

ARTZ in the Neighborhood: Continuing a Community-Driven Program Development Project By and For People Living with Dementia and Their Care Partners in the Age of COVID-19

Executive Summary:

We are seeking support from Friends Foundation for the Aging in the amount of \$30,000 to continue our program development project “ARTZ in the Neighborhood.” Funded by FFA in 2019-2020, 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 *by and for* people living with dementia and their care partners. We have partnered with two community “hubs” and hired two community liaisons for the project, each a long-time resident who is helping us to build trust and mutual respect within her neighborhood. We are seeking funds to continue the project into Year Three, reshaped by COVID-19: to continue funding our community liaisons and project evaluator; to solidify *online* programs we have begun to develop together during 2020; and to introduce new arts-based initiatives that will function both *online* and (eventually) in person and support sustainable programs.

Project Details:

What problem are you addressing? Evidence of need, why this solution chosen, demographics, description of community and people to be served; community and organizational partners.

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 the months-long periods of quarantine and isolation enforced by its outbreaks and spread. And 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 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 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 do not discriminate; nor, we believe, should the 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 and their sense of community. With “ARTZ in the Neighborhood,” we have 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 help), 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.

We have established partnerships in two North Philadelphia communities where we had not previously

offered programs: Hunting Park and the Germantown, Logan, Olney and West Oak Lane neighborhoods of Northwest Philadelphia. Our organizational partners – Esperanza Health Center in Hunting Park and LaSalle University Art Museum and Neighborhood Nursing Center in West Oak Lane -- have helped us to connect with other community members.

Community Demographics:

- Hunting Park residents are 52% Hispanic/Latino, 41% African/African American, 5% white. The household median income of residents over 65 is under \$25,000, just a few thousand dollars above the poverty line.
- Germantown residents are 77% African/African American, 15% white, 3% Hispanic/Latino and 2% Asian. The household median income of residents over 65 is \$27,846.
- Logan residents are 59.7% African/African American; 29.1% Hispanic/Latino; 5.4% Asian; 3.9% white. The household median income of residents over 65 is \$28,974.
- Olney residents are 50% African/African American and 26% Hispanic/Latino; the household median income of residents over 65 is just over \$27,000.
- West Oak Lane residents are 94% African/African American; 2% two or more races; 1% Hispanic/Latino; 1 % white. The household median income of residents over 65 is \$31,600.

What action(s) will you do?

Community-driven program development is recognized as a best practice when it comes to working with many underserved communities. However, it is a virtually non-existent practice when it comes to serving people living with dementia. The stigmas associated with dementia can cause those who live with it to be viewed as "less than" -- less respected than, less solicited for feedback than... in essence, less human than others (Stites & Karlawish, 2018). However, in so many of our programs, we have seen evidence that when offered the opportunity to play an active role in writing their own destiny (even in small ways), people living with dementia can feel re-enfranchised.

In Year One of this project, we brought together in each community an advisory group comprised of 8-10 people working and/or living in the neighborhood; living with dementia or caring for someone with dementia; and committed to building a community-driven program with us. We hired a part-time community liaison in each neighborhood: a longtime neighborhood resident who is on the advisory group and works closely with us to build strong relationships and facilitate outreach. The shared stories that came out of our meetings and outreach efforts provided the initial "data" that helped us to create pilot programs that enhanced QoL for community members in the first year-and-a-half. We gathered the stories and conversation prompts developed with advisory group members in Hunting Park into a bilingual "flipbook" that would assist them in spreading the word about the project, engaging with community members who might be served by the project. The feedback in Year One included testimonials from our community liaison in Hunting Park -- "Growing up in a Hispanic family and neighborhood, I wanted to be the voice for people who can't express themselves. It makes a difference because I'm being a bridge for the community. People feel I'm able to understand where they're coming from because I'm from the neighborhood" and of one of our pilot programs, "It was so beautiful. Just watching the smiles and excitement on everyone's face was priceless." Community advisory group members from Hunting Park told us "This program really had me all in from the beginning, always thinking of ways to contribute," and "You're right, and it's good for us too."

In Year Two, September 2019 through August of 2020, we continued these efforts to broaden neighborhoods' understanding of and engagement with people living with dementia and their care partners. We continued regular advisory group meetings and story circles that served as anecdotal needs assessment and program development tools. We continued program pilots begun in Year One, including programs based on advisory group members' input that engaged community members from diverse backgrounds sharing their varied musical heritages with each other; and a program based on the sharing of cherished recipes for favorite foods and conversation about the memories associated with those foods. In January 2020, an outside evaluator began to assess project and program impact, contributing to our ongoing "manualizing" of process and program creation. Then, in March 2020, the practices and protocols we had been building -- and the communities we were serving -- were side-swiped by the outbreak of COVID-19 in the Greater Philadelphia area and across the globe. All of our communications, meetings and programs for this project either went online or were diverted into the more traditional modes of snail mail and phone calls (and texts). The significance of the community formed around the project and the power of mutual

respect and love generated by it – even in the midst of a pandemic -- was expressed by Rosa, a Black resident of Hunting Park who, the week after George Floyd was killed, had a heartfelt conversation on Zoom with Ruby, an immigrant from Colombia preparing for her citizenship test, Thierry, our project evaluator, also Black, and Susan. Rosa said “I love you [Susan]. And I love Ruby and Thierry. It makes sense to me. I’m sad because of what’s going on in the country, but see, I’m sad because my parents taught me that all of us was human beings. When I look at you and Ruby and Thierry I don’t necessarily tune into color or race. You’re just people. . . . Doesn’t it make you feel good that you know you truly are around people that just see you as a human being? That’s one of the things I like about ARTZ and Esperanza. . . . All of us are of the same mindset and when you get people of the same mindset – good things happen.” Several months later, having been unable to attend the group’s Zoom meetings for a time because she was babysitting her great-grandson, Rosa told everyone on the call “I just miss you all so much.”

Our projected actions for Year Three (January – December 2021) reflect the fact that the neighborhoods in which we are working have been changed by COVID and by the civil unrest in the streets that gave vent to the agony brought to the surface by multiple murders of Black men and women by police. The needs of our stakeholders for strong, safe, supportive community have increased, and their opportunities to find these in person have decreased. Our organizational practices have also changed – our official policy is that until there is a widely available, tested and safe vaccine for COVID, we will be doing very little programming in person. Actions will include:

1. Continuing biweekly community advisory group meetings via Zoom (12 months instead of the 10 months prior to COVID; this was explicitly requested by group members). Meetings include story-telling, biweekly responses to the questions “What brought you joy, these past two weeks?” and “What challenges have you encountered?” and “How can we help – as a group?”
2. Continuing every-other-day check-ins with group members via text, phone, mail.
3. Continuing to assess and address technology needs of community members related to full engagement with and participation in the project.
4. In-house care-mapping workshops for community advisory group members made possible by free educational materials posted online by [Atlas of Caregiving](#) in response to COVID (a hold-over from Year Two, when we had planned in-person workshops with Atlas of Caregiving’s CEO).
5. New arts-based initiatives:
 - a. Co-create with community members in both neighborhoods a thematic series of “community conversations” books modeled on the Hunting Park “flip book” created in 2018 and 2019 (see attachment); themes to include food, music, poetry, visual art; community members’ stories (as in flip book) as the scaffolding; and illustrations of community members engaged in activities relevant to themes – illustrations by community artist, the daughter of our NW Philadelphia community liaison, who has just published a coloring book for children spotlighting children of color (<https://www.amazon.com/Color-Culture-Coloring-Raquel-Algarin/dp/0578736454>) and whom we will commission to create a coloring book for elders, of and with Community Advisory Group members (“Coloring for the Ages”). This work will be carried out exclusively online.
 - b. Partnership with Mural Arts Philadelphia; beginning in July 2021, ARTZ in the Neighborhood and community members from the Hunting Park neighborhood will collaborate with Mural Arts and a resident bilingual mural artist to co-create a mural inspired by community members’ stories around dementia. The design phase will take place online, and each community member will be able to create squares at home that will ultimately all be brought together to create a full-scale community mural on a wall opposite the entrance to Esperanza Health Center on 6th and Cayuga.
 - c. Community advisory group members and their networks will recommend and vet musicians for the 2nd year of the ARTZ Notes music-based program (exclusively online at this point). Five of the ten monthly programs will focus on musicians and music that speaks directly to the cultural and ethnic backgrounds of community members. We have engaged in building a related partnership with Esperanza Arts Center, the Philadelphia region’s premier center for Latino arts and culture, which is located just a few blocks away from Esperanza Health Center (the two are not related except in the communities they serve).

What outputs (measurable, specific) do you expect?

During Year Three, we expect to **engage at least 50 additional participants in each neighborhood (for a total of at least 100)**, through the online meetings, programs and initiatives described above. In addition, we expect to train

5-6 community advisory group members in the process of care-mapping through informal workshops facilitated by the project team. Each advisory group member will then be able to share this valuable process with at least 5-10 people in their own immediate community circles, **for a total impact on another 25-60 community members.**

What outcomes do you expect—what change will occur, what impact will it have?

Our goals for this project are: to engage community members with dementia and care partners in interactions around arts and culture who have historically been denied access to such programs; on a larger scale, to develop a consistent practice of seeking direct participation by and mentoring from community members living with dementia in developing resources intended to meet their needs; to set and promote a new standard of community-driven practice in the field for all of us serving people with dementia; to “manualize” the community-driven best practices that evolve during this project, to disseminate the information and catalyze a policy shift in caring for people living with dementia and their care partners throughout the service sector. A new set of aspirations and anticipated changes has arisen with the COVID outbreak. We had already seen in the first year-and-a-half of the project some of the outputs and outcomes towards which we had been working. These were highly dependent upon the in-person community-building strategies in which we were engaged. Our challenge in the age of COVID-19 is to achieve similar outputs and outcomes, but through almost exclusively virtual means.

How will you measure outputs and outcomes?

Outcomes related to the community-based process we are implementing--including impacts on advisory group and other community members, community liaisons, artists and facilitators--will be measured through pre- and post-program and -event surveys; focus group interviews ***designed and facilitated by the project evaluator***; and self-assessments and evaluator observations based on standard QoL measures. Impacts to be assessed will include:

- 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, as they did in Years One and Two.
- Community members with dementia and care partners continue to feel "heard" by their community, some for the first time, others, in new ways, as they began to do during Years One and Two.
- 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.
- 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.
- 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 (the latter if and when possible).

How will you sustain the project after the grant period?

ARTZ Philadelphia—from the Board to the Executive Director to the staff and volunteers – is committed to serving all of the neighborhoods of Philadelphia, particularly those neighborhoods whose cultural richness is great but whose socio-economic vulnerabilities are equally great.

How will your results be shared and replicated?

This project is primarily driven by neighborhood community members and stakeholders. As a result, its entire structure is predicated on a model of dissemination that begins with the project's community liaisons (each of whom resides in her respective neighborhood) and community advisory groups, and grows through their individually- and group-driven outreach to their neighbors, family, friends, acquaintances from church and other community members. This is still very much in evidence despite the fact that we have ceased in-person programming. Additionally, through the involvement of community hubs such as Esperanza Health Center, Esperanza Arts Center and Mural Arts, along with neighborhood libraries, senior centers, and other community centers with whom we had connected pre-pandemic, there is a network of dissemination already in place: both for the project programs and for the best practice models that will result from the project overall. Because of the COVID pandemic, we need to

revisit the structures for dissemination that we had in place prior to the outbreak and investigate how to make the most of them by virtual means. Additionally, we will seek opportunities to present project outcomes and lessons at regional and national professional conferences, where we hope this new model of program development will be of interest to other communities across the country.

How does this project fit with Friends Foundation values?

This project upholds Friends Foundation values including service to diverse populations through equity and inclusion; the potential to create change in practices that are unjust or demeaning of older adults, building on the potential for self-determination and contribution by people in their later years who are living with dementia; leveraging of resources and collaboration with other organizations to create sustainable programs beyond their pilot phases; engagement of stakeholders in playing critical leadership roles; providing services that address a full range of seniors' and communities' needs and recognizing that emotional, physical, and spiritual needs are often inextricably intertwined. We look forward to working on a continuing basis with Friends Foundation throughout the arc of this and other projects intended to serve those living with dementia in the diverse communities of North, West, and South Philadelphia.

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

Budget Narrative:

ARTZ Philadelphia Executive Director will serve as the project director for this grant. Her annual salary is expected to be \$52,000 in 2021; she will spend 25% of full time on this project. ARTZ Philadelphia's Community Engagement Coordinator will serve as the primary staff person for this project. Her annual salary is expected to be \$45,000 in 2021; she will spend 50% of full time on this project. Project management and technical support will be provided by a new staff position, Digital Projects and Program Manager at 25% of full-time, annual salary of \$50,000. The contract project evaluator will receive a project fee of \$10,000 each year. ARTZ Philadelphia and Mural Arts will cost-share the fees for the lead mural artist on our collaborative project. The fees for our ARTZ Notes lead program facilitator (responsible for overseeing the program administratively and its creative driver) will be cost-shared 50/50 between this project and our operating budget. The neighborhood artist commissioned to illustrate our series of themed "community conversations" books and a coloring book for elders is identified in the budget as "Community Documentation Artist."

Timeline:

January - December 2021: biweekly community advisory group meetings on Zoom

January – October 2021: ongoing process evaluation by outside evaluator

January – October 2021: ongoing "manualization" of best practices and processes by project director

January - February 2021: informal, virtual care-mapping workshops for advisory groups

January - February 2021: selection and vetting of program facilitators for 5 multicultural ARTZ Notes programs

February - November 2021: monthly, community-led virtual programs, including continuation of Café for Carers in NW Philadelphia and Cafés para Dos in Hunting Park, programs first piloted in-person in 2019 and online 2020

March 2021: "ARTZ in the Neighborhood" presentation at American Society for Aging conference (accepted)

March – June 2021: compilation of themed "community conversation" books

March-June 2021: mural project planning meetings with project staff and advisory group members

March – November 2021: multicultural ARTZ Notes programs take place every other month

July - September 2021: design and creation of Hunting Park mural (virtual and in-person if pandemic permits)

October-November 2021: program impact assessments by outside evaluator

December 2021: delivery of comprehensive report by process/project evaluator

Other Sources of Financial Support for Project and General Operating Support:

Janssen Pharmaceutical, Inc, \$5,000 in hand; Connelly Foundation, \$10,000 in hand; Fox Chase Bank Charitable Fund, \$7,000 in hand; Patricia Kind Family Foundation, \$15,000 pending; Henrietta Tower Wurts Memorial/The Philadelphia Foundation, \$3,000 pending; dedicated individual donations in hand: \$10,000