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MICHIGAN CAREGIVER NAVIGATION TOOLKIT



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The Michigan Health & Hospital Association (MHA) Keystone Center encourages use of this guide to assess the current state of hospital implementation of key strategies aimed at building caregiver navigation programming. This resource will guide organizations in prioritizing and acting on identified gaps to start – or build upon – a caregiver navigation program. Sections of the guide include:

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Henry Ford Health C.A.R.E. Program - Henry Ford Health is a Michigan not-for-profit corporation that provides vital services to the communities it serves. Henry Ford Health, led by Robert G. Riney, provides health insurance and health care delivery, including acute, specialty, primary and preventive care services backed by excellence in research and education. In 2015, the Henry Ford Health C.A.R.E. (Caregiver Assistance Resources and Education) Program began when former CEO, Nancy Schlichting, left an endowment fund to support family caregivers and employee family caregivers. The C.A.R.E. Program is a comprehensive service that offers support groups, educational classes, art therapy sessions, one-on-one support, an employee resource group (iCare4U) and resource navigation for caregivers of all types, at no cost. The main focus of the C.A.R.E. Program is to support caregivers and reduce their caregiving burden while increasing confidence in their caregiver abilities. In 2021, the C.A.R.E. Program team received the Schwartz Center Compassionate Caregiver of the Year Award. The C.A.R.E. Program supported over 20,000 caregivers in 2022, while simultaneously supporting the MHA Keystone Center as subject matter experts for the development of this toolkit.



The Institute of Gerontology (iOG) - iOG was founded in 1965 at Wayne State University, a Carnegie I Research Intensive University, and Michigan's only urban university. The iOG is home to a vibrant multidisciplinary community of nationally and internationally recognized faculty and staff dedicated to discovering new insights into aging and later life and to improving the lives of older adults and families. Its premier programs focus on research, advanced training of pre- and post-doctoral scholars, community outreach and continuing education for health care providers. Dr. Peter Lichtenberg, iOG Director, and Dr. Amanda Leggett, iOG faculty, were consultants and subject matter experts on the development of this toolkit.



Dignity Health - Dignity Health is a multi-state nonprofit network of more than 41 acute care hospitals and 400-plus care-centers, including community hospitals, home health and primary care clinics. Dignity Health provides compassionate, high-quality, and affordable patient-centered care with special attention to the poor and underserved. Dignity Health's Central Coast market began developing its Family Caregiver Support Program in 2014 in partnership with the Santa Barbara Foundation's Community Caregiving Initiative. Under the leadership of Dr. Kathleen Sullivan, Dignity Health worked collaboratively with the MHA Keystone Center early in the development of the Michigan Caregiver Navigation Toolkit. Dr. Sullivan and her team have served over 1,300 caregiver/care recipient dyads and continue to report significant successes in reducing acute care rehospitalizations, emergency department visits and caregiver burden.



Michigan Health Endowment Fund - The Michigan Health Endowment Fund is a philanthropic foundation that works to improve the health and wellness of Michigan residents while reducing healthcare costs. Thanks to the Michigan Health Endowment Fund's support, this toolkit is free to users.

INTRODUCTION

PURPOSE OF THE GUIDE

The MHA Keystone Center is committed to supporting its member hospitals to ensure that every person in every community receives high-quality, and safe care. The Michigan Caregiver Navigation Toolkit was created to help hospitals and health systems implement and maintain a caregiver navigation program – designed to support caregivers in their role by providing connections, support and education.

The Michigan Caregiver Navigation Toolkit is meant to serve as a resource for healthcare staff looking to develop or improve the caregiver navigation program across their system. Although caregiving is relevant across all age groups, this toolkit is primarily intended for use on adults aged 18 years or older, with a special focus on older adults. The toolkit allows users to assess current structures to identify gaps and opportunities for improvement in caregiver support. It also provides guidance to create actionable plans for program development and expansion.

KEY ISSUES RELATED TO CAREGIVER SUPPORT



For the purposes of this toolkit, a **caregiver is defined as:**

any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition.

These individuals may be:



- Primary or secondary caregivers.



- Live with or separately from, the person receiving care.



- May care for their care recipient with function (e.g., activities of daily living) or health needs (e.g., chronic or acute illness such as cancer or dementia).²



As of 2020, approximately

1 IN 5 AMERICAN ADULTS

48 million individuals are considered caregivers.

- This number is anticipated to grow alongside the number of adults living with chronic illness and disabilities.

○ Researchers have described caregiving as a 36-hour day as they fill many roles including assisting with:

**MEDICAL
CARE TASKS**



**FUNCTIONAL TASKS
OF DAILY LIVING**



**EMOTIONAL AND MENTAL
HEALTH SUPPORT**



**CARE
MANAGEMENT**



ADVOCACY



**ADMINISTRATIVE
TASKS**



TRANSPORTATION



27



Increase in caregivers providing care
for **two or more** health issues.

Caregivers are providing care for more health and functional needs than they were five years ago, and a larger proportion (47 vs. 35%) are providing care for two or more health conditions than was the case five years ago.²

CAREGIVING CHALLENGES AND CURRENT DATA

◉ WHY CARING FOR CAREGIVERS MATTERS



- ◉ The support that caregivers provide and caregiver well-being have direct associations with patients' healthcare outcomes. For example, poor social support structures for patients during COVID-19 are key drivers of hospital readmissions. Therefore, **family caregivers are essential partners that facilitate the recovery of recently hospitalized patients and reduce potentially preventable readmissions.**^{15, 27, 29}



- ◉ Dementia caregivers' distress related to behavioral and psychological symptoms of dementia was associated with a nearly three-fold higher rate of emergency department and inpatient utilization.



- ◉ **Family members themselves may also be at increased risk post-hospitalization.** For example, prior research has identified a high risk of mental health symptoms, coined post-intensive care syndrome-family, among caregivers of critical care patients post-discharge. Thus, caregivers play a critical role in patient outcomes post-hospitalization yet may also negatively impact themselves from such interactions. **Caring for caregivers can directly impact patient and caregiver health, healthcare utilization and costs.**¹³



- ◉ More broadly, decades of research have established an increased risk for stress, depression and anxiety symptoms for caregivers compared with same-age non-caregiving peers, with dementia care noted as particularly stressful.

- **Stress associated with caregiving responsibilities has been linked with:**

- Decreased well-being
- Depressed mood
- Anxiety
- Anger
- Guilt
- A sense of being trapped
- Feelings of loss
- Vulnerability to disease
- Varying levels of stress hormones/increased allostatic load
- Higher morbidity^{12,16, 24, 25,32}



COVID-19'S IMPACT ON CAREGIVERS – PLANNING FOR FUTURE PUBLIC HEALTH EMERGENCIES

- COVID-19 carries a particularly high risk for severe complications and mortality among adults with preexisting health conditions.¹⁶
- Recent studies show that caregivers experienced increased psychological stress, fatigue, burden, overload and somatic symptoms during the pandemic than before.^{8, 9, 10, 17, 23, 28}
 - Caregivers were tasked with helping their care recipients stay safe, maintain physical function while isolating, follow distancing principles and other public health guidelines while still accessing proper medical care. However, some tasks increased in complexity as caregivers were forced to determine whether to abide by distancing or continue providing hands-on care and deal with healthcare in new modalities such as telehealth. Many experienced increased difficulty in service seeking and a lack of availability as long-term care facilities went into lockdown, and many respite care and in-home care services abruptly stopped or reduced their services.²³
 - Caregivers reported facing challenges during the pandemic, including physical, mental and cognitive declines among care recipients because of isolation, maintaining safety from COVID-19, lack of received support and changed tasks and responsibilities.^{18,19}

SECTION 1

UNDERSTANDING KEY TERMS

The MHA Keystone Center has compiled a list of terms relevant to this work to provide a common language and understanding. This glossary lists terms that may be frequently used across our efforts; however, it is not exhaustive nor a definitive list of correct/incorrect terms.

- **Activities of Daily Living (ADLs)** – Everyday tasks related to personal care usually performed for oneself on a normal day, including bathing, dressing, grooming, eating, walking, taking medications and other personal care activities.
- **Advance Care Planning** – An ongoing communication process that involves clarifying and documenting an individual's wishes, values, preferences and goals regarding future medical care in the event they lose the capacity to make healthcare decisions.
- **Caregiver** – Any relative, partner, friend or neighbor who has a significant personal relationship with and provides a broad range of assistance for another person. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care.
- **Caregiver Assessment** – A systematic process of gathering information that describes a caregiving situation and identifies the particular programs, needs, resources and strengths of the family caregiver.
- **Caregiver Intensity Index (CII)** – An assessment created by ARCHANGELS, which is a web-based caregiver 'quiz' designed to engage caregivers, assess the intensity of their current caregiving situation, and provide a score with their specific intensity buffers and drivers.
 - **Buffer scores** – A calculation based off the CII outlining resources or coping mechanisms that help reduce the negative effects of Caregiver Intensity.
 - **Driver scores** – A calculation based off the CII outlining factors that increase the emotional, mental, and physical intensity of caregiving.
 - **Mental Health Impacts** – A calculation quantifying the impact of caregiving on mental health (e.g., depression/anxiety). 90% of caregivers with high intensity ('in the red') have at least one adverse mental or behavioral health symptom.
- **Care Recipient** – An adult with a chronic illness or disabling condition or an older person who needs ongoing assistance with everyday tasks to function on a daily basis. The person needing assistance may also require primary and acute medical care or rehabilitation services (e.g., occupational, speech and physical therapies).
- **Consumer Assessment of Healthcare Providers and Systems (CAHPS)** – Standardized patient experience surveys that ask patients (or in some cases their families) about their experiences with, and ratings of, their healthcare providers and plans, including hospitals, home healthcare agencies, doctors, and health and drug plans, among others.
- **Designated Caregiver Act** – An act in Michigan that is intended to allow for the designation of a caregiver; to prescribe the duties of a designated caregiver; to enable a hospital to assist in designating a caregiver; and to prescribe the duties of state departments and agencies.
- **Electronic Health Record (EHR)** – Digital version of a patient's paper chart. EHRs are real-time, patient-centered records that make information available instantly and securely to authorized users. While an EHR does contain the medical and treatment histories of patients, an EHR system is built to go beyond standard clinical data collected in a provider's office and can be inclusive of a broader view of a patient's care.

- **Healthcare Staff** – A team member associated with a formal service system, whether a paid worker or someone from a volunteer organization.
- **Health Literacy** – Refers to how well a person can access and understand the basic health information and services they need.
- **Person and Family Advisory Council (PFAC)** – An organization of current and former patients, family members and caregivers that works together to advance best practices at a hospital or healthcare organization. Through partnership and collaboration with staff, PFACs promote person and family engagement and help establish a culture of person- and family-centered care throughout programs, services and policies.
- **Person and Family Engagement (PFE)** – Strategies designed to foster collaboration between patients, families and clinicians working together towards mutually agreed-upon goals, that help support building a person-and family-centered care health system and culture.
- **Plan, Do, Study, Act (PDSA) Model** – The Plan-Do-Study-Act (PDSA) cycle is shorthand for testing a change — by planning it, trying it, observing the results, and acting on what is learned. This is the scientific method, used for action-oriented learning.
- **Screening** – A short, rapid review with caregivers that identifies those at risk, leading to an opportunity for a full assessment for those wishing to proceed.
- **Small-Test-of-Change** – A quality improvement methodology to follow the Plan, Do, Study, Act model. Implementing a change on a smaller scale ensures testing is easier and improvements are made before the change is launched on a wider scale.
- **SMART Goals** – SMART is an acronym for Specific, Measurable, Achievable, Realistic and Timely. Therefore, a SMART goal incorporates all these criteria to help focus efforts and increase the chances of achieving the goal.
- **R.A.I.S.E. Act** – The R.A.I.S.E. Family Caregivers Act, directs the Secretary of Health and Human Services to develop a national family caregiving strategy. The strategy will identify actions that communities, providers, government and others are taking and may take to recognize and support family caregivers.
- **Respite Care** – Provision of short-term relief (respite) from the tasks associated with caregiving.
- **The Michigan Caregiver Designation Act** – Legislation to allow for the designation of a caregiver; to prescribe the duties of a designated caregiver; to enable a hospital to assist in designating a caregiver; and to prescribe the duties of state departments and agencies.

SECTION 2

CAREGIVER NAVIGATION PROGRAM OUTLINE

There are many components of developing a caregiver navigation program. There are seven key domains. These seven domains are outlined below. Each domain is a crucial part of a comprehensive program and can be worked on independently of the other domains. For example, if all tasks under the fundamentals of [Healthcare Staff](#) are complete, the hospital can move into the advanced stage of that domain. While working on the advanced stage of [Healthcare Staff](#), the hospital can also work on the fundamentals of [Education](#). All fundamental tasks must be completed before moving on to the advanced stage of each domain, but each domain can be worked on independently of the others.

* Please note this section of the guide is simply an outline. [Section 4](#) of the guide provides more direction for conducting a gap analysis.

DOMAIN	FUNDAMENTAL	ADVANCED
Healthcare Staff	<ul style="list-style-type: none"> Name an executive sponsor (C-suite support). Identify frontline champions. Assign a project manager to oversee program development. Identify primary pilot group members (employee track versus patient/caregiver track). 	<ul style="list-style-type: none"> Budget dedicated healthcare staff time. Train dedicated healthcare staff. Consider: Caregiver Patient Navigators, C.A.R.E. Program Specialist (or other title(s)). Foster dedicated ancillary support (volunteers, IT, administrative).
Assessments	<ul style="list-style-type: none"> Ensure compliance with The Michigan Caregiver Designation Act (inpatient only). Build Electronic Health Record (EHR) questions and clinical workflows. Choose standardized assessments to identify caregivers (e.g., patient as a caregiver, caregiver burden/coping). 	<ul style="list-style-type: none"> Implement standardized caregiver assessments (e.g., Zarit). <p>OR</p> <ul style="list-style-type: none"> Conduct individualized conversations with trained staff (health coaching).
Community Partnerships	<ul style="list-style-type: none"> Perform an environmental scan of the community. Network and align common goals. Develop organizational Person and Family Advisory Council (PFAC). 	<ul style="list-style-type: none"> Create formal partnerships with key community organizations (e.g., Program of All-Inclusive Care for the Elderly). Initiate involvement in community collaboratives.
Education	<ul style="list-style-type: none"> Educate staff on the The Michigan Caregiver Designation Act. Identify caregiver educational materials and develop a catalog of ongoing and past events. Work with community partners to provide resources and facilitate education. 	<ul style="list-style-type: none"> Support ongoing staff and provider education and awareness on programming (consider continuing education credit). Implement advance care planning (e.g., advanced directives). Provide a dedicated person for support groups and 1:1 concierge service offerings. Develop consistent educational sessions for caregivers and the community. Conduct specialized programs based on feedback and needs.
Integration into Health Systems	<ul style="list-style-type: none"> Revise patient visitor policies to include public health emergencies. Identify current resources and capacity. Identify piloted service line to deploy programming. Perform gap analysis and develop action plans for desired state (using SMART Goals). 	<ul style="list-style-type: none"> Once desired state is achieved, spread programming throughout other service lines. Develop a caregiver employee resource group. Include programming in new hire orientation. Convene an internal governing body (e.g., PFAC, quality department, performance excellence, population health etc.) to have the program report to. Include caregiver program information on all discharge documents.
Marketing and Referrals	<ul style="list-style-type: none"> Create website with referral link. Develop dedicated marketing materials. Initiate a communications plan (e.g., newsletters). 	<ul style="list-style-type: none"> Create EHR integration opportunities (e.g., referral orders). Perform employee needs assessment (for employee track). Set-up a dedicated phone number that is monitored.
Program Monitoring, Evaluation & Sustainability	<ul style="list-style-type: none"> Identify priority process and outcome metrics. Measure impact by embedding outcomes/impact into new or existing quality metrics. 	<ul style="list-style-type: none"> Develop internal dashboard around chosen metrics. Share learnings with other Michigan hospitals.

SECTION 3

DEFINING THE SEVEN DOMAINS



- **Healthcare Staff** – The term staff refers to paid employees in the hospital, health system, or clinic (e.g., registered nurse). For the purposes of this guide, staff will not be referred to as caregivers. Staff leading the caregiver navigation program should be trained to identify and support caregivers and guide decision-making regarding program activities and updates. It is also important early in the process to include vital staff in program development, such as naming an executive sponsor, identifying frontline champions and designating a project manager to oversee program development.



- **Assessments** – A systematic process of gathering information that describes a caregiving situation and identifies the particular programs, needs, resources and strengths of the caregiver. Several assessments have been provided to allow each organization the flexibility of choosing the tools that fit best within its organization. Once assessments are chosen, they must be built into the organization's EHR, dedicated staff must be fully trained in their delivery, and the new process is to be hardwired into daily workflows.
 - **Modified Caregiver Strain Index** – Free
The Modified Caregiver Strain Index (MCSI) is an easy-to-use tool that can quickly screen for caregiver strain in long-term caregivers.
 - **Caregiver Intensity Index (CII)** – Pay for use
The CII is a web-based caregiver 'quiz' designed to engage caregivers, assess the intensity of their current caregiving situation and provide a score with their specific intensity buffers and drivers.
 - **Caregiver Assessment Questionnaire** – Free
The Caregiver Assessment Questionnaire assesses a caregiver's well-being and understands how they feel mentally and physically.
 - **SF-36 (Quality of Life Assessment)** – Free
SF-36 is a set of generic, coherent and easily administered quality-of-life measures. These measures rely upon patient self-reporting and have been widely used.
 - **McMaster Family Assessment Device** – Free with permission
The McMaster Family Assessment Device (FAD) is a 60-item questionnaire that measures an individual's perceptions of their family.
 - **Benjamin Rose: Selected Caregiver Assessment Measures** – Free
The Benjamin Rose: Selected Caregiver Assessment Measures is an aggregation of caregiver assessment measures for use by researchers and practitioners.



- **Community Partnerships** – Working with external community partners is vital in leveraging all available resources to address caregiver needs. Performing an environmental scan of the community being served is a fundamental step in creating partnerships to generate referrals, embarking on joint educational offerings and working together to achieve better outcomes for patients and caregivers.



- **Education** – This domain is a cornerstone for patient and caregiver education and staff and community education. For inpatient acute care units, thorough education regarding the Michigan [Designated Caregiver Act](#) should be completed with all pertinent staff. The organization should also begin developing a master education plan regarding caregiver navigation, which acts as a catalog of ongoing and past events. This should include the basic universal definition of a caregiver and their role. Whenever developing or deploying educational materials, consider each community partner and how their expertise could be leveraged to help achieve common goals.



- **Integration into Health Systems** – Following a [small-test-of-change](#) in the chosen piloted service line – and once processes are satisfactory as the desired state – the caregiver navigation program can be adopted across the health system as a new organizational practice. This is the phase of spreading best practices and hardwiring those into daily workflows. Early in this process, a gap analysis is performed (utilizing the tool in [Section 4](#)), which will help prioritize key milestones that should be achieved to advance programming in the chosen service line (e.g., an outpatient diabetes clinic).



- **Marketing and Referrals** – Marketing and referral generation are key to identifying caregivers who may need services provided by the program. The organization will first add caregiver programming information to its website and create dedicated marketing materials for the community, staff and healthcare providers. Once these systems are in place, the referral should be built into the [Electronic Health Record \(EHR\)](#).



- **Program Monitoring, Evaluation and Sustainability** – In the final domain, organizations will identify process and outcome measures in efforts to evaluate the success of the caregiver navigation program. It is recommended to start with existing quality metrics (e.g., readmissions) while creating an encyclopedia of measures the organization would like to monitor moving forward. ([See Section 7](#)) for suggested metrics). During advanced implementation, internal dashboards around chosen metrics can be built to monitor ongoing improvement and share results with other Michigan hospitals and health systems.

SECTION 4

CAREGIVER PROGRAM GAP ANALYSIS

Using a gap analysis to identify areas of strength and opportunity can be an effective tool in improving a caregiver program. In this case, you can utilize the gap analysis in this guide to identify if your hospital or health system is in a fundamental or advanced stage and where there are opportunities for growth. If your hospital or health system meets all the fundamental requirements for any or all of the seven domains, you may move forward and progress into advanced implementation. For example, suppose your organization has completed all the fundamentals for the [Healthcare Staff](#) domain, but only one for [Education](#). In that case, you can move on to the advanced implementation of [Healthcare Staff](#) while working on the fundamentals of [Education](#).

It is important to note that as a program is developed and becomes sustainable, the gap analysis may need to be adjusted to continue identifying strengths and areas of opportunity.

CAREGIVER NAVIGATION GAP ANALYSIS

DOMAIN Healthcare Staff	FUNDAMENTAL <ul style="list-style-type: none">• Which of the following staff have you dedicated to your caregiver program? (Select all that apply)<ul style="list-style-type: none"><input type="checkbox"/> An executive sponsor (C-suite support)<input type="checkbox"/> Frontline champions<input type="checkbox"/> A project manager (to oversee program development)• Which pilot group have you selected for implementation?<ul style="list-style-type: none"><input type="checkbox"/> Employees as caregivers<input type="checkbox"/> Patient caregivers <hr/> ADVANCED <ul style="list-style-type: none">• Does your organization budget for healthcare staff and support include: (Select all that apply)<ul style="list-style-type: none"><input type="checkbox"/> Formal caregiver position(s) (e.g., Caregiver Patient Navigators, C.A.R.E. Program Specialist, etc.)<input type="checkbox"/> Training of healthcare staff<input type="checkbox"/> Dedicated ancillary support (e.g., IT, marketing, administrative)
DOMAIN Assessments	FUNDAMENTAL <ul style="list-style-type: none">• Is your organization compliant with the Michigan Designated Caregiver Act (inpatient only)? <input type="checkbox"/> yes <input type="checkbox"/> no• Has your organization evaluated and mapped clinical workflows related to caregiver navigation programming? <input type="checkbox"/> yes <input type="checkbox"/> no• Has your organization chosen a standardized assessment(s) to identify and/or assess caregivers? <input type="checkbox"/> yes <input type="checkbox"/> no• Are all assessments and fields built into the EHR test environment? <input type="checkbox"/> yes <input type="checkbox"/> no <hr/> ADVANCED <ul style="list-style-type: none">• Which assessment approach has your organization standardized? (Select all that apply)<ul style="list-style-type: none"><input type="checkbox"/> Standardized caregiver assessments (e.g., Zarit)<input type="checkbox"/> Individualized conversations with trained staff (health coaching)<input type="checkbox"/> None

DOMAIN

Community Partnerships

FUNDAMENTAL

- Which of the following fundamental community-based activities has your organization engaged in?
(Select all that apply)
 - ☐ Performed an environmental scan of the community.
 - ☐ Networked and aligned common goals.
 - ☐ Developed organizational [Person and Family Advisory Council \(PFAC\)](#).

ADVANCED

- Which of the following advanced community-based activities has your organization completed?
(Select all that apply)
 - ☐ Formal partnerships with key community organizations.
 - ☐ Involvement in community collaboratives.

DOMAIN

Education

FUNDAMENTAL

- Are all pertinent inpatient staff given education on [Michigan Designated Caregiver Act](#)?
☐ yes ☐ no
- Has your organization begun developing a “working catalog” of caregiver educational materials? ☐ yes ☐ no
- Does your organization work with community partners to provide resources and facilitate education? ☐ yes ☐ no

ADVANCED

- Which of the following advanced educational activities has your organization completed?
(Select all that apply)
 - ☐ Ongoing staff and provider education and awareness on programming.
 - ☐ Advance care planning process in place (e.g., advanced directives).
 - ☐ Dedicated person for support groups.
 - ☐ Dedicated person for 1:1 concierge service.
 - ☐ Organized consistent educational sessions for caregivers and the community.
 - ☐ Conducts specialized programs based on feedback and needs.

DOMAIN

Integration into Health Systems

FUNDAMENTAL

- Does your organization have an updated patient visitor policy to address public health emergencies (mitigations to allow caregivers at the bedside)? ☐ yes ☐ no
- Is there leadership support with necessary resources allocated to the Caregiver Navigation program to ensure success? ☐ yes ☐ no
- Is a piloted service line chosen to deploy this work via a small-test-of change? ☐ yes ☐ no
- Has your organization created a fundamental action plan to begin caregiver navigation programming? ☐ yes ☐ no

IF YES – Does the action plan include SMART goals?

ADVANCED

- What advanced activities has your organization implemented to support this work? (Select all that apply)
 - ☐ Developed a caregiver Employee Resource Group.
 - ☐ Includes programming in new hire orientation.
 - ☐ Program reports to an internal governing body (e.g., PFAC, quality department, performance excellence, population health etc.).
 - ☐ Includes caregiver program information on all discharge documents.
 - Based off your organization's Caregiver Navigation action plan, has your desired state been met in your piloted service line? ☐ yes ☐ no
- IF YES – Has an action plan been created to spread programming throughout other service lines?
☐ yes ☐ no

DOMAIN

Marketing and Referrals

FUNDAMENTAL

- Which fundamental marketing and referral generating activities has your organization completed? (Select all that apply)
 - ☐ Created a website with a referral link.
 - ☐ Created dedicated marketing materials.
 - ☐ Developed a communications plan.

ADVANCED

- Which advanced marketing and referral generating activities has your organization completed? (Select all that apply)
 - ☐ Integration in [Electronic Health Record \(EHR\)](#) (e.g., referral orders).
 - ☐ Performed an employee needs assessment (to expand to employees).
 - ☐ Dedicated phone number is active and supervised.

DOMAIN

Program Monitoring, Evaluation & Sustainability

FUNDAMENTAL

- Which fundamental evaluation and sustainability techniques has your organization completed? (Select all that apply)
 - ☐ Identified priority process and outcome metrics.
 - ☐ Embedded outcomes into new or existing quality metrics.

ADVANCED

- Which advanced evaluation and sustainability techniques has your organization completed? (Select all that apply)
 - ☐ Developed internal dashboard around chosen metrics.
 - ☐ Shared learnings with other Michigan hospitals.

PDSA METHODOLOGY

During the development of a caregiver navigation program, it is important to have an action plan for implementation. By following the [plan, do, study, act \(PDSA\) model](#), hospital staff can identify and resolve issues in the programming before launching across the hospital or system. Consideration of each component will aid in achieving the highest level of care for patients and their caregivers.

1

PLAN – What is your desired state in your piloted service line? What will you do to achieve it?

- Choose an employee or a patient and caregiver pilot track.
 - When deciding where to have a pilot site, consider piloting the program with employees first. Employees can provide feedback quicker and test different components of the program in different settings. This may also create more support from employees because they have firsthand experience with the program. If piloted with patients and their caregivers first, hospital staff can reach a wider range of caregivers who will have different levels of access to components of the program. Both pilot groups will provide valuable feedback, but each will offer different perspectives.
- Complete the [Caregiver Navigation Gap Analysis](#).
- Identify your current state and desired state.
- Create action plans addressing the seven domains.
 - Action plans should include SMART Goals.
- Identify key priority outcomes and performance metrics (HCAHPS, burden scores, readmissions, etc.).

2

DO – How do you carry out your action plans? Are you tracking outcomes of chosen metrics?

- Implement the action plans using [small-tests-of-change](#) in chosen piloted service line.
- Evaluate chosen metrics on an ongoing basis.

3

STUDY – What did you learn? Did you meet your measurement goal?

- Analyze outcomes of chosen metrics with a cross-functional and multidisciplinary team to determine the current level of implementation.
- Compare data to your predictions.
- Summarize and reflect on what was learned.

4

ACT – Has your desired state been met or not? Take action on the identified areas of opportunity and commit to reaching the highest implementation level.

- Refine changes based on what you learned from the small-test-of-change.
- Determine changes that need to be made.
- Prepare a plan for the next cycle of improvement.

SAMPLE IMPLEMENTATION TIMELINE

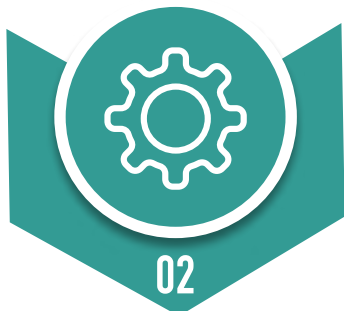
The following table is a sample implementation timeline that provides key deliverable examples over a three-year period. This is not intended to be prescriptive or all-encompassing, but an example of how an organization could begin quantifying program implementation over time.



YEAR 1

Program Launch

- Select caregiver navigation program track and piloted service line.
- Identify a clear current state and desired state.
- Complete [gap analysis](#) at the beginning of the first year.
- Identify process, outcome and self-reported metrics.
 - See examples in [Section 7](#).
- Form program team and develop a fundamental action plan addressing the seven domains using SMART Goals.
- Implement the fundamental action plan.



YEAR 2

Full Implementation

- Evaluate previous year’s fundamental action plan using Plan, Do, Study, Act (PDSA) methodology. Complete a gap analysis at the beginning of the second year.
- Track process, outcome and self-reported metrics consistently.
 - See examples in [Section 7](#).
- Form an advanced action plan addressing the seven domains using SMART goals.
- Implement advanced action plan.



YEAR 3

Maturation and Sustainability

- Evaluate previous year’s advanced action plan using PDSA methodology.
- Complete a gap analysis at the beginning of the third year.
- Create evaluation and sustainability plan with tracked metrics.
- Form an action plan focusing on any unaddressed advanced interventions as well as plans for widespread adoption outside of chosen piloted service line.

IMPLEMENTATION CONSIDERATIONS

Services offered through technology (e.g., support groups and educational talks) can increase access to individuals living in rural areas, those with interfering work schedules or other hard-to-reach populations who may have difficulty traveling to a health system at a given time. Additionally, technology-based services may enable individuals to access specialized services (e.g., a support group targeting individuals caring for a specific diagnosis that may not have enough in-person attendance but may reach interested individuals from a broader radius through online services). However, while the goal of offering services through technology is to make access easier, it's important to understand that not all individuals have access to, or knowledge of, the technology needed to utilize some of the available resources. Consider the following while developing caregiver programming:

- **Technology literacy** – How familiar is the caregiver with technology? Do they know key terms like Wi-Fi and video conference?
- **Remote services** – Does the caregiver have access to a tablet, phone or computer with a camera?
- **Internet access** – Does the caregiver have reliable access to the internet at home, or will they need to leave their house to join a virtual support group?
- **Language barriers** – What language does the caregiver speak? Are the resources available in multiple languages?
- **Health literacy** – Does the caregiver understand health-related language? It is a good general rule to keep health information presented in plain language to make sure information is accessible to all individuals.

⦿ Potential Solutions:

- Consider screening the caregiver for their access and understanding of technology when they start in their program.
- Simplify content on websites and online tools.
- Create a printed PDF guide on how to access the resources with easy-to-read instructions and in multiple languages.
- Utilize existing online resources, such as the [Home Alone Alliance](#), to give caregivers options for self-paced, online learning resources related to caregiving.
- Offer multiple ways to engage in activities; calling into a virtual meeting via telephone, hosting in-person activities and sending out virtual and physically mailed newsletters.
- Consider having someone on call to help troubleshoot technology issues a caregiver may have in joining a group, using the chat function, etc.
- Leverage person and family engagement (PFE) strategies (e.g., [Person and Family Advisory Councils](#)) to co design more person-centered caregiver services and systems by partnering and engaging with individuals that truly reflect the communities served. Ensure your caregiver programs/policies reflect what matters most to them:
 - Consider the needs, perspectives, interests, values and beliefs of all individuals.
 - Address barriers to effective engagement and utilization of your resources, including communication barriers and limited health literacy.
 - Include patients and families from all backgrounds as active partners in their healthcare.

SECTION 7

SUSTAINABILITY AND PROGRAM MONITORING

It's crucial to use metrics and monitor outcomes to continue the caregiver navigation program past the implementation phase, ensuring it is successful and sustainable long term. While some metrics may be found in data already collected (e.g., readmissions and ED visits), qualitative data and caregiver-reported data may need to be gathered to gain insight into what is making a positive impact and what is not. Quantitative data (e.g., questionnaires or scales where scores can be calculated) may provide a quick assessment of the caregiver's burden or level of readiness to implement care practices at home. On the other hand, qualitative (e.g., open-ended questions) may be used to gather feedback from caregivers to understand barriers or facilitators experienced in utilizing the program. Assessing multiple types of measures (e.g., outcome, process and caregiver-reported) provides the most insight into the successes and failures of the program.

CLINICAL OUTCOME MEASURES

Clinical outcome measures (e.g., readmissions) can be used to examine data objectively. **Although looking at these measures can be helpful, not seeing a change in this data does not indicate program failure.** Clinical outcome measures may or may not change when implementing a caregiver program. A few examples are:

- **30-day Readmissions:**

Numerator: Patients 65 years and older who are readmitted within 30 days.

Denominator: Patients 65 years and older who had a recent hospitalization and are at risk of readmission.

- **Emergency Department "Super Utilization":**

Numerator: Patients 65 years and older with at least four admissions or at least five ED visits, observation stays, and admissions combined in the 12-month period.

Denominator: Count of annual emergency department visits.

CAREGIVER-REPORTED MEASURES

The caregivers share caregiver-reported measures via a survey, verbal conversation, etc. These anecdotal accounts can provide valuable insight into common barriers or gaps. For example, if most participants report that they are not happy with their level of social activity, the implementation team can consider adding more social activities to the programming. Outcomes can be evaluated by comparing the caregiver's reported score at the beginning of the program and their reported score at the time of the survey, outcomes can be evaluated. In addition, patient experience scores, such as HCAHPS, can be utilized to measure improvement in patient experience domains. This could be done specifically in the program's pilot site to assess if pre- and post-program implementation significantly improved the patient experience.

There are many resources available to collect self-reported measures from caregivers, such as:

- [PROMIS Global Health](#)
- [Zarit Burden \(at a cost\)](#)
- [Health in Aging Caregiver Self-Assessment](#)

PROCESS MEASURES

Process measures evaluate the efficacy of implemented processes. There should be a scientific basis for believing that the process, when executed well, will increase the probability of achieving a desired outcome. Continually evaluating process measures allows the healthcare organization to assess if steps in each process are performing as planned in overall efforts to improve the system as a whole.



Some examples of process measures related to caregiver programming include:

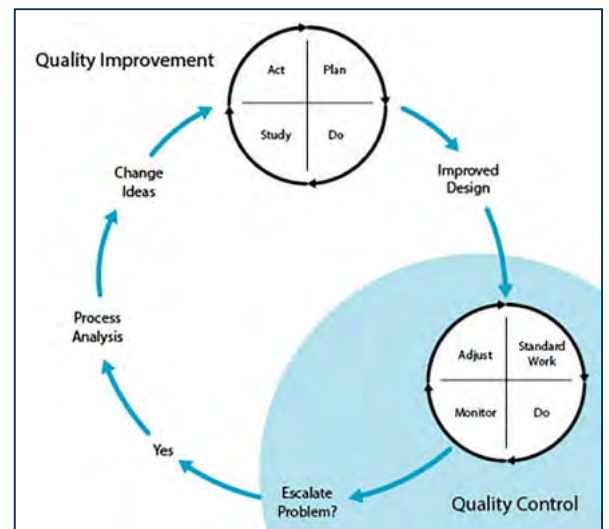
- Demographics of caregiver.
- Demographics of care receiver/patient.
- Number and type of referrals to the program.
- Number of admissions to the program.
- Number and type of staff encounters/visits with a caregiver.
- Number of participants in education classes.
- Number of community presentations given.
- Number of community partners.
- Length of caregiver engagement in the program (# of days.).
- Number and type of healthcare providers trained.^{34,35}

SUSTAINABILITY

As part of all Quality Improvement efforts, it is crucial to develop a long-term sustainability plan to ensure the newly implemented program is hardwired into daily practices and continually improved upon using the PDSA cycle. According to the Institute for Healthcare Improvement (IHI), “Sustainability is ultimately the responsibility of senior leaders. Such responsibility goes beyond mission statements, marketing copy, and policy pronouncements. It also requires practical direction, support, and recognition for frontline clinical leaders — those who most directly impact patient experience of care. The standard work of senior leadership includes establishing an infrastructure for Quality Planning, and taking an active, daily role in Quality Control.”³⁶

The IHI also has identified the following six quality control practices as:

1. **Standardization** denotes specific, detailed, documented standard procedures. These are not just for healthcare staff, but also for supervisors, higher level managers, and executives.
2. **Accountability** means a process is in place to review implementation of standard work.
3. **Visual Management** involves the use of clear, simple data displays at the unit level that show performance on key quality measures over time, and track problems the team is currently addressing.
4. **Problem Solving** means methods are available for developing frontline improvement skills so staff can address issues as they arise. (e.g., Huddles provide a forum for raising and triaging quality problems, disposing of simple ones, and escalating more complex problems that require a formal QI project).
5. **Escalation** involves frontline staff scoping issues and raising those that require management action to resolve. Problems that frontline staff cannot solve immediately, or that require interdepartmental coordination, are escalated to the appropriate level of management that can commission an improvement initiative.
6. **Integration** means active communication and consistency of purpose between levels of management and professional staff, and across departments.³⁶



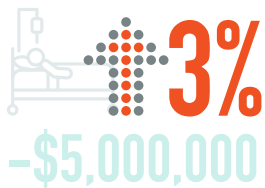
Other examples of sustainability activities include:

- Commit to sustainability as a priority of the program with senior leadership oversight.
- Update policies and procedures.
- Ensure a sustainable training plan is in place.
- Build the process into orientation.
- Build the process into the EHR.
- Assign an individual to continually monitor outcomes.
- Use auditing and accountability tools.
- Develop a plan to spread the small-tests-of-change across more departments or the entire organization.
- Once processes are hardwired, develop a plan to share learnings and processes with other healthcare organizations.

SECTION 8

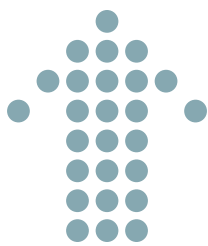
CASE STUDY

In 2024 and 2025 the MHA Keystone Center partnered with a large academic medical center in southeast Michigan to test the implementation of this toolkit. Approximately one-third of patients aged 65 or older at the pilot organization had caregivers at home. Most of the patients with caregivers had chronic diseases or conditions that required complex care.



The readmission rate for these patients were **3% higher** than that of the general population and the avoidable cost was **more than \$5 million** annually.

This pilot aimed to implement the Michigan Caregiver Navigation Toolkit on a small scale using the Plan Do Study Act (PDSA) cycle of improvement to implement new caregiver programming. Following a two-year implementation period, this organization has already gathered promising outcome data that shows significant improvement in caregiver strain, burden and overall care intensity.



58%
caregiver intensity
index scores

54%
mental health
impact scores

63%
assessment
driver scores

22%
assessment
buffer scores

- Preliminary data showed exponential improvement in caregiver intensity index scores (58% improvement), mental health impact scores (54%), assessment driver scores (63%), and assessment buffer scores (22% improvement) from admission to the caregiver program compared to a 2-month follow-up assessment following interventions.*

In addition to these promising results, other potential impacts that are anticipated include:

IMPROVING
SOCIAL ISOLATION



RECONNECTING CAREGIVERS
WITH CARE RECIPIENTS



REDUCING AVOIDABLE
HOSPITAL READMISSIONS
AND ED VISITS



IMPROVING THE OVERALL
COMFORT OF CAREGIVERS IN
THEIR ROLES



In addition, lessons learned from this pilot were used to edit this toolkit as well as the gap analysis based on real-world feedback.

* For definitions of the Caregiver Intensity Index, driver scores and buffer scores, please visit **Section 1** of the toolkit.

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