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(Re)Discovering Story and Voice: The Adaptive Community Theatre Project

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Abstract: The Adaptive Community Theatre Project (ACTP) at the University of Central Florida (UCF) served to honor the voices and stories of community members with aphasia and other acquired neurocognitive disabilities, while combatting the isolation and depression often felt by this demographic. This paper will explore the ways in which the pilot year programming of ACTP evolved over time, due in part to the primary author’s perceived disinterest of the neuroatypical participants. Though initially the neuroatypical participants expressed interest in the project, erratic rehearsal attendance, transportation issues, cognitive fatigue, and stage fright presented challenges for the participants and created obstacles to the theatre process. This led to multiple modifications, including shifting from an ensemble-based mixed-ability devising model to an ethnographic model, and shifting from a full performance to a staged reading and community discussion.

This paper offers an overview of the ACTP and the challenges that led to multiple structural revisions throughout the development of the project. Written from the perspective of the ACTP artistic director, a reflection and analysis on the project’s pilot year concludes with a proposed model for successful community-based theatre work with participants with acquired neurocognitive disabilities and neurotypical volunteers. This paper asks: What are the best practices for creating theatre with/for participants with neurological/neurocognitive deficits? What tensions in objectives, communication, and access arise when a team of neurotypical individuals creates artistic and extracurricular programming for neuroatypical individuals? And how can neurotypical theatre-makers interested in accessibility and inclusion adapt their approach to rise to the challenges presented by these tensions?

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Introduction

Dawn¹, a participant in the Adaptive Community Theatre Project and an individual who has aphasia, arrives at the theatre to prepare for the day’s performance. Due to limited access to transportation, Dawn has not been present at any of the rehearsals, and the company is now working to integrate her into the performance half an hour before curtain. Thankfully, her presence allows the directors to catch an egregious error; upon hearing the play for the first time, Dawn responds to a line with surprise, saying, “I don’t have a cat named Pepper!” To the creative team’s shock and embarrassment, they have unwittingly combined two aphasia interviewee’s materials into one story, and now must work quickly and creatively to fix this mistake.

The Adaptive Community Theatre Project (ACTP) launched in August 2017 under the guidance of UCF clinical associate professor in Psychology, Megan Sherod. As a lifespan neuropsychologist, Sherod works with patients of all ages and is invested in their continued rehabilitation and quality of life post-hospitalization. ACTP is one subprogram of a three-pronged initiative called the UCF Adaptive Community Program, developed by Sherod to use theatre, music, and athletics to build community, provide recreational opportunities, and increase

¹ For anonymity and privacy, this and all other patient names are pseudonyms and all potentially identifying details have been changed.

visibility for members of the Orlando community impacted by stroke or other acquired neurocognitive disabilities.

Elizabeth Brendel Horn, an assistant professor in Theatre for Young Audiences at UCF, partnered with Sherod as the artistic director of the ACTP, alongside UCF associate professor in Theatre, Belinda C. Boyd, who served as producing director. Together, Boyd and Brendel Horn oversaw the development and performance of a staged reading of an original play titled “Never Stop Living,” performed by neuroatypical participants and neurotypical undergraduate volunteers.² The piece and accompanying post-performance community dialogue debuted on April 6, 2018 to a private audience at the Dr. Phillips Center for the Performing Arts in Orlando, FL during the UCF Celebrates the Arts festival.

This paper is written from the perspective of the primary author, Brendel Horn, and will use first person henceforth. In this paper, I will provide an overview for the rationale of the ACTP and the challenges that led to multiple structural revisions throughout the development of the project. These revisions took place throughout the entire year of the pilot project, and even on the day of the performance—as described in the opening of this paper. My reflection and analysis on the project’s pilot year will focus on my perception of the neuroatypical participants as being disinterested; the multiple evolutions of the project to meet participant interest; the fulfillment of project objectives; the challenges of non-disabled leaders in a creative process with

² The term "neuroatypical," used throughout this paper, is consistent with the preferred biopsychosocial language of "atypical development" and refers to a person who has demonstrated either an acquired impairment in central nervous system functioning, or developmental impairments. The term "neuroatypical" was used here to include individuals with cognitive deficits that directly impacted the individual's speech, as well as individuals with motor impairments secondary to neurological injury that affected their speech and articulation, but who otherwise did not demonstrate cognitive deficits. Additionally, the term "neurotypical" is consistent with the preferred biopsychosocial language of "typically developing" and refers to a person who demonstrates no deficits in central nervous system functioning.

participants who are disabled; and questions and observations of how to best create community-based work with and for participants who have acquired neurocognitive disabilities. In my reflection and analysis, I will ask: How can theatre created with/for neuroatypical participants best serve this population? What tensions in objectives, communication, and access arise when a team of neurotypical individuals creates artistic and extracurricular programming for individuals with neurocognitive disabilities? And how can neurotypical theatre-makers interested in accessibility and inclusion adapt their approach to rise to the challenges presented by these tensions?

Initial Objectives and Reservations

The UCF Adaptive Community Program and the ACTP are service-learning programs aimed to improve the quality of life for survivors of stroke and traumatic brain injury through building community, providing a space through which to explore new and old hobbies, and creating positive interactions between the neuroatypical participants and the neurotypical UCF student volunteers. Sherod created the Adaptive Community Program to honor the voices and stories of members of the community with aphasia and other acquired neurocognitive disabilities, many of whom also have acquired physical disabilities. The program was fueled by the isolation and depression expressed by patients to Sherod during group therapy sessions at Aphasia House, an outpatient and community facility at UCF. Since stroke greatly impacts the ways in which survivors engage in work, hobbies, socialization, and self-care, stroke presents an increased risk for anxiety and depression, as both a direct neurophysiological consequence of the stroke itself, and as an indirect result from the psychosocial consequences and change in quality

of life, with roughly half of survivors developing an anxiety or depressive disorder (Døli, Helland, & Andersen Helland, 2017).

In informal conversations during the planning phases of this project, Sherod, who has no background in theatre and served as coordinator and director of the Adaptive Community Program, expressed the belief that performing in the spotlight would provide a positive experience for the aphasia participants and would create a literal physical and visual shift to their usual marginalization within society. Sherod also perceived that the multiple modes of visual, textual, and physical expression in theatre would provide an inclusive model for the varying communicative modes of the aphasia participants. As examples, though one patient Ken, is non-verbal, he is known for an endearing gesture of kissing his fingers and pointing to the sky, an expressive and meaningful gesture that could inspire onstage movement or choreography. Seeing an actor communicate via an electronic speech generating device (SGD) might be unique and memorable to an audience member unfamiliar with such devices; observing how an SGD works on stage might demystify it and even make it seen as a thing of artistic beauty in the gaze of a non-disabled audience member. Sherod’s instinct as a clinician of the potential benefits of individuals with aphasia engaging in theatre is supported by studies analyzing the effectiveness of pantomime as a communicative tool for aphasia patients (van Nispen, Mieke, van de Sandt-Koenderman, & Kraemer, 2018), and the use of dance theatre and digital storytelling to aid stroke survivors in self-expression (Patterson, Langenhuizen, Young, & Mackay, n.d.).

I am a non-disabled applied theatre artist and theatremaker accustomed to working with diverse populations and people both with and without prior theatre experience; I am less versed in the needs of the disabled. Despite one such past project providing performance opportunities

for senior citizens, many of whom required physical or cognitive accommodations, the majority of my work as a theatre educator and artist has admittedly made accommodations on the back end—after an individual is identified as requiring accommodations, rather than on the front end—explicitly recruiting and aiming to serve individuals with disabilities. Given my relative newness to working with individuals who are disabled, I found myself approaching this project with several trepidations. I was well aware of the growing conversation in the field of theatre about providing access and inclusion to audience members of varying abilities through sensory-friendly programming and adequate staff training (Fletcher, Parrish, & Sherman, 2018), and worried about how to properly train our neurotypical volunteers in accommodating various needs both in the development process and in their final performance of the staged reading. I knew the potential benefits of drama therapy in working with people of varying abilities and trauma survivors (Cherney, Oehring, Whipple, & Rubenstein, 2011), but was wary of the thin line between drama therapy and theatre with therapeutic elements; I did not want to present our project as one that would provide therapy to these participants, especially as doing so while preparing for a formal performance would feel conflicting and exploitive. I was familiar with using theatre for social change techniques such as forum theatre with varying abilities (Kozáková, 2016), but like many applied theatre initiatives, the ACTP did not fall neatly into the category of theatre for social change. Perhaps, through their involvement, the aphasia participants would address some internal oppressors created as a byproduct of the systemic oppression of the disabled, but could this performance serve as a catalyst for social change for participants and/or audience members, and if so, how? I knew of other models of arts programming for individuals with aphasia, such as aphasia choirs (Zumbansen et al, 2017; Tamplin, Baker, Jones, Way, & Lee, 2013), but am also aware of the potential benefits of choral

singing for those with aphasia (Racette et al, 2006); would participants be able to successfully and confidently engage in a spoken theatre project, or would it further perpetuate their communicative frustrations? I worried that perhaps participants did not actually want to be on stage and that at its worst, this performance could read as a self-aggrandizing parade of our own good will. Communication challenges caused by caregivers serving as interpreters (“Detecting Stress,” 2017), delayed speech, and even my own insecurities in how to communicate and connect with this population, worsened my fears that the aims of this project might be serving our own needs, rather than the needs of the disabled population we wished to serve.

Perhaps most importantly, I was aware that we were crafting an experience for them based largely on a clinician’s (Sherod) empirically-informed perspective that participation in the ACTP would be beneficial and enjoyable to the aphasia participants; I worried that a project set out with good intentions might unintentionally reinforce a medical model with individuals who have already successfully completed rehabilitative therapy and were now seeking community-based extracurricular activities. Individuals with disabilities who create art such as Petra Koppers (2011) are able to speak to, and create within, their own identity as a part of disability culture; I am an outsider looking in. Little theatrical work has been fully motivated and created by individuals specifically with aphasia, such as that of Joseph Chaikin, a director and actor who had a thriving theatre career with Open Theatre and Public Theatre prior to his stroke, and for whom several playwrights created new plays specifically to accommodate his needs post-stroke (Chevigny, 1998). Thus, my expectations were formed most strongly by my own experiences, then by Sherod’s, and then by the observations I gathered of the population with whom we would work; a hierarchy that caused me to operate from my own position—a tension I explore further in this paper.

Adapting Our Model

While the medical term “adaptive” can refer to rehabilitative efforts to help a patient adapt to societal expectations, it can also refer to the ways in which activities can be adapted to suit the needs of an individual, such as using Braille to read or wheelchairs to play basketball. The Adaptive Community Program uses the term in the latter sense, aiming to adapt the sports, choir, and theatre offerings to serve each individual’s unique needs. The focus of the Adaptive Community Program is also found in the word “community,” for, by making these adaptations alongside neurotypical volunteers, the program aims to help both those with disabilities and the non-disabled see themselves as part of a greater community.

The plan for the Adaptive Community Theatre Project shifted multiple times throughout its yearlong pilot project; the primary cause for each modification to our plans grew from an unspoken and perceived negative feedback from the aphasia participants caused by inconsistent attendance. The small and continuously dwindling number of participants at weekly rehearsals was cause for concern, which reinforced some of the questions raised in my initial apprehensions about the project. Admittedly, we were not always able to fully identify the reasons for poor attendance; was it related to scheduling and transportation, or disinterest? Communication challenges with the aphasia participants brought to the forefront the difficulties in navigating how we, as neurotypical and non-disabled leaders, could best create a program to serve this population. We had placed ourselves in a position of privilege, and decisions made in how to move forward with the project depended on our best interpretations of what was communicated by our participants, both verbally and through their actions. With each reiteration, the project leaders (Boyd, Sherod, and myself) strove to hone in on the core objectives of the project and

further examine how to best serve the participants’ wants and needs, though in hindsight greater emphasis could have been made on directly communicating with the participants themselves. In this section of the paper, I will provide an overview of the ways in which we adapted the project due to both the real and perceived needs of the participants, in an effort to further complicate the relationship between neurotypical facilitators working with individuals with neurologically-based disabilities.

The project began in August 2017 with the goal of a devised piece featuring both individuals with acquired neurocognitive disabilities and neurotypical individuals. Devised theatre is the creation of original material for performance, in this case based on the true stories collected by project participants. Aphasia House offers two sessions of extracurricular programming on Fridays with a one-hour break in between sessions. We planned to hold rehearsals for the ACTP during this one-hour window with the hopes of being accessible to both morning and afternoon Aphasia House participants. The first rehearsal had three neuroatypical participants and approximately twenty neurotypical volunteers from UCF’s Psychology and Theatre programs. This low attendance of neuroatypical participants was despite Sherod’s efforts to promote the project at Aphasia House, across campus, and to individuals with acquired neurocognitive disabilities in networks across Central Florida. However, we approached the project with a newness and vigor; despite these skewed numbers, all of the participants eagerly dove into theatre exercises designed to build community and generate a story. It was our hope and belief that creating a positive experience for the few neuroatypical participants in attendance would help our numbers grow.

As attendance fluctuated and then declined with our neuroatypical participants, with only one regular attendee, attendance also suffered for our volunteers; many volunteers were drawn to the project for the opportunity to build a stronger community with individuals with neurocognitive disabilities. In group discussions, these volunteers expressed feeling discouraged by the lack of attendance and meaningful engagement with disabled participants, and as a result their own attendance declined. In hindsight, we championed the feedback we received from these volunteers, who were more easily able to articulate to us what they hoped to gain from the project; the first of many moments throughout the process where I now realize we centered the experiences of the non-disabled participants, which I will explore further in this paper.

Based on the non-disabled volunteers’ feedback, we revised the model to emphasize creating positive interactions between the neuroatypical participants and the neurotypical volunteers. We shifted away from a collaboratively devised script toward an ethnographic script, in which the neurotypical volunteers interviewed the neuroatypical participants and documented their interviews through audio recordings, notes, and personal reflections. This new structure did not allow the neuroatypical participants the same agency and collaborative buy-in we initially sought with the project. However, their lack of attendance made this option a way in which we were able to still incorporate the words, stories, and ideas of many neuroatypical participants without asking much commitment from them, since individuals with aphasia and other communication disorders could volunteer to be interviewed during their regularly scheduled programming at the Aphasia House. This raw material was then combed through for similarities in theme and content and crafted into a short script, which I wrote. (I acknowledge here, and will explore further in later sections of the paper, the challenges presented by me, as a non-disabled facilitator of the project, having the privilege of determining the final content of the script. While

this veered from our intended programming, it was the only viable way we found to move forward with the project, as there were no disabled participants who expressed interest in working on the script.) A rough draft of the script was presented by predominately undergraduate students (along with our one regular neuroatypical participant) at UCF’s Aphasia House in December 2017, with the hope that hearing a tangible script would build excitement for Aphasia House participants to join rehearsals in preparation for our final performance.

While the feedback on the initial staged reading was positive, we once again found attendance to be an issue when school reconvened in January 2018. At this point, volunteer attendance had steeply declined. Our assessment of this suggested two things in addition to volunteers feeling discouraged by the poor attendance of the aphasia participants: one, that the start of a new academic semester had led to schedule changes for several students; and two, that several of the psychology students who were interested in building community with the aphasic population were not interested in performing on stage. This again required us to revisit our objectives and reassess our model. While we acknowledged that the initial vision of the project involved individuals with acquired neurocognitive disabilities exploring a new skill (in this case, theatre performance), this objective was deemphasized due to my perception of disinterest of the neuroatypical participants from their lack of attendance. When we realigned the core values of the project, we identified two areas of focus: increased visibility for members of the aphasia community, and positive interactions between mixed ability members of the community. We recognized that the art form of theatre has the opportunity to provide increased visibility for the neuroatypical participants through the sharing of their stories, though their representation is admittedly limited when those stories are gathered and documented by volunteers, curated by a playwright/director, and potentially performed by neurotypical performers. In an effort to

address this, we planned to enhance the neuroatypical participants’ presence by incorporating digitally projected photographs of them throughout the performance; while this did not achieve the same level of visibility as having them perform would have, it was an effort toward this goal.

One could argue that positive interactions between the neuroatypical participants and the neurotypical volunteers were already achieved in the community building and interviewing that took place during the fall semester. However, while all of the neuroatypical participants interviewed were invited to perform in the final piece, we recognized that, were they to choose not to, they would lose agency due to their words and stories being performed by others. Hoping that many of the interviewees, as well as others with neurocognitive disabilities, would be present at the final performance, we increased our attention to this goal by adding a post-performance community dialogue. During this dialogue the audience and performers would break into small groups, striving for both disabled and non-disabled individuals in each group, to share their responses to the questions raised by the performance. Again, this is not the same level of inclusion and collaboration we initially hoped for, but allowed us to advance the project in a way that kept the exchanges between the neuroatypical participants and neurotypical volunteers and audience members at the forefront of our choices.

Inclusion at a Product-Driven Pace

It is common in the field of theatre to discuss process versus product; often, projects are defined as process-driven (where the emphasis is on the experience and growth of the participants) or product-driven (where importance is placed on a polished, quality final performance). While the ACTP was process-driven, the looming final performance and unexpected revisions to our project plans caused us to need to adopt a swifter pace and to more

clearly establish delineations between the directors and the actors; these logistical needs created a rehearsal process that felt more product-driven. In this section of the paper, I will examine the tensions between our desires to be inclusive and our necessity for a product-driven pace.

As we solidified our final script and prepared for rehearsal, we recruited theatre student volunteers who, along with two of our non-disabled volunteers from the fall semester, would rehearse and perform the staged reading. To accommodate the scheduling needs of the theatre students, we created a condensed rehearsal period of three sixty-minute evening rehearsals. We suspected that three hours of rehearsal would be sufficient for theatre students with previous acting experience (although admittedly this was making an assumption about the abilities of these performers), and as the majority of them had no previous investment in the project we used a condensed rehearsal schedule to garner more volunteers and work within their busy schedules.

This new model, however, created a tension with the neuroatypical participants, who were still invited to participate. Two aphasia participants that were previously interviewed did participate in the three rehearsals and final performance, but for others, evening rehearsals presented scheduling challenges for transportation needs, the schedules of their caregivers, and participant cognitive fatigue. Moreover, the quick pace of the sixty-minute rehearsals, now focused on our swiftly approaching final performance, was a familiar efficiency to the theatre students but not as conducive to the cognitive processing time required for the aphasia participants.

It is unknown whether more neuroatypical participants might have attended rehearsals had they been scheduled at a more convenient time. In reflection, I recognize that the schedules of the theatre students were championed over the needs of the neuroatypical participants; the

neuroatypical participants had historically not attended sessions, and we found ourselves with a completed script and in need of performers. But was it for this reason that we created a schedule to accommodate the theatre students, or was it also us centering our own perspective as non-disabled leaders in the process?

As Alison Kafer describes in her use of the term “crip time,” we were asking any disabled participants who wanted to be a part of the final performance to bend to our expectations of time, rather than “bend[ing] the clock to meet disabled bodies and minds” (2013, p. 27).³ As the ACTP artistic director, I believed this model was necessary to work toward a presentable final product, though even now I am questioning what or whose standards qualify a performance as “presentable,” and where individuals with disabilities fit within that notion. We recognized that our rehearsal schedule presented challenges to the neuroatypical participants, but attendance records suggested that they were less interested in performing, and more interested in having their stories told. However, we may have found ourselves caught in a vicious cycle, where our assumptions that they did not want to participate in rehearsals made us design a rehearsal process that was neither accommodating nor appealing to them. It was not until I was standing in the rehearsal space with two aphasia participants that I realized how quickly one hour could fly; when working with individuals with delayed speech, even simple introductions took several minutes. Moreover, the quick pace with which I am accustomed to delivering instructions as a director of theatrical productions was a challenge to the processing time of the aphasia participants.

³ The word “crip” is used as an inclusive term to recognize the vastly unique needs of all individuals with disabilities, and disabled people who are marginalized for reasons in addition to their disabilities (such as race, gender, or class). The term “crip time” is used in this spirit as an extension of Crip theory.

However, as the overall director of the Adaptive Community Program, Sherod continued to champion for the neuroatypical participants to be on stage during the performance. Three additional neuroatypical participants, for a total of five, expressed interest in being on stage during the performance, although these three were not present for any of the rehearsals. To accommodate their desire to be on stage despite their absence from rehearsal, the decision was made that they would be present on stage. They would then move to the front of the stage as their story was spoken by an accompanying theatre student; the theatre student would place their hand on the shoulder of the aphasia participant to signify that they were telling that person’s story. As we made these plans for how the neurotypical actors would interact with and incorporate these unrehearsed disabled participants on stage, my fear of tokenism deepened. What message would it send about visibility and inclusion to have the neuroatypical participants present on stage, but not engaged in any dialogue or movement?

The Performance

After the successful completion of the three-rehearsal period with two neuroatypical participants and six neurotypical undergraduate volunteers, we arrived at the Dr. Phillips Center for the Performing Arts for our final private performance on April 6, 2018. As described in the previous section, we made arrangements for the three neuroatypical participants who did not attend rehearsals—Dawn, Mary, and Ken—to join us prior to the performance to rehearse spacing and transitions. While I had been previously concerned about the narrative that might be conveyed by these silent and still bodies on stage (a choice, as aforementioned, made so that they could participate in the performance without any prior rehearsal time), I had no idea just how impactful their presence would be to our final performance.

As described in the incident that opens this paper, Dawn’s absence from the rehearsal period meant that it was not until the day of the performance that we realized we had mistakenly combined the stories from two interviewees into one. Minutes before opening the doors to the audience, actors worked with Dawn to fact check all of the lines to determine which were about her and which were about the other interviewee. Meanwhile, I communicated script changes with the remaining actors and technicians, as this change created several cuts, including some prerecorded voiceovers. After everything was sorted, we realized that there was little in our script that was about Dawn, the result of her interviewer not submitting much content following the interview (a surprise, given Dawn’s bubbly and charming personality). Faced with my fear—that Dawn would simply be seen as a token body on stage rather than someone with a story to celebrate—we made a drastic last-minute adjustment. I asked one of the neurotypical performers and Dawn if they would be comfortable conducting a live interview on stage at a marked point in the script. They both agreed, and the result was an intimate, authentic, memorable moment in the performance. Witnessing this live interview allowed the audience to appreciate what the interview experience was like during the development of the script, and to see a genuine, unscripted conversation between two people with varying abilities. It created a shared exchange between Dawn and the neurotypical performer who interviewed her; both participants were jointly responsible for co-creating this organic and spontaneous moment. As a theatre practitioner, I delighted in how improvisation added another layer to the theatre forms explored in the script. Given the opportunity, I would repeat this choice in future performances of this project, granted with more time to prepare. It is not lost on me, however, that this drastic adjustment was made successful only because Dawn had the cognitive and verbal skills to

recognize that she was being misrepresented, to articulate that point, and to successfully engage in an onstage interview during the final performance.

When Mary arrived, she expressed interest in reading her story aloud for the audience. While the various interviews were integrated throughout the text, several accounts of the strokes or accidents that led to their neurological deficits were kept intact in monologue form, and Mary worked backstage with some of the actors to practice speaking her monologue. The actors generously and enthusiastically supported Mary in this moment, and while it did not create a major change to the script, similarly to Dawn’s case I now question what would have happened had Mary’s cognitive and verbal abilities not allowed her to both share her desire to tell her story and to do so on stage. Since some of the other neuroatypical participants required their own microphones or projected captions in order to be heard and understood, this last-minute change could have been technologically more difficult to accommodate without advanced preparations and without Mary’s level of verbal skills. I am left troubled by the notion that, had Mary not been able to communicate with us in this way, we might have been unaware of her desire to tell her story on stage, or even if we did understand her desire we might not have been able to accommodate with such short notice. This realization causes me to continue grappling with other ways in which non-disabled facilitators could strive to better communicate with disabled participants (perhaps through gesture or kinesthetic responses), and to continue seeking more diverse ways that these participants could share their stories other than verbally.

While Ken did not speak during the performance due to the severity of his neurological injury, his presence on stage was equally impactful to the final performance. Ken remained emotionally engaged throughout the performance, and his vocal responses of laughter and

“Ahhh!” solicited strong reactions from the actors and audience alike. Considering that the majority of the theatre students were brought into the project for just the final rehearsals, this opportunity to meet and interact with Ken (as well as the other neuroatypical participants) brought a new level of emotional understanding to their performance. And, as Sherod predicted, when the script referenced Ken’s endearing gesture of kissing his fingers and pointing toward the sky, he was always right on cue.

The connections and communication between individuals with disabilities and those who are non-disabled carried from the performance into the post-show discussion. Led by a psychology student facilitator, the audience and actors were encouraged to mingle into groups of 4-5, striving for mixed abilities within each group. The facilitator then asked questions such as “Which moments in the play resonated with you and why?” and “What are the needs of individuals with physical or neurocognitive disabilities, and how can we as a society better work to address those needs?” Participants were given five minutes to respond to each question within their small group, and then the opportunity to share with the full audience their findings. While I was thankful that we included this effort to further engage individuals with disabilities and those who are non-disabled (both performers and audience members), the post-show discussion was flawed in its efforts to create an inclusive dialogue. Five minutes was not enough time for some participants to respond to the questions, and the noise level in the theatre challenged some participants’ cognitive processing and vocal abilities. While I could not be present in each small group discussion, I observed that within my own group, one participant with aphasia appeared frustrated with her inability to articulate her thoughts, and she was often cut off mid-thought as the facilitator moved to the next question. This again pointed to the tension between needing to keep on schedule and the need to accommodate “crip time.” Furthermore, all of the commenters

who volunteered to share reflections in front of the full audience were neurotypical individuals, suggesting that those with disabilities either could not, or did not, feel empowered to engage on this level. In reflection, I am struck by how in our planning and facilitation we again centered our perspective as non-disabled individuals. The discussion format and questions were determined by a non-disabled individual, facilitated by a neurotypical performer, and the individuals most seen and heard in the discussion were the neurotypical individuals who volunteered to speak. In future iterations, we could seek input from the disabled participants on questions they would like to pose, engage them as discussion facilitators, and explore ways in which we could better structure the discussion to make it more inclusive.

Despite the shortcomings of the discussion portion of the event, the audience and performers responded positively to the show and discussion. The energy continued into a lobby reception, where audience and performers alike had the opportunity to respond to the event through writing or photographs, elements that were incorporated to offer various modes of expression to nonverbal participants. In writing, audience members shared thoughts such as “Powerful, real, emotional performance. I laughed. I cried. I will remember it forever!” and “Thank you for this experience and the lives you touched today!” and “Courage.” One of the neuroatypical participants replied with one word that speaks to Sherod’s original intent to address the depression and isolation expressed by those with acquired neurocognitive disabilities: “Friendship.”

Conclusion and Future Model

Given the unexpected shifts in the final performance, it became apparent that Sherod’s initial instincts were correct: while some of the neuroatypical participants appreciated being

included in the interview portion of the project but did not want to perform, others were eager for their time in the spotlight. What I perceived as lack of interest was more likely due to barriers in attending rehearsals due to participant and caregiver schedules, transportation, and cognitive fatigue.

Despite the challenges presented in multiple revisions to the ACTP, the process helped us arrive at a repeatable and sustainable model to serve our core project goals: providing a theatrical opportunity for neuroatypical participants, increasing visibility of individuals with neurocognitive disabilities, and providing meaningful exchanges between disabled participants and non-disabled volunteers. This final model consists of seven components: 1) the project leaders observe activity at Aphasia House (or equivalent partner facility) to learn about the population and the culture of the facility prior to the start of the project; 2) community-building and trust-building exercises for any interested participants, both those with acquired neurocognitive disabilities and neurotypical volunteers; 3) a one-day intensive interview process, during which teams of volunteers interview individuals with acquired neurocognitive disabilities and report back on their interview findings through audio recordings, transcriptions, and personal reflections; 4) a playwright(s) combines the raw material into an ethnographic script using verbatim quotes; 5) a director(s) and both disabled and non-disabled actors prepare the script for a staged reading or full performance; 6) photos, video, and audio recording are incorporated as available and appropriate to offer increased visibility to the interviewees who may not want to perform onstage; and 7) the performance is accompanied by a post-performance community dialogue to incite interactions between performers and audience members with mixed abilities.

The above model is still flawed, as evident by some of the challenges faced in the pilot year of the ACTP. The neuroatypical participants, who already face neurocognitive challenges in the communication of their stories, have their agency over their stories thrice-removed from them in this process: first, their stories are interpreted and reported by the interviewees; second, the inclusion or exclusion of their stories in the final script is at the discretion of the playwright; third, should they choose not to perform in the final performance, their stories are then interpreted by neurotypical actors. Ways to give further agency to the neuroatypical participants might include encouraging them to write or record their own stories (depending on their physical and neurocognitive abilities), including them as playwrights, creating a formal process for them to offer feedback on early drafts of the play, engaging them in the development of the post-show discussion or reception, and inviting them to observe rehearsals to provide feedback to performers. Of course, each of these suggestions must take into consideration each participants' varying communicative needs.

Another challenge is when and how to incorporate the neuroatypical participants into the rehearsal process and final performance. As discussed, the three-rehearsal period to prepare for the final performance did not allot ample time to accommodate the needs of the disabled participants, nor was it scheduled at a time that suited their transportation and cognitive needs. In the end, I commend Sherod for continually championing for the opportunity for them to be on stage, and for her recognition that their absence in rehearsal was likely not due to lack of interest. However, while we worked quickly in the spirit of accommodation to integrate Dawn and Mary's requests into the final performance, had they needed additional accommodations such as subtitles or individual microphones we may not have been able to meet those needs. This could have been alleviated by requiring neuroatypical participants who wanted to be on stage to attend

just one final rehearsal, a compromise that would hopefully accommodate their transportation needs but still allow the theatre technicians and directors a few days to make adjustments rather than mere minutes. However, I suggest that no measures could have prepared us for the fact that these participants wanted to speak on stage, given their lack of attendance in rehearsals and their previously expressed desire to be on stage but not speak. Perhaps these last-minute changes were the result of the magic of the limelight, which brought out of the neuroatypical participants a desire for self-expression that even they had not previously realized. If this project or a similar is repeated, I may simply go into the performance better prepared to expect the unexpected and with accommodations and inclusion at the forefront of my goals.

More importantly than the logistical insights gained from the ACTP pilot year are the larger questions it leaves about what inclusion and access look like for the creation of theatre in the rehearsal room, on stage, and in the audience. At the crux of this experience was my own frustration that we were not able to receive important information from our participants: that they did, in fact, want to be involved despite their spotty attendance. My experience with ACTP has encouraged me to continue reimagining the theatre-making process to create space for people with disabilities. How can theatre artists discover (or rediscover) the devising of original theatre pieces, the rehearsal space, the ensemble, the audience, the performance, audience/actor interactions, and the ways in which an actor’s body, voice, and mind is present and expressed in performance? Watching the unscripted interview between Dawn and the neurotypical student performer reminded me that the lines can be blurred between what is theatre and what is theatrical. If we as an audience rarely have the opportunity to watch an individual with a disability and one who is non-disabled interact, a simple exchange can take on theatrical

properties; the characters of real people and the conflict of communication challenges can have the same intrigue as any dramatic plot when presented with vulnerability and authenticity.

In reflecting on the Adaptive Community Theatre Project, I return again to the word “adapt”; when I as a non-disabled individual create experiences for those who are disabled, am I asking them to adapt to my expectations of norms, or am I working to actively adapt to their specific and varied needs? While we were constantly revising our model throughout the arc of the ACTP, I question whether we were truly adapting, as the shifts we made as non-disabled leaders were based on our perceptions and opinions that may have projected assumptions on the disabled participants.

Despite the many shortcomings and opportunities in the pilot of the ACTP, I know it was our intent and our goal to best serve the project and all of its participants, evident by the ways in which we constantly adapted throughout the process and performance (even if at times these adjustments centered our perspective as non-disabled leaders). Moving forward, I hope to challenge myself and the non-disabled people with whom I work to be willing to further de-center our own experiences to better make space for the bodies, voices, and perspectives of disabled participants in the theatre process. In doing so, from first rehearsal to final performance, may we actively practice the ways in which we make space for those bodies, voices, and perspectives in everyday life.

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