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ABSTRACT
Museums and disabled people can create co-designed spaces that lead to a more authentic agency for museums as well as their audiences. Together they can center disability as significant program and exhibition content, include disability representation and perspectives, and ensure that environments — physical, communication, sensory, and attitudinal — are accessible, respectful, and welcoming. This article reports on survey responses by disability community members and their allies when asked to imagine museums as spaces where disabled people can find common ground and discuss important topics. It also provides guidance to museum educators about ways to open new conversations with their local disability communities, advocate for change within the museum, bring disabled people into their museum’s leadership, staff, and volunteer corps, and strive to provide in museums a space, as described by journalist s.e. smith, “where everyone has that soaring sense of inclusion.” [smith, s.e. “The Beauty of Spaces Created for and by Disabled People.” in Disability Visibility: First Person Stories from the Twenty-First Century, edited by Alice Wong, 274. New York: Vintage Books, 2020.]

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Introduction
In their essay, The Beauty of Spaces Created for and by Disabled People,1 journalist s.e. smith eloquently describes “A Crip Space” as a place where disabled people experience a “sense of unexpected and vivid belonging.” It is a physical or emotional space where disabled people feel truly welcomed, not just tolerated, and provides a platform that is “necessary for people to have intra-community conversations and … create[s] a safe environment for talking through complex issues.”2 This article poses the necessary question and challenge for museum educators: Could and should such a space be cultivated in museums and, if so, how can that happen?

U.S. museums have a long and uneven history in their relationship with disabled people. Starting in the nineteenth century, people with disabilities were exhibited in freak shows and as medical anomalies. During the 1960s and 1970s, reinforced by disability rights activism demanding the signing of regulations for the Rehabilitation Act of 1973’s Section 504,3 there was a shift to accommodating disabled people as museum visitors instead of derogatorily displaying them as content. “Special” programs were developed, but they were segregated, limited in number and content scope, and inconsistently offered. With the passage of the Americans with Disabilities Act of 1990 and the authoring of the Principles of Universal Design in 1997,4 the 1990s and early 2000s saw a powerful
move toward accessibility and universal/inclusive design of facilities, exhibitions, and programs.

Today a resurgent awareness of the incontestable requirement for diversity, respect, and dignity for every human being appears in museum mission statements across the country. DEAI — Diversity, Equity, Accessibility, and Inclusion — is to be addressed in all museums are and do.\(^5\) Too often, however, the inclusion of disabled people is relegated to the “A” for “Accessibility” silo in DEAI and checked off as completed with only selected physical and communications changes. The concepts of social justice and equity are unevenly applied to issues of disability rights. It is past time for a revised understanding that people with disabilities are a vital part of the world’s overall diversity, on their own and as members of every other group defined by society. For a space such as smith describes to grow and flourish, disabled people must lead the conversations about what makes museums truly inclusive and welcoming for them.\(^6\)

In this essay, the authors examine how museums can collaborate with disabled individuals to create physical and emotional spaces that embrace visitors and staff who have disabilities. They began this exploration from the premise that the space’s name, definition, functions, and future must be decided by disabled people — the spaces’ integrity and value must originate from the individuals who will make it happen, guide its implementation, and participate in it.

**Gathering community input**

The authors gathered initial recommendations and reactions through a survey posted on the website of the Institute for Human Centered Design (IHCD) and received in-depth responses from 48 people, most of whom identified as disabled people or non-disabled people with a deep interest in museum accessibility, disability rights, and overall advocacy for full inclusion for disabled people.\(^7\) The authors accepted all responses and directly incorporated as many as possible into this report, either in text or as word graphics.

As part of the survey process, the authors also conducted video conference interviews with six individuals with profound and varied experience in disability rights advocacy and interest in cultural access: s.e. smith, journalist; Judy Heumann, disability rights leader and activist; Shelby Seier, accessibility consultant; Sandy Guttman, independent curator and art historian; Robin Marquis, artist and museum professional; and Aimi Hamraie, associate professor. The interviews were structured primarily around the survey questions; however, conversations expanded differently with each interviewee as the authors followed the subject’s thinking and views.

The authors intuitively knew — and had their beliefs confirmed — that this community is diverse in every way, especially in opinions. They did not anticipate consensus on any of the issues, and their hypothesis was quickly confirmed by the responses. By seeking direct feedback from disabled individuals, however, they were rewarded with invaluable insights, rich thinking, and innovative ideas and attitudes.

**A note about language**

Language by and about the community is always evolving. After decades of advocating for person-first language, made most visible by the *Americans with Disabilities Act*
(ADA) of 1990, there is a growing preference by some members of the community to use identity-first or identity-only language (i.e. disabled people, blind individuals, a/Autistics). The authors chose to adopt identity-first language in this survey and article instead of person-first language to respect the activists who birthed and supported this concept of a space where disabled people feel welcomed and comfortable. This choice, however, raised concern among some of our respondents. We intend no disrespect for anyone or their language choices. Language choices may even be seen here as an example of one of the difficult conversations that will occur in and around this defined space.

The survey as posted and distributed to the community

Survey About Museums Designed for and by Disabled People: Responses Requested by September 15, 2021

Dear Colleagues,

We are writing an article for the Journal of Museum Education to imagine museums as spaces where disabled people can find common ground and discuss important topics. We want to address environments of all kinds — not just physical but also sociocultural — that facilitate emotional responses and provide an intangible access to a sense of welcome. These are spaces where disabled people see their perspectives and themselves in exhibitions, research, programming, and the workforce. Spaces that are not only accessible and equitable but are designed for and by disabled people and include people without disabilities. And, we need your help. We are seeking ideas from disabled people to redefine and redesign museum spaces that envelop people at the entrance in the sense of confidence and comfort and reflect their experiences, talents, and knowledge in innovative and vibrant ways.

We think this museum space could become what s.e. smith calls a “crip space.” Smith writes in “The Beauty of Spaces Created for and by Disabled People” that a “crip space is unique, a place where disability is celebrated and embraced” and creates a “sense of unexpected and vivid belonging and an ardent desire to pass this experience along.” It is a space where there is “a communal belonging, a deep rightness that comes from not having to explain or justify your existence.” Smith concludes that there is a need for such spaces where “everyone has that soaring sense of inclusion, where we can have difficult and meaningful conversations.”

We would like to explore possibilities that would make museums beautiful spaces that are by and for disabled people and then shared with people who have just become disabled and are transitioning their identity, people who have disabilities but do not identify as being disabled, and people who do not have disabilities. Perhaps it is or is not called a “crip space.” How could it be best described? It must comply with all legal requirements for accessibility, but what are the characteristics that elevate it to a space for accessing, understanding, and making disability culture? We want to dig deep into people’s thinking and personal experiences about how to design and define those spaces so they are communal for all people with all disabilities and their diverse intersectional identities. A place where you can bring your whole self.

Will you help us build a vocabulary, assemble concepts, imagine environments, and define the essence of a museum that will give everyone a soaring sense of inclusion, where we can have difficult and meaningful conversations?
Please answer as many of the questions below as you would like. If there are others you think we should ask, please include those with your responses. And, if you would prefer to talk through your answers with us, please leave your name and contact information and let us reach out to you.

Thank you so much for helping us explore this topic. We want to share your and our ideas with museum educators and other museum leaders widely to push the parameters of the meaning of an inclusive and welcoming museum space.

Best regards,
Beth Ziebarth, Access Smithsonian
Jan Majewski, IHCD

What the respondents told us

What are your thoughts on whether a museum should be a “unique place where disability is celebrated and embraced”? To what extent are museums valid or appropriate places to have difficult and meaningful conversations?

Respondents stated that museums should not be unique in their role of celebrating the lives and contributions of disabled people (many other organizations could and should assume like roles), but they should take on that role and are appropriate places to meaningfully challenge misinformation and facilitate discussions about topics honestly and in depth.

Selected respondent comments:

Disability deserves to be celebrated and embraced in museum spaces, both because museums have contributed to harm against the disabled community and because disabled people are among the patrons of museums. In the same way that women and people of color benefit from seeing themselves reflected in exhibits, disabled people do as well. Additionally, because many museums in the past have presented inaccurate and stereotyped views of disability, modern museums have a responsibility to do better. - C.W.

Museums are a trusted place of education and belonging, and part of that education should be teaching visitors about ways of living other than their own. By embracing and ESPECIALLY celebrating disability, museums can normalize for able-bodied visitors the experience of disabled visitors. Museums should entertain but also challenge their visitors and should ABSOLUTELY be a place for difficult and meaningful conversations. - M.P.

Disability rights leader Judy Heumann stated that museums must make the case why they should be a place for difficult conversations. She feels museums can offer disabled people an “out-of-the-box” opportunity to think in a way they have not before. Critical discussions among disabled people can occur on topics that positively or adversely impact them.

Art Museum Curator Sandy Guttman said “museums are safe places for unsafe conversations.” Museums can then encourage a level of community engagement that becomes a model to be adopted and adapted by other types of organizations.

Do you think a museum COULD be such a space? What might make it possible or impossible to make a museum function in this new and richer way?
Most respondents believe museums could become such welcoming spaces, in accordance with their missions of community education and cultural inclusion. However, work must first be done to make museums fully accessible, which requires consensus with the diverse disability community about what that means and how to implement it. Vital to many is the effort to make museums places that neither tokenize disabled people nor focus solely on disability, to the point of segregation from the rest of the community.

Selected respondent comments:

I believe there are two main factors in this: 1. how the local community perceives and engages with the museum, and 2. whether the museum organization/staff are willing and able to function as this kind of space. Both must be in alignment and attempting to force one or the other may end in poor or negative results, as opposed to positive change. - M. M.

By having disability justice-centered framework and focused conversations and representation (disabled BIPOC) on planning boards and implementation at all phases. This would of course include apparent, non-apparent, chronic illness folx [sic]. Starting with most-marginalized who overlap and intersect with all other identities covers such a wealth of topics with range, nuance, and complexity. - H.W.

Yes, it could. It would take extensive re-thinking on how exhibits, art, what-have-you, are presented. It would be best to begin at the end result—imagining ALL the possible ways an individual could experience an exhibit or a work, no matter what an individual’s limitations might be. Then find an experience to match each individual’s multiple capabilities. - R.L.

I believe so, though it may take a radical upheaval of everything we know about museums. First, museums must make amends. Museums full of architectural barriers were exclusionary to the disabled population at the time of [those] building’s [sic] creation. How can museums make up for that? Perhaps a series of acknowledgements. Perhaps the physical infrastructure that’s inaccessible can be archived into the museum’s collection. - S.S.

What is the experience of a museum designed by and for disabled people? What are the most important factors of this empathetic museum space?

Journalist s.e. smith says that an inclusive museum space is where people can see themselves, and there is a sense of “I see you, you see me” in a shared community. Artist Robin Marquis wants a place for sharing disabled people’s own stories with one another and with people without disabilities. “Crip becomes a conversation, not a name,” Marquis said. For most respondents, this is an accepting, flexible, inclusively designed and conducted space where everyone feels they have an equal place to engage, learn, enjoy, and relax.

Selected respondent comments:

A museum designed by and for disabled people tells us that we are not only welcome, we are important. “Reasonable accommodations” are the bane of every disabled person’s existence; they mean we are a hassle, a problem to be gotten around. We should START from an accessible place, and communicate that disabled bodies are important from the beginning. I can only feel that I belong if I feel that I have been prioritized. - M.P.

In terms of the content of the exhibits themselves, they should acknowledge the contributions of people with disabilities. Artists and historical figures who were disabled should be discussed as whole people with disabilities. Efforts should be taken to avoid tired, ableist narratives such as “the tortured mentally ill artist” and “the individual who succeeded despite their disability.” - C.W.
A space where disability issues become a non-issue. - J.B.

Such a space would be designed to give visitors experiences they do not have on a regular basis. For example, as a wheelchair user I am always looking up; I would design a space that gives people a reason to look down. - A.A-M.

Providing the sense of “equal,” no more, no less, is meaningful to this audience. - J.O.

Putting the needs of PWD [people with disabilities] first and not a side or last-minute addition. - E.B.

When it is designed by disabled people, they already have the knowledge of things that need to be fixed. - M.S.

I imagine it would be a place of respite and profound relief. Disabled people are the best at accommodating other disabled people. - S.S.

How is this empathetic space different from what you experience in museums today?

C.M.’s comment summarizes the general assessment by respondents of museum experiences today: “More museums are beginning to understand that pwd [people with disabilities] are an important [part] of their visitorship and employee base, but still [have] a long way to go.”

Many respondents painfully explained they have not yet experienced even basic accessibility in many museums they have visited. Integrated accessible entrances, seating, tactile experiences, accessible wayfinding, auxiliary aids and services that do not require extended advance planning and request, and staff that offer welcome rather than a sigh of burden (real or perceived by the visitor) at having to provide any accommodation are not predictably found in U.S. museums. There is a strong, pervasive sense by disabled people of feeling invisible to museums, even as organizations set their DEAI priorities.

Selected respondent comments:

Access in museums today is too often the responsibility of the disabled person. Make your interpreter reservations two weeks in advance — no spontaneous dropping in on a program for you (and don’t cancel last-minute, they booked interpreters for you). What do you mean you need an ALD? What’s that? Oh, here they are, looks like they’re broken. Front-line staff aren’t well trained on dealing with disabled visitors and frequently seem to be stressed when we need help. - M.P.

In short, museums have improved over time, but disabled people are still an afterthought in the design process. - C.W.

One of my most frustrating experiences seems particularly emblematic in retrospect: I was at the bottom of a staircase that led to the latest big-name exhibition, sitting next to an unattended chairlift that could not be operated by someone in a wheelchair. - L.S.

Some museums are completely inaccessible as a blind person who ends up just walking in, wandering around for a bit, and then having to leave as no exhibits are understandable without being able to see them. Other museums go the extra mile to make sure every experience is available, while some are somewhere in-between. It would be really nice to be able to walk into a museum and take in the culture on offer on the same level as my sighted peers. - A.J.H.
What would be the first thing you would change in a museum to make you feel like you absolutely belong there?

Most survey respondents insist that museums must significantly and correctly address disability as exhibition and program content with disability representation and perspectives in the contents’ development. A museum with nothing about disability or directly involving no disabled people in its content’s creation is not viewed as a safe space where

*Figure 1.* Survey respondents’ statements flow together to describe the characteristics of a fully inclusive and welcoming museum space for disabled visitors.
complex and honest conversations can take place. But even more strongly, respondents simply want accessibility and respect from museum staff (Figures 1–2).

Selected respondent comments:

Create really good wayfinding [for people who are blind]. - J.D.

A[s] a blind person, tangible 3-D models would be a significant improvement. - G.K.

More places to take breaks. And the ability to carry a small bag with me. I have supplies I need to carry with me and checking my bag is always a pain. - R.P.

To have a museum experience from website to phone inquiry to actual visit that does not require the pwd [person with a disability] to do extra work or sacrifice anything in order to have the full museum experience. - C.W.

The staff - employ more people with disabilities on the front line so that you see yourself reflected there. - C.O.

To be given agency to experience the art in different ways rather than go through a didactic, one-size-fits-all experience. To not assume that I know what I’m seeking. - M.F.

Should it be called a “crip space”? If not, what would you call it?

The authors were advised when they initially considered calling this museum space concept a “crip space,” echoing s.e. smith’s phrase in their essay, that the name may not be acceptable to all or even many of the respondents. This was verified early in the receipt of survey answers. Most people did not want to connect any disability
terms to the space and instead felt the focus should be on what the space is intended to do and how it functions.

Selected respondent comments:

The word “crip” is currently a bit politically charged in disability circles; there is debate about who gets to use it and how in ways that strongly parallel discussion of “queer” in

Figure 3. One of a series of six posters available as a download through an online exhibition about the many and varied roles of disabled people throughout American History.
LGBTQ+ circles. I would therefore prefer terminology such as “disability-centered space,” especially if the museum is not entirely operated by disabled individuals. While I don’t believe the word “crip” is necessarily a word that only disabled people can use, I would argue that its history as an active slur is recent enough that unless everyone involved in the museum was disabled, I would not trust them to understand how to navigate discussions surrounding it with the proper sensitivity. - C.W.

Absolutely. A crip space is where I have my disability acknowledged (I’m not “handi-capable,” thanks, my ears don’t work and my needs met the way I want them met. I don’t want a one-size-fits-all solution; ask me what I need. That’s a crip space to me. - M.P.

Why call it anything special? Isn’t it just space as it should be/could be? - J.D.

I find the term to be controversial. I would call it a universally accessible space. As everyone will either have a disability in their lifetime or know someone who has a disability. In that sense, you’re building this space to be as inclusive as possible. - A.R.

Journalist s.e. smith told the authors that they enjoy confrontation and see value in reclaiming language about disability that has a derogatory connotation to some people. For them, the name should be explained and if it is not used there is a flattening of the purpose of the space.

Professor Aimi Hamraie said “crip space” challenges normalcy.

Artist Robin Marquis said “crip space” is aspirational and vastly different from an accessible space and something a museum must work with the community to achieve. Museums will need to work within their disability communities to understand what they may gain or lose when they use a name like crip space.

The call to action

Museum education is where complex conversations happen and grow into great ideas. Museum educators, public programmers, and docents have been the heart of accessibility and the force behind it for decades. Education departments were responsible for a large proportion of the early grassroots efforts to meet the requirements of Section 504 and to support a prospective audience that was until then, mostly ignored. Staff at museums, National Park Service sites, historic homes, aquariums, and zoos created outreach programs, adapted existing tours, advocated for touch tours, and trained docents to conduct programs that often were designed to make up for inaccessible buildings and exhibitions. Too often, key programming and design decisions were made about rather than by the community and financial support for those efforts was limited to one- or two-year grants. When that funding expired, so did the programs.

While accessibility efforts have struggled through the ups and downs of attention and funding, educators, through public and school programs, online resources, and input into exhibition design, now often focus on meeting this diverse audience where it is. This professional museum force needs to grow and expand its role by fostering and advocating for disability justice by and with disabled people.

As museums focus seriously on the spectrum of issues to be addressed under the mandates of DEAI, now is the time for educators to heed the call to action and give priority to accessibility, inclusive design, and social justice for disabled visitors and staff:
Diversify the education staff to include professionals with disabilities. Reach into the disabled community for paid consultants and contractors as well as advisors and volunteers.

- Develop long-term connections to the community and relinquish as much control as possible to its members to decide what this “space” is and how it functions.
- Advocate within the museum to acknowledge and present the myriad roles disabled people have played in the history, art, science, and culture that museums research, collect, and display.
- Understand that wholeheartedly including disabled people in the museum’s culture benefits every staff member and visitor in sometimes unrecognized ways. For example, one global story today is that temporary and permanent injuries and age-related functional limitations are extremely common in our society. It is not the role of disabled people to demonstrate or educate about their everyday innovations for living with disability; however, all who work and enjoy the museum alongside them accrue understanding and resources to call upon as they continue along their own natural spectrum of ability.
- Ingrain attitude and acceptance of people with disabilities in and outside of the museum and move to growing the “connective tissue,” as respondent H.W. put it, between the museum and the disabled community that will forever enhance a museum’s content and culture.
- Address the “space,” whether onsite, solely online, or hybrid to ensure that all of the baseline accessibility requirements are met and inclusion is designed from conception through implementation.

Accessibility, inclusion, and crip space create a pyramidal welcome for disabled individuals. Legal accessibility requirements are the foundation; universal/inclusive design is the central structure that builds upon that foundation with diverse, user-focused design of places, things, information, communication, and policy, in the widest range of situations without special or separate design; and, co-design, with a significant disability representation, is the apex of this pyramid where people experience a “sense of unexpected and vivid belonging.”

About Access Smithsonian and IHCD

Access Smithsonian has been a resource for the Smithsonian and museums globally since 1978. First known as the Special Education Program in the Office of Elementary and Secondary Education and then as the Accessibility Program, Access Smithsonian is a catalyst for consistent and integrated inclusive design that provides meaningful access to the Smithsonian Institution museums and content for visitors with disabilities.

The Institute for Human-Centered Design is a 43-year-old international education and design non-profit dedicated to enhancing the experiences of people of all ages, abilities, within all intersectional identities, through excellence in design. IHCD works with museums around the globe to design for inclusion in everything they do. Known originally as Adaptive Environments, IHCD was one of the original ten authors of the 1997 Principles of Universal Design.
Notes

2. Ibid., 273.
5. “Diversity, Equity, Accessibility, and Inclusion.”
6. During the April 14, 2021, Smithsonian Associates virtual program Disability Visibility: Intersectionality in Art, Design, and Museums with smith, Alice Wong, disabled activist, writer, and Founder and Director of the Disability Visibility Project, artist Riva Lehrer, and moderator, Beth Ziebarth, Director of the Access Smithsonian office, the discussion turned to Crip Space and whether museums could be such a space. Panelists agreed museums were not yet engaging disabled people on their perspectives and representations in programming even though any museum, whether dedicated to history, art, culture or science, can be inclusive for disabled people.
7. The authors drafted the introduction and questions and asked three colleagues and activists to review the draft. Once the questionnaire’s content was finalized, it was posted on the Institute for Human Centered Design’s (IHCD’s) website in an accessible Google Form. The survey was available on the website from August 10, 2021, to September 15, 2021. The link was emailed to colleagues and friends with disabilities – who then forwarded it to selected advocacy organization sites, social media, and other friends – and sent it to ADA technical assistance sites, cultural access listservs, and the IHCD-Smithsonian user/expert database in both Washington, D.C. and Boston.
8. This and the following four quotations are all from Wong, Disability Visibility, 271–275.

Disclosure statement

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

Notes on contributors

Beth Ziebarth has a personal interest and professional responsibility in advocacy for disabled people. As the director of Access Smithsonian, Beth develops and implements accessibility policy and guidelines for the Institution’s 21 museums, the National Zoo, and 9 research centers, ensuring that the Smithsonian’s 20+ million annual visitors experience a welcoming environment that is inclusive of individuals of all ages and abilities. Her work includes staff training on accessibility and disability topics, facility and program technical assistance, accessibility services, stakeholder engagement, and five signature programs with disabled people.

Jan Majewski is Director, Inclusive Cultural & Educational Projects, at the Institute for Human Centered Design. Her inclusion advocacy is richly informed by lifelong experiences with disabled family and friends. Jan began her career in museums at the Smithsonian as the Coordinator for Special Education in the Office of Elementary and Secondary Education. She later founded the Institution’s Accessibility Program and led the teams that wrote the Smithsonian Guidelines for Accessible Exhibition Design and the docent training manual, Part of Your General Public Is Disabled.
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