

**Art Access: Accommodating Adults with Intellectual Disabilities in the Art Museum**

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THESIS

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## **LIST OF ABBREVIATIONS**

AAIDD	American Association on Intellectual and Developmental Disability
ADA	Americans with Disabilities Act
ADAAA	Americans with Disabilities Act Amendments Act
AFPH	American Federation of the Physically Handicapped
ASL	American Sign Language
CCAC	Chicago Cultural Accessibility Consortium
CITI	Collaborative Institutional Training Initiative
DDA	Disability Discrimination Act
IRB	Institutional Review Board
IQ	Intelligence Quotient
MAC	Museum Access Consortium
MLC	Museum Learners Club
NEA	National Endowment for the Arts
NFB	National Federation of the Blind
OPRS	Office for the Protection of Research Subjects
UIC	University of Illinois at Chicago
UN	United Nations

## **SUMMARY**

A study related to accommodations, or lack thereof, for adults with intellectual disabilities in art museums. Information from existing resources was collected and the research drew on the author's personal and professional experiences working both in museums and with populations of adults with intellectual disabilities.

This study argues that basic accommodations should be made for adults with intellectual disabilities due to the Americans with Disabilities Act, the positive effects museums can have on a person's wellbeing, and the desire for these programs to exist from the community.

This study also acknowledges difficulties of creating these accommodations, such as lack of resources or money, perceived lack of interest from the community, and the lasting stigma that museums are for an elite group of people (i.e. well-educated, white, wealthy).

## Introduction

### Purpose of Study

This project came from a fairly simple assignment in a Museum Collections class. We were instructed to work with a collection that had its foundations in social justice work. I knew I wanted to work with a collection that related to an intellectual or psychological disability. I became aware of an organization called Arts of Life, a studio and gallery space for artists with intellectual disabilities. There, I worked on a storage plan for the studio, but more importantly, I was able to observe how the organization functioned. I was impressed by the breadth of accommodations that were considered and provided. Accommodations went well beyond the standard accessible restrooms and ramps for artists who were wheelchair users; they included a room dedicated to providing the artists with a quiet space to collect themselves if they were overstimulated, called a wellness room, and workshops that promoted self-advocacy. Their Quality Statement states that the organization is committed to “dedication to its artists and excellence in the field of developmental disabilities.”<sup>1</sup>

The Arts of Life is doing great work with accessibility, so I assumed that art museums in the city must be doing the same, as they are both in the nonprofit realm. However, in my searching for these programs, I found myself continually disappointed. Most museums simply had wheelchair accessible entrances and elevators under their accessibility pages online which, while very important, are not the only accommodations people with disabilities need, because so many types of disabilities exist. Why aren't more art museums providing accessible programs and accommodations for visitors with intellectual disabilities? Is it an oversight? Is there not

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<sup>1</sup> “Our Mission,” *Arts of Life*, accessed November 5, 2015, [ArtsOfLife.org/our-mission](http://ArtsOfLife.org/our-mission).

funding available to make these programs available? If there is a desire to create these programs, what accommodations would be necessary? These were all questions I asked myself, and questions to which I didn't have the answers. Upon researching the subject, I found that there was little scholarship on museum accommodations and programs for people with intellectual disabilities. The majority of existing research focuses on children with intellectual disabilities and the benefits of art education for this group, but there is not much regarding accommodations for adults with intellectual disabilities in museums.

I believe that these questions and the lack of scholarship are both vital to address, and this is an important topic to conduct research on, as museums have a responsibility to provide this population with the necessary accommodations. The population of people with disabilities constantly grows, due to circumstances like aging, accidents, and other trauma. Under the Americans with Disabilities Act (ADA), museums must provide accommodations for visitors with impairments. Likewise, museums provide many benefits to visitors that go beyond education of a specific topic, but helping to foster personal and interpersonal growth. Why should visitors with intellectual disabilities be excluded from experiencing this growth? Finally, based on my research and personal experience with this community, I believe that there is a desire within the community of adults with intellectual disabilities to utilize resources museums have the capability of providing them.

I understand the importance of creating a comfortable environment for as many visitors as possible, because oftentimes, museums can be overwhelming for me. Simple solutions – a guide stating where crowded areas of the museum tend to be, and where quieter areas are located, perhaps – would be useful for my personal needs when going to a public place, and I am certain that others would benefit from similar accommodations, as I know that I am not alone in

my position. It is my belief that museums are for everyone from every walk of life, not just for a select few, and I believe that many museums have lost sight of that, and are slowly working to correct this oversight. In my experience, the least successful exhibitions I've attended have been ones that ignore concerns of their visitors and focus solely on the art exhibited. The René Magritte exhibition at the Art Institute of Chicago in the fall of 2014 was an atmospheric retrospective of the artist's work, with dark walls and dim, moody lighting. However, it was immensely difficult to see the wall labels, and the way in which the show was set up led to an interrupted flow of the exhibition space. The museum undoubtedly hoped that this would be a popular exhibition, so why was there an oversight in considering how actual bodies move through the space? At the time, it seemed to me that the curators were more concerned with fitting as many pieces of art in the exhibition as they could, rather than allowing visitors to comfortably view the art at their own pace, without worrying about the overcrowded galleries.

An expected argument against creating broad accommodations for those who do not regularly attend museums, including people with intellectual disabilities, is that it is impossible to create the same experience across the board for everyone. While I agree that this a very difficult task, it does not mean that we should not try. That argument, that things are never going to be perfect, so it is pointless to try to make it so, is, in my belief, an excuse to allow things to remain as they are. Museums have tremendous potential to create change. It is time that they used that potential to make a positive impact on the way our society views disability.

### **Defining Intellectual Disability, Ableism, Access, and Accommodation**

Intellectual disability is defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) as “a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and



practical skills. This disability originates before the age of 18.”<sup>2</sup> The determination of intellectual functioning is based on an intelligence quotient (IQ) test. Adaptive behavior includes conceptual skills, social skills, and practical skills. Intellectual disability can include conditions like Down Syndrome and, in some cases, Autism.<sup>3</sup>

For the purposes of this study, intellectual disability is defined by the individual. Individuals with intellectual disabilities were intended to be part of this study via focus group. The participant’s medical diagnosis would not have been recorded, because the individual’s diagnosis is not pertinent, only their experiences are. Anyone with an intellectual disability would have been eligible to participate in the focus group that would produce knowledge that would benefit Chicago institutions as well as those with intellectual disabilities. In this study, conditions like dementia will not be considered an intellectual disability, because it is a degenerative condition and considered a disability separate from intellectual disability, though the two overlap in some instances.

Ableism is defined broadly as the discrimination against people with disabilities. Ableism takes many forms and, like any form of discrimination, is detrimental to the well-being of the individual. One ableist misconception regarding adults with intellectual disabilities is that these individuals have a chronological age and a mental age. Mental age is the idea that, though an individual is legally an adult, they essentially have the mind of a child. This notion is harmful because it limits individuals from making their own decisions and takes away their agency and independence.

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<sup>2</sup> “Definition of Intellectual Disability,” *American Association on Intellectual and Developmental Disabilities*, accessed November 7, 2015, [Aaidd.org/intellectual-disability/definition](http://Aaidd.org/intellectual-disability/definition).

<sup>3</sup> *Ibid.*

Accommodation in this context is defined as a service provided by an institution that is specifically meant to address a barrier caused by an impairment. For example, an accommodation that many institutions and businesses provide are ramps, used when access to a building's entrance requires stairs. While this accommodation was intended for wheelchair users, others benefit and use this accommodation. Accommodations often times start out as being meant solely for people with disabilities of various kinds, but end up being beneficial to other groups of people.

Access is defined as the ability to enter a space. Access and accommodation may seem like interchangeable words for the most part, but there is a subtle difference between the two. For example, a person with an intellectual disability who is also a wheelchair user can physically enter a museum by means of ramps and elevators, but that does not necessarily mean that the space is accommodating – there may be few accessible restroom stalls, crowded walkways that are too narrow for a wheelchair to comfortably move, and, as this paper argues, the collections may not be presented in a way in which a person with an intellectual disability can understand.

## **Methods**

In order to completely understand what challenges this population faces when attending an art museum, it is absolutely necessary to speak directly with members of the community. Thus, this study intended to include a focus group of roughly twelve adults with varying intellectual disabilities as defined above. However, there were a number of difficulties related to gaining approval from the university to conduct this focus group that made it impossible to properly execute this focus group.

Including adults with intellectual disabilities in this study is not only part of best research practices, but an integral part of disability studies. A popular saying in the field of disability studies is “nothing about us without us,” meaning that it is essential for members of the disability community to be a part of activism, lawmaking, and advocacy. I cannot assume to understand what accommodations are best for people with intellectual disabilities because I do not have an intellectual disability, and because these accommodations will vary from person to person. A focus group would be the most appropriate way to reach these conclusions because it allows for an in-depth conversation that allows participants to build on the ideas of others, something for which one-on-one interviews do not facilitate. The results yielded from such focus group would not have been an indication of what every person with an intellectual disability needs, but rather would have started the conversation of what art museums can do to open their doors to an underserved population that has not previously been considered in the creation of exhibitions and programs. This is a vital fact to remember when reading this paper: the suggestions for accommodations are not the end point, but a starting point in the larger discussion about how best to serve individuals with intellectual disabilities of various kinds within art museums.

The intention of this study was to include a focus group that engaged adults with intellectual disabilities. This focus group was to be a central part of this project’s research, but for several reasons did not occur. This section will outline the structure of the intended focus group and discuss the difficulties of securing permission to execute the focus group.

The study was intended to take place in two locations, as there were to be two separate focus groups. The first focus group would have taken place at The Arts of Life. Because of my brief experience at this organization, I decided to contact them to aid me in my study. They were familiar with me, interested in my work, and could be assured that I would treat each artist that

would participate with respect, as I had demonstrated before. At their request, I would conduct the first focus group at the organization for the sake of ease for the artists. Many of the artists utilize services like Pace to travel from their homes to the studio, and although the studio is in close proximity to the University of Illinois at Chicago (UIC)'s West Campus, it would still require public transportation, which many of the artists are either not comfortable using or not capable of using due to physical disabilities. This focus group would have a maximum of eight participants.

The second focus group would take place at the university, either on the West Campus or East Campus. The room would be accessible by elevator and have a restroom nearby. These are two concerns that needed to be addressed, in part due to UIC's inaccessible campus. Many of the buildings have only one restroom for the entire building, often located on the second floor. Most of the buildings feature elevators, but in some buildings, they are more difficult to access. The subjects for the second focus group would be recruited from Access Living, a disability services organization in Chicago. Their mission statement reads:

Access Living is a cross-disability organization governed and staffed by a majority of people with disabilities.

Access Living fosters the dignity, pride and self-esteem of people with disabilities and enhances the options available to them so they may choose and maintain individualized and satisfying lifestyles. To this end, Access Living offers peer-oriented independent living services; public education, awareness and development; individualized and systemic advocacy; and enforcement of civil rights on behalf of people with disabilities.

Access Living recognizes the innate rights, abilities, needs and diversity of people with disabilities, works toward their full integration into community life and serves as an agent of social change.<sup>4</sup>

Therefore, this organization would be an excellent resource for recruitment. Upon initial contact, the organization sounded excited at the prospect of recruiting for this research.

In order to execute this focus group, it was necessary to go through the university's research protocol through the Office for the Protection of Research Subjects (OPRS)'s Institutional Review Board (IRB). For the purposes of this section, this research protocol will be referred to as the IRB protocol. I wrote a total of five protocols, with each one being rejected. The process is confusing, as the majority of the language used in the IRB protocol is based on the assumption that there will be some form of medical research, but absolutely necessary in ensuring the protection of all potential research subjects. Because adults with intellectual disabilities are decisionally impaired (as defined by the IRB), they are considered to be a vulnerable population and therefore require extra attention.

A major roadblock I came across was the recruiting process. Because I would not be doing the recruiting myself, I needed to ensure that the staff members at both Access Living and Arts of Life appropriately asked potential subjects to be part of this study. This is not to discredit the organizations or question the staff's professionalism, but rather a precautionary measure taken by UIC to make sure that these subjects were in no way coerced or felt pressure from staff members to consent to the study. In order to assure this, UIC's IRB requested that these staff members complete the Collaborative Institutional Training Initiative (CITI) program or another similar research training. This training is required of all students completing a capstone project

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<sup>4</sup> "About Us," *Access Living*, accessed May 5, 2016, <https://www.accessliving.org/about>.

or thesis by UIC to ensure the research being conducted is ethical, and helps aid the student in completing an IRB protocol. This training can take a considerable amount of time, and, given the situation, I was not entirely comfortable asking my contacts at Arts of Life and Access Living to complete this training. This was mostly due to the time commitment, and the fact that the training was something that their job did not require.

Another stipulation was regarding the issue of guardians. The IRB requested proof that the guardians signing the consent forms were the legally authorized representatives. This would require access to records that the Arts of Life held, and ones that Access Living would not necessarily have. Likewise, the IRB requested proof by diagnosis that the participants were intellectually disabled. These two requests felt invasive considering the nature of my research, and, again, I did not feel comfortable asking these organizations for this information.

Many small requests were also made. Appendix A shows the most recent protocol letter, with a list of requested changes. The first IRB protocol was submitted in October of 2015; the most recent was submitted in late April of 2016. The final IRB protocol excluded Access Living and the second focus group from the research proposal due to time constraints. Appendix B shows the materials submitted to the IRB, excluding the protocol itself, which comes to a total of thirty pages. This shows the amount of information needed by the IRB to make an educated decision of whether or not to approve research. This appendix includes consent forms, guardian consent forms, assent forms for those with guardians, a consenting script which is to be read after reading the consent forms aloud (to ensure that subjects fully understand the consent form), sample questions asked during the focus group, and a questionnaire. In addition to these documents, I was also required to include a letter from The Arts of Life agreeing to host the focus group at their studio.

I include all of this information as advice to those who wish to do similar research as myself. The process of working with vulnerable populations, which include children, those in prison, and those with intellectual disabilities, is difficult, but often times necessary. It was necessary for this study, but for the sake of time, it was not able to be executed within the time frame of my graduate program. I still maintain the belief that people with disabilities must be included in the conversation of accessibility and accommodation, but now understand the difficulties in doing so. In order to ensure that our institutions are truly accessible and welcoming to people with disabilities of all kinds, these conversations must happen. However, because this conversation did not occur for this research, please consider the following suggestions for accommodations as a starting off point for future discussions that include people with intellectual disabilities and their friends and advocates.

The requirements under the ADA were addressed via research regarding both the law itself and reactions to the law from various populations. I did this in order to fully comprehend all possible ramifications of this landmark US law, from reactions of people within the disability activist community, lawmakers, and businesses. Questions of the ability of museums specifically to provide these accommodations – questions like, “Why are there not more programs that serve adults with intellectual disabilities” – were addressed through personal experience working in museums. Because of my personal and professional experiences within museums, I feel confident in making assumptions that there are issues with overworked staff and small budgets which are likely big reasons that many museums don’t offer this type of programming, along with the larger assumption that museums don’t see a need for these programs, and therefore are not anxious to create them.

## **Existing Programs in Chicago and in Art Museums Across the U.S.**

Currently, there are no programs in museums specifically meant for adults with intellectual disabilities in Chicago. However, there are some program available for children with intellectual disabilities. The Chicago Children’s Museum offers a program called “Play for All”, in which children with disabilities and their families can experience the museum privately. This is held the second Saturday of each month, and the first 250 visitors to register are admitted for free. They also offer a Therapeutic Play Guide in both English and Spanish. This play guide is a tool for parents to help direct their children once entering the museum to make the experience less overwhelming. It gives questions to ask, things to listen and watch for, words to use, objects to play with, and what to think about when in each exhibit. Another useful accommodation the Chicago Children’s Museum provides is a social story, which gives the rules of the museum as well as a guide to each of the exhibitions, and processes such as standing in line to buy a ticket and walking through each specific exhibition. This guide is presented as a slideshow presentation and gives the viewer an idea of what to expect of the museumgoing experience before the fact, to ease anxiety caused by an unfamiliar situation. Social stories are a way for parents to prepare their children for a visit to the museum, which, because of the amount of visitors and the amount of stimuli, can be overwhelming for some.

Beyond Chicago, there is one major art museum that offers some accommodations for visitors with intellectual disabilities of all ages: The Metropolitan Museum of Art in New York. The Metropolitan Museum of Art, also known as the Met, has programming for visitors with intellectual disabilities both under and over the age of 18. These programs are guided tours that culminate with an art activity. The Met also provides services for visitors with sensory processing disorders and autism, which include a sensory map, indicating which areas of the



museum tend to be crowded with visitors and which galleries have natural light, among other details. Other services include social stories for both children and adults.

Clearly, there is a lack of meaningful programming for adults with intellectual disabilities in major American art museums, and Chicago art museums in particular. The goal of this study is to provide an argument that these programs are absolutely necessary, as well as to provide solutions to problems that may arise when attempting to implement such services.

## Literature Review

### Disability Studies

Disability is a term that has multiple meanings, depending on which group is defining it. A nondisabled person might define it as, “a condition that damages or limits a person’s physical or mental abilities” or “the condition of being unable to do things in the normal way.”<sup>5</sup> However, in the disability studies discipline, disability is defined as a constructed condition that stems from society’s inability or refusal to adapt the “normal” environment for those with impairments. A common way of explaining this is using a wheelchair user as an example. With a wheelchair, a wheelchair user doesn’t have a disability. This person only has a disability when confronted with stairs. This way of thinking about disability is known as the social model, discussed in *Keywords for Disability Studies*. In *Keywords*, the authors discuss terms like “disability,” “access,” “accommodation,” “cognition,” “design,” and “representation.” This collection of terms is discussed from disability studies and disability rights perspectives and is a way to introduce the reader to the basics of disability studies from a variety of viewpoints. Authors and editors Rachel Adams, Benjamin Reiss, and David Serlin discuss disability from a historical perspective, examining the word from its origins in the sixteenth century, which was used to describe such incapacities as “inability to pay a debt or to worship God with a full heart, while some conditions currently treated as disabilities were not regarded as such.”<sup>6</sup> In the nineteenth century, disability was linked with statistics and medicine, and related to words like “deviance” and “abnormality.”<sup>7</sup>

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<sup>5</sup> “Disability,” Merriam-Webster.com, accessed February 5, 2016, <http://www.merriam-webster.com/dictionary/disability>.

<sup>6</sup> Rachel Adams, Benjamin Reiss, and David Serlin, eds. *Keywords for Disability Studies* (New York: NYU Press, 2015) 6.

<sup>7</sup> *Ibid.*

The idea of normality and abnormality is discussed at length by Lennard J. Davis in the introduction to his *Disability Studies Reader*. Davis discusses the idea of normality, rather than disability, because he recognizes that the idea of disability has come from the concept of normalcy, which has been constructed over the past few centuries and continues to shift. During the nineteenth century, foundations were laid for the eugenics movement, which used the Darwinian theory of evolution as a point of inspiration.<sup>8</sup> Eugenics, or the scientific practice of “improving” the human race through selective reproduction, encouraged the sterilization of disabled people in order to prevent impairments to be passed on to children.<sup>9</sup> Thus came the shift in language surrounding disability away from scientific terms and toward the effectiveness of the body, with words like “defective” and “feble-minded” being used to describe those with disabilities during this time period of the late nineteenth century and early twentieth century.<sup>10</sup> “Normal” was used as a justification for the sterilization, discrimination, and segregation of people with various disabilities, who fell outside of that constructed meaning. Davis’s introduction serves as a framework for the rest of the reader, which features articles and essays by different authors, much like *Keywords for Disability Studies*, that is divided into sections titled “Historical Perspectives,” “The Politics of Disability,” “Stigma and Illness,” “Theorizing Disability,” “Identities and Intersectionalities,” “Disability and Culture,” and “Fiction, Memoir, and Poetry.” This Reader offers a comprehensive look at the issues talked about in the disability studies field, and covers topics ranging from the public display of disability to disability and blackness to issues surrounding “new genetics” and prenatal testing. Though the volume discusses historical perspectives of disability, one of its weak points is that it doesn’t discuss the

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<sup>8</sup> Lennard J. Davis, ed., *The Disability Studies Reader, Fourth Edition* (New York: Routledge, 2013) 3.

<sup>9</sup> Ibid.

<sup>10</sup> Ibid.

roots of the disability rights movement between the 1930s and 1990, a very important time in the history of disability within the United States.

Beginning in the 1930s, associations dedicated to people with disabilities of many kinds protested against employment discrimination. Organizations like the National Federation of the Blind (NFB) and the American Federation of the Physically Handicapped (AFPH) were involved in issues of labor for those with disabilities who wished to work. After the end of World War II, many soldiers returning from war had been permanently disabled, leading to the formation of groups like the Blinded Veterans Association, the Paralyzed Veterans of America, and civilian groups like Just One Break. These groups tended to work independently from one another.<sup>11</sup> This initial movement, and subsequent movements leading up to the passing of the Americans with Disabilities Act, is documented in Fred Pelka's *What We Have Done: An Oral History of the Disability Rights Movement*. In his introduction, Pelka discusses the history of the disability rights movement very generally. Inspired by the Civil Rights movement of the 1950s and 1960s, activists began to call for expanded rights for people with disabilities that went beyond equal access to employment, which addressed needs that needed to be met in order to live independently. Activists took notes from the Civil Rights movement and addressed "their own internalized oppression and [questioned] the assumption that disability was a flaw or defect rather than an intrinsic part of the human condition."<sup>12</sup> With this movement came the independent living movement, which originated in Berkeley, California, and was triggered by student Ed Roberts' experience at the University of California, Berkeley. Roberts lived in the hospital on campus, because it was the only residence on campus that could accommodate his

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<sup>11</sup>Fred Pelka, *What We Have Done* (Amherst, MA: University of Massachusetts Press, 2012) 19-22.

<sup>12</sup> *Ibid*, 23.

“iron lung”, which, as a survivor of polio, he needed to use at night. The work of the organization the Rolling Quads, later the Disabled Students Union, and people with disabilities in the San Francisco Bay area, led to the formation of the first Center for Independent Living, which was founded in 1972 to, “provide severely disabled people the services they needed in order to leave or stay out of nursing homes and other chronic care facilities.”<sup>13</sup> A number of legislation was passed on the national level between 1980 and the ADA of 1990, including the Civil Rights of Institutionalized Persons Act of 1980, the Voting Accessibility for the Elderly and Handicapped Act of 1984, the Air Carrier Access Act of 1986, the Fair Housing Amendments Act of 1988, and the Civil Rights Restoration Act of 1988.<sup>14</sup> Pelka spends the remainder of his book recounting the experiences of people with all types of disabilities, ranging from their experiences in childhood to their experiences in institutions and their experiences with discrimination. Pelka, too, includes stories of activism and advocacy to provide a complete picture of the history of the disability rights movement during the 20<sup>th</sup> century.

Since the passing of the ADA, more accommodations have been made for people with disabilities. That is not to say that there is no discrimination or that the world is completely accessible to people with disabilities. In his book *Disability Politics & Theory*, A.J. Withers discusses different issues facing the community today. Though he is a Canadian scholar, his ideas are still applicable to the United States, because the climate of disability rights and accommodations being offered are similar in each country. *Disability Politics & Theory* discusses different models of looking at disability, like the eugenic model, which has previously been discussed, and the medical model, which focuses on the disabled body as something that

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<sup>13</sup> Ibid., 24.

<sup>14</sup> Ibid., 28.

needs to be improved upon and views disabilities as problems that need to be eliminated instead of an inevitability of life. Another model he discusses is the charity model, which he includes with the subtitle “For us, not with us”. He states, “rather than advocating for change, the charity model and charity industry are typically invested in the status quo. As disability is an individual tragedy, solutions are based on eliminating or reducing disability rather than addressing social barriers.”<sup>15</sup> Withers points out that the majority of money raised by disability charities are funneled back into the organization itself rather than go towards making the lives of people with disabilities better. He discusses the fact that money is not used to provide housing, health care, assistive devices, or attendant care, and that people with disabilities are disproportionately living in poverty and therefore need these services that charities presumably provide. Rather, the focus of charities like the Easter Seals, which made \$750.2 million in 2009-2010, is a cure, which relates back to the medical model, and funding the organization itself.<sup>16</sup> Withers addresses charities by referring to them as an “industry”, thereby asserting their role as a money-making entity, rather than a social service. He also discusses the problematic nature of using “poster children” as advertising tools, because they are seen as worthy of saving, while adults with the same impairments are seen as an economic drain on society.<sup>17</sup> Likewise, these poster children are almost always white, which again relates back to the idea that only certain people are worthy of being “helped” or “saved”. Withers’ book is another excellent introduction to disability studies, because it addresses historic and modern ways of thinking about disability, both positive and negative.

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<sup>15</sup> A.J. Withers, *Disability Politics & Theory* (Winnipeg, Manitoba, Canada: Fernwood Publishing, 2012), 58.

<sup>16</sup> *Ibid.*, 59.

<sup>17</sup> *Ibid.*, 66.

## **Museology, Social Justice, and Disability**

Richard Sandell of the University of Leicester's School of Museum Studies is one of many proponents of museums as vehicles for social change and empowerment, as evidenced by his abundant writing about the subject as well as his edited volumes related to social justice in museology. Among his writing is "Museums and the Combating of Social Inequality: Roles, Responsibilities, Resistance", in which he makes the statement that "museums and galleries of all kinds have both the potential to contribute towards the combating of social inequality and a responsibility to do so."<sup>18</sup> This bold statement is followed by evidence supporting this thesis, which includes the idea that museums should be responsive, "not to short-term, party political objectives but rather to longer-term, paradigmatic shifts in thinking and...the 'prevailing moral spirit' of society as a whole."<sup>19</sup> As society evolves, so must museums. In a world in which we are slowly learning to celebrate differences that once were cause for extreme violence and conflict, and to some extent still are, museums must reflect this. Museums can facilitate this process of learning about different cultures and communities in a respectful, non-sensationalized way, as it is one that is relatively new and still met with skepticism or outright disapproval from some. Sandell acknowledges that not everyone will be happy with this direction, and uses an example of a visitor comment, in which the visitor complained that the way in which a gallery represented its collection was "rubbish", and that even in the age of "political correctness" they disagreed with the gallery's decision to make vaguely political statements and to steer away from a colonial presentation, and preferred the only room in the gallery that had been untouched since the 1970s.<sup>20</sup>

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<sup>18</sup>Richard Sandell, ed. *Museums, Society, Inequality* (New York: Routledge, 2002), 3.

<sup>19</sup> *Ibid.*, 18.

<sup>20</sup> *Ibid.*, 16.

Sandell's example of reframing a collection to reflect a more acceptable message reflective of our world today is echoed in several scholars' work, including Sandell himself along with Jocelyn Dodd. With particular regard to disability, there is ample opportunity to re-present existing collections, especially in art museums, to tell a narrative about disability and its role in the artists' work and lives. Often, an artist's disability is hidden or erased from the narrative told by art museums. By reworking the collection and telling a story about disability, it gives more opportunity for visitors to make a connection with a particular work of art, which surely is a goal of each art museum. Sandell and Dodd discuss reframing not collections, but political figures. Their example of reframing the way we view a historical figure is the 2001 addition to the Franklin Delano Roosevelt memorial in Washington D.C., in which a sculpture of the former president sitting in a wheelchair is located. The sculpture drew criticism, because many did not believe that the former president should be shown as "weak". At the time Rosemarie Garland-Thompson spoke against the controversy, stating that the sculpture is meant to, "avoid repeating the persistent stereotypes of disability – the ones that tell us that disability is a shameful personal problem...[and] inappropriate in the public sphere."<sup>21</sup> In "Activist Practice", Sandell and Dodd also acknowledge that a major reason for not reframing collections is the fear that exhibitions focused around disability will somehow alienate their audience, either through inadvertent stigmatization of differences in bodies and/or abilities that would anger visitors with disabilities, or encourage the wrong kind of conversation among visitors without disabilities. The authors say, "How could the invisibility of disabled people be addressed without recreating inappropriate forms looking reminiscent of the freakshow?"<sup>22</sup>

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<sup>21</sup> Richard Sandell, Jocelyn Dodd, and Rosemarie Garland-Thompson, eds., *Re-Presenting Disability: Activism and Agency in the Museum* (New York: Routledge, 2010) 12.

<sup>22</sup> Ibid.



Rosemarie Garland-Thomson has written a great deal about the gaze and forms of looking, in particular in her book *Staring: How We Look*. She also talks about this in her essay “Picturing People with Disabilities”, where she discusses the importance of people with disabilities being depicted in classical portraiture to be displayed in museums or galleries. Classical portraiture, she says, is a way to combat the forms in which people with disabilities are typically presented: “The most prevalent picture of people with disabilities have come to us through the genres of freak-show photography, charity campaigns or medical photography. These images portray disability narrowly as sensational, sentimental or pathological.”<sup>23</sup> She says that classical portraits demand the respect and attention of its audience, citing the portraits of the Italian Renaissance painter Pollaiuolo (Figure 1) and the *Venus de Milo* (Figure 2) as examples against Chris Rush’s *Swim II* (Figure 3) and Marc Quinn’s *Alison Lapper Pregnant* (Figure 4), respectively. Classical portraiture is a way to give agency to subjects that historically have been exploited in the type of portraiture they are shown in; the examples of *Swim II* and *Allison Lapper Pregnant*, visibly disabled bodies are presented without apology and in a way that has historically been used to express idealized beauty. These classical portraits force the viewer to rethink what we consider to be an acceptable body to be. Garland-Thomson then quotes Nancy Fraser, who argues that recognition “is essential not simply for individual self-realization but, more importantly, as the cornerstone of an ethical political society.”<sup>24</sup> Therefore, presenting disability within the museum is both important and essential to this population as they continue to empower themselves through activism of various kinds.

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<sup>23</sup> Ibid., 23

<sup>24</sup> Ibid., 37

Susan Davis Baldino discusses alternative ways of teaching within museums in her essay “Museums and Autism: Creating an Inclusive Community for Learning”. While she discusses the creation of a program specifically for people with autism, the principles are applicable to a variety of people in a variety of circumstances. The most frequently used methods of teaching “posits teachers as experts and students as passive learners.”<sup>25</sup> Baldino says, “If we understand humans as reflective of the societies and culture in which they live, they cannot be passive receivers. Therefore, we should be skeptical of educational institutions that extract knowledge from our cultures and present it in a linear, decontextualized manner.”<sup>26</sup> The program she refers to, the Museum Learners Club (MLC), creates a different environment of learning in which there is a facilitator that helps students work together and learn together on a more equal level. Baldino cites social anthropologist Jean Lave, learning theorist Etienne Wenger, and learning scientists Borwn, Collins, and Duguid in stating that this “communal setting and co-participation [is] fertile ground for learning.”<sup>27</sup> The MLC “experiment” involved students of different learning abilities that were both neurologically typical and neurologically atypical. Students learned together, with Baldino as their “knowledge activist”, and resulted in positive results that included increased participation over the course of the day, which she interprets as, “Passive learners [becoming] active learners and reticence [gives] way to full participation. Followers [become] leaders. There [is]...acceptance of differences and enhanced tolerance. There [is] an increase in confidence and friend-making.”<sup>28</sup> This study is an example of how adaptive learning

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<sup>25</sup> Richard Sandell and Eithne Nightengale, eds., *Museums, Equality and Social Justice* (New York: Routledge, 2012) E-book.

<sup>26</sup> Ibid.

<sup>27</sup> Ibid.

<sup>28</sup> Ibid.

environments can be beneficial, to more groups than the ones they target directly. In this case, neurologically typical students gained equal benefits from this type of learning environment as students with autism.

These foundational texts in both the disability studies and museum studies fields provide the necessary information to understand why disability studies and disability rights are important, and what connection they have to current trends in museum studies, which is increasingly looking at its practices through a social justice lens.

## **Types of Accommodations Art Museums Can Provide**

There are several ways in which art museum professionals can create an environment that encourage people with intellectual disabilities and their families to visit. Note that these ideas come from personal experiences interacting with adults with this type of disability.

### **Adaptive/Alternative Labels**

Labels are a way for museums to provide context for their collections and educate visitors when docents or other museum educators are not present. In science and natural history museums, these labels are often interactive. Labels are often phrased as a question that requires the visitor to lift or slide the label to reveal the answer. These labels are usually short and user-friendly. Art museum labels are different, in part because it is difficult to have this type of interactive component that encourages touch next to paintings and sculptures, which cannot be touched by patrons. These labels give biographical information about the artist, historical context for the work, or technical information about how the work was created, depending on how the curator is framing the art object. Often these labels are longer than their counterparts in science or natural history museums and use more complex language. There is no clear answer as to why this is. Art labels can be confusing for many, and people with intellectual disabilities may have difficulty accessing the information presented in labels. Therefore, a solution would be to provide an alternative label in more simplified language.

Simplified language does not equate to simplifying the message or content of an art object. It is entirely possible to convey complex ideas in simple language, the example being the previously mentioned science and natural history museum labels. There is a lack of willingness to simplify label language that is attached to art objects, perhaps due to pressure from artists who

insist on keeping their complex ideas attached to their work, or perhaps due to the desire of art museums to have their collections being taken seriously. Whatever the case may be, it would be beneficial to have alternative labels in less complex language to aid people with intellectual disabilities in fully accessing and comprehending collections within art museums.

This simplified language does not have to be dry and straightforward. Individuals working in art museums have a great love and respect for art and are undoubtedly creative people. Taking a creative approach to adaptive label writing would be beneficial, because it has the potential to make the label reading experience more interesting. Utilizing questions and playing with the sentence structure are two ways that curators can convey complex ideas presented by art objects without explicitly outlining everything the work is about. Art is open to interpretation, and labels should reflect that. Marlene Chambers of the Denver Art Museum says “we must offer messages that give visitors something to do – such as agree with the ideas, disagree, use them as building blocks in making conclusions, or make discoveries of their own.”<sup>29</sup> This sentiment is an excellent goal, but again, without adapted labels, is a difficult one for adults with intellectual disabilities to achieve. It should not be the responsibility of a companion to explain and educate a visitor with an intellectual disability about the artwork on the wall, it should be the responsibility of the museum. Museums act as institutions of learning: “the museum is...a workshop of education, in which objects are handled, descriptions are given, questions are asked and answered, and, as far as possible, visitors are moved to attempt, chiefly in school or at home, to produce objects of interest to themselves or of instructional value to the

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<sup>29</sup> Beverly Serrell, *Exhibit Labels: An Interpretive Approach* (Walnut Creek, CA: AltaMira Press, 1996) 83.

community.”<sup>30</sup> By ignoring the need for plain-language labels, museums are ignoring an array of populations, including those with intellectual disabilities (about 1.2 million in the US<sup>31</sup>), those who may be re-learning to read after a stroke (which occur at a rate of 750,000 per year in the US<sup>32</sup>), those who are English language learners (immigrants are currently 13.3% of the US population,<sup>33</sup> and roughly 70,000 refugees were resettled in the US in 2015 alone<sup>34</sup>), and those whose reading comprehension is below the average level for most Americans (over 45 million<sup>35</sup>). There are a variety of uses that implementing plain language labels can offer to the public. Likewise, these labels may be less intimidating for visitors who are new to learning about art. Often times, curators or those who write museum text can forget that the general public does not have the same level of education as they do. That is not to say that these labels should talk down to the reader. Rather, they should use direct language that helps facilitate conversation and ask questions that provoke critical thinking.

One of the Art Institute of Chicago’s most famous paintings in the collection is Georges Seurat’s *A Sunday on La Grande Jatte* (Figure 5). The museum’s label used in the gallery can also be accessed online:

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<sup>30</sup> John Cotton Dana, *A Plan for a New Museum, the Kind of Museum it Will Profit a City to Maintain* (Woodstock, VT: The Elm Tree Press, 1920) 49-50.

<https://archive.org/stream/aplanforanewmus00danagoog#page/n6/mode/2up>.

<sup>31</sup> “Americans with Disabilities,” *US Census*, accessed March 5, 2016, <http://www.census.gov/prod/2012pubs/p70-131.pdf>.

<sup>32</sup> “Stroke Statistics” *Stroke Center*, accessed March 5, 2016 <http://www.strokecenter.org/patients/about-stroke/stroke-statistics/>.

<sup>33</sup> Karen Ziegler and Steven A. Camarota, “Immigrant Population Hits Record 42.1 Million in Second Quarter of 2015,” *Center for Immigration Studies*, accessed March 5, 2016, <http://cis.org/Immigrant-Population-Hits-Record-Second-Quarter-2015>.

<sup>34</sup> “Refugees and Asylees in the United States,” *Migration Policy Institute*, accessed March 5, 2016, <http://www.migrationpolicy.org/article/refugees-and-asylees-united-states>.

<sup>35</sup> “Literacy Skills of adults, by type of literacy, proficiency levels, and selected characteristics: 1992 and 2003,” *National Center for Education Statistics*, accessed March 5, 2016, [https://nces.ed.gov/programs/digest/d14/tables/dt14\\_507.10.asp](https://nces.ed.gov/programs/digest/d14/tables/dt14_507.10.asp).

In his best-known and largest painting, Georges Seurat depicted people relaxing in a suburban park on an island in the Seine River called La Grande Jatte. The artist worked on the painting in several campaigns, beginning in 1884 with a layer of small horizontal brushstrokes of complementary colors. He later added small dots, also in complementary colors, that appear as solid and luminous forms when seen from a distance.

Seurat's use of this highly systematic and "scientific" technique, subsequently called Pointillism, distinguished his art from the more intuitive approach to painting used by the Impressionists. Although Seurat embraced the subject matter of modern life preferred by artists such as Claude Monet and Pierre-Auguste Renoir, he went beyond their concern for capturing the accidental and instantaneous qualities of light in nature. Seurat sought to evoke permanence by recalling the art of the past, especially Egyptian and Greek sculpture and even Italian Renaissance frescoes. As he explained to the French poet Gustave Kahn, "The Panathenaeans of Phidias formed a procession. I want to make modern people, in their essential traits, move about as they do on those friezes, and place them on canvases organized by harmonies of color." Some contemporary critics, however, found his figures to be less a nod to earlier art history than a commentary on the posturing and artificiality of modern Parisian society.

Seurat made the final changes to La Grande Jatte in 1889. He restretched the canvas in order to add a painted border of red, orange, and blue dots that provides a visual transition between the interior of the painting and his specially designed white frame.<sup>36</sup>

While this gives a comprehensive history of the iconic painting, it is, by many standards, too long to function as an object label. The use of a quote is interesting here, but can be confusing to those unfamiliar with the "Panathenaeans of Phidias," commonly known as the Parthenon frieze. Likewise, the sentences are often long and complex, making them somewhat difficult to follow.

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<sup>36</sup> "About this Artwork – A Sunday on La Grande Jatte," *The Art Institute of Chicago*, accessed May 14, 2016, <http://www.artic.edu/aic/collections/artwork/27992>.

This label gives excellent information, but perhaps could do so in fewer words. In order to adapt this label to a different audience, these concepts can be condensed:

Seurat was the inventor of Pointillism. Pointillism uses small dots of color to make a larger picture. This way of painting requires time and patience, because each dot is important to the whole painting. Seurat was inspired by Greek sculpture and Italian Renaissance portraits. He liked that the subjects of these art forms were shown as being very important. He also liked Impressionist painters, who painted scenes from everyday life. This painting is a mixture of both of these things. The people in this painting are in an everyday scene, and the way they are posed shows that they are important.

This label would be more suited to people with intellectual disabilities, because I used simpler language that is more direct and easy to understand. It is also one hundred words shorter than the original label but keeps most of the same content. However, it is, for lack of a better word, boring. Art museums are filled with creative people. Shouldn't their labels (and adaptive labels) reflect that? Another way of writing this label is as follows:

Take a close look at this painting. What do you see? These tiny dots that make up this big painting is a style called Pointillism. Seurat invented this way of painting. Notice how the people in the painting are standing. Try posing like them. Stand or sit with your feet together, your back straight, your shoulders back, and your head high. How do you feel? Seurat wanted us to see these people as important. Why do you think Seurat put these important people in an everyday scene?

This label is the shortest yet at 87 words. I make use of questions and engage the reader by asking them to use their body to mimic the subjects of the painting. By ending with a question, it allows the reader to come to their own conclusions about why Seurat chose to mesh these two very different ways of depicting people together, between the Egyptian, Greek, and Renaissance permanence and fleeting Impressionism. It also encourages conversation between visitors.



In order to make a label applicable to more than one audience, it needs to be interesting enough to hold the attention of adults. It can be easy to assume that intellectually disabled readers need concepts spelled out for them. This makes labels uninteresting and not challenging. The language is the only aspect of labels that need to be simplified, not the concepts. It is much more interesting and beneficial for people to come to their own conclusions about an art object, because it gives it more personal meaning to have come to that conclusion. Labels like the one above can be beneficial to a range of different populations who, for many reasons, have a reading level that is below what curators and those writing the labels expect. To create labels that are more accessible and interesting to a variety of different groups of people is a challenge, but one that museum workers must be up to taking.

### **Guided Tours**

Designated guided tours would be useful in making people with intellectual disabilities feel welcomed in art museums. Most museums offer guided tours, and many major museums include audio tours in a variety of languages. Educators and curators cannot convey all important information about art objects in a label. Likewise, not every object has an extended label, but rather often only tell the title, date, artist, and, if applicable, location an artwork came from. Docents and other tour guides provide additional information for visitors, and usually speak to a certain theme in the museum as a whole or offer in-depth tours of a specific exhibition or collection. The Art Institute of Chicago has several different types of tours for different learning levels, mostly targeted at school aged children. Their website indicates that they are willing to accommodate students with different learning, physical, or behavioral needs.<sup>37</sup> They also have

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<sup>37</sup> "Students with Disabilities," *The Art Institute of Chicago*, accessed May 14, 2016, <http://www.artic.edu/learn/k-12-teachers-and-students/student-tours/students-disabilities>.

designated guided tours for visitors who are blind or low vision, Deaf visitors, and senior visitors. Senior visitors have the option of participating in one of four programs designated for seniors without dementia, and includes one program for seniors with dementia.<sup>38</sup>

There are ample resources available on the Art Institute of Chicago's website. It is clear that this museum in particular has the ability to provide an array of different tours due to the amount of docents that volunteer with them. The Art Institute has thought of its disabled visitors with guided tours in American Sign Language (ASL) and its touch tour gallery, as well as guided tours for blind and low vision visitors. While these tours require some special training, they are not impossible to implement. What's stopping the Art Institute, and other institutions, from providing tours that are specifically meant for adults with intellectual disabilities? Why not expand programming to adults with different learning abilities, as is done for children? I do not believe that this omission is maliciously done by the institutions to alienate this group, but is likely an oversight in programming. Docents can be trained to work with this population, to ask questions that are engaging in a way that is easy to understand, and to convey the type of information given in other standard guided tours. This requires some time and patience, but, if the Art Institute's ASL tours are any indication, will have a great payoff.

### **Sensory Maps and Social Stories**

Many times, a person with an intellectual disability may have sensory processing difficulties as well. My personal experience in working with adults with intellectual disabilities has informed this; many of the people I have worked with have become overwhelmed throughout the course of the day, and need to retreat to a quiet area to collect themselves. People with

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<sup>38</sup> "Lifelong Learning," *The Art Institute of Chicago*, accessed May 14, 2016, <http://www.artic.edu/learn/adults/lifelong-learning>.

Autism and Sensory Processing Disorders, too, may also have intellectual disabilities. How can museums address the need to have a quiet area for those who have these disabilities, or simply become overwhelmed or overstimulated at times, as I expressed in the introduction to this paper, when gallery space becomes more and more precious as collections grow? A simple and inexpensive solution is to offer a sensory map.

Sensory maps outline the entire museum and indicate which areas of the museum tend to be more popular, which tend to be quiet, and which ones utilize natural light versus artificial light. This may seem strange to some, but can be an incredible tool utilized by many different people. One institution that offers this option is the Met, which has a map that indicates crowded, loud, naturally lit, and dimly lit areas of the museum by name and gallery numbers, and are indicated by color on a PDF file available on the museum's accessibility page of their website.<sup>39</sup> This alerts visitors to which areas of the museum to avoid, and which areas they can retreat to if need be. Installing more benches in these less crowded galleries can be a way to encourage visitors to stop and take a rest if they become overwhelmed, stressed, or tired during their visit, but still want to continue to see the collections.

Social stories have been utilized by special education teachers and therapists for students and clients with Autism. These social stories are stories that utilize simple language and pictures to outline a social event or interaction. This is meant to be a tool to teach students the standard way of interacting with others, but can also be used as a tool to prepare an individual for an event or experience that they have not had before. The Met, too, has social stories for children and

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<sup>39</sup> "Sensory Friendly Map," *The Metropolitan Museum of Art*, accessed May 15, 2016, <http://www.metmuseum.org/-/media/Files/Events/Programs/Progs%20for%20Visitors%20with%20Disabilities/Sensory%20Friendly%20Map.pdf>.

teens that outline the process of entering the museum, including going through security and standing in line to buy admission tickets. Often times, the unknown can create anxiety for people, especially if they have a disability, because they are unsure if their needs can be met.

Social stories can be useful tools for adults as well. The same principles of writing interesting museum labels apply here: the language used must be simple and direct, yet age appropriate. The Met's social stories show this difference; the concepts in the children's social stories and teenagers' social stories are the same, but the language is slightly different. For example, the social story meant for children refers to an adult chaperone and uses more simplified language, while the social story for teens and young adults recognizes that they may not be with a chaperone and instead direct them to ask security guards questions. In addition to including the steps one must take in order to enter the museum, it may also be beneficial to include the disability services the institution offers, to quell some of those fears that a person's needs may not be able to be met. Social stories and sensory maps are useful tools, but are often available online. Though, for social stories, this is vital, as it is a tool to be used prior to a museum visit, it would be beneficial to provide sensory maps as a physical copy in the museum so that visitors who do not have regular access to a computer or the internet can still utilize this resource.

These accommodations are by no means the only ones that museums can offer. However, they are a starting point in assuring adults with intellectual disabilities and their friends, families, and other advocates that this group of people are not only allowed to come to art museums, but are encouraged and welcome to enjoy them.

## **Museums' Responsibility to Provide Accommodations**

What are the arguments that it is not only beneficial for museums to provide these accommodations, but that museums have a responsibility to do so? There are three basic arguments that relate to one another: museums are required to provide services under the Americans with Disabilities Act, museums are able to provide esteem-building skills that people with intellectual disabilities should not be excluded from, and people with intellectual disabilities are asking for these programs to be put in place.

### **Requirements Under the Americans with Disabilities Act (ADA)**

A United States museum's responsibility to create accommodations for people with intellectual disabilities is clear. They are legally required to do so under the Americans with Disabilities Act of 1990, commonly known as the ADA. Under Title III of the law, titled "Public Accommodations and Services Operated by Private Entities", the ADA states that "a museum, library, gallery, or other place of public display or collection" is considered a public space for the purposes of the law.<sup>40</sup> Further, §1218.b.1.A.i. states:

It shall be discriminatory to subject an individual or class of individuals on the basis of a disability or disabilities of such individual or class, directly, or through contractual, licensing, or other arrangements, to a denial of the opportunity of the individual or class to participate in or benefit from the goods, services, facilities, privileges, advantages, or accommodations of an entity.<sup>41</sup>

This means that, under the protection of the ADA, a museum must provide accommodations for people with disabilities. A truly compliant institution offers accommodations for those who have sensory, developmental, and/or intellectual disabilities, not only for those who use wheelchairs.

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<sup>40</sup> "The Americans with Disabilities Act of 1990, As Amended," *The Americans with Disabilities Act*, accessed January 7, 2016, <http://www.ada.gov/pubs/adastatute08.htm#12131>.

<sup>41</sup> Ibid.

In addition to these requirements, there are a number of prohibitions. § 12182.2.A defines discrimination as both, “a failure to make reasonable modifications in policies, practices, or procedures, when such modifications are necessary to afford such goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities” and “a failure to take such steps as may be necessary to ensure that no individual with a disability is excluded, denied services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services.”<sup>42</sup> This means that, unless accommodations fundamentally change the services provided, public institutions must provide accommodations for people with disabilities, and these accommodations must not segregate disabled and non-disabled populations from one another. If an institution fails to do these things, they are both breaking the law and at risk for being sued for discrimination under the ADA. Amy Hasbrouck, former Director of Education and Advocacy at the Boston Center for Independent Living, stated, “most of the discrimination is really subtle”<sup>43</sup> in *People with Disabilities Explain It All For You*. It is doubtful that museums and other institutions intentionally exclude people with intellectual disabilities, but by ignoring this group of people when considering programming and accommodations to provide their public, they are being discriminatory.

The ADA does not explicitly state what accommodations must be made. The law is intentionally vague so that these accommodations are not limited. This has caused critics of the law to argue that the ADA has triggered “frivolous suits”<sup>44</sup> that overwhelm federal courts. Likewise, people like Supreme Court Justice Sandra Day O’Connor criticized its vague

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<sup>42</sup> Ibid.

<sup>43</sup> Mary Johnson, ed. *People with Disabilities Explain It All For You*, (Louisville, KY: Advocado Press, 1992) 15.

<sup>44</sup> Ruth Colker. *The Disability Pendulum: The First Decade of the Americans with Disabilities Act* (New York: New York University Press, 2005) 7.

language, blaming the eagerness to get the law passed for its lack of specificity.<sup>45</sup> However, the reason for this generic language was to reflect the diversity of disabilities that exist. To include specific language and specific accommodations for each disability would be incredibly difficult because the type and degree of impairment varies from person to person. Most institutions, including museums, choose to not read the law this way. Instead, they interpret it as narrowly as possible, claiming that they are being compliant to the law when, in reality, they have done the bare minimum of what is required of them. Proponents of the law say that the guidelines outline in the ADA were meant to be “the floor, not the ceiling”<sup>46</sup>, meaning that the instructions and requirements specifically expressed in the law were meant to be starting points, not the only requirements to become ADA compliant.

What, then, constitutes a disability in the eyes of the law? The Americans with Disabilities Act Amendments Act (ADAAA) of 2008 was created in part to make this definition less ambiguous. The ADAAA states that a disability constitutes, in part, “a physical or mental impairment that substantially limits one or more major life activities of such individual.”<sup>47</sup> The law goes on to define major life activities, which include, among other things, caring for oneself, learning, reading, and communicating.<sup>48</sup> Therefore, intellectual disabilities are covered under the Americans with Disabilities Act.

The ADA should not be a threatening law that burdens institutions, but should rather be an exciting incentive to reach new, broader audiences. “The floor, not the ceiling” should be a challenge to institutions to come up with increasingly creative and effective ways of engaging

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<sup>45</sup> Ibid.

<sup>46</sup> Ibid., 16

<sup>47</sup> “Americans with Disabilities Act Amendments Act,” *U.S. Equal Employment Opportunity Commission*, accessed January 10, 2016, <http://www.eeoc.gov/laws/statutes/adaaa.cfm>.

<sup>48</sup> Ibid.

and reaching out to the community of people with disabilities. The solutions mentioned above are three of countless possibilities for programs and accommodations provided that are even more exciting than the basic accommodations that should, at bare minimum, be provided. Museums should be taking the law seriously, and should be excited to do so, to try something different.

### **Museums Providing Enriching Services to Patrons**

Heather J.L. Smith, Barry Ginley, and Hannah Goodwin discuss the ADA and the UK equivalent, the Disability Discrimination Act (DDA) in their essay “Beyond Compliance? Museums, Disability and the Law”. They argue that only using the law as an argument for accessibility can be a problem because:

There is a danger that a reliance on the law to achieve change can focus too much attention on what (minimum) changes are deemed necessary to meet legal requirements, rather than fostering a climate in which a genuine concern for (and commitment to achieving) full equality of rights is embedded.<sup>49</sup>

Though the argument that museums have an obligation to provide accommodations under the ADA is the strongest, we must look at other reasons to implement accommodations because of the above statement. Likewise, there are countries that do not have laws like the ADA or the DDA to protect people with disabilities.

Lois Silverman addresses some of these reasons in her book *The Social Work of Museums*. Silverman makes an argument that museums offer various services that benefit the person, in various ways pertaining to the individual and the group. These services should extend to those with intellectual disabilities as well. Her first point is that of competence, in which she

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<sup>49</sup> Richard Sandell and Eithne Nightingale, eds. *Museums, Equality and Social Justice*



says “everyone needs to be effective at the things they aim to do,” and further says, “for others, however, the achievement of competence is complicated by individual difference, social exclusion, and/or limited opportunity.”<sup>50</sup> Adults with intellectual disabilities fall into all three categories. Though this group is considered a vulnerable population, not much is being done to include them into the mainstream via accommodations. As previously stated, a common misconception is that adults with various intellectual disabilities are perpetually child-like and have a mental age comparable to that of a child. This idea is ableist, and also suggests that children are a group that should be ignored or pushed aside if they do not understand certain concepts. There is the tendency in our culture to not take the time to explain concepts to those who may not understand them when presented a certain way. If the aim of a person with an intellectual disability is to attend a museum and look at the art, there are a number of barriers in the way, namely, the exhibition text, including wall labels. While the current trend of writing wall labels attempts to target the majority of museum visitors, people with limited knowledge of a topic, many labels still use jargon and difficult to understand words, phrases, and sentences that can be inaccessible for a number of different populations, including those with intellectual disabilities.

Silverman continues her argument by saying, “while communication competence is essential for everyone, some individuals may be at risk for its development because they lack access to relevant opportunities.”<sup>51</sup> Silverman believes that communication competence is a basic human need that can again be fostered in a museum setting. Going beyond adaptive wall labels, a guided tour would be useful in cultivating skills in self-expression. Docents and museum

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<sup>50</sup> Lois Silverman, *The Social Work of Museums* (New York: Routledge 2010), 48.

<sup>51</sup> Silverman, *The Social Work of Museums*, 49.

educators frequently give tours that ask visitors questions related to the art that rely on the visitor's own observations, including what they see and what they feel when looking at art. If guided tours were available specifically for people with intellectual disabilities, they could be adapted to ask questions in a way that inspires critical thinking while in a comfortable setting. Large groups that guided tours tend to have can be intimidating for anyone, let alone someone who may have difficulties with communicating, or who may have sensory difficulties. By providing a service for those with these difficulties, communication competence may be more successfully achieved.

Silverman also discusses the importance of membership and affiliation. She says, "Museum artifacts communicate shared meanings among group members. By viewing or discussing such objects, people can learn, remember, or affirm their sense of affiliation and membership, a frequent museum experience."<sup>52</sup> This, again, can be fostered through the museum by offering simple accommodations like designated guided tours and adapted labels.

In his book *Pedagogy of the Oppressed*, Paulo Freire says:

Any attempt to 'soften' the power of the oppressor in deference to the weakness of the oppressed almost always manifests itself in the form of false generosity...true generosity consists precisely in fighting to destroy the causes which nourish false charity...true generosity lies in striving so that these hands – whether of individuals or entire peoples – need be extended less and less in supplication, so that more and more they become human hands which work and, working, transform the world.<sup>53</sup>

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<sup>52</sup>Ibid., 55

<sup>53</sup> Paulo Freire, *Pedagogy of the Oppressed* (New York: Bloomsbury, 2000) 26-7.

Silverman, too, acknowledges the existence of oppressed groups, and in particular, the importance of membership and affiliation for those oppressed:

Political and social oppression can further reduce opportunities for affiliation and the expression of group membership. In such circumstances, museums can play a particularly profound role by educating people about the groups to which they belong, affirming their identity, and fostering self-esteem through engagement with collections, exhibits, mass media, and other means.<sup>54</sup>

How does this relate to the discussion of accommodations for adults with intellectual disabilities in art museums? This “false generosity” from Freire’s work relates to the idea that people with intellectual disabilities should be pitied and regarded as a “special” group that a museum is kind enough to help, rather than a group of visitors who should be regarded like other paying visitors, who just happen to need extra accommodations to fully access the collections. This relates to Smith, Ginley, and Goodwin’s argument mentioned above, that there needs to be a climate that fosters real and lasting change. Silverman argues that museums can create this climate by reframing their collections to reinforce different identities, including disability. By reinforcing elements of artists’ personal lives – their learning disabilities, their physical disabilities, or their mental health struggles – museum educators can create a connection between artists and visitors with intellectual disabilities.

Finally, Silverman discusses meaning-making. She says, “visitors experience and express their individuality through personal meaning-making, those subjective responses like opinions, evaluations, feelings, imagination, and memories that arise when they encounter museum objects and exhibits.”<sup>55</sup> This individuality is taken away from individuals with intellectual disabilities

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<sup>54</sup> Silverman, 55.

<sup>55</sup> Ibid., 57.

because they may not be able to achieve personal meaning-making without some help. Again, this should not solely be the responsibility of non-disabled family or friends of person with an intellectual disability, but of the museum, which exists to educate. Silverman warns that, “those who are socially isolated because of physiological or legal reasons are at extra risk since they lack opportunities to gain perspective or new views.”<sup>56</sup> Here, a guided tour would be especially useful, because docents regularly facilitate this process for non-disabled populations. A designated guided tour would allow this population to partake in meaning-making, which is beneficial, because it allows, as Silverman says, for gaining new perspectives.

People with intellectual disabilities are continually called a vulnerable population, yet not much is done to decrease their vulnerability, or address its sources. Simple solutions can lessen this feeling of vulnerability in a museum setting, which, as Silverman argues, may benefit the individual outside of the museum as well. Her argument for her book *The Social Work of Museums* is that museums can teach valuable life skills that allow a person to grow in their personal lives, to achieve confidence, and to learn more about themselves. This is a revolutionary way of thinking about museums. Why should those with intellectual disabilities be excluded from these benefits? Connie Martinez, a woman with an intellectual disability, told disability activists, “there’s no difference [between us and nondisabled people]. It’s just a tag we have; a tag. A person has a right to be out with everyone else. No one – no one – has a right to keep us out.”<sup>57</sup>

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<sup>56</sup> Ibid., 62

<sup>57</sup> Mary Johnson, ed. *People with Disabilities Explain It All For You*, 35

Janice Majewski and Lonnie Bunch argued in 1998 that museums needed to address the philosophical issues of, “abolishing the ‘meeting special needs’ veneer (i.e. doing just enough about accessibility to feel altruistic or legally compliant)” as well as “integrating sensory and cognitive access concerns in the exhibition development process.”<sup>58</sup> In their work, Majewski and Bunch have identified three layers to accessibility of an exhibition: access to the exhibition’s physical elements, access to the exhibition’s content, and access to reflections in an exhibition. The second and third tier are part of Silverman’s argument that being able to understand and think critically about exhibition content is part of the beneficial aspects of attending a museum. Majewski and Bunch agree that those with intellectual disabilities may not have access to the content of an exhibition and therefore will not be able to reflect deeply upon it, which is both detrimental to the individual and defeats the purpose of attending an exhibition in the first place. A key point in Majewski and Bunch’s argument is that the goal is not to “dumb down” exhibitions, as they put it, but to “offer a reasonable level of interaction to anyone interested in participating.”<sup>59</sup>

The United Nations (UN) Universal Declaration of Human Rights, written and ratified by countries including the United States in 1948, states in Article 26 that, “Everyone has the right to education...education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms.”<sup>60</sup> This is included in the Universal Declaration of Human Rights because the writers recognized that education can be a force for great change within a person. Further, Article 27 states, “Everyone has the right freely

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<sup>58</sup> Janice Majewski and Lonnie Bunch, “The Expanding Definition of Diversity: Accessibility and Disability Culture Issues in Museum Exhibitions,” *Curator*, September 1998

<sup>59</sup> Ibid.

<sup>60</sup> “Universal Declaration of Human Rights,” *United Nations*, accessed February 22, 2016, <http://www.un.org/en/universal-declaration-human-rights/>.

to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.”<sup>61</sup> If access to education and culture are basic human rights, and museums exist as cultural leaders and educators, then museums have the obligation to educate and serve all groups of people, not just certain groups. There is evidence via Silverman to suggest that educational opportunities offered by museums are beneficial to a person’s wellbeing and is, in many cases, an empowering action. And yet, museums don’t offer opportunities for adults with intellectual disabilities, and this lack of opportunity is rarely questioned.

The question to be asked is, “why do we not want to give people with intellectual disabilities the opportunity to empower themselves?” The answer is simple: we live in an ableist society. We do not believe that people with intellectual disabilities can handle being advocates for themselves, or make their own decisions, because of the lasting stigma of mental age. Mental age is so harmful because it permeates our perception of adults who have intellectual disabilities. We see them as a vulnerable population, as previously stated, and yet we are not willing to make the necessary steps to allow them to become empowered, whether that is through education, advocacy, or another avenue. This must be changed, and museums must reflect this change in perception.

### **Desire for Programs to Exist**

Though I did not execute my planned focus group, I am confident in my assertion that there is a desire and a demand for these programs to exist. In Chicago, there are countless social services for adults with intellectual disabilities. In addition to services provided by Arts of Life and Access Living, there are services like Esperanza Community Services and group living facilities like L’Arche, which has two Chicago area locations, and Misericordia. Esperanza

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<sup>61</sup> Ibid.

Community Services has an arts program, and often times recruits artist from Arts of Life to lead a class and instruct community members on artmaking. There is clearly a vibrant community of adults with intellectual disabilities in Chicago and the surrounding suburbs.

Access to art museums may seem like a low priority for people with intellectual disabilities and their advocates, but I would argue that this *is* an important issue, along the lines of employment opportunities and safety in group homes. By demanding that museums accommodate their needs, people with intellectual disabilities are demanding to be taken seriously as consumers of culture and leisure. Since the Industrial Revolution, leisure activities have become an important part of the lives of both children and adults. Leisure activities are already very limited to those with intellectual disabilities, due to their living situations or other similar factors. These activities are closely monitored and guided, with staff members at group homes choosing activities for them. By demanding that museums open its doors to them, they are taking control of their own interests. There are communities of artists with intellectual disabilities all over the country, and undoubtedly have a great interest in visiting art museums to see their favorite artist's work or to gain inspiration.

By creating services for these artists, and others who are not artists but have an interest in art, museums are sending the message that they value their time, that they recognize them as serious consumers of art who want to learn along with the hundreds of thousands of children, teens, and adults that visit art museums every day. Adults with intellectual disabilities want to come to museums to learn, and that, in my opinion, is reason enough to create accommodations for them.

### **Why Are Accommodations Not in Place?**

Given that there are numerous reasons provided that museums have a responsibility to provide, at the very least, accommodations, and that there are a number of ways in which museums can reasonably accommodate visitors with intellectual disabilities, why there are not more institutions creating these accommodations and programs that would directly benefit intellectually disabled adults?

### **Lack of Money and Resources**

Being mostly nonprofit organizations, museums struggle to find the financial means to launch new programs and create positions that would allow them to become more inclusive. Museums, especially smaller museums, are often understaffed and overworked, with one person juggling multiple jobs. If approached with this core question, “why are there not more accommodations in place for intellectually disabled visitors”, a predictable response has been “we don’t have the money or resources to do so” in my casual conversations with museum workers.

While this is a valid and understandable reason, this problem is not without solutions. A number of grants are available that would solve this fundamental and very real problem museums face. Grants are available through a number of federal and private organizations, like the National Endowment for the Arts (NEA) and MetLife offer grants that pertain to accessibility and underserved populations. One such example of a NEA grant is the Challenge America grant, which, “offers support...for projects that extend the reach of the arts to underserved populations – those whose opportunities to experience the arts are limited by geography, ethnicity,



economics, or disability.”<sup>62</sup> An institution could use the grant money to partially fund a position that primarily focuses on greater accessibility for the museum, or to fund a project led by existing staff members. Other institutions, like the Institute of Museum and Library Services, offer grants that can pertain to creating accessibility programming and accommodations. The Museums for America grant, for example, is awarded to institutions that create projects “that strengthen the ability of an individual museum to serve its public.”<sup>63</sup>

Before an institution is awarded a grant, it must understand what needs must be met. This can be a daunting task, because there are a number of ways to accommodate different disabilities to ensure that each person who enters the museum can access the collections and services it provides. However, there are a number of resources that exist for this purpose. The Chicago Cultural Accessibility Consortium (CCAC) exists to answer any questions museums and other cultural institutions may have when beginning to think more deeply about accessibility. Though based in Chicago, the work produced by the group is not necessarily limited to the Chicago area, but can be translated to other locations across the U.S. The CCAC’s online archive includes documents from past events as well as video recordings of them. These events have included: “Getting Down to Business: Creating an Access Plan”, “Funding Accessibility”, “The Elements of Outreach: Strategic Marketing to the Disability Community”, and “Providing Programs and Services for Visitors with Various Cognitive and Behavioral Disabilities”, among others.<sup>64</sup>

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<sup>62</sup> “Challenge America Grant Program Description,” *National Endowment for the Arts*, accessed January 10, 2016, <https://www.arts.gov/grants-organizations/challenge-america/grant-program-description>.

<sup>63</sup> “Museums for America,” *Institute of Museum and Library Services*, accessed January 10, 2016, <https://www.ims.gov/grants/available/museums-america?GrantId=11>.

<sup>64</sup> “Archives,” *Chicago Cultural Accessibility Consortium*, accessed January 10, 2016, <http://www.chicagoculturalaccess.org/archives.html>.

The CCAC's archive can be utilized by any institution, and the archive is constantly expanding to cover different aspects of creating an accessibility plan for cultural institutions including libraries, theaters, zoos, and museums. Support for museums in New York City also exists through the Museum Access Consortium (MAC), which "strives to enable people with disabilities to access cultural facilities of all types."<sup>65</sup> They "define accessibility broadly, to include architectural, physical, programmatic, communication, attitudinal and other forms of access."<sup>66</sup> The MAC, like the CCAC, have an archive of past workshops and professional development podcasts with such titles as "Adults on the Autism Spectrum Share Their Museum Experiences", "ADA Update and Technical Assistance Session", and "Welcoming Families with Disabilities: Parents Speak".<sup>67</sup> Though these podcasts are dated between 2007 and 2013 and the archive is no longer being updated, the information provided may be a start for museums to begin to understand what accessibility entails. These two resources are both accessible to museums with internet access and free of charge, making them excellent resources to utilize.

Another possibility for museums to gain understanding for what accommodations need to be put in place is to hold a series of focus groups, much like the ones I hoped to hold for this research. Smith, Ginley, and Goodwin state, "disabled people remain poorly consulted on improvements and temporary, ill-thought-through (and often ineffective) attempts to overcome poor access are often introduced in place of long-term solutions."<sup>68</sup> Holding occasional focus groups to check in on the efficacy of a new program or accommodation put in place would be a solution to many longevity problems museums face when creating these new initiatives to make

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<sup>65</sup> "Museum Access Consortium," *City Access New York*, accessed January 10, 2016, <http://www.cityaccessny.org/mac.php>.

<sup>66</sup> Ibid.

<sup>67</sup> Ibid.

<sup>68</sup> Sandell and Nightingale, eds. *Museums, Equality and Social Justice*

their institutions more accessible. As mentioned previously, the only sure way to understand what needs the intellectually disabled community has is to ask the community and their advocates themselves.

### **Perceived Lack of Interest from the Community**

As previously stated, it is highly unlikely that accommodations and programs for this population don't exist because museum administrators and educators are maliciously excluding them purposefully. It is much more likely that they see these programs as low priority, because there is not more vocal outcry from the community to put these programs in place.

Museums must make difficult choices on a daily basis of where to allocate funds from and where funds should be put once raised. Directors and executive boards regularly decide whether to approve or reject proposals for exhibitions and programs from curators and educators. If there is no obvious pressure from a certain community to be represented in museum programming, it is very likely that they will be forgotten and pushed to the side. However, it should not be the responsibility of underrepresented communities to bring themselves to the museum's attention, but the museum's responsibility to reflect the diversity of our country.

By recognizing that adults with intellectual disabilities have interests in art, museums, and learning, museum workers are giving them respect that so often is not given to them. They are treating them as equals. By continuing to ignore them, museums are sending the message that only those with a certain intelligence level can understand art. In my conversations with artists at Arts of Life about their art, they have continually said to me, "It doesn't matter what I think it is about, it only matters what you think it is about." These artists understand the importance of personal meaning-making. Why don't art museum professionals and, in many cases, other

artists? Museums should be providing personal meaning-making opportunities for all of their visitors for all of the reasons mentioned above. If these institutions provide services and experiences for new audiences, new audiences will take advantage of these institutions.

### **Lasting Stigma that Museums are for the Elite**

In her essay “Museums and radicals: A history of emergencies”, Linda Nochlin states that, in part, “the creation of the museum was a token of art’s impotence, its final severance from the social structure, setting it apart, like religion for weekend.”<sup>69</sup> Later, Nochlin says, “[the museum allowed] to all a share of the cultural manna which had formerly been the food of a privileged few. As the shrine of an elitist religion and ... a utilitarian instrument for democratic education, the museum may be said to have suffered from schizophrenia from the start.”<sup>70</sup> Ableist language aside (the use of “schizophrenia” here is both an incorrect use of the word, as she meant that the museum’s identities seem to be at polar opposite ends of a political spectrum, and is an inappropriate use of it, as schizophrenia is a mental health condition, not something an institution can “suffer” from), Nochlin is referring to the revolutionary nature of museums, specifically art museums, in that they publicized private collections held by royal families for centuries. She is also discussing the idea that these institutions are for the educated, because those are the only population who will act “appropriately” and understand the collections. This idea still has power today, though many museum educators are trying to confront and destroy it. In the 2012 Survey of Public Participation in the Arts (SPPA) conducted by the NEA, it was found that whites made up the largest percentage of museum visitors (roughly 24%), and those

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<sup>69</sup> Linda Nochlin, “Museums and radicals: A history of emergencies” (Art In America, Inc, 1971) 1.

<sup>70</sup> Ibid.

with graduate degrees were the overwhelming majority of visitors at 49.3%.<sup>71</sup> This view of museums clearly has an impact on visitor trends, with many viewing museums as only a place in which educated, white visitors can relate. This limits an institution's audience, and therefore, its income. Though educators are attempting to create more user-friendly environments, there may be a lingering assumption that some places, like art museums, simply are not "for" some people. The American Alliance of Museums (AAM) attempts to confront these assumptions by creating a museum "fact sheet", in which the AAM states that museums serve the public:

Many museums offer programs tailored to veterans and military families...some museums invite veterans to tell first-hand accounts of events in our nation's history or work with veterans to address post-traumatic stress disorder.

Museums also provide many social services, including programs for children on the autism spectrum, English as a Second Language classes and programs for older adults with Alzheimer's or other cognitive impairments. Some museums also facilitate job training programs, provide vegetable gardens for low-income communities and serve as locations for supervised visits through the family court system.

Museums preserve and protect more than a billion objects and help communities better understand and appreciate cultural diversity.<sup>72</sup>

It is evident that museum programming and education efforts are trying to reach out to broader audiences to both educate and serve more diverse communities than graduate school-educated white individuals between the ages of 45 and 65. However, is this mission at odds with curatorial departments, particularly in art museums? The language of labels can be inaccessible to many, including those whose reading comprehension is at a lower level than the average visitor. This

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<sup>71</sup> "How A Nation Engages with Art," *National Endowment for the Arts*, accessed February 27, 2016, <https://www.arts.gov/sites/default/files/highlights-from-2012-sppa-revised-oct-2015.pdf>.

<sup>72</sup> "Museum Facts," *American Alliance of Museums*, accessed February 27, 2016, <http://www.aam-us.org/about-museums/museum-facts>.

population, as previously discussed, can include children, English language learners, and those with intellectual disabilities. There is a disconnect between the changing mission of museums, one that is more oriented in serving the publics of their geographic location, and curatorial departments within these museums. Art museums must hire curators that have similar goals as the education and programming departments or encourage collaboration between curatorial and education departments, or else this trend of fewer and more niche visitors will continue. This robs potential visitors of the chance to participate in and learn from a cultural experience in their neighborhood or city, and hurts the museum, if not anything but financially.

## Conclusion

Majewski and Bunch ask in their article, “Am I destroying an experience for the majority by catering to the minority?”<sup>73</sup> The answer is an absolute and resounding no. Many programs and accommodations provided for people with disabilities can be used and be beneficial for people without disabilities. For example, the Art Institute of Chicago offers ASL gallery talks that are well attended by hearing and Deaf people alike. Tours for blind visitors and visitors with low vision can provide greater insight on the visuals of a painting or sculpture for seeing people. Direct language provided in adaptive labels can be useful for those who are not familiar with art or who are intimidated by the long and sometimes confusing labels. Often times, accommodations meant for people with disabilities are utilized by people without disabilities and are often more comfortable for all.

Museums should be offering programs for people with intellectual disabilities that are as exciting as those provided for those without intellectual disabilities. Community label writing initiatives (in which members of a given community can be part of the label writing process of new or existing objects in the collection) can be a way to engage this population with the collection, give them opportunity for personal meaning making, and enable them to create labels that have the potential to be more accessible - and interesting - than the ones provided by only museum workers. Focus groups can also be utilized to create a conversation around museum accessibility, ensuring that the accommodations put in place are truly accessible. These focus groups can also be used to brainstorm new ideas for accommodations, as there may be a barrier

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<sup>73</sup> Majewski and Bunch, “The Expanding Definition of Diversity: Accessibility and Disability Culture Issues in Museum Exhibitions”

that museum workers did not anticipate. The opportunities for growth are endless because so little is being done right now. This is an exciting opportunity for museums to try something new and to reach a new audience.

As previously stated, museums have a tremendous amount of power in our society. They are symbols of culture and of learning. Because of this position, they have the responsibility to be leaders in serving those who find themselves at the margins of society not considered or represented in an increasingly diverse world – low income individuals and families, LGBTQ+ people, and people with disabilities. This can range from creating exhibitions surrounding issues important to these groups or others like them to creating programming targeting certain demographics. By including these groups in the makeup of museums and their educational efforts, others can learn more about these groups. I wholeheartedly believe that bigotry and prejudice comes from a lack of understanding, and though museums cannot completely erase prejudice, they can be leaders in starting conversations surrounding these populations.

Including people with disabilities, especially people with intellectual disabilities, in the conversation of art and culture is vital in order for this population to be accepted as equals. A learning difference is no excuse to exclude an entire group of people from understanding and enjoying a museum's collection. Not only is it detrimental to a museum's pockets to exclude groups, but it is detrimental to a person's wellbeing. Lois Silverman argues that making personal connections with art and coming to personal conclusions about what an art object means can be an esteem building activity. It allows a person to have a deeper connection with art. Adults with intellectual disabilities are more than capable of making these connections and seeing themselves



in art, as they have the same emotional intelligence as anyone else. It may take a bit more effort for them to come to these conclusions, but they are able to do so, and should be given every opportunity to experience art the same way as everyone else.

Adults with intellectual disabilities are adults and should be treated as such. They experience prejudice that leads others to treat them without the respect that they would treat another because of their IQ level. Art museums and other cultural institutions ignore this group for a variety of reasons, including a perceived lack of resources, assumed lack of interest from the community, and the lasting assumption that art museums are for the elite, that only certain people are welcome within its walls. However, not only *should* museums provide services for people with intellectual disabilities, they *must*. They are legally obligated to under the ADA, museums can provide beneficial services that contribute to a person's emotional well-being, and there is a desire from the country's vibrant community of adults with intellectual disabilities for these services to be put in place. Museums have the capacity to do great things. It is time for them to live up to their potential.

FIGURE 1



Piero del Pollaiuolo

Profile Portrait of a Young Lady

1465

Oil on Wood

FIGURE 2



Alexandros of Antioch

Venus de Milo

Between 130 and 100 BCE

Marble

FIGURE 3



Chris Rush

Swim II

n.d.

unknown medium

FIGURE 4



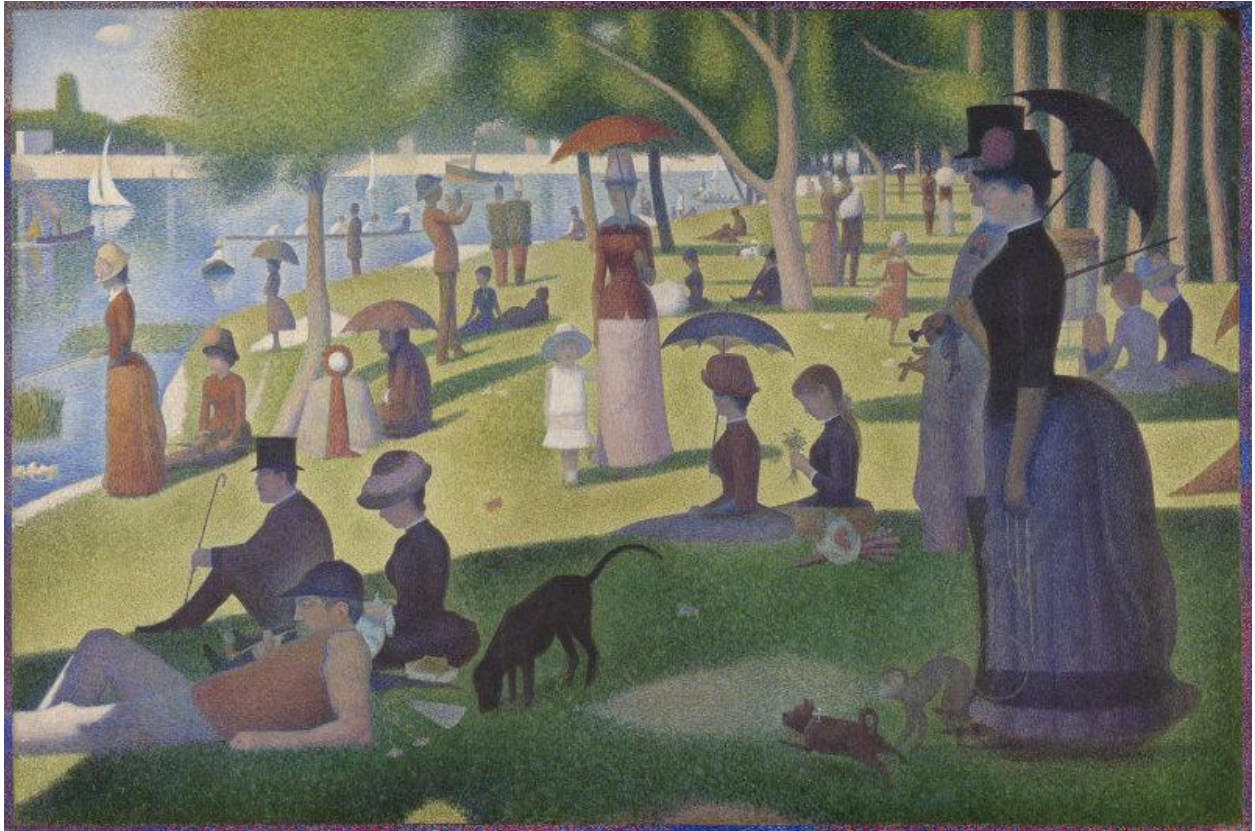
Marc Quinn

Alison Lapper Pregnant

2005

Unknown medium

FIGURE 5



Georges Seurat

A Sunday on La Grande Jatte

1884-1886

Oil on canvas

APPENDIX A

UNIVERSITY OF ILLINOIS  
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)  
Office of the Vice Chancellor for Research (MC 672)  
203 Administrative Office Building  
1737 West Polk Street  
Chicago, Illinois 60612-7227

**Request for Modifications and/or Information**

**Expedited Review**

**Initial Review (Response to Modifications)**

April 28, 2016

Courtney Sass, BA  
School of Art & Art History  
929 W. Harrison St.  
M/C 033  
Chicago, IL



RE: **Research Protocol # 2015-**  
**“Programs for Adult with Intellectual Disabilities in Art Museums”**

Dear Ms. Sass:

Your Initial Review application (Response to Modifications), received on April 13, 2016, was reviewed by members of the Institutional Review Board (IRB) # 2 under expedited review procedures [45 CFR 46.110(b)(2)] on April 21, 2016. It was determined that modifications and/or additional information about the research are required. The IRB requests the following:

1. Issues regarding research protocol and /or research protocol application:

1.1 *Initial Review application:*

1.1.2 (#1.1.4 in previous letter): The Board strongly encourages the investigators to do one of the following with regard to obtaining subjects' names prior to the focus group, particularly if the important issue is the need for a final count of how many focus group members to expect:

(a) collect the names and contact information of the potential subjects and request a waiver of consent for this under Section XVII.B OR

(b) have the date and time of the focus group communicated to the potential subjects but do not collect their names and contact information and encourage them to contact the investigators if there is a problem or question.

1.1.3 (#1.1.6 in previous letter): Please note that the subjects will not be anonymous and revise all language to state that the data will be confidential.

1.1.4 (#1.1.11 and #1.1.13 in previous letter): The Board strongly recommends that subject first names and contact information be collected, and a waiver

of consent be requested for this purpose in Section XVII.B; the alternative procedures proposed are unnecessarily confusing and convoluted.

1.2 (#1.2 in previous letter): Please note that it appears that non-UIC personnel will recruit, screen, and consent subjects. If so, kindly provide their investigator training or other qualifications for conducting research and interacting with research subjects.

1.3 *Appendix V:*

1.3.1 (#1.3.2 in previous letter): Please clarify whether there is a research subject - not a client, staff, and/or volunteer - screening process in place on the Ages of Life website. If so, kindly provide a copy of this as it will be considered research subject recruitment material.

1.3.2 (#1.3.4 and #1.4.3 in previous letter): Please verify that consent documents will be returned to/collected by non-UIC personnel and that non-UIC personnel will verify, using non-UIC agency records, that a Legally Authorized Representative (LAR) has signed the document if the subject does not have the capacity to consent for themselves.

1.3.3 (#1.3.5 in previous letter): Please note that Page 4.3 now states that there are both no risks for the research, and that breaches of privacy and/or confidentiality are risks of the research. This is contradictory.

2. Issues regarding the informed consent process and/or document:

2.1 Please submit clean copies of the following documents with the revisions incorporated and the highlighting/strikethroughs removed, as all three copies of the documents



submitted with the last response had highlights/strikethroughs and cannot be stamped with these editorial tracking marks:

Recruitment Materials Text, version 4, 3/15/2016

Consent Form for Adults with Intellectual Disabilities, version 4, 3/14/2016

Guardian Consent Forms, version 4, 3/14/2016

2.2 *Recruitment Materials Text:*

2.2.1 (#2.6.1 in previous letter and #1.1.2 and #1.1.4 above): Please consider obtaining potential subject names and contact information, with a waiver of consent, and revise the language regarding subject initials and the number of subjects in this script/text.

2.2.2 (#2.6.3 in previous letter): Please clarify why and how the investigators will contact the LAR directly, as this question from the previous letter was not answered.

2.3 *Assent Form:* Please review the document and consistently use the term parent/guardian instead of switching between parent and guardian in the document; this may make it seem as if two different individuals will be asked to give permission for the subject to participate in the research.

2.4 *Consent Forms for Adults with Intellectual Disabilities:* Please note that a disabilities and human development reviewer has pointed out that the language used in this document may be too sophisticated for many I/DD subjects and consider either revising this document or using only the assent form for this population.

When submitting your response provide **1 original and 2 collated copies** (3 total) of the following:

1. A cover letter that references this letter (date) and that responds to each specific item by listing the IRB's requirements from that letter. Use the same numbering system as in the IRB's letter and list your responses after each item.
2. A copy of this letter.
3. For modifications that involve the research protocol and/or research protocol application form:
  - a. Provide the revised research protocol and/or research protocol application with the modifications and information incorporated.
  - b. **Please highlight** or shade the additions and ~~strike through~~ the deletions on **each of the three (3) copies**.
  - c. Include the next sequential **version number and date on each page**.

4. For issues that involve the informed consent document(s) and/or consent process:
- a. Provide **one original and two (2) copies** of each revised informed consent document.
  - b. On **two (2) copies**, please **highlight** or shade the additions and ~~strike through~~ the deletions.
  - c. Leave the **original unmarked** so that it can be date-stamped and returned to you.
  - d. Leave sufficient blank space for the IRB approval stamp (2-1/2 inches wide by 1-1/2 inches high) in the upper right corner of the first page.
  - e. Include a **short descriptor** (to describe each document and differentiate among various documents in the same research protocol) in the footer of each page.
  - f. Include the next sequential **version number and date** in the footer of each page.
  - g. Be sure the pages are numbered: Page 1 of #, Page 2 of #.

The IRB has determined that your response to these required modifications may be reviewed under expedited review procedures without being scheduled for review at a convened IRB meeting. Based on your response, the IRB has the right to ask further questions, seek additional information, require further modifications, or refer your response to the convened IRB.

Please note that you *may not* initiate the research, including the recruitment of subjects, until you receive a *written notice of IRB approval* that will include the date-stamped informed consent documents to use when seeking consent from subjects.

If you do not respond to the IRB's requests within 90 days of this letter, your research protocol submission will be automatically withdrawn from the review process and the IRB will not take any further action.

If you have any questions or need further help, please contact the OPRS office at [REDACTED] or me [REDACTED]. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

## APPENDIX B

### University of Illinois at Chicago

#### Research Information and Consent for Participation in Social Behavioral Research

##### Art Museums and Programs for Adults with Intellectual Disabilities

You are being asked to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator: Courtney Sass

Department and Institution: Museum and Exhibition Studies, University of Illinois at Chicago

Contact information: [REDACTED]

Faculty Advisor [REDACTED]

#### **Why am I being asked?**

You are being asked to be a subject in a research study about art museums and their programming for adults with intellectual disabilities. You have been asked to participate in the research because of your personal experiences with disability.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois at Chicago. **If you decide to participate, you are free to withdraw at any time without affecting that relationship.**

#### **What procedures are involved?**

This research will be performed through a focus group at The Arts of Life. You will need to come to this site one time. This study will only last one day. This focus group will be recorded for research purposes.

This visit will take about one and one half hours. The study will involve one questionnaire and questions asked of you regarding your experience with museums.

#### **What is the purpose of this research?**

The purpose of this research is to find out problems that adults with intellectual disabilities face when going to a museum as well as find out obstacles museums face in creating programs targeted towards this or similar populations.

#### **What are the potential risks and discomforts?**

Potential risks and discomforts are minimal. There is the risk that a breach of privacy (others will know the subject is participating in research) and confidentiality (accidental disclosure of identifiable data) may occur.

#### **What about privacy and confidentiality?**

The people who will know that you are a research subject are members of the research team,

other members of the focus group, and members of Arts of Life. Otherwise information about you will only be disclosed to others with your written permission, or if necessary to protect your rights or welfare (for example, if you are injured and need emergency care or when the UIC Office for the Protection of Research Subjects monitors the research or consent process) or if required by law. Although we ask everyone in the group to respect everyone’s privacy and confidentiality, and not to identify anyone in the group or repeat what is said during the group discussion, please remember that other participants in the group may accidentally disclose what was said.

Though this session will be recorded, only the head researcher will have access to it. This will be stored on a locked device, and will be deleted after it is transcribed. The transcribed material will be kept in a locked drawer that only the head researcher will have access to.

**Can I withdraw or be removed from the study?**

If you decide to participate, you are free to stop participating at any time.

**Who should I contact if I have questions?**

You can contact the investigator, Courtney Sass, at [REDACTED] if you have any questions regarding the study. You can also contact faculty advisor [REDACTED].

**What are my rights as a research subject?**

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at [REDACTED] or e-mail OPRS [REDACTED].

**Remember:**

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name

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Signature of principal investigator

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Date

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Printed Name of principal investigator

Questions to be asked after reading the consent form and explaining what each section means:

Who can you ask if you have questions?

Why are you being asked to help me with my research?

Can you stop answering questions if you don't feel like talking anymore?

What procedures are we doing today? What does a focus group mean?

Why am I doing this research?

What are some risks of this focus group?

Are we supposed to talk about what other people said outside of the focus group?

(reminder that someone may accidentally say something they're not supposed to someone not in the focus group)

If you don't feel like answering questions anymore and decide to leave, will there be any consequences?

## University of Illinois at Chicago

### Research Information and Permission for Participation in Social Behavioral Research

#### Art Museums and Programs for Adults with Intellectual Disabilities

You are being asked to permit your dependent to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you and your dependent to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator: Courtney Sass

Department and Institution: Museum and Exhibition Studies, University of Illinois at Chicago

Contact information: [REDACTED]

Faculty Advisor: [REDACTED]

#### **Why am I being asked?**

You are being asked to allow your dependent to be a subject in a research study about art museums and their programming for adults with intellectual disabilities. Your dependent has been asked to participate in the research because of their personal experiences with disability.

Participation in this research is voluntary. Your decision whether or not to allow their participation will not affect their current or future dealings with the University of Illinois at Chicago. If you allow your dependent to participate, you are free to withdraw them at any time without affecting that relationship.

#### **What procedures are involved?**

This research will be performed through a focus group at the (University of Illinois at Chicago, in Henry Hall Room [TBD]) / (The Arts of Life). They will need to come to this site one time. This study will only last one day. This focus group will be recorded for research purposes. This visit will take about one and one half hours. The study will involve one questionnaire and questions asked of your dependent regarding ~~you~~ their experience with museums.

#### **What is the purpose of this research?**

The purpose of this research is to find out problems that adults with intellectual disabilities face when going to a museum as well as find out obstacles museums face in creating programs targeted towards this or similar populations.

#### **What are the potential risks and discomforts?**

Potential risks and discomforts are minimal. There is the risk that a breach of privacy (others will know the subject is participating in research) and confidentiality (accidental disclosure of identifiable data) may occur.

#### **What about privacy and confidentiality?**

The people who will know that your dependent is a research subject are members of the research team, other members of the focus group, and other members of Arts of Life ~~or Access Living~~.

Otherwise information about them will only be disclosed to others with your written permission, or if necessary to protect their rights or welfare (for example, if they are injured and need emergency care or when the UIC Office for the Protection of Research Subjects monitors the research or consent process) or if required by law. Although we ask everyone in the group to respect everyone’s privacy and confidentiality, and not to identify anyone in the group or repeat what is said during the group discussion, please remember that other participants in the group may accidentally disclose what was said.

Though this session will be recorded, only the head researcher will have access to it. This will be stored on a locked device, and will be deleted after it is transcribed. The transcribed material will be kept in a locked drawer that only the head researcher will have access to.

**Can I withdraw or be removed from the study?**

If you allow your dependent to participate, you are free to stop their participation at any time

**Who should I contact if I have questions?**

You can contact the investigator, Courtney Sass, at [REDACTED] if you have any questions regarding the study. You can also contact faculty advisor [REDACTED].

**What are my rights as a research subject?**

If you feel your dependent has not been treated according to the descriptions in this form, or if you have any questions about their rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at [REDACTED] or e-mail OPRS [REDACTED].

**Remember:**

Your dependent’s participation in this research is voluntary. Your decision whether or not to allow their participation will not affect their current or future relations with the University. If you decide to allow participation, you are free to withdraw them at any time without affecting that relationship.

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to allow my dependent to participate in this research. I will be given a copy of this signed and dated form.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_



Printed Name

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Signature of Investigator

---

Date

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Printed Name of Investigator

## **ASSENT TO PARTICIPATE IN RESEARCH**

### **Accommodations for People with Intellectual Disabilities in Art Museums**

1. My name is Courtney Sass.
2. We are asking you to take part in a research study because we are trying to learn more about how museums can make their buildings more comfortable for people with intellectual disabilities.
3. If you agree to be in this study you will be asked some questions about how you go to museums, what you see when you go to museums, and anything you don't like about museums that you would want to change.
4. There is only one risk of this study, which is a breach of confidentiality or privacy. This means that someone in this group may accidentally talk about things you've said during this focus group to other people. We want to make sure that this doesn't happen, so please try not to talk about our conversation with other people.
5. A benefit of this study is that some of your suggestions on how to make museums more comfortable and accessible may be taken by some museums, or give a good idea of where to start with some of these changes.
6. Please talk this over with your guardian before you decide whether or not to participate. We will also ask your guardian to give their permission for you to take part in this study if you have one. But even if your guardians (if you have one) say "yes" you can still decide not to do this.
- . If you don't want to be in this study, you don't have to participate. Remember, being in this study is up to you and no one will be upset if you don't want to participate or even if you change your mind later and want to stop.

8. You can ask any questions that you have about the study. If you have a question later that you didn't think of now, you can call me at [REDACTED] or ask me next time.
  
9. Signing your name at the bottom means that you agree to be in this study. You and your guardian (if you have one) will be given a copy of this form after you have signed it.

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Name of Subject

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Date

---

Signature

## Demographic Questionnaire

Age: \_\_\_\_\_

Gender: Male \_\_\_\_ Female \_\_\_\_ Other \_\_\_\_

Ethnicity: White \_\_\_\_  
Hispanic or Latino \_\_\_\_  
Black or African American \_\_\_\_  
Native American or American Indian \_\_\_\_  
Asian/Pacific Islander \_\_\_\_  
Other \_\_\_\_  
Prefer not to answer \_\_\_\_

### Sample Questions for Focus Group:

Although we ask everyone in the group to respect everyone's privacy and confidentiality, and not to identify anyone in the group or repeat what is said during the group discussion, please remember that other participants in the group may accidentally disclose what was said.

How often do you go to an art museum?

How do you get there? Is it hard to get there?

Do you like going to museums?

Is there anything that's hard about being in a museum?

Do you think museums are accessible to people with disabilities?

Is there something you wish museums would do that they don't already?

If you were to build your own museum, what would it have for people with disabilities?

Are museums usually loud or quiet? Do you like loud places or quiet places?

Do you read the wall labels? Are they easy or hard to understand?

What would help you have more fun at an art museum?

Who do you go with to museums?

What do you like to look at when you go to an art museum?

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