

QUESTIONS OF PRACTICE

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## "Sometimes We Need to Get Uncomfortable:" On Working with Artists in the Disabilities Community



Shantell and Kathy. Photo by JJ Tiziou, courtesy of the Institute on Disabilities at Temple University.

This April, the Institute on Disabilities at Temple University premieres the Center-funded A Fierce Kind of Love, a world premiere play by theater artist Suli Holum, directed by David Bradley. The production is the centerpiece of a year-long series of programs and explorations of Pennsylvania's Intellectual Disability Rights Movement. Performed by a mixed ability cast, the theater work uses word, movement, and song to reveal how past activism has informed present-day issues.

We recently sat down with Lisa Sonneborn, producer of A Fierce Kind of Love, and Matthew Higgs, director and chief curator of the New York alternative art space White Columns, to discuss a number of questions that arise from their work with the disabilities community. Higgs has organized numerous exhibitions by visual artists with developmental disabilities through his work at White Columns and, previously, at Oakland's Creative Growth Art Center which provides professional studio and gallery space for artists with developmental, mental, and physical disabilities.

*In the excerpts that follow, Sonneborn and Higgs discuss the responsibilities of presenting the work of these artists, the importance of "complicating" audiences' preconceptions, and more.* 

## On presenting the work of artists with disabilities:

**Matthew Higgs:** The nature of each individual's disability is so distinct and idiosyncratic, that you can't generalize, you can't generalize about anything. So each time you encounter a new artist in this work, it's almost like you have to recalibrate, learn a new language, and then deal with that individual.

Each time you present the work of an artist with disabilities, the circumstances are always so different that it just forces you to address the question, how does one go about this? How can you be respectful to the intentions of the artist, if the artist doesn't have any conventional forms of communication? How do you present the work of an artist when the artist has no larger understanding of the art world?

And for me, the key is to create a long-term, lasting conversation around the relationships between creativity and disability, individuals with disabilities who are artists, the centers that support those artists, and organizations like White Columns. And how can we make that a more productive, interesting conversation for all concerned?

**Lisa Sonneborn:** These questions are very similar to the ones we asked ourselves when we were working on our photo/audio installation, Here. *Stories from Selinsgrove Center and KenCrest Services*. We had to ask ourselves repeatedly if our narrators with disabilities understood the context of the work they were participating in. Were our narrators willing to tell their story, or were they working under some sense of obligation? Would sharing their story be personally beneficial? Most importantly, would sharing their story have a negative impact on their lives, or put them in harm's way?

Personal memory is critical to our understanding of the history of institutionalization. Hundreds of thousands of people with disabilities were institutionalized in this country in the 20th century. Pennsylvania still operates five state centers; they are supported with our tax dollars, but how many of us truly understand the day-to-day experience of living in a segregated environment? I believe we have an obligation to gather accounts of institutional life from those who remember it, or still live it.

We talked with 19 people who lived in a state center or worked in a sheltered workshop. You know, we went in with a plan, and the only thing we really understood right away was that the plan had to be tossed, and new plans had to be formed all the time. But I think what we came away with was the idea that just the act of listening was a radical act in and of itself, because these are folks who aren't asked to tell personal stories. And they're monitored; they're asked if their house is clean and safe, if their transportation is good, but they're not asked about what's essential to them. And just listening to that, however those stories were told, was an incredibly radical act.

**MH**: At Creative Growth, I think what was radical was the advocacy, to break down all of the barriers and prejudices that exist for individuals with disabilities, and to move the creative labels out of the ghetto of outsider art or the arts and disabilities community—which is an extraordinary community—and move it into the larger realm of contemporary art.

So from the beginning, [Creative Growth's founders, the Katzes] were insistent that the work produced at their centers would be shown outside of them, and that the galleries in the centers they established wouldn't exclusive-ly be for the artists there, but the work would be presented alongside more conventionally trained artists from outside of the center.

## On the ability of work by artists with disabilities to "complicate" what we know:

**MH:** From my experience, [this type of work] raises myriad questions outside of its status as an object, like the question of responsibility, and the question of the dialogue with new artists, and the question of intentionality. These aren't questions

that are necessarily provoked by contemporary art anymore because it's so assimilated into a kind of universal language. Art objects [by people with disabilities] are disruptive in the best sense because they disrupt conventionally-held narratives...about what art is and what art might be; about where art is made; who art is made by; and who art is for. These works gently disrupt all of these ideas simultaneously. And I think that's quite a lot for an object to do; for an object to be able to do it consistently, and multiple objects by different makers to do it consistently, is really interesting.

**LS:** I'm sure most of us instinctually avoid complication, but *A Fierce Kind of Love* is complicated by design. The Institute on Disabilities is not an arts organization. Yet it finds itself producing a theatrical work with a mixed ability cast; creating arts programming in partnership with cultural arts practitioners, people with disabilities and families; looking for a method of content delivery that's meaningful and accessible to diverse audiences; and perhaps even redefining what audience diversity means.

**MH:** I think, as [work by artists with disabilities] moves into other contexts, that's where the conversation gets much more interesting, and much more complicated. When the larger institution embraces this work and then starts to collect this work, what does that mean for the institution, for the collection? And then how is this work subsequently contextualized within the displays, and so on? The objects are very generative, because they open up a dialogue about something that, for the most part, we don't necessarily talk about yet, which is the relationships between disability and creativity and the place of people with disabilities socially in society. And then, what does it mean for those kinds of conversations to come into institutions?

LS: There's not one fixed way to have a public conversation around our work, or around the issues that are important to the disability community. What we're learning as a disabilities center is that we have to include non-traditional partners in that conversation if the Intellectual Disability Rights Movement is to advance. Local theater producer Ronee Penoi recently wrote, "to make real strides that not only benefit us but everyone around us, sometimes we need to get uncomfortable, and convince someone else to get uncomfortable with us." Our Fierce Kind of Love partners have agreed to do just that, and we're incredibly lucky to have them.

## On audiences and accessibility:

LS: The question "who is this work for?" is one we continually ask ourselves. The answer is complicated, and has required us to think carefully about the diversity of our audience. Cultural organizations and practitioners talk about engaging diverse audiences all the time, but it is rare to see cultural events that are truly welcoming to individuals with intellectual and other disabilities. Most theaters and museums make an effort to create environments that are physically accessible, and some have even embraced the concept of sensory friendly programming. But planning beyond physical accommodation isn't really on most practitioners' radars. If an event is accessible, is it accessible every night of the week? Is every performance equally welcoming, or do we ask people with disabilities and their families to attend special events designed for the disability community? If we really believe that art can be a connector, why is it so hard for many people to be part of the broader conversation?

Successfully addressing these issues depends on our willingness to let our process be complicated. As practitioners, we avoid complications because they slow things down and often feel a lot like barriers. Our work on *A Fierce Kind of Love* has taught us a few things: we need to help our 'typical' audience members feel comfortable with the idea of looking and listening differently; we need to make all of our performances as accessible as possible in terms of both physical access and content delivery; and we need to do all of these things with input (even direction) from people with intellectual disabilities and families. This can be the most challenging aspect for our work; sometimes people tell us what they need, and it's hard to provide. But if we're successful—if we're truly inclusive—we can bring people together who would never have met in the community, and that enlarges and enriches the conversation. Lisa Sonneborn's documentary film and video work has been used to promote social action in the disability community. Lisa produces the Visionary Voices Project for the Institute on Disabilities at Temple University, which aims to preserve the history of Pennsylvania's Intellectual Disability Rights Movement through oral history interviews with the movement's leaders. To date, the project has collected over 60 interviews, preserved four personal papers collections, and produced three short documentaries on Pennsylvania's disability history.

Matthew Higgs is director and chief curator of White Columns, an alternative art space in New York. He has organized over 250 artist projects and exhibitions, and written for more than 50 publications and art magazines. Born in the U.K., Higgs trained and worked as an artist before becoming known for his independent publishing and curatorial projects. Prior to his work in New York, Higgs served as curator of the Wattis Institute for Contemporary Arts at the California College of the Arts, and later the co-chair of the College's MFA program, and continues to collaborate with the nonprofit organization Creative Growth, which supports developmentally disabled artists.