Consulting Service: Webinar Series

Promoting Arts Accessibility for People Living with Paralysis
Sponsored by the Christopher and Dana Reeve Foundation

Presented by
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The Society is grateful to the National Endowment of the Arts for its support of the Consulting Service, which strives to provide affordable assistance to organizations wishing to establish or advance the arts in healthcare.
Promoting Arts Accessibility for Persons Living with Paralysis

Part I: Introduction & Selected Exemplary Practices

Photo: Easel designed by Marlene Moore Alexander in collaboration with artist who uses mouth painting technique; courtesy of Marlene Moore Alexander, Creative Arts, Bend, Oregon, 541-382-3950

Ermyn King, MA
Society for the Arts in Healthcare Consulting Service
2010 Renewal Webinar

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Thanks to our generous sponsor...
The Christopher & Dana Reeve Foundation

Photo: Artist creating with Wikki Stix; courtesy of Marlene Moore Alexander, Creative Arts, Bend, Oregon
According to a study initiated by the Christopher & Dana Reeve Foundation, nearly 1 in 50 people in the U.S. live with paralysis – approximately 6 million people.

Almost 1.3 million of these individuals have a spinal cord injury (SCI).
Causes of Paralysis in the U.S.
(data from One Degree of Separation: Paralysis and Spinal Cord Injury in the U.S., a survey initiated through the Reeve Foundation)

- stroke (29%)
- spinal cord injury (23%)
- multiple sclerosis (17%)
- other (9%)
- cerebral palsy (7%)
- post-polio syndrome (5%)
- traumatic brain injury (4%)
- neurofibromatosis (4%)

N = 5,596,000
The Reeve Foundation’s *One Degree of Separation* study also showed that...

- varied types of **accidents** account for most SCI
- 54% of those who reported being paralyzed were **males**
- 61% of those who reported being paralyzed due to SCI were **males**
- males were almost **twice** as likely (1.77) to incur SCI as **females**
- 67,000 (7%) of those who reported becoming paralyzed as a result of accident or injury also reported that the paralyzing accident or injury occurred **while serving in the military**
Access Paradigms

Barrier-Free or Accessible Design: enforceable and prescriptive minimum design requirements that comply with the Americans with Disabilities Act (ADA) of 1990; has often resulted in separate and stigmatizing solutions

Universal Design (UD): usable by the widest range of people to the greatest extent possible, without need for multiple separate adaptations or designs; addresses both accessibility and inclusion via a broad-spectrum solution

Photo: Inclusive and accessible ArtStream, Inc. theater production; courtesy of ArtStream, Inc., Bethesda, Maryland, www.art-stream.org
Benefits of Engaging in the Arts for People Living with Paralysis

- strengthened motivation
- broadened expressive range
- positive shifts in identities, roles, and self-perceptions
- development of interests, goals, and projects
- increased interaction in wider social contexts
- enhanced freedom, independence, and potential income

Individuals living with paralysis engage in all arts modalities.
Digital Wheel Art

interactive art-making system developed by Younghyun Chung, in which wheelchair movements detected by infrared signals are digitally projected as lines onto a screen in real time

Photo: Artist and Digital Wheel Art (entitled “Going Home,” with each color representing a different family member at home awaiting the artist’s discharge from healthcare setting); courtesy of Younghyun Chung, New York, New York, www.risknfun.com
Digital Wheel Art System Overview

Photo: Digital Wheel Art system overview; courtesy of Younghyun Chung, New York, New York
Digital Wheel Art Users

Photo: Digital Wheel Art users; courtesy of Younghyun Chung, New York, New York
The EyeWriter Project

eye-tracking apparatus and custom software developed by an international team, to allow graffiti writers and artists with paralysis from Amyotrophic lateral sclerosis (ALS) to draw using their eyes.

Photos: Courtesy of The EyeWriter project team (members of Free Art and Technology, OpenFrameworks, and the Graffiti Research Lab, working with LA graffiti writer, publisher, and activist Tony Quan, aka TEMPTONE, who was diagnosed with ALS in 2003); www.eyewriter.org
Zot Artz Arts For All Adaptive Tools in Use

Girls using Little Pogo Paint Poles

Wheelchair bubble blower in use

Boy using “Give It A Whirl” device

Photos: top l. – Carol Seago; top r. and bottom l. – Brian Castillo; center – Geoff Coe; bottom r. – Dwayne Szot; courtesy of Dwayne Szot/Zot Artz Arts For All, Bayfield, Wisconsin, www.zotartz.com
ArtStream, Inc.
inclusive and accessible theater companies

Photo: Courtesy of ArtStream, Inc., Bethesda, Maryland, www.art-stream.org
Dancing Wheels
integrated dance workshops and performances

Photo: Courtesy of Lori Bowman/G.G. Greg Agency for Dancing Wheels, Cleveland, OH, www.gggreg.com
Ms. Bowman (800-901-8485) may be contacted when scheduling a Dancing Wheels workshop or performance.
Soundbeam and Sensory Studio

Youth controlling light pattern and sound through his movement with Soundbeam

Sensory Studio designed by Joe Fialko for Baker Victory Services’ Early Childhood Program, Lake Lackawanna, New York

Photos: Joe Fialko; courtesy of Joe Fialko, Soundbeam USA & Sensory Expressions, Inc., Snyder, New York
Inglis House Art Program

includes Residents’ Arts Council, filmmaking, poetry workshops, theater collaborations, art making, exhibitions, and concerts
The Art of Healing Loss (AHL): Applying Expressive Arts Techniques in Veteran Healthcare Settings

(offered through The Center for Health and Learning, with support from the Society for the Arts in Healthcare/Johnson & Johnson and The Educational Foundation of America)

training on Oct. 20-21, 2010 and Jan. 2011 (exact dates TBD) of two cohorts of mental health providers to work with veterans, using the complementary arts-based AHL approach for helping them address PTSD and process trauma and grief; program manual, veterans’ art exhibit, and evaluation findings will be disseminated
Medical Missions for Children’s
Giggles Children’s Theater

Photos: Courtesy of Medical Missions for Children/Giggles Children’s Theater, Paterson, New Jersey, www.mmissions.org
Virtual Field Trip to Rain Forest from *Giggles*, St. Joseph’s Children’s Hospital, Paterson, NJ

Example of a *Giggles* virtual field trip via Polycom equipment---in this case, to the Panama rain forest; other such virtual trips have included swimming with manatees, building puppets, etc.

Photos: Courtesy of Medical Missions for Children/*Giggles* Children’s Theater, Paterson, New Jersey
Hospital Audiences, Inc. (HAI) Omni*Bus

- HAI Omni*Bus
- HAI Omni*Bus full of veterans with paralysis and other disabilities in Veteran’s Day Parade
- HAI Omni*Bus Holiday Lights Tour
- Walter Reed Army Medical Center soldiers with family at MoMA after HAI Omni*Bus transport there--part of NYC weekend for the group organized through HAI

Photos: Courtesy of Hospital Audiences, Inc. (HAI), New York, New York, www.hospitalaudiences.org
More Exemplary Arts Programs for Persons Living with Paralysis

Therapeutic Arts Program, The Mount Sinai Rehabilitation Center, New York, New York: weekly program (mostly visual arts) founded by Eliette Markhbein, for whom drawing and writing came naturally while in rehabilitation after sustaining a traumatic brain injury and SCI
www.hektoeninternational.org/Trauma_on_Canvas.html

Fine Arts and Performing Arts Program, Northeast Center for Special Care, Lake Katrine, New York: award-winning program at the world’s largest brain injury treatment center, including visual arts, writing, theater, music, and movement
www.northeastcenter.com/fine_arts_program.htm
Mission Statement

The Mission of the Arts Access Program is to provide people with disabilities the opportunity to create and perform fine art.
Philosophy of Arts Access

- Freedom of choice
- Facilitator neutrality
- Artists assisting artists
- No preconceptions
The Facilitation Process

• What is facilitation?
• What are characteristics of a facilitator?
• What is the difference between a facilitator and an educator?
• Why do we facilitate?
• How do we facilitate?
Communication is the key!

- Verbal
- Limited verbal
- Physical gesture
- Communication device
Communication Systems

- Sculpture
- Painting
- Dance
When the Work Is Done

Untitled - Cindy Shanks
Untitled, Alex Martinez

Untitled, Karen Frascella

4 People, 1 Body, Natalia Manning
Overcoming Perceptions