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DisArt: Redefining the Construct of Participation

Abstract

DisArt, an arts and culture organization based in Grand Rapids, MI, provided the cover art for the Spring 2018 issue of the *Open Journal of Occupational Therapy* (OJOT). The piece, a somatic sculpture by Petra Koppers, was featured at the 2015 DisArt Festival in Grand Rapids. Koppers is a disability culture activist and community performance artist who connects people, both disabled and nondisabled, in public spaces. DisArt's mission is to increase the participation of disabled people in our communities through disability art exhibitions, cutting edge public events, and consultation. In a recent interview, DisArt co-founders and executive directors, Dr. Christopher Smit, PhD, and Jill Vyn, MSW, share how DisArt is redefining the construct of participation for people with and without disabilities.

Keywords

occupational therapist, occupational therapy, DisArt, disability, participation, culture, community, inclusion

Poet and playwright Neil Marcus (1996) writes “Disability is not a brave struggle, or ‘courage in the face of adversity’ . . . Disability is an art. It’s an ingenious way to live.” Over 25 years ago, the Americans with Disabilities Act (ADA) was signed into law to prohibit discrimination against people with disabilities. Despite the passing of federal civil rights laws in the 1960’s, accessibility is not guaranteed. People with disabilities continue to experience discrimination, including barriers to participation in the environments where they live and work. Barriers to participation do not happen to all of us. Full cultural participation provides all members of the community equal opportunities to actualize their potential. This requires supports in the traditional sense (e.g., environmental modifications), but also in terms of preparing people in the community to welcome differences and to help develop a natural support system (Grady, 1995). History has shown that focusing solely on people with disabilities does not necessarily eliminate participation disparities. Cultural transformation will require contributions from all members of the community.

DisArt, an arts and culture organization based in Grand Rapids, MI, provided the cover art for the Spring 2018 issue of the *Open Journal of Occupational Therapy* (OJOT) (see Figure 1). The piece is a somatic sculpture by Petra Koppers, a disability culture activist and community performance artist who connects people, both disabled and nondisabled, in public spaces. DisArt’s mission is to increase the participation of disabled people in our communities through art exhibitions, cutting edge public events, and consultation. In a recent interview, co-founders and executive directors, Dr. Christopher Smit, PhD, and Jill Vyn, MSW, shared how DisArt is redefining the construct of participation for people with and without disabilities.

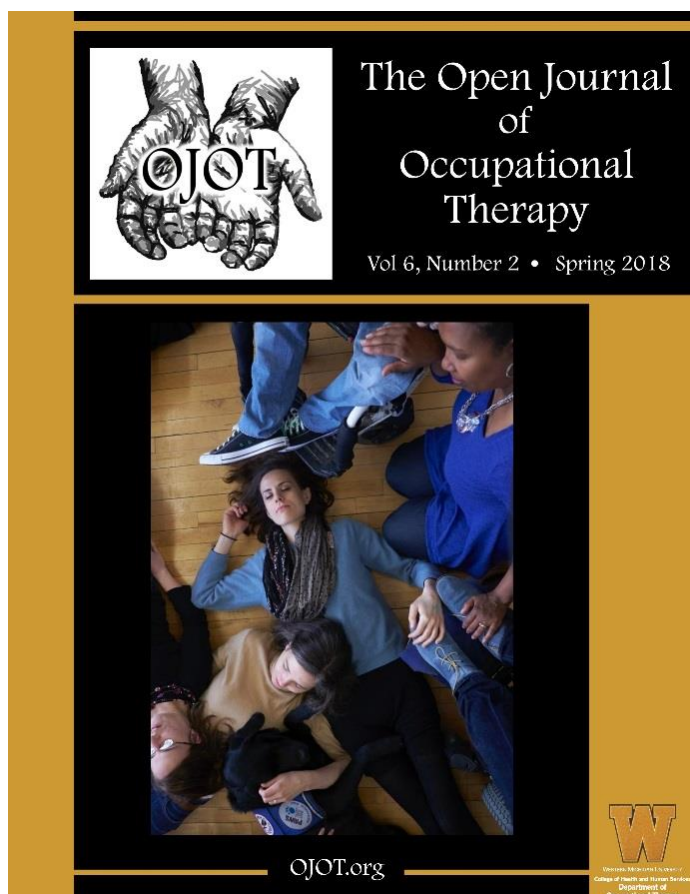


Figure 1. Spring 2018 Cover of OJOT.

In 2014, DisArt began as a project at Kendall College of Art and Design (KCAD) at Ferris State University in Grand Rapids, MI. Smit and Vyn were strategically introduced by David Rosen, former president of KCAD. The purpose of the meeting was to initiate a 2-week disability arts festival in Grand Rapids, MI. Oliver Evans, interim president of KCAD (2014-2015) envisioned the disability arts festival as a project for the college. With the support of David Eisler, president of Ferris State University, and former mayor George Heartwell, a year-long Arts + Access Initiative began. KCAD hired Smit and Vyn on contract to lead the Arts + Access Initiative. The goal of the initiative was to produce an international disability arts festival that would engage faculty and students at KCAD; invite audiences to reconsider definitions of disability through the power of contemporary art; and engage Grand Rapids in a larger civic conversation about the place of disability in its community. Following a successful inaugural festival, DisArt was strategically positioned to create its own programming, board of directors, and 501(c)(3) status. Although not the intention of the partnership, the collaboration between KCAD's administrators and other strategic partners made it possible for DisArt to become its own independent organization.

Although Smit, a college professor, and Vyn, a social worker, were from different backgrounds, they shared common interests in disability culture and art. "When we started our work, we had a general idea that art could change perceptions of people with disabilities," said Smit. "We engaged with the idea of community development, relational politics, and ways of learning," added Vyn. Soon, a collective vision came to the surface. "We wanted to create arts-based environments that would allow people with and without disabilities to flourish," said Vyn. Smit and Vyn develop arts-based platforms in their own community and around the world.

DisArt promotes the benefits of understanding disability as a culture with shared values, norms, behaviors, symbols, and expressions (DisArt, 2018). As an indication that disability is a cultural identity rather than a physical or mental condition of body or mind, DisArt intentionally capitalizes the "D" in disabled (DisArt, 2018). Although person-first language is preferred in the health professions, DisArt believes the phrase "people with disabilities" unnaturally separates disabled people from their cultural identity. Like person-first language, identity-first language is also purposeful. Identity-first language fits well with the social model of disability. DisArt wants to influence the use of language in disability culture. "We believe disability is a unique cultural identity, but we also think community dialogue is the way to go," said Smit. "The only way to flourish is to work together. We do not focus solely on disability, we are inclusive of everyone," adds Vyn.

In April of 2015, the city of Grand Rapids hosted the inaugural DisArt Festival, a 2-week celebration of the arts that included a film festival, a runway fashion show, music and dance performances, and several art gallery exhibitions. Experiential learning opportunities and hands-on workshops stimulated conversation about creativity and disability. "Art takes out the socio-economic factor," said Vyn. "It levels the playing field for a universal understanding of disability." The festival not only showcased the work of disabled artists, it also aimed to change the perceptions of people with disabilities. "When disabled people are given a voice, it is often through a case study or inspirational speech. These narratives are very limited," said Smit. "If a work of art is good, it demands a reaction."

The DisArt Festival also served as the U.S. premiere of "Art of the Lived Experiment," an international art exhibition that debuted in 2014 at DaDa Fest, a well-respected international disability arts festival based in Liverpool, England. Supported by a National Endowment for the Arts (NEA) Art Works grant, the U.S. exhibition featured works by 33 international artists, including seven from North

America. The variety of mediums included sculpture, video, painting, photography, and performance arts. Themes of experimentation and creative play were a means to explore change and the possibility of transformation (Hutter, 2015). Due to the scope of the exhibition, works were divided among three art galleries in downtown Grand Rapids. The event brought in almost 50,000 visitors over a 3-month period. DisArt's first ever festival made its mark as the largest disability arts festival in America. At the end of the festival, Smit and Vyn took time to reflect and discovered that their vision of disability and access needed some work. "We realized a 2-week long simultaneous event really did not respect the disabled experience. We needed to do better," said Vyn. As Smit and Vyn began to narrow their focus, the guiding principle behind what they were really trying to do became clear: participation.

The construct of participation is significant in rehabilitation and research; however, in the field of occupational therapy, the term participation is used so frequently that some argue it has become a buzzword (Mirza, Magasi, & Hammel, 2016). These claims are not unfounded. The word participation is used more than 100 times in the *Occupational Therapy Practice Framework: Domain and Process* (3rd edition) (AOTA, 2014). Furthermore, the terms occupation and activity are used interchangeably to describe participation in daily activities. As a consequence, the meaning of participation may be conceptualized in ways that are incongruent with the experiences and goals of people with disabilities (Mirza et al., 2016).

In 2014, the American Occupational Therapy Association (AOTA) released an official document titled "Occupational Therapy's Commitment to Nondiscrimination and Inclusion" to outline the profession's stance on nondiscrimination and inclusion. Inclusion requires that we ensure not only that everyone is treated fairly and equitably but also that all individuals have the same opportunities to participate in the naturally occurring activities of society, such as attending social events, having access to public transportation, and participating in professional organizations (Hansen & Hinojosa, 2014, p. S23). In the health professions, inclusion and participation are often considered the same. Community-based programs are uniquely designed to address the needs of vulnerable and underserved populations. The underlying principles are humanistic and client-centered; therefore, objectives mesh well with the field of occupational therapy. Thus, for occupational therapists who are developing participation goals, it is important to remember that meaningful participation is a lived experience that differs by person and context. According to Vyn and Smit, since the creation of the ADA, society has focused on making physical access to public spaces possible; however, there is a difference between whether someone can do something and whether they will or would do something. What is missing here is *meaningful* participation. DisArt refers to this as the participation gap. "We are trying to get rid of the participation gap," said Smit.

With a renewed focus on participation, Smit and Vyn began looking for ways to use art and community-making to advocate for the full participation of disabled people. Future planning would include cutting edge access designs that would enable people with multiple levels of disabilities to participate fully in community events. DisArt began collaborating with production companies to help make their vision a reality. Smit and Vyn believe the design process is just as important in community planning because there are different levels of understanding of disability culture. "We are always seeking opportunities to invite others into the conversation in a way that is not threatening. People really appreciate having this opportunity," said Vyn. "Culturally, we are myopic when it comes to disability," said Smit. "We tend to use one lens . . . pity, fear, etcetera. DisArt is providing a new lens to show the world what disability can be." Smit and Vyn hoped to use the models and access designs

they developed as educational opportunities for professionals in the community. The idea of participation is a process of self-discovery for everyone. People with disabilities are particularly adept at learning how to interact with the world around them to establish their unique voice. “How does creativity play a role in our lives and allow us to participate more fully?” asked Vyn. Use of creativity and tactical strategy was a good place to start.

In 2016, Smit and Vyn produced an arts-based platform that would take access and participation to a whole new level. ELEVATE: A DisArt Fashion Show was produced in collaboration with artists, architects, the production company KBOgroup, and SiTE:LAB, an artist-led organization that creates temporary site-specific art projects. The setting for the event was unconventional: a downtown neighborhood block consumed by abandoned buildings. SiTE:LAB installed a piece titled “Hybrid Structures,” a series of 25-foot-tall ramps connecting three abandoned buildings. The ramps would also serve as the fashion show runway. “Hybrid Structures” was conceived by artist Alois Kronschlaeger in collaboration with artist Paul Amenta, architect Ted Lott, and Smit. “This architectural intervention was in response to the abandoned buildings that lined the north side of Rumsey Street,” said Vyn. The buildings included a deconsecrated Catholic church, rectory, school building, and convent. “The series of ramps traverse, pierce, and connect these structures providing accessible and inclusive exploration of the site,” adds Vyn. Inside one of the buildings, DisArt’s hybrid gallery featured a photography exhibition titled “Access is a Civil Right” by renowned disability rights photographer Tom Olin. They created new vantage points into the abandoned buildings as well as onto the surrounding site, thus granting visitors an opportunity to experience Rumsey Street in new and extraordinary ways. The access became art.

ELEVATE: A DisArt Fashion Show proved to transcend the normal boundaries of bodies and buildings. During the event, live video was projected on the exterior of the buildings, while digital audio and a laser light show captivated the audience. The “Hybrid Structures” installation provided barrier-free access to models while at the same time serving as part of the art. Disabled models wore curated fashions made by designers from New York, Chicago, Mexico, and West Michigan (see Figure 2). Smit explains, “The significance of this exercise becomes deeper as the community interacts with the key issues of inclusion, diversity and disability itself.” The experience was also meaningful to the models who participated. “They are advocates and very prideful. An unexpected advocacy community was created through this event,” said Smit. “Hybrid Structures” was an official entry in ArtPrize 2016, an international arts festival that takes place annually in the city of Grand Rapids.

In 2017, DisArt took their ideas for innovative and accessible spaces global during the DisArt Symposium. The guiding themes of this 3-day event included identity, design, and community. The conference attracted artists, scholars, and critics from all over the world. Participants and presenters who were unable to participate in person could attend the event virtually. Individuals took advantage of live streaming in the UK, Australia, Canada, Israel, and several other countries. Preparation for the event involved several community partnerships. For example, interior design students from KCAD developed the design for the symposium space with multiple seating options (pods) that included soft and hard surfaces, couches, yoga mats, and bar height tables. Accessibility tools, such as live captioning, ASL interpretation, live projections, and Twitter and Instagram feeds were also available. A quiet space for respite allowed participants to leave the larger event space and still follow the event through a video monitor. “We wanted to offer people some of the comforts they may not expect in a community setting,” said Vyn.



Figure 2. Disabled Models at ELEVATE: A DisArt Fashion Show courtesy of Artprize, 2016.

The symposium concluded with a seminar on accessible event planning offered to professionals who wanted to learn more about designing public events that were functional, welcoming, and accessible. “Our community partners want to learn how to plan events and look at spaces differently,” said Smit. “They want to do better, but they do not know how to go about it.” Moving forward, DisArt hopes to expand their consultative services and provide resources for the professional development of disabled artists. Their consultations currently include providing education about the culture of disability, accessible event planning, and internal and external communication to assist outside organizations in becoming confident in approaching audiences of all abilities. Artist development will fall in line with direct service provisions, sponsorships, and scholarships. “We want to support our clients as artists and individuals,” said Vyn.

In a blog post for the *Hyperallergic Newsletter* titled “Is there space for disabled artists at art fairs?”, Vyn and Smit share a personal experience with inaccessible public spaces at the 2017 Paris Outsider Art Fair. Outsider Art is a term used to describe the work of self-taught artists who are not part of the mainstream art world. Smit, who relies on his electric wheelchair for mobility, spent hours searching for accessible entrances at historical venues in Paris’ 9th Arrondissement, a popular arts and culture district. At one location, staff members and volunteers attempted to help Smit by assembling a makeshift wooden ramp out of found materials. As a crowd of spectators gathered in the street, the incident began to feel like its own “Outsider Art” performance. “Disabled people always have to explain themselves. Every day is a struggle. That translates into a disabled culture that is exhausted all the time. If the environment changes, maybe that will take care of some of the stress,” said Smit. Unfortunately, once Smit gained access to the venue, he was restricted to the main floor. The galleries

located on the second and third floors were accessible by staircase or an elevator that was too small for Smit's wheelchair. Ironically, disabled artists have been a mainstay of Outsider Art since it debuted in the late 1940's. "The Outsider Art world seems to have little room for the physical presence of an 'outsider' – even though the art itself reveals much about the individualized experience of disability" (Vyn & Smit, 2017, para. 4). Suddenly, a new query emerged: How do you empower others when the system is not designed to empower you?

Although they left the art fair feeling discouraged, the experience led Vyn and Smit to ponder the various factors that support and inhibit people to engage with art. In the US, the ADA has mandated accessible environments in public spaces; however, the guidelines most often apply to people with physical disabilities. People with communication disabilities, sensory impairments, and cognitive deficits are often left out of the conversation. "What we have found, in general, is that while most art fairs and galleries are physically accessible, they are not equipped to encourage engagement through audio description, captioning, large font, respite spaces, etc." (Vyn & Smit, 2017). According to Erevelles (2011), a more inclusive conceptualization of participation ought to be rooted in the possibilities of interdependence and community supports, not in the autonomous individual. During subsequent international trips, Smit and Vyn have also encountered public spaces that were more accessible than some in the US. "You just don't know until you get out there," said Smit. "This is a global conversation." Vyn and Smit applied what they learned during their trips abroad to ensure future DisArt events were functional, welcoming, and accessible to everyone.

DisArt is quickly becoming one of the world's most recognized producers of innovative disability art events. Smit and Vyn will continue to develop cutting edge exhibitions that engage a variety of audiences in dialogues about the lived experience of disability. On September 22, 2018, Frederik Meijer Gardens and Sculpture Park will host DisArt's Process and Presence Fashion Show. In true DisArt fashion, this event will not be your typical runway show. The evening of high fashion, artists, and disabled models aims to make a collective statement about the disabled body in the fashion world. Inspirations for the show will come from the Process and Presence: Contemporary Disability Sculpture Exhibition occurring simultaneously at Meijer Gardens. The exhibition will focus primarily on abstract, process-based art. Designer fashions featured in the show will be created by artists and designers from around the world. Over 2,000 people are expected to attend this event. DisArt's Process and Presence Fashion Show will be an official entry in ArtPrize 2018.

Smit and Vyn believe disability is a cultural identity. What comes along with a cultural identity are opportunities to be included in the fabric of a community. Barriers to participation, such as inaccessible environments, can make full cultural participation all but impossible. In the health professions, the term participation may be used in ways that are unrelated to the lived experiences of disabled people. As a facilitator of participation, the field of occupational therapy may benefit from adopting a more comprehensive understanding of the term that is more in alignment with the disability rights community. Full cultural participation of disabled people respects participation preferences and may require supports to be set in place at the personal and community levels. Cultural transformation requires buy-in from the community at large. Changing the collective conscious of a community is daunting. Through their innovative use of contemporary art, collaborative partnerships, and accessible designs, Smit and Vyn have proven it can be done.

Related Links

- Visit the OJOT Gallery: http://scholarworks.wmich.edu/ojot_occupationandartist/22/
 - Learn more about DisArt: <http://disartnow.org/>
 - Subscribe to the DIStopia Podcast: <https://itunes.apple.com/us/podcast/distopia-podcast/id1100828007?mt=2>
 - Take a 3D Tour of Arts + Access: A DisArt Symposium: <https://www.perspective3-d.com/3d-model/disability-arts-now-2017-symposium/fullscreen/>
 - Learn more about the strategic partnership behind Hybrid Structures: https://www.youtube.com/watch?time_continue=699&v=a3N4oy5y7Wk
 - Connect with DisArt on Social Media:
 - Facebook: <https://www.facebook.com/DisArtFestival/>
 - Twitter: <https://twitter.com/DisArtFestival>
 - Instagram: <https://www.instagram.com/disartfestival/>
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