



UNIVERSITY of  
DENVER

COLORADO EVALUATION  
AND ACTION LAB

## Caregiver Support in Colorado

### Lessons Learned from an Evaluation of the Tailored Caregiver Assessment and Referral (TCARE) Process

#### Report Highlights:

*Case managers in Colorado appreciate TCARE's focus on caregiver needs but question how the model fits into their role or agency.*

*Offering easier ways for agencies to access region-specific resources for caregivers is a strategic way to increase caregiver support at agencies that typically do not focus on caregiver needs.*

*Most case managers interviewed confirmed that TCARE has changed how they think about serving caregivers in a positive way.*

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## Data Sources

The evaluation team used data collected from virtual interviews with staff members who were assigned a TCARE license at participating agencies as well as screener and assessment data pulled from the TCARE system.

## Suggested Citation

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## Introduction

Colorado is home to an estimated 584,000 caregivers who provide support for a friend or family member.<sup>1</sup> Over time, caregivers may struggle with depression and burnout as they deal with high levels of stress and the emotional and physical demands of providing daily care. Case management and long-term care agencies can play a role in alleviating caregiver burden by offering information, resources, and referrals to caregivers, including guidance on navigating respite services. Research has shown that caregivers who receive respite services report improvements in household management, ability to participate in and enjoy social activities, personal health, and overall confidence as a caregiver.<sup>2</sup>

Colorado took an important step towards better understanding respite care services in the state with the creation of the Respite Care Task Force. House Bill 15-1233 created this task force within the Colorado Department of Human Services (CDHS) to take a data-informed approach to addressing systematic barriers to respite care access and availability.<sup>3</sup> The task force is charged with determining the dynamics of supply and demand of respite and related caregiving services in Colorado and making recommendations to improve services for non-professional caregivers (e.g., those taking care of aging loved ones and those taking care of children or adults with developmental disabilities).

Tailored Caregiver Assessment and Referral (TCARE) is a care management protocol to prevent family caregiver burnout. TCARE extends beyond just respite care to connect caregivers to other programs and services that may help them manage their stress. TCARE identifies caregivers at high risk for burnout and facilitates the creation of individualized care plans to target the root causes of burnout, such as stress and depression.<sup>4</sup> TCARE uses an algorithm based on responses to assessment questions to create a caregiver profile and suggest a service plan that care managers can then tailor as they see fit.<sup>5</sup>

**TCARE is designed to support family members who are providing care to adults or children with chronic or acute health conditions or developmental disabilities through an array of services for the caregiver (e.g., respite care; stress buster classes).**

Colorado selected TCARE as the vehicle to examine caregiver outcomes based on the model's strong evidence base and success in other states. A study on TCARE in Washington state found that 84% of caregivers who participated in the program for six months reported improved levels of stress and depression.<sup>6</sup> The study found that caregivers' levels of stress and depression continued to be lower after 12 months of participation in the program, and these results were statistically significant. TCARE was also selected to better understand caregiver needs and effective interventions that go beyond respite as the primary recommendation.

*“From personal experience, my mother is enrolled in adult waiver programs, and this [TCARE] would have been very valuable for me and also for people who aren’t familiar with state programs that are available...I was really excited that its primary focus is on the caregiver themselves.”*

- Case Manager



The purpose of this report is to inform the work of the Respite Care Task Force and CDHS' evaluation of the efficacy of TCARE across Colorado systems that support caregivers. The project was conducted in partnership with CDHS and Easterseals Colorado.

Challenges with implementing TCARE across participating agencies and funding reductions in Colorado for State Fiscal Year 2021 that were driven by the COVID-19 crisis resulted in a less robust pilot than originally planned. The unique political and economic climate created by the spread of COVID-19 provides important context for understanding the pilot's trajectory. In addition to the implementation and timeline challenges detailed in this report, funding reductions in the spring of 2020 led to a shortened project timeline and an early end to data collection. Because of this, follow-up data were not able to be tracked and analyzed. In the last few months of the pilot, COVID-19 shifted both state and local priorities to providing essential services and dealing with the crisis first and foremost.

## Description of the Pilot

The purpose of this project is to understand the viability of implementing the TCARE model in Colorado. This pilot includes both a quantitative and qualitative component. Due to challenges with implementation (described in the following sections), the qualitative follow-up was added to the program evaluation to understand the barriers that participating sites faced in adopting and using TCARE with their clients.

Easterseals Colorado recruited seven agencies in Colorado to participate in the pilot, from non-profits serving individuals with developmental disabilities to county human services agencies and the regional Area Agency on Aging (AAA). AAAs provide services to residents who are age 60 and older, with the goal of making it possible for these individuals to remain in their homes and communities as long as possible. Because of this alignment in goals, TCARE is often used to support AAAs in particular. All 16 AAAs in Colorado were invited to participate; however, only two accepted. The pilot includes a mix of agencies that focus on providing in-home services and support to aging adults and those that provide services to adults and children with disabilities. Regardless of who their primary client is, all agencies in the pilot have some level of interaction with caregivers. Some provide dedicated services to caregivers, while others interact in a less structured way with caregivers who serve as representatives of their loved ones.

## Quantitative Pilot Design

The pilot was originally designed to assess the impact of the TCARE process on caregivers in Colorado through three key aims:

1. Examine the potential effect of access to the TCARE program on caregivers' use of preventive health care.
2. Replicate previous findings that when case managers have access to TCARE, caregivers subsequently report lower levels of depression, identity discrepancy, and burden.
3. Describe the services and supports that are recommended by the TCARE treatment planning process to inform efforts to improve access to caregiver supports across regions.

The design of the pilot as a randomized controlled trial (RCT) was the result of a collaboration with CDHS and Easterseals Colorado based on their goals of understanding the impact of TCARE. The RCT design was ambitious given the newness of TCARE for the agencies involved. RCTs are the most rigorous method of determining if a new intervention is more effective than regular services—in this case, ensuring that





Colorado obtains accurate information on whether TCARE leads to improved outcomes for caregivers. Randomization also ensured that each case manager had an equal chance of participating in TCARE or continuing with business as usual.

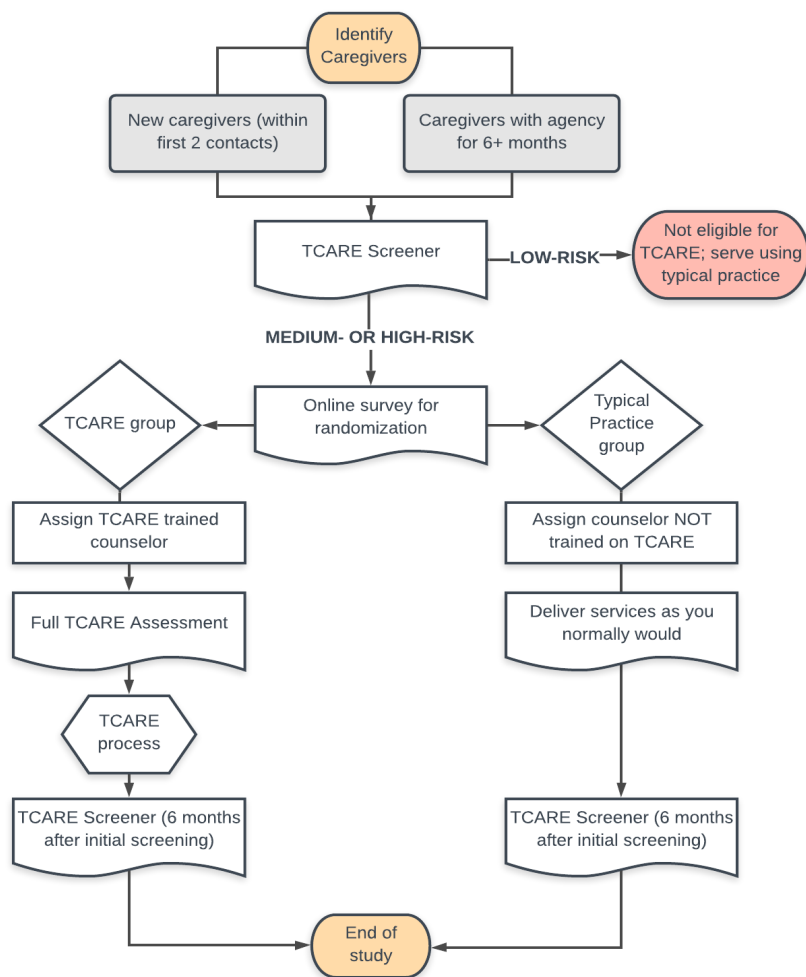
The initial RCT design incorporated a two-stage randomization process for randomizing both case managers and caregivers, as described in the next steps.

**Stage 1:** At the beginning of the project, each participating agency provided a list of its case managers by county. Within each county, case managers were randomly assigned to be trained in TCARE or to continue with their typical practice. Once case managers were randomly assigned, they were instructed to complete the TCARE training to activate their license. The TCARE training involves a series of modules, instructional videos, and tests to prepare users to implement the protocol consistently and accurately with caregivers. Completing the training in full and passing the certification test at the end of the training allows case managers to activate and begin using their TCARE license with caregivers. Case managers were told the training would take four to six hours to complete, depending on user speed.

**Stage 2:** Throughout the project, agencies were instructed to:

1. **Invite caregivers to take the TCARE screener.** A short online assessment assigned caregivers a risk score of “low,” “medium,” or “high” across a variety of measures.
2. **Randomize eligible caregivers.** Caregivers who scored as “medium” or “high” risk on the screener were eligible for TCARE. Randomization requires inputting basic information into a survey that immediately informs the case manager whether the caregiver falls into the “TCARE” or “Typical Practice” group. Caregivers who scored “low” risk on the screener did not need to be randomized but could be served as usual.
3. **Assign caregivers to a case manager for their “group.”** If the caregiver was assigned to the “TCARE” group (treatment), then they went to a case manager who is trained in TCARE. If they were part of the “Typical Practice” group (control), then they were served by team members *not* trained in TCARE.
  - a. **TCARE group:** Trained case managers administered the full TCARE assessment and served clients according to the resulting recommendations.
  - b. **Typical Practice group:** Case managers served clients as they typically would, which may have included routing them to a caregiver coordinator who was *not* trained in TCARE.

Figure 1: Process Overview of Two-Stage Randomization



For agencies with only one case manager serving caregivers, the research team paired or grouped these agencies in blocks and randomly assigned each agency to have their case manager trained in TCARE or to have that case manager continue with their typical practice. Only those case managers trained in TCARE were instructed to invite caregivers to take the TCARE screener.

### Changes in Pilot Design

Participating sites were instructed to begin randomization in October 2019; however, no sites were able to successfully randomize caregivers.

In the months immediately following randomization, the research team met with each participating agency individually to answer questions and troubleshoot issues that arose. The most common point of confusion centered on the randomization steps and how sites could effectively randomize both case managers and caregivers without disrupting their usual caseloads and intake procedures. Several sites expressed concerns about randomization since there were often other factors at the agency dictating which case managers served particular caregivers. This meant that many caregivers could not be randomly



assigned to the treatment or control group because that would risk assignment to a different case manager.

Confusion and logistical challenges with randomizing caregivers led Easterseals Colorado, CDHS, and the research team to suspend the RCT in late November 2019. The design of the evaluation shifted to the goal of presenting descriptive statistics on caregiver outcomes as opposed to making causal claims about the impact of TCARE on caregiver outcomes. The ability to report on caregiver outcomes was still dependent on sufficient follow-up data collection. In conversation with Easterseals and CDHS, we also made the decision to add a qualitative component to the pilot to better understand the challenges and barriers sites faced with implementing TCARE. With funding reductions that resulted from the COVID-19 crisis, the pilot ended earlier in 2020 than originally planned, preventing more robust data collection efforts and analysis.

### **Qualitative Pilot Design**

All case managers who were randomized to TCARE were invited to participate in an interview. Those who were assigned a license but did not complete the training or did not complete screenings and assessments using the platform were still encouraged to participate. Interview participants received an incentive in the form of a \$20 gift card.

## **Key Findings**

Because of limited data collection through the TCARE system, findings from interviews with case managers provide the most insight into Colorado's adoption of TCARE.

### **Case managers appreciated TCARE's focus on caregiver needs but question the model's fit for their agency.**

While all case managers agreed on the value of providing dedicated support to caregivers, opinions differed on whether TCARE is the right model to provide those resources in Colorado. Case managers struggled with completing TCARE's required training and conveyed mixed opinions about using the online TCARE platform with caregivers. Most case managers do not anticipate incorporating TCARE into their work going forward but are open to other ways of providing resources and support to caregivers.

### **Case managers faced individual and systemic barriers to implementing TCARE.**

Based on analysis across 14 interviews with case managers, the research team identified five common barriers to implementation:

1. Not having the time or capacity to use TCARE.
2. Not being the right person at their organization to implement TCARE.
3. Not being able to find caregivers who are willing to participate.
4. Not being able to guarantee that caregivers who do participate will gain access to new or valuable resources.
5. Encountering technical issues or logistical challenges with implementing TCARE to fidelity.





## Case managers largely agreed that participating in the TCARE pilot has shifted their approach to working with caregivers.

Despite challenges that case managers faced, they overwhelmingly reported that being involved in this TCARE pilot changed how they thought about or approached caregivers in a positive way. Changes include becoming more attentive to signals of depression and burnout, better understanding the caregiver experience, and making more of an effort to share resources.

## Implications

Interviews with case managers reinforced the idea that support for caregivers is a sometimes overlooked but critical area of need. Allowing caregivers to focus on their own well-being through dedicated services and resources strengthens their ability to care for themselves and for their loved ones. While the need is apparent, this pilot offers insights into how the TCARE model fulfills that need in Colorado. More extensive data collection and analysis is required to determine the impact of TCARE on caregiver outcomes.

Ultimately, sites were not to the point where they were ready to fully implement TCARE at the start of the pilot. Because TCARE was a new system for many of the participating agencies, they needed more time to (1) explore whether the model was the right fit for their agency's mission and goals, (2) obtain buy-in from case managers and develop both an understanding of and a workflow for accomplishing TCARE tasks, and (3) create staffing plans to target the right workers to implement TCARE and ensure they have the ability to incorporate TCARE into their ongoing workloads. Once an agency makes the decision to implement TCARE, it needs time to onboard and incorporate TCARE into its array of services.

*“The cost of clients going into a nursing home or assisted living is so great. I know there are families all over that step up to the plate. Because they love their person, a lot of it is done out of love without skills and experience. All the support they can get is huge, and in the long run, it saves a lot of money.”*

- Case Manager

**TCARE is not a one-size-fits-all solution. The pilot in Colorado demonstrates that the TCARE model may work better for certain types of agencies than for others.**

Beyond creating the space, time, and staffing capacity to accommodate TCARE, agencies should thoroughly assess whether TCARE fits into their organizational model as a whole. Case managers who were interviewed did not always perceive their role as a good fit for TCARE, but that could be due in part to the need for a cultural and systemic shift within the agencies that want to implement the model. Agencies that want to continue using TCARE should embed how they talk about the model and its implementation in their core organizational values. By communicating to case managers that caregiver support is a priority and is, in fact, a core part of their role—in addition to client support and services—agencies can begin making a more purposeful, structured shift towards TCARE. This could also be part of a system-wide shift across the state to embed caregiver support in a greater variety of agencies.



Interview findings suggest that TCARE may be more effective when implemented by agencies who serve aging adults or who serve caregivers directly. That does not mean, however, that caregiver support should not become an objective at other agencies. The challenges that sites faced with implementing TCARE indicate that other methods of supporting caregivers may be worth exploring. Case managers recognize the importance of caregiver support and are open to less time-intensive ways of offering resources. Creating repositories of region-specific resources that are available for caregivers and training agency staff on how to thoughtfully and constructively approach caregivers within the context of their particular roles could be one path to providing additional support.

## Methods

### Interview Protocol and Data Analysis

The research team developed a semi-structured interview protocol with 12 open-ended questions. The interview protocol was designed to explore the experiences that case managers had with onboarding and using TCARE and to collect information to inform our understanding of whether TCARE is a viable care option in Colorado. The interview guide is divided into three primary sections:

1. Background questions for context about each case manager's organization, role, training and experiences that shape their work, and average caseload.
2. Experiences with TCARE, including overall impression of the model, experience with the training, use of TCARE going forward, and shifts in attitude towards serving caregivers.
3. Recommendations for organizations considering adopting TCARE and recommendations on Colorado's investment in TCARE.

Finally, the interview protocol ended with an optional section on general demographic information.

Interviews were conducted via phone or Zoom and lasted between 15-30 minutes, depending on how much each participant wished to share. Interviews were recorded, and detailed notes were taken to allow for subsequent coding of the data. The research team coded interviews based on themes that emerged from the data.

### Interview Sample

All case managers who were assigned a TCARE license from the seven agencies in the pilot were invited to participate in an interview. Interviews were conducted with a total of 14 case managers across six of the seven participating agencies. Case managers at one agency were unable to participate due to work disruptions from the COVID-19 crisis in the spring of 2020.

Case managers in the interview sample served an average of 19 clients per week. The length of time they have worked for their respective agencies ranges from one year to 24 years, with an average tenure of 6.2 years. Six case managers provided services to clients over the age of 60. Three case managers worked solely with children with disabilities, and four case managers worked with clients with disabilities of all ages. Only one case manager interviewed provided services directly to caregivers. Roles represented in the sample included case manager, in-home service provider, enrollment case manager, community outreach coordinator, long-term care case manager, care navigator, and shift counselor. For ease of reporting and



to protect participant anonymity, all participants were referred to as “case managers.” This is an approximation of their role and does not necessarily reflect each participant’s official job title.

To gain an understanding of how they approached their interactions with caregivers outside of the TCARE framework, case managers were asked to describe what shapes their work with caregivers. Below are examples of the types of training and experiences that case managers drew upon:

- Behavioral skills training
- Mental health training
- Person-centered or client-centered training
- Training on behavioral and physical needs of individuals with disabilities and/or high needs
- Training on how to approach difficult situations
- Training on administering assessments
- Medicaid training

Case managers also drew on their personal experiences, past work experiences, and education (e.g., degrees in counseling and social work) to inform their approach. Case managers who worked with youth emphasized that they try to incorporate caregivers (i.e., parents) during their sessions to ensure consistent implementation of skills at home.

The pilot was designed to include options counselors—professionals who match adult caregivers with services and supports. Based on availability and staffing considerations at participating sites, only one individual interviewed provided options counseling services. Findings presented in this report should be understood in the context of the roles represented in the pilot.

## Demographics

The interview sample consisted of 14 case managers who were assigned a TCARE license. The sample was largely female, and the average age of the sample was 41.3 years old. The majority of the sample identified as Caucasian.

Total Sample Size	14 Case Managers
Gender	12 Female 2 Male
Age	Average = 41.3 years old
Race/ethnicity	12 Caucasian 2 Hispanic
Education level	1 High school credential 1 Some college, no degree 10 College degree 2 Graduate degree



Total Sample Size	14 Case Managers
Years of experience in the field	5 with 1-10 years 6 with 11-20 years 3 with 21-30 years

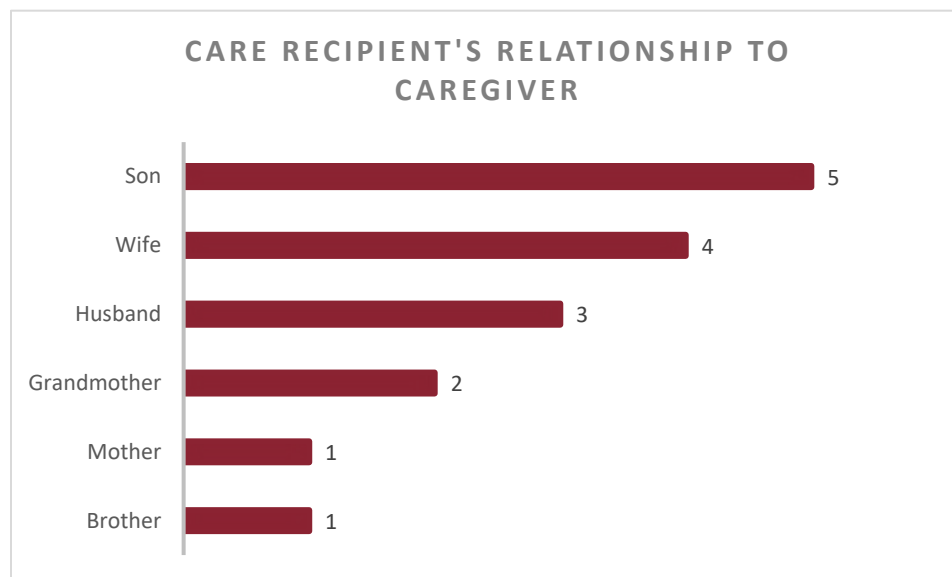
## Quantitative Results

Because of minimal data collection, analysis was not able to be performed as set forth in the original design. However, data that were collected were analyzed to present basic descriptive statistics. This analysis provides an overview of caregiver responses from their first round of participation in TCARE. Follow-up data are not available for these caregivers.

Sixteen screeners and assessments were completed across five sites during the pilot period. Because of the overlap in questions and content between the screener and the assessment, these data are presented together where overlap occurs. The data collection period began on October 7, 2019 and ended on May 31, 2020. Participating agencies were encouraged to use TCARE and enter data into the system during this time frame. However, the first record was entered into the TCARE system in December 2019, and the last record was entered in March 2020. Although case managers were instructed to complete a screener with each caregiver to assess eligibility before moving on, five assessments or care plans were created for caregivers who did not first complete a screener.

Caregivers who participated in TCARE were largely taking care of a spouse or child. Figure 2 shows the care recipient's relationship to caregivers who participated, where five caregivers took care of their son and seven took care of their husband or wife. A smaller number of caregivers provided care for a parent, grandparent, or sibling.

Figure 2: Care Recipient and Caregiver Relationship



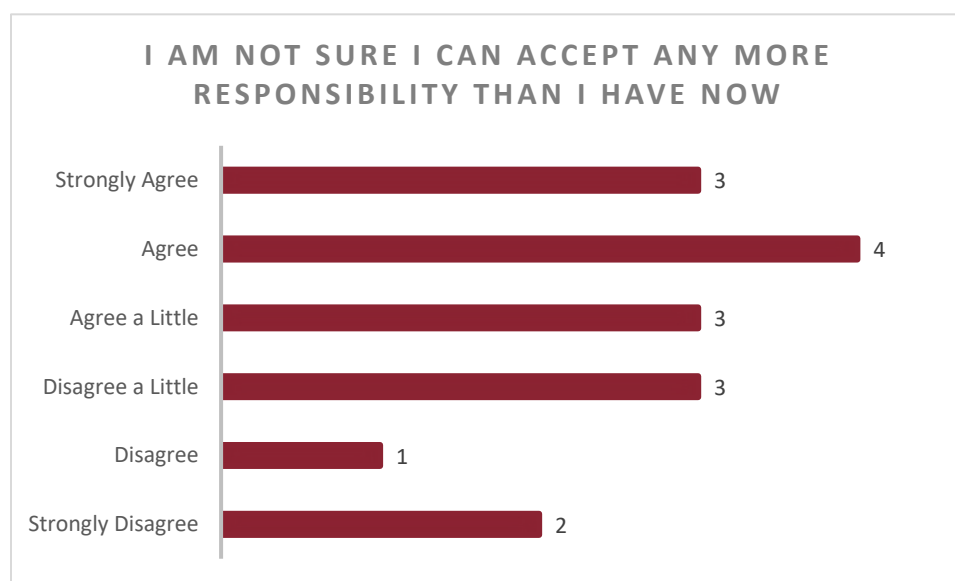
Note: N=16



The TCARE screener and assessment ask a series of questions to assess whether caregivers are approaching a state of burnout. Questions focus on caregivers' daily activities, caregiving responsibilities, household management, personal time and habits, and feelings towards a number of topics. Caregivers are also asked to provide a self-assessment of their burden (see Figure 3) and describe their current state of thinking on whether they would consider placing their loved one in a different setting (see Figure 4).

Ten caregivers agreed that they could not accept any more responsibility than they had, while the remaining six felt that they could assume more responsibility if needed. When asked whether they struggled with accepting full responsibility for caring for their loved one, seven agreed, while nine disagreed. This indicated that while many caregivers felt a desire or need to take care of their loved ones, they did not feel capable of taking on any more responsibilities beyond those that they already had.

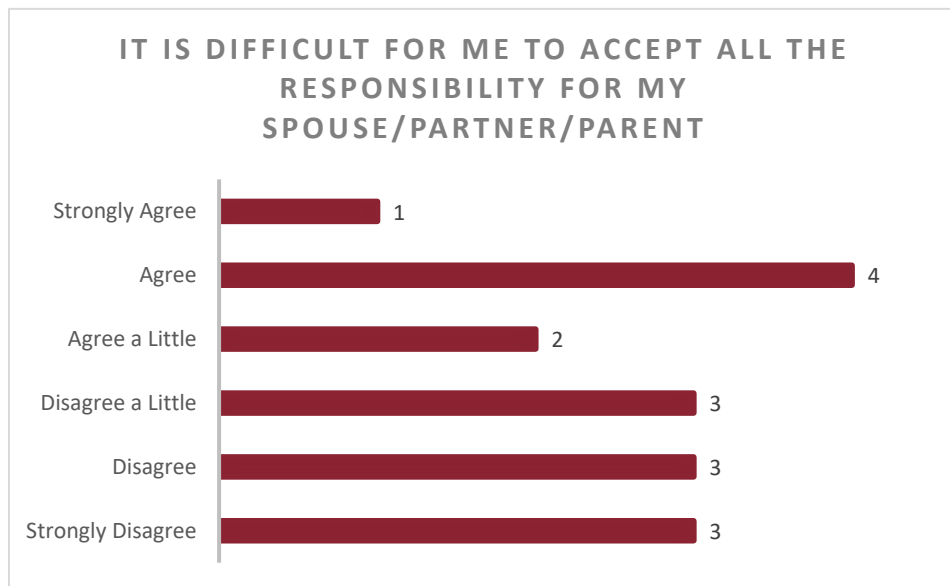
Figure 3: Caregiver Self-Assessment of Burden



Note: N=16



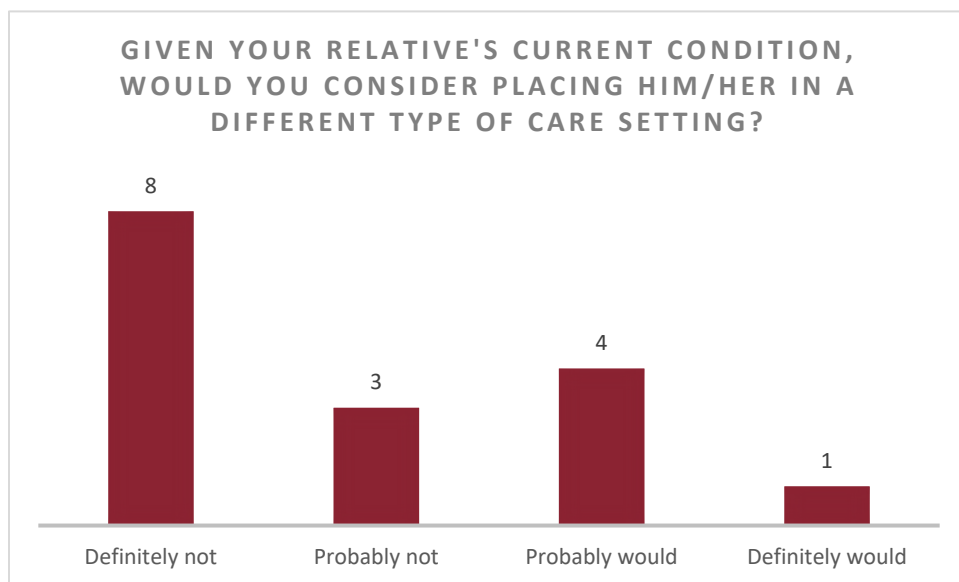
Figure 4: Caregiver Self-Assessment of Responsibility



Note: N=16

The willingness to care for their loved one was echoed by the majority of caregivers reporting that they had no intention to place their loved one in a different setting, such as a nursing home or another care facility for long-term placement (see Figure 5). This question was also asked of parents and their children, in which case placement is a more complicated issue and would not be considered a viable option by many parents.

Figure 5: Caregiver Intention to Place



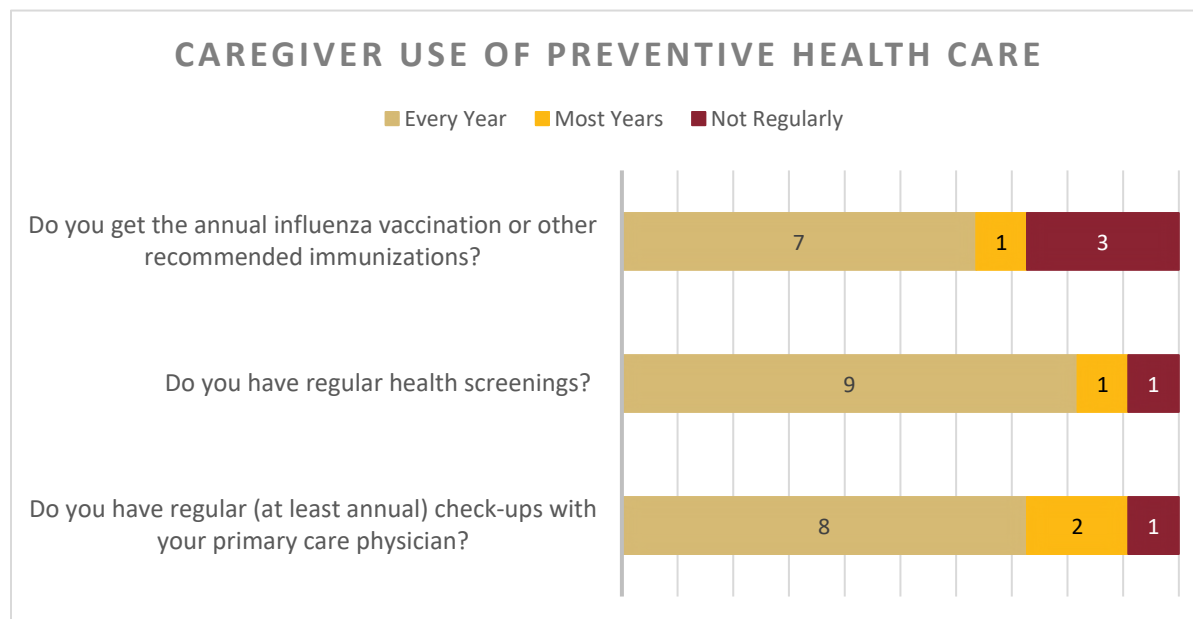
Note: N=16





For this pilot, three questions were added to the TCARE screener to assess caregivers' use of preventive health care measures. These questions asked whether caregivers participated in annual physical check-ups, have regular health screenings (e.g., tests for blood pressure, cholesterol, and diabetes and/or screenings for cancer), and get their annual influenza vaccination or other recommended immunizations. These areas served as a proxy for utilization of preventive health care. Figure 6 indicates that caregivers do largely engage in preventive health care, with the majority responding that they participate in each activity on an annual basis.

Figure 6: Caregiver Preventive Health Care Utilization



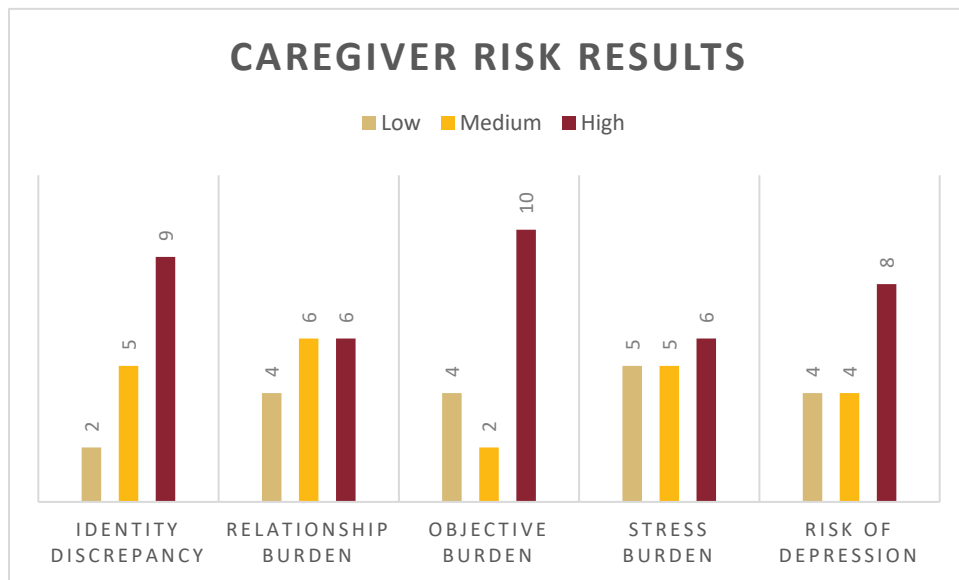
Note: N=11 (responses are not available for caregivers who did not complete a screener)

One of the primary goals of the TCARE process is to assess the caregiver's risk of burnout via their levels of stress and depression. Getting a good sense of where caregivers fall along these levels helps TCARE and the care managers who use the system to create tailored care plans for each caregiver. TCARE assigns a risk rating of "low," "medium," or "high" along the following measures: identity discrepancy, relationship burden, objective burden, stress burden, and depression. To qualify for the full assessment, caregivers must receive a result of "medium" or "high" in at least one of these areas.

For the categories of identity discrepancy, objective burden, stress burden, and depression, more caregivers scored high than medium or low (see Figure 7). Relationship burden saw the same number of caregivers with a medium and high score. This indicated that many caregivers struggled with the burden of their caregiving duties and exhibited signals of impending burnout.



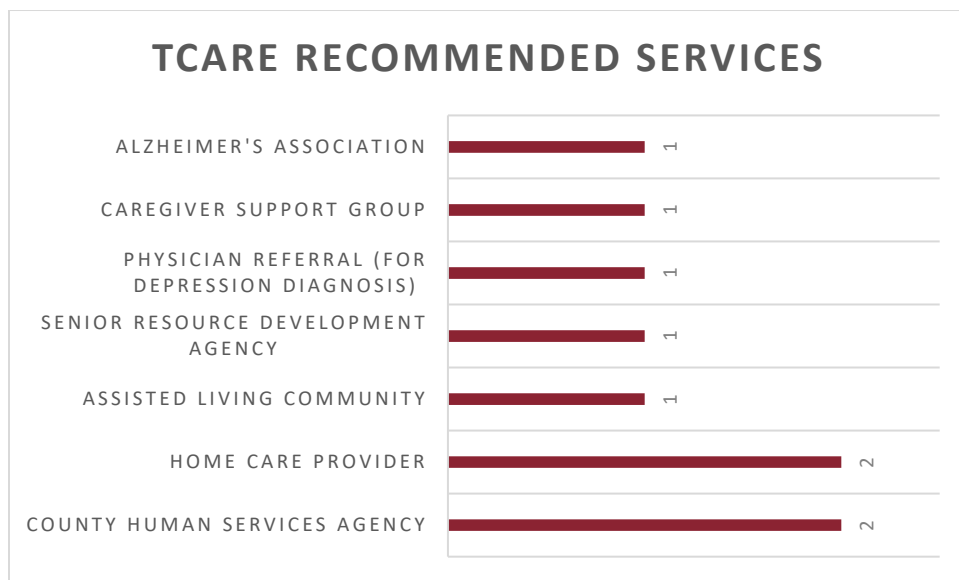
Figure 7: Caregiver Risk Assessment Results



Note: N=16

At the end of the assessment process, TCARE recommended specific services and resources to caregivers based on their assessment results (see Figure 8). Caregivers were most commonly referred to home care providers and their county human services agency. TCARE also referred caregivers to an Alzheimer's association, caregiver support group, personal physician, senior resource development agency, and assisted living community.

Figure 8: Services and Resources Recommended to Caregivers by TCARE



Note: N=4 (some caregivers were referred to multiple services)



## Detailed Interview Findings

### Impressions of TCARE

Across the board, case managers agreed that any additional resources and support that can be offered to caregivers was a great thing. Whether TCARE is the right model to provide those resources in Colorado was up for debate.

#### TCARE Model

Most case managers interviewed expressed an appreciation for TCARE's focus on caregiver needs. They described the idea and concept of TCARE as "fantastic," "worthwhile," and "coming from a great place."

Many recognized the importance of increased support for caregivers, especially when providing dedicated services to caregivers was not part of an agency's typical functions. TCARE provides an opportunity to think about caregiver needs in a focused, action-oriented way.

While all case managers recognized the value in the TCARE model, many questioned how well it fit into their particular role or organizational structure. Case managers who had minimal interaction with caregivers struggled to use TCARE to its fullest extent, as did case managers who primarily served children. These case managers conjectured that the TCARE model would be better utilized by caregivers serving aging adults as opposed to families of children with disabilities.

*"Our main point of contact with families or individuals was providing services to their kids or the individual enrolled in services, whereas this gives us a supplementary program for the caregiver themselves...I love the idea of TCARE providing options to caregivers in terms of support groups or educational seminars."*

- Case Manager

Three case managers relayed their concerns with the language used in the TCARE tools. One case manager noted that some of the questions seemed intruding and could offend caregivers if not re-worded with greater sensitivity. Another case manager said they had to be thoughtful about which caregivers would not be offended by some of the questions before inviting them to participate. One case manager found the wording on burnout particularly problematic for parents of children with disabilities:

*"I felt like it maybe wasn't a great fit for parents of children, but it seems like it was really geared for elderly spouses. From the beginning, I've been concerned with some of the wording they wanted us to use for parents and burnout. The wording talks about placing them, but there's not really placement for children. Parents are pretty sensitive to that when it comes to children with disabilities."*

Some case managers wholeheartedly stood behind the concept of TCARE but found the process of getting certified and going through the screening and assessment tools to be overwhelming. As one case manager described:



“My overall impression of TCARE is that the concept is a wonderful concept. However, the whole process to do it was extremely overwhelming and very complicated.”

Whether case managers found the TCARE platform to be user-friendly and intuitive varied widely. Some case managers said they found the platform and process straightforward and easy to navigate, while others reported the exact opposite. There was not a clear consensus—and there were, in fact, opposing opinions across case managers—on the usability and value of the TCARE tools. Because fewer than half of the case managers interviewed were able to use TCARE with a caregiver, some may have formed an impression of the tools based primarily on their experience with the training.

### TCARE Training

**Thirteen of the 14 case managers interviewed completed the TCARE training. One case manager started the training but did not finish. The training took 14 hours, on average.**

All case managers who completed the training said that it took them significantly longer than anticipated. Case managers went into the training with the expectation that it would take four to six hours. However, case managers reported that they spent anywhere from three to 35 hours on the training, with an average of 14 hours. One case manager likened the length of training to that of taking on a new job. Because case managers and supervisors were not able to appropriately plan for the length of the training ahead of time, the training caused a delay in implementation for all sites in the pilot.

Many case managers noted that the training was repetitive and often unnecessary given their own background, education, and on-the-job training to be a case manager. They said it would be helpful to have a condensed version of the training for those with a background in social work, who would already be familiar with many of the concepts presented. Case managers who administer assessments regularly also thought the leap to doing the TCARE assessment was an easy one for them to make and did not necessitate as many hours of training.

Case managers were split in their opinions about the content of the training. About a third of those who completed it found the training “straightforward” and “user-friendly” and found the videos that accompanied the training to be very helpful. Others struggled with the format and content of the training, with one case manager saying:

“I don’t consider myself a stupid person, but honestly, ‘what?’ I didn’t get it. I felt like you had to be a genius to go through some of the questions...It should be something that is easily digested and that you explain to people in a better way.”

Some case managers reported that they had to re-take the test at the end of the training after not passing it the first time. Overall, most case managers found the training to be cumbersome, whether that was a byproduct of its difficulty or simply a matter of the time it took. The words “frustrating” and “overwhelming” came up in over half of the interviews when describing the training. This perception of the training may have created a negative predisposition towards TCARE in some case managers from the outset of the pilot.



## TCARE Screener and Assessment

**Five case managers who were interviewed completed a screening, and three completed an assessment with at least one caregiver. Nine case managers did not complete a screening, and eleven did not complete an assessment.**

Of the case managers who completed assessments, one reported that the caregiver found it helpful because it made them stop and think about how they feel in a way they typically would not. The other two did not think the assessment resulted in valuable resources for the caregiver.

Similar to the training, case managers offered differing opinions on how user-friendly and helpful they found the screener and assessment. One case manager took the screener themselves so that they could get a sense of what the experience would be like for caregivers and answer any questions they may have about the process. They noted that the survey was “informative and straightforward,” and the questions were “concise and understandable.” Another case manager called it a “very user-friendly application and screening process.”

Several case managers did recognize the importance of the assessment based on its ability to make caregivers slow down and think about their own feelings and needs in a directed way. While they recognized the value to caregivers in going through the screening and assessment process, the barriers outlined in the following section stood in the way of more extensive implementation.

## Key Barriers to Implementation

### Time Constraints and Capacity

The most consistent themes that came up during interviews were, by far, the time constraints that case managers faced and the lack of capacity to properly implement TCARE. All 14 case managers interviewed mentioned time as being an issue with implementing TCARE.

Most case managers were asked to add TCARE onto their regular workload without shifting other responsibilities. When prioritizing work, TCARE fell to the bottom of the list, and many did not have the capacity to dedicate time to using TCARE.

As noted above, completing the training posed a challenge for many case managers in the pilot. Although all but one were able to complete the training, many had to spread the training out over several months to fit it into their regular work schedules. According to one case manager, the time constraints they faced meant that they “really just tried to cram it in” but did not have the time to fully understand TCARE, making it harder to stand behind. The longer than anticipated training time created a significant delay in onboarding and using TCARE with caregivers. One case manager provided context on fitting TCARE into a larger caseload:

*“The key issue in all of this—whether it be the onboarding or the caregiver or anything—is the time. The idea and the concept are great, but it’s got to be slimmed down if it’s going to work.”*

- Case Manager



“The training was not what we were told it would be...We have caseloads of about 100 and we have a lot of different people we are trying to track down and serve, so it’s really important to know how much time we need to allot for things. The time we were told was very grossly underestimated.”

The TCARE pilot began in October 2019, a time which several case managers noted was their busiest of the year. Between upcoming holidays, annual deadlines, and open enrollment periods, many case managers already found themselves stretched thin. Several case managers commented that the summer would be a more ideal time to start the process. However, those case managers may still have run into time constraints based on their ongoing workloads and agency staffing structures.

In addition to completing the training, case managers also faced time constraints in using TCARE with caregivers once they were set up and ready to go. One case manager with a specialized role within their county noted that their workload was not decreased to make ongoing work on TCARE possible, largely because no one else on staff was able to take on their clients. Another case manager described TCARE as being in direct competition for their time with their other duties:

“In case management, you are never actually caught up. There’s always something else to do. So I have to make a decision to put something aside to do TCARE.”

Several case managers mentioned that they would need to dedicate extra time to meeting with caregivers in addition to meeting with their regular clients, which is not something that was built into their workflow.

*“The concern would be what that caseload looks like for someone as it builds up over time because a lot of our case managers already have a caseload of 30-40 clients, and if you’re adding 10-20 caregivers on top of that, I’m not sure how that would look.”*

- Case Manager

Although case managers did not explicitly bring this up during the interviews, the COVID-19 crisis could have further hindered their ability to prioritize TCARE in their work duties. Case managers who were still actively using TCARE and already feeling the time constraints may have struggled to focus on TCARE with the changing schedules and agency priorities that resulted from the crisis. Many agencies throughout the state shifted their focus primarily to dealing with the crisis and meeting clients’ basic needs, especially as some clients struggled with job insecurity and financial hardship during this time.

### Staffing Considerations

**Agencies in the pilot primarily serve individuals with disabilities and older adults as their main clientele, not their caregivers. Most case managers felt that TCARE would be more successful if implemented by agencies who directly serve and maintain regular, structured points of contact with caregivers.**

A theme that came up consistently throughout interviews was the importance of staffing the right people at each agency to administer TCARE. Over half of the case managers interviewed felt that they were not the right person at their agency to administer TCARE. Several case managers expressed concerns that they





might not be targeting the caregivers who could really benefit from TCARE services, in part because they did not have a formalized touchpoint with those caregivers.

One case manager who provides in-home services for children noted that their lack of regular contact with the parents presented one of the greatest challenges to administering TCARE. Two case managers who work on the enrollment side of their agency thought that TCARE may be a more valuable tool for active case managers. Active case managers build relationships with their clients and have touchpoints throughout the year. This is especially pertinent for case managers who work with children because the parents are usually not in the headspace to receive services themselves when they are actively trying to enroll their children in services and ensure their children's needs are met first.

It is important to note that while many case managers did not perceive their role as the best fit for TCARE, this could change if agencies undergo a systematic shift to prioritize the model as part of their core functions. Agencies can change how they talk about caregiver support to make it a more integral part of their organizational culture. By consistently communicating the value of the TCARE model—or other ways of supporting caregivers—to case managers, agencies can develop an understanding among their staff members that implementing TCARE is a core competency of their role. These findings present an opportunity for agencies to look at families more holistically and recognize that by supporting caregivers, they are directly supporting those they care for.

### Finding Clients Who are a Good Fit

Finding caregivers who could dedicate the time to participating emerged as one of the larger challenges that case managers faced. Case managers who serve children with disabilities struggled with getting parent buy-in for TCARE. Parents are often more focused on meeting their child's needs than their own. Many of the parents that case managers interact with juggle full-time jobs and caring for their children. This makes it difficult to schedule regular appointments, let alone time for going through the TCARE process.

Even when serving aging adults, however, case managers saw resistance from caregivers to focusing on their own needs. Four case managers reported that the hardest part of using TCARE was convincing caregivers to take the time to participate given how busy they were with what they would consider more pressing concerns. As one case manager relayed:

*“I honestly feel like it’s a really great program, and I would love to get more of my clients involved in it... But for a lot of parents, getting enrolled into services is the most important part, so they’re more focused on their kid than on their own level of burnout.”*

- Case Manager

“The time commitment that I would be asking the caregiver to take on definitely puts me in an uncomfortable situation.”

Four case managers who did not complete any assessments reported that they did offer TCARE to multiple caregivers who declined to participate. The main reason for turning down the opportunity was not having the time given their other responsibilities. Even framing their participation as an opportunity to access more resources was not enough to sway them.



Three case managers suggested that it would be more fruitful if they could navigate directly to the resources that could benefit a caregiver without taking the time to go through the full screening and assessment. For caregivers who do complete the two to three hour assessment process, case managers highlighted the need for strong resources they could recommend to make it worth the caregiver's time. Some case managers felt that TCARE did not do enough in terms of offering new and helpful resources (a theme explored in more detail in the following section).

### Available Resources and Regional Considerations

In their attempts to find caregivers who were open to participating in TCARE, case managers often cited a lack of useful resources at the end of the process as another barrier to implementation. Four case managers found it challenging to gain caregiver buy-in for the TCARE process because they could not guarantee that it would provide caregivers with new resources. In some cases, especially in rural areas with fewer available resources, case managers were confident that they already knew about all the resources they could refer to caregivers and did not anticipate that TCARE would provide new options. As one case manager explained:

"The other really big piece is that my clients don't get anything out of it. The suggestions they have are basically respite care, and this program already offers that. So I'm really hesitant to spend my time and even more so the caregivers time to go through a really detailed process when it's really not going to get them very much."

One case manager who works with disabled children relayed their concerns about the resources available for parents. The option for respite providers is more prevalent for caregivers of older adults than for caregivers of children, although even families caring for older adults can face challenges finding respite services. Case managers with younger clients found it difficult to ask families to go through a lengthy process with little benefit at the end of it.

All case managers based in rural areas thought that TCARE would be more useful in larger cities, where there are more options for caregivers. A case manager based in Colorado's Western Slope said they struggled to see how TCARE could be helpful for caregivers in their region. Because rural areas often have more limited resources for caregivers, case managers are typically aware of the resources in their region and have already spoken with caregivers about resources they qualify for before going through the TCARE process. Another case manager based in a rural part of the state said that there are no hospice options and very few service providers in their area. Because of that, caregiver support is especially crucial, but TCARE itself does not offer new resources or opportunities. One case manager suggested:

"If Colorado does continue to invest [in TCARE], they would have to put a lot more energy and money into making the database useful. If the database came to me already set up with [city]-specific things, and there was someone responsible for keeping it up to date, then yeah, it might be much more valuable."

It is important to contextualize comments about resource availability by noting that some of these case managers did not complete any screenings or assessments via TCARE. Some case managers, therefore, presumed that useful resources would not be available at the end of the process, but they did not go through the process with caregivers to confirm their assumption. These case managers may have gotten a sense of the type of resources that TCARE recommends through their participation in the training, but they did not have access to TCARE's full list of resources. This points to the possibility that there was



resistance to the TCARE model from experienced case managers who already felt knowledgeable about caregiver resources.

### Implementation Challenges

The final theme that came up during interviews as a barrier was technical issues and various levels of breakdown in implementing TCARE at particular sites. Technical issues were typically not perceived as the primary barrier to implementation but rather as a confounding factor to the barriers outlined above. Technical issues may have impacted case managers' overall impression of TCARE more than their ability to use TCARE with caregivers, while other implementation challenges presented practical barriers to onboarding and tracking caregivers using the TCARE system.

Five case managers faced technical issues with the TCARE platform. However, four of those reported that the TCARE team was responsive and helpful in resolving technical issues promptly. One reported that TCARE was responsive about 75% of the time and either not responsive or not helpful the remaining 25%. Case managers received help from TCARE technical support via online chats and Zoom meetings.

While some called the platform "user-friendly" and "straightforward," others found it confusing to navigate between the various online platforms (e.g., training site, screening tool, online portal). One case manager said they were reluctant to use TCARE with caregivers with "the system being so cumbersome and not user-friendly or intuitive." In general, case managers who perceived the TCARE tools as difficult to navigate may have been more reluctant to use TCARE with caregivers.

Practical and logistical issues with implementing the TCARE process to fidelity also posed a barrier for some. These challenges ranged from not understanding how to track clients on the TCARE platform to not understanding TCARE eligibility criteria or the sequence of administering the screener and assessment.

One case manager reported that they sent the screener to multiple caregivers who struck them as being open to completing it, but they did not know how to follow up and check their results. Because the case manager had not completed the training, they did not have access to the TCARE system and, therefore, could not move forward with caregiver engagement via TCARE in a meaningful way. This represents a lack of understanding about the TCARE process that may have prevented some case managers from fully utilizing the services available. Three case managers completed assessments on the TCARE site without first administering a screener, highlighting another example where implementation was not carried out with fidelity. The number of completed screeners and assessments that case managers self-reported during the interviews was higher than the number of records in the TCARE database, pointing to potential technical or implementation issues as the reason for this discrepancy.

### Opportunities for Using TCARE Going Forward

**Of the 14 case managers interviewed, three said they do see opportunities for incorporating TCARE into their work going forward, while nine do not want to continue using TCARE. Two case managers said they would continue using TCARE conditional on certain factors.**

One case manager said they see an opportunity to use TCARE if their role shifts from enrolling families to working with families on an active caseload. Another case manager said they saw the potential in TCARE



but still are not sure at what stage it makes the most sense (e.g., intake with new clients versus long-term clients whose caregivers may be starting to reach the point of burnout).

Case managers who do not see an opportunity for using TCARE in the future cited one or more of the barriers listed above as the reason (i.e., time constraints, staffing considerations, caregiver fit, available resources, etc.). One case manager explained their practical limitations for continuing to use TCARE:

“When you’re grant-funded, you have to do the things you put into the grant. So if this isn’t something you are grant-funded to do, it will get constantly pushed to the side. For it really truly to work, it has to be one of your primary business focuses.”

## Approach to Working with Caregivers

**Nine of the 14 case managers interviewed confirmed that TCARE has changed how they think about serving caregivers in a positive way.**

Despite the challenges that case managers faced with onboarding and using TCARE at their agencies, case managers overwhelmingly reported that being involved in this TCARE pilot changed their approach to working with caregivers. Some are now more attentive to signals of depression and burnout because they have a better understanding of the caregiver experience. They also try to be more thoughtful about the resources that are available to caregivers, even if those resources are not necessarily available through TCARE. One case manager noted that they tend to be more candid with caregivers since participating in the TCARE pilot, speaking with them more directly about situations they want to avoid.

Case managers who were not able to complete the training or who do not interact with caregivers on a regular basis did not find that being part of the TCARE pilot changed their approach.

## Case Managers’ Recommendations

**Five case managers definitively recommend that Colorado continues to invest in TCARE, while four recommend continued investment with a few caveats. Five said that they did not feel it was the right model for the state.**

Those who would like to see Colorado continue to invest in TCARE expressed the desire to reach more caregivers to provide necessary supports and prevent future burnout crises. They recognized the need in their area for more tools and resources dedicated to caregivers who are often put on the backburner. Those who recommended continued investment conditional on certain factors cited caveats such as:

- Continue to invest if Colorado can get more organizations involved and additional support to provide resources.
- Continue to invest for agencies whose clientele are caregivers or in other settings that are a good fit for the model.
- Continue to invest for use in the Eastern Slope/Denver metro area where there are more opportunities for caregivers.

Case managers also offered their recommendations for other organizations who might consider adopting



TCARE. Nine case managers agreed that the easiest way to implement TCARE consistently is to appoint staff whose sole or primary role is administering TCARE. Adding the use of TCARE to case managers' already high workloads proved to be a significant barrier to implementation. Some case managers even suggested having a small team dedicated solely to TCARE if there is the expectation that caregivers be treated like other clients and served for the long-term. One case manager suggested that TCARE could even be implemented by someone at the administrative level and not necessarily a case manager or social worker. In terms of caregiver selection, some case managers recommended focusing on clients who have been in services for a while and whose caregivers may be moving towards burnout.

All case managers emphasized the importance of fully understanding the TCARE screening and assessment process before getting started, including the time commitment necessary for training and implementation. Having supervisors plan appropriately for their team's time would help alleviate the stress of adding another work duty and prevent case managers from becoming overwhelmed. This encompasses setting aside a realistic amount of time for case managers to complete the training without having to break it up across months.

One case manager suggested that it would be helpful to have a script for introducing TCARE to caregivers and families. They could not come up with a great way to preface the goal of their participation and found the TCARE process overwhelming to explain to families.

Several case managers wanted to be able to more easily access resources for caregivers without having to go through the TCARE screening and assessment process. Case managers have the desire to support caregivers, and becoming more educated about available resources they can offer is an easier, less time-intensive way to do that.

*“We work with so many systems already, so adding TCARE and another intake assessment is tough. Having a designated person who does just that and is familiar with it would be better, and caregivers would get more out of it.”*

- Case Manager



## Conclusion

Fully implementing the TCARE model requires a significant change in practice for some agencies and adequate time to develop the knowledge and staffing plans to support strong implementation. Agencies participating in the pilot were new to the TCARE model and are still in the early stages of implementation. It is possible that agencies who dedicate the time to implementing TCARE with full fidelity will see results for the caregivers they work with. Agencies may need to undergo a cultural shift to incorporate caregiver support into their organizational values and reinforce TCARE implementation as a priority for staff members who do not currently see it as part of their core functions. Agencies who have been through the TCARE pilot may also decide that the model is not the right fit for them.

Comprehensively examining the implementation of the TCARE model across Colorado presents the opportunity for agencies to think critically about the level of services and supports they offer to caregivers. While TCARE is one tool that can be used to support caregivers, it is not the only one. Examples of other caregiver supports in Colorado include hands-on caregiver simulations and a caregiver module developed by Colorado's Department of Health Care Policy and Financing (HCPF).

- In 2020, Easterseals Colorado and CDHS partnered to host a caregiver simulation for professionals supporting older adults and individuals with disabilities in order to help them better understand the challenges of accessing resources and juggling the demands of providing care. The simulation was developed by the Alabama Lifespan Respite Resource Network, who shared their materials and supported Colorado's efforts. The first caregiver simulation was postponed due to COVID-19 but will be offered in the future when it is safe. Simulations like these can serve as a valuable tool in increasing awareness of and empathy toward caregiver needs.
- From March 2019 to May 2020, HCPF piloted an assessment for Medicaid-funded long-term services and supports that included a caregiver module. The caregiver module asked questions to assess the level of support that informal caregivers provide and to identify situations where caregivers require relief or support to continue with their caregiving duties or where they would benefit from paid support. Caregivers are then offered recommendations to help them continue caring for their loved one. HCPF is implementing a new assessment and support planning process in July 2021, which will allow for data collection that informs new services and policies to better support individuals in services and their caregivers.

Studies of other caregiver support models and resources available in Colorado could provide valuable information for agencies throughout the state on alternatives to TCARE.





## Endnotes

- <sup>1</sup> Colorado Respite Coalition. (2020). About Us. Retrieved from <https://www.coloradorespitecoalition.org/about>
- <sup>2</sup> ARCH National Respite Network and Resource Center. (2020). Expert Panel on Respite Research and the ARCH Respite Research Consortium. Retrieved June 3, 2020 from <https://archrespite.org/respites-research>
- <sup>3</sup> Colorado Respite Coalition. (2020). Respite Care Task Force. Retrieved from <https://www.coloradorespitecoalition.org/our-programs/respites-care-task-force>
- <sup>4</sup> TCARE. Area Agencies on Aging. (2019). Retrieved from <https://www.tailoredcare.com/solutions/area-agencies-aging/>
- <sup>5</sup> Montgomery, R. (2014). *Has the use of Tailored Caregiver Assessment and Referral® System Impacted the Well-being of Caregivers in Washington? Report to the Washington Aging and Long-Term Support Administration* (pp. 1-4.)
- <sup>6</sup> Montgomery, R. (2014). *Has the use of Tailored Caregiver Assessment and Referral® System Impacted the Well-being of Caregivers in Washington? Report to the Washington Aging and Long-Term Support Administration* (pp. 1-4.)