



New Foundations: Principles for Disability-Inclusive Museum Practice

Ross Edelstein

To cite this article: Ross Edelstein (2022) New Foundations: Principles for Disability-Inclusive Museum Practice, Journal of Museum Education, 47:2, 192-205, DOI: [10.1080/10598650.2022.2073093](https://doi.org/10.1080/10598650.2022.2073093)

To link to this article: <https://doi.org/10.1080/10598650.2022.2073093>



Published online: 24 Jun 2022.



Submit your article to this journal [↗](#)



Article views: 35



View related articles [↗](#)



View Crossmark data [↗](#)



New Foundations: Principles for Disability-Inclusive Museum Practice

Ross Edelstein

ABSTRACT

This paper seeks to provide museum professionals with a practical road map to improving outcomes for people with disabilities in their museums. Written by a museum researcher with autism, this paper weaves museum research with interdisciplinary studies, while prioritizing the voices of people with disabilities, in order to develop clear, well-defined, and customizable steps for making the museum as an organizational unit more welcoming for people with disabilities. It examines several issues within the field, such as the overwhelming childhood focus of museum accessibility programming, the need to include people with disabilities in the process of creating inclusive practices, the importance of focusing on the larger picture as opposed to small issues, creativity in accessibility, and the dangers of performative accessibility and suggestions to avoid it, combining literature on each topic with the author's own knowledge of disability and museum accessibility.

ARTICLE HISTORY

Received 21 January 2022

Revised 28 April 2022

Accepted 29 April 2022

KEYWORDS

Accessibility; museums; inclusion; equity; guidance; administration; disability

“Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.” This is section one of Article 27 of the United Nations’ Universal Declaration of Human Rights. Indeed, people with disabilities are a huge part of society; about 1 in 4 Americans have a disability. Yet overwhelmingly, people with disabilities are excluded from engaging in cultural activities, often because those who lead cultural organizations are unaware that they are creating spaces that exclude disabled people beyond the bare legal minimum requirements.

Through my time working in museums, researching accessibility, and helping cultural organizations be more inclusive, I have discovered that despite the moral obligation stated above, and legal obligations stated in the Americans with Disabilities Act, many museums are still inaccessible and institutionally ableist, often despite the best efforts of those at the helm. After all, the process is difficult, akin to being forced to pilot a boat to land in a storm.

However, this does not mean it is impossible. Anti-ableism is a journey, and just like any journey, the hardest part is getting started. Yet from the experiences I have had both as a person with a disability and from the perspectives of museum worker, visitor, and researcher, I have realized that many do not know where that starting point is. Any activity run without the full support of an institution’s culture, leadership, and staff will fail to be anything more than a single, fleeting experience. The first step to promoting a culture of anti-ableism is helping to shift your organization’s attitude.

This paper seeks to provide guidance for the first steps in making your institution anti-ableist. Drawing on perspectives from academic research on museum accessibility, and the lived experience of the author, this paper suggests five general principles that emphasize attitude over activity. These five guiding principles of anti-ableism are:

- Accessible practices are not just for kids
- Including people with disabilities in your process provides opportunities to promote inclusion within your organization
- The minutiae are not as important as building bonds
- Being creative and trying new types of initiatives and programming will help promote anti-ableist behavior
- Avoiding performative accessibility makes room for stronger institutional initiatives

Context: a survey of museum websites

As part of this paper, the author conducted a brief, non-scientific survey of museum websites, particularly those of larger institutions. The full list of parameters for this survey can be found in the Appendix, but the primary aim was to see the kinds of supports museums provided for people with disabilities. The chosen websites were generally those of large, influential institutions, institutions committed to inclusive practice, or other organizations that the author is aware of who are working to include people with disabilities at their organization. This list does not seek to represent the state of the field; instead, it represents a snapshot of some programs at some organizations. Some of these organizations were chosen due to personal connections the author has, such as prior work as a contractor or employee, or previous experience with engaging with these staff as part of coursework for his Master's. Others were chosen as museums that are culturally significant, or are otherwise known for accessibility work more generally. The full list of how each museum was selected can be found in the Appendix and [Figure 1](#). All 20 websites surveyed had some form of programming or supports for people with disabilities. This was defined as any information that discusses accessibility, from programs to policies to other supports offered for people with disabilities. Below, I discuss the five general findings from this survey.

Not just for kids

Museum support for people with disabilities is primarily child-focused. Take the literature on people with autism: of the four major works published on the subject during the surge of support for people with autism over the past 10 years – Langa et al.'s "Improving the Museum Experiences of Children with Autism Spectrum Disorders and their Families;" Cho and Jolley's "Museum Education for Children with Disabilities;" Lurio's "Engaging Children with Autism at Historic Sites;" and Greenberg and Levinsky-Raskin's "Supporting Transitions" – three of the four are focused exclusively on children with autism.¹ The fourth, by Greenberg and Levinsky-Raskin, discussed the transition out of the school-services sector and into employment with a focus on museums.² Even this article, which is doing important work to drive institutional change, has a focus on young adults.

Museum Name	Programs or Supports for People With Disabilities	Programs for Adults	Programs for Kids	Is there a listed advisory group?	Advisory Group Contact Information	"Uncommon" Programs or Supports	Website	Access Date
Chicago History Museum	1	0	0	0	0	0	https://www.chicagohistory.org/visit/accessibility/	03-10-21
Children's Museum of Indianapolis	1	0	1	1	1	0	https://www.childrensmuseum.org/visit/accessibility/	03-10-21
Ellisoging Museum	1	0	0	0	0	0	https://ellisoging.org/policies/accessibility-services/	03-10-21
Field Museum	1	0	0	0	0	1	https://www.fieldmuseum.org/visit/accessibility	03-10-21
Gateway Arch National Park	1	0	0	0	0	0	https://www.nps.gov/gaif/playyourvisit/accessibility.htm	03-10-21
Getty Museum	1	1	1	0	1	1	https://www.getty.edu/visit/center/accessibility/	03-10-21
Glazer Children's Museum	1	0	1	0	0	1	https://glazermuseum.org/mobility	03-10-21
Illinois State Museum	1	0	0	0	0	0	http://www.illinoismuseum.org/content/form-spr/infield-visitor-information	03-10-21
Indiana Medical History Museum	1	1	0	0	0	1	https://www.imhm.org/dlars-your-visit/accessibility-language-assistance	03-10-21
Indiana State Museum	1	0	0	0	0	1	https://www.indianamuseum.org/accessibility/	03-10-21
Missouri History Museum	1	1	1	0	1	1	https://mohistory.org/visit/accessibility	03-10-21
Museum of Science and Industry	1	0	0	0	0	0	https://www.msichicago.org/visit/accessibility/	03-10-21
Nelson-Atkins Museum of Art	1	1	1	0	0	1	https://www.nelson-atkins.org/accessibility/	03-10-21
Newfields	1	0	0	0	0	0	https://newfields.org/visithings-to-know	03-10-21
Smithsonian Access Smithsonian	1	1	1	1	1	1	https://access.si.edu/	03-10-21
Smithsonian Air and Space Museum	1	0	0	0	0	1	https://airandspace.si.edu/visit/museum-do/accessibility	03-10-21
The Art Institute of Chicago	1	1	1	0	0	1	https://www.artic.edu/visit/accessibility	03-10-21
The Intrepid Museum	1	1	1	1	1	1	https://www.intrepidmuseum.org/access.aspx	03-10-21
The Metropolitan Museum of Art	1	1	1	0	0	1	https://www.metmuseum.org/visit/accessibility	03-10-21
The Museum of Modern Art (New York)	1	1	1	0	0	1	https://www.moma.org/visit/accessibility/	03-10-21
Total	20	9	11	3	3	13		

Figure 1. Disability- related offerings on museum websites. "1" indicates the presence of the support, "0" indicates the lack of the support.

This is also true across many museum programs: the focus is on children, primarily those at younger ages. Of the museums surveyed in the Appendix, only 9 had specific programs for adults (such as sensory-friendly times, touch tours, or other similar programs), while 11 had specific programs of the same types for children. Where programming was not indicated as specific for either adults or children, it was counted in both categories. Many more general supports are often coded towards children – one website described weighted blankets as “security blankets,” a term that evokes Linus from *Charlie Brown*, not an adult that needs a few minutes to collect themselves after an overwhelming time.

There is just one problem with the focus on children in museum accessibility and inclusive practice: most often, people do not grow out of their disabilities. Contrary to the way disability services are provided in the United States, and to how many people think of what “helping disabled people” means, people with disabilities do not stop being disabled when they become legal adults at age of 18 or 21 (depending on jurisdiction). Many encounter what is known as the “services cliff” – the sudden drop in services experienced by people with disabilities once they become adults. As a disabled person, I have experienced this first-hand, losing access to my psychiatrist at 21 due to the public funding of their practice as well as their childhood focus. Most have it worse: in a Drexel University Life Course Outcomes blog by autism researcher Anne Roux, 70% of families of people with autism reported expending “some” or “great” effort to secure services, while one-quarter of youth on the autism spectrum were unable to receive services upon reaching adulthood.³ This gap often leads to poorer social outcomes – the inability to connect to others, or have opportunities to connect that are safe and welcoming.

Museum programming often perpetuates this lack of offerings for disabled people. Adult programming in museums is often geared to the loud, exciting, and frankly inaccessible – happy hours, parties, and most importantly extra expenses that leave people with disabilities, who often are un- or underemployed, unable to be full and equal participants.⁴ Designing programming for and with adults with disabilities – or even adjusting current adult programming to be inclusive – can help reduce the social gaps that people with disabilities face, a need that has widely been noted in research on the subject.⁵ While it may sound difficult to change adult programming to become more accessible, there is a fairly straightforward way to do so: talking with people with disabilities to learn about what they would want.

Talk to disabled people

“Nothing About Us, Without Us” is the slogan of the Autistic Self Advocacy Network and of many self-advocates across the disability community, coming from all backgrounds and needs, for many, many years.⁶ Self-advocates exist for all disabilities, and people with disabilities are able to advocate for themselves no matter their needs. A growing trend in research demonstrates the institutional importance of the voices of people with disabilities. A foundational piece of museum literature, “From Being about Something to Being for Somebody,” by influential museum researcher and writer Stephen Weil, mirrors this: Weil’s argument may not be specifically about disability, but it makes a similar claim.⁷ The work that museums do is for people and must be participatory in nature, and this includes anti-ableism; this work is to make people with disabilities feel welcome in the museum world, and more broadly make museums for

people with disabilities. Unfortunately, the body of research on the power of participatory research and practice in museums with regard to disabled people is relatively recent and limited in scope, since few museums are at a point where people with disabilities have a chance to be collaborators in programming.⁸ Meanwhile, researchers from other academic specialties have written extensively on this subject. Disability researchers Milner and Frawley's 2018 article, "From 'on' to 'with' to 'by,'" provides an academic view of the importance of including people with disabilities as decision-makers in research activities and as co-researchers.⁹ By bringing in people with disabilities as co-researchers, Milner and Frawley were able to gather data that may normally be left out by researchers, and invite people with disabilities to fully be a part of the research process, something that is often overlooked in academia.¹⁰

That this article is part of a special issue, and that accessibility and anti-ableism issues in museum research are not routinely published, highlights another reality: people with disabilities often feel left out of institutional practice. Once again, views from the community on their interactions with research institutions provide a glimpse into institutional practice. In disability and ethics research conducted in McDonald et al.'s "You Can't be Cold and Scientific," people with intellectual and developmental disabilities, alongside family members and service providers, were interviewed about their feelings about participation in research."¹¹ The participants describe their lack of trust in institutions and research situations. Past experiences had made them feel they needed to be wary of researchers, as they may have their trust violated.¹² Museums, as institutions that may unintentionally cause harm, can often create similar situations and violate the trust of people with disabilities. For example, I often have to bring a significant number of things with me to museums – I need clunky, bulky headphones to cancel out noises, as well as to play music to support my recovery. I have been told at some institutions that bags were not allowed. In one case, a guard began lecturing me on every rule the institution had, just because I was wearing a backpack on my back instead of my front, as the institution required. Not only was I on a date at the time and humiliated personally, but it was loud enough for others to hear. It took me a year to feel comfortable enough return to this institution, despite the fact it is a favorite of mine, and still took significant mental energy to prepare, knowing I might have similar experiences just for being disabled.

In McDonald et al., three individuals with intellectual disabilities shared similar sentiments, revealing a similar lack of respect in more general disability research. These three people shared that respect was an important part of building trust with disabled communities.¹³ Milner and Frawley argue that trust is something that needs to be built up over time, with work and a dialogue between participants.¹⁴

It is important to remember that the lack of trust comes in part from historical trauma. Medicine and research have been responsible for many atrocities against people with disabilities, such as eugenics and forced sterilization and medical experimentation, some of which continue to this day.¹⁵ Museums have their own history of harm done to people with disabilities, such as the display of people with disabilities as circus "freaks" or oddities, as discussed in research conducted by Sandell et al.¹⁶ People with disabilities have, over the years, found themselves punched down at by museum policy, practice, and behavior. The field of disability research, which has its own history of atrocity against people with disabilities, can help point the way forward.

Perhaps the most important way that museums have centered their accessibility practice on the experiences of people with disabilities is by developing advisory councils. In the study of 20 museum websites, three listed advisory groups as along with ways to engage with those groups. This is an appallingly small proportion of museums publicly seeking out the input of people with disabilities publicly.¹⁷ Having people with disabilities as public advisors is incredibly important. Not only does it tell people with disabilities considering your museum that you value them, but it also shows those advisors that you value their input. I have had excellent experiences with two institutions that have sought my advice. The first, the Children's Museum of Indianapolis, has brought me into many advisory roles. These include making suggestions for social narratives, as well as more formal advisory positions both as an expert with lived experience and expert with professional and research experience.¹⁸ The former, earlier in my career, provided personal satisfaction; the idea that they took my advice to give a visual representation of what a 6-foot distance means in their COVID-19-focused social narrative, and to include a picture of their mascot, Rex, waving on a page that said "we hope to see you soon," was amazing to me at that stage of my career, both as a self-advocate and emerging museum professional. The fact that the Children's Museum of Indianapolis has both taken my concerns and suggestions seriously and provided me compensation for my time has shown me that my experience is legitimately valued. I have had a similar experience with Access Smithsonian's advisory groups. While I am relatively new to participation there, they always offered compensation prior to my acceptance of any opportunity to offer them feedback as a person with autism, as well as low pressure regarding my participation. In both situations, I have not felt like I needed to speak for every person with autism or with a disability – just from what I knew and have experienced. The pressure I have felt in other situations to represent beyond my ability was not there, something that should inform other advisory councils or groups. This is what makes me want to devote my time and energy to supporting a program, not just as a person with a disability, or researcher, but as a human. It is what makes me feel like they care about me and my needs.

In the development of these advisory groups, it is important to remember that people with disabilities have just as much expertise as an art conservator or evaluation specialist. Sharing lived experience that cannot be replicated is work – a type of work that often remains unpaid and unappreciated. People with disabilities are often unfairly tied to the work of anti-ableism, even if they are not interested in doing it. DEAI programs do value lived experiences, but in a way that forces marginalized groups to do the work of making change from outside of an organization, or from within an organization in a way outside of their job responsibilities, and often without compensation for the work. While the means to give high levels of compensation may be limited by budget, as with any other expert consultant, it must be a priority to make sure that people with disabilities are given some sort of compensation, even if it is just a membership. People with disabilities already often lack the financial means to visit museums due to the higher rate of unemployment they face, and museums can be expensive, so even offering a membership can help.¹⁹ Compensation recognizes that museums benefit tremendously by developing authentic relationships with people with disabilities as advisors. Trust is gained, and the authentic experiences, needs, and desires of people with disabilities come to the forefront in a way that cannot otherwise be done. This is how

ableism is fought most effectively – not only with a program, or training on disability, but by actively connecting to people with disabilities themselves and giving them the chance to make a real impact on the organization in the long term – not just for a single event.

Do not sweat the small stuff

Non-disabled people have many concerns when involving people with disabilities – using the right language, making the right accommodations, and most of all trying to be “perfect.” Winston Churchill put it well when he said “perfection is the enemy of progress.” Take the very recent example, published by the Pew Research Center in August 2020, that people who identify as Hispanic/Latino overwhelmingly do not use the term *Latinx* to self-identify.²⁰ In fact, just 3% use the term, and a majority do not believe it should describe the population. However, in museum discourse, the term “*Latinx*” has grown to occupy a prominent position. This could potentially alienate the intended audience, despite the intention to be perfectly inclusive.

The same risk exists with people with disabilities, beyond the realm of language. Staff without a background in designing experiences for people with disabilities can be paralyzed by the fear of doing something wrong. I have felt this way in some of my own programming and design. In one instance, I was working with a museum where I was given tasks to help develop a social narrative. This is a project that I have researched and completed before, for many different groups. Despite my expertise, the narrative had to be relayed through the museum’s marketing department. They were easy and helpful to work with, but despite the design pattern I provided, the need to meet a strict marketing plan, review what I had written, and design it to their internal specifications required additional time that prevented the support from being given to those who needed it earlier.

Even so, most people with disabilities will be glad you are doing something, even if it is not perfect. If you have included people with disabilities in your process, and made decisions centered on their needs, that will make most mistakes – forgetting to use identity-first language for someone who identifies as autistic instead of a person with autism, accidentally using a graphic with low levels of contrast, or other small issues – less important. The point of anti-ableism is not a perfect program or set of supports. It is to be the most inclusive and welcoming institution possible, and striving for improvement at every turn.

Try new things

In my brief survey of 20 museums, most supports described were the same. The posted information was typically equivalent to saying that the defined parts of the ADA were met. Most kids’ programs were quiet times for people with autism, coded to focus on families, with lights and sounds lowered or eliminated. For adults, touch tours for people who are blind or have low vision and adult art classes for people with autism were common, as well as dementia programming focused on object interaction. This pattern held across all the websites surveyed (see the Appendix).

The ADA, America’s law supporting people with disabilities in public places, is a national law, and so rightly the ADA-compliant information is going to be the same across the country. However, every children’s program with autism was about lessening the experience – taking away things like light and sound that are otherwise a part of the

experience. These are the quiet hours, sensory playtimes, and other “autism friendly” experiences across the country, in museums from the Met to the Field Museum. The adult programs, while likely having slightly different flavors based on instructors and museum objects, are frankly in one of two categories: an adult version of the same sensory-friendly time, or an art creation program. Some museums have both, such as the Met; others may simply have adult times at their institutions, such as the Smithsonian.

While this makes it so that a program consistently operates a certain way, offering a level of comfort for people with disabilities, it also means that there is nothing new for people with disabilities. Even if the theme of an art program changes, it is still a similar art program. People with disabilities are just that: people, who have disabilities. Often programming gets reduced to the fact that it must support the disability aspect, while not focusing on the people aspect. Other programs at museums, such as days centered on specific topics with vendors and special activities, are different each time in a fundamental way. Why not do the same for your disability programs? Why not design sensory-friendly activities centered around a temporary exhibit, so that people who seek sensory engagement can have it? Why not offer “behind the scenes” touch tours that non-disabled visitors can take as well? Why not be creative and offer new kinds of programming that have never been seen before?

It is not an impossibility – many museums have innovated in accessible programming in the past, and many will continue to innovate. The Met, for example, has offered courses across the lifespan for autistic visitors, and has seen people grow up through their programs. The Eiteljorg Museum, through a collaborative partnership with the Indiana School for the Blind and Visually Impaired, offered *Please Touch!*, an exhibit about the works and life of Native American artist Michael Naranjo, who is blind, and was intended as an art exhibit in a traditional, mainstream art museum that was as meant to be touched as it was to be looked at. Museums have an opportunity to be creative with their collections, and must take that creativity into account when supporting people with disabilities.

Avoid performative accessibility

Slow, solid work changes attitudes. Constant exposure to new ways of thinking, new ideas, and the awareness that your institution is doing the good work of accessibility will help encourage long-term change. Too often, organizations only offer performatively accessible programs. These are not inclusive, nor anti-ableist – they do not work to change the structure of power that negatively affects disabled people. Of the organizations surveyed for this paper, for example, all mentioned something about meeting the basic guidelines of the ADA. However, few offered anything beyond the programs and supports that met the basic guidelines of compliance such as wheelchair access and presence, service animal acceptance, the ability to get sign language interpretation if reserved ahead of time, or offered other pre-visit materials as static support. While more than half, 13 out of 20, offered “uncommon” supports, most of these were static supports such as assistive technology at a desk, or mobile applications; few mentioned inclusive programming or opportunities for programs that were designed with disability needs in mind. If your institution starts with something massive, and assumes because it

went well, they do not need to reconsider accessibility or inclusion but only run more of that program or provide more of that support, you are doing performative accessibility. Not every access need requires a massive program. For someone who is disabled, performative accessibility is easy to see, and makes your institution look worse in the long run. An organization I was working with very closely purchased a contract with AccessiBe, a service that provides a widget that is supposed to make a website more accessible. Despite my connections to many parts of the organization and my service as an advisor, I was not involved in this decision. Many in both legal and disability circles have decried the company, and those like it, as many self-advocates find is not truly accessible and can make a website even less accessible.²¹ When I brought this to the attention of staff, no change could be made due to the contract.

Conclusion

I have seen many of these attitude changes take place myself. I have watched the Children's Museum go from having few supports for people with autism to developing clear plans to develop accessible exhibits. I have seen the Eiteljorg Museum in Indianapolis, where I did my internship for my Master's, expand offerings into more permanent institutional changes, such as the first permanent quiet room I know of in the United States. I have seen how even the largest museums, such as the Children's Museum of Indianapolis, have built up stronger access programs with the help of people with disabilities. Those who are just starting down the path, such as the Indiana State Museum, one of my longest partners, have taken massive strides towards anti-ableist practice simply by listening to the voices of people with disabilities, and working to be better. In all of these institutions, and many more, I have seen the principles described in this article being put into action. Each museum is different, and each cultural institution is different. But each has found ways to support people with disabilities in their own unique and powerful way.

In being anti-ableist and truly inclusive, most institutions do not even know where to start. The five principles of this paper – that accessibility is not just for children, that including people with disabilities in your process provides opportunities to help promote inclusion within your organization, that the minutiae are not as important as building bonds, that being creative and trying new types of initiatives and programming will help promote anti-ableist behavior, and that avoiding performative accessibility makes room for stronger institutional initiative – provide an excellent way to start the work of taking your organizational culture from that of legalistic access to true anti-ableism. While there may be many steps in the journey, *how* an institution gets there is the most important. It is attitude, not your activities, that makes your museum more inclusive.

Notes

1. Langa et al., "Improving the Museum Experiences of Children"; Cho and Jolley, "Museum Education for Children with Disabilities"; Lurio, "Engaging Children with Autism at Historic Sites"; Greenberg and Levinsky-Raskin, "Supporting Transitions."
2. Greenberg and Levinsky-Raskin, "Supporting Transitions."
3. "Falling Off The Services Cliff."
4. Bolton et al., *Policies for Increasing Employment*.

5. Eaves and Ho, "Young Adult Outcome of Autism Spectrum Disorders"; Wyman and Claro, "The UCLA PEERS School-Based Program"; Blazer and Research Services Miami-Dade County Public Schools, *Review of the Research on Inclusive Classrooms*.
6. "Autistic Self Advocacy Network – Home." The term seems to originate, according to James Charlton's aptly named *Nothing About Us, Without Us* (1998), in the disability rights movement of South Africa.
7. Weil, "From Being about Something to Being for Somebody."
8. Seale et al., "A Participatory Approach"; Rix et al., "Emergent Analysis and Dissemination".
9. Milner and Frawley, "From 'on' to 'with' to 'by'."
10. Ibid.
11. McDonald et al., "You can't be cold and scientific".
12. Ibid.
13. Ibid.
14. Milner and Frawley, "From 'on' to 'with' to 'by'".
15. Mitch Smith, "Justice Department Investigates Experiments"; Ilyes, "Psychology's Eugenic History."
16. Sandell et al., "In the Shadow of the Freakshow." Comment: <http://www.dsqsds.org/>.
17. Please note, that this research is not intended to imply that people with disabilities are not sought for advice at these museums or other museums, however, only that there is no public acknowledgement of those who are spending their time and effort to support these museums.
18. Social narratives, also known as social stories, are a kind of support used to help autistic people understand social situations. Using a visual format to show the components of a social situation, for example a museum visit, the intent is to help establish the context of a social situation. Often they are similar to comic books or story books.
19. Alicia Bolton et al., *Policies*.
20. Noe-Bustamante, Mora, and Lopez, *About One-in-Four U.S. Hispanics Have Heard of Latinx*.
21. Roselli, "#accessiBe Will Get You Sued"; Glaser, "Blind People, Advocates Slam Company Claiming to Make Websites ADA Compliant."

Disclosure statement

No potential conflict of interest was reported by the author(s).

About the author

Ross Edelstein is a Special Education PhD Student at Indiana University and a Graduate Assistant at the Eppley Institute for Parks and Public Lands. He has a Master's in Museum Studies from Indiana University – Purdue University – Indianapolis, and has worked with many museums in the Indianapolis area to help promote accessibility. His research primarily focuses on cultural accessibility, with a particular emphasis on how institutions can support people with autism. He has an extensive background in research, training, and advocacy. He is also a person with autism.

Bibliography

- "Access+Mobility." The Glazer Children's Museum. Accessed October 3, 2021. <https://glazermuseum.org/mobility>, 2021.
- "Access Smithsonian." Access Smithsonian. Accessed October 3, 2021. <https://access.si.edu/>, 2021.
- "Accessibility." The Chicago History Museum. Accessed October 3, 2021. <https://www.chicagohistory.org/visit/accessibility/>, 2021.

- "Accessibility." The Metropolitan Museum of Art. Accessed October 3, 2021. <https://www.metmuseum.org/visit/accessibility>, 2021.
- "Accessibility – Museum in Dc." The Smithsonian National Air and Space Museum. Accessed October 3, 2021. <https://airandspace.si.edu/visit/museum-dc/accessibility>, 2021.
- "Accessibility & Services." The Eiteljorg Museum. Accessed October 3, 2021. <https://eiteljorg.org/policies/accessibility-services/>, 2021.
- "Accessibility and Language Assistance at the Museum." The American Museum of Natural History. Accessed October 3, 2021. <https://www.amnh.org/plan-your-visit/accessibility-language-assistance>, 2021.
- "Accessibility and Programs." The Nelson-Atkins Museum of Art. Accessed October 3, 2021. <https://www.nelson-atkins.org/accessibility/>, 2021.
- "Accessibility Resources." The Intrepid Museum. Accessed October 3, 2021. <https://www.intrepidmuseum.org/access.aspx>, 2021.
- "Autistic Self Advocacy Network – Home." Autistic Self Advocacy Network. Accessed October 8, 2021. <https://autisticadvocacy.org/>, 2021.
- Blazer, Christie, and Research Services Miami-Dade County Public Schools. *Review of the Research on Inclusive Classrooms: Academic and Social Outcomes for Students with and without Disabilities; Best Practices; and Parents' Perceptions of Benefits and Risks. Information Capsule. Volume 1701*. Research Services, Miami-Dade County Public Schools. 2017. <https://proxyub.uits.iu.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=eric&AN=ED587808&site=eds-live&scope=site>.
- Bolton, Alicia, Dahlia Shaewitz, Mindy Larson, Workforce National Collaborative on, and Youth Disability for. *Policies for Increasing Employment among Opportunity Youth with Disabilities. Dialogue Report*. National Collaborative on Workforce and Disability for Youth. 2019. <https://proxyub.uits.iu.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=eric&AN=ED598527&site=eds-live&scope=site>.
- Cho, H., and A. Jolley. "Museum Education for Children with Disabilities: Development of the Nature Senses Traveling Trunk." [In English]. Article. *Journal of Museum Education* 41, no. 3: (2016): 220–229. <https://doi.org/10.1080/10598650.2016.1193313>. <https://proxyub.uits.iu.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=edselc&AN=edselc.2-52.0-84978829350&site=eds-live&scope=site> <https://www.tandfonline.com/doi/full/10.1080/10598650.2016.1193313>.
- Eaves, L. C., and H. H. Ho. "Young Adult Outcome of Autism Spectrum Disorders." *Journal of Autism & Developmental Disorders* 38, no. 4 (2008): 739–747. <https://doi.org/10.1007/s10803-007-0441-x>. <https://proxyub.uits.iu.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=105733599&site=eds-live&scope=site> <https://link.springer.com/content/pdf/10.1007/s10803-007-0441-x.pdf>.
- "Falling Off the Services Cliff." Access to Services, Drexel University, Updated August 31, 2015. Accessed 10/8/2021, 2021. <https://drexel.edu/autismoutcomes/blog/overview/2015/August/falling-off-the-services-cliff/>.
- Glaser, April. 2021 "Blind People, Advocates Slam Company Claiming to Make Websites Ada Compliant." Online Article. (May 9, 2021). <https://www.nbcnews.com/tech/innovation/blind-people-advocates-slam-company-claiming-make-websites-ada-compliant-n1266720>.
- Greenberg, Aliza, and Sheri Levinsky-Raskin. "Supporting Transitions: Cultural Connections for Adults with Autism Spectrum Disorders." *Journal of Museum Education* 42, no. 4 (2017): 332–344. <https://doi.org/10.1080/10598650.2017.1376268>. <https://proxyub.uits.iu.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=asu&AN=126590996&site=eds-live&scope=site> <https://www.tandfonline.com/doi/full/10.1080/10598650.2017.1376268>.
- Ilyes, E. "Psychology's Eugenic History and the Invention of Intellectual Disability." [In English]. Article. *Social and Personality Psychology Compass* 14, no. 7 (2020). <https://doi.org/10.1111/spc3.12537>. <https://proxyub.uits.iu.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=edselc&AN=edselc.2-52.0-85086226873&site=eds-live&scope=site>.

- Langa, Lesley A., Pino Monaco, Mega Subramaniam, Paul T. Jaeger, Katie Shanahan, and Beth Ziebarth. "Improving the Museum Experiences of Children with Autism Spectrum Disorders and Their Families: An Exploratory Examination of Their Motivations and Needs and Using Web-Based Resources to Meet Them." *Curator: The Museum Journal* 56, no. 3 (2013): 323–335. <https://doi.org/10.1111/cura.12031>. <https://proxyiub.uits.iu.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=asu&AN=89024606&site=eds-live&scope=site>.
- Lopez, Luis Noe-Bustamante, Lauren Mora, and Mark Hugo. *About One-in-Four U.S. Hispanics Have Heard of Latinx, but Just 3% Use It*. Race & Ethnicity, Pew Research Center. <https://www.pewresearch.org/hispanic/2020/08/11/about-one-in-four-u-s-hispanics-have-heard-of-lat-inx-but-just-3-use-it/>, 2020.
- Lurio, Ansel. "Engaging Children with Autism at Historic Sites: Developing an Audience-Appropriate Curriculum." *Journal of Museum Education* 41, no. 3 (2016): 165–173. <https://proxyiub.uits.iu.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=eric&AN=EJ1128190&site=eds-live&scope=site> <https://doi.org/10.1080/10598650.2016.1193315>.
- McDonald, K. E., N. M. Schwartz, C. M. Gibbons, and R. S. Olick. "'You Can't Be Cold and Scientific': Community Views on Ethical Issues in Intellectual Disability Research." [In English]. Article. *Journal of Empirical Research on Human Research Ethics* 10, no. 2 (2015): 196–208. <https://doi.org/10.1177/1556264615575512>. <https://proxyiub.uits.iu.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=edselc&AN=edselc.2-52.0-84960477978&site=eds-live&scope=site>.
- Milner, Paul, and Patsie Frawley. "From 'on' to 'with' to 'By': People with a Learning Disability Creating a Space for the Third Wave of Inclusive Research." *Qualitative Research* 19, no. 4 (2019): 382–398. <https://doi.org/10.1177/1468794118781385>. <https://proxyiub.uits.iu.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=138097902&site=eds-live&scope=site> <https://journals.sagepub.com/doi/10.1177/1468794118781385>.
- Roselli, Adrian. "#Accessibe Will Get You Sued," June 29, 2020, <https://adrianroselli.com/2020/06/accessibe-will-get-you-sued.html>.
- Rix, Jonathan, Helena Garcia-Carrizosa, Simon Hayhoe, Jane Seale, and Kieron Sheehy. "Emergent Analysis and Dissemination within Participatory Research." Article. *International Journal of Research & Method in Education* 44, no. 3 (2021): 287–302. <https://doi.org/10.1080/1743727X.2020.1763945>. <https://proxyiub.uits.iu.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=eft&AN=150165026&site=eds-live&scope=site>.
- Seale, J., H. Garcia Carrizosa, J. Rix, K. Sheehy, and S. Hayhoe. "A Participatory Approach to the Evaluation of Participatory Museum Research Projects." [In English]. Article. *International Journal of Research and Method in Education* 44, no. 1 (2021): 20–40. <https://doi.org/10.1080/1743727X.2019.1706468>. <https://proxyiub.uits.iu.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=edselc&AN=edselc.2-52.0-85077881472&site=eds-live&scope=site>.
- Sandell, Richard, Annie Delin, Jocelyn Dodd, and Jackie Gay. "In the Shadow of the Freakshow: The Impact of Freakshow Tradition on the Display and Understanding of Disability History in Museums." *Disability Studies Quarterly* 25, no. 4 (2005). <https://doi.org/10.18061/dsq.v25i4.614>. <https://proxyiub.uits.iu.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=mzh&AN=2005873463&site=eds-live&scope=site> Comment: <http://www.dsq-sds.org/>.
- Smith, Mitch. "Justice Department Investigates Experiments on People with Disabilities." *The New York Times*. (December 13, 2019). Accessed October 8, 2021. <https://www.nytimes.com/2019/12/13/us/iowa-human-experiments.html>.
- "Visit." Newfields. Accessed October 3, 2021. <https://discovernewfields.org/visit#things-to-know>.
- "Visitor Information." The Illinois State Museum. Accessed October 3, 2021. <http://www.illinoisstatemuseum.org/content/ism-springfield-visitor-information>.
- Weil, Stephen E. "From Being About Something to Being for Somebody: The Ongoing Transformation of the American Museum." In *Reinventing the Museum: The Evolving*

Conversation on the Paradigm Shift, edited by Gail Anderson, 170–190. Lanham, MD: AltaMira Press, 2012.

Wyman, Joshua, and Anthony Claro. “The UCLA Peers School-Based Program: Treatment Outcomes for Improving Social Functioning in Adolescents and Young Adults with Autism Spectrum Disorder and Those with Cognitive Deficits.” *Journal of Autism and Developmental Disorders* 50, no. 6 (2020): 1907–1920. <https://proxyiub.uits.iu.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=eric&AN=EJ1255403&site=eds-live&scope=site> <https://doi.org/10.1007/s10803-019-03943-z>.

Appendix: Brief Survey of Museum Websites

This brief survey of museum websites was developed in conjunction with the author’s own experience. Museums in this survey were not scientifically chosen; rather, they were chosen based on the author’s awareness of their resources prior to writing the paper, as well as based on their ability to support access programming. The information in this survey should be considered informal, and not a statistically representative set of data, however, it may serve as a tool to compare what your museum might include with what other museums do or do not include on their websites. It sought information in six categories: whether there were any programs or supports for people with disabilities, whether there were any adult oriented programs, whether there were any child-oriented programs, whether there was a listed advisory group, whether that advisory group provided information on joining said group, or if there were any “uncommon” supports. Each category will be defined below. All sites were accessed in the fall of 2021. Institutions that have each kind of program or support will be marked with a 1, and those that do not will be marked with a zero.

- The author has either been previously employed by or currently works with the Children’s Museum of Indianapolis, the Eiteljorg Museum, the Indiana State Museum, and Access Smithsonian on accessibility programming or support as a community member.
- The author has connected with the Field Museum, the Glazer Children’s Museum, the Indiana Medical History Museum, Newfields, the Intrepid Museum, and the Metropolitan Museum of Art through his work during his Master’s program, but has not actively worked for them in creating any programming for their organizations.
- The author, through his own experiences as a visitor of museums and lover of museums, as well as professional knowledge of the museum industry, selected the Chicago History Museum, Gateway Arch National Park, the Getty Museum, the Illinois State Museum, the Museum of Science and Industry, the Nelson-Atkins Museum of Art, the Smithsonian Air and Space Museum, The Art Institute of Chicago, and the Museum of Modern Art (New York) as large museums with a high likelihood of providing support for disabled visitors.
- Programs or supports for people with disabilities are any sort of action taken by the museum to promote accessibility, from curb cuts to inclusive programming, as listed on the website.
- Programs, for both adults and kids, are defined as any event led by museum staff held on a regular or semi-regular basis to support people with disabilities. These can be tours offered regularly, special events such as days celebrating disability, or special classes or workshops. Programs that have to be triggered by people with disabilities, such as ASL tours offered on request, were not counted, as they are not regular offerings of the museum with designated dates and times, and only happen when asked for.
- Adult programs were defined as any program that specifically mentioned adults (18+) or any synonyms, or uses language coded towards adults, such as mentioning the presence of alcohol.
- Programs for kids are defined as any program that specifically mentions kids (under 18), or is coded towards kids, such as involving characters from children’s television or literature.
- Programs that did not have any specifically-coded language were assumed to be for all ages, and counted towards both groups.

- Advisory groups are counted as an external group of people with disabilities who are listed as being regularly consulted for support.
- “Uncommon” supports or programs are any program beyond basic accessibility. ASL tours offered upon request, curb cuts, the presence of wheelchairs or physical access, captioning, and assistive listening devices are required by law, and meet the basic access needs of many people. Programs utilizing new technologies, offer inclusive experiences, or otherwise go beyond the requirements of federal and state accessibility laws are considered “uncommon.”
- Information about access dates and specific websites used is included in the paper’s bibliography.