

What problem were you addressing?

The overarching problems we sought to address and redress through our project in 2019-2020 were as follows:

1. Enhancing quality of life for people living with dementia and care partners in two underserved neighborhoods of North Philadelphia: Hunting Park and Northwest Philadelphia.
2. Employing community-centric, culturally-specific approaches to developing programs enhancing quality of life: most notably, to create programs designed and implemented in collaboration with and in direct response to the needs and priorities of community members. To follow where the community members lead.

What change did you expect to create? What were the desired objectives, outcomes and outputs of the program and progress made toward each during the reporting period?

We expected to continue the efforts begun in the first year of the project (2018-2019) to broaden neighborhoods' understanding of and engagement with people living with dementia and their care partners.

Objectives:

1. Continue regular advisory group meetings and story circles serving as anecdotal needs assessments and program development tools. ***Objective met, though on smaller scale than anticipated.***
2. Continue program pilots begun in Year One, including programs based on advisory group members' priorities and preferences. ***Objective met, though through virtual rather than in-person programs and on a smaller scale than planned.***
3. Begin systematic project and program impact evaluation by an outside evaluator. ***Objective met.***
4. Continue ongoing "manualizing" of process and program creation. ***Objective met.***
5. Provide supplemental care-mapping workshops for advisory group members through workshops facilitated by [Atlas of Caregiving](#) for the purpose of offering them further tools for enhancing and deepening their communities' understanding of care networks. ***Did not happen due to COVID.***
6. Launch a continuing, monthly program in each neighborhood to enhance QoL for people living with dementia and their care partners. ***Did not happen due to COVID.***

Outputs:

1. Engage at least 100 participants in each neighborhood (for a total of at least 200). ***Engaged approximately 120 total due to the constraints of COVID.***
2. Train 8-10 community advisory group members in the process of care-mapping through Atlas of Caregiving workshops. 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 80-200 community members. ***Did not happen due to COVID***

Outcomes:

1. Dignity preservation, enhanced quality of life for community members living with dementia and their care partners. ***Successful outcome, though under different circumstances and using different measures.***
2. Advisory group members identify newly-developed skills that enhance their own resilience and self-esteem. ***Successful outcome, though under different circumstances and using different measures.***
3. Advisory group members experience increased comfort and sense of safety in sharing their own stories related to struggles with memory loss or other early signs of dementia; learn what adds meaning or joy to their lives; create opportunities for fellow community members to feel safe and validated in sharing *their* stories; and listening closely to those stories and how they can reveal struggles with cognitive challenges but can also reveal the most meaningful ways to achieve joy or contentment, despite those struggles. ***Highly successful outcome, though under different circumstances than anticipated.***
4. Restored or heightened sense of community, mutual support and trust, increased happiness, and dignity preservation for advisory group members and community members with dementia. ***Highly successful outcome, though under different circumstances than anticipated.***
5. Care partners and others develop greater capacity to empathize and connect with people living with dementia and seek in their stories "joy-makers" that might be implemented programmatically. ***Uncertain outcome because of COVID-influenced parameters, preventing expansion of project to wider community.***

Measures of success, qualitative and quantitative; numbers/demographics; diversity, equity and inclusion

Outcomes were measured through focus group interviews carried out by project evaluator; self-assessments and evaluator observations based on standard quality of life measures; and project evaluator analysis of video and audio recordings of advisory group meetings. Impacts assessed included:

1. Community members with experiences of the stigmas and isolation of living with dementia continued to articulate increased hope and restored sense of community through participating in the project, as they began to do in Year One. **Successful outcome, though on a smaller scale than anticipated due to COVID.**
2. Community members with dementia and care partners continued to feel "heard" by their community, some for the first time, others, in new ways, as they began to do during Year One. **Successful outcome, though on a smaller scale than anticipated due to COVID**
3. Community members with dementia and care partners experienced 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. **Successful outcome, though on a smaller scale than anticipated due to COVID**
4. Community members gained 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. **Successful outcome, though on a smaller scale than anticipated due to COVID**

Because of the profound strategic and programmatic changes necessitated by the COVID outbreak, our scope of impact narrowed substantially from the goals, outputs and outcomes outlined in our 2019 proposal. We focused all of our efforts on cementing and reinforcing the relationships we had established in 2019 and early 2020 with our community advisory group members. It was not feasible to expand our outreach beyond them, especially given the heightened and intensified needs of the advisory group members themselves during COVID. Due to the impact on emotional, psychological and physical well-being during the quarantine, a number of our advisory group members displayed the onset or exacerbation of dementia-related symptoms. In addition, several lost multiple close family members and friends to COVID and related illnesses and were unable to experience the comfort normally provided by gathering with others to mourn. All of our work turned to supporting and connecting with them by any and all means, including biweekly Zoom meetings, handwritten notecards sent out to those unable to join us via Zoom; multiple texts and phone conversations every week with every member of the advisory group in Hunting Park and some members of the NW Philadelphia advisory group. With the blessing of our project funders, including FFA, funds were reallocated as necessary to purchase tablets and provide WiFi hot spots to those community advisory group members without reliable access to technology, in order that they be able to maintain connection with us and with other members of the advisory groups.

Collaborations, leveraged resources, staff empowerment

We continued to collaborate closely with our colleagues at Esperanza Health Center in Hunting Park throughout the grant period, finding ways to enhance the impact of each others' programs through mutual support and strategy-sharing. At the start of the COVID outbreak in early March, ARTZ Philadelphia established protocols for programmatic shifts and pivoted quickly to online engagement for community members. Esperanza followed a couple months later with online programming for community seniors. They encountered substantial challenges in drawing attendees, so we shared with them the bilingual materials we created in March and have updated frequently during the past months to provide user-friendly and cognition-boosting technical support to our advisory group members, guiding them step by step in using Zoom. Esperanza included ARTZ in the Neighborhood palm cards we had printed up for the project in food bags they were delivering to community members every other week with groceries. ARTZ in the Neighborhood and Esperanza are currently synching our online programming schedules to strengthen our respective outreach capacity and effectiveness, and to build on each other's "fan base."

As described above, our Community Engagement Coordinator – our lead staff member for this project – and our community liaisons in both Hunting Park and NW Philadelphia took on the vital work of adapting strategically to the ever-changing circumstances on the ground in our two historically underserved and highly vulnerable neighborhoods. With the events of each week, we would all regroup and brainstorm about how to connect more effectively and consistently, and how to amplify the voices and needs and desires of our community advisory group

members. Our fluid, flexible and responsive staff accommodations of these needs and desires in the time of pandemic and protest will be an unanticipated but critical focus of our “manualizing” of best practices.

Unanticipated outcomes and barriers

Virtually all unanticipated barriers, changes in outputs and outcomes, and altered strategies resulted from the COVID-19 outbreak. Some also resulted from the protests and looting that shut down areas of Philadelphia – including our partner neighborhoods – for weeks at a time after the murder of George Floyd. (It is worth noting that the same unrest triggered very significant conversations among advisory group members across racial and ethnic lines, opening up moving exchanges about what it feels like to be an immigrant to this country seeking citizenship at a time when the systemic racism of the country is being exposed, and what it feels like to be a Black person seeking out common ground with a prospective new citizen at such a time as this.)

We have described above some of the impacts on our objectives, outputs and outcomes, particularly in relation to our work in Hunting Park. Unfortunately, our partners in Northwest Philadelphia were hit very hard by the COVID outbreak. LaSalle University closed the doors of its Neighborhood Nursing Center and furloughed its staff along with our colleagues at the University Art Museum. So an already complex endeavor to bridge campus and neighborhood communities through their shared experiences around dementia was further complicated by the loss of our key partner hubs. The patient services coordinator for Einstein Neurology Associates and Einstein Hospital’s newly-opened Behavioral Neurology program -- who had enthusiastically joined our Community Advisory Group in January – was also furloughed, upending our plans to collaborate with her and the dementia care specialist with whom she worked in bringing more North Philadelphia community members into the project.

Sharing and replicating results

The reports and documentation of the project compiled by our project evaluator will be vital to our sharing of our process (a very different process than we had envisioned as recently as January/February 2020) and its results. We are already sharing our strategies and results with colleagues informally, and plan to present on our project in several professional forums over the next year (including at the 2021 annual conference of the American Society on Aging in a workshop that was supposed to have taken place at the 2020 conference, canceled due to the COVID outbreak).

Project Financial Statement, Variances, and Sustainability

We have attached a project financial statement for the period of the grant, from September 2019 through August 2020. We have included notes describing the reasons for variances from the original budget. While no one can predict with certainty what the next year will look like, we are taking the following steps to ensure the project’s sustainability for 2021 and beyond: 1. ARTZ Philadelphia has recently embarked on a comprehensive strategic planning process that is intended to yield a new 5-year plan. Our partners in Hunting Park and NW Philadelphia will be interviewed at length as part of the planning process and their insights will be given priority during the Board’s discussions. 2. The Board has committed to recruit new members who will come from the Latinx/Hispanic and the African diasporic and African American communities at the heart of ARTZ in the Neighborhood. 3. ARTZ Philadelphia as an organization has been very clear and direct with our constituents regarding the emphasis we will place moving forward on ensuring diversity/equity/inclusion best practices in our organizational systems. ARTZ in the Neighborhood, its objectives and its practices are and will continue to be the centerpiece and a key driver of our DEI efforts. 4. We will continue to support the project through grant funds but will also be discussing during the strategic planning process the possibility of creating dedicated lines within our operating budget for at least one of the part-time community liaison positions and for a program facilitator from North Philadelphia who would work directly with our North Philadelphia partner communities.

Feedback on interactions with FFA

Friends Foundation for the Aging has been an extraordinarily helpful partner in ensuring that we have the flexibility and the support we need (moral, financial and otherwise) to sustain our work in North Philadelphia. Susan’s obvious personal commitment to FFA grantees is exceptional. All of our funders have been tremendously flexible during this challenging year, but not all of our funders have shown the capacity or the desire to be true partners in the efforts of their grantees. It is the greatest of gifts to have found that in FFA.