

Teaching *ARTZ in the Neighborhood*: Documenting Lessons Learned During 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 \$15,000 for one, critical component of the wrap-up to our “ARTZ in the Neighborhood” project: a “how to” manual that documents lessons learned from our community advisors during the project. Funded by FFA in 2019-2023, 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 compile the first draft of a “how to” manual in order that we be able to disseminate the lessons learned and best practices developed during the project. This has been a priority “visible product” of the project from the outset.

Project Details:

Has the problem you have identified changed?

The systemic problems that our project was created to address in 2018 are more pressing today than they were then. Dementia is still the most pervasive chronic illness in our country: still more dreaded than cancer and as stigmatized as cancer used to be. The overlay of COVID-19 deepened the isolation and alienation from community, friends and family that are the hallmarks of lived experiences around dementia. COVID 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. COVID 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. Finally, it is a devastating fact—documented by the Alzheimer’s Association -- that more than 50% of primary care physicians describe themselves as “uncomfortable” and “ill-equipped” to discuss dementia with their patients.

It is even more evident now than when we began this project that the only reliable interventions available to us continue to be those that focus on enhancing quality of life (QoL). Pharmaceutical treatments such as aducanumab and even lecanemab, newly approved by the FDA, are limited in their applicability, efficacy, and availability and carry with them potentially life-threatening side effects. QoL-enhancing programs, providing joy and meaning through opportunities for agency, creative self-expression, community-building, and dignity preservation are widely applicable and have no such limitations or dangers associated with them.

That having been said, 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 designed 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.

Have your objectives changed?

Our overall objectives for “ARTZ in the Neighborhood” as a comprehensive project have not changed. We continue to engage through the project as a whole 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; and 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. However, for the term of this grant, should we be fortunate to receive it, we are honing in on the objective of collating and analyzing the voluminous data acquired through informal and formal assessment of the project, its processes, and its outcomes from 2018-2023 in order to compile a first draft of a manual of culturally- and community-specific “best practices” in community-driven program development for people living with dementia and their care partners. The outcome we ultimately seek through this process is to disseminate the information and catalyze a policy shift in caring for people living with dementia and their care partners throughout the service sector.

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

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 project evaluator and a part-time graduate assistant with the specialized skills and experience needed 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.

Project timeline and benchmarks:

January 2024:

- Executive director and project evaluator hire qualified graduate student to assist in data collation and analysis for “how to” manual and outlining content of manual in consultation with both

February 2024:

- Monthly meetings scheduled to monitor progress of manual
- Project evaluator and graduate assistant create timeline for collating and analyzing existing data (evaluator’s notes and reports and transcripts from past focus group interviews; observational notes by evaluator and prior project assistant; Zoom recordings of conversations from 2020-2022; four years of project team notes in Slack; and other sources) for “how to” manual

March - June 2024:

- Monthly meetings scheduled for executive director, project evaluator, and graduate assistant to monitor progress of manual
- March/April: project evaluator and graduate assistant continue to collate and analyze data for “how to” manual
- May: project evaluator and graduate assistant map out projected content of manual in consultation with executive director, based on categories of data compiled and analyzed as well as process-related information from executive director and project coordinator
- **June, 1st bilingual community review:** executive director, project evaluator, graduate student meet with project coordinator, community liaisons, community advisors, who review, assess, and give feedback on draft outline of categories of content for manual

July-August 2024:

- July: integrating feedback from community review, graduate assistant revises and fleshes out framework of manual
- August: Content outline FINALIZED for manual

September-December 2024

- Monthly meetings scheduled for executive director, project evaluator, and graduate assistant to monitor progress of manual
- **September, 2nd bilingual community review:** executive director, project evaluator, graduate student meet with project coordinator, community liaisons,

- community advisors, who review, assess, and give feedback on draft content for manual
- October: graduate assistant integrates feedback from community review; starts fleshing out content in consultation with project evaluator and with periodic review by executive director
- **November, 3rd bilingual community review:** executive director, project evaluator, graduate student meet with project coordinator, community liaisons, community advisors, who review, assess, and give feedback on draft content for manual
- By December 15: feedback from community review integrated in draft form by graduate assistant

What will success look like?

Success will entail the following outcomes:

“Deliverables”:

1. First draft of manual.

“Impacts”:

1. 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 2024 will be \$40,560.

ARTZ Philadelphia Executive Director will serve as the project director for this grant. Her annual salary is expected to be \$61,735 in 2024; she will spend 15% of full time on this project. Community liaisons (2) will each be paid \$1,500 for their time associated with this project. The contract project coordinator for ARTZ in the Neighborhood will spend an estimated 60 hours @ \$30 during the year. 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 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 monthly stipend of \$1,500 attached to it.

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

Acadia Pharmaceuticals, Inc., \$5,000 in hand (sponsorship specifically for this project);
Connelly Foundation, \$10,000 pending (gen ops); Fox Chase Bank Charitable Fund, \$5000

Friends Foundation for the Aging
Returning Applicant Grant Request, ARTZ Philadelphia
September 15, 2023

5

pending (gen ops); Janssen Pharmaceuticals, Inc, \$7,500 pending (project); TD Bank, \$10,000
pending (project); PECO Powering the Arts, \$8,000 (project)