Dementia Friendly Memory Institutions: Designing a Future for Remembering

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Abstract

On November 3, 1906, at the 37th Meeting of South-West German Psychiatrists, Dr. Alois Alzheimer, reported on "a peculiar severe disease process of the cerebral cortex". The disease with which he is associated has continued to elude a cure and is forecast to afflict one in eighty-five persons globally by 2050. Health care providers, researchers, and governments are on notice to explore different ways of understanding and addressing Alzheimer's Disease and Related Dementias (ADRD) as demands for resources and funding escalate. One of those approaches, person-centered care (PCC), puts a focus on the individual, not the disease, emphasizing ability and enablement, and recognizing people with dementia as having rights of choice, personal empowerment, and self-determination. We expand on the concept of "dementia friendly communities," embodying PCC, to envision how spaces, programs, and services within cultural heritage institutions such as galleries, libraries, archives, and museums (GLAM), could be re-thought and designed to enhance the everyday life experience of persons with ADRD. Impetus for such initiatives is provided further through the articulation, acceptance, adoption, and promotion of the rights of those with dementia as the rights of persons with disabilities. This emphasis on rights is important as it has behind it the force of international agreement and legally-binding United Nations' Convention on the Rights of Persons with Disabilities (2008). We argue that cultural heritage institutions have a responsibility and a rationale for servicing those who have been marginalized across time by what they have rather than who they are.

Keywords: Alzheimer's Disease; cultural heritage institutions; dementia friendly communities; rights of persons with disabilities

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Introduction and Context

I n a paper presented at the 1994 conference of the International Society for Knowledge Organization, Roland Hjerppe used the phrase, "memory institutions of society" to refer to libraries, archives, and museums. Lorcan Dempsey (2000) noted their common goal of organizing the intellectual and cultural record, observing that:

> Their collections contain the memory of peoples, communities, institutions and individuals, the scientific and cultural heritage, and the products throughout time of our imagination, craft and learning. They join us to our ancestors and are our legacy to future generations. They are used by the child, the scholar, and the citizen, by the business person, the tourist and the learner. These in turn are creating the heritage of the future. Memory institutions contribute directly and indirectly to prosperity through support for learning, commerce, tourism, and personal fulfilment. They are an important part of the

civic fabric, woven into people's working and imaginative lives and into the public identity of communities, cities and nations. They are social assembly places, physical knowledge exchanges, whose use and civic presence acknowledge their social significance, and the public value accorded to them.

Other scholars, such as Baker (2013) and Robinson (2012), have argued that the term memory institution masks nuance and diversity in approaches to the interpretation and representation of history and cultural memory, and in professional practices for acquiring and managing collections. Regardless of perspective, characterizing libraries, archives, and museums as memory institutions emphasizes the centrality of collections as repositories of, and conduits to, cultural and social memory, however fluid. Our expectation, however simplistic or flawed, is that they preserve our memory.

This paper invites another interpretation of memory institutions, suggesting a more direct engagement with preserving memory, not at the societal or institutional level, but at the point of individual memory. While acknowledging the importance of collections to remembering, I invite a further step towards applying all assets of libraries, archives, and museums, their spaces, programs, services, staff, and knowledge resources more deliberatively to preserving and enhancing individual memory, particularly where memory is in decline. In a sense, this offers an opportunity for these important "parts of the civic fabric" to become recognized and valued as institutions *for* memory, as well as *of* memory. As Dempsey (2000) and others recognize, libraries, archives, and museums support and service a broad base of individual, community, and societal needs and activities. The "common good" may be proscribed by convention, through funding, by law, through precedent, by the norms and values of professional practice (and ethics), and so on. "Special needs" may be identified and defined as such, and may fall outside provisions for supporting a broader constituency, a majority of those served. As community and social values change, and as laws are enacted to include "special needs" as fundamental human rights, the framework within which public institutions operate changes. Incorporating what have been determined previously as needs beyond operational requirements and corresponding resources is no longer a matter of institutional choice, but of legal mandate. By demanding a response, such change also offers opportunities for creative re-thinking of programs, services, and the resources to support them.

I begin by examining a well-recognized disease entity responsible for cognitive decline and memory loss across the life-course. I then trace how perceptions of Alzheimer's Disease and Related Dementias (ADRD), and approaches to treating those living with ADRD have evolved since its identification in 1906 by Aloysius Alzheimer. Since the late 1990s, the focus has shifted to include not only medical interventions but also person-centered care through non-therapeutic activities that engage individuals with ADRD and their careers. There has since been a change in how we view the place and role of individuals experiencing progressive memory decline, and their fundamental rights as persons with a disability. I chart the evolution and implementation of such rights through assessments of (1) the United Nations Convention on the Rights of Persons with Disabilities, which came into force in 2008, (2) the establishment by the World Health Organization (WHO) of the Global Network of Age-friendly Cities and Communities in 2010 (WHO, 2018), and (3) the key principles of Dementia Friendly Communities articulated by Alzheimer's Disease International (ADI) in 2016. It is this framework of rights that provides a lens for examining how libraries, archives, and museums have responded to individuals with ADRD in the past, and more recently, and how they might re-think programs, services, and spaces moving forward. What roles and responsibilities do memory institutions assume when rights are

mandated, legislation protective of those rights enacted, and individuals subsumed, not as those with special needs, but as part of a broad constituency of adults to be served? While resources are always an issue for publicly funded institutions, I will argue that evolving perceptions, policies, and laws at local, national, and international levels of governance, offer new opportunities for libraries, archives, and museums to establish themselves as dementia friendly partners within communities.

Defining the Scope, Nature, and Treatment of ADRD

In its most recent World Alzheimer Report (Patterson, 2018), Alzheimer's Disease International, a federation of 100 Alzheimer associations globally, reported that there are nearly 50 million individuals diagnosed worldwide with ADRD. This number is estimated to rise to 152 million people or one in eighty-five by 2050. The current cost of the disease is about a trillion U.S. dollars a year, forecast to double by 2030. The National Institute on Aging's Alzheimer's Disease Fact Sheet notes, further, that, while Alzheimer's disease is currently ranked as the sixth leading cause of death in the U.S., recent estimates suggest that it may rank third behind heart disease and cancer as a cause of death for older people (U.S. Department of Health & Human Services, National Institute on Aging, 2019).

The WHO fact sheet (2019) defines dementia (of which Alzheimer's Disease is the most common form) as, "a syndrome—usually of a chronic or progressive nature—in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement" (p. 1). Cognitive impairment may be accompanied by changes in social behavior—often seen as out of character—a loss of emotional control and a decline in motivation. Deteriorating memory, especially short-term memory, is the most common early symptom of dementia. Across time, deficiencies worsen, interfering with day-to-day activities and jeopardizing an individual's ability to live independently. Nonetheless, as a discussion paper on developing a dementia strategy for Ontario (Canada) observes,

> While living with dementia can be challenging, it is important to remember that dementia does not change who a person is. Many people with dementia are capable of pursuing their interests, making decisions about their health, maintaining relationships and aging well." (Ontario Ministry of Health and Long-Term Care, 2016, p. 6).

This mirrors an earlier systematic review of 27 qualitative studies where accounts of the subjective experiences of people with dementia contained evidence of positive states, experiences or attributes. As authors Wolverson, Clarke, and Moniz-Cook (2016) concluded, "people living with dementia can retain important strengths and have positive experiences in spite, and even because of, living with the condition" (p. 697). An individual with Lewy body dementia sharpens the point, adding, "I'm living with dementia not dying from it" (Cayton, 2004, p. 15).

Individual memory is the sum total of what we remember. While a complex process, at its simplest, committing something to memory involves forming a short-term memory from the initial perception or sensory memory of a stimulus, then converting what is deemed valuable to long-term memory by means of memory consolidation. Recall or remembering is, essentially, a reversal of that process. With the stimulus of a cue or trigger, stored fragments from our experiences of people, places, events, and objects are reconstructed as part of our personal

reminiscences or life histories. Mild, moderate, or severe cognitive impairment, whether from disease, trauma, disability, or genetic predisposition, can disrupt the reassembly process, impeding access to memory. In a way, memory is lost because we cannot find our way back to it. For those experiencing mild cognitive impairment (MCI) through the onset of early-stage dementia, brain injury, or other neurodegenerative causes, drug and alternative clinical interventions have been devised to slow decline in cognition, or, as in dementia, specific memory loss. The theoretical and applied research literatures of gerontology, nursing, social work, and cognitive psychology/cognitive science describe approaches to reinforcing an individual's "cognitive reserve," defined as, "increased numbers of synapses, or and increased ability of the brain to cope with physiological insults, e.g., as a result of neural plasticity or neural compensation" (Bain, 2006, p. 247). In short, healthy aging nerve cells can regenerate (Khachaturian, 2007).

Intelligence, educational level, occupation attainment, and (cognitive) leisure activities have been associated with reduced risk of dementia and cognitive decline, and are, consequently, used as proxy measures of cognitive reserve (Bain, 2006; Vemuri, 2014). Cognitive reserve represents a baseline to be preserved as much as possible in slowing the onset of ADRD and has been the goal at the heart of both medical and other therapies that have been developed since its identification. Specific nonpharmacological therapies used as clinical interventions may include music programming (Topo et al., 2004; McDermott, Orrell, & Ridder, 2014; Elliott & Gardner, 2016; Evans, Garabedian, & Bray, 2019), art therapy (Mottram, 2003; Beard, 2011; Chancellor, Duncan & Chatterjee, 2014; Sauer, Fopma-Loy, Kinney, & Lokon, 2016; Moss & O'Neill, 2019), reminiscence therapy (Kim et al., 2006; Haslam et al., 2010; Westerhof, Bohlmeijer, & Webster, 2010; Dempsey et al., 2014; Gonzalez et al., 2015; Critten & Kucirkova, 2019), and performative therapy (Basting, 2009; Basting, Towey, & Rose, 2016), among others. Such therapies not only encourage the preservation of arts-based abilities developed over a lifetime prior to the onset of ADRD, but in some cases offer an opportunity for learning a new skill or building further on existing talent. Whether listening to or playing music, whether drawing, painting, sculpting, or discussing a work of art, whether telling, writing, reading, or listening to stories, or whether participating in developing, narrating or acting out a part, or watching a play, participants in nonpharmacological therapy activities are engaged, often animated, are recalling memories, are making memories, are being creative and, in most cases, enjoying a positive experience—individually and socially with others. While examples of nonpharmacological therapies will be examined in more detail at a later juncture, their relatively recent use within clinical settings showcases what has become an essential application in the shift from disease-focused to person-centered strategies for slowing, even treating, the progression of ADRD.

Evolving Perspectives on ADRD: From Disease-Focused to Person-Centered

As part of the United States' National Institutes of Health Cognitive and Emotional Health Project, a critical evaluation study committee was charged with assessing the state of epidemiological research on demographic, social, and biological determinants of cognitive and emotional health in the older adult (Hendrie et al., 2006). Its review of longitudinal cohort studies (n=36) noted that the majority were disease-focused, with research on healthy brain aging lagging noticeably behind. Descriptions of drug and (other) medical interventions to maintain cognitive health or prevent decline were well represented in the literature. Possible lifestyle interventions received less attention, but, nonetheless, revealed several protective factors, including higher education levels, occupational attainment, higher socioeconomic

status, specific cognitive activities (e.g., playing board games, singing, playing a musical instrument, reading), social engagement, emotional support, instrumental mastery and self-efficacy, resilience, and vitality (Bain 2006; Hendrie et al. 2006; Jedrziewski, Lee, & Trojanowski, 2005). The critical review committee concluded that "There is now widespread public interest in developing strategies to maintain or enhance cognitive and emotional health in the elderly" (Hendrie et al., 2006, p. 26). Emphasizing the need for future research that considers brain health *maintenance*, as well as disease prevention, the committee recommended that biomedical investigators join forces with other disciplines, such as social sciences and bioethics, to "change the paradigm of successful cognitive and emotional aging" (Hendrie et al., 2006, p. 28).

Subsequent studies have likewise reported on strategies or specific interventions for maintaining quality of life and building on retained abilities across the course of ADRD, in particular. While outcomes for individuals with dementia may have improved, the reasons are not always clear, undermining study reproducibility, perceived reliability of findings, and robust theory-building. Studies of nonpharmacological therapies alone offer evidence of "possibility" and "potential" of interventions without any verifiable determination of causation. A systematic review and meta-analysis of the efficacy of nonpharmacological therapies in ADRD (Olazarán et al., 2010) noted, "an exponential increase in the research literature" on nonpharmacological therapies in ADRD as well as "a significant lack of funding for the systematic research of nonpharmacological therapy" (p. 162). The authors reflected on current limits on the effectiveness of drugs while also observing "opportunities for environmental, social and therapeutic intervention …to improve services and care for persons with ADRD" (Olazarán et al., 2010, 162). The 176 randomized clinical studies that were analysed suggested that, while nonpharmacological therapies and drugs should be understood as complementary approaches, interventions (number of categories = 26), such as reminiscence, recreation therapy, music therapy, physical exercise, activities of daily living training, and so on, "emerge as a useful, versatile and potentially cost-effective approach to improve outcomes and [quality of life] for both [persons with dementia] and [caregivers]" (Olazarán et al., 2010, p. 162).

A more recent randomized controlled trial (Reisberg et al., 2017) examined the added benefits of a comprehensive, individualized, person centered management program (CI-PCM) in combination with a commonly prescribed to drug treatment of memantine for individuals with moderate-to-severe Alzheimer's Disease. The comprehensive, individualized, person centered management program was based on thirteen principles, which included, for example, (#6) treating persons with Alzheimer's Disease with dignity and respect as a person, not as an object, (#7) learning the Alzheimer's Disease person's history, individual tastes and preferences, talents, shortcomings, and personal needs, (#9) establishing a healthy, supportive, structured and flexible routine with daily fun scheduled in the routine, and (#10) using Memory Coaching to teach the Alzheimer's Disease person new skills, or skills they may have forgotten, helping to rebuild the Alzheimer's Disease person's self-esteem and self-respect (Reisberg et al., 2017, pp. 104-105). The program also promoted success gauged against an individual's achievements and not by his or her disabilities. Techniques and procedures encouraged individualized, meaningful, safe, and enjoyable activities, recognizing that persons with moderate-to-severe Alzheimer's Disease have the capacity to learn and to maintain or regain functioning in basic activities of daily living. Examples of activities included making a cell phone call, eating with a knife and fork again, playing a musical instrument, reading aloud, clearing dishes from the table and washing them, purchasing new clothing, exercising (including strengthening, stretching, coordination and balance, and aerobic exercises), socializing, visiting parks, museums, and so on, and going to

movies, plays, and concerts, and other similar activities. While many of the activities required memory coaching or direct caregiver assistance, all were tailored to individual preferences and intended to build confidence and improve the mood for the person living with Alzheimer's Disease (Reisberg et al., 2017, pp. 105-106).

The results of the study indicated that the combination of person-centered program interventions in combination with drug therapy was "97% more beneficial for individuals with moderate-to-severe Alzheimer's Disease than memantine treatment alone" (Reisberg et al., 2017, p. 100). The study also highlighted the role of memory coaching in relearning lost skills, maintaining current abilities for a longer period of time, and even learning new skills for those beyond the early or mild stages of Alzheimer's Disease. Other research likewise emphasizes benefits accruing from arts-based programming for persons in the middle to late stages of dementia (Young, Camic, & Tischler, 2015; Humphrey et al., 2019). Both the Olazarán et al. (2010) and Reisberg et al. (2017) studies confirm the efficacy of including person-centered programming in the treatment of persons across the multiple stages of ADRD. Over the past 20 years, there has been a steady shift from seeing dementia and those who "suffer" from it solely as a disease entity to be treated medically, to a chronic, progressive condition that benefits from interventions that build on an individual's capacity to learn and foster good quality of life. This change has also moved the focus beyond strategies for treatment, to public policy and legal frameworks for addressing the needs of those with ADRD and their carers. It is to these initiatives that we now turn.

Great Leap Forward: Dementia Friendly Initiatives as Disability Rights

In 2006 WHO conducted research across 23 countries to determine what programs and services cities and communities could undertake to encourage active aging. Older adults were asked to identify both positive and negative experiences relating to eight elements, including (1) housing, (2) transportation, (3) information and communication, (4) outdoor spaces and buildings, (5) community support and health services, (6) social participation, (7) civic participation and employment, (8) respect and social inclusion. Findings from the study, which also included input from caregivers and service providers across public, private, and voluntary sectors, resulted in the development of an age-friendly cities approach, along with a set of checklists for cities and communities to follow. As the age-friendly initiative grew, WHO established the Global Network of Age-friendly Cities and Communities in 2010 (WHO, 2018, p. 2). The Global Network of Age-friendly Cities and Communities is a key plank in the World Health Organization's strategy for healthy aging, and its commitment to enhancing functional ability, inclusion, safety, and quality of life with the support of multiple sector partners. The age-friendly cities and communities framework has also served as a model for the concept of dementia friendly communities, which will now be addressed.

Japan is widely credited for being the nation where "dementia friendly communities" began. In 2005 the government developed a community-focused policy, emphasizing, among other elements, (1) awareness-raising, (2) challenging the stigma of dementia, and (3) training volunteer supporters for individuals with dementia. The Japanese model was initially adopted and adapted by governments and non-governmental organizations within Australia (since 2013), Northern and Western Europe, the United Kingdom, the Republic of Ireland (as reported by Williamson, 2016), and subsequently within the U.S. (largely since 2014) and Canada (largely since 2015/2016). The second edition of the Alzheimer's Disease International's (2017) report on dementia friendly communities worldwide updates the development of policies, programs, and services across Africa, Asia Pacific, and the Middle East, as well as within Europe and the

Americas. Because dementia friendly communities are a social construct, there is no single model for all. Nonetheless, Alzheimer's Disease International (2016) identifies five key outcomes which it believes should be pursued within dementia friendly communities (p. 7). These include the following:

- Increased awareness and understanding of dementia;

- Increased social and cultural engagement with the person with dementia;

- Legal and other measures in place to empower people with dementia to protect their rights;

- Increased capability of health and care services to develop services that respond to the needs of people with dementia;

- Actions to improve the physical environment, whether in the home, residential care, hospitals, or public places.

While there are many examples of approaches to the development of dementia friendly communities (e.g., Dementia Friendly America's® Dementia Friendly Communities Toolkit [2019]; Alzheimer Society of Saskatchewan's Dementia Friendly Communities: Municipal Toolkit [2017]), the City of Burnaby (Canada)'s Burnaby Dementia-Friendly Community Action Plan (2017) serves as a readily accessible and step-wise blueprint of how to incorporate dementia friendly actions into existing work programs and policies. The action plan was developed following extensive consultation across a broad range of stakeholders and community partners. Focus groups were held with people living with dementia and their caregivers. City Planning and Engineering staff, responsible for designing Burnaby's public realm street standards, conducted a walking interview with an individual with ADRD who shared his experiences of getting around the neighborhood. Frontline City staff (Parks, Recreation and Cultural Services, Tax Department, Burnaby Public Library, Citizen Support Services) and representatives from Fraser Health Community and Home Health, the police, and Fire Department engaged in focus groups, sharing experiences of interactions with citizens living with dementia. The resulting action plan includes key recommendations involving City departments, other agencies and staff, community partners, and those living with dementia, their families, and caregivers (City of Burnaby, 2017, p. 12). Specific actions, partners, and roles are articulated under each recommendation. Each recommendation is associated with one of the following four pillars (City of Burnaby, 2017, pp. 16-18):

1. People, Knowledge, and Awareness—increasing awareness and understanding of dementia, resources, and supports

2. Things to Do—creating programs and activities (physical, cultural, recreational, educational, etc.) for staying engaged and connected with community

3. Your Surroundings—designing the physical environment (signage, accessibility, quiet spaces, etc.)

4. Advocacy—for adequate health care and services; for adopting dementia friendly features and practices

One can observe in the action plan outcomes that Alzheimer's Disease International (2016) has identified as important pursuits for a dementia friendly community (p. 7). We also note the importance of partnerships of a broad constituency of stakeholders and community agencies, not least of which are the individuals who are living with ADRD. As Alzheimer's Disease International key principles emphasize (2016),

> Being dementia friendly is less about being "friendly" and more about accessible communities and human rights. … If it's about us without us, it cannot be dementia friendly. Only by ensuring that initiatives are inclusive of people living with dementia at all stages of development, will we success in giving them the sense of respect, dignity and purpose they seek. (pp. 9-10).

That said, and as will be illustrated later, there remain initiatives where those living with ADRD are absent from the table, their voices silent.

The broader lens of community within which dementia is now considered derives not only from early initiatives in Japan, but also from the concept of "age-friendly", developed by the WHO in 2006, as discussed, above. Both age-friendly and dementia friendly initiatives are notable in promoting a shift in narrative from deficit and burden to contribution and inclusion. In this discursive change in direction, we can see the influence of a growing commitment to inclusion of those with ADRD through the articulation, acceptance, adoption, and promotion of disability rights, and, more particularly, through the perception of the rights of those with dementia as the rights of persons with disabilities. While this may appear a double-edged sword, where dementia as disease may be compared with disability, what is important is the focus on rights of accessibility where the approach foregrounds, "the creation of supportive, inclusive, and enabling environments that maximize independence through collaboration with diverse community stakeholders" (Hebert & Scales, 2019). To the extent that accommodations for ADRD foster accessibility for the community as a whole—the concept of universal design—the more readily differences in ability disappear. As we have witnessed, clear signage, automatic doors, cut-aways in sidewalks, and the availability of ramps and other similar accommodations, benefit all.

The emphasis on rights is important as it has behind it the force of international agreement through the legally-binding United Nations' Convention on the Rights of Persons with Disabilities (United Nations, 2008). At the core of the Convention is the consideration of disability,

> not …as a medical condition, but rather as a result of the interaction between negative attitudes or an unwelcoming environment with the condition of particular persons. By dismantling attitudinal and environmental barriers—as opposed to treating persons with disabilities as problems to be fixed—those persons can participate as active members of society and enjoy the full range of their rights." (United Nations, 2019).

The Convention came into force on May 3, 2008, having, as of August 2019, 162 signatories and 180 parties, which includes 172 states and the European Union. Earlier medical models that considered ADRD primarily as a disease requiring the institutionalization of those suffering from it, often led to individuals being removed from their homes—some forcibly—being held against their will, and in some cases, being restrained (physically or chemically), physically and emotionally abused, and submitted to treatment without their consent. While the adoption of the person-centered model of care addressed the most egregious of those abuses, and ensured

humane treatment and a variety of modes of intervention—both medical and nonpharmacological therapies —the current move towards dementia friendly care (and communities) with its underpinning of legal, fundamental, and enforceable human and disability rights, has encouraged a re-thinking of possibilities, at individual and societal levels. Reducing stigma, increasing understanding of persons with dementia, and ultimately normalizing ADRD are core objectives, as is that,

> of empowering people with dementia by respecting their rights and capabilities so that they feel respected and, to the extent that they are able, empowered to take decisions about their lives … with the understanding that dementia is a disability. (Alzheimer's Disease International, 2016, pp. 4-5).

As noted previously, key principles articulated in the Alzheimer's Disease International report (2016) also emphasize the need for and importance of community partnerships. It is to that commitment that we now turn.

Towards Dementia Friendly Libraries, Archives, and Museums

Over the past dozen years there has been a sea change in the number and variety of programs and services offered by libraries, archives, and museums to individuals living with dementia. The phrase, "dementia friendly", as a search term, yields examples relating to individual libraries and museums, though, in relation to archives, more usually refers to archives about dementia, or to the archives *of* ADRD associations. Prior to this decade, programs or services that did exist were largely piecemeal, and often the creation of individuals with a particular interest in, or personal commitment to, supporting individuals with ADRD. Often such programs were subsumed under other areas, such as services to older adults, or with special event funding procured for a limited-time offering. The next section explores, by sector, examples of initiatives directed at those living with dementia, their characteristics, and evolution.

Museum Initiatives for Persons Living with Dementia

One of the earliest initiatives, which has provided a robust model for other art museums to follow, was "Meet me at MoMA". Offered monthly, persons in the early to middle stages of dementia and their carers engaged with museum educators in viewing and discussing selections from the collections of the Museum of Modern Art (MoMA) in New York City (Rosenberg, 2009; MoMA, 2019). The program continued from 2007 to 2014, with outcomes uniformly assessed as intellectually stimulating, providing shared experiences and social interaction in an accepting environment. The MoMA Alzheimer's Project website (MoMA, 2019) continues to be accessible to those galleries or museums with interest in developing a similar program. Assessments of similar programs for engaging individuals living with ADRD with collections and other hands-on activities within art museums and galleries likewise report positive experiences and outcomes (MacPherson, Bird, Anderson, Davis, & Blair, 2009; Camic, Tischler, & Pearman, 2013; Flatt et al., 2015).

Also established in 2007, and continuing today, is the Art and Dementia program offered by the National Gallery of Australia, Canberra. Small groups of persons living with ADRD and their carers tour the gallery with educators, discussing individual works in the collection. Specific program aims include the following (National Gallery of Australia, 2019):

- To promote wellbeing and quality of life through engagement with the visual arts;

- To provide intellectual stimulation in a socially inclusive environment;

- To reconnect people living with dementia to their sense of identity;

- To build community arts and health partnerships to improve the care for people living with dementia;

- To raise awareness of and reduce the social stigma associated with dementia.

Viewing a video on the program website of a tour held in 2012, one sees participants fully contributing to discussions with museum educators and others, engaging in interpretation, recalling memories, laughing together, dancing in response to a particular painting, and sharing stories. Findings from MacPherson et al.'s study (2009) of a similar six-week program at the National Gallery of Australia likewise reported that participants were engaged from the outset and remained engaged. They became animated, gained confidence, and were able to discuss and interact with the artworks and the social process. Such responses align with those reported from "Meet me at MoMA" and similar collections-based discussion tours.

Another among these is the Art Access Program at the Art Gallery of New South Wales, first offered in 2010 as a pilot project. In 2015, the Gallery commissioned a study by researchers at the University of Technology Sydney to investigate the experience of people living with dementia and relevant stakeholders participating in the Art Gallery of New South Wales Art Access Program across the year. As the report explains,

> The study explored whether engaging with artworks and discussion about artworks facilitates and promotes "in the moment" pleasure and thereby contributes to positive wellbeing. In doing so, it sought to gain an understanding of the environment and context in which people experience the artworks, and take into account the views of stakeholders in the care and wellbeing of people living with dementia—that is professional care staff, family, primary carers, and facilitators at the Gallery. (Kenning, 2016, p. 6).

An extensive and detailed discussion of findings notes many examples of "in the moment" pleasure expressed in words, laughter, and behaviours that involved leaning the body towards paintings and people as they spoke. Positive experiences also included opportunities for social interaction and engagement with peers, staff, and caregivers, and a calm, comfortable, and safe environment for telling stories, reminiscing, reflecting quietly, and self-identifying with people depicted in the artworks (Kenning, 2016, pp. 10-14).

The Artful: Art and Dementia program delivered by the Museum of Contemporary Art Australia began in 2016 as a three-year research collaboration among the Museum of Contemporary Art, the Brain and Mind Centre, University of Sydney, and Dementia Australia. With a final report due towards the end of 2019, the study has been exploring the question, "Can an art program enhance neuroplasticity and wellbeing in people with dementia?" Like "Meet me at MoMA", and the Art and Dementia program at the National Gallery of Australia, Artful includes a tour of selected works within the Museum of Contemporary Art. Further to this, each two-hour visit across the six-week program includes hands-on, creative art-making sessions with trained artist-educators. An "Artful at home" pack with art-making activities and all required materials is given to each

participant. The intent of the pack is to extend creative engagement between visits to the Museum of Contemporary Art. As the program website notes, "On Week 6, the program concludes with an open celebration and exhibition session, to coincide with one of our Artful Community Days, where family and friends are invited to view the participants' work made during the program" (Museum of Contemporary Art Australia, 2019). While findings regarding the research question have not yet been published, one sees in the Artful program an evolution from viewing and discussing art museum collections, to engaging in creative, interactive artmaking as a group and individually. Anecdotally the Museum of Contemporary Art reports that,

> Previous participants have expressed that Artful offers new avenues for meaningful connections between people living with dementia and their carer partners. We have also seen the impact art and creative expression can have on participants, leading to improved self-esteem, wellbeing and social inclusion. (Museum of Contemporary Art Australia, 2019).

The Visual to Vocal project which has been offered by the Dulwich Picture Gallery (England) since 2012, is an innovative ten-week program involving individuals living with dementia, their carers, youth from local schools, and the English Touring Opera. Together they write song lyrics and compose melodies in response to visiting the Picture Gallery's Permanent Collection. This intergenerational collaboration culminates in a public performance of a mini-opera, replete with dialogue, and dramatic effect (Dulwich Picture Gallery, 2017). Like the Artful project, described above, Visual to Vocal offers a multiple-arts approach that would not only reinforce existing abilities in participants, encouraging feelings of self-efficacy and wellbeing, but also encourage new learning—targeting neuroplasticity, and adding to individual capability. Intergenerational engagement addresses stigma, with student participants reporting that their interactions with those living with dementia have helped them understand and appreciate who their theatrical colleagues are, and not what they may be lacking physically and cognitively. Appreciation is a two-way street where the energy and particular talents of the youth from local schools are obviously valued and thoroughly enjoyed as can be seen in online videos of different performances across time (Dulwich Picture Gallery, 2017). While this is an exemplary program, it does draw substantially on the resources of the gallery, local schools, and the English Touring Opera. Such resource demands may not be readily accommodated by other museums interested in developing programming for those living with dementia and their carers.

On a much smaller scale, perhaps more appropriate and achievable for museums of any size, is the program for museum object handling offered by the Tunbridge Wells Museum and Gallery (Kent, England). An 18-month study involving seventy participants was conducted to determine if handling objects from the museum's collection would have an 'in the moment' impact on wellbeing for people at the early and mid-stages of different types of dementia. Wellbeing is manifested in feelings of contentment, enjoyment, confidence, and in making connections that bring meaning to one's life and stimulate learning. While the course of dementia is irreversible, activities, such as exploring through touch and discussion, a random selection of unique, unusual, or unknown museum objects can increase a sense of wellbeing. Further, activities that yield such positive outcomes among persons living with ADRD can be done with a handful of objects and the facilitation of one member of museum staff—a high impact program with low demand on resources (Kimmel & Camic, 2015).

While there are other examples of museum initiatives for people living with dementia and their carers, those highlighted, above, suggest that individual and group engagements with museum

collections per se, represent the dominant model for programming, with more recent innovations branching out to include other visual and performing arts, for example, art-making, music (composing, playing, singing), and theatre performance. Programs most often also include family and caregivers, and are sometimes intergenerational. The museum's approach to education and the user experience of collections is expanded to include those at various stages of cognitive decline with goals of stimulating ability and creativity, facilitating social engagement and interaction, building self-esteem, and a sense of wellbeing within a safe, comfortable space, and reducing stigma. While programs seem largely to be devised for individuals with ADRD by museum staff and others, there may be room for ensuring that those living with dementia are leading or contributing at the front end, creating or co-designing programs for individuals with ADRD, by persons living with dementia. This will be discussed later in the paper.

Library Initiatives for Persons Living with Dementia

Within the library sector, 2007 marked the publication of a set of guidelines for libraries around the world to consider in addressing the needs of patrons with dementia. The then International Federation of Library Associations and Institutions (IFLA) Standing Committee on Libraries Serving Disadvantaged Persons (LSDP) (Mortensen & Nielsen, 2007), used examples drawn largely from public libraries in Denmark to scaffold the model. As the introduction to the Guidelines for Library Services to Persons with Dementia explains:

> The purpose of this guidelines publication is to raise awareness in libraries, among library professionals, care givers, public policy makers, as well as among families and friends of persons suffering from dementia, that many types of library services and materials can help stimulate the memory while providing pleasure and entertainment. Experience shows that even persons with a middle-stage dementia can benefit from reading literature and obtaining information. These guidelines give practical recommendations on how to provide mental stimulation with books and other library materials. The publication also includes suggestions for library staff on how to tailor such services to the target population. (Mortensen & Nielsen, 2007, p. 3).

While expressing the still prevalent notion then of ADRD as "suffering", the guidelines reflect programs and services focused on making books and other information available to persons with dementia and their caregivers. The authors also list the importance of music, audio-visual materials, and "reminiscence kits", noting a growing trend in Nordic country libraries, "to develop their own reminiscence kits, sometimes in co-operation with caregivers and local historical societies" (Mortensen & Nielsen 2007, p. 10). Service delivery targets the "homebound", those in care facilities, as well as in public library branches, per se. The guidelines cannot be considered to be dementia friendly as defined, though they do advocate strongly for greater public library engagement with a population that could clearly benefit from the materials and services that it offers.

> Most public libraries do not have special services for persons with dementia, although their services are supposed to meet the informational and recreational needs of all population groups. In a democratic society, the right of access to culture, literature, and information extends to all, including persons with disabilities. Quality of life is an important factor, and everybody is entitled to participate fully in society as long as possible. (Mortensen & Nielsen, 2007, p. 7).

The IFLA Guidelines (Mortensen & Nielsen, 2007), provided the framework for the design of an innovative library program, Tales and Travel, developed by American librarian Mary Beth Riedner, and first offered at the Gail Borden Public Library (GBPL) in Elgin, Illinois, in 2011. The program brings together about a dozen individuals living with ADRD who are invited to read books, summarize passages of text, and share stories, facts, and personal experiences around travel. Each session, which simulates the act of visiting different countries and the U.S., and includes a physical globe at the table to locate the destination, encourages participation and conversation. Resources and facilitation are provided by library staff. Tales and Travel has been widely adopted by public libraries in North America and is also offered on an outreach basis to library community partners, such as residential and long-term care facilities.

Riedner has also been instrumental in forming and sustaining the Alzheimer's and Related Dementia's Interest Group (IGARD), of the Association of Specialized and Cooperative Library Agencies, within the American Library Association. IGARD has taken a lead on providing information on, and extensive examples and assessments of dementia friendly library materials, programming, resources, and case studies for those living with ADRD across various stages, their families, and caregivers.[1] A review of public libraries in North America that self-report as dementia friendly offers many of the materials and programs identified by IGARD. Preferred materials for a dementia friendly library collection follow the principles of person-centered care that is stage-appropriate, and may include books and magazines, talking books, moving images (TV, film, video), music, puzzles, toys, board games, kits (memory boxes, reminiscence kits, mixed-material packs to take home), objects/realia (tactile stimulation; reminiscence), and technology (touchpad and memory applications). Materials may draw from existing library collections and may be augmented by products that are available from commercial or not-for-profit agencies. Materials should accommodate cultural and linguistic diversity and be stage-appropriate to various users. For example, selecting a children's picture books might not be viewed as age-appropriate to an adult living with dementia, but would be appropriate to his or her stage of ADRD.

As the IGARD Toolkit advises, programming for dementia friendly libraries should be designed to include meaningful activities, to provide opportunities for entertainment and enjoyment, to improve quality of life for individuals living with ADRD, and to accept and respect them as full persons recognizing what they can do and not on the basis of lost abilities. Activities reflective of these criteria may include Memory Cafés (a relaxed, comfortable space for sharing conversation, activities, and experiences in a café environment), art, music, poetry, and drama programming, educational sessions about and for individuals living with dementia and their caregivers, displays of materials about ADRD, outreach, mobile services, and deposit collections, one-on-one appointments for selecting materials, and opportunities (and space) for meeting with a dementia specialist for counselling, memory testing, or community referrals. Many public libraries across North America have adopted some or several of these programming options.

In addition to developing collections and programming appropriate to individuals living with ADRD, dementia friendly libraries have also focused on the design of physical place and space. Best Alzheimer's Products, a private company providing information and products relating to ADRD, has summarized in a post on its website, key considerations for the design of a dementia friendly library (Best Alzheimer's Products, 2018). These include the following:

1. Provide lighting that is bright and even but not glaring. Shadows are confusing and may even be misinterpreted as doorways or even holes in the floor.

2. Ensure that flooring is as even as possible in every way. There should be no tripping hazards, actual or perceived. Designs and patterns in rugs or other flooring look like objects to one who is perceptually impaired.

3. Whenever possible use contrasting colors. Select furniture to contrast with walls and floors. Walls should contrast with floors.

4. Restrooms should also offer plenty of contrast. A white toilet is lost against a white floor and wall.

5. Signage aids navigation and can help avoid confusion and the resulting anxiety

A number of these features are incorporated in the public library in Sandal, a suburb of Wakefield, West Yorkshire. Newly renovated in 2015, it was purported to be the first dementia friendly library in England. Its design included such features as no reflective surfaces, no mirrors, no patterns in the furnishings, clearly defined entrances, exits, and wall edges, appropriate signage with clear symbols and pictures, tables with a plain design and chairs and sofas that are easy to get in and out of, a deep red color scheme making it warm, friendly, and calming, and a large clock displaying the day, the part of the day, and the time. A lounge was refurbished to serve as a reminiscence room with sofas and a flat-screen television playing digitized images from the local history collection (Taylor, 2018).

Three years later, an integrated public library building situated within the Great Sankey Neighbourhood Hub in Warrington, England, opened in March 2018. Color contrasts, high levels of natural and artificial lighting, acoustics, furniture and fittings, and signage were essential considerations to having the small library and other components of this leisure complex compliant with accreditation standards for dementia friendly public spaces (Designing Libraries, 2019). A growing number of public libraries in England are being refurnished or purpose-built to be accessible to individuals living with ADRD. Their design features are such as to also make them universally accessible and appropriate for all ages and stages of the life course. As discussed earlier, this is a positive development for the wellbeing of a community as a whole, and not simply for a particular target group.

Libraries that have adopted dementia friendly approaches have tended to focus on what has traditionally been considered strengths, namely, collections, services, and facilities (places and spaces). As will be discussed later, there seem opportunities for building further on these strengths, as well as collaborating with museums with their unique collections and focus on user experience through programming to offer a rich suite of resources, services, staff, and purpose-build places and spaces to support those living with ADRD. There is also a need to assess the extent to which initiatives are undertaken for, and not necessarily with or by persons living with dementia.

Archives and Initiatives for Persons Living with Dementia

A search of community programs and services offered by archives and designed for persons living with dementia leads to archives *of* ADRD associations, or archives *about* dementia. That said, there is growing interest in community-based, community-initiated archives, and an appreciation for preserving hard copy and digital historical records for so-called memory projects. Archives are natural candidates for providing historical materials important to memory, to remembering,

to reminiscence, and, consequently, of great value to persons with dementia. It remains for individuals living with dementia, their families, caregivers, or other service providers or agencies to access archival collections themselves, rather than through a program offered by a particular archive—perhaps notwithstanding exhibitions of documents for general interest (e.g., photographs from an event, a place, or of a person or persons). With rich collections of analogue and digital records, stored in a variety of media formats, archives would also seem to be logical partners to contribute resources and staff to developing programs supportive of the preservation of memory by those living with ADRD. This is potentially fertile ground for innovation and collaboration, and for involving those who might benefit most in the co-creation of materials and programs supportive of remembering.

Conclusion: Making the Case for Dementia Friendly Memory Institutions

As has been addressed across various sections of this paper, there has been a steady evolution in how we think about dementia and those with ADRD. Such individuals are no longer viewed primarily as persons whose diagnosis will result, in most cases, in institutionalization for the remainder of their life course. The current lens views those with ADRD as citizens with a disability who have legal rights and protections, and who can expect certain levels of service in support of autonomy, independence, and a reasonable quality of life in the community for as long as they determine or as deemed personally safe to do so. The shift to recognize inherent individual rights within dementia friendly communities also has required a re-thinking of public and private sector services across the board. Governments are having to respond to both legislative requirements (e.g., access to places and services for those with disabilities) and increasing citizen demand to develop national, provincial, state, and other strategies, and to provide funding for persons with ADRD and their carers.

Falling naturally into this evolution of perspectives, this paper has argued, are the programs, services, materials, places, and spaces that libraries and museums do offer and archives could offer. Framed by a requirement to offer dementia friendly initiatives in accordance with rights of persons with disabilities—now inclusive of those living with ADRD—and with the benefit of a greater impetus towards sharing resources, expertise, technology, and even physical space through examples of convergence among so-called memory institutions, there is opportunity for taking a leadership role in advancing quality of life for those living with dementia. Museums have responded with tours and discussions of collections scheduled for those living with dementia and their carers, as well as with mixed-arts programming (music, art-making, theatre, object handling). As public institutions housing, in many cases, valuable, irreplaceable artefacts and works of art, the specific requirements for preserving and displaying collections limits a physical design of space more accommodating to those living with ADRD. Colour, lighting, surface textures, spacing, seating, signage, and so on, are not necessarily readily adaptable to particular needs. Moreover, programs tend to be limited in number and scheduling because of resource requirements, and, relative to public exhibitions, for example, delivered to a relatively small number of people.

A steadily increasing number of libraries, on the other hand, have been able to incorporate new physical designs more accommodating to individuals with dementia, and, in doing so, have made spaces more accessible to all. Programming has tended to focus on collections and on ensuring the availability of information and resources *for* and *about* persons living with ADRD. Initiatives, such as Memory Cafés, the Tales and Travel program, memory boxes and reminiscence packs that can be borrowed, music, art, poetry, and storytelling activities, education programs for and

about persons living with dementia, and community outreach initiatives, are readily found in dementia friendly libraries. Nonetheless, such programs are subject to the availability of resources, whether staff, space, collections, or simple demand. When public libraries are accountable for funding on the basis of usage counts, a small group of eight engaged in a resource-intensive art or music therapy program (for example) can be vulnerable to being cut, particularly as budgets are under review. Staff training for multiple or specialized programming may also be problematic, again given that the target community may be relatively small in number.

What, then, remains to be done? Museums and libraries are engaging in dementia friendly activities and programming based on the strength of their respective collections, staff, and commitment to community service. Libraries also embrace a role of advocacy, ensuring access to all, while museums are steadfast proponents of a quality user education and experience. Both sectors encourage learning, with museums also recognizing the importance of memory and the value of remembering. While perhaps a generalization or a simplification, libraries make accessible ideas recorded in various media, while museums preserve and display objects. It would behoove each of the two sectors to consider opportunities for collaborating and sharing the best of what each has to offer. Innovative programming by museum staff could be offered in more flexible spaces offered by libraries. Libraries could adopt multiple arts and intergenerational programming that has received such positive feedback in museums. Staff from both institutions could share their particular expertise, engage in exchanges or co-instructional programming, and take training together. Sharing of parts of or pieces within collections could be contemplated to enhance object handling or reminiscence sessions depending on the fragility and value of items. Applications for funding and advocacy for specialized programming could be jointly made with persuasive efficiencies and best use of available resources.

These are modest suggestions, but ones with a common goal of promoting the social inclusion, self-efficacy, and capacity building of individuals living with dementia. Archives are not currently part of the mix of dementia friendly. With collections that hold clear value for preserving memory and fostering activities of remembering, archives are a logical partner with an important contribution to make. The idea of convergence among so-called memory institutions is well documented in the scholarly and professional literature. A common commitment to partnering on dementia friendly initiatives seems another area amenable to convergence, or at least aspects and activities thereof. While thinking about collaboration among themselves, libraries, archives, and museums must address the issue of having those living with ADRD engaged at all stages of program and service development. Respecting their insistence that, "If it's about us without us, it cannot be dementia friendly", memory institutions will need to ensure more than token voices at the table—at planning stages, at points of implementation and assessment, and as active members of committees, boards, and so on. This has, to this point, been more readily agreed in principle than exercised in practice. There is another opportunity for getting dementia friendly right from the get-go.

The "way" has been established, through recognizing those living with ADRD as individuals with the rights of persons with a disability, rather than solely as patients with a terminal disease. This removes them from the domain of the medical clinic to the public realm of community. As citizens of a community, they now benefit from the policies and services available to all, with rights protected in law, and with access to publicly funded agencies and institutions. Libraries, archives, and museums are obligated to serve the broad constituency of citizens, which includes those living with ADRD. Libraries and museums have demonstrated a "will" to do so, with positive

outcomes. They have experiences and innovations to share with archives, with opportunities for collaboration to be viewed through a lens of openness to convergence, and to having all voices at the table. Mortensen and Nielsen, (2007) noted in their section, "A Challenge to Libraries", that, despite the large and growing number of persons with dementia,

> it does not appear that public, health, and social services in most countries are sufficiently prioritized to meet their growing needs. With the rate of dementia related diseases growing, it would benefit all segments of society to respond in a more responsible manner to the needs of persons with dementia. (p. 7).

Their advice would seem to be as relevant and as urgent to contemporary memory institutions as it was to the international library community over a decade ago.

Endnotes

1 See for example its Toolkit at https://www.asgcladirect.org/resources/alzheimers-related-dementias-interest-group-igard/.

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