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## Accessibility to Art Museums and Museum Education Programs for an Elderly

Population with Dementia

By

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For Honors in Art History

May 3, 2017

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#### Abstract

This thesis focuses on the ways in which exposure to visual art at the Samek Art Museum can improve the wellbeing of people with dementia. This thesis argues that the practices of contemporary museum education and the discipline of Disability Studies have largely been running parallel to each other since the rise of Disability Studies in the 1980s. Museum educators and their institutions have been conditioned to concern themselves with only the able-minded and able-bodied. However, Disability Study scholars force us to question this status quo through their writings about normalcy and its flaws. I argue that if museums were able to alter what they consider to be normal, then they would be more inviting places to people with all forms of disability. My thesis encourages the Samek Art Museum to alter what they have considered to be normal. For this project, I collaborated with the Museum to create three museum visiting sessions for residents both with and without dementia from local long term care facilities. During these sessions, residents engaged in conversations about various artworks from the collection, led by a gallery teacher. The goal of these visits was to provide the residents with a museum experience outside of their everyday activities and to improve their short term wellbeing. To determine whether or not the participants were positively affected by the art viewing experience, I administered questionnaires assessing wellbeing and attitudes towards art prior to the visit and then immediately following. The results of the small scale quantitative study indicated that participants did not have any significant increase or decrease in their scores after the art viewing experience; however, the qualitative comments did show an enjoyment of their experience and a desire to learn

more about art.

In the future, this research should be conducted again with a larger sample size and other museums, besides the Samek, should engage their local population with dementia to improve their wellbeing. People with cognitive impairments deserve to be included in society and not stigmatized.

### Introduction

The concept for this thesis project was formulated in the spring of 2016 when I determined that I wanted to explore a connection between art history and psychology. I had been previously working on a project with Professor Halpern in the Psychology Department on neuroaesthetics relating to music and I became fascinated by the topic. As an art history major, I wanted to see if I could find a project that was similar but instead involved the visual arts. Therefore, I began to brainstorm with Professor Halpern and she suggested exploring the Meet Me at MoMA program at the Museum of Modern Art (MoMA) in New York City, New York. My preliminary research of the program revealed that it engages people with Alzheimer's, a type of dementia, and their caregivers in an art viewing experience at the MoMA to improve the participant's affect and wellbeing. I then approached Professor Rothman with the concept of focusing on accessibility to art and art museums which led to this thesis project.

Through our discussions and brainstorming sessions several ideas emerged about how to connect Meet Me at MoMA and art history. Specifically, it was determined that engaging in a discussion about the history of art museums and their audiences, and the scholarly field of Disability Studies would properly address the issues of accessibility and art. However, I wanted to take the project further and I proposed creating a version of the MoMA program at the Samek Art Museum at Bucknell University in Lewisburg, Pennsylvania. This came to fruition in the spring of 2017 when local residents of long term care facilities were invited to the Samek Art Museum for a dialogical art viewing experience. The following thesis discusses the history of art museums and their audiences, Disability Studies, dementia, Meet Me at MoMA, and the program that was created at the Samek Art Museum which I entitled "Broadening Horizons".

Chapter one provides a history of art museums and their audiences. In this chapter, I argue that the purpose of art and the art museum has morphed to accommodate an ever-evolving audience with varying ability levels to combine preservation, education and leisure. Chapter two focuses on the scholarly field of Disability Studies, which is a field that seeks to eradicate social stigma and the social construct of disability. I argue that museum educators and institutional leaders can benefit from understanding Disability Studies to create more accepting and inclusive spaces for people with impairments. Chapter three provides information about dementia so that one can understand the nature of this disease and why it is so important that people with dementia remain engaged in society. Chapter four explores the Meet Me at MoMA program at length, and it includes results from a study that was conducted in 2008 which showed that the conversational art viewing experience offered at the MoMA positively impacted both the cognitively compromised person's affect and their caregiver's. In this chapter, I argue that it would be valuable to recreate this program at other museums, like the Samek, so that people from various geographic locations can experience a positive change in their affect and wellbeing. In chapter five, I explain why it is important for the Samek Art Museum to recreate a program like the one at the MoMA and I outline the version of the program that I proposed and executed. Additionally, this chapter includes the results of a small scale study that I conducted on the participants that visited the museum to see if their

affect positively changed after discussing several artworks. Following chapter five, there is a conclusion and then there are two appendices which include copies of the surveys given to the participants during my study.

### Chapter 1: The History of Art Museum Audiences

The focus of this thesis is the use of art to enrich the lives of adults with dementia. To understand the context in which museums have begun to reach out to this particular population, it is important to look back at the history of museums and their everexpanding efforts to reach out to a larger group of people. With an ever-evolving population, the museum purpose has shifted to combine preservation, education and leisure. The preservation aspect of the museum allows for ancient objects and works of art to continue living in modern times, thus allowing for museum goers to learn about previous civilizations through tangible objects. The educational aspect of a museum seeks to engage people in art and the culture in which it was made. This educational component is intimately related to the preservation purpose of a museum because people can learn about the objects by looking at the originals. The leisure component of the museum relates both preservation and education because without preservation, there would be no objects for the audience to see. This allows the viewer to walk through the museum at their own pace and to learn about a work of art by looking at it and reading the wall text without a formal tour or program. The leisure aspect of the museum allows for the imagination of the viewers to flow while walking through the museum because they can look at the artwork and impart their own ideas onto the artworks. Understanding how the purpose of an art museum has shifted from a strictly research institution to one that combines preservation, education and leisure is critical to accommodating the everexpanding audiences that go to museums.

To understand the museums of the modern day, their audiences and their purposes

of preservation, education and leisure, it is critical to understand the first museums, their audiences and their purposes. Some of the first museums can be linked to the Ancient Greeks who existed from around 2000 BC to 600 AD. The Greeks used the term "*mouseion*" (Mondello) meaning the "...seat of the Muses..." (Lewis 2000) to describe a place for meditation and reflection which was associated with temples. These spaces of the Ancient Greeks do not differ appreciably from the ones that we have today in the twenty-first century, because the artwork was displayed in a pinakotheke, "a picture gallery in ancient Greece and ancient Rome..." (Encyclopedia Britannica "Pinacotheca" 2008). The artwork was for the pleasure of the spiritual gods and goddess. The artwork's purpose was devotional and the only people that could see it were the artist, the god or goddess whose spirit dwelled in the building and the person who placed it there, most likely a priest. The display that the Ancient Greeks had is similar to contemporary museums; however today, the works of art no longer function as devotional objects and the viewing audience is much greater, including anyone who wants to see the artwork.

The Ancient Greek museums offered an art viewing experience for a very limited audience. The first use of the word 'museum', the Latin form of *mouseion*, representing the art institutions of today that combine preservation, education and leisure for audiences of all ages and ability levels, was during the Roman Empire. The museums of the Roman Empire were a place for philosophical conversations. To fulfill the purpose of a museum, Ptolemy I Soter founded the Museum at Alexandria in the third century BC. This museum served as a site for scholars to engage in scientific and literary studies, aligning with the educational purpose of modern museums. According to Strabo, a Greek geographer and historian, there were many buildings and lush gardens on the property. This complex was populated by scholars and learned people who wanted to expand their minds. Unfortunately, part the museum complex was destroyed by civil strife in the third century AD; however, it still remained an intellectual site because some education and research continued on the premises in buildings that were not destroyed until the fifth century AD ("Alexandrian Museum" 2006).

From the period of Ancient Greece until the fifteenth century, gods, goddesses and scholars were the viewers of art. Following that period, there was less of an emphasis on scholarship surrounding art and more of an emphasis on private collecting which involved buying up artwork from around the world and commissioning artwork for the private viewing pleasure of public leaders and wealthy civilians. According to Shearer West, an Art Historian, political leaders sought the commission of artworks to legitimize their power by connecting them with past rulers and successful time periods depending on the artist they chose and what they had depicted. Along with the art commissions to legitimize rulers, there was a debate that was sparked by the humanists about the purpose of the visual arts during the Renaissance (West 1996: 34). Humanists judged the visual arts in a similar way that they judged literature: based on its ability to communicate with the viewer or reader. This notion of communicating with the viewer through paintings and sculpture challenged artists and required them to think about how they could convey their feelings through the subject and ultimately to the viewer (West 1996: 37). Artists altered how they communicated with the viewer depending on the education of the patron. For example, if the artist was creating artwork for display in a private home

he/she would be able to use "learned or classical allusions, symbols and emblems..." (West 1996: 39). However, if they were creating art for the Church they would not be able to use the same symbols because not all people looking at the artwork would have the same level of education. Following upon this logic, West argues that with the rise of private galleries lined with commissioned artworks and museums for the elite, in government buildings and palaces, art was not readily accessible to the public. Therefore, in the late fifteenth century the gap between the elite and the poor grew in size (West 1996: 39). That is to say that the wealthy were accumulating more material goodsartworks that they had commissioned or purchased- while the poor were not, so the gap as it relates to material possessions and wealth grew. Additionally, the educational gap grew between the wealthy and the less fortunate because complicated symbols were used in artwork for the learned, like the Greek gods, goddesses, and the ancient Roman scholars. In contrast, art for less educated involved less complex symbolism. Complex symbolism can be considered to be related to mythology which might have only been understood by a select few, whereas less complex liturgical symbolism such as the dove used to represent the Holy Spirit was more widely understood as a part of the faith (Appleton and Bridges 1959: 32).

The gap that West refers to, was perpetuated by the elitist families of the Renaissance who privately commissioned artwork and served as patrons of art for the government. The most prominent of these families was the Medici family of Florence, Italy. The Medici's commissioned many works of art for their palace in Florence and country villas throughout the region of Tuscany, while also collecting art from outside of Italy. Inventories of their private collection from 1456 and 1463 documented intaglios, cameos, precious stones, and Byzantine icons. However, an inventory taken in 1465, showed that the collection had grown significantly in size in two years to include "...Flemish tapestries, musical instruments... and Cordovan leathers" (Bazin 1967: 44). Further documentation from 1492, when Lorenzo de' Medici died, revealed paintings and sculptures that were at one of their country villas, Villa Large. Several of the artists documented include Rogier van der Weyden and Jan van Eyck, both from the Netherlands showing the family's interest in Flemish paintings. Both of these artists created naturalistic artworks with both religious and non- religious subject matters rich in symbolism.

One can think about the works of art that the Medici family had as components of their own private museum or gallery. Therefore, we see that a Renaissance museum equated to a private familial art collection with commissioned and non- commissioned works of art. The purpose of their private museum was to please their family members and to show off their great wealth to their guests. Since the works of art were acquired for private viewing, the artist could include complex symbolism, representations of the family crest, and humanistic ideals of the time period because of the educated nature of the viewers. While the purpose of their museum involved preservation and leisure, education did not appear to be a priority.

Further evidence of a Medici family private collection comes with the documentation of Lorenzo Medici's collection of books and gems which were referred to as the "*museo dei codici e cimeli artistici*" (Bazin 1967: 44) which translates to the

"museum of codes and artistic memorabilia." Unpacking this translation reveals that, to Lorenzo Medici, a museum was one of symbols and artistic memorabilia, which is partially representative of twenty-first century museums. However, the audience was only the Medici family and their guests. Lorenzo Medici's concept of a museum can be seen as a place that preserves artwork and provides a leisure experience to the viewer, however there does not seem to offer an explicit educational component, which we will see in later museums. Therefore, Lorenzo Medici's museum does represent several of the modern goals of a museum, however it lacked the educational component. Arguably, given the learned audience, the educational component seems less important. Additionally, the symbols that were used in the artworks would have been things that the viewer would recognize and understand, thus reducing the educational value of the art.

The Medici collection, as previously stated was a private collection that was largely not on display to the public emphasizing the status of the family and their ability to commission and purchase artworks for their own leisure viewing. The public finally got to see the masterpieces in the Medici collection when it was given to the state in 1743 to be displayed for all people to see in the Uffizi Palace. The Uffizi Palace, which had been administrative offices, was given the Medici family collection when the last member of the family died, Anna Maria Luisa de' Medici. Her wish was that the collection would stay in Florence and the artworks "would remain as decoration for the State, for the utility of the Public and to attract the curiosity of Foreigners..." (History of the Uffizi Gallery). The artwork was finally displayed for the public at the Uffizi Gallery in 1769. This gallery space allowed for the artworks to be preserved and anyone could come and view the art. Viewing the art also became a leisure activity for the masses, previously only associated with the wealthy.

The exposure of the Medici family collection to the world in 1769 was not the first time that we see a private collection being shared with the public. In fact, in 1683 the University of Oxford was the first "corporate body to receive a private collection, erect a building to house it, and make it publicly available..." (Lewis 2000). The collection of Elias Ashmole included treasures from the Tradescant Collection and was given to the university under the condition that a building would be built to house it. The importance of the building was that it provided a place for the artwork to be preserved, a foundational purpose of modern museums. The building was named the Ashmolean Museum and was open to the public as well as the students and scholars at the university ("History of the Ashmolean" 2012). The experience that a person had at the Ashmolean Museum in the seventeenth century is very similar to what we experience today when we go to a museum: we have to pay to enter (at many museums), there are catalogs about artwork for purchase, and artwork lines the walls of the space. With that being said, the only thing that seems to have changed is the art that lines the walls and the people who pay to see it. That is to say that only people who can afford to go to a museum are fortunate enough to see the artwork. Therefore, even though the museum is open to the public and some museums are free, as we will see, those that charge an entrance fee can only be accessed by those with the monetary funds.

With the acquisition of a private collection by a corporate body completed in the seventeenth century and the rise of the museum as we know it today with the purposes of

preservation, education and creation of a leisure space in the eighteenth century, London, England became a cultural hub for the creation of more museums that were open to the public. The art that was displayed in these museums was influenced by the Enlightenment of the eighteenth century which focused on reason and rationality that could be achieved through a study of science. Thus, the art of this time reflected this rationality and it rejected the ideas of the Rococo, a style characterized by romance, pastel colors and flowing lines. Art of the Enlightenment sought to depict morality and right versus wrong. The emphasis on reason and science resulted in the government better understanding the importance of the preservation of art and antiquities. This led to the building of the British Museum in 1759 to house the art collections of British aristocrats such as Sir Hans Sloane ("History of the British Museum"). Access to the museum was free for the public, however people had to fill out an application for entrance into the museum because there were only a set number of tickets that they would gave out each day (Lewis 2000). According to the British Museum website, all people who were "...studious and curious..." ("History of the British Museum") were admitted into the museum. This demonstrates that the museum was open to the public, and those interested could visit. In the nineteenth century, "any person of a decent appearance" (Sloane qtd. in Alexander 1979: 45) could go to the museum during set visiting times. During this time "the Museum attracted crowds of all ages and social classes, particularly on public holidays" ("History of the British Museum"). Soon after the opening of the British Museum, the Louvre was opened in 1793 during the French Revolution and was thought of as one of the first national art museums (Alexander 1979: 23); however it was closed in May of

1796 because of "bad structural condition..." (Alexander 1979: 24) and it did not fully open "again until July 14, 1801" (Alexander 1979: 24). The British Museum and the Louvre mirrored the Ashmolean Museum of centuries before because of their openness to the public, their desire to preserve art, and the hope of education and leisure. Museums in Rome also appeared in the eighteenth century and the growing number of museums throughout Europe created a global desire to build similar places for conservation of antiquities everywhere.

Whereas the Louvre had to close down for a while and was not fully open to the public until 1801, the United States saw its first art museum in 1786 when the Philadelphia Museum (Peale's Museum) opened on July 18th of 1786 (Richardson et al. 1983: 18). Charles Willson Peale was an American "artist... scientist and... naturalist" (Hansen 2008). He was well known for his portraits of Revolutionaries, and little did he realize but he was a revolutionary himself when he opened the "first public museum of art and science in America" (Brigham qtd. in Hansen 2008). The museum grew out of his great desire to display a bone of a mastodon that he acquired in 1786, which was displayed in his painting room. People flocked to see his exhibition of this bone, resulting in a collection of other items and gifts to add to his museum. This was monumental in the United Stated because "he created the first marketing campaigns [and] the first solicitations for gifts to his museum" (Brigham qtd. in Hansen 2008). People could buy "an annual ticket to the museum" that cost one dollar, "and early members included everyone from presidents to congressman to merchants and skilled laborers" (Hansen 2008). The museum was very successful and his collection grew so quickly that it was

taken from Peale's house and shown in Independence Hall in Philadelphia, Pennsylvania for a period before it was broken up in the nineteenth century. The marketing campaign that Peale created engaged audiences who might not have known about the art museum prior to his advertisements, and whether they joined or not he offered them exposure to art. The eighteenth century brought extensive growth in the museum world because of the number of institutions that were opened and available to the public.

A critical shift occurred in the nineteenth century when numerous private collections became public. The collectors desired for their art to have a safe space where it could be housed, fostering the preservation purpose of an art museum. With the creation of a museum, art was no longer in the hands of the elite-like the Medici family, or limited to scholarly viewing, like during Ancient Roman times- but rather it was in the hands of the public who wanted to learn more. Museums were rapidly being built to accommodate the collections of both art and other objects including the Smithsonian in Washington D.C. (1858), the American Museum of Natural History (1869) and the Metropolitan Museum of Art (MET) (1870) both in New York City, New York. When the MET opened in 1870 part of its Mission Statement read that the museum was supposed to "encourag[e] and develop... the study of the fine arts, and the application of arts to manufacture and practical life, of advancing the general knowledge of kindred subjects, and, to that end, of furnishing popular instruction" ("About The Met"). This statement shows us the educational focus of the museum, which by the 1900s became the broad museum purpose of many institutions, shifting from research and devotion, as we saw with the Ancient Greeks, to education.

With the shift in museum purpose to one of education the museum became a space of "public enlightenment" (Alexander 1979: 12). The public enlightenment that Alexander is referring to is the democratic freedom that a person has when they become educated about a subject, in this case the subject is art. A key factor in understanding who the museum engaged to experience this public enlightenment comes from looking at who their audiences were for their educational programs. Beginning around 1905 the MET began gallery tours and lectures, "programs for visiting school groups, traveling exhibitions to schools, Saturday- morning story hours, and radio programs for handicapped children" (Alexander 1979: 34). In 1907, the Museum of Fine Arts in Boston hired its first docent to "help their visitors see the beauty of their collections" (Alexander 1979: 12). The creator of the term *docent*, Benjamin Ives Gilman, thought of this job as one that would "sharpen... the spiritual sight" ("The Museum Docent" 1977) of the visitor. Therefore, the docent would provide the viewer with some art historical background to help the viewer to better understand the artwork. The availability of the docent, seemingly, expanded the audiences because they knew that they could acquire knowledge about the art in addition to having a leisurely walk around the art museum.

These programs such as tours for children and the hiring of a docent altered the audience of museum goers and the purpose of art displayed in a museum. Museum audiences expanded to include children and all people interested in looking at and learning about art. Furthermore, twentieth century museums served as a space of leisure and education for members of the public, thus expanding upon the foundational audiences of previous museums and aligning with the educational purpose of the twentyfirst century museum. Now children were able to go to a museum for a tour as a school trip, art was able to be brought to them, and children who were handicapped could be engaged through listening to information about art and culture on the radio.

The art world of the twentieth century was a time of countless artistic movements, all experimental in nature, and focused on the individual artist rather than on schools of artists with similar training. These new artistic movements were all in response to ones that had come before them and/or were reflective of the state, which faced several large wars in the twentieth century. Artworks were no longer being commissioned like they had been during the time of the Medici so it allowed the artist to have greater agency over his or her work of art.

The evolving definition of art and the ever-expanding audiences of museums continues to grow in the twenty-first century. The art in the museums is educational, it provides the viewer with a challenge, and in some cases attacks societal issues head-on. Museums have grown to accommodate people with varying ability levels, however the museum can never be fully accessible to the masses. For example, the storage and library spaces are often closed off to the public and require special dispensation to enter, no matter your physical or mental ability level. The fact that no museum goer will ever have access to the entire museum, is something to recognize as we discuss the ever-expanding needs of the museum audience. Therefore, people who are impaired and those who are able, must remain in the same museum spaces, which in a way creates equity between the two groups. In addition, no matter one's ability level, the museum allows for individual reflection about a work of art and it can encourage conversation and the exchange of new perspectives, because not everyone will have the same ideas about a given work of art.

This space of reflection and the possibility for conversation makes the museum a leisurely place where people of varying statuses and abilities can spend the day surrounded by culture to enrich and challenge the mind. The leisure aspect of the museum relates to John Falk's discussion of the six criteria of leisure, first defined by Marilyn Hood. Each of which can be thought about through the eyes of someone who is disabled and their experience at the museum (Falk 2009: 49). The first criterion for leisure is being with people and socially interacting, which is critical for the disabled person to live well with their impairment (Hood 1989; Falk 1992: 16; Falk 2009: 48). Part of living well, especially with dementia, are the positive social interactions that one can have in a museum. Inclusive museum programs allow for people with impairments to be in an accepting environment where they can meet new people and enjoy the benefits of looking at art at the same time.

The second criterion is about making the experience worthwhile (Hood 1989; Falk 1992: 16; Falk 2009: 48), and going to the museum has been shown by Johnson et al. (2015) to improve wellbeing. The study conducted involved 66 early to middle-staged dementia patients and their caregivers. Each person participated in three tasks: "object handling, a refreshment break, and art viewing in small groups" (Johnson et al. 2015: 1). To monitor the hypothesized change in affect of the participants, each was given a visual analog scale allowing them to rate their wellbeing before and after the three tasks (Johnson et al. 2015: 1). The data showed that wellbeing increased throughout the session no matter in what order it was completed and that there was significant improvement in wellbeing after participating in the object handling and the art viewing session; however, there was no improvement after the refreshment break, which was meant to be a social time (Johnson et al. 2015). This study supports the notion that programs for people with dementia can positively impact its participants and improve their mood and wellbeing.

The next criterion is feeling comfortable in the environment (Hood 1989; Falk 1992: 16; Falk 2009: 48), which might take some time at first especially for people who have been stigmatized. However, through the structure of the programs and the guide there can be understanding and open mindedness which will reduce social stigma so that the environment can feel more inviting. The fourth criterion is to be open to the challenge of new experiences (Hood 1989; Falk 1992: 17; Falk 2009: 48), which relates to the previous one and feeling like you fit it. The last two I will combine: the ability to learn and the ability to participate actively (Hood 1989; Falk 1992: 17; Falk 2009: 48). Both of these are crucial to the person's experience in a museum, especially if they are on a tour. The job of the educator is to make sure that the participants are able to have conversations and have their ideas heard so that they can feel valued and a part of the dialog. The leisure nature of museums allows for both silent reflection and education.

The educational programs and tours that happen daily at museums across the world attract audiences of all ages and ability levels, with the caveat that not all people can access the museum at any given time. For example, people who live in rural communities without a museum would have to travel to a museum if they wanted to see works of art, which would cost them money. Additionally, children spend their days in school, so they can only access the museum if they go on a class trip during the day, if the art is brought to their school, if they go after school, or if they go on the weekends. Therefore not everyone can go to a museum; however, if a person has the means and time to get there, they are sure to be culturally enriched. These enriching initiatives allow for immersion in culture and history. To accommodate the ever-expanding audiences and their needs, museums offer listening devices that can amplify the sound of a presenter. Additionally, many museums offer audio devices which have a preloaded tour that the viewer can follow around the museum, simultaneously looking at the artwork and listening to the information. The listening devices along with other accessible items such as ramps, elevators and seating in many galleries allows for people to have an enjoyable and informative museum experience.

Besides these items that museums offer to all people, some museums offer special programs for people with varying impairments. For example, several museums offer 'Touch Tours' for people who are visually impaired. During these sessions participants can feel and touch art objects, engage in discussions, and listen to detailed descriptions of the artworks. This experience of touching the artwork requires the participants to wear gloves, however early museums had less stringent policies about viewers touching the art. According to Constance Classen, a scholar on culture and its relation to the senses, at museums in the seventeenth and eighteenth centuries, "the curator, [acted] as a gracious host, [and] was expected to give information about the collection and offer it up to be touched..." (Classen qtd. in Denis 2013). Some museums continued this practice into the nineteenth century until the audience of the museum began to shift to include lower classes, and then the policies about touching art changed. Visitors were no longer allowed

to touch the objects because they were considered to be unsophisticated and no longer worthy of touching the objects (Denis 2013). Touch Tours began at the MoMA in 1971 when the educators realized how important it was to engage people with visual impairments in art. In the beginning, the participants were able to use their bare hands, however that changed when the art preservers were concerned that oils from the hands would ruin the art. From that point on, the participants had to wear gloves to touch the artwork, however they were not cumbersome and could still allow for the participant to feel the texture and features of the artwork. The twenty-first century has proven to be the most progressive yet in terms of the programming offered for people of varying ability levels, broadening the museum audience because now many more people can be engaged in art education.

Throughout history, we find that museums have expanded their audiences through the creation of public spaces that can accommodate an increasingly diverse population. Beginning with the Ancient Greeks and up until the fifteenth century, museums were places of contemplation for gods, goddesses and scholars. In the fifteenth century, elite art collections, like that of the Medici family, were displayed strictly for the pleasure of the family and their guests. It is not until the seventeenth century that the public was able to go to a museum, as we have today, and interact with art. This was afforded by the Ashmolean Museum at the University of Oxford in England in 1683 and by the Uffizi Gallery in Florence which opened its doors to the public in 1769 to display the Medici Family collection, a mere 287 years after the first inventory was documented. With the rise of the Ashmolean Museum in the eighteenth century and the exhibition of the Medici Family collection in the eighteenth century, peoples' desire to interact with art, in part, led to the creation of other museums such as the British Museum, the Louvre and the Peale Museum among others in Rome and throughout Europe. The success of museums in the eighteenth century led to the nineteenth century age of museums in which museums such as the MET and the Smithsonian were able to make great strides in expanding their audiences. This was accomplished in the late nineteenth and early twentieth- centuries through the creation of educational programs for the public. Some of the most important educational programs created in the twentieth and twenty-first centuries that continue today include touch tours for the visually impaired, sign language tours for those with hearing difficulties, art making sessions and tours for people with dementia and learning disabilities, among countless other programs at museums around the world. The transition of the museum from a private familial collection to the large institutions that have been built over the past approximately 350 years has positively impacted society, because people of most ability levels from various walks of life are able to use the museum as a place of cultural enrichment.

### **Chapter 2: Disability Studies**

Through examining the history of art museums we have found that throughout history, museum audiences have evolved and the purpose of the museum has shifted from a strict research institution to one with an educational priority. As the museum audiences have broadened, museums have had to accommodate them in order to create an inclusive space for able people and those with impairments. Some museums offer more accommodations and programs for people with impairments than others, however I argue that all museums need programming for people with impairments. This can be achieved by understanding the field of Disability Studies, which seeks to reduce stigma against those who are impaired by empowering individuals to make a difference. These individual changes can sum to create broader institutional change to accommodate the needs and mindsets of a broader public. Furthermore, the accommodation of people in museums with impairments such as visual, hearing or even those with dementia runs parallel with the scholarly field of Disability Studies. Therefore, understanding the field of Disability Studies will explain why it is important to engage people with impairments in society and why it is imperative for stigmas to be destroyed so that people can have a good quality of life despite their medical impairment.

The field of Disability Studies arose in the 1980s when the Society of Disability Studies emerged out of a previous association for chronically ill, impaired, and disabled patients. It was first founded as a course of study by Stephen J. Taylor at Syracuse University in 1994. At the conception of the program, Taylor said "Disability studies starts with accepting the disability. Then it asks the question: 'How do we equalize the playing field?"" (Taylor qtd. in Simon 2013). Taylor's words concisely explain the goal of Disability Studies: acceptance of people and better integration of them into society so that everyone can be viewed equally, no matter their ability level. In order to equalize the playing field, scholars examine disability as a social construct perpetuated by institutions throughout history and into the present day. In addition, disability scholars seek to unpack and "defamiliarize" (Davis 1999: 504) the concept of normalcy. Some scholars want to reshape the concept of normalcy to include people with disability, while others think that there should be no normal. This desire to have a more inclusive society in which there is no power difference between those who are able and those who are disabled, is the great challenge for the field of Disability Studies because of the deeply ingrained stigmas towards those who are impaired.

A discussion of the field of Disability Studies, would not make sense without first understanding the distinction between a disability and an impairment. A disability, according to the World Health Organization, is defined as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (World Health Organization 1980: 143). An impairment then is, "any loss or abnormality of psychological, physiological or anatomical structure or function" (World Health Organization 1980: 47). For example if a person is involved in a car crash, the resulting impairment might be severe damage to the nervous system. The resulting disability is that they are confined to a wheelchair and may not be able to do the tasks expected of them. That is to say, if the person was a car mechanic prior to the injury, it might be challenging for them to return to work because of the physical nature of the job. Since this person would no longer be able to perform the tasks considered to be 'normal' for their job, at least for the short term, they would be classified as disabled.

Societal constructs are what create the distinction between an impairment and a disability. This distinction can also be called "ableism." According to Michel Bérubé, ableism is the "distance in social constructions such as "the stare," that telling glance directed toward people with physical differences" (Bérubé qtd. in Davis 2002: 35). Bérubé's discussion of "the stare" leads to a discussion of the gaze which perpetuates the concept of normalcy.

The "range considered normal," as stated in the definition of disability, that is lost because of a medical condition is a social construct that is deeply rooted in our society and contributes to the tension created between the abled and the impaired as defined by the concept of ableism. Kenny Fries, a disability scholar writes:

Throughout history, those who have disabilities have been defined by the gaze and the needs of the nondisabled world. Many times, those who live with disabilities have been isolated in institutions, experimented upon, exterminated. We who live with disabilities have been silenced by those who did not want to hear what we [people with impairments] have to say. We have also been silenced by our own fear, the fear that if we told our stories people would say: "See, it isn't worth it. You would be better off dead" (Fries 1997: 1).

The gaze that Fries is referring to is a tactic used by people who are not impaired to seem superior to those with impairments by othering them, as if they were outcasts. Michel Foucault, a French historian and philosopher writing in the mid to late twentieth century,

is one of the first scholars to write about madness and 'the gaze.' In his book Madness and Civilization from 1961, Foucault identifies lepers as people who were sectioned off from society and put into care facilities for 'mad' people (Foucault 1988: 5). Other people who were considered to be 'mad' were banished from their towns and were supposed to be ostracized and enclosed because they were seen as threats to the other people of society. In particular, they were seen as close to death and as having a forbidden knowledge related to the end of the world, thus threatening the existence of life and reason (Foucault 1988: 65-84). In a later text from 1975 Discipline and Punish: The Birth of the Prison, Foucault discusses the gaze. For Foucault, maximum power meant maximum gaze (Foucault 1975: 171). The mechanism by which this occurred was a panopticon, which was first created by Jeremy Bentham in the late eighteenth century as a prison structure in which the guard house was positioned in the middle with all of the transparent cells encircling the guard tower. This meant that the prisoners were being watched at all times and this fear of being surveilled was supposed to keep them in line. The structure of the panopticon allows for the prison guard to look out at his prisoners and to judge all of their actions (Foucault 1975: 195-231). When you judge someone's actions that makes you seem superior to them, as if to say that you would not make such poor judgments. This creates a position of power resulting in the formation an in-group and an out-group. The in-group would be the prison guards who did not do anything wrong and the out-group would be the prisoners (foreigners) who have been accused of wrongdoing.

Thinking more deeply about the gaze and understanding it through Foucault's

texts allows us to comprehend the gaze experienced by people with an impairment. The initiator of the gaze is typically the able person onto the impaired person, or in the case of Foucault's text the superior figure onto the subordinate. This power struggle, as it relates to people with impairments, created between these two parties is what leads to fear as described by Fries. The fear of an impaired person stems from their feelings of discomfort when they try to engage in society because the gaze, "disables physically impaired people" (Finkelstein qtd. in Fries 1997: 7). This physical impairment can refer to any number of motor or cognitive impairments. That is to say, that a person's medical impairment becomes a disability when the person is gazed at because they seemingly can no longer perform the 'normal' actions of everyday life as defined by able-minded and able-bodied people. One can also argue that someone who might gaze at a person with an impairment is trying be sympathetic; however, many times the gaze represents a form of othering. This precisely is the social model of Disability Studies in which disability is defined as a social construct.

In contrast with the social model of disability, which sees disability as a social construct, the medical model of disability, which is practiced by doctors, sees the disability of the person as equivalent to their impairment. For physicians, disability and impairment are not separate or causal, but rather equal, thus leading to disability being seen as a curable entity (Thomas 2002: 38-57). When someone is ailing and needs to be cured, they could be pitied and the person will have labeled actions that they can and cannot do. For example, a person who just had a leg amputation will not be able to walk or run for a while until they heal and can acquire a prosthesis. Until they have their

prosthesis, they will have a hard time doing certain things unassisted. This requires help from others and the possibility for ruminating on what they can and cannot do, mostly with emphasis on what they cannot do. This emphasis on what the person cannot do is the antithesis to the teaching of Disability Studies which seeks to be inclusive of all people no matter their ability level. Therefore, I disagree with the medical model of disability, because it sees the person with the impairment/disability as needing to change to fit the environment, as opposed to the environment working to accommodate the person. The social model of disability offers this accommodation because it sees the person with an impairment labeled as disabled in an environment that needs to be altered. In other words, the person with the impairment should not have to change, but rather the environment around them should (Thomas 2002: 38-57; "The Social Model of Disability").

In order for society to embrace people with impairments, instead of judging and stigmatizing them, people need to first understand the mechanisms that lead to the idea of the dominant banding together to separate themselves from the outcasts. People within one's in-group are those that have similar interests, backgrounds and beliefs. In contrast, the people in the out-group are those who have opposite interests, backgrounds and beliefs to those of a particular in-group, and they are often the out-group and have prejudiced attitudes towards them. This notion fuels the creation of social stigmas and social constructs in which one group feels superior to another. If the superior group is able to influence the beliefs of others about said out-group, then many groups will be prejudiced against them; thus a social stigma and construction of prejudice through social

interactions.

The othering that occurs when a person is categorized as disabled, because they can no longer conform to society's concept of normal, is perpetuated by entertainment outlets such as cinema and TV. Laura Mulvey, a British feminist film theorist, writes in her 1975 essay *Visual Pleasure and Narrative Cinema* that the gaze extends into the world of cinema, specifically as it relates to the relationship between a man and a woman. In film, as in other art forms, the gaze creates a power dynamic in which the gazer objectifies the gazee. Mulvey, argues that women pose a threat to men because of their physical sexual differences, thus leading to the fear of castration and an inability for pleasure in men (Mulvey 1975: 6-18). This threat that a man experiences can be thought of in parallel to the threat that mad people posed to non-mad people in Foucault's argument.

In the entertainment world we see freak shows as the beginning of the use of disabled characters for the pleasure of others. The use of disabled people to provide an entertainment experience to others, reminds us of Kenny Fries' discussion of people with impairments being gazed at to fulfill the needs of the nondisabled world. Dr. Katie Stringer wrote *Disability, the Sideshow, and Modern Museum Practices* in 2013 about the Barnum American Museum in New York City, New York that opened in 1840 as a site of freak shows where their exhibitions were "advertised as educational and scientific activities..." (Stringer 2013: 16). The term "freak" according to Rachel Adams, a writer and Professor of English at Columbia University, "serves as a classification for those who performed or displayed themselves for the public... those who [were] called freaks

'announce themselves as the antithesis of normality by participating in

exhibitions'"(Adams qtd. in Stringer 2013: 19). Their opposition to the concept of the normal means that their actions were dehumanizing and allowed for a viewer to watch and exploit the performer as an "object of curiosity" (Adams qtd. in Stringer 2013: 19). The freak show exhibitions at the Barnum Museum in the nineteenth century are now looked down upon because of the exploitation of the disabled person, showing a positive alteration in the mindset of people because they no longer want to see disabled people as objects of curiosity. I would argue, that if it were not for the programs like those at art museums that are designed to integrate impaired people, they would be forgotten.

In twenty-first century entertainment, we see a greater use of impaired characters in movies, for example in X-Men (2000) and its sequel X-2: X-Men United (2003), Charles Xavier who is the "leader of the X-Men, better known as Professor X, cannot walk and makes use of a wheelchair..." (Chemers 2004). Professor X's team is populated by outcasts who are not liked by others. These fictional movie characters mirror the nonfictional world that a person with an impairment experiences when they are themselves are considered to be an outcast. However, if we could get rid of the title of outcasts and incorporate them into our society, then we would be achieving the main goal of Disability Studies. Yet, this is only possible when the distinction between in-groups and out-groups has been mitigated.

The othering that occurs between in-groups and out-groups leads to stereotypes and stigma formation about said out-group. According to Mike Oliver, discrimination and othering is "rooted in the economic and social structures of capitalism..." (Oliver 1996: 33). A boss' decision to not hire a person with an impairment was (and still is) discrimination and created a power struggle between the able and the unable. For the purposes of this text, the in-group represents people that are able-bodied and ableminded, while the out-group are those who have an impairment and become disabled because of societal constructs. Rosemarie Garland Thomson, in her book *Extraordinary Bodies*, discusses Stigma Theory and how it relates to the marginalization experienced by people with impairments. Thomson states that Stigma Theory is concerned with the perception of difference between groups and how these differences create discrimination and infringement (Thomson 1997: 30-32). This harkens back to Oliver's "industrial capitalism" (Thomas 2002: 46) which begins a vicious cycle of stigmatization by people with influence.

The power struggle rooted in capitalism identified by Oliver is something that Simi Linton, a Disability Studies scholar, equates with the concept of normalcy. In her text, *Claiming Disability Knowledge and Identity*, Linton says that "*normal* and *abnormal* are convenient but problematic terms" (Linton 1998: 22) because:

*norm* or *normal* are terms describing individuals or characteristics that fall within the center of the normal distribution on whatever variable is measured. However, as the notion of *normal* is applied in social science contexts and certainly in general parlance, it implies its obverse*abnormal*... [therefore] those... not deemed normal are devalued and considered a burden or problem, and people with those characteristics are considered disabled (Linton 1998: 22).

Lennard Davis, another Disability Studies scholar, expands upon Linton's discussion of normal versus abnormal when he states:

[T]he very term that permeates our contemporary life- the normal- is a configuration that arises in a particular historical moment. It is part of a notion of progress, of industrialization, and of ideological consolidation of the power of the bourgeoisie. The implications of the hegemony of normalcy are profound and extend into the very heart of cultural production" (Davis qtd. in Linton 1998: 23).

Davis' point about the constant use of the word 'normal' perpetuates social stigmas against people with disabilities, however Linton points out that "the absolute categories *normal* and *abnormal* depend on each other for their existence and depend on the maintenance of the opposition for their meaning" (Linton 1998: 23).

Thomson, Linton and Davis each champion Disability Studies and seek to challenge the societal status quo. For Thomson, this manifests itself through a critical look at Stigma Theory and how it perpetuates a vicious cycle of discrimination. Linton points out that if we define normal, then there is a guaranteed category that is abnormal and populated by those who seem to be burden to society (i.e. people with impairments). Davis expands upon Linton's argument by acknowledging that the word 'normal' is problematic because its constant use perpetuates social stigmas, as defined by Thomson.

These scholars that I have presented- Thomson, Linton and Davis- and others in the field of Disability Studies seem to combine both physical and mental impairments under the same umbrella. In my research, I have not come across a scholar who specifically acknowledges the different experiences that a person with a physical impairment would have in comparison to a person with a cognitive impairment. I hypothesize that the experience is different in some ways, however both groups would still be considered as outcasts. Physical impairments, such as being wheelchair bound requires extensive planning to participate in society. For example, if the person is totally immobile, then the vehicle used to transport them must be wheelchair accessible. The destination location must have an elevator, if there are multiple floors, and big enough doors for the chair to fit through. Most public places will be wheelchair and handicap accessible because of the Americans with Disabilities Act that was passed in 1990, however there may still be some locations that are not wheelchair accessible.

In contrast, people with cognitive impairments, like dementia, may be ambulatory in the early stages of their condition. This means that they can get around fine but remembering where they are or where they need to return to might be the challenge. For someone with dementia, specifically, they can be very easily disoriented within a space because of the difficulties that they experience when they try to make new memories ("Stages of Alzheimer's"). The implications of this in an art museum might be not understanding one's proximity to the artwork and also visiting the same galleries repeatedly during the visit because they may not remember their environment. That is to say, that a person may visit the same cafe every day, but each time it feels like their first visit. Conversely, someone who is physically impaired may have a hard time getting into the cafe and feeling comfortable there, but unless they have a cognitive impairment as well, they will remember that cafe and it will become associated with memories over time.

Thinking about these examples presented, how can society better accommodate people, no matter their impairment, so that they can have the best quality of life? Art museums provide us with a good template for this. For example, many art museums have begun educational programming for people with both physical and mental impairments. Through programs such as Touch Tours for the visually impaired at the Metropolitan Museum of Art and the Museum of Modern Art (MoMA) and Meet Me at MoMA, for people with dementia, museums are working to accommodate people with all types of impairments. The creation of separate programming for people with physical versus cognitive impairments makes the experience more valuable to the participant because their needs, given their condition, can be better accommodated. In particular, having programming for people with dementia at a museum helps for the person and their companion/caregiver to have a better quality of life. However, this is only possible when the barriers of stigma are broken down. When there is reduced stigma and decreased ingroup and out-group affiliation, the field of Disability Studies will have overcome its greatest challenge- altering people's notions of what is and who defines the concept of normal.

Through examining the field of Disability Studies, we see that it seeks to level the playing field for all people and it encourages us to question who determines what is normal. To some degree, the questioning of the status quo can be seen in museums because they no longer exhibit freak shows but rather have evolved to understand the value of including and educating people with impairments about art. This inclusion helps to ensure a better quality of life for people with impairments and their companion/ caregiver. In conclusion, even though social stigmas are deeply rooted in our society, stemming from industrial capitalism, it is obvious that when institutions make a change their followers (i.e. in-group) begin to be more accepting and welcoming to those in the

out-group, which helps to reduce social stigma and stereotyping more broadly.

## Chapter 3: Dementia

Disability Studies seeks to equalize the playing field for everyone and encourages its followers to reduce stigmas and to reject the concept of normalcy so as to promote a more inclusive society. The scholars of Disability Studies discuss impairments as becoming disabilities because of social constructs in which a person who is "different" is considered to be in a separate group to the one that the majority identify with. A common group that falls victim to othering and stigmatization are those with dementia. Therefore, this chapter will focus specifically on the psychological mechanisms and effects of dementia.

The word 'dementia', describes a cognitive impairment such that the mental abilities of a person are compromised and thus interfere with their day to day life. The medical impairment of dementia is the deterioration of the brain and its nerves. Dementia, becomes a disability when society assumes that the impaired person can no longer function 'normally.' Thus, the person with dementia gradually disappears from society, though often times not by choice, because of the social stigmas surrounding their condition. With this unfortunate fact in mind, I argue the importance of including people with dementia in society.

To understand the disability, one must first understand the mechanisms that cause the impairment. Dementia is a progressive cognitive impairment typically affecting older people, however there are cases that began before a person turns 65. Dementia is an umbrella term for Alzheimer's, vascular dementia, mixed dementia, dementia with Lewy bodies, frontotemporal dementia and several other forms of dementia (Rosenberg et. al

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2009: 12; "Types of Dementia"). Each type of dementia can affect different functionalities of a person, such as language, mobility and personality or a combination of all three. According to the Alzheimer's Association, Alzheimer's accounts for 60-80 percent of all dementia diagnoses, making the other forms of dementia under diagnosed. The symptoms for all of these types of dementia are similar, because they make it challenging for a person to participate in their usual activities. This inability to perform "normal" tasks as defined by able-bodied and able-minded people harkens back to the principles of Disability Studies in which there is a power struggle between those who are able and those who have an impairment and are thus considered to be disabled. As we learn from Foucault, Simi Linton and countless other Disability Studies scholars, we see that this power struggle impacts the ability to create an even playing field for all people in our society.

When thinking about how we can even the playing field we can look to art museums who have created educational programs for people with dementia. One of the most notable is the program entitled Meet Me at MoMA at the Museum of Modern Art (MoMA) in New York City, New York. This program is for people specifically with Alzheimer's, and since this population is the largest under the dementia umbrella, I will focus my discussion specifically on Alzheimer's.

Alzheimer's specifically affects a person's "memory, thinking and behavior" ("What is Alzheimer's?"). The cognitive changes are progressive and can begin in a person's 40s or 50s. When it is diagnosed in someone so young, it is classified as Younger/Early Onset Alzheimer's. This classification means that they are younger than the typical age for people diagnosed with Alzheimer's; however, a diagnosis earlier in life may not be indicative of an earlier stage of impairment. For example, a young person could have a very progressive and late-stage version of the cognitive impairment despite their young age. Diagnosing Alzheimer's in a younger person is challenging, because their symptoms can be mistaken with other diseases and with stress. Some of the symptoms of Alzheimer's are memory loss, difficulties with problem solving or planning, alteration in mood, decreasing judgement, and feeling disoriented in time or in space (Gaugler et. al 2016: 8). As the cognitive impairment progresses the person might not be able to live alone because they can no longer take care of themselves.

In order to diagnose any person with Alzheimer's there must be a holistic approach involving an understanding of the symptoms that the person presents with, their medical and family history, a discussion with people who know the person well to find out about behavioral changes, neurological exams, blood tests, and brain imaging (Gaugler et. al 2016: 8-9). Doctors are typically able to diagnose a person with dementia, however sometimes it is hard to determine exactly which type of dementia the person has.

At the cellular level, healthy neurons in the brain fire based on a stimulus and then release a neurotransmitter, a chemical messenger, into a synapse for the next neuron to take up and respond. In a healthy brain, there are billions of neurons and even more synapses. These neurons and their signals allow for us to perform every single action that we do, and if they become damaged they are very difficult to repair. Some neurons can repair themselves, however others cannot and when you have constant degradation of the neurons, like in dementia, it makes it nearly impossible for them to repair themselves. Alzheimer's is a type of dementia in which the neurons eventually die because their normal mechanism breaks down. Specifically:

the accumulation of the protein beta- amyloid... *outside* the neurons and the accumulation of an abnormal form of the protein tau (called tau tangles) *inside* the neurons are two of several brain changes believed to contribute to the damage and destruction of neurons... result[ing] in memory loss and other symptoms of dementia. As brain changes advance, information transfer at synapses begins to fail, the number of synapses declines, and neurons eventually die. The accumulation of betaamyloid is believed to interfere with the neuron- to- neuron communication at synapses and to contribute to cell death. Tau tangles block the transport of nutrients and other essential molecules inside neurons and are also believed to contribute to cell death (Gaugler et. al 2016: 9).

The rate of Alzheimer's progression is partly determined by the rate of neuronal cell loss that a person experiences. In the early stages, there are still neuronal synapses and the signaling mechanism remains relatively intact; however, over time as the tau tangles build up and the synapses are no longer functional, the disease progresses and the person's behavior changes. This ultimately leads to severe memory loss, an inability to form new memories, a lack of control over one's speech, an inability to focus, and a feeling of being easily disoriented because of a lack of memory.

The cellular mechanisms of this impairment greatly impact the behavior of the person and as a result they might require a caregiver if they can no longer take care of themselves. As the rate of neuronal breakdown increases, the person will have a harder time doing any of the activities that they used to enjoy prior to their diagnosis.

People in the early-stage of Alzheimer's might be able to continue on with their daily lives, however they will notice that they have reduced memory capabilities and they may have difficulty organizing and planning. As the brain continues to change and the impairment progresses into the middle-stage, the person may experience fluctuations in personality and increased memory loss relating to events in their life. In the final stages of the impairment, the person will most likely require constant care and monitoring because they have decreased motor functions and often to ability to recognize their surroundings ("Stages of Alzheimer's"). When the person can no longer complete daily tasks and remember their surroundings, they may be forced to remain in their homes or go to live at a long term care facility where there is around the clock care. Whether they are confined to their homes or to a care facility, their interactions with the outside environment are likely to be limited. These decreased interactions with the environment can be attributed to two factors: the progressive nature of the disease and the person's fear of how society will view them. As discussed in the Disability Studies chapter, there are stigmas that our society create around those who are not in the same group, thus making it socially awkward and uncomfortable for a person with an impairment to participate in societal activities because of the "othering" that occurs. These social stigmas, which sometimes falsely assume that people with all stages of dementia cannot speak, are detrimental to the person's wellbeing resulting in their isolation from society.

In order to make the most of one's life while suffering from Alzheimer's, Thomas Kitwood, a social psychologist, identifies five needs that a person with dementia has:

comfort, inclusion, identity, occupation, and attachment (Kitwood 1997: 13-22). In a study in 2016 by Kaufman and Engel they "aimed to examine... Kitwood's model of psychological needs and well-being in dementia based on the self-report of individuals with moderate or severe dementia to differentiate and elaborate this model in the light of the empirical quantitative data" (Kaufman et al. 2016: 774). At the completion of this study, their data displayed how aspects of Kitwood's five needs manifest themselves within people. The need for comfort displayed itself as finding pleasure in the little things in life, such as listening to music, interacting with family and friends, and being praised by and helping others. The need for inclusion manifested itself as a desire to be a part of a community. This stemmed from the person wanting to feel like an equal to the other people around. The need for identity presented itself such that the person was able to recognize and keep their humanity intact. Kaufman et al.'s data indicated that some people tried to continue the same lifestyle that they had prior to their diagnosis with the hopes of living a life of satisfaction. Kitwood's need for occupation was displayed in different ways for different people, however the people talked about leisure, exercise, and participation in activities along with several other ways to spend their time. Attachment manifested itself as the desire to be around people and animals, and the ritualization of a task; thus rooting the person in a behavior that they may repeat over and over again (Kaufmann et al. 2016: 781-783).

When taking the Kaufmann et al. (2016) data together about how Kitwood's needs reveal themselves in the lives of people with Alzheimer's, we see that it is possible for a person with dementia, to live-well as long as their needs are met. In order for a

person with Alzheimer's to feel comfortable in their own environment, and in the outside world, there needs to be a drastic reduction in stigmatization of people with cognitive impairments by both individuals and institutions. We see this happening with the broadening of the art museum audience to include specific museum programs for people with dementia like Meet Me at MoMA. When a world-renowned global institution, like the MoMA, shows inclusivity towards a group other people considered to be outside their typical audience precedent is set for other museums to do the same thing. The MoMA program in particular, will be elaborated on in the next chapter, and provides a framework for other museums to create similar programs for people with Alzheimer's at their respective museums.

#### Chapter 4: Meet Me at MoMA

Living well with dementia is crucial for the person to have a good quality of life despite their diagnosis. As part of having a good quality of life, reduced social stigma and a feeling of comfort in social situations is an imperative element in leveling the playing field for people with both physical and mental impairments. As we have seen, museums have gradually reached out to different populations by providing audio devices for the hearing impaired, programs for the visually impaired and learning sessions for children and their families. More recently, museums have incorporated programming for people with cognitive impairments. In particular, museums that have created inviting spaces for people with dementia, have been proven to positively impact the person's affect. This programming also contributes to the trend of museums accommodating wider audiences. An example of an institution that has reached out to people with dementia is the Museum of Modern Art (MoMA) in New York City, New York. Their program called Meet Me at MoMA engages people with Alzheimer's through an art viewing experience led by a museum educator.

Meet Me at MoMA was piloted in 2003 with residents from long term care facilities and it began meeting regularly in 2006 with the initial support of The Fan Fox and Leslie R. Samuels Foundation (Rosenberg et al. 2009: 45). The Fan Fox and Leslie R. Samuels Foundation seeks "... to improve the health care and overall quality of life for the elderly of New York City. [Their] success will be measured by the positive impact that the program has on people's lives" ("The Fan Fox... Samuels Foundation"). In 2007, the MetLife Foundation gave a generous grant which lasted until 2014 ("The History of

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the MoMA Alzheimer's Project") during which time educational materials were developed and made public so that other art institutions could create similar programs for their respective local populations. Additionally, MoMA museum educators traveled to other museums and held training sessions for people who wanted to implement a version of the program at their own art museum. Even though the grant ran out in 2014, the museum visits for people with dementia and their companions continue to take place monthly on Thursdays from two-thirty to four in the afternoon.

According to Francesca Rosenberg, the Director of Community and Access Programs, the program was started in 2003 with the aim:

to contribute to an ideological shift in the way both institutions and individuals think about Alzheimer's disease, a move away from concentrating on deficiency toward focusing on the many rich and satisfying emotional and intellectual experiences that are newly possible (Rosenberg et al. 2009: 9).

This goal statement of the MoMA project mirrors the goals of Disability Studies in that it seeks to promote institutional change so as to focus less on the person's ability status and more on their quality of life with their impairment. Disability Studies scholars would see this as a restructuring of the concept of normal, resulting in a decrease in othering that occurs when there are two groups that are perceived to be different. Furthermore, this desire of the MoMA to provide a rich and satisfying emotional and intellectual experience supports Kitwood's needs that a person with dementia has to live well. Specifically, looking past the person's impairment to the person's true identity, as it relates to retaining their humanity, manifests itself in the program's goal to move away from concentrating on deficiency and to move towards engaging the people in stimulating conversations and activities.

In order to better understand this program, I had the chance to sit in on a session and I saw the goal statement being enacted in the way that the people were treated and respected. Prior to arriving at the museum, the participants are required to preregister for the session and as a part of the pre-registration there is a question about what stage of dementia the person is in. This information is necessary so that the people of similar stages can be grouped together for the tour. The group that I followed had six people with a form of dementia, three of whom were nonverbal, and five of whom were companions. I learned that there could be upward of 100 people during any of their Thursday programs, however the groups remain relatively small in number of people so that it is easier to hear the presenter and to engage in the conversations.

Upon arrival, participants check-in and are given a name tag with their first name, which helps them to retain their identity and sense of self because they know that someone is going to take the time to call them by name. One MoMA participant specifically commented in relation to the name tags that "everything is geared to draw people in and to break down those barriers" (Rosenberg et al. 2009: 22). After checking-in, the participants are brought to their group meet up spot and they are given an optional listening device and if needed, a lightweight collapsible stool that they can carry around with them throughout the museum. It is 40

not uncommon for people to show up early for the session because of the excitement and ritualization that they experience as a part of going the museum (Rosenberg et al. 2009: 20). While they wait for the session to begin, some chat with the other people and with the museum educator. This, we know is valuable given Kitwood's needs for a person to live well with dementia. Even before the program formally begins, the person can experience a positive change in affect. At two-thirty in the afternoon, educators lead their groups to the first of four or five artworks that they have chosen for that day. While I was there, I asked how the artworks are chosen and the educator told me that it is up to the guide to decide what works throughout the museum that they wanted to show off. She expressed that most guides try to pick artworks that are large and without a reflective surface so it is easier for the participants to see. Once in front of the artwork, the participants are encouraged to take a close look at the work and then the conversation begins.

The initial questions posed by the guide are about the observations that the participants have about the given work and then the guide tries to get them to elaborate as much as possible. The educator repeats what the person says to the entire group so that everyone can hear and also so that the participant knows that the guide was listening to them and showing them respect. The guide tries to get each person to say why they shared their comment so that the participant can be fully engaged and can use more critical thinking mechanisms. As the time progresses at one particular work of art the educator tries to ask deeper questions

about the artwork as it relates to a specific theme and then will occasionally weave in art historical facts, however they are few and far between. The few facts that are provided are the key things that the participants need to understand or think about as it relates to the work. These facts include, but are not limited to, relevant information about the artist, medium, and iconography. After having shared some art historical background, the guide asks the participants more questions about the work of art based on the facts to lead them to a deeper understanding. This process happens in front of each of the artworks that they see. At the conclusion of the day, the participants are given a pass to come back to the museum if they choose and they are encouraged to return for the next session. As previously mentioned, there is a ritual aspect to the experience for those who go often, because it is something that they can do outside of their daily activities and it encourages conversations and engagement with others. One participant, with Alzheimer's, spoke about the experience they had at the museum saying that, "the program gave me the confidence to know that I had been able to retain my appreciation of art and that I could zero in on the points that were necessary in the artwork that I was seeing" (Rosenberg et al. 2009: 38).

In 2009, the museum published *Meet Me: Making Art Accessible to People with Dementia* a book about the program with dialogues of tour sessions, other quotations from participants and conversations with scholars in the field of Alzheimer's. Interviews were conducted with members of the Alzheimer's Association, Mount Sinai School of Medicine personnel, Dr. Richard Taylor- the author of *Alzheimer's from the Inside Out* (2007)-, and scholars studying aging. The consensus from each of these conversations was that meaningful activities such as visiting a museum with a companion and having an art viewing experience can be very beneficial for a person with Alzheimer's and their companion/ caregiver. When looking at the MoMA as a world renowned institution, they are setting a precedent for other programs, they break down stigmas, and fulfill the needs for someone to live well with dementia.

Based on the quotations and dialogues published in the *Meet Me: Making Art Accessible to People with Dementia* by Rosenberg et al. (2009) we know that this can qualitatively impact the wellbeing of a person, but how about the quantitative data? The main study of the program was done in conjunction with the New York University (NYU) Center of Excellence for Brain Aging and Dementia in 2008. The goal of the study was to evaluate the effectiveness of the Meet Me at MoMA program for people with the early stages of Alzheimer's and their companions. The early-stage population was the target cohort because they would most likely be able to fill out and understand the questionnaires on their own. The study involved self-rating scales that were to be filled out right before the session and then one week after the program, observer-rated scales and a take-home evaluations were completed (Rosenberg et al. 2009: 89-90). The ideal participants were those with early-stage dementia and planned to come back for all three visits. They were recruited when the person registered for the MoMA session.

During the first visit, the participants were told to arrive at one in the

afternoon to fill out the consent form and the initial questionnaire. Every participant with dementia had a helper dedicated to them for the questionnaire period so that they could ask questions and receive help in completing the survey. Participants were also given lunch, and then right before and right after the tour all participants were given a Smiley-Face Assessment Scale to find out how happy or sad they were at that given moment (Rosenberg et al. 2009: 90). At the conclusion of the program they were given an evaluation form to take home and then return to the museum several days later.

During their second visit, the participants filled out the same questionnaire as they did on day one and they again had lunch, but this time they were engaged in a discussion with a museum educator during their meal. They also received gifts, passes to come back to the museum, and they were invited to stay after the tour that day to further explore the museum. During the third visit, a smaller focus group was formed and the participants were placed into one of two focus groups, either in June or August of 2008. "This session was designed to record participants' perceived benefits from the Meet Me at MoMA program and to enable them to offer comments and suggestions to MoMA staff (Rosenberg et al. 2009: 91).

After the three visits, the data collected was based on thirty-seven people with dementia and thirty-seven companions, most of whom were spouses. Some of the results were statistically significant, while others were not. For example, 100 percent of participants with dementia indicated that they enjoyed their time at the 44

museum and 96.4 percent of the participants with dementia reported to be in a better mood following the session (Rosenberg et al. 2009: 102).

The companions/caregivers were asked about the number of people in their social support network and after the first week there was "a meaningful change from an average of 7.0 to an average of 9.38 people" (Rosenberg et al. 2009: 92). Additionally, the moods of the companions improved significantly throughout the study, which was great to see because their ability to live well while caring for someone with dementia is also very important. The smiley-face assessment revealed statistical significance for both companions and people with dementia with people feeling happier after the art viewing experience.

In addition to the self-assessment questionnaires, observers were placed with the tour groups to note the interactions between the people with dementia, their companions, and with the educator. They also looked at how long the person with dementia paid attention to the work of art and to the educator in comparison to their companion. Through their observations, they found that people with dementia paid more attention to the artwork and the educator than to their companion. This shows that cognitively compromised people were engaged, focused and interested in the art and what was being said.

The take-home evaluations showed that the museum visit had a positive impact on both the person with dementia and their companion. This was attributed to the museum educator's ability to "encourage... interaction and group cohesion, lead[ing] to a socially as well as emotionally and intellectually satisfying experience. The feeling of enhanced self-esteem, and the desire for more programs like Meet Me at MoMA suggest that both the structure and content of the program are ingredients of its success" (Rosenberg et al. 2009: 103).

The focus group discussions provider a deeper insight into how the program affected the people with dementia and their companions. The results of these discussions showed that "people with dementia pointed to the pleasure of enjoying a stimulating experience in a safe environment and to the resulting enhanced feelings of self-worth they derived from participation and learning" (Rosenberg et al. 2009: 103). The companions, most of whom were the spouse of a participant with dementia, felt that the art viewing experience was "…enhanced by sharing it with their spouses and with other couples facing the same diagnosis" (Rosenberg et al. 2009: 103). The companions also felt relieved and appreciative "knowing that their spouses… [would] be treated with dignity and that all [of] their responses… [would] be met with acceptance…" (Rosenberg et al. 2009: 103).

When looking at the results specifically from the focus group discussions, a connection can be made between Meet Me at MoMA and living well with dementia. We see that the program benefits the person with dementia and it also improves the life of the companion. These benefits can partly be attributed to several things: the people are outside of their normal environment, both people are engaged and both peoples' ideas are valued. Taking all of the data collected in this study together, it is undeniable that this program has positively impacted the lives of its participants. All aspects of Kitwood's needs to live well with dementia are met through Meet Me at MoMA: the participants are

intellectually stimulated, they are socializing with others going through a similar experience, they are in an institution that is accepting of their needs, and they experience an improvement in their self-esteem and overall affect even after their visit has ended.

The benefits of such a program are tremendous for its participants, both with and without dementia. In the next chapter, I will discuss a recreation of this program, which I have entitled, "Broadening Horizons," at Bucknell University's Samek Art Museum in Lewisburg, Pennsylvania to benefit dementia residents at local long term care facilities. Meet Me at MoMA and Broadening Horizons further expand their respective museum audiences and help them to achieve their educational goals. Chapter 5: A Case Study at the Samek Art Museum

MoMA has set a precedent and created a framework for how museums can engage people with cognitive impairments. With the Meet Me at MoMA project in mind, I argue that Bucknell University's Samek Art Museum should have a similar program for local community members with dementia. Such a program would expand the museum's audience, be more inclusive of the community, and help the museum to better fulfill its mission statement as an extension of the Bucknell community.

Prior to describing the program that I suggested and implemented called "Broadening Horizons", we must have a clear understanding of why such a program is valuable at the Samek Art Museum. The Samek Art Museum, formerly known as the Center Gallery ("Samek Art Museum: About"), began collecting art in 1853 and then opened its first gallery in 1983. The current Mission Statement for the museum reads:

The Samek Art Museum is a program of Bucknell University that creates meaningful encounters between artists, students, scholars, the public and works of art. These encounters occur in the Samek Gallery, the Downtown Gallery, the Museum Collection Study Room, and the Connections Gallery. These spaces activate the intellectual life of campus arts and challenge students and extend their creativity. The Museum is an academic art lab where experimental art, innovative curatorial practices, and co-curricular programming generate new ways to engage and inspire audiences ("Samek... Mission Statement)".

The desire for outreach to the University community and beyond is strongly articulated in this mission statement when it states that the museum wants to provide "meaningful encounters between artists, students, scholars, the public and works of art." If we further

unpack the mission statement, we find that there is extensive programming for people in the community and the students; however, there have not been any specific programs to accommodate people with impairments, specifically those with dementia. Current museum programming is based around the exhibitions installed either in the Downtown Gallery or in the on campus museum. The Samek Art Museum installs a new exhibition in the on campus museum and at the Downtown Gallery, several times a year, depending on when classes are in session. All of these exhibitions have separate themes to help activate and challenge the student to extend their creativity. Additionally, the senior studio art majors have an exhibition of their culminating projects displayed in the on campus museum at the end of each spring semester. Programs that typically surround each of these exhibitions include an opening talk and reception for members of the community to come and learn about the exhibition. In addition, throughout the semester there are curatorial talks and speakers that are invited from around the world to present on a relevant topic. Art in Bars, which happens occasionally throughout the semester, specifically engages the local community because the museum selects several works from the Campus Collection and takes them to a local bar and pairs them with various drinks. They then have a conversation about the artwork and how the drink relates. These receptions and the talks are open to anyone which promotes the Samek's mission of engaging artists, students, scholars, the public and works of art.

Students are engaged with the museum through class projects, they can be hired as museum guides and they can be a member of the Gallery Engagement Team (GET). GET is a group of students who act as the liaisons between the museum and the student body. They plan a student gala around each on campus exhibition and they work hard to bridge the gap between the museum and the student population. The purpose of mentioning these programs is to show that the museum does have a wide outreach and that they do engage the local community, however they lack specific programs for people with dementia. I want to clarify that it is possible that people with cognitive impairments attend the current programs; however, it is unknown whether or not they attend. More simply put, people with cognitive impairments are not specifically engaged through programs that would improve their quality of life and better accommodate their needs. Therefore, as a part of my honors thesis I suggested to the Samek Art Museum that they offer conversational art viewing sessions for people with dementia and their caretakers, similar to Meet Me at MoMA, and they agreed to host the programs.

## Broadening Horizons- A Case Study at the Samek Art Museum

### **Content of the Program**

Broadening Horizons consisted of three museums visits over the course of three months, one in January 2017, another in February 2017 and the third in March 2017. Residents both with and without dementia were invited to participate from local long term living facilities and it ran similar to Meet Me at MoMA. Each time the residents arrived at the museum, there were introductory remarks made and then the participants were seated and the discussion of the artworks began. During each session three works of art were discussed surrounding a specific theme. The themes were determined by the presenter of the art works for each session. The theme of the first session was stories in art and Greg Stuart, the former Public Programs and Outreach Manager for the Samek Art Museum, presented several works from the Kress Collection. When asked in an email how Greg came up with the theme he wrote:

...I knew I wanted to use the Kress gallery as our location, and "storytelling" is a theme I've worked with before in connecting works in that gallery. I did consult the "Meet Me at MoMA" research and saw that storytelling was a theme that they suggested for the program as well, so I was pleased to see it fit nicely with what they had been doing (Email exchange with Greg Stuart on March 25, 2017).

The artworks presented under this theme were the *Judgment of Paris* (1548-1588) by Paolo Veronese, *Polyphemus and the Sea Nymphs* (1620-1640) by Francois Perrier, and *Landscape with Tobias and the Angel* (1619-1630) attributed to Agostino Tassi.

The second session, was co-led by Greg and myself surrounding the theme of unconventional portraits. This theme was determined after I had chosen the two works that I was going to present. I knew that I wanted for the viewers to experience looking at portraiture, because portraiture can at times allow for the viewer to place themselves in the portrayed person's position. Therefore, after having chosen the two portraits that I was going to present, Greg chose the third work of portraiture. We examined all three works and realized that each portrait seemed non-traditional so it was determined that the theme would be unconventional portraits. Greg presented *Untitled* (20th Century) by Joseph Beuys and I presented *A Couple of Ways of Doing Something: Self- Portrait of Chuck Close* (2003) by Chuck Close and *Untitled* (20th Century) by Karel Appel.

During the final museum session the theme was emotion in art and I presented

these works on my own. The theme and selection of artworks for this final session was influenced by my time observing the Meet Me at MoMA program and then perusing the Samek art collection to find works that would be engaging and feasible. Emotive properties appeared to be a common thread in the collection of artworks that I had chosen and thus the theme of emotion in art. The works that I presented during this session were *Bob* (20th Century) by John Koch, *Untitled* (1922) by Wassily Kandinsky and *Middlesex Election of 1804* (1804) by James Gillray.

During each session and for each of the artworks, the participants had a chance to look closely at the work. For the second and third sessions color reproductions were provided to each of the participants, allowing for the participants to look at the artwork more closely from their seat, whilst also having the chance to look at the artwork in person on the wall or as it was walked around by Erin Bradford, the museum Registrar. Following the observational period, participants were asked questions about the art as it related to the theme of the respective visit. The beginning questions included "What do you see and why do you say that?" and then the questions progressed to provide a deeper understanding of the artwork given some art historical background and its relation to the theme of that day. Some of these questions included "What is the relationship between the work of art and the theme?" and "Given the information about the artwork and the artist that was presented, how does this advance your understanding of the artwork and its relation to the theme?" A sampling of several of the artworks used and the comments from the participants about the works of art can be found in Appendix C.

The modeling of questions I have described is a blend of several different

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museum teaching strategies and theories. The first theory that will be explored is Visual Thinking Strategies (VTS). VTS follows a basic progression of questioning beginning with- "What do you see? What makes you say that? And what more can you find?" These questions are a good way to start a tour, however they fail to move beyond a novice level of questioning, resulting in only a superficial understanding of the work of art. A key debate within VTS is the amount of art historical information that should be shared with participants (Yenawine 1999: 1-7). A good museum educator will have all of the art historical information about a work of art in their back pocket, and then can share parts of it when necessary to drive the conversation towards a deeper understanding of the artwork. The second theory used within museum tours is the Inquiry Method, which involves steering the conversation from superficial observations to an evaluation of the success of the work of art in communicating a theme. Typically, these conversations have specific scholastic goals in mind, thus limiting how much you can engage in a creative discussion (Grinder 1985: 72-78). An alternative approach also used at the Samek, is a dialogical one in which the guide poses questions but acts as a bystander so that the conversation shifts towards the viewer's agenda rather than the guide's (Burnham 2011: 87-92). These teaching theories mentioned only represent a fraction of the ones that exist, however blends of these three are the ones used most often by the Museum Guides at the Samek and by myself and Greg during our presentations to the residents of the long term care facilities.

Through these various teaching models, the participants were able to gain a deeper understanding of the artworks while having their comments heard and repeated to

the group. This validation is a factor in living well with dementia and it reminds us of importance of fulfilling someone's needs to live well with dementia. In this case, feeling like you and your ideas matter is paramount to a person's comfort, sense of inclusion, and sense of identity. Each of these needs has to do with the affect of the person and the way that they feel in a certain situation. In the case of Broadening Horizons, the participants filled out questionnaires, approved by the Bucknell University Institutional Review Board, about their affect and interest in art both before and immediately following their museum visit.

# **Participants**

Participants were recruited from Buffalo Valley Lutheran Village A Diakon Senior Living Community and Nottingham Village for the first two sessions and then RiverWoods brought residents for the final session. Table 1 shows the breakdown of participants from each facility, however not all sixteen residents came back for all three sessions. I was blind to the diagnosis of the participants, the only identifying factor that I knew was their name.

Residents with dementia from the respective facilities all had an early-stage diagnosis so that they could fill out the surveys of the program. Additionally, people with early-staged dementia are able to benefit from and actively participate in the art viewing experience because their visual perceptual skills remain intact. This was shown by Halpern et al. (2008) in a study in which people with early-staged Alzheimer's were asked to sort art cards in order of most liked to least liked and then to redo the task two weeks later. They also participated in a control task in which they were asked to order

images of objects based on real world size from largest to smallest such as a truck and a key (Halpern et. al 2008: 68). The results showed that the people with Alzheimer's did just as well as those without Alzheimer's on the control task showing that the people with early-staged Alzheimer's still had their visual perceptual skills intact (Halpern et. al 2008: 69). The results also showed that people with Alzheimer's had the similar aesthetic preferences two weeks later when they completed the task again, leading to the conclusion that people have stable ways to appreciate art (Halpern et. al 2008: 69). The Halpern et. al (2008) study and the fact that people in the early stages of dementia have their language skills still intact, reinforces why this population is appropriate to engage in an art viewing dialogical experience.

Facility	Residents with Dementia	Residents without Dementia
Buffalo Valley	2	3
Nottingham Village	3	4
RiverWoods	3	1
Total	8	8

Table 1: Participant count by facility and diagnosis of dementia

## **Format of Sessions**

Prior to coming to the museum the residents were instructed to fill out a consent form, in order to fill out the questionnaires asking about their experience. For copies of the questionnaires please refer to Appendices A and B. There were two versions of each of the questionnaires given in which only the order of the questions had been altered. Following the completion of these documents, participants boarded buses provided by their respective facilities and traveled to the museum. They arrived around two o'clock in the afternoon, were greeted and given name tags. There were brief introductory remarks given before each art viewing session welcoming them and thanking them for their participation. Then they were guided into the gallery where they were seated facing the artworks. Once everyone was settled the session began and the presenter encouraged the participants to look closely at each of the artworks and then began the conversation using the questioning methods previously described. At the conclusion of the session, participants were guided into Arches Lounge, in the Elaine Langone Center, where they filled out a post questionnaire asking about their experience at the museum.

### **Results: Quantitative**

There were sixteen participants in this study, however only three participants without dementia and one resident with dementia came to all three sessions. The five participants from Buffalo Valley did not come back after the first session, and then four participants were recruited from RiverWoods for the final session so that there would be several more people than just those from Nottingham Village, who brought people for all three sessions. Additionally, several people left various questions blank on both the pre and post surveys.

The pre and post surveys had a one to nine point scale with nine as strongly agree with the given statement and one as strongly disagree with the given statement. Several questions appeared on both the pre and post surveys so that I could look for a change in affect, interest in art, and alertness. The three questions that overlapped of importance were: Right now I feel... (Very Happy=nine to Very Sad=one), How in interested in art are you? (Very Interested=nine to Not at all interested=one), and How alert do you feel right now? (Very Alert=nine to Not at all alert=one).

It was hypothesized that the residents would show an increase in their scores on the post survey. However, that is not what the data showed. The data were averaged across all participants and across all three sessions in order to determine the scores and the standard error for each value was calculated and is represented by the error bars in the figures below. Residents with dementia showed a slight decrease for all of the common pre to post questions (Figure 1). Residents without dementia also showed a slight decrease for all of the common pre to post questions (Figure 2).

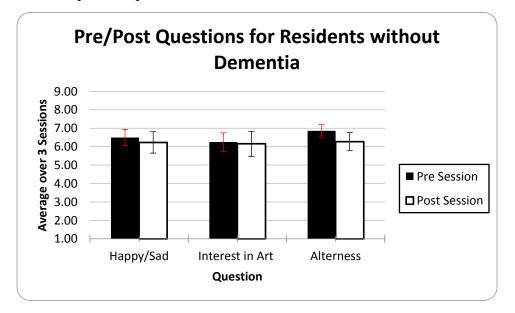


Figure 1. Pre to post comparison of scores for residents without dementia

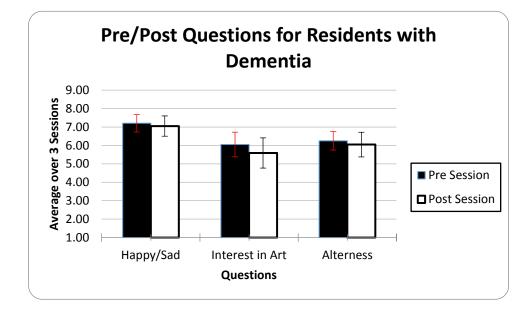


Figure 2. Pre to post comparison of scores for residents with Dementia

As previously stated, both Figures 1 and 2 show that there was not a significant decrease in affect, interest in art, and alertness after the sessions; however, they were based on a very small sample size so that must be factored in when trying to understand this data.

The difference scores between the pre and post surveys as seen in Tables 2 and 3 indicate that there was a wide range of ratings possible for the same program. Negative difference scores indicate that, on average, the person had a higher pre score than they did for their post survey. Conversely, a positive difference score indicates that, on average, the person had a higher post score than they had on their pre survey. The positive values support the hypothesis that following the art viewing experience, the participants will indicate a higher score. Tables 2 and 3 look at each question across each visit providing a better sense of responses as opposed to when they are all averaged together, because there were some positive difference scores for several questions as seen

# in Tables 2 and 3.

Difference Scores Post-Pre for Residents without Dementia				
Visit #	Question (9=Feeling, 10=Interest in Art, 11=Alertness)	Difference Score Averaged for all Participants		
1	9	-0.83		
2	9	-0.17		
3	9	-1.67		
1	10	-0.20		
2	10	0.50		
3	10	-0.83		
1	11	0.20		
2	11	-0.83		
3	11	-1.83		

# Table 2. Difference Scores Post-Pre for Residents without Dementia

Table 3. Difference Scores Post-Pre for Residents with Dementia

Difference Scores Post-Pre for Residents with Dementia			
Visit #	Question (9=Feeling, 10=Interest in Art, 11=Alertness)	Difference Score Averaged for all Participants	
1	9	-0.63	
2	9	2.00	
3	9	-0.75	
1	10	0.38	
2	10	0.50	
3	10	-2.13	
1	11	-0.25	
2	11	0.25	
3	11	-0.63	

The data presented in the above tables and figures indicates the scoring for questions that appeared on both the pre and post surveys. However, there were also questions that only appeared on the post survey. The post survey asked about the person's experience at Broadening Horizons and their interest in going to other art museums and/or coming back to the Samek Art Museum. The rating scale for these questions was also one to nine ranging from strongly disagree to strongly agree, respectively. Average scoring for these questions indicated that people indicated a six or higher for many of the questions as seen in Tables 4 and 5.

<u>Table 4.</u> Post- survey question responses for people without dementia that did not overlap with the pre-survey

Post- survey question responses for people without dementia that did not overlap with the pre-survey		
Question	Average Score Over the 3 Sessions (n=13) (*n=14)	
I enjoyed my time at Broadening Horizons	6.37	
I would like to go to another art museum	5.87	
I would like to come back to this museum	6.82	
I am likely to go to another art museum in the near future	4.87	
I learned a lot today about art	6.10	
I enjoyed meeting other people	6.10*	

Table 5. Post- survey question responses for people with dementia that did not overlap

with the pre-survey

<b>7</b> 1 1	ses for people with dementia that with the pre-survey
Question	Average Score Over the 3 Sessions (n=11)
I enjoyed my time at Broadening Horizons	7.13
I would like to go to another art museum	6.38
I would like to come back to this museum	6.25
I am likely to go to another art museum in the near future	5.74
I learned a lot today about art	6.75
I enjoyed meeting other people	6.15

To make sense of all of the data one must remember the incredibly small sample size that these numbers are based on. Additionally, on the rating scale of one to nine the average score could be a five and as seen in Figures 1 and 2, all of the pre and post scores were averaged to be above a score of five. Therefore, people scored above the average for the questions that appeared on both the pre and post surveys, however there was a decrease in scoring following the sessions.

Similarly, Tables 4 and 5 indicate that people scored above the average of five for all of the questions and across the populations with the exception of the residents without dementia whose average score for how likely they were to attend another art museum in the near future was a 4.87. This score slightly below the average could possibly be attributed to them considering the logistical aspects of visiting another museum.

### **Results: Qualitative**

The quantitative data over all did not indicate a strong change in positive affect; however, on the post survey, there was a blank space for comments to be written. Several of the comments following the first visit indicated that some of the residents had a hard time hearing the presentation and/or seeing the artworks, therefore I utilized a microphone for the remaining two sessions and I also provided color reproductions of the art works created to each of the participants so that they could have a copy of the work of art in front of them throughout the conversation. Despite this constructive criticism from Buffalo Valley Residents, Table 6 indicates that many of the other people had a positive experience at the museum. In fact, several of the participants continued the conversation with each other and with me as I was guiding them out to their buses. Many were curious if the program was going to continue because they had an interest in coming back.

Table 6. Comments	from the	participants	over the	three sessions

Residents with Dementia	Residents without Dementia
"Very well presented"	"I love art and hope to come back"
"I would like to learn more about art this year!"	"Kress collection is well-selected, informative growth of pictures"
"Greatly enjoyed sturying (sic) up memory and perception and preception (sic)"	"Excellent choice of illustrations. Discussion aety (sic) led!"
"It was nice I enjoyed it"	"Very interesting how view things differently"
"I was more interested than I thought I'd be"	

#### Discussion

The quantitative data showed that people typically scored each question above the average indicating at least some interest and enjoyment of the program. When looking at the difference scores of each individual museum visit, perhaps the theme of that particular set of artworks made a difference in the participants experience at the museum. I think that one of the most successful themes was the unconventional portraits theme of the second session because Tables 4 and 5 indicate the most positive difference values for that visit across both groups of people. These positive values indicate that the participants chose a higher and more positive post score than pre score.

While there was not an uptick in the average scores from pre to post as was hypothesized, the qualitative data showed that people generally had a good experience and enjoyed the artwork that they saw. Some of the comments written in Table 6 indicate that the people wanted to come back and that they had a better time than they thought they would, which to me, shows that this program was effective on some level. With this in mind, it is imperative for the Samek Art Museum to continue to offer a program like this that can positively impact people, especially those with dementia. Regularly offering this type of programming at Bucknell will not only positively impact its participants, because they can actively engage in conversation and look at the artwork because of their early-stage diagnosis, but it is a necessity for the museum to fulfill its Mission of "creat[ing] meaningful encounters between artists, students, scholars, the public and works of art." This programming not only helps the Samek to fulfill their Mission Statement which reads:

Bucknell is a unique national university where liberal arts and professional programs complement each other. Bucknell educates students for a lifetime of critical thinking and strong leadership characterized by continued intellectual exploration, creativity, and imagination. A Bucknell education enables students to interact daily with faculty who exemplify a passion for learning and a dedication to teaching and scholarship. Bucknell fosters a residential, co-curricular environment in which students develop intellectual maturity, personal conviction and strength of character, informed by a deep understanding of different cultures and diverse perspectives. Bucknell seeks to educate our students to serve the common good and to promote justice in ways sensitive to the moral and ethical dimensions of life. Bucknell's rich history and heritage will influence its planning for the future. Bucknell's potential as an institution of higher learning extends beyond that of a traditional liberal arts college by virtue of its larger size and expansive programs. The University's broader spectrum of disciplines and courses of study within a diverse and active residential campus community enhance the quality of all aspects of the undergraduate experience, both in and out of the classroom ("Bucknell... Mission Statement").

The connection between these two mission statements is that the Samek Art Museum is an extension of Bucknell University, and its desire to educate students to go forth and to "serve the common good and to promote justice." As the student, this thesis has allowed me to use my Bucknell education to engage folks who have previously been marginalized by inviting them to the museum for an art viewing experience that worked to improve their affect. To me this is nothing short of "serv[ing] the common good and... promoting] justice."

### Conclusion

This honors thesis has combined the history of art museums and their audiences with Disability Studies and a program to improve the lives of people in the local community, specifically those with dementia. Since the 1980s, Disability Studies scholars have encouraged people and institutions to be inclusive of all people no matter their ability level, so as to create a society where there is less stigmatization and othering. Art museums have grown from private collections to public venues for art with the purposes of preservation, education and leisure. When determining how important each purpose can be, I argue that the educational component of the museum, is the most important because it can engage people who have previously been marginalized, like those with cognitive impairments. Furthermore, it allows for people with varying levels of education to listen to and learn about art and art history. Institutional programs such as Meet Me at MoMA and Broadening Horizons directly engage communities of people with cognitive impairments, thus diversifying the museum audience, reducing stigmatization, and educating community members about art.

In the future, it is important that other museums create a program similar to Broadening Horizons and Meet Me at MoMA to engage their local community members with cognitive impairments. Even though the results of my study did not show any increase in affect, this was not a robust enough data set to draw any strong conclusions either way. Therefore, it would be beneficial to conduct another study at a similar size museum to Samek with more participants and perhaps different works of

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art to truly determine how an art viewing experience can positively impact a person with a cognitive impairment outside of a large institution such as the MoMA.

If this program were to be recreated at other institutions or continued at the Samek Art Museum, I would recommend engaging as many people from the local community as possible as opposed to focusing specifically on inviting people from several of the local long term care facilities to participate. Additionally, if at all possible it would be beneficial to have the companion of the person with dementia accompany them to the museum to make them feel more comfortable and possibly less disoriented. Finally, for institutions starting this program for the first time, following the MoMA organizational guides can be very helpful in thinking about the details of the event such as name tags, the length of the program, the artworks to discuss, how to best prepare, and what types of questions will be most engaging.

Exposing people with dementia to the static and sculptural visual arts has been the primary focus of this thesis, however there may also be benefits to exposing them to performance art. A similar program could be created in which people watch and/or listen to a performance and then they have a conversation about it around a theme, similar to the discussions of the static paintings and prints. The difference between watching a performance scene in comparison to looking at a static work of art, is that most likely the performance can never be replicated as it was first performed. When looking at a static work of art, one might notice something new when they look at it for a second or third time, but the painting or print itself will most likely not change.

In sum, it is important that museums and institutions continue to engage people

that have previously been marginalized, because their engagement has the chance to positively impact them and to positively impact society's views of them so that we can create more welcoming and diverse spaces.

#### Bibliography

- "About The Met." *The Metropolitan Museum of Art: About The Met*, The Metropolitan Museum of Art, www.metmuseum.org/about-the-met. Accessed 27 Mar. 2017.
- Alexander, Edward P. 1979. *Museums in Motion: An Introduction to the History and Functions of Museums*. Nashville: American Association for State and Local History.
- Appleton, LeRoy H, and Stephen Bridges. *Symbolism in Liturgical Art*. New York, Scribner, 1959.
- Bazin, Germain. The Museum Age. Translated From the French by Jane Van Nuis Cahill.Universe Books, 1967.

Bucknell University Mission Statement: http://bucknell.edu/Mission

- Burnham, Rika, and Elliott Kai-Kee. *Teaching in the art museum: Interpretation as experience*. Getty Publications, 2011.
- Chemers, Michael. "Mutatis Mutandis: An Emergent Disability Aesthetic in X-2: X-Men United." *Disability Studies Quarterly* 24.1 (2004).
- Davis, Lennard J. "Crips strike back: The rise of disability studies." *American Literary History* 11.3 (1999): 500-512.
- Davis, Lennard J. Bending over backwards: Essays on disability and the body. NYU Press, 2002.

- Denis, Daphnée. "Please Touch the Art: Grasping the Beauty of the Museum of Modern Art's Collection on a Tactile Tour for the Blind." *Medium*, Narratively, 14 Aug. 2013, medium.com/@narrativelyny/please-touch-the-arta822bf714045#.8ny3vgsco. Accessed 27 Mar. 2017.
- Falk, John H. *Identity and the Museum Visitor Experience*. Walnut Creek, Calif.: Left Coast Press, 2009.
- Falk, John H., and Lynn D. Dierking. *The Museum Experience*. Washington, D.C.: Whalesback Books, 1992.
- Foucault, Michel. *Discipline and Punish: The Birth of the Prison*. 2nd ed., New York, NY, Vintage Books, 1995.
- Foucault, Michel. Madness and Civilization: A History of Insanity in the Age of Reason. New York: Vintage Books, 1988. Print.
- Fries, Kenny. Staring back: The disability experience from the inside out. Plume Books, 1997.
- Gaugler, Joseph, et al. 2016 ALZHEIMER'S DISEASE FACTS AND FIGURES. New York, NY, Alzheimer's Association, 2016.
- Grinder, Alison L., and E. Sue McCoy. *The good guide: a sourcebook for interpreters, docents, and tour guides*. Ironwood Press, 1985.
- Halpern, Andrea R., et al. ""I know what I like": stability of aesthetic preference in Alzheimer's patients." *Brain and Cognition* 66.1 (2008): 65-72.

- Hansen, Liane. "Philadelphia Museum Shaped Early American Culture." NPR, NPR, 13 July 2008, www.npr.org/templates/story/story.php?storyId=92388477. Accessed 27 Mar. 2017.
- "History of the Ashmolean." *Ashmolean Museum of Art and Archaeology*, University of Oxford Ashmolean Museum, 2012,

www.ashmolean.org/about/historyandfuture/. Accessed 27 Mar. 2017.

"History of the British Museum." The British Museum,

www.britishmuseum.org/about\_us/the\_museums\_story/general\_history.aspx.

- "History of the Uffizi Gallery." Uffizi.org Guide to the Uffizi Gallery Museum, www.uffizi.org/museum/history/.
- Hood, Marilyn G. "Leisure Criteria of Family Participation and Nonparticipation in Museums." *Marriage & Family Review* 13.3-4 (1989): 151-169.
- Johnson, Joana, Alison Culverwell, Sabina Hulbert, Mitch Robertson, and Paul M. Camic. "Museum activities in dementia care: Using visual analog scales to measure subjective wellbeing." *Dementia* (2015): 1471301215611763.
- Kaufmann, Elke G., and Sabine A. Engel. "Dementia and well-being: A conceptual framework based on Tom Kitwood's model of needs." *Dementia* 15.4 (2016): 774-788.

Kitwood, Tom. "The experience of dementia." Aging & Mental Health 1.1 (1997): 13-22.

Lewis, Geoffrey D. "History of Museums." Encyclopædia Britannica, Encyclopædia Britannica, Inc., 25 Sept. 2000, <u>www.britannica.com/topic/history-of-museums-</u> <u>398827</u>. Linton, Simi. Claiming disability: Knowledge and identity. NYU Press, 1998.

- Mulvey, Laura. "Narrative cinema and visual pleasure." *Visual and Other Pleasures* (1975).
- Oliver, Mike. "A sociology of disability or a disabilist sociology." *Disability and society: Emerging issues and insights* (1996): 18-42.

Richardson, Edgar P, et al. "Important Dates in the Life of Charles Willson Peale." *Charles Willson Peale and His World*, 1st ed., Harry N. Abrams, INC., New York, NY, 1993, pp. 17–19.

- Rosenberg, Francesca, et al. *Meet Me: Making Art Accessible to People with Dementia*. New York, NY, The Museum of Modern Art, 2009.
- "Samek Art Museum: About." *Samek Art Museum Bucknell University*, Samek Art Museum, museum.bucknell.edu/about-us/. Accessed 27 Mar. 2017.
- Samek Art Museum Mission Statement: <u>http://www.bucknell.edu/samek-art-</u> <u>museum/about-the-samek-art-museum.html</u>
- Simon, Cecilia Capuzzi. "Disability Studies: A New Normal." *The New York Times*. The New York Times, 1 November 2013. Web. 11 Nov. 2016.
- "Stages of Alzheimer's." Alzheimer's Association,

www.alz.org/alzheimers\_disease\_stages\_of\_alzheimers.asp. Accessed 2 May 2017.

Stringer, Katie. "Disability, the Sideshow, and Modern Museum Practices." *Scientia et Humanitas* 3 (2013): 15-28.

The Editors of Encyclopædia Britannica. "Alexandrian Museum." Encyclopædia Britannica, Encyclopædia Britannica, Inc., 15 June 2006,

www.britannica.com/topic/Alexandrian-Museum.

- The Editors of Encyclopædia Britannica. "Pinacotheca." Encyclopædia Britannica, Encyclopedia Britannica, Inc., 28 Aug. 2008, www.britannica.com/topic/pinacotheca.
- "The Fan Fox & Leslie R. Samuels Foundation, Inc." *The Fan Fox & Leslie R. Samuels Foundation, Inc.*, Samuels Foundation, www.samuels.org/. Accessed 27 Mar. 2017.
- "The History of The MoMA Alzheimer's Project." *MoMA: Meet Me Research and Development*, The Museum of Modern Art,

www.moma.org/meetme/resources/index#history. Accessed 27 Mar. 2017.

"The Museum Docent." *Roundtable Reports*, 1977, www.jstor.org/stable/40478299.

"The Social Model of Disability." The Social Model of Disability. Accessed October 28,

2016. <u>http://www.pwd.org.au/student-section/the-social-model-of-disability.html</u>.

Thomas, Carol. "Disability theory: Key ideas, issues and thinkers." (2002): 38-57.

Thomson, Rosemarie Garland. Extraordinary bodies: Figuring physical disability in

American culture and literature. Columbia University Press, 1997.

- "Types of Dementia." *Alz.org*, Alzheimer's Association, <u>www.alz.org/dementia/types</u> ofdementia.asp. Accessed 27 Mar. 2017.
- West, Shearer, ed. The Bulfinch guide to art history: A comprehensive survey and dictionary of western art and architecture. Bulfinch Press, 1996.

"What Is Alzheimer's?" Alz.org, Alzheimer's Association,

www.alz.org/alzheimers\_disease\_what\_is\_alzheimers.asp. Accessed 27 Mar. 2017.

- World Health Organization. International classification of impairments, disabilities, and handicaps: a manual of classification relating to the consequences of disease; publ. for trial purposes in accordance with resolution WHA29. 35 for the Twentyninth World Health Assembly, May 1976. na, 1980.
- Yenawine, Philip. "Theory into practice: The visual thinking strategies." In *conference, Aesthetic and art education: A transdisciplinary approach, Lisbon, Portugal.* 1999.

Appendix A

# Pre Museum Experience Survey- Version A

	bletely anonymous and w by art.	Please ci	rcle or write i	ı yo	ur a	nsu	er.		-	5	
1.	Sex:		Female						N	fale	•
2.	Age:										
3.	How many years of schooling have you had?										
4.	In what town/city did you grow up?										
5.	How many art classes have you taken in school or after graduation?										
6.	How many years of formal art training do you have?										
7.	Do you consider yourself to be a visual artist? Details:				YI N						
8.	On average how often d		0-1	2-:	5	6-1	0	M	ore	thar	1 10
9.	Right now I feel		1 Very Sad	2	3	4	5	6	7	8	9 Very Happy
10	). How interested in art ar	e you?	1 Not at all interested	2	3	4	5	6	7	8	9 Very Interester
11	. How alert do you feel ri now?	ight	1 Not Alert	2	3	4	5	6	7	8	9 Very Alert

# Appendix B

# Post Museum Experience Survey- Version A

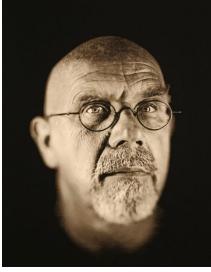
1. On average how often do you go to art museums in a year?	0-1	2-5		6-10		More than			ι 10
2. Right now I feel	1 Very Sad	2	3	4	5	6	7	8	9 Very Happy
3. How interested in art are you?	1 Not at all interested	2	3	4	5	6	7	8	9 Very Interested
4. How alert do you feel right now?	1 Not Alert	2	3	4	5	6	7	8	9 Very Alert
5. I enjoyed my time at Broadening Horizons	1 Strongly Disagree	2	3	4	5	6	7	8	9 Strongly Agree
6. I would like to go to another art museum	1 Strongly Disagree	2	3	4	5	6	7	8	9 Strongly Agree
7. I would like to come back to this museum	1 Strongly Disagree	2	3	4	5	6	7	8	9 Strongly Agree
8. I am likely to go to another art museum in the near future	1 Strongly Disagree	2	3	4	5	6	7	8	9 Strongly Agree
9. Today I learned a lot about art.	1 Strongly Disagree	2	3	4	5	6	7	8	9 Strongly Agree
10. Today I enjoyed meeting new people.	1 Strongly Disagree	2	3	4	5	6	7	8	9 Strongly Agree
11. Other comments									

### Appendix C



Paolo Veronese Judgment of Paris 1548-1588 Oil on canvas Samek Art Museum

Questions/Comments: "What is the dog in the bottom corner?" "Why are they naked?" "It looks like they are modeling" "What is he holding?



Chuck Close A couple ways of doing something: Self Portrait of Chuck Close 2003 Digitally printed daguerreotype on paper Samek Art Museum

Questions/Comments: "He looks very peaceful" "He looks like he is thinking about something"



James Gillray *Middlesex Election of 1804* 1804 Hand colored engraving on paper Samek Art Museum

Questions/Comments: "It looks chaotic" "What are the papers falling on the ground?" "There is a dead rat"