LOWERING BARRIERS TO USER-CONTROL:

CONSIDERATIONS FOR MUSEUM VISITORS WITH SEVERE MENTAL ILLNESSES

By

Kayle J. Rieger

A thesis presented in partial fulfillment of the requirements for the degree of Master of Arts in Museum Studies

Approved April 19, 2016 by the thesis committee:

Dr. Peter Welsh, Chair Dr. Ruth Ann Atchley Mary Madden

Abstract

Surveying the current state of museum accessibility to visitors with severe mental illnesses, this report aims to illuminate an almost entirely invisible issue. While many museums nationwide are creating special programs for families of children on the autism spectrum, adults with Alzheimer's disease and other dementias, and even adults with post-traumatic stress disorder, visitors with many more marginalized forms of severe and persistent mental health issues are largely neglected. These disorders include major depression, child and adolescent depression, bipolar disorders, schizophrenia, and many others. Stigma may slowly be eroding, but that audience still remains "untouchable." However, museums can offer great benefits to individuals living with severe mental illnesses. This study will outline ways that museums can reorient how they think about accessibility within their walls in order to offer more universally accessible, supportive, and constructive experiences to visitors living with severe mental illnesses.

Diversity and inclusivity rising among their priorities, many museum professionals now consider how to create visit experiences for audience members on the autism spectrum, with different learning styles, and with low vision. But do museum staff—educators, volunteer coordinators, curators, exhibition designers—know how to provide welcoming and constructive experiences for a visitor with problems socializing, in a depressive state, or with occasional hallucinations? In four years the second largest health problem worldwide is predicted to be a severe mental illness and these are some of the symptoms that can be experienced by someone living with one. The United Kingdom's Museums Association, also looking four years into the future in its "Museums 2020 Discussion Paper," rightly asserts, "every citizen has the right to museum services that meet their interests and needs;" this should include those living with serious mental health issues, despite the challenges they present.²

Below I present a report of the current status of mental health care and its relationship with museums along with support for why such relationships should be fostered. Once it is clear why this constituency requires inclusion, a qualitative case study examining a museum's experiential environment will introduce accessibility concerns. Assessing how museums can increase accessibility to visitors with severe mental illnesses will no doubt bring up more questions than answers, and the following discussion is meant to provide general points for consideration, a reorienting of thought, and first steps in welcoming and providing positive museum experiences for visitors with serious mental health issues. To address this invisible audience it first takes equally imperceptible measures and assuring the sometimes all-too-

^{1. &}quot;Reducing the Stigma of Mental Illness," The Lancet, 2001, sec. Editorial.

^{2. &}quot;Museums 2020 Discussion Paper" (United Kingdom: Museums Association, 2012), http://www.museumsassociation.org/download?id=806530, 6.

conspicuous visitors, too, calls for charitably inconspicuous changes. If museums are to become more accessible and even enriching to visitors with severe and persistent mental illnesses, they must first work to lower barriers to user-control within visit experiences.

Background

An Invisible Audience

One important factor in increasing accessibility to a particular audience is understanding its members and what makes their needs different. This has proven challenging when it comes to people with severe and persistent mental illnesses (SPMI), likely in part because of the wide spectrum of symptoms coupled with their general severity, but also an inherent lack of visibility despite their increasing prevalence. Over 200 forms of mental illness are officially classified and they are generally grouped into five major categories: anxiety disorders, mood disorders, schizophrenia/psychotic disorders, dementias, and eating disorders.³ Of these categories, four include disorders commonly considered severe and persistent mental illnesses (typically anxiety disorders are excluded), sometimes more simply called severe or serious mental illnesses (SMI).⁴ A severe and persistent mental illness is a diagnosable mental disorder causing "functional impairment which substantially interferes with or limits one or more major life activities [work and/or school, social functions, and personal hygiene]...All of these disorders have episodic,

^{3. &}quot;The Five Major Categories of Mental Illness" (Mental Health Association in Forsyth County, 2011), http://www.triadmentalhealth.org/what-is-mental-illness/.

^{4. &}quot;Serious Vs. Non-Serious Mental Illness" (Blue Cross Blue Shield of Illinois, n.d.), http://www.bcbsil.com/provider/standards/serious vs non serious.html.

recurrent, or persistent features." Further, they significantly reduce one's "mental capital"—the capacity for resilience, self-esteem, cognition, and emotional intelligence— as well as a sense of self, values, and purpose; agency, choice, and responsibility; and hope. Some of these disorders include major depressive disorder, obsessive-compulsive disorder, childhood and adolescent depression, bipolar disorder, and schizophrenia. About 25 percent of American adults (61.5 million) experience mental illness in a given year and about one in 17 adults lives with a severe and persistent mental illness; this number is even higher in adolescents aged 13 to 18, where it is one in five. Compared to the rates of children on the autism spectrum (1 in 68), with peanut allergies (1 in 125), or diagnosed with cancer (1 in 285), a child is at least 13 times more likely to develop a severe mental illness in adolescence, and four times more likely to develop one in adulthood. The need for increased attention to individuals with severe and persistent mental

^{5.} The Federal Register in "Director's Blog: Getting Serious About Mental Illnesses," National Institute of Mental Health, accessed February 21, 2016, http://www.nimh.nih.gov/about/director/2013/getting-serious-about-mental-illnesses.shtml.

^{6.} Jocelyn Dodd and Ceri Jones, *Mind, Body, Spirit: How Museums Impact Health and Wellbeing*. (Leicester: Research Centre for Museums and Galleries, 2014), 24; John Pollard, "Therapeutic Museums and Mental Health: Why, Where, What, and How?" (PowerPoint, Touch & Wellbeing Workshop: Heritage, Health and Wellbeing: Mapping Future Priorities and Potential, London, 2011), 7.

^{7. &}quot;Serious Vs. Non-Serious Mental Illness" (Blue Cross Blue Shield of Illinois, n.d.), http://www.bcbsil.com/provider/standards/serious vs non serious.html.

^{8. &}quot;Mental Illness Facts and Numbers" (National Alliance on Mental Illness, 2013), http://www2.nami.org/factsheets/mentalillness factsheet.pdf.

^{9. &}quot;Autism Prevalence," Autism Speaks, accessed February 21, 2016, https://www.autismspeaks.org/what-autism/prevalence; "Food Allergy," National Institute of Allergy and Infectious Diseases, accessed February 21, 2016, https://web.archive.org/web/20100407195412/http://www.niaid.nih.gov/topics/foodAllergy/understanding/Pages/quickFacts.aspx; "U.S. Childhood Cancer Statistics," American Childhood Cancer Organization, accessed February 21, 2016, http://www.acco.org/us-childhood-cancer-statistics/.

illnesses should seem an obvious conclusion, yet this population remains grossly underserved by both museums and society at large.

An Incredible Need

Briefly, while mental illnesses are treatable in the long term, they are challenging to manage and this is exacerbated by the reluctance or inability of individuals to receive proper care. Without delving into the innumerable barriers preventing people from achieving access to mental health treatment, it remains possible to see that there is an extremely wide gap between being diagnosed and receiving further treatment. In the United States, for example, 60 percent of adults and 50 percent of youth (aged 8 to 15) do not receive necessary mental health services. ¹⁰

These numbers are even worse for minority groups: African Americans and Hispanic Americans at about one-half the rate and Asian Americans at about one-third the rate of Caucasians. Further, despite the fact that many severe mental illnesses first present around early adulthood and there are increasing numbers of diagnosed students on campuses, even large universities struggle to or simply cannot provide the proper support their students need pre- and post-diagnosis. ¹¹ With stigma and misunderstanding still rampant and the mental health care sector struggling to serve those most in need, it is perhaps not surprising that museums are reluctant to step into the ring.

As Joanna Besley sums up in her work, "Compassionate Museums?" "despite the increasing willingness of museums to address the social exclusion and cultural rights of disadvantaged groups and individuals, those with mental health issues remain largely off-

^{10. &}quot;Mental Illness Facts and Numbers."

^{11.} Kelly Cordingley, "More Students Are Coming to KU with Mental Health Issues, but the University Struggles to Keep Up with the Demand," The University Daily Kansan, November 29, 2015, sec. News, http://www.kansan.com/news/more-students-are-coming-to-ku-with-mental-health-issues/article 2b0fc8ac-96fa-11e5-91fa-cff01258e110.html.

limits." ¹² Truly, according to the American Alliance of Museums' 2013 report "Museums on Call: How Museums Are Addressing Health Issues," while numerous museums across the country are offering programming about health and illness as well as for individuals and families living with health challenges, there is a startling absence of programs specifically relating to mental health. 13 Of the 142 museums surveyed, only seven offered programs on the topic of mental health, compared to 22 programs devoted to Alzheimer's/dementia inclusion and 40 programs for people on the autism spectrum (each of which was considered *separately* from the mental health topic within the report). Further, of the seven programs listed three were simply conversational, such as lectures and tours *about* the topic of mental illness, while only four were enriching—programs designed for visitors with mental health issues—with half of those being solely for veterans. In addition to the quantifiable lack of initiative shown, the lack of professional discussion is also quite apparent. For example, the Center for the Future of Museums' very first discussion paper, covering challenges for the next quarter century, explores projected demographic changes including larger elderly and minority populations, and even a new gender gap, yet there is no mention of increases in mental illness prevalence. ¹⁴ The aforementioned AAM "Museums on Call" report also shows a discrepancy between discussions of mental illness versus those of other health issues: the topic of mental health is discussed in less than 130 words whereas all other health topics are given an average of 388 words; autism

^{12.} Joanna Besley, "Compassionate Museums?," Museum Worlds 2 (2014): 148.

^{13. &}quot;Museums on Call: How Museums Are Addressing Health Issues" (American Alliance of Museums, 2013), http://www.aam-us.org/docs/default-source/advocacy/museums-on-call.pdf? sfvrsn=8.

^{14.} James Chung and Susie Wilkening, "Museums & Society 2034: Trends and Potential Futures" (Center for the Future of Museums; American Alliance of Museums, 2008).

receiving the most coverage with 574 words. ¹⁵ It seems that museums—professionals and the sector as a whole—do not know what to say about mental health issues, especially severe ones, and are not comfortable discussing any sort of relationship or responsibility to addressing them. In the museum profession, mental illness is still, as Besley says, off-limits.

While the issue of mental illness is a difficult one to address—inside museum walls and otherwise—some museum and institutional programs have shown it is possible and worthwhile. ¹⁶ In fact, Lois Silverman lists five ways museums contribute to health issues: "promoting relaxation; producing an immediate beneficial change in physiology, emotion, or both; encouraging introspection; health education; and advocacy for public health by enhancing the health care environment." ¹⁷ So not only is it possible to address challenges for people with mental illnesses within museums, such efforts offer significant benefits to both visitor and institution alike

Benefits Across the Board

Health Programming Benefits to Museums

Before discussing how museums can benefit mental health care and its clients, consider how such collaboration and programming could be advantageous to museums. In addition to acting as contact zones between different communities of people, museum programs that are

^{15. &}quot;Museums on Call."

^{16.} See, for example, Dodd and Jones, *Mind, Body, Spirit*, and Anne-Sophie Gutsche et al., eds., Museums' 4 Values- Values 4 Museums (Germany: Network of European Museum Organizations, n.d.), http://www.ne-mo.org/fileadmin/Dateien/public/NEMo_documents/ NEMO_four_values_2015.pdf.

^{17.} Chia-Li Chen et al., "Beautiful Minds: The Role of Museums in Interacting with Visitors with Mental Illness," Museum Worlds 2 (2014): 137.

more accessible and supportive can more effectively meet the needs of those communities. ¹⁸ As explained by Michelle Lopez in AAM's "Museums on Call" report, "participating in health care also helps the museum reach a more diverse population [because] 'other community organizations may serve a specific race, religion, gender, age group, or income level, but the hospital serves everyone," and contributing to health care—including mental health care—means reaching the widest audience possible. ¹⁹ With a wider audience comes more diversified perspectives and better understandings of that audience's needs, which will influence future public programming goals. This creates a positive feedback cycle where increasingly accessible and enriching programming welcomes new visitors, diversifies the whole audience, and further shapes and improves programming. One way Jocelyn Dodd and Ceri Jones suggest museum program evaluation be redirected is by focusing efforts on how participants feel about themselves during and after a program, rather than how they felt about the program itself. ²⁰ Only by working with the mental health sector and individuals with mental illnesses will museums elucidate new ways of serving, engaging with, and diversifying their audiences.

Broadening audience engagement can also lead to new collaborative partners as pioneering museums "demystify" working with individuals with mental health issues and forge new institutional links within the mental health sector.²¹ These partnerships represent an untapped resource not only for improving accessibility and providing programming for visitors

^{18.} Dodd and Jones, Mind, Body, Spirit.

^{19. &}quot;Museums on Call," 11.

^{20.} Dodd and Jones, Mind, Body, Spirit.

^{21.} Pollard, "Therapeutic Museums and Mental Health."

with mental illnesses, but also for further increasing audience diversity. As one reflected on a museum collaboration:

I hadn't thought about [museums] in any particular detail before I was approached to do this project...what this project has done is open my eyes to the use of museums in this way. And it's a completely different angle to anything else that's being delivered at the moment.²²

It is likely that a partnership between mental health care provider and museum could continue to flourish and, in addition to increased and diversified audiences and broadened staff perspectives, shared resources and even new funding opportunities could be among the many advantages.

There is potentially no limit to the benefits that working with mental health care and its clients could bring to the museum sector, and the same could be said for the target audience: those living with mental illnesses

Museums Benefit Visitor Mental Health

Museum programming—particularly when designed with individuals with mental illnesses in mind—has the potential to impact visitors with mental illnesses, their health support staff, and the mental health care sector as a whole in myriad ways. The first of these are raising awareness and informing staff practices. By offering programming related to mental health, whether conversational or supportive, museums become contact zones between different communities, thus enhancing understanding and normalizing the existence of mental illnesses.²³ And when more people understand that mental illnesses are "not the result of moral failings or

^{22.} Marie Billyeald in Dodd and Jones, Mind, Body, Spirit, 20.

^{23. &}quot;Museums 2020 Discussion Paper."

limited willpower, but are legitimate illnesses that are responsive to specific treatments, much of the negative stereotyping my dissipate."²⁴ Additionally, when mental health care staff attend programs with their client groups they gain new perspective and insight into clients' needs as well as ways of supporting their health outside the museum setting.²⁵ In this way, museums become voices for the voiceless, thus addressing the contributions of education and advocacy suggested by Silverman. In short, museum programs for visitors with mental illnesses impact the mental health sector from the outside through community awareness and from the inside by informing staff practices.

Museum contributions to mental health care can reach far beyond education and advocacy and move into enrichment; museums and their programs already show benefits to visitor mental health. First, Silverman suggests that individuation (independence) and integration (socialization) are "fundamental goals" when addressing mental health and these are two significant ways that museums impact visitors. ²⁶ For example, art making activities help to counteract the feelings of helplessness so common among individuals living with severe mental illnesses and engaging in projects boosts confidence and autonomy. ²⁷ In programs centered on museum object handling, participants attach personal value to being allowed to work with

^{24. &}quot;Reducing the Stigma."

^{25.} Erica E. Ander et al., "Using Museum Objects to Improve Wellbeing in Mental Health Service Users and Neurological Rehabilitation Clients," British Journal of Occupational Therapy 76, no. 5 (2013): 208–216, doi:10.4276/030802213X13679275042645.

^{26.} Chen et al., "Beautiful Minds," 138.

^{27.} Iyna Caruso, "The Pictures of Health: Art's Healing Powers," Saturday Evening Post, 2009.

artifacts and this also helps to restore self-esteem.²⁸ Museum programs specifically aimed at visitors with mental illnesses offer many avenues toward increased individuation via strengthened self-esteem and autonomy. And with positive changes in personal identity and individuation come additional improvements in integration, or socializing experiences; as John Pollard explains, "museums…offer stories that relate to personal identity. They can address and help us explore our common humanity and universal concerns."²⁹

When visiting museums in groups, individuals with mental health issues are afforded numerous opportunities for improved integration, the second fundamental goal of mental health care. By working in groups, individuals experience "peer support and a sense of belonging" contributing to improved social skills and social inclusion, and even making friends. These supportive group experiences within a new setting "can offer a unique forum and even therapeutic setting for communicating difficult thoughts and feelings" thus further improving communication and social integration. Given that those with mental health issues tend to live in solitude and rarely participate in cultural activities, even feeling comfortable and welcome as an individual visiting a museum can aid in feelings of social integration and normalization. By offering opportunities for improved individuation and integration, museums then benefit individuals with mental illnesses by improving their emotional states and general wellbeing.

^{28.} Ibid.; Dodd and Jones, Mind, Body, Spirit.

^{29.} Pollard, "Therapeutic Museums," 8.

^{30.} Ander et al., "Using Museum Objects."

^{31. &}quot;Is There a Place for the Arts in Our Modern Health care System?," Perspectives in Public Health 133, no. 1 (2013): 20, doi:10.1177/1757913912468648.

^{32.} Chen et al., "Beautiful Minds;" Morris, Margaret, interview by author, February 18, 2016.

As Silverman points out, museums contribute to health issues by promoting relaxation, producing physiological and emotional benefits, and encouraging introspection; these are among the plethora of additional benefits that museums can provide visitors, particularly those with mental health issues.³³ Museums provide safe places to visit, shelter from the elements, clean restrooms, and places to sit and rest.³⁴ Further, they are generally considered familiar and comfortable with staff that are kind and caring, and this contributes to their promotion of relaxation and physical and emotional benefits. 35 Physiologically, studies show that spending just 30 minutes in an art gallery setting reduces the stress hormone cortisol 10 times faster than normal.³⁶ And, emotionally, object handling sessions have been shown to both increase positive emotions and decrease negative emotions as well as enhance feelings of vitality in participants.³⁷ Inpatient clients also benefit from a new sense of freedom in getting away from their ward and learning together.³⁸ In addition, Pollard identifies several other ways museum settings can benefit individuals with mental illnesses: "Creating one's own personal interpretations of heritage can help us get in contact with our freedom and responsibility; encouraging active engagement rather than passive learning can empower; museum objects can act as powerful healing and inspiration symbols," and, perhaps most importantly, "museums, at least implicitly, state that things change,

^{33.} Chen et al., "Beautiful Minds."

^{34.} Ander et al., "Using Museum Objects."

^{35.} Ibid.; Dodd and Jones, Mind, Body, Spirit.

^{36.} Mark O'Neill, "Cultural Attendance and Public Mental Health--From Research to Practice," Journal of Public Mental Health 9, no. 4 (2010).

^{37.} Ander et al., "Using Museum Objects."

^{38.} Lorinda Peinaar, Geoff Ward, and Helen Shearn, "Using the Arts to Reduce Isolation in Dementia," Nursing Times 110, no. 42 (2014): 18.

general, none should be taken lightly when considering the stress, hopelessness, isolation, and loss of agency that is so frequently felt by individuals living with severe mental illnesses. The numerous physiological, emotional, and psychological benefits museums provide can be even more significant in the lives of those that are struggling with mental illness than in those that are not. The question now is not can museums benefit individuals with severe mental illnesses, but how can they provide these experiences? How can museums be more accessible to and supportive of visitors with severe mental illnesses?

Case Study:

A Museum Through the Lens of Severe Mental Illness

Methodology

To explore the question of how museums can be more accessible to people with severe mental illnesses I used a combination of various qualitative approaches. I assembled a group of self-selected individuals recruited from the psychology and social welfare departments at the University of Kansas to participate in an observational visit to a local war museum. The museum was chosen based largely on its subject matter as it had the potential to be challenging to visitors, particularly those with severe mental health issues, and it might also mention topic-related mental illness (i.e. shell shock/post-traumatic stress disorder) within the exhibitions. In this way, both the environment and content could be examined. Participants were selected specifically from the psychology and social welfare departments because of their academic knowledge of mental illnesses as well as direct work with clients who have mental health issues.

^{39.} Pollard, "Therapeutic Museums," 9-11.

Prior to the visits, each participant was given a questionnaire to evaluate his/her general view of museums and of whether museums are accessible, welcoming, and appropriate places for people with severe mental health issues. Upon arrival at the museum the participants were each given an outline of elements to potentially consider during their observations such as signage, advertised programming, and the sensory environment. The participants were given 60 minutes to observe the museum environment during which time they could view any of the public spaces and exhibitions. Following the observation time, I discussed with the participants their observations, thoughts, and evaluations of the museum's level of accessibility and the specific factors contributing to their assessments. The post-visit discussions lasted about 45 minutes each.

A considerable limitation of this study is that the number of observation participants was extremely small (two observers) due to the barrier of driving an hour to the museum. That, coupled with the two hour commitment to observations and discussion, meant dedicating four hours to participating. This proved simply too much for busy faculty and graduate students despite efforts to offer multiple date options over two academic semesters. The observations were also made by individuals who do not identify as being diagnosed with any severe mental illness, and their demographics were not diverse: of the four (including those who only responded to the questionnaire), three were women and all four were well-educated and Caucasian. Therefore, it is imperative to note that these evaluations come from very knowledgable but "outside" observers and the results cannot be considered generalizable to all individuals with severe mental illnesses. This study is not meant to be exhaustive, but rather offers a glimpse into what factors can shape the visit experiences of patrons with severe mental illnesses: a reorienting of thought.

Results

The pre-visit questionnaires revealed several similar perceptions among the respondents that could be revealing of both museums' perceived and actual accessibility to individuals with mental illnesses. First, three out of four questionnaire respondents considered themselves "museum goers" (note that two questionnaire respondents were unable to attend the museum observation visit). Art and anthropology/archaeology museums were most enjoyed followed by history, and natural history and science museums were listed as least enjoyable. One respondent also listed music museums as a favorite. Three quarters of respondents further indicated that they would consider a museum as part of a client's mental health treatment, although none were familiar with any museum programs specifically for such visitors. Their reasoning behind considering museums as a part of treatment included that a museum can be culturally enriching. calm and quiet, a safe place to explore stressors, and an "un-rushed space of gathering people" that allows for sensory and social experiences in a more subdued manner. However, that same number of respondents (3/4) also felt that museums are *not* welcoming to people with mental health issues. One respondent explained that museums are "not set up or welcoming to individuals who do not fit into our molded expectations of how someone is supposed to act in public." This sentiment seemed to riddle the visit observations as well.

To start, while the museum visit observations and discussion proved valuable, they were not well attended; only half of the questionnaire respondents were able to participate in the visit portion of the study. After compiling the visit observation data, the majority of factors fell into either environmental aspects or content aspects, as well as some miscellaneous observations. I

will begin with the content observations as they are likely less generalizable to various museums than the environmental aspects.

Scenes of war and violence as well as the somber mood of the exhibitions were one principle concern. As one participant explained, people with depressive symptoms will react more strongly to negative imagery than to more positive displays. Additionally, a gallery of war portraits upon entering the exhibition space lends itself to self-referential thoughts on the part of the visitor, either positively or negatively. However, the effective use of personal stories throughout the museum was also noted as potentially positive because it allows visitors to make their own personal connections to the stories and content. Negatives stories were also "wrapped up," leaving more positive and hopeful final impressions for visitors; this is important given that visitors may make personal connections to them. One final note about the museum's content was that the topics of shell shock and post-traumatic stress disorder were not noticeably discussed. This was disappointing to participants who noted that its lack of mention—or of visibility paralleled current issues for people with severe mental illness. So while the content overall conveys a somber tone and may produce stronger negative reactions, particularly for those with depressive symptoms, the prevalence of personalized stories also allows visitors to make connections to stories of struggle, perseverance, change, and—ultimately—hope: a paramount goal for individuals living with severe mental health problems.⁴⁰

Whereas the content of the museum was significant but likely less generalizable, the environmental aspects of the participants' museum visit experiences featured most prominently

^{40.} Pollard, "Therapeutic Museums."

in the post-visit discussions and were much more universal concerns. The museum's main-level exhibition area is a large and open space but has few signs or other way finding aids. Laid out like the spokes on a bicycle tire, with linear exhibition areas radiating from a central arched timeline wall, the space has a suggested traffic flow but only one true point of entry and exit making it a problem to leave the exhibition: visitors must walk all the way around the arched design to make it to the central exit. The sprawling space is also occupied by a plethora of benches and about a dozen elderly white male volunteers. One participant speculated that the volunteers may have personal experiences of being part of war and even post-traumatic stress disorder, and for those reasons may be able to relate with visitors who also experience mental health issues. During the visits there were dozens of high school aged students on field trips. While this did add a lot of people to the gallery spaces, the groups were well contained with their docents and were mindful of other visitors as they moved throughout the exhibitions.

There were also a handful of design features within the exhibitions that were discussed by participants including an interactive table, audio rooms, light projections, lenticular or "flicker" images, and large-screen videos. There are two different large-screen videos within the exhibition and each provides optional closed-captioning. Moving light projections are used in a few areas too, particularly on the floors. A large interactive table features prominently in the exhibition. The table allows for multiple interactions, such as designing a war poster using imagery from posters on display. The table did present some potentially disturbing imagery and was difficult to figure out. There were no instructions nor was the process completely intuitive, and it was not always functioning properly. However, the interactive nature allowed for visitor control and creativity, factors which will be discussed later. Finally, there were a few audio

rooms in the same area as the interactive table. These individual rooms with glass walls and doors facing the rest of the interactive table area greatly dampened the sounds from the exhibition and also offered the visitor options to listen to songs, audio recordings, and other sounds related to the exhibition while seated inside. The rooms were praised for being very quiet, calm, and safe and secluded spaces within the exhibition area as well as for their comfortable seating and user-controlled nature. However, it was noted that some of the audio recordings were loud and jarring and the volume was not adjustable.

Perhaps the most significant overall observation from the participants was the extent of the sensory experience within the exhibition environment. The majority of the exhibition galleries have dim lighting which could be a positive or negative experience, both providing a more safe, secluded feeling for some but potential areas for fear and confusing sensory perceptions for others. But what was of most concern was the cacophony of sounds that were immediately heard upon entering the exhibition. The noises were unrelenting as participants made their way through the space, often hearing more than one or two sounds—including artillery fire and explosions—competing with each other from adjacent exhibits.

Additional miscellaneous observations were also noted as follows. The gallery map laid out a good visual of the gallery arrangement—as described above—however, it did not include mention of any accessibility accommodations. The volunteers also did not convey any understanding of mental illness. As I mentioned to one volunteer that the group was making observations related to mental illness-related accessibility, he began discussing *physical* accessibility issues within the gallery spaces. However, he later mentioned leading a Wounded Warriors tour group and how some of the men self-selected not to view the large panorama video

after being advised about the jarring sound effects, including explosions. So, while the volunteer did not recognize the semantic difference between physical and mental accessibility issues, he did seem to understand and was sensitive to the potential effective differences for that particular tour group.

Discussion

The qualitative data gathered from the questionnaires and visit observations lead to several conclusions about museums' perceived, actual, and potential accessibility to visitors with severe mental illnesses. As the pre-visit questionnaires indicated, 3/4 of respondents selfidentified as museum-goers and the same proportion also indicated they would consider a museum as part of a client's mental health treatment. However, these two factors were not directly correlated as one respondent indicated that she is a museum goer yet she would not consider including a museum in a client's treatment plan. So while it may initially appear that a provider who enjoys and benefits from museum visits would also see the potential benefit to clients, this is not always the case. This is closely linked to the respondents' perceptions of museums as unwelcoming to people with severe mental illnesses (3/4 of respondents). As one respondent explained, "Museums are...challenging for people with a range of mental health problems...[It] is a social space that requires spending time with strangers (even large crowds of people) [and] require[s] visitors to behave in a very particular way."41 A second respondent echoed similar concerns about expected behaviors and each mentioned examples such as being quiet, respecting personal and institutional boundaries, and following social protocols like not

^{41.} Anonymous respondent, "Museums and Mental Illness" questionnaire. November, 2015.

standing in front of one exhibition so long as to inhibit others' viewing opportunities. A third respondent further added:

People with mental health issues may be perceived as dangerous or unpredictable in their behaviors. [They] may ward off other museum visitors, may be talking to themselves causing disturbance [sic]. Museums may not want a group of people with mental health issues coming because it might decrease museum attendance.⁴²

These negative perceptions keep even the most willing providers and visitors from engaging with museums. However, museums' accessibility issues do not end at their front doors.

Based off all the visit observations and discussions, most concerns would suggest one particularly significant need of patrons with severe mental illnesses: user-controlled experiences —both sensory and social. Congruent and even foundational to the goal of user control are also needs for safe and/or "escape" areas and normalizing experiences. Briefly, to begin, visitors who have severe mental illnesses need to be afforded "normal" experiences at museums, allowing for the individuation and integration prescribed by Silverman.⁴³ This normalization can be understood best in a comparison to physical accessibility and universal design theory. Also known as inclusive design, the concept of universal design produces environments that are inherently—and in theory—accessible to everyone regardless of physical ability. Rather than creating *additional* and *separate* features to accommodate those with physical disabilities, it designs for a broad spectrum of abilities and offers a single, universally accessible option.⁴⁴ This

^{42.} Ibid.

^{43.} Chen et al., "Beautiful Minds."

^{44. &}quot;What is Universal Design?" Universal Design.Com, accessed January 31, 2016, http://www.universaldesign.com/about-universal-design.html.

sort of approach should be considered for visitors with varying mental health statuses as well, as each will experience unique combinations of symptoms and stressors. An intentionally universal design allows for more normalized, "single stream" experiences for individuals with and without mental illnesses enjoying the museum side by side, neither being singled out as "other" by the design. These normalized experiences thus lay the foundation for vital user-controlled experiences.

First, users should have control of their sensory experiences. As became clear through the visit observations, museums are inherently sensory places—some more than others—and for visitors whose mental health symptoms may include changes in sensory perception, hallucinations, or strong anxieties these can be overwhelming and potentially harmful. To allow for greater individuation and normalization, visitors should be able to control what level of sensory experience they encounter. Just as the gentlemen in the Wounded Warriors tour mentioned earlier were able to self-select what not to view or experience, so too should any visitor, without being singled out or needing the intervention of another person. The individual audio rooms at the museum provided a welcome way for visitors to control what sounds they heard—whether the available audio in the rooms or simply avoiding the sound effects outside in the exhibition space. Given the overwhelming presence of sound effects in the exhibitions, other avenues for controlling that sensory experience would have been favorable. For example, this could be in the form of sound-blocking headphones available for check-out to visitors with concerns about particular sounds and/or noise levels. The museum galleries in this study were already set up for audio-guided tours, with stops marked by small headphone icons on the walls, so a similar approach could indicate to visitors what types or levels of sound are featured in a

gallery space, thus allowing them to choose whether or not to hear them. Similar thought should also be given to visual images and lighting effects. What is important is that visitors do not need to rely on a volunteer, tour guide, or other care giver to direct or mediate their experience, but are equipped to effectively control their own museum visits.

The second form of user control of prime concern is over social experiences. Literature on the subject of mental health care makes it clear that social experiences—while potentially extremely challenging—should be integral to a client's treatment and daily life; this is what Silverman calls integration, or the process of becoming and feeling like a part of society and participating in regular social experiences. 45 As mentioned, the gallery spaces in this study were well controlled from a social standpoint: groups were prevalent but not obtrusive, as were volunteers. This allowed visitors to feel further in control of their own social experiences; they were not forced to interact with others in order to experience the exhibitions. User-control over social experiences can also be achieved by providing useful finding aids (gallery maps and signage), giving visitors clear direction so they may move at their own pace and not require them to ask; two forms of user-control in what may otherwise be a daunting situation.⁴⁶ And when direction is needed, volunteers and staff should, of course, be clearly identifiable in order to limit visitors' confusion or anxiety about not knowing whom to approach with questions. What is important in user-controlled social experiences is that each visitor has an equal opportunity to socialize, but his or her sense of direction, understanding of the exhibitions, and overall experience do not require what could be uncomfortable levels of socialization.

^{45.} Ander et al., "Using Museum Objects;" Chen et al., "Beautiful Minds."

^{46.} Chen et al., "Beautiful Minds."

Finally, congruent to the goals of user-controlled experiences in museum environments are the presence of safe areas and easy exits—"escapes." Providing unparalleled support for visitors with severe mental illnesses, these safe areas are equally important to user-controlled sensory and social experiences. They should offer more isolated spaces where visitors can remove themselves from stressors by restricting their sensory or social environments. Escaping stressors may also mean exiting an exhibition altogether. As discussed previously, the visited museum's layout did not provide a quick exit route; visitors had to follow the exhibition through to the end or backtrack to the beginning where the only entry/exit was located. However, if the exit was too far, the audio rooms did provide an alternative and discreet safe-space. One study participant also noted that dimmed areas could also provide some brief privacy for visitors to calm themselves. Additionally, to contribute further to social control, if such safe spaces are available (in whatever form) they should be clearly indicated on gallery maps and other signage; if visitors with severe mental illnesses do not know where they are, they cannot utilize them. So, in order to facilitate the individuation and integration afforded by user-controlled sensory and social experiences in museums, exhibitions need to be complemented by "escapes" for removing stressors and retaining vital control and agency for visitors with severe mental illness.

Conclusion

As museums endeavor to increase accessibility and inclusivity within their walls they must also continue advancing their understanding of what those goals require. With the prevalence of mental illnesses on the rise and access to proper treatment still a nationwide issue, it is time for the museum sector to question what its role is within this struggle. Should museums provide programming for visitors with severe mental illnesses? Should they put efforts into

increasing their accessibility to such visitors? The clear and innumerable benefits to visitors, museums, and the mental health sector make the answer clear: treatment of severe mental illnesses can and should be supported by museum programs and accessibility. This study shows that museum environments can be stressful for visitors with severe mental illnesses, but they can also be equally inspiring, relaxing, and safe places for individuation and integration. In order to succeed in increasing accessibility to, and even support and enrichment of visitors with severe mental illnesses, museum staff need to reorient the ways they consider the visitor experience and aim for greater user control. All visitors, especially those living with severe mental health problems, should have equal access to normalizing experiences because of options for controlling both their social and sensory experiences within museum environments, including easy "escapes." Lowering barriers to user control is likely only the first step, but this study offers significant factors for further consideration and implementation. While the problems of those living with mental illnesses often remain invisible, with these veritably imperceptible changes, accessible and supportive museum environments can allow visitors to step more confidently through their doors and into the light.

Bibliography

- "2010 ADA Standards for Accessible Design." Department of Justice, September 15, 2010. http://www.ada.gov/regs2010/2010ADAStandards/2010ADAStandards.pdf.
- Ander, Erica E., Linda J.M. Thomson, Kathryn Blair, Guy Noble, Usha Menon, Anne Lanceley, and Helen J. Chatterjee. "Using Museum Objects to Improve Wellbeing in Mental Health Service Users and Neurological Rehabilitation Clients." British Journal of Occupational Therapy 76, no. 5 (2013): 208–216. doi:10.4276/030802213X13679275042645.
- Aron, L., R. Honberg, K. Duckworth, A. Kimball, E. Edgar, B. Carolla, K. Meltzer, et al. "Grading the States 2009: A Report on America's Health Care System for Adults with Serious Mental Illness." Arlington, VA: National Alliance on Mental Illness, March 2009.
- Besley, Joanna. "Compassionate Museums?" Museum Worlds 2 (2014): 148-151.
- Caruso, Iyna. "The Pictures of Health: Art's Healing Powers." Saturday Evening Post. 2009.
- Chen, Chia-Li, Chun-Hung Lin, Shih-Ku Lin, and Tak-Cheung Lau. "Beautiful Minds: The Role of Museums in Interacting with Visitors with Mental Illness." Museum Worlds 2 (2014): 136 147.
- Chung, James, and Susie Wilkening. "Museums & Society 2034: Trends and Potential Futures." Center for the Future of Museums; American Alliance of Museums, 2008.
- Coleborne, Catharine. "Mental Health and the Museum: Institutional Spaces for Memories and Interaction." Museum Worlds 2 (2014): 162–166.
- "College Students Speak: A Survey Report on Mental Health." National Alliance on Mental Illness, 2012.
- Cordingley, Kelly. "More Students Are Coming to KU with Mental Health Issues, but the University Struggles to Keep Up with the Demand." The University Daily Kansan, November 29, 2015, sec. News. http://www.kansan.com/news/more-students-are-coming-to-ku-with-mental-health-issues/article_2b0fc8ac-96fa-11e5-91fa-cff01258e110.html.
- "Director's Blog: Getting Serious About Mental Illnesses." National Institute of Mental Health. Accessed February 21, 2016. http://www.nimh.nih.gov/about/director/2013/getting-serious-about-mental-illnesses.shtml.
- Dodd, Jocelyn, and Ceri Jones. *Mind, Body, Spirit: How Museums Impact Health and Wellbeing*. Leicester: Research Centre for Museums and Galleries, 2014.

- Fujimoto, Alissa, and Molly Douglas-Fujimoto. "Art as a Portal Into the Minds of Those with Mental Illness." The American Journal of Psychiatry 165, no. 7 (2008): 819.
- Gale, Colin. "A Museum of the Mind." Museum Worlds 2 (2014) 167-169.
- Gutsche, Anne-Sophie, Mira Hoschler, Geraldine Kendall, and Julia Pagel, eds. Museums' 4
 Values- Values 4 Museums. Germany: Network of European Museum Organizations, n.d.
 http://www.ne-mo.org/fileadmin/Dateien/public/NEMo_documents/
 NEMO four values 2015.pdf.
- "Is There a Place for the Arts in Our Modern Health care System?" Perspectives in Public Health 133, no. 1 (2013): 19–20. doi:10.1177/1757913912468648.
- Kirchner, JoAnn E., Chris Rule, Teresa L. Kramer, Leigh Ann Bennett, and Sharon Otwell. "Blending Education, Research, and Service Missions: The Arkansas Model." Academic Medicine 82, no. 1 (2007): 107–112.
- Koh, Eugen. "The Cunningham Dax Collection: A Unique Mental Health Resource." Australasian Psychiatry 22, no. 1 (2014): 41–43. doi:10.1177/1039856213517951.
- "Leicestershire's Open Museum Makes a Positive Contribution to Mental Health." Targeted News Service. 2011.
- "Mental Illness Facts and Numbers." National Alliance on Mental Illness, 2013. http://www2.nami.org/factsheets/mentalillness factsheet.pdf.
- "Museums 2020 Discussion Paper." United Kingdom: Museums Association, 2012. http://www.museumsassociation.org/download?id=806530.
- "Museums on Call: How Museums Are Addressing Health Issues." American Alliance of Museums, 2013. http://www.aam-us.org/docs/default-source/advocacy/museums-on-call.pdf?sfvrsn=8.
- Nauert, Rick. "Mental Health Is Underserved." Pysch Central, 2007. http://psychcentral.com/news/2007/03/27/mental-health-is-underserved/709.html.
- O'Neill, Mark. "Cultural Attendance and Public Mental Health--From Research to Practice." Journal of Public Mental Health 9, no. 4 (2010): 22–29.
- Peinaar, Lorinda, Geoff Ward, and Helen Shearn. "Using the Arts to Reduce Isolation in Dementia." Nursing Times 110, no. 42 (2014): 18.
- Pollard, John. "Therapeutic Museums and Mental Health: Why, Where, What, and How?" PowerPoint presented at the Touch & Wellbeing Workshop: Heritage, Health and Wellbeing: Mapping Future Priorities and Potential, London, 2011.

- "Reducing the Stigma of Mental Illness." The Lancet, 2001, sec. Editorial.
- Re-Presenting Disability: Activism and Agency in the Museum. Routledge, 2010.
- "Schizophrenia: Public Attitudes, Personal Needs." National Alliance on Mental Illness, June 10, 2008.
- "Serious Vs. Non-Serious Mental Illness." Blue Cross Blue Shield of Illinois, n.d. http://www.bcbsil.com/provider/standards/serious_vs_non_serious.html.
- "State Mental Health Legislation 2014: Trends, Themes & Effective Practices." Arlington, VA: National Alliance on Mental Illness, 2014. https://www.nami.org/legreport2014.
- "The Five Major Categories of Mental Illness." Mental Health Association in Forsyth County, 2011. http://www.triadmentalhealth.org/what-is-mental-illness/.
- "What is Universal Design?" Universal Design.Com. Accessed January 31, 2016. http://www.universaldesign.com/about-universal-design.html.

Appendix

Pre-Visit Questionnaire

Would you identity yourself as a "museum goer?" Yes No
Do you have a favorite museum? Yes No If so, which one?
Please rank the following types of museums in terms of the ones you, personally, would be more likely to visit: (1=most likely, 5=least likely; it's okay to give the same ranking to several types). • Anthropology/Archaeology • Art • History • Natural History • Science • Other:
Are you aware of any museum programs that benefit people with mental health issues?
In your view, museumsare / _are not welcoming to people with mental health issues. Why do you think that?
Thinking as a mental health care provider, would you ever consider a museum visit as a component of a client's care or treatment? Why?
Please share any general impressions you have of museums with regard to people with mental health issues: