

**Advancing *ARTZ in the Neighborhood*:
Implementing Lessons Learned During the Pandemic in a Community-Driven Program
Development Project Of, By and For People Living with Dementia and Their Care
Partners in North Philadelphia**

Executive Summary:

We are seeking support from Friends Foundation for the Aging in the amount of \$30,000 to advance our program development project “ARTZ in the Neighborhood.” Funded by FFA in 2019-2022, this project is a direct collaboration with members of underserved communities of color in North Philadelphia for the purpose of developing quality-of-life-enhancing programs of, by and for people living with dementia and their care partners. We are seeking funds to continue the project into Year Five, reinvigorated by our challenges and learnings of the past four years.

Project Details:

Has the problem you have identified changed?

The systemic problems that our project was created to address in 2018 are more pressing than ever. Dementia is still the most pervasive chronic illness in our country: still more dreaded than cancer and as stigmatized as cancer used to be. However, the overlay of COVID-19 has deepened the isolation and alienation from community, friends and family that are the hallmarks of lived experiences around dementia. COVID has hastened the onset and progress of dementia in community members, in part due to the direct impacts of the virus itself but even more broadly due to extended periods of isolation, stress, and loss brought on by its outbreaks and spread. Further, COVID has only deepened the healthcare inequities that have historically left communities of color at extreme disadvantage when it comes to diagnosing and providing care to those living with dementia.

It is even more evident now than when we began this project that the only reliable interventions available to us at this point are those that focus on enhancing quality of life (QoL) -- providing joy and meaning through opportunities for agency, creative self-expression, community-building and dignity preservation. QoL-enhancing programs for people with dementia have historically served predominantly white, middle-to-upper-middle-class constituents. Alzheimer’s Disease and other dementias leave no populations unscathed. However, Black and Hispanic populations are substantially more likely to be affected by these conditions and their comorbidities, and therefore in even greater need of resources and opportunities intended to combat their devastating impact. People who live in the shadows of dementia within high-risk communities have limited or no access to arts-based or cultural interventions. They are thus without access to experiences that can alleviate isolation or depression, and restore a sense of community. This is truer now, in the age of COVID-19, than ever before.

We aim through our programs to dispel isolation and provide opportunities for participants with dementia to rebuild their self-esteem through increased agency and restored sense of community. With *ARTZ in the Neighborhood*, we have intentionally embarked on a project that departs

significantly from our and others' standard ways of developing programs for people with dementia. We have established a practice and set of protocols centered on enlisting the end users in creating the programs themselves (with our support), rather than bringing in one-size-fits-all programs forged in other communities with cultural needs and mores that do not speak to the life experiences of those living in the neighborhoods of North Philadelphia.

With the continuing constraints on in-person communication and programming caused by the Omicron variants (and others that may follow), we have purposefully turned our focus in the past year to alternatives that keep everyone healthy and safe but also build on and honor how our community advisory group members can most comfortably and authentically work with us to expand the reach of the project and its resources. In the coming year, we intend to build on those strategies and advance the timeline of the project.

Have your objectives changed?

Our overall objectives have not changed. We seek to engage community members with dementia and care partners in interactions around arts and culture who have historically been denied access to such programs; to broaden our practice of seeking direct motivation and participation by community members living with dementia in developing resources intended to meet their needs; to co-pilot and co-create with our community partners sustainable and neighborhood-specific programming driven by people living with dementia and their care partners; to “manualize” the community-driven best practices that are evolving during this project, disseminate the information, and catalyze a policy shift in caring for people living with dementia and their care partners throughout the service sector.

After two years of almost exclusively online interactions with community members, we have been able to harness both virtual and in-person opportunities in 2022 to reinforce the positive impacts of the project, building on the lessons we have learned about tailoring our communications and co-creating programs that honor the preferences and expectations of individuals within our partner neighborhoods. We have experienced and documented many valuable learnings during our organizational collaboration with Mural Arts of Philadelphia in particular, and through our assessment of community members' experiences during that collaboration (see final report for 2022). These have brought us to a critical inflection point in the life of *ARTZ in the Neighborhood*.

In 2023, we look forward to making the most of this inflection point, taking a substantial leap forward in realizing some of the most important goals of the project. Top priorities for the year include:

1. ***Re-dedicating ourselves to solidifying and supporting community advisory group members' leadership roles in biweekly meetings and in the programs and events they generate.***
2. While our community advisors and other community members may not have experienced the degree of agency we had hoped they would have in the design and creation of the Hunting Park/*ARTZ in the Neighborhood* mural, all have agreed that a rare and wonderful opportunity lies ahead, once the mural has been installed. ***Our community advisors are***

- eager to re-take ownership of the mural by utilizing it as a vehicle for change in how people living with dementia in the Hunting Park neighborhood are seen, understood and valued.* They have agreed to reaffirm our project's mission of inclusiveness by utilizing the mural as a primary tool for outreach, in neighborhood faith communities and beyond. The mural spotlights the historic role of Pastor Manny Ortiz ("Pastor Manny") in seeding neighborhood faith communities and resources from schools to legal clinics to Esperanza Health Center itself that are essential to the character of the neighborhood today in residents' minds. Pastor Manny was also the beloved husband of one of our community advisory group leaders and the father of one of our staff liaisons at Esperanza, so his presence in the mural has become a fulcrum of connection for all of us.
3. The mural draws on and makes visible to all who see it recurring themes that have emerged during the years of *ARTZ in the Neighborhood* as we asked our advisory group members and others the central questions "What brings you joy?" and "What brought you joy *before* that you now miss, and can we find ways to restore some version of those joyful experiences regardless of dementia-related illness?" *These themes will once again shape in-person programming driven by community members and supported by our team at ARTZ, now against the backdrop of the mural and its influence.* One of our community advisors has reflected that "The mural can act as a reminder or inspiration [to others in the community] which is why what's in the mural is important."
 4. *We will complete a first draft of the manual of community-driven program development best practices for work with people living with dementia* that has always been a crucial goal for this project and its ongoing impact. We will work closely with our process/project evaluator and a part-time assistant to collate and analyze the diverse data we have gathered since the start of *ARTZ in the Neighborhood* – meeting transcripts, observation notes, interviews with community advisors, organizational notes and documentation (including staff and community liaison communications recorded in email, via texts and on Slack), focus group findings, and creative, visual expression and imagery. The manual will draw explicitly and in detail on the learnings we have accrued through project successes, through the many challenges we have encountered, but above all on the lessons we have gained from our deep, connected collaborations with our community advisors.

What action(s) will you take to address the changes to problems/objectives?

Our projected actions for Year Five (January – December 2023) continued to reflect the fact that the neighborhoods in which we are working have been changed by COVID. The needs of our stakeholders for strong, safe, supportive community have increased, and their opportunities to find these in person are still variable. Our organizational practices have also changed, as evidenced by the fact that our continuing policy is still to be highly attentive and responsive to the numbers of COVID-related infections as we move forward with restoring in-person interactions, programs and events as fully as possible. Actions will include:

Continuing:

1. Continuing biweekly community advisory group meetings via Zoom when necessary and in person when possible.

2. Continuing regular check-ins with group members between regular meetings, via text, phone, mail.
3. Continuing to address technology needs of community members related to full engagement with and participation in the project. Use of our ARTZ app, which community members have already been starting to use on their cell phones, will enhance the ease of joining online meetings and streaming events for those not comfortable with Zoom technology.
4. Continuing to develop online and in-person community-led programs piloted from 2020 through 2022.

New and/or improved:

1. Renewed efforts to introduce the project, its programs and services to faith communities within each neighborhood through connections facilitated by community advisory group members and community liaisons.
2. Arts-based initiatives (continuing and new):
 - a. Printing of *ARTZ in the Neighborhood* conversation/coloring book, distribution to all community advisory group members and ongoing distribution within North Philadelphia and to other stakeholders. Ebook version will be posted to ARTZ Philadelphia Web site for free download.
 - b. Community-guided mural-based programming. Programs could include such forms of engagement as facilitated conversations about what the neighborhood means to individual participants and their families, what the mural shows, what it leaves out, opportunities to create community poems, images, music in response to the mural or filling in perceived gaps, possible exhibition of multimedia work generated by these programs.
 - c. Community advisory group members and their networks will continue to recommend and vet musicians for our “ARTZ Notes” online music program and “Music in the Neighborhood,” an interactive music program launched in July 2021 and renewed by its corporate sponsor to continue through June 2023. Programs are presented in person (held outside on a seasonal basis) from April-October and online from November through March, COVID numbers permitting.

What will success look like?

Success will entail the following outcomes:

“Deliverables”:

1. Mural-related programming in person and online, ***engaging 50-60 people.***
2. Printing and posting of e-book version of community conversation book, ***engaging 40-60 people through dissemination.***
3. Delivery of monthly “Music in the Neighborhood” music programs online, outdoors in Hunting Park or in NW Philadelphia, ***engaging 100-200 people.***
4. Continuation of regular FaceBook Live programs (***reaching on average 100 people per program***) and posts and discussions on “Life After Dementia” FB page, reaching an ***additional 150 regular viewers***

“Impacts”:

1. Community members with experiences of the stigmas and isolation of living with dementia continue to articulate increased hope and restored sense of community through participating in the project.
2. Community members with dementia and care partners continue to feel "heard" by their community, some for the first time, others, in new ways.
3. Community members with dementia and care partners experience a new sense of self-determination and dignity through participating in a project whose mission is to hear, understand, and meet their needs in various ways.
4. Community members gain sense of self-esteem, empowerment and connection by encouraging and attending to each other's stories around dementia and taking on the responsibility for making such connections.
5. The compounded sense of isolation and alienation resulting from the impacts of COVID-19 on people living with dementia and their families will be measurably lessened and QoL increased by both online and in-person programs.
6. We begin to “manualize” the innovative best practices we have developed during the first four years of the project, and to share our learnings with community advisors, both to solicit their feedback and to reaffirm their agency in the development of these practices.

Project budget, including other sources of support, budget narrative.

Budget Narrative:

The total budget for this project in 2023 will be \$90,050.

ARTZ Philadelphia Executive Director will serve as the project director for this grant. Her annual salary is expected to be \$65,000 in 2023; she will spend 25% of full time on this project. ARTZ Philadelphia's Community Engagement and Volunteer Manager will continue to serve as the primary staff person for this project. Her annual salary is expected to be \$56,000 in 2023; she will spend 60% of full time on this project. Technical support, photography, and video documentation will be provided by our Digital Projects and Program Manager at 20% of full-time, annual salary expected to be \$56,000. (All full-time salaries are based on a projected COLA of close to 10% in 2023.) Community liaisons (2) will each be paid \$7,500. The contract project evaluator will receive a project fee of \$5,000 for the year. He is reducing his fees by 50% in order that we be able to hire an additional evaluation team member. We have added a new paid project position to assist in compiling, sorting and analyzing data collected over the past four years in order that we be able to work with our evaluator to put together the first draft of a manual. This new position – which requires advanced research, data collection and data analysis skills -- has an estimated stipend of \$5,000 attached to it.

Provisional Sources of Additional Financial Support for Project and General Operating Support:

Acadia Pharmaceuticals, Inc., \$5,000 in hand (project); Janssen Pharmaceuticals, Inc, \$5,000 pending (project); Connelly Foundation, in hand \$10,000 (gen ops); Fox Chase Bank Charitable Fund, \$5000 pending (gen ops); Henrietta Tower Wurts Memorial/The Philadelphia Foundation, \$5,000 pending (gen ops); earmarked individual donations in hand: \$2,500.