

Editorial

Patricia Morrissey, PhD

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We are living in unprecedented times and, more than ever, it is crucial that our overlapping communities find creative ways to support one another. This responsibility extends to those of us at the Center on Disability Studies, College of Education, University of Hawai'i at Mānoa who have the honor of publishing this journal, *Review of Disability Studies, an International Journal*. I wish to share with you some changes you may anticipate in the journal and the reasons for them. There are four, all related to expanding and supporting our readership and author pool.

First, I am pleased to announce that Raphael Raphael PhD will be taking over as the editor of the journal on October 1, 2020. He graciously agreed to join our staff as editor on June 16, 2020. He has served on the editorial board of the journal since its inception, so he knows the history of the journal and the multiple efforts to make it as vibrant and useful to the readership as possible. He has done amazing work in tracking the perspectives on persons with disabilities reflected in the media in past positions and has taught online courses in disability studies and history for the Center on Disability Studies for many years. Most recently, he has also served as a researcher for the Academy of Motion Pictures Arts and Sciences and their efforts to profile the neglected contributions of individuals with disabilities, as well as other marginalized people in the film industry. I am so pleased that he has joined us. I know he will bring fresh ideas, structure, and innovation to the journal's publication.

Second, as an interdisciplinary publication, we have had an eclectic approach to articles published in the journal over the last several years and have focused only on specific topics, called forum issues, once yearly. To better serve our readers, beginning in December of this year, we will offer readers more thematic ties in the journal. Part of each issue will focus on one specific unified topic. While we will continue to include works in each issue connected to a broad range of topics, we hope these thematic connections will be valuable for readers.

In December, we will focus on the pandemic and how it has impacted people with disabilities in all aspects of their lives. Because we are taking this focused approach going forward, we will be issuing calls for papers addressing a particular topic every quarter. This approach will expand our readership and allow any particular volume issue to become a reference document for many people on an important topic related to disability studies and its intersection with other disciplines, contexts, and social issues.

Third, to better support our increasingly global readership, also beginning in December, we will have two submissions in each issue selected from a range of authors whose native languages is other than English. Their submissions will be printed in their native language, and an abstract of their submission will be translated into English. This is in

keeping with our desire to make the journal a truly international vehicle for presenting and triggering conversations about disability studies worldwide.

Fourth, to better support our varied readers, we are making renewed efforts to make our publication platform as user-friendly and as accessible as possible to all people with disabilities. This will also extend to efforts to make our content accessible and relevant for a global readership concerned with creating inclusive spaces for all.

I have enjoyed serving as editor for the past year and I am enjoying helping Raphael with his transition to editor of the journal. Please share our plans with your friends and colleagues so that, especially in these most extraordinary times, the journal may best support as many in all of our intersecting communities as possible. The challenges of this moment have certainly given us all much to do, much to reflect upon, and moreover, they have made clearer than ever all that needs to change for the better. Continuing to bring disability studies into these global conversations and actions is an agenda we here at the journal embrace with enthusiasm.

Patricia Morrissey, PhD

Editor



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Supplemental Editorial

Raphael Raphael, PhD

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I would like to thank Pat Morrissey for her ongoing leadership. This current issue is a testament to her clear editorial voice as well as the value of the global, interdisciplinary space to explore disability that RDS continues to offer international readers. The power of art is an important theme that weaves through many of the works in this issue. Elaine Gerber's "Theater By the Blind" shows how Art may be an important way to help understand (and express) our collective experience of disability. Gina Wong's "The Role of Assistive Technology in Enhancing Disability Arts" also reveals the neglected role assistive technology has played in the shaping of artistic expressions, from Beethoven to present. Furthermore, it shows how art may at times also help push social/political actions, a process that is itself ultimately tied to educational opportunities and access in the first place. "The Dream: Freud & Szasz in Conversation" by Douglas Waxman also takes a playful, artistic approach to exploring the limits of our psychoanalytical understandings of mental illness.


In the reviews, Maria Teresa Houar's consideration of Cynthia Barounis' *Vulnerable Constitutions* illustrates how essential disability is in our understanding of the politics that inform gender, sexuality and national identity. And Casey L. Woodfield's review of Edlyn Vallejo Peña's edited volume *Communication Alternatives in Autism* explores its innovative mix of personal narrative and theoretical frames to better understand (and minimize) barriers to full participation.

I look forward to talking more about future plans for continuing the journal's service to readers. For now, I wish to briefly mention the editorial team that will be helping to shepherd it: Mary Jean Hande (Associate Editor, Research and Essays); Kara Ayers and Jenifer Barclay (Associate Editors, Topical Forums); Raphael Raphael (Creative Works and Multi-Media); Sona Kazemi and Hemachandran Karah (Associate Editors, Global Perspective on Disability Studies [formerly Best Practices]); and Associate Editor Susan Levy. Sandy Shitanishi will also continue in her role as Managing Editor.

Best wishes,

Raphael Raphael

Editor-in-Chief Elect,
Review of Disability Studies

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Research Article

Theater By The Blind: A Retrospective Look at an Off-Broadway Troupe, an International Blind Theater Festival, and the Making of Disability Culture

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Abstract

This historical, ethnographic account examines Theater By The Blind from 2000 to 2005 and the following disability-art themes: 1) identity politics and authenticity/representation; 2) audio description and the Blind In Theatre (BIT) Festival; 3) gaze and resistance. This paper historically documents an emergent cultural movement and highlights the powerful cultural work of blind theater to challenge stereotypes.

Keywords: blind theater, gaze, audio description

Change the world, she needs it

—Brecht on Brecht¹

Introduction

Theater By The Blind (TBTB) was an off-Broadway theater troupe in New York City that integrated blind, low vision, and sighted artists. In 2008 it changed its name to Theater Breaking Through Barriers to reflect a change in mission to include all disabled artists (see TBTB.org). The reflections herein date from 2000 until 2005 and refer to the original TBTB, when it boasted of being the only professional blind theater company in the United States. Times have changed. What follows is a historical case study about the development of identity and blind culture in the context of emerging ‘disability arts’ (Thompson & Warne, 2018). It centers on three areas: (1) identity politics and issues around authenticity and representation, such as what is, or should be considered, blind theater; (2) the Blind In Theatre (BIT) Festival and the opportunities it created for the development of blind culture, including advancements in audio description; and (3) issues of politics, resistance, and the gaze. My intention is to highlight the phenomenally powerful cultural work blind theater can do and to historically document the vibrancy of this emerging movement. Details show the transformative power of the arts to challenge cultural stereotypes.

A note on language: I use the term *blind* throughout this essay because that is the language of TBTB and the BIT festival. It is used broadly to refer to any level of legal visual impairment (e.g., low vision and partially sighted to totally blind) unless otherwise specified.

Research Methods, Ethics, and the Ethnographic Context

TBTB was founded in 1979 by Ike Schambelan, a sighted Yale drama graduate who loved classical theater and directed many performances of Shakespeare by TBTB in New York (“Our Founder,” n.d.). They were a professional troupe that operated under Equity Union contracts and often received rave reviews (e.g., <http://www.tbth.org/brecht.html>). TBTB emphasized that these were high quality professional productions, and not community theater nor a form of rehabilitation/recreational therapy. In fact, Schambelan would often highlight the quality of their performances— “so good you couldn’t tell who was blind and who wasn’t”—as part of their marketing, promotion, and fundraising pitches (Weber, 2015). This invisibility, of not being able to tell who was blind, served as some form of proof of the excellence of their craft. While this might seem anachronistic in 2020, especially when spoken by a sighted director of a blind company, it is important to remember that TBTB began before the ADA was passed—and the stories herein reflect a world that existed a mere 10 years post-ADA. At that time, this approach was both admirable and problematic, a contradiction that is discussed in greater detail below.

Although I was trained as an anthropologist and worked at the American Foundation for the Blind (AFB) as a researcher between 2000 and 2005, my connection to the theater company was personal. I was first friends with, and eventually married to, one of the company’s blind actors.² Throughout, I identified and was treated as non-disabled. Although I have several invisible impairments that were present then, these were not vision-related. My knowledge about blindness comes both from my professional work as a researcher and ally and through living life with my blind partner.

I had been involved in fieldwork centering around disability generally, and blindness in particular, for nearly 20 years at the time of writing this, in both personal and professional contexts. However, the insights below come predominantly from my role as a participant-observer of blind theater. I use the term *participant-observer* lightly, as I was never an actor and never performed with TBTB. However, I twice attended (2001, 2003) the international blind theater festival (BIT), which has been held biannually in Croatia since 1999,³ and during which I was treated as a troupe member by both the host organization and TBTB. Additionally, between 2000 and 2005 I conducted hundreds of hours of participant-observation: during the week-long theater festivals in the capital of Zagreb; with members of TBTB traveling to and from the festival and around the countryside in Croatia; and at off-Broadway theater performances, readings, and rehearsals in New York City both prior to and upon returning from the festivals. I also conducted multiple intensive, open-ended interviews with blind and non-blind members of the theater companies that attended the BIT Festival. Lastly, using a modified photovoice methodology (Wang, 1999; Sutton-Brown, 2014), both a video camera and audio recorders were made available to troupe members so they could record their own interviews and impressions of the festival and the reactions by the general public to their presence. Some of this content has been integrated into the discussion below.

I received no institutional support or funding for this project. AFB did not sponsor this research, and my invitation to participate with TBTB and attend BIT did not come from my

position at that organization. I took unpaid vacation-time to attend the festival and all the equipment used was purchased privately. Thus, there were also no honoraria provided to participants and no IRB oversight. Nonetheless, my professional ethics dictated that in all cases, troupe members and other festival participants knew that I was both a personal guest and an anthropologist. Verbal consent was solicited prior to beginning any travel to Croatia and again upon being introduced to new theater companies and new festival participants, and I provided accessible/non-print means for participants to contact me. The head of the Croatian troupe sponsoring the festival, Vojin Perić, gave me permission to videotape the performances, rehearsals, and interviews, and performers and interviewees were explicitly told when recording devices were being used. Unless otherwise requested, names and identifying features of the troupe members discussed below have been altered for privacy.

BIT: *Novi Zivot* and the International Blind Theater Festival

BIT is an abbreviation for Blind In Theater, which was chosen intentionally by the festival organizers for its clever word-play. *Bit* (pronounced 'beat') in Croatian also means "the essence of things." As Nina Kleflin, one of the festival producers explained on opening night in 2001, "...Often we say that blind people see the essence of things with their inner eyes, which I think is very important in their theater performances. So this component of meaning, the essence, is also very important. As you know, 'beat' in English means 'the rhythm,' and the rhythm is very important for the plays, especially for our plays."

The performances took place at the Vidra Theatre, a 150-seat capacity, proscenium-type theater located in central Zagreb. The Croatian National Blind Society was located on the third floor of same building and contained offices and other rooms that were used for rehearsals, roundtable discussions, workshops, and social gatherings. There was a stylish café in front of the theater that was frequented by theater-goers who wanted to meet prior to performances for a drink. It was accessible from the street and open to the general public who similarly used it as a gathering space. Bar stools and wall coverings were designed with a variety of tactile materials (such as natural-haired cowhide contrasting with smooth leather), but it otherwise had no obvious indications that it was a 'blind café.' The staff at the café was acclimated to the presence of blind people and this was apparent in their social interactions (e.g., verbally announcing their presence rather than presuming a patron knew they were standing nearby to take their order). In general, the degree of integration I witnessed at the café and in the surrounding businesses struck me as impressive.

The theater itself also integrated blind and non-blind events. Priority for its use belonged to *Novi Zivot*, the theater troupe associated with the Croatian National Blind Society and the organizers of the BIT Festival. However, they hosted mainstream and non-blind performance events there when the theater was otherwise not in use.

The BIT Festival has continued to grow each year. The second year I attended, the program had nearly doubled in size: there were 10 different companies with troupes representing Croatia (2), Italy, Spain⁴, US (3), Great Britain, Slovenia, Hungary, Norway, and Brazil. In previous years it had featured companies from Belgium and Russia as well. The festival is ongoing; 2019 marked the 11th time it has been held. The years I attended the

festival, the organizers provided each visiting company, depending on their size, with one or two translators. These translators doubled as both tour guides and sighted guides, helping blind visitors navigate the city. During performances the translators provided simultaneous live translation.⁵ The translators also performed double duty during performances by providing spontaneous audio description (more below).

Blind Theater and the Politics Of Identity, Authenticity, and Representation

What Is, or Should Be Considered, Blind Theater?

Since 2005, the growing disability rights movement has led to the development and proliferation of a number of professional theater companies with blind artists. Whether the presence of blind performers alone is sufficient to constitute a primary aspect of their identity as a troupe, however, remains open (let alone, how many, or what percentage would be needed to reach critical mass). Further, is it sufficient for a company who employs disabled actors but who otherwise does not engage in a disability identity to consider themselves part of the disability arts movement? Do they have to be performing disability content (whatever that may be), or is their mere presence in the professional arts world sufficient standing to be considered a disability arts organization? These questions were debated at the BIT Festival both years I attended and were pervasive in scholarly venues at that time (Fahy & King, 2002; Lewis, 2004), and they remain ongoing concerns within disability arts (Kuppers, 2014; Thompson & Warne, 2018).

For example, in Croatia 2001, TBTB performed *Misalliance*, written by a playwright without impairments (George Bernard Shaw) and not involving disability issues.⁶ In addition, the performance had a low ratio of disabled to non-disabled troupe members, approximately one to three. (The ratio had originally been about 1:1 but not all actors were comfortable flying within the month after the 9-11 attacks in New York. Further skewing the numbers, that year TBTB also brought with them a sighted stage manager, as well as another sighted partner and myself.) During the time I was involved with TBTB, approximately one-fifth to one-half of the company had some degree of visual impairment, and one of the two co-artistic directors (George Ashiotis) was blind.

TBTB was critiqued by other troupes at the festival that year for being ‘not blind enough.’ In addition, TBTB members themselves made frequent criticism of the content chosen by the director for not being centered around disability themes, not having been written by a notably disabled author, or not containing disabled characters. Other troupes criticized the sighted director as a ‘puppeteer,’ pulling the strings of the blind marionettes on stage. Some other companies also had sighted directors, however the ratio of sighted to blind actors in TBTB made this a particularly poignant issue. In fact, Schambelan *was* reluctant to turn over the reins and allow other members to direct or select works. However, this seemed more about his ego and role in the company than it was, for him anyway, an issue of ‘sighted vs. blind,’ nor did it seem to reflect a belief that blind people were incapable of leading the organization or directing themselves.⁷ Nonetheless, this imbalance violated the “Nothing About Us Without Us” (Charlton 2000) principle of the disability rights movement and was a

notable issue both within the company and for outside troupes. Further, Schambelan's disability politics raised additional questions about 'acting blind' and the value or downside of 'passing' (Brune & Wilson, 2013), as indicated below.

'Acting Blind'— Blind Gesture and 'Blindisms' versus Assimilation and Passing

It was in this context that BIT participants debated what was meant by 'blind theater' and what it meant to 'act blind.' At that time, there was no consensus. Hiding one's blindness or being read as 'not blind' by the audience was clearly important to the majority of participants, even if they chose not to do it in all performances. For them, it served two goals: (1) it substantiated the professional quality of their performance as actors, and (2) it was more about disrupting categories and stereotypes than it was about 'passing.' As Jane, a visually impaired member of TBTB described it, "the goal is *not* passing or true assimilation as a sighted person, any more than it is for sighted actors playing the role of a dog to be truly passing as a dog."

Hana, one of the sighted, Croatian translators, reiterated Schambelan's notion that the invisibility of blindness demonstrated true quality:

"How many barriers they have in front of them...especially when there are three or four blind actors on the stage, how to see each other's faces, how to react, you know, because they can't see. And, how will you make the expression of, let's say, sorrow, if you are sad or something, if you can't see yourself, and make that expression. We can do it in front of a mirror, as an exercise; they can't... so I think you know, this shows they are really really excellent."

By contrast, some BIT participants expressed concern that 'passing' actually disables blind people: that forcing blind people to rearticulate the gesture of sighted people, rather than to explore a fully new, creative form of expression, did a disservice to blind people, that it reinforced an internalized oppression that 'your way of doing things' is less good. This was particularly true in discussions regarding people who have no usable vision and/or have never seen. Dirk Van Den Broeck, the (sighted) director of the Belgian company, *Licht in Zicht*, explained,

"It is more difficult when you work with people who have never seen. They have no language of movement, of gesture. And I am trying to find out something about how they move, how they make gestures. Because I don't think that we have to, that seeing people have to oblige them to move like us. [Other participants interrupted and applauded] ... We have to be creative."

As an outsider and sighted guest—let alone, anthropological observer—I did not jump into the conversation. However, if I had, I might have commented that the director's perspective seems somewhat essentialist, or more accurately, it says more about the stereotypes of blindness (and/or that these people perhaps have not had much inclusive education or been offered effective 'rehabilitation') than it does about some inherent gestural or bodily language associated with poor functional visual acuity or as 'belonging' to blind

people. My position echoes that of the ‘social model,’ which locates disability in the social environment rather than individual bodies (Shakespeare 2014).

By contrast, Vojin Perić, the (blind) Croatian director disagreed with the Belgian director’s politics, stating, “...there are times when a gesture becomes a tic, and this happens unconsciously. And it can deform an artistic creation.” Tics, sometimes also referred to as ‘blindisms,’ have a negative connotation and sordid history within blindness rehabilitation, as a form of behavior that is to be avoided, prevented, and ‘retrained’ (Scott 1981). The Belgian director refuted, “People have to accept that. That’s the way to integrate.”

For Schambelan and TBTB the last point regarding being ‘blind enough’ or ‘acting blind’ also had to do with the de-ghettoization of disability: they felt that it was important for disabled actors not to be limited to performing only disabled content or roles. To be blind and play a non-blind character or to be a blind company that does a standard production of Shakespeare was considered evidence of equality, true integration in the arts.

Who should be performing what types of roles is still debated within disability arts today, although the ‘passing’ is reversed: able-bodied actors are critiqued for playing disabled characters, in what is known as ‘disability drag’ or ‘cripface’ (Davis, 2009; Evans, 2015; Harris, 2014). The desire for theatrical realism—meaning, it is important for actors to not only look like the parts they are playing, but to ‘be’ a member of the group they are portraying (Pao, 2011)—is taken as a given and reflects our contemporary cultural preferences. That is, today’s realism is preferred because it is suggestive of a more authentic portrayal or representation, yet it also has both political and economic consequences (Fox & Lipkin, 2002; Sandahl & Auslander, 2005). Disabled people face a harder time finding acting work than their non-disabled peers, and are rarely, if ever, hired to play non-disabled characters. Furthermore, there are cultural consequences that can result, by informing, reinforcing, or challenging stereotypes about blindness and performance. Even in 2020 it is quite unusual for disabled actors to play non-disabled characters. Yet this is exactly what was happening very early in blind theater. TBTB and the other troupes deserve credit for this progressive stance.

Blind Theater Culture and Audio Description

BIT also provided an opportunity for the creation of blind theater culture. The festival held performances during the evenings and hosted other events (workshops, trainings, information sessions) during the day with translators playing a critical role in facilitating cross-pollination of ideas and interactions between members of the different troupes. Importantly, innovations in audio description (AD), a technique used for ‘translating’ visual material into an aural format, were experimented with both in performances and in workshops. AD is used in television, film, dance performances, many museum exhibits, as well as in live theater. It involves the verbal narration of non-verbal content (e.g., settings, costumes, gestures) generally inserted between dialogue to provide ‘radio-quality pictures’ and is an essential accommodation for blind people in order to have equal access to cultural content. (For readers unfamiliar with the technique, you can hear a sample, and learn more about it, here: <http://www.acb.org/adp/ad.html>). The UK company, Extant

(<http://extant.org.uk>), for example, played with AD to indicate location on stage: louder narration for action closer to the audience, softer narration for items further away. TBTB experimented with ‘open description.’ (‘Open description’ is a term I coined to reference the way that captions are provided to the Deaf community: as either closed captioned—only those selecting this option will see them—or open captioned, meaning they are visible to all). By reading the stage directions written by Shaw aloud on stage, TBTB introduced what they called a ‘Talking Program’ for *Misalliance* in 2001 and performed what may have been the first live piece with open description in professional theater.

While much has been written about AD since then (Fryer, 2018; Kleege, 2016; Kleege & Wallin, 2015; Rodas, 2015; Thompson, 2018), many of the ideas for best practices were explored and debated during the festival. For example, the voice of the narrator as something ‘objective,’ a say-what-you-see approach (see Snyder, 2014) as opposed to something that is part of the tools for storytelling, where it can convey emotion, subjectivity, and interpretation was discussed prominently (see Bridge Multimedia, <http://www.bridgemultimedia.com/audiodescription/>, which has experimented with “social and emotional language”). Maria Oshodi, the blind artistic director of Extant, preferred the narrator’s voice to match that of the ‘vibe’ of the production, such as using a cockney accent for a production based in working class London; using a ‘high class’ or standard English accent for the voiceover seemed jarring and took her out of the performance.

Most AD is designed for a disabled audience. That is, it evolved and remains a way of increasing access to visual content for non-sighted audiences. However, at BIT, some played with AD as a tool for blind actors, not just audiences. By reading Shaw’s stage directions aloud onstage, as TBTB did with their ‘talking program,’ it enabled actors themselves to recognize visual cues, such as when someone had “silently opened the door” or was now “waiting, hidden in the hallway.” Thus, AD has the ability to improve the theatrical experience for blind audiences, but it also can enhance the work of blind actors as well.

This type of sharing, or what anthropologists call cultural diffusion, occurred in both formally structured workshops and informally. It is hard to convey here in academic writing the emotional camaraderie, excitement, and sense of being on the cusp of something profoundly transformative that came from collectively interacting with each other. There was a sense of play and possibility, an overwhelming amount of joy, and of course, always, music. There were spontaneous outbursts of singing and performing, of rhythms and lyrics. Troupes who couldn’t effectively communicate with each other because of language barriers would sing, sometimes individually, sometimes together. Music was a universal language of the festival.

When translators were present, there was a tremendous amount of sharing and cross-cultural comparison—over lunch, in the hallways, and on breaks—about what it was like to be blind elsewhere or how to get non-print access to scripts and other tips of the trade. People discussed how to use high contrast set design or suggested running cords underneath rugs on stage, as ways to increase access for blind actors. The Slovenian troupe saw a TBTB actor on the street and received a quick lesson on how to navigate crowded sidewalks and call extra

attention to oneself with the addition of a Bergman Bell⁸ attached to their white canes. This non-standard rehabilitation strategy also served as another way to invite the public gaze (more below).

Sharing also occurred more formally through workshops. Extant conducted multiple movement workshops that challenged the notion that blindness impedes physical performance. Another company taught the groups how to do improv and used the common experience of housing discrimination against blind people as the subject for spontaneous skits.⁹ The workshops often morphed from information and training sessions into outright acts of resistance. The culture of blind theater is a culture of resistance, and these troupe members overtly and consciously recognized the political nature of their work.

For example, the second time I attended (2003), the companies worked together to collectively perform a piece based on the revolutionary work of Augusto Boal. It had an explicitly political goal and an interactive approach: it was designed to challenge oppression and devise solutions by re-scripting and re-enacting scenarios about blindness in positive ways (Boal 1985, 1995, 1999). Companies also discussed forming an international organization, to gain greater political leverage. And in 2005, the festival intentionally coincided with the national ‘disability pride’ parade and disability rights march, allowing troupe members to be involved in both.

I witnessed these experiences create transformation: in what ‘blind theater’ ought to be, in advancing techniques of audio description, and in challenging the status quo of blind actors and the discrimination they face. As a direct result of interacting with blind people from other countries, learning the rights and opportunities they possessed, the Croatian company legally challenged the admission policy into nationally-sponsored schools for performing arts, which at the time were legacies of the soviet-style state programs that denied entrance to anyone with a sensory impairment (Perić, personal communication, October 8, 2013). The BIT Festival, thus, represents the rise of a nascent social movement, advocating for disability rights. In a broader sense as well, the festival was overtly political.

Politics, Resistance, and the Gaze

The political dimension of the festival was clearly recognized by the organizing troupe. They overtly and strategically tried to harness the power of the arts in the development of the Croatian economy and its symbolic position as a tourist destination in order to advance the cause of blind people. There were flyers hung across town to announce the festival, posters covered bus kiosks, and banners were suspended across the main street and above the central square. These objects did more than provide publicity for the festival. They proudly announced blindness and did so in a non-stigmatizing way. They advertised that BIT was bringing in theater from all over the world, including England and the United States, and the accompanying cultural capital that is attached to places like Broadway, Hollywood, and the West End.

Similarly, BIT also pointed to the role of blind culture in the creation of citizenship for a struggling, post-soviet economy and the extent to which disabled people are able to mobilize

State resources. The Dalmatian coast of Croatia along the Aegean Sea had been a tourist destination for much of eastern Europe and former Soviet bloc countries. However, Croatia was at war between 1991 and 1995. Among other consequences, the war decimated the region's once thriving tourist economy. The first BIT Festival was held only four years after peace accords were signed. *Novi Zivot* (literally, New Life), the blind association that sponsored the BIT Festival, recognized the opportunity to support the larger nation-building mission that was just underway in 1999 when the festival began. They were conscious of this opportunity and successfully exploited it. The festival was pitched as a way to bring in international dollars and to revive Croatian tourism and Zagreb's reputation as an arts center. (Zagreb is also home to an acclaimed international film festival.) The BIT Festival was attended by the nation's Ministry of Culture, the country's Vice President, and the Mayor of Zagreb, all of whom spoke about the social, humanitarian, and artistic functions of the festival during the ceremonial opening night events in 2001. Except for perhaps a rare performance at the Kennedy Center in Washington, DC, I cannot think of a single disability culture event in the U.S. that would draw the same level of governmental dignitaries or national attention.

In addition to state politics, BIT also functioned on the level of cultural politics. Just doing the work, acting, was political and a powerful end in itself. Theater as social space occupied by blind people is atypical. Thus, by becoming performers, these actors destabilized notions of appropriate behavior for blind people, going from objects of pity to agents of cultural production. Ritualized public displays on stage inverted the currency of blindness, as something that sighted people want to gaze upon, not because it is grotesque but because it is valuable. Inviting the gaze in this way creates a shift in identity that serves political ends.

Disabled people have often been subjected to public scrutiny; in academic language, they are objects of the 'social gaze' (Foucault, 1975; Garland Thompson, 1997; Koppers, 2003; Schweik, 2009). Blind people actively manipulate this gaze through theater. As artists inviting the gaze—by performing on stage—they illustrate that people do not simply react to, or are a product of, their environments. Rather, they actively manipulate and, in fact, invert the power dynamics associated with looking. By controlling who is doing the gazing, when, and at what, blind theater turns the gaze outward and, in so doing, reframes social model questions about which and how environments blind people.

Furthermore, blind theater also allows us to learn more about the power and processes of the gaze in general. Blind people, for example, demonstrate that gaze itself is multisensory. In other words, it can be heard and felt, not just seen. The gaze for blind people is often aural, the equivalent to silence: a room hushes quiet when they enter. One can literally hear people staring.

The growth of blind theater is a conscious, overt effort at manipulation, at forcing the gaze: these blind people want to be seen, in large part to disrupt the categories of blindness—sightedness and the stereotypes of what blindness means. Many of the performers played with and/or removed the 'props' of blindness on stage—e.g., white canes, dogs, sunglasses—and invited the public to witness their true, artistic selves. In other words, it is the performance and presentation itself that was central and not the fact that they were blind doing it: they

wanted recognition as an actor playing a role of a doctor, for example, not a blind doctor nor a blind person playing a doctor.

Blind actors play with cultural symbols of blindness and sightedness, and manipulate opportunities to gaze and be gazed upon, because they are aware of the assumptions and stereotypes that others in their social environment hold. In the words of Lynn Manning, a blind African American artist performing his “Magic Wand” poem at the 2003 festival, said as he unfolded his white cane, “I go from Black man to blind man, with a flick of the wrist... from white man’s burden to everyman’s burden... the metamorphosis is always profound but the final form is not of my own choosing. I wield the wand, but you alone are the magician.”

Conclusion

In conclusion, this article shows that blind theater has historically been a vibrant place for cultivating identity and for challenging cultural stereotypes. By presenting ethnographic examples from TBTB and the International Blind Theater Festival in Croatia, I have demonstrated how blind people are agents of cultural production, who consciously manipulate the gaze and their environments towards empowering ends. I document various innovative practices, including around audio description, that they have developed to increase access to the stage for both audiences and performers. Further, I have described ways that blind theater can destabilize cultural assumptions about blindness for the political goal of improving disability rights. It can also, simply, be great art. This retrospective analysis has shown that change is slow, but possible. Although there has been much progress since these observations were made, culturally there is still a long way to go towards breaking down negative assumptions of blindness and before blind people are deemed capable and welcome on stage, if not elsewhere in society.


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Endnote

¹ TBTB performed “Brecht on Brecht” in NYC in 2002, which included this line; they also performed it in Croatia at the BIT festival I attended in 2003. “Brecht on Brecht” is a compilation of the life and works of Bertolt Brecht, formatted for the theater by George Tabori (Brecht & Tabori n.d.).

² I later learned that I also shared another connection to TBTB (my mom’s first cousin and Schambelan knew each other from college). To say that “we,” the troupe and I, were friends is an understatement. From weddings to funerals, we were involved in each other’s lives: we spent hours and hours together socially, outside of the theater and rehearsals, having dinner parties, sharing music, hanging out. I mourned the loss of this community, when my connections to them ended.

³ For more information about the festival, see: www.novizivot.hr/bit.html

⁴ The situation for blind people in Spain is different than for those from many of the other countries present. In Spain the national organization of the blind, ONCE, runs the state lottery and thus has a comparative wealth of resources. Although there was only one troupe from Spain present, ONCE sponsors a national blind theater competition each year and sends the winner to an international festival of their choosing. Needless to say, the quality of their performances was outstanding. (<http://www.once.es/new/otras-webs/english>)

⁵ At the time, members of each troupe tended to sit near one another so they could hear what was being said. However, there were times when this system broke down, either because not everyone could get close enough to hear, the dialogue was too fast to interpret so quickly, or because the translators only spoke Croatian and another language and/or English, but not the language of the performance. (For example, one translator assigned to TBTB in 2001 spoke a minimum of four languages fluently, however, none were Spanish, and therefore was unable to translate the performance by the Spanish troupe from ONCE.) It is also difficult to provide spontaneous translation and audio description at the same time. More recent technological advances might change how this process is handled, e.g., by providing simultaneous live translation via podcast or smartphone.

⁶ Although George Bernard Shaw won the Nobel Prize in Literature in 1925, some retrospectively presume he had learning disabilities akin to ADHD (see <https://www.nobelprize.org/prizes/literature/1925/shaw/biographical/> and <https://www.thebrainworkshop.com/in-the-spotlight/nobel-prize-winner-in-literature-george-bernard-shaw-and-his-struggle-with-learning-difficulties/>). However, this was not necessarily known about Shaw at the time and never once was raised as a reason in the decision to perform his works. Further, *Misalliance* itself is a comedy with no disability content (<https://www.gutenberg.org/files/943/943-h/943-h.htm>).

⁷ Schambelan and I discussed his legacy, and from those conversations it appeared that he did not want *anyone* – blind or sighted – to usurp his role, at least while he was still alive and involved with TBTB.

⁸ The “Bergman Bell” is an ad hoc, non-standard adaptation to the traditional white cane made by Gary Bergman (TBTB member); he used it to clear pedestrian traffic from and generally facilitate navigation of the sidewalks in New York City. Bergman attached a standard bike bell to his cane just below the grip, so his thumb was able to ring the bell without modifying his hand position as he walked. It was also a way to announce his presence at the festival, by ringing it, as he was the only blind person there with this adaptation. Troupes from other countries thought it was a fantastic innovation and assumed it was part of standard rehabilitation practices in the U.S. It is not.

⁹ This workshop was called, “Cultural confrontation: the game for human rights” by presenters Natasa Govedić and Vili Matula.

The Role of Assistive Technology in Enhancing Disability Arts

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Abstract

Historically, disabled artists have been using assistive technology (AT) to enhance their artistic creativity, even before AT was formally defined in law in the United States (US). This exploratory study reviewed both empirical and anecdotal evidence of the impact of AT on disabled artists in their K–12, postsecondary, and professional careers as well as the impact of AT in museums and performance spaces. The literature review revealed an incremental progress in disabled artists' participation in the arts. The author conducted field visits to five museums in New York City and San Francisco and one performance venue in New York City. From observation, all five museums offered comprehensive accessibility services that included AT tools to visitors with disabilities. The performances attended brought AT into a new light as disabled artists incorporated AT as creative elements in their acts. However, the findings from the field study cannot be generalized across the US. There is a lack of empirical research that studies the unique experiences of SWDs in their K–12 and postsecondary education systems; most of the literature reviewed presents the experiences of educators use of AT to teach art. There is also a lack of empirical evidence-based practice with regard to AT devices for professional disabled artists. Presently, artists are using a combination of AT from a wide range of categories such as low-, mid-, and high-technologies. However, the decision to use a particular tool is affected by the following factors: functional capabilities, personal attitudes, prior technology knowledge and experience, affordability, and preference. There is no one-size-fits-all AT, and there is also a rapid turnover of devices. Moreover, research suggests that modern digital tools may present new complexities and barriers to the disabled artist. It is mutually beneficial for the end-user and product designer to work together to create solutions. This paper will spotlight the experiences of randomly selected visual and performance artists, and musicians with their AT. Finally, resources of mainstream software, input devices, adaptive tools, and organizations will be provided in the appendices that may be useful to end-users and educators.

Keywords: disability arts, assistive technology, accessibility

Where would humanity be without art, music, dance, and film? It would be dull and boring. There are beliefs that the arts and art education improve cultural engagement (O'Farrell & Kukkonen, 2017). Some studies link the arts to promoting literacy, math skills, memory, and critical thinking skills (Baker, 2013; Coleman & Cramer, 2015; "Integrating the Arts," n.d.). The arts are a reflection of societies and cultures (Wexler & Cardinal, 2009); therefore, everyone should have access to the arts. Historically, people with disabilities have been excluded because of ableism (Linton & Gotkin, 2019). However, over the last thirty positively boosted their identities as artists with disabilities (Sulewski, Boeltzig, & Hasnain, 2012). During this time, advances in assistive technology (AT) has allowed more artists with disabilities to partake in self-expression, to increase awareness of disability in the arts, and to advance disability inclusion in the arts and culture (Boeltzig, Sulewski, & Hasnain, 2009). The purpose of this exploratory paper is to show how AT has enhanced the participation of disabled artists to create art in their school careers, professional work, and community participation. Methods of research include a literature review, Google search, field study and the writer's analysis. These research questions guided this study:

- 1) How has AT impacted art education for students with disabilities (SWDs) in the K–12 system and in higher education today?
- 2) What factors do disabled artists consider when selecting from a range of low-, mid-, high-tech tools? Are there barriers to the implementation of their chosen AT?
- 3) How has AT revolutionized accessibility in museums and performance spaces today and what does this mean in terms of increased opportunities to showcase disability art?

This paper aims to provide examples of disabled artists and their individual experiences with a broad range of AT tools and their strategies employed to eliminate their barriers in creating, performing, or exhibiting their art. Finally, a list of AT resources will be provided in the appendices that may be useful to end-users and educators.

Historical Artists with Disabilities and Assistive Technology

"Necessity is the mother of invention" is an old proverb that captures the spirit of how AT has advanced throughout civilization (Steenhout, 2018). The history of AT is thought to be as long as that of humankind (Lewis, 1998) and has undergone its own evolution. It was during the Foundation Period, anytime earlier than 1900 when AT was discovered, researched, and defined as a tool that may assist and enhance the lives of individuals with disabilities to perform tasks that would be otherwise challenging or impossible to do (Gatchalian, 2019). Historically, disabled artists used AT that were designed and adapted specifically for their individual abilities and functional needs. Nicolau & Montague (2019) point out that, recently, there are two schools of thought about AT design: Design for All and Design for Individuals. These issues are too complex to elaborate in-depth for this study, but, it is important to mention Design for All and Design for Individuals because AT that disabled artists use today can be either mainstream products bought off the shelves that were designed with accessibility and flexibility features that can be adapted, or they are customized to fit the

individual's functional limitations. Steenhout (2018) reminds us that many of the technology available today has evolved from technology developed by or for people with disabilities. Design for All has a Universal Design concept, that is, disability-related solutions are incorporated into the design of everyday products (Steenhout, 2018; Nicolau & Montague, 2019). Some examples include adjustable height desks, pencil grips, or music instrument stands. Design for the Individual, on the other hand, is more inclusive and takes into consideration the "individual human abilities to context" and "what the user can do;" universal design focuses "on design for what everyone can do" (Nicolau & Montague, 2019, p. 319). However, product designers must always take into consideration accessibility, that is making the product open to all, and inclusivity, which means involving the diverse contributions of people with disabilities in how they arrived at that design (Holme, 2018). In particular, this study will provide examples of disabled artists who are collaborating with engineers to design their AT and disabled artists who use mainstream AT.

Ludwig van Beethoven actively participated in the design of his AT. He is arguably the most famous deaf pianist and composer, but not many realize that he used ear trumpets of varying sizes to improve his hearing and needed them for composing music. The ear trumpets were designed by his inventor friend Johann von Malzel (Ealy, 1994; Krehbiel, 1898; Shaver-Gleason, 2018). Figure 1 in Appendix A shows the various ear trumpets used by Beethoven ("Digital Archives," 2002). Ealy (1994) remarked that Beethoven also asked his friend Andreas Streicher to build a piano with the loudest volume adapted to his hearing capabilities. So, despite the worsening of his hearing, Beethoven was able to compose music at the keyboard by improvising, wearing ear trumpets that were attached to headbands that allowed his hands to play. Moreover, he used a drumstick held between his teeth to touch the distal end of his piano as the wooden drumstick conducted vibrations to the bones of his middle ear (Ealy, 1994); an adaptation that allowed him to hear with his teeth. Furthermore, Beethoven requested Conrad Graf to design a resonator that was placed on top of his piano that conveyed tone more distinctly to Beethoven's middle ear to help him compose (Ealy, 1994; Shaver-Gleason, 2018). As he lost his hearing completely, Beethoven began to write more music without having to hear, and music scholars believe that he wrote his new music going against the grain of compositional conventions of his time with increased loudness, unexpected changes, and repetition to make them easily recognizable (Mayne, 2011; Simonis, 2015). Wallace (2019) wrote that Beethoven's story is not about triumphing over adversity, but about acceptance of his irreversible hearing loss and his creative adaptation using tools. Presently, there are modern technology equivalents to the AT that Beethoven used—hearing aids and cochlear implants, music software, and sound apps. Even the design of the modern piano was influenced by Beethoven, who tried several versions with many personal adjustments for his specific needs (Shaver-Gleason, 2018). Moreover, cutting edge technology today has made it possible for musicians with severe hearing impairments to write and enjoy listening to music with the invention of wearable technology such as SUBPAC that capture the physical dimension of sound. (Grabbitz, 2016).

Henri Matisse used a manual wheelchair during the last fourteen years of his life following surgery for duodenal cancer which made him frequently weak and tired (Morgan, 2014). Nonetheless, it was remarkable that he produced more art during this period by replacing his paintbrush with a large pair of tailor scissors to cut out paper shapes drawn using chalk on the end of a stick (Morgan, 2014). Additionally, he hired assistants to place the cut-out shapes on a paper background mounted on a wall with his direction (Morgan, 2014). Today, the adaptive technique that Matisse popularized has been borrowed by art teachers, not only for their students with disabilities but for all students because the cut-out technique is so fascinating and exciting (Rhoades, 1993).

Clayton “Peg Leg” Bates was a famous rhythmic tap dancer from the 1930s to the 1970s (Escamilla, 1997). When he was twelve years old, his left leg was caught and mangled in a conveyor belt while working in a cottonseed mill and was later amputated at the knee (“Clayton,” n.d.). Clayton’s uncle made him a wooden peg leg to dance in jazz clubs around the United States and in Paris. Bates was very popular and performed with the well-known orchestras of Count Basie and Duke Ellington; he had thirteen different peg legs to match the color of suits he owned to perform in (Escamilla, 1997). Bates has inspired modern-day artists like Evan Ruggiero, a one-legged tap dancer and Broadway actor who boasted that “Peg Leg” Bates is his idol (Ruggiero, 2018). Ruggiero mentioned that before his leg operation, he posted a video of Bates dancing on the Ed Sullivan Show and believed that he, too, will be doing this after his recovery. Since becoming an amputee, Ruggiero embraces his disability and is very active in his career; he owns nine prosthetics, but instead of wood, Ruggiero’s peg legs are made of alloy or titanium (Ruggiero, 2018).

Types of Assistive Technology Used by Disabled Artists

The broad definition of AT is any device, software program, or service that is used by persons with disabilities with the potential to maintain, increase, or improve their functional capabilities as defined in the United States Assistive Technology Act and the Individuals with Disabilities Education and Improvement Act (Lewis, 1998; Dell et al., 2017; “What is AT?, “ n.d.; Coleman & Cramer, 2015). The AT that disabled artists use are categorized as low-, mid-, and high-tech devices, whether commercially bought ready to use, adapted, or customized to fit the individual’s needs (Steenhout, 2018; Gatchalian, 2019). Examples of low-tech devices are pencil grips, slant boards, adaptive pencils/erasers, adaptive scissors, rolled-up towels, and stands, (Coleman & Cramer, 2015; Dell et al., 2017). Mid-tech includes battery-operated communication devices, manual wheelchairs, adjustable height desks, touch-sensitive pads, and switches; and high-tech are more advanced and complex tools such as hydraulic lifts, electric wheelchairs, eye-tracking devices, and computer software such as synthetic speech communication tools, speech to text, sound amplification systems, Braille, and many more (Dell et al., 2017; Coleman & Cramer, 2015; Coleman & Grim, 2015.) High-tech options may be expensive and require training to use.

The focus of AT is “not on the disability but on the remaining functional capabilities that people use to accomplish their chosen objectives” (Weiner, 2010, p. 159). Disabled

artists may use a combination of tools to accomplish their objectives, and today, the choices of tools are many. Each individual must consider factors such as ease of use, preference, product availability, technology familiarity, and cost (Dell et al., 2017; Creed, 2016). Disabled artists decide which AT works best for their needs, functional capabilities, personal attitudes, prior technological skills, knowledge, preference, and budget. For a list of AT resources see Appendices B (visual artists), C (musicians), and D (performance artists). Because of the constant changes in modern technology, the lists in the appendices may also change accordingly. Therefore, a few organizations are included to give up-to-date and active links to relevant resources.

Federal disability and education laws that impact the use of AT in art education

Since the passage of the Assistive Technology Act (Tech Act), Individuals with Disabilities Education Act (IDEA), and the Americans with Disabilities Act (ADA), in the United States inclusion and access are the goals for students with disabilities (SWDs) to engage in art as learners, creators, and consumers (Bailey & Cody, 2015; Dell, Newton & Petroff, 2017; Coleman & Cramer, 2015; Yoder, 2018). The IDEA, and its 2004 reauthorization, were instrumental to SWDs because they mandated that all K–12 public schools provide AT equipment and services to SWDs in special education to gain equal access to a free appropriate public education in the least restrictive environment. The Tech Act reauthorization in 2004 also guaranteed that there will be increased funding for AT use in the classrooms (Gatchalian, 2019; Akpan & Beard, 2013; Derby, 2012; Lewis, 1998). Furthermore, the ADA and its amendment acts required that schools are responsible for recognizing students with visible and invisible disabilities that present challenges in their learning, thus AT became part of a student’s Individualized Education Plan (IEP) (Akpan & Beard, 2013; Gatchalian, 2019). In addition, Sections 504 and 508 of the Rehabilitation Act mandate that schools provide AT to SWDs (Dell et al., 2017). AT and adaptive supports have increased participation and heightened experiences for SWDs in art classes (Coleman & Cramer, 2015).

Notwithstanding the aforementioned legal mandates to provide AT, the National Endowment for the Arts conducted a survey which revealed limited arts education and training opportunities in art schools, lack of necessary accommodations, and teachers that were not adequately trained to provide support and accommodations to students with different types of disabilities, both visible and invisible (NEA, n.d.). Another barrier mentioned is the limited funding for art supplies and training opportunities (Careers in the Arts, n.d.).

Furthermore, there is a dearth in research that “demonstrates the effectiveness of assistive technology in increasing access to the art curriculum through the use of assistive technology” for SWDs (Coleman & Cramer, 2015, p. 7). However, traditional low-tech and mid-tech AT tools have been used by art educators to provide students with disabilities opportunities to create works of art in the K–12 education system (McCord & Malley, 2017).

There is a lack of empirical research on the use of AT in postsecondary education programs. Educators are familiar with using low-tech traditional tools. Traditional tools could be easily adapted to teach visual art and music to students with varying disabilities because these do not require training to use, are easily adapted in any setting, and are not expensive (McCord & Malley, 2017; Coleman & Cramer, 2015). These include large handled paintbrushes, grips attached to writing utensils, adaptive scissors, adjustable height desks, and rolled up towels placed under the arm for stabilization as well as giving assistants verbal directions to assist students and using alternate body parts such as mouth or foot to hold the brush. (Coleman & Grim, 2015; Coleman & Cramer, 2015). In the music classroom, some students have their instruments adapted or customized with Velcro straps, touch-sensitive pads, large knobs and buttons, stands that hold instruments, and large or twisted guitar picks to accommodate limited hand movement (McCord & Malley, 2017). Modern mid-tech digital technologies such as tablets and apps allow students with physical disabilities to play, create, and listen to music (McCord & Malley, 2017). However, recent research by Coleman & Grim (2015) noted that AT devices were rarely or sometimes used in the classrooms. Art teachers who work with students with physical, visual, severe, and multiple disabilities in mainstreamed classrooms feel inadequately prepared to use adaptive strategies, accommodations, and modifications or are unaware of the various types of AT available and their functions (Coleman, Cramer, Park, Bell, & Coles, 2015). One reason that can shed light on the issue of inconsistencies and underutilization of AT in the classrooms is the notion that schools across the US may have varying resources and may not have clear policies and guidelines to implement AT (Yoder, 2018). Seale (2014) established this argument in her book: "...stakeholders have to translate legislation into policies and strategies that are meaningful to them in the context in which they are working" and "stakeholders must define and agree what benchmarks of best practice might be" (p. 11).

How can a school system adapt and develop a realistic solution to implementing AT in the classroom? One solution that comes up in a few studies is to have an expert such as an adaptive art specialist in schools to adapt tools, media, and techniques so that SWDs can participate appropriately in the arts curriculum (Coleman et al., 2015; Loesl, 2012; Yoder, 2018). Preservice teacher programs addressing arts education for SWDs are emerging in more colleges, such as Kent State University, Buffalo State College, State University of New York, New Paltz, University of Iowa, and Florida State University (Malley, 2012). Teachers who have extensive knowledge in using technology could make a world of difference for students with significant disabilities. With comprehensive preservice teacher programs, teachers can feel more comfortable teaching an adaptive arts curriculum (Coleman et al., 2015; Loesl, 2012; Malley, 2012). MyTalkTools is a type of communication software that music teachers use to personalize learning for non-verbal students by using pre-recorded sounds that are attached to pictures and videos which has been found useful in improving music literacy and introducing learners to the emotions that are projected through music (McCord & Malley, 2017). This classroom application is possible with high technology, but teachers need to be aware of these types of AT, know where to get them, and learn how to use them (Gatchalian, 2019). One program that has invested in training teachers and students

is the Berklee Institute for Arts Education and Special Needs. It trains teachers to work with students with autism spectrum disorders. See Rhoda Bernard, managing director of the Boston Conservatory Program for Students with Autism, in this video interview *Training Students & Music Teachers in the Gifts of Autism-Meet Dr. Rhoda Bernard* at <https://youtu.be/vuGC1E4sTsQ> (Evans, 2010).

In addition, there are art colleges in the US with a strong commitment to supporting disabled students. One college worth noting is the School of the Art Institute of Chicago (SAIC). Alumnus and current faculty Riva Lehrer, an individual with spina bifida, recalls the lack of resources for SWDs in the 90s, when she was a student, in a *Chicago Magazine* interview (Voon, 2018). Lehrer and other disabled college peers Jude Conlon Martin, a sculptor with spinal cord disability, and Bill Shannon, a dancer with a hip disorder, started a disability in the arts awareness movement that resulted in the creation of a robust SAIC Disability and Learning Resource Center (Voon, 2018). Recently, Bri Beck, a disability artist alumnus at SAIC organized a Disability Arts Showcase titled *Sixty Inches From Center* “to share the varied story of disability and to bring together those that are disabled and those that work within this community to further grow and define a collective voice and community” (Art Therapy, n.d., para. 2). Linton & Gotkin (2019) are strong proponents for disabled students’ access to the arts rooted in disability identity and would like to see the education system at all levels hire disabled artist-teachers who can share their unique experiences to help design innovative disability arts pedagogies.

These examples illustrate how disabled artists are positioning their disability in their work (Linton & Gotkin, 2019). More disabled artists are enrolling in college programs today and there are also increased opportunities for grants and scholarships in the arts such as the VSA Young Emerging Artists Program for SWDs ages 16–25 living in the United States (Boeltzig et al., 2009; Kennedy Center, n.d.). Jessy Yates is an actor with cerebral palsy studying drama at Yale University. She is a performance artist, a comedian, and wheelchair user (Holmes, 2019). In January 2019, she was the recipient of the Ruderman Family Foundation Scholarship, the first recipient for actors with disabilities at Yale (Holmes, 2019). There is a rise in SWDs enrolling in higher education pursuing undergraduate and graduate programs such as Bachelor of Fine Art, Bachelor of Science in Art, or Master of Fine Art (Boeltzig et al., 2009).

Creed’s Research on AT Used by Disabled Visual Artists

For professional disabled visual artists, “[t]raditional assistive tools such as mouth sticks, head wands, and custom-designed grips (for holding brushes) can make creative work somewhat accessible” (Creed, 2018, p. 1104). However, Creed (2018), citing the research of Perera, Eales, and Blashki (2007), pointed out that traditional approaches have led to complications in health for some artists. Traditional assistive tools were “slow, tedious, and tiring” for individuals with disabilities leading to chronic neck strain and teeth damage (p. 1106). In Creed’s research, he established that traditional tools also contributed to stiffness in hands/fingers and increased fatigue in many of the artists in his study. On the other hand,

digital assistive tools were game changers and were more commonly used by visual artists with disabilities in Creed's (2018) study. Modern mainstream artistic software and apps such as Photoshop, Illustrator, Sketchbook Pro, Manga Studio, and Procreate, and hardware such as an alternative mouse, keyboards, trackballs, and switches could be easily purchased (Creed, 2018). Moreover, modern tools can be customized to support the artist's functional capabilities such as voice recognition software, eye gaze tracking devices, and motion tracking devices (Creed, 2018). However, Creed's research ultimately found that modern AT tools do not "completely remove the need for personal supports" to accomplish their artistic goals (p. 1110). Equally important is the need for individuals to evaluate their needs and skills for AT, have training on how to use AT, and have personal supports to trouble-shoot and repair technology. Cook (2009) describes these as soft technologies "without which the hard technologies [tangible AT] are ineffective," and points out that "they are highly dependent on human knowledge" (p. 129). The artists in Creed's (2018) study complained about difficulty controlling a stylus; repetitive strain injuries from difficulty operating multi-touch tablets, the use of trackballs as a mouse replacement, and equipment that are too big and heavy; difficulty in selecting small icon targets with eye gazers; and frustratingly poor voice recognition of speech to text software. "It is not yet clear whether technologies such as eye gaze tracking and speech recognition can genuinely enhance the practice of disabled artists more widely or whether they simply introduce more complexities and challenges" (Creed, 2018, p. 1117). However, disabled artists may be successful in using these devices if they invest time and effort to get training on how to use them and seek product support. For example, Sarah Ezekiel, a professional artist, uses an eye gazer called Tobii PCEyes to create her art and for communication ("Paralyzed Artist," 2015). Before motor neuron disease, Ezekiel was a successful painter and had full command of her speech (Ezekiel, 2019). Ezekiel remarked that TobiiPCEyes is a game-changer but admitted that the process of creating artwork with this high-tech tool can still take a long time. However, she noted that her artwork using this tool is quite similar to the work she used to do with her hands ("Paralyzed Artist," 2015). Watch Ezekiel in this video <https://youtu.be/-kpgKO6EMoU> (Tobii AAC, 2013).

Factors that Influence AT Selection

Do disabled artists have a preference for traditional tools vs. modern digital tools? Creed's (2018) study found that disabled visual artists who use both traditional tools and digital technology have adapted working methods and patterns such as working on a smaller scale, working for shorter periods, and using tech-savvy personal assistants. Despite modern technology's appeal and easy access, disabled artists utilize both traditional and digital tools that are useful to them. The choice is very individual. Modern digital tools are not necessarily better for the individual artist who cannot afford it, finds it too complicated to learn, and has negative attitudes about technology in general (Creed, 2018). It is also worth considering the individual's openness to emerging technology—younger individuals with disabilities may have been using sophisticated AT since early in their educational careers as a result of the IDEA and ADA, while the older artists with newly acquired disabilities may take longer to

perceive the value of investing more time and effort to learn how to use complex modern tools. To the novice, technology can be overwhelming, and without product support and adequate training the experience is likely to be negative (Seale, 2014). Furthermore, “costs associated with ATs are highlighted as one of the major barriers to the equal access of devices,...[and] “that purchase costs not only include the price of a device but also costs for services and training needs associated with the technology” (European Parliamentary Research Service, 2018, p. 9). However, the silver lining is prices will drop over time as more technological innovations enter the market, perhaps related to the increased number of competing companies. And, if disabled artists are given opportunities to have their voices heard on the usability of mainstream AT, the training cost could be significantly decreased. One suggestion is for companies to recruit artists with varying disabilities in surveys to get ideas of what they need and involve them in the beta testing stage of software. Disabled artists must not hold back in giving their honest feedback in order to fix issues in accessibility and usability.

Disabled Artists Involvement in AT Design

How can users and developers of AT work together to create products that are inclusive? In the past, artists collaborated with design engineers just like Beethoven had worked with inventors to make ear trumpets, resonators, and pianos. This participatory design is apparent in creating AT that takes into account the individual’s lifestyle, functionality, and usability of the device, as well as aesthetic (Newell, Gregor, Morgan, Pullin, & Macaulay, 2011. Clayton “Peg Leg” Bates had his uncle customize his wooden limbs in different colors, and Evan Ruggiero has different prosthetics made for dancing and walking. Below, there are other examples of artists who were involved in the development of computer software; prosthetic limbs, some with sophisticated artificial intelligence; and motorized wheelchairs to engage in their art form as musicians, tattoo artist, and dancers. However, it is important to note that the opportunity for participatory design is not common. There should be a push for user-sensitive inclusive design when creating AT. This concept focuses on the users of AT firstly as people with a specific disability instead of subjects, and this new paradigm could lead mainstream engineers to efficiently design equipment that is sensitive to the varying needs of people with disabilities (Newell et al., 2011. Technology companies should take the initiative to conduct product satisfaction surveys to ascertain whether the AT is effective to the users.

Impact of AT on Disability in the Arts

Presently, AT has boosted the presence of disability in the arts. Because of AT, there is more representation of people with disabilities in the visual arts, in music, and in dance. AT tools help promote inclusion and provide opportunities to people with all types of disabilities. Inclusion, according to Shelly (2019), is broader than accessibility and diversity; accessibility and diversity are focused on disability while inclusion is about “making the experience of marginalized people... straightforward, enjoyable, and fair” (p. 302). AT has increased disabled artists’ participation in the local, national, and international art scene, and

it has led them to advance on a professional level (Boeltzig, et al., 2009). Thus, the advancement of AT has impacted the emergence of disability in the arts (Boeltzig et al., 2009). The US Bureau of Labor Statistics (BLS) 2006 data revealed that there were 218,000 disabled artists employed and BLS projected that there will be a 16 percent growth through 2016 (Boeltzig et al., 2009). Furthermore, AT has also impacted inclusive arts education. Boeltzig et al. (2009) remarked that the majority of the artists in their study who were attending or had completed postsecondary education had benefited from arts education in their early school years and developed their own strategies such as painting with their mouth and feet, using computer graphics or digital photography, and employing an art assistant under their direction to create art. These authentic stories of disabled artists may be instrumental in raising public awareness of artistry rooted in disability (Linton & Gotkin, 2019). Disability artistry has a long history, but most of its existence has been on the margins. But in the past several years, disability arts have achieved greater recognition. More artists are also using accessibility tools as part of their art (Linton & Gotkin, 2019). For example, the dance production by Kinetic Light titled *Descent* includes “a sonic immersive experience designed for non-sighted audience members,” and the “set piece is a wildly designed curving ramp, truly usable only by a wheelchair user;” furthermore, the disabled artists were actively involved in the set design (Linton & Gotkin, 2019, p. 25). Lastly, AT has also impacted full physical access to museums, stage arenas, and other venues for cultural programs, which has increased access to all audiences (John F. Kennedy Center, n.d.). Inclusion can lead to inspiring many more disabled individuals of any age to pursue art and identify with other disabled artists socially and culturally, further advancing disability in the arts.

AT Increases Access: Museums, Theaters, and Cultural Programs

Since the passage of the ADA, our society is moving toward the direction of “social participation, with the goal of equality in opportunity through universal design” (Steinfeld, Maisel, & Levine, 2012, p. 21). A universal design (UD) focus demands that designers change their perspectives beyond accessibility regulations and create products, buildings, and interiors to be usable by a large majority of people. The Guggenheim Museum in New York City was one of the first buildings designed with the UD principle where Frank Lloyd Wright designed the interior as one continuous ramp (Steinfeld et al., 2012). The ADA requires that any new constructions or alterations of public accommodations structures must meet accessibility standards, with the exception of historically landmarked or older buildings that are very challenging to adapt. UD is only required to provide a minimal level of access (28 C.F.R. § 35.151). Thus, UD in architecture has made it more possible for individuals with disabilities to have full physical access to museums, stage arenas, and other venues for cultural programs (John F. Kennedy Center, n.d.). But accessibility services and AT devices offered at museums and performance spaces are largely dependent on the financial costs of accessibility initiatives. The John F. Kennedy Center has the resources (financial and staff) to design its performance space with designated accessible seating for disabled audiences, and the stage, backstage, orchestra pit, and other production areas are made accessible to

performers, artists, employees, volunteers, and interns with disabilities (John F. Kennedy Center, n.d.).

The types of AT that are currently offered by museums and performance venues include assistive listening devices, sign language interpreters, captioning, audio description, labels and texts in Braille, large print programs, touch tours, and sensory-friendly performances (“About Accessibility,” n.d.; Art Beyond Sight, n.d.). The Metropolitan Museum of Art, Museum of Modern Art, Whitney Museum of American Art, New Museum in New York, and San Francisco Museum of Modern Art were visited in this field study and the author observed that visitors with disabilities had straightforward physical access to the museum space; however, a disabled individual may require staff assistance for other communication-related services and touch tours and may need to schedule accessible tours in advance. However, the field study was only limited to observation; an interview survey would have determined whether these services offered in the museums met the disabled individuals’ physical and sensory needs.

Another venue that was visited was the Performance Space New York. Through a collaboration with Whitney Museum of American Art and Arika (a political arts organization based in the United Kingdom), the Performance Space New York held a three-day show, April 11–14, 2019, created by and for disabled artists, writers, and their supporters: <https://bit.ly/2EHIQCS>. The play, titled *Nearly Sighted/Unearth the Dark*, by Kayla Hamilton used an ASL interpreter, real-time captioning, and audio descriptions as part of the show. The author observed the enjoyment on the faces of audience members with visual impairments in adjacent seats as they listened to the audio descriptions of the props used, actions on stage, and facial expressions of the actors. Furthermore, a dance performance by Alice Sheppard, a disabled dancer, titled *Where Good Souls Fear*, offered a new technological innovation called SUBPAC. Audience members with hearing impairments wore this low-profile backpack that transmits pulse sound through the body and allows individuals to feel the base. SUBPAC is also used by artists with severe hearing impairment to write music (Grabbitz, 2016, 1:00). See this video (<https://youtu.be/z60Dp958iEA>) titled *Meet Mitchell*, a young musician with hearing and vision impairments and autism spectrum disorder who uses various AT such as SUBPAC, hearing aid, and the app Garage Band to write and play his music on his bass guitar (Grabbitz, 2016, 3:12). See Appendix 3 for AT resources for performance artists.

Examples of Exciting Practice

This section will give examples of artists—visual, musicians, dancers, performers—and the AT that they use to create their art. The selection includes disabled artists who are established professionals and new emerging artists; their disability categories are varied and include paralysis, amputations, and learning and developmental disabilities. Some of the disabled artists featured in the paper are collaborating with designers and engineers to create customized AT. However, most disabled artists use a combination of store-bought technology

that ranges from traditional low-, mid-, and high technology. What is clear from these anecdotal examples is that AT enhances their creation of art.

Visual Artists. One of the advantages of visual art is to convey thoughts, show skills, and portray emotions. According to a Brooklyn Rail interview, Chuck Close (Brooklyn Rail, 2008) remarked: “In the 7th grade, I made a 20-foot long mural of the Lewis and Clark Trail while we were studying that in history because I knew I wasn’t going to be able to spit back the names and the dates and all that stuff on a test.” In this same interview, Close revealed that he has dyslexia, but it was not diagnosed in the 1940s. Nonetheless, he pursued his passion for visual art and graduated from Yale University. He became famous for his works in photorealism using a large Polaroid camera to create giant pixelated portraits that are based on photographs in the 1970s. He also has prosopagnosia, or face blindness, which impairs his recognition of faces (Martin, 2018). In 1988, Close became a quadriplegic but did not give up creating portraits using the same techniques. In addition to a Polaroid camera, Close used a brush strapped to his wrists and adapted his studio to include a hydraulic lift that helped him in to position to paint (Latchem, 2004; Phillips, n.d.). He also employs art assistants to help him work; he shares his process of making art in this video interview:

https://www.sfmoma.org/artist/chuck_close/ (SFMOMA, 2005). Today, it is not uncommon for museums to have a collection of Close’s artworks before and after his disability, and they could be hung side by side. The author of this paper had visited the San Francisco Museum of Modern Art and saw the collection of Chuck Close portrait paintings. Many art experts find it very difficult to differentiate work before and after his paralysis (Ravin, J & Odell, P., 2008). Three photographs were taken at the museum that is shown in Figure 2 (Appendix E): *Phyllis*, 1983-1984, *John II*, 1993, and *Roy I*, 1994. It is, indeed, very difficult to notice any difference in quality between the works. He continues to paint in the same style as before, the only difference now is he no longer works standing, learned to use a brush differently, and replaced the ladder with a hydraulic lift (Latchem, 2004; Phillips, Smith, Farrell & Morant, n.d.).

JC Sheitan Tenet is an example of a young emerging tattoo artist who lost his lower right arm when he was ten years old. He collaborated with Jean-Louis Gonzalez, an artist-engineer in the creation of a prosthetic arm that doubles as a tattoo machine (Jozuka, 2016). Tenet uses his shoulder to move the device that is described as having a “terminator-esque aesthetic” (Jozuka, 2016, para. 6). Both Tenet and Gonzales discuss the creation and the use of this device in this video interview *The Cyborg Artist: Tattooing with a Custom Prosthesis* (Great Big Story, 2016: <https://youtu.be/LB7Ljo2iFnU>

Sometimes AT is designed by disabled artists educators. In the following example, Tim Lefens conceptualized the Artistic Realization Technologies (A.R.T) program when he was teaching students in the community with cerebral palsy or quadriplegia (Purdy, 2001). Tim Lefens became progressively blind in his career, but before he lost most of his vision, he found that he could improvise a target laser, which was commonly used for aiming guns, to function as a virtual brush that was placed in the hand of his student or attached to their head (Purdy, 2011). With the help of trained trackers (assistants), artists who only had eye control

were able to point the laser to a brush, color, brush size, and textures of paints, and the tracker would support the creative process as the ‘hands’ of the students (“A.R.T.”, 2007). Tim Lefens captured the spirit of A.R.T. in this statement:

“When you have no means of expressing yourself, the whole world going on around you, without you, and all of a sudden you can place the exact amount of the exact color you want, where you want it on the canvas, a lifetime of pent up energy comes out through a very concentrated channel. For the individual we work with, painting is not recreation. It’s life” (“Community Access to the Arts,” n.d. para 2).

Today, the mid-tech A.R.T. techniques are used by art teachers across the United States (Khmara, 2017). This video (<https://youtu.be/jpUfiSKJPfc>) of an amateur visual artist Rafael Garcia and Tim Lefens (Only Good TV, 2017).

Musicians. AT has come a long way since Beethoven’s time, but the experience of feeling the vibrations of notes still provides inspiration for modern technology that is available today. Since there are varying levels of deafness and different causes of hearing loss (i.e., problems with inner, middle, and outer ear; infection-related; noise-induced hearing loss; tinnitus; hyperacusis; deafness from birth, childhood, teens, or adulthood), there are also different types of AT used by deaf or hard of hearing musicians (Fulford, Ginsborg, & Goldbart, 2011, pp. 447–464). Fulford et al. (2011) mentioned that there is academic audiology and psychology literature about how cochlear implants and digital hearing aids can make pitch perception worse; however, analog and digital hearing aids can be optimized through customization of the following: frequency compression, amplification, and noise reduction parameters. But the caveats of customization are the costs in time and money (Fulford et al., 2011).

Richard Einhorn, a successful professional music composer for operas and film soundtracks, has severe hearing impairment in his right ear. He has been composing music on his computer with music software since the mid-1980s, and he uses a “custom-fitted single in-ear monitor that features four proprietary speakers and sums a stereo signal to mono” (Einhorn, 2012, p. 180). Einhorn wrote that he has also used his “good musical imagination” when writing to compensate for his inability to “perceive all the antiphonal effects” that he likes to incorporate in his music (p. 180). He uses music editing software and the help of a talented music assistant to “look out for bad-sounding splices and other problems” (p. 180). For him, music rehearsals are challenging because of difficulty understanding sound in the ambient space. However, Einhorn uses what he calls his “portable sound rig” that consists of his iPhone with sound apps such as SoundAmp R or Fire 2, in-ear-style earphones, a stereo cardioid microphone from Blue Microphones called Mikey that connects to the iPhone power jack. He uses this personal assistive listening system minus his hearing aid so he can hear well in rehearsals (pp. 180–181). And, he uses a good earphone instead of his hearing aid to listen to a music recording because, for him, the combination of a Bluetooth coupling over his hearing aid gives a very unpleasant, grainy, and hollow quality sound. However, Einhorn

wears his hearing aid, ReSound LiNX2 t-coil when he attends performances in venues with hearing loops installed (p. 182).

Jason Barnes owns two prosthetic arms that were custom designed for him so he could play the drums and piano through collaboration with the engineers at Georgia Tech College of Design (Leary, 2017). The process of creating a prosthetic limb is complicated, especially when it involves artificial intelligence. Barnes' piano playing arm required sophisticated technology so that each individual finger had the dexterity to play notes on the piano with the ability to add the intended dynamics of the music (Leary, 2017). This new prosthetic limb is called Skywalker Hand and a demonstration is seen in this video (<https://youtu.be/8t8p43m1Iuw>) (Georgia Tech Center For Music Technology, 2017).

Additionally, it is worth mentioning the available high-tech AT used by visually impaired or blind musicians. The dominant technologies preferred by these musicians and used with various combinations for recording, editing, mixing audio, and composing music are Cakewalk software, Goodfeel, CakeTalking for Sonar studio software, Sound Forge or Cool Edit for audio editing, Window-Eyes and Jaws screen readers, Braille display, Dancing Dots Braille music software, Optican and SADIE's jog wheel for tactile and physical controls, physical-digital audio workstations such as Roland VS, and Tascam DAWS (Metatla, Stockman, & Bryan-Kinns, 2011; Kent, & Mandel, 2001; Ingber, 2012). To illustrate, Raul Midon, a Grammy-nominated blind jazz songwriter, singer, and record producer and an alumna of Frost School of Music at the University of Miami, uses Dancing Dots and Cake Talking products (Contreras, 2018; "Raul Midon," 2019; "Songwriter Raul Midon," 2010). Dancing Dots is a Braille software company that was founded by a blind musician and programmer, Bill McCann (Ingber, 2012). Watch how Midon applies the technology of Dancing Dot's CakeTalking in this video <https://youtu.be/pDRuj5Od4y8> (Raul Midon, 2009).

Dancers. Today, disabled dancers are challenging normative dance by using their disability as a form of art, and at times the customized wheelchair seems to be another dancer in the performance. Moreover, the usual choreography of using the wheelchair as an aid while the "wheelchair dancer sat rather passively" has been challenged and reworked so that the wheelchair dancer is expressing creative movement outside the traditional expectations (Morris, 2015, p. 5). Also, both assistive and adaptive technology design has undergone a metamorphosis from the traditional "medical" function to be an aesthetically creative movement instrument "to better match identity, interests, and desires" of users (Morris, 2015, p. 6). Merry Lynn Morris, a dance choreographer and inventor, has designed a 'smart' Rolling Dance Chair while working with dancers with disabilities at the University of South Florida. Through a complicated programmed algorithm, the chair can decode the user's movements and follows the dancers. The base of the chair hides the wheels to prevent costumes from getting caught (Ferro 2016; Leibach, n.d.). Watch this video <https://youtu.be/DdfUJHQPqec> that demonstrates the Rolling Dance chair in a dance studio (Arts and Disability, 2016).

Another trailblazer in disability dance is Kitty Lunn. In an interview with Michelle Vellucci of the Brooklyn Rail (2009), she discussed how her life changed from being a soloist dancer for the Washington Ballet to becoming a paraplegic dancer in her customized wheelchair. Lunn and her husband collaborated to design a wheelchair that is lightweight, with a sports chair base and a low back, purposely not equipped with brakes to facilitate easier movement for dancing. In 1995, Lunn started the Infinity Dance Theatre, a mixed ability dance company, and has taught dance to disabled students at Hunter College and completed teacher training workshops at New York University and National Dance Education Organization in Washington, D.C., to name a few (“Infinity Dance Theatre: Education,” n.d.; New York State Dance Education, 2019).

Conclusion

The promise of efficiency that AT brings can be alluring. Disabled artists have been using AT to create their art forms throughout history, but the artists of the past did not have the variety of tools available today. Therewithal, the fast-paced turnover of low-, mid-, and high-tech tools can be overwhelming and intimidating for users and art educators. In addition, the more high-tech AT tool requires a significant amount of time to learn how to use before the user can become adept. For example, the eye gazer or Photoshop software will require practice and persistence to learn how to use their applications productively. The length of time to become adept at using AT varies for every disabled artist because of the differences in technological skills, knowledge, and functional capabilities. However, disabled artists have developed their own strategies, such as using a combination of tools or adapting working methods like working for shorter periods and using personal assistants to create art.

More SWDs are now using mainstream technology such as the iPad to create art, too, and art educators have to become comfortable with exploring how AT can be used in the classroom, how it can be customized for the SWD, and how to evaluate whether the tool is the right fit for the individual. Besides these, educators must be familiar with the different categories of disabilities and functional limitations associated with the disability and must realize that an AT that is effective for one student may not be the best for another. There is no one-size-fits-all AT. It is vital that educators receive pre-service training addressing arts education for SWDs to integrate the use of AT in the arts. It is necessary for schools to hire disabled artists to teach in schools and impart their unique disability perspectives. The IDEA, ADA, and Sections 504 and 508 of the Rehabilitation Act have been instrumental in advancing the use of AT in education settings to level the playing field. The IDEA, which applies to the K–12 setting, mandates that schools must provide AT to SWDs as part of their IEPs and, as a result, teachers should be trained to use and implement technology in the art classroom so students succeed. This could only lead to more SWDs enrolling in postsecondary schools to pursue art programs and as a result, higher education faculty in the arts could get more experience working with SWDs. Furthermore, this snowball effect could lead to more money invested in developing inclusive programs for disabled artists. However, there is a need for empirical research on issues such as the effectiveness of pre-service

training and evaluation of best practices in the adaptive art curriculum, which include the voices of SWDs, educators, and education administrators.

Over the last three decades, museums and performance spaces have invested more money in attracting disabled audiences through accessibility services and AT. Exposure to the arts can be empowering to individuals with disabilities who want to pursue their creative talents, and even more when the art, music, or performance they are viewing, or hearing are created by disabled artists. However, not all museums and performance spaces have the same budgets allocated to accessibility initiatives, and there is no one-size-fits-all solution to inaccessibility for a heterogeneous group of disabled individuals. But there is a trend towards integrating AT to enhance engagement in disability artistry.

There is not one perfect AT for all individuals with disabilities. However, product designers can learn how to think of new ways to improve the usability and effectiveness of their products from artists with disabilities. Factors that are important to users are whether products are easy to use, easy to adapt and customize, reflect the individual's preference, and affordability. User-sensitive inclusive design is not only ideal but necessary to develop or improve AT for individuals with varying functional limitations. Some types of AT, such as prosthetics with artificial intelligence, require active participatory design, other software products can be beta-tested on the disabled artists, and other AT tools can be created by the artist with disability through collaboration. Professionals working with disabled students, such as educators or art therapists could also be instrumental in the design and improvement of AT. Technology companies should consider inviting professionals who work with SWDs and disabled artists to share their experiences with the AT products that they use or give ideas about new products that they need. One of the barriers disabled artists and educators face is not having the support to learn how to use the AT. For both disabled artists and professionals, this could lead to frustration and a waste of valuable time. If they are given opportunities to communicate with product support, the training cost could significantly decrease. This could also increase persistence and confidence in using AT. If users are abandoning the tools because of a lack of training, this is costly. Some mid-and high-tech tools can be expensive to purchase. However, as technology is becoming more ubiquitous and there seems to be a constant influx in the market, prices may drop over time. Although funding for AT was not at all discussed in this study, resources are included in the appendices that could provide grants, scholarships, and AT device loan programs and financing services to artists with disabilities.

Lastly, this study found a lack of scholarly research done on the perceptions of professional disabled artists regarding the benefits of using AT to create art. But there was more anecdotal evidence that supports how AT has enhanced the productivity, access, and engagement in the arts for this group. One supposition for the lack of evidence-based research could be related to the fast turnover of technology. Another factor could be related to difficulty in recruiting a sample group from a heterogeneous group of disabled artists with varying characteristics such as age, preferences, attitudes, learning styles, and types of AT used. Given these factors, the research results may also be difficult to generalize. However,

despite these limitations, it is important to develop new approaches to study the efficacy and usability of emerging AT.

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Appendix A

Figure 1.

Beethoven's Ear Trumpets

<https://www.beethoven.de/en/media/view/5217893683822592/Beethovens+Hörrohre,+gefertigt+von+Johann+Nepomuk+Mälzel,+1813?fromArchive=6609072782573568>



Appendix B (Visual Artists) Mainstream software, input devices

Adobe Products (<https://www.adobe.com/accessibility/products/indesign.html>)

Photoshop Sketch (<https://www.adobe.com/products/sketch.html>)

Photoshop After Effects (<https://www.adobe.com/products/aftereffects.html>)

Adobe Illustrator (<https://adobe.ly/2TuAghY>)

Flash Player (adobe.com/products/flashplayer)

Lightroom (<https://lightroom.adobe.com/>)

GIMP (<https://www.gimp.org/>)

Artrage (<https://www.artrage.com/>)

Sketchbook Pro (<https://sketchbook.com/>)

Manga Studio (<https://manga-studio-ex.en.softonic.com/#tab-review>)

Infinite Painter (<https://www.infinitestudio.art/discover.php>)

Tablets (<https://www.toptenselect.com/top-10-best-tablets-artists/>)

Wacom Pen Tablets (<https://www.wacom.com/en-us/products/pen-tablets>)

Apple iPad Pro (<https://www.apple.com/ipad-pro/>)

Trackball mouse replacements (Different trackball models are [available](#).)

Eye gaze trackers (<http://www.eyewriter.org/>)

Tobii (<https://www.tobii.com> › Tobii Group › About)

Eyetribe (theeyetribe.com/)

Dragon NaturallySpeaking (www.nuance.com/)

Virtual Reality Tools and Motion Tracking

MS Kinect technology (<https://bit.ly/2He1SSx>)

Tiltbrush (<https://www.tiltbrush.com/>)

Cameras with easy use shutter release port, mounting system, camera switch)

[Canon Eos Rebel T3 digital SLR: https://www.usa.canon.com/internet/portal/us/home](https://www.usa.canon.com/internet/portal/us/home)

Ultimate Switch: <https://advopps.org/ultimate-switch-offers-ultimate-accessibility/>

Magic Arm: <https://enablingdevices.com/product/magic-arm-mounting-system/>

MovieMaker (<https://www.topwin-movie-maker.com/>)

iMovie (<https://www.apple.com/imovie/>)

Surface adaptations (slant boards, desk liners, PVC pipe paintbrush, mouth sticks, velcro straps)

Organizations

Art Beyond Sight (<http://www.artbeyondsight.org/sidebar/aboutsite.shtml>): Provides educational resources, handbook for museum practitioners, teacher resource center provides lesson plans and curriculum ideas for K–12 teachers and museum educators, and career guidance for the blind, visually impaired

A.R.T./New York (<https://www.art-newyork.org/accessibility>): Provides support to theatres that are developing accessibility programs for their own companies

Augsburg University: (<https://www.augsburg.edu/class/groves/assistive-technology/everyone/>): Provides a comprehensive list of the latest information on a variety of AT

Disability Arts International (<https://www.disabilityartsinternational.org/artists/>): Developed by the British Council, promotes the work of disabled artists, disabled-led companies, and inclusive arts organizations

Infinitec (<http://www.infinitec.org/adaptive-artists>): Provides information on hundreds of devices that promote disability arts

Mouth and Foot Painting Artists of the World (<https://mfpausa.com/>): Brings together artists who have lost the use of their hands to paint with a brush and paint with their mouth and feet; markets, exhibits, and sells works done by artists; gives financial assistance

National Endowment for the Arts (<https://www.arts.gov/>): Independent federal agency that funds, promotes, and strengthens art opportunities and participation to all Americans

Assistive Technology Act Training and Technical Assistance Center (AT3) (<https://www.at3center.net/stateprogram>): Provides information and resources on state Tech Act such as demonstration opportunities, device loan programs, AT reutilization, and AT financing services

Appendix C (Musicians) Mainstream artistic software

Apple GarageBand (<https://www.apple.com/mac/garageband/>)

Digital Ear (<https://www.digital-ear.com/>)

MIDI controllers (<https://ehomerecordingstudio.com/midi-controllers/>)

Skoog (<https://skoogmusic.com/>)

Virtual Reality Systems (https://youtu.be/_cNJI_fSURM_)

Dancing Dots low vision and blind performers
(<https://www.dancingdots.com/main/index.htm>)

JAWS: <http://www.freedomscientific.com/Products/software/JAWS/>

Goodfeel: www.dancingdots.com/main/goodfeel3.htm

Sound Forge: <https://sound-forge-pro.en.softonic.com>

Breath and head powered instruments

Jamboxx: https://youtu.be/x_eIRX7hHpl

Yamaha breath powered keyboard: <https://pianoandsynth.com/yamaha-pianica-p37e/>

Bite switches and page turners

Conceptus (www.conceptusinc.com/spneeds.htm)

Adaptive Tech Solutions (<https://www.adaptivetechsolutions.com/bite-switch/>)

Airturn (<https://www.airturn.com/products/categories/Bite+and+Tongue+Switches>)

Tilt switch pedal control (<https://www.enablemart.com/adaptation-dipsy-tilt-sensitive-switch>)

Jam Studio (<http://www.jamstudio.com/Studio/index.htm>)

Rock Our World (rockourworld.pbworks.com/)

Organizations

Coalition for Disabled Musicians (<https://disabled-musicians.org/links/>): Non for profit volunteer ran organization dedicated to supporting physically disabled musicians

Drake Music (<https://www.drakemusic.org/about-us/>): UK based enables disabled musicians to create music, develop outreach, training and education

Appendix D (Adaptive Tools and Organizations for Performance Artists)

American DanceWheels Foundation: [ADF's website](#)

Augmentative and Alternative Communication:
<http://www.everyonecommunicates.org/stories/individualstories.html>

Axis Dance: <http://www.axisdance.org/>

Boston Ballet Adaptive Teacher Training: <https://bit.ly/2W4Nch6>

Gibney Dance: <https://gibneydance.org/disability-arts-nyc-task-force/>

Infinity Flow: <http://www.infiniteflowdance.org/home>

REVolutions Dance: <http://www.revdance.org/>

Infinity Dance Theatre (classes, instructional videos):
<https://www.infinitydance.com/shop.html>

Integrating Deaf Performers in Live Musical Theatre: <https://bit.ly/2WzMfKE>

Mellon Foundation Grants in the Performing Arts (<https://bit.ly/2JhGDkY>): Grantmaking in the performing arts

National Arts and Disability Center (<https://www.semel.ucla.edu/nadc>): leading consultant in the arts and disability community

National Theatre for the Deaf (www.ntd.org/): Touring theatre company of Deaf artists

Rolling Dance Chair: <https://www.sciencefriday.com/articles/a-chair-fit-for-dancing/>

Shadow Interpreting in Theatre Stage: <https://bit.ly/2vQFpVf>

Appendix E

Figure 1.

Phyllis, 1983–1984 [Photo] Original work at SFMOMA



Figure 3.

John II, 1993 [Photo] Original work at SFMOMA

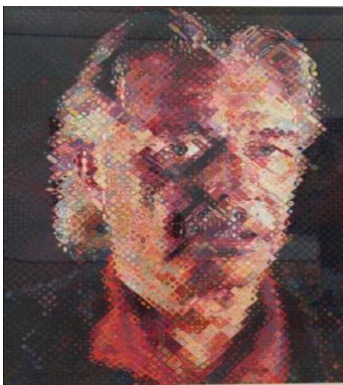


Figure 4

Roy I, 1994 [Photo] Original work at SFMOMA





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Creative Works
The Dream:
Freud & Szasz In Conversation

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Abstract

A humorous, fictional but academic conversation between two of psychiatry's giants Sigmund Freud and Thomas Szasz. Or is it a dream? Through their animated dialogue and critique of each other's theories is elicited a contrasting exploration of their conceptual differences. The dialogue canvases: the origins of psychiatry; the medical-scientific approach to mental illness and the medicalization of the language of psychiatry; psychiatry as science vs. the social construction of mental illness; hysteria; the causes of mental illness; patients' social responsibility vs. illness; the unconscious mind; sublimation of individual freedom vs. metarules of society and coercion vs. treatment. The conversation demonstrates the sharp contrasts between the seminal works of both theorists; on the one hand Szasz's *The myth of mental illness: Foundations of a Theory of Personal Conduct* and Freud's *Studies in hysteria* (with Breuer) and *Civilization and its discontents*.

Keywords: Freud, Szasz, psychiatry, mental illness

Sigmund Freud's work in *Studies on Hysteria* (1893) [the *Studies*] launched the concept of mental illness as a medical diagnosis and introduced us to the idea of the subconscious. Thomas Szasz's work, *The Myth of Mental Illness* (1961), galvanized a reexamination of psychiatry, critiques the medicalization of mental illnesses and perceives of mental illness as a social construction. The ensuing is a critical text analysis presented as a humorous but scholarly fictional dialogue between these seminal theorists. The use of fictional dialogue allows each work to be used as a lens to view the other. The juxtaposition of these authors' ideas highlights the tension in their divergent views and invites a new way of critically examining their ideas. The dialogue highlights the controversies that arise in the origins of psychiatry and whether hysteria is a medical condition or a social choice. Our two authors explore whether patients are socially responsible for their actions or whether actions can be excused based mental illness. They explore the tension of involuntary psychiatric interventions vs. personal autonomy. Lastly, they discuss whether society's discontents arise due to sublimation of individual freedom leading to neurosis, as Freud claims, or a result of lack of mastery of societies metarules, as Szasz opines. Their conversation offers us greater insight into these controversies.

Although Freud wrote at the turn of the last century, and Szasz published nearly a lifetime later, the debate between the two remains salient over a half-century later. It is a debate that continues to be germane to critical disability studies and the study and practice of sociology, psychology and psychiatry.

(Note: To distinguish the speakers, Freud's comments appear in regular font and Szasz's are italicized.)

The conversation

We find Thomas Szasz at his desk in his Syracuse, New York home late one September evening circa 2011. It is a modest, 1950's, suburban house, typical of its time. The residence is a short drive to the State University of New York's Upstate Medical University, where Professor Szasz lectured. Szasz is at his computer writing his latest screed about psychiatry. We hear a voice from the shadows.

Freud: Are you bashing my work again?

Szasz: Who's there?

Freud: Who do you think?

Szasz: Who is it?

Freud: I would have thought you would recognize my Viennese accent.

Szasz: I don't know anyone from Vienna.

Freud: Are you sure? I am quite well known in many circles. I think you have read some of my work.

Szasz: I have? Step out where I can see you.

Freud: (Stepping out of the shadow). I think you know me, yaw.

Szasz: How did you get in here?

Freud: I have a very strong id, or maybe you do, but that is for another conversation.

Szasz: Who let you in? You must be one of the new grad students. Who put you up to imitating Herr Freud? I must say that you look remarkably like him.

Freud: My dear fellow, I have not been a grad student since 1881, in Vienna. Those were the days, with such uncharted territory still ahead.

Szasz: All right, enough. Who are you?

Freud: I am I. It is Jung who thinks we are different people in different places. I had such hope for Carl and he disappointed me, just as you have.

Szasz: What are you talking about? Enough already! Who are you?

Freud: I am sure you know in your subconscious, but If you need me to say it, I am Dr. Sigmund Freud, not quite in the flesh, though I think I look remarkably well given that I have been deceased since 1939.

Szasz: That is impossible. I must be dreaming. It must be something I ate.

Freud: Yes, one should never eat bratwurst before bed. You know, I did quite a lot of work on interpreting dreams, but that is not exactly what I am here to talk about. Do you mind if I smoke? (He pulls out a cigar from his vest pocket and sits down in an armchair across from Szasz's).

Freud: Chairs were much more ornate in my day. I am here to talk to you about your denigration of psychoanalysis. What do you have to say?

Szasz: I obviously have much to say. First, you follow your mentor Charcot in calling malingerers hysterics and dressing hysterics up as science.

There is no reason to believe that every person who complains of being ill or who looks ill or who is disabled –or who manifests all three of these features - must also have a psychochemical disorder of his body! This does not deny the possibility that there may be a connection between such complaints and bodily diseases. The nature of this connection, however, is empirical, not logical. Once this is clear, it becomes a matter of scientific and social choice whether we prefer to emphasize the similarities – and place hysteria in the category of illness; or whether we prefer to emphasize the differences and place it in the category of nonillness” (Szasz 1974, 25).

My criticism of Charcot was his “covert use of scientific prestige to gain certain social ends” (Szasz 1974, 30), being the “acceptance of the phenomena of hypnotism and hysteria by the medical profession in general” (Szasz 1974, 30).

Freud: Charcot was a beginning not an end, my good doctor. I had many teachers and collaborators over my career, including Meynert, Bruke, Fleiss, Breuer, Blueler, Junge, Adler, but you seem to ignore all these other men of science (Strachey 1974). As I said, Charcot was a starting place. I used hypnosis for differential diagnosis, and “[t]he success of the treatment confirmed the choice of diagnosis” (Freud & Breuer 1974, 65) but you ignore that I was not immune to progress, and that I did move away from hypnotic suggestion, to free association (Strachey 1974). What I do is not so unlike what you do with your patients, I would assume.

You forget that these were nascent studies, that these were primitive, initial considerations of mental illness. We had little in the way of diagnostic technology (Webster 1996). As I state in my *Studies on Hysteria*, “Even today I regard them not as errors but as valuable first approximations to knowledge which could only be fully acquired after long and continuous effort” (Freud 1974, 50). Our works on hysteria have been described as “pre-psychoanalytical,” and “the embryonic moment of psychoanalysis” (Bowlby, 2004, xvi-xvii).

If I had not discovered the unconscious and the neurotic symptoms resulting from the conflict between unconscious impulses and conscious impulses you would probably be a plumber today. There would be no schools of psychology for you to teach at or psychiatric techniques

for you to criticize. There would be no psychoanalysis and therefore no psychoanalysts (Bowlby 2004). The entire enterprise of psychiatric medicine may not even exist today.

Szasz: Yes, the “therapeutic state” (Szasz 1984), where everyone one who claims to be depressed is instantly medicated. But we can talk of that later.

In fact, I claim that we should, “abandon the entire medical approach to mental illness and substitute new approaches for it appropriate to the ethical, political, psychological, and social problems from which psychiatric patients suffer and which psychiatrists ostensibly seek to remedy” (Szasz 1974, 79). I say this on the basis that your and Breuer’s patients were not necessarily hysterical, but simply “unhappy or troubled”, not unlike my own, expressing their distress through bodily complaints (Szasz 1974, 74). In fact, you do “not actually identify and treat disease of organisms or bodies” (Szasz 1974, 73).

Freud: Yes, I understand there are some effective pharmaceuticals that have been developed since my day. I actually published the first inquiry into the use of cocaine for medical purposes (Strachey 1974).

With respect to treatment, however, that is incorrect;

we found, to our great surprise at first, that each individual hysterical symptom immediately and permanently disappeared when we had succeeded in bringing clearly to light the memory of the event by which it was provoked and in arousing its accompanying affect, and when the patient had described that event in the greatest possible detail and had put the affect into words (Freud & Breuer 2004, 10).

Language becomes a substitute for action (Freud & Breuer 2004), “abreacting” trauma by allowing the strangulated effect, which caused by a suppressed memory, to escape into normal consciousness (Freud & Breuer 2004, 19).

Let’s assume for a moment what you say is correct. It seems to me, that the same can be said of your work. At any rate, as you would know, my work did not stop with *Studies on Hysteria*. As I stated before, “[t]he developments and changes in my views” even during the brief “course of thirteen years of work”, as between the first and second edition of *Studies*, had “been too far-reaching for it to be possible to attach them to my earlier exposition without entirely destroying its essential character. Nor have I any reason for wishing to eliminate this evidence of my initial views” (Freud 2004c, 3). Furthermore, Dr. Breuer and I expressly stated in *Studies* that we do not cure hysteria, but have developed a therapeutic advantage (Freud as cited in Strachey 1974), “that this has brought us nearer to an understanding only of the mechanism of hysterical symptoms and not of the internal causes of hysteria. We have done no more than touch upon the aetiology of hysteria” (Freud & Breuer 2004, 20). I don’t see why this is any different than any other medical condition, subject to research.

Szasz: That is the point. When we discover the cause of a mental disease, typically it ceases to be a mental illness and becomes a physical illness. “[N]o doubt there are diseases that

they do not know how to detect today. But it is one thing to admit this, and quite another to maintain that, because of these historical facts, that persons psychiatrists now call schizophrenic suffer from an as yet undetectable form of organic disease, and it is only a matter of time and research until medical science discovers the lesions 'responsible' for this disease" (Szasz 1974, 84).

Freud: My dear sir, Breuer and I see therapy as 'cathartic', and that the illness could be stimulated in this way "suggests that the illness . . . [is] not primarily organic or hereditary" (Bowlby 2004, viii). Breuer postulated a physical cause to hysteria. He analogized that,

a great number of physical processes, such as the secretion of saliva or tears, variations in the action of the heart, and so on, it is possible and plausible to assume that the same process can equally well trigger by ideas as by peripheral or other non-physical stimuli. The opposite needs to be proved and we are still very far short of that. Indeed, it seems certain that many phenomena termed hysterical are not caused by ideas alone" (Breuer 2004, 191–192).

He talked of a number of possible physical causes, such as "tonic excitation" (197). For my part, I am convinced, that the case studies in *Studies on Hysteria* and many subsequent cases I have analyzed and treated, "produce a confirmation of the physical mechanism, of hysterical phenomena proposed by us, simply because the analysis revealed that these cases were, simultaneously, sexual neuroses" (Freud 2004a, 262).

While you protest much, and while from a sociological perspective you have made a contribution, your works are somewhat disfavored. I understand they are not taught much (Oliver 2006); whereas my works on hysteria have had a bit of a renaissance; reprised by a number of academics under the rubric of "new hysteria" (Bowlby 2004, xv).

Do you have any *sacra tort*, per chance?

Szasz: Syracuse is not exactly known for its Viennese pastries. I must also protest the way you and your cadre conflate medical and psychological language. "[T]o speak of . . . 'organic symptoms' and to place them in the same category as hysterical pains and paralyses is a misuse of language" (Szasz 1974, 85). Moritz Schlick said it well, "The so called 'psycho-social problem arises from mixed employment of both modes of representation in one and the same sentence" (Schlick 1935, 403).

Freud: You are correct. I spoke of "illness" and of "the psychology of ordinary life", sexuality and science (Bowlby 2004, xxvii). I answered this initially in the *Studies* itself.

I have not always been a psychotherapist, but was trained like other neuropathologists to use local diagnosis and electro-prognosis. I myself still find that the case histories that I write read like novellas and lack, so to speak, the serious stamp of science. I have consoled myself with the thought that the nature of objects rather than my own personal preference is clearly responsible for this; local diagnosis and electrical reactions are simply not effective in the

studying of hysteria” (Freud 2004b, 164–165).

You are no doubt familiar with my later writings, where I expressly said we must recollect that all our provisional ideas in psychology will presumably one day be based on an organic structure (Lear 2005). This accounts for my synthesis of psychological and biological ideas. I had no doubt that science would in time correct my errors. We had limited neuroscience in our time, leaving us to speculate in many regards, but faith in the corrective power of scientific progress allowed for a bold hypothesis (Lear 2005).

Szasz: We will have to agree to disagree. I do not believe that mental patients, particularly hysterics, suffer from illnesses, symptoms, causes, and are subject to medical treatments. Rather, they need to change their life orientations. The way to treat them is to see them as imitating illness and to understand and translate the special idiom of body signs into ordinary language (Szasz, 1974).

Freud: Of course we do disagree. I do not think you can divorce psychoanalysis from science and medicine. Yes. Yes. I know all about your proto-language analysis, and no matter what you call them, they are still symptoms.

Szasz: You do?

Freud: I happen to have a lot of time on my hands now, so I read quite a lot. At any rate, your theory is interesting sociology, however unduly skeptical of psychiatry. I give you your due, for your accomplishments in patient advocacy but your continued insistence on mental illness as a myth ignores the medical progress of your own time.

Szasz: You have many critics as well (Tanabe, 2013). Many support my criticism, that your theory’s logical conclusion is a society in which we do not treat individuals as responsible persons but instead treat them as irresponsible patients (Szasz 1974).

Freud: Not so, nothing is more responsible than liberating oneself from debilitating psychological symptoms. But if you mean to say, that I believe there is an unconscious aspect to the mind, that causes a repressed consciousness, to not always be conscious or in control of one’s actions (Tanabe, 2013), yes. The mind does act to defend itself from traumatic experience.

Szasz: But if there are these irrational forces, where a person is excused from responsibility for their actions; we then have a world where we replace responsibility with illness. “[T]he issue or question for the patient becomes to what extent is he willing to recognize his evasion of responsibility often expressed as symptoms” (Szasz as cited in Carey 2000). “The goal is to assume more responsibility and therefore gain more liberty and more control over one’s life” (Szasz as cited in Carey 2000).

Freud: That is the indirect goal, which is accomplished by the direct goal of treating symptoms. We differ, in that my assertions are backed by clinical evidence, whereas your assertions seem more semantic. You may ask Anna O, Emmy von N., and the other of my

patients in the cases we present in the *Studies*, if they did not improve. A recent discussion of my work put the nay saying this way; “[m]uch of the criticism of psychoanalysis as extravagant - as well as much of the emptiness of academic debates – occurs because theoretical terms are invoked in isolation, cut off from clinical reality” (Lear 2005, 9). You forget that, I also listened to human suffering and that my theories are grounded in resolution of symptoms (Lear, 2005).

You complain about the impact of psychology on society, but society creates discontent in its citizens by sublimating the individual’s freedom (Freud 1961), in exchanging “a portion of happiness for a portion of security” (Freud 1961, 100). As a result, “[i]t was discovered that a person becomes neurotic because he cannot tolerate the amount of frustration which society imposes on him in the service of its cultural ideals” (Freud 1961, 59).

Szasz: Our understanding of societal rules is not so different. I also talk about the rules of society, but instead of leaving off with neurosis, I offer the idea of creating metarules, or, rules about rules formed from our ability of abstraction, as a way to cope with the compulsion of social rules on the individual. “Acquiring such understanding constitutes a form of mastery. Only by practicing what may be called the metarule attitude – which is actually a special case of scientific attitude applied to the domain of rules – can we acquire a secure yet flexible integration of rules as behavior regulating agencies” (Szasz 1974, 161). People do shape their own destinies to some extent, “no matter how much they might bewail the superior forces of alien wills and powers” (Szasz 1974, 151).

Freud: Again, we are going to have to disagree. Metarules just sound like a way to reframe the treatment of neurosis.

Any espresso?

Szasz: I am a terrible host, but I have never hosted a specter before, particularly one I am so antithetical towards.

Freud: Are you sure I am a specter? If I am, this is a neat trick for a sceptic.

Szasz: You mentioned your theory’s being grounded in clinical research, but you cannot escape that there is a normative element to how you interpret your data. You are “a moralist in the guise of science” (Szasz 1974, 153). “Virtually all behavior with which the psychoanalyst and psychiatrist deal is learned behavior. Since such behavior cannot be properly described or analyzed without dealing explicitly with norms and standards that regulate it, and goals it seeks to attain, psychoanalytical theory is foreordained to be unable to offer an adequate account of such conduct” (Szasz 1974, 153-154). Mental illness must then be socially constructed (Grohol, 2012), with a self-sustaining self-interested cadre of the psychiatric industry.

Freud: I have always maintained neurosis is ultimately biological (Hacking 1999). I believe that I have been entirely objective in this regard. As I have said, what our method lacks in scientific sounding analysis it makes up for in, “in-depth portrayal of the workings of the

inner life” (Freud 2004b, 164-165), which “does allow me to gain a kind of insight into the course of hysteria” (Freud 2004b, 164–165). This lack of scientific sounding analysis may account for your discomfort.

Szasz: My discomfort is that you diagnose hysteria by declaring it mental illness (Szasz 1974). But let’s move on. “I am opposed on moral and political grounds to all psychiatric interventions which are involuntary and on personal grounds to all such interventions which curtail the client’s autonomy” (Szasz 1974, 261). I know with great certainty, civil commitment really means imprisonment and that forced treatment generally means assault (Breeding 2011).

Freud: Coercion existed long before me, and sadly, may exist long after you. However, you can’t have it both ways. You cannot accuse me of being both pro-treatment and pro-coercion. Obviously, I believe treatment is preferable. Moreover, in fact, I believe my theories have been used in support of a movement to reform the treatment of criminal offenders, including sex offenders, by moving away from punishment to treatment (Fisher 1968).

Szasz: So, you believe that people are never responsible for their actions and that they should be excused by pleas of insanity?

Freud: I think you confuse two concepts, not being legally responsible by way of incompetence, and mental illness. The former means the accused does not understand the nature of the proceedings and is unable to instruct legal counsel. This is essentially a legal construct albeit applied by psychiatrists. I, on the other hand, with respect to the latter, maintain that crimes are often committed due to a conflict of natural drives that overtake individual liberty, which are in tension with society’s order, causing guilt and neurosis. It is the guilt that leads to crime. “According to this view, crime is not the result of a criminal personality, but of a poorly integrated psyche” (Bryant 2012). Therefore, being deterministic, crime, and particularly sex crimes, are uncorrectable by punishment (Fisher 1968).

Szasz: Feminists accuse that line of thought as being “deeply suspect for having highlighted fantasy and desire, rather than brute reality and sexual exploitation” (Forrester 1997, para. 3). And there are many other criticisms of your views in relation to “therapeutic efficacy, questions of scientific explanation, and questions concerning . . . scientific probity” (Forrester 1997, para. 6). Many have had questions about the ethics of psychoanalysis (Forrester 1997). More specifically, several claim that there has been a high level of misdiagnosis with regard to the symptoms of hysteria, with many such symptoms being merely the product of untreated organic illnesses (Webster 1996). Moreover, hysteria has been dropped from the Diagnostic and Statistical Manual of Mental Disorders (DSM), since 1952 (Webster 1996).

Freud: There are misdiagnoses in every form of medicine, and as for the *DSM*, hysteria is there, in the description of other disorders listed (Webster, 1996).

To the contrary, you have been accused of being too absolute in your views. You ignore known brain diseases and the possibility that the etiologies of other mental diseases have yet to be determined, as well as the fact that medications work for certain disorders, such as schizophrenia and depression, and that there are certain diseases that can only be identified by behaviors, such as Alzheimer's disease (Sullum, 2005). You also ignored new diagnostic technology that has occurred in your lifetime (Webster, 1996). Most importantly, you raise many issues about psychiatric diagnosis, without offering solutions (Frances 2012) and you leave no hope for cures (Oliver, 2006).

We both suffer from psychiatry being a relatively young science. I have faith, that in time science will satisfy us both, by finding causes and treatments to currently untreatable mental disorders and maybe in doing so, will make mental illness more of a "myth".

At any rate, the hour is late, and I must take my leave and you your "sleep, per chance to dream" (Shakespeare).

Conclusions

Mental illness, of course, is not a dream. The World Health Organization (2001) estimates that 450 million people suffer from mental or neurological disorders worldwide. A more recent report puts the prevalence of mental health disability globally at more than 970 million people (James, Abate, Abate, Abay, Abbafati, Abbasi, Abbastabar et al. 2017). And while the dialogue is humorous, with intent to be engaging, it is not intended to make light of the serious nature of mental health issues.


The dialogue has illustrated a number of tensions between these seminal theorists' perspectives. The dialogue elicits the controversies as to whether mental illness is a medical condition or a social choice; whether psychiatry is a science and mental illness is clinically proven or whether mental illness is socially constructed reflecting norms and standards of society. These perspectives are still studied, debated and critiqued in critical disability studies, sociology, psychology and psychiatry. Regardless of one's opinion, these controversies are relevant to psychiatry's past and likely to be reflected in its future. But more significantly, these issues are salient to societies' treatment of persons with mental health disabilities.

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Multimedia

A Review of *Vulnerable Constitutions: Queerness, Disability and the Remaking of American Manhood* (2019)

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Abstract

Invited Review by Maria Teresa Hourar

Vulnerable Constitutions: Queerness, Disability and the Remaking of American Manhood

By Cynthia Barounis

Philadelphia, PA. Temple University Press. 2019

Keywords: queerness, biopolitics, disability, masculinity, immunity, pathology

Vulnerable Constitutions: Queerness, Disability and the Remaking of American Manhood is a timely analysis of how the biopolitics surrounding both queer and disabled identities have been leveraged toward constructing an ideal of American Manhood and likewise, American citizenship, as a kind of “prophylactic” body. Cynthia Barounis picks up from a widely accepted critique of the social construction of disability in order to further look at how these social constructions are produced in part by a layering of nascent medical knowledge in sexual science, pathology and psychology during the 20th Century upon idealized models of “masculinity”. Eugenic and ableist visions of national identity circulated images of bodies as fit, immune, and homogeneous throughout popular culture such, and eventually came to define the model American citizen.

Barounis offers a compelling reading of how these narratives appear in the work of male American authors Jack London, William Faulkner, F. Scott Fitzgerald, James Baldwin, Samuel Delany, and Eli Clare, giving theoretical framing to the political potentiality of models of “antiprophyllactic citizenry” to challenge normative masculinities. Through the reappearance of legible forms of queer-crip masculine expressions within these authors’ respective works, Barounis offers an imagining of how the strength of both individual and national bodies might be understood as contingent upon their capacity for vulnerability, exchange, and debility, rather than ability. For scholars working in the field of disability studies, this text brings together conversations in the lineage of queer-crip theory following McRuer (2006) and Garland-Thomson (1997) and applies them not only to American Literature, but also to contemporary global politics, offering rigorous if not challenging critique of events like the imprisonment of Chelsea Manning, discussions of immigration reform, cultures of “trigger-warnings” and safe-spaces, and the failure of so-called white American neo-liberalism. Barounis neatly unpacks appearances of the medical gaze and the power of its regulatory authority and cultural influence in each chapter, revealing how narratives around the stigmatization of formerly pathologized “deviant” sexualities such as homosexuality, hypersexuality and “frigidity” or asexuality, as well as gender dysphoria, are

used within American literature as a potent allegorical site for the interrogation of relationships between men, and between citizen and state.

While queer and disabled identities are centered in their productive futurity, Barounis's argument for the ways in which defense and prophylaxis are in fact dangerous to nations is most persuasive when attending to racial politics within the work of Baldwin. If we contextualize Baldwin's writing within a larger context of the role he also played as a key theorist of democratic reconstitution, his argument linked the stigmatizing of homosexual intimacies to racial discrimination, as a political tool which shifts attention away from recognizing the real threat to citizens- our continued faith in a failed model of representative democracy adopted by our founding fathers. Baldwin "marshals love as the glue of a just society" (Barounis, 2019, p. 128), and through erotic metaphor he argues for a union between races, classes, genders, sexualities and abilities, suggesting that such unions have the power to disrupt binaries of American independence and dependence, but only if white liberal allies are willing to "relinquish those defenses- physical, psychological, and political- whose danger lies in the promise of safety." (Barounis, 2019, p. 131) Similarly, Barounis argues that able-bodied, cisgender and heterosexual allies might best express commitments to equity and social reform by abandoning "normative" cultural privilege in favor of a lived, embodied ethics of antiprophyllactic citizenry.

Vulnerable Constitutions is a dense but accessible work and oscillates between both challenging and entertaining the audience. It is highly recommended reading not only for scholars in disability studies but also for those in the field of gender and sexuality studies, as well as those interested in American literature. Barounis leads readers through a challenging territory at the intersection of these fields, examining how interrogating our notions of safety and precarity might mobilize the next generation in the endeavor of remaking America.

Maria Teresa Houar is a queer scholar of Indigenous Latinx and Haole descent, born and raised in Hawai'i on the outer islands of Kaua'i and Maui. Maria Teresa is a Ph.D. candidate in Performance Studies at UH Mānoa researching dance performance through intersectional lenses of sexuality, fetish, queerness, disability, militarism and consent as a means of dismantling the colonized view of the body.

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Multimedia

A Much-Needed Addition to the Literature on Autism and Education:

A Review of Communication Alternatives in Autism: Perspectives on Typing and Spelling Approaches for the Nonspeaking (2019)

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Abstract

This manuscript reviews Edlyn Vallejo Peña's edited volume, *Communication Alternatives in Autism: Perspectives on Typing and Spelling Approaches for the Nonspeaking (2019)*. The volume includes ten chapters by autistic authors active in the field as activists, self-advocates, artists and leaders, along with Peña's experiences as a parent and original research.

Keywords: autism, augmentative and alternative communication, inclusive education

Communication Alternatives in Autism: Perspectives on Typing and Spelling Approaches for the Nonspeaking (2019), edited by Edlyn Vallejo Peña, is comprised of ten chapters written by autistic authors, activists, bloggers, students and/or self-advocates who use letterboards and keyboards to communicate. Peña bookends these chapters with personal experiences as a parent, and findings from her research on best practices for educators supporting students on the autism spectrum who type and spell to communicate. Harnessing the disability rights mantra "Nothing about us, without us" this volume centers on the voices and experiences of contributing authors as they recount navigating educational and community spaces not designed with them in mind, in the midst of controversy around their chosen augmentative and alternative communication (AAC) methods, such as Rapid Prompting Method (RPM) and Facilitated Communication (FC). In her introduction, Peña situates the authors' stories within the debates and research surrounding teaching individuals with autism to communicate through pointing, spelling and typing. The ten chapters that follow are divided into three major sections that span three generations of social, educational and political realities for autistic people. The narratives reveal shifts to increased access and illustrate barriers to inclusion and access to communication that remain a reality for many autistic students who do not use speech as their most reliable form of communication.

In Section 1—*Escaping the Institutionalization Mindset*—Tracy Thresher (Chapter 1), Larry Bissonette (Chapter 2) and Amy Sequenzia (Chapter 3) tell stories of growing up at a time where institutionalization of autistic children was common. Key themes include

consequences of low expectations, ableism, presumption of competence, and support and solidarity. All three authors detail experiences across what Sequenzia terms “non-learning environment[s],” (p. 56) ranging from segregated special education classrooms, special schools and residential institutions. They each describe childhood and adolescence without formal access or consistent support for communication through typing, often coupled with segregation. Their narratives illustrate nuanced experiences navigating the world with bodies that do not always cooperate with their intentions. Their narratives highlight how sensory, movement and medical needs impact access to communication, educational and social opportunities in an ableist society.

Thresher, Bissonette and Sequenzia are united as “survivor[s] of low expectations” (p. 41) and by their continued contributions to a paradigm shift around autism through writing, film, poetry, art and advocacy. Thresher and Bissonette share a common experience as co-stars in the documentary *Wretches and Jabberers* (Wurtzburg & Biklen, 2010); they describe the life-changing experience of filming and the continued impact of their work in countering deficit discourses of disability. Sequenzia emphasizes the impact of social media on her connections, continuing education and advocacy. True throughout many chapters in the volume, each author ends with words of guidance. Thresher highlights the presumption of competence as key to breaking down barriers, while Bissonette centers the vital need for inclusion, urging others who type and spell to communicate to “make laps around the noisy field of jabberers [speaking people] with your typed words” (p. 50). In a poetic end, Sequenzia emphasizes “Access/Support/Respect” as bedrocks of learning for all, including nonspeaking, students (p. 65).

In Section 2—*A movement toward full inclusion*—Ido Kedar (Chapter 4), Samuel Capozzi (Chapter 5) and Dillan Barmache (Chapter 6) detail experiences living at a time of transition: part of the generation of access to education for all, which impacted their adolescence and young adulthood. Like many of the co-authors, they describe isolating experiences of not having reliable means of communication early in life. They discuss: unmet motor needs in behavioral interventions, inaccurate assumptions based on communication, regulation, and movement differences, and the power of support for access and self-confidence. While Kedar, Capozzi and Barmache experienced a range of educational placements, their narratives converge around how learning to use letterboards and keyboards to communicate as adolescents ushered in increased educational and community inclusion. Yet they make clear that those transitions were not seamless, necessitating their own and their families’ advocacy efforts. Kedar details years of hard work to gain entry to inclusive settings, including honing his motor planning for pointing and tolerance for sitting through lengthy classes. Barmache underlines the tenuous nature of his communication and inclusion as dependent on others’ willingness to honor his typing, and on his own efforts as a self-advocate. Capozzi reflects on his experiences at the intersections of disability and privilege, particularly as it plays out in inequitable opportunities for autistic students like him to access higher education.

The authors in Section 2 call for increased communication access and support for sensory and movement differences. Kedar encourages parents to resist deficit discourses and urges people with autism not yet accessing communication to: “have hope...I am fighting for your freedom and so are others. Hang in there.” (p. 82). Capozzi, too, offers hope, along with reminders that autistic people should be leading the direction of their own lives. Barmache urges educators, families and communication partners to balance communication, sensory, motor and emotional supports for autistic students, and move away from interpreting their capabilities based solely on observable behavior.

Section 3, *Triumphs and Obstacles in Navigating the Educational Maze*, Henry Frost, Emma Zurcher Long, Philip Reyes and Rhema Russell discuss recent experiences as students across a range of educational settings. They highlight: agency, self-advocacy, relationships, and self-expression. All four authors describe struggling to access communication until learning to spell and type to communicate by early adolescence, and associated advocacy for inclusive education. They, too, offer insider views of living with sensory and movement differences. Frost, Reyes, Zurcher Long and Russell describe navigating gaps in communication access between home and school, and highlight barriers created by segregation, ableism and limited access to trained communication partners. Each author discusses significant friendships and/or mentor relationships as crucial to their journeys, made possible through reliable access to communication. Frost underscores the importance of seeing himself represented in autistic peers and mentors, arguing that AAC be used in academic *and* social inclusion. Zurcher Long emphasizes the relationship between communication and agency, noting that upon learning to type, she “...went from being told most things, to being asked” (p. 135).

Section 4 authors offer examples of how communication can, and must, serve to support individual agency, along with/through advocacy, connection, friendship, and inclusion—in every sense of the word. Frost details his viral advocacy campaign “I Stand with Henry” to attend his neighborhood school and resist segregation. Zurcher Long tells of her love and use of music, rhythm, and movement as part of her identity. Reyes describes using writing—through letters to his neurotypical peers and his blog—to foster understanding about autism as a way of being. Russell collages advocacy letters, narrative and poetry to tell her story. She ends her chapter—and the final section of the book—with a poem highlighting the beauty and urgency of connection for communication.

Peña concludes the volume by connecting themes raised across the authors’ narratives to results of her research study about best practices in education for students who use letterboards and keyboards to communicate. This is a fitting end to what seems like a resounding call from all ten co-authors for a paradigm shift and educational practice tailored to experiences of nonspeaking and unreliably speaking people. Based on interviews with 14 school and college educators, informed by themes across the authors’ chapters, Peña lays out a framework for supporting students who use letterboards and keyboards to communicate. She offers these findings grounded in the intersecting necessities of: establishing foundational

beliefs in students' competence and remaining grounded in humility, providing access to communication and associated supports, including those to address sensory and movement needs, and constructing opportunities for inclusive participation and engagement.

This book is a much-needed addition to the literature on autism and education; it models how published work can, and should, amplify the voices of autistic people as authorities on their own experiences. As Peña notes, "The growing community of minimally speaking and nonspeaking students who demand communicative accommodations and inclusion in educational settings suggests that we are at a tipping point in history" (p. 189). *Communication Alternatives in Autism* evidences and contributes to this historical moment. Given that history grounds the volume's structure, additional contextualization of the authors' narratives within the history of disability rights, as well as scholarship and activism around neurodiversity, would have been helpful. Overall, I highly recommend this text for anyone whose personal or professional experiences reflect, intersect with or impact the lives of autistic people. There is a critical need for this information to get to educators, administrators, therapists and parents to change practice. There is also great value and possibility for autistic people, particularly whose communication access is emerging, to build community, forge connection and learn from autistic-led representation. In line with the authors' guidance, I encourage you to let powerful narratives guide your actions. As Barmache reminds us:

Reading my story is not enough—it is a beginning. Take what I have said with you as you look to other people who are impacted by autism. Take lessons from each typer in this book and really believe that every autistic child can achieve this level of expression if you reach out with an open mind. (p. 111)

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Endnotes:

x In this review, I alternate between use of person first, identity first language and language referencing the autism spectrum to mirror and honor the varied representation preferences amongst the authors, and across the autistic community.

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