

“A Lot of Stories in My Mind”:  
Perspectives of Children and Elders Living with Dementia  
On Intergenerational Collaboration in a Participatory Music Project

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## Abstract

Trends of music engagement include a shift towards presentational music culture, as well as inequitable access to participatory music-making for some populations. Meanwhile, trends of societal engagement include ageism and age-segregation. Especially for people living with dementia, stigma often prevents equitable access to creative participatory arts. This convergent, mixed-methods case study design explored participation in an intergenerational, participatory creative arts project. Participants included children from an elementary school and senior adults with dementia in a memory care neighborhood. The purpose was to explore the meaning of participation and interaction in the project from participants' perspectives. Participants collaborated in eight sessions of original storytelling/ songwriting, as well as discussion and surveys about the sessions. I concluded participatory creative arts were valuable not only in making space for participants, but also in honoring diverse access routes to the creative process. Both senior adults with dementia and children perceived these utilities for participatory creative arts. While seniors' perspectives remained relatively stable and positive throughout the program, children demonstrated increasing cross-generational connection. Data discrepancies likely indicated cognitive dissonance for some children in processing the experience, yet overall, more consistent program attendance corresponded with more positive experiences for children. There is a need for more research and advocacy to fully explore and highlight voices of senior adults living with dementia collaborating with children in creative, participatory arts settings.

## CHAPTER 1: INTRODUCTION

### **Background of the Study**

Changing generational demographics in the United States have not only re-narrated paradigms of community across the age continuum, but also caused increasing trends of age-segregation and stigma (Albert & Ferring, 2013; Basting, 2009; George, 2011; Myers, 1994). As the senior adult population in the United States grows, researchers have begun to examine these societal narratives surrounding aging. Many researchers have identified stigmas surrounding Alzheimer's Disease and related dementias; these stigmas are one of the most negative narratives about aging (e.g., Allison, 2008; Baker et al., 2017; Basting, 2009; Friedman, 2011; Fritsch et al., 2009; George, 2011; George et al., 2011; Reynolds, 2016; Thoft et al., 2018; Varvarigou et. al, 2011; Wiersma et al., 2016). Those same researchers also suggest dementia stigmas can negatively impact mental health, disempowering people from living well. Response to this negative narrative surrounding dementia has become a matter of social justice. Researchers suggest that successfully changing dementia stigma depends on people across all generations to intentionally pursue connection (e.g., Basting, 2009; Harris & Caporella, 2018; Wiersma et al., 2016).

### **Intergenerational, Dementia-Friendly Community**

As one response to dementia stigmas, stakeholders and advocates have begun promoting various types of intergenerational initiatives. Although in some contexts the term *intergenerational* refers to heterogeneous age groupings including

people of any age, other contexts narrow the term to include specific age subsets. Throughout this document, the term *intergenerational* will refer to groups composed of children and senior adults. In his review of intergenerational research, Kaplan (2002) asserted that both children and seniors tend to benefit from intergenerational relationships. Not only so, but many community organizations have turned to intergenerational programs as a means of addressing dementia stigma (e.g., Basting, 2009; George, 2011). These types of programs are often labeled *dementia-friendly*, meaning they seek to honor and support people living with dementia by advocating for equitable access (Dementia Friendly America [DFA], 2018). The dementia-friendly movement has drawn increasing support from non-profit organizations such as the Alzheimer's Association, the American Association of Retired Persons (AARP), and the National Association of Area Agencies on Aging (DFA, 2018).

Dementia-friendly intergenerational programs aim to honor participants by empowering their voices as valued members of their community (e.g., Allison, 2008; Basting, 2009; Friedman, 2011; Harris & Caporella, 2018; Wiersma et al., 2016). Researchers such as Basting (2009), George (2011), and Harris and Caporella (2018) suggest that successful dementia-friendly, intergenerational programs foster meaningful relationships through means of collaborative, project-based settings. Program settings typically overlap with various parts of the community: banks, grocery stores, restaurants, workplaces, schools, faith communities, healthcare, and the like (DFA, 2018). One such domain of particular interest to this project is the arts, and specifically music-making communities.



## Music Engagement

Discussion of music in intergenerational settings benefits from examining music engagement trends. Although music has historically been a source of connection across generations (Allison, 2008; Feierabend, 1999; Mark, 1996), trends of music participation have also evolved (Turino, 2008). In particular, Turino (2008) identified a shift from a socially inclusive, participatory music-making culture, to a presentational music culture in which people regard music as an art commodity to be passively experienced. Turino suggested this shift occurred as Western consumers increasingly identified music as a commercial product:

The strength and pervasiveness of the music industry and its mass-mediated products during the past century have helped to create this habit of thought. If we briefly consider the products of the music industry over time, we can glimpse cosmopolitans' gradual shift in thinking of *music making* as a social activity to *music* as an object. (p. 24)

Turino chronicled a gradual commercialization of the arts industry to support his assertion that Western culture prioritizes presentational music. To consider the validity and implications of his assertion in an intergenerational setting, it would help to take a closer look at the music engagement trends of both seniors and children. As outlined in the next few paragraphs, researchers (e.g., Basting, 2009, Elpus & Abril, 2011; Friedman, 2011; Kinney, 2018) have raised concerns about trends of music engagement in both age groups.

Many American senior adults report active engagement in both participatory and presentational arts; in the most recent National Endowment for the Arts (NEA)

report (2017) 84% of seniors indicated involvement with some type of arts activity. As researchers have increasingly suggested benefits to such involvement (Creech et al., 2013; Cohen, 2006; NEA, 2017), participatory arts access for seniors has expanded and diversified (Bunt & Stige, 2014). Yet the robust portrait shown by the NEA report neglects to consider arts access for the 5.8 million senior adults living with dementia.

For many people living with dementia, participatory arts access remains limited or even stigmatizing since arts opportunities tend to position people with dementia as passive and unable to contribute (Basting, 2009; Friedman, 2011). For example, Basting (2009) argues that nursing facilities are typically not dementia-friendly arts outlets, since in most facilities “social programming is distributed like a sprinkler--to cover the largest area and the most people” (p. 105). As a result, these facilities tailor arts programming to occupy and pacify seniors with dementia; they are situated as audience members who listen to music without opportunity to actively participate (Allison, 2008; Basting, 2009; Friedman, 2011). Some advocates, such as *TimeSlips Creative Storytelling* and *Songwriting Works*, have recently begun to address this inequality of access by creating participatory arts programs specifically intended for persons living with dementia. However, making participatory arts outlets truly inclusive and dementia-friendly requires further advocacy efforts.

On the other end of the age spectrum, children are also experiencing changing trends of music engagement. In particular, some educators are concerned about trends of students’ disengagement with school music (Elpus & Abril, 2011;

Jellison, 2000; Kinney, 2018). Other educators have suggested this issue may connect to the prevailing presentational ensemble model in school music (Jellison, 2000; Lowe, 2011; Myers et al., 2013). Many children involved in school music do not continue music participation after graduation, or at least not in the manner anticipated by their formal music education (Jellison, 2000; Williams, 2014). Not only may presentational ensemble models contribute to attrition from school music programs, but in some instances their structure even prevents equitable access for children (Elpus & Abril, 2011; Kinney, 2018). Music educators have responded with diverse approaches to revitalize school music and offer more participatory, inclusive access (Kinney, 2018; Lowe, 2011; Myers et al., 2013, Thibeault, 2015; Waldron et al., 2017).

Intergenerational music-making offers one unique response to these concerns about students' disengagement with school music. Intergenerational school models such as the LaSalle Band program (Benyon & Alfano, 2013) and the East London Music for Life program (Varvarigou et al., 2011) have demonstrated ability to increase student engagement, supplement learning opportunities, and strengthen children's connections with seniors. Likewise, in community settings researchers have observed intergenerational music programs to boost children's arts access and inroads to participation (Benyon & Alfano, 2013; Sattler, 2013). Furthermore, researchers studying specifically *dementia-friendly* intergenerational music-making settings, such as the John Carroll University choir program (Harris & Caporella, 2018) and the Bournemouth University Dementia Institute orchestra

project (Reynolds et al., 2016), have suggested intergenerational music-making can help deconstruct dementia stigma.

Overall, the increasing awareness of the factors leading to dementia stigma has sparked interest in intergenerational initiatives to connect senior adults and children (e.g., Basting, 2009; George, 2011; Kaplan, 2002). Music is one tool intergenerational programs can use to increase cross-generational engagement and combat dementia-stigma (e.g., Benyon & Alfano, 2013; Harris & Caporella, 2018; Reynolds et al., 2016; Varvarigou et al., 2011). However, music is certainly not a panacea. Both seniors and children alike experience troubling inequalities in arts access and arts engagement. In particular, participatory music opportunities equitably include neither senior adults living with dementia (Allison, 2008; Basting, 2009; Friedman, 2011) nor children disinterested in the prevailing presentational ensemble models at schools (Elpus & Abril, 2011; Lowe, 2011; Kinney, 2018).

### **Statement of Problem and Need**

Though a large body of research surrounds both intergenerational music programming and dementia-friendly music programming, in most of these studies researchers tend to focus on presentational music outlets (e.g., Brummel-Smith, 2008; Bunt & Stige, 2014; Clair, 2008; Cohen, 2006; Cuddy et. al, 2012; Norton, 2016; Rio, 2016; Rossato-Bennett, 2014; Shiltz et. al, 2015). Many researchers have focused on using presentational music as a tool to facilitate memory connection and provide therapeutic benefits during dementia (Bunt & Stige, 2014; Clair, 2008; Norton, 2016; Shiltz, 2015; Tesky, 2011). Yet the resulting body of literature lacks research focusing specifically on inclusive participatory arts opportunities (e.g.,

active opportunities to create, explore, and play) for seniors with dementia. In fact, relatively little research has focused on the agency of people living with dementia to creatively contribute to an intergenerational community through participatory arts (Basting, 2009). This does a great disservice to people with dementia, since even throughout the progression of dementia all people are capable of actively engaging in creative processes (Basting, 2008; Camp & Antenucci, 2011; Friedman, 2011; Hallam & Creech, 2018). Likewise, although research highlights children's creative agency demonstrable from a young age (Campbell, 2009), few studies focus on children exercising that creative agency in intergenerational, dementia-friendly settings, nor do those studies tend to highlight the children's own perceptions regarding their experiences. Overall, although I found some research existing at the convergence of intergenerational, dementia-friendly, and participatory arts spheres, few of these studies highlighted the voices of children and seniors living with dementia, rather than simply reporting on these participants' actions from the researcher's perspective.

Not only does the surrounding body of participatory arts research lack studies highlighting perspectives of children and seniors with dementia, but also I personally observed people of these two age groups experiencing disempowerment through lack of access. This observation surfaced during my personal experience as an elementary music teacher. On several occasions I took elementary and middle school choir students to visit retirement homes and perform. During these trips, I noticed students desired to connect with the seniors, but there seemed to be little time or space for meaningful connections to occur since the visit largely centered on

a presentational music performance. Some children also seemed fearful of unpredictable interactions with seniors, or at a loss to find points of connection without adult assistance. Likewise, while seniors seemed to enjoy the entertainment, to some extent the presentational structure excluded them from meaningful participation. I wondered whether the transactional nature of our visits was subliminally teaching the children that the seniors were incapable of any role besides that of an appreciative audience. I also suspected the presentational format of our visits discouraged both children and seniors from authentic connection by confining them to “performer” and “audience” roles. My discussion with facility staff about their expectations for cross-generational arts programming indicated that this dynamic (i.e., children performing while seniors provided a polite audience) was a typical occurrence, not just unique to my experience.

Ultimately I arrived at the need for this study through two experiences: first, by identifying a gap in the literature surrounding participants’ perspectives on intergenerational, dementia-friendly participatory arts programs; and second, through my personal curiosity about finding better ways to musically empower connections between students like mine and senior adults living with dementia. The purpose of this study was to explore the meaning of participation and cross-generational interaction in a participatory, intergenerational music project from the perspectives of children and senior adults living with dementia. Resulting data from the study highlights cross-generational voices and perspectives of both senior adult and child participants. Their voices contribute valuable dialogue to the growing body of research on the meaning and value of participatory arts within

intergenerational, dementia-friendly communities. These perspectives can inform future researchers, theorists, policymakers, caregivers, teachers, and arts facilitators regarding issues of dementia stigma, intergenerational relationships, and participatory arts settings. Such insights can benefit future advocacy efforts to build participatory arts programs that truly honor the needs, preferences, and creative agency of both children and senior adults living with dementia.

### **Procedural Overview and Research Questions**

I designed the project as a convergent mixed methods case study design (Creswell & Plano Clark, 2018), in which qualitative and quantitative data were collected simultaneously, analyzed separately, and then combined in order to compare and contrast results. Both qualitative and quantitative data were collected in keeping with the overarching goal to empower seniors' and children's voices; the data was intended to explore and describe participants' perspectives regarding their experiences. To gain context for creating this case study, I reviewed research surrounding other successful intergenerational programs, dementia-friendly programs, and participatory arts programs. I distilled those programs' successes into five key themes. These five themes included: (a) prioritizing hospitality, (b) communicating with intentionality, (c) embracing flexibility and spontaneity, (d) honoring personal autonomy, and (e) respecting the past while looking to the present. In planning the project structure, I considered these five themes of successful programs, as well as other studies' potentially problematic tendency to examine participants' behavior as subjects rather than seeking their perspectives. I leaned on insight from researchers (e.g., Basting, 2008; Reynolds, 2016; Thoft, 2016;

Wiersma, 2016) whose studies sought to approach data collection in a dementia-friendly way, honoring participants' perspectives and goals rather than studying their behavior.

For the case study intervention, I created an intergenerational after-school program. The participants were senior adults living in a memory care neighborhood and children from an adjacent elementary school. I facilitated a series of eight creative sessions during which participants collaborated in a series of activities including storytelling and songwriting. Both seniors and children assisted in shaping the project's trajectory by choosing the direction and outcomes of our creative processes during these sessions. Participants generated original creative material and also shared opinions about the creative process during discussions; these contributions provided qualitative data. Additionally, the children completed surveys about the sessions, which provided quantitative data. My intent in collecting both quantitative and qualitative data was to compare results from both sources, in order to provide a more comprehensive understanding of participants' experiences and impressions. By doing so, I planned to observe whether children's survey responses differed from ideas voiced during creative sessions or discussion, and if so, how that information might contribute to a better understanding of the overall meaning they attributed to their participation.

I generated the following three research questions, focusing on the perceptions of participants and the role of participatory creative arts:

1. How can the value of participatory creative arts as a dementia-friendly tool be observed in intergenerational settings?



2. How do senior adult participants living with dementia and child participants perceive the meaning and value of cross-generational relationships in context of participatory creative arts?
3. How do qualitative and quantitative data compare or contrast regarding cross-generational collaboration in participatory creative arts processes?

## CHAPTER 2: REVIEW OF THE LITERATURE

### **Relationships Across Generations**

Intergenerational projects benefit from understanding paradigms of human relationship and their impacts on both senior adults and children. Researchers (e.g., Albert & Ferring, 2013; Basting, 2009; George, 2011; Harris & Caporella, 2018; Ling & Campbell, 2011; Putnam, 2001; Seltzer, 2019; Turkle, 2017) have identified various changing aspects of generational demographics and social norms, as well as resulting societal narratives of age-segregation and dementia stigma. Recently, these researchers' findings have sparked initiatives to rewrite more positive narratives surrounding aging and dementia. In considering the efficacy of such initiatives, it is important to begin with a foundational look at the cross-generational climate in Western society.

### **Changing Generational Demographics**

Shifting generational demographics in the United States create both challenges and opportunities regarding interpersonal connections (George, 2011; Harper, 2014). Both mortality and fertility rates have decreased over the past decades, and typical life expectancies have lengthened (Albert & Ferring, 2013; George, 2011; Harper, 2014). Census Bureau (2019) data indicates by 2060 life expectancies will have further increased by nearly sixteen years. As a result, population projections expect continually increasing numbers of senior adults (Albert & Ferring, 2013; Harper, 2014). Sociologists such as George (2011) have predicted this “graying” of the population will necessitate unprecedented change—not only in resource allocations, but also in our cultural structures (p. 450).

Meanwhile, human interactions are changing across the age continuum. The early-20th-century model of the nuclear family no longer represents the majority of United States households. The trends affecting 21st-century family models include (a) shifting gender roles, (b) changing marriage rights, (c) increased fluidity in the status of couple relationships, and (d) continual increases in the number of single-parent families, step-families, and cohabitating partner families (Harper, 2014; Seltzer, 2019). Data from the National Center for Health Statistics (2018) shows decline in marriage rates over the past twenty years, while the Census Bureau (2019) indicates a trend of steady increase in median age for marriage. Additionally, family members have become increasingly mobile and more likely to spread over a wider geographic area (Albert & Ferring, 2013). As family structures diversify, some sociologists such as George (2011) expect that cross-generational family ties will continue to loosen, while others suggest this is only a myth, pointing out that vertical family relationships across generations have overall become more commonplace, albeit different (Albert & Ferring, 2013; Harper, 2014). Regardless, although increasing life expectancies mean more opportunities to interact with people of other generations than ever before, it is also increasingly accepted for youth to diverge either geographically or culturally from their elders' traditions (Albert & Ferring, 2013). Researchers studying intergenerational dynamics suggest there are "intergenerational differences in value orientations" (Albert & Ferring, 2013, p. 155), with American youth tending to value "individual success over family loyalty" (Myers, 1994, p. 293).

## **Concerns about Social Interaction**

Changing societal demographics influence new paradigms of community for people across the lifespan. Regarding such changes, researchers (e.g., Ling & Campbell, 2011; Putnam, 2001; Turkle, 2017) have raised many questions about interpersonal connection. They point out possible advances to social connection, but also raise concerns about possible social disconnection. Especially regarding vulnerable populations such as senior adults and children, such issues of access to healthy social connection are important considerations for wellbeing. For instance, not only are children especially susceptible to negative impacts from feelings of social disconnect (Danneel et al., 2017), but also their increased feelings of loneliness correlate with heightened social anxiety and challenges to interpersonal interaction (Maes et al., 2019). Alarming, one study by Madsen et al. (2019) found that the overall prevalence of children who identified feelings of loneliness slowly but steadily increased from 1991 to 2014. This trend of increased loneliness also appears to be true for senior adults, according to researchers such as Creech et al. (2013) and Federizzi et al. (2019). They suggest increasing numbers of senior adults are experiencing social disconnect, living in isolated situations, and reporting loneliness or depression. Just as with children, loneliness detrimentally impacts senior citizens' health and quality of life (Tan et al., 2020). The emerging evidence about social disconnect paints an incomplete and at times conflicting picture, admittedly oversimplified in its brief inclusion here. Yet it is important to recognize the existence of such concerns since this project explores the meaning of social participation in a community including both youth and elders.

## **The Problem of Age-Segregation and Ageism**

In many cases, the cocktail of factors reshaping socialization for senior adults and children also widens gaps between generations, breeding a culture of age-segregation and ageism (Aday et al., 2008; Basting, 2008; Harper, 2014). As society increasingly idolizes youth and independence, many American senior citizens perceive that they are “devalued in terms of their [societal] relevance” (Myers, 1994, p. 294). At best, American tendency is to view elders with warm feelings yet discount them as less productive members of society. At worst, society reacts to the aged with attitudes of fear and prejudice (Basting, 2008). These responses begin from an early age, with children as young as age three describing elderly people with unfavorable words and throughout elementary school tending to articulate negative impressions about growing older (Aday et al., 2008). By the time children reach age twelve they typically internalize ageist sentiments observed from adults; left unchallenged during the adolescent years these attitudes become more difficult to change later in life (Aday et al., 2008; Gilbert & Ricketts, 2008).

Harper (2014) contends that age-related stereotypes have shown little improvement since the 1950s largely because societal structures continue to support the myth that “older people are unproductive potential burdens on society” (p. 23). For evidence, Harper points to stereotypical perceptions regarding senior adults’ role in the economy:

Despite the fact that there is little practical evidence to support the view that those over age 50 are consistently less able to perform modern economic activity than those younger, such stereotypically [*sic*] views remain, are

widely published in the popular press and other outlets, and appear to impact upon employer behaviour. Slow work speed, low adaptability, particularly to new technologies, low trainability, low skills uptake, and too cautious, are all stereotypes expressed by employers. The perception that age and characteristics are related appears embedded in our current societal perceptions. (p. 23)

Until recently, little research has attempted to untangle the strands contributing to this knot of stereotyped narratives surrounding aging. However, lately more attention has been garnered by attitudes about aging, especially regarding one of aging's most negative buzzwords: dementia.

### **Perceptions about dementia.**

Dementia, one of the most fear-inducing words related to aging, is a general term encompassing a variety of medical conditions which damage memory, alter personality, and detrimentally impact some cognitive functions (Brummel-Smith, 2008). Alzheimer's disease, one of the most well-known forms, accounts for over 60 percent of all dementias (Brummel-Smith, 2008). Diagnoses of Alzheimer's disease and related dementias are on the rise (Brummel-Smith, 2008; George, 2011; Reynolds et. al, 2016). In fact, "the worldwide prevalence . . . is predicted to double every 20 years to 65.7 million afflicted by 2030," with American diagnoses comprising 13.5 million of that number (Shiltz et al., 2015, p. 10). As evidenced by the wording of this prediction, dementia's increased prevalence is accompanied by an increasingly fear-based narrative about such an "affliction."

People's fear about the "affliction" (Shiltz et al., 2015, p.10) of dementia may be little wonder in light of medical facts. Dementia's progression has debilitating effects on a person's cognition, behavior, and physical condition. In its earliest stages, dementia may manifest as decline in recognition and memory, ongoing difficulty and confusion in daily tasks, erratic behavior, an onset of depression, or repetitive, obsessive activities (Clair, 1996; Graham & Warner, 2014). Scientists now understand these symptoms occur due to an irregular protein produced in the brain which impairs the function, health, and communication of a person's nerve cells (i.e., neurons). As the disease progresses, neurons die and some parts of the brain may decrease in size and capacity, most notably the temporal lobe, which is responsible for memory (Graham & Warner, 2014). In later stages, up to seventy-five percent of people living with Alzheimer's disease experience more violent effects: "[a]nger, blaming, verbal outbursts, psychotic symptoms such as hallucinations or delusions, and physical aggression" (Brummel-Smith, 2008, p. 187). Family caregivers also often incur physical and emotional effects from the strain of caring for loved ones living with dementia (Clair, 2008).

### **Societal responses to dementia.**

To understand societal fears regarding dementia, it is important to acknowledge the large number of unknown factors surrounding its origin and progression. For instance, it is still unclear why the irregular proteins causing dementia begin to appear, or how to reverse their effects; currently no approved medications effectively cure dementia or reliably slow its progression (Alzheimer's Association, 2020; Shiltz et al., 2015). Even one of the most prominent drugs

prescribed for dementia, Aricept, has shown such inconsistent results in trials as to be determined not cost-effective by the British Health Service, although its worldwide sales continue, due to drug companies' intensive advertising (Brummel-Smith, 2008). In fact, pharmaceutical reports assessing Aricept predict that by the year 2022, this inconsistent drug will retain the most "trustworthy reputation" of any available option for dementia treatment (GlobalData PharmaPoint, 2013, p.2). Continued drug research includes two approaches: finding drugs to improve cognition, and finding drugs to alleviate negative symptoms or counteract undesired behaviors (Alzheimer's Association, 2020; Brummel-Smith, 2008). Although clinical trials of new drugs continue to advance doctors' understanding of dementia, on the whole most medications still remain cost-prohibitive, produce inconsistent improvements to quality of life, and sometimes entail serious negative side effects (Brummel-Smith, 2008; Shiltz et al., 2015), all of which contributes to people's fears about dementia.

People's fears likely relate not only to the lack of cure, but also the need for skilled nursing care during dementia and criticisms associated with nursing facilities (Basting, 2009). Although seniors with dementia most often live with their families, many will also be placed in skilled care nursing facilities, which since the 1960s have become increasingly prominent models for coping with dementia (Allison, 2008). Commonly these facilities bear some resemblance to hospitals because of the need for specialized medical care, the legal risks associated with such care, and similar requirements for staffing. In skilled nursing facilities, legislation strictly regulates many aspects regarding the living environment (Allison, 2008).



Although reforms beginning in the 1980s have attempted to improve quality of life, most nursing homes still depend on a somewhat medicalized model of care. This model has been criticized as creating a sterile, dehumanizing experience for people living in nursing homes (Allison, 2008; Brummel-Smith, 2008). Criticism typically suggests that the inflexible living environment disregards individuals' dignity and causes friction as "*people* from the community become [viewed as] *residents* of the institution, but they carry with them their belief systems, values, and experiences as adults in larger society" (Allison, 2008, p. 223). For many people, confinement to an institutional setting is a dreaded situation which threatens their sense of humanity and community. In fact, on average people with dementia living in long term care spend only thirteen percent of their waking hours communicating or participating in other engaged social activities; the remaining majority of their time is spent "sleeping, doing nothing, or watching TV" (Baker, 2017, p. 213). Attempts to unpack the origins of dementia stigma benefit from understanding these criticisms of skilled nursing facilities.

### **Negative narratives and stigma surrounding dementia.**

Ultimately, the combination of the increasing generation gap, ageism, and the medicalized care climate associated with dementia fuels a multifaceted set of societal fears. Author and activist Anne Davis Basting (2009) assessed this set of fears as encompassing: (a) dementia's unknown origin and seemingly random occurrence, (b) the impending loss of autonomy in daily life activities, (c) the inability to retain treasured memories, (d) the shameful feelings associated with becoming an imposition on family or caregivers, (e) the financial strain of seeking

medical help and institutional care, and (f) the perception of life with dementia as a pointless existence devoid of meaning. Brummel-Smith (2008) additionally suggested that fears about dementia may originate from the Western tendency to glorify science and perceive cognitive or intellectual power as one of the highest determinants for quality of life. Furthermore, dramatic media portrayals have nursed these fears about dementia (Basting, 2009). Basting highlighted several such portrayals in twenty-first century mainstream media, stating:

Dementia is associated with two types of tragic story. First, there is the one in which dementia is represented as a calamity that can only be eliminated if scientists are given enough time and money to find the cure. Second is the tale of the loss of an accomplished, inspiring person, a person slowly emptied out by a devastating illness. (p. 33)

Though Basting (2009) did not intend to trivialize dementia's negative impacts, she and others questioned the widespread acceptance of this tragic narrative, which has increasingly stigmatized and disempowered those living with dementia (Friedman, 2011; Reynolds et al., 2016; Thoft et al., 2018, Wiersma et al., 2016). In fact, Wiersma et al. (2016) suggested people tend to perceive a dementia diagnosis as overshadowing a person's entire identity, and often form corresponding assumptions about that person's incompetence. Individuals who suspect they may have dementia but dread the accompanying social stigma are likely to hide their symptoms, resist help, or delay seeking necessary care (Harris & Caporella, 2018; Reynolds et al., 2016). Their relationships with family may also suffer from a "societally imposed [shift] as others increasingly position the family

member as a ‘care-giver’ . . . [versus] the person with dementia as ‘dependent’ and potentially a ‘burden’” (Wiersma et al., 2016, p. 416). As a result, quality of life is compromised both for the individual living with dementia and others around them. For some people embarrassment about their diagnosis has even caused measurable decreases in cognitive functioning; they succumb to a “self-fulfilling prophecy” by internalizing the narrative that continued memory loss is shameful and unavoidable (Basting, 2009, p. 28). As research continues to reveal the negative impacts of our societal narratives surrounding dementia, many stakeholders have begun looking for better ways to respect and empower people living with dementia (George, 2011; Reynolds et al., 2016; Thoft et al., 2018).

### **Impetus for dementia-friendly communities.**

After the 2012 world report of Alzheimer’s Disease International called attention to the “dehumanizing, demoralizing effects” of dementia stigma, many countries developed plans to change age-segregation and stigma by building more “dementia-friendly” communities (Harris & Caporella, 2018, p. 2). The dementia-friendly movement envisions communities where people with dementia and their families experience acceptance, receive support, feel valued as contributing members of society, and become empowered to live with dignity (Harris & Caporella, 2018; Reynolds et al., 2016; Wiersma et al., 2016).

The dementia-friendly movement aligns with Kitwood’s 1997 Theory of Personhood, which prioritizes people over their diagnosis and recognizes every individual’s capacity to define meaning (Brummel-Smith, 2008). Kitwood’s Theory of Personhood places responsibility on family, friends, and caregivers not to shy

away from a person living with dementia even when their situation is difficult to understand. This model affirms people with dementia as individuals who possess unique resources, represent valuable cultural heritage, and need meaningful social engagement (Brummel-Smith, 2008). These ideas are not new to organizations serving seniors with dementia; concerns about “person-centered” care appeared in literature in the 1960s and by the 1980s social worker Naomi Feil brought the issues to public attention when she published her landmark book on the Validation Method, a theory of empathy and respect for persons with dementia. Yet despite positive changes to date, barriers to person-centered care still exist, including lack of education and lack of funding. Furthermore, lasting change to the stigmatized model for dementia care cannot occur without community engagement (George, 2011; Harris & Caporella, 2018). Basting (2009) suggested lasting change will require communities to lay aside fixation with finding a cure for dementia and focus on rewriting their societal narrative for dementia from that of a tragedy to a celebration of continued personhood. Progress requires honoring people with dementia as “human beings who are members of families, neighborhoods, communities, and a local and global ecology” (George, 2011, p. 448).

Researchers, for their part, have taken various strategies towards promoting more dementia-friendly communities by uncovering fears and deconstructing misconceptions (Harris & Caporella, 2018). For instance, some researchers have initiated community discussions and created support groups as safe spaces for conversation about aging-related fears (e.g., Wiersma et al., 2016). Other researchers have restructured the research model to empower people with

dementia in the research process itself, recognizing that their prior participation only as studied subjects has contributed to stigma (e.g., Reynolds et al., 2016).

### **The Need for Connection Across Generations**

Other studies have painted the problem of dementia stigma with an even larger brush, suggesting that stereotypes will never change unless people across all generations more intentionally pursue interconnectedness and community (Harris & Caporella, 2018; Wiersma et al., 2016). Cross-generational interactions have traditionally proved beneficial in family settings for young and old alike (George, 2011; Kaplan, 2002), but it remains to be determined what healthy intergenerational connectedness will look like for the twenty-first century, given the changing family demographics and shifting paradigms of socialization discussed earlier. Many organizations in community and educational spheres have turned increased attention to intergenerational programming in pursuit of building cross-generational connections and reducing stereotypes (Harris & Caporella, 2018; Kaplan, 2002).

#### **Intergenerational programming.**

Intergenerational programming typically aims to connect youths and seniors through contexts such as history, performing arts, technological skills, and other common interests. Participation in such programs has become generally accepted as a beneficial way for both seniors and children to break down generational barriers (Kaplan, 2002). Studied benefits include educational or cognitive gains, reduced stress, anxiety, and depression, and a host of enhanced social factors including self-esteem, relational engagement, feelings of connectedness, increased empathy, and

overall higher perceptions of personal wellness and quality of life (Baker, 2009; George, 2011; Kaplan, 2002; Varvarigou et al., 2011).

Especially for senior adults with cognitive disabilities, intergenerational interactions tend to significantly increase social engagement—even for people whose participation is simultaneously declining in other types of daily life activities (Baker et al., 2017, Belgrave, 2011). For example, Baker et al. (2017) studied the engagement of seniors with dementia at one facility during an intergenerational collaborative project and found that

residents felt more positive (i.e., happier, calmer, and more valued) and less negative (i.e., sad or anxious) after . . . student visits relative to after usual [residential facility] lifestyle activities. Residents were also more engaged during student visits relative to usual activities. (p. 217)

Not only did Baker et al. (2017) find that seniors felt more engaged in the intergenerational visits compared to other activities, but their study also indicated these trends of increased engagement were particularly evident for seniors exhibiting “greater cognitive impairment,” even more so than those senior participants with more mild memory loss or no signs of dementia (p. 217). This would seem to indicate that intergenerational engagement remains beneficial for seniors regardless of the degree to which dementia has impacted their other activities of daily life.

Youth participants also benefit from intergenerational programs. Children who participate in intergenerational programming tend to demonstrate some degree of positive shift not only in their attitudes towards senior adults but also in

their overall connotations with aging and dementia (Baker et al., 2017; Belgrave, 2011; Harris & Caporella, 2018). Some studies have noted that the extent to which youths' attitudes change correlates with the amount of time—and quality of time—they spend with seniors. For instance, programs promote comparatively little intergenerational growth when children participate infrequently over a short span of time, the program has unclear purpose, or it offers limited opportunities for interaction (Baker et al., 2017; Kaplan, 2002). By contrast, programs showing the most significantly positive intergenerational growth are those “embedded in local tradition” which purposefully integrate with the larger community (Kaplan, 2002, p. 316). The most successful programs also adhere to a well-organized, consistent structure while still allowing relationships to develop organically over an extended period of time (George, 2011; Harris & Caporella, 2018).

***Chicago Memory Bridge Institute.***

One such successful example of intergenerational connection is The Chicago Memory Bridge Institute, a program which since its conception in 2005 has connected over 4,000 junior high and high school students with senior adults living in dementia care facilities (Chicago Memory Bridge Institute [CMBI], 2018). Now funded by the US Department of Education, CMBI was originally a local start-up which served at-risk students by offering an after-school program involving science, arts, and service learning. Students participating in the program learn about medical and social aspects of dementia, and then they are paired with a senior adult “buddy” who is living with dementia (CMBI, 2018). With the help of social workers and family members, students and buddies get to know each other through sharing

stories and pictures of their lives in a series of structured visits (Basting, 2009). The program culminates with students creating and delivering a personalized gift for their buddy. Throughout the experience, the CMBI program encourages students to wrestle with difficult life questions: “What is identity? How can people connect across dementia? What can we learn from each other?” (Basting, 2009, p. 82).

### ***The Intergenerational School.***

Another successful example of a program facilitating intergenerational connection is the Intergenerational School in Cleveland, Ohio, which was founded in 2000 on a “model of education that challenges traditional age segregation and embraces learners of all ages within a lifespan learning community” (The Intergenerational School [TIG], 2020, para. 2). Classrooms de-emphasize age and learning disabilities, creating environments inclusive to people of varying ages learning together (George, 2011). Today over seven hundred K-8 students attend the school at three different campuses with multi-age classrooms (TIG, 2020). Though typical senior adult participants at TIG are not necessarily persons living with dementia, TIG has also hosted a community intervention research study during which elders with dementia volunteered as mentors in classrooms, and children also visited their elder mentors’ assisted living facilities throughout the year (George, 2011). The program spanned five months and used a curriculum developed in collaboration between a researcher and teachers at the school. Curricular goals focused on the intergenerational exchange of narrative through shared activities including singing, reading, writing, storytelling, reminiscence, discussions about heritage, arts & crafts, and interviewing (George, 2011).



### **Theoretical frameworks supporting intergenerational communities.**

In order to make sense of the effectiveness of intergenerational programs in reducing dementia stigma, it is useful to consider theoretical frameworks: for instance, research on prejudice and the intergroup contact theory, first proposed by Allport in the 1950s but since expanded by other researchers including Pettigrew et al. (2011) and Harris & Caporella (2018). The intergroup contact theory suggests that a healthy sense of community can be built and prejudices reduced by championing common goals, facilitating meaningful relationships, and promoting opportunities for cooperation (Harris & Caporella, 2018; Pettigrew et al., 2011). Thus, to the extent an intergenerational program facilitates these goals, its participants can successfully build community with one another. Similarly, Wiersma et al. (2016) promote a “social citizenship framework” to reduce stigma surrounding dementia. This model parallels the intergroup contact approach and suggests additional metacognitive steps toward building healthy community: “opportunities for growth, change and development; . . . a power analysis that recognizes how one’s social locations help shape one’s experiences of the world; . . . respect for personal meaning-making and finding purpose; . . . promoting active participation (as opposed to simply being included)” (Wiersma et al., 2016, p. 417). These types of principles are evidenced in both the Chicago Memory Bridge Institute and The Intergenerational School. Both organizations have documented resulting positive interactions between seniors with dementia and children, as have many other researchers using similar frameworks including Baker et al. (2017), Harris & Caporella (2018), Kaplan (2002), Sattler (2013), and Varvarigou et al. (2011). Such

theoretical frameworks offer insight into the structural considerations necessary for intergenerational programs to successfully facilitate relationships across the age spectrum. Regardless of program setting or context, these theoretical frameworks suggest the most important ingredient for an intergenerational program's success is participants' access to actively engage in a shared process.

### **Music Engagement and Generational Trends**

Intergenerational programs take place in various contexts and rely on various tools to facilitate relationships. One such tool of specific interest to this project is creative arts, and in particular music. In order to understand the potential role of music in an intergenerational setting, it is helpful to first consider patterns of music engagement throughout history, and current generational trends of music engagement. .

#### **Historical Trends of Music Engagement**

Throughout American history, music traditions have been one means used to strengthen interpersonal connections and build community (Allison, 2008). In the nineteenth and early twentieth centuries, family and community music-making was a cultural practice shared across generations. Social engagements often included music-making in home settings, and children participated with others of all ages in active music-making experiences such as singing, dancing, and playing instruments (Feierabend, 1999). Furthermore, the informal transmission of music heritage intersected with and influenced formal music education practices (Myers, 1994). Music performance might typically include both notated repertoire and music

recalled from collective cultural memory (Turino, 2008). As such, a person's music participation entailed connection across a wealth of generational history.

**Changing paradigms of music engagement: participatory to presentational.**

Trends of music participation today are typically not so dependent on intergenerational connections as in the past. Just as generational demographics and social interactions have shifted in America, so also the ways people prefer to engage music have evolved. This can be seen both in the way individuals engage with music in social and family settings, and in formal music learning and teaching contexts.

Turino's (2008) research offers a helpful perspective on this shift by defining specific categorical language to describe music and music-making practices. Turino asserted that despite Western culture's broad application of the word *music*, modern human music-making actually encompasses several distinct art forms. Namely, he identified a difference between "participatory" music culture, where music is an inclusive social activity, versus "presentational" music culture where music is an object to be experienced (p. 23). He suggested Western culture has undergone a broad societal shift from participatory music culture to a more presentational music culture beginning with the advent of audio recording and radio broadcasts, which increasingly professionalized access to music (Turino, 2008). In fact, Turino (2008) suggested in the twenty-first century youths are more likely than in past generations to experience comparatively passive music engagement as audience members who *listen* to music or consumers who *purchase* music as a recorded object, rather than actively creating music in daily life. Many

factors may have influenced this shift, including postmodern worldview, capitalist society, consumer mindset, and high value on individualism over cultural continuity (Myers, 1994; Turino 2008).

### **Changing paradigms of music engagement across the lifespan.**

Turino (2008) did not imply that this portrait was a generalized description fitting every community of music practice; however, the participatory/presentational lens provides a helpful perspective for understanding other trends of music engagement across the age spectrum. When considering music as a potential tool for intergenerational settings, it becomes important to explore how people of different generations perceive musical engagement. In particular I will explore trends surrounding two age groups' participation: first, senior adults' music involvement, followed by children's involvement in school music.

### **Music Engagement for Senior Adults**

On the whole, senior adults report substantial participation in both presentational and participatory arts. According to the National Endowment for the Arts (2017) report, of older adults aged 55 and above, 84.1 percent reported some involvement in either presentational or participatory arts. Among that 84.1 percent, 64 percent engaged in participatory settings (i.e., "created art of their own") and 68.7 percent engaged in presentational settings (i.e., "attended arts events") (NEA, 2017, p. 2). Additionally, 48.6 percent engaged in both settings, (i.e., "both created and attended,") while only 15.9 percent reported no arts participation of any type (NEA, 2017, p. 2). Closer inspection is merited to determine whether such robust

survey numbers give a completely accurate picture, yet it is important to recognize these basic statistics representing seniors' arts participation.

### **Music engagement for health in senior adulthood.**

NEA's assessment of high senior participation in the arts is likely related to increased research on health benefits from arts participation in senior adulthood. Cohen (2006) found myriad health improvements for older adults involved weekly in arts programming. As compared to the control group, treatment group participants reported significant reduction in depression, loneliness, use of medication, number of falls, number of doctor visits, self-perception of health, quality of life, and morale. Cohen suggested the arts had a "positive impact on maintaining independence and on reducing dependency," (p. 1) and thus active participation in the arts offered "potential beyond problems" (p. 3) in regards to age-related health issues.

Emerging research on health in senior adulthood continues to suggest that arts participation can help address a broad range of age-related challenges including Alzheimer's disease and related dementias, Parkinson's disease, depression and other mental health concerns, cardiac and stroke rehabilitation, stress management, and even exercise goals (Clair, 1996). Most recently, researchers from National Endowment for the Arts (2017) study, which included data collected from 2002 to 2014, observed that

older adults who participated in both Creating Art and Attending Art had higher levels of cognitive functioning and lower rates of limitations to daily

physical functioning, as well as lower rates of hypertension, relative to older adults who did neither type of activity. (p. 10)

Likewise, participants in the UK *Music for Life* research project (Hallam & Creech, 2018) reported perceived improvements not only to their social and emotional states, but also to their cognitive and physical health. Interestingly, the majority of *Music For Life* participants also believed their enhanced sense of physical health stemmed from access to other socio-emotional benefits: namely, an increased sense of interpersonal affirmation, connection with their community, and empowerment to create meaning in their community (Hallam & Creech, 2018). Similarly, in the 2017 National Endowment report, the majority of older adults surveyed indicated they perceived the arts as valuable in benefitting their social, mental, and physical health.

Heightened awareness about the well-documented benefits of music in senior adulthood has increased the overall availability of such programming for some senior adults (Bunt & Stige, 2014). For instance, health providers in the UK, where the arts and health services are increasingly connected, commonly promote various kinds of musical community as a means to enhance senior adults' health and well-being. Similarly, in the United States, national music therapy organizations presented research studies and individual testimonies before the Senate in 1991 to promote the availability of music for health in senior adulthood. At face value it may seem that such national recognition and increased research means seniors have better arts access than ever before. Yet although the efforts discussed to this point

are admirable, they do not represent a full picture of arts access during senior adulthood.

### **Concerns about equal access for seniors living with dementia.**

Despite the fact that 77 percent of older adults surveyed in the 2017 National Endowment for the Arts report affirmed their interest in arts participation, about one in every three respondents also indicated they experienced challenges to doing so (NEA, 2017). In some situations, resources are still scarce to offer seniors inclusive music programming. In fact, access to most senior adult music programming in the United States has traditionally been tailored towards participants in relatively independent states of mental and physical wellbeing. The advocacy efforts for music in senior adulthood discussed above arguably do little to address the concerns about dementia-friendly communities mentioned earlier in this chapter. What about the estimated 5.8 million people living with dementia in 2020 (Alzheimer's Association, 2020)? For many of these seniors, the negative narrative surrounding dementia has precluded access to music-making settings (Basting, 2009). These barriers to access will likely remain without further advocacy efforts (Bunt & Stige, 2014).

Furthermore, elders with dementia are typically stigmatized as unable to actively engage in creative participatory arts and capable only of being entertained by presentational arts (Basting, 2009). Why might this be, especially given research that active music participation yields higher therapeutic efficacy than passive activities such as listening to music (Creech et al., 2013)? The types of music opportunities offered for seniors with dementia generally center on music's power

to access memories, with a goal of unlocking access to the past self. Though there is nothing inherently wrong with celebrating music's power to access memories, Basting argues society has become overly fascinated with researching music's potential to counteract memory loss; she suggests this idealistic fixation on music as a cure ultimately only strengthens dementia stigma (Basting, 2009). In other words, viewing music as a cognitive elixir to alleviate perceived deficiencies during dementia leaves people living with dementia little opportunity to employ music as a tool for self-empowerment (George, 2011). Basting's research challenges us to examine whether our typical perspective on music and dementia is too limiting and even oppressive to people living with dementia.

#### **The value of participatory arts for seniors living with dementia.**

Music can do more than connect seniors with dementia to "lost" memories from their past (Basting, 2009; George, 2011). Music participation offers seniors a path to ignite the power of imagination and access creative abilities which are not "lost" in dementia (Allison, 2008; Bunt & Stige, 2014). Gene Cohen, Director for Center of Aging at George Washington University, described the importance of this process for people living with dementia: "Imagination is so core to the human experience; it's what . . . contributes to us wanting to climb mountains, explore space. It's even more fundamental, in many ways, than memory, that [imagination] is accessible" (Godoy, 2007, 26 min., 18 s.). All senior adults, including those living with dementia, ought to have equal access to imagination as a means of empowerment to address mental and physical wellness.



Not only should senior adults with dementia have equal access to participatory arts, but also their participation in participatory arts communities may be a crucial missing puzzle piece to improve societal dementia stigma. Along with researchers such as Allison (2008), Basting (2009), and Friedman (2011), George (2011) suggests why prioritizing interconnected social roles is so crucial to promote wellness and prevent stigma:

[H]uman wellness is not just about a race for longevity or cognitive stimulation, but also about preserving relationships over time. . . wellness is not just about the health of a brain, because that brain is one facet of a person who exists as part of a family, a neighborhood, a community, and a natural environment. Real commitments to wellness must look beyond the brain to the whole person, and consider the enormous promise of community-based solutions to contribute to a vital and purposeful existence. (pp. 464-465)

Participatory arts settings by nature prioritize these types of interconnected social roles, positioning participants as integral members of the community (Sattler, 2013; Turino, 2008). For this reason, participatory arts settings can be a valuable resource in pursuit of building genuinely dementia-friendly communities. The 2007 documentary *Do Not Go Gently* helps us envision what this type of community could look like. The film celebrates three American artists over the age of eighty-five as “leaders and innovators” due to their ongoing creative contributions and community engagement throughout late adulthood. *Do Not Go Gently* prompts us to imagine a community which rejects age and dementia stigma, embracing seniors’ creative contributions in a way both beneficial to society and our elders (Godoy, 2007).

### **Examples of participatory arts settings for seniors with dementia.**

Though these types of participatory arts opportunities for seniors living with dementia are not common, several successful examples exist. In particular, my project drew structural guidance from two model programs, the *Songwriting Works* program and the *TimeSlips Creative Storytelling* program. These two programs were initially created for senior adults but have expanded over the past three decades to various types of participants. These two programs both empower elders living with dementia to take participatory, collaborative roles in creative arts projects.

#### ***Songwriting Works program.***

The *Songwriting Works* organization describes itself as a group of “professional songwriters delivering research-based, musical innovation across the lifespan” (Songwriting Works [SW], 2019, para. 1). Begun by Judith-Kate Friedman in 1990 as an artist-in-residency program, *Songwriting Works* has expanded to serve over 3,000 people in communities across the United States and Canada . Their workshops partner with community organizations to create and perform original music in a workshop setting accessible to people “across differences in age, culture, class, education, language, ability, and musical experience” (para. 1). Friedman (2011) likens the *Songwriting Works* process to the creation of a mural or patchwork quilt, in which participants are each recognized as valuable contributors who help define the unique musical aesthetic for a given song by seeking group consensus on all creative choices. *Songwriting Works* has a unique community-building impact through this process of collectively generating new creative material (Allison, 2008). For example, individuals reserved during initial sessions

become more likely to participate during subsequent sessions, and during unaccompanied singing sessions even seniors in late-stage dementia showed increased engagement and gave creative responses (Friedman, 2011). In her case study of one particular *Songwriting Works* program in a Jewish nursing home, Allison (2008) also observed an increased sense of community and heightened quality of life for program participants. Interestingly, although improving memory is not the program's goal, the participatory process does spark formation of new memories (Allison, 2008; Friedman, 2011). In one *Songwriting Works* study, eighty-five percent of participants were diagnosed with neurodegenerative conditions yet the majority of participants remembered lyrics and melody to the group's original songs and reproduced them from one session to the next without prompting (Friedman, 2011).

***TimeSlips Creative Storytelling program.***

The *TimeSlips Creative Storytelling* program uses a similar model to *Songwriting Works*, except with the medium of storytelling instead of songwriting. Since its beginnings in 1998 by Anne Davis Basting, *TimeSlips* has expanded to include over eight hundred trained facilitators around the world who use prompts to lead group creative storytelling sessions for senior adults with dementia. *TimeSlips* sessions are based on the vision that “creative expression, growth, and meaning is available to us at every stage of life, no matter where we live or our abilities” (TimeSlips, 2019, para. 4). Multiple researchers (e.g., Fritsch et al., 2009; George et al., 2011; Swinnen et al., 2018) have observed a variety of positive benefits from the *TimeSlips* program: not only higher engagement, sense of self-

worth, creative enjoyment, and overall increased quality of life for senior adult participants who live in care facilities, but also more frequent, more positive, less stigmatized interactions between seniors and staff in those facilities. George & Houser's (2014) study also demonstrated that *TimeSlips* positively impacted the overall sense of community in a nursing home by fostering improved relationships and atmosphere. While most researchers have observed these types of benefits for senior participants in beginning to middle stages of dementia, other researchers have observed participants with severe dementia demonstrate increased interpersonal connection during *TimeSlips* participation through gestures of communication such as smiling, laughter, and relaxation (Bahlke et al., 2019; Vigliotti et al., 2018).

### **Music Engagement for Children**

Shifting attention away from the trends affecting senior adults' music engagement, and these model participatory programs for seniors living with dementia, it is also important to consider trends impacting children's music engagement and participation. In particular, this project benefits from understanding music engagement in relation to school music programs, which are one of many cultural institutions both shaping and responding to children's music preferences. To some extent, children's patterns of engagement or disengagement with school music programs can help identify trends in children's overall music engagement. The next few paragraphs briefly address a number of issues with school music engagement which educators are working to address, as well as the

potential of intergenerational music programs to help revitalize children's music engagement.

### **Presentational music concerns and school music.**

Historically, the dominant outlets for children's music participation in American schools have most often been presentational music models. For example, students might typically choose from course offerings such as band, choir, and orchestra, all of which tend to emphasize learning music through large ensemble membership and formal performance. Yet for the past quarter-century, stakeholders in education have increasingly voiced concern about students' decreasing engagement with this model (Jellison, 2000; Myers et al., 2013). Not only is students' interest in school music dwindling, but also researchers have raised concerns about statistics of attrition from music education programs (Elpus & Abril, 2011; Kinney, 2018). Many children involved in school music do not continue music participation after graduation from secondary school, or at least not in the manner anticipated by their formal music education (Jellison, 2000; Williams, 2014). Furthermore, school music programs no longer equitably engage the student population. American school music programs tend to serve certain populations while underrepresenting others. Students enrolled in school music programs are "significantly more privileged than their non-music counterparts [in every dimension associated with social strata and economic resources]" including "race/ethnicity, socioeconomic status (SES), native language, parents' education, standardized test scores, and GPA" (Elpus & Abril, 2011, pp. 128, 138). Kinney (2018) suggested this inequitable access occurs because at a structural level school music programs continue to appeal more

to students within certain demographics, while students outside those demographics are not only less likely to join a music ensemble but also less likely to continue their participation.

### **Participatory alternatives for school music.**

Among other researchers, Myers et al. (2013) have suggested that these concerns might be addressed by exploring alternatives to the traditional ensemble paradigm. Music educators have embraced diverse approaches to restructure presentational music classes into more participatory, engaging formats (Lowe, 2011). A few brief examples include updating curriculum to prioritize material more culturally relevant for students, deconstructing the divide between choral and instrumental music to offer more diverse types of ensembles, offering more collaborative music experiences which center on student interests rather than only teacher-directed learning, and promoting technology-based musicianship through varied media outlets (Stewart, 2002; Thibeault, 2015; Williams, 2014; Waldron et al., 2017). Though this brief sampling of changes in music education presents an oversimplified picture, Myers et al. (2013) suggested that many such approaches have very successfully revitalized students' interest in school music. Yet Waldron et al. (2017) contended that despite these efforts, school music remains far from achieving a fully participatory model:

On the one hand, both researchers and policy makers are placing an increasingly strong emphasis on participation, creativity, and collaboration in music education. On the other hand, recent studies suggest that in music education institutions, the focus of teaching is still noticeably in individual

skill acquisition and reproduction of repertoire and and enculturation in existing musical traditions. (p. 293)

Besides celebrating successes in music education, this appraisal also points out further room for improvement, especially regarding the agency of students' own voices in the music classroom.

### **Intergenerational Music Engagement**

One path to revitalizing a participatory music culture which has received little attention in school music programs is intergenerational music. In considering the complex issues of school music through a wider lens, it is fair to wonder where these issues overlap with societal trends discussed earlier (e.g., the shift away from participatory music culture, ageism, dementia stigma). Might pursuing exclusively student-centered solutions to school music problems unfortunately mirror those larger societal trends? If so, music educators would do well to consider whether focusing on *music for youths* as an insular cultural activity isolates students from intergenerational communities which might encourage music access (Benyon & Alfano, 2013; DeVries, 2011; Mark, 1996). Looking forward, intergenerational music participation offers a way to honor changing demographics, interests, and needs of people on both ends of the life spectrum.

#### **Intergenerational models and school music.**

Despite the typically age-segregated format of most American schools, school music holds great potential for intergenerational collaboration. In keeping with the linear progression of K-12 school systems, many programs build hierarchical ensembles which separate learners by age and musical ability (Myers et al., 2013).

Likewise, school music curriculum typically stratifies activities of music learning as age-specific tasks (Williams, 2014). To some extent this structure fulfills a pedagogical necessity: it allows teachers to address the unique challenges which K-12 students experience at varying levels of study. Yet school music programs' hierarchical structure and curriculum do not necessarily preclude intergenerational music-making possibilities. In fact, a few music programs already defy the age-segregated paradigm and include cross-generational participation as a regular part of school music.

***LaSalle Band program.***

The *LaSalle Band* at LaSalle Secondary School in Ontario has existed since 1994 under the direction of Chris Alfano, including both retired senior adults and high school students (Benyon & Alfano, 2013). The adult band course is cross-listed with the high school concert band ensemble. Most of the senior adult musicians are beginners who have never read music notation or played an instrument. The adult band members attend rehearsals during the school day with students and perform together with students; members from both age groups describe favorable impressions of this learning environment. In 2016 Alfano was honored with a Canadian Meritorious Service Medal for the positive impacts the *LaSalle Band* has made on its community's collaborative atmosphere and overall quality of life (Lea, 2016). This public recognition and appreciation of the program suggests its success in connecting generations across the school and larger community.

***East London Music for Life program.***



The LaSalle program is somewhat unique in its depth and long-term establishment; however, similar intergenerational school programs occur in short-term settings. For instance, the East London *Music for Life* program included a two-month intergenerational collaboration between a primary school and senior housing facility, during which thirty-five children and eleven senior adults met for weekly music sessions and ultimately gave a joint public performance (Varvarigou et al., 2011). In addition to observing positive interpersonal and social benefits during the course of these sessions, Varvarigou et al. (2011) noticed themes of peer learning and reciprocity. They concluded that “the teachers’, the pupils’ and the seniors’ development and progression in music skills and confidence indicate that intergenerational projects can offer benefits to the participants that are not only social and emotional. Intergenerational programmes can be used as a way of sharing expertise, skills and ideas on repertoire and activities in music making” (p. 217). Despite its relatively short-term trajectory, the *Music for Life* intergenerational music collaboration bolstered children’s music learning and participation in ways similar to the *LaSalle Band* program.

### **Intergenerational models in community music.**

Besides occurring in school music settings, the benefits of intergenerational music-making have also been observed in many community settings. In the context of this study, *community music* refers to any group of people in some community setting other than a school who have gathered for music-making purposes. These types of community music outlets commonly involve intergenerational participation to some degree. While some community settings intentionally include people of

multiple generations, in other examples the intergenerational engagement arises in unanticipated ways.

***New Horizons Band program.***

Intended for senior adult beginners, the *New Horizons* bands were not specifically designed with intergenerational participants in mind; Sattler's (2013) study initially only intended to explore senior participants' experiences in several *New Horizons* bands throughout the United States and Canada. However, Sattler's focus shifted when he was surprised by substantial intergenerational impact emerging in each musical community he observed. Sattler noticed that every band community included a variety of informal intergenerational pairings. For instance, one band held rehearsals in a space shared by several community organizations, and teachers from a neighboring preschool regularly brought their students to dance and move along with the music during rehearsals. In several other groups, retired band members had formed support committees for local elementary school bands, volunteering their time to work one-on-one with beginner students. Many bands also connected with local university communities to offer support for students and advocate for arts. Finally, he observed one band which overtly encouraged intergenerational music by recruiting student participants to play alongside the seniors. Sattler concluded that these instances of organic intergenerational collaboration were "quietly influencing a generational imbalance prevalent in much of western society: reintroducing and revaluing perspective and life experience through all-age ensemble activity with elders acknowledged as leaders and mentors" (p. 318).

### ***Amabile Choir program.***

The Ontario *Amabile* choir is another example of an intergenerational framework in a community music context. *Amabile* includes four choral ensembles of about 150 male singers ranging in age from eight to sixty-eight; they often rehearse and perform in mixed age groupings (Benyon & Alfano, 2013). Their directors use age-blended rehearsal techniques with the goal of promoting learning across the lifespan. Positive impacts are especially obvious for adolescent male singers who are navigating the uncertainties and frustrations of changing voices and may consider quitting a choir rather than face the associated social discomfort. In *Amabile*, seating arrangements mix younger boys among changed-voice mentor singers, who model vocal strategies during rehearsals and if necessary can suggest part adaptations to fit boys' daily range fluctuations. Several of these adult mentors have been singing in the group since they were adolescents themselves; they credit *Amabile's* responsive, empathetic rehearsal setting as the reason they chose to continue singing into adulthood. Public school music teachers who are choir members report anecdotal perceptions that *Amabile* has directly caused the increased number of boys and men singing in their community. In this way, *Amabile* builds a cross-generational "symbiotic relationship" which nurtures lifelong learning in the community by immersing children in music-making with people across the life continuum (p. 124).

### **Intergenerational models with dementia-friendly perspective.**

The *LaSalle Band*, the *Music for Life* program, the *New Horizons* bands, and the *Amabile* choir all demonstrate the benefits of intergenerational musical

collaboration. Yet as discussed earlier, since access to these types of programs is tailored towards young adults and seniors in relatively able-bodied states of wellbeing, these programs still arguably do little to directly address dementia stigma. Do any intergenerational music outlets exist which are specifically dementia-friendly? The two dementia-friendly participatory arts programs mentioned previously, *Songwriting Works* and *TimeSlips Creative Storytelling*, were created for senior adult participants, although both programs have now expanded to include intergenerational participants (Songwriting Works, 2019; TimeSlips, 2019). Mentioned below are several additional programs which have also focused on creating specifically intergenerational and dementia-friendly music settings.

***John Carroll University intergenerational choir program.***

In one such program, researchers considered intergenerational relationships' effect on dementia stigma in a choir at John Carroll University including undergraduate students and senior adults with dementia (Harris & Caporella, 2018). The group rehearsed together for one season culminating in several performances. College students' participation in the choir tended to deconstruct their perceptions about senior adult peers and highlight the two groups' "commonalities and strengths. . . to reach across the boundaries of age, disabilities, and abilities to develop meaningful friendships" (p. 2). Program facilitators utilized the structures of choral rehearsal and performance to build social interaction, connection, and empathy among group members while also elevating senior adult participants in designated leadership roles as mentors. Their collected data focused mostly on attitudes of the younger population and uncovering any misconceptions

about dementia. Harris and Caporella reported significant shifts in participants' connotations (i.e., positive, negative, or neutral) regarding dementia; while 64% of participants reported a negative connotation with dementia upon joining the choir, 71% indicated a positive connotation with dementia at the conclusion of the study. Many students expressed admiration for senior adults with dementia, while seniors expressed perceived acceptance and inclusion in the community; both age cohorts indicated their surprise at intergenerational friendships resulting from the program which they reported had grown not out of obligation but genuine mutual appreciation.

***BUDI Orchestra program.***

Reynolds et al.'s study (2016) of the Bournemouth University Dementia Institute's (BUDI) intergenerational orchestra project also observed positive effects on dementia stigma. The *BUDI Orchestra* includes members living with dementia as well as other people of various ages: family members, student volunteers and professional musicians. Its performances intend to challenge negative perceptions of persons living with dementia and educate audience members about their experience. During a study of the *BUDI* project's effects, audience members were asked to complete a questionnaire before and after the performance detailing their experiential understanding of dementia and their post-performance observations. Pre-concert surveys revealed key themes of negative descriptive language surrounding dementia and perceived disabilities of those experiencing the disease; for instance in regard to music capability, over half of the audience reported "low or no expectations" of quality from an orchestra whose members were living with

dementia (p. 222). Yet in post-performance surveys, all audience members but one indicated a shift in perspective to celebrate the abilities of people living with dementia as inspiring, based on analysis of positive descriptive language regarding orchestra members' perceived successes in overcoming challenges. In conclusion, Reynolds et al. suggested that the participatory nature of the *BUDI Orchestra* created a "positive impact on the perceptions of dementia, demonstrating the power and potential of participatory approaches showcasing the achievements of those living with dementia when attempting to raise awareness of dementia and challenge negative perceptions" (pp. 219-220).

#### **Intergenerational, dementia-friendly models and participatory arts.**

Positive outcomes demonstrated by these intergenerational music performance ensembles (the *LaSalle Band*, the *Music For Life* program, the *New Horizons* band collaborations, the *Amabile* choir, the John Carroll University study, and the *BUDI Orchestra*) all suggest the efficacy of such intergenerational programs to address needs of both senior adults and children. Participation in intergenerational performance ensembles offers potential benefits to people of both age groups. The growing body of research suggests presentational music interventions like those detailed above can successfully build cross-generational relationships and dementia-friendly communities.

Yet comparatively few studies have focused on participatory music interventions in the same types of contexts. More research is needed to help understand the potential of participatory arts to engage people across the age spectrum and build dementia-friendly, intergenerational communities. In fact,

participatory music-making settings by definition are a natural outlet to support intergenerational participation. Unlike many presentational music ensembles, in which membership requires people to meet certain criteria for performance capacity, participatory music empowers “simultaneous participation of everyone across the age and ability spectrum with all participants’ contributions equally valued” (Thibeault, 2015, p. 4). In addition to this inclusive ethic, participatory music settings can accommodate participation at varying levels of music skill, and Turino (2008) observed that many participatory traditions result in complex music-making processes. Participatory settings accomplish this by offering participants a “variety of roles that differ in difficulty and degrees of specialization required. . . so that people can join in at a level that offers the right balance of challenge and acquired skills” (Turino, 2008, p. 31). In this way participatory music settings are a natural fit for intergenerational groupings with members at varying degrees of music experience and faculty (Thibeault, 2015). This project seeks to contribute to the gap in research on intergenerational, dementia-friendly programs using participatory arts.

### **Music, Dementia, and the Brain**

In order to more fully understand the potential of participatory arts for use in a dementia-friendly context, it is important to understand the effects of music on our brains, especially for those of us experiencing dementia. Any choices in program design for a dementia-friendly program using music should be informed by a neurological understanding of musical cognition during dementia.

## Music and Memory

Unsurprisingly, one of the most studied neurological aspects connecting music and dementia is memory. In recent years the unpredictable potency of music memory has received increasing publicity and research attention. Anecdotal evidence of this phenomena notably appeared in the 2014 documentary *Alive Inside*, which chronicled a project initiated by social worker Dan Cohen to demonstrate “music’s ability to combat memory loss and restore a deep sense of self to those suffering from it” (Alive Inside Foundation, 2016, para. 2). Although, as mentioned previously, fixation on music memory as a panacea which will cure the suffering of memory loss could be problematic (Basting, 2009), still it is helpful to understand research regarding music and memory during dementia. *Alive Inside* offers case studies of several people experiencing dementia for whom music not only facilitated detailed memory recall, but also opened unexpected channels of communication (Rossato-Bennett, 2014). Those same types of effects have been documented by a large body of research, suggesting not only the brain’s ability to retain music-related memories but also music’s ability to prompt recollection throughout stages of memory loss (Clair, 2008; Friedman, 2011; Norton, 2016; Rio, 2009; Shiltz et al., 2015). In fact, Dr. Peter Davies, who discovered the science behind the dementia drug Aricept, states, “I have spent thirty-eight years now working on Alzheimer’s disease, and I haven’t done anything for patients that’s as effective as [music] is. I wish I had, and I’m still trying. But I really haven’t seen anything as positive as that” (Rossato-Bennett, 2014, n.p.).



### **Potential for musical memory retention throughout dementia.**

One of the most curious aspects of music memory is its potential for intact longevity throughout dementia, compared to other mental functions. One notable series of studies at Queen's University and University of Victoria measured senior adults' ability to process language throughout the progression of dementia, as compared with their ability to process melody (Cuddy et al., 2012). In language tasks, participants exhibited varying degrees of impairment from the earliest stages of Alzheimer's Disease; for instance, inability to recall common cultural adages, point out grammatical errors, or recognize distortions to the lyrics of a familiar song (when spoken, not sung). By contrast, some participants demonstrated trends of long-term retention for melodic memory even through late stages of Alzheimer's Disease (Cuddy et al., 2012). For example, significant numbers of participants were able to sing a familiar song with complete or partially accurate melody and lyrics, as well as identify pitch distortions to its melody. These results led researchers to conclude that in comparison with language memory, "musical semantic memory may be spared through the mild and moderate stages of [Alzheimer's Disease] and may be preserved even in some individuals at the severe stage" (Cuddy et al., 2012, p. 479). Interestingly, studies of people with dementia creating original music in the Songwriting Works program also revealed that same trend regarding retrieval of more recently created memories (Friedman, 2011). Even participants assessed as experiencing "advanced cognitive decline" still "retained words and music to the original songs that they and/or their community had collectively composed" (Friedman, 2011, p. 334).

This phenomenon remains somewhat obscure: why and how does musical memory sometimes defy the progression of dementia? Neurologist Oliver Sacks suggested an explanation:

Music is inseparable from emotion. So it's not just a physiological stimulus. If it works at all, it will call the whole person—the many different parts of their brain, and the memories and emotions which go with it. The philosopher Kant once called music the 'quickenning art,' and [people experiencing this phenomena are] being quickened, [they are] being brought to life. (Rossato-Bennett, 2014, n.p.)

On a neurological level, music participation truly does “quicken” multiple parts of the brain—various sections across the brain are actively involved in processing roles during music-making activities (Peretz & Zatorre, 2005). Although it remains unclear exactly how musical memory remains intact during dementia, it is not so surprising given the complex nature of music cognition and the interconnected processes of brain activity required for musical thought (Friedman, 2011). Some have even claimed that music engagement is “the most extensive exercise for brain cells and for strengthening synapses” (Friedman, 2011, p. 338).

### **Neurological understanding of memory.**

Consideration of this complex interaction between music and memory also benefits from a neurological understanding regarding the brain's process of remembering. Contrary to common perception, retrieval of a given memory does not simply require the brain to select one bite of information from some mental storage bank and call it to consciousness. Rather, the complex process of

remembering requires the brain to filter through layers of our lived experiences and perceptions (Basting, 2009).

We have several types of memories, each of which originate in separate portions of the brain and serve different functions (Dickerson, 2017). *Episodic memory* helps us recall events, people, or other specific pieces of experiential information related to our life. *Semantic memory* includes a general body of common facts and functional knowledge about our environment but not specific to us personally, such as the names of countries in the world. *Procedural memory* encompasses multi-step processes acquired through practice and continual repetition; this type of memory allows us to perform certain tasks without having to give conscious attention to each detailed step. Our memories can include both implicit (i.e., subconscious) or explicit (i.e., conscious) memories, and the brain determines when to transfer information out of our short-term memory into long-term storage (Basting, 2009). Some researched methods exist to improve memory retrieval (Camp & Antenucci, 2011). However, since our brains must constantly process the massive amounts of sensory information inundating us each day, some degree of memory loss is normal; our brains choose what is important to retain, and what may be discarded (Basting, 2009).

### **Memory and brain activity during dementia.**

What happens to stored memories, then, during dementia? Popular perception associates dementia's cognitive decline with complete memory loss (Harris & Caporella, 2018; Reynolds et al., 2016), but this is not a neurologically accurate understanding. In fact, for comparative perspective, while a healthy brain

has one hundred billion neurons, a brain undergoing stages of dementia will still retain between sixty billion and ninety billion neurons (Camp & Antenucci, 2011). Certain parts of the brain will sustain loss to their normal function during dementia, leading to its associated symptoms of behavioral and cognitive changes.

Yet research shows that not all portions of the brain are always affected by dementia, nor are they all affected in the same way. For instance, when memories are lost it typically occurs in an inverse order compared to the way they were learned; in other words, memories acquired at the earliest stages of human life—such as how to grasp an object and pick it up—are more likely to be maintained through late stages of dementia (Camp & Antenucci, 2011). Similarly, although the brain's episodic memories of specific personal experiences are often compromised fairly early in the course of dementia, the procedural memories usually remain through later stages. Dementia's effect on the memory does not preclude learning new things, or the creation of new memories. The brain retains "capacity for neural growth and engagement even amidst significant decline" (Friedman, 2011, p. 339). In some cases, the human brain's plasticity allows the capability for re-learning old procedural memories which have been compromised, as well as obtaining new skills (Camp & Antenucci, 2011; Hallam & Creech 2018).

### **Musical cognition throughout dementia.**

This understanding of the brain's process for making, retaining, and re-learning memories also holds true for musical tasks, which explains why many people living with dementia may continue to experience relatively unhindered music ability through the first phases of dementia. This is especially likely to occur

when their music participation stems from automatically familiar skills ingrained in the procedural memory (Clair, 2008; Davidson & Fedele, 2011). In addition to retaining musical memories, some seniors living with dementia may even maintain capacity to “learn (or re-learn). . . increasingly complex musical skills” (Creech et al., 2018, p. 89). Yet how might music ability be affected with continued progression of the disease?

### ***Mid-stage dementia.***

Throughout the course of dementia, some cognitive abilities affecting music participation do tend to decline. In the middle phases of dementia when deteriorating language fluency causes disjointed conversational speech, fluency with music notation may likewise decrease (Clair, 1996). The ability to interpret unfamiliar written musical material often becomes more difficult, and notated music typically becomes a barrier to music participation rather than an aid (Clair, 1996, 2008). Yet despite decreased skill to visually process music, aural processing skills often offer secondary access to music participation through middle stages of dementia (Norton, 2016). Though it is an overgeneralization to assume that everyone with dementia retains the ability to sing and actively make music even when they can no longer speak, many people do retain melodic ability, possibly even more commonly than retention of language (Clair, 1996; Cuddy et al., 2012; Davidson & Fedele, 2011).

### ***Advanced stages of dementia.***

Even through late stages of dementia most people continue to demonstrate capacity for music participation. For example, most people retain a tendency

towards rhythmic entrainment, or syncing with a common steady beat, and even if unable to sing words most can vocalize approximate melodic contours (Clair, 1996, 2008). Even in advanced dementia nearing end stages of life, the presence of music can increase alertness, sociability, and sense of mood (Clair, 2008; Creech et al., 2013; Friedman, 2011). Given elongated response time, people in advanced dementia can respond to music even when remaining unresponsive to other cognitive stimuli (Clair, 1996; Friedman, 2011). Most typically this type of response occurs during unaccompanied singing, and the trigger is usually a person's musical memories from earliest life, such as "folk songs learned in school and ethnic music that was part of family life" (Clair, 1996, p. 74). This type of music "carries with it a full range of well-integrated associations, emotions, and memories" which are still accessible to the brain (Clair, 1996, p. 74).

### **Benefits of Music During Dementia**

These typical expectations for music cognition throughout dementia have informed various therapeutic applications. Research enumerates a list of psychosocial benefits for those living with dementia who participate in music-making, including emotional and relational connection, increased capacity for self-expression, sense of resolution, and encouragement (Creech et al., 2013; Norton, 2016).

#### **Therapeutic applications.**

Singing is one of the most common music outlets for people with dementia because of its easy availability and its ability to create a "connected moment. . . [and] bolster a sense of autonomy" (Norton, 2016, p. 91). Not only the melodic aspects of

sung music, but also music's rhythmic properties prove helpful to energize, facilitate communication, or release tension (Bunt & Stige, 2014). Patterned actions structured around a regular pulse can facilitate rhythmic entrainment, the process of naturally playing in sync with others. Entrainment can help people with dementia to access a purposeful structure for interaction and settle into a relaxed state of social connection (Clair, 1996). Playing instruments like drums offers tactile stimulation which can lead to musical communication through imitative patterns, call and response, and improvisation. These considerations regarding music elements of melody, rhythm, and instrumentation have informed many therapeutic applications of music.

***Alleviating undesirable symptoms.***

Many studies have suggested music's ability to alleviate various undesirable symptoms of dementia. Music participation can increase capacity for attention, interaction, communication, and healthy sleep patterns, as well as counteracting agitation, stress, and combative feelings (Creech et al., 2013; Norton, 2016). For instance, one study measured the effectiveness of evening singing sessions in nursing facilities to help people with sundown syndrome, the phenomenon of experiencing increased agitation and restlessness in evening hours (Norton, 2016). In addition to decreased anxiety, the people who participated in evening sessions were able to maintain their focus 75% of the time during singing and for an extended time after the activity, as compared to evenings without music, on which the majority of participants exhibited restless wandering behaviors and wandering associated with Sundowner's Syndrome. The researchers concluded that the

regulative functions “inherent to singing” helped positively regulate the Sundowners’ behaviors also (p. 105).

Similarly, in another case study a person with dementia and their caregiver used rhythm to counteract agitation (Clair, 1996). Sometimes the individual experienced relief as their caregiver walked alongside them while singing, holding their hands, and rhythmically swinging arms in time to the music. Other times, the caregiver walked alongside holding a drum and a mallet, playing rhythms at a tempo and volume corresponding with the individual’s agitated mood. As their playing relaxed with decreased volume and tempo, the individual felt calmed. Although unable to access language, the individual was also able to communicate their feelings via rhythmic call and response patterns on the drums .

Shiltz et al. (2015) also focused on whether music’s regulative properties could offer a less invasive alternative to sedative medications for agitated dementia patients at a hospital. Participants were given individualized music playlists with songs they considered popular or personally significant. For many participants, time spent listening to the music correlated with decreased stress hormones and other lessened depressive symptoms. Though the effects were not conclusive enough to warrant reduction of medications, the positive trends supported further study.

### ***Facilitating interpersonal connection and communication.***

Other studies have suggested music’s therapeutic benefits extend to interpersonal settings. For example, Göttell and colleagues studied the emotional tone of interactions between people with dementia and their caregivers during morning care routines such as washing and dressing at a Swedish nursing home



(Norton, 2016). The study compared regular, non-musical sessions of daily living activities with some sessions during which background music played, and other sessions during which caregivers sang. Researchers generally found that sessions with background music facilitated more positive moods. Both people with dementia and caregivers responded favorably to music popular for their generations. When caregivers sang during sessions it “created an atmosphere that was less light-hearted than the background music condition. . . [but with] a sense of sincerity, openness, intimacy, and even vulnerability [leading to] mutual vitality” (p. 104). The personal connections sparked by singing affirmed patients as individuals capable of experiencing joy and creating joy, rather than being an object of burden to their caregivers.

Davidson and Fedele (2011) suggested similar findings in their study of singing groups formed with caregivers, during which participants with dementia were observed to have “positive gains including lucidity and improved social interaction within session, as well as enjoyment, singing engagement, and carry-over memory and recall from one week to the next” (p. 402). Researchers also observed people with dementia and their caregivers demonstrated improved communication during the singing sessions.

***Providing preventative measures.***

Some studies have even claimed music participation may not only effectively relieve negative symptoms, but also provide preventative measures against dementia. Such studies typically suggest that music participation may help “protect against cognitive decline” by fostering “enhanced speed of information processing”

(Creech et al., 2013, p. 93). For instance, we know that improvisatory music creation has been observed to “increase the level of complexity in brain activity” in brain scans of jazz musicians (Friedman, 2011, p. 339). Similarly, when individuals with Alzheimer’s disease listen to personalized playlists of favorite music, scans of their brains show not only activation in regions associated with memory, but also “widespread increases in functional connectivity [in brain networks], . . . suggesting a transient effect on brain function” and overall improvements to the brain’s operative abilities (King et al., 2018, p. 1). Tesky et al. (2011) even associated cognitively stimulating music interventions with potentially decreased risk of developing dementia. Though most researchers are cautious about presenting music as a panacea, many express curiosity about whether music applications might eventually help prevent dementia (Friedman, 2011).

### **Imagination and Creative Processes During Dementia**

Yet even more valuable to this project is the body of neurological research which shows that contrary to popular belief, dementia does not preclude the ability to imagine and create (Allison, 2008; Bunt & Stige, 2014). The amygdala, the brain’s emotional center, often continues working throughout the course of dementia, even acting as a “compensatory mechanism” in creative portions of the brain (Camp & Antenucci, 2011, p. 404). Creativity stems from three processes in the brain: firstly the *interpreter* function, through which people imagine some artistic representation of our perceptions; next the *actor* function, throughout which they externally render their perceptions by acting, drawing, playing an instrument, or the like; and finally the *comparer* function by which people recognize whether their perceptions make

sense and are well-received by others, and determine whether to adjust their output accordingly. Notably, the interpreter and actor functions often continue operating throughout stages of dementia, while the comparing function which acts as “brake system” may often be compromised, decreasing inhibitions that would typically constrain creativity (p. 404). So while the creative processes necessary for making art continue to function, the accompanying self-regulative responses may be altered.

This neurological research supports the value of participatory music-making experiences for people living with dementia. One teaching artist who leads performing arts workshops at the organization Arts for the Aging, Inc., offers a supporting anecdotal observation: “I think offering to them the use of their imagination is very powerful. Suddenly it takes them out of the realm that they have to think of something... or that they have to remember something. But in the moment, they can imagine something... always! That never seems to fail” (Godoy, 2007, 29 min. 35 s.). Overall, neurological research evidences the continued capacity for creativity throughout dementia, and studies of therapeutic applications offer a better understanding of how music can function in meaningful ways for people living with dementia.

### **Connecting Research and Practice**

The previous sections have discussed trends of societal engagement and music engagement, followed by the intergenerational music programs’ potential to counteract age stigma and build dementia-friendly communities, and finally physiological understandings of the brain and creativity during dementia. Given all

this knowledge, I wondered how I would move forward with building my own program which would use participatory music as a tool to connect people across generations. To answer that question, it was helpful to turn back to some of the model programs introduced earlier and look more closely at practical aspects of their successes. Not only has research demonstrated positive effects from these programs, but also many studies have offered practical insight into why and how they were so effective. In the following section I will address structural aspects of building an intergenerational, dementia-friendly program using participatory arts. I will first consider the hallmarks of a participatory setting, and then explore five key themes of successful facilitation that emerge from model programs.

### **Definitions of “Participatory”**

First, it is important to clarify the overlapping uses of the word “participatory,” which can sometimes be used in context of *music-making processes* and other times in context of *research processes*. The body of research on which this project stands sometimes uses the label “participatory” in one sense but not the other. For instance, some previous researchers have implemented a participatory methodological approach while studying presentational music-making processes. Conversely, many studies use non-participatory methodological approaches to report on participatory music-making processes. In this project, although the music-making processes were participatory, the research process was not participatory research, although in determining session structure I did lean upon advice from some participatory research studies. The methods chapter of this document will

explore practical insight I gained from participatory *research processes*, while this chapter explores practical considerations of participatory *music-making processes*.

### **Building a Participatory Environment**

Presuming the use of music participation to build community raises some ethical questions surrounding the culture of any given community, the identity of its people, and their perceptions about music-making. In order to honor participants' voices rather than impose a narrative on them, it becomes important to take care how music-making processes are implemented. To this end, Turino's (2008) portrait of participatory music culture offers helpful indicators for ethical practice. As discussed earlier in this chapter, Turino's research encourages recognition of informal music-making in social settings not as a lesser version of *presentational performance art*, but as a distinct category of *participatory performance art*.

According to Turino (2008), certain characteristics tend to define an inclusively participatory experience. Participatory settings by nature tend to welcome as many people as possible, all of whom are "actively contributing to the sound and motion of a musical event through dancing, singing, clapping, and playing musical instruments when each of these is considered integral to the performance" (p. 28). Barriers are dissolved between "artist" and "audience;" people present assume only roles of "participants and potential participants" (p. 28). The participation of each individual is not simply valued as important, but rather required as necessary. Participatory environments prioritize the active, ongoing, and communal nature of the musical process, rather than focusing on its end product. For this reason, perceptions of value in participatory settings are judged

more by the participants' experience and level of involvement, rather than by any listeners' opinions of the musical products. Ideally involvement in a participatory experience naturally builds a sense of community; as Turino explains, "this heightened concentration on the other participants is one reason that participatory music-dance is such a strong force for social bonding. It also leads to diminished self-consciousness, because (ideally) everyone present is similarly engaged" (p. 29).

### **Five Key Themes of Facilitation**

In addition to considering these cultural hallmarks of a participatory environment, I also considered other research-based indications of success in intergenerational, dementia-friendly, and participatory arts programs. Even among programs with differing formats which serve different populations, many similarities emerge regarding successes. Those emergent similarities have here been distilled into five key themes of facilitation which have been proven effective in connecting people across generations, counteracting dementia stigma, and creating accessible participatory spaces. These five key themes of facilitation, each discussed in more detail below, are (a) prioritizing hospitality, (b) communicating with intentionality, (c) embracing flexibility and spontaneity, (d) honoring personal autonomy, and (e) respecting the past while looking to the present.

#### **Prioritizing hospitality.**

How might facilitators build a positive environment for group members? The body of music therapy and community music literature has helpfully distilled that question into the concept of *hospitality* (Higgins, 2012). Thibeault suggests building a culture of hospitality simply begins with exploration: asking questions about the

“structures, values, and social relations found in a particular setting” (Thibeault, 2015, p. 3). Furthermore, Wiersma et al. (2016) suggest that all participants must be encouraged to engage these types of exploratory questions, because people with dementia tend to express more confidence that a given setting is safe for participation when they feel a sense of solidarity with others who demonstrate empathetic respect. Similarly, a hospitable facilitator seeks to empower the group’s members rather than to control their input. This means the facilitator remains ready to help if needed, but equally ready to refrain from doing so in deference to preferences that arise from within the group (Friedman, 2011; Higgins, 2012). Higgins (2012) describes hospitable facilitators as guides who “offer routes towards suggested destinations and are ready to assist if the group journey becomes lost or confused, but they are always open to the possibility of the unexpected that comes from individuals in their interactivity with the group” (p. 147). Facilitators build a culture of hospitality by giving careful attention to dynamics of relationship within their group.

### ***Building relationships.***

Research shows the most effectively hospitable facilitators are those who prioritize relationships; they value getting to know people in the group and building interpersonal rapport (Basting, 2009; Friedman, 2011; Higgins, 2012; Wiersma et al., 2016). This trait in a facilitator is evidenced by their knowledge of participants’ needs, their empathy for participants’ challenges, and their desire to share “celebratory narratives” regarding participants’ musical or personal successes (Higgins, 2012, p. 156). For example, such “celebratory narratives” might involve

moments of connection for a person living with advanced dementia who is otherwise withdrawn from the group. Research on the Songwriting Works program concurs that celebrating relationships is key to creating a hospitable atmosphere:

Observational study has shown a palpable connection between sincere interest and engagement on the part of a facilitator and the increased involvement and positive affect on the part of elders, including individuals who have advanced dementia, and family caregivers who initially appeared reticent to participate (Friedman, 2011, p. 341).

In other words, the dynamic between group facilitator and group members plays a large role in the extent to which a program nurtures authentic relationships.

Kitwood's Theory of Personhood discussed earlier provides a model for building healthy relationships with persons with dementia: striving to see the person first and their diagnosis as secondary, considering any social interactions in light of contextual culture, and recognizing that every individual will cope with challenges in specific, personal ways (Brummel-Smith, 2008).

***Group structure.***

Furthermore, when the group is cross-generational, a hospitable facilitator must take care to ensure participants of both generations feel included and relationally connected. For instance, child participants benefit when the program structure includes educational preparation before partnering them with senior adults with dementia, and debriefing after interactions (Baker et al., 2017). This scaffolded approach to interactions gives children a safe structure through which to understand their elders' unique needs and potential challenges, accept the



complexity of unexpected interactions, and develop more empathy, all of which leads to more meaningful relationships (Baker et al., 2017; Basting, 2009). Likewise, senior participants living with dementia may appreciate informal discussions which allow them space to build relational context, define their own preferred roles within the group, and offer feedback (Thoft et al., 2018).

Choices about group size and composition also affect the dynamic of hospitality between facilitator and group members. Thoft et al.'s (2018) study suggested the efficacy of small groups over large groups to boost participants' comfort during discussion. Similarly, in musical settings, smaller group interactions or one-on-one opportunities for musical collaboration have proved more effective than large group settings (Belgrave, 2011). Furthermore, hospitable facilitators build relationships not only with group members, but also with any other stakeholders in the peripheral community such as family members, caregivers, clinical staff, and aging services partner organizations (Daykin et al., 2017). Inclusion of all these members in the community and respect for their input is an important part of program success (Friedman, 2011). Friedman's imagery of patchwork offers an analogy for an inclusive relational ideal where "each participant has a voice. As in a mural or quilting project, every song contains unique elements that contributors recognize as their own while the whole serves as a portrait of community" (Friedman, 2011, p. 330).

### ***Overcoming challenges to hospitality.***

In certain settings, the theme of prioritizing hospitality may prove more challenging than in others. Specifically, in nursing home settings an authentic sense

of relational community can be especially difficult to build since these settings tend to include diverse and transient populations of not only people residing in the home, but also staff members and visitors (Allison, 2008). Furthermore, connection between these different populations may be hindered by potentially divisive differences including “functional and cognitive abilities, ethnic heritage, religious beliefs and practices, professional training, and social roles within the community” (p. 224).

In such situations, hospitable facilitators focus on building a new cultural repertory of fresh traditions, objects, or experiences (Allison, 2008; Basting, 2009). For example, group interactions anchored around a common project or goal can inculcate a sense of belonging for participants, as in the case of the Songwriting Works programs during which new original songs are created to be shared with the community (Friedman, 2011). Involvement in this process allows participants to “engage in localizing processes,” gaining relational ownership in their environment (Allison, 2008, p. 239). Building a new cultural repertory in this way “fosters a real sense of neighborhood and transcends the artificiality of the institutional life” (p. 240). Thus even in seemingly challenging settings hospitable facilitators can affirm participants’ basic human need for relational connection and interdependence (Bunt & Stige, 2014; George, 2011).

### **Communicating with Intentionality.**

The degree to which facilitators can successfully build relationships and prioritize hospitality is closely related to the second key theme for facilitation: *communicating with intentionality*. Intentional communication is powerful; for

people living with dementia, “attentive conversation [affirms the value of the individual and] . . . can directly combat the feelings of isolation, low self-esteem, and anxiety that many who live with memory loss face” (StoryCorps, n.d., p. 5). Although our means of communication have changed drastically throughout the course of human civilization, humans have always used various types of storytelling to communicate. The acts of both telling stories and listening to stories help us define not only our purpose as individuals but also the meaning of our interconnected lives (Basting, 2009; Meuser & LaRue, 2011). Especially when told and heard in a communal setting, stories can spark powerful interpersonal connections as listeners acknowledge the teller’s experience and identify as sharing similar or different experiences (Meuser & LaRue, 2011).

Since this exchange of stories is so potent throughout the lifespan, facilitators working with an intergenerational population can use narrative-based activities to build healthy communication (Basting, 2009; George, 2011). The most effective narrative-based activities equip students with communication strategies and encourage them to participate equally in roles of both speaker and listener: feeling heard while they tell their stories, and actively listening to others’ stories (Baker et al., 2017; Basting, 2009; George, 2011; Harris & Caporella, 2018). Program structure and logistical details should foster this equal narrative interaction. Practical examples include (a) making intentional introductions of each participant, (b) choosing seating arrangements which encourage conversation, (c) structuring opportunities for interaction by offering suggested conversational prompts or a list of questions to spark connection, (d) keeping the program schedule flexible to

moments of conversational digression, (e) interjecting social cues to encourage humor, (f) including provisions such as food and drink which socially cue interaction, and (g) having adequate staff available throughout the program to support participants' interactions (Basting, 2009; Baker et al., 2017; Harris & Caporella, 2018).

### ***Overcoming communication barriers.***

Yet the key theme of communication can also be challenging for members of the community living with dementia, since aspects of communication tend to become impaired during dementia. Child participants likewise may feel at a loss for how to interact with an older adult whose communication abilities are different than theirs. In response to this challenge, several organizations have launched initiatives to provide research-based strategies for dementia-friendly communication. The following tips come from people living with dementia themselves, as well as the Memory Loss Initiative volunteer training for the StoryCorps oral history organization and Windle et al.'s (2019) Creative Conversations training for care staff, a model which "moves away from formal education and fact-based learning" towards "compassionate communication and relationship quality" (p. 9). Insight from these sources can inform respectful communication practices in any intergenerational, dementia-friendly setting.

### ***Language makes a difference.***

The Dementia Engagement and Empowerment Program (DEEP) in Liverpool brought together a group of people living with dementia to discuss language surrounding dementia and make recommendations (DEEP, 2014). Participants

identified several words and expressions as being harmful, contributing to societal stigma, and inappropriate to use when talking or writing about dementia. These words included “dementia sufferer,” “demented,” “senile,” “burden (e.g., people are a burden or cause a burden),” “victim,” “plague,” “epidemic,” “enemy of humanity,” and “living death (e.g., dementia is a living death)” (p. 2). The term “dementia patient” was also identified as negative if used to broadly reference all persons with dementia outside of a specific medical context; such usage implies these people are primarily patients, not persons with dignity (p. 3).

Conversely, DEEP participants identified their preferred language for dementia: “person/people with dementia,” “person/people living with dementia,” or “person/people living well with dementia” (2014, p. 2). DEEP participants additionally requested that others portray dementia with accurate facts rather than with “extreme and ‘sensationalist’ language;” likewise they reminded others that the general term “dementia” encompasses many different conditions and people may choose to identify themselves accordingly (p. 3). The baseline for respectful, effective communication in any dementia-friendly program is respecting these recommendations from people living with dementia (Basting, 2009).

### ***Communication strategies.***

Furthermore, research by the *StoryCorps* program (n.d.) provides additional tips on respectful communication. When speaking with people with dementia, facilitators should articulate clearly and at a normal pace and volume, positioning themselves at eye level and not using an exaggerated or childish tone. If asking questions, it helps to begin by framing them in short sentences with simple ideas,

instead of asking complex questions that encompass several ideas. For instance, beginning with questions easily answered as yes or no before moving on to more open-ended questions may help the facilitator understand another person's communicative abilities and gauge comfortable conversation topics. In particular the StoryCorps research suggests that “*what* and *where* questions are good places to start. Consider using these before moving on to bigger-picture *why* and *how* questions. Remember that *when* questions are likely to be the most difficult” (p.5).

Facilitators should ask questions in general terms which allow for broad types of answers rather than asking questions which require people to pinpoint a specific memory in order to answer (Basting, 2009). Facilitators should also recognize that people living with dementia may need more time to process questions and verbalize their ideas; it can be overwhelming to follow up quickly with another question if a person does not answer immediately (StoryCorps, n.d.). On the other hand, sometimes it may also help to ask the same question in a different way or provide more context. Regarding musical communication, people living with dementia typically find it easier to engage at slower tempos and singing in a lower pitch range; F3-C5 is typically a comfortable range for women, and an octave lower for men (Clair, 1996).

### ***Nonverbal communication.***

Facilitators must also recognize nonverbal interaction as a valuable part of communication during dementia. If a person has limited verbal capability, Windle et al. (2019) suggest reframing perspective on the interaction: rather than being discouraged that words seem ineffective, appreciate the diverse nontraditional

communication strategies accessible during dementia. Seek communication that is “full of variation (gestural, verbal, silent) and responsive to diverse needs” (p. 7). This begins by being observant of any nonverbal cues a person with dementia may give and allowing those cues to guide the interaction. Facilitators can help by giving calm and encouraging feedback through their own body language: they can show warmth, patience, and emotional investment in others’ self-expression without conveying anxiety if a person with dementia does not remember something or responds unexpectedly (Friedman, 2011). If a person becomes disgruntled, confused, or discouraged by verbal communication, an effective facilitator will respect their frustration, express reassurance, and patiently explore whether some alternative route might allow for a point of connection: for instance, matching their tone or aligning body language with theirs (Windle et al., 2019).

### **Embracing flexibility and spontaneity.**

The third theme of effective facilitation is willingness to embrace flexibility and spontaneity. Though planning and structure is valuable, Higgins (2012) found the most effective group facilitators were those who demonstrated creative flexibility and willingness to embrace a spirit of playfulness, considering musical rules and limitations as “bendable” to meet individual participants’ needs (p. 151). Furthermore, sometimes innovative simplicity is key to meaningful interaction, as suggested by Windle et al.’s (2019) Creative Conversations approach:

Preplanned and elaborate activities were not always necessary to foster an authentic connection. . . . Simple activities provoked discussion, curiosity and amusement from residents, opening new channels for communication. Staff

reflected on the potential for the more unassuming and subtle activities to be weaved into everyday care tasks, therefore, even a brief encounter with a resident can be made meaningful.” (p. 6)

In the context of intergenerational programming, these findings might encourage facilitators to promote a relaxed, open approach to sessions rather than imposing rigid structure. For instance, if participants seem uninterested in one creative topic, an effective facilitator encourages them to move on; when other topics spark an enthusiastic response, the facilitator might say, “Tell me more,” and allow participants to take creative discussion on an unexpected path (StoryCorps, n.d., p. 5). This style of facilitation recognizes and encourages the tendency of intergenerational interactions to “[spiral] in more and more creative directions” (Bunt & Stige, 2014, p. 246). Allison (2008) explains how music offers a naturally fitting setting to incorporate and celebrate unexpected results in the case of the *Songwriting Works* model:

In the face of cognitive impairment, the facilitator and participants can never tell with certainty if an apparently unrelated comment derives from an error in cognitive processing, a language issue, or a sophisticated allusion to a recalled image or memory. Because of the potential for the musical text to carry both the concrete and the esoteric, the day-to-day and the emotionally charged, the songwriting process provides a unique and flexible interpersonal dynamic that allows for seemingly unrelated comments to be accepted by the group and incorporated into songs as they emerge. (p. 228)



When facilitators appreciate this type of spontaneity, participants' unexpected contributions become central points of celebration in the creative process, rather than disruptions to be ignored or resented because they alter the facilitator's predetermined plan.

### **Honoring personal autonomy.**

In order to embrace this type of flexible, spontaneous approach, the fourth key theme of effective facilitation also becomes crucial: honoring personal autonomy. Understandably, Creech et al. (2013) demonstrated that people with dementia did not enjoy taking part in intergenerational music programs "when they perceived these to be limited, token gestures rather than serious and valued music events" which respected their dignity (p. 97). Likewise, Allison (2008) found that when participants felt their participation in songwriting activities was dignified and valued, the experience concluded with group members exhibiting "a strong sense of ownership and pride in the final product" (p. 230). For this reason, effective participatory arts facilitators must start with the assumption that all participants have valuable, original creative material to contribute to the process (Allison, 2008; Basting, 2009, Friedman, 2011). Facilitators can foster this respectful attitude by simply seeking to understand participants' creative preferences: what music genres, songs, texts, and other creative material do enjoy, find meaningful, or feel represents their heritage (Allison, 2008; Basting, 2009; Friedman, 2011; Harris & Caporella, 2018)?

However, facilitators may face practical challenges in finding the right balance between honoring personal autonomy and also structuring session content

to be accessible and inclusive (Creech et al., 2013). Effective facilitators seek not only to empower participants and respect their autonomy, but also to offer assistance when necessary (Allison 2008; Basting, 2009; Friedman, 2011; Hallam & Creech, 2018; Higgins, 2012). One framework which helpfully addresses this challenge is the “I’m Still Here” Montessori-based approach, which seeks to offer persons with dementia dignified entry points into group activities (Camp & Antenucci, 2011). The “I’m Still Here” perspective encourages facilitators to actively discard the preconceived notion that they must shepherd the group members through a set progression of tasks which are necessary to achieve a specific product. Instead, facilitators should embrace the perception that group members are the leaders, and the only measurement of *right* or *wrong* outcomes is their engagement and interaction. Thus the focus is not the activity itself but the process, and when unexpected outcomes emerge they are never viewed as a failed “product” but rather a successful opportunity to strengthen relationships (p. 412). This lens promotes group members’ dignity and autonomy by focusing on their ability to contribute rather than fixating on something they cannot do.

***Strategies for promoting autonomy through creative choice.***

The “I’m Still Here” approach (Camp & Antenucci, 2011) helpfully aligns with Turino’s (2008) hallmarks of inclusive participatory arts settings discussed earlier; facilitators can successfully foster this type of environment by employing the tool of creative choice. For instance, both the *Songwriting Works* and *TimeSlips* creative storytelling processes begin with asking open-ended questions, followed by the verbatim collection of participants’ responses and ideas (Basting, 2009; Friedman,

2011). The facilitator verbally echoes each participant's comments, careful to accurately reflect their same language, emotional tone, facial mannerisms, and gestures; each contribution is then written word-for-word on a large flipchart or whiteboard visible to all group members (Basting, 2009; Friedman, 2011). In the case of songwriting, these textual ideas are crafted into lyrics; then the facilitator solicits musical ideas to set the text in a tune with rhythm and melody (Friedman, 2011). The facilitator identifies unique melodic ideas which individuals contribute and echoes these melodies, inviting the group to do the same and helping the group identify several different melodic options. The facilitator then seeks group consensus, which might be determined formally through a vote, or informally by gauging indicators of group emotion such as laughter or silence (Basting 2009; Friedman, 2011). As individuals continue to spontaneously contribute new creative material, the facilitator invites the group to echo those ideas in order to determine how each piece might be incorporated into the whole creative work (Friedman, 2011).

***Overcoming challenges to autonomy.***

Even when a facilitator is prioritizing autonomy, in some cases the group setting may include barriers to choice, such as participants responding “I don’t know,” giving no response, voicing hesitation or uncertainty, or disagreeing with one another. In these situations, effective facilitators intervene to offer assistance (Friedman, 2011). For instance, *TimeSlips* training suggests facilitators should respond to the comment “I don’t know” with validation and a request to include those words themselves in the story; this response can help diffuse any pressure to

contribute the person may perceive (Basting, 2009). Likewise, when participants have limited music ability, *Songwriting Works* facilitators might provide several options within a given framework and then ask group members to choose which they like the best: for instance, using a lyric device like couplets to spark ideas, suggesting a melodic structure that could accommodate two fragments of melody sung by two different participants, or offering a variety of harmonic progressions in varying accompaniment styles (Allison, 2008; Friedman, 2011).

In some settings, the theme of honoring personal autonomy may lead facilitators to plan some type of presentation of the group's creative work. Sharing a performance product, while not the main goal, may not only boost participants' dignity but also counteract dementia stigma and enable other stakeholders in their community to recognize their creative agency (Allison, 2008, Camp & Antenucci, 2011). In this way the "stigma, learned helplessness, and excess disabilities imposed on persons with dementia will be replaced by a focus on the person, who happens to have dementia" (Camp & Antenucci, 2015, p. 416). As discussed earlier in this chapter, programs such as the *BUDI Orchestra* and the John Carroll University intergenerational choir have demonstrated the power of these types of public events to create societal change by breaking down stereotypes surrounding dementia (Camp & Antenucci, 2015; Harris & Caporella, 2018; Reynolds et al., 2017). However, a concluding performance may not be appropriate for every program. Facilitators should consider their participants' identities and unique environment to determine whether performance would offer a fitting sense of dignity and closure to the program (Allison, 2008).

### **Respecting the past while looking to the present.**

Finally, the fifth key theme of successful facilitation is respecting the past and any accompanying tension or sadness associated with memory loss, yet seeking to find joy in the present (Basting, 2009; Daykin et al., 2017). Basting (2009) describes this concept as an attitude of “hope that embraces the person as he or she is rather than solely looking to the future (for a cure) or the past (exalting who the person was)” (p. 68). It is important to recognize that even if reminiscence is not the focus of an intergenerational program, connections to memories will inevitably emerge. In these situations, asking questions about various periods of a person’s life can help the facilitator gauge whether certain types of memories are more accessible and enjoyable for discussion. For example, for many people living with dementia, memories of their earlier life are often more accessible than recent memories, although this may not always be the case (StoryCorps, n.d.). Effective facilitators also respect seniors adults’ ability to handle difficult memories if they do arise (Meuser & LaRue, 2011). If seniors are hesitant conversationalists but they have often recounted certain stories in past interactions, encouraging them to share those favorite memories again can inspire confidence in their voice and sense of self-worth (StoryCorps, n.d.; Windle et al., 2019). However, ultimately, the tool of participatory arts frees facilitators from focusing on the past in order to explore creativity in the present (Basting, 2009; Daykin et al., 2017). As Higgins (2012) asserts, “the self-worth that comes from being ‘enabled’ to invent is powerfully affirming” (p. 148). Thus the most effective facilitators look beyond memory and

stigmatized views of memory loss to empower participants through communal creative engagement in the present (Basting, 2009).

## CHAPTER 3: METHODOLOGY

### **Methodology Overview**

The purpose of this study was to explore the meaning of participation and cross-generational interaction in a participatory, intergenerational music project from the perspectives of children and senior adults living with dementia. I used a convergent mixed methods case study design (Creswell & Plano Clark, 2018), in which qualitative and quantitative data were collected simultaneously, analyzed separately, and then combined to identify comparing or contrasting perspectives, developing a more comprehensive understanding of the case. I implemented quantitative and qualitative strands concurrently, putting more emphasis on the qualitative strand while embedding a smaller quantitative strand; Creswell and Plano Clark (2018) suggest notating this design as quan + QUAL.

The instrumental case for this study was an eight-week intergenerational intervention program which I designed for senior adults and children to connect in an intergenerational participatory creative setting. Participants included elementary-age children and senior adults living with dementia at an assisted living facility. I generated qualitative data through recording, transcribing, and in vivo coding of intergenerational creative sessions and discussions with participants. I used the qualitative data to explore perspectives of both children and seniors regarding the creative sessions and their interactions with one another. Additionally, I created surveys which generated quantitative data from the children regarding their perceptions about creative sessions and interactions with one another. Although I had initially intended to collect quantitative survey data from

senior adults as well as children, I was not able to accomplish this due to logistical constraints of the project.

I chose this convergent mixed methods case study design to examine how children's survey responses differed from ideas they voiced during creative sessions or discussion, and how that information might contribute to a better understanding of the overall meaning child participants attributed to their experiences. Since I only collected quantitative data from the children (i.e., not also from the senior adults as originally intended), mixed methods analysis focused only on children. I studied senior adults' perspectives through qualitative data streams.

Data was used to answer the following three research questions, which focused on highlighting participants' perceptions regarding their own participation and the role of participatory creative arts:

1. How can the value of participatory creative arts as a dementia-friendly tool be observed in intergenerational settings?
2. How do senior adult participants living with dementia and child participants perceive the meaning and value of cross-generational relationships in context of participatory creative arts?
3. How do qualitative and quantitative data compare or contrast regarding cross-generational collaboration in participatory creative arts processes?

In designing the case study intervention through which to answer these research questions, my primary goal was to create a dementia-friendly space for intergenerational interaction, offering participants of both demographics a platform to participate to the extent they wished to do so. My guiding ethic in designing each



session was respect for participants' dignity, their agency, and the inherent value of their voice. This study was approved by the James Madison University Institutional Review Board, Protocol Number 20-1138.

### **Positionality**

My work on the project was significantly influenced by my personal connections with and investment in family members and friends with dementia, some no longer living and some currently living with dementia. In approaching the study, these relational experiences shaped my initial notions regarding many factors such as the cognitive and artistic abilities of people living with dementia, the effects of dementia stigma on loved ones, the value and meaning of cross-generational interactions for people living with dementia, and the potential role of music in such situations. Additionally, my positionality was shaped by volunteer experiences at several other nursing care facilities which I perceived to have varying styles of care models compared to the host facility for this project. One of these volunteer experiences occurred concurrently with this study and in the same town, while others were prior experiences in a different state.

My positionality as an elementary school music teacher in my eighth year of practice was another primary factor influencing my work on this project, as was my identification as white, middle class, and non-disabled. Although this project did not include any students from the school where I teach, the children were of similar age and expressed similar musical backgrounds and interests to children at my school. My interactions with the children in the project were also influenced by my personal teaching tendency to expect certain musical outcomes in my school music position.

For instance, my musical background and training occurred through the primary lens of Western art music, and my teacher training tended to emphasize a music teacher's leadership role in structuring ensemble performances, due to which I certainly imposed my own aesthetic familiarities and organizational vision on the creative process to some degree despite my intent not to do so. Likewise, when planning session logistics, my thought processes tended to include the same types of skill-based observations that would occur to me while planning lessons to fulfill an elementary school curriculum (e.g., thinking about the children as "students" and automatically observing whether they readily demonstrated a sense of steady beat, had any difficulty matching pitch with their singing voice, and the like). These factors regarding my teacher training influenced the way I understood the children's perceptions about participation in the project.

An additional element influencing my positionality was my lack of experience with improvisation or composition. Although the creative processes the group undertook during this project included a great deal of improvisation and composition, my training as a musician had not focused much on those activities, nor did I feel comfortably fluent with the musical skills I expected those activities might require. Although I had completed certification to lead the *TimeSlips* creative storytelling method, and as a classroom teacher I had previously explored improvisatory or compositional activities with my students, overall I did not self-identify as a confident improviser or composer when I began the study. This inexperience with composition especially impacted participants' experiences since I was not only positioned as researcher but also facilitator. In keeping with typical

facilitative practices for these types of programs, throughout the sessions I sometimes gave input which shaped participants' decisions about harmonic structure or other elements of the songs. For instance, during some sessions I chose a series of several different chord progressions which might accompany the lyrics participants had created; I played these options on the ukulele and asked participants to choose one. After each session I reflected on my facilitation habits and reviewed Camp et al.'s (2011) Montessori-based facilitation method in attempts to minimize my impact on the creative process. Yet it is important to note that I was acting not only as the researcher but also as the facilitator while having had no formal training in leading group songwriting. This inevitably impacted participants' experience.

### **Sample**

Study participants were selected through purposive sampling as outlined by Leavy (2017). Since I did not have the means to host my intended case study intervention, I contacted two potential partner sites to ask whether they would be interested in participating. The first site was a private elementary school founded on faith-based principles (from here forward, assigned the pseudonym Elementary School, or ES), and the second site was a private retirement community affiliated with those same faith-based principles (from here forward, assigned the pseudonym Retirement Community, or RC). I intentionally contacted these two sites because they represented possible participants who could provide insight to the central phenomena of the study (i.e., children interested in participating in an intergenerational participatory music project, and senior adults living with

dementia interested in participating in the same project). I also chose to approach these two hosts because of the unusual physical proximity of the RC and ES facilities. This made the two institutions naturally well-suited for collaboration, which was important since I would be unable to provide transportation for children during the project and I hoped it would alleviate transportation strain on parents if children could simply walk from ES to RC. Both institutions, RC and ES, expressed interest in hosting and participating in the project respectively as a means to pursue more connections between their constituents.

### **Recruitment.**

The activities director at the private faith-affiliated retirement community (RC) and the principal at the private faith-based elementary school (ES) agreed to help recruit participants at their campuses. At ES the principal sent a flyer via email inviting any families with children in grade two through grade six to participate in the study. The ES principal and RC activities director agreed upon these targeted grade levels as being the most appropriate range for this type of program. Both hosts felt that children in the second to sixth grade age range would not only benefit themselves from the project, but also be better equipped to form meaningful relationships with the seniors during this after-school time period, during which children of a younger age might be too overstimulated. The ES principal directed interested families to contact me and I corresponded via email with interested families, several of whom asked for more clarification on program details before deciding whether they wanted their child to participate. With these interested families I shared assent forms (two different reading levels of assent form were

available, depending on the age of the child) and guardian consent forms, both of which are included in Appendix C. These consent forms detailed the project procedures, session content, and research process. Several families expressed initial interest but declined to participate due to schedule conflicts.

Ultimately a total of eight students expressed interest. Upon receiving signed assent and consent forms from those families, I enrolled all eight students in the program with the support of the school. Of the eight children who initially committed to participate, one dropped out after the first session because she wanted to participate in a conflicting extracurricular activity, two attended every session, and others had several absences due to illness, family travel, and school conflicts. Details about the child participants are included in Table 3.1; names have been changed for the confidentiality of participants.

**Table 3.1**

***Child Participants from Private Faith-based Elementary School (ES)***

Name	Grade	Gender	Sessions attended
Savannah	6	F	1 out of 7
Gemma	5	F	7 out of 7
William	5	M	4 out of 7
Tucker	5	M	6 out of 7
Kaylin	2	F	6 out of 7
Sophia	2	F	7 out of 7
Elena	2	F	5 out of 7
Miriam	2	F	6 out of 7

At RC, the activities director recruited people residing in a specific memory care neighborhood which the RC executive board determined would host the project. In order for the executive board to make this decision, I was asked to create a volunteer project proposal including the logistical details and session content which the activities director submitted to the board for approval. The board approved only audio recording of the sessions, not video recording. The details of that approval process and appropriate neighborhood selection were not made entirely transparent to me. The activities director suggested that the facility had recently experienced several concerns with privacy and protection of people living in the facility, for which reason the board preferred to exercise authority in selecting locations for any volunteer project, and was unlikely to grant video permission. According to the activities director the neighborhood choice was based on their staff's assessment of interested seniors, facility calendars, and appropriate physical space for the program.

After the activities director received approval from the executive board, RC listed the project on the monthly activities calendar in order to inform seniors it would be beginning, and RC staff helped personally invite the neighborhood residents. The activities director met with seniors who expressed interest and read them the assent forms. They either signed the form or indicated verbally that they assented to participate, in which case the activities director recorded this on the assent form in keeping with RC policy and IRB approval. All seniors living in the neighborhood also had another person (either family member or RC staff member) designated as their authorized representative who legally acted on their behalf to

sign the consent forms for participation. The activities director returned all signed assent and consent forms to me before the project began.

Each week when we arrived RC staff knocked on the senior participants' doors and invited them to join the program in the common area. Some seniors participated in the full session every week, while others only attended one or two sessions, or chose to attend portions of the sessions, entering and exiting the room multiple times throughout. As a result, the roster of senior adult participants varied throughout the program and I did not keep an exact record of their attendance at each session as with the children. All participants were female except for one male participant, who attended one session only; other weeks he indicated to staff he was not interested due to having visitors or other varying reasons. The senior participants' ages and specific diagnoses were not disclosed due to RC privacy policies, but seniors' residency in the neighborhood indicated some degree of memory impairment due to a diagnosis of mild to moderate dementia. This meant they were experiencing some degree of cognitive decline yet still able to participate in many activities of daily living at a somewhat independent level. This neighborhood was separate from other neighborhoods in the facility which housed people with later stage dementia who were experiencing more advanced cognitive decline, restricted mobility, or less independent ability to participate in activities of daily living.

Ultimately the sample included eight children and roughly eight senior adults, although the number of senior adults present at any moment during a given session was inconsistent. The child participants all seemed familiar with each other

to a degree despite their varying grade levels, and senior participants likewise were neighbors in the same community, but none of the children and seniors had met before, nor had I met any of the participants prior to this project.

### **Session Procedures**

The framework for the study was a series of eight afternoon sessions hosted by RC with cooperation from ES. The first session included senior adults at RC only; then the ES children joined them at RC once a week for seven more sessions. I met children after their dismissal at the ES campus. Students had a break time to eat a snack, put on a nametag, and then discuss different aspects of the project. Though discussion content was largely child-directed, I offered some prompts throughout the sessions regarding the nature of dementia and memory loss, questions students might have about the RC environment or people they had met, children's observations about the sessions, and their input for upcoming sessions. I recorded these discussions to later generate transcriptions which would undergo in vivo coding. After or during discussion, we left ES's campus and walked to the RC campus across the street.

Upon arrival at RC, I gave students a name tag for a senior adult who would be their "buddy" in an informal sense. These buddy pairings changed each week and were determined by the children's preferences. Then we entered the neighborhood to greet the seniors, offer name tags, and begin the creative sessions which centered around the generation of original creative material. I recorded all of these sessions in order to later generate transcriptions which would undergo in vivo coding. At the end of each session I offered the group questions for discussion and reflection,



answers to which I also recorded in order to later generate transcriptions for in vivo coding. I intended for each session to include forty-five minutes of cross-generational interaction, but factors such as travel time shortened the sessions to range between twenty-five and forty minutes in length on varying days. At five of the sessions, I gave the children a pre-session survey to complete before arriving at RC and a post-session survey after leaving RC, both of which collected quantitative data. As outlined by Creswell & Plano Clark (2018), these surveys utilized parallel questions which addressed concepts similar to those in discussion questions which were used to generate qualitative data. Included below in Table 3.2 is an overview of the seven sessions, number of child participants present at each, session content each week, and types of data collected during each session. One type of data collection not indicated on this chart is field notes, which I made every week. I analyzed these field notes through in vivo coding for emergent themes to help myself challenge any preconceived notions regarding the other data sources. I have addressed those emergent themes in my positionality statement rather than focusing on them during Chapter Four, since the intent of the study was to highlight participants' voices, not my own.

A typical format for each intergenerational session was to begin with a group welcome, acknowledging all participants by name, and then either sing a familiar song or recap original creative content from the previous week. For the remainder of the session, students and seniors collaborated to generate various kinds of original creative material as listed in Table 3.2. The creative content included a mixture of material either written, spoken, sung, or played on instruments.

**Table 3.2*****Overview of Creative Sessions at RC***

Session (date)	Children present	Session Content	Data collected
Session 1 (14-Oct)	0 of 7	Use <i>TimeSlips</i> creative storytelling process to create a story in prose poetry format	Recordings for transcription (QUAL)
Session 2 (21-Oct)	7 of 7	Retell seniors' story created during session one. Begin a new <i>TimeSlips</i> storytelling process	Recordings for transcription (QUAL); surveys (QUAN)
Session 3 (28-Oct)	7 of 7	Retell the session 2 <i>TimeSlips</i> story; add a musical soundscape with percussion. Determine topical content for new song, "Memories," and begin brainstorming lyrics	Recordings for transcription (QUAL); surveys (QUAN)
Session 4 (4-Nov)	6 of 7	Finish lyrics to the "Memories" song; add melody and harmony	Recordings for transcription (QUAL); surveys (QUAN)
Session 5 (11-Nov)	7 of 7	Determine topical content for new song, "Thanksgiving." Begin brainstorming lyrics and some melody	Recordings for transcription (QUAL); surveys (QUAN)
Session 6 (18-Nov)	2 of 7 <sup>a</sup>	Finish melody and harmony for "Thanksgiving."	Recordings for transcription (QUAL); surveys (QUAN)
Session 7 (25-Nov)	6 of 7	Add percussion instrument parts to "Thanksgiving." Determine topical content for the last song, "New Things."	Recordings for transcription (QUAL); surveys (QUAN)
Session 8 (2-Dec)	5 of 7	Finish melody and harmony for "New Things."	Recordings for transcription (QUAL)

*Note.* QUAL denotes data collection which contributed to the qualitative data pool;

QUAN denotes data collection which contributed to the quantitative data pool. <sup>a</sup>The

week of November 18 was fall break at the children's school.

Session format and activity content evolved over the eight weeks. The first two sessions generated only written material in a prose poetry format, using Basting's (2009) *TimeSlips Creative Storytelling* process. The following sessions followed a similar structure but also incorporated elements of musical play and exploration by creating soundscapes with instruments and voice to accompany written content. Finally, in the last several sessions we shifted the framework to focus on writing original song content using voice and instruments. I loosely modeled my facilitation of this songwriting process on Friedman's (2011) *Songwriting Works* framework. Although in the first two sessions the group used prompts from the *TimeSlips* process, during subsequent sessions we discarded the use of any external prompts as the participants determined their own prompts. More detailed lesson plans explaining the step-by-step process for creative activities during each of the eight sessions are in Appendix A.

### **Ethics in session procedures.**

Session design included several ethical considerations to respect both seniors living with dementia and children. Although this project was not participatory research, I leaned on ethical suggestions from participatory research models, or studies in which researchers partner with community stakeholders to approach "a particular community-identified problem or issue" in a project format which "values collaboration, power sharing, and different kinds of knowledge" (Leavy, 2017, p. 224). Especially regarding persons living with dementia, participatory research has recently problematized the tendency for researchers to focus on clinical aspects of dementia without seriously attending to the voices of

those living with it (Baker et al., 2017; Basting, 2009; George, 2011; Thoft et al., 2018; Wiersma et al., 2016). It is important here to clarify this project's differing uses of the word "participatory." This project was *participatory* in a musical sense, as used to describe its creative ideology during intergenerational sessions, but not *participatory* from a methodological standpoint and did not aspire to use a participatory research framework. However, advice from participatory researchers did prove helpful in the process of determining my own role as both researcher and facilitator, in order to set parameters for how to interact ethically with seniors and children and honor their voices. Namely, I sought to avoid actions which would portray participants of either age group as "passive receivers of care, rather than active agents in their own right" (Thoft et al., 2018, p. 4). With this in mind, as facilitator I sought to relinquish control over the process to some degree.

Participatory researchers envision their own participation less as that of an expert guiding the direction and more as "a supporter and a learner" who depends on the participants' insight and thus allows the research to be molded into a process more "relevant for the participants" (Thoft et al., 2018, p. 8). Thoft et al. points out that such a model "demands a constant balancing act," much of which depends on a positive relational dynamic and community atmosphere among everyone involved (p. 14). Likewise, I sought to balance my own role as researcher and facilitator in such a way that participants felt welcomed to participate in the community and contribute to session activities.

***Balance between facilitation and research.***

Since I was acting in the role of both facilitator and researcher, I gave consideration to practical elements of facilitation style and how they would affect all participants' access and inclusion in the sessions. For example, during generation of creative material I aimed to echo all participants' contributions verbatim with matching rhythm, melodic quality, and emotional tone, a practice recommended by the research-based TimeSlips and Songwriting Works processes (Basting, 2009; Friedman, 2011). Asking for clarification as needed, I then wrote the participants' comments word-for-word on a flipchart visible to all participants and also offered verbal affirmation of their contributions. When asking seniors a question, I paused for an extended wait time to honor their possible need for enough space to process a question and determine their response (StoryCorps, n.d.) This facilitative process of echoing contributions and affirming participants meant that my voice was also included frequently throughout the sessions. Since the program sought to highlight participants' voices, I never purposefully contributed to the creative generation of material; yet, it is important to recognize that the continued presence of my own voice as facilitator necessarily influenced other group members' experience of participation.

Throughout the project, participants sometimes also expressed interest in contributing in spontaneous ways which deviated from anticipated session structure. While facilitating, I attempted to keep sessions flexible to allow those unanticipated contributions while still seeking group consensus on the overall creative direction. For instance, I respected individuals' desire to add an instrument

at an unexpected time, enter and/or leave the common area during sessions, or stand up to move and dance while the others continued revising song lyrics or melody. When creative direction unexpectedly diverted from the session's original intent, we pursued that new direction with the exception of occasions when time constraints prevented. In those situations, during subsequent sessions I recalled the group's attention to those previously suggested departure points, asking them to choose whether we should pursue that creative direction or not.

Sometimes more outspoken individuals' preferences seemed to be dominating the creative narrative to the exclusion of others' ideas. In these situations, as recommended by both Basting (2009) and Friedman (2011), either RC staff or I respectfully intervened to create more space for others (e.g., by turning to directly address a quieter participant and asking for their opinion). Several times children expressed differing opinions on creative choices, and when this occurred I tried to refrain from intervening and allow organic resolution whenever possible. In some situations divisive opinions continued and frustration or irritation arose among children. In these situations, I suggested choices that might either reconcile differing ideas, include both ideas, or follow the majority's preference.

### **Data Collection and Analysis**

Consistent with Creswell and Plano Clark's (2018) convergent mixed methods case study design, I simultaneously collected quantitative data and qualitative data from ES child participants and RC senior adult participants. I collected quantitative data using a researcher-designed survey, and qualitative data through (a) audio recordings of creative sessions, (b) audio recordings of discussion,

and (c) my own field notes. Using the quan + QUAL = converge format, I designed the study to give priority to qualitative data collection, though the survey data also included a smaller source of quantitative data throughout the process. In keeping with the Institutional Review Board's approval for data collection, I stored all of this written and audio data securely throughout the duration of the project and data analysis.

I initially intended to collect and analyze both types of data equally representing both children's perceptions and senior adults' perceptions. However, my underestimation of logistic challenges and transition times changed this plan. I had anticipated having enough time at the beginning and end of each session for senior adults to complete the same surveys as the children with the help of RC staff. From the first session it became evident this plan was impractical. During transitions the RC staff were busy helping seniors with other things, while the children needed assistance from me in a chaperone capacity (e.g., gathering supplies, getting coats on, finding the restroom). As a result, children completed surveys while seniors did not. This meant senior adults' voices were not highlighted at all in the quantitative (i.e., survey) data, and skewed the overall data collection towards a much more detailed view of children's voices and perceptions. However, qualitative data collected through recordings of the sessions provided a more equitable representation of both child and senior participants' voices.

### **Surveys.**

I developed the quantitative survey for children by considering questions which other researchers had used in similar situations to address people's

perceptions regarding musical or intergenerational experiences (Kaplan, 2002; Varvarigou, 2011). The survey had a pre-session and post-session component, both of which asked children to rate several aspects of their perspective on a five-point Likert-type scale. Surveys are included in Appendix B. As recommended by Creswell and Plano Clark (2018), the quantitative survey included parallel questions addressing concepts similar to those addressed in the generation of qualitative data. Before several sessions, students completed the pre-session portion of the survey. After these same sessions, students also completed a written post-survey with questions corresponding to the pre-session surveys. I administered these pre-session and post-session surveys during five separate weekly sessions. The data from week five included only two survey responses, as the school was on fall break and most students chose not to participate in the group that week. I did not administer any surveys during the first or last weeks of the program, since during these weeks I focused on collecting data through discussion. I made this choice since it required a considerable amount of time for children to complete the surveys each week, but it seemed more worthwhile for children to spend their limited time directly interacting with the seniors, especially the first week (i.e., meeting them) and last week (i.e., saying goodbye).

### **Audio recordings and field notes.**

I used a recording device to audio-record intergenerational sessions for later selective transcription. In deciding which portions to transcribe, I selected portions of the recording which highlighted participants' creative generation of original material. I had originally intended to video-record the sessions but this was not



permitted as per RC executive board's decision. I also recorded all discussions before and after sessions. I discussed the project with children in a variety of formats, both individually and as a whole group, both before and after sessions. Additionally, after each session while the students and seniors were together in the room, I asked the whole group to share their perspectives on the sessions and ideas for the upcoming sessions. I also audio-recorded these conversations for later transcription. After each session, I also wrote my own field notes regarding personal observations and impressions.

#### **Ethics in data collection.**

In keeping with the procedural ethics and session flexibility described above, I kept my approach to data collection flexible throughout the study in order to respect needs expressed by seniors or children. For example, while I had expected most participants would be in fifth or sixth grade, in actuality the majority were second graders, so before the study began I altered survey questions to more appropriately meet their reading level. Additionally, as the sessions progressed, it became apparent that the discussion format I had planned needed to be adapted to honor the participants' agency and voices.

Regarding discussion, it became particularly clear I needed to substantially change my plan in order to respect the students' expression of preferences during the after-school time period. I had originally planned to have large-group discussions before and after every session, which I thought would allow children space to fully express their perspectives. However, it quickly became apparent that in actuality they did not feel empowered but rather frustrated and overstimulated

as they perceived that this type of data collection was an extension of their school-day formal learning setting. The following interaction with second graders Elena and Kaylin gives one example of the students' exhaustion at a time of day when activities that felt like schoolwork were not developmentally appropriate:

Me: How did you feel about visiting with the people today?

Elena [*sighing, with an irritated tone*]: Why are you specifically asking me all these questions when we write them down on the paper?

Me: 'Cause sometimes you don't get to say everything you want to say on a piece of paper where you can only circle smiley faces. So I'm asking everybody too... just in case. Like if there's anything you want to say and can't say it on the paper. Or if not, it's okay.

Elena: Umm... Okay. No.

Me: Okay. What about you, Kaylin, is there anything else you want to say about today?

Kaylin [*distracted, wanting to eat her snack*]: Mmmm... No. I think it was great.

Attempting to respect this sentiment and several other similar instances, I lessened my expectations for how much discussion data I would collect before and after sessions. In other words, instead of requiring students to participate in formal discussions for an extended period of time, I modified data collection into brief individual conversations with students and smaller group discussions while walking to and from RC.

### **Data Analysis**

In keeping with Creswell & Plano Clark's (2018) guidelines for convergent mixed methods case study design, I analyzed qualitative and quantitative data separately throughout the study. Then at its conclusion I combined data for final analysis. This final analysis helped answer my mixed methods research question.

**Survey analysis.**

I analyzed survey results by using Microsoft Excel to calculate the mean, standard deviation, median, and mode of participants' answers for each question. Then I used these descriptive statistics to create various types of comparative graphs in Excel. First I created graphs comparing participants' answers with one another on each survey question. Next I created graphs comparing individual participants' answers with one another across the progression of sessions, and finally graphs showing the trajectory of individual participants' answers throughout the sessions. I used these graphs to look for any patterns or correlations which might emerge regarding my first research question: "How can the value of participatory creative arts as a dementia-friendly tool be observed in intergenerational settings?"

**Transcription analysis.**

I selectively transcribed audio recordings of both participants' interactions in the creative sessions and their contributions during pre/post-session discussions. I did not transcribe the entirety of every session, choosing only to transcribe (a) the main portion of the session which included the generation of original creative material, and (b) the discussion portion which occurred after the session, with the understanding that some incidental speech may have been missed in this process. I employed in vivo coding of the transcriptions by extracting verbatim phrases of the transcript and then organizing them into categories to find emergent themes in the instrumental case study process (e.g., Leavy, 2017). I organized all of the qualitative data into two separate streams, each of which I coded and themed separately.

The first qualitative data stream I generated was taken from recordings of the sessions themselves, during which children and seniors were engaged in generation of creative material. During these portions of the session, children and seniors were either brainstorming together about beginning a new story/song, or mid-stream in the creative process as they reviewed an original story/song begun last week and added new ideas. In order to discern whether different thematic material might emerge from children as compared to seniors, I divided this data stream into two collections: contributions from the children, and contributions from the seniors. In my analysis, I combined these two collections and applied this stream of data to consideration of the first research question: “How can the value of participatory creative arts as a dementia-friendly tool be observed in intergenerational settings?”

The second qualitative data stream I generated was taken from recordings of the pre-session and post-session discussions. I similarly divided this data stream into two collections: contributions from the children, and contributions from the seniors. I used both these collections of data in consideration of the second research question: “How do senior adult participants with dementia and child participants perceive the meaning and value of cross-generational relationships, especially in context of participatory creative arts?”

### **Field note analysis.**

I kept a journal of field notes after each session, which I also analyzed through in vivo coding to find emergent themes regarding my perceptions of intergenerational interactions and the sessions. Rather than considering these

emergent themes as part of a separate qualitative data stream, I referred to the field note material during my analysis process to challenge my own preconceived notions about the other data streams. After I analyzed qualitative and quantitative data strands separately, I referred to my field notes during the process of merging all the data streams, comparing and contrasting their results to help answer my mixed-methods research question, “How do qualitative and quantitative data compare or contrast regarding cross-generational collaboration in participatory creative arts processes?” My goal was to filter out prejudices and personal impressions obvious in my field notes. Some portions of my field notes are included in the results of this study to provide context. However, most thematic material from the field notes is included in my positionality statement rather than the study results, since the purpose of the study was to highlight participants’ voices, not my own perspectives.

### **Mixed Methods Analysis.**

After analyzing both qualitative and quantitative data strands respectively, I converged the results as outlined by Creswell and Plano Clark (2018). First I looked for common concepts addressed across both qualitative and quantitative data sets. Then I created a table summarizing data results, and compared results in those tables to determine whether the data strands demonstrated discrepancies or confirmation of one another. In instances of discrepancy between the qualitative and quantitative results, I returned to closer consideration of both data strands to understand why this may have occurred. I used this process to interpret the meaning of discrepancies and confirmations, which ultimately provided a more

comprehensive exploration of the project's purpose statement and research questions.

## CHAPTER 4: RESULTS

In determining results, I considered the study's overall purpose to explore the meaning of participation and cross-generational interaction in a participatory, intergenerational music project from the perspectives of children and senior adults living with dementia. The data generated from both qualitative and quantitative streams is here arranged in light of three research questions:

(1) How can the value of participatory creative arts as a dementia-friendly tool be observed in intergenerational settings?

(2) How do senior adult participants with dementia and child participants perceive the meaning and value of cross-generational relationships in context of participatory creative arts?

(3) How do qualitative and quantitative data compare or contrast regarding cross-generational collaboration in participatory creative arts processes?

### **Quantitative Survey Data**

I devised three questions for child participants to share their feelings about (a) their visit to RC on that day, (b) a previously-composed group story, and (c) getting to know adult participants from RC. For all three pre-session survey questions, response options included the following choices: Very poor (1)/ Poor (2)/ Fair (3)/ Good (4)/ Excellent (5). Descriptive statistics summarizing the quantitative data collected from the three pre-session survey questions are displayed in Table 4.1, Table 4.2, and Table 4.3. Participants were generally positive about their feelings toward visiting RC (Table 4.1), the stories/songs they had

created at previous sessions (Table 4.2), and getting to know the RC residents (Table 4.3); notably, 5/"Excellent" was their most common response.

**Table 4.1**

*Children's Responses to Pre-Session Survey Question 1, "How do you feel about visiting RC today?"*

Session (date)	<i>n</i>	<i>M</i>	<i>SD</i>	Median	Mode
2 (28-Oct)	7	4.29	0.95	5	5
3 (4-Nov)	6	4	1.26	4.5	5
4 (11-Nov)	6	4.33	0.82	4.5	5
5 (18-Nov)	1	3		3	
6 (25-Nov)	6	4.08	4.25	4.25	5

**Table 4.2**

*Children's Responses to Pre-Session Survey Question 2, "How did you feel about the story/song the group created last time?"*

Session (date)	<i>n</i>	<i>M</i>	<i>SD</i>	Median	Mode
2 (28-Oct)	7	3.86	0.90	4	3
3 (4-Nov)	6	4.17	1.33	5	5
4 (11-Nov)	5	4.2	1.30	5	5
5 (18-Nov)	1	4		4	
6 (25-Nov)	4	4.25	0.96	4.5	5



**Table 4.3**

*Children's Responses to Pre-Session Survey Question 3, "How do you feel about getting to know the people living at RC?"*

Session (date)	<i>n</i>	<i>M</i>	<i>SD</i>	Median	Mode
2 (28-Oct)	7	4.14	1.21	5	5
3 (4-Nov)	6	4.33	0.86	4.5	5
4 (11-Nov)	6	4.25	0.99	4.5	5
5 (18-Nov)	1	5		5	
6 (25-Nov)	6	4.17	0.98	4.5	5

On the post-session surveys, response options for the first two questions included the following choices paralleling the pre-session survey responses: Very poor (1)/ Poor (2)/ Fair (3)/ Good (4)/ Excellent (5). For two other post-session survey questions addressing connection or group inclusion, the response options were slightly modified to include the following choices: Never (1)/ Rarely (2)/ Sometimes (3)/ Often (4)/ Always (5). On the post-session surveys 5/ "Excellent" or "Always" was children's most common response to questions about how the visit to RC went (Table 4.4), how they felt about the story/song they had created (Table 4.5), the degree to which they felt included in the group (Table 4.6), and the degree to which they made connections with people at RC (Table 4.7). Quantitative data collected from these four post-session survey questions are displayed below in Table 4.4, Table 4.5, Table 4.6, and Table 4.7.

**Table 4.4**

*Children's Responses to Post-Session Survey Question 1, "How did you think the visit to RC went today?"*

Session (date)	<i>n</i>	<i>M</i>	<i>SD</i>	Median	Mode
2 (28-Oct)	7	4.57	0.79	5	5
3 (4-Nov)	6	4.83	0.41	5	5
4 (11-Nov)	7	4.43	0.53	4	4
5 (18-Nov)	2	4.5	0.71	4.5	
6 (25-Nov)	5	4.6	0.55	5	5

**Table 4.5**

*Children's Responses to Post-Session Survey Question 2, "How do you feel about the story/song the group created?"*

Session (date)	<i>n</i>	<i>M</i>	<i>SD</i>	Median	Mode
2 (28-Oct)	7	4.57	0.79	5	5
3 (4-Nov)	6	4.83	0.41	5	5
4 (11-Nov)	7	4.71	0.76	5	5
5 (18-Nov)	2	4.5	0.71	4.5	
6 (25-Nov)	5	4.6	0.55	5	5

**Table 4.6**

*Children's Responses to Post-Session Survey Question 3, "Did you feel included in the group today?"*

Session (date)	<i>n</i>	<i>M</i>	<i>SD</i>	Median	Mode
2 (28-Oct)	7	4.43	1.13	5	5
3 (4-Nov)	6	4.67	0.82	5	5
4 (11-Nov)	7	4.43	0.79	5	5
5 (18-Nov)	2	4.5	0.71	4.5	
6 (25-Nov)	5	4.4	0.55	4	4

**Table 4.7**

*Children's Responses to Post-Session Survey Question 4, "Were you able to make connections with the people at RC?"*

Session (date)	<i>n</i>	<i>M</i>	<i>SD</i>	Median	Mode
2 (28-Oct)	7	4.43	1.13	5	5
3 (4-Nov)	6	4.5	0.84	5	5
4 (11-Nov)	7	4.14	1.21	5	5
5 (18-Nov)	2	4	1.41	4	
6 (25-Nov)	5	4.6	0.55	5	5

### Survey Data Interpretation

To interpret survey data, I took three different approaches. First, I considered children's responses in comparison with their program attendance. Next I compared children's responses throughout the course of the program. Finally, I

considered the trajectory of individuals' responses throughout the sessions. This included not only individuals' change in response regarding parallel questions from pre-session to post-session surveys each week, but also their change in perceptions over time regarding specific survey questions.

### **Students' Responses and Attendance**

The two students with the lowest overall session attendance (i.e., William and Elena, who attended four and five of the seven sessions respectively) consistently showed lower scores than other participants on all three pre-session survey questions: "How do you feel about visiting RC today?," "How did you feel about the story the group created last time?," and "How do you feel about getting to know the people living at RC?" On post-session survey questions, Elena and William scored similarly to other students, with two exceptions. Elena's responses to the question, "Did you feel included in the group today?" were consistently lower than any other participant. Likewise, William's responses to the question "Were you able to make connections with the people at RC?" were consistently lower than any other participant.

### **Comparisons of Individuals' Responses**

The questions on the pre-session survey addressed similar concepts to the questions on the post-session surveys. I compared children's responses on these three questions from pre-session to post-session surveys each week. Table 4.8 shows a comparison of how the similar questions were worded on pre-session and post-session surveys. Despite addressing similar concepts, wording on some corresponding questions did use slightly different wording in attempting to capture

the children’s perception at a given moment in time (e.g., the shift in Question 1 from “feel,” implying current emotion, to “think,” implying cognition about a past event).

**Table 4.8**

*Comparison of Corresponding Questions on Pre-Session Surveys and Post-Session Surveys*

Question	Pre-session survey wording	Post-session survey wording
1	How do you feel about visiting RC today?	How did you think the visit to RC went today?
2	How did you feel about the story/song the group created last time?	How did you feel about the story/song the group created?
3 and 4	How do you feel about getting to know the people living at RC?	Were you able to make connections with the people at RC?

Due to small sample size, my comparisons of the survey data did not use inferential statistics, only descriptive statistics. For these three sets of corresponding questions in Table 4.8, I subtracted each child’s pre-session survey responses from their post-session survey responses to find any change in that child’s answers from pre-session to post-session. Table 4.9 shows types of change that occurred in children’s scores on the comparable questions from pre-session survey to post-session survey. One child, Tucker, showed no change in his responses on survey questions during any week he attended the program. The other children showed a variety of changes from their pre-session survey responses to corresponding post-session survey responses.

**Table 4.9**

*Children's Change in Response on Comparable Questions from Pre-Session Survey to Post-Session Survey*

Child	Changes in Responses from Pre-session to Post-session
Tucker	No change
Kaylin	No change/ higher scores
Gemma	No change/ higher scores
Sophia	No change/higher scores
Elena	No change/ higher scores
William	No change/ higher scores/ lower scores
Miriam	No change/higher scores/ lower scores

At every program session, the question garnering the largest amount of net change in response from pre-session survey to post-session survey was question two (“How do you feel about the story/song the group created last time?”/ “How did you feel about the story/song the group created?”). For all students except Miriam, scores on this question always increased from pre-session responses to post-session responses.

### **Students' Responses Throughout the Sessions**

I also considered whether individual students' responses to certain questions changed over the course of the sessions. In order to do so, I created bar graphs which compared all responses individuals gave to a certain question over the course of the program. The response trajectories for two of those pre-survey question

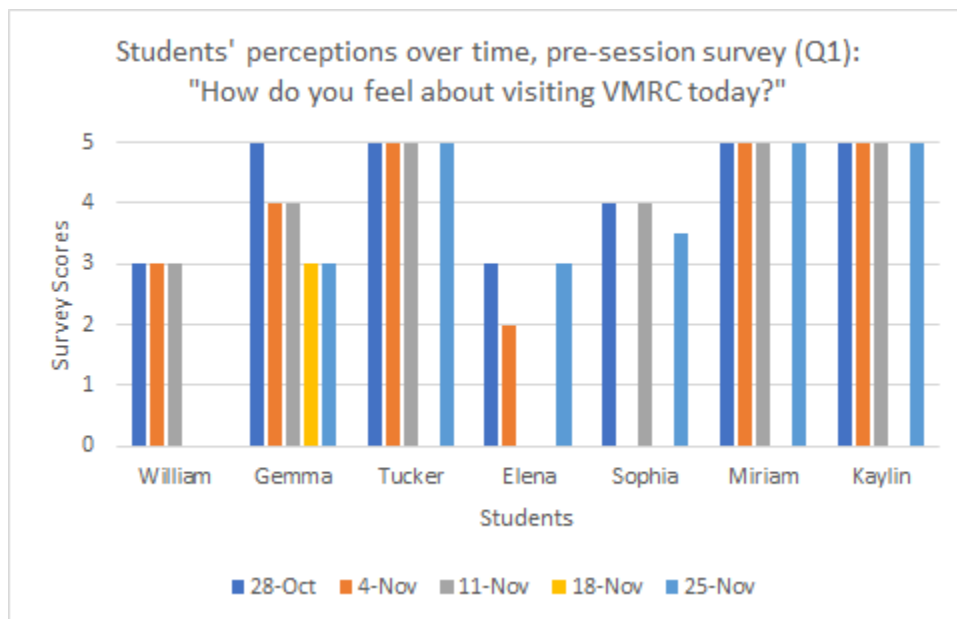
responses and their corresponding post-survey question responses are displayed in the following figures.

**Pre-session survey: “How do you feel about visiting RC today?”**

Most participants did not show substantial change in their response to this pre-session survey question over the course of the sessions (see Figure 4.1). Three students (i.e., William, Sophia, and Elena) showed variability in their responses to this item over the course of this study. Three other students (i.e., Tucker, Miriam, and Kaylin) indicated the same score on every survey they completed throughout the program. The exception was Gemma’s scores, which were initially high and lowered throughout the study.

**Figure 4.1**

*Students’ Perceptions Over Time Regarding Pre-Session Survey Question 1, “How do you feel about visiting RC today?”*

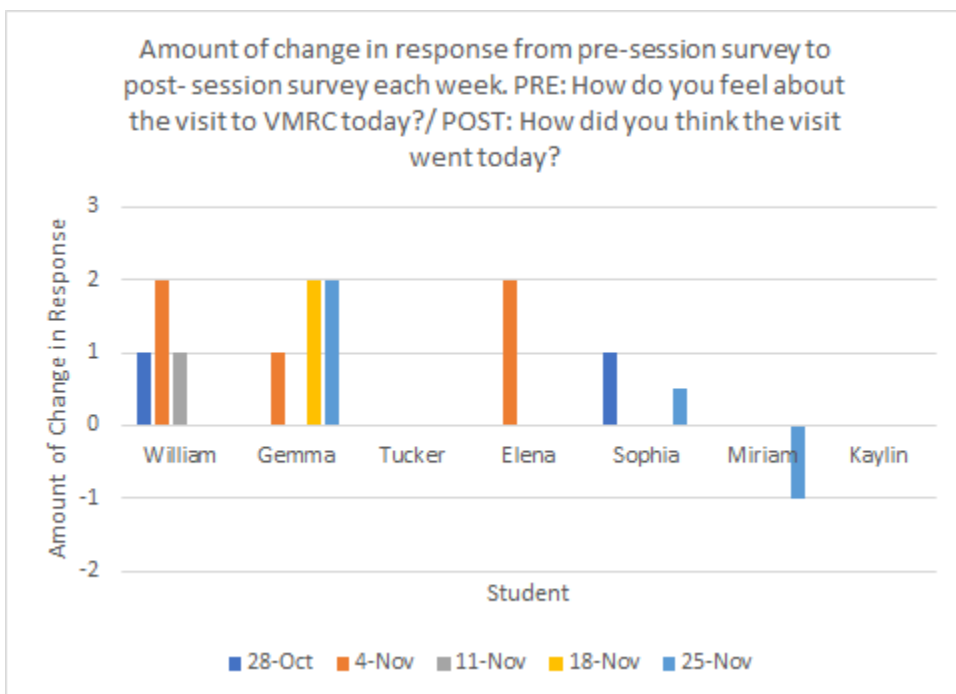


***Comparison with the corresponding post-session survey question.***

However, when answering the corresponding question on the post survey (“How did you think the visit to RC went today?”), four of the seven participants frequently indicated a different score than they had done on their pre-survey response (see Figure 4.2). William, Gemma, Elena, and Sophia tended to rate their perceptions about the visit higher on their post-session surveys than on their pre-session surveys. By comparison, the three students who consistently scored their enthusiasm for visiting at a 5 on the pre-session survey (i.e., Tucker, Miriam, and Kaylin) showed either no or very little change on the corresponding post-session survey. Miriam’s score for this question mostly remained the same from pre- to post-session, though one week it decreased on the post-session survey.

**Figure 4.2**

*Amount of Change in Responses to Question 1 from Pre- to Post-Session Survey Each Week*



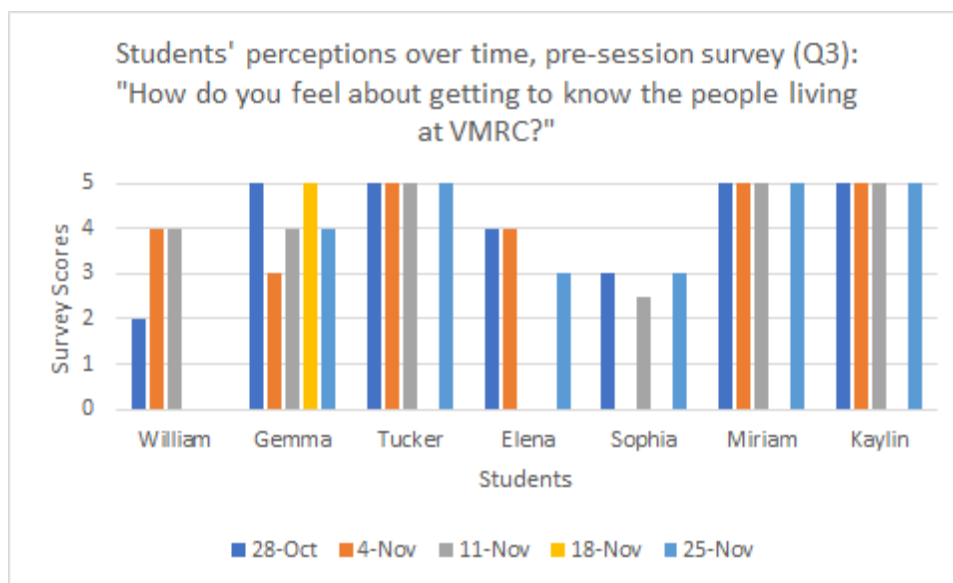


**Pre-session survey: “How do you feel about getting to know the people living at RC?”**

Three of the seven students’ responses for this question did not change at all throughout the program. William’s scores for this question increased throughout his participation in the program, while Elena’s scores decreased. Gemma and Sophia’s responses varied throughout the program, as shown in Figure 4.3.

**Figure 4.3**

*Students’ Perceptions Over Time Regarding Pre-Session Survey Question 3, “How do you feel about getting to know the people living at RC?”*



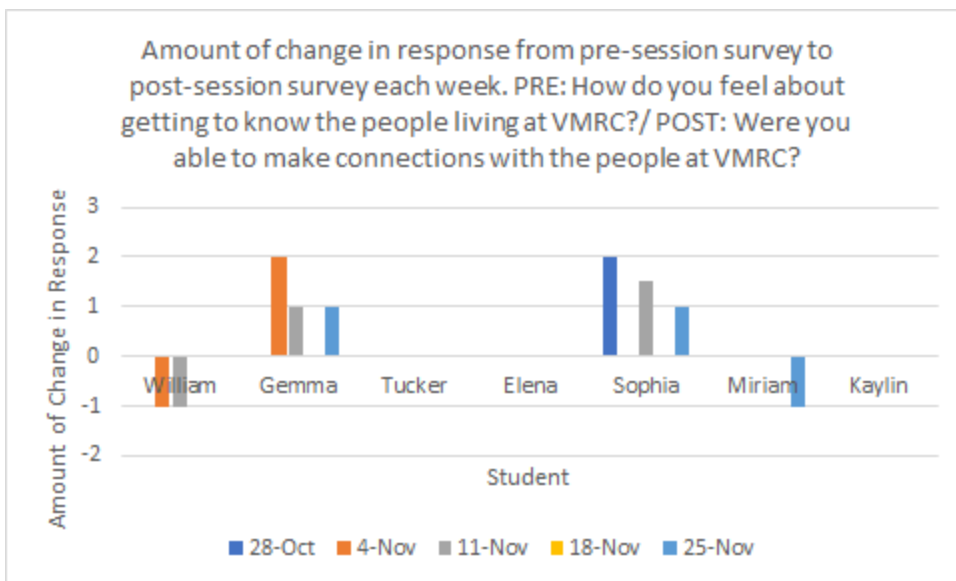
***Comparison with corresponding post-session survey question.***

Each week on the corresponding post-session survey question (“Were you able to make connections with the people at RC?”), Gemma and Sophia showed either an increased score or no change in response from pre-session to post-session. Tucker, Elena, and Kaylin consistently showed no change from their pre-session

survey responses to their corresponding post-session responses. William and Miriam showed either no change or decrease from their pre-session to post-session responses (see Figure 4.4).

**Figure 4.4**

*Amount of Change in Responses to Question 3 from Pre- to Post-Session Survey Each Week*



*Note.* One the pre-session surveys, question 3 asked, “How do you feel about getting to know the people living at RC?” On post-session surveys, the corresponding wording was, “Were you able to make connections with the people at RC?”

### **Qualitative Data: Creative Sessions and Discussion**

I kept the qualitative data generated during the creative sessions distinct from the qualitative data generated during the discussions. I considered these two streams of qualitative data separately, employing in vivo coding with each stream to find emergent themes. First, I dealt with the stream of qualitative data generated from the creative sessions themselves, during which children and seniors were

actively engaged in generating creative material. Next, I dealt with the stream of qualitative data generated from discussions, during which the children and seniors were sharing impressions about the sessions' format and content.

### **First Qualitative Data Stream: Creative Session Themes**

In the voices of both seniors and children, four common themes emerged throughout the creative sessions: (a) cooking and food, (b) cultural traditions, (c) changes or transitions, and (d) expressions of preference and agency in the creative process. The following section will present these four common themes as evidenced by dialogue excerpts from the sessions. As discussed in chapter three, although the project's focus was on participants' perspectives, my own voice as facilitator is frequently included in the dialogue as well. In the following transcription excerpts, for brevity I have removed most instances where my own voice was echoing participants as I wrote their contributions on the flipchart. My voice remains in the transcription when my words introduced material other than a verbatim echo of other participants.

The four creative session themes (i.e., cooking and food, cultural traditions, changes or transitions, and expressions of preference and agency in the creative process) all surface in the following dialogue excerpt, Figure 4.5. This conversation occurred partway through the group's third session as storytelling began to gravitate towards the topic of food.

### **Figure 4.5**

*Dialogue Referencing Four Common Creative Session Themes*

Me: Dolly, what about food?  
 Dolly (senior): Food?... What food?  
 Me [*echoing and writing*]: Food? What food?  
 Activities Director: Dolly, you like to cook!  
 Dolly: I used to, but...  
 Activities Director: Uh-huh...  
 Dolly: it's gone by the wayside.  
 Activities Director: Yeah.  
 Me: Yeah... it's a lot of work.  
 Kitty (senior): \*mumbles to Elena, reaches out to hold her hand\*  
 Sophia (child): I like cooking! I cook with my grandma. My favorite thing to cook is soup.  
 Georgia (senior): Soup? Ohhhh!!! You can do so many different kinds of soup, but you don't have to have a recipe for... you can just... just - think about them and.... put them all together.  
 Sophia: Yeah, my grandma helps me, helps me make up my own soup.

**Food and cooking.**

When the topic of food arose during this session, children and seniors frequently repeated each others' comments and added details. An example of this occurred in the dialogue above (Figure 4.5), where Georgia's elation at Sophia's mention of soup sparked further group discussion about favorite types of soup. This type of interaction also occurs in the following excerpt, Figure 4.6, where William echoes Connie's suggestion of "turkey." In this following excerpt, the conversation about food had narrowed to holiday foods. This shift prompted responses from Connie and Susan, two seniors who had previously made few verbal contributions in any other transcribed sessions.

**Figure 4.6**

*Discussion of Thanksgiving Food*

Me: What do you want for Thanksgiving, Connie, what kind of food?

Connie (senior): Oh boy... Nice big turkey.

Me: That sounds good. Roasted in the oven?

Connie: *[nodding vigorously]*

William (child): Turkey....

Georgia (senior) *[speaking first quietly to Sophia, then repeating to the group]:*

It'd be interesting to see somebody making pies... Making pies with your hands, wouldn't it? That would be a good... a good-lookin' party.

Me: Yeah, that would be a good party, wouldn't it? What do you think, Susan, what kind of food do you like?

Susan (senior) *[very softly]:* Anything...

Georgia: Did she say? – anything?!

*[Nurses & residents laugh & talk about this response from Susan]*

Outside of this dialogue excerpt, Connie overall contributed fewer verbal comments than most other senior participants. Similarly, Susan participated throughout all sessions by swaying, clapping, or dancing but rarely participated verbally.

**Cultural traditions.**

Throughout the discussion group members frequently brought their own traditions to the group conversation, as in the first dialogue excerpt (Figure 4.5) when Sophia mentioned her practice of cooking alongside her grandma to create her own type of soup, and also in the second excerpt where ideas surfaced about Thanksgiving, ways to make pies, and parties. At times seniors made these mentions of family history and cultural traditions through a type of parallel storytelling, by which they interjected bits of their own family history and cultural traditions into the larger group dialogue at intervals throughout the session. For instance, the below dialogue excerpt with Maggie, Figure 4.7, occurred midway through a session. Previously during the same session Maggie had already quietly mentioned comments about “my little girl” to the child sitting next to her, Gemma. At this

moment in the session, discussion had momentarily paused as we were beginning to recap what the group had created so far by reading aloud everything already written on the flipchart. During this process Maggie shared some new information and affirmed that it could be added to the group story:

**Figure 4.7**

*Maggie's Parallel Storytelling*

Maggie (senior) [*beginning to speak to Gemma again about "my little girl"*]: It was so easy for her. It would be twice as hard for anyone else.

Me: It was so easy for her? Is this your little girl, Maggie? [*Echoing her words and pointing at other words on the flipchart which Maggie had previously shared about "my little girl"*]. When your little girl was little, there was nothing she couldn't play. Everything was easy for her!

Maggie [*Gesturing into the air, vigorously*]: She's a WINNER!

Me: She's a winner! Can we put that in the story, Maggie? Can we add... She's a winner?

Maggie: Yes. Yes you can. [*Turns and continues speaking quietly to Gemma*]. If she were here, we could get ahold of her....

Me: Okay. [*Continuing to retell the story*].

Although Maggie had initially brought up this bit of family history as an aside spoken quietly to Gemma, when her story was acknowledged within the larger group context she was willing for those words to be included in the story.

**Changes or transitions.**

Seniors brought up ideas of changes or transitions throughout many sessions, for instance in the Figure 4.5 dialogue where Dolly mentioned that she "used to" cook, but "it's gone by the wayside." Another example of seniors' interest in change or transition is evidenced below (Figure 4.8) by Georgia's suggestion of "memories" related to "a girls' growing up story." The conversation surrounding

Figure 4.8 occurred at the end of a session, when I asked group members what the story should be about next week.

### **Figure 4.8**

#### *Georgia's Ideas for Next Week*

Me: What do you think, Georgia? What could we tell a story about next week?

Georgia (senior): What I was thinking of, may not have to do with the topic you have... but it has to do with, uh, things I might find in my room, but I don't know... how much of a discussion... but possibly, thinking about, memories, maybe. And, uh, I was thinking... these girls [*pointing at the children near her*], well, they won't be back next week, will you?

Me: They will be back next week!

Georgia: Ohhh!

Me: Yeah, they'll come back next week to visit again.

Georgia: Oh, okay.

Me: Yeah.

Georgia: Well I have uh, a couple of things, ah, that I thought they might like... uh... if they like, special things, they could ah, have it permanently. Girly things, and maybe it's okay to tell... ah, maybe a girls' growing up story?

Me: A girls' growing up story. That sounds good.

Georgia: I don't know if this is the right time to do it or not.

Me: Maybe next week, how does that sound? Would that be okay?

Georgia: Oh, next week, that's what I think...

The children did not show much evidence of reciprocating on this theme of change and transition until the last week, when the activities director mentioned having heard that the children were moving into a new school building. That comment sparked extended dialogue between children and seniors alike on their experiences regarding the theme of change and transition, as shown in the excerpt below, Figure 4.9.

### **Figure 4.9**

#### *Dialogue on Change and Transition*

Gemma (child): Next week we're moving schools!

Me: What else?... Georgia, one time you talked about moving...?

Georgia (senior): Well, okay, we could talk about some other things. I had to move three boys, and I didn't have any girls to help me feed us while we were moving, or anything like that.

Me: Oh my. That was a lot of work, wasn't it?

Georgia: Just boys... and boys would... not... cook!

Me: Boys would not cook. I bet they wouldn't!

Gemma: I can cook mac & cheese! If my mama lets me.

Georgia: That's right. Boys work, but do not cook.

Sophia (child): My dad cooks!

Me: [*Echoing previous comments, writing*] That sounds like a good line for a song.

Georgia: Boys work, but *may* not cook.

Activities Director: Oh that's true! [*Laughs*]

Georgia: Well sometimes now, they do... or... are *ordered* to do.

Sophia: But my dad cooks!

Me: Yes right! What else?

Georgia: What do I keep... from my old house... and what do I throw away?

Activities Director: That's true.

Georgia: What to give away, or... some other word, if you can find it?

Throughout this dialogue excerpt and the surrounding conversation, the children's enthusiasm to discuss their upcoming change in school building also sparked discussion of other general life transitions (e.g., Georgia's mention of the moving process and what to keep). Additionally, this conversation in Figure 4.9 also touched upon the first two themes of cooking and food, as well as cultural traditions (e.g., Georgia's mention of gender roles, and Sophia's response).

### **Expressions of preference and agency in the creative process.**

One way in which seniors and children demonstrated perceived meaning of participation in the project was through expressions of preference and agency in the creative process itself. Both seniors and children expressed preference and agency in the creative process, though while doing so, some differences in approach arose between the two age groups. The children tended to make confident expressions regarding their own preferences and ability to make creative choices; seniors



likewise expressed some confident expressions of preference but also tended to express some degree of doubt regarding their own ability to make creative choices.

***Children's expressions of preference and agency.***

Children commonly used phrases referencing personal approval such as “I love” or “I don’t really like.” They also voiced ideas referencing creation (e.g., “I have an idea,” and “I have a story”) as well as consideration or planning (e.g., “Could we,” “Can we talk about,” “I don’t think,” and “Let’s...”). These types of comments regularly sparked further conversation or directed the group flow. While some children verbally participated very little during the transcribed sessions except to voice agreement with others’ ideas or respond to a direct question, other children frequently spoke up to express agency. In particular, Sophia and Gemma expressed collaboration and confidence in their ideas about the group’s creative direction. In the following instance, Figure 4.10, these two children were offering suggestions regarding the decision-making process for adding instruments to their song:

**Figure 4.10**

*Sophia and Gemma Crafting a Song*

Sophia (child): This time, could we try it multiple times to see what... uh... what instrument sound, like what instrument sounds go in what parts?

Me: Oh, okay. So you want to put those shakers in the song... where?

Sophia: Maybe throughout the whole song, cause... well, yeah.

Me: Okay. So what about the tambourines?

Gemma (child): Yeah! So they can do the slow beat and we can do the fast beat. [*demonstrates use of the tambourine to play a rhythmic ostinato while Sophia plays the steady beat on shaker*]

In this instance, Sophia expressed desire for the group to try singing and playing a small portion of the song multiple times as part of the decision-making process regarding how and where certain instruments might be included. Gemma supported

Sophia's suggestion, and added her own input on the use of one specific instrument, the tambourine.

***Seniors' expressions of preference and agency.***

The seniors similarly voiced some positive expressions of preferences including, "I was thinking," "I think," "I guess you might say," "I love," "Can we say..." (referring to their desire to use specific words to express a certain concept in the song lyrics) and "That would be good." However, the seniors were also more likely to downplay their own contributions or demonstrate lack of confidence in their own creative agency, as in the following two interactions with Georgia which took place during two separate sessions. In the first example, Figure 4.11, we were nearing the end of a session; at this point the children were continuing to add quite a few new ideas to our poem and I was soliciting ideas from seniors about whether they would like to contribute anything:

**Figure 4.11**

*Georgia's Contributions When Ending a Song*

Me: Georgia, what do you think?

Georgia (senior): I could always talk more, but I should not... we should be finished.

During another session Georgia expressed a similarly low confidence in her own creative agency, this time regarding choosing the first line for a new song. This interaction is shown in Figure 4.12.

**Figure 4.12***Georgia's Contributions When Beginning a Song*

Me: Okay! What do you guys think, is that a good way to start [*the song*]?

Several kids: Yeah...

Georgia (senior): Happy or sad, good or bad. To have another way of... -- you don't have to put that down! [*Speaking to me as she sees that I am beginning to write what she is saying*]. That's just a little something to think about... somewhere...

Me: That's a good little something to think about...

Georgia: Ah... this doesn't have to be put in, but maybe somewhere, leaving out old friends. That doesn't have to be put in there [*referring to the group's song*], but it might be an idea for sometime.

Me: That's a good idea, can I write it down?

Georgia: That's up to you... I'll let you.... consider it...

In this interaction Georgia contributed two original phrases which no one else had yet mentioned (i.e., “happy or sad, good or bad” and “leaving out old friends”), but simultaneously expressed doubts about whether she wanted those phrases to be included in the song or even acknowledged on the group’s brainstorming list. Her comment “That’s up to you... I’ll let you consider it” implied an impression that for some reason I ought to make the choice on her behalf.

*Seniors' deference to children.*

In addition to expressing uncertainty about their contributions, it was also common for senior participants to defer to the children’s eager participation. For instance, in the Figure 4.5 conversation excerpt, after Georgia stated her idea about “what to give away” and wondered about finding “some other word” to express that idea, Gemma interjected with her own story about a family move and Georgia did not pursue her idea any further. Similarly, near the ends of sessions when I directly asked senior participants whether they felt the story/song was complete or not,

seniors would defer to children's opinions, as in the following statement, Figure 4.13, by Maggie.

**Figure 4.13**

*Maggie Deferring to Children*

Me: Maggie, what do you think... is the story all finished?

Maggie (senior): Not if they're still messin' with it [*pointing to the children*]

My field notes noted this type of behavior from Maggie occurring during other sessions as well. For example, I made the following observation about Maggie nonverbally deferring to children during the fifth session:

*I think sometimes when the seniors decline to add their ideas, it is out of deference to the children's enthusiasm. They can see that the children have a lot to say and sometimes it seems like they just prefer to listen. For example several times today I asked Maggie for her ideas... in response she just raised her eyebrows, widened her eyes, and pointed at a child nearby who clearly had something they would like to say.*

The seniors were also overall less likely than the children to contribute ideas at the beginning of the creative process. The below conversation, Figure 4.14, occurred after brainstorming content ideas for a new song. Most seniors expressed uncertainty about how the song ought to begin, using phrases such as "I don't know." The exceptions were Dolly's confident idea and Georgia's response, which seemed to riff off of Maggie's comment and spin the brainstorming process in a new direction.

**Figure 4.14***Brainstorming Song Content*

Me: Okay we've got lots of good ideas up here now. How should we start the song?

Tucker (child): Boys work but do not cook.

Me: Okay, that's a good line...

Sophia (child): *[singing, exploring an idea to set that text to melody]*

Me: Georgia, what do you think? How should we start the song?

Georgia (senior): I don't know...

Me: I don't know either!... Dolly, what do you think?

Dolly (senior): A happy something in the beginning.

Me: Okay! It's nice to start with a happy something. Maggie, what do you think?

Maggie (senior): I haven't been able to think yet.

Me: Okay. Larry, what do you think? How would we start the song?

Larry (senior): I don't have a suggestion...

Me: Okay.

Georgia: She said she couldn't think yet *[Looking towards Maggie]*.... Does that have anything to do with when we're going to fix up the new house, or something, you're thinking... ah, what do I do, or what do I get for there? You're making, ah, I don't know what...

Me: Making choices?

Georgia: Ah, some kind of choices, can we say... what word... making new choices?

Activities Director: Making new choices can be happy or sad...

Georgia: Oh, yes-- Oh yes, *that!*....

Though Dolly and Georgia both voiced an opinion, neither felt very firmly regarding how their idea ought to be incorporated; Georgia was either pleased or possibly relieved when the activities director reframed Georgia's idea in a modified, more concise wording.

*Seniors' need for more time or space.*

An additional sub-theme of needing more time or space to express preference and agency arose from Maggie's comments in this instance. Even before commenting, "I haven't been able to think yet" (Figure 4.14), Maggie had already expressed several similar statements or fragmented ideas during the same session:

“Oh I wish...,” “Or something...” “I need... more time to think,” and “I don’t have anything to say yet, I don’t know.” These expressions were mostly made as unsolicited interjections while another participant was speaking. These comments received relatively little direct response from other participants. Noticing these types of interactions, I also wondered in my field notes whether the children’s enthusiastic, energetic participation might be preventing some seniors from participating:

*The seniors seem to talk less overall now that the kids are present than they did the first week when no kids were at the session. Is this because the kids are so eager and quick to talk? Or are the seniors just quiet because they’re happy to listen to the kids? It seems the kids may not be listening to the seniors’ responses sometimes, as it’s hard for them to be patient. How could both groups talk and share more equally?*

### **Creative Session Songs**

As a result of their collaboration during the creative sessions, the children and seniors wrote three original short songs together. They titled these songs “Memories,” “Thanksgiving,” and “New Things.” These three songs are included in Appendix D.

### **Second Qualitative Data Stream: Discussion Themes**

In analysis I kept separate children’s discussion responses after meeting the senior adults, and their discussion responses prior to meeting the seniors for the first time. In the initial discussion, children were first prompted to discuss “what dementia means” before hearing any formal description of dementia. During this discussion three themes emerged, as highlighted in Figure 4.15: Sense of place, sense of order versus disorder, and effects on communicative cognition. For

instance, children made comments regarding their expectations for the senior adults they would meet.

**Figure 4.15**

*Children's Impressions of Dementia*

William: Like, your brain stops working properly...?

Sophia: Um... Part of your brain, it... isn't working the way it's supposed to, so it's hard to remember things...

Elena: You can barely talk, you can mostly only sing.

Gemma: Um... so, it's a part of your brain where memories are stored, it gets messed up because of this disease. It, like... it only affects this one place, and it gets messed up . . . or... mostly your brain gets scrambled.

After analyzing this initial discussion, I separately analyzed all other discussions with the children regarding their impressions and perceptions. This remaining discussion data included the post-session discussions on the first day of the program, as well as pre-session and post-session discussions from all of the six subsequent program sessions. Notably, since Sophia and Gemma were the only two students who attended every session and they also happened to be two of the more talkative children in the group, their voices are more prominent than those of some other children in the following discussion excerpts. In these discussions, themes emerged of enjoyment, medicalization, sense of relative group identity (in relation to the senior adults), impressions of how the seniors communicated, and perceptions about the children's own communication in return.

**Enjoyment.**

When asked to describe what they thought about sessions, children responded throughout the seven sessions with phrases including, "Good," "I liked it

a lot," "It was really fun," "Pretty good," "Fun," "Super fun," "Exciting," "The story was good today," "I think it was great," "Awesome," and "Amazing."

In particular the children's perception of enjoyment seemed to be connected with interactions with the seniors which they found "fun" or humorous, as seen in Figure 4.16 with Gemma's slightly surprised appreciation that a senior adult had a sense of humor, punctuated by Tucker's agreement:

**Figure 4.16**

*Finding Enjoyment in Humorous Interactions*

Gemma: She's [*referring to one of the seniors*] ... fun... She's fun! And she has a lot of sarcasm.

Tucker [*responding to Gemma*]: That was pretty good.

Gemma: Yeah, it was super fun. And she's... I don't know, but for some reason, sometimes what she says, like when I could understand her, she always made me giggle, cause she's so funny.

In other instances, the children's perception of enjoyment was related to some aspect of shared experience, either socially or artistically. This sentiment emerges in Figure 4.17 with Sophia and Miriam's comments about social interaction, and William's comments about creative interaction:

**Figure 4.17**

*Enjoyment in Shared Experiences*

Me: What did you think about today?

Sophia: I liked it!

Me: How come?

Sophia: [*shrugging*] Mm, mmm...? . . . I talked to my partner more than I ever have.

Me: Really? What did you say this time?

Sophia: I forget.

Me: Who was your partner... Georgia?

Sophia: Yeah. She's easy to talk to.

Me: Yeah, I think so too. What did you ladies think?

Miriam: Good. Exciting too.



Me: Why exciting?

Miriam: Cause we got to hear all the other people's past.

Me: Elena, what did you think?

Elena: Good.

William: The story was good today.

While Sophia and Miriam based their enjoyment on conversation and hearing about seniors' past, William based his enjoyment on his perceived outcome of the creative process.

### **Medicalization.**

Discussion after the first session yielded comments about medical aspects of life in the host community. These comments mostly stemmed from Gemma's recounting in Figure 4.18 of a senior participant, Kitty, receiving medicine from a nurse during the session.

### **Figure 4.18**

#### *Perception of Medicalization*

Gemma: Yeah, like Kitty, she had to drink something, in the middle [of the session]... And at first, the doctor was like, 'Come on, drink,' and she was like, 'Uh...', and the doctor said, 'No, you can drink it,' and then the doctor said, 'One more sip,' and she finished it up.

In response to Gemma's impression, the second grade participants also asked medical questions: "Do they have doctors there?" and "Were some people blinded?" However, as sessions progressed, the theme of medicalization did not continue to emerge much in discussion, except in one instance after the fifth session when Gemma expressed perceptions of value judgment about medical aspects of life in the host facility by saying, "It [*referring to the senior adults' residence at a nursing facility*] doesn't mean we have to treat them like they're dolls or fragile," and also, "It

doesn't matter if she can't see." This second comment referred to Annie, who had some degree of visual impairment.

### **Sense of relative group identity.**

In discussion after the first session, the children related to the seniors' group identity with somewhat detached, generalized language. Gemma referred to them "people who are much older and experienced much other things than me" and people whose "minds don't work as well as ours do." Elena compared the seniors to "one of my grandma's friends" who "lived in a place like that," and Kaylin wondered, "Why were they all girls? What about boys? No boys."

During discussion after the second session, at which Gemma and Sophia were the only two children in attendance, the girls expressed a sense of uncertainty, sadness, or frustration regarding their perceptions of the seniors' relative group identity. These feelings emerge in Figure 4.19.

### **Figure 4.19**

#### *Gemma and Sophia Discussing Relative Group Identity*

Me: what was your least favorite part today?  
 Gemma: The time when... I just couldn't understand Kitty.  
 Me: Yeah. Why was that your least favorite part?  
 Gemma: Because I just couldn't *understand* her!  
 Sophia: Mine was when the person next to me.... who was she?  
 Me: Ahh... was that Georgia? Georgia was sitting behind you?  
 Sophia: No, when she left... she *left* [referring to Susan, who had stood up and exited the group seating area during the session].  
 Me: Oh, Susan. When she left... Why was that your least favorite part?  
 Sophia: No, no, no, no – because she was trying to talk to me, and *say something* to me, but it, she – I – it... just sounded like mumbling to me, so I couldn't understand.

Gemma: Oh, oh, that was my least favorite part because then I thought she [referring to Susan] wasn't interested in us and we were... boring... she wasn't excited. Made me sad.

Me: Hmm... why else do you think she might have been leaving?

Gemma: Well maybe she had something to do... but then she hung around the room. And then she just wanted to walk around, like... stretch her legs?

The uncertainty, sadness, or frustration Gemma and Sophia were feeling was connected to their perceived difficulties communicating with specific seniors, or even Gemma and Sophia's overall perception that some interactions had not gone in the way they would have preferred. By the fifth session, during a similar conversation with the same two girls, Gemma and Sophia used comparative language to indicate their changing impressions of seniors' relative group identity. Figure 4.20 shows that in particular the two girls perceived changes in Annie, Kitty, and Dolly's roles within the group.

### **Figure 4.20**

#### *Gemma and Sophia Discussing Changing Group Identities*

Me: What did you guys notice when we were visiting today?

Gemma: They were much livelier! They weren't as quiet. Annie talked a lot more, Kitty was a lot louder than usual, and she actually sung along this time.

Me: She did, I saw that too. That was pretty cool...

Sophia: And, Dolly was talking to me.

Gemma: See, the more we do it, the closer they get to us.

Me: Oh, why do you feel that way?

Gemma: Yeah, because, the first day, they were like, really quiet, and I was nervous, and like now, as I'm getting used to them I can hold their hand...

In this conversation, Gemma and Sophia perceived seniors as more lively, not as quiet, more talkative, more interactive, and closer to the children in some way. After this particular session, Gemma also dominated the group discussion in her eagerness to share a specific interaction she had with Annie. Figure 4.21 explains

how Gemma perceived this interaction with Annie and shows Gemma's resulting perceptions about the seniors' identity within the group.

**Figure 4.21**

*Gemma's Perception of Seniors' Identity*

Gemma: And then, I didn't know Annie was such a talker!

Me: What did she talk about today?

Gemma: Well, she didn't talk to me... but I saw she talked a lot more.

Me: Hmm... well I wonder if we had an unfair impression before because Annie can't see. Maybe we assumed she wouldn't be able to participate as much?

Gemma: Well... no.. I said, 'Hey, do you have an idea?' And then she *nodded*... I think she just nodded, and then -- and then she *shared an idea!* It was the idea... what was it?... it was about, 'to God,' the 'great God' part? Yeah.

Me: Yeah, that was an important part of the song.

Gemma: Yeah I wanted... I wanted for her to participate, so I asked her, 'Do you have any ideas?' And she nodded, and she said it. So all you have to do is invite them! And that way they will share.

Me: Hmm. So at the beginning, you said you felt nervous. Do you feel nervous anymore?

Gemma: No!

Me: Okay. Why do you think it's different now?

Gemma: Because... I realize that they're equals. Just because they have some other...er, just because they're different from us, doesn't mean we have to treat them like they're dolls or fragile.... They can have a little fun too! Being treated like a doll and fragile isn't very fun.

Me: How do you think people feel when they are treated like that?

Gemma: Uh, I don't think they like it. They like when we interact with them. Find out what they *can* do and then talk to them about it. Instead of talking about what they *can't* do.

Me: Sophia, what do you think?

Gemma [interrupting Sophia]: Like, Annie... I thought that she can talk, so I'll ask her if she has any ideas. It doesn't matter if she can't see if she can sing along, right? So all you have to do is ask her, and then there she goes, off talkative!

In the interaction Gemma described, Annie had spoken up to suggest that the lyrics in the group's Thanksgiving-themed song ought to include "some grace to God." Gemma had drawn the group's attention to Annie's suggestion, and in

response the group members had all agreed the song's penultimate line should be changed to "Giving thanks as we gather/ with some grace to God."

I also made the related observation that during pre-session and post-session discussions over the course of the program, the students began to identify more seniors by name more frequently. In discussion after the first session only Kitty was mentioned by name, but over the next few weeks in pre-session and post-session discussions the children made multiple references by name to Kitty, Annie, Georgia, and Dolly.

### **Children's impressions of how the seniors communicated.**

Students shared various impressions of the seniors' communication throughout the program. Statements about perceived positive communication included language such as:

Gemma: They were pretty slow talkers, but if you waited a while they'd give you a response. . . just taking a little time to adjust to what you're asking. . . she understands me anyway.

Sophia: I talked to my partner more than I ever have!

Miriam: [It was] exciting... [because] we got to hear all the other people's past.

Gemma: She looked down at me, and she said, 'Hi!' and I said, 'Hi!' And we had a little conversation.

Children also made statements perceiving confusing or uncertain communication with the seniors, as well as articulating questions about communication, as in the following examples:

William: We described it to her [*referring to Annie*], and she couldn't understand what it looked like [*referring to Annie's inability to see a visual prompt the group was using*].

Sophia: She [*Susan*] was trying to talk to me, and say something to me, but it, she – I – it... just sounded like mumbling to me, so I couldn't understand.

Gemma: I couldn't understand her... and she kept on trying to tell me . . . I could understand a word or few, and I tried to make it out, but I couldn't really hear her, and then I couldn't really grab it...

Kaylin: What do you do if you don't understand them?

Sophia: How did you know what they were saying?

My field notes also included some instances where I perceived students as being confused about things the seniors were communicating, as in the following example where it seemed to me that Gemma either misunderstood or ignored a clear cue from Maggie:

*Should I (and how) discuss with Gemma the situation today where she was trying to hand Maggie a drum? It seemed that Maggie was clearly indicating she did not want to play or hold the drum, but Gemma kept forcing the drum towards Maggie. Gemma's posture was like a teacher. She used an infantilizing voice and body language as if talking to a small child. To me it seemed clear that Maggie was communicating she did not want to hold or play the drum and would prefer that Gemma played it herself, but Gemma didn't seem to notice that cue. Eventually a nurse went over to assist and Maggie consented to play the drum like Gemma wanted her to do.*

### **Children's perceptions about their own communication.**

Through in vivo coding of the discussion data, a theme also emerged around Gemma and Sophia's perceived efforts to communicate with the seniors despite interactive challenges. When these two girls expressed perceived barriers to communication, they typically also perceived themselves as making efforts to adjust their own communication in response. Although a few other children indicated agreement when these concepts arose during discussion, Gemma and Sophia were almost always the originators of these types of ideas. This is evidenced in Figure

4.22, documenting a conversation which was led by Gemma with Tucker expressing brief agreement and William mentioning a tangentially related idea about a blind person.

**Figure 4.22**

*Children's Perceptions about Adjusting Communication*

Gemma: Some of them did speak . . . they were both pretty slow talkers, but if you waited a while, they'd give you a response.

Me: You're right.

Gemma: Just taking a little time to adjust to what you're asking. Cause their minds don't work as well as ours do, so I sort of have to talk slowly so they understand me, but she understands me anyway. And then she nods, or she talks softly and I put my ear close. She's... fun. She's fun! And she has a lot of sarcasm.

Tucker: That was pretty good.

Gemma: Yeah, it was super fun. And she's... I don't know, but for some reason, sometimes what she says, like when I could understand her, she always made me giggle, cause she's so funny.

William: Did you know there was actually a blind person who got so good at echolocation that he could ride a bike?

Me: Well that's amazing. . .

In this dialogue, Gemma explained how she perceived her multi-step role in the communication process: (a) speaking slowly in order to be clearly understood, (b) waiting "a while" to receive a response, (c) recognizing either verbal or nonverbal reactions from seniors, and (d) listening carefully to understand them. As compared to Gemma, Sophia tended to articulate less complex perceptions of her own response to communication barriers, as in the following comment:

Me: So what do you do when you can't understand [what they are saying] at all?

Sophia: I just nod my head at it.

In my field notes, I observed that the children tended to show increased attempts at interaction with certain seniors whom they perceived as having

initiated some type of verbal or physical connection. After the second session, my field notes recorded emotional connections sparked by physical interactions between children and seniors:

*The children do not seem to know how to interact at all with Susan, and they are hesitant about talking to Connie. They interacted most comfortably with Georgia, Kitty, and Maggie. Those seniors have initiated with the children in some way.... Kitty reached out multiple times today to hold Elena's hand, and Maggie gave all the children high-fives at the end of the session which led to laughter and smiling from everyone including the nurses.*

My observation of physical touch sparking communication also arose from Gemma in Figure 4.23, a conversation where she mentioned her perceived positive experience with having held Annie's hand, as contrasted with my own experience of shaking Annie's hand and unintentionally startling her with my hand's cold temperature.

### **Figure 4.23**

#### *Gemma's Perceived Connection with Annie*

Gemma (child): The first day, they were like, really quiet, and I was nervous, and like now, as I'm getting used to them I can hold their hand...  
 Me: I saw that - did she ask to hold your hand, or did you reach out to her?  
 Gemma: Well I reached up, and she [Annie] looked down at me, and she... she said, "Hi!" And I said, "Hi!" And we had a little conversation.  
 Me: That's nice. What did you talk about?  
 Gemma: Well, uh... she just said, "Your hand is warm."  
 Me: Oh, haha... that's better than when I shook Annie's hand... and she said, "Ahhhh!!! Your hand is cold!" So you made her feel comfortable.  
 Gemma: Yeah. Well she had smiled at me, and I asked, "Could I hold your hand?" And she said, "Sure."

Other children besides Gemma also perceived physical interaction as part of the communication process. For example, after another session my field notes observed the children's increasing preferences to sit with certain seniors who they perceived as more prone to initiate interaction:



*The children have begun to ask for name tags of certain senior buddies - they remember certain people by name (sometimes) and express preferences for sitting by them. They tend to prefer being paired with seniors who are more talkative and interactive with them (like Maggie, Dolly, and Georgia). Some of the quieter children (like Miriam) who were anxious at first about having a senior buddy continue to ask to have another child their own age also partnering with their senior buddy.*

### **Seniors' perceptions.**

As discussed in the methods chapter, I collected a comparatively small amount of data through discussion with the seniors regarding their perspectives about the sessions. Though in less quantity, seniors' discussion data demonstrated similar themes to the discussion data collected from children. Emergent themes included enjoyment, relative group identity, and perceptions regarding communication with the children. The post-session conversation with Dolly in Figure 4.24 demonstrated her perception of the children's youthful, creative energy:

#### **Figure 4.24**

##### *Dolly's Impressions of Interacting with the Children*

Me: Dolly, thank you!

Dolly: Yes, you're welcome. You're certainly welcome.

Me: What did you think today about our story and our song?

Dolly: Yeah, yeah, I think... they're about the age where they can really enjoy it [referring to the children].

Me: Yeah you're right... they have lots of creative ideas, don't they?

Dolly: Sure, absolutely...? Don't you remember when you were that age?

Me: Sort of... it feels like a long time ago!

Dolly: *[Laughing]* I'm 82 years old.

Me: Oh my goodness! Well you have lots of creative ideas, too.

Dolly: Well thank you!

Dolly connected her observation about the children with a memory of being that age herself. In Figure 4.25, Maggie also expressed positive feelings of enjoyment during a post-session discussion, as well as uncertain feelings regarding future sessions.

**Figure 4.25***Maggie's Impressions Regarding Participation*

Me: Thank you Maggie!

Maggie: You're welcome! I'm so thankful I get to come here and visit. I just can't believe you would let me come.

Me: Oh, we are glad you could come. What did you think about our song today?

Maggie: Yes, everything was okay. I'm just glad I could come.

Me: Thanks Maggie. We'll see you again...

Maggie: I hope to see you soon. I doubt it if they'll let me come next week... I'll think on it.

Finally, in Figure 4.26, Gloria's comments in post-session group discussion indicated perceptions about herself in comparison with the children, as well as the children's impact on her thought processes during collaborative activities.

**Figure 4.26***Gloria's Impressions of Interacting with the Children*

Me: What did everybody think about the story today, do you have anything to share?

Elena: Good

Gemma: I liked it a lot, it was really fun to be able to interact with people who are much older and experienced much other things than me.

Me: Boy, how about that. You all have some wisdom to share.

Activities Director: That made Kitty smile! – Didn't it, Kitty? We don't always get told that, do we?

Georgia: As far as I'm concerned, being as old as I am, I have forgotten some things, when I... what happened when I was your age. And now?... When you get back in with me, ah... I start remembering them again. Go up, and up, and up, and I... I have a lot of stories in my mind.

**Integrating Data: Mixed Methods Analysis**

Consistent with my convergent mixed methods case study design, I integrated quantitative and qualitative data by: (a) putting both datasets side by side, (b) reflecting on their similarities and differences, and (c) discussing those observations with another researcher to consider their comparative meaning. Findings from this

analysis are summarized in Table 4.10. These findings included comparisons regarding students' attendance and attitudes, as well as comparisons regarding two different subsets of students: Gemma and Sophia versus Tucker, Kaylin, and Miriam.

**Table 4.10**

*Mixed Methods Data Analysis*

Major topics	Quantitative Results	Qualitative Results	Mixed Methods comparison
Students' attendance and attitudes	Consistent attendance corresponded with more positive attitudes on surveys	Students with more consistent attendance discussed more positive perceptions regarding participation	<i>Confirmation:</i> Students with higher program attendance rated their experiences higher on surveys, and confirmed these ratings by indicating more positive perceptions during discussion.
Gemma and Sophia	More unpredictable/variable survey scores throughout; rated several aspects of their experience lower than other children	Participated in creative sessions and discussion more frequently; expressed more agency regarding creative decisions; quick to share positive and/or multifaceted impressions regarding seniors' role in the group	<i>Discrepancy:</i> Gemma and Sophia's consistent expression of agency during creative sessions and their enthusiastic participation in discussion were incongruent with their lower survey scores.
Tucker, Kaylin, and Miriam	Typically rated the highest possible scores on all surveys throughout	More reserved during creative sessions and discussion; less likely to volunteer suggestions which redirected the creative process; expressed less complex perceptions of the seniors' role in the group	<i>Discrepancy:</i> Tucker, Kaylin, and Miriam's infrequent participation and/or expression of agency during creative sessions and discussion was incongruent with their higher survey scores.

## CHAPTER 5: CONCLUSIONS

### Conclusions

To draw conclusions, I considered my results through the lens of my purpose statement, which was to explore the meaning of participation and cross-generational interaction in a participatory, intergenerational music project from the perspectives of children and senior adults living with dementia. Taken together, my analysis of qualitative and quantitative data answered three research questions:

(1) How can the value of participatory creative arts as a dementia-friendly tool be observed in intergenerational settings?

(2) How do senior adult participants with dementia and child participants perceive the meaning and value of cross-generational relationships in context of participatory creative arts?

(3) How do qualitative and quantitative data compare or contrast regarding cross-generational collaboration in participatory creative arts processes?

In response to my purpose statement and research questions, I drew five conclusions. These conclusions, which I describe in the following paragraphs, were:

(a) Participatory creative arts can effectively make space for cross-generational participants to find dementia-friendly commonalities; (b) Participatory arts settings are valuable in that they offer honor numerous, diverse routes of access to the creative common space for both seniors and children; (c) For children, more consistent program attendance corresponded with overall more positive experiences; (d) While seniors' perspectives regarding cross-generational relationships remained stable and positive throughout the program, children's

perspectives about cross-generational relationships evidenced shifts towards more positive perceptions about seniors and more meaningful interactions with them; and (e) More research is needed to understand the impact of these types of programs and how to accurately represent participants' perceptions about them, since considerable discrepancies emerged among the qualitative and quantitative data during this study.

### **Utility of Participatory Creative Arts to Make Space**

From my results I concluded that participatory creative arts can effectively make space for cross-generational participants to find dementia-friendly commonalities. The participatory nature of the program sessions clearly allowed topics of commonality to arise among both child and senior adult participants. During this project, these emergent topics of commonality fit into certain thematic categories; namely, food and cooking, cultural traditions, and change or transition. Participants of both age groups expressed interest in conversing about these themes and actively contributed ideas connected to these themes during group discussion. From the platform of these common topics, participants of both age groups demonstrated agency to collectively explore, express creative preference, and generate original creative material. In this way both children and seniors indicated overall positive experiences with use of participatory creative arts as a tool. In many instances this tool sparked positive cross-generational interactions, through which participants indicated an increased sense of group belonging and more energized connections with their cross-generational peers.

Furthermore, specifically regarding participants with dementia, these topics offered dementia-friendly points of interaction from which seniors felt comfortable participating with the children. Dolly evidenced this by expressing her enjoyment in being involved with the children's creativity (Figure 4.24). Georgia's comment at the end of the second session (Figure 4.26) also succinctly expressed this perceived sense of group solidarity and the value of participatory arts to offer her space within the cross-generational setting:

As far as I'm concerned, being as old as I am, I have forgotten some things, when I... what happened when I was your age. And now?... When you get back in with me, ah... I start remembering them again. Go up, and up, and up, and I... I have a lot of stories in my mind.

Though the type of memory recall Georgia mentioned was neither the intent of the project nor a specific focus of data generation, it is notable that during creative sessions seniors frequently contributed memory-related content. These contributions demonstrated the utility of the emergent creative themes (i.e., food and cooking, cultural traditions, and changes or transitions) to honor memories when they organically surfaced, yet without pressuring seniors to produce specific memories or fixating on memory recall.

### **Utility of Participatory Creative Arts to Honor Diverse Access Routes**

From my results I also concluded that participatory arts settings are valuable in that they honor numerous, diverse routes of access to the creative common space for both seniors and children. Within the participatory creative context, both seniors and children found inroads to contribute in their own unique ways. Children indicated appreciation that the participatory arts medium provided them freedom to determine creative topics and guide session content. This was often evidenced

through their eager collaborative agency in the songwriting process, for instance, Sophia and Gemma's confident creative decisions regarding where and how certain instruments would be added to a song (Figure 4.10). For seniors, inroads to access were evidenced through more individualized expressions of creative agency. One example was Maggie's engagement in parallel storytelling alongside the large group discussion (Figure 4.7), through which Maggie's unique contributions were validated and included by the group. Another example was Georgia's plan to bring out items from her room next week, which she determined would relate to the group's chosen creative topic (Figure 4.8). Though the idea of doing this was not suggested by me or any other participants, Georgia determined it would be a fitting way for her to contribute to the group process.

Although these examples demonstrated that both child and senior adult participants expressed agency in accessing the creative process, the children tended to express more natural confidence in their unique creative approaches than did the seniors. Furthermore, in the group context seniors were more reticent than children and often deferred to the children's ideas (Figures 4.13 and 4.14). It is important to note that although I concluded the participatory creative arts setting was capable of honoring multiple routes of access for participants, in some instances the project's structure seemed insufficient to fully accommodate everyone's preferred creative participation, as I discuss more fully in the Limitations below.

### **Consistent Program Attendance and Positive Experiences**

Data suggested that for children, more consistent program attendance corresponded with more positive experiences. For the majority of children, more

consistent program attendance corresponded with more positive attitudes towards their experiences (i.e., seniors, the intergenerational setting, and the participatory arts collaboration). Integration of quantitative and qualitative data through mixed methods analysis (see Table 4.10) confirmed that higher attendance corresponded with a more positive experience. It was unclear from the data whether consistent attendance caused more positive experiences, or whether consistent attendance was an effect of more positive experiences. There likely were many other complex factors involved in this relationship which I did not examine in this study.

### **Seniors' Stable Perspectives and Children's Shifting Perspectives**

I concluded that while seniors' perspectives regarding cross-generational relationships remained stable and positive throughout the program, children's perspectives about cross-generational relationships evidenced shifts towards more positive perceptions about seniors and more meaningful interactions with them. Throughout the course of the program, seniors consistently expressed appreciation for the children and enjoyment of the cross-generational interaction (Figures 4.24, 4.25, and 4.26). By contrast, children expressed shifting perceptions of their own role within the group and seniors' roles within the group. After the first and second sessions, many children expressed confusion or even mild unease about aspects of the seniors' behavior, medicalized aspects of life at RC, and their own uncertainty about how to respond and interact with seniors (Figure 4.19). Some children appeared to resolve this perceived problem relatively easily, or at least just without much need to further discuss it, as the observations they made during discussion gradually shifted away from fixation on perceived differences and towards



observations about the shared creative process. For other children, the shift was more nuanced: they expressed a heightened sense of respect for the seniors as making valuable contributions and having equal status within the group (Figures 4.20 and 4.21). Notably, children also perceived adjustments to their own roles within the group; they expressed agency to adapt their communication approaches in order to connect with seniors in a way they deemed more successful (Figure 4.22).

Overall, by the end of the program the majority of the students expressed perceived warmth in communication with the seniors. This shift was not evident from survey responses, in which the children did not rate any substantial increase or decrease over the course of the program regarding their ability to make connections with the seniors. Yet through their discussion responses and the trajectory of their session participation, children indicated a degree of increasing comfort with being physically present in the RC memory care neighborhood and interacting with seniors.

### **Need for More Research to Address Data Discrepancies**

Finally, I concluded that more research is needed to understand the impact of these types of programs and how to accurately represent participants' perceptions about them, since considerable discrepancies emerged among the qualitative and quantitative data during this study. The way children expressed their perceptions on the surveys was to some degree inconsistent with perceptions they expressed through session participation and discussion. Two different kinds of interesting

discrepancies emerged: one kind regarding Gemma and Sophia, and another kind regarding Tucker, Miriam, and Kaylin.

#### **Data discrepancies regarding Gemma and Sophia.**

The first data discrepancy emerged regarding Gemma and Sophia. These two children had overall more unpredictable, variable survey scores and they rated several aspects of their experience lower than other children, yet during the sessions Gemma and Sophia not only participated more frequently than most other children but also expressed higher perceived agency regarding generation of creative material. Also, during pre-session and post-session discussion, Gemma and Sophia tended to engage more than other students and were quick to share positive impressions about the seniors and the sessions.

#### **Data discrepancies regarding Tucker, Kaylin, and Miriam.**

In contrast with Gemma and Sophia's participation versus their surveys, the opposite discrepancies arose regarding Kaylin, Tucker, and Miriam. These three children typically rated the highest possible scores on all their pre-session and post-session surveys for the duration of the program, yet during the creative sessions and discussions they were much more reserved than Gemma and Sophia. Kaylin, Tucker and Miriam were also less likely to volunteer suggestions that would redirect the creative process, nor did they typically express complex perceptions about the seniors' role in the group the way Gemma and Sophia did.

### **Discussion**

To understand my conclusions in relation to existing literature, I returned to my purpose statement, which was to explore the meaning of participation and

cross-generational interaction in a participatory, intergenerational music project from the perspectives of children and senior adults living with dementia. Overall, I found that my first two conclusions regarding the utility of participatory arts were in keeping with findings from similar past research studies (e.g., Allison, 2008; Bahlke et al., 2019; Basting, 2009; Benyon & Alfano, 2013; Friedman, 2011; Harris & Caporella, 2018; Thibeault, 2015; Turino, 2008; Varvarigou et al., 2011; Vigliotti et al., 2018). Likewise, I was unsurprised by the connection between children's attendance and their overall experience, in light of research about best practice and logistical considerations for intergenerational programs (Baker et al., 2017; George, 2011; Harris & Caporella, 2018; Higgins, 2012; Kaplan, 2002; Wiersma et al., 2016). Need for more speculative discussion arose in regard to my conclusions about discrepancies between qualitative and quantitative data among certain subsets of children. Below I discuss these points of connection to my conclusions.

### **Utility of Participatory Arts**

As a result of this study, I made two conclusions about the utility of participatory creative arts: (a) that participatory creative arts can effectively make space for cross-generational participants to find dementia-friendly commonalities; and (b) that participatory arts settings are valuable in that they offer honor numerous, diverse routes of access to the creative common space for both seniors and children. Both of these conclusions paralleled much existing literature about participatory, dementia-friendly, and intergenerational communities. As has been observed in other intergenerational music-making settings, both children and senior adults living with dementia expressed perceived benefits of their musical

collaboration (e.g., Benyon & Alfano, 2013; Harris & Caporella, 2018; Sattler, 2013; Varvarigou et al., 2011). Notably, participants' expression of these perceived benefits was intimately connected with their appreciation of—or growth in—cross-generational relationships throughout the program. This finding supports prior researchers' assertions (e.g. Allison, 2008; Basting, 2009; George, 2011; Friedman, 2011) that in regard to building dementia-friendly communities, overall wellness is intrinsically linked to community-building initiatives. Furthermore, in keeping with previous researchers' assertions (e.g., Basting, 2009; Bahlke et al., 2019; Friedman, 2011; Sattler, 2013; Thibeault, 2015; Turino, 2008; Vigliotti et al., 2018), the participatory creative arts setting provided participants with a powerful tool to make these interpersonal connections and maximize their resulting sense of community. As researchers have also suggested (e.g., Basting, 2011; Higgins, 2012; Meuser & LaRue, 2011; Wiersma et al., 2016), the reason for participatory arts' utility is likely its process-oriented nature, through which individuals collaborate to create and re-tell original stories or songs; their resulting joint ownership of this creative material naturally inculcates a sense of group hospitality and solidarity leading to empathy and respect among participants. This process makes sense in light of intergroup contact theory (Harris & Caporella, 2018; Pettigrew et al., 2011).

Specifically regarding dementia and participatory creative arts, seniors' contributions to this project powerfully affirmed previous researchers' assertions that dementia does not preclude the ability to imagine, create, and express meaning (e.g., Allison, 2008; Bunt & Stige, 2014; Camp & Antenucci, 2011; Friedman, 2011; Godoy, 2007). Not only did seniors affirm their overall perceived value of

participation in an arts project as has been observed in many other landmark studies of arts in senior adulthood (e.g., Cohen, 2006; Hallam & Creech, 2018; NEA, 2017), but also seniors' participation overcame stereotypical expectations about arts abilities while living with dementia. As in previous studies of participatory arts settings (e.g., Allison, 2008; Basting, 2009; Friedman, 2011; Songwriting Works, 2019), the seniors living with dementia in this project demonstrated agency as equal partners with the children in the creative process. This likely occurred because the participatory arts setting allowed the group to honor seniors' memories yet without regretful fixation on the past or regret over perceived losses in ability, as has been suggested by Camp and Antenucci (2011), Daykin et al., (2017), and StoryCorps (n.d.).

### **Attendance and Experiences**

Data suggested that for children, more consistent program attendance corresponded with overall more positive experiences. It was unclear whether consistent attendance was a cause of children's positive experiences or an effect of their positive experiences. Likely the appearance of this correlation was influenced by a complex set of other factors which I did not study during this project. Yet overall, the small-scale appearance of such a connection aligns with the body of research suggesting the extent to which intergenerational programs are effective correlates with the amount and quality of time children spend with seniors (Baker et al., 2017; Kaplan, 2002). In the case of this program, children who attended consistently most likely felt a higher sense of belonging and investment in the group. This aligns with researchers' suggestions that significantly positive

intergenerational growth occurs when participants develop relationships organically over a more extended period of time (George, 2011; Harris & Caporella, 2018; Kaplan, 2002). In contrast, the children with lower attendance likely felt less connected to the other participants and the group purpose, in keeping with researchers' suggestions that without interpersonal rapport, people cannot enjoy meaningful group membership (e.g., Basting, 2009; Friedman, 2011; Higgins, 2012; Wiersma et al., 2016). Especially considering the participatory nature of session activities, the children with lower attendance may have felt less comfortable, since participatory environments depend upon all participants' active, ongoing, and communal engagement (Turino, 2008).

### **Children's Shifting Perspectives**

I concluded that while seniors' perspectives regarding cross-generational relationships remained relatively stable and positive throughout the program, children's perspectives about these relationships evidenced shifts towards more positive perceptions about seniors and more meaningful interactions with them. Children did initially evidence some tendencies of internalized dementia stigmas, in keeping with typical findings of other researchers (e.g., Aday et al., 2008; DEEP, 2014; Gilbert & Ricketts, 2008; Harper, 2014). Overall, the children's lessened tendency towards dementia stigma throughout the program showed a similar trajectory to the results of comparable studies by George (2011), Harris and Caporella (2018), Reynolds et al. (2016), and Wiersma et al. (2016). Notably, for some of the children this shift occurred in connection with change to their own perceived roles in the group. As the children developed increasing understanding of

how to communicate with the seniors and creatively adjusted their own interactions and responses, they were paralleling research by Allison (2008), Basting (2009), Friedman (2011), StoryCorps (n.d.), and Windle et al. (2019) on how to overcome communication barriers when interacting with people living with dementia.

### **Addressing Data Discrepancies**

Because of the discrepancies emerging between children's survey data and their participation in sessions and discussion, I concluded more research is necessary to find more nuanced ways to explore and highlight children's perspectives in these types of contexts. A number of factors may have affected these data discrepancies; possibly certain children did not find the survey questions and rating scales a useful tool to clearly express their perspectives, or the manner in which I facilitated sessions or discussion did not offer them adequate space to contribute. However, it is also possible that the particular discrepancies which arose during this study offer more complex insights into the children's experiences. Although the reasons for these discrepancies remained unclear In Kaylin, Tucker, and Miriam's data, the surrounding body of literature offered insight into those in Gemma and Sophia's data.

#### **Data discrepancies: Gemma and Sophia.**

A number of factors may have been involved in the discrepancy between Gemma and Sophia's qualitative and quantitative data. Since, as mentioned previously, Gemma and Sophia were the students with the highest attendance of any children, their higher level of engagement may simply make sense in light of the research on intergenerational bonding (Baker et al., 2017; George, 2011; Harris &

Caporella, 2018; Kaplan, 2002). Windle et. al's (2019) theory of creative care may also help explain why Gemma and Sophia's tendency to more personalized investment may have offered them more opportunities to recognize, familiarize themselves with, and appreciate the seniors' subtly diverse ways of communicating. In fact, as compared to other students, Gemma and Sophia expressed heightened awareness about their empathy and concern regarding senior adults' identity and belonging within the group. Possibly this empathy led both Gemma and Sophia to have a more turbulent experience of emotionally high and low moments during the project, when they either perceived that communication and creative activities were going well, or they felt discouraging incidents had occurred. This may explain these two children's variable survey scores. Although at first glance their survey responses seemed inconsistent with their session participation, both types of data considered together may actually have indicated a higher degree of cognitive dissonance occurring for Gemma and Sophia as they processed the complexities of their interactions with seniors.

***Gemma's cognitive dissonance and resolution.***

For Gemma in particular, this experience of cognitive dissonance and resolution seemed to pivot around her perception of one specific interaction with Annie, the moment when Annie added a line to the "Thanksgiving" song. Since Annie had spoken comparatively little in previous sessions, several other adult participants in the room besides Gemma seemed especially touched by Annie's intentional point of entry to the group's creative process and the thoughtful contribution Annie chose to make to the song. However, for Gemma this experience



seemed to have an added dimension. Gemma perceived her own role in the situation as being the first person who noticed Annie's intent to participate and personally made space for Annie to contribute a creative idea of great aesthetic value to the group. It was an instance of Gemma noticing and highlighting a "celebratory narrative" (Higgins, 2012, p. 156) on Annie's behalf.

This perspective from Gemma was markedly different from her perspectives about seniors during the first few sessions, during which she was highly engaged in the creative process but expressed interest in the seniors' contributions mainly because she perceived them as amusing, not necessarily equal partners. At the beginning of the program it also seemed likely Gemma was working through frustrations about unmet expectations regarding the seniors' participation. One example of this was Gemma's expression of disappointment bordering on personal offense when Susan chose to leave the room during a session: "I thought she wasn't interested in us and we were... boring, she wasn't excited. Made me sad." Another example was the instance recorded in my field notes from the third session where Gemma seemed strongly convinced Maggie ought to hold a drum and urged her to do so in an infantilizing voice, either unaware of or unconcerned by Maggie's non-verbal cues that she would prefer not to take the drum. In both of these instances, Gemma expected the senior participants to fulfill a certain role in the group and expressed disappointment or frustration when they did not. By contrast, after Gemma experienced a "celebratory narrative" (Higgins, 2012, p. 156) with Annie during the sixth session, she expressed a different perspective about the seniors'

role in the group which was not unlike Kitwood's Theory of Personhood (Brummel-Smith, 2008):

I realize that they're equals. Just because they have some other... just because they're different from us, doesn't mean we have to treat them like they're dolls or fragile... They can have a little fun too! Being treated like a doll and fragile isn't very fun... I don't think they like it [when we treat them like that]. They like it when we interact with them. Find out what they *can* do and then talk to them about it. Instead of talking about what they *can't* do... like Annie, I thought that she can talk, so I'll ask her if she has any ideas. It doesn't matter if she can't see if she can sing along, right? So all you have to do is ask her, and there she goes, off talkative.

Since Gemma expressed this shifted perception in context of interaction, it seems likely the tool of participatory arts was here helping Gemma develop increased respect for the seniors' creative agency and dignity. Gemma's experience was similar to participants in George et al.'s (2011) research, which makes sense in light of Windle et al.'s (2019) theory of creative care. Through this interaction Gemma possibly even came to view herself in the role of a facilitator, in the style of Camp and Antenucci's (2011) Montessori-based approach. In fact, Gemma's statement above directly echoes Camp and Antenucci's advice that facilitators make more meaningful connections and diminish stigma when they focus on celebrating what participants can do rather than regretting what they cannot do.

**Data discrepancies: Kaylin, Tucker, and Miriam.**

In contrast to Gemma and Sophia, Kaylin, Tucker, and Miriam rated the highest possible scores on surveys, yet they: (a) participated less during creative sessions and discussions, (b) were less likely to demonstrate agency in the creative process, and (c) expressed less complex understandings of their roles in relation to the seniors adults. The reasons for this did not clearly emerge during this study.

Possibly these students were already very familiar with someone living with dementia in their family or community; as a result, they may have felt no need to entertain the same level of cognitive dissonance that Gemma and Sophia seemed to experience. It is also possible some aspects of the program structure did not provide them with an environment comfortable enough to be more open about their perceptions, or perhaps the program did not provide enough educational support and debriefing as Baker et. al (2017) suggest is necessary. Or, as explored more fully below in the limitations, the participatory arts framework may not have offered these children their preferred type of creative space.

### **Limitations, Implications and Recommendations**

In addition to the data-driven conclusions presented and discussed above regarding the meaning of participation and cross-generational interaction from the perspectives of children and senior adults living with dementia, some limitations and implications also emerged from this study. It was clear that a number of other complex factors affected participants' experiences, as well as my ability to understand and accurately portray participants' perspectives. Further research could help address some of these issues and explore further questions which arose during my data generation and analyses.

#### **Need for Additional Space in the Creative Process**

Although my participatory arts experience provided participants multiple points of access to creative space during this project, in some instances the program structure did not fully accommodate all participants' needs. In particular, it seemed some participants would have benefitted from being offered more space, different

types of space, or different outlets for participation in the creative process. Not only the storytelling/songwriting process but also the data generation and analyses focused mainly on participants' verbal contributions; this likely limited a few participants who indicated potential to contribute in other ways. As facilitator I was prepared with strategies to honor all types of verbal contributions, even unexpected ones, but I had not budgeted room for sessions to include other modes of creative expression. For instance, while Susan verbally contributed very little throughout the program, she frequently swayed in her seat, moved rhythmically, and several times stood up to dance during songwriting or singing. These actions may have indicated that Susan would have preferred to contribute in a different way other than collaborating on lyrics and melody. Although during the sessions the RC activities director helped acknowledge and include Susan's contribution by dancing with her, my overall group process and data collection did not equitably represent and honor Susan's contributions. Likewise, Maggie repeatedly expressed a need for more space or time to think (e.g., Figure 4.14), possibly indicating some aspect of the program structure was incompatible with her creative needs. This occurred not only with seniors, but also with children. For example, Tucker did not verbally contribute to the creative process unless directly addressed, but in conversation after one of the sessions he briefly mentioned that he particularly enjoyed drawing and often made his own comic strips. Yet not only did the session format prevent Tucker from any opportunities to employ visual arts, but also my data collection included very little opportunity to recognize or highlight his potentially preferred mode of artistic expression. As a result of these observations, I identify a need for future research to

explore possibilities for participatory arts programming to offer more creative space, different types of spaces, and different outlets for creative expression.

### **Recording Considerations**

RC's privacy requirement restricted data generation to only recording audio during sessions, without video. Unfortunately, this restriction prevented complete acknowledgement of participants' perspectives, since many participants communicated in nonverbal ways including gestures, facial expressions, and body language or movement. While meaningful, these contributions were lost during transcription as they could not be discerned by listening to the audio recording alone. The lack of video also prevented full understanding of the nature of individual seniors' participation, because some senior participants chose to be present for certain parts of the sessions and leave the room at other times—yet the audio recordings did not provide enough information for me to accurately transcribe those details. Finally, for convenience I chose to use my phone app to record the sessions, and to some degree the resulting audio quality proved insufficient to provide a complete transcription of everything occurring during sessions (e.g., when quiet conversations occurred at the edge of the group). For these reasons, future researchers might consider finding more robust audio recording solutions or securing access to video-record sessions, in order to more fully and accurately represent participants' contributions.

### **Logistical Considerations**

Given that the study focused on building community yet the sessions only spanned eight weeks' duration, time constraints likely also affected the results. The

timing of the program during the fall season made consistent attendance difficult for some families due to holiday travel commitments. Additionally, the after-school period was not an ideal time for this type of program. Many students were tired from the school day and ready for a less structured after-school activity. Especially for younger students, it was sometimes apparent that mental fatigue hindered their ability to participate. Future programs and researchers might carefully consider how choices regarding session logistics could impact intergenerational interactions. Where possible, further research attempting to generate data through methods children view as academic (e.g., surveys and formal discussion) might best be implemented as a part of the regular school day rather than after school. Additionally, whenever possible these types of intergenerational programs ought to involve a broader range of community stakeholders including teachers, children's parents, and family members or caregivers of people living with dementia. Doing so would help provide a more organically-supported, well-integrated experience for all participants.

### **Fully Representing Seniors' Voices**

Due to the combination of logistical constraints and the children's naturally higher energy as compared to the seniors, I ultimately generated more diverse and comprehensive data highlighting the children's perspectives. By comparison, data highlighting the seniors' voices was equal neither in depth nor scope. I originally intended to offer seniors surveys like the ones children completed, but was unable to do so. As a result, seniors were only able to express their perspectives during sessions and group discussion. Furthermore, even during sessions some seniors

evidenced a need for more intentional space to think and contribute during the participatory arts activities (e.g., Maggie, in Figure 4.14). At times the children's quick responses filled the creative space so quickly that more reticent senior participants were left little chance to contribute. The comparatively small amount of data I generated from seniors limits the generalizability of my findings regarding their perspectives. It would be helpful for future researchers to highlight senior participants' perspectives more fully, as championing their voices could help combat dementia stigma. Having multiple facilitators and/or researchers participating in intergenerational programs could not only help mitigate this imbalance in data collection but also help better support all participants.

### **Deconstructing Stigma**

Considering the children's shift in their initial negative impressions about dementia and the overarching societal need to build dementia-friendly communities, in future projects it would be helpful to generate more data regarding children's previous experiences with dementia. I did not specifically address this type of information in data collection, yet it seemed evident that most child participants had to some degree already internalized a complex and layered narrative surrounding dementia. These narratives were certainly not deconstructed—nor even fully explored—by the eight participatory arts sessions alone. More in-depth opportunities to build relationships with participants could have helped to uncover and more specifically address individual stigmas. In particular, it would be helpful for future researchers to explore whether child participants have had previous experiences interacting with people with dementia

in school, at home, or in their communities. Conducting more research on the origin of children's narratives surrounding aging and memory loss would help future facilitators understand how to better structure dementia-friendly intergenerational programs.

### **Role of Participatory Arts**

Although the program's main tool of participatory creative arts led to several exciting successes, it could also be argued the program's fixation on this tool restricted participants' abilities to form meaningful relationships in other ways. In one sense, engagement in the shared process naturally counteracted stigma, but in another sense, it focused participants away from each other. The sessions' exclusive focus on creative generation at times left participants little space to organically communicate. Future programs like this one would benefit from the inclusion of more flexible, unstructured time for participants to interact in large groups, small groups, and one-on-one. By the end of this program, child participants began to suggest their own ideas for how this could be practically accomplished. For instance, children wanted to play games or do crafts with seniors, have a sharing time to show seniors things they had done at school about which they were particularly proud, or sing Christmas songs and do other seasonal activities together with seniors as the holidays approached. Though this project did not have the capacity to expand on those suggestions, future programming ought to consider a more well-rounded structure incorporating these types of suggestions from its participants. Participatory arts should be used as supplemental activities in context of broader



social interactions, not as a replacement for other types of relationship-building activities.

### **Epilogue**

Throughout this project it has been an honor to explore the perspectives of children and senior adults living with dementia regarding their participation and interactions during our participatory music program. In considering this project's overall meaning, it seems best to return to the participants' voices. I would suggest second-grader Sophia and senior adult Georgia's conversation about cooking soup might be borrowed as a metaphor:

Sophia: I like cooking! I cook with my grandma. My favorite thing to cook is soup.

Georgia: Soup? Ohhhh!!! You can do so many different kinds of soup, but you don't have to have a recipe for... you can just... just - think about them and.... put them all together.

Sophia: Yeah, my grandma helps me, helps me make up my own soup.

As both Georgia and Sophia have experienced, the joyful spontaneity of making soup is found in not always adhering to a recipe. As Georgia surely knows through her years of accumulated wisdom, "you can do so many different kinds of soup;" the only thing required is some creative thought regarding the ingredients on hand and how to "put them all together." As Sophia adds, it works even better when someone "helps me make up my own soup." In this same way, RC elders and ES children showed admirable vulnerability to approach this collaborative project without a recipe; often they extended cross-generational help to one another through their creativity and spontaneity. Although continued research on participatory music and intergenerational interactions is vital in the efforts to break down stigma and build more dementia-friendly communities, we would also do well to more often let our

children and our elders living with dementia take the lead by getting into the figurative creative kitchen to just go ahead and “make up [their] own soup.” Akin to Friedman’s (2011) description of the participants’ voices shining through the *Songwriting Works* process as integral parts of a patchwork quilt or mural, in this project the children and seniors’ voices each contributed unique and unexpectedly delightful flavors in a cross-generational musical gumbo. What other creative ventures might our elders and children undertake if given more chances to collaborate? They surely have more left to tell; as Georgia put it, “And now?... When you get back in with me, ah... I.... Go up, and up, and up, and I... I have a lot of stories in my mind.”

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## APPENDIX A: SESSION PLANS

### SESSION ONE PLAN

**Group Welcome:** No children will be present for the first session. Upon entering the neighborhood, the facilitator will greet each participant, welcome them, give them nametags, and then invite them to sing a familiar song together.

#### **TimeSlips creative storytelling:**

- Facilitator explains that participants are going to make a creative story together. Seniors are welcome to share their ideas, or to listen to others' ideas.
- Facilitator shares a prompt (prompts are provided by the TimeSlips program)
- Facilitator asks open-ended questions to begin the story: who, what, where, when?
- Facilitator asks questions about sensory details to expand the story, especially directing participants' creative attention to aural aspects of the story such as noises, sound effects, or musical experiences.
- Facilitator echoes each participant's contributions to affirm and validate all ideas
- Facilitator records all shared ideas in writing on a large flipchart visible to the storytellers. Ideas are captured in chronological order, or by grouping similar ideas.
- Facilitator pauses several times during the collaborative process to retell the story and ask the storytellers for more detail or clarification.
- When the group energy fades, ask the group to decide whether the story is over.
- Facilitator gives a final dramatic retelling of the story, enlisting group participation.

**Group Discussion/Closure:** After the facilitator thanks all the participants for their contributions, seniors will be asked to share their perceptions and give ideas for next week's session: "What did you think about the story we made today? What part did you like the best/least? What instruments/music should we add to our story? What story should we create next week?" If time, the group will close with a familiar song.

### SESSION TWO PLAN

**Student Discussion:** This is the first session children will attend. After school dismissal, students will eat a snack and walk to RC with the facilitator. Before this session, children will be asked to briefly share their experiences and ideas about dementia: "What do you know about dementia/people living with dementia?" Upon arrival at RC the students will meet in the lobby with a RC staff member who will



give them an introduction to the memory care facility and share information with them about interacting with seniors living with dementia. This is a typical procedure for new groups volunteering at RC.

**Group Welcome:** Upon entering the neighborhood, children will be given nametags and paired with a senior “buddy,” also wearing a nametag. Buddy pairs will be seated in a semi-circle in the central gathering space. Students may be prompted with questions to ask their buddies, depending on participants’ communicative ability. After a brief time to greet one another, participants will be welcomed and invited to sing a familiar song together.

**Retelling:** The facilitator will lead retelling of the story written last week, enlisting help from seniors and allowing time to make changes or add new ideas if desired.

**Creating a new story:** The facilitator will explain that we are going to create a new story together today. Providing a new TimeSlips prompt, the facilitator will lead the same storytelling process as last week.

**Group Discussion/Closure:** After thanking all the participants for their contributions, children and seniors will be asked to share their perceptions and give ideas for next week’s session: “What was your favorite/least favorite part of the session today? What should we add next week?” If time, the group will close with a familiar song.

**Student Debriefing:** Upon leaving Elm neighborhood, students will be asked to complete the six-question survey. Students will walk back to ES and parents will pick them up at the school.

### **SESSION THREE PLAN**

**Group welcome:** Students will eat a snack and walk to RC. Upon entering the Elm neighborhood, children will be given nametags and asked to find their senior “buddy,” also wearing a nametag. Buddy pairs will be seated in a semi-circle in the central gathering space. Students may be prompted with questions to ask their buddies. After a brief time to greet one another, participants will be welcomed and invited to sing a familiar song together.

**Retelling:** The facilitator will help with retelling last week’s musical story; students and seniors may assist if comfortable.

**Musical Story Play:** Facilitator will offer opportunities to add music to the spoken story.

- **Instruments:** The facilitator will provide a box of various hand percussion instruments accessible to students and seniors (small drums, shakers, sound effects, etc.). Students and seniors will be invited to explore the timbres of each instrument. The facilitator will ask open-ended questions about sounds

which might accompany each story, and the group will collaborate to choose instruments to add to the story. Certain words or phrases in the story might lend themselves to rhythmic recitation, or alternatively the instruments might be used to create a soundscape unrelated to the words of the story.

- **Melody:** The facilitator can also ask participants to give a melody matching words or phrases in the story. If several ideas are given, group consensus will help determine which to keep or how to combine the ideas into one. If the group does not have ideas, the facilitator might offer several ideas to spark creativity.
- Facilitator pauses several times during the collaborative process to retell the story with musical components and ask the storytellers whether they like it or not.
- When the group energy fades, the facilitator asks the group to decide whether the music is complete.
- The creative process builds to a final dramatic retelling of the story with musical accompaniment, enlisting student and senior participation.

**Group Discussion/Closure:** After thanking all the participants for their contributions, children and seniors will be asked to share their perceptions and give ideas for next week's session. If time, the group will close with a familiar song.

**Student Debriefing:** Upon leaving Elm neighborhood, students will be asked to complete the six-question survey. Students will walk back to ES and parents will pick them up at the school.

#### **SESSION FOUR PLAN**

**Group welcome:** Students will eat a snack, put on a nametag, and walk to RC. Upon entering the Elm neighborhood, children will be asked to find their senior "buddy" and give them a nametag also. Buddy pairs will be seated in a semi-circle in the central gathering space. Students will be prompted with a discussion question for their buddies about the fall season and favorite things/favorite foods, etc. After a brief time to greet one another, participants will be welcomed and invited to sing a familiar song together.

**Retelling:** The facilitator will lead retelling of the story/poem written last week, enlisting help from students and seniors and allowing time to make changes or add new ideas if desired.

**Musical Play:** The facilitator will offer opportunities to add music to the spoken story. One possibility could be adapting the poem into a song by choosing certain favorite sections of the written phrases and altering them to become lyrics. Alternatively, the participants might prefer to keep the poem in its entirety and create a soundscape accompaniment with instruments.

- **Instruments:** Facilitator will provide a box of various hand percussion instruments (small drums, shakers, sound effects, etc.). Students and seniors will be invited to explore the timbres of each instrument. The facilitator will ask open-ended questions about sounds which might accompany each story, and the group will collaborate to choose instruments to add to the story. Certain words or phrases in the story might lend themselves to rhythmic recitation, or alternatively the instruments might be used to create a soundscape unrelated to the words of the story.
- **Melody:** The facilitator might also ask participants to give a melody matching words or phrases in the story. If several ideas are given, group consensus will help determine which to keep or how to combine the ideas into one. If the group does not have ideas, the facilitator might offer several ideas to spark creativity.
- Facilitator pauses several times during the collaborative process to retell the poem with musical components and ask the storytellers whether they like it or not.
- When the group energy fades, the facilitator will ask the group to decide whether the music is complete.
- The creative process builds to a final dramatic retelling of the piece with musical accompaniment, enlisting student and senior participation. If the group feels the piece is not yet complete, we might retell today's work and then plan to return to the piece next week.

**Group Discussion/Closure:** All participants will be thanked for their contributions. Both children and seniors will be asked to share their perceptions and give ideas for next week's session: "What do you think about our piece? What was your favorite/least favorite part of the session today? What should we add next week?" If the group agrees that the "Memories" poem is complete, ideas will be solicited for a new poem/song topic next week. If time, the group will close with a familiar song.

**Student Debriefing:** Upon leaving Elm neighborhood, students will be asked to complete the six-question survey. Students will walk back to ES and parents will pick them up at the school.

## **SESSION FIVE PLAN**

**Group welcome:** Students will eat a snack, put on a nametag, and walk to RC. Upon entering the Elm neighborhood, children will be asked to find their senior "buddy" and give them a nametag also. Buddy pairs will be seated in a semi-circle in the central gathering space. After a brief time to greet one another, participants will be welcomed and invited to sing a song together.

**Retelling:** Children and seniors will participate to their degree of comfort in the retelling, playing, and singing of the "Memories" poem/music created last week.

**Songwriting:** The facilitator will introduce the idea of creating a new piece of music centered around one of the topics suggested last week. The facilitator will encourage discussion about the topic towards group consensus (Topic chosen: Thanksgiving)

- **Make a word list:** The facilitator will ask students and seniors to name words associated with the topic; all contributions will be written on the flipchart. Depending on the topic and the amount of answers given, the facilitator may also ask additional questions and create several different related lists.
- **Begin writing lyrics:** The facilitator will ask, “How do we want to start our song?” If participants are uncertain, additional questions related to the word list may prompt discussion. All contributions will be recorded on the flipchart. Once various phrases are on the flipchart, see whether any might rhyme, be easily made to rhyme, or connect in some other way. Two rhyming lines might begin the song, or alternatively a line repeated several times might begin the song.
- If time allows, this process may continue for the creation of a chorus or a second verse. If not, build to a final performance of what has been written so far, and then close with the intent to continue next week.

**Group Discussion/Closure:** Both children and seniors will be asked to share their perceptions and give ideas for next week’s session.

**Student Debriefing:** Upon leaving Elm neighborhood, students will be asked to complete the six-question survey. Students will walk back to ES and parents will pick them up at the school.

## SESSION SIX PLAN

**Group welcome:** Students will eat a snack, put on a nametag, and walk to RC. Upon entering the Elm neighborhood, children will be asked to find their senior “buddy,” greet them, and give them a nametag also. Buddy pairs will be seated in a semi-circle in the central gathering space.

**Retelling/Reviewing:** Once everyone has been greeted, children and seniors will participate as comfortable in singing the beginning lines of the “Thanksgiving” song created last week, and also the first verse of the hymn one of the seniors introduced last week - “We Gather Together.”

**Songwriting:** The group will review the list of words from last week related to Thanksgiving (reorganized by facilitator into several categories). Additional words may be added.

- **Rhyming words:** If participants choose, they may create a list of words that rhyme with the ending word of the first line/lines. Then, participants will create sentences that end with one of those rhyming words and can fit

rhythmically with the first line. Continue this process to build on the song until a first verse is created.

- **Choosing a harmony:** The facilitator will offer various simple, repeated chord pattern improvisations (e.g. C, F, amin, G, or C, F, amin, etc.) and participants choose one they prefer.
- **Creating a melody:** The facilitator will ask participants to improvise a melody that will fit the lyric for the next line of the verse. Participants think or hum their melody quietly while the facilitator plays the chord progression. Repeat this several times while participants build confidence in their idea. Then, participants sing out loud, and with less accompaniment. Point out and echo the ideas, especially if some participants' ideas combine into similar threads. Allow the group to come to consensus about which to use.
- **Cumulative verse creation:** Sing what has been created together, then ask participants to individually improvise the next line, etc. If the second line emerges the same as the first, encourage the third line to be something completely different – different starting pitch, different melody, etc.
- **Inclusion of the hymn:** Might the suggestion of the hymn “We Gather Together” be included with the original song in some way?
- If time allows, this process may continue for the creation of a chorus or a second verse. If not, build to a final performance of what has been written so far, and then close with the intent to continue next week.

**Group Discussion/Closure:** Both children and seniors will be asked to share their perceptions and give ideas for next week's session.

**Student Debriefing:** Upon leaving Elm neighborhood, students will be asked to complete the six-question survey. Students will walk back to ES with the researcher and parents will pick them up at the school.

## SESSION SEVEN PLAN

**Group welcome:** Students will eat a snack, put on a nametag, and walk to RC. Upon entering the Elm neighborhood, children will be asked to find their senior “buddy,” greet them, and give them a nametag also. Buddy pairs will be seated in a semi-circle in the central gathering space.

**Retelling/Reviewing:** Once everyone has been greeted, children and seniors will participate as comfortable in singing the “Thanksgiving” song created last week.

**Additional verses:** If the song is not finished, last week's process may be repeated to continue adding verses until participants agree it feels completed.

**Musical Play:** If participants agree the song is completed, the researcher will facilitate opportunities to add additional pieces to the “Thanksgiving” song, e.g., adding instruments:

- **Instruments:** The facilitator will provide a box of various hand percussion instruments accessible to students and seniors (small drums, shakers, sound effects, etc.). Students and seniors will be invited to explore the timbres of each instrument.
- The facilitator will ask open-ended questions about sounds which might accompany each verse, and the group will collaborate to choose instruments to add to the song accordingly. Certain words or phrases in the song might lend themselves to rhythmic patterns on instruments, or alternatively the instruments might be used to create a corresponding soundscape before/after/during the song but unrelated to the lyrics.
- Throughout the process facilitator will prompt repetition of what has been created so far, building to a final performance of the song with instrumental accompaniment.

**Group Discussion/Closure:** Both children and seniors will be asked to share their perceptions and give ideas for next week's session.

**Student Debriefing:** Upon leaving Elm neighborhood, students will be asked to complete the six-question survey. Students will walk back to ES and parents will pick them up at the school.

## **SESSION EIGHT PLAN**

**Group welcome:** Students will eat a snack, put on a nametag, and walk to RC. Upon entering the Elm neighborhood, children will be asked to find their senior "buddy," greet them, and give them a nametag also. Buddy pairs will be seated in a semi-circle in the central gathering space.

**Retelling/Reviewing:** Once everyone has been greeted, children and seniors will participate as comfortable in singing the songs created the past weeks.

**New song:** Following the same process as previous weeks, the group will conclude their final song.

**Group Discussion/Closure:** Both children and seniors will be asked to share their perceptions and ideas about the program.






**Student Debriefing:** Upon leaving Elm neighborhood, students will participate in verbal discussion about the program. Students will walk back to ES and parents will pick them up at the school.

## APPENDIX B: SURVEYS


## Pre-session survey

Name: \_\_\_\_\_ (PRE)



1. How do you feel about visiting RC today?

				
Very poor	Poor	Fair	Good	Excellent

2. How did you feel about the story the group created last time?

				
Very poor	Poor	Fair	Good	Excellent

3. How do you feel about getting to know the people living at RC?

				
Very poor	Poor	Fair	Good	Excellent

4. What should we write a story/song/poem about next week?

## Post-session survey

Name: \_\_\_\_\_ (POST)

1. How did you think the visit to RC went today?

				
Very poor	Poor	Fair	Good	Excellent

2. How did you feel about the story the group created?

				
Very poor	Poor	Fair	Good	Excellent

3. Did you feel included in the group today?

				
Never	Rarely	Sometimes	Often	Always

4. Were you able to make connections with people at RC?

				
Never	Rarely	Sometimes	Often	Always

5. My favorite part today was:

6. A part I didn't like today was:



## APPENDIX C: CONSENT/ASSENT FORMS

### CHILD ASSENT FORM (Ages 7-10)

IRB # **20-1138**

#### INTERGENERATIONAL CREATIVITY IN DEMENTIA-FRIENDLY COMMUNITY

We would like to invite you to be part of a study. The study is for students at your school, and older adults who live in the assisted living home across the street from school.

In this study we will try to learn how music and stories can help people. To do this study we will ask you to stay after school on Mondays. We will walk across the street and meet older adults who are living with dementia. Living with dementia means that the older adults' memories and thoughts do not always work the same way they used to.

In the group everyone will work together to write stories, sing songs, and play instruments. Then we will ask you to answer questions to tell us what you think about it. Some of the questions will be on a paper. Other questions we will ask you to answer out loud. Each week we will record the sound of your voice (but not a video).

Doing this study will not hurt you in any way. You should not be part of the study if you do not want to walk across the street to the assisted living home and meet older adults living with dementia. You should not be part of the study if you do not want to play music and write stories.

Your parents have been asked to decide whether it is okay for you to take part in this study. Please talk about it with your parents before you decide whether or not to be part of the study. You do not have to be in this study if you do not want to. If you decide to be part of the study, you can stop coming at any time.

If you have any questions at any time, please ask one of the researchers.

IF YOU PRINT YOUR NAME ON THIS FORM IT MEANS THAT YOU HAVE DECIDED TO BE PART OF THE STUDY AND HAVE READ EVERYTHING THAT IS ON THIS FORM. YOU AND YOUR PARENTS WILL BE GIVEN A COPY OF THIS FORM TO KEEP.

\_\_\_\_\_  
Name of Child (printed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Date

Cameron Dusman  
School of Music  
James Madison University  
dusmance@jmu.edu

Dr. David Stringham  
School of Music  
James Madison University  
Telephone: (540) 568-5279  
stringda@jmu.edu

**CHILD ASSENT FORM (Ages 10-12)**IRB # **20-1138**

## INTERGENERATIONAL CREATIVITY IN DEMENTIA-FRIENDLY COMMUNITY

We would like to invite you to take part in this study. We are asking you because you are a student at ES, and your school wants to offer more opportunities for students to make connections with senior adults who are living at RC.

In this study we will try to learn more about how students and senior adults with dementia can interact through creative activities and making music together. To do this study we will ask you to attend eight sessions after school on Mondays. We will walk across the street to RC and meet senior adults with dementia who are living there. We will ask you to participate in creative art activities along with the senior adults at each session including storytelling and making music (singing, moving, playing instruments, or creating songs). After each session we will ask you to complete a survey to tell us about your experience and your ideas. We will also ask you to participate in group conversations to tell us what you think about music, relationships, and people in different generations. We will record your voice (but not a video) during the sessions.

Participating in this study will not hurt you in any way. You should not participate in this study if you do not want to attend the arts sessions and take place in creative activities such as storytelling and making music. You should not participate in this study if you do not want to meet senior adults living with dementia. The reason we are doing this study is to better understand how creative arts can help students and senior adults make connections and live in community together.

Your parents have been asked to give their permission for you to take part in this study. Please talk this over with your parents before you decide whether or not to participate. You do not have to be in this study if you do not want to. If you decide to participate in the study, you can stop coming to the sessions at any time. If you have any questions at any time, please ask one of the researchers.

**IF YOU PRINT YOUR NAME ON THIS FORM IT MEANS THAT YOU HAVE DECIDED TO PARTICIPATE AND HAVE READ EVERYTHING THAT IS ON THIS FORM. YOU AND YOUR PARENTS WILL BE GIVEN A COPY OF THIS FORM TO KEEP.**

---

 Name of Child (printed)

---

 Date

---

 Signature of Investigator

---

 Date

Cameron Dusman  
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## **PARENT/GUARDIAN INFORMED CONSENT**

**IRB # 20-1138**

INTERGENERATIONAL CREATIVITY IN DEMENTIA-FRIENDLY COMMUNITY

### **Identification of Investigators & Purpose of Study**

Your child is being asked to participate in a research study conducted by Cameron Dusman from James Madison University. The purpose of this study is to explore the potential of participatory creative arts as a tool to facilitate intergenerational relationships and build dementia-friendly community. This study will contribute to the researcher's completion of her master's thesis.

### **Research Procedures**

Should you decide to allow your child to participate in this research study, you will be asked to sign this consent form once all your questions have been answered to your satisfaction. This study consists of participation in eight creative arts sessions, including completing short surveys and interview questions that will be administered to individual participants at ES and RC. All sessions will take place in the memory care neighborhood at RC. The researcher will chaperone all participants in walking across the street to the RC complex after school, and students will return to ES with chaperone after the sessions to be picked up at the school. During their participation, your child will be asked to provide answers to a series of questions related to their perceptions about intergenerational relationships, people of other generational demographics, and their musical interests/preferences.

Participation in weekly sessions and discussion will be audio-recorded (no video). Information collected on the audio recording may include words and phrases either spoken or sung by participants in response to the researcher's prompts, or any other audible sounds contributed by participants, as well as incidental comments or conversation between participants during the creative activities. Discussion with participants before and after sessions will also be recorded. The verbal responses shared in answer to discussion questions will provide data for the project. Audio recordings are for data and research purposes only and will not be shared; the researcher is the only person who will listen to the recordings, and they will be destroyed after the project. Please see the confidentiality explanation below for further information about how the audio recordings will be handled.

### **Time Required**

Participation in this study will require between forty minutes and one hour of your child's time each Monday afternoon over the course of eight weeks. At participants' discretion the study may also include a culminating creative arts event, to be determined throughout the course of the study by the children and seniors participating in the sessions. In total, participation is expected to take no more than approximately ten hours.

### **Risks**

The investigator does not perceive more than minimal risks from your child's involvement in this study (that is, no risks beyond the risks associated with everyday life).

### **Benefits**

Potential benefits from participation in this study include the opportunity for your child to participate in intergenerational activities and build relationships with people of other generational demographics, as well as the opportunity to participate in creative arts programming. The results of the study may provide beneficial information for caregivers of seniors with dementia, educators, parents, therapists, and professional artists.

**Payment for participation**

There is no payment for participating in this study.

**Confidentiality**

The results of this research will be presented in a master's thesis document. Additionally, the creative processes and products associated with participation in the study may be presented to family members, caregivers, teachers, or other community members at the discretion of participants. Your child will be identified in the research records by a code name or number. The researcher retains the right to use and publish non-identifiable data. When the results of this research are published or discussed in conferences, no information will be included that would reveal your child's identity. All data will be stored in a secure location accessible only to the researcher. Upon completion of the study, all information that matches up individual respondents (including audio recording) with their answers will be destroyed. There is one exception to confidentiality we need to make you aware of. In certain research studies, it is our ethical responsibility to report situations of child abuse, child neglect, or any life-threatening situation to appropriate authorities. However, we are not seeking this type of information in our study nor will you be asked questions about these issues.

**Participation & Withdrawal**

Your child's participation is entirely voluntary. He/she is free to choose not to participate. Should you and your child choose to participate, he/she can withdraw at any time without consequences of any kind.

**Questions about the Study**

If you have questions or concerns during the time of your child's participation in this study, or after its completion or you would like to receive a copy of the final aggregate results of this study, please contact:

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School of Music  
James Madison University  
dusmance@jmu.edu  
[stringda@jmu.edu](mailto:stringda@jmu.edu)

Dr. David Stringham  
School of Music  
James Madison University  
Telephone: (540) 568-5279

**Questions about Your Rights as a Research Subject**

Dr. Taimi Castle  
Chair, Institutional Review Board  
James Madison University  
(540) 568-5929  
[castletl@jmu.edu](mailto:castletl@jmu.edu)

**Giving of Consent**

I have read this consent form and I understand what is being requested of my child as a participant in this study. I freely consent for my child to participate. I have been given satisfactory answers to my questions. The investigator provided me with a copy of this form. I certify that I am at least 18 years of age.  I give consent for my child to be audio recorded during their participation in creative sessions and during group discussion/interview. (parent's initial)

\_\_\_\_\_  
Name of Child (Printed)

\_\_\_\_\_  
Name of Parent/Guardian (Printed)

\_\_\_\_\_  
Name of Parent/Guardian (Signed) Date

\_\_\_\_\_  
Name of Researcher (Signed) Date

**SENIOR ADULT ASSENT FORM**

IRB # 20-1138

## INTERGENERATIONAL CREATIVITY IN DEMENTIA-FRIENDLY COMMUNITY

We would like to invite you to be part of a study. The study is for senior adults in the memory care neighborhood, and students at the elementary school across the street from RC.

In this study we will try to learn how music and stories can help people. To do this study we will ask you to join us for a group when the children visit on Monday afternoons.

In the group everyone will work together to write stories, sing songs, and play instruments. Then we will ask you to answer questions to tell us what you think about it. Each week we will record the sound of your voice (but not a video).

Doing this study will not hurt you in any way. You should not be part of the study if you do not want to join the group on Mondays and meet the children from the elementary school. You should not be part of the study if you do not want to play music and write stories.

Your legal guardians have been asked to decide whether it is okay for you to take part in this study. You do not have to be in this study if you do not want to. If you decide to be part of the study, you can stop coming at any time. If you have any questions at any time, please ask one of the researchers.

IF YOU PRINT YOUR NAME ON THIS FORM IT MEANS THAT YOU HAVE DECIDED TO BE PART OF THE STUDY AND HAVE READ EVERYTHING THAT IS ON THIS FORM. YOU AND YOUR GUARDIANS WILL BE GIVEN A COPY OF THIS FORM TO KEEP.

---

 Name of participant (printed)

---

 Date

---

 Signature of Investigator

---

 Date

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 dusmance@jmu.edu

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 Telephone: (540) 568-5279  
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## **LEGAL GUARDIAN INFORMED CONSENT**

**IRB # 20-1138**

INTERGENERATIONAL CREATIVITY IN DEMENTIA-FRIENDLY COMMUNITY

### **Identification of Investigators & Purpose of Study**

Your family member is being asked to participate in a research study conducted by Cameron Dusman from James Madison University. The purpose of this study is to explore the potential of participatory creative arts as a tool to facilitate intergenerational relationships and build dementia-friendly community. This study will contribute to the researcher's completion of her master's thesis.

### **Research Procedures**

Should you decide to allow your family member to participate in this research study, you will be asked to sign this consent form once all your questions have been answered to your satisfaction. This study consists of participation in eight creative arts sessions, including completing short surveys and interview questions that will be administered to individual participants at ES and RC. All sessions will take place in the memory care neighborhood at RC. The children will walk across the street from ES on Monday afternoons to join your family members in the memory care neighborhood for creative activities including storytelling and music. During their participation, your family member will be asked to provide answers to questions related to their perceptions about intergenerational relationships, people of other generational demographics, and their musical interests/preferences.

Participation in weekly sessions and discussion will be audio-recorded (no video). Information collected on the audio recording may include words and phrases either spoken or sung by participants in response to the researcher's prompts, or any other audible sounds contributed by participants, as well as incidental comments or conversation between participants during the creative activities. Discussion with participants before and after sessions will also be recorded. The verbal responses shared in answer to discussion questions will provide data for the project. Audio recordings are for data and research purposes only and will not be shared; the researcher is the only person who will listen to the recordings, and they will be destroyed after the project. Please see the confidentiality explanation below for further information about how the audio recordings will be handled.

### **Time Required**

Participation in this study will require between forty minutes and one hour of your family member's time each Monday afternoon over the course of eight weeks. At participants' discretion the study may also include a culminating creative arts event, to be determined throughout the course of the study by the children and seniors participating in the sessions. In total, participation is expected to take no more than approximately ten hours.

### **Risks**

The investigator does not perceive more than minimal risks from your family member's involvement in this study (that is, no risks beyond the risks associated with everyday life).

### **Benefits**

Potential benefits from participation in this study include the opportunity for your family member to participate in intergenerational activities and build relationships with the children from EMES, as well as the opportunity to participate in creative arts programming. The results of the study may provide beneficial information for caregivers of seniors with dementia, educators, parents, therapists, and professional artists.

### **Payment for participation**

There is no payment for participating in this study.

### Confidentiality

The results of this research will be presented in a master's thesis document. Additionally, the creative processes and products associated with participation in the study may be presented to family members, caregivers, teachers, or other community members at the discretion of participants. Your family member will be identified in the research records by a code name or number. The researcher retains the right to use and publish non-identifiable data. When the results of this research are published or discussed in conferences, no information will be included that would reveal your family member's identity. All data will be stored in a secure location accessible only to the researcher. Upon completion of the study, all information that matches up individual respondents (including audio recording) with their answers will be destroyed. There is one exception to confidentiality we need to make you aware of. In certain research studies, it is our ethical responsibility to report situations of abuse, neglect, or any life-threatening situation to appropriate authorities. However, we are not seeking this type of information in our study nor will you be asked questions about these issues.

### Participation & Withdrawal

Your family member's participation is entirely voluntary. He/she is free to choose not to participate. Should you and your family member choose to participate, he/she can withdraw at any time without consequences of any kind.

### Questions about the Study

If you have questions or concerns during the time of your family member's participation in this study, or after its completion or you would like to receive a copy of the final aggregate results of this study, please contact:

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Dr. Taimi Castle  
Chair, Institutional Review Board  
James Madison University  
(540) 568-5929  
[castletl@jmu.edu](mailto:castletl@jmu.edu)

### Giving of Consent

I have read this consent form and I understand what is being requested of my family member as a participant in this study. I freely consent for my family member to participate. I have been given satisfactory answers to my questions. The investigator provided me with a copy of this form. I certify that I am at least 18 years of age.

I give consent for my family member to be audio recorded during their participation in creative sessions and during group discussion/interview. (legal guardian's initial)

\_\_\_\_\_  
Name of family member (Printed)

\_\_\_\_\_  
Name of Legal Guardian (Printed)

\_\_\_\_\_  
Name of Legal Guardian (Signed)      Date

\_\_\_\_\_  
Name of Researcher (Signed)      Date

## APPENDIX D: SONGS

## Thanksgiving

Elm &amp; EMES

C F C G C C Am  
 Pump-kin pie, cran-ber-ry pie, app-le pie too, with whipped cream and ice cream,

4 F G C C Dm G C  
 don't for-get the gra-vy! Jui-cy tur-key and flu-fy mashed po-ta-toes,

7 C Dm G C C Am  
 spe-cial sweet po-ta-toes, and a lit-tle bit of stuf-fing. Giv-ing thanks as we ga-ther

10 F G C C Am C<sup>sus</sup> C  
 with some grace to God. All a-ges to-ge-ther han-ging de-cor-a-tions.



# Memories

Elm & EMES

G D Em C G D

Old mem - o - ries are sto - ries from last year; On the swing, in the

7 Em C G D Em

wind, home is near. Chess, food, fun and his - tor -

12 C G D Em C

y, Co - zy and cold, cake and ice cr - eam.

# New Things

VMRC & EMES

Em C G

Fin-ding some - thing you rea - lly, rea - lly like, a lit - tle some-thing bad where it

4 D Em C

used to be nice, Some-thing you re-mem-ber from the old \_\_\_ place, \_

7 G D Em C D Em

Ma - king new friends \_ puts a sm - ile on your face...