

Article

Seeking Performance Sustainability
within Disability

Seeking Performance Sustainability within Disability

By Molly Joyce

Introduction

We want to give our all as performers, but we don't want to give so much that we're unable to do anything for three weeks after. That's the conundrum as artists; we're all willing to push ourselves for our artistry, but what happens to us when the presentation is done? (Christine Bruno, 2022)

The above quote is from Christine Bruno, a disabled actor responding to what sustainability looks like for presenting her work. For me, sustainability involves an overall endurance and rigor in maintaining and developing an artistic practice, especially in this case with performance and the inevitable wear on the body. This question is deeply personal for me as a disabled artist in music and performance. At the age of seven, I was in a car accident that nearly amputated my left hand. Following the accident, I transitioned from instruments including cello and trumpet. I was eventually drawn to music composition, as I did not have to strongly consider what my physically impaired left hand could or could not do since it primarily involves writing for other performers. However, as my practice has extended into performance, further issues concerning my disability have emerged. Specifically, I use my right hand more frequently than my left hand. Therefore, as my performance activity has developed, specifically with the impact of COVID-19 and more time on the computer in consistent, static physical positions, I have noticed more significant pain in my right hand. This pain has caused me to question the overall sustainability of my performance practice. While I have sought physiological answers for this, I still wonder how to develop sustainable performance practices to allow for long-term longevity and endurance with my artistry.

Therefore, as someone who acquired a disability and is continually adapting to my changing body, I have become curious about how collegial disabled artists across performance implement sustainability in their practices. Artistic sustainability and endurance can sometimes feel like an endless task for any artist, and especially for disabled artists with embodied and accessibility challenges, it is ever more pertinent to investigate further.

Thus, for this article, I interviewed dancer Antoine Hunter, actors Christine Bruno and Gregg Mozgala, and media/sound artist Andy Slater on what sustainability means to them regarding practice, process, and presentation. I chose these artists because their practices span discipline specialties, disabilities involving physical, hearing, and vision impairments, and a further range of identities, including race and gender. While these viewpoints may not be sole representations of the disability community, they hopefully offer singular insights into the practices of disabled artists in performance.

Context

With my disability, I have to rely on other people for assistance. They need to accept and acknowledge that I know what's best for me, and that if they're not blind, they're wrong. (Andy Slater)

Throughout artistic disciplines worldwide, there has been an increasing and vital presence of disability arts. Sutherland (2005) defines it as “art made by disabled people which reflects the experience of disability” (para. 2). Disabled artists and disability artistry as a concept have become more prevalent, fueled by contextual and scholarly considerations of the intersection of disability and aesthetics, performance, and culture. However, as disability artistry has become more widespread, disabled artists are continually at the margins of mainstream art contexts and sustaining one's practice with disability is not equitably considered.

I will therefore detail facets below to provide context and theory for the interview content, share methodology and excerpts from the interviews, discuss emerging themes, and provide recommendations for proceeding. While my engagement with disability, performance, and sustainability scholarship is not comprehensive, to make space, I have opted to hone in on a few readings that inform an understanding of how disabled artists can implement sustainability.

Disability and Performance

Private bodies and public stories meet in the performance. Difference leaves its allocated spaces and mixes in the street. (Petra Kuppers 2003, p. 1)

The field of disability studies, and specifically disability culture and arts, largely emerged in the 1980s and 1990s, with early scholarship from Michael Oliver (1990), Rosemarie Garland-Thomson (1997), and Simi Linton (1998). An essential output is Petra Kuppers's *Disability and Contemporary Performance: Bodies on the Edge* (2003). She investigates how disabled performers challenge stereotypes and disrupt existing assumptions about disability and artistic practice. Kuppers proclaims that disabled performers are “often aware of the knowledge that have been erected around them” and how these views vary from pity to helplessness (ibid, p. 3). She expands on how disability is never secondary for the disabled; it is always simultaneously primary and secondary (ibid, p. 14). Therefore, disability performance begins to enact the clashing of stereotypes and knowledge (ibid, p. 11).

Carrie Sandahl and Philip Auslander extend Kupper's discussion of primary and secondary roles by considering social and personal implications. In *Bodies in Commotion* (2005), they define disability as a disjuncture between body and environment (p. 62). They explain how disabled bodies are “bodies in commotion,” dancing across artistic and discursive boundaries and challenging our understanding of disability and performance. Sandahl and Auslander elaborate that performance outlets provide prime platforms for considering disability since performance revolves around the deployment of bodies in space. It allows us to consider the “ways in which disabled people choose to represent themselves” (ibid, p. 76). Ultimately, they describe how the disabled performing artist holds a “double-edged sword” in exhibiting the body as a material object and metaphor, representing a set of experiences and ways of being (ibid, p. 825).

Disability Aesthetics

We cannot get beyond the fact that we are bodies. The body is, simply put, where everything in human culture begins and ends. (Siebers 2010, p. 135)

Tobin Siebers pioneered the concept of disability aesthetics, describing it as prizing “physical and mental difference as a significant value in itself” (Siebers 2010, p. 19). He elaborates that it drives forward the appreciation of disability through art, and I would extend to the artists detailed in this article. They recognize disability as a legitimate identity and experience through artistic outputs and as a resource for creative practices. Siebers also describes the beauty of disability as compelling imagination on the “basis of accessibility rather than exclusion” (ibid, p. 68) and, therefore, training audiences to accept rather than reject differences (ibid, pp. 70-71). However, as detailed in the interview excerpts below, the challenge often arises when the personal, yet political experience of disability intersects with sustaining the disabled artist’s practice overall.

Disabled Artists at the Margins

There is a lot of talent offered by disabled artists, which audiences will never be able to see as long as disabled people are deprived of their opportunities to present their work. (Rosanna Kataja 2020)

Across disciplines, disability is often the least represented among artists and arts workers. For example, in the United States and the United Kingdom, an estimated 25% of the adult population have disabilities (Penty 2020) (Kataja 2020); however, disabled artists and arts sector workers typically make up the least represented group in the performing arts field.

Within the performing arts, disabled artists face substantially more significant obstacles than nondisabled artists, often due to a lack of inclusivity and accessibility (Kataja 2020). While the platform for disability arts is more developed than ever (Penty 2020), disability art and performance are often “haunted by past cultural production” due to ableist facets that shape flawed cultural norms that still resonate today (Jones, Changfoot and Johnston 2021, p. 324, 328).

Therefore, the continual lack of representation for disabled artists leads to a flawed cycle that results in practicing disabled artists frequently not being represented, not included, and not having equitable artistic spaces and careers. This leads to a lack of sustainability in pursuing compelling careers, which will be detailed multiple times in the accompanying interview excerpts.

Sustainability

We cannot have a conversation around sustainability without getting everyone to the table. (Beyond Green 2019)

The disability community is traditionally left out of sustainability conversations. Disability is seen as a “blind spot” in such frameworks (Miethlich 2019) and is not often part of sustainability metrics (Beyond Green 2019). However, as Beyond Green points out, sustainability is about more than the environment. It is about the people that shape the environment, including disabled voices, and therefore critical to incorporate these voices when considering sustainability contexts. For

practicing disabled artists, sustainability frequently comes up as a query of how long a disabled artist can effectively keep practicing and in what frameworks, as well as in consideration of their artistic community.

A Methodology of Authenticity and Mutual Experience

In my work, what I bring to the stage is things people are afraid to talk about. (Antoine Hunter, 2022)

My questions focused on facets related to performance sustainability, such as endurance and perseverance, solo and collaborative endeavors, the creative process, and presenting one's work. These pillars of approach and presentation are continual lines of inquiry for my artistic practice, especially with varying realms ranging from solo to collaborative endeavors across disciplines. This questioning includes solo contexts, such as composing on the computer and overusing my right hand, or collaborative contexts, such as establishing successful accessibility frameworks with others. Furthermore, this involves presentation, in attempting to get one's work heard and seen but also implementing accessibility with it.

During the interviews, I asked four questions to each interviewee orally. I recorded each interview via Zoom and my phone and attempted to incorporate as much accessibility as possible. For example, with Antoine Hunter's interview, I hired a sign language interpreter and enabled Zoom auto-captions to incorporate greater verbal speech accessibility. For length and clarity, I edited the responses of each interview, and the interviewees reviewed them to ensure their viewpoints were accurately represented.

Given that this study involves four participants, my intentions are not to theorize on a grand scale but rather to offer individual viewpoints that provide insights into perspectives of sustainability and disability regarding performance. In addition, I hope that these stories will spark sharing of other accounts and ongoing inquiry into the lives and practices of disabled artists. My goal is to offer many interpretations within a continuous process of constructing and reshaping meaning (Smith 1993), and therefore I rely on an interpretive approach to inquiry. Now I pass the metaphorical microphone to Christine, Antoine, Gregg, and Andy.

Interviews

What does sustainability mean for you as a disabled artist working in performance?

Christine Bruno stated that sustainability means constantly working on her craft. This is more difficult in theatre practices because she feels the need to work herself beyond her limits: "If I don't push myself, there are always ten people behind me – or a hundred – willing to work to the point of exhaustion." She continued that sustainability has been more difficult during COVID-19 because more is asked of actors, such as self-taping auditions. For Bruno, that is an added access consideration, adding further financial costs such as an in-home voice-over setup. She expressed how these facets add hours to preparation time so that by the time she gets to acting, she is exhausted and preoccupied with technical considerations typically handled by a casting director.

For Antoine Hunter, sustainability is respecting each other's individuality as a "capsule of intersectionality." He is often in inaccessible spaces where it is challenging to make art; therefore, respect and continual conversation about access are essential. Additionally, Hunter noted that being

disabled is expensive, such as paying for hearing aids and caretakers. Therefore, sustainability for disabled artists requires sufficient funding to support one's needs.

Gregg Mozgala responded that sustainability is a term often discussed; however, he has never clearly defined it for himself. He articulated the need to expend energy efficiently, especially as he ages. Mozgala noted the lack of recognition for disabled artists within the arts field; the longer he is artistically active, the "more the lack of attention from the larger field becomes apparent" to him. He added that there is incremental progress; however, it is astounding to him "how little attention and consideration" goes towards disabled artists. Mozgala added that sustainability introduces questions of how to stay interested and animated, especially in contrast to the obstacles actors face to practice their art, along with "inherent obstacles and systemic ableism" for disabled actors. A visible physical disability becomes "double-edged," as it has provided him with opportunities. Yet, simultaneously, the possibilities are "very few and far between." Mozgala is, therefore, "constantly balancing and negotiating" those poles, namely the tension in his life along with the "genuine, actual physical tension" within his disabled body.

For Andy Slater, sustainability correlates with health and connection to his body and routines. He stated that "keeping routines solid and sustaining them" is essential for his ongoing work, even if he is outside his comfort zone or expertise. Slater also expressed a desire to make everything as accessible as possible. With his disability (blindness), he has to rely on other people for assistance; therefore, they need to accept and acknowledge that he knows what is best for him, especially if they are not blind. Lastly, Slater described how sustainability goes beyond himself. It is "much more than keeping my physical self under control and manageable, but also sustaining the relationship between my collaborators or curators or whoever is commissioning me."

What do you need to sustain your practice?

Bruno commented that during the pandemic, she discovered that time is an access need for sustaining herself, especially for embodying a role. However, she has not figured out how "to ask for that time as a reasonable accommodation effectively," and sometimes, her work has suffered because of it.

Hunter expressed that communication is necessary to sustain his practice. However, he articulated that too much communication is based on verbal language, and as a Deaf person, he desires more patience in communicating with him as an individual.

Mozgala stated that accessing his body, nervous system, and finding unity between the two is essential for sustaining his practice. For years he thought he had no choice with his physicality and disability, as his cerebral palsy is "an incredible bully" within his body demanding attention. Finally, however, he found a way to communicate with and work to rewire it. Dance gave him a "greater understanding, awareness, and way to communicate and articulate" not only with himself but with other people. Therefore, he makes a conscious decision every day to calm his body and nervous system on a cellular level. Often, an artistic project will give him a frame for this care: "the work becomes the reason to take care of myself and be more gentle with myself."

For Slater, he ensures additional time for soundchecks to learn the stage space, ask the production team questions, and set up equipment without interruption. Since he sets his equipment up strategically and by touch due to his low-vision, he needs to ensure that nothing will be moved between soundcheck and performance. Therefore if he can prepare everything accordingly, he knows he took every cautious step possible, contributing to his confidence in performing.

What do you need to sustain creative processes, either solo or collaborative?

Bruno expressed that community is critical for sustaining her creative process. Especially with a community of disabled individuals, there is much less need to “expend emotional labor to educate nondisabled folk,” which leaves time and energy to focus on art.

For Hunter, accessible space is a priority. He is “always fighting for space to be accessible for all,” ranging from bathrooms to elevators, and wants everyone included.

Mozgala relates it to “awareness and a sense of community.” In the past, he was distanced from others because of his cerebral palsy. However, he realized it is a human experience. Mozgala elaborates that disability and theater allow him to be a person: “Theater enables me to be more human, which means less alone.”

Slater responded that ensuring communication is there and sustaining the trust of his collaborators is essential. Being informed of collaborators’ processes is helpful to “know how they’re going to do it and that they can do this,” and for him to know when to back them up musically if necessary.

What does sustainability look like for presenting your work?

Bruno described how acting is different because it is a collaborative process. Especially with better representation of disabled actors, Bruno receives more auditions than ever. She, therefore, has a “tendency to push everything else in my life to the back burner when an audition comes in because of the time-sensitive nature of auditioning.” She elaborated that that way of working is “not sustainable in the long term” because she is active in many different areas; therefore, time management is crucial. She now builds additional time in rehearsals or performances, along with bodywork, to be in constant dialogue with her body: “It will always tell me what it needs from me to support me best.”

Hunter commented that accurate representation is necessary for sustaining his artistic presentations, particularly having the Deaf community trust that he will give accurate representations. In addition, he wants to bring to the stage things people are afraid to talk about, such as Deaf experiences in the prison system. For example, many Deaf individuals stay in prison longer because they do not know how to pay taxes or have an interpreter to assist. Hunter explained that the “only reason that happened was the lack of information,” and he seeks to highlight these issues on the performative stage.

Mozgala responded that maintaining his career is tied to “doing work and telling stories and connecting with other people to make that happen.” He has become a producer, director, and arts administrator as a necessity and desire to stay connected. In particular, he did not see someone like himself represented on stage until he was on it. He realized that the “general public’s audiences had no frame of reference or context for what my experience is” and has a continual curiosity for how to express his experience best. He furthered that “if every character I am going to play is to have cerebral palsy, ...how do I bring that into the character in both large ways and small?” As a result, he is often an audience’s first exposure to a visibly disabled actor on stage. This engagement keeps him sustained in presenting work, as it helps him better determine inquiries regarding artistic practice and content creation. At the same time, he is frustrated with often being the sole representation of disability: “I’m exhausted, I’m fucking tired. But, at the same time, I can speak in a way I know many people can’t.” However, he acknowledged that his form and existence “puts fear in people,” which can be an incredible power and attention: “I think that’s why I’m an actor going on stage.”

Because in my own life, I have a hard time with people looking at me. I might become more whole if I can make that attention spectacular.”

For Slater, he needs not to spread himself too thin but simultaneously sustain interest in his attention deficit disorder. Therefore, he seeks ample room for spontaneity, such as improvising and continually being informed by research, fieldwork, or demos.

Discussion

As a disabled artist, the longer I'm in this field...the more the lack of attention from the larger field becomes apparent to me. And while I can see incremental progress, it is mind-boggling how little attention and consideration goes into this area. (Gregg Mozgala, 2022)

In light of the above interviews, I have drawn out the below themes:

Theme – Accessibility

All of the artists mentioned a need for greater accessibility within their practices. Accessibility is a constantly changing facet within disability populations and, therefore, can be challenging to define precisely. Carolyn Lazard aptly describes accessibility as an “ongoing, creatively generative conversation that evolves with the needs of the community” (2019). I believe accessibility means having options and flexibility, specifically for artistic contexts with multiple sensory outputs of the presented content.

Hunter and Slater expressed how making everything as accessible as possible is crucial, especially within artistic spaces. Hunter added that access is the first thing he checks for with creative processes, especially language interpretation. Petra Kupperts (2003) states how her disability experiences shift with time, yet many view accessibility services as a stable, fixed decision. Kupperts expands that breaking these certainties around access needs is critical to many disabled people (2003, p. 8). I would extend this to the artists interviewed, viewing access as constantly in flux, and leaving room for flexibility and accommodation.

Theme - Interdependence and Community

The artists mentioned belonging and community as integral to sustaining their practices, especially a constructive relationship with colleagues. As Gerpott et al. (2018) write, interdependence is a “fundamental characteristic of social interactions” (p. 716). For disability culture, interdependence evolves as understandings of embodiment, culture, and accessibility develop, especially since the lives of disabled people are “most of all characterized by continuous dependence on others” (Bostad and Hanisch, 2016, p. 372). Trust in community and relationship with others was also mentioned. Bruno mentioned a “shared understanding of folks’ lived experiences.” Hunter expressed being consistently involved in community, especially artistic communities that involve various disabilities. He highlighted that it was necessary to have the Deaf and disabled community trust his dance company to represent their experiences accurately. Slater emphasized sustaining trust in collaborative relationships, while Mozgala continually makes space for others who understand the shared experience of disability.

Theme - Care

The interviewees expressed a desire to implement care within their artistic practices, particularly self-care. Auslander and Sandahl write that caring for the body requires specific ethics, “one that takes touch as axiomatic, emotional attachment as a value, and interconnection as constant” (2005, p. 1940). In particular, Bruno articulated that self-care is critical for managing multiple tasks and job duties. Mozgala expressed the need to calm his body and nervous system daily, and how structured projects give him a framework to be gentle.

Theme - Time

The artists desired a greater consideration of time within their practices. Petra Kupperts writes how performance is time-based and thus “takes time, rehearses time, restructures time, overlays time” (2003, p. 8). The disabled experiences provide further complications to this sense of artistic time, with greater time requirements resulting from access and physical needs. For example, Slater requires more time than usual for sound checks, specifically to set up equipment amenable to tactile/touch operation. In my experience as a musician, I know soundcheck can often feel rushed. I believe Slater’s sentiment represents a critical need for accommodating disabled artists within mainstream artistic contexts. Additionally, Bruno added the importance of time management and realizing that time is an access need, especially to feel entirely comfortable in a role.

Additionally, the artists’ sentiments relate to the concept of “crip time.” Kafer (2013) describes crip time as challenging us to reimagine “what can and should happen in time” and “recognizing how expectations of ‘how long things take’ are based on very particular minds and bodies” (p. 27). I believe this relates to the overall longevity and endurance of the disabled body in performance, in considering time accommodations for disabled performing artists to feel comfortable and primed to perform.

Conclusion

Disability is now and will be in the future an aesthetic value in itself in the future. (Tobin Siebers 2010, p. 139)

In recent years there has been a considerable push toward diversity within the arts, especially in response to movements such as #MeToo and Black Lives Matter. Despite these progressive movements and artistic reorganizations, disability and disabled artists specifically are often overlooked. Regardless of audience accessibility advancement, disabled artists are frequently not considered in the creative equation for promoting diversity and equity in the arts.

Kupperts highlights disability as inherently experiential, and “this knowledge stands in a complex relationship to discursive knowledge formations” (2003, p. 15). I believe this experiential knowledge, especially the wisdom offered by the interviewed artists, provides alternatives to normative artistic procedures. Options that ask for more significant support structures surrounding community, care, and time, and not solely short-term, reactive temporary solutions but relatively longstanding measures. Furthermore, I conducted these interviews in February and March 2022. In light of the COVID-19 pandemic, only one artist mentioned the pandemic impacts during their interview. This aspect represents how the discussed issues are not only about the pandemic but much longer lasting.

Additionally, Mozgala highlighted the exhaustion of needing to advocate for ourselves as disabled artists (“the longer I’m in this field..., the more the lack of attention from the larger field

becomes apparent to me”). I continually experience this as a disabled artist. Even if I participate in an artistic performance or panel centered on diverse perspectives, many do not know how to address disability and are even afraid to say the word “disability.” In my view, this represents the lack of recognition of it as a legitimate minority and identity. As Mozgala expressed, this is exhausting. It is exhausting to continually advocate and explain your art form, as one grounded within the experience of disability. It is exhausting to legitimize it to the world, on top of managing one’s disability embodiment and the added physiological issues that come from it.

Lastly, disability is one of the only identities that can be congenital, acquired, temporary, and permanent. All of us are susceptible to becoming disabled and even more severely disabled. Therefore, solutions to supporting disabled artists are not only self-serving but also long-lasting for society. They allow disabled artists to become integral components of the performing arts and counter the flawed view of disability as inferior within society.

Molly Joyce has been deemed one of the “most versatile, prolific and intriguing composers working under the vast new-music dome” by *The Washington Post*. Her music has additionally been described as “serene power” (*New York Times*), written to “superb effect” (*The Wire*), and “unwavering” and “enveloping” (*Vulture*). Her work is concerned with disability as a creative source. She has an impaired left hand from a previous car accident. The primary vehicle in her pursuit is her electric vintage toy organ, an instrument she bought on eBay and engages her disability on an artistic level. Molly is a graduate of Juilliard, Royal Conservatory in The Hague, Yale, an alumnus of the YoungArts Foundation, and holds an Advanced Certificate in Disability Studies from the City University of New York.

Bibliography

- Bruno, C. (2022) Zoom interview with Molly Joyce, 7 March.
- Hehir, T., 2002. Eliminating Ableism in Education. *Harvard Educational Review*, 72(1), pp. 1–33.
- Hunter, A. (2022) Zoom interview with Molly Joyce, 3 March.
- Kafer, A., 2013. *Feminist, queer, crip*. Bloomington: Indiana University Press.
- Kataja, R., 2020. Inclusion, Don’t Forget About Us: Disabilities in Performing Arts. *Harvard Political Review*, (online). Available at: <<https://harvardpolitics.com/disabilities-in-performing-arts>> (accessed 10 April 2022).
- Kupfer, R., 2020. Disabled musicians Face “SIGNIFICANT Barriers” to music EDUCATION, new study shows. EDM.com, (online). Available at: <<https://edm.com/industry/uk-study-shows-barriers-for-disabled-people-music-access>> (accessed 9 September 2021).
- Kuppers, P., 2013. *Disability and Contemporary Performance: Bodies on the Edge* (Kindle iOS version). Abingdon: Routledge.
- Lewis, P., 2020. Disability Discrimination Act: 1995 and now. House of Lords Library, (online) . Available at: <<https://lordslibrary.parliament.uk/disability-discrimination-act-1995-and-now>> (accessed 10 April 2022).
- Mozgala, G. (2022) Zoom interview with Molly Joyce, 3 March.

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Penty, S., 2020. Why is there a lack of disability representation in the arts?._The Boar, (online). Available at: <<https://theboar.org/2020/01/disability-arts>> (14 April 2022).

Sandahl, C., and Auslander, P, eds. 2005. *Bodies in Commotion: Disability and Performance*. Ann Arbor: University of Michigan Press.

Siebers, T., 2010. *Disability Aesthetics*. Ann Arbor: University of Michigan Press.

Slater, A. (2022) Zoom interview with Molly Joyce, 25 February.

Sutherland, A., 2005. What is Disability Arts?. Disability Arts Online, (online). Available at: <<https://www.disabilityartsonline.org.uk/what-is-disability-arts>> (accessed 6 May 2020).

Lazard, C., 2019. Accessibility in the Arts: A Promise and a Practice. New York: Recess. Available at: <<https://promiseandpractice.art>> (accessed 1 May 2022).

