

Family Caregiver Navigator (FCN) Pilot

Year 1 Evaluation Report

June 2021

Evaluators: Destinie Triplett MHS and Sarah Toevs PhD
Boise State University
2020-2021

The production of this report was supported by the Money Follows the Person Grant 93.791 from the Centers for Medicare and Medicaid Services. Its contents are solely the responsibility of Boise State University and do not necessarily represent the official views of the Department or the Centers for Medicare and Medicaid Services.



Table of Contents

Executive Summary	3
1. Background	9
1.1. Family Caregiver Navigator Pilot	9
1.2. Logic Model	10
1.3 Stakeholders	10
2. Evaluation Methodology	11
2.1. Evaluation Purpose and Type	11
2.2. Process and Outcome Dimensions and Importance Weighting	11
2.3. Data Collection Procedures and Methods	12
3. Evaluation Results	12
3.1. Process Evaluation	12
3.2. Outcome Evaluation	17
<i>Dimension 1: Change in awareness, knowledge, and attitudes among family caregivers using TCARE for self-care, resources and services</i>	<i>18</i>
<i>Dimension 2: Change in self-reported measures of caregiver stress, burden, and likelihood of placement among family caregivers using TCARE</i>	<i>18</i>
<i>Dimension 3: Change in work flows in healthcare systems, agencies and other referral sources to recognize and refer family caregivers to the FCN</i>	<i>19</i>
4. Conclusions and Recommendations	21
5. References	23
Appendix A: Logic Model for FCN	25
Appendix B: Outcome Evaluation Plan and Collection Methods	26

Executive Summary

Background

The Family Caregiver Navigation (FCN) Pilot Project was initiated to extend and sustain the impact of the Money Follows the Person (MFP) program by maximizing the capacity of natural support systems, i.e., family caregivers, siblings, and friends. The project was launched in May 2020 in the southwest region of Idaho with active recruitment of caregivers to the evidenced-based Tailored Care (TCARE) intervention beginning in September 2020. This telephonic/web-based support program is designed to prevent family caregiver burnout and is CMS 1115-approved and ACL-accredited.

The contents of this report include process and outcome results from the evaluation of Year 1 of the FCN pilot program. The Executive Summary identifies key findings and opportunities and challenges with additional detail included in the body of the report.

Methodology

The evaluation used a mix of qualitative and quantitative strategies to monitor implementation processes and assess the effectiveness and benefits of the FCN program. Process evaluation data was gathered from meeting minutes, attendance records, and observation of program activities. The outcome evaluation was guided by three dimensions identified through synthesis of stakeholder input and findings from previous research on TCARE and similar caregiver support initiatives. These dimensions were change in:

- awareness, knowledge, and attitudes among family caregivers using TCARE for self-care, resources and services
- self-reported measures of caregiver stress, burden, and likelihood of placement of the care receiver in a long-term care facility among family caregivers using TCARE; and
- workflow in healthcare systems, agencies and other referral sources to recognize and refer family caregivers to the FCN.

Data for the outcome evaluation was gathered from caregivers participating in the program, referral records maintained by program staff, and the Navigators.

Results

Qualitative and quantitative results have been integrated and used to evaluate implementation activities and the impact of the pilot on family caregivers.

Process Evaluation of Implementation Activities

The following information identifies the key process evaluation dimensions and a brief overview of activities and progress.

Table 1. Process Evaluation Dimensions and Overview of Progress and Activities

Process Evaluation Dimension	Activities and Progress
Engagement of stakeholders	An advisory committee representing a broad range of stakeholders was established and met seven times in Year 1. Three workgroups composed of members of the advisory committee worked on specific activities.
Implementation and reach of marketing and communication materials	The FCN website and other social media tools were launched, over 150 presentations were made to community and professional groups, and print, video, radio and electronic outreach and referral materials were developed and distributed.
Cataloging of available resources and services	A caregiver focused database populated with over 1400 resources was established and the public-facing caregiver resource tool available on the ICA website has been expanded.
Implementation of TCARE	The TCARE platform was successfully launched in September 2020 including the training of navigators, working closely with the TCARE organization to enhance the system, and aggressive outreach to sources of caregiver referrals.
Development of a sustainability plan	Sustainability as evidenced by funding support and discussions of project continuation was documented.

The FCN has successfully implemented robust engagement, outreach and marketing efforts. Opportunities and challenges to consider as the project moves into year 2 include the need to sustain established levels of interest, prioritize communication efforts to maximize reach to target populations and garner support to sustain and expand the program statewide.

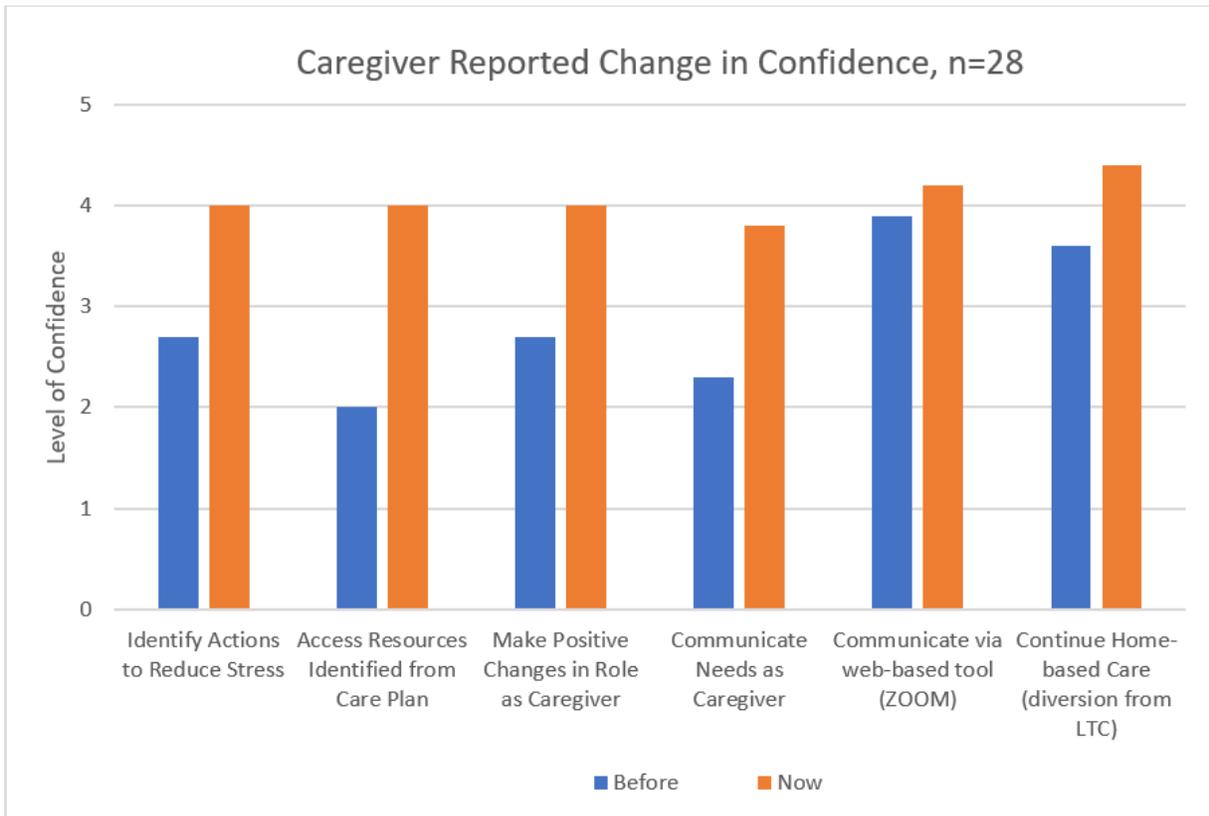
Outcome Evaluation

Since the launch of the TCARE intervention in September 2020, 221 caregivers have been in contact with a navigator, 193 cases have been entered into the TCARE system, 361 assessments (screening, initial, and follow-up) have been conducted, and more than 140 care plans have been completed. Caregivers represent the lifespan with care recipients presenting with a range of conditions.

Dimension 1: Change in awareness, knowledge, and attitudes among family caregivers using TCARE for self-care, resources and services

A retrospective survey designed by the evaluators was the primary tool used to measure this dimension. Based on a convenience sample from 38 % (28 of 73) caregivers who completed a care plan a change in awareness, knowledge and attitudes among caregivers was documented.

Table 2. Caregiver Reported Change in Awareness, Knowledge, and Attitudes

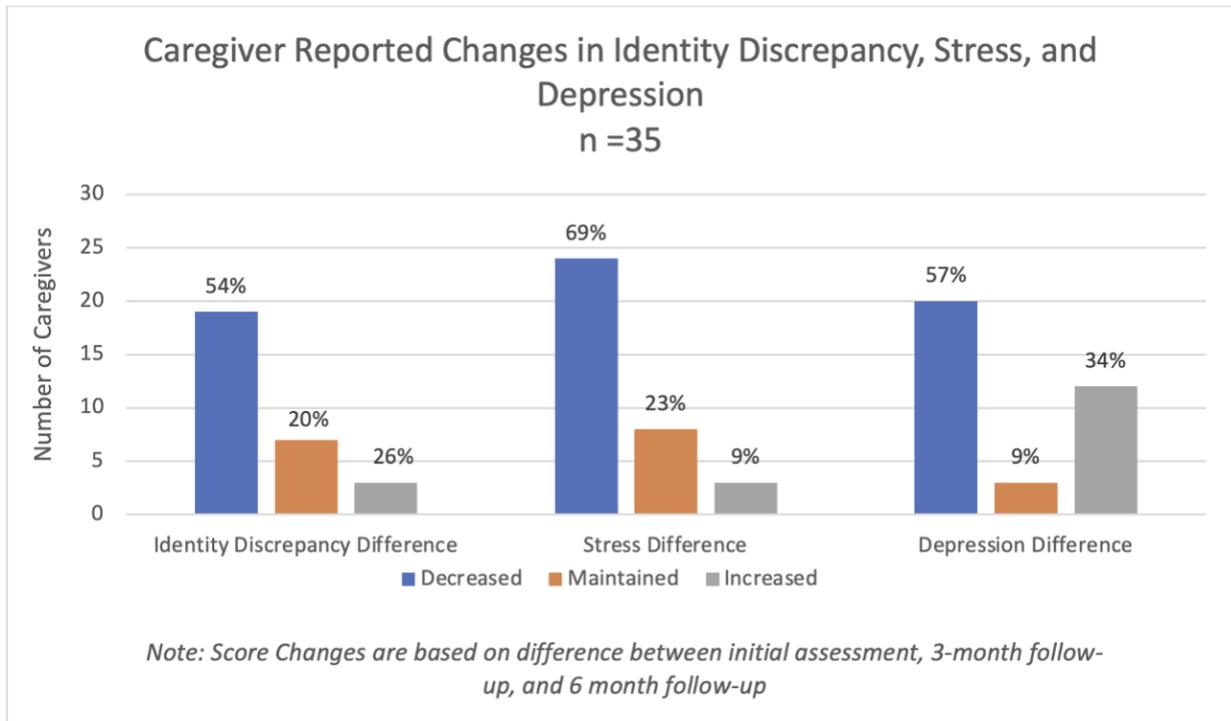


Dimension 2: Change in self-reported measures of caregiver stress, burden, and likelihood of placement in a long-term care facility among family caregivers using TCARE

Change in self-reported measures of caregiver stress and burden

Data extracted from the T-Care system from 35 caregivers who have completed at least two assessments was used to assess changes in Identity Discrepancy, Stress, and Depression. The score changes were based on the difference between the initial assessment, 3-month follow-up, and 6 month follow-up. Between assessments, scores decreased for identity discrepancy, stress, and depression.

Table 3. Caregiver Reported Changes in Identity Discrepancy, Stress, and Depressions



Change in self-reported intent to place care receiver in a long-term care facility

Evaluators used additional TCARE data to assess the impact on nursing facility diversion or intent to place. The caregiver’s current intention to place the care receiver in a nursing home or another care facility is assessed using

- a 4-point scale ranging from definitely not to definitely would given the care receiver’s current condition
- scores range from 2 to 8 with higher score indicating a greater intention to place the care receiver in a nursing home or other facility

Analysis revealed that **80% of caregiver’s “intent to place” decreased or did not change** from initial to 3- or 6-month assessment. Twenty percent reported an increase in “intent to place”.

Dimension 3: Change in workflow in healthcare systems, agencies and other referral sources to recognize and refer family caregivers to the FCN

The integration of TCARE into the workflow in healthcare systems, agencies and other referral sources has been challenging.

Efforts in Year 2 will continue to focus on supporting changes in workflow within entities that could serve as trusted referral touch points for family caregivers. The FCN team will also

explore ways to acknowledge referring entities by sending an automated thank you message, recognizing referring agencies in the ICA monthly news, and other similar activities.

Conclusions from Year 1 Evaluation

This evaluation included an assessment of both process and outcome measures. Evidence from program records and longitudinal data from participants suggest that significant progress has been made toward maximizing the capacity of the natural support systems, i.e., family caregivers, siblings, and friends, essential to the sustained success of Money Follows the Person (MFP) program in Idaho. This initiative has benefited family caregivers with no negative outcomes reported by caregivers.

The findings must be interpreted in light of the formative stage of development of the program and the launch of the program during the COVID-19 pandemic. Initial funding of the program commenced in May 2020 and in 4 months, the program went live with robust marketing and outreach materials, an interactive website and phone line, an engaged advisory committee, 1.5 FTE navigators, and an enthusiastic core of community advocates. The ability to implement a complex intervention in a very short period of time speaks to the leadership and creative capacity of the team. Implementing a new program is hard work, but the FCN team has accomplished this and more with preliminary results demonstrating value to unpaid family caregivers and potential savings to Idaho by delaying or preventing costly long-term care expenditures.

Limitations of Evaluation

As is the case in many programs in a formative phase of development there were unknowns and unexpected events. This formative stage of implementation led the evaluator's to create a "home grown" retrospective survey to assure that feedback 30-days after completion of the care plan would be available to inform marketing and continuous quality improvement efforts. The implementation of this survey, in addition to challenges associated with the COVID-19 pandemic, limited the capacity to conduct other proposed evaluation activities, i.e., interviews with caregivers, care recipients, members of the advisory committee, etc.

The formative nature of the initiative and funding capacity also precluded the recruitment of a comparison or control group of caregivers. This limits the ability to draw conclusions about the impact of the intervention beyond recognizing observed associations in pre- and post-intervention changes in confidence, stress, burden, identity discrepancy, intent to place, and other variables.

Recommendations

Research suggests that programs designed to support family caregivers can enhance the quality of life for the caregiver and care receiver as well as reduce or delay the intent to place the care receiver in a long-term care facility (Montgomery, Rowe, & Kosloski, 2007; Montgomery, Kwak, Kosloski & O'Connell, 2011; Browne, Nishita, Chun, 2015). To our knowledge, this is the first

attempt to implement a caregiver focused intervention in Idaho and the results from Year 1 suggest that the program has value to caregivers and Idaho.

The activities from Year 1 have established a foundation for Year 2 of the pilot. Based on findings from this evaluation, the following are offered as recommendations.

- Continue to clarify the navigator position description and role expectations. Early in the pilot, two navigators left the project due to lack of available time and the stress (reliving of their own caregiver experiences) related to serving as a navigator.
- Conduct regular check-ins with the navigator team to assure systems and processes are focused on providing consumer-directed support to the caregiver (and not the care receiver). This reorientation to the caregiver dictates continued development of databases, populated with resources that address the **needs of caregivers** across the life span.
- Employ a student intern (graduate or undergraduate) to manage the resource database. This experience would include organizing and validating resources, identifying new resources, attending ICA meetings, and participating in other networking opportunities.
- Facilitate the submission of resources for listing in the database through the use of an online submission form on the ICA website. The resources identified through the ICA portal could then be added to the FCN caregiver database.
- Build on relationships established with the Master of Social Work Program as a means of expanding the number of available navigators and providing students with a powerful learning experience.
- Implement a network of support for the navigators to minimize compassion fatigue and burnout. Many of the conversations with caregivers are difficult. The weekly navigator meetings should include periodic support provided by a professional counselor to reduce stress and increase employee satisfaction and retention.
- Conduct a process evaluation with community partners to determine if the website referral form and other FCN referral resources are effective.
- Continue to build relationships with community partners to make “warm handoffs” from the navigators to resources smooth and effective. This could include:
 - expansion of the existing list of contacts embedded in organizations that are prepared to respond to calls from family caregivers
 - the addition of an ambassador or community liaison tasked with contacting partners on a regular basis to provide reminders.
- Recognize individuals and organizations who refer caregivers to the navigators. This could be accomplished by sending an automated thank you message or giving a shout-out to referring entities in the ICA newsletter.
- Recognize individuals and organizations who refer caregivers to the navigators. This could be accomplished by sending an automated thank you message or giving a shout-out to referring entities in the ICA newsletter.
- Continue to integrate referrals to FCN into existing workflows. The program is enthusiastically received during presentations to health care providers, community-based organizations, and human resource professionals, but referrals have not been

robust. While it is important to continue broad outreach and promotion, the FCN team may want to focus efforts on organizations with a clearly stated interest in caregivers.

These could include, but are not limited to:

- staff providing Information and Assistance at the Area Agencies on Aging,
 - navigators with the Idaho Careline 2-1-1,
 - support groups hosted by the Idaho Alzheimer's Association and Kinship/Relatives as Parents support programs,
 - parents and leadership involved in Rays for Rare
 - volunteer leaders and participants in Powerful Tools for Caregiver class,
 - community health workers (CHW) through engagement with healthcare systems, the Idaho Community Health Worker Association, and other entities employing CHW.
- Offer an incentive to caregivers who complete the retrospective survey administered 30-days after completion of a care plan in order to increase the response rate.
 - Continue to work with TCARE to enhance data reporting and analysis capacity of the software platform. For example, TCARE just recently added fields to capture caregiver and care recipient health insurance coverage based on feedback provided by the Idaho navigator team.
 - Explore moving the TCARE caregiver reassessment from 3-months to 6-months. This will provide caregivers with additional time to implement their plan of care and may make incorporation of the TCARE intervention into the workflow at area agencies on aging more realistic.
 - Continue to network with key partners to continue to build sustainability, i.e., APS project with Idaho Commission on Aging, health systems as a component of value-based care, a benefit or support provided by payers (Medicaid, Molina, Blue Cross, Regence, and others)

1. Background

1.1. Family Caregiver Navigator Pilot

The purpose of the Family Caregiver Navigation (FCN) Pilot Project is to develop, implement, and evaluate a telephonic/web-based support program specific to unpaid family caregivers in Idaho. The goal of this initiative is to extend and sustain the impact of the Money Follows the Person (MFP) program by maximizing the capacity of natural support systems, i.e., family caregivers, siblings, and friends provide to community dwelling individuals with significant intellectual or developmental disabilities or physical, mental health or adult-onset cognitive disabilities. Additionally, testing this model of support will assist in determining its value to unpaid family caregivers as well as its cost effectiveness and quality in terms of preventing more costly health or long-term care expenditures.

This project leverages the capacity of the Idaho Caregiver Alliance (ICA) to enhance resources available to family caregivers. It also builds on knowledge of the reluctance of family caregivers to identify themselves as such, and the need to implement a robust referral process

with encouragement provided by health care providers and others who come in contact with family caregivers.

In June 2020, the Division of Medicaid within the Idaho Department of Health and Welfare provided funding to the ICA to initiate a two-year endeavor to maximize partner engagement, to develop and implement an outreach plan, and launch a family caregiver navigator pilot program.

1.2. Logic Model

Implementation of FCN is designed to help caregivers get the guidance and HCBS supports they need to help the person for whom they care remain at home or return home after transitioning from another care setting.

The logic model for the FCN pilot (See Appendix A) provides an overview of the means and end results of the program.

- Resources: Facilities, tools, materials, data, personnel, etc. that the program will use
- Activities: Processes the program will execute
- Outputs: Evidence of implementation of processes (e.g. # of visits, # of patients served)
- Outcomes: Changes in knowledge, behaviors, health status and healthcare delivery system

1.3 Stakeholders

There are four types of stakeholders for the FCN pilot: upstream stakeholders, local stakeholders, direct impactees, and indirect impactees.

Upstream Stakeholders

Support and funding for the Caregiver Navigator Project comes from the Idaho Department of Health and Welfare. The key upstream stakeholders are the following:

- Centers for Medicare and Medicaid Services
 - Division of Medicaid, Bureau of Long-Term Care, Idaho Department of Health and Welfare
 - Idaho's Money Follows the Person Program: Idaho Home Choice
- Administration on Community Living
 - Idaho Commission on Aging
 - Center for the Study of Aging, Boise State University

Local Stakeholders

The individuals implementing the FCN pilot are the local stakeholders of the program.

- FCN staff
- FCN Advisory Committee

- Area 3 Senior Services Agency (A3SSA)
- Referral source partners such as, but not limited to health care systems, Idaho Parents Unlimited, Independent Living Centers
- Idaho Caregiver Alliance

Direct Impactees

The participants in the FCN pilot are the direct impactees of the program.

- Family caregivers served by the FCN in SW Idaho (Ada, Adams, Boise, Canyon, Elmore, Gen, Owyhee, Payette, Valley, Washington Counties)
- Care recipients (prevention and/or delay of costly institutionalized care)

Indirect Impactees

Success or failure of the FCN pilot will have an impact on not only the immediate recipients of the program, but also other groups of people.

- Referral source partners
- Healthcare/service providers
- Assisted Living and Skilled Nursing Facilities

2. Evaluation Methodology

2.1. Evaluation Purpose and Type

This formative evaluation will use process and preliminary outcome data to describe key activities of the FCN pilot program and assess the impact of the program on family caregivers and those entities referring family caregivers to the program. Upstream and local stakeholders will use the evaluation findings to improve the program, determine the effectiveness of the program, and guide future decisions about expansion of the program. This approach mirrors the Agile Method of design and evaluation used in software development and other rapid prototyping ventures.

Figure 1

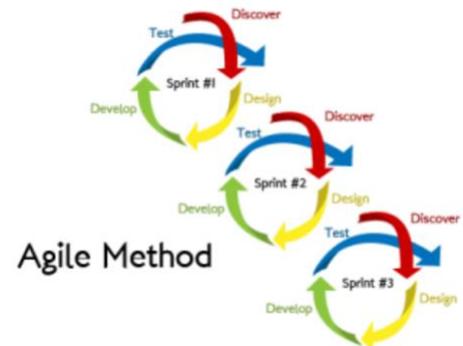


Figure retrieved from:
<https://www.codeproject.com/Articles/1064114/Agile-Software-Development-Basics>

2.2. Process and Outcome Dimensions and Importance Weighting

Based on information from the project proposal and communications with stakeholders the following process and outcome evaluation dimensions will be assessed:

Key process evaluation dimensions include:

- Implementation and reach of marketing and communication materials

- Representation from key stakeholders within sectors
- Cataloging of available resources and services available to family caregivers
- Implementation of TCARE
- Development of a sustainability plan

Outcome evaluation dimensions and relative importance weighting (IW) include:

- Change in awareness, knowledge, and attitudes among family caregivers using TCARE to self-care, resources and services (IW: Critical)
- Change in self-reported measures of caregiver stress and burden among family caregivers using TCARE (IW: Critical)
- Change in work flows in healthcare systems, agencies and other referral sources to recognize and refer family caregivers to the FCN (IW: Very Important)

2.3. Data Collection Procedures and Methods

The evaluation team used multiple sources of data and data collection methods. Process evaluation methods relied on program records including, but not limited to, number and type of marketing, communication, and outreach activities and project deliverables as outlined in the program scope of work. Outcome evaluation methods will rely primarily on information generated by the TCARE system. Additional information will be gathered via surveys from TCARE participants and key informants in healthcare settings, agencies and other caregiver referral sources, see Appendix B for proposed Outcome Evaluation Plan and Collection Methods.

3. Evaluation Results

Qualitative and quantitative results have been integrated and used to describe the impact of Year 1 of the FCN pilot and to identify opportunities and challenges.

3.1. Process Evaluation

The following five process evaluation dimensions were documented in Year 1.

- Engagement of stakeholders
- Implementation and reach of marketing and communication materials
- Cataloging of available resources and services
- Implementation of TCARE
- Development of a sustainability plan

Engagement of Key Stakeholders

A total of 41 members were invited to serve on the committee with representation from a broad range of stakeholders. The type and number of organizations represented on the Advisory Committee were:

- State (5) - Idaho Commission on Aging (ICOA), Behavioral Health (IDHW), Idaho Home Choice (IDHW), Division of Public Health (IDHW), 211 Idaho (IDHW)

- Community (7) - A3SSA, Legacy Corps, Idaho Parents Unlimited (IPUL), AARP Idaho, Idaho Foodbank, LINC, Alzheimer's Association
- Veteran Services (1) - Veteran Affairs (VA)
- Health Systems and Providers (6)- St Luke's, St Alphonsus, ADA County Paramedics, Terrace Home Health, FMRI, Kootenai Health
- Health Insurers (2) - Molina, Blue Cross of Idaho

Seven web-based Advisory Committee meetings were held during Year 1. The type and number of organizations who attended advisory committee meetings frequently (four or more) were:

- State (5) - ICOA, Idaho Home Choice (IDHW), Division of Public Health (IDHW), 211 Idaho (IDHW)
- Community (4) - A3SSA, Legacy Corps, IPUL, LINC
- Veteran Services (1)- Veteran Affairs
- Health Systems and Providers (3) - St Luke's, St Alphonsus, Terrace Home Health
- Health Insurers (2) - Molina, Blue Cross of Idaho

The notes from committee meetings reflected a focus on the following project areas:

- Effective Outreach Strategies - messaging, community presentations and events
- Building of Resource Database - sharing of resources with committee members and resource submission
- Generation of Marketing Tools - flyers, RX pads, Measuring positive changes in caregivers, radio ads, and videos
- Connection with community partners - establishment of warm hand-offs and trust within communities

In addition to support from the Advisory Committee, three work groups functioned during Year 1. The Marketing, Outreach and Evaluation Work Groups guided start-up and implementation of key activities.

A review of committee membership and attendance demonstrates broad support and engagement. As the project moves into Year 2 the addition of stakeholders representing faith-based communities and employer organizations should be considered.

Year 2 activities will also be informed by a Latinx Advisory Committee. This group was initiated as a stand-alone entity with plans for merger with the larger group during Year 2. The work of the Latinx Advisory Committee will be:

- Identification of effective Outreach Strategies
- Building of Resource Database

- Generation of Marketing Tools
- Building connections with community partners

Implementation and reach of marketing and communication materials

Marketing efforts were split into two audiences – direct-to-consumer messaging to caregivers as well as B2B messaging to Providers and Professionals in the health systems, community-based services and organizations. Over 150 presentations were given to these audiences, with an average of 15-25 attendees per presentation, though some webinars reached upwards of 75.

A downloadable toolkit was created through the website with materials in English and Spanish, and a suite of printed materials including posters, Rx pads, postcards, brochures, magnets and webcam covers were created to be distributed at outreach events and with our community partners. Consumer-facing campaigns on social media, newspaper and radio ads supplemented email marketing and print advertising. A complete list of outreach activities can be found in the [monthly reports](#) filed.

The tracking of referrals to the FCN provides evidence of the impact of marketing and communication materials and broad reach of the project. Approximately 175 referrals have been made to the FCN from over 20 different entities. The five most common referral organizations, agencies, and sources events were:

- Idaho Caregiver Alliance (n=35)
- St Alphonsus Health System (n=31)
- St Luke’s Health System (n=16)
- Word of Mouth (n=13)
- Outreach Events and Presentations (n=11)
- Legacy Corps (n=10)

Cataloging of available resources and services available to family caregivers

At the close of Year 1, an internal resource database of 1423 caregiver-focused service and support listings has been established. These resources are maintained in the TCARE system and a shadow spreadsheet. A smaller database of “permanent” resources is maintained in a searchable database on the ICA website, <https://idahocaregiveralliance.com/resource-library/>. Primary sources used to populate the databases were: AARP Caregiver Guide, ICA resource web-page, A3SSA, and other community resource documents. Resources are also added using the online submission form available on the FCN website and as FCN and ICA staff discover new services.

Data management components of the TCARE user agreement include regular data-mining of the front-facing resource databases throughout the state and a bi-annual (every 6 months) verification that the resource is still available.

Process indicators for Year 2 will focus on expansion of the database to meet the needs of caregivers living in rural areas and those who have limited English speaking skills and/or limited reading ability. Plans for Year 2 include increasing the number of services offered by faith-based organizations and hiring a student intern to manage the maintenance of the database.

Implementation of TCARE

The following is a brief overview of the onboarding process for the navigators and relationships established with the TCARE platform. The internal processes of communication systems, implementing a scheduling software, and internal tracking of activities has not been included in this report. These internal processes have been detailed in the [Family Caregiver Navigator Orientation and Training Manual](#) developed by the lead navigator.

As of April 30th, 2021 six navigators and one intake specialist have completed the TCARE training. Two of these individuals are employed by the A3SSA and four are with the Center for the Study of Aging at Boise State. Two of the navigators employed through the Center are students from the Master of Social Work Program at Boise State. These individuals are dovetailing their work as a navigator with required MSW field placement hours.

One of the individuals from the A3SSA had to step away from the project due to the lack of time and the lead navigator, employed by Boise State, plans to leave this position in July 2021 to assume a statewide leadership role as a Program Specialist for Alzheimer's Disease and Related Dementia.

All navigators complete the online TCARE training which includes an introduction to the TCARE philosophy, research findings that support the intervention, and guidance on how to utilize consumer-directed/options counseling skills when conducting an assessment and building a care plan. After completion of the training and receipt of TCARE certification, navigators are mentored by the lead navigator and other members of the navigator team. The following provides an overview of the mentoring activities:

- Work directly with the lead navigator to complete a full assessment and care plan.
- Shadow members of the navigator team during a caregiver appointment.
- Orientation to internal FCN documents and resources, such as, the [Orientation and Training manual](#), [Navigator Specific Spreadsheet](#), and [FCN/TCARE Shadow Database](#)

After completion of a first assessment and care plan with a caregiver the navigator meets with the lead navigator to review the process and discuss strengths and identify opportunities for further development.

A weekly meeting with the navigator team is held to allow for debriefing on cases, peer support, and implementation of quality improvement activities. These meetings are structured with an agenda and meeting notes are maintained

Since the Idaho launch of TCARE, the navigator team and FCN staff have worked closely with TCARE management and software development team. These meetings have resulted in significant improvements in the TCARE platform and data reporting capacity. The Idaho team has contributed to multiple updates to the TCARE system, such as, more comprehensive tracking of caregiver and care recipient health insurance coverage, updating language to reflect a more inclusive perspective (preferred pronouns and language, removing “disease” from discussions of a developmental disability, ability to opt-out of responding to specific questions [income, ethnicity]), and the addition of an Emergency ID Card for caregivers in the printout of the care plan, see Figure 2.

Along with TCARE software implementations, the navigator team maintains a [resolution log](#) to document communications with TCARE. This allows for the tracking of requests and services received.

Priority activities for Navigators in Year 2 will include restructuring the team with the exit of the lead navigator, a focus on outreach to members of the Spanish-speaking community in southwest Idaho, and continued testing of integration into the A3SSA infrastructure and workflow.

Figure 2



Development of a sustainability plan

Evidence of a developing sustainability plan include achievement of the following outputs:

- Active engagement and buy-in among members of the FCN Advisory Committee and ICA Leadership Team
- Establishment of contract relationship with the A3SSA to hold the licenses for TCARE navigators
- Expansion of the caregiver resource database and public-facing availability of database on the FCN and ICA websites
- Supplemental funding specifically for the FCN pilot from St Luke’s Health System, Blue Cross and Molina
- Negotiations with the Idaho Commission on Aging to include the FCN intervention as a resource to Adult Protective Service professionals statewide
- Inclusion of the FCN intervention in a proposal submitted by the Area 4 Senior Services Agency to the Administration on Community Living. If funded, resources would be used to expand FCN in the Area 4 region with a focus on enhancing support available to individuals with dementia and their caregivers.
- Preliminary findings that suggest the capacity of a caregiver support intervention to delay/divert individuals from needing services provided by long-term care facilities

While no sustainability plan for support for FCN beyond Year 2 of the project has been established, progress has been made to secure public/private funding. For example, Molina Healthcare of Idaho, Blue Cross Insurance, and St. Luke’s Health Systems provided resources to support the FCN initiative. A significant portion of these funds were allocated to the A3SSA to support a navigator focused on serving caregivers who care for individuals with Alzheimer’s disease and related dementias and/or individuals from the Spanish-speaking community. In addition, ICA and FCN and the Idaho Commission on Aging are exploring integration of TCARE into the Adult Protective System as a preventive strategy for individuals and families at risk to abuse, neglect, and exploitation.

An essential sustainable output achieved during Year 1 is the robust resource database designed to address the needs of unpaid family caregivers. This searchable database will continue to be available on the ICA website.

3.2. Outcome Evaluation

Since the launch of the TCARE intervention in September 2020, 221 caregivers have been in contact with a navigator, 193 cases have been entered into the TCARE system, 361 assessments (screening, initial, and follow-up) have been conducted, and more than 140 care plans have been completed. The majority of caregivers have been women (80%) with 87% identifying as white and 10% as Hispanic. Caregivers engaging in the intervention represent the lifespan with care recipients presenting a range of diagnoses or conditions, Table 6.

Table 4. Care Recipient Diagnosis/Condition

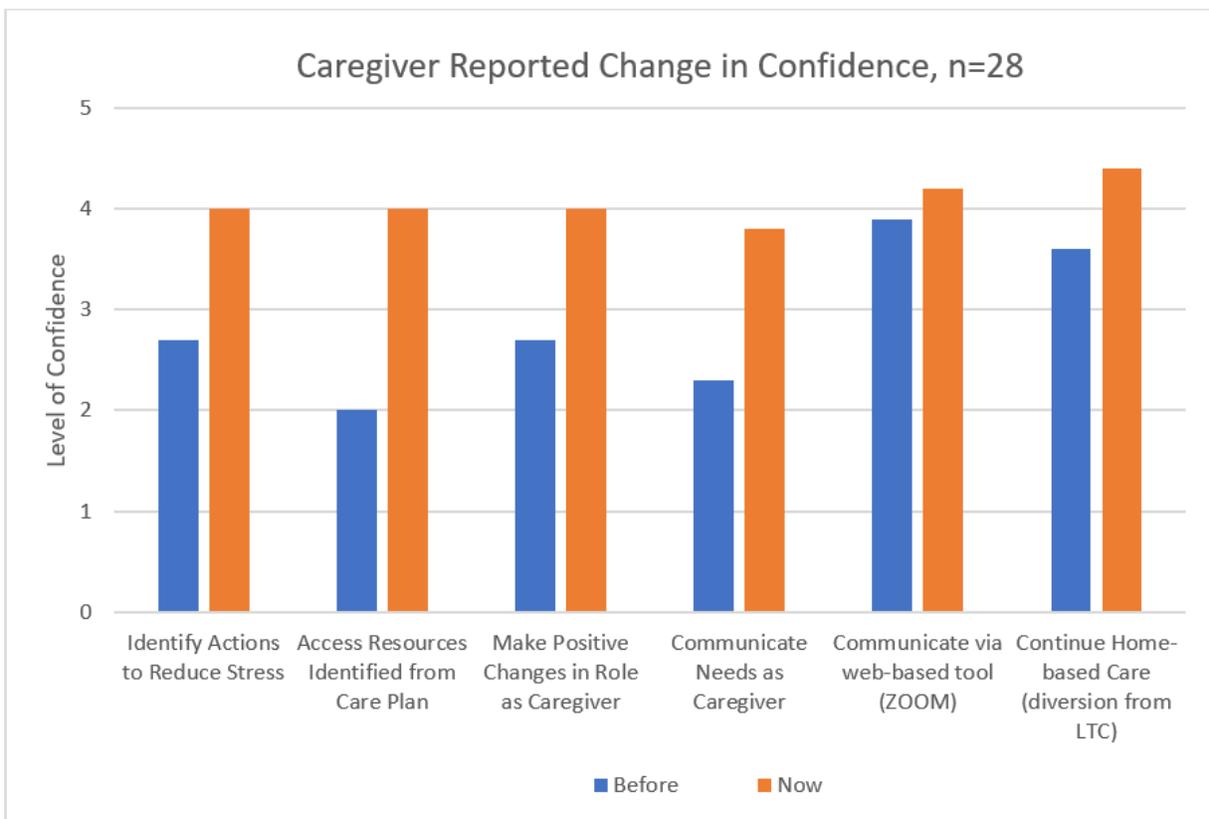
Diagnosis/Condition	Percent
Alzheimer’s/Dementia	39%
Chronic Conditions (cancer, diabetes, other)	27%
Developmental Disability	15%
Autism	7%
Age-related (undiagnosed changes)	4%
Parkinson’s Disease	4%
Mental Health	2%
Traumatic Brain Injury	2%

Dimension 1: Change in awareness, knowledge, and attitudes among family caregivers using TCARE for self-care, resources and services

Since the launch of the TCARE intervention in September 2020, 221 caregivers have been in contact with a navigator, 193 cases have been entered into the TCARE system, 361 assessments (screening, initial, and follow-up) have been conducted, and more than 140 care plans have been completed. Caregivers represent the lifespan with care recipients presenting with a range of conditions.

A retrospective survey designed by the evaluators was the primary tool used to measure this dimension. Based on a convenience sample from 38 % (28 of 73) caregivers who completed a care plan a change in awareness, knowledge and attitudes among caregivers was documented.

Table 2. Caregiver Reported Change in Awareness, Knowledge, and Attitudes

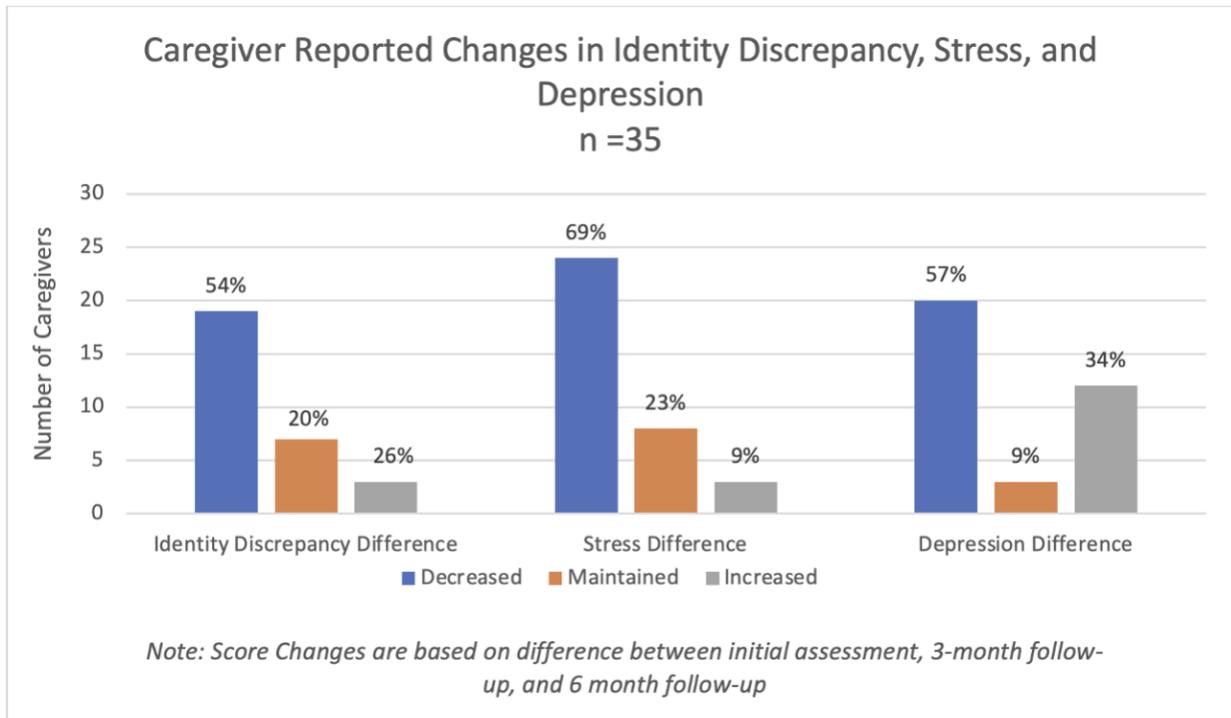


Dimension 2: Change in self-reported measures of caregiver stress, burden, and likelihood of placement among family caregivers using TCARE

Change in self-reported measures of caregiver stress and burden

Data extracted from the T-Care system from 35 caregivers who have completed at least two assessments was used to assess changes in Identity Discrepancy, Stress, and Depression. The score changes were based on the difference between the initial assessment, 3-month follow-up, and 6 month follow-up. Between assessments, scores decreased for identity discrepancy, stress, and depression.

Table 3. Caregiver Reported Changes in Identity Discrepancy, Stress, and Depressions



Change in self-reported intent to place care receiver in a long-term care facility

Evaluators used additional TCARE data to assess the impact on nursing facility diversion or intent to place. The caregiver’s current intention to place the care receiver in a nursing home or another care facility is assessed using

- a 4-point scale ranging from definitely not to definitely would given the care receiver’s current condition
- scores range from 2 to 8 with higher score indicating a greater intention to place the care receiver in a nursing home or other facility

Dimension 3: Change in work flows in healthcare systems, agencies and other referral sources to recognize and refer family caregivers to the FCN

Some change in work flows has been realized in partnering organizations, but as expected, accomplishing this objective has been slow and complicated by challenges healthcare systems,

providers, and organizations experienced due to the COVID-19 pandemic.

Three organizations accepted the FCN invitation to become early adopters. These were Saint Alphonsus Geriatric/Palliative Clinic, Legacy Corps/ Powerful Tools for Caregivers housed at Jannus Inc., and Dispatch Health, a home health service.

The following is a summary of FCN early adopter experience with Saint Alphonsus Geriatric/Palliative Clinic, Legacy Corps and Powerful Tools for Caregivers, and Dispatch Health.

- The Saint Alphonsus Geriatric/Palliative Clinic functions as “part of the hospital’s Accountable Care Organization, part of their mission is to help improve quality and decrease cost of care for terminally ill and geriatric patients. These are medically and socially complex patients and benefit from a multidisciplinary team’s care: a social worker, clinical pharmacist, nurse practitioners, physicians, and a chaplain.”¹ The St Al’s team was initially very excited about the project, but after referring several caregivers their interest dissipated. When asked why they indicated that they feared the FCN project was redundant with what they were offering to caregivers of their patients”. Ongoing discussions have resulted in the St Al’s team continuing to refer caregivers because of the data collection and sharing capability. FCN staff are working with caregivers referred from the St Al’s clinic to obtain permission to share their assessment information with the St Al’s team. Staff with FCN and St Al’s also have a shadowing opportunity planned in June 2021 so FCN staff can see the caregiver process and identify ways to dovetail support and services. A reciprocal referral system is also under development with staff from St Al’s requesting that the navigators provide caregivers with the contact phone number for the Clinic. An additional outcome of the St Al/FCN relationship is making a change to the survey sent to caregivers 30-days after completion of the care plan. The following questions have been added based on input from the St Al’s team; 1) Does your care recipient's healthcare provider ever address you as a caregiver? 2) Do you feel that your care recipient's healthcare provider provides enough time to address your caregiving concerns as it relates to the care recipient? 3) Does your healthcare provider ask you about your caregiver responsibilities?
- Legacy Corps and Powerful Tools for Caregivers through Jannus – Legacy Corps is a volunteer respite services provider to caregivers of military or vets. These volunteers develop a long relationship with the families they serve. Powerful Tools for Caregivers (PTC) is an evidence-based caregiver educational course which is conducted over a 6-week period, free for the caregivers. Currently, reciprocal referrals are made through an exchange of emails between programs. This process has demonstrated some success with the bulk of the referrals being made to PTC from the FCN.
- Dispatch Health is a home health service designed to send health professionals to an individual's home to address an emergency clinic type visit. The health care providers

¹ <https://www.adamedicalsociety.org/Kara-Kuntz>

do not provide continuous care and thus do not have an established patient provider relationship. Staff with Dispatch Health have used the FCN script pads to make referrals and FCN staff have provided contact information for Dispatch Health in a caregiver care plan when appropriate.

The A3SSA should also be recognized as a key partner in testing the embedding of a navigator within an existing workflow. As of May 2021, there is a dedicated bilingual navigator housed at the A3SSA serving caregivers of Alzheimer's and dementia and caregivers from the Spanish-speaking community. To date, this individual has been dedicating a significant amount of time in the community conducting outreach to existing networks and building awareness to the FCN program. The A3SSA and the FCN team have worked together to assure adequate TCARE training and data collection for the navigator. A challenge that emerged early in this process was how best to integrate or align the GetCare intake software with the information gathered through TCARE. A software plug-in that enables the two systems to "talk" is available, but has not been purchased at this time.

4. Conclusions and Recommendations

Research suggests that programs designed to support family caregivers can enhance the quality of life for the caregiver and care receiver as well as reduce or delay the intent to place the care receiver in a long-term care facility (Montgomery, Rowe, & Kosloski, 2007; Montgomery, Kwak, Kosloski & O'Connell, 2011; Browne, Nishita, Chun, 2015). To our knowledge, this is the first attempt to implement a caregiver focused intervention in Idaho and the results from Year 1 suggest that the program has value to caregivers and Idaho.

Evidence from program records and longitudinal data from participants suggest that significant progress has been made toward maximizing the capacity of the natural support systems, i.e., family caregivers, siblings, and friends, essential to the sustained success of Money Follows the Person (MFP) program in Idaho. This initiative has benefited family caregivers with no negative outcomes reported by caregivers.

The findings must be interpreted in light of the formative stage of development of the program and launching the program during the COVID-19 pandemic. Initial funding of the program commenced in May 2020 and in 4 months, the program went live with robust marketing and outreach materials, a consumer-friendly, interactive website and phone line, 1.5 FTE navigators, and an enthusiastic core of community advocates. This ability to implement a complex intervention in a very short period of time speaks to the leadership and creative capacity of the team. Implementing a new program is hard work, but the FCN team has accomplished this and more with preliminary results demonstrating value to unpaid family caregivers and potential savings to Idaho by delaying or preventing costly long-term care expenditures.

Recommendations

Research suggests that programs designed to support family caregivers can enhance the quality of life for the caregiver and care receiver as well as reduce or delay the intent to place the care receiver in a long-term care facility.^{1,2,3} To our knowledge, this is the first attempt to implement a caregiver focused intervention in Idaho and the results from Year 1 suggest that the program has value to caregivers and Idaho.

The activities from Year 1 have established a foundation for Year 2 of the pilot. Based on findings from this evaluation, the following are offered as recommendations.

- Continue to clarify the navigator position description and role expectations. Early in the pilot, two navigators left the project due to lack of available time and the stress (reliving of their own caregiver experiences) related to serving as a navigator.
- Conduct regular check-ins with the navigator team to assure systems and processes are focused on providing consumer-directed support to the caregiver (and not the care receiver). This reorientation to the caregiver dictates continued development of databases, populated with resources that address the **needs of caregivers** across the life span.
- Employ a student intern (graduate or undergraduate) to manage the resource database. This experience would include organizing and validating resources, identifying new resources, attending ICA meetings, and participating in other networking opportunities.
- Facilitate the submission of resources for listing in the database through the use of an online submission form on the ICA website. The resources identified through the ICA portal could then be added to the FCN caregiver database.
- Build on relationships established with the Master of Social Work Program as a means of expanding the number of available navigators and providing students with a powerful learning experience.
- Implement a network of support for the navigators to minimize compassion fatigue and burnout. Many of the conversations with caregivers are difficult. The weekly navigator meetings should include periodic support provided by a professional counselor to reduce stress and increase employee satisfaction and retention.
- Conduct a process evaluation with community partners to determine if the website referral form and other FCN referral resources are effective.
- Continue to build relationships with community partners to make “warm handoffs” from the navigators to resources smooth and effective. This could include:
 - expansion of the existing list of contacts embedded in organizations that are prepared to respond to calls from family caregivers
 - the addition of an ambassador or community liaison tasked with contacting partners on a regular basis to provide reminders.
- Recognize individuals and organizations who refer caregivers to the navigators. This could be accomplished by sending an automated thank you message or giving a shout-out to referring entities in the ICA newsletter.

- Continue to integrate referrals to FCN into existing workflows. The program is enthusiastically received during presentations to health care providers, community-based organizations, and human resource professionals, but referrals have not been robust. While it is important to continue broad outreach and promotion, the FCN team may want to focus efforts on organizations with a clearly stated interest in caregivers. These could include, but are not limited to:
 - staff providing Information and Assistance at the Area Agencies on Aging,
 - navigators with the Idaho Careline 2-1-1,
 - support groups hosted by the Idaho Alzheimer’s Association and Kinship/Relatives as Parents support programs,
 - parents and leadership involved in Rays for Rare
 - volunteer leaders and participants in Powerful Tools for Caregiver class,
 - community health workers (CHW) through engagement with healthcare systems, the Idaho Community Health Worker Association, and other entities employing CHW.
- Offer an incentive to caregivers who complete the retrospective survey administered 30-days after completion of a care plan in order to increase the response rate.
- Continue to work with TCARE to enhance data reporting and analysis capacity of the software platform. For example, TCARE just recently added fields to capture caregiver and care recipient health insurance coverage based on feedback provided by the Idaho navigator team.
- Explore moving the TCARE caregiver reassessment from 3-months to 6-months. This will provide caregivers with additional time to implement their plan of care and may make incorporation of the TCARE intervention into the workflow at area agencies on aging more realistic.
- Continue to network with key partners to continue to build sustainability, i.e., APS project with Idaho Commission on Aging, health systems as a component of value-based care, a benefit or support provided by payers (Medicaid, Molina, Blue Cross, Regence, and others)

5. References

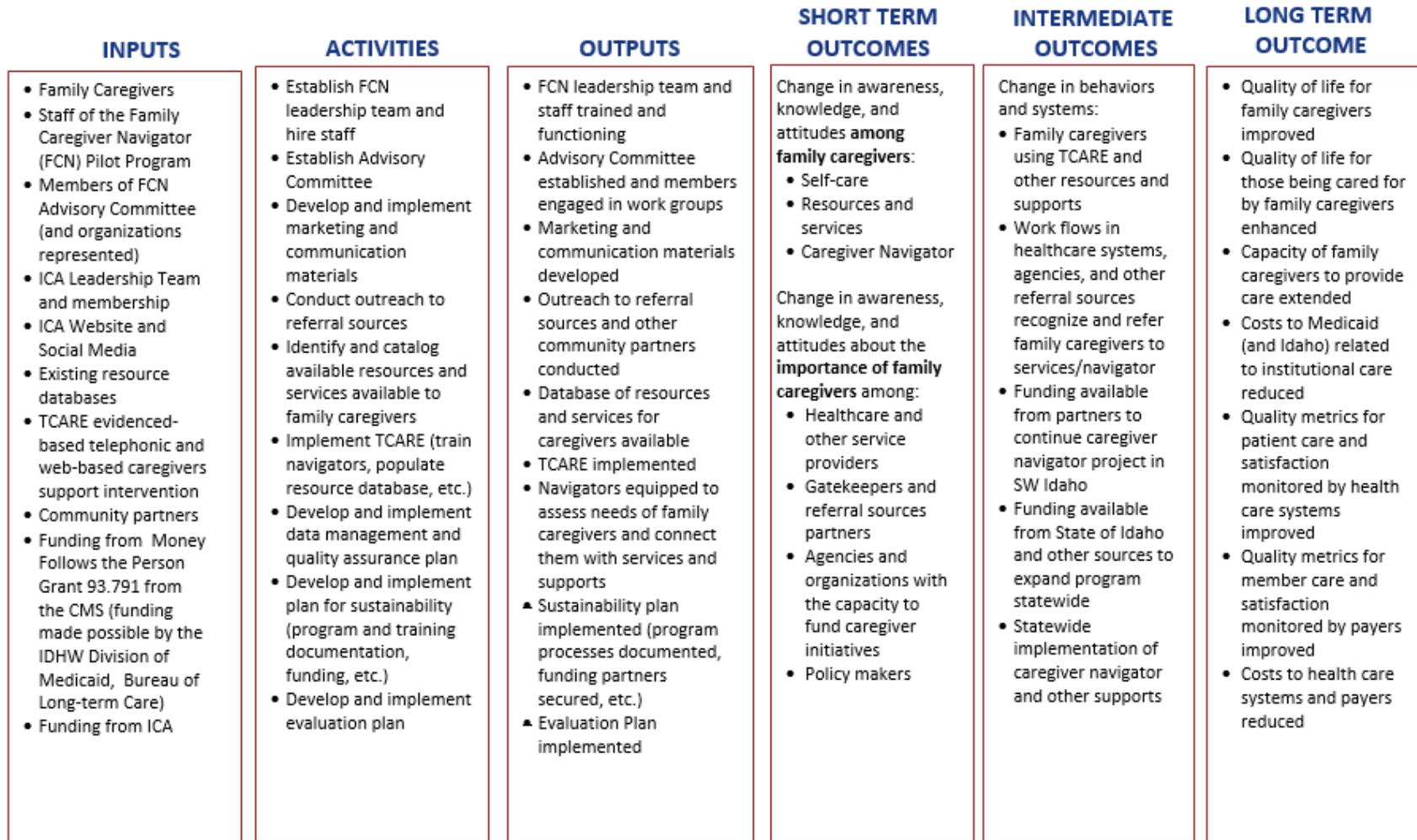
Browne, C., Nishita, C., Chun, H. (2015). An evaluation by the University of Hawai`i to explore the feasibility of implementing the evidence-based TCARE program statewide and improve the quality of services provided to caregivers in Hawai`i.

https://www.hawaiiadrc.org/Portals/_AgencySite/TCARE_Eval.pdf.

Montgomery, R.J.V., Kwak, J., Kosloski, K., & O’Connell Valuch, K. (2011). Effects of the TCARE® intervention on caregiver burden and depressive symptoms: preliminary findings from a randomized controlled study. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 66(5), 640–647, doi:10.1093/geronb/gbr088

Montgomery, R. J. V., Rowe, J. M. & Kosloski, K. (2007). Family caregiving. In J.A. Blackburn & C. N. Dulmus (Eds.), *Handbook of gerontology: Evidence-based approaches to theory, practice, and policy* (pp. 426-454): John Wiley & Sons.

Appendix A: Logic Model for FCN



 Evaluation strategies provide evidence to inform use of resources, decision making, and planning

Appendix B: Outcome Evaluation Plan and Collection Methods

Dimension	Data Collection Method	Instrument to Be Developed and Used	Rationale for Using Multiple Sets of data
1. Change in awareness, knowledge, and attitudes among family caregivers using TCARE to self-care, resources and services IW: Critical	1-1. TCARE Assessment	1-1. TCARE baseline, 3 and 6 month assessment	This is a critical dimension; thus, it is important to obtain comprehensive information.
	1-2. TCARE Care Plan Checklist	1-2. Care Plan Review Checklist	
	1-3. Interviews with navigators	1-3. Qualitative Interview Questionnaire	
	1-4. Participant survey (approved by Boise State Institutional Review Board)	1-4. Web-based survey (3-month follow-up)	
2. Change in self-reported measures of caregiver stress, burden, and likelihood of placement among family caregivers using TCARE IW: Critical	2-1. T-CARE Assessment	2-1. TCARE baseline, 3 and 6 month assessment	This is a critical dimension; thus, it is important to obtain comprehensive information.
	2-2. Interviews with navigators	2-2. Added to 1.3 (1-3 and 2-2 completed in same interview)	
	2-3. Participant survey	2-3. Added to 1.4 web-based survey	
3. Change in work flows in healthcare systems, agencies and other referral sources to recognize and refer family caregivers to the FCN IW: Very Important	3-1. Qualitative interviews with “early adopter” participants/organizations conducted by Lead Navigator (St AI, Legacy Corp, PTC)	3-1. Interviews with early adopters of the referral process associated with TCARE as collected by Lead Navigator throughout the project period.	Information from key informants and participants will provide a more complete picture of referral activities
	3-2. Web-based survey OR interviews with key informants in identified entities	3-2. Web-based survey and/or interviews administered to key informants	
	3-3. Web-based survey given to participants (1-4) will gather information about ease of access (referrals, etc.)	3-3. Added to 1.4 web-based survey	
<p>In summary, the following instruments are/will be developed:</p> <ul style="list-style-type: none"> ● One document review checklists (1-2) ● Two web-based survey questionnaires (1-4 and 3-2) ● Two interview instruments (1-3/2-2, 3-1, and 3-2) 			

IW, Information weighting