

MOVING FORWARD, LOOKING BACK



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"In Celebration of Down Syndrome" Exhibit Now Open

By Nicole Forgione, Marketing Communications Manager, People Inc.



The grand opening event for the Museum of disABILITY History's "In Celebration of Down Syndrome" exhibit, held on May 7, was a tremendous success! With nearly 100 people in attendance, it was a beautiful day as we marked the opening of our new exhibit honoring the lives of individuals who have Down syndrome. The exhibit explores medical history, myths and facts, success stories and popular culture.

Our keynote speaker for the opening event was Dr. David Wright, professor of history at McGill University in Montreal, Canada. He presented "Down syndrome: Learning from the Past, Looking Toward the Future."

Featuring vibrant multimedia and Hollywood memorabilia, the exhibit includes a centerpiece highlighting photography by Eva Snoijink from her book, *Down's Upside: A Positive View of Down's Syndrome*. Rather than stereotypical images, the display features portraits of happy children.

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Pictured L-R: Amy Monson, president, Down Syndrome Parents Group of Western New York; Doug Farley, director, Museum of disABILITY History; Keller Vogelsang; David Mack-Hardiman, associate vice president, People Inc.; Engelic Everett; Rhonda Frederick, president and CEO, People Inc.; and Eric Johnson.

Message from the Director



Welcome to the summer issue of *Moving Forward, Looking Back.* I hope you enjoy reading our latest news.

Looking back, we have hosted several amazing programs in early 2016, many drawing record breaking crowds. In January, we held our largest on-site event to date, welcoming over 110 people when we launched the Museum's latest

publication, *Buffalo State Hospital: A History of the Institution in Light and Shadow*. It's apparent that the

treatment of mental health in the 19th and 20th centuries is a topic of great local interest.

In February, we hosted a Dialogues on disABILITY Workshop, featuring Susan Conners, MEd, president and founder of the Tourette Syndrome Association of Greater New York State and author. She presented "Tourette Syndrome and Associated Disorders in the Classroom" to 30 healthcare and education professionals. We were pleased to attract media attention for this event on several occasions – all of which helped spread awareness of our Museum and the diverse programs we offer.

Visitation was bolstered in March by our Museum of disABILITY Film and Speaker Series. The event featured *Capturing Grace*, a film about dancers with Parkinson's disease joining forces with a famed modern dance company to stage a unique performance. A reception between screenings featured speakers from our two co-sponsors, Danceability and the National Parkinson's Foundation WNY.



Capturing Grace screening.

In April, we were pleased to present a Dialogues on disABILITY Speaker Series entitled, "All Things Are Possible," by artist Nancy Hall. In May of 2000, Nancy was in a tragic motorcycle accident leaving her paralyzed from the neck down. Nancy is now an acclaimed artist who paints by mouth and a student of the International Association of Mouth and Foot Painting Artists.

Also featured in April was "Understanding Historic Institutions for the Disabled in NYS," a program held in collaboration with the WNY Genealogical Society. We had about 50 guests who were interested in learning more about what the Museum can do to help

them find their ancestors who lived at NYS institutions.

Our May program included the official unveiling of our new exhibit, "In Celebration of Down Syndrome." Please see our cover story for more details.

As we look to the future, please save the date, Saturday, July 16 when we will celebrate, "Mubu's Summer Costume Party" (see page 5 for more information). On Saturday, July 30, we are joining forces with WNY Association of Historical Agencies to present "Grave Matters," a full day informative seminar and hands-on cemetery restoration event.

We're glad you have chosen to partner with the Museum of disABILITY History, and we look forward to your next visit!

Doug Farley, Director Museum of disABILITY History

One-of-a-Kind Museum is Resource to The New York Times

Journalist Dan Barry writes in *The New York Times* about society's long struggle to find the proper terminology for people with intellectual disabilities. Museum of disABILITY History Curator Douglas Platt was interviewed and said: "A lot of this has to do with the terminology for what you think normal is. Normal meaning me, or you, or us. People who aren't like us are something...." To view the article, go to *The New York Times* website, nytimes.com, and enter the article' title, "Giving a Name, and Dignity, to a Disability" in the search option.

To learn about Dan Barry's new book that is available in our gift store, see page 8.



3826 MUSEUM of disABILITY History

TRAINING CENTER FOR HUMAN SERVICE EXCELLENCE

Building Dedicated to James M. Boles Ed.D.

Megan Bomgaars of A&E Reality Show Visits Museum of disABILITY History

On May 27, Megan Bomgaars and her mom Kris, who star in *Born This Way*, visited the Museum of disABILITY History. *Born This Way*, airing on A&E with a second season starting later this summer, is a reality show that follows seven young adults who have Down syndrome. We were happy to have them visit and see our "In Celebration of Down Syndrome" exhibit, which includes a cast photo from the show. Megan was in town as she was the keynote speaker on May 26 for the Developmental Disability Awareness Day at the Conference & Event Center Niagara Falls. The event, which celebrates, educates and advocates for individuals with developmental disabilities, is the largest conference of its kind in the United States,

Megan is a self-advocate with Down syndrome, an artist and a rising entrepreneur, with a business called Megology. She has developed her skills as a public speaker and travels across the country sharing her experiences and presentations on a variety of topics. Megan composed the video "Don't Limit Me," which went viral. Her mother, Kris, is known as her "Dream Maker," and the two are strong advocates. The Museum of disABILITY History looks forward to following their accomplishments!



L-R: Nicole Forgione, marketing communications manager, People Inc.; Kris Bomgaars; Megan Bomgaars; Jack Monson; Amy Monson, president, Down Syndrome Parents Group of Western New York; Doug Farley, director, Museum of disABILITY History.



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"In Celebration of Down syndrome" continued from page 1

Kelly's Hollywood, an inspirational documentary, is available to view as part of the exhibit. The movie is film director Brian Donovan's tribute to his sister, Kelly, who was born with Down syndrome. A Buffalo native, Brian moved to Hollywood and became a writer, actor, director and producer. The film is about a brother's quest to help his sister fulfill her dream of becoming a Hollywood diva.

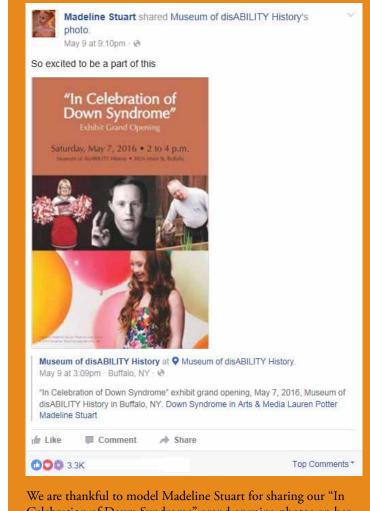
Additionally, the "Unspoken Voice" artwork exhibition by Bailey Bastine was unveiled during the event. An artist from East Aurora, NY who has Down syndrome, Bailey shares her talents and experiences through her work. The artwork will be displayed until the end of the year.

Many family members who have loved ones with Down syndrome are impressed with the exhibit and shared sentiments of appreciation during the opening event. "People with Down syndrome tend to be over looked and their abilities underestimated due to outdated stereotypes," said Amy Monson, parent and president of the Down Syndrome Parents Group of Western New York. "It is our hope that people will see 'In Celebration of Down Syndrome' and realize that individuals with Down syndrome have so much more to offer than they are often given credit for. They are all unique individuals with their own interests, abilities and talents."

As visitors view the exhibit, they may see some familiar faces. The pop culture exhibit panel incorporates photos of actors with Down syndrome, including Jamie Brewer, Christopher Burke and Lauren Potter. The photos were contributed by Gail Williamson, founder of Down Syndrome in Arts & Media and talent agent for the Diversity Department of KMR Talent Agency, both based outside of Los Angeles, CA.

Also highlighted on the pop culture panel is Madeline Stuart, a model from Brisbane, Australia who was born with Down syndrome. She has been internationally recognized for her work promoting acceptance and changing perceptions of beauty.

"In Celebration of Down Syndrome" is supported by a grant from the New York Council for the Humanities and a donation from the Down Syndrome Parents Group of Western New York. It will be on display until the end of 2016. For more information about the exhibit or to arrange a guided tour for yourself or organization, email info@ museumofdisability.org or call 716.629.3626.



We are thankful to model Madeline Stuart for sharing our "In Celebration of Down Syndrome" grand opening photos on her Facebook page, resulting in an extensive reach for our exhibit and our Museum's mission.



"We had a very enjoyable time making new friends and visiting with some former ones too! Thanks for continuing to raise positive awareness for individuals with Down syndrome and other developmental disABILITIES!

- Andrea Sirianni, Ambassador of The Family and Friends Down Syndrome Association of Niagara, Inc. (Andrea and family with keynote speaker Dr. David Wright)

Guest Contribution

New Book in Mubu the Morph Children's Series

By Stephen Nawotniak, OTR/L, Author, Speaker, Occupational Therapist

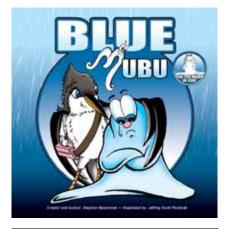
"Sometimes no matter what we do, we can't help but feel real blue. But how to change from sad to glad, THAT'S the adventure Mubu had."



Blue Mubu, the third book in the *Mubu the Morph* children's book series, is a story about emotions. Mubu has been feeling "blue" for a week and is in search of his smile. He goes to his friend KooKoo-ah-choo (a Cuckoo bird with allergies) for help. She gives him a supportive place to work through his state and it is there that he finds gratitude and thankfulness as keys to help him change through his "blues."

While feelings of happiness and success are easy emotions to talk about, our more uncomfortable emotions are more difficult. *Blue Mubu* is inspired by my personal experiences with bipolar depression and shares the lesson that no matter how we feel, gratitude and thankfulness can help us through it. It is important to realize that gratitude is different from happiness because we don't simply switch from sad to happy. We can, however, find specific things to be thankful for. In doing so, we are able to create some calm amidst the storm and this changes the paradigm from which we live.

Such conversations and concepts are difficult to have with children but learning to live with uncomfortable emotions is an important skill to develop while growing up. It is my hope that this simple tale provides a vehicle for such a conversation and understanding.





"While feelings of happiness and success are easy emotions to talk about, our more uncomfortable emotions are more difficult."





Pictured Above: Jennifer Stevens, Eileen Weand, Patrice Vibbert, Amy Weand and James Boles. Eileen Weand (owner of the property) donated the papers to the Museum.

Trip to Pennsylvania Results in Donation of Dr. Skinner's Newspapers

By James M. Boles, EdD, Founder, Museum of disABILITY History, and Author



Last month, the Museum of disABILITY History was contacted by a family sorting out a large old estate in Bucks County Pennsylvania where they found copies of *The Mute & the Blind from the 1860s.* Patrice Vibbert, the researcher of the group, tracked us down using internet searches and found a reference to our publication, *Dr. Skinner's*

Remarkable School for Colored, Deaf, Dumb and Blind Children, and a newspaper article about the Museum's Skinner display at the Niagara Falls Library. After a number of emails and phone calls, my wife Paige and I traveled to a stone house in rural Bucks County, Pennsylvania.

In an old trunk, we found papers dating back to the 1700s. There were eight copies of Dr. Skinner's newspaper, *The Mute and the Blind*. Although the Museum has earlier copies of the paper, we knew little about the Skinner's school in Trenton, New Jersey. This recent discovery has provided us with valuable information about this third and last school for disabled African-American children.

The papers were found in unusually good condition despite the manner in which they were stored.



Old estate in Jamison, Pennsylvania where the Skinner newspapers were found. The house and hundreds of acres of land date back to the 1700s.

continued on page 11

Guest Contribution

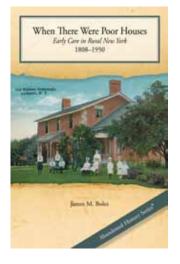
Book Review: When There Were Poor Houses: Early Care in Rural New York, 1808-1950

By Ann Marie Linnabery, Assistant Director, History Center of Niagara

The republication of the James M. Boles 2012 book, *When There Were Poor Houses: Early Care in Rural New York, 1808-1950* gives readers the opportunity to revisit this very intriguing but little known aspect of Niagara county history. The book traces the evolution of how the poor and disabled were cared for in charitable and government institutions in the 19th and early 20th centuries. Boles has divided the book into four different time periods with an explanation of each organization, both secular and religious, that opened during those years. He examines how each responded to the changing attitudes and medical knowledge at various times in the county's history.

Each chapter contains a brief narrative, a map of the site's location and historical photographs. Some also include newspaper articles, census data and other visual materials. What is especially appealing is that Boles does not end each synopsis with just the demise or current status of the organization, but carries it forward with information and a photograph of "what's there now."

When There Were Poor Houses: Early Care in Rural New York, 1808-1950 is rich in historical research but does not bog the reader down with unfamiliar jargon or excessive detail. It is an enjoyable and informative read for anyone interested in the history of Niagara county.





Curator's Corner: Advocacy and Advice from a Time-capsule

By Doug Platt, Curator



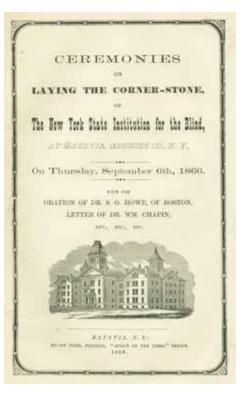
The Museum of disABILITY History archives contain many documents that shed light on disABILITY History – here is one which turns 150 years old this September and features the thoughts of Dr. Samuel Gridley Howe. It is a booklet entitled "Ceremonies on Laying the Corner-stone of The New York State Institution for the Blind, At Batavia, Genesee Co., NY. On Thursday, September 6, 1866. With the Oration of Dr. S. G.

Howe, of Boston."

In his remarks to the assembled, Howe comments on attitudes towards "the blind" – "We are safe in saying that as far as possible, they should be considered and treated just as ordinary persons, our equals and friends, are treated and not singled out as special objects of pity."

Howe also offers a warning regarding institutionalization: "All great establishments in the nature of boarding schools ...where the charms and refining influences of the true family relation cannot be had – all such institutions are unnatural, undesirable, and very liable to abuse. We should have as few of them as possible, and those few should be kept as small as possible."

And to reiterate: "We should be cautious about establishing such artificial communities, or those approaching them in character, for any children and youth; but more especially should we avoid them for those who have any natural infirmity; or any marked peculiarity of mental organization."



New Book in Development: Camp Cornplanter

By David Mack-Hardiman, Associate Vice President, People Inc.

After a welcome dinner in the dining hall, everyone at



Camp Cornplanter would cross the bridge over Dunkle Run each Sunday evening. The anticipation would build as we sang traditional camp songs; lyrics which were silly, patriotic or spiritual. Those who could not sing would clap along or perform gestures

that accompanied the lines of the songs. Some of the music required foot stomping which produced a deep, guttural rhythm under foot.

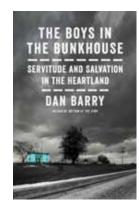
In the air, there was a distant whiff of kerosene which signaled that the magic was about to begin. Across the bridge, "Chief Cornplanter" and his torch-bearing entourage proudly strode in. The "Chief" and his friends bore remarkable resemblances to some of the camp staff. They welcomed everyone to camp and uttered magical phrases. The huge campfire within the rock- rimmed ring suddenly exploded in flames. The magic fire was born! There were shrieks and whistles as sinewy coils of smoke crept up through the towering pines. The fire crackled and added a glowing warmth to the fading summer daylight.

Built in the Roosevelt era by the Civilian Conservation Corps, Camp Cornplanter served many purposes over the years. In 1959, a three-week session was designated for people who had disabilities. Thus, it became one of the first residential camps to serve this population in the United States. It was a rugged setting in the Allegheny National Forest and rigorous hiking was a routine part of every day. The facility was shared with bats, snakes, deer, bears and lazy porcupines. Hawks ruled the day skies and owls did the same at night.

The story of Camp Cornplanter, named for the renowned Seneca warrior Chief, begins with his birth in the 1700s. It contains many elements which visit the story more than once: fire, flooding, treaties and betrayal. It traces the timeline of the evolution of care, from the archaic practices of widespread institutionalization to progressive movements in community care. And, it is a beautiful story of devoted families who resisted the stereotypes of the time. They worked tirelessly, creating a glorious refuge for people who had disabilities. It was indeed, their Shangri-La.

We are pleased to have the book be part of our publication collection: *The Story of Camp Cornplanter*.

Now Available in Our Store Visit to purchase your copy



The Boys in the Bunkhouse: Servitude and Salvation in the Heartland, By Dan Barry During his 21-year career as a reporter and columnist at *The New York Times*, Dan Barry has crisscrossed America to explore the spectrum of the human experience. In covering everything from natural disasters to the aftermath of September 11th – to the enduring charm of the county fair – Barry has taken readers to the hidden places of this country, finding heartbreak, joy and great wonder. His forthcoming book, *The Boys in the Bunkhouse* (Harper / May 17, 2016), is a truly transformative piece of narrative non-fiction.

In a work of hauntingly detailed reportage, Barry explains how and why these men came to live in the schoolhouse and were

nearly forgotten for so many years. Through exhaustive interviews, he dives deeply into the lives and testimonies of the men, recording their memories and suffering, their small moments of joy and persistent hopefulness for better times ahead. Barry explores why this small heartland town remained all but blind to the men's plight, details how those responsible for such profound neglect justified their actions, and chronicles the lasting impact of a dramatic court case that spurred advocates—as well as President Obama –to push for just pay and improved working conditions for people with disabilities. The book also lays out how state social workers and one local reporter doggedly stayed on the case, and how a determined labor lawyer worked day and night to hold the accountable parties responsible for their profound and chronic negligence.

"In researching the social history of intellectual disability, I visited the Museum of disABILITY History in Buffalo, New York - absolutely worth the trip - and relied on many books and publications, including *No Offense Intended: A Directory of Historical Disability Terms* (Buffalo: People Ink Press, in association with the Museum of disABILITY History).... Douglas Platt at the Museum of disABILITY History shared many artifacts that reflected society's changing views of intellectual disability."

- Dan Barry, Author, journalist

Dan Barry is a writer and columnist for *The New York Times*. In 1994, he was part of an investigative team for the *Providence Journal* that won the Pulitzer Prize for a series of articles on Rhode Island's court system. He is the author of a memoir, a collection of his About New York columns, and Bottom of the 33rd, for which he won the 2012 PEN/ESPN Award for Literary Sports Writing.

SAVE THE DATE!

Museum of disABILITY History Film and Speaker Series Featuring

000 MILES



A documentary about a cross-country road trip that changed them for a lifetime.

Friday, August 12, 2016

The Screening Room, 3131 Sheridan Drive, Amherst

Stay tuned to museumofdisability.org and our Facebook page for more details.

If your company would be interested in sponsoring our event, contact Doug Farley at dfarley@people-inc.org or 716.629.3626.

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Support the Museum, Become a Member!

Want to support the Museum of disABILITY History? Membership opportunities are available! With different levels available, you can choose the one that is right for you. All supporting membership levels are good for one year. **To become a member, call 716.629.3626 or log on to our website at museumofdisability.org.** Click on the "Support Us" tab, choose "Membership," and "Click Here to Become a Member." Thank you for your support!

New Members!

A warm welcome to our newest members who recently joined and renewed:

Individual/Student

Bailey Bastine Mary Bonato Robert Colangelo Pat Kibler-Fries Barbara Guancial Assemblyman Michael Kearns April Kimball Donna McDonald Joan Murray Judy Naylor New York State Senator Robert Ortt Linda Siragusa Claudia Sweeney

Family/Dual

Bernice and George Baeumler Dave and Kathy Greenfield Howard and Valerie Rosenhoch Patricia Schaus

Friend

Don Bach's Towing Robert Dunford Ron and Diane Pokorski Jeff and Trudy Sanderson Joyce Sirianni, PhD

Sustainer

Susan Mann Dolce Long Associates Architects

As a member, you receive free admission to the Museum and events, and a 10% discount in the Museum Store!

Hello from Australia! New Member Recognition



Our Museum of disABILITY History reaches thousands and we provide assistance for various research projects and act as a model for others across the United States. Our scope has recently reached Australia! We are pleased to share that Dr. Donna McDonald of Menzies Health Institute Queensland at Griffith

University in Australia recently became a member of the Museum of disABILITY History.

Dr. Donna McDonald is a senior research fellow with the Menzies Health Institute Queensland at Griffith University (Australia). She was the convenor of Disability Studies in the School of Human Services and Social Work at Griffith during 2011-2015. In 2015, Donna led an industry-university National Disability Insurance Scheme Readiness research partnership examining people's experiences of disability services delivery and hopes for their future.

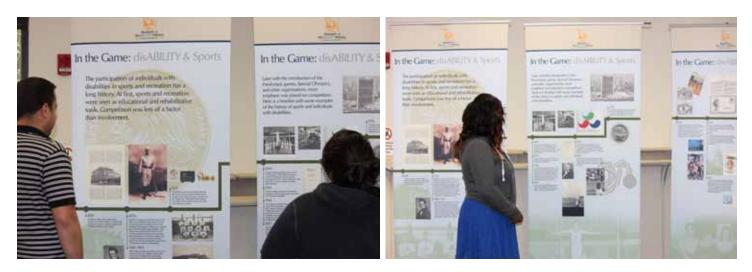
Donna has extensive policy networks, developed throughout her 30-year career in public policy as a social worker, policy adviser and writer working at federal, state and local government levels in Australia and England. Her publications include: *The Art of Being Deaf: A Memoir* (Gallaudet University Press, Washington. 2014).

Donna's rehabilitation and disability research priorities include exploring the teaching and community awareness potential of visual arts narratives of people with disabilities. In her research, Donna works with her own drawings and looks at the work of other visual artists to find new ways of understanding the history and experiences of people with disabilities. In early 2016, she exhibited a suite of her drawings, "Talking back to Diane Arbus," in The 5 FIVE Show: Queensland Artists Thinking, at the Logan West Library's Artists' Walk."

"You were insightful and engaging and the students enjoyed the event immensely. I hope I can count on you again for future tours in the course."

- Clancy M. Seymour, EdD Assistant Professor, Director of Physical and Health Education Teacher Education, Department of Kinesiology, Canisius College

Canisius College students from the Capstone in Kinesiology visited the Museum of disABILITY History for a tour that included a comprehensive historical analysis of the disabled as a minority group from both a domestic and global context. The presentation closed with a discussion about the role that sports has played historically in the advancement of disability civil rights.



In April, our "In the Game: Sports and Disability" traveling exhibit was on display at Miami Dade College in Miami, Florida. The threepanel banner timeline exhibit chronicles events and individuals who have transformed sport and recreation for individuals with disabilities.

The Museum of disABILITY History provides a variety of disability themed traveling exhibits available to rent for conferences, events, college and businesses locally and across the country. They can easily be shipped. For more information, email info@museumofdisability.org or call 716.629.3626.

"Donation of Dr. Skinner's Newspapers" continued from page 6

We have been collecting information about the Skinners for the past eight years in order to create an expanded publication about the life of Dr. and Mrs. Skinner.

One of the main purposes of the Museum is to serve as a repository for disability related information and artifacts. This recent donation of these rare papers is a great example. They will be archived at our Museum and available for future research.

The Museum will forward hard copies and CD's of the newspapers to the family as their intent is to keep a copy of this material with the house. They also plan to provide copies to local Bucks County, Pennsylvania historians and libraries.

We would like to thank the family and their researcher for their forethought and efforts in finding these rare documents a home. We are very pleased to have them as a part of our archives.



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SAVE THE DATE!

Every Vote Counts-Yours Matters An Accessible Voting Training Event

> Monday, September 12 11 a.m. to 2 p.m. Museum of disABILITY History 3826 Main Street, Buffalo

Learn how to use machines that make voting possible for those who are blind, visually impaired or otherwise unable to mark a traditional ballot. Feel comfortable casting your vote with a machine provided by the Erie County Board of Elections.

For more information, call 716.629.3626.



Awareness and Etiquette

If you are speaking through a sign language interpreter, be sure to pause occasionally to allow him or her to translate completely and accurately.



To find more disability etiquette messages similar to this, Like our Museum of disABILITY History Facebook page at facebook.com/ museumofdisability.



Disability Etiquette Programs Available

Host a disability and etiquette training for your staff – it's a great learning opportunity for human resource professionals, medical and direct support staff, and people who work in the transportation and retail fields. For more information, contact Doug Farley, director, at dfarley@people-inc.org or 716.629.3626.

MUSEUM INFO

3826 Main Street, Buffalo NY 1422 716.629.3626 info@museumofdisability.org museumofdisability.org store.museumofdisability.org

MUSEUM HOURS

Monday-Friday: 10 a.m. - 4 p.m. Saturday: 10 a.m. - 2 p.m. Sunday: Closed

ADMISSION

General Admission: Museum Members......

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| Adults | \$6.0 |
| Students, Seniors, and Human Service Employees | \$3.50 |
| Children ages 6-17 | \$3.0 |
| Children ages 5 and under | |

Group Tour Rates:

All groups (greater than or equal to 10 people): \$4 per person **Rental of the KeyBank Room** (1st Floor, up to 20 people): \$50 fee added to the total amount per person

Rental of the Main Training Room (2nd Floor w/ elevator access, up to 80 people): \$100 fee added to the total amount per person

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MISSION STATEMENT: The Museum of disABILITY History advances the understanding, acceptance and independence of people with disabilities. The Museum's exhibits, collections, archives and educational programs create awareness and a platform for dialogue and discovery.