

# NEA ARTS

NUMBER 1. 2015

## CHALLENGING NOTIONS

ACCESSIBILITY + THE ARTS

# THIS ISSUE

When the milestone Americans with Disabilities Act was passed on July 26, 1990, individuals with disabilities were guaranteed equal access to social realms that most of us take for granted: employment, public transportation, and commercial facilities such as shopping malls, restaurants, and hotels.

To celebrate the 25th anniversary of the law's passage, this issue highlights organizations and individuals that capture the spirit of the law by making art accessible to every American—something the NEA supports and strives to achieve. We explore how museums bring visual art to those with limited sight, and how the Matheny Medical and Educational Center enables people with severe disabilities to create their own masterpieces. We also look at how acclaimed architect Michael Graves used his own disability to transform healthcare design, how theater can build confidence in children who stutter, and how the inaugural DisArt Festival is challenging people's notions of what it means—and doesn't mean—to be an artist with a disability.

According to our new Arts Data Profile #7, the 2012 Survey of Public Participation in the Arts showed that the nearly 28 million U.S. adults, or 12 percent of the adult population, who have some type of disability were equally likely as all adults to have engaged in some forms of arts participation, such as creating visual arts, doing creative writing, or consuming art via electronic media. Not every mind or body will experience art the same way. But every mind and body is entitled to the experience.



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**(Cover) Tape Construction #3 (2014) by Stephen Proski, a visually impaired artist living in Kansas City, Missouri. Proski uses pieces of tape and collage to create a textured approach to painting. IMAGE COURTESY OF STEPHEN PROSKI**



*Gold Lamé (2014)* by Tony Heaton at the DisArt Festival. The piece is an adapted Invacar, used in the 1940s-70s by the British Ministry of Health to transport individuals with wheelchairs.

PHOTO BY BETH BIENVENU

# IMAGINING WHAT DISABILITY ACTUALLY IS

THE DISART FESTIVAL IN GRAND RAPIDS, MICHIGAN

BY VICTORIA HUTTER



▲  
**Chris Smit, director of  
the DisArt Festival.**  
PHOTO BY ROBERT ANDY  
COOMBS

**C**HRISTOPHER SMIT HAS SPENT HIS LIFE AND career at the intersection of art, culture, and disability. An associate professor of communication arts and science at Calvin College in Grand Rapids, Michigan, Smit has edited a collection of essays on disability and film, written cultural critiques on popular music, and fronted a folk and roll band called the New Midwest. Smit also has had spinal muscular atrophy, a form of muscular dystrophy, since birth. “As a person living with a body that didn’t quite fit into the cultural categories of normality, I have always had a keen interest in the way that difference is experienced and communicated,” he said. “Art, a natural vehicle for discussions about being different, has always offered me a rich terrain to investigate, critique, and celebrate the experience of physical disability.”

This spring, he has channeled his interests into DisArt Festival, the largest disability art festival in U.S. history. Held from April 10 through 25, 2015, in Grand Rapids, this inaugural festival featured a touring international exhibition, local gallery shows, a film festival, dance and theater performances, a fashion show, workshops and discussions, and family activities.

The idea for the festival began in June 2013 when Smit and fellow board members of Disability Advocates of Kent County (DAKC) began to discuss ways “to help Grand

Rapids imagine what disability actually is.” He thought tackling that goal via an arts event would be a fun and effective approach. As Smit said, “I firmly believed then and I believe it even more now that art is one of the best ways to mess with people’s preconceptions.”

With the tagline, “Changing perceptions about disability, one work of art at a time,” the DisArt Festival sought to ignite conversations about what it’s like to live with disability and how that experience informs how art is made and shared.

When it comes to “messaging with peoples’ preconceptions,” Smit said, “I hope that when you leave our events or our galleries that you will be unable to *not think* about what it means to be living in a body that doesn’t work in a so-called ‘normal’ way. And I don’t use those words easily. There is no normal, only a perception of what normal is.”

One of the first exhibits to sign on was *Art of the Lived Experiment*, which debuted in 2014 at DaDaFest, a well-established and well-respected international disability arts festival in Liverpool, England. The exhibition featured works by artists with disabilities in a range of mediums including sculpture, video, painting, photography, and performance. The works centered on the themes of experimentation and creative play as the means to explore change and the possibility of transformation.

Amanda Cachia, who curated the exhibit’s U.S. installation, noted that this was “a very fortuitous collaboration between two international disability arts festivals.” The collaboration resulted in a distinct collection of art and experiences for the growing field of disability art in both the United States and around the world. Supported by an NEA Art Works grant, the U.S. premiere of *Art of the Lived Experiment* included 33 international artists with disabilities, including seven from North America.

The original UK exhibit was curated by Aaron Williamson, a London-based performance artist. “Aaron has developed a powerful theme, looking at disability from an experimental point of view,” said Cachia. “There’s so much baggage tied to the language of disability.” But an exhibition framed around experimentation was liberating for the participating artists. It allowed them to engage different mediums and ideas, to explore the themes of change and adjustment as well as the kinds of transmutations once believed possible through the medieval practices of alchemy.

Cachia added, “Unfortunately, the history of the disabled body is one in which, from a medical perspective, the body has been experimented upon as a specimen in a hospital or in a lab. [In this exhibition] this concept has been turned around such that the disabled person has the agency to experiment on their work and on their lives. Their lives could be considered playful experimentation as they adapt to ‘able-ist’ architectures and ‘able-ist’ points of view.”



For artist, writer, and curator Riva Lehrer, the festival celebrated what she has known for years but believes has been hard to break through to the larger public consciousness: that art created by people with disabilities has long surpassed the days when it was viewed as art therapy or the work of a few individuals processing their physical challenges. “Disability arts has matured into a movement that is self-conscious and interconnected,” said Lehrer, whose work focuses on issues of physical identity and the socially challenged body. Artists with disabilities not only share certain truths but interact with and are inspired by each other.

She adds that the festival, where she exhibited her work and delivered a gallery talk, offered people fascinating things they’ve never seen before. But more importantly, it opened doors. “There is something so profound about

permission. Like any marginalized community, it starts with one or two people doing gutsy work who step forward, and by so doing, give others permission to share their own personal vision.” She hopes other artists will be emboldened by the festival to join the movement.

Beyond visual arts, one of the more unique elements of the festival was the fashion show, which presented clothing designed specifically for disabled bodies. The garments were developed by Open Style Lab, a collaborative and interdisciplinary program at the Massachusetts Institute of Technology. Using the principles of user-centered design, interdisciplinary teams of students and mentors worked with disabled clients to create individually designed clothes that were both functional and attractive.

Festival attendees could also take in a number of events at the independent film festival. Among the offerings was

▲  
**Olympia (2013)**  
 78" x 84", mixed  
 media on found linen.  
 The piece, by artist  
 Katherine Sherwood,  
 was featured in *Art of  
 the Lived Experiment*  
 at the DisArt Festival.

IMAGE COURTESY OF  
 KATHERINE SHERWOOD  
 AND GALLERY PAULE  
 ANGLIM, SAN FRANCISCO,  
 CALIFORNIA

## “Art is one of the best ways to mess with people’s preconceptions.”



**(Left) Photographer Tom Olin, who documented the disability rights movement, has his exhibit *Access Is a Civil Right: The Photography of Tom Olin* presented at the DisArt Festival by curator and art history professor Elizabeth VanArragon.**

PHOTO BY BETH BIENVENU

**(Right) A performance of Raphaëlle de Groot’s *OFF* (2009) at La Centrale Galerie Powerhouse in Montreal. The piece was featured in *Art of the Lived Experiment* at the DisArt Festival.**

PHOTO BY DAVID JACQUES

a conversation with actor Mat Fraser of *American Horror Story: Freak Show* fame. Christian von Tippelskirch and Simi Linton talked about their documentary, *Invitation to Dance*, a powerful film about Linton’s life as a disabled woman and the emergence of the disability rights movement.

All told, Smit hoped that the various events would draw 20,000 visitors. But his goals for the festival extended beyond attendance. Quoting his friend, writer David Dark, Smit said, “I want to ‘rearrange the mental furniture’ of this city and really change the way we commune together. We think we can rebrand Grand Rapids not only as one of the fastest-growing cities in the Midwest and one of the best cities to live and be employed in, but also as the first universally accessible city.”

Smit is heartened by the accessibility progress already achieved through ArtPrize, an international art festival also hosted by Grand Rapids, which emphasizes programming that removes the cultural and physical barriers to contemporary art. He also credits Grand Rapids Mayor

George Heartwell and his vision, commitment, and energy promoting accessibility, especially via his declaration of 2015 as the Year of Arts and Access. Smit said, “By doing this, he is committing all of us to celebrate creativity and empowerment.”

Mayor Heartwell added, “The City of Grand Rapids is indeed proud and honored to host the inaugural DisArt Festival. I extend the cultural imagination of our city to the artists featured in this show. This arts festival continues the rich tradition of inclusiveness celebrated throughout our community.”

Smit has been known to cite the words of another friend and artist Neil Marcus: “Disability is an art—an ingenious way to live.” From this perspective, disability is not focused on struggling against adversity but rather experiencing one’s disability as a *form of art*; day-to-day living that requires creativity, perseverance, honesty, and courage; a manifestation of how radical both art and disability can be.

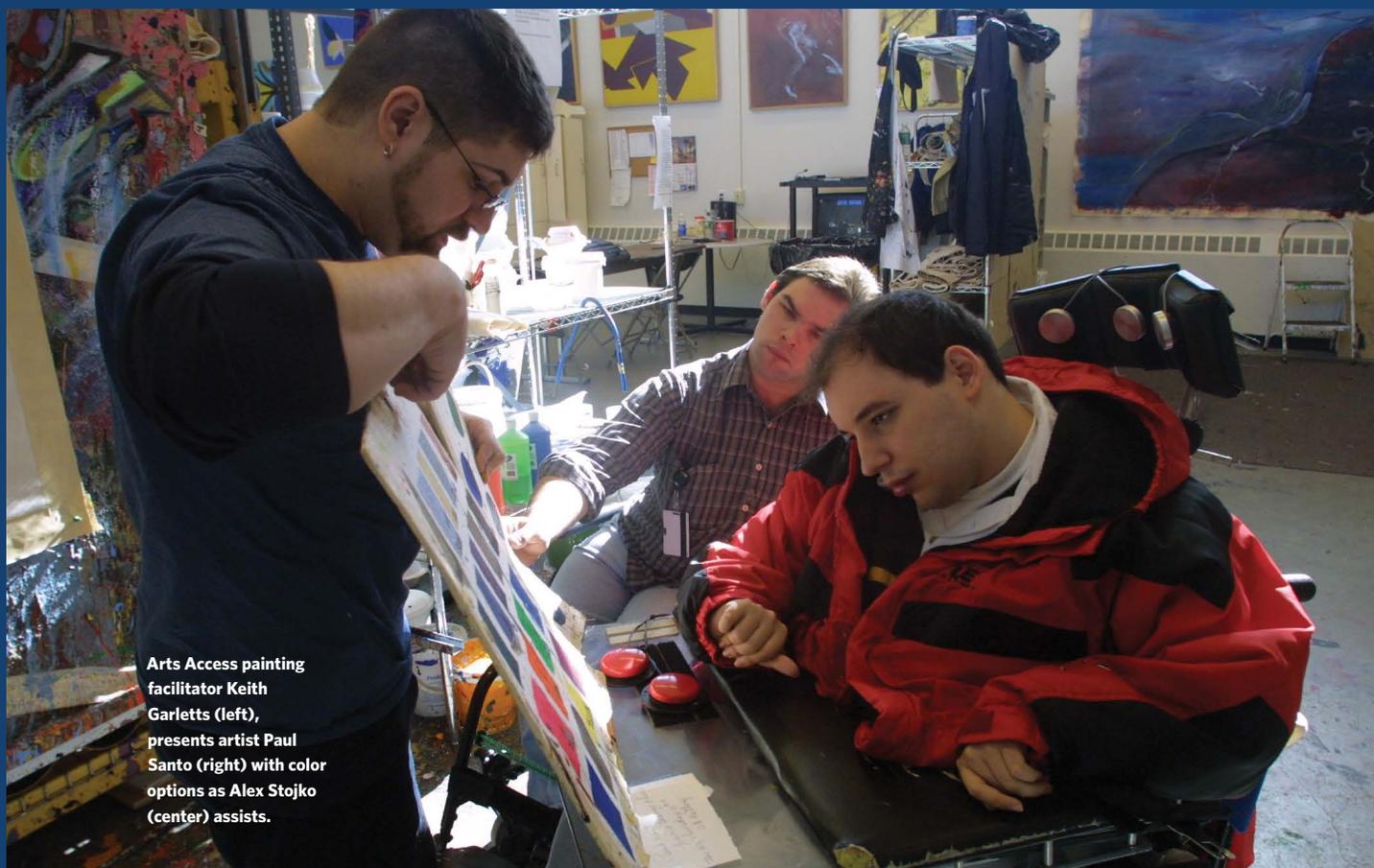


# ANOTHER SET OF HANDS

MATHENY MEDICAL AND EDUCATIONAL CENTER'S  
ARTS ACCESS PROGRAM

BY REBECCA GROSS

ALL PHOTOS COURTESY OF MATHENY ARTS ACCESS PROGRAM



Arts Access painting  
facilitator Keith  
Garletts (left),  
presents artist Paul  
Santo (right) with color  
options as Alex Stojko  
(center) assists.

**M**OST OF THE PATIENTS AT MATHENY Medical and Educational Center will never have the physical ability to leap across a stage or even grasp a paintbrush. Some will never form the words to recite a poem or a line of script from a screenplay. Individuals treated at the Peapack, New Jersey, facility live with exceptionally complex disabilities, from cerebral palsy to unusual conditions such as Wolf-Hirschhorn syndrome, rendering many quadriplegic and non-verbal. The most mundane of tasks, from eating to nose-blowing, require assistance, and both minor and major decisions are often yielded to caregivers by necessity.

But the limits of their world dissolve once they enter the art studio. Through Matheny's innovative Arts Access program, founded in 1993, patients have become painters, poets, playwrights, and choreographers. Their creative wishes are executed by "facilitators," professional artists who serve as a neutral set of arms and legs whose actions are dictated by participants.

"We're a lot like computers in that we can't do anything unless we're specifically programmed to do it," said Keith Garletts, Matheny's outreach coordinator and program specialist. "The client artists program us, they tell us exactly what they want."

The system has given individuals like Natalia Manning the ability to choreograph works, act and dance onstage, and create paintings, several of which have sold. Manning, who has cerebral palsy, uses a wheelchair and communicates through an iPad, which vocalizes the words she taps out one letter at a time. She grinned when asked what medium was her favorite, but demurred, saying, "each helps me in a different way." Her artwork, she said, was a way for her to let people know "I am normal. I am like everybody else."

To help artists like Manning convey the complexities of their artistic visions, Arts Access has developed a novel communication system. Every art form is broken down into its most basic forms, with visual menus presenting options such as brush size, stroke, color, and shape for painting, to filmed snippets of various dance movements for choreography. As long as artists possess yes/no communication, which might entail eye or eyebrow movements rather than words, they make every artistic choice, from the placement of actors on a stage to whether paint will be splattered or dabbed.

"[Facilitators] need to be able to offer infinite artistic choices in a manageable form," said Arts Access Director Eileen Murray. "They bring their technical know-how and artist mindset in knowing that there are important ques-

**Arts Access director, Eileen Murray (right), speaks with Arts Access writer Jenny Durr (left) at the annual Full Circle event, Arts Access' celebration of the artists and their art.**  
▼





## “They’re expressing what we all want to express—their joy, their sadness, their pain.”

tions to ask. It makes a difference if you want a size-two brush or a size-three brush.”

To maintain neutrality, questions cannot be framed in a leading manner, yet facilitators must continually seek affirmation. Do you want more paint on the brush? Is this how you want it to look? Does something need to change so it looks how you’d like it to? It is a painstaking and lengthy process, but one that has given new meaning to the concept of artistic freedom.

“They can direct the design of building a sculpture. They can direct the movement of a dancer onstage. They’re making these physical things happen. They’re controlling their environment,” said Kenneth Robey, the director of research at Matheny. For individuals without the use of their limbs, this is nothing short of seismic. Further, “they’re controlling the means through which they communicate their internal world to everybody.”

For non-verbal participants especially, who have no easy mechanism for self-expression, this is again revolutionary. “They’re expressing what we all want to express—their joy, their sadness, their pain,” said Murray. “It’s

freedom and it’s liberty, and they’ve been deprived of it by the nature of their disability.”

The question for Robey was whether this sense of control over one’s physical and emotional worlds extended beyond the studio. In a study funded by the NEA’s Art Works: Research program, Robey and his team are looking at whether arts participation among disabled individuals is related to an increased sense of self-determination, and a stronger belief that they can dictate the events and outcomes of their lives rather than some external force. The study’s subjects include Arts Access participants and non-participants, as well as individuals at Hattie Larlham, an organization for disabled individuals in Ohio with a similar arts program.

Although final results won’t be analyzed for several months, Robey believes findings could be “good ammunition for arts programs in the never-ending search for funding,” and might encourage organizations for disabled individuals to install or expand arts programs of their own. But he noted that there are other benefits from Arts Access that are “painfully obvious,” to the point where no formal research is needed to appreciate them. The big one, he said, was self-esteem.

This is perhaps most evident during exhibitions and festivals of Arts Access’s work, including shows at Rutgers New Jersey Medical School, the Grounds for Sculpture sculpture garden, and the New Jersey Theatre Alliance’s Stages Festival. Arts Access also hosts an annual multi-disciplinary showcase called Full Circle, which has received NEA funding.

“It’s one of the very few times in [these artists’] lives that they are the center of attention and they’re being applauded for who they are and what they’ve done,” said Murray.

**Jessica Evans admires her paintings on exhibit at the Morris Museum in Morristown, New Jersey (left), and performs her original poem “My Brain Is on Fire” with professional actors and dancers (right).**



▲  
**Natalia Manning (center) performs her original multimedia performance piece, *4 People, 1 Body*, with the Roxey Ballet company dancers.**

“There are so many life events that are important to us that we take for granted,” she said, citing graduations, new babies, first cars, and new homes. “These are all things that Matheny individuals don’t have and won’t have. Through the arts, they are truly celebrated and they receive the acknowledgment and praise that they deserve.”

Beyond applause, these exhibitions and festivals offer Arts Access participants a chance to interact with the wider community in a way that’s typically difficult. Garletts noted that for individuals without significant disabilities, it’s relatively easy to form connections with others: we say hello to neighbors, we strike up conversations at bars or dinner parties, we join clubs or volunteer. Not only are such social interactions less likely for Matheny patients, but the aphorism that it’s not polite to stare often prompts a total avoidance of eye contact. “If a bunch of people are actively looking away from you, you notice that,” said Garletts.

But no one is uncomfortable staring at and admiring a piece of art. Through this act, the conversation shifts, and

becomes about the artwork rather than about a person’s physical condition. “When [audience members] see and experience the art, that’s a connection to the individual as a person and not as a person with a disability,” said Murray. Regardless of an artist’s verbal ability, “They can converse with that stranger who’s come to see their work. They converse with them through their art.”

Like most art shows, the events also function as a marketplace; part of the goal behind Arts Access is to provide vocational opportunities for individuals at Matheny. Garletts recalled a time a few years ago when an Arts Access artist excitedly told him that he had just sold a painting. “He just looked at me and said, ‘Man, you have no idea how good it feels to make a buck,’” Garletts remembered. “We take for granted the fact that we have the ability and privilege to work and hold a job.”

But for Arts Access participants, gaining recognition as a working artist is nothing to take lightly. Natalia Manning seems to agree. “Before Arts Access, I hated my life,” she said. “It showed me I can do anything.” ▲

# SOLUTIONS

TO CHANGE  
PEOPLE'S LIVES

MICHAEL GRAVES' LEGACY

BY REBECCA GROSS

Architect and designer  
Michael Graves.

PHOTO COURTESY OF  
MICHAEL GRAVES AND  
ASSOCIATES



▲  
**The Wounded Warrior  
homes at Fort Belvoir,  
Virginia.**

PHOTO COURTESY OF  
MICHAEL GRAVES AND  
ASSOCIATES

**O**N THE DAY WE WERE SCHEDULED TO interview Michael Graves, the celebrated architect, designer, professor, and National Medal of Arts recipient passed away at the age of 80. But as is often said, an artist speaks through his work—and through his products and buildings, Graves’ legacy carries on.

Graves first gained acclaim in the 1960s and ‘70s for his post-modernist buildings, and received widespread recognition for projects such as the Portland Building in Portland, Oregon, and the Humana Building in Louisville, Kentucky. However, the architect extended his influence into our homes when he began designing products for Target, a line that later moved to J.C. Penney. Dismissing all notions of highbrow and lowbrow, Graves was intent on making great design accessible to every household, down to our clocks, vases, lamps, and shears.

This populist ideal became more pointed in 2003, when Graves contracted a spinal cord infection that left him paralyzed from the chest down. It was during that initial hospital stay that Graves began to realize the extent to which medical design did not accommodate individuals with disabilities. From his wheelchair, he was too low to see the bathroom mirror. Neither could he reach the faucet, the bathroom’s electrical outlet, or window shade cords. Furthermore, he frequently said that it was simply too ugly a facility in which to die. Great design, it seemed, still eluded the healthcare industry.

Over the past decade, Graves redirected his firm to increasingly focus on healthcare projects and products. In many cases, he had his staff use wheelchairs, walking sticks, and walkers to understand the needs and limita-

tions of someone who might rely on one on a daily basis. Until a person experiences a home or sidewalk with a mobility aid, “you can’t really understand the emotional impact of it,” said Rob Van Varick, principal of product design at Michael Graves Architecture & Design. “Only then can you design a complete, holistic product.”

The four projects highlighted here demonstrate how Graves used design to make difficult medical experiences more manageable, more enjoyable, and easier on the eye. “The most important thing about healthcare design is you get the opportunity to truly change people’s lives for the better. Not many people get that opportunity. It was Michael’s passion,” said James Wisniewski, the senior associate director of architecture at Michael Graves Architecture & Design. “It’s about coming up with solutions that change people’s lives but are also beautiful. Those things aren’t isolated.”

**WOUNDED WARRIOR HOME PROJECT AT FORT  
BELVOIR (FORT BELVOIR, VIRGINIA)**

In 2011, two model homes for wounded service members were unveiled at Fort Belvoir, Virginia, where the NEA supports visual art and writing therapy. To accommodate complex conditions that might entail paralysis, prosthetic limbs, burns, and post-traumatic stress disorder, “we had to design as many solutions as we could throughout the house,” said Wisniewski.

To start, this included designing hallways wide enough for someone in a wheelchair and a companion to pass by one another, and flush conditions throughout the entire footprint. This meant eliminating steps and raised thresholds, and ensuring the front and back yards were “at grade,” or flat. This allows someone in a wheelchair to seamlessly move between yard, home, garage, and even shower without assistance. In the kitchen, the stove, sink, and countertops can all be adjusted vertically, and dishwashers have a pull-out drawer instead of a drop-down door, which can be difficult to manage for those in wheelchairs. “This is how someone who’s trying to get back to their life needs to operate,” said Wisniewski. “They need to be able to cook and do the dishes so they can start to get their life back together.” To foster a sense of security, there are video monitoring systems, large windows with low windowsills, and a glassed front door so residents can see who’s approaching.

Of course, upholding aesthetic beauty was a consideration throughout. “I think that’s the real magic,” said Van Varick. “You walk through that home and you think, ‘Wow, I want to live here.’”

**PRIME TC: HOSPITAL TRANSPORT CHAIR**

The design for most wheelchairs used in hospitals was patented in 1933. Needless to say, it was time for an update.

To develop the Prime TC, a collaboration with the medical technology firm Stryker, Graves' team studied 38 hospitals and shadowed patient escorts, whom they found were walking eight to 13 miles a day through hospital halls. Through their research, they discovered that of the one million annual falls that occur in hospitals, many involve wheelchairs, particularly as people transition in and out of them. Chairs are also a risk for spreading infection: the large rear wheels are rarely wiped down as chairs are wheeled in and out of patient rooms, and bacteria can quickly gather along the tire circumference. As soon as a patient brushes against these, "the hospital is on their hands," said Van Varick.



To counteract these issues, the Stryker chair has smaller wheels that are out of reach for patients, minimizing the spread of infection. Footrests pop up as soon as feet are lifted, eliminating a notorious tripping hazard as patients transition to or from the chair. To maximize the comfort of escorts and prevent back strain, push handles were raised to elbow level, and foot-activated brakes replaced hand levers at the bottom of the chair.

These simple changes can shift the way a patient experiences the hospital and a staffer experiences his or her work. "When people are going to hospitals, they're in a vulnerable position. Something is wrong," said Wisniewski. "You want to create a set of spaces and products that they can react to in a positive way.

#### **YALE NEW HAVEN HOSPITAL CENTER FOR RESTORATIVE CARE (NEW HAVEN, CONNECTICUT)**

The Center for Restorative Care is a geriatric facility for patients aged 65 years and older. In doing research for this 10,000-square-foot renovation project, Graves' firm found that this age group needed three times as much color contrast and four times as much light in order to distinguish between objects. Knowing this, the firm began to question whether these two factors could help prevent the risk of falls, a major concern for geriatric patients.

"If [patients] can't see the difference between the wall and the grab bar, or the wall and the floor, they're much more likely to fall," said Wisniewski. For this particular project, "color isn't used for color's sake. It's used as a device to help create solutions." For instance, there is a high-contrast visual threshold between rooms and around door frames, and walls and floors are never the same color. In showers, the back wall, side wall, and floor are tiled in different hues, and the shower nozzle, soap dish, and toilet paper dispenser all double as grab bars.

#### ▲ **A patient room at the Yale New Haven Hospital Center for Restorative Care.**

IMAGE COURTESY OF MICHAEL GRAVES AND ASSOCIATES

#### ◀ **The Prime TC hospital transport chair.**

IMAGE COURTESY OF MICHAEL GRAVES DESIGN GROUP





▲ Rendering of the planned Madonna Rehabilitation Hospital in Omaha, Nebraska.

IMAGE COURTESY OF MICHAEL GRAVES AND ASSOCIATES

**“It’s about coming up with solutions that change people’s lives but are also beautiful. Those things aren’t isolated.”**

**MADONNA REHABILITATION HOSPITAL (OMAHA, NEBRASKA)**

Set to begin construction in 2016, the Madonna Rehabilitation Hospital offers long-term rehabilitation for those who have experienced traumatic brain injury, stroke, spinal cord injury, and other similarly debilitating conditions. “We worked with them on how to emphasize holistic rehabilitation,” said Wisniewski. “So not just how to heal the body, but how to heal the mind and the soul.”

They began at the beginning: the entrance. “We studied a lot of cases where there are these grand atrium spaces,” said Wisniewski. “Often what that does is create a scale and proportion issue for someone in a vulnerable position.

If the space is so large and grand, it actually makes them feel smaller.” Instead, Madonna features a more intimate two-story entrance, which maintains a sense of openness while remaining warm and inviting. This sense of warmth continues with natural wood tones, which play off views of wooded wetlands, and complement bright spring accents. All patient rooms are wheelchair accessible, and were designed to accommodate visiting family members with sleeping alcoves and extra storage space. “All these pieces are interconnected—the surroundings of the patients, the color, the texture, the lighting,” said Wisniewski. “How they make people feel and affect healing is really starting to puncture the mindset.” ▲

Stuttering Association  
for the Young Confident  
Voices participant  
Jeremy performs in  
a short play.

# CONFIDENT VOICES

## TAKE CENTER STAGE



STUTTERING ASSOCIATION FOR THE YOUNG'S  
THEATER PROGRAM

BY MICHAEL GALLANT

ALL PHOTOS BY MIKIDO, COURTESY OF THE STUTTERING ASSOCIATION FOR THE YOUNG

**W**HEN TARO ALEXANDER WAS FIVE, he developed a noticeable and persistent stutter when he talked. It took two decades for him to meet another person who spoke the same way he did—and for Alexander, that was two decades too long.

“I remember so much loneliness, confusion, and shame growing up stuttering, and such a strong desire to meet other people who shared the same challenges that I did,” Alexander said. “Like every kid, I so desperately wanted to feel cool. And a big reason why I never did was because of the stuttering.”

He now leads the Stuttering Association for the Young (SAY), a vibrant arts-based nonprofit created to allow children and teenagers who stutter to face those challenges together instead of by themselves.

“I started SAY in 2001 to make a place where young people who stutter could come and feel okay about who they are, and know that someone who stutters can be successful at life, that stuttering doesn’t have to hold you back from doing whatever you want to do,” said Alexander, speaking from the organization’s headquarters in midtown Manhattan. “I want young people who stutter to know that stuttering can be *a part* of who they are but doesn’t have to *define* who they are. I also just wanted to make it a cool hang,” he added, laughing.

**SAY Confident Voices participant Jeremiah performs in a short play with teaching artists.**





For the past 14 years, Alexander's efforts have garnered widespread recognition and support, manifesting into programs that reach hundreds of children and teenagers every year. SAY's initiatives include Camp SAY, a summer sleepaway program open to young people who stutter, as well as their friends and young family members; a variety of in-person and remote therapy resources to help participants speak with more confidence and less fear; and the *My Stutter Blog*, where participants can share poems, stories, and media related to their stuttering struggles and triumphs.

Perhaps SAY's most innovative initiative, though, is Confident Voices, an after-school and weekend program rooted in theater and actively supported by the National Endowment for the Arts, as well as by arts figures like actor Paul Rudd and singer and songwriter Carly Simon. Through Confident Voices, participants collaborate with instructors and mentors, including Academy and Tony Award-winning professionals, to create and present original works. Any given Confident Voices show could see students performing onstage alongside noted theater and screen actors. Or those same professional actors might bring to life the writing, direction, lighting design, and other creative visions of their young SAY colleagues.

Travis Robertson, who became a professional actor despite his stuttering, wrote about his experience working with SAY students on the *My Stutter Blog*: "Seeing the courage and imagination of these students is so familiar and inspiring to me. Working with SAY has given me a profound joy that I never saw coming. And the beauty of it all is that for as far as I've come, I only have to look back to this past week to find the last time I had a stuttering block. I still get nervous before a show, but I'm not afraid of what will be."

Noah Cornman, SAY's executive director, said, "I love that the performances these kids put together are real, compelling, high-quality art. You might experience some of the most hilarious comedy or gripping drama you've ever seen."

As an example, Cornman cited one SAY student who performs at the organization's galas in front of hundreds of people, winning the crowd over year after year—he has even performed with comedian and HBO star John Oliver. "These teens do a great job of supporting each other, collectively expressing themselves, and feeling on top of the world," Cornman said. "That's a feeling every young person, whether they stutter or not, should have the opportunity to experience."

In a nutshell, creating a completely safe space, where such creative collaborations can germinate, is what SAY is all about. "If, because of stuttering, it takes a little longer for our kids to express to a designer how the lights should flash on or off at a given time, everyone involved has the time to listen," Cornman said. "Everyone's vision will be heard and then performed onstage for a raucous, amazing crowd. We particularly love it," he added, "when school teachers check out the shows and are blown away by

◀ **SAY Confident Voices participants Tyler, Lexi, and Klanell perform in a short play with teaching artists.**

**A performance by SAY Confident Voices songwriters Antonio and Mac.**  
▼



seeing their students, many of whom act quietly and sit in the back of the classroom during the school day, just letting loose and *killing* it onstage.”

Many SAY students, including 13-year-old Isabella Negron from Wheatley Heights, New York, stay involved in the program over multiple years. “SAY has helped me accept my stutter and [understand] that it is a part of me,” she said, “and that I have a voice and that what I say is important.” A regular performer with SAY and an enthusiastic singer, Negron was first referred to the organization by a speech therapist who thought it would be a good fit.

SAY students like Negron are among the 70 million people worldwide who stutter. Yet despite such large numbers, relatively little is known about the neurological disorder behind the condition, other than that it’s genetic, said Alexander, and has nothing to do with intelligence (or lack thereof). “About 60 percent of people who stutter have a family member who also stutters,” he said. “Also, recent research has revealed that people who stutter process language and speech a little bit differently than people who don’t stutter.”

The very nature of stuttering can make the condition and its ramifications invisible to many. “The suffering can be hidden if the person who stutters simply chooses not to speak,” said Alexander, “and it’s 100 percent effective. People might think you’re quiet, stupid, shy, or whatever, but they will not think you stutter if you simply don’t open your mouth.” And there are many young people who do just that. “James Earl Jones chose not to speak from

ages ten to 14 because of his stuttering,” said Alexander, describing the legendary actor who provided the voice for *Star Wars*’ Darth Vader. “His story has a pretty remarkable outcome, of course, but lots of kids who suffer do so in isolation. Really, nobody knows.”

Whether onstage, at camp, or elsewhere, SAY’s efforts are making a difference for those who stutter, and their friends, families, and communities as well. Cornman describes one current SAY student who became so inspired by his work with the organization that he made a presentation to his assembled seventh-grade class about the condition. “He introduced himself as somebody who stutters and defined both what it meant and what it *didn’t* mean,” Cornman said. “It’s a powerful thing to stand in front of your peers and teachers and say that stuttering does not indicate that you don’t know what you want to say or that you’ve forgotten your own name—just that you might need a little more time to communicate.”

So many of SAY’s participants have become unofficial advocates, Cornman continued, speaking up for people who stutter within their communities throughout the United States, in countries like the United Kingdom and Israel, and beyond. “And they’re doing it on their own,” Cornman said. “There are no better ambassadors than the kids themselves.”

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A performance by  
SAY Confident Voices  
songwriters Tyler  
and Terrell.



# TOUCH AND SEE

ACCESSIBILITY PROGRAMS FOR PEOPLE WITH  
VISION IMPAIRMENTS AT THE ART INSTITUTE OF CHICAGO

BY PAULETTE BEETE

ALL PHOTOS COURTESY OF THE ART INSTITUTE OF CHICAGO



THE ELIZABETH MORSE  
TOUCH GALLERY

Artwork in the Elizabeth Morse Touch Gallery at the Art Institute of Chicago.

**B**Y ITS VERY TERMINOLOGY, ONE MIGHT THINK that an appreciation of visual art depends on the sense of sight. Likewise, one might think visiting an art museum is of little interest to people who are blind or have low vision. Wrong on both counts, according to Lucas Livingston, assistant director for senior programs in museum education at the Art Institute of Chicago. Instead, said Livingston, “One comes to the museum for a social experience—or maybe it’s a spiritual experience for some people—and the contemplation and discussion and going in-depth into the principles and theories and motivations of the artists and the cultures that produce these works. A lot of this is entirely independent of the visual perception.”

The Art Institute receives 1.4 million annual visitors, and Livingston and his team focus on making the museum experience fruitful for patrons of every type of vision ability. As he explained, “It’s not that we’re necessarily authentically reproducing the sighted experience. That’s not our chief goal. [Our goal is] to reach each visitor through whatever means is most appropriate, or through whatever means is most effective.”

The Art Institute employs a number of strategies to assist patrons with vision disabilities in experiencing its collection, including making its audio guides available free of charge and training volunteers to give descriptive tours of various exhibits. Several of its accessibility efforts, however, focus on exploring art through touch.

One of its flagship efforts is the Touch Gallery, a version of which has existed since the 1920s. The Touch Gallery comprises four European, American, and Asian works from the permanent collection that visitors can explore with their hands, such as the head of an ancient Chinese Buddhist guardian warrior.

“Everybody loves to touch. It’s a way that we learn about our environment and the world around us from cradle to grave. Touch is an intrinsic form of understanding,” said Livingston.

Located outside the museum’s ticketed perimeter, the Touch Gallery is a favorite of visitors with every type of vision ability. In developing the current iteration, the museum paid close attention to principles of universal design, which propose ways in which spaces can be constructed to be accessible for people with a range of abilities. “[We tried] to make it appeal to a broad range of visitors, not just persons with blindness or low vision, but also the general sighted public, in part to increase awareness that part of the museum-going audience is people with blindness or low vision and disabilities at large,” said Livingston.

Patrons with vision disabilities can explore the Touch Gallery with sighted volunteers who deepen the experience with investigative questions aimed, according to

Livingston, at “soliciting the visitor’s voice to explore the emotion and the sensitivity of the touch, the different materiality of the objects.”

The sense of touch also comes into play through the museum’s use of TacTiles. These 8x10” handheld plastic tablets are machine-etched relief carvings of works in the museum’s collection, such as Joan Miró’s *Personages with Star*. TacTile Kits, available free of charge, comprise a TacTile, a color photograph of the work, and both large-type print and Braille descriptions of the work.

The five TacTiles in circulation—drawn from European painting, Japanese art, and the art of the ancient Americas—were designed by Helen Maria Nugent, chair of the designed objects program at the School of the Art Institute of Chicago. Livingston described how Nugent “spends many an hour on the computer manipulating the two-dimensional information to raise certain layers—and to sink other layers—to create foregrounds and backgrounds and gradation of depth.” As she works, Nugent also thins out some of the details so that users aren’t overwhelmed by tactile information.

While the TacTiles are an interpretation rather than an exact replica of the original artwork, Livingston posits that in some cases the visual and tactile sensations are similar, such as in the case of Pierre Auguste Renoir’s *Two Sisters (On the Terrace)*. “[This TacTile] somewhat accurately, authentically reproduces the visual sensation of an Impressionist work of art where’s it’s visually challenging to discern certain shapes and forms in the background of the painting. It’s all somewhat blurred together. So likewise on the TacTile, we might find it a little bit of a challenge to discern the ships from the vegetation from the water,” he explained.

Through use of the TacTiles, museum-goers can use their fingers to learn fundamentals of painting, such as perspective and composition. There are limitations—TacTiles can’t



A TacTile kit from the Art Institute of Chicago offers visitors a reproduction of the composition and texture of Adriaen van der Spelt and Frans van Mieris's *Trompe-L'oeil Still Life with a Flower Garland and a Curtain* (1658), making it legible through the fingertips.



express variations in color—but Livingston points to new variations on the TacTile theme, such as the work of Sally Barker, an artist who produces fabric-based TacTiles in which different textures represent different colors.

Thanks to a Spark Ignition grant from the Institute of Museum and Library Services, the museum has also started experimenting with three-dimensional printing as a way to make artwork accessible to people with blindness or low vision, as well as for outreach to those with Alzheimer’s disease and dementia. The objects in the 3D collection are printed on a 1:1 scale and tend toward more functional works of art. There are about eight currently in circulation, including an Ancient Greek drinking cup and pre-Columbian whistles.

While Livingston confessed to being just short of skeptical about the usefulness of the technology, he is now a proponent thanks to the enthusiastic responses from museum consumers who have tried the objects. “I think that’s most significant to me, hearing what the participants had to say about the experience, about how valuable

it was to them to get their hands on these replicas. That very much propelled the 3D printing technology forward in my mind as an extremely resourceful and legitimate way of making these works of art accessible to people with blindness and low vision.”

As the Art Institute has deepened its accessibility programs for museum-goers with vision disabilities, they have made sure to involve members of that community in the process. It has also turned for guidance to NEA grantee Art Beyond Sight, a leader in the accessibility field.

The New York-based organization, originally called Art Education for the Blind, was founded in 1987 by Elizabeth Axel and offers numerous resources to promote accessibility efforts in the form of workshops, publications, social media, and toolkits. Echoing Livingston’s words about raising awareness of people with different vision abilities as museum consumers, Axel said, “Our fundamental belief is that people who are blind or visually impaired must have access to the world’s visual culture if they are to participate fully in their communities and in the world

**The Elizabeth Morse Touch Gallery at the Art Institute of Chicago.**  
▼



## THE ELIZABETH MORSE TOUCH GALLERY

This gallery gives visitors the rare opportunity to experience how the sense of touch can enrich their appreciation of art. Through touch we can discern an artwork’s form, line, size, style, temperature, and texture as well as further our knowledge of the object in ways that sight alone cannot provide.

Made of bronze and marble and representing different time periods and places of origin, the four sculptures in this gallery offer both visual and tactile information. Compare the way each artist approached the subject. Using touch, can you identify whether the sculpture depicts a male or female? What are the distinct facial features? The expression? The hair texture? The clothing or jewelry? Can you determine what material the artist used?

The sculptures in this gallery have been carefully treated with a protective wax so that visitors may touch them. Normally, visitors are not permitted to touch paintings and sculptures in museums, in order to protect them from damage. Hands that appear clean might have small amounts of corrosive salts, oils, moisture, and microscopic dirt particles on them. If transferred to works of art, these compounds build up over time and can ultimately ruin the objects. Therefore, please do not touch objects located elsewhere in the museum. With your cooperation, we can preserve the Art Institute’s treasures for future generations.

Please remove rings, bracelets, watches, and cuff links before beginning your tour of the Touch Gallery.

**“People who are blind or visually impaired must have access to the world’s visual culture if they are to participate fully in their communities and in the world at large.”**

at large. It improves the quality of their lives and helps them gain skills crucial to their education and employment opportunities.”

She cites as best practices many of the tools employed by the Art Institute of Chicago, including touchable exhibits and tactile renderings of two-dimensional works. She also remains optimistic regarding future developments. “We have yet to define the limits! Museum curators and educators are coming up with new ideas all the time, and it’s difficult to keep up with the advances in technology. For example, blind people routinely use the VoiceOver feature of iPhones to find access through apps that provide verbal description and wayfinding tools.”

While there have been great strides in making museums accessible to visitors with varying vision abilities, both Axel and Livingston noted that there are also challenges. There are the usual suspects—a lack of funding and time to develop and implement programs—but sometimes even the physical space of a museum can be a barrier if it was built before the advent of the Americans with Disabilities Act.

Axel noted that sometimes there’s also reluctance by museum staff to involve people who are blind or have low vision in the planning process for accessibility programs because of a lack of education about that community.

“They may be uncomfortable interacting with people with disabilities because of a lack of experience. Second, staff may be unfamiliar with the tools available for providing access to museum facilities and exhibitions.” In both cases, Axel believes that accessibility training is the answer.

She added that ideally, it shouldn’t just be outreach or educational staff who are engaged in these efforts. “I’d



love to see more museums transition from an isolated approach of providing accommodations to a more integrated and collaborative approach to creating inclusive programs. Creating an inclusive environment really requires involvement from museum professionals across all departments.”

Despite the challenges, Livingston and Axel remain passionately committed to making museums more accessible to people with disabilities of any kind. “I like the phrase I once read that we are all ‘temporarily abled,’” Axel said. “Meaning that becoming disabled is an aspect of being human, and will happen to all of us in some way. As soon as you need reading glasses you are visually impaired, no matter how little the magnification. The population of Boomers entering old age will bring many more people with vision loss to museums. They are not ‘other,’ they are us.”

▲ Visitors to the Art Institute of Chicago interact with 3D objects that bring the Greek, Roman, and Byzantine art galleries to life.



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## ONLINE

As part of our online content for this issue, which you can find by visiting [arts.gov](http://arts.gov), we feature an excerpt from the documentary on NEA National Heritage Fellow Sidiki Conde, *You Don't Need Feet to Dance*, directed by Alan Govenar of Documentary Arts; talk with visually impaired artist Stephen Proski; and listen to deaf hip-hop artist Sean Forbes.

Don't forget to check out our *Art Works Blog* ([arts.gov/art-works](http://arts.gov/art-works)) for daily stories on the arts around the country.

**(Above)** 2007 NEA National Heritage Fellow Sidiki Conde performing at the awards concert in Washington, DC. Born in Guinea, Conde lost the use of his legs to polio at age 14, but went on to become a dancer, singer, and teacher. PHOTO BY MICHAEL G. STEWART

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