

Using Participatory Design & Community Engagement to Develop Online Caregiver Support



TLC Research Team

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Participatory Design is the process used to develop product in which the people destined to use it play a critical role in the design of it.

Community Engagement refers to research practices where researchers collaboratively work with and build meaningful partnership, including shared leadership roles, with members of the populations and communities of interest.

Frustrated with traditional intervention work that prioritized treatment fidelity and overly controlled research environments – which lead to good “science” but little translation of the intervention, our research team adopted a commitment to participatory design and community engagement in the (re)development of a behavioral intervention that supports family caregivers to persons with Alzheimer’s Disease or Related Dementias (ADRD) called “Time for Living & Caring” (TLC).



TLC coaches family caregivers to better plan and use their respite time, with the assumption that better respite time-use will improve their well-being and health. Originally, TLC was an in-person workbook-based program, facilitated by a trained interventionist over the course of 15-20 home visits. **This was not practical**, meaning that TLC would never be implemented in a non-research setting: caregivers would never benefit from it. Respite providers would never be able to implement it to their clients.

With funding from NIA (**R01-AG061946, 2019-2023**), our team is redeveloping TLC as an online, self-administered intervention, and will be conducting a pilot test to establish its feasibility and initial efficacy. We believe that our commitment to community engagement and participatory design will

- 1) allow us to **recruit a more diverse sample of ADRD caregivers** to participate in our pilot sample,
- 2) lead to the TLC intervention being more **scalable** and eventually being implemented to support ADRD caregivers in a cost-efficient manner.

Useful Resources: <https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources> (ADORE)

Examples of How We Are Doing It.

We engage key stakeholders, including current and former family caregivers, social service providers who were working with ADRD caregivers in the community, and leaders representing diverse local communities, throughout the conceptualization, technical development, and research processes:

- ❖ **2 Community Engagement Studios** to prioritize content and functionality of the redeveloped TLC online tools (i.e., focus groups with 10 providers and 10 caregivers). This was done prior to writing the grant proposal; the feedback both confirmed and enhanced our ideas. It was as important as, if not more so, than traditional pilot testing. Each participant received \$50 gift card for participation in a 90-minute session.
- ❖ Creation of a **Community Advisory Board (CAB)**. CAB members attend quarterly meetings with the research team. They provide feedback as we design and prototype the online TLC tools. CAB members are considered “consultants” and are paid an hourly wage for their ongoing participation throughout the study period.
- ❖ Occasional **community education events**, led jointly by CAB members and researchers. Topics are of public interest, such as “What is Alzheimer’s Disease?” and “Who Takes Care of the Caregiver?” This is a way for researchers to give-back to the communities being studied, but also provides an opportunity for the researcher to get a more authentic understanding of how these communities think about and talk about the topics of interest.
- ❖ Use CAB members to help with **recruitment and retention** of pilot sample. CAB members are invested in the TLC product, since they are involved in its development. They receive training from the TLC researchers about study eligibility and research protocols. Then, they make connections in their communities of potentially eligible participants and do a warm hand-off to the TLC research staff.

These activities are helping us create intentional & equitable community engagement, which is enhancing our understanding as researchers of the populations we are trying to serve. As the thought bubbles to the right illustrate, we are listening and learning. The very language we use has shifted from our work with our community partners.

Loved One.

Of course, this is a term we use for the person receiving care.

Stories.

Stories help humanize and normalize the research process for participants.

Caregiving.

This is just what a family does.

Respite.

What is it? Is it the same as “me time” or R&R or self-care?

The TLC intervention and our research is stronger from investing in these relationships.



TLC Community Advisory Board

Heather Brown
Pastor France Davis
Yeftal Delgadillo
Debbie Hall
Valentine Mukundente
Ed Napia
David Pascoe
Esperance Rugomwa
Sarah Scott
Melanie Scott
Harmony Starr
Fahina Tavake-Pasi
Maurice Wells
Brienne Witte

Community Collaboration & Engagement Team; Community Faces of Utah
Pastor, Calvary Baptist Church
Hispanic Health Care Task Force
Utah Pride Center
Community Collaboration & Engagement Team (University of Utah)
Urban Indian Center
Chaplain (hospice, palliative care, pediatrics)
Best of Africa
Director, Adult Day Services at Neighborhood House
Utah Coalition for Caregiver Support; Stepping Stones Counseling Solutions
GSLC (creative and technical developers of TLC online resources)
National Tongan American Society
Volunteer, Alzheimer’s Association
Community Collaboration & Engagement Team (University of Utah)

** Most CAB members are also current or former family caregivers