

# Engaging Persons with Dementia and their Family Caregivers in the Community: A Lake County Music & Memory Initiative

## Seniors Making Connections through Music

Lake County Senior Citizens Collaborative Initiative  
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Fund

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## **Project Summary**

In 2015, MCS Consulting Service produced a report “Lake County, Ohio Senior Citizens: Today, Tomorrow, and in the Future” that presented research findings detailing demographics on Lake County’s seniors, information on the county’s service delivery system, unmet needs in the community, and recommendations for future directions. The report detailed gaps in the following domains: Physical and Mental Health Well-Being and Social and Civic Engagement, with the least amount of needs met in the social and civic engagement category. In the physical and mental well-being category, the report called for greater support for the growing number of persons living with dementia in the community. In addition, to address the high rate of unmet needs in the social and civic engagement domain, it was recommended to increase opportunities for meaningful connections with family and friends, attendance at senior centers, and encourage greater volunteer participation in these efforts.

In response to the report findings and grant initiative as part of the Lake County Senior Citizens Collaborative Initiative, the overall goal of this funded project was to address the above unmet needs detailed in the report through the development of a group music-therapy based intervention for persons with dementia living in Lake County that would be led retired senior volunteers and held in a number of Lake County senior centers. In addition, the current project went a step further and evaluated the feasibility, acceptability, and efficacy of the developed program titled Seniors Making Connections through Music (SMCTM). Data collection efforts focused on program satisfaction for participants, caregivers, and volunteers, as well as engagement levels of participants.

## Goals and Objectives

### *1. Physical and Mental Health Well-Being Domain*

Unmet need: Engaging in Activities that Promote Well-Being and Support for Growing Numbers with Dementia

**Goal #1:** A group music therapy-based intervention for seniors 60+ who are living with dementia will be developed. All materials and protocols developed will be provided to participating senior centers and will remain with the centers for future delivery of the program beyond the project period.

**Goal #2:** Engage persons living with dementia (N=100) and their family caregivers in the newly developed SMCTM program. Involving persons living with dementia in this meaningful activity presents a unique opportunity for socialization for the individuals living with dementia, as well as their family caregivers, who are often in need of a break from caregiving demands.

**Goal #3:** Conduct individualized playlist assessments for each group participant, and provide music kits (iPod loaded with songs from the person's personalized playlist, headphones, charger) for home use following the Music and Memory™ program protocols.

**Goal #4:** Provide educational information for family caregivers after each session to address care challenges at home and enhance communication and participation in music listening beyond the project period.



## ***2. Promoting Social and Civic Engagement***

Unmet needs: Participation in Social/Recreational Activities and Increase in Volunteer Involvement

**Goal #5:** Address gaps in creating meaningful connections with family, neighbors, and friends and specifically increase attendance at senior centers. This will be accomplished by offering the newly developed group music program (SMCTM) at 2 senior centers and one assisted living facility in Lake County to start.

Recruitment of other Lake County senior centers to be involved with the project will continue throughout the project period, with hopes to set up the program within all Lake County senior centers by the end of 18 months.

**Goal #6:** Increase volunteer involvement by training a group of 20 senior volunteers as group leaders, program assistants, notetakers, and technology specialists in order to run the groups solely using volunteer support. Volunteer trainings will be designed to include a dementia education component, communication with persons with dementia, conducting personalized music playlist assessments, loading music on iPod Shuffles using iTunes, and how to conduct the program.

**Goal #7:** Create a collaborative group that meets quarterly in order to address program development, marketing, implementation, and sustainability.

Collaborative group members will continue to meet and address sustaining the program beyond the project period.



## ACTIVITIES AND ACCOMPLISHMENTS

Detailed descriptions of the intervention materials, data collection instruments, and training protocols are included in the below narrative. Copies of materials are included in the attached appendices (Appendices A-E). Major project accomplishments include the:

- Development of a program binder for training and conducting the program. Included are step-by-step descriptions of the protocol for each session, including musical selections, materials used, and discussion questions. The SMCTM program was developed by Silvia Orsulic-Jeras, Principal Investigator, and Benjamin Rose Institute on Aging (BRIA) research staff, with initial musical selections and discussion questions drafted by a board certified music therapist. Based on a review of the outcomes from the current project, a program manual will be created to support future replication of the program.
- Development of a Program Modification Form for volunteers was developed, allowing volunteers to record suggestions for revisions for the program, as well as record positive interactions with the participants and caregivers. Based on a review of the volunteers' feedback and session observations by the PI, the program was revised to incorporate some of the suggested changes. Some changes included simplification of some of the session materials, adjustments to songs and discussion questions, and changes to language used when addressing PWDs in session.
- Development of pre-group (Time 1) and post-group (Time 2) assessment interviews for both persons with dementia and caregivers. Outcomes measured include dyadic relationship, mood, anxiety, agitation, and quality of life. In addition,

Time 2 interviews included items measuring satisfaction with the program and their experiences at the senior center.

- Recruitment and training of volunteers. The senior volunteers proved to be an important part of the study, providing ongoing feedback on how features of the program worked, and helping in various ways to ensure the program was implemented successfully.
- Recruitment and training of interviewers.
- Development and refinement of outreach and recruitment procedures to identify persons with dementia and caregivers for participation in the program.
- Expansion of program to other counties in Ohio.
- Completion of analysis of findings of the study.
- Dissemination of findings at professional conferences.
- Preparation of manuscripts for publication.

## ***Objective 1: Physical and Mental Health Well-Being Domain***

The unmet needs addressed in Objective 1 include engaging Lake County's seniors in activities that promote well-being and building supportive systems within the community to handle the growing numbers of persons with dementia (PWDs) and their family caregivers (CGs).

**Goal #1:** A group music therapy-based intervention for seniors 60+ who are living with dementia will be developed. All materials and protocols developed will be provided to participating senior centers and will remain with the centers for future delivery of the program beyond the project period.

### **A. Program Development**

Seniors Making Connections through Music is a 6-session, music-therapy based group intervention developed for PWDs and their family CGs. With the assistance of a board certified music therapist, BRIA research staff developed the program during the first quarter of the project period. Features of the program include [See Appendix E for documents listed below]:

- Outlines for 6 individually themed sessions
- Songs selected for each theme with discussion questions developed with the consultation of a board certified music-therapist
- iPod shuffle and speaker
- Theme orientation session boards
- Props including percussion instruments, pinwheels, and scarves



- Photos used for supporting discussion questions
- Laptop for each senior center to host their iTunes library

See Appendix E for a complete list of materials.

**Goal #2:** Engage persons living with dementia (N=100) and their family caregivers in the newly developed SMCTM program. Involving persons living with dementia in this meaningful activity presents a unique opportunity for socialization for the individuals living with dementia, as well as their family caregivers, who are often in need of a break from caregiving demands.

## **B. Recruitment, Screening, and Enrollment**

Marketing Strategies. Participant recruitment was led by RSVP of Lake County in conjunction with participating senior center sites, as well as Lantern of Madison. Senior center directors shared program information in their monthly newsletters to help with recruitment. RSVP of Lake County conducted radio interviews on WINT 1330 AM Radio, wrote news briefs in the News Herald, and an article in the Council on Aging Bridge. There were also announcements sent to all members of the Lake County Church Network, Facebook posts by RSVP and the Lake Co Commissioners Senior Services, flyers given to the Alzheimer's Association and all Senior Center sites, information posted on the HChoices health TV at all Senior Centers, and many communications via email to RSVP members and agencies.

In early December 2017, Cristen Kane met with the Lake County Alzheimer's Association staff to update them on the program's progress. Outcomes from the meeting were positive; it was decided that a member of the Alzheimer's Association staff would

participate with BRIA staff in the new volunteer training session to be held in January 2018 by providing a presentation on dementia education. As a result, Stacy Heffernan from the Association presented a dementia training to our volunteers at a training session in January 2018. In addition, the Association agreed to distribute flyers for the program to their caregiver support group attendees in order to help boost enrollment in our program. This did not prove to be an effective strategy in bringing awareness to families of the program's existence.

RSVP also collaborated with the Willoughby-Eastlake Public Library System and Mentor Senior Center to offer informational sessions for caregivers of persons living with dementia to learn more about the program before registering. In January 2018, two introductory program sessions were held by Cristen Kane, one at the Willoughby Public Library and another at the Mentor Senior Center. The goal of these introductory sessions was to engage family caregivers in Lake County in learning more about our program and how music can help with socialization and quality of life. There was 1 attendee in Willoughby and 5 in Mentor.

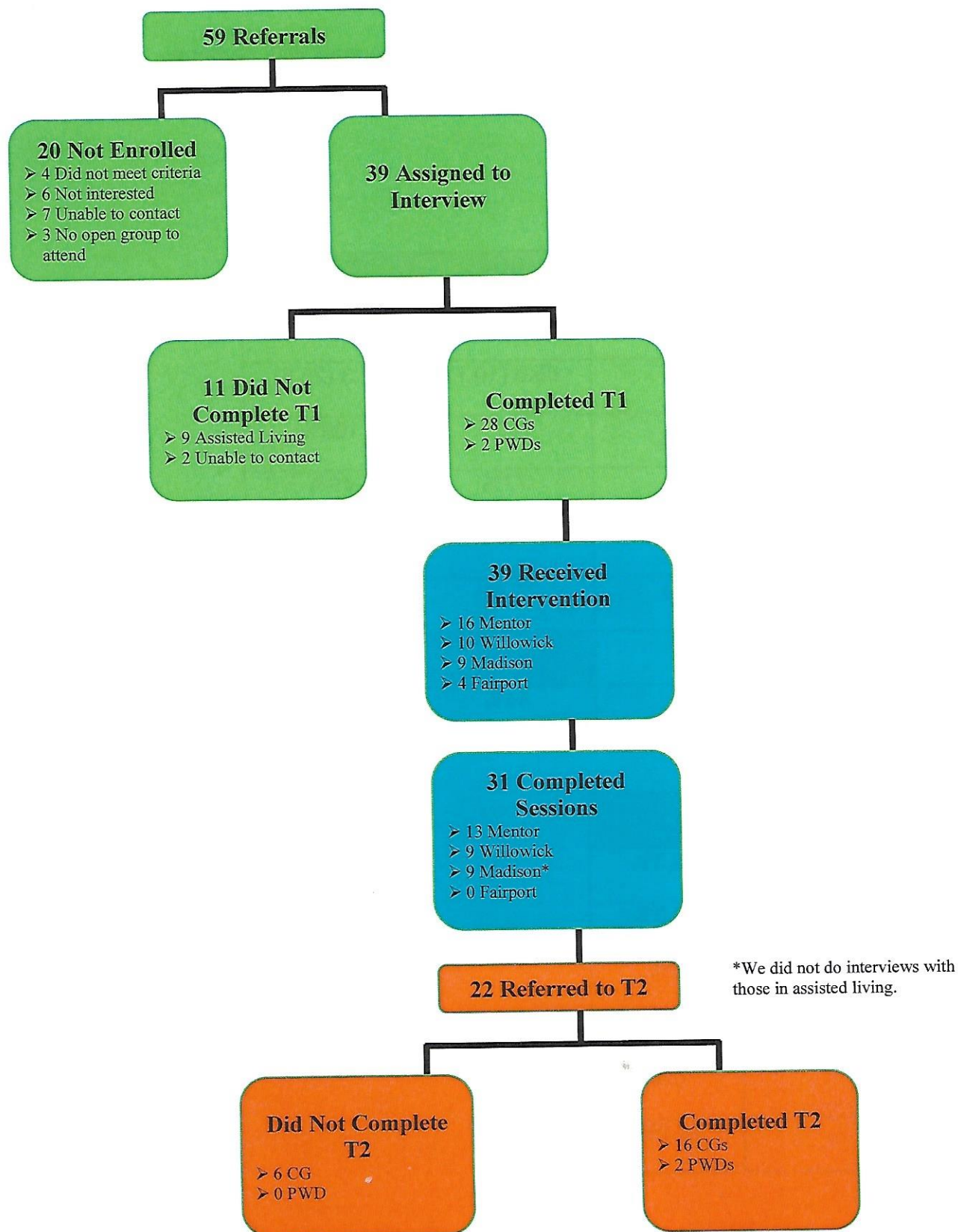
Marketing Materials. Marketing materials underwent a series of revisions throughout the project period in order to better reach more potential participants [See Appendix D]. Volunteers provided valuable feedback during a refresher training in November 2017, and some of their suggestions were used to make changes to better reach potential participants and caregivers. In December 2017, program volunteer Jerry Hinkel spent several days posting 2018 program flyers throughout Lake County including Panera locations, doctor offices, and libraries.

In addition, RSVP collaborated with the Lake County Council on Aging and provided 900 newly updated flyers for the agency to include in their monthly Meals on Wheels client mailing. The flyers were distributed in December 2017 to all of their Meals on Wheels clients. RSVP also posted new flyers for all subsequent sessions on the RSVP website and Facebook page.

*Participant Screening and Enrollment.* We had contact with 59 potential families who had either requested information from RSVP after receiving a flyer or responding to one of our other recruitment efforts. The majority (78%) of potential participants were recruited from the senior centers or Lantern of Madison. Of the original 59 families, 39 met our initial screening requirements and were enrolled in the program. Some of the reasons why 20 participants did not screen into the program include: PWDs were too impaired, CG or PWD unwilling or unable to participate, or did not meet criteria. Three interested families did not have a group to join due to their location not being able to fill a full group, and were unable to travel to a further senior center. Figure 1 below provides additional information on the recruitment and enrollment numbers.



Figure 1. Participation and Refusal Chart



### C. Demographic Characteristics of Participants

Characteristics of the initial sample of caregivers (CGs) and persons with dementia (PWDs) is shown in Table 1.

**Table 1. Sample Demographics**

N = 39	CGs	PWDs
Gender (% female)	77%	51.3%
Age (mean, SD)	65.6 (10.7)	72.3 (25.8)
Race (% white)	100%	100%
Marital Status (% married)	77%	49%
Education (% more than high school degree)	79%	30%
Employment Status (% employed)	21.4%	0%
Short Blessed Score (mean, SD)		22.7 (17.84)
Caregiver type (% spousal)	44%	

Caregiver Relationship	
Husband	10.3%
Wife	33.3%
Son/Son-In-Law	0%
Daughter/Daughter-In-Law	28.2%
Other Relative	0%
Non-Relative	28.2%

## **D. Acceptability and Feasibility**

Session Evaluations. Participants (PWDs) and caregivers (CGs) filled out an evaluation after each session was completed, responding to a series of satisfaction questions about their experiences (See Appendix B). For the purposes of analysis, a participant was considered to have received a full “dosage” if they participated in 4 or more sessions. Volunteers were effective in keeping the session times as prescribed, with the average length of the all the sessions was 60 minutes. Session 2 had the longest average length of 61 minutes, while Session 1 had the shortest average length of 58 minutes.

Across all sessions, PWDs (100%) and CGs (99%) felt the length of the group music sessions was the right amount of time (PWD mean=3.63, SD=.49; and CG mean=3.73, SD=.47; 1=Strongly disagree, 2=Disagree, 3=Agree, 4=Strongly Agree). In addition, the majority of PWDs and CGs found the discussion questions useful (PWD mean=3.49, SD=.54; and CG mean=3.60, SD=.49), music selections enjoyable (PWD mean=3.66, SD=.48; and CG mean=3.66, SD=.48) and relevant (PWD mean=3.56, SD=.57; and CG mean=3.66, SD=.49) and enjoyed the materials used such as instruments and photos (PWD mean=3.56, SD=.56; and CG mean=3.61, SD=.55). Further, most PWDs and CGs connected well with the volunteer group leaders (PWD mean=3.67, SD=.50; and CG mean=3.77, SD=.43), and felt the group leaders were easily understood (PWD mean=3.61, SD=.57; and CG mean=3.75, SD=.44).

High levels of satisfaction were reported across nearly all items with respondents agreeing or strongly agreeing with satisfaction items (See Table 2 for detailed results for individual sessions). Overall, our results confirm the feasibility and acceptability of the Seniors Making Connections through Music intervention. Both care partners were able to



engage actively in the program and reported high levels of satisfaction across multiple domains (e.g., length of sessions, appropriate song selection, group leader).

**Table 2. SMCTM Session Evaluation Means**

Session	PWD	CG
	Mean (Range) SD	Mean (Range) SD
1	3.49 (2.5-4) .47	3.47 (2.4-4) .47
2	3.65 (2.9-4) .46	3.67 (3-4) .39
3	3.58 (2.9-4) .49	3.68 (3-4) .45
4	3.74 (3-4) .39	3.81 (3-4) .31
5	3.51 (3-4) .44	3.68 (3-4) .39
6	3.74 (3-4) .36	3.85 (3-4) .33

### **E. Participant Engagement and Affect**

Volunteers in the Notetaker role were trained to complete engagement forms for each participant present at each session (151 total engagement forms completed across all groups; n = 30 participants). The following domains were assessed for each participant over the entire session period (60 minutes), and were marked 'Yes' if the behavior was displayed throughout the session, unless otherwise noted (\*See below and Appendix B):

- Engagement (Clapping, singing, foot tapping, using instruments, looking at photos, answering discussion questions, etc.)
- Agitation (Anxiety, trying to leave, hand wringing, distraction, repetitive and worried verbalizations)

- Sleeping or staring into space (\*more than 2 instances or for longer than 10 minutes during the session)
- Pleasure/Happiness (Smiling, laughing, hugging, holding hands, etc.)
- Altruism (Help/assist other group members or volunteers)

Overall, 97% of participants were actively engaged and showed pleasure during the sessions, whereas only 3% displayed agitation. Further, only 8% of participants slept or were non-engaged. Finally, there were 13 episodes observed of participants helping other participants or volunteers during sessions. Although helpfulness or altruism was not a goal or expected outcome of the program, it was certainly a positive observation and something we may consider focusing on in future studies.

Caregiver Overall Program Evaluation. Table 3 details responses at the end of the 6 sessions from CGs on questions focused on the group benefits (n = 18; See Appendix B for questionnaire). Overall, CGs reported high levels of agreement regarding the benefits of the program both for themselves, and their care partner. These findings strongly support the idea that this program is beneficial across a variety of domains: socialization, engagement, and support. In addition, 95% of CGs reported considering other programs and activities for their relative, suggesting that participation in this pilot program may contribute to continued participation in enjoyable activities.

**Table 3.** Percentage of Responses from Final Caregiver Evaluation (n=18)

<b>Because of this program:</b>	<b>Strongly Disagree/Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I have made friends by participating with others who provide care.	5%	67%	28%
My relative has gained support by interacting with other people with dementia.	6%	39%	56%
I have learned from others who provide care.	0%	59%	41%
My relative is more engaged overall.	6%	56%	39%
My relative benefits from socializing with other people (e.g., better mood, more conversation).	0%	33%	67%
I benefit from socializing with other people.	0%	33%	67%
I am considering other activities or programs with my relative.	6%	17%	78%

*Participant Engagement and Affect.*

**Goal #3:** Conduct individualized playlist assessments for each group participant, and provide music kits (iPod loaded with songs from the person's personalized playlist, headphones, charger) for home use following the Music and Memory™ program protocols.

As part of an existing grant to the Benjamin Rose Institute on Aging (BRIA) through the Ohio Department of Aging (ODA), \$10,000 in funds were earmarked to support the provision of iPod kits to all 100 families served through this current Lake County grant initiative. In order to facilitate the playlist assessment procedures, research staff trained a Masters-level Nursing Education student to conduct telephone-based playlist assessments with participants of the SMCTM intervention. Thus, 39 playlist assessments were conducted. Based on the information from the playlist assessments, personalized music



plans were created for all participants, and 39 iPod kits were distributed to families at the end of their participation in the SMCTM program. Two trained technology volunteers loaded the music on the individual iPods for distribution, and assisted with making adjustments to the iPods as requested by the families (See Goal #6 below for more information on volunteer training; See Appendix A for playlist assessment).

**Goal #4:** Provide educational information for family caregivers after each session to address care challenges at home and enhance communication and participation in music listening beyond the project period.

It was decided early in the project period to include family caregivers in the SMCTM sessions for a number of reasons. First, as we were enrolling a mix of stages and levels across the disease spectrum, we did not want to exclude participants that may need assistance with personal needs that were beyond the scope of what senior center staff and project volunteers could provide. Second, we trained project volunteers to maximize the existing strengths of participants in order to increase their engagement with the music and materials. These are skills we also wanted to model for family caregivers to utilize at home in order to support independence and participation in enjoyable activities for as long as possible. Thus, we developed the following post-session educational handouts for CGs based on information published in reputable sources (Handouts can be found in Appendix E):

- 1) Strategies for Dementia Care at Home
- 2) Resources

- 3) Communication Tips
- 4) Home Environment
- 5) Activities

## ***Objective 2: Promote Civic and Social Engagement***

Goal #5 supported Objective 2 by addressing gaps in creating meaningful connections with family, neighbors, and friends and specifically increase attendance at senior centers by offering Seniors Making Connections through Music groups at 2 senior centers to start. In addition, our hope was to address the need for more volunteers by creating a sustainable collaboration between RSVP Lake County and two area senior centers. Recruitment of other Lake County senior centers to be involved with the project was attempted but was unsuccessful during this project period. However, sustainability and future expansion of the program will remain goals of the collaborative effort.

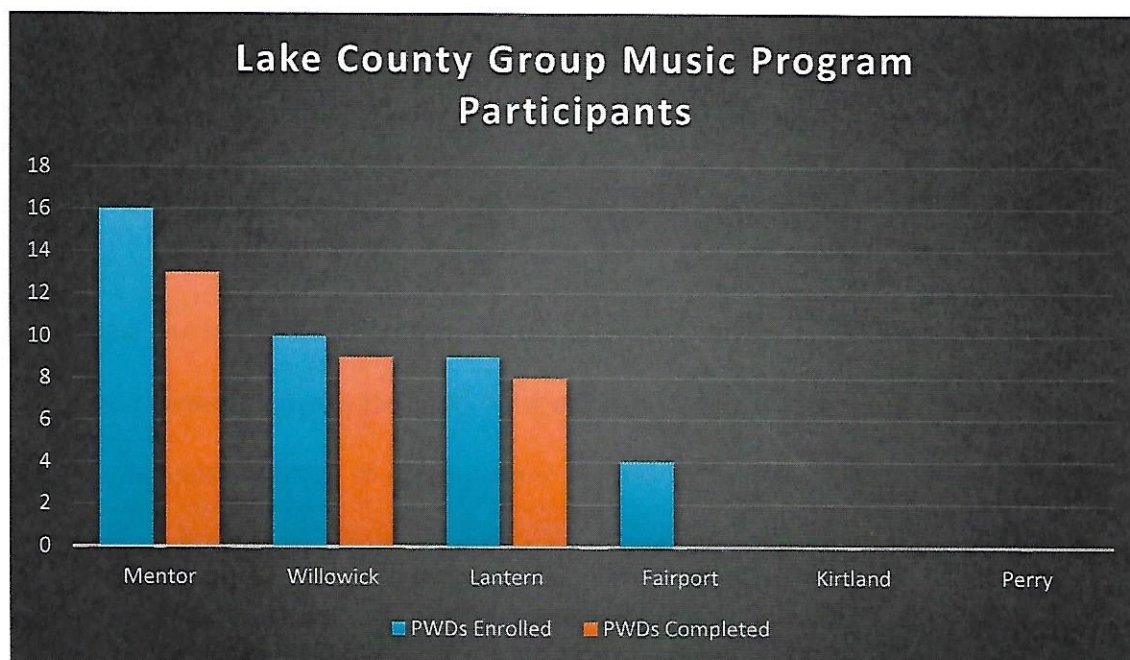
**Goal #5:** Address gaps in creating meaningful connections with family, neighbors, and friends and specifically increase attendance at senior centers. This will be accomplished by offering the newly developed group music program (SMCTM) at 2 senior centers and one assisted living facility in Lake County to start. Recruitment of other Lake County senior centers to be involved with the project will continue throughout the project period, with hopes to set up the program within all Lake County senior centers by the end of 18 months.

### **Senior Center Recruitment and Participation**

The following senior centers were recruited to participate in this project: Mentor, Willowick, Kirtland, Perry, and Fairport (See Figure 1). Mentor, Willowick, and Kirtland

were on board at the start of the project. After various attempts to recruit participants in Kirtland and surrounding communities, the Kirtland Senior Center dropped out as a site for this project due to lack of participation. Similarly, Perry Senior Center, who came on board later into the project period, experienced recruitment difficulties and well, and were not able to assemble a group. There were 2 families in Perry waiting for enrollment, but were unable to relocate to Mentor or Willoughby centers. The addition of Fairport Senior Center was promising. However, after beginning one small group in the summer of 2018, the SMCTM participants did not attend more than one session.

Figure 1. Lake County Group Music Program Participants



*Mentor Senior Center.* In total, Mentor Senior Center hosted 3 separate SMCTM groups:

- Group 1 ran from 6/8/17 through 7/13/17 (PWD n = 5; CG n = 5)
- Group 2 ran from 2/20/18 through 3/27/18 (PWD n = 8; CG n = 8)



- Group 3 ran from 9/2/18 through 10/9/18 (PWD n = 3; CG n = 3)

Out of the 16 total PWD participants in Mentor sessions, over 80% completed the program (n = 13), with 75% of participants attending 5 or more sessions. Mentor had 5 groups scheduled to occur within this project period. However, only 3 groups had enough participants to run the program.

Willowick Senior Center. In total, Willowick Senior Center hosted 2 separate SMCTM groups:

- Group 1 ran from 7/20/17 through 8/24/17 (PWD n = 6; CG n = 7)
- Group 2 ran from 2/1/18 through 3/8/18 (PWD n = 4; CG n = 4)

Out of the 10 PWD participants in Willowick, 90% completed the program (n = 9), and 70% of participants attended more than 5 sessions. Willowick attempted a total of 4 groups to be scheduled to occur within this project period, but only 2 groups had enough participants.

All participants enrolled in this program, whether completed or not, were issued iPod kits for home use. Several attempts were made to conduct playlist assessments with all enrolled participants. Those for whom we were unable to conduct playlist assessments, iPods loaded with playlists containing general music from each session were provided along with instructions on how to conduct the playlists assessments at home. Technology support to help add or change music was made available to these families through our technology volunteers and their local senior center.

Lantern of Madison – Assisted Living Facility. One goal of this project was to pilot this program in an assisted living setting, as well as to provide a community hub within this area of Lake County. Lantern of Madison offered to provide space within their facility to

house a SMCTM group for persons living with dementia in and around Madison. Even though we were not successful in bringing a community-based sample of participants to Lantern as a site, we were able to conduct 2 groups with Lantern residents. Due to challenges in scheduling and availability, CGs did not attend Lantern sessions as in the senior center groups. In total, Lantern of Madison hosted 2 separate group sessions:

- Group 1 ran from 9/7/17 through 10/12/17 (PWD n = 6)
- Group 2 ran from 10/26/17 through 10/14/17 (PWD n = 4)

Out of the 9 PWD participants at Lantern, 89% completed the program (n = 8), and roughly 50% of participants attended more than 5 sessions. Although the program was a great fit for residents at Lantern, due to issues with scheduling and competing activities on the days the groups were scheduled, some residents could not attend. For example, the original SMCTM groups were planned on a shopping day, and many residents enjoyed that outing and did not want to miss out by joining the program.

### **Senior Centers as Community Connection Points**

The piloting of this program using senior centers to connect with populations isolated within communities, such as persons living with dementia and their family caregivers, demonstrated some promising findings, yet highlighted significant challenges. Family caregivers who participated in the program answered a series of questions about the Senior Center they attended for their SMCTM group at the end of their participation. Results of those responses are presented in Tables 2-4 below. Caregivers (CGs) that responded to these questions in Time 2 follow-up interview (n = 15) expressed high levels of satisfaction with the senior center they attended (87% were very satisfied; 13% somewhat satisfied). In addition, 100% of CGs rated the senior

center environment (the building, room, accessibility, time of sessions) very high (Table 4). However, when asked how likely they were in the future to visit the senior center to make adjustments to the iPod (64% likely), or participate in programs for themselves (35% likely) or their care partners (27% likely), responses were considerably less positive. Finally, 95% of CGs reported the once per week for 6-weeks protocol as highly acceptable.

Although reasons behind the responses were not gathered in this study, these findings are useful in considering ways in which Lake County senior centers could strive to become more dementia friendly in the future. Senior centers are structured to serve those who are aging healthily and living independently in the community, and often overlook the unmet needs of persons with memory and thinking challenges and their isolated care partners. Since senior centers are not equipped with staffing and resources to handle the personal care needs of persons with dementia, through targeted programs such as Seniors Making Connections through Music, centers can provide specific programs that are acceptable and feasible to families.

**Table 2. Satisfaction with Senior Centers**

Question	CG Mean Mean (SD)
*In general, how satisfied were you with the senior center?	4.87 (.35)

\*Questions were asked using a 5-point Likert scale (5 = Very satisfied; 4 = Somewhat satisfied; 3 = Neither satisfied or dissatisfied; 2 = Somewhat dissatisfied; and 1 = Very dissatisfied).



**Table 3. Future Senior Center Use**

Question	CG Mean Mean (SD)
**Thinking about the future, how likely do you think you are to visit the senior center to make adjustments to your care partner's iPod?	2.00 (.89)
**In the future, how likely do you think are to visit the senior center for other programs for your care partner?	1.82 (.87)
**In the future, how likely do you think you are to visit the senior center for other programs for yourself?	2.38 (1.26)

\*\* Questions were asked using a 4-point Likert scale (4 = Very likely; 3 = Somewhat likely; 3 = Somewhat not likely; and 1 = Very not likely).

**Table 4. Satisfaction with Senior Center Environment**

Question	CG Mean Mean (SD)
The building where the sessions occur is in a convenient location for me and my relative.	3.75 (.48)
The room we meet in is comfortable.	3.75 (.45)
The room we meet in is easy to access.	3.75 (.48)
The start time of the sessions has been convenient for me and my relative.	3.69 (.48)

\*\* Questions were asked using a 4-point Likert scale (4 = Very likely; 3 = Somewhat

**Goal #6:** Increase volunteer involvement by training a group of 20 senior volunteers as group leaders, program assistants, notetakers, and technology specialists in order to run the groups solely using volunteer support. Volunteer trainings will be designed to include a dementia education component, communication with persons with dementia, conducting personalized music playlist assessments, loading music on iPod Shuffles using iTunes, and how to conduct the program.

**Table 4. Baseline Characteristics of Volunteers (n = 21)**

	% or Mean
<b>Age</b> (mean [range])	69.74 [57-80]
<b>Gender</b> (% Female)	95%
<b>Residing City</b>	
Chesterland	5%
Concord	10%
Kirtland	10%
Mentor	33%
Painesville	24%
Wickliffe	5%
Willowick	5%
Perry	10%
<b>Education</b>	
High School Grad (or GED)	19%
Some College	10%
College Degree	38%
Master's Degree	33%
<b>Race/Ethnicity</b> (% White)	90%
<b>Marital Status</b>	
Single	14%
Married	43%
Widowed	24%
Divorced	19%
<b>Employment Status</b>	
Employed Part-Time	14%
Retired	71%
Retired – Looking for Work	14%
<b>Volunteer Frequency</b>	
Daily	5%
Weekly	52%
Monthly	10%
Occasionally	33%
<b>Number Hours/Week Volunteering</b> (mean [range])	8 [0-28]
<b>Years as RSVP Volunteer</b> (mean [range])	1.4 [less than a year-6]
<b>Primary Occupation</b>	
Finance/Sales	13%
Education	39%
Clerical	13%
Medical	13%
Recreation/Fitness	9%
<b>Past Dementia Experience</b>	62%

*Volunteer Recruitment:* Recruitment of volunteers was led by Cristen Kane from the Retired Senior Volunteer Program of Lake County (Lake County RSVP). Potential volunteers received emails, phone calls, and flyers describing the project and the volunteer opportunity. Those interested were signed up and given dates for training.

Volunteers signed photo/video releases prior to training and filled out a survey that included basic demographic information as well as questions on their employment and volunteer histories (See Table 4 for a description of our volunteer sample).

*Volunteer Training.* Eighteen RSVP senior volunteers were trained in May 2017, and 3 more in January 2018. For the original 2017 training session, we offered two options for the required two-day training: May 17<sup>th</sup> and 18<sup>th</sup> (Session 1; N = 5) and May 23<sup>rd</sup> and 24<sup>th</sup> (Session 2; N = 13). The 2018 training session included 3 new volunteers along with 10 existing volunteers that were



interested in refreshing their training and adding information about their experiences with the program up to that point. For all trainings, volunteers were provided with informational folders that contained the following [See Appendix C]:

- Training Agendas
- Powerpoint presentation – Introduction to Lake County’s Group Music Program
- What is Dementia Fact Sheet

**Source URL:** <https://www.caregiver.org/is-this-dementia-what-does-it-mean>

- Six Session templates
- How to Use iTunes and iPod Shuffle
- Contact information for all project staff

*Follow-up Trainings.* A volunteer kick-off meeting was held on June 1, 2017 at Mentor Senior Center. This meeting served as an extension of the May training, and the whole six-session program was presented to volunteers. Each volunteer received a program binder that contained instructions on how to run each of the 6 sessions. Session materials were presented and described, and room setup was explained and demonstrated. In November 2017, a refresher training was held at RSVP to review all program modifications made after two groups were held (Agenda for this meeting can be found in Appendix C). Video clips from Mentor and Willowick sessions were shared with volunteers to enhance training for subsequent groups. A project wrap-up meeting with volunteers took place in December 2018 at RSVP and included senior center directors. The goal of this meeting was summarize volunteer experiences, discuss potential changes to the program, and brainstorm ways to ensure sustainability of the program



with volunteer support. In addition, preliminary results were shared with volunteers, and dates for groups to be held beyond the project period were discussed.

Post-Session Debrief Meetings: As part of an ongoing training strategy, BRIA research staff, led by Principal Investigator (PI) Silvia Orsulic-Jeras, held 10-15 minute post-session debriefing meetings with volunteers to go over such things as program procedures, participant or caregiver reactions to session material, potential improvements to sessions, song choices, use of materials, or changes in volunteer roles. During these sessions, volunteers had the opportunity to ask any questions or discuss challenges and successes. One major goal for these meetings was to provide more dementia education to volunteers based on real-world examples demonstrated by group participants. Since these were held after each session, only the 12 volunteers who participated in groups benefited from these trainings. At the end of the program, volunteers overwhelmingly stated this feedback proved most valuable in terms of dementia training and for increasing their knowledge of program delivery.

Volunteer Roles. Of the 21 volunteers trained, 12 in total participated in the program either as group session leader, program assistant, notetaker, or technology volunteer. Nine volunteers did not participate after training due to their assigned groups being cancelled (Kirtland, Perry, Fairport), illness, or lack of availability. Roles were assigned based on interest and request. In addition, it is possible to participate in multiple roles (e.g., volunteer is session leader one week, and assistant another).

Volunteer Role	Number of Volunteers (n = 12)*
Session Leader	7
Assistant	7
Notetaker	4
Technology	4
*Some volunteers participated in multiple roles (Session leaders were counted if led at least one session).	

**Session Leader:** Volunteers trained for this role were responsible for leading each session. Session leaders introduced the songs, modeled the use of props and materials, asked the discussion questions, and ended the session.

**Program Assistant:** There were 3-4 program assistants per group. Program assistants passed out props and materials to participants, helped engage participants when needed, and helped with setup and cleanup.

**Notetaker:** One volunteer was assigned per session to be the Notetaker. This role included observing each participant and documenting their levels of engagement, positive/negative affect, and attendance (See Appendix B for form).

**Technology:** Technology volunteers were in charge of purchasing and managing songs in iTunes and downloading the music requested from the playlist assessments on the iPods that group participants would be given at the end of the program.

Overall, volunteers reported needing more training and practice to feel confident carrying out the role of session leader (58% felt sufficiently trained), and only 45% felt confident with their training on dementia. In terms of technology training, only 22% of volunteers felt sufficiently trained and prepared to carry out the technology role. Moreover, most volunteers cited not being computer savvy and fear of technology as barriers to learning more about the technology role (See Table 5 below for volunteer quotes about their training experiences).

**Table 5. Quotes on Volunteer Training Experiences**

Topic	Quote
Dementia Education	"I learned a lot. I keep trying to gain more information because of a family member. It was helpful receiving information based on what we were seeing with participants."
Volunteering	"Brainstorming, collaborating, and staying positive are the keys to our success."
Technology	"We received enough training, yes. However, the old lady 'fear' required ongoing support for a while."
Session Experience	"Wonderful experience, several participants opened up quickly. I need a little more practice in keeping the session moving along."

*Volunteer Values.* At the start of the study, we surveyed the volunteers about what was most important to them as it relates to making their volunteer experience successful and rewarding. Questions representing these values were asked using a 3-point Likert scale (3 = Very important; 2 = Somewhat important; and 1 = Not important). The information gathered indicated the majority of volunteers strongly felt the following values were important: Mission or purpose of the organization they were volunteering for (95%); volunteer role they would perform (95%); having good and helpful supervision (95%); opportunity to work directly with clients (95%); flexibility in scheduling (95%); being with other volunteers (95%); and using their prior experience and knowledge in their volunteer role (85%). Interestingly, only 29% of volunteers reported that being recognized for their contributions was important to them. This is not surprising, however, considering the literature supports the notion that many people volunteer for altruistic reasons and social connectedness, as opposed to self-focused reasons (Konrath, et al., 2012).

After volunteering for the SMCTM program, volunteers were asked to respond to a series of questions relating their values for volunteering with their experiences volunteering in this program, as well as questions on program quality (Results are



summarized in Table 6 and Table 7, respectively). At project completion, results showed that volunteers felt they were able to utilize their existing knowledge and experience volunteering for SMCTM (100% agreed or strongly agreed with this statement). Since 62% of our volunteers reported having either personal or professional experiences with dementia, and roughly 60% had careers in education, medicine, or therapeutic recreation, the opportunity to use their expertise to contribute to the program was invaluable. Further, all volunteers reported receiving good and helpful supervision from research staff, demonstrating not only a need for support during sessions, but an increase in knowledge and experience in while conducting group sessions as a result of that supervision.

**Table 6. Volunteer Values and Experience with SMCTM (n = 12)**

Questions: How much do you agree or disagree with the following?	CG Mean Mean (SD)
I was able to use my knowledge and experiences during each session	3.20 (.42)
I received good and helpful supervision from the Benjamin Rose staff	3.55 (.52)
This volunteer opportunity easily fit into my schedule	3.11 (.78)
I felt appreciated during my volunteer experience	3.64 (.51)

Questions were asked using a 4-point Likert scale (4 = Strongly agree; 3 = Agree; 2 = Disagree; 1 = Strongly disagree).

At baseline, 95% of volunteers reported flexibility for scheduling as being very important. After their participation, 78% felt the program easily fit within their schedules. However, 22% disagree and reported having to make adjustments with other commitments in order to participate. Unfortunately, due to other senior center programming and space availability, group scheduling was limited to what worked best for the centers and families, and volunteer availability, although considered, was not the

main deciding factor. This proved difficult for some volunteers to participate, despite having the desire to take part in the program. One volunteer noted “Volunteers need to be included in scheduling. Without being consulted for the 2<sup>nd</sup> session, I have had many conflicts.”

At baseline, only 29% of volunteers reported that being recognized for their contributions was important to them. However, at the end of the program, 100% of volunteers reporting feeling appreciated for their roles. Further, 100% of volunteers reported they would volunteer for the program again in the future. One volunteer stated “I see potential because I have personally seen the effect of music even in this short term time we were together” and another stated “I would participate in any role that is needed.”

Volunteer Satisfaction. Overall, volunteers reported high levels of satisfaction on measures that assessed program quality, length, music selection, etc. (See Table 7). High levels of satisfaction were reported on all items with the exception of two items that were reported as average: ease of use of props (mean=3.00, SD= .82, range 2-4) and tools (mean=2.89, SD=.60, range 2-4). In light of the findings related to props and tools, we recommend changes to some of these materials as well as the volunteer training which we describe in the Lessons Learned section. All volunteers reported they would volunteer for this program again, yet 100% also reported suggested changes to program outline and props/tools used in session. In addition, some volunteers requested additional training and practice in the role of session leader as well as working with technology tools such as iPods and speakers.

**Table 7. Volunteer Satisfaction with SMCTM**

Questions: How much do you agree or disagree with the following?	CG Mean Mean (SD)
The quality of the program was outstanding	3.33 (.50)
I would recommend this program to other organizations and families looking for programs to participate in	3.45 (.52)
I learned a lot of useful information about working with people with dementia	3.67 (.50)
The sessions were the right length	3.50 (.53)
The session props were easy to use (i.e. photos, scarves, instruments, etc.)	3.00 (.82)
The session tools were easy to use (i.e. session snapshots, iPod, speaker, poster board)	2.89 (.60)
The music played was relevant	3.50 (.53)
This program has made a positive impact in the community	3.50 (.55)

Questions were asked using a 4-point Likert scale (4 = Strongly agree; 3 = Agree; 2 = Disagree; 1 = Strongly disagree).

*Program Modification Forms.* At the end of each sessions, volunteers filled out program modification forms in order to document what went well in the session, if there were any issues with songs, discussion questions, or props, and to suggest potential revisions to the program or its protocols. Out of a total of 106 modification forms completed throughout the project period, 50% of comments were positive statements about the sessions, 11% were related to song selection, 15% were general observational comments on participations, and the remaining 26% were related to opportunities for improvement, changes to protocols, training issues, and supplies. Project modification suggestions were discussed during session debrief meetings with research staff, and appropriate changes were made to the program as a result. Volunteers made very targeted and beneficial suggestions throughout the project period, and seemed to enjoy taking ownership over the program and making contributions to its improvements.



**Goal #7:** Create a collaborative group that meets quarterly in order to address program development, marketing, implementation, and sustainability. Collaborative group members will continue to meet and address sustaining the program beyond the project period.

Community Screening of Alive Inside. On April 26, 2017, RSVP of Lake County and BRIA hosted a screening of the documentary Alive Inside. The goal of the screening was to include members of the community, volunteers, and professionals of Lake County in a discussion on the effectiveness of music-based therapies, activities, and treatments. Small presentations were given by Cristen Kane of RSVP, Silvia Orsulic-Jeras from BRIA, and music therapist Lucy Brown who served as a consultant on the project. The local chapter of the Alzheimer's Associations and BRIA had staffed booths outside of the theatre to answer questions about services and programs for persons living with dementia and their family caregivers. Approximately 50 people were in attendance for this event.

Collaborator Meetings. At the start of the project, Ms. Orsulic-Jeras conducted individual site visits at Mentor, Willowick, and Kirtland senior centers. During these visits, spaces for the groups were selected and short meetings with senior center directors took place. BRIA's research team and Ms. Kane remained in close contact with center directors throughout the project development period, as well as for scheduling purposes before our first pilot groups kicked off in June 2017. The initial project collaborator meeting took place on March 2, 2017 at RSVP of Lake County.

A second meeting of project collaborators took place on August 8, 2017, also at RSVP. All senior center directors involved with the project were in attendance along with BRIA and RSVP staff. A progress report was presented detailing information learned from the first two pilot groups that took place in Mentor and Willowick senior centers. The goal of the August meeting was to brainstorm more ways to recruit participants in the program, as well as to have discussions around how to keep participants and their caregivers connected to their site senior center after the program had ended. We discussed having senior center directors visit the participants during Session 6, the final session, introduce themselves, and provide them with membership and other information. Per the suggestion of senior center staff, contact information for the seniors was added to the closing letter sent to families at the completion of their participation.

Subsequent collaborator meetings took place again in April 2018 at the Council on Aging and a final meeting at the conclusion of the project in December 2018. Senior Center directors from Mentor and Willowick were in attendance, and dates for 2019 sessions in those senior centers was discussed. As a result, informational sessions and groups were tentatively scheduled for May 2019 for Mentor, and September 2019 in Willowick (See Appendix D for flyer). This collaborative group will continue to meet in the future with a focus on project sustainability and continued attempts to expand throughout Lake County.

## LESSONS LEARNED AND RECOMMENDATIONS

### 1) Recruitment

**a. Marketing.** The collaborations with Mentor and Willowick senior centers were strong and fruitful in terms of recruiting participants into this program. However, depending upon the senior centers to bring in participants is not a sustainable plan over the long term.

The relationship with the local Alzheimer's Association chapter, although positive, did not yield a large number of participants, despite of their access to families who would be most appropriate for this program. The chapter has pre-existing relationships with families and organizations within Lake County, and thus, moving forward, it is recommended to continue building a stronger relationship with them in order to engage more families in the future.

**b. Screening.** Overall, the screening protocols used in this project were successful in determining appropriateness and interest in this program. It was determined, based on information provided by participants that did not complete the program, it is important to assemble groups of participants that are in similar stages of the disease. For example, one group was compromised mainly of moderate to advanced persons with dementia, and those that were in the early stages had a hard time emotionally with some of the behaviors and progressed symptoms exhibited by the other participants. This was a challenge for research staff throughout the project period, as we had a limited number of participants and not enough to divide participants into more matched groups. All screening materials are available to RSVP in order to assist with future groups that will take place in senior centers as part of our sustainability efforts.

### 2) SMCTM Intervention Protocols



We have made numerous revisions to the SMCTM program as a result of volunteer, PWD, and CG feedback.

**a. Volunteer Training and Supervision.** In the current project, we conducted three separate volunteer trainings over a period of 4-6 hours. Volunteers requested more specific information on program delivery and examples of sessions for future trainings, as most stated that most learning took place during sessions as opposed to the training sessions alone. Moving forward, volunteer trainings will include all revised session protocols, a more targeted training protocol by role, and extensive use of video examples that were taken throughout the current project period to illustrate how to conduct the program. Post-session volunteer debriefing sessions were reported as beneficial by volunteers, and thus, are suggested to continue for future sessions. Since research staff will not be present for those sessions, volunteers are encouraged to debrief with each other, with more experienced volunteers taking the lead in providing feedback and suggestions.

**b. Refinement of Program.** Based on family and volunteer feedback, it was determined that adjustments to session structure, content, and materials were required to develop and refine the program.

- i. Volunteer use. Groups that took place during this project period utilized up to 3-5 volunteers to perform all roles. Since the Notetaker's role was to collect research data, this role will not be required for future sessions. In addition, SMCTM groups that have taken place outside of Lake County as part of a greater expansion effort funded by the Ohio Department of Aging (ODA) have successfully utilized fewer volunteers. Thus, it is recommended that groups can run effectively with as

few as 2 volunteers: A session leader and program assistant. Sessions leaders have successfully passed out materials and props efficiently in between songs, leaving the program assistant to manage the iPod/speaker system to play the music.

- ii. Song selection. Throughout the project period, certain songs were replaced based on observed PWD and CG reactions and volunteer feedback. Some song selections that were more slow and soft would often fail to gain a response, and songs that seemed unfamiliar to the majority of participants were also switched out. Final protocols for Sessions 1-6 are included in Appendix E.
- iii. Props and materials. Photos that were difficult to see due to clutter or poor contrast were replaced. In addition, use of other materials, such as scarves, were limited or presented as optional; many male participants did not seem to want to utilize the scarves and would simply put them down or not use them.
- iv. Length and number of sessions. Both length and number of sessions were rated highly acceptable and feasible by PWDs, CGs, and volunteers. Thus, length and number of sessions will remain unchanged for future implementations of this program, and will be evaluated further.

## DISSEMINATION AND NEXT STEPS

### 1) Expansion

In the fall of 2017, after a short presentation to ODA regarding the development and implementation of the SCMTM program in Lake County, BRIA researchers were awarded \$70,000 in additional funds to expand the program to other counties in Northeast Ohio. As a result, the program has been expanded to 7 additional sites across Cuyahoga and Geauga counties. Two future groups are scheduled in early 2019 in Summit County. The continued expansion of this program and continued interest in its refinement will undoubtedly contribute to sustaining the program within Lake County. All program revisions and enhancements will be shared with Lake County collaborators in order to continue to provide this opportunity to Lake County families that will benefit.

### 2) Future studies

The results of this pilot study show promise of the feasibility and acceptability of the SMCTM program. Our goal is to continue to seek funding to further study this promising program, and will focus on conducting a randomized controlled trial in order to confirm our acceptability and feasibility but to also determine the program's efficacy and effectiveness.

### 3) Presentations and Manuscripts

Presentations. A presentation on the preliminary findings of this pilot study were presented at the annual meeting of the Gerontological Society of America (GSA) Conference in Boston, MA in November, 2018 (See reference below). In addition, another presentation is scheduled for the American Society on Aging (ASA) conference in New Orleans, LA in April, 2019 (See reference below). BRIA's research team will



continue to present the findings of this pilot study across local, national, and international conferences.

**GSA Presentation:** Orsulic-Jeras, S., & Nicolay, S. (2018, November). Preliminary Results of a Group Music Intervention for Persons with Dementia Using Retired Senior Volunteers as Leaders. Poster presentation at the 2018 Annual Scientific Meeting of the Gerontological Society of America, Boston, MA.

**ASA Presentation:** Orsulic-Jeras, S., & Nicolay, S. (2019, April). Using Retired Senior Volunteers as Leaders of a Group Music Intervention for Persons with Dementia. Roundtable presentation to be given at the 2019 annual meeting of the American Society on Aging, New Orleans, LA.

Manuscripts and Newsletters. We anticipate submitting manuscripts for review to professional and peer-reviewed journals for dissemination purposes. In addition, we are in the process of designing a summary of the SMCTM project's findings to be available to the public as well as a newsletter to be sent to all participants and volunteers in the spring of 2019.