, the schools, whatever it happened to be, auditoriums, gymnasiums, what was the biggest obstacle, physically, you felt for the whole group, not just yourself, for your performing?

AS: I remember this one time we couldn't get Ana in, and Margaret too, but I remember Ana was there first, and I was there, and we were like, "What are we gonna do?" Because it wasn't accessible! And another one, they didn't have an accessible bathroom, and that was a problem because Margaret was gonna use the restroom like the rest of us before she was gonna leave and head all the way back to St. Genevieve, which is forever away, and so I just remember this look on her face of just, "What am I supposed to do?" And that was a big moment that also reminded me of my day-to-day job. That's something we can help alleviate, is that whole, "What am I supposed to do?" Because you're not supposed to have to go through this, "What am I supposed to do," just to go to the restroom. So those were two obstacles that I remember running into.

JK: Did you ever get a chance to work with Jennifer Medina?

AS: Oh yes, so much.

JK: What was that like? Because I know she wasn't there at the beginning. I know she joined.

AS: It was dance. The whole element of dance became part of our production, and it took our production from an already model-A piece in my opinion to A++. It added this majestic feel to it, and it gave it this essential flow that it didn't have before, and I loved it. I was never really good at dancing. I love to dance, but I love the *Angie Bilyeu dance*, well, *Angie Schaeffer* now. They always called it the *Angie Bilyeu dance*, but now it's Angie Schaeffer, so I love the *Angie Schaeffer dance*. So dance was something new for me to get accustomed to, and then we had these dancers that were in here and so to learn to get comfortable with other people physically, and to be in a close proximity, touching hands or backs to backs or whatever the motion was, that was slightly challenging at first. I went to SLU, St. Louis University, for theatre and I had a number of classes that were all about movement, and so I was used to having to be forced outside that comfort zone, and I was, once again, pleased to have that thrust into my life, because I was thinking to myself, I get to use some of my talents that I learned while I was at school, once again! This is great! And it added such an element to our shows.

JK: Who did you actually work with? Did you work with the other actors from your group or did you work with some of Jennifer's dance students?

AS: Both. I worked with both.

JK: Who did you work with within the DP?

AS: Me and Malia worked together a lot. Did you interview Malia?

JK: Not yet.

AS: Not yet?

JK: I sent it to her very late, unfortunately. I'm not the greatest at remembering everything. I'm, like, "I know I'm missing someone," and then on Monday, I'm, like, "Malia!" It'll probably be a FaceTime interview.

AS: All right. We tag-teamed a lot of things, and she was much better at the whole dancing thing than I was, so I tried to take notes.

JK: I've made dance teachers cry.

AS: I just can't do it.

JK: I just can't do it! … I'm gonna ask a little bit about David because it's important to me. I hated that part, because you find out on Facebook, and it just … I know my students probably were, like, "Why are you sad today?" But what was your relationship with him?

AS: Me and David we were so close. I might cry right now.

JK: I'm sorry.

AS: That's okay. I miss him so much. Not only were we in DP together, but we also went to church together, so I saw him every Sunday that he was at church.

AS: He wheeled his chair all the way to church, and it wasn't too far from where he lived, and we would email sometimes and just talk about life and his struggles, and there's always something wrong with his chair, and we'd always talk about those darn people that always took those parts to his chair and hadn't brought them back yet.

JK: Had he been there before you'd joined?

AS: At DP? Yeah, he was there for a lot of years before I was.

JK: I saw him again, the first time. Anybody who was in my shoes would have been jealous. There was so much talent on that stage. I mean that sincerely. I went back and I was angry at my kids, like, "Hey, start working here!" They got this thing down, because, again, you talk about how close you were, and I think that shows in your performance. Overall what does it mean to you, a person with a disability, to be able to perform on that stage? That's the crux of it. That's my main question, is, what does that do to your life?

AS: It's very liberating. Liberating is the word. Disabilities … I think society wants to define us, and confine us, and I think that acting is the polar opposite of conviction like that. I think it is the ability to break out of a shell and be whoever you want to be, and the coolest part of DP is you get to play the part of you and you get to tell your story and it's just liberating. It fills you with this positive energy, and it lets you know that the world's not so dark, because I'm bright in it, and it's just good. Every single show, every single rehearsal felt so good. I knew that I was doing justice for our world because I was spreading the news about equality and love and just letting it be. Once again, it was fulfilling.

AS: It made me feel like I was making a difference, my small difference, but it was a difference I was making. And I love telling my story, and I love telling about my ups and my downs, and my ins and my outs, because people do tend to get inspired, and then they look at me and they would never have expected that story to come out of my mouth. When it does, they usually are just taken aback, and they oftentimes are in awe of the whole thing, and sometimes in utter disbelief, because they can't believe it, like, "Oh, someone like you would never!" Well, you don't even know someone like me, so that's not even a thing! It was liberating. It feels good to know that I'm not confined by disability. So I have these different disabilities. It doesn't mean that I can't do something; it just means I do it different. And it was liberating.

JK: What kind of responses have you received from your students, because you've performed in front of…?

AS: So many standing ovations. These little kids look like a light in their world went on, and their faces are just so engrossed. Of course, they're little kids, so sometimes they're distracted, but during some of our monologues they were just so engrossed, like they were soaking up everything that we were saying, and that it was going to make a difference in their life. Maybe someday Johnny is gonna grow up and he's gonna think differently about his friend Jennifer because she has a disability but it doesn't matter anymore, because that one time he saw that show, and so many kids looked like that and that's my hope and my prayer, is that at least part of them grew a little bit in their hearts and changed their perspective as best as they could.

JK: I'm gonna ask you a different question because I heard Margaret's version, but what kind of questions do you get from the kids? Because that's a unique thing.

AS: I'm trying to think of any kid questions. Nothing really comes to mind.

JK: She had talked about how they would ask, "How do you drive," and things of that nature.

AS: They ask a lot of wheelchair questions, that's for sure. That's for sure.

JK: What was it like to perform in front of the 100,000 at the one venue? I know there was one venue where you did that.

AS: Probably the art museum. That was probably our biggest crowd that we've had. That's the biggest one that I remember. Exhilarating, once again, liberating. It feels so good to stand in front of people and share your story, and it was mostly adults that were there, and to see their faces look so engrossed, pretty much the entirety of the show. And just to know maybe I'm making a difference in their lives, and it's harder to make a difference in an adult's life because they've been so conditioned, right? They've grown for years to believe the things that they believe and to act the way they act and change is not easy but I think that we helped change. There's so much change in this world and little by little and show by show we impacted so many people, and the bigger the audience, the more exciting it was. Of course it was always exciting, but the more people we had in front of us, the more people I knew I had a chance to make a difference in.

JK: I'm looking back at my questions. I think we covered them all but I never like reading off the list, like, "Okay, answer number five now." Can you name something that's not been addressed, as far as disability rights and performing arts? Explain why it's important. Anything at all that you might want to change, like…

Kellie Kochensparger: He tends to ask the question and then start to answer it, so I'm trying to stop that.

JK: I'm so bad at that.

AS: Say it one more time for me.

JK: Let me look at it again, because I wrote these! Anything at all that has not been addressed as far as disability rights in the performing world and why that's important.

AS: I think that when it comes to shows, there is definitely a depiction of what people think the actor is supposed to like and breaking barriers … There was a friend of mine who's in a wheelchair and they were given a lead role in a play, of someone who's supposed to be a walkie. You know, a walkie or a wheelie, that's what we call them in DP. And they had to adapt the whole entire show around his disability, but they did it, and it was beautiful. I think he was a prince or something like that. It was one of those lovely stories about a prince and a princess and it was so neat to see that, breaking those boundaries down.

JK: What was the show?

AS: I have no clue.

JK: That's okay.

AS: I don't remember.

JK: That’s okay. I mentioned to the other two that one of my professors, who is a deaf professor, Brenda Brueggemann, she had us read *The Curious Incident of the Dog at Night*.[104] I’m trying to remember the whole thing. It’s on Broadway now. She had us read the book a decade ago, and here it is! It’s about an autistic person who solves a mystery, but the actor who plays him is non-disabled, and they just announced that they have an autistic person playing that role.

AS: Oh wow.

JK: And I’m going nuts about it! Like, it’s the coolest thing. I’m like, “Why not? Would that have been so difficult to make that choice from the beginning?”

KK: I’ll be right back.

JK: That was like we had at *Spring Awakening*. I don’t know if you’ve heard about *Spring Awakening*.

AS: *Spring Awakening* is my favorite musical.

JK: And that’s the one where a woman in a wheelchair was a part of the main cast and that was really unique. I’m waiting to see how this goes. But that’s me. So why are you no longer with … Or are you still with? I know they’re not as active. I know that.

AS: I resigned because I was getting busy working at my office job so much, and it was really becoming a lot, and I just didn’t have the time every Saturday to put into it. And they deserve somebody that’s going to just put in the time, put in the heart, put in the soul, and I didn’t feel like I was of that caliber. I just felt like it wasn’t where I needed to be anymore. They served their purpose and they served mine, and I helped tell a story, and they helped tell me.

JK: I was wondering. I didn’t know.

AS: Definitely no falling-out. I love all those people so much, and I miss them terribly.

JK: We suspected as much, because you’ve got a family you’ve got to take care of, right? And you’re not paid for the DisAbility Project. It’s all volunteer?

AS: Right, no. Actually, we do get, most shows we would get twenty dollars.

JK: Okay. And that comes from…?

AS: The school, the grant, whatever organization it is that pays for it, it would come out of that. But all the rehearsal and everything else, that’s all volunteer.

JK: I know Joan sort of alluded to that.

AS: It was just essentially to pay for gas.

JK: I know we have some for our schools that we pay to bring in, and you’ve got to have that, or else, you know, there’s changes. What’s it like working with Vanessa?

AS: She’s wonderful. She is so into the world of drama and she knows so much about the world of drama. She was so knowledgeable. I always thought of her as the knowledge book. She had an answer to every question we had. Every time we wanted new blocking, she would come up with it like that. She was just so on point all the time. It was overwhelmingly wonderful. She’s a go-getter. She’s really wonderful.

JK: What about Becky?

AS: Oh, Becky. She was also super organized and I don't know how she managed to, we always used to say, not put up with Joan, but she used to cater to Joan in every way possible, because we all used to say, "I couldn't do it. I just couldn't do it." And she just had such will. Just a will to be there for Joan, and I was like, "I gotta get me a Becky. I gotta find me one." [laughing]

JK: Last words about the DisAbility Project, to put this on paper?

AS: The DisAbility Project absolutely changed my life, 100%. It opened my eyes in ways that I didn't know. I got to be dearest friends, closest friends with people in wheelchairs, and I'd only had, I think, one other friend that was in a wheelchair, and it was my mom's friend more than my friend, so I just knew her and I talked to her infrequently and I didn't know her, and I knew her story but I didn't know her. To get to know people in wheelchairs, and to genuinely realize these people are the same as a walkie, as a wheelie, there really is no difference. They just sit more than you do. And that's all there is to it, and I mean they say that the Grinch's heart grows three times, or however many times? I think that the Grinch's heart couldn't possibly have grown as much as mine did, just by being a part of this production, and just by seeing that, it's inspiring. The whole show was so inspiring, because all of us have a story and all of us have something that's happened to us, or multiple things that have happened to us that have knocked us down or shoved us aside, and we stood back up or wheeled right through, or whatever it was, and it just, inspiration is what it was. It just made me feel like I was doing God's will. I'm a big believer in God too, and this just made me feel like this is God's will. This is God's story, coming out of our mouths, and it is us making a difference and inflicting love on people and showing them what positivity can look like, and it just, I could cry about that show. I love that show, and it was the best.

JK: If you don't mind, could you share your disability?

AS: Sure. Where to begin? I have epilepsy and I have bipolar disorder and I have depression and I'm a cancer survivor. We don't really call that my disability but it was a disabling time in my life. That's for sure. Those are all different things I've dealt with for a number of years. I was diagnosed with epilepsy when I was 21, and I actually studied abroad a semester in London, and I started having seizures when I was in London and we didn't know what was wrong, because I don't have grand mal seizures. I have tonic-clonic seizures, so they're very different, and they kind of have more of a staring-off look to them, and they last forever. So it was really weird and confusing and we didn't know what was happening. That was just a really terrible part of that journey. Great journey in London, but that was a tiny bad part. The depression and bipolar, I was diagnosed with bipolar disorder when I was seventeen years old and the highs and the lows of my life just were related more to my emotional side than to the reality of the world, and the world didn't always turn as fast as I did, and that was something that I always knew was different. Depression, I was diagnosed at the age of fifteen. I went through some really, really low times. I was suicidal for a number of years, and hated myself and everything else. And lo and behold, as I grew up, I realized that I was gay, too, and so on top of everything else that was one more thing that I was fighting against in my world. Accepting that and accepting my other disabilities—that aren't disabilities; they aren't disabling, they're just different—I've grown so much. That show, the DisAbility Project, it brought to light the reality that yes, you can accept that you've gone through a hard time, and yes, you can overcome it, and yes, you can share your story, and yes, you can make a difference. Just the whole experience just really pulled everything together and I'm just eternally grateful.

JK: Thank you so much.

AS: You’re welcome.

Interview with Angie Schaefer (continued)

JK: Angie, take two. This is one other part of Angie’s acting roles. This is great. So you just finished a short film?

AS: So I just finished a feature film.

JK: A feature film.

AS: Yes. I played the part of Mrs. Carter. I was a theatre school teacher, for a high school student, and I was the one that made the biggest … I was, like, the impact of the film. The student found himself … he lost himself, rather. He lost himself, and ended up getting into drugs and alcohol and making poor choices, and theatre was the one thing that pulled him back into reality, and his theatre teacher was the one that guided him away from those poor choices and that made him want to be different, and made him want to be better, and get away from everything that was negative in his life and I had the honor of being that role and that was awesome. I love to be comedic, and so I was the comedic relief in the whole film, and my character was just so, “Woohoo!” Oh my god, it was so fun. She was just so out there, and I loved it. I combined her as part of one of my drama teachers and Ms. Frizzle from *The Magic School Bus*.

AS: I combined these two human beings and created this Mrs. Carter, and it was just awesome.

JK: Is that locally produced?

AS: Yes. It’s *an independent film by Five Star Productions*, that’s the name.

JK: You were able to do that, work that into your schedule?

AS: Yes, they were super flexible with my schedule. I just tell them, “I can’t be there from this time to this time or any of these days,” and then they just work it all around you. Sometimes we’ll have ten-hour film days, but that’s okay, because then you get ten scenes out of the way at the same time, so you make a lot of headway that way. I’ve got a short film coming up! I don’t know what it’s called yet. It’s actually going to be a prequel, because I did another short for … David, is the director, and David wrote this short, and it’s about these people that are in the FBI, and they’re getting down and dirty and bad things are happening to them and there’s a big explosion, things like that. I was one of the friends of the FBI agent that goes missing. It was a real short film though, it was only, like, maybe fifteen minutes long, and he decided he needed to make a forty-five-minute-long prequel to it, so now he’s working on writing that, to get the whole backstory of what actually went wrong in their lives and how we ended up the way we did. What’s kinda fun is that my hair, I’m growing my hair out, so I had my short hair for the first time that we did the film and now it’s going to be long for the prequel, and so he’s writing something in there about why my hair was cut off for the second film, for the first one that was supposed to be second, so it’s just kind of fun.

JK: I’ll take that. That way you don’t have to worry about it. That’s the end. We’re good with the end.

AS: Save!

JK: Save this.

Interview with Ana Jennings

Ana Jennings has been a performer with The DisAbility Project since 2000. Jennings contracted tuberculosis of the spine and spinal meningitis when she was 18 and a freshman at Louisiana State University. On the day the original interview was scheduled in St. Louis, Missouri Jennings' mother passed away. This interview took place months later on September 3, 2017 over the telephone.

Jonathan Kochensparger: All right. All right, I've got my recording device on. This might actually work. That would be fantastic. Thank you so much, first of all, for helping me with this. I do appreciate this. I'm coming to the end of this project, as it goes through, and I'm looking forward to it being ended and for me to go ahead and move on with what I was talking to all of you about before, about the theatre I'm going to start out here in Dayton, but I have to get this done first to make that happen. So this helps me tremendously, and I know this is taken out of your personal time, so thank you again. I appreciate it.

AJ: It's no problem at all.

JK: If you don't mind, for the beginning of this—I've forgotten this on a couple of them because I just enjoy talking to you all so much—if you can say your name and your position as far as your work is concerned, and then you can go right into it, when you got started with the DisAbility Project and how that all began, if you don't mind.

AJ: Okay. Do you need me to spell my name or anything?

JK: No, that'll be perfectly fine. I'll redo it. The transcript is for myself and I already have all that information, so that's not a problem.

AJ: Okay. Ana Jennings. I'm actually not employed but I am an advocate for people with disabilities. I have a disability myself and I was attracted to the DisAbility Project just because of the entertainment value, and because it sends a message to a lot of people of all ages and education. I think it makes a statement with regards to what people with disabilities can and cannot do, just as a good forum for displaying the abilities of people with disabilities. Not just as someone as– [audio cuts out suddenly]

JK: Are you still there?

AJ: Yes.

JK: Okay, good. Margaret had mentioned to me, when I talked to her, that Margaret actually looked up many of these different companies that were available, and then she started working with Joan. Is that how you came across it? Were you looking for a company? Were they looking for you? Because it's different for every one of you I've met.

AJ: A friend of mine actually invited me to watch him and I went to see a performance and I just was so much in love with it. It was so funny, and in some ways kind of emotional for me, because I would laugh and cry at the same time, and I just wanted to be a part of it.

JK: Do you remember what time frame that was? About what year, roughly?

AJ: It was about the year 2000, and I think it was March or April, and I approached Joan about possibly joining the group, and she invited me to a rehearsal, and like I said, I just loved it. I'm really a ham at heart. I'm not sure if you've ever noticed that about me.

JK: [laughs] Yeah, you subtly showed that to me.

AJ: [laughs]

JK: We are all alike, I think. We are kindred souls, every one of us. I am right with you on that. Oh my. So then you started right away, as soon as Joan invited you, then, correct?

AJ: Yeah, pretty much. Her rule was, when we first started, was to come to a few rehearsals to get our feet wet and see what we liked to do, and she actually arranged, as the director of the group, she basically put us in the places that she thought we would best be placed, in terms of the roles that we took and everything. She really was very, very hands-on to begin with. She was the woman in charge. She still is, to some extent, but she's really let other directors come in and do what they wanted to do. Ultimately, whenever she's in the room, she is the boss, applesauce.

JK: How has that changed over the years, since you've been with it now for seventeen years? You said other directors? I know Vanessa because of meeting her. Obviously, Jennifer Medina, I've talked with her, so which people came in? Were they local people? Were they people from other theatre departments from throughout the country? How did that work?

AJ: It was people that Joan brought in. They were usually people in theatre already. They may not have had experience with working with people with disabilities, and a lot of times they seemed surprised at what we could do.

AJ: They would work with us with regards to what different messages we wanted to bring out, and we worked on a lot of new pieces, with whoever came in. It was mostly local talent, but there have been people from everywhere, literally. One lady worked with us who was from Boston. Another, a man, worked with us; I think he was from New York originally. There have been a lot of people from a lot of different areas.

JK: When you saw the first piece it was, obviously, something they were already in the middle of producing. After you joined, were the pieces you were working with things that had already been written? Were they composed by the group? Was it a combination? How did they go about figuring out what pieces, because you mentioned there's many different pieces you've gone through as you've been with the organization, so how does that come about as far as which pieces you're working with?

AJ: Well, it definitely is organic. Whoever touches it changes it a little bit. Joan is always saying that a lot of the pieces in the DisAbility Project were pieces we brought in, or things that we made changes to, according to our own abilities. When somebody different is in it, it obviously has to be according to what their abilities are. I did come into, I believe they had twenty pieces when I first got into the project, and so I was fit into a lot of the pieces, and, like I said, as things evolved, I would bring in some of my experiences like the parking skit. We had the parking thing, from my own experience in New Orleans. I was telling Joan about this thing that they had in New Orleans called the Quad Squad, where people with disabilities were deputized to give tickets to people who had parked illegally in the festival parking spaces.

JK: [laughs] Excellent.

AJ: She loved that idea. She was like, “The Quad Squad?” I love that she jumped up and down thinking of ways to put it in there.

JK: I remember that part of the *Worlds* piece that you had worked together, *One World*. When I came in, I thought, “This is brilliant work.” I just wanted to share this because I wanted to have this on transcript. You were talking to me at the first rehearsal I watched, and you were so worried that it wasn’t such a great rehearsal, and I remember telling you that I wish my groups, the groups that I work with more often, had been that well-trained at that point in time, because they never have. I thought, “Wow, this is as smooth as can be,” and you were kind of surprised, or at least that’s the reaction I got from you, but no, this is well done; the transitions that you had with everything were so smooth. This leads me to my next question. How many different roles do you have to remember in case there is someone who cannot make it for various reasons? I know sometimes it’s weather, sometimes it’s transportation or illness, et cetera. Do you have to know everyone’s parts, so that it can be seamless and you can just have another actor take on that role?

AJ: That’s ideally the case. I’ve been with the group for so long that it’s like osmosis. You just hear it enough and enough and enough that it does come like second nature, to come into another role. That is unfortunately the case. I’ve been hospitalized, and Margaret had problems with transportation, so I had to fill in for her. Ideally we know more than one role, and it makes for a better entertainment, I think.

JK: It’s good that you know each other’s. That’s the same with any production anywhere; you have to know everyone else’s lines so you can be ready for your own, but I find it fascinating that you can so smoothly transition from one to the other and you just act that part out. I was just so surprised by that, and that’s where I had my perception of the rehearsal. And you maybe weren’t happy because you’re perfectionists—and I love that, and that’s great—but I just thought, “Wow, if I could only have that, if I could also have that, I would feel less nervous when I work with my students that I have to work with.” Okay, so we touched on this. What are the most, I don’t want to say it this way, but what are the most difficult things you’ve had to face when having to put on a production at the various places? You have many different venues you work with. That’s also another difference. Instead of “Okay, we have one venue and we just bring the audience in,” instead you’re going out to the audience members, for the most part. What are the biggest difficulties you’ve faced? I know you all have talked about this but I need to have it for this. Things that you have had to change for, change times, places, venues, whatever it may have been, the most difficult things that you had to deal with when you’re trying to perform?

AJ: The biggest thing would be the accessibility. There’s been lots of times when we could not get on the stage because of accessibility, so we had to make do with what we had. A lot of times we’ll be on the same level as the audience because we just won’t be able to get onto the stage. If we could get onto the stage that would add to the performance, but the biggest problem has been accessibility, especially with old buildings. Accessibility would be the biggest stumbling block, especially with older buildings, and, like I said, you just have to make do with what you’ve got.

JK: My understanding from talking with the others is, a lot of times you communicate from the DisAbility Project and say, “Here’s who’s coming, here are our needs,” and then you get there and that becomes an issue of, they either didn’t fulfill their end of it and help out, or even just basic needs such as a place to go to the bathroom, food, et cetera. You face those complications, too, am I correct?

AJ: Oh yeah. The protocol has always been to check out the environment first, especially for someone with a disability, to make sure it’s accessible, but then last-minute things will happen, where the venue we talked about is not available or something so we have to scramble and try to make do with what we have. A lot of times venues are helpful in that respect and then sometimes they’re, like, “You’re on your own.” We just have to brainstorm in terms of what we can do, and just go on with the show, right?

JK: I know but that’s the frustration, is just my personal take, from everything I’ve heard when you call a group. In my circumstance, since I do teach at a high school, if I book someone, I don’t care who it is, then well in advance I’m working with everybody from Buildings and Grounds, et cetera, saying, “Okay, here’s who’s coming in at this time, we need to have these facilities available, be ready,” just so we’re ready, because I have to take care of a lot. I’ve done that with many different groups that have come in, so when you tell me that you’ve done your part on your end and then they dropped the ball, that frustrates me, especially in my field, because I’m just, like, “Why would you do that?” I’m very confused by that. Like, “Wow, I get this fantastic group coming in, and I’m just going to hope everything works when they come in.”

JK: That's just me, though. That's me going on my soapbox. Is there … There was a … I'm trying to remember, because it's been about a month since I've talked with someone about this, was there a performance in Las Vegas at some point in time?

AJ: Oh god, yes, but I didn't get to go to that one. I was not invited to that one, but I would have loved to have gone.

JK: [laughs] Do you know why they were heading there? What was the reason?

AJ: I believe it was a conference for … oh god. Joan went, of course. I believe it was a conference for … psychology? I don't know. I'm sorry.

JK: That's okay. I just didn't know who all was part of that. That's why I was going to ask.

AJ: Let me tell you, everybody who went to Las Vegas was never in the project after that.

JK: [laughs] Okay, so we left them all there.

AJ: Everybody that was part of the project, even Joan, eventually just kind of went their own way.

JK: That's the next phase of it that I wanted to talk to you about. How have things progressed with it or changed with it since you started, as far as leadership roles and, actually, actors? Because when I met with you the first time—and I'm not saying this to get anybody sad, because it happened when I talked to Angie, but I talked about David, because he had talked at the time about one issue where he was basically stranded at a school because they weren't open that day when you were supposed to perform somewhere.

JK: That would have just made my blood boil when I heard that, because they should have said, “Oh, by the way, we don’t have school this day,” and he had to be picked up. How has everything changed as far as the membership, et cetera?

AJ: When I first was introduced to the group, I believe there were twenty or thirty people at the time, and so there was some competition with regards to who would get a role and that kind of thing. So the better prepared you were, the better you can memorize lines and that kind of thing, the more you’d be guaranteed a place in a skit or whatever, but Joan was always very diplomatic with regards to that, very democratic in terms of who was in things. She wanted to give everyone a chance. It wasn’t a matter of, “Well, you’re going to be in this and it doesn’t matter who else is here.” Everyone had an opportunity to shine. But there has been so much change in terms of people coming and going, and the leadership, and even the daily operations has gone through different hands. I mean, geez. It’s just been so … It’s just different, you know. I don’t know how to explain it. From the beginning of when I started to now, it’s just literally night and day. It’s just like an evolution of changes. I think the most consistent people have been me and Bryan.

JK: Yeah, yeah.

AJ: Because everybody else … Unfortunately, there have been deaths, and there have been people that have moved away. We’ve had a lot of students that come in and once they’re finished with school they go back to whatever state they came from or whatever, or they go to their career or whatever.

JK: I will share with you that, when talking with the others, because I got to talk to everyone but you, every one of them, to a tee, said, “Make sure you ask Ana that, because she knows everything.”

AJ: [laughs]

JK: They really depend on you to have the memory of everything, which I thought was telling and so wonderful, and what a compliment that was, and I thought, “Wow, that makes sense.” All the way down, that’s from Joan all the way down, that was every single person. And I know you mentioned the deaths. I know that’s the most difficult part of it, because that’s not something you can change, and, as I tell my students, that’s the one part of my job that I hate, is that I’ve been down to the funeral home way too many times. And that’s just the nature of it. I have students all the time and things happen that I want to fix and I can’t. That’s my biggest weakness, I guess, is that I feel helpless with that.

AJ: Yeah.

JK: As you go on and continue the productions, though the only one I knew was David, I know there are many others you’ve lost. Like Angie, for example, then she went on to work full-time, or at least that was my conversation with her, so she couldn’t put in as much time as was needed. Does that play into it? Do you think, some of it, you’re working throughout the year and if people have jobs it’s a little more difficult to get time off?

AJ: Oh yeah especially performance during the day and that’s usually, obviously going to schools is going to be during the day, on a weekday, when people are actually working.

AJ: It's nice when we can have a performance at night or on a weekend, but that's not always available, especially when we're doing an inservice or a training or something like that. That's when people are working, and if somebody has a job, you can't tell your job, "Well, I'm doing this other thing and I can't be at work." That would be okay, maybe, once or twice, but it's not a consistent kind of thing, unfortunately.

JK: I see that. The work you've done with Jennifer Medina, were there other people who were dance instructors that joined with you before her, or was she the first one? How did that come about?

AJ: Oh, no, there have been plenty of dance instructors that have come and gone and put their own interpretations and things like that with our ensemble. We used to dance to Prince's *Kiss* and we had a whole choreography involved with that. It was a group choreography. I really wish you could have seen that, Jon. It was so great. You know the song?

JK: Oh, yeah.

AJ: It's such a great song. It's such a great song, and we just had this whole group choreography with that. It was so great. Literally everyone that was involved in that group thing is gone except for me.

JK: Oh my. How long ago was that part? I saw the one that was outside, the *One World* project, and you had to wait in the freezing cold outside the center, that one celebration of ADA, and I was feeling horrible for you because you were all waiting to go on and then someone decided they wanted to talk some more and I about…

AJ: [laughs]

JK: I've gotta tell you, I about jumped onstage and tackled him, like, "We don't need to hear you! I appreciate this, that you want to talk, and I've dealt with this before, but there's a performance going on and it's freezing outside!" I remember one of the dancers from Jennifer's company had come a little bit late, but then just marched right in and everything was so smooth. I know I keep saying this, but the transitions were fantastic, no matter how cold you all were! And I know how cold you were because I spoke with you about that. So when was the *Kiss* number done compared with this? Because this was more recent.

AJ: At least fifteen years ago.

JK: Okay.

AJ: It was really, really early on and I really wish I could remember the name of the choreographer. He was so good and so sweet and so patient with all of us. He tried to work within our abilities in terms of dancing and in terms of how to transition in and out and that kind of thing, and at first it was a big mess, and then it all came together. It seems like a lot of our productions seem to be that way, for me anyway. It's a big mess and then we get onstage and hear "Wow, you're so good!" It's, like, "Okay, thanks!"

JK: I expected that from you, because I see the perfectionist in you, and I know it's in me too, like "Oh, it's just not the best it needs to be," but there are others that look at it with outside eyes and all of this is just some of the best work I've ever seen. I do mean that sincerely. What I saw in that freezing cold was just phenomenal.

JK: I thought, “Wow, I finally got to see a final product.” I saw you in rehearsal, but then you just dealt with the elements and just put that on my mind once things started. It was just a beautiful piece of music. I thought, “Wow, this is just fantastic how all that worked together.” How long ago did Bryan join you? You’re mentioning that everybody turned over, so he and you are the most consistent right now. Do you know about how long ago he joined with you?

AJ: I believe it was November of the same year that I started, but I’m not really definite on when he started. I just know that I had started in March or April of 2000 at the same time as—I’m not sure if you ever met Alison Chancellor. We started at the same time and she was in the group for quite a while until we did this thing for *Tom Sawyer*, I’ll show you a part about that, and unfortunately her attendance was wavering and she was in and out. We had to be dependent on people to actually be there because there were definite roles and when she was kind of flaky about it, unfortunately she couldn’t be in it, and when she was told she couldn’t be in it, she just got mad and didn’t come back, so that’s unfortunate.

JK: It is, but that’s like any other theatre troupe, right?

AJ: Right, right.

JK: It’s the same thing.

AJ: People get mad. If you can’t do something, just say you can’t do it. Otherwise, people have to be dependent on you, especially when you’re doing specific roles and people have to be dependent on when to come in for those kinds of roles.

JK: Did you get any feedback from anybody else in Missouri at the conference that I went to where you performed in that frozen tundra?

AJ: [laughs]

JK: Did you hear back from anybody? How was that received by people that attended the conference?

AJ: Oh god, we got a lot of really, really good feedback from that. And we got some bookings from that too! People were really interested in us coming to their school or their job. Every performance is a good way to show our abilities. You can describe us to some people, but you wouldn't really know what we do until you see us. I think seeing us is a really good way of showing our abilities and marketing us, you know?

JK: Yes, I do. I know Becky's role has changed; now she's more of the go-to person, contacting everybody and making sure everybody has great communication, but what do you see as her role with everything that you do?

AJ: She's the spine. I think we would fall apart if it weren't for her. She evolved into that role too. I mentioned Alison Chancellor; Alison Chancellor just started watching and then started performing with us, and I don't think … I say that she started in April, but Becky has mentioned the fact that Alison was interested in the DisAbility Project way early on, and she was too, but because of school and other things that Becky was involved in, she wasn't always part of the DisAbility Project, but she knew about the DisAbility Project way early on. Her commitment to the group has really gotten a lot more intense, in terms of all of her responsibilities.

JK: Excellent, because I just see that she has a passion for it, and I saw that because I was able to interview her after I interviewed Joan, and we came at the same time, so it was really very nice to hear her end. I'm not sure how many times people ask her, "Hey, Becky, what do you do?"

AJ: EVERYTHING.

JK: So it was really nice for her. I know! And Joan more than admits that. She says, "Here's my right hand person."

AJ: Oh yeah. It's not just the DisAbility Project; it's the whole Uppity Theatre group.

JK: Yes, yes. And I'm still not sure how Joan does this travelling between all the different places she goes to. That's not something I can do, and I even mentioned to her, "Your prolific writing, I can't write worth anything, trust me." When I get these transcripts for this, I'm going to be dependent on that person for getting everything right. I wish I could write as fluently as Joan, but she's always posting, posting, posting, and it's never anything that's fluff. It always has some meaning to it.

AJ: Oh yeah.

JK: I don't know how she does that and keeps everything going. It's just a puzzle to me how someone could keep all these balls juggling in the air and still keep a focus, but, like you mentioned, she puts people in charge who can help out with this. So, Vanessa. Talk on her, if you don't mind, because, again, these are people I've talked with and they've been generous enough to give me their time, like you are. When did Vanessa get involved and what has her role been this entire time?

AJ: Oh, Vanessa! She's so wonderful. You talked about Joan being so imaginative, I mean, Vanessa, she's another amazing person in terms of her creativity and her work ethic and her ability to keep everything together and have a focus for the product. I was so glad when she became part of the group, because, like I said, she's a mother, and she's a director, and if something is not working, she'll tell us. If somebody tries to infringe on our accessibility or anything like that, she's a mama. [laughs]

JK: [laughs]

AJ: That's a great thing. That's a great thing. There's been more than once where she's had to help me out because somebody's parked too close to my van and I can't get in. She'll yell at people. I love that about her. She just, oh god, I love her!

JK: So your rehearsal space, you mentioned that that frustrates her too, because you don't have a consistent rehearsal space?

AJ: Yeah, we have to make do.

JK: Has it changed? Are you in different places at different times? Is there anything consistent at all?

AJ: Not really. We used to have the lobby part of the OT school, but they made a lot of changes in there. Because they were making construction changes, we had to find a place. We had a classroom but classrooms change, unfortunately. We're like the nomad group of acting. We have to make do with what we find.

JK: I was going to say, I don't remember where it was when I first met you and we had that conversation. That was in, I forget which building, I thought it was a hospital or something. Maybe not. It was down the road from where Joan was and all of a sudden I'm walking there and I'm thinking. That's where I met you, in the lobby, but I just thought, "Wow, there's not an actual rehearsal space that's dedicated for you?" I just didn't know how you were able to overcome that. That's an obstacle that is tremendously difficult, because when you have consistency, everybody knows where to go at all times, and then you can rest, and chill, and, "Hey this is our space," but when you have to share with others, they're not always willing to share with you. That's what I've noticed.

AJ: Right, right.

JK: I will ask this big question. This is my overbearing question for everything with this. What is the biggest thing, the most important thing about theatre for people with disabilities? Why do you think that is important for people who are artists, with live theatre specifically, to be involved with theatre projects? Why do you think that's important to their lives? Just expand on that, if you don't mind, please.

AJ: I think the voice. I think having a voice. Having a voice and being heard and being able to scream at the top of your lungs if you need to, laugh from the bottom of your tummy, making an impression. Unfortunately, people with disabilities can be put to the side and ignored or considered less-than, and we're not less-than. We're here. We can make an impact if you just give us the chance.

AJ: And even if you don’t give us a chance, we’ll make the chance! People with disabilities, we’re one-fifth of the population! People with disabilities … Unfortunately, anybody can be a person with disabilities, at any time, at any point in your life, and as reality goes, the older you get, you’re not going to get healthier. People become more and more disabled or lose some of their abilities, so having a voice and being seen and being heard, I think that people with disabilities in the theatre being seen and having the ability to express yourself is so cathartic. It’s very cathartic, and I don’t know if people who are watching us feel that way, but I’ve felt their emotion. I’ve felt their gratitude. I’ve had children come up and hug me. I’ve had adults come up and hug me, because of what we do. That’s what I appreciate. That’s what I appreciate so much about the DisAbility Project and being able to have a voice. And the fact that I’m a big ham, so that helps.

JK: [laughs] You segued into what I really wanted to hear also. I was trying to connect the DisAbility Project to … What has the DisAbility Project as a whole done to people who want to perform who happen to have a disability? How does that promote the opportunity for people to go ahead and perform? Should other companies emulate what the DisAbility Project has done?

AJ: I think so. Just talking about Vanessa, Vanessa was in theatre for many many years and doing movies and that kind of thing, and I don’t think she really considered a lot of people with disabilities. I’m not sure; I can’t speak for her. In some ways, I think we opened her eyes in terms of what people with disabilities can and cannot do, and what we can bring to the stage or to any kind of forum.

AJ: I think the more people see, the better we are. I see it all the time on commercials and things, people with disabilities, they're not highlighted, but they're, like, part of the scenery, and that's what we are. We are in the population and we can make a difference. Look at the governor of the state of Texas! He uses a wheelchair but nobody's saying, "Oh, this wheelchair-bound guy." No, he's the governor, and he's making a difference and he's doing what he can for his state, and it's not about him using a wheelchair. It's about him making changes, making a difference, being a leader. Like President Roosevelt! Unfortunately, he didn't want to be seen in a wheelchair, because people would think he was weaker and to me, it seems he's stronger to be able to do that and still get elected four times! I think visibility is a really, really important thing. Visibility and making a statement is very important, and I think the DisAbility Project really helps with that.

JK: Excellent.

AJ: I wish we were able to perform all the time and be seen all the time. There are things on YouTube of us that we've done, performances, and in that sense, that's a good thing.

JK: Not as powerful as that live performance though. Boy, that live performance just grabs you. But that's what I think about theatre in general. That's what I think of live theatre as compared to TV or movies, which are fine, but that live performance just grabs you.

AJ: Yeah—

JK: Go ahead. Go ahead.

AJ: I was just going to say, you can't beat that live performance. It really does grab you, and you can't always replicate that on film, unfortunately.

JK: And I think that’s great for what it does, but it’s the performers. It’s just that energy you have during that interaction. I’m going to leave with a light thing here. I’ve heard from a few of them and you already alluded to this but, during all these performances, dozens, hundreds of performances you’ve done, you sometimes will have questions from the audience. I know you do. Are there any of these that you don’t mind sharing that are memorable to you? Kids or adults, or things that they’ve asked you, when you’ve performed and are having the talkbacks after? I would love to include those.

AJ: We’ve had people actually thank us for coming, and I thank them for having us. I wish I could remember something that was poignant.

JK: Even if it’s just the most unusual question. I know there have been a couple of unusual ones they’ve asked you, because a couple of them shared and said, “Well, they asked this,” but I want you to put your spin on it, if you just happen to have one or two that you can remember.

AJ: I remember going to an elementary school and kids are so great.

JK: Lord.

AJ: [laughs] I know! They come up with … This one child, it wasn’t anything about the disability, nothing, literally nothing about the disability. He asked our favorite color. [laughs]

JK: [laughs]

AJ: I was like, “Wow, that’s such a profound question!”

JK: Well it’s so important to him.

AJ: It is so important! “I like fuchsia!” “Oooo.”

JK: You're right. I think that children have a lot better perspective, and if you can reach them early, that tends to be the easiest part.

AJ: Yeah, that's great.

JK: All right, well, I've held you up for so long, and I thank you so much for your time on this. This is tremendous, and I appreciate all you've done to help me, and I'm hoping to do all of you justice with what I write.

AJ: I'm sure you will.

JK: Oh, thank you. I hear you, but you have a lot more faith in my writing than I do.

AJ: Oh no, I've got tremendous faith in you, Jon. I know how smart you are. You've kicked my ass in Words with Friends!

JK: Oh, do not even go there! I'm gonna stop the recording now.

Interview with Joan Lipkin

Joan Lipkin is the co-founder of The DisAbility Project with her colleague Fran Cohen. Joan is the Producing Artistic Director of That Uppity Theatre Company which is the umbrella organization that includes The DisAbility Project in St. Louis, Missouri. Joan works extensively with people with disabilities, women with cancer, GLBTQ youth and adults, people with early stage dementia and Alzheimer's, and at-risk youth. Joan is a playwright, director, activist, educator, and social critic. Her work has been published throughout the world and on television, radio, and theatrical journals. This interview took place in the lobby of Lipkin's apartment building in St. Louis, Missouri on June 2, 2017. Lipkin's apartment serves as the headquarters for That Uppity Theatre Company. Becky Galambos, Lipkin's office manager, entered into the lobby during the interview to assist Lipkin with her schedule.

Joan Lipkin: I need to do something like that.

Jonathan Kochensparger: That's the beauty of it. We had various settings, because with Margaret it was in her home. That was easy. With Bryan, we had to go outside, and it sort of picked it up, because I listened to all of them. With Angie, it was in a coffee shop, and I thought, "Oh, this is going to be the worst." She had it directly up to her mouth and you could hear everything she says.

JL: Who else do you need to meet with?

JK: We were gonna meet with Ana this morning, but obviously Ana's mom just died.

JL: Ana's mom just passed away?

JK: That was just yesterday as far as I know.

Kellie Kochensparger: We saw it on Facebook. I saw it this morning on Facebook. Someone had tagged her. She's in New Orleans.

JK: Probably one of her sisters, if I could figure that out. Someone tagged her, not the same last name. And then she called us this morning and apologized.

KK: He got out of the shower and said, "I'm not sure if it's her grandmother or her mom, but it looks like somebody really close."

JK: I said, "Don't worry. This is not important."

KK: How she was able to call is beyond my comprehension.

JL: Maybe you could do an interview with her another time. She is really crucial to us. I mean, everybody is, but in the sense of longevity. I didn't know. Facebook is so weird. There are things that cross your feed and things that don't, and I didn't know. I mean, I'm devastated for her.

JK: Yeah, and I didn't know if it was public or not.

JL: If she posts it on Facebook, it's public.

KK: It was someone tagging her in a post.

JK: When somebody does that, I'm, like, "Okay, how close is this person?"

JL: We need to follow up. You need to talk to her. Who else do you need?

KK: We talked to Jennifer.

JK: We talked to her on FaceTime.

JL: How was that?

JK: That was great.

JL: She did beautiful work with us on this piece that we did, international human rights and disabilities, beautiful work.

JK: She's excited about her new space. She's working, but she couldn't be here, of course. She posted pictures. She's out of town this week. She said, "Could we do this by FaceTime?" And I said, "That's fine," because I'm gonna have to do that with the people at Graeae when I do that end of it.

JL: Oh sure.

JK: I mean, there's no way that's gonna … I mean, I'd love to, going and visiting that one time was just brilliant. To see them facilitate, to talk to all the people who were involved, a couple of them were available to us and the rest of them sort of waved to us and they were generous with their time, like you were when we first came in, so this is fantastic.

JL: What about Rich? Have you set something up with Richard?

JK: No.

JL: Have you connected with him?

JK: Not yet.

JL: What about Katie?

JK: Not yet.

JL: Okay, so I think those would be two really good people for you to talk with.

JK: Melina hasn't gotten back with me yet, or, Malia, I'm sorry.

JL: Yeah, Malia.

JK: Bryan called her Melina. It was interesting, because I know it's Malia, but he corrected me. I was like, "Who did you dance with during that part, Malia?" He was like, "Oh, you mean Melina." It's interesting because he's very specific about details. That's just an interesting…

JL: That is very interesting.

KK: We thought we'd been calling her the wrong name.

JK: I remember when you guys performed the last time we saw you, it was so cold, and I remembered someone speaking. I was, like, "Let them perform! You can speak whenever!"

JL: Yes. Yes. Interesting

JK: I asked all about that experience of working with Jen, and how that worked, and how that changed them and it was wonderful. I know everything about your background that's been written. That's not with this is about. My important thing is to find out, when you did first start, how you reached out to people, and how you chose the people you did, because that to me tells a lot about the whole birth of the DisAbility Project.

JK: You had all these others with Uppity, and then you had this with Fran. How did you decide on the people you were gonna take, who you weren't, because it's an acting company, so how did that come about?

JL: Okay. I've always been interested in disability and I am kind of one of those people who is not in the room, as well as who is in the room, and I was just aware that people with visible disabilities were not in the theatre, either in audiences or on the stage. I was very interested in that. I went to work with the late theatre director Joe Chaikin in 1996 at the Atlantic Center for the Arts. He was interested in disability and I was interested in that. I went to go work with him as an associate director. He was an interesting guy, because he founded an experimental theatre company in New York called the Open Theatre, and then he had a stroke in 1984 and he was aphasic, so mentally he was very strong, but his speech was not typically communicative. And yet he continued working as an artist, which interested me, because it's like Matisse. When Matisse couldn't stand, he was elderly and in ill health, and he couldn't stand to paint. He began to do these cutouts. That speaks to me about the creative spirit. We have a drive to create and to be in the world, especially if we're artists with a history and a real drive to make things, we're adaptive. It's like a model. I went to work with Joe Chaikin, and at the time I was an artist-in-residence at Washington University, and the WashU record posted that I was off doing this, I think. So Fran Cohen, who was a professor of occupational therapy, asked me if I would come and give a talk. Have I told you this?

JK: No. You're putting the pieces together; it's great.

JL: There are a lot of pieces, I know. She asked me if I would come and give a talk about what I did at the Atlantic Center for the Arts, in New Smyrna Beach, Florida. I didn't know her at the time, and I said, "Well, I'd be happy to meet with you, but I'm not really interested in giving that kind of talk. What I'm interested in doing is taking what I've learned and taking what arose for me and starting a theatre project that looks at disability. If you're interested in doing that, let's get together." So we got together and I didn't have this huge goal for myself. I think you can overwhelm yourself with a big goal, although I encourage you to have your big goal.

JK: I know. The hardest thing is, how do I get that building to become our venue? And it can be! It used to be one of the greatest theatres in Dayton, Memorial Hall, so many players went through there, and it just sits there. It's been sitting there way too long. I said, "We're done with that." I'm too old to just sit there. We don't have time for that. The people I'm getting in touch with, they know this is serious work.

JL: That's great, so I think it's great to both have big goals and I think it's great to have small goals. I think that we can have a really big goal and it can intimidate us. What I wanted to do was see what was there. I wanted to try things and see what the response was, rather than my coming in and imposing some vision. You have to remember this was 1996. This was just a few years after the Americans with Disabilities Act was passed. I said to her, "What I'd like to do is convene a meeting of leaders in the disability community in St. Louis, and ask them what they think of the idea of our trying to put together a group to make a performance about disability." I didn't think that I should come and say, "This is what I'm going to do."

JL: I thought that I should have a conversation to see what they thought about this idea. She had the context for that. She was a professor in occupational therapy. She was highly respected, and knew a lot of people. I said, "Do you think you could help us put that meeting together? Let's just have a conversation and see what people think." She said, "I can do that." This was huge, right? She opened the door. The people who were at that meeting! Max Starkloff, who was one of the founders of the disability rights movement, who founded Paraquad, he was at the meeting. Jim Tuscher, who is another person who has since died … I'm telling you! I don't want to get emotional while doing this, but it makes me both proud of what we have accomplished and really sad when I think of all the people that we have lost. But Jim Tuscher was vice president of public policy, and he had paraplegia. He was at the meeting. There were a number of people who were at the meeting and I said, "I don't know most of you. Or, I should say, you don't know me. I know who some of you are." Some people said, "Actually, we do know who you are, because you're a well-known theatre artist and director." I said, "Well, okay, good. So what I would like to do is to, I'm concerned about the lack of visibility for people with disabilities, both onstage and in the audience. I'm also concerned about the lack of opportunities for adults with disabilities, for a certain kind of creative expression, and a certain kind of community. So I'd like to know what you think about the idea of my convening a group and seeing where it goes." I said, "The work will come out of their concerns and their experiences. I will help with my particular skill set to develop the stuff, but this will come out of what they're concerned about, what their lives are about." Almost everybody in the room thought it was a great idea. There was one person who did not like the idea. I can't remember what her last name was. Her first name is Alice. She at the time was a lawyer, I believe at Monsanto, and she was blind, and she said, "I don’t like this idea at all, because I have spent my life trying to get away from the label of being disabled and being seen that way, and I don’t want to define myself that way.” I’m, like, “Okay, I really get what you’re saying.” Do I want to be described as a woman writer? I said, “I mean, I get it, and I appreciate where you’re coming from,” but the other people in the room did not feel that way. Max Starkloff, who I became friends with, said, “We need as many fields of representation as possible. We’re trying to change things.” So he was supportive. He thought it was a great idea. On the basis of that, I decided I would convene a group that would hopefully meet once a week. We didn’t have space, Jonathan, so through Fran Cohen's connections, we used the lobby of the OT school at WashU. We used the lobby to meet in, because on a Saturday, there weren’t that many people there. Then what happened is, I was diagnosed with breast cancer really soon after we had this great meeting. I thought we could keep things going, but I was really sick and I couldn’t. I couldn’t. I had to put it on hold for at least six months. I tried to stay connected but I just was really ill. It just solidified my belief that we are all temporarily non-disabled. This is a category of identity that any of us could join at any time. So Fran helped us find people, and she would talk to people, and Jim Tuscher and a lot of people that were at the meeting told other people, and then I think I wrote about the fact that we were doing this, and so some people found out about it, maybe because it was on our website, and tracked us down. Originally I conceived of it as a project for adults because I figured that children with disabilities had many more options for socializing and for expression, and people that were in high school, well, they were going to be busy with all kinds of things, but it feels like as soon as you’re twenty-one, the world sort of walks away certain kinds of supports

JK: That’s my perception.

JL: So I wanted to focus on adults and I also figured they would be more available, but we had a couple of people who were teenagers who wrote to us. In fact, Alison Chancellor, her nickname was Ali “The Internet” Chancellor, because she found us on the Internet and she said to me, “You have to take me. I want to do this.” She was a teenager.

JK: This was back in ’96, roughly?

JL: Here’s what happened. I had met a couple of times, and I invited all kinds of people, and there were some people that I invited, that it just wasn’t right for them, because we were fledgling. That’s twenty years ago, and since then, I have made work with so many different populations. I know how to go into a room and make work with a group of people that I don’t know in a class session. But back then, I wasn’t really sure how to do this. I just knew that I wanted to do this. There were people who prefer that you just give them a script, or people that want to do something that’s in the canon. I had a group of gay men for a while, an ensemble called the Louies, and I made work with them, and there were people in the group who loved it because we created original work about their lives or whatever their concerns were. Then there were other people who checked us out and said, “I would really rather be doing this play or that play.” That particular process didn’t speak to them, but for many people who were in that group it did, and we made work together for three years.

JK: I just want to say how great your website must have been, because that was a time when the Internet was just starting, and they found you. That means they were looking. That’s a key component. Right now you can find if you look, and it doesn’t take as much effort, but back then.

JL: It took a lot of effort.

JK: That speaks highly of them.

JL: Well, it speaks highly of them, but it also speaks of what the need was. We had several teenagers that joined us. Somebody would say to somebody … For example, at one point, we had a lot of people with MS in the group, and there was an MS support group, and we were in contact with the MS Society, and somebody would say to somebody, “Well, you know, you need to come, and you should check this out! You would like this.” With any population, especially a marginalized population, a lot of stuff that happens is through word of mouth, right? When I say we started small, I mean, it’s always new when I make work with any people, but at that time I wasn’t as experienced in the art of devising as I am now. It’s twenty years later. I’ve worked with many, many populations since then. I didn’t know how to devise as well. There was that. We had to figure that out with them. I also wanted to focus on the process, not on product. I wanted us just to be in relation to each other and to see where it went. That was different. Because if we did that, then nobody would feel pressured. We could just explore without pressure. We would have these things that we called sharing circles, and we would go around and people would talk about their lives. And as people would talk about their lives and what was going on with them, they would talk about attendant care, or people illegally taking their parking space, they were sharing with each other and with us the culture of disability. We were not calling it that. We were talking. As we were listening, I was like, “Oh, okay, well, obviously we need to do a piece about parking. We need to do a piece about attendant care.” The other thing is, people would talk. We’d have this sharing circle.

JL: We would do a lot of exploratory work, too. It wouldn't just be, "Oh, attendant care, let's make a piece." We would do all kinds of things, movement work, to explore developing our own movement vocabulary. Also, in the process of the sharing group, we were knowing each other, and we were building trusting relationships. Not unlike consciousness raising, right? Consciousness raising, in the second wave of the feminist movement, right, was a kind of consciousness-raising of that experience, so when we had maybe six or eight pieces together, I said, "What would you think if we would just invite a few family members and friends, as a very gentle sharing, so people can see what we've been doing and we can get some feedback?" It was very gentle. I didn't have this huge vision. I felt there was a value in just what we were doing, right? There was a woman who was in the group, and her name was Patty Clay, and Patty was a double amputee. Her sister had a little coffeehouse and made baked goods, and her sister wanted to support what we were doing, so she would make these fabulous cupcakes and scones. So we would woo our family and friends to come and see our little showing. In the lobby of the occupational therapy building! I just gave a talk for students at a high school in New Jersey, theatre students who are in a vocational high school, that was sponsored by the McCarter Theatre, and I spoke to them, and I used so many principles that I developed and came to understand through the DisAbility Project. We can make theatre almost anywhere, and we don't wait for someone else to give us permission. You can wait a long time for a gatekeeper to understand that what you have to say is important. I was there Friday and I said, "Do pop-up theatre! The world is your stage!" We were in the lobby of the occupational therapy building having scones and doing these little performances. We began to build things. Some people tried it a couple of times and said, "This is just not my thing, making work this way," and other people were like, “Wow, I have been waiting for this.” So we did this. I was looking, and I was trying to be able to put together a timeline for this. We did this for two or three years, of having these little showings. That was a long time.

JK: Was it in various locations?

JL: No. We stayed in the OT school. Then we learned about, and/or were invited, Fran might have had a very big part in this, she really was my partner in this. She was my partner. She was older than me, much older, and she introduced us to the woman who ran the international post-polio organization, and they were going to be having an international conference at the Marriott downtown, and somehow it transpired that we were going to perform for them. [emotional pause] You’re taking me so far back! It’s very moving to me, when I remember what it was. It’s a long time ago! It was really huge. That night was huge. So I said to the group, “We have been invited to perform at the international post-polio conference. This is not in the lobby of the OT school. If there’s scones, it’s because we’re going to bring them later. Who’s in?” We did a number of pieces. We even did a piece where I said to the audience, “This is so new that we aren’t even off-book, but we have something we want to share with you.” I remember going onstage, and I used to narrate our performances, and I remember going on the stage looking out on a sea of two to three hundred people many of whom were polio survivors, some of whom were on ventilators, many of whom were in wheelchairs. I said, “We’re really honored to be with you tonight. We have our own disabilities, and we want to share with you what our world is like. It’s been quite a day for you.

JL: How about if we all kind of breathe deeply and do a little stretching?” And all these people start to raise their hands and stretch, and I’ve directed and performed for a long time, but to see the way they responded to us… And then we performed and it was just tremendous. I suddenly realized that we had been quietly building up to this moment, but I didn’t put that on myself when we started, because I think that would have been, maybe for some people that would spur on their creativity and for others it would have impeded it. Sometimes you just have to see what is there, and who is there, and what are people comfortable with and capable of, without a lot of pressure? Now I know that we probably didn’t need to do that for two or three years. But I was also recovering from cancer! I was trying to get my life back on track after having been really ill. Then we had this potluck dinner, and we had a meeting with everybody who had been there. I think there were fourteen or fifteen people in the performance. I said, “Some of you did this with us, and wanted to work on this, or wanted to work with me, and there’s no expectation that you have to continue, but I have a feeling that there’s something really special that happened here that can continue. I want to continue.” One by one, I met with everybody and I said, “I want to know, how do you feel?” I didn’t want to do it in a group setting because I didn’t want anybody to feel pressured! I wanted people to be able to say “You know, Joan, this has been great, but I really want to do something else,” or, “Joan, I’m scared but I want to try,” or whatever it is. I wanted them to be able to have that conversation. Some people didn’t choose, but most people decided that they wanted to stay and we had to figure out real organizing principles for the group, and some of those people agreed with them and others didn’t. My feeling was that anybody who would show up who would consistently invest creatively and who was capable of socializing with the group in our times together should have a place. There was disagreement in the group. Some people thought that there should be an audition process. Some people thought that we shouldn't take people who had behavioral challenges or cognitive issues. There was hierarchical stuff that went on even within the disability group.

KK: Interesting.

JL: Right? And there were some people that were actually disappointed that this was the direction I was taking it. Some people wanted us to have people who had disabilities in, but they wanted it to be much more canonical.

JK: Interesting. With the students I work with, the range is humongous, between this person who may have autism and this person who has an iPad that she speaks with. It ranges all over. I have a young lady who works with me in the regular theatre. I couldn't be there during one of the regular rehearsals because I had an appointment with Allie, and I said, "Can you take this for me?" Because I trust her, and they have their teachers with them, and I asked her afterwards, I said, "Caitlyn, what would you have done differently?" She's in the mold of you. I've brought your name up to her several times. She said, "Well, I didn't know how you blocked it." I said, "Do you understand why they were in the positions that they were in?" She said, "No." I said, "This young man here is not allowed to be near that young man there, because they have this, they're still willing to work together, but they have this antagonistic thing where they can't be in the same space." They have different disabilities but their range is huge. This past time, I wish you could have been there, they all spoke. They all had words to say. We used a regular script because we're not up to that level yet of, "We're going to create this together," but that was tremendous because every one of them got to hear their voice.

JK: One young man just went, “Yeah!” right after he spoke, like, that is exactly it, because he was performing. They had to use a change of venue too, because we weren’t able to use the same place, and they adapted to that quite well, but we had what you describe, that’s not something I’ve ever dealt with because it’s always whoever wants to be a part of this.

JL: I felt like I wanted to have what we call a group conscience. I wanted to know what people thought. We had people who were really gifted performatively and really cognitively sharp but were physically quite challenged. We had a whole range. If I had the resources, which I didn’t, and if this was my singular focus, which it’s not … It has been a major focus of my work and my life but it’s not my only focus. I’m involved in many other issues of social justice that we explore through the theatre. But if I had the resources, and maybe you can do this, Jonathan, I would have several projects. I would have a project that anyone could be in. I would have a project where you do Broadway material that people audition for. I would do many tracks. It would just be a theatre company that offers many different things, but, you know, we were pioneers. The only companies that I’m aware of, I’ve only known of three that are as long-running as we were, maybe even pre-dated us. One was Actual Lives in Austin, Wry Crips in Berkeley, and the Mickee Faust Club which is in Florida. We were trying to figure out what we were doing, and so then we decided. What interested me was that we would be equal parts education and entertainment and that we would help to change people’s understanding and perception of disability and thus response and behavior towards people with disabilities through our work.

JL: That's what I was interested in doing. I wasn't interested in doing *Guys and Dolls,* and offering that as an opportunity for people with disabilities to do that. I thought someone else could do that. I didn't think I was needed to do that. I was all about the culture of disability and people's experience and then the fascinating slippage between somebody performing and you see their body and their lived experience and what they're saying and you know there's a real relationship between what they're saying—even if it wasn't strictly autobiographical because we moved stuff around—and who they are.

JK: How much … I didn't mean to interrupt you. How much of your creative writing skills help them form their stories? I know the stories come from them, because it's their experiences, but how does it come down to the written word, just going from what I saw?

JL: It would really vary. Stuart Falk, who is not with us anymore … Stuart Falk, Thea de Luna, David [inaudible], Lucy Grondahl, Jim Tuscher, they're all gone. They're all gone. And Stuart was really gifted. He was a really gifted storyteller, so one day people will give you the stuff. It's not so much that I am, quote, a good writer. It's that I'm a good listener. You listen, and then you edit. People are giving you nuggets all the time. They make jokes, and then you say, "Well, what does that look like if you push it to an extreme?" And they give it to you and I would take it and shape it. Stuart was talking about how he was being hospitalized yet again for another urinary tract infection. Stuart had multiple sclerosis. He said, "Oh, it's like Club Med." I said, "What do you mean?" He said, "Oh, you get three meals a day," and he starts to tell us this joke, and I said, "Oh, this is fantastic, keep going, keep talking, but keep it within this metaphor of Club Med," and he did.

JL: Ann Fox, who did not have a disability, she was an assistant professor at the time at Washington University, a colleague of mine where I was an artist-in-residence, and I invited her to come to the DisAbility Project and that was her entry into the early stages of disability studies and now she's become a major disability scholar.

KK: She's wonderful.

JK: She was so generous to give her time, because she had to speak the next day and here's this crazy guy from Dayton shouting about Ohio State University at night in her hotel lobby.

KK: She spoke very highly of you.

JK: Oh my god, we had a wonderful conversation.

JL: She's wonderful.

JK: And the next day, I got to attend her conference, and it was powerful listening to her words, just, plain as day. She just gave them the facts.

JL: She's tremendous. She and I went back to her place and we typed it up and we brought it back to rehearsal and we started playing with this and it became a signature piece for him. Or we would give people a writing prompt. Not everybody can write physically but there are many ways to write. So people tell stories and then we would edit them. I do hope you get to meet Rich Scharf. He's a dentist. He's really busy. I really do hope you get to meet Katie Banister. She is a tremendous performer and she was with us for five years and she is one of the people that wanted us to take it in a different direction, and I think she got frustrated and she needed to grow in different ways and she left, but her presence was a huge gift.

JL: She was tremendous. She did a piece called *Go Figure*. It was a piece that we intercut with her experience of after she became disabled and she became a quadriplegic. She wanted to have a relationship with a man and she wanted intimacy in her life again, so it's about how she started trying to date again and to be sexual. Rich wrote about what it was like for him to be a gay man, and they started, so we took the story and it became a split subject. It was Katie's language. It was Katie's story and I might have helped edit it, but it was her story. It's not so much that I have to be a good writer. I have to be a good listener and a good editor and a good prompter, but I will also say to people, "What's on your mind?" The sharing circle would become a place where people would … For example, Ana Jennings talked about somebody else in the group who came to us, she was a student at St. Louis University, and she has since gone on and got her doctorate in psychology, so she's not here anymore. She talked about getting parked in, and Ana said, "Yeah, well, in New Orleans, we had the Quad Squad, and we'd leave notes." I said, "Really?" So then it turned into a piece and we put the pieces together and we would assemble things that would be age- and audience-appropriate. We wouldn't do *Go Figure*, which is a piece about the desire for intimacy and a different kind of sexual expression, for school kids, but we would do it for adult audiences. So we had a repertoire of twenty-five pieces or more, and then in 2010, we found out about something called The Big Read, which is the National Endowment for the Arts. I don't think they're doing this anymore, but at the time, there would be a book that they would pick that would be available to everybody in the community. So they were doing *Tom Sawyer*, so we decided that we would do a disabled version of *Tom Sawyer*, and this was going to be really challenging for the group, because it was going to be a thirty-minute through-line musical. We commissioned somebody else to write the book with music and then we tweaked it. We wanted to say, “You know, people with disability want adventures, too,” and what is the role of Becky Thatcher? You think that’s an adventure? Try riding MetroLink! We would do this collaging of different pieces that we would put together and they would deal with disability culture, they would deal with accessibility, they would deal with healthcare, they would deal with attendant care, attitudinal barriers, both physical and societal. We looked at language, we looked at dating, we looked at all kinds of things. We did a rap, which we did all the time. We looked at religion, parking. If you start to think about it, there are so many things that you can do pieces on, so we would collage things. Here’s another thing that happened. It was going to be the anniversary of the Americans with Disabilities Act and I guess it was the tenth anniversary.

JK: Was it ‘91?

JL: When we did this performance at the Marriott for the international post-polio conference it was around the time of the anniversary of the Americans with Disabilities Act, and it’s hard for me to fathom that this would happen now, because of the nature of journalism, and the nature of funding and resources, but at the time the *St. Louis Post-Dispatch* assigned Lorraine Kee to follow us for months.

JK: Really?

JL: She did a five-part series in the *Post-Dispatch* about us that led up to our performing at the international post-polio conference. She profiled all these different people in the group and that gave us a level of visibility, and then we started calling schools in different places, and more people started calling us and asking us to perform.

JK: That's what I was going to ask, did you start calling people, or did they contact you? How did that work?

JL: It was both.

JK: Both? Okay.

JL: We were on the front page of the *Post-Dispatch* for five days in a row, big photos, big stories about it, sidebars about the Americans with Disability Act, our stories, what we were trying to do as a company, and that gave us a lot of visibility. Then we started calling. A lot of schools then began to pay more attention to disability and they'd have disability days and everything. I said to Becky, could she print out for me an estimate of where it is that we had performed, and I just wanted her to do an estimate, to save a few trees, but… [many papers rustling]

JK: [laughing]

JL: This is not even up to date. And this is all places that we have performed

JK: And you would do that during the week?

JL: We went during the week.

JK: So everyone who was involved, if they had work, did they have to take off? That's another thing I meant to ask you. This is overwhelming. Did they have to take off work? Were they still paid?

JL: Everyone got an honorarium. A lot of people were not working. Here's the thing about the DisAbility Project, the way we had conceived it, it was a real commitment, because you needed to come to rehearsal.

JL: At one point we had meetings with the whole group, where one of our group members who was a skilled facilitator mediated and tried to hash out what our principles were. I didn't think that I should do that. I felt like somebody else should do that, and I would listen, but it was like, you have to be able to get to rehearsal, because I didn't have the resources to set it up for people to get there. You have to be able to interact and socialize in some degree in different ways with people. It doesn't mean you have to be super articulate. We were not set up to deal with somebody who had no socialization skills. So as it was, we had a lot of people who had real special needs in the group that became more complicated as time went on. One of the people who was in the group was epileptic, so we had to figure out, if we has a seizure, like he did onstage, he fell on somebody. We had this meeting to mediate and figure things out. You had to be able to come pretty consistently. How can you put a company together and how can you learn pieces if people don't come consistently? And also how can you develop relationships? We would say, "You need to come to a certain number of rehearsals." Then we really wanted to expand the group and invite people in, so it became, "You need to attend x number of rehearsals before you can perform, but you need to come to a performance to see what it is." We would assign new buddies to people who knew people that came in. We would do all kinds of things to increase the social mechanism. When these gigs started coming, and they would be during the week, during the school day, because all these schools wanted us, we had to figure that out. A number of people would take time off, but it's not really different from another project that I run, which is called *The Big Fat LGBT Show*, where we perform, and that's scripted material and also some unscripted stuff and people come, and they're actors, so they have other jobs, because most actors need other jobs, but they would have to take off from their other jobs to go and perform at

Boeing or Edward Jones or all these places that we were performing with that particular show, so it's no different from that. But the logistics were intense. The organizational logistics were a lot of work

JK: I remember when we first came, and you sent us to see a rehearsal with Becky and the group, and David had shared that he was left at a place, he had been dropped off at a school and they didn't have school that day and didn't bother to let you guys know that.

JL: There was a lot of that.

JK: That to me is…

KK: Unacceptable.

JK: It just burns me up thinking about it. I cannot even picture it. If I'm in charge of something on my school, I'm talking to that person every day. If something comes up, I'm gonna call you, I don't care what it is, so I can let you know, "Don't come the next day." There's so much that has to happen and then somebody had to come pick him up.

JL: This happened a number of times. It was very concerning. We would try and check and double-check. We would do site visits, so we would always have a site visit, so people in the project would go on a site visit with me or with whoever our associate director was at the time, to measure things, to make sure that it would work. A lot of the schools that we went to were not as described, because a lot of people aren't dealing with these things on a regular basis. But you know what would be wonderful? If you had a space and people came to you, if schools come to you.

JL: For a while we had this gig at the Ethical Society and a lot of different schools would come, but one of the things that is so concerning is where we are in terms of resources, and where we are in terms of the politics of the country, because when we were doing things ten years ago, we had more requests than we could keep up with. The funding was different. There was not as much testing. A lot of times this testing comes up, and they don’t know what the testing is or when it’s gonna be. It feels like there’s a lot of disorganization and a lot of pressure in the public school system, so things have changed. You could say, “Yes, we’ll have this facility and everybody will come there,” but then the issue is how do people get there? How do schools and different groups get there? We didn’t have a venue, other than the OT school, which was a lobby, so we decided we would go out to schools and to the community. There was another reason for that, even though it put a lot of responsibility on us to organize. Everybody had to be able to get there, sometimes people would carpool, they would take Call-A-Ride, we would drive people, but if you give people the option to say come and see this group perform about their lives with disabilities, the general population is not going to come, because this is something that they’re, for the most part, uncomfortable with. It’s an area that really frightens people, so they don’t want to come, for the most part. However, if you go to them and it’s a school assembly, or you go to a community of faith and you perform for their congregation, or you go to a conference, you have a built-in audience, and they are there. They may not want to be there, but something happens when they see the performance, and usually they have a transformational experience. They wouldn’t go to that performance necessarily if they had the option, but if it’s a requirement, there they are and suddenly they’re having a different experience, and suddenly they’re changed. For years we went to the Missouri Scholars Academy, which was a program at the University of

Missouri in Columbia that they did for several weeks every year in the summer. It was for gifted high school students. It was across the boards, whether it was a public school or a private school, and the kids all wore t-shirts so you couldn't necessarily tell who went to the expensive private schools, and we performed. We would come in, we'd drive to Columbia, we'd have to figure out the housing and the needs, taking care of the needs of the people who went. But we really believed in the mission of what we were doing, but then the students would see us. I remember there was a student who saw us and he came up to us afterwards, and he said, "I am the president of my student government in Kansas City, and we are having a convention of student government leaders in Kansas City, and I want you to come." I said, "Okay!" I said, "How many people?" He said, "A thousand. There'll be a thousand student government leaders," because he saw us at the Missouri Scholars Academy and it was meaningful for him. I remember, we went all the way to Las Vegas and we performed for a conference on spinal cord injury and psychologists, I don't know. It was people who specialized in working with people w spinal cord injuries. We went to Las Vegas and we performed for them. A very important part of our work is our post-show discussions. I know that post-show discussions are the bane of many people's existence in the theatre; they hate them, because they think that they're poorly run, or people grandstand, or they ask questions that nobody's interested in. That's a different kind of post-show. With this kind of community-based work, we have offered our lives in a different way. Because we have been open, it opens the space for the audience to witness to their experience, so for us, it's very important that people have a chance to talk after we perform. I remember, we were performing at this spinal injury conference in Las Vegas and this guy stood up and said, "I don't understand. I work with this kind of stuff all day long and I feel like I see it and I understand it in a way that I never have before."

JK: Amazing.

JL: We said, "Well, thank you. That's art. It gives us a different window." This kind of project is really important for audiences. I gave a talk a few years ago. They wanted me to give a talk about how this kind of work is therapeutic. It was for the Women's Club in St. Louis, and I remember saying to them, "Well, now, who is it therapeutic for," and they said, "What do you mean?" I said, "Well, it's therapeutic for the people who are in it, but I kind of think it's therapeutic for the audience, because they understand this differently." They were coming from this place of objectifying us, right, "It's going to be therapeutic for them to get together and tell their stories," all of which is true, but they didn't understand, because they hadn't seen us, that it is therapeutic for them. It is therapeutic for all of us. We understand there's a kind of interdependence. If we're really present with our humanity, we understand that there's an interdependence of how we all connect, and that disability is a category of identity that is unstable and that we can all join that community at any time. There are things that are really significant, and given that it's therapeutic for an audience, and given that people often want to talk afterwards. There are things that happened for the group. It provides a kind of foundation, a community, an outlet for creative expression, a place to develop relationships. We had a lot of romances come up out of the group, short-lived and longer-term, right? That's how it goes, right?

JK: I'm sorry. She's conked out again.

KK: She's asleep on the floor.

JL: I have no issue! People should sleep if they need to.

JK: The trip to Vegas, was that a road trip? Was that by plane?

JL: Oh no, we had to fly. No, no, it was not a road trip. We had to negotiate that. They had to be able to cover bringing a certain number of people. We had to deal with attendant care. For us, as our group has aged and some people have become more ill or more challenged, some of the travel has really diminished, but it's also because the funding has…

KK: Dried up?

JL: It has, from my perspective! Maybe somebody else would be better at raising money than I would, but I remember, for example, the Reeve Foundation, the Christopher Reeve Foundation, gave us money for years and then didn't. We would call them and say, "Is there something we're doing wrong? We have performed at x and y and z," and they said, "Not at all; there's just too much need out there and we need to spread it around." We would have a sense of being on a treadmill. A place would fund us for a while and they would say, "We're funding you for a while because we need you to find somebody else who will do it." It's an issue. I'm sure that somebody can do a better job of figuring that out than me. That is not my strength. Development and all of that is its own thing. My strength is fostering community with a group of people and helping them to find their creative expression and find formats in which they can shine. I know what my strengths are. Maybe somebody else can do a better job with it. Maybe you can do a better job of it. Here's the thing. We did approach a number of places to partner with us and we just didn't get anywhere with it. We asked Paraquad.

JL: No, they were really focused on their capital campaign. We asked the OT school. No, they were really focused on their academics. I kept thinking that if we could find a really solid foundational partner that it would make it easier for us to do some of this, but we didn't. We couldn't. Again, maybe this is a deficit on my part. Maybe somebody else could have done that better. We tried. Fran tried, and Fran was very persuasive. I just think that it's an area that people are less comfortable with. A big corporation would rather donate to an arts organization or an arts event which maybe they can bring more of their business associates to. Maybe it's more advantageous for them to donate to the symphony instead of to a small group that's working with people with disabilities. I don't know.

JK: That logic goes out the door though, because your group doesn't require that much, not compared to some of those bigger groups. And Graeae had that same situation, where they kept fighting back and forth with the government, "Are you still gonna fund, are you not?" They've been able to keep it going but that's something they're constantly having to…

JL: Really? The funding situation and the sense of responsibility to the arts is much stronger in the UK than it is here.

JK: It helped that they had the Paralympics there in 2012 when we were up there. A big part of the festival was them, and the opening act was the Graeae.

JL: They're tremendous. [phone alarm]

JK: What's that?

JL: That's me, so I could keep track of the time.

JK: Okay. I thought it was Allie.

KK: Allie, honey, do you want to lay on the couch? Come here, sweetheart. Just keep your feet off the couch.

JL: Becky's so funny. She just sent me some notes. She said *Actual Lives* closed in 2010 after ten seasons. So we have kept it going for over twenty years. They did beautiful work. I saw them. We've done, easily around a hundred or more elementary, middle, and high schools.

JK: That's amazing.

JL: Thirteen colleges. Many, many conferences.

KK: Wow.

JK: That's incredible. Where is it at now? What's the state of it today? We were talking about funding. We might as well…

JL: One of the things I wanted to share with you is that we had a couple of things, offshoots for the DisAbility Project that I thought were related, so we did a project with people with Alzheimer's and early stage dementia that I called *Think Tank*, and I worked with people with those challenges for six months through the Alzheimer's Association, and I ran a theatre class with them, and we made a performance.

KK: Wow.

JL: It was tremendous. I wrote about it. I can send you the chapter if you want, in a book that's coming out.

JK: That would be wonderful.

JL: Yeah, anything I’ve written you can have.

JK: Oh, thank you.

JL: Yeah! And then I also did a residency at the Missouri School for the Blind, where we worked with children of all different ages for a number of weeks and we made a piece.

JK: Did you approach them or did they approach you?

JL: They approached me.

JK: Because they know your work?

JL: That’s the thing, and that was also the thing when I decided to start the DisAbility Project. I called it the DisAbility Project because it was a thing that we were gonna explore, not the Disability Theatre Company. Max Starkloff knew who I was! These places approached me. We’re thinking about a number of things now. And then Webster was gonna have a big international conference on disability and human rights and they asked us if we would make a piece, and we worked with Jennifer and we made this beautiful piece. Where we are now is, we’re looking into maybe having an expressive movement and some art-making activities for families, which interests me a lot. Again, let’s just see what it is. Not pressure, let’s just have a place where people can do things. That’s one of the things we’re thinking about. We have other performances that we will do. I’ve also started a new group called Playback NOW! St. Louis which is a form that was developed by Jonathan Fox and Jo Salas in Hudson.

JL: Playback is about thirty-five years old, where, like, you would tell me a story and we would share and enact it onstage. That's another thing we're thinking of involving the DisAbility Project. We're looking at different forms to take on what we have, because the nature of our group has changed and people's needs and availability have changed. Margaret was very devoted. She's had a really hard time. She was in a car accident. Did she tell you about that?

JK: Yeah.

JL: She was in a car accident and now she's been ill. How can we serve the needs of the people that we have? That's one of the things we're thinking about, is doing an expressive movement class and things like that.

JK: She shared that she had to earn her way to perform. She said, "I contacted Joan," and just the way you described it, come to some rehearsals, see what we do, and she couldn't believe that you had put her in the lead role for that…

KK: *Tom Sawyer*.

JK: She said that you really want to do this and she just talked up the world about you. That's the effect you have. I've gotta ask you this. How do you keep everything in line? I can't write nearly as well as you do. I've seen your posts on Facebook. Everyone has a purpose and meaning, and you're throwing them out there. I can't keep up with you. You have so many projects.

JL: I have a lot of projects.

JK: How do you keep everything in order?

JL: I’m really fortunate. For example, Becky who you’re gonna talk with in a few minutes, Becky manages many things. I really ran the DisAbility Project for a very long time, and as I had more demands on my time with other projects, and, if I can use a word like career; I don’t like that word, but more demands on my career as a theatre artist, I began to say to myself, “Where am I most needed? Is there somebody else who can do certain things? Could not the group benefit by working with somebody else?” I felt like in the early years, and for a very long time, I really was foundational, but I feel that something should not be the vision of one person, so we’ve had a lot of guests and associate artists that we’ve worked with that have been very important. Do they do things the way I would do them? Not necessarily. They do them their own ways and who’s to say that their way is not better or different in a way that’s stimulating? Vanessa’s been tremendous and you should talk with Vanessa Roman. She’s been tremendous. She managed things, and we would talk, but I could also then focus and do other things. At this point I feel like I hold the wider vision for what my company’s trying to do. Some projects I do very specifically, and I do in relationship with other people, and other things I say to somebody, “You know what? You run this, and I’ll come in and I’ll talk with you about it.” Because I can’t do everything! It means that I have to realize that I can’t do everything, and not just that I can’t do everything but that other people have gifts. To make a space for them to do it means that we can do more in the world. I’m interested in the idea of doing this class of expressive movement and I am not the person who will run that, although I could, but why should it be me? Why shouldn’t it be somebody else?

JK: Exactly. That’s my goal. I know that I can’t be there forever, so I don’t want it to just be something that when I go away it’s done. I need it to go on.

JL: That's the thing I struggle with. That's why I was trying to find some other places that would partner with us. Not everybody recognizes, really, how significant the arts are. They don't! They recognize the important of a building, but they don't recognize the important of the arts.

JK: We're very fortunate. There are a number of companies that have opened up in the last two years, brand new theatres.

KK: We're spoiled rotten.

JK: Dayton's not that big of a city!

KK: You can see a different show almost every night.

JK: And I thought, "Talk about striking at the right time." This is the time. There are a number of groups, the Schuster center is named after the Schuster family who's donated so many monies to different organizations, different theatrical productions, for various different reasons.

JL: Are you hoping to do this full-time?

JK: I'm in my 28th year of teaching, so I'm within a few years of retirement.

JL: I was going to say, because you're a teacher, right? What is it that you teach?

JK: I teach social studies and acting. I'm the only one that has the same degree in both.

JL: What grade?

JK: It's high school, 7-12.

JL: So you're almost at retirement.

JK: I’m close. Within five years I can. And I have the summers, so I can go ahead and work full-time then with it, but I want to see it during the year, too. I can go ahead and thrust myself into it, but I want to make sure it’s built the right way.

JL: Something you might want to think about is how you build it. Something you might think about is, do you want it to be disabled and nondisabled? I wanted it to be disabled and nondisabled because I wanted to model inclusion. That was what my concept was. You might have a different concept for yourself.

JK: It’s not fully fleshed out. With the students I’m working with right now, some of them are with their peer helpers who are there to help support if they need them to, but they’re not there to take over for them, just if they need a little help to move to a microphone or to remember their lines, because that’s difficult for some, although we found one person who had his lines memorized before I even started working with them. They gave him a script and he was ready to go. And if I made a mistake he let me know. Every time. Which was fantastic, because I wanted him to do that. I said, “You're right. My game has to be much better than yours, because I gotta be ready for all of you.” It’s both. It’s a combination. I know Graeae is all disabled, but I think a combination is what I’m looking for. Then it will be larger and it can grow. I want the growth.

JL: We made stuff that was specifically about disability, but there are many ways into disability. You could have a group of people who are disabled and they could tell stories about the holidays. Just because it is coming through their experience, it would read a particular way. It doesn’t have to be literally about the culture of disability.

JL: You could do anything you wanted to. You could do fairy tales. You could do a version of *Tom Sawyer*. You could do *Wonder Woman*. You could do superheroes. You could do anything you wanted to. If you had the time and energy, it's fantastic.

JK: We try to go with their strengths. There's some who like to dance, some who like to sing, and we try to incorporate that with whatever. It doesn't even have to exactly fit because it's their narrative.

JL: That is one of the reasons, Jonathan, why I created original material, because when you devise, you can meet the needs of whoever is in the room, and not just the needs but the desires of whoever is in the room, right?

JK: Absolutely. We had a young man last year, he would not be onstage, he had to be pre-recorded, but he was in the audience watching, so we showed him.

KK: He saw the applause they got onstage and they got to bow. He wanted to bow.

JK: He's constantly talking about every last movie on earth and who's the actor, this is his life.

JL: Okay so this is interesting. So when I worked … I'd better text her and tell her she can come down. When I worked at the Missouri School for the Blind there was a little girl who loved … "Do you want to come down?" … Would you like a chocolate chip cookie?

KK: That would be marvelous.

JK: Yes, please. [laughing]

JL: Do you want some water too?

JK/KK: Yes, please.

JL: “Water and cookies appreciated.” I’m gonna have to leave in about ten minutes. So, again, a lot of what we did with the students, we did a lot of movement work. We did a lot of trying to open up their bodies, because they were constricted, but we did story circles. I would say, “So what is your favorite song?” So this little girl loved *My Favorite Things* from *The Sound of Music*, right? She wanted to sing that. So I used that as a template for figuring out what their favorite things were, favorite time of day, favorite clothing, favorite teacher, favorite this and that, favorite food, and then she wanted to sing it. And there were other children who were in the group who didn’t like the song, and I said, “Okay, so you can write a rap.” So she sang the first few bars of this. These are children who are completely visually impaired. She sang the first few bars of *My Favorite Things*, and then somehow we did a needle scratch, and then they cracked it open and then it became a rap, and it was a way that we could incorporate everybody’s desires and everybody’s cultural differences. This is the value of devising. It isn’t just, it should never be, “What is it that you want people to do?” It should always be, “What is it that interests them, and then how do you create the container?” They may not be able to create the container, but you can. What is it that they want to do, right? I also think it’s important to have some kinds of rules and some sense of etiquette and responsibility. Otherwise you have chaos. Everybody needs some structure.

KK: Speaking of structure, you need to ask the very last question, hon.

JK: Oh, my lord. I’m so sorry.

JL: You have another question for me? It’s okay. I want to make sure I’m not…

KK: You also need to do the consent form.

JK: I know.

JL: Oh, you need a form?

JK: It's just a signature, and I'll be sending everybody the same thing, because we have to have it sent over to IRB.

JL: I can't believe that whatever I'm saying to you is gonna end up in a vault someplace.

JK: I know, and they're really adamant, like, "What are you going to do with this?" And I had to make sure I had it exactly right. I hated every aspect of that because what I want to do is just do the work and get this done, because I think that having this in my background will open up more doors so that someone will listen to someone like me. You're well-known and I'm just some strange person from Dayton.

JL: You're not a stranger. Well you are strange, but…

JK: [laughing]

JL: I'm kidding. You've been a high school teacher for thirty years. Listen, whatever I can do to be helpful, just let me know.

JK: Thank you.

JL: We can send you whatever. If you want to use our scripts and do a little reading and a fundraiser, whatever you want to do, just let us know.

JK: Thank you so much. I asked everybody this last one: Name something that has not been addressed so far in disability rights and performing arts and why that's so important. So anything at all that you think, and I asked everyone this. We needed to see the actors' perspective but what do you think still hasn't been addressed as far as live performance for disabled actors? I have my own but I don't want to…

JL: Things have changed a great deal since I founded the DisAbility Project with Fran, and there have been a lot of changes in disability culture. We've had a lot of shifting, and there is a new wave of visibility in popular culture in terms of characters on television with disabilities, and film, in terms of memoirs, new initiatives in dance and theatre to make more things available for audiences but performers are still really sidelined, and a lot of companies will not cast somebody who has a disability if the role is not disability-specific, because they think it somehow will overweight whatever that character is. We're still incredibly marginalized, as far as I'm concerned, but we made a decision, twenty years ago, as far as I'm concerned that we were gonna try to influence the public position on disability. I don't think we're anywhere near where we want to be. Hi Becky!

Becky Galambos: Hi!

JK: [laughing]

JL: I was just saying, Jonathan was asking what's next, and I was saying, we have other performances. I haven't had a chance to talk to you about all of this yet. We have other performances that we're working on. We had talked about the idea of doing some kind of expressive movement class. Do you remember that we talked about that?

BG: Mmhmm.

JL: And I'm hoping that we might be able to use Playback as a way to help tell stories and that's kind of where we are. I need to go because I have something at 5:00, but what I want is for you to think about what we've talked about, and you're gonna be here till when?

JK: We're actually leaving tonight. We were going to stay until tomorrow but we have other appointments in Dayton tomorrow, so we'll be doing a lot of phone interviews with a lot of people. We're just going to have to. We got to as many people as we could.

JL: That's fine. It's a lot of work.

JK: It's a very short window I gave everybody, and everybody responded so positively!

JL: So here's the thing. You're leaving tonight, so as you think about this, if there's anything you wanted to talk to me about that you didn't have the chance to. Just write to me and say, "Hey Joan, I have these questions," and I'll make the time to address them. I think it's wonderful, what you're doing. I want to do whatever I can to support it. I need to go. How are you?

BG: Good.

Interview with Becky Galambos

Becky Galambos has been promoted from Arts Administration Assistant for The DisAbility Project to Office Manager for That Uppity Theatre Company. Galambos' work with each branch of the umbrella organization is vital to keeping the company's day to day activities in order and ensure each one has what it needs during Lipkin's travels. Galambos gave her interview immediately following Lipkin's on June 2, 2017 in the lobby of Lipkin's apartment building.

Becky Galambos: It's been a hell of a year.

Kellie Kochensparger: Yes, it has.

Jonathan Kochensparger: This thing [voice recorder] has worked out brilliantly. I was worried because we had Bryan outside of the Magic House. I thought, "Oh, this is going to be a lot of ambient noise," but this thing is good. I'm not used to technology.

BG: The last time I saw you in person, I guess, was at the museum?

JK: The museum, yes, that's when we had the outdoor…

BG: And that's a year ago, fall?

JK: Was it?

KK: It was freezing.

BG: Yeah. I wanna say it was October 2015.

JK: Okay, so that'd be, yeah, a year and a half.

BG: And since then, my mom's gotten sick, my mom's passed away.

JK: Oh, I'm sorry.

KK: That's what she said; it's been a hell of a year.

BG: Yeah.

KK: All those adjustments that come.

BG: Yeah, and then with Joan, my mom passed away twenty-eight days after the first anniversary of Joan's mom, so we've both been … It's been a mess. And of course Joan threw herself into work and she's kept me at the grindstone, so I've hardly had time to think in the past year. I think I'm finally going to have to pull what I did in 2013 and plan a vacation in a country where Joan can't get ahold of me and doesn't speak the language.

JK: [laughing]

BG: I ran off to Germany and somebody who we needed to contact did still manage to find me.

JK: Are you serious?

BG: I got a phone message, like, "There's a phone message from the dean at Yale." I was, like, "Aw, crap." She needed something, and I was able to email it from the hotel.

JK: So if you don't mind, let's talk about your beginnings with DisAbility Project.

BG: Okay. My beginning with the DisAbility Project started shortly before the DisAbility Project itself did. My very first day of high school, a former member of the group, Alison—I went to high school with her—and I met her that day. I had seen her around and opened the door for her before that, but we didn't really talk until she rolled over my foot in the hall and broke it.

JK: Really?

BG: She broke three of my toes, and her mother invited me home, and over the next few years, I became her personal attendant for school trips and things, because her parents didn't want to always have to. Her parents came with us to Chicago and other choir trips, but a lot of times I went with just Ali. Ali joined the group in 1999, I think, so about two years after Joan had started, and I started going to rehearsal with her because her mom didn't want to have to stay.

JK: I was going to say, I didn't get a chance to ask Joan that. Were there a lot of people in your same position who came with others to help out?

BG: There were a few, like Barb who … Her partner was in the group and she ended up joining the group herself for quite a while. They're still engaged after fifteen years. They haven't gotten married yet.

JK: [laughing]

BG: I don't know. But I came with Ali, and I just morphed into helping anybody who needed it, because most of them had attendants who were by the hour, not friends, so a lot of them would just get dropped off.

BG: So until I went away to college, I would go to rehearsal with Ali and do that, and at the end of the year, at Christmas and all that, we would have potlucks and I would help out with food, fixing plates and things like that. That went on for about a year and a half before I went away to college. Then when I was home on breaks, I was home on break when Joan called me and said, "Yeah, can you come with Alison? I need you and we were filming a documentary," which I think I have on VHS. I'll have to see if I can lend it to you. It's upstairs, and I've got makeup credit on it because we had the crappy leftover high school makeup and it was bad enough that I pulled my powder and lipstick out of my purse and anyone who was close enough used mine so we all looked identical. It was hilarious. So I helped out with that and when I came home from college I would go to a rehearsal occasionally but didn't really … Because Ali was trying to get out of the group by that time. Our friendship split up in 2012 and I kind of stayed away for a while, but thankfully most of the group stayed on my side because they got the same treatment from her.

JK: Oh, I'm sorry.

BG: Yeah, but, so I ended up sticking with the group because right around the time the friendship split up, Joan was giving away some stuff that she needed to get rid of. She was downsizing her collections and things, and Alison wanted some of it, and she convinced me to come meet her and come up to Joan's apartment, and Joan was, like, "Yeah, I need some help," and Ali's, like, "Well Becky's unemployed right now, which is why she was able to help me!"

BG: So I started coming in two days a week to get her mail while she was out of town and tidy up the apartment, and then she was home a little bit more after her parents got settled in New York, and then she remembered that her housekeeper had a theatre degree, and she started throwing scripts at me. This went on for about six months, and then her assistant quit with no warning whatsoever, and I walked out one day as part-time housekeeper and I walked in the next day as full-time assistant in charge of the entire office.

JK: Oh my god.

BG: I had to learn by the seat of my pants, and I do all of the logistics for everything for Uppity. I learned a lot of things with the DisAbility Project. I ended up taking on, for a while, you know, when Cowboy Kevin left, I ended up taking on the entire logistics arm of the DisAbility Project office.

KK: Can you talk a little bit about what that involves, in terms of logistics, with the DisAbility Project?

BG: Okay, logistics. Every time we go somewhere, we have to make sure it's accessible. We actually had to cancel a performance once because they wanted us to perform at a venue that didn't have an accessible bathroom. They wanted us to go down the street to McDonald's if we needed to pee. It's, like, "No, that's not okay." So we do a site visit to the venue. We each have a thirty point checklist. We check, is everything accessible, are the restrooms accessible, we even check the height of the towel dispensers because if it's accessible but it's too high, we make sure to let people know that they can take one of the ambulatory members who can pull down towels.

BG: We check out the space and sound and whatever lighting options we have, where the plugs are, because in addition to having sound equipment we need to be able to have an emergency plug in in case somebody's wheelchair runs low during rehearsal. Alison, one day, forgot to bring her charger, and my back will never be the same, because I pushed her 400-pound chair all over the stage.

KK: Oh god, no.

BG: And then I did it again when we were on vacation and I did it all throughout the Field Museum. Either Vanessa or I will do that [site visit], and then we will set up the contract and we will stay in touch with who our person's gonna be. We have a contact person at the venue and usually if it's at a school it'll be a teacher, or if it's at a museum it'll be their head of education. We have study guides for each grade level, for elementary and middle and secondary, and we're working on a college one, because we've had a lot more college than we have younger kids lately. Our last big performance was at Maryville and they needed us to … They had to have a certain number of hours in disability training for people who wanted to be occupational, physical, music, and other therapy students, and we did that as a class period for them because it's a lot more interesting than having people come and sit and say, "Yeah, this is why you should treat people with disability well."

JK: Absolutely.

BG: We've been to over a hundred different schools. I think our total is about 240 or so. I have a five page list.

KK: I have the list.

BG: Oh good, you have a copy? There's a few missing off there.

JK: But still.

BG: We haven't updated it, but it's on the website and we'll eventually get it updated.

JK: So you're in charge for all of Uppity?

BG: Yeah. I do that for every Uppity project, and this upcoming June we have two in three days. I don't know what she was thinking. *After Orlando*. We're doing readings on the Friday, and then Wednesday we're doing a birthday party for the resistance outside of Vintage Vinyl, and that one Joan wants to be community so we have various groups we're partnering with. We're gonna have kids coloring flags, we're figuring out how to order a couple hundred cupcakes at a decent price. We have people who are gonna be reading the Constitution out loud, because Flag Day just happens to be the president's birthday.

JK: Oh good.

BG: So we're having a birthday party for the resistance.

JK: Maybe he'll learn how to spell or … We'll have to edit that little part out.

BG: So it's equal parts activism in all different ways. We do LGBT activism, political activism … Joan's business card says, "Educator, social critic, and civic engagement."

JK: Where is your headquarters? Is it her office up here?

BG: Yes.

JK: Okay, that's the headquarters.

BG: Yeah, we've got the office. She has a bedroom for when she's here in town, and then the other two bedrooms are the office. I'm kicking her out of her office. She's always had the big office, and she splits her time, and it makes no sense for her to have three interns and me in the little office. So I convinced my father to paint the little office and so we're gonna put her in there, and she'll have her own little office. Then into the big office we're going to move me and the interns.

JK: So you have interns that are helping you out? That's excellent. Are they from local universities?

BG: This summer we have one from Mizzou. That's the furthest away we've had. We have a grad student named Blake, and then last semester, we had two students from Webster University, and then we have at least one from Webster every semester. The one we had spring before last? We liked him so much; we hired him for the summer to handle marketing and try to teach us two old people some new tricks. We set up a company Twitter and to figure out how to use the Facebook events.

JK: I'm sorry, are you calling yourself old? You look as young as anything. You're gonna tell me an age and I'm not going to believe it.

BG: Thirty-five.

JK: You do not. You look like you're in your early twenties. I'm sorry, but you really do. I can never get a grasp of, "How old is Becky, because she doesn't age?" I look a lot older. Well, this is fantastic. So you have students that help you keep everything organized.

BG: Yeah, and they take on chunks of projects. They take on little bits, and it takes some of the load off me, but I consider it a good week if I only work forty hours. Sometimes during a show week it'll be fifty-five or sixty. During Briefs, it was, like, seventy. There were two nights that week I didn't even get home. Joan and I looked at each other, and she was just, like, "Go climb on the couch and go to bed." We're like, "Good night, Joan," and we were back up at six a.m. and doing it all over again, because we had four performances in a week, and we had actors and everything else to muster.

JK: With the DisAbility Project, roughly how many different actors have you worked with, and directors also? I know we mentioned Vanessa, and that's the one I know, but I know there were others before her.

BG: At the very beginning, there was a very large group of actors, about thirty, and I've known, even if I didn't work with them, I've known most of them over the years in one capacity or another, and we've stayed on top. A year or two ago, Stuart, one of our founding members, passed away, and we had a mini reunion. As many of us as could make it, about twenty members, came to the funeral, and we try to get together every once in a while. Whenever we have a party, we invite former members to come. Some have gone on to do great disability activism, like Katie Banister who's written a children's book. She's a motivational speaker now, and goes out to schools and does talks and things about disability. Others have moved into … Like, Malia worked with a special school district. It left a mark on all of us. The core group is down to about eight or nine right now.

BG: It’s a really big time commitment, because it’s at least four to six hours a week, when it’s not a performance week, with rehearsal and practice time and all of that. And a lot of people don’t want to make that commitment, particularly people with disabilities. Some may only have a limited number of spoons to use, and they never know when that’s gonna happen. Some have, their disabilities have become severe enough, like, Tom had brain surgery, and he can’t manage the lines anymore. His short-term memory … We all stay in touch. Email, Facebook, we have a little Facebook group that we don’t use. We just all post on everybody’s wall.

JK: I was gonna say, I know there’s a lot of connections I have with all of you … Messenger on Facebook, Joan. It’s hard to keep up with all of that. That’s one of the things I asked her. She writes so prolifically. I can’t write that well, and I can barely answer, like, “I am in the kitchen.” That’s a lot for me.

BG: Joan’s idea of tweeting is to write an email to me and say, “Here, tweet that.” One of her former girlfriends said to me, “I can always tell when it’s her, because you correct your spelling and she doesn’t bother.”

JK/KK: [laughing]

JK: That’s wonderful. So she travels from California to New York to St. Louis, is that right?

BG: She’s been in LA house-sitting a lot in the last year. She had an eight-week session out there. One of her former friends passed away, who was the editor of *Ms. Magazine,* and she asked her partner if there’s anything she could do and she was like, “Yeah, I have an eight-week teaching job, and I don’t know what to do with the dogs.”

BG: So she went out and watched the corgis for eight weeks. She’s got an apartment in New York, ‘cause her dad’s in New York, and he’s ninety-nine. Unfortunately I didn’t get to see him this last trip, because Joan and I were both sick the whole time we were there.

JK: I’m sorry. He doesn’t look 99. You guys are … There’s something you have in the water. You're doing very well.

BG: He has dementia, but he still reads the newspaper out loud and when I saw him last July, eleven months ago, he was still hanging in there. Joan comes from very good stock. He was the first licensed psychologist in Chicago, and her mom was one of the first women in Chicago to have a master’s degree.

JK: Really? Wonderful.

BG: In social work, and so she’s kind of blended those into her work, and I am the last assistant that will ever have the privilege of being trained on how to handle Joan by her mother. Her mother told me exactly how to handle Joan, and if something would happen with Joan, she would call me and be, like, “Yeah, this is what you need to do.” One time Joan was not feeling well and I said, “I promise I’m taking care of her,” and she was silent for a moment, and she said, “Well, somebody has to, because she’s lousy at it.” You know Joan runs full-tilt. She doesn’t know how to stop.

JK: There is no pause.

BG: Trust me; I’ve tried to find a pause. Keeping up with Joan is a full-time job.

JK: That's what I was going to say. I admire the heck out of you for that. That takes a skill that I do not have, that you can keep everything so organized. Like I said, there were a lot of kind comments about you, everybody said. The fact they said they missed you, I don't think that's a testament to, "Oh, we're not doing anything." I think that's a testament to what effect you've had and what the DisAbility Project has had on them. That's what I'm gaining from all the comments. They just loved every aspect of it and all the work you put into it.

BG: I wish we had videotapes of some of the stuff. Like, the last piece we created, we don't have on video at all. We did *The Three Bears*, except we turned it into *Three Little Pigs*, and we mixed our stories. Three little pigs, and they build an ice cream store, and they didn't have a ramp so the big bad wolf, BB Wolf Construction, was building them ramps and blowing. The first ramp is straw, blow it down, sticks, no, we need a concrete ramp, and that was one of the first pieces I ever saw with Coffeehouse. It was a really long and preachy piece from the early 2000s and we took it and rewrote it for little kids, because we discovered we needed more little-kid material, because one of the schools we went to, that I will not mention for posterity, they switched our audience on us. We went in prepared for fourth through sixth grade, and they said, "Oh no, you have K-3."

JK: Are you kidding me?

BG: We had half an hour. Instead of running through things, we had to completely revamp what we were going to do and tone down things, because another school we went to, the kindergarten teachers absolutely went insane, because we used the word 'butthead' and 'sucks' in the bully piece.

BG: So we very quickly changed our language, and we've all become very proficient in faking profanity, and it's bled over into various other things.

JK: When you go, does that happen more times than not? Do they all of a sudden spring some surprise on you? That's a huge thing to have to change.

BG: That's the first time that's happened when I had been in charge with things, and we'd just pull through and did it. Some of the stuff in the bully piece we toned down, because hopefully our K-3 are not all on the Internet.

JK: Well it's a big thing right now. I don't know about Missouri schools. I can only speak for Ohio, but we have a major thing about anti-bullying so that, to me, no matter what level, it's going to be appropriate, because they need to hear it.

BG: We just changed some of the situations and language a little bit and made it more little-kid appropriate. Like we changed the computer lab to the playground.

JK: Yeah. Oh goodness.

BG: We changed some of the words that we used.

JK: What are some of the other big obstacles that you've had to overcome? It could be something physical or something like that, just a change of kids, when you've gone to the different schools—or wherever, it doesn't necessarily have to be a school—while working with the DisAbility Project? What are the challenges you've had to deal with?

BG: Some of the biggest challenges are, even with a site visit, accessible is not … We went for the site visit and the space was totally clean, and we went to do the show and there was a crap-ton of stuff piled on the ramp, and I just had to find a place to stick it. I just carried everything offstage and stuck it in the corner of the gym till we were done. You just have to be prepared for anything, with a traveling show. We always bring our own snacks and water. Those of us who are in charge are trained for specific things, like if Angie would have a seizure, or if David, who was HIV- positive, would get a cut, we had specific procedures we had to use. Because we couldn't go to the school nurse, unfortunately, because a lot of the times they wouldn't be as accepting and would flip out. We had to be prepared for that. We had to be prepared for if something else would happen, like if a wheelchair … I bought a Swiss army tool that had a wrench and things because of wheelchair repairs. I've become a very adept amateur wheelchair repairer. The first time, I had to call my dad, and he taught me how to do the basic stuff. It was Margaret's chair, the wheel.

JK: I know about that. I shouldn't know about that, but I met her twice and I know all about Margaret's chair.

BG: We crowdfunded her a new chair after one of them. The DisAbility Project kind of pioneered crowdfunding in the St. Louis area. We had an arts theme that was done by Annie. We were in the first group of people, and that platform has since gone away, called Power To Give, and as far as I know we still hold the national record for most different donors in a campaign.

BG: We were able to raise ten thousand dollars when we did *One World,* to be able to do … That's how we were able to do several big performances. It takes a lot of time and effort just getting that many people with disabilities, and transportation is another big hurdle. We've had to deal with things like Call-A-Ride, like David … That one, we showed up at a performance and the principal had forgotten to call us to tell us school had been cancelled ahead of time.

KK: That's when David got left? David told us that story the first time we were here.

BG: We have a very flexible group. We have to be, so we put him in Ana's car and we were like, "Well, we're all here. We've all blocked off the time. What do you want to do?" So we went to Jilly's Cupcakes and sat and talked and had cupcakes for an hour. Joan's, like, "You went and had cupcakes without me?" And I'm, like, "I brought you one in the fridge." If I don't bring her one, I'm mean; if I do, I'm ruining her diet.

KK: That's how that works.

JK: I mentioned to all of them about that, since I am an educator, when I am in charge of different groups coming in, they probably hate me because I want to make sure, even the night before, "Okay, this is still clear," so they know. They're guests. We should treat them [well] and everything should be ready, and we had that with a guest judge we had brought in. I had everything ready, and he surprised us, because he decided to show up early, but I was ready for it. You have to be because … Schools should treat you better if you're the guests coming in, and they're going to get a great performance.

BG: This was the same school that when we went back, they flipped the grades on us, so we have not gone back to that school. The following year, we left them out of our solicitation letter. To top it off, this was a funding performance through the [inaudible] Arts, so the school wasn't even paying! Someone else was paying, so we had to do a mile of paperwork, because we were being funded by an outside arts organization for that performance. They don't have the funding to do that anymore, but for several years they paid for us to do two performances a year for the schools, free of charge to the school.

JK: That's excellent. So you said you send solicitation letters to the schools saying, "This is what we have to offer. Would you like us to come?" Does that come straight from you? Is that your primary responsibility?

BG: Yeah. Kevin and Vanessa and I tag-teamed on it for quite a while, and this year we didn't send them out. We decided to do email instead. We've moved into the modern age. That saved us about two hundred dollars in postage a year, because stamps keep going up and up and up.

JK: Oh yeah. Have you gotten a good response from the emails?

BG: Not as much. Professional people seem to ignore email, and we'll follow up and call and they'll say, "Oh yeah, I saw a couple of those." Even though a lot of them, they don't read it. When they open it, they call us and, "Oh, it costs money?" It's like, "Yeah!"

JK: Nothing's free. You know that.

BG: I need to just win the lottery so I can just endow the project. Bryan would be over the moon.

BG: We did a day trip, we went out to New Haven because the Missouri Arts Council has a program through them, that a school can apply for funding to bring us in, and they applied for it and got the grant, and they're a very small district so we did every kid in the district within a day, because they have one middle/high and one elementary. They had forty-six kids in their graduation class. They're tiny, so we did elementary in the morning, and secondary in the afternoon. We road-tripped down there and picnicked.

JK: Nice. Did you go on the trip to Vegas?

BG: No, I did not.

JK: Were you part of it during that time?

BG: Sort of. That was kind of my in-and out period, with college.

JK: Until she mentioned it, I did not know she had to make sure they funded the flying and there was a lot of detail involved, but it's stunning that they had that. What would you like to see happen within the next few years? You're young. You're young! I'm going to say that to you, because, again, you are. What would you like to see happen?

BG: I would like to see being able to see some more actors. We need to grow the troupe, because not everyone can do every performance. We'd have to find a solid rehearsal space that's accessible, that we don't have to worry about being able to get in, and we don't have to crunch space-wise.

JK: What was the space we met in, that first time we met?

BG: That was a cafeteria at the OT school.

JK: Okay.

BG: We just, even after twenty years, we're meeting wherever we can find space. Everybody wants us but nobody wants to fund us. Fran, who was Joan's co-founder, made Joan promise that she wouldn't let anything happen to the group, and I just wanna get Fran to go haunt some people, like, "Give us money," because frankly some of the Scrooges in the art world right now? We need it. It's obvious with, every day you see in the news people getting mistreated because they have a disability, and the current thing with, now that they're talking about starting to chip away the ADA.

JK: That'll hurt people.

BG: The activism is so needed. Disability is not the cause of the day anymore and we don't have the support that we need. Pretty much finding support to carry on our mission, and be able to grow, and maybe publish an anthology of some of our work, because I know there are other groups that want to start in several places. I think there's five? Six? Most of them are in different theatres that have done programs like this. There's a program in Texas. There's a program in Florida, but Texas is no longer extant. They write all their own material and some of them that aren't as funny to the audience, I'm cracking up backstage, because I was there when it happened, and like, Alison's service dog did eat my bra. That was part of the attendant care. We had to change things around because people needed a break, so they wrote commercials for in between the skits, and she wrote one that was for a fancy service dog, like, it was a robot or something like that.

BG: We used that in there. So pretty much, you know, you have to watch what you tell the group, because it will end up in a skit somewhere. I would like to see the program continue because it's so needed. Maybe be able to travel a little bit more, to have the funding to travel would be amazing. To be able to go, if you want to get your group started, for us to be able to go and…

JK: You have no idea the plans I have for you, because when this thing goes, we've got to make it a big splash, because otherwise we won't have the attention we need to make this thing go, so we are going to be talking to you a lot. Last question, this is the last one for everybody. I don't have to look because I know it. Can you name one thing that has not been addressed as far as disability rights in performing arts and explain why that's important? Anything in performing arts. What hasn't been addressed yet and what should be given more attention?

BG: Oh, that's definitely the portrayal of people with disabilities on the stage, because, you know, they just had this revival of *The Glass Menagerie,* and the character of Laura, the director did not want to see the disability onstage. He's, like, "The chair can speak for itself." No, it can't! Several of Joan's friends who were disability people went to go see it and they were like [displeased noise]. They were hiring people without disability to play a role of people with disability and I know not all the time is there an actor with that disability to play the role, but when there is, they need to be given first crack at it, because we need diversity. I think when Deaf West did theirs, they made a hilarious video of somebody's autocorrect, the actors are 'mostly deaf instead of 'deaf,' and they actually took that and ran with it and made a hilarious PSA video about language in the theatre.

BG: It's just hilarious, with, "They have the profoundly dead, and the mostly dead," and people are dragging them across the stage and one of the actors is, like, "We all go to dinner; we all get along." That's activism where it's needed. But Actors' Equity needs to stand up and do what they need to do, and they're not. Particularly, we need to be more careful about stereotypical portrayals. We need to be more careful of using language that's ableist, even if it's not meant that way. I got into a really, really big fight with a friend a couple of weeks ago. She's talking about people who are mean, and love of self, and greed and [she was saying that] all of those things are disabilities. I'm, like, "No!" I couldn't get her to see that. She was, like, "It's not about that; it's about my feelings." I was, like, "But the way you're expressing your feelings has a negative impact on other people." People just need to be more mindful of how they say things and what they say, like using the words 'retarded' and 'lame,' and we need to start teaching that earlier. Why is that not built into character education in elementary school? Why is that not part of workplace diversity? Why is that not … For God's sake, the need to put our parking thing in every workplace diversity thing. Don't park in the place you don't need! Because people are assholes. Unless you teach them gently the way they need to be, they will do all these things.

KK: Becky, how has being in the DisAbility Project enriched your life?

BG: Oh, I have met so many people I would not otherwise have met, that have really enriched my life in various ways. Bryan is just a ray of sunshine even on the gloomiest of days.

JK: Oh my lord, yes.

BG: Oh, I'm gonna have to rush to get it done for Christmas, but oh my god, he's gonna be so excited. I can share because I know this isn't gonna get back to the group.

BG: I am working on making a quilt for every current member of the DisAbility Project, including Joan. Joan's is going to be a story quilt, with patches from everybody, and fabrics that remind me of different skits. Like we did Briefs together, and so I found a print of underwear.

JK: Do you know how happy we're going to be when you get it done and you can say [inaudible]?

BG: I had started a Noah's Ark quilt because that's his favorite Bible story, but I changed my mind and I'm making a Superman quilt. Malia's is baking stuff, but hers is going to be really simple, because it focuses on the fabric, and not the quilt pattern. Pretty much they're just crappy quilts in everybody's favorite colors, and then the names have something to do with something they're known for saying or doing or being. Like, Ana's is some variation of the princess quilt because there's one skit, "My daddy says I'm a princess." We call her the princess, the diva, so hers is a rainbow star pattern. I liked it so much I'm working on a queen size for myself, and I'm hoping to have some of these done in time. One of them has been tentatively accepted into a show for fall.

KK: Congratulations!

BG: I'm hoping to have my big queen-size done to go in the show as well. I don't know if I'm gonna get them all done by Christmas, but I'm gonna try.

KK: That's amazing.

JK: [sarcastically] Well, you know, all that free time you have.

BG: Becky's summer activities include selling the crap out of the basement to afford the quilting, because I can't get them all quilted. There's no way. So I piece fifteen minutes at a time, in my spare time, and I send them out. I wanted them to have that, because the reality is, people with disabilities, they're eventually going to need to be looked after somewhere and are gonna be separated from us. I wanted them to have something that will remind them of the group and the love that we have for each other.

JK: That's … The word I heard was family, over and over again.

BG: Yeah. When we need something, we call each other first. Margaret, her new car, did she tell you about the saga with her car?

JK: She had an accident; we know that.

BG: I knew it was bad when they let me into triage, because she was just having a panic attack and she was bleeding out. They told me get in there and calm her down. The radio dial hit her in the head, and it peeled back … She was just bleeding like crazy. They called me and they said, "She's not doing well, because she can't hear or see because of the bandages. Can you come?" So I spent the night at St. Anthony's with her, but we all pitched in. Paula called the insurance company while I was on the phone with the lawyer who was an aunt of Malia's, and then our company lawyer, who is a friend of Joan's, took on the case, because it was totally not her fault, and they were trying to weasel out of it. We finally did get it settled. She had to wait to get a new car until she got it settled.

BG: She was without a car for, like, a year. She calls me and says, “I need help. I have to get it up to a workshop in St. Louis so I can get the modifications, so I can drive it,” so my father went down. His brother was visiting so we went down. I visited with her for a few minutes and I took her some fried chicken. I said, “What can I bring from St. Louis,” and she said, “Some Lee’s fried chicken.” Then we drove back up in two cars and the workshop picked up the car from our driveway and put the modifications for the chair topper on it, and Margaret’s hopefully going to be able to come back up herself to do the second wave of modifications. They’re going to put a tilt thing on it that would eliminate the need for the sliding board.

KK: That would be great.

BG: Yeah. But she’s had one setback after another. She’s been so sick.

KK: She’s fighting for insurance to come through for a new hip.

JK: She told us last night, or Wednesday.

BG: We call each other, talk to each other. I was in the hospital last year; she could only have one visitor. People who don’t have family here in town, I’m listed as a lot of their emergency things, because they’re out with me a lot and I know how to get ahold of people, so that’s how when Margaret had her accident, I was the one who got the call. I was at rehearsal. I said to Ana, “That was the paramedics. Margaret had an accident. You’re driving,” and Ana and I left rehearsal and took off like bats out of hell to St. Anthony’s, and the whole group picked up and moved and we moved rehearsal to the waiting room at St. Anthony’s.

BG: And we just talked through the script while we were waiting, and we went back in intervals once we were allowed to, when she got settled, and we all just pitched in. Everybody pitched in and did what needed to be done, and then when her car was ready up here, Vanessa and Ana were gonna drive it, they drove it down and then Ana drove Vanessa back up, and so we all just pitch in for each other. Even when we're not rehearsing we try to keep tabs on each other as to what's going on. We send cards and emails and have an unofficial phone tree. We keep tabs with, if something happens with somebody who's peripheral to the group, like a former member, we'll call the people that would know that person and be, like, "Hey, this happened," or Angie's getting married, or, "Hey, Kellie moved," or, you know, when Stuart got sick we all had the warning with that one, and then with David, we had no warning whatsoever, and his family had no pictures. Not one. They just kind of disowned him when he came out. I went through the twelve years of archives, and I made a CD for the funeral of all the good pictures of him at various functions, and him with the group, and that's what they used, and I printed off copies for his mother, and his mother apparently cried. He had that second family. We were there when he needed us, when they weren't. Unfortunately that's a common story with a lot of us. Like, Tom, both of his parents have passed, and Margaret has a stepmom but that's still … Ana's family is all out of town, and so we built a family. And, as in any family, some members are closer than others. Ana and Margaret are sisters. That's an easy one. Some of us are cousins. Joan is kind of the mother that sits around it all. Joan's parents, occasionally Joan's mom would forget the time and would call during rehearsal and we'd pass the phone around and, "Hi Evelyn! Hi Stan!" We all knew Joan's blood family peripherally and would see them occasionally. If someone new comes along we just fold them in and keep going.

KK: It’s been great to see you.

JK: It’s been fantastic.

Interview with Vanessa Roman

Vanessa Roman is the Artistic Associate with The DisAbility Project. Roman earned her degree in English/Media Communications from Webster University. Roman continues her work in stage and film in addition to her duties with DP. This interview was conducted through Face/Time between St. Louis, Missouri and Dayton, Ohio on June 4, 2017.

Jonathan Kochensparger: I'm holding it up to the microphone on the phone here, so it should record okay. If you could please go ahead and tell me, I've got to have you say your name, and how long you've been involved with theatre in general, and then we're going to talk about the DisAbility Project, if that's okay.

Vanessa Roman: Hi, my name is Vanessa Roman. I've been involved with theatre for, it feels like, my whole life, because my mother took me to my first Shakespeare play when I was five years old, so I've been hooked and dedicated since then. I was as much as I could get into it in high school and college, and pursued it wholeheartedly ever since.

JK: Excellent. How did you get involved with the DisAbility Project, if you could talk about how that actually took place? I know some of what everybody's gone through, but I didn't know the specifics of what actually happened. Did you contact them? Did they contact you? What actually happened there?

VR: Okay, so, Joan Lipkin and I kind of connected. We met at a film festival event, and we talked briefly, and then some time later she had seen me on Facebook. She had talked to people about me, and she invited me to come and direct a play for her during her Briefs festival. I directed a one-act for her. I suppose this was her audition for me. I didn't know this at all, because I was just one of the directors for … .The Briefs festival is a gay and lesbian short play festival

JK: That was for the Uppity theatre, that you did that?

VR: Yeah, she did that. It was with her and a couple of other groups that all came together. It was Uppity Theatre and Vinyl Voice, and there was another group involved, so they did that. So I directed for Briefs, and I guess she liked my work, because after, she said, "Hey, can we meet? Listen, I need somebody to run the DisAbility Project." That's how that came about.

JK: About what year did you start with DisAbility, roughly?

VR: [sighs] Let's see…

JK: No, that's okay. I'm getting that same answer from a lot of people.

VR: I'm trying to remember. I think it was probably about seven years ago. That's my guess. No, hang on. It might have not been that long. It was 2011 or 2012, somewhere around there.

JK: When you got aboard DisAbility, what did she want you to do with DisAbility? Did she have you take on the role you have now, or did it evolve over time or…?

VR: She brought me in as a director, she brought me in to work with them, to write new things, to get stories, and she knew that what she was getting was a package. Basically I'm a playwright, I'm an actor, and I'm a director. She was getting that package.

JK: Good. The actors you got involved with initially, the numbers, are they different from what they are today? I've seen you twice, and it's been basically the same people. The only difference was, I think the second time, when we were at the festival that was outside, the celebration of ADA … That was the coldest day.

VR: It was.

JK: The only difference in the cast members, I think, was that we didn't have Angie and we didn't have David at that point in time, whereas the first time I visited you, both of those two were still there, so I got a chance to talk to both of them at that time. When you first started, was it big or small? What was that like?

VR: Let me see. It was the basic core group that we kept. As Joan, I'm sure, has told you, DisAbility Project was much, much bigger but by the time I came along, I guess there were about six of them. There was another cast member, Bobbie Williams, who was involved. Bobbie and I went way back with theatre projects, and Bobbie was also in a film that I directed.

JK: And that was before you were involved with the DisAbility Project?

VR: Yes, yeah, I'd known Bobbie for several years before because I was a board member and a director at a theatre company called First Run. Bobbie did several productions with them and was also in a short film that I directed in 2009, so I knew Bobbie before.

VR: She was the only member that I knew before, and then there was another woman. Her name was Paige Elias and she was a friend, she was Joan’s assistant for a while, and she had worked with the DP. She was another person I talked to before, like, “What is the DP? What is it about?” I talked to Bobbie, I talked to Paige, because I didn’t really know anything, so after Joan made the offer, I looked everything up and found everything out. I’d heard of the DisAbility Project but I was just talking to everybody, because I was like, before I jump into this I should know something about it! So that’s what came about.

JK: How did you handle being the new person on the block? Because you said the core group had been there for a while. What was their perception of working with you, because I know what it’s like to jump into a project where there are people that already have preconceived ideas and that’s the nature of it, so how did that work with you?

VR: First of all, they couldn’t have been more welcoming. I walked in and observed a rehearsal. That was our first contact. I just sat and watched. I observed a rehearsal. I saw what they did. At the time Kevin Chestnut was one of the people; he was their grant writer and he was a lot more. He did a lot with the group. He kind of walked me through a lot of the logistics of things. I went in, I observed the rehearsal, I talked to everybody. Ana was the one who broke the ice, basically. I think everyone else was a little more shy, just waiting to see who I was, but Ana just jumps right in. Ana’s, like, “Come on in! We don’t bite!”

JK: I know!

VR: Basically, I would say, across the board, they welcomed me right off the bat. I would say our connection was almost immediate, within the first couple of rehearsals. There were two other members that were there, Ali and Reed, back in the early days. They weren't at the first first rehearsal, but they kinda came back in and I worked with them in the first year.

JK: So the work that you started when you worked with them, was it something that was already written that you were working on, or were you collaborating on something at that point?

VR: We had a core bunch of scripts, basically. I went through and I read what we had. We talked about basic shows, and I watched them put together their first show. I also watched a performance before I even took over, so I would understand what was going on. Then I read through as many scripts as I could get through. There's so many that go back years and years and years, but immediately right away I talked to the group to figure out what they wanted, where they wanted to grow, because every time they get a new director, it evolves. They hadn't written material in years.

JK: Really?

VR: They were starved. They loved what they were doing, don't get me wrong. What they had was fantastic, much kudos. We always incorporated material that came before. It often evolved but it was always, always there, because you have to respect what came before. There was never a performance where we didn't do the rap. Immediately we started working on new projects. We explored for several rehearsals about what our topics wanted to be, what was our next thing, and we landed on anti-bullying initiatives.

JK: When you first saw them perform, was it at a school was it at a bigger setting than that, [like] the historic society?

VR: The first performance I saw, it was a group of office people, counselors, I can't remember exactly where.

JK: The thing I was leading to was, did you see any physical obstacles that they had to overcome to go ahead and perform? I've talked to a few of them about what is your biggest obstacle when you go out, because every venue's going to have something, I know that, and I'm trying to encompass that, but what's the biggest obstacle you've faced? And there have been many difficulties they've had, and you'll perceive something differently based on who you are. What did you see?

VR: Okay, so, for the first performance I walked in just like an audience member. I didn't know anything. I didn't see them before. I didn't see them after. I walked in and I sat down just like an audience member and experienced it just like that so I didn't see any of their obstacles or what they had to go through. I just walked in, sat down, and watched the show.

JK: Afterwards, once you took over, then, what would have been some of them? You can mention a few. That's fine. The biggest physical obstacles that have been in the way of performance?

VR: I was given a list, basically. I was very well-prepared. For every show, we do a site visit. I go in advance, show up, make sure there's accessible bathrooms, make sure that we have an accessible staging area, and then parking. They have to be able to get in and out, they have to be able to park, and they have to be able to go to the bathroom.

VR: I have to make sure they have a greenroom, I have to make sure they have water and sometimes snacks, because we're gonna be there for several hours. At the very least we have to have water. Are they gonna give us this, are we gonna provide it? There is a list of things we go through. Obviously for regular performers this is a concern, but for performers with disabilities … Transportation, we have to make sure transportation is set and in place. Basically it's a checklist of things. I would go in advance. I would look through it. I would make sure we had a clear path. I would make sure we had clearly marked parking, all of that.

JK: Did you get to go on the trip to Las Vegas? Joan mentioned that you had had a performance there.

VR: No, that was way before my time.

JK: I should know that, but my mind's trying to sort out all the dates and times.

VR: Not your fault.

JK: That would have been a very cumbersome situation.

VR: I would have loved to. One of the things that was in the works right when I joined was a trip to Lake of the Ozarks. It would have been great. But that would have been a site visit which would have been extremely difficult to do, because I would have had to go all the way down to Lake of the Ozarks. Instead, through questions, we discovered they had no accessible bathrooms. It was a deal breaker. I was like, well, we can't. They came back with, "Can't they just hold it for the performance?" Really? No.

JK: That’s an important part of this paper, what you just said. That’s such a basic need, and everybody … Why they would think that?

VR: I don’t know. I don’t know! I was just, like, “Here you go, there’s a tree.” I was like, “We’re not going camping, guys. This is a performance. We can’t just…” We were figuring out how to get down there. Honestly, they wanted to do it all in one day. I was, like “Can’t we do an overnight and have a nice hotel?” It’s a long drive there. It’s three hours there and then back. That’s a huge day. That’s a long day for anybody without disability, but we couldn’t work it out. Their facility had no accessible bathrooms? That’s it. What can you do?

JK: You tell them no! That’s right. That's the way life is.

VR: So yeah.

JK: So where would you like to see the project go from this point forward? I know it’s in a sort of resting stage right now because the last act of work I saw was the ADA celebration. I know there was one other live performance that was done between that time and now, what was that?

VR: We went and did a school in between.

JK: What would you like to see happen from now going forward with it?

VR: Well with Joan it was the door is open, basically. It’s just, we lost David, I’m sure you heard.

JK: Yeah. [loud music blaring] I’m sorry that I’m outside, but my grandson who’s inside is a little bit loud and we have a neighborhood that really likes their music.

VR: I mean, basically, I told Joan, the day she just wanted to formally put a pause on things, I was like, "Listen, call me if anything comes up." Becky's still working. Where would I like to see it go? I would love to see the DisAbility Project inspire other projects like it, for sure. I would love to see it evolve into … As you know, it's been twenty-one years, so a lot of the structure has changed about the way schools are doing things. I would hate for this to go away ever. There's such a need for it. It would be great if it could evolve and be … I don't want to say relevant, because it's always relevant. There is no part of the DisAbility Project that's even remotely irrelevant. It's just, the model that was created twenty-one years ago? The schools are evolving, so I would like to see them figure out how the DisAbility Project fits into schools once again. I don't know why that changed. It's something that we haven't really figured out, but it's just, some of it is, it costs money to run it and the budgeting has changed and schools have to tighten their belts and their priorities are in different places. And when we don't have a president and a secretary of education that support these initiatives, this is what we're left with. Actually, very firmly the secretary of education right now is … I mean, I don't want to get too political, but…

JK: It's okay! It's your interview, and trust me, you'll be fine.

VR: What it is, is, we have more kids than ever with learning disabilities and that's the other thing that we did. I have a son with autism, and that was what was new about me, and we incorporated that in, learning disabilities. Now my daughter Marissa also performed with the DP, especially when we were short on people or when someone got sick.

VR: She came in and she was an occasional performer with them. Marissa has always been an actress, so she loved the DP. It was an easy transition. During the course of me being with the DP, my youngest daughter was diagnosed with ADHD, and then my daughter Marissa developed multiple sclerosis.

JK: Oh no.

VR: Yeah, at the age of eighteen.

JK: That’s just…

VR: I know. And you never know when something like that is going to happen, but I think, you know, my experience with the DP was like, “Okay, I can weather this storm for her.” I don’t know.

JK: You’ve echoed a lot of what Joan said about the changes in the funding. That’s stressful to her and I know why and I see it on my end, even in Ohio, everything she mentioned is similar, we’re not unique. That’s nice in one respect, so you don’t feel like you’re alone, but it’s horrible in the other respect, because why is this happening? A lot of it focusing on testing, and we had trouble getting certain guest artists in, not this past year because I fought past it, but the year before that, the initial year of the changes, I thought, “Oh my gosh, I don’t have time to bring them in.” It really frustrated me for the students, because it seemed like they were pushing them into rote learning, and you’re going to have tests all the time.

VR: Yeah!

JK: This past year I fought as best as I could and we brought them back, but it took a lot of effort, and that's frustrating, because the guest artists are like, "Well, we want to be there," but then we get stuck with a very small calendar that says, "Hey, we only have x amount of days; can you be there on that day?" And if that doesn't work then…

VR: Looking at No Child Left Behind, it's a similar act of, I would go into the schools and talk to them, and we would even get grants and funding for free performances for lower-income, you know, at-risk schools, I would call them up and I would say, "Hey, we've got a free performance to give away." They'd say, "What's the catch?" And I'm, like, "No, no, no, there's no catch. It's free," and once we worked through that it was, like, "We can't have anybody in because this month is testing." That makes a huge difference for us. Funding, and school restrictions, and even, there was often a climate of suspiciousness, of, "Who are you, what are you going to do?" I'm giving something away. Which was super frustrating for all of us. That's some of the frustrations of trying to get in there, and then we always tried to bring different [inaudible], and some, there's just no way they could afford it. And we're not that expensive! Joan went sliding-scale with it, "What can you afford, what can we do?" I can't tell you how many performances she gave away at half-rate or less, or things like that, because her mission is to get them in there. We have to have enough to continue because you know … Unfortunately it doesn't come for free. That's the way it is. It was just simple things. Our performance was never that expensive but when funding structures changed, when testing becomes the priority, when it's, again, proficiency versus…

JK: I know.

VR: Exactly. You know what I'm saying.

JK: Oh boy.

VR: It's not a system that is working for the students, so then they're in a process of education that's not working for the students. These issues are hugely important. I can't tell you how many counselors and teachers come up to us afterwards, "We had no idea." Even those people that are trained in the field, it's the simple dignities of living with disability. Within a very short period of time between me saying, "Okay, I'm gonna do the DisAbility Project" to, "This is my first rehearsal," my mother was struck by a catastrophic illness that put her in a wheelchair— [emotional pause]

JK: …I'm sorry, I'm sorry. We can stop if you want.

VR: It's okay. The DP got me through that.

JK: I'm hearing more and more of that from everyone. We have to have this essential question. I keep forgetting that terminology. I hate the term, but my essential question is, what does live theatre do to help improve the life of people who are performing who have disabilities?

VR: First of all, there's nothing better than performing for kids. They meet you where you are, accept you for who you are. [emotional pause] I'm sorry.

JK: See, if we were there with you, we'd be hugging this thing out as best we could, and I'd have Kellie there with me. That's what it was like, trust me, with Angie, once I brought up David. And I wasn't trying to cause any anxiety.

VR: We’re all very emotional people to begin with, so. These people in the DP have been through struggles that I’ll never know. I’ll just take Ana for example; at eighteen years old, was in her first year of college, struck with a terrible, terrible illness and tuberculosis of the spine and years and years of rehab and trying to get better and having to accept that a wheelchair is her life. A lot of these people went from active to dealing with being in a wheelchair. So they go from everybody else to everybody is looking down on them, whether they’re looking down at them or on them. [emotional pause] So you take these people. They are heroes to these kids. [emotional pause] They are performers. They are speakers. [emotional pause] We now have people looking up at them.

JK: Yeah.

VR: And seeing them! And this is not just life-affirming, it’s amazing. [emotional pause]

JK: We first talked with Margaret. That was our first visit, because we wanted to get to her. I had not been to St. Genevieve before, and that was a long drive, and that was fine, but she was so strong when we talked to her. We know what she just recently has dealt with but she was just ready for us.

VR: Margaret has so much dignity.

JK: She said, “Well, I’m dealing with this part of the board, but I’m going to be out of that in a couple of days.” She’s got a will that I wish I had an eighth of, and then I could lift the world. She’s so strong compared to what all she’s had to deal with.

VR: Oh yeah. Oh yeah. That's what I'm saying. I'm not saying it very eloquently but we have kids looking up at them. [crying] They see them for the heroes they are! They're not heroes because they're in a wheelchair. They're heroes because of the good that they have in their heart and what they share. These kids see them as human, but their perception, and forever after that, their perception of that guy in the wheelchair is gonna change. That person with the wheelchair, that person with the cognitive disability, they become, instead of this scary, awkward … The kids come up to them and they touch them and to get this performance in, especially when they're young, is so important, because we have to shatter that fear. Adults still carry it. Adults still have it, but it just becomes, 'Look at what they're capable of.' At what juncture in life, these kids are going to have a challenge. They're going to walk into school with a challenge because school is already a social challenge, navigating everything to begin with, you know, but the stage has always been a teacher.

JK: Excellent. On the creative side, it's just amazing what I saw, and I told them at that first rehearsal, I was astounded, and Ana didn't think it went so well, and I told her, "If all my rehearsals went that well, I'd just be in seventh heaven, because it does not go that well." Their transitions were seamless, even with people missing. I think we touched on that. All the actors have to know everybody's parts, is that correct?

VR: We work on that. We switch parts, because, again it's just, like, these people, a lot of times have extra challenges. They get sick. They're more susceptible to illnesses, and if we're performing in the winter, which, a lot of times, we were, it didn't happen often, but once in a while I was having to restructure everything, like, 'We're either going to cut that piece, or I'm gonna play this, or you're gonna play that.'

JK: And that's what you mentioned, your daughter would step in sometimes. I know you've stepped in.

VR: Oh, sure.

JK: Whatever you need to do for that time, but that has to be done right before the show, am I correct, if you find out someone's just not going to make it? How do you handle that, as a professional to a professional, how in the world do you handle that last-minute change? You know that changes all the choreography of it because you have different dynamics and different people in the play. How do you handle that on a show-by-show basis?

VR: I remember there was one show, it was a winter show, and it was just like, we had to change everything at the last minute, because Margaret was desperately ill. I don't remember what we did honestly but we worked it out and we always did, because Margaret was in a very bad car accident, but it was at rehearsal, it wasn't at performance, and every single member of the DP we just went to the hospital. We were, like, you know what? Everybody got there. We found out what happened. We sat there and talked to each other for five minutes, and I was just like, "I can't be here. Let's go to the hospital."

JK: If that's the same one Becky referenced, and I think she did, she said you all took turns going back to see her and basically had rehearsal there in the hospital.

VR: Basically [laughing] we also figured out how we were going to do without her. We were like, "Okay, so we don't have Margaret now. What are we gonna do?" Because we had a performance in two days. We worked it out. It didn't even take that long because everyone is so flexible.

JK: Great. I got this last question that I love asking, and then Kellie always throws in an extra, Kellie just got home and she's inside with my grandson, keeping him from banging on the window for me, because he likes to do that. Can you name one thing that's not been addressed as far as disability rights in performing arts and explain why that's important? It could be a couple of things. I say one thing but I don't want to limit you. Anything you can think of that has not been addressed.

VR: In what way do you mean that? Like, in society ways?

JK: Any way you feel like, as far as live theatre. I want to limit it to live theatre. If you say movies and TV, that takes us down several angles, but anything with live theatre, whether it's a physical thing, whether it's opportunities? I don't want to throw words in your mouth.

VR: We're definitely getting better about a lot of things, for sure. Because when my son was diagnosed with autism, he was diagnosed in the fifth grade, which seems like a late diagnosis now. They're catching it much earlier today, but I can't say that it's not being addressed now, because it certainly is, so lots of positive changes. Specifically in the theatre world, what is happening? I have a really good friend, Sydney, she's an actress. She never worked with the DisAbility Project, but I have worked with her on a couple of Shakespeare productions and things in the theatre. She had a spinal cord injury. She fell off the back of a bicycle; her mother was riding a bicycle and she fell off the back. It was a bike accident that caused this. Sydney has never wavered in her desire to be an actress and she is very talented, but what is missing a lot is mainstream actors with disabilities, period.

VR: They're out there. We never see them. We see non-disabled actors climbing into wheelchairs. That's what we see. Because that's easy for them. That's convenient. We have not managed to break through that yet. When it happens, it's a novelty, you know? A lot of actors with disability don't show up for auditions because why would they get cast? I think this is a huge need out there, that we cast actors with disability in roles with disability that are written for them! Yeah, this is in the theatre world, if that answers your question at all. That's what I see is lacking.

JK: You're echoing me. I just can't be the one to say it, so I'm so glad to hear you say that. We had a discussion with my professor at Ohio State, Dr. Lesley Ferris, and she's marvelous. She's like Joan. She's so supportive, but I said that's my issue with it, and she mentioned the *Spring Awakening* production, and how they incorporated the young lady in the wheelchair, and that was wonderful, and also with the signing that took place. But the most recent one, I don't know if you've heard of this, I just ran across this last week so I don't know how widespread it is, but my one professor is Dr. Brenda Brueggemann, and she's a deaf teacher I had. She was marvelous, and she had us read *The Curious Incident of the Dog in the Night-Time* and the lead actor is supposed to have autism. Well, they just cast a lead actor who has autism in that role, and I couldn't believe that! I was thrilled to hear about that, like, finally! The actors are out there. You just have to reach out!

VR: Definitely. I have a writing partner, Susan Berardi. She and I have collaborated on several productions, and both of us have children with autism. Her son with autism was the lead actor in a play that we co-produced. Susan wrote it and co-produced it for Action for Autism, which is a charity that partnered with us.

VR: Altogether [inaudible], and in every show we had actors with autism. It was important. The second show we wrote, we wrote together, the first show she wrote and I directed, and then we co-produced both of them, but it's so important. It's not that, there are lots of actors with autism in the world. You wouldn't even know it.

JK: I just, that's exactly what I'm thinking. I don't want people to necessarily agree with me, because I don't think I'm always right, but on that specific subject…

VR: Well, yeah. It's a spectrum. It comes in many different forms and layers and all of that to go with it, but we all know that Robin Williams had ADHD.

JK: I know!

VR: That is how it is. It comes with some genius and it comes with some challenges.

JK: I will let you know, our daughter, our youngest, didn't get diagnosed until the last time I saw you. And she just turned eighteen now, so you talked about, "Oh, they're doing it earlier," and I appreciate that, but when you fight for a diagnosis and it finally comes through and everybody knows it? She was in a classroom with a teacher and she works so well, Jen Schmidt, with all of these kids who have some basic form of autism, they're at various levels. And she's high-functioning, but it took that long just to get the medical diagnosis that she's past the years where any kind of additional help could have been available to her, you know?

VR: It's so frustrating. When my son was diagnosed they knew so little. I didn't know what was out there. I'm irritated, to tell you the truth, because these interventions that are so widely available now, weren't. So I was constantly catching teachers up to how he was. I spent so much time explaining my son to people, you know?

JK: Yes, I know. I really do. I'm right there with you.

VR: Sometimes it makes a difference and sometimes they just don't care.

JK: It's there. You're right. Well, thank you so much. I appreciate all the time you gave me. As I mentioned to Joan and the rest, the overall goal once the paper is done and all of this is completed is to get out there, and we're having a meeting this summer with a person who can get me more information on a site that's available, that was something you mentioned, was that you have to keep moving sites. Well, we have a site that's available. Memorial Hall, here in Dayton. I don't know why, but Dayton has a ton of new theatre. We had two or three new groups open last year of live theatre performance, in addition to the ones that are already here, in universities and schools, so. Once that's opened and we can get that taken care of, there's going to be funding for this, I know that. That's when my next question will probably be, "Hey, when can I get you out here?" Because that's what I really want to do, to is bring DP out here and have them be one of the feature performers, because that's my ideal, what I'd love to happen.

VR: That'd be great, yeah.

JK: I think that'd be fantastic and I'm sorry you'd have to do that drive, because that was an interesting drive, but I've got a wonderful family to share it with, so it went by very quickly.

VR: Right. I think we could handle it!

JK: I think you could too. That's the big goal, and I'm working because, like I said, I'm too old to say no. We've gotta go fast-forward on this, so hopefully I can make you guys proud and do the best I can to start out in this sense.

VR: Thank you. Thank you. I have to add one tiny thing because my conscience was … Joan Lipkin is a crazy genius. She's a brilliant, compassionate woman. Her ideas are so beautiful. She wants to change the world. I love her so much for bringing me in and working with me, and I'm grateful every day that she thought of me.

JK: Thank you. Remind me of one thing, I'm sorry, just real quick, what was it like when you added Jennifer Medina into the process? I didn't want to leave this out.

VR: Okay, Jennifer Medina is my lifelong friend now. That's it. We bonded immediately. Jennifer and I just creatively clicked. Writing and creating that piece together was, and again Joan Lipkin brought us together, had this idea, brought us together, and was just like, "Run, go, create. Here's your model. Now you have all the freedom you want to make something beautiful." Jennifer, I don't know. Creating with her is so easy. I love her so much. She's the most generous and kind and compassionate person. It's just … She just makes it look easy. You walk into a room and she sees possibilities of everything. She's a genius. I appreciate her so much. It's more than she's a creative genius; she's just not a mean person. She's the kindest. I love Jennifer. I can't say enough good things about her.

JK: I'll ask this, since you directed, so I'll make sure I've got this straight. The pieces that you had, did you have blocking first of all and then choreography went in, or was it just a combination of both? Because the piece I saw was just amazing.

VR: We had nothing. [laughing] We had zero.

JK: It was amazing. I've gotta tell you that. I didn't say it enough back then. I watched that and I was, like, "This is brilliant. It really is."

VR: Jennifer and I walked in together on the first day and we had, I would say, barely a road map. It was, like, "Here, take these stories and make something of global significance. Here you go!" But very, very quickly, we sat down, and we talked, and we created a model for this. I would say Jennifer and I did this in six weeks. Then after every rehearsal, we consulted with Joan, because Joan was in New York while we were creating this. Jennifer and I would work for the entire rehearsal. We would talk, we would create stories, and we had the dancers there. I don't think we had the dancers right away. I think she brought them in very shortly after. The first thing we did is we sat down and told our stories. Jennifer and I decided which stories we were going to use. We had origin stories, I guess, is what we were doing, and the topics we were gonna focus on. We had a general idea of the topics we were gonna do but literally we had nothing. And then in six weeks we had everything. So that's how it came about and then we talked it over with Joan. We sent her videos, and Joan would come in and give us notes on this and that, and Joan and Becky, at the end, they figured out the end dialogue.

JK: Good.

VR: I wrote all the stories based on all that, and every piece of movement that went into that was Jennifer. She took those words and made them mean something in movement.

JK: It was, like I said, one of the most touching things, really one of the best pieces of theatre I've seen in my life, and I've seen a lot. I try to explain that to people. I'm old, too. I've seen a lot of theatre, because I compare that what I saw, to *The Garden*, we saw in London when we were in London in 2012, that production, and they had poles … That production, we're going to be comparing and contrasting DP with theirs. You're community-based and they're professional actors and everybody has a disability that is involved, the directors, the producers, everything. And this thing they put together on this raked stage that had four corners in it? They put these poles that bent, and these disabled performers climbed those poles, and then they'd sway with the wind, and I couldn't have done it in a million years. And they would just add to the scene or take away, or they'd add a flower down there or a dust jacket, and it was during the time of the Paralympics that was being held there in London. They were so nice, first of all, in letting me talk to them, just like you guys have been, and they went ahead and said, "Hey, come see the show," and it was right there on the bank of the Thames. It was during the Thames Festival, same time frame, everything. I was just stunned by that, and then I saw yours, and I was, like, "Wow, it just keeps getting better and better, what the heck?" And I just kept on seeing these great pieces of work, but like I said, it's the collaboration.

VR: It was very lucky, because Jennifer and I were just, like, boom. It was instantaneous. The first time we met, I was just, like, "I can create with this person," and she was just, like, "I can create with this person," and that's how that worked. I don't know. It was just magic.

JK: Hey, that's what's needed. Thank you again, so much, for everything. I appreciate all this time. Have fun at the movie. I'm looking forward to seeing it myself when I get a chance.

APPENDIX B DisAbility Project Script #1

The following script is one of the performance pieces written and produced by The DisAbility Project. It is reproduced here with permission from Joan Lipkin, producing artistic director.

15 Things that annoy people with disabilities

1. Patting me on my head.

2. Continuing to insist on helping me even after I have said "no thanks."

3. Talking over the top of my head.

4. Telling me I "don’t look disabled."

5. Speaking slowly to me because I am in a chair.

6. Not inviting me to an event to try and protect me from embarrassment-let me figure it out.

7. Congratulating me for things like going to the grocery store like it is worthy of a medal.

8. Telling me how "brave" I am while waiting at the bus stop.

9. Parking too close to my accessible space-I need the extra room.

10. People telling me that "it’s a shame" that I am disabled.

11. Accessible restrooms that aren’t accessible, I need room to get in AND get the door closed.

12. The tongue-clucking and sighing when you look at me (demonstrate.)

13. Not looking at me!

14. Heavy Doors!

15. Talking about me like I am not here.

APPENDIX C DisAbility Project Script #2

The following script is another performance piece written and produced by The DisAbility Project. It is reproduced here with permission from Joan Lipkin, producing artistic director.

The DisAbility Project Rap

Hook – (sung by all)

Round and round, the wheels keep on turnin'

Every sound, our hearts keep on learnin'

See the soul behind the difference

If ya wanna know the truth, release your resistance.

Rap

Release the resistance - get to know who I am.

Don't walk by like you won't understand.

And don’t assume what I’m capable of.

We’re all human beings – We all need love.

When you stare or ignore, you restrain who I am.

The talents I have, the future I plan.

Our worlds may vary, but it’s my reality.

My identity is more than a “disability”

Hook – (sung by all)

Round and round, the wheels keep on turnin’

Every sound, our hearts keep on learnin’

See the soul behind the difference

If ya wanna know the truth, release your resistance.

Rap

Now, every little time you see someone new.

They may be different, but they're people too.

Celebrate life, think of what you might add –

Just look at these folks and the lives that they've had:

Jackie Joyner Kersee and Albert Einstein –

Musician Ray Charles, who happened to be blind,

Vincent Van Gogh, cartoonist Walt Disney –

Even Julius Caeser had a disability.

Hook – (sung by all)

Round and round, the wheels keep on turnin'

Every sound, our hearts keep on learnin'

See the soul behind the difference

If ya wanna know the truth, release your resistance.

Rap

Mr. Stevie Wonder played the keys without his sight.
Franklin Roosevelt wheeled around with all his might.
Christopher Reeve with spinal injury –
Believes in his future – doesn't give up easily.

Composer Beethoven couldn't hear a note he wrote,
But his melodies live on – on his symphonies we dote.
Bruce Willis and Tom Cruise have had challenges as well,
But both have come through, like Alexander Graham Bell.

Hook – (sung by all)

Round and round, the wheels keep on turnin'
Every sound, our hearts keep on learnin'
See the soul behind the difference

If ya wanna know the truth, release your resistance.

Round and round, the wheels keep on turnin'

Every sound, our hearts keep on learnin'

See the soul behind the difference

If ya wanna know the truth, release your resistance.

Rap

Release the resistance - get to know who I am.

The talents I have, the future I plan.

Our worlds may vary, but it's my reality.

My identity is more than a "disability"

All rapping:

My identity is more than a “disability”

My identity is more than a “disability”

My identity is more than a “disability”

My identity is more than a “disability”

Sung by rapper to close song:

If ya wanna know the truth, release your resistance.

Appendix D: Interviews with The Graeae Theatre Company

The following interviews were conducted through email between myself and Jenny Sealey [MBE CEO/Artistic Director] and Carol King [Women's Royal Army Corp from 1983-1990 and cast member of *This Is Not For You*]. I requested responses from the entire cast. These questions cover the specific work accomplished by the production of *This Is Not For You* which was performed at the Greenwich & Docklands International Festival by the Graeae Theatre Company in conjunction with Blesma: The Limbless Veterans and 1418-Now:WWI Centenary Art Commissions. The performances took place the weekend of June 30 and July 1 2018. The production was held in an outdoor facility in the direct sunlight during a particularly hot and sunny week.

Interview with Jenny Sealy

Jenny Sealey is the Artistic Director of The Graeae Theatre Company and has directed projects including *Blood Wedding*, *The Garden*, and *This Is Not For You*. I attended the performance on June 30, 2018 of *This Is Not For You* and had the honor of meeting with Sealey for a few minutes after the first showing. Sealey asked me to wait until her interpreter could join us and I was able to share my views of the show which she appreciated. Sealey was especially interested in my reaction to the music that was used as it was composed by Oliver Vibrans from Graeae. The interview material was received on September 2, 2018.

Jonathan Kochensparger: How many years have you been involved with theatre in any form?

Jenny Sealey: Since 1987.

JK: How long have you been involved with your current theatre project?

JS: *This Is Not For You* (TINFY) took four years to realise-to create a narrative, to raise money, to convince funders I knew what I was doing and was worth the ‘risk.’ It was a painful process and one where often myself, my writer and designer lost confidence but because we believed in the importance of the story we kept going.

JK: What reflections do you have for *This Is Not For You*? Please remark on the rehearsal process, performance, and reactions from audiences.

JS: Because of money we only had two weeks rehearsal which was not enough for people who for the most part never engaged in the theatre making process. We had had a storytelling week and circus training but the shift from this to rehearsal was enormous and demanding-not least because such diverse physicalities/personalities/PTSD/and an expectation that I would run rehearsals like a military exercise. I tried to explain there is a real discipline in theatre but until we get that bit the process is messy, trying out new stuff, engaging with emotions, objectives, subtext etc. etc. but by the time it gets to the performance then it becomes more disciplined (but still emotionally charged). The military on the other hand is disciplined from the start but the aftermath of war is incredibly messy emotionally and psychologically etc.

However hard the process was-bit by bit the team began to see how it would work. They were so far out of their comfort zone but when they just went for it they we just brilliant and then by the time we got to performance they really did own it and embraced it. I was so so proud of them. We had so much against us-time, the extreme heat, delays with sound, bringing in the choir which added a new dimension. But we got there and by Stockton Riverside Festival they started to play and enjoy performing to a crowd. Stockton audiences just loved it and clapped at the end of arias, clapped when the troops marched on and were in tears at the final song.

JK: What is your perception about non-disabled actors portraying people with disabilities on stage or other media?

JS: They should not do it until there is absolute equality in the casting process.

JK: Name one thing that has not been addressed as far as disability rights in performing arts and explain why this is important.

JS: Training is still an issue-I need to think more about this question XX

Interview with Carole King

Carole King was a member of the Women's Royal Army Corp serving from 1983-1990. She decided to take part in *This Is Not For* You after responding to a request from Blesma (The Limbless Veterans) to join the program. The following email response from King was in answer to Jenny Sealey's request on my behalf for this dissertation. King wrote an essay response to my questionnaire which I am reproducing here. King's responses came to me on September 4, 2018 through November 15, 2018.

Jonathan Kochensparger: How many years have you been involved with theatre in any form and specifically with your current project? Please comment on your personal reflections on *This Is Not For You*.

Carol King: A small brief about me and how I have evolved over the years and coming up to training and performing with Graeae.My name is Carole King, I am 53 and a single mum. My daughter is now 22, her and her dog called Rosie live with me. We all live in a small town called Exmouth in Devon. I have not always lived here, I was born in the St. Mary's Hospital Islington in the East End London June1964, but times there were not always good. From and Up to the age of 13 I had been into care 12 or more times. This had to end so my sister and brother could have a better quality of life, the only way this was going to happen was for me at the age of 13 to get a court injunction against my mother.

CK: At the age of 13 was when it was legal to speak for myself, I got a court to make an order so that my mother could not take us out of care anymore. We finally ended up in a Newland Homes a Children's Orphanage in Hull where I stayed until I went to live with foster parents. In 1980 I moved out of the home, where I went to live a couple in a foster home. This never worked out and I felt quite restricted, so I moved out to live on my own. My very first place was still in Hull in a shared house in this shared house was a boy named T who also was from the homes who took me under his wing in making sure I was ok. The room was quite tiny enough for a single bed and cabinet. The rest was shared facilities. But it was mine and I loved it. April 1983, I joined the Women's Royal Army Corp, where I served in in the UK and B.A.O.R. Whilst serving Blackdown Barracks RAOC I had a terrible trampoline accident this was going to change my life and end my career in the Army. I was sent Headly Court for rehabilitation after the accident. I had many operations on my back and left knee to bring me back to full military fitness alias this was not meant to be, so I was medically discharged in May 1990. May 1990 started another chapter in my life and I went to work for NAFFI at 42 Coy RM in Devon, still having to have more operations to my leg. I left NAFFI service and came to live in Exmouth. I choose elected surgery to have my left leg amputated from above the knee. This choice was not taken lightly but was the best for quality and healthier life. This was the beginning of being a BLESMA member. With their help they helped me in with find suitable accommodation as I was in a house and need to be living in a bungalow. I have grown with BLESMA in confidence carrying a disability, With BLESMA I have done many things that were not even on a bucket list, Sky Diving, Skiing and Scuba Diving, Queens garden party, and made serval Remembrance Parades in London, I also took photography up as a hobby and even a very short stint as a model.

As well as the many events with BLESMA I was also introduced to the Community Drive Project run by The Drive Project. This was an awesome week, we learnt much more about ourselves and how to tell our stories to inspire children adults and how to overcome diversity and to say its ok.

BLESMA put out a shout for women to come forward and try an experience day with Graeae at National Centre Circus Arts NCCA with view to joining a troop of likeminded veterans also from BLESMA. This would be a challenge and would be a test of my strengths and abilities. The National Centre for Circus Arts is a registered charity and one of Europe’s leading providers of circus education. Based in a magnificent Victorian power station adjacent to Hoxton Square, we involve thousands of people in the creation and performance of circus arts every year. Over half of the annual income needed to run the National Centre comes from grants and donations. Our diverse range of work includes a BA Hons degree in Circus Arts, a structured progressive training programmed for under 18s and professional development opportunities for aspiring and established performers. Adults and young people can take part in a range of recreational classes and we provide workshops and away days for the business community.So now I am working with Graeae and taking my own life story to another level, but this time will be in aerial arts. This were I have relearned how to strengthen my core and balance on one leg, wow, this is going to be amazing. This will be very interesting time being able to do aerial work, but as a former gymnast and trampolinist, heights were never going to be that much of a problem. But back then I had two legs. I feel that this is going to my build confidence levels up that I feel I have lacked over that last of couple years. I know that just sitting back at home doing nothing is more depilating. So, the more that I do will give the boost I have needed for a long time and what a way to say hey I’m back and rearing to go. The beginning. **S**o, who are Graeae and what is *This is Not for You?*

This Is Not for You is an epic outdoor performance paying moving tribute to Britain's wounded veterans from the First World War as well as more recent conflicts, both men and women, whose contributions to history often go unnoticed. The piece is directed by Jenny Sealey, written by Mike Kenny and performed by Blesma, The Limbless Veterans, professional performers and local community choirs. *This Is Not For You,* part of 14-18 NOW, the UK's arts programmed for the First World War centenary, is a story of veterans' fight for respect and remembrance, told with heft. beauty and wry humor, both on the ground and off it, with audio description and sign language as integral parts of the production. Graeae, with the National Centre for Circus Arts, has trained 25 disabled veterans in performance especially for the piece. A Rabbit in Head Lights. March 2018. Today is my first day with Graeae. This morning I set of from Exeter St. David's to London Paddington Station. The air was fresh and not a snow drop in sight, but as my journey got nearer to London the more snow that I could see. As the train pulled into Paddington train Station I was greeted by snow. Not the best for me as I struggle underfoot with snow. So I'm not sure what to expect feel like a rabbit in head lights. This is a long way from home and feeling I wish I was home back in my box. First, my fears of getting lost and confused start as soon as I get off the train. Also, I stress and struggle with stairs and escalators and the London underground brings sheer dread. It is times like this I wish I could turn back, but this is not an option, as I will be letting team Graeae, BLESMA the guy and girlies but most of all myself down. I must get to the NNCA, so to arrive chilled made the choice to go to NCCA by taxi. As I wait in the foyer for the other BLESMA members to arrive, I was hoping that there will be other members that I know. As the troops start to arrive there was good news. As I had already worked with and met some off them previously through other Blesma activities. So, made stepping through the door a much easier. We all set of to the gym get ready. We were introduced to the instructors and staff for a quick warm up. Then split into twos and threes for our initial physical assessments. We went through a series of exercises, although I do exercises at home, I was surprised to see how unfit I was. Some exercises I could do but need to gain more strength in my core to be stronger. The aerial part I struggled with as my hands were slipping down the ropes part of the assessment, also I could not swing onto the Ariel hoop, this was a new practise that I have never used one before. My shoulder strength was very poor, and I could not pull myself up onto the swing. Very disappointed that I unable to do this task. This was not at all what I thought it would be, but then again, I was totally blind going into the gym, but found although very hard to do what was asked of me, I tried my best. I had the reassurance from Jezz, Paul and the instructors, they said and felt that with more training I could master this. They will be doing a schedule for us all to do at home. Up to now I thought I did ok with the limb being on and thought I should do the exercises with my limb off. However, I have taken the step to keep my prosthetic leg on at this stage. Only to help with confidence than being vulnerable to falls without it on. I understand that this is not going to be a walk in the park, it’s going to be hard but with the right training and motivation as well as working as a member of a team, being committed at home to do the exercises given I can do this. But most importantly yes, it’s out of my comfort zone. I will nail this overcome. I am going to enjoy the experience and my time with Graeae. Home training: So, this is my second week and I know have a training programmed to help build our strength and endurance. These programmes were based from the session last week to our weakest points. This is not bad but with self-discipline at home we all will become stronger person in strength and endurance. For me personally I have received 2 types of exercise training programmes to do in my home.

Because I was struggling with the floor exercises and doing crunches, I have also invested a sit-up-bar for under the door. I am very aware that I need to master some of the core disciplines, so I have adapted a little. So not lost sight of my goal. How to work your grip strength anywhere you go utilizing a tennis ball (Get a Grip) all you need is a tennis ball for this one, but the idea is to carry it around in the car or your pack and get it out and give it 10-20 squeezes in your hand throughout the day. You can carry it with you pretty much wherever you go, and at the end of the day you've gotten in some great grip work. As well as the tennis ball I have bought some hand spring grips, which will have that lot more resistance than a ball. With the above two programs in mind I have also made a weekly plan which I shall incorporate the above, my exercise that I have included are-Swimming- 40 lengths no time limit. Varied styles of swimming. Plus, one swimming exercise class per week. The swimming will alternate one-week Tue, Thurs and next week Mon, Wed and Fri. Walking for 30 minutes but this is split into 2 sets of 15 minutes. This is not a rushed walk, it’s controlled, correction of posture pull from the abdomen and stretching the neck keeping shoulders down and relaxed. Pull up bar**.** This is fun and already I can see a result from last Tuesday. I struggled to hold myself and bring my knees up and but my legs straight out in front. I can do both of those disciplines, I have started at 30 seconds and will add each time 5/10 seconds my goal for the end of the week is to hold for 10 minutes. These will include just free hold, knees up and legs straight out in front. The reparations and stopping and starting will come in time and practice. The bar is hung on the door frame going into the kitchen so every time I go in I have a quick hang of up to 10sec, job done.

Planking basic/elbow/reversed. Wow how hard, my poor arms hence I am starting at 20 secs and will build up to 2 minutes. My balance and control of my body is slightly hindered that I am unable to lock my prosthetic leg, on a reversed plank, my good leg must be the one to support. I have proved to myself I can do this so now it controls, endurance, styles and technique. This looks quite a heavy program, my aim for the day is to do 1 hour per day. That time does not include the swimming. The hour is the least time I want to work at the longer for me will be better. Diet and Eating: My friend Shelley whom works with Herbalife, is helping me with my food. She has given me a weekly meal planner so that I am eating healthier and my body will be able to cope with the sudden exercise program that I am doing. I Know I am the world's worst eater I have breakfast then drink water all day maybe some fruit in between. I just don't eat, and it is not good. Later, as the training becomes more intense she will help me, and it will have to be changed, so I don't crash and burn. I would like to give a big Thankyou to my friend/ consultant @ Herbalife, Shelly Kitchen. I have lost a stone in the month and very pleased. I'm losing the unsightly back fat, and toning will come as the weeks go on. Whilst doing my journey I have made some life style changes. By doing this I have more energy and sleeping much better. I am not dieting just eating smaller amounts during each meal. At time there, days I was ready to give up and throw in the towel but So, Graeae have invested me. Also, I have invested in myself some home gym equipment to help me on my way. I have even printed a body progress checker so put all my vitals in and by week four will see some changes if they come sooner great. I also realize that doing to much as well could cause me to crash and burn. So, with that in mind everything thing is done in controlled situation, it's not speed that I need. I have 14 weeks to the first performance. I'm sure this will come around.

When we all meet up again for our next session at NCCA, the instructor should see some improvement from our home training. We all come together as a group/team and are there to help the slowest as well as ourselves if that is the case. It been a long time since I have had the motivation to progress and move forward and this is right up my alley. It also stops me moving furniture and decorating. The day starts with the journey back to London to the NCCA. It was nice to have some company on my train journey I felt more at ease on the train. Also travelling to the center, I know get a taxi for each session. We startup with group war up called the 'HIT'. Then to work out how to get onto the hoop. The rope is still not my friend I am still struggling to hang and hold on without looking like it's a death grip. I do feel at this stage the pull up, bar and work I have done in the home made this a little easier. With direction from the staff on unusual ways to first get my leg up onto the hoop. So far, I have worked with my prosthetic on, but this is proving to be difficult and not helping me in any way or form. Given that I find a way which worked for me, there is not much grace now I may add, and I seem very clumsy. But bingo, I found a way to get onto and off the hoop much quicker and more controlled so please with myself I felt like the cat with the cream having mastered the art of getting on and off the hoop and to make shapes, by small movements controlled but more strength. So, by doing this with less effort and having more style. On paper it sounds easy, but it's hard using muscles and the body for support especially ones that never get used on a day to day basis. My baby soft well moisturized hands are taking a good old beating. A very good day of training, we all worked well, and the support from everyone is brilliant we are all in the same boat and need to put our trust in each other to hold and support when performing and training. The group is good we laugh but train harder. I need to believe more I myself and my abilities. This week I had a little bit of a set back whilst gardening, I had managed to puncture my wrist on a rusty nail while sorting it out. Had to go to the hospital to sort it out my hand swelled quite quickly. Luckily no nerve damage but will be sore for a few days just while the swelling and infection go caused by a rusty nail. Few days later and some good news for me the swelling I was going down and not as tight as it was previous which is a relief. I don’t cope well it bits not working or being ill. Antibiotics doing their job. I will resist doing home gym for another day. But back to training tomorrow seemingly being positive is working. Not beaten just yet. No, our *This Is Not for You* performers aren’t swinging from the ceiling on a trapeze today! They are however focusing on their audience, and the journey they want to take them on. At a group script read-through this morning, it was striking to listen to the stories of those involved and how many emotions, questions and images came to the forefront.

This Is Not For You is premiering this summer at Greenwich & Docklands International Festival then Stockton International Riverside Festival. So, the weekend of training was cancelled, instead I was carrying boxes suitcases and moving my daughter back home. If the truth be known, I’d ache less doing my training. Two days of rest and chill now before London on Tuesday. These little things are sent to help us grow strong. On a much brighter note. It’s almost four weeks since that I took on with Graeae, major challenge that I’m truly enjoying and loving.. The day started with a number sequence rolls, followed by ‘H.I.T exercises to warm up. I have chosen the hoop again and was partnered with Paul has helped me we get on well and help each other along the way.

So, the aim of Day was to control the ascend and descend with the minimalist amount of effort. There was a couple of ways that I can do this, but a lightbulb moment happened, and we tried without the limb on. This made the routines and given exercise much easier and I had more control of my body. This still must be perfected and much slicker and not a like a buffoon.

The next task was to see how we could hang from the hoop, shoulder, feet and knees. Also, I need to stop moisturising the palms of my hands and the back of my knee joint this will give me much more grip when doing the exercises and help prevent rope burns on the back of my knee but with time that should strengthen up. These photos show how I get onto the hoop roll and come off. I am not wearing my prosthetic and by doing so I have a much smoother motion. The issue of controlling the hoop is easing as it's my upper body that commands how I am with in the hoop. What have I achieved? So, since I have started with Graeae and putting a few train journeys under my belt by traveling to and from London. Facing my fear full on has not been as bad as I expected. I'm not 100% sure I would have been as confident if I had to change at many stations and use the tube. So, I now arrive fresh and relaxed instead of being stressed to the hilt. Also, dismissed any pressure caused from being tired from driving. The train is quite relaxing, normally have a book or listen to a book on my kindle. The journey is about 3 to 4 hours so is the car journey. We are currently doing one day a week until Intense training starts. The hours can be very long, the times vary but still not getting in till after 10pm that's when I can get the connecting train to Exmouth otherwise it's around 12am. I am now enjoying my train journeys.

I had to find a way to get on and off the hoop. In a safe and controlled none erratic way. Since having worked out a way to do this, I feel more in control to point that I can start to enjoy the aerial arts and experience. There is much more to come but at present I must think of now and not runaway with myself. I arrived so chilled and ready to go. Fab bunch of girls and boys we all work well together. The H.I.T. gets everyone warmed up. Paul and I have paired up with the hoops we work well together. The trust issue is getting stronger each time I attend. Still struggling with people in my own space but hopefully I will get used to this. There is no midweek training in London this week, but we are having a full weekend in London, 14th & 15th April. Staying at in Union Jack Club. There will also be some filming and heavy training, just love it two days no week break. Training is starting to pick up now with more dates in the month. New appointment at the limb centre to help as my walking gait is not so good. Few minor adjustments needed. Since starting I was unsure what the whole Graeae was about and my part within the team also to why we were doing aerial work, when we have no aerial acrobatics with in the show. The reason is so we can get to fitter and be able to undertake the tasks due to be given. That bit will come apparent once we start rehearsals at Woolwich, but for the present time I am using a hoop and love the way things are going, even though which makes it better, means I must try a lot harder for the results, that’s progress. My upper strength is good, and my body seems to be coping well at the moment, but I am sure as the training intensify, I feel that I will be using muscles and body parts that I don’t use in day to day life at hope. Since starting I have finally stopped using hand cream on my palms and cream for the backs of legs this is so that I can have a better grip, so the trainers will be pleased. Weekend of rest and pick up on Monday.

There are lots of people that are also on their own journey just like me, but I have decided that I would write a piece after each session of my journey. I already knew some of them and others I will get to know as the time goes on. We will be spending a lot of time with each other so need to get on as one big team. Without the input from the fellow Blesma members it would be a hard journey. We all have various degrees disabilities. We all understand that it will take a little longer to master what is asked if us by the trainers. It’s a journey with Graeae, Drive Community Project, Blesma Veterans, Trainers from NCCA and the Administration team. Thank you all. This is nothing major, but I feel I can share as you are my friends. To some it’s nothing but how dry are my hands, I have never had a tube of hand cream last so long. So my hands are now going commando no cream. My Journey with Graeae Company. Trying not to use cream as I have no grip with the ropes, if no one looks at my palms I’ll be fine. So I am all booked in the Union Jack Club, for a fully packed weekend intense training, trip to the theatre and some filming of the group I believe. My room with a view. So last night was an informal meet and greet the guys that have travelled from Sheffield, this is the first time that we train with the guys from the North. We also a meal with Jenny the Boss Director of the play: Jenny Sealey MBE CEO / Artistic Director. Jenny’s directing career began with Interplay Theatre, co-directing *Sea Changes*, then directing *Stepping Stones* and *Mad Meg*. Jenny has been Graeae’s Artistic Director since 1997. April 14: So today is the first time Sheffield meets London that is the whole production team meeting up at NCCA. Which is exciting. So, lots of things happening today training and filming. More direction of our roles and what we will be doing on performance, so I am refreshed and rearing to go. Even the suns out, not that we will be seeing much of it. In the meantime, I’m going for a bit of breakfast, as well as my shake. Then a little wonder... more to follow. What a day. This morning was filming.

The guys had to do a march pass past me. I had a small talking part saying *This Is Not For You*. Then in the afternoon when we’re seeing how many ways we could get around onto inside of a cube. This I found a little hard as it pulled on my back. But tomorrow we are going to find a way where it will not be to stressful on my back. Then this evening we went to the Roundhouse in Camden to watch Relentless of Carabina presenting. *Relentless Unstoppable Human Machine*. The show was awesome. Loved it all. The comedy music and the amazing stunts by the artists.We are all back at the UJC, I have bowed down and come to bed, nice earlyish night.

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