

The logo for C+TAC, featuring the letters 'C', '+', 'T', and 'A', and 'C' in a bold, white, sans-serif font. The '+' sign is a solid orange square.

COALITION TO TRANSFORM
ADVANCED CARE

The Compendium of
Evidence-Based and
Promising Practices to Care
for Those with Serious Illness





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Executive Summary

As the numbers of Americans caring for people facing serious or other life limiting illnesses continues to increase,ⁱ either at home or in institutions, so too do urgent calls for reform of related health care service delivery and payments.ⁱⁱ Luckily, new healthcare financing options in Medicare Advantage, Medicare fee-for-service, commercial insurance, and Medicaid have offered flexibilities to direct resources in ways that optimize care for people living with serious illnesses.ⁱⁱⁱ Additionally, health care leaders have sought grant-funding or even self-funded efforts to reimagine the delivery of serious illness care in their communities. This Compendium seeks to briefly profile some of these innovations in order to accelerate the scale and adoption of such models.

C-TAC selected models that embody **four of the most practical, promising opportunities for impact**, which were identified by former and current policy makers interviewed for this publication, as well as clinical and community leaders:

- 1. Embedding serious illness programs within broader risk-based, population-health payment models where many populations are included**
- 2. Reaching populations with serious illness at home**
- 3. Addressing health equity through faith-based partnerships**
- 4. Meeting the needs of pediatric populations facing serious illness**

We hope that readers might use this Compendium as a guide to what is possible in transforming care in the community and as a tool to meet the **Moonshot Goal** that the 12 million people experiencing serious illness will have a high quality of life by 2030.

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ABOUT C-TAC

The Coalition to Transform Advanced Care (C-TAC) is a diverse, bipartisan alliance of over 200 organizations dedicated to the vision that everyone impacted by serious illness should have the care that they need, when and where they need it. To learn more about C-TAC's work on innovative models of care and how to partner with us, please visit our website, thectac.org.

Introduction

This Compendium provides a high-level overview of several types of care models to support the comprehensive needs of patients and families facing serious illness.

This Compendium is meant to be used by readers to orient themselves to options for care delivery, prioritizing programs that align with **CORE PRINCIPLES FOR CARE MODELS**¹ and have demonstrated financial impacts. The intended audiences for this Compendium are decision-makers within a variety of settings such as health care provider systems, health plans, states, and federal agencies.

Leaders in the health care sector face increasing pressure to find solutions to improve care and reduce costs, especially given that health care costs and expenditures continue to rise faster than the gross domestic product (GDP) year over year.^{iv} Various studies have demonstrated that individuals with serious illness (specifically, potentially life limiting illness that impact function and/or burden caregivers)^v often incur the highest per capita health care costs.^{vi} The quality of this care can be low, typically left to the patient and their caregivers to coordinate across multiple settings and provider types, and decimating their personal finances.

There are many potential models to address gaps in care for those with serious illness, especially given the complexity of serious illness itself and the frequent need to deliver and coordinate care across multiple settings and providers. This Compendium highlights a range of models that can help decision-makers identify common elements across programs that may be implemented in different service settings (e.g. home, hospital, acute).

The Compendium is intended as a menu of models that illustrate important elements that can be integrated into a care continuum based on the most pressing challenges decision-makers are facing. Readers interested in learning more about featured program models, or identifying additional models to be highlighted can contact info@thectac.org.

This compendium highlights a range of models that could help decision-makers to identify common elements across programs. It is intended as a menu of models that illustrate important elements that can be integrated into a care continuum based on the most pressing challenges decision-makers are facing.



[1] [See the C-TAC Core Principles for Care Models](#)



ADVOCATE AURORA HEALTH

Approach

CATEGORIZATION OF PROGRAMS

Building on C-TAC's and the Center to Advance Palliative Care (CAPC)'s past reports on care models,² authors have organized the Compendium around key challenges and questions decision-makers wrestle with when determining whether to invest in or scale pilot programs focused on care for people with serious illness. As described above, authors identified these challenges through conversations with key informants ranging from current health system and health plan executives to policymakers and consumers.

CHALLENGES INCLUDE

- ▶ Embedding serious illness programs within broader risk-based, population-health payment models where many populations are included
- ▶ Reaching populations with serious illness at home
- ▶ Addressing health equity through faith-based partnerships
- ▶ Meeting the needs of pediatric populations facing serious illness

[2] See the C-TAC [Serious Illness Program Design & Implementation Framework](#) and the CAPC Toolkits on [Starting a Program](#), including the [Home-based Care Guide](#).

FEATURED PROGRAMS

This publication primarily focuses on programs being driven and implemented by provider organizations, including both health care and community-based organizations. In general, authors sought to feature programs that: (1) represented a diverse array of geographic settings and organization types (2) fulfill some or all aspects of [C-TAC's Core Principles](#); and (3) have demonstrated research or evidence to indicate cost

avoidance. Some featured programs are testing an evidence-based concept (even if the individual program example has not been researched) and are noted as such. Some programs may include design elements that address multiple outlined challenges and are categorized based upon the primary or most relevant challenge that is addressed by the program.

Featured programs include the following:

CHALLENGE	PROGRAM NAME	BRIEF DESCRIPTION	ADMINISTRATOR OF PROGRAM	LOCATION
Embedding serious illness programs within broader risk-based, population-health payment models where many populations are included	Facey Medical Group of the Providence Health Care System	Home-based palliative care within accountable care organization	Multi-specialty group practice/Health System	CA
	Advocate Aurora Health	Home-based palliative care within value-based health care contracts	Health System	IL
	Sharp HealthCare Transitions Program	Family/caregiver education and ongoing monitoring within value-based health care contracts	Health System	CA
Reaching populations with serious illness at home	TigerPlace Intermediate Care Facility	Primary care within intermediate care facility	Senior Living Provider (collaborates with University)	MO
	Housecall Providers	Primary care, palliative care, and hospice at home	Coordinated Care Organization	OR
	UCSF Care at Home	Primary and palliative care at home	Health System	CA
	Alivia Care	Community hospice and palliative care	Non-Profit Organization	FL, GA
Addressing health equity through faith-based partnerships	AC Care Alliance	Faith-based initiative	Community collaborative	CA
	Louisville Community of Care	Faith-based initiative	Community collaborative	KY
Meeting the needs of pediatric populations facing serious illness	Ryan House	Pediatric respite, palliative care, and hospice services	Community-based organization	AZ
	CompassionNet	Perinatal ³ palliative care and pediatric palliative care	Home care provider and payer collaboration	NY

A NOTE ON TECHNOLOGY COMPANIES

In this Compendium, authors did not profile newer analytics and technology companies, as many of these efforts have not been formally evaluated. Additionally, the criteria and considerations for investments in analytic and technology companies may be different than those outlined in this Compendium.

A NOTE ON PAYERS

Health care payers, particularly within Medicare and Medicaid, have a wide variety of payment approaches to support holistic care for people with serious illness, that are deployed in a wide array of implementation contexts across the country. This publication provides an overview of some standardized Medicare and Medicaid payment models to address serious illness, rather than individual program profiles (see sidebar: Standardized Medicare and Medicaid Programs That Support Comprehensive Needs During Serious Illness).

[3] Refers to 20 weeks of pregnancy until a child is one month old

Standardized Medicare and Medicaid Programs That Support Comprehensive Needs During Serious Illness

The Medicare and Medicaid programs include a number of programs that are focused on individuals with significant, serious illness. These programs are implemented across the country, with many different sponsors and permutations, but still adhere to the standards put forth in legislation and regulation. Below we have highlighted a few such program examples.

MEDICARE

PACE

The Program of all Inclusive Care for the Elderly (PACE) is a Medicare/Medicaid program that covers all Medicare/Medicaid services and is available to individuals 55 and older who meet a nursing-home-level of care but are able to reside in the community with requisite supports. It is estimated that the vast majority^v of PACE participants are living with serious illness, and a number of PACE programs have taken specific steps to integrate palliative care practices and specialists into their care delivery.^{iv}

I-SNP

Institutional Special Needs Plans (I-SNPs) are a special type of Medicare Advantage Plan for Medicare Advantage eligible enrollees who require or are expected to require long term care for 90 days or longer. As part of the Medicare care model, I-SNPs provide on-site advanced practice providers (APPs) to supplement the medical care of the primary care team, and these APPs focus on managing pain and other symptoms, clarifying goals of care, educating patients and family members on what to expect and advance care planning.

Medicare Value-based Insurance Design Hospice Component

Starting in 2021, the Center for Medicare and Medicaid Innovation has been testing additional features and flexibilities

in Medicare Advantage, including a track that folds in the Part A hospice benefit into the Medicare Advantage benefits package. The participating plans must build a network of hospice providers, oversee their quality, manage referrals to hospice, ensure at least 30 days of concurrent hospice and treatment benefits (which can be an unlimited number of days beginning in 2024), and ensure access to palliative care services for those enrollees who are not eligible for hospice benefits but still require specialty palliative care.

MEDICAID

Health Homes

The Affordable Care Act created a new state plan amendment option for states to create “health home” programs for individuals with chronic illness, including serious illness. Under such programs, states can create reimbursable programs that support comprehensive care coordination for eligible individuals, including assessment, care plans, and ongoing monitoring and coordination. Health homes meet many of the palliative care needs of patients, including comprehensive needs assessment and care planning to meet those needs, and coordination of the care plan across all providers.

Community-based Palliative Care Benefit

Several states have [created community-based palliative care programs](#) within Medicaid, leveraging different Medicaid authorities.

IDENTIFICATION OF PROGRAMS

In order to identify programs for this publication, authors developed and disseminated a detailed survey that was distributed to C-TAC members in July 2022 and promoted the survey through social media channels. In addition to the survey, the C-TAC team also spoke with experts such as the National Partnership for Healthcare and Hospice Innovation (NPHI); Humana Home Solutions; the Hospice and Palliative Care Association of NY and the C-TAC advisory team to identify

additional programs. The C-TAC team reviewed a number of directories and publications from Altarum, the Center for Healthcare Strategies, the Center to Advance Palliative Care (CAPC), and the American Academy of Nursing Edge Runners. Additionally, C-TAC interviewed intended users of the Compendium, many of whom oversee organizations that serve sizable populations of individuals with serious illness.

Program Profiles

The profiles included in this publication are meant to provide a snapshot of the program, **categorized by challenge**, including a high-level overview, the program's strategy for addressing the challenge, and key implementation considerations. At the conclusion of each section, authors have noted key takeaways.

CHALLENGE

Embedding serious illness programs within broader risk-based, population-health payment models where many populations are included

Across the country, systems of care have developed value-based, population health models^{vii} that aim to provide services and supports to a wide array of individuals that improve outcomes, lower costs, and enhance the experience of care. One example are accountable care organizations (ACOs) or groups of doctors, hospitals, and/or other health care providers that collaborate to serve a defined population of individuals. These populations are often quite sizable, for example, ACOs like the Medicare Shared Savings Program (MSSP) require 5,000 attributed beneficiaries at a minimum^{viii} and some commercial ACOs encompass millions of attributed lives.^{xi}

Additionally, many integrated health systems that offer inpatient, outpatient, and specialty care serve large populations, numbering in the millions.^x Executives leading value-based population health models and at health systems have asked C-TAC about how to identify and meet the unique needs of people with serious illness without detracting from the larger programs they are managing. The programs below reflect examples where individuals designed programs focused on people with serious illness that were nested in broader population-based payment models.

FEATURED PROGRAM

Facey Medical Group of the Providence Health Care System^{xi}

ORGANIZATIONAL TYPE:	Multi-specialty group practice within a large national healthcare system
SERIOUS ILLNESS FOCUS:⁴	Palliative care
GEOGRAPHY:	Southern California
DESCRIPTION:	Facey Medical Group (FMG) leads an Accountable Care Organization (ACO) that maintains value-based contracts with commercial payers. The President of Facey Medical Group recognized that a consistent group of their seriously ill patients were repeatedly hospitalized and worked with their health system's palliative care team to create a home-based program to avoid crises.

1. HOW DID THE PROGRAM GET STARTED?

Leaders operating the ACO were thoughtful in using available data to identify opportunities for quality and cost improvement. They noticed that there was a consistent population who experienced repeated hospital admissions and ED visits, which the care managers were not able to prevent – that “something was missing after they left the hospital.” The President of FMG in particular believed that by adding the extra layer of support through a palliative care team, these patients could be better managed.

They began this effort with an outside vendor, who was unable to achieve the desired cost and quality results. Rather than terminate the program, Facey turned to their internal colleagues, who at that time had launched a grant-funded home-based palliative care program. The Facey leaders and the palliative care leaders worked together to create a pilot to serve Facey patients. This pilot was quite successful, which led to continued efforts to identify appropriate patients for home-based palliative care services. They currently refer about 40 patients each month to the program.

2. HOW IS THE PROGRAM MAINTAINED WITHIN THE LARGER INITIATIVE AND DID LEADERS DECIDE TO HIRE DIRECTLY OR COLLABORATE TO DEVELOP CAPACITY?

The home-based palliative care program is sustained through a financial arrangement with Facey Medical Group, which reviews the program's performance each year and decides

to continue the arrangement. Interestingly, the original champion left soon after the relationship was established, but because of those continuing solid outcomes, the home-based program remains within the risk-based contract's operations.

As leadership continues to change, the question of maintaining the relationship continues to be raised. Not only are the quality and cost outcomes a key reason that the program is sustained, but also because of the program's moral value and alignment with the Providence mission and ministry, it is recognized as “the right thing to do” for high-need patients.

As noted, the internal relationship was not the first choice of FMG, but they found that their palliative care colleagues were able to deliver high-quality, impactful care better than a vendor solution. Nonetheless, in other parts of the Providence system, interest in outside vendor relationships continues, and the home-based program must continue to prove its value.

3. WHO IS SERVED BY THE PROGRAM AND HOW ARE THEY IDENTIFIED?

Facey Medical Group has put effort into proactively identifying the patients that would benefit from home-based palliative care services. The current criteria is one hospital admission and at least three of a selected list of co-morbidities. They have noticed that heart failure patients are especially at risk for repeated hospitalizations.

[4] Throughout, authors have aligned the described serious illness focus with the care model taxonomy described in the C-TAC publication [Toward a Serious Illness Program Design & Implementation Framework](#)

Once a patient is referred, the home-based program then risk stratifies their patients, across three levels, and varies the visit frequency based on the patients' needs.

4. HOW IS THE PROGRAM STAFFED?

The program operates with a full interdisciplinary team, comprising physicians, advance practice providers, registered nurses, social workers, and chaplains. The individual encounters are based on each patient's care plan and their risk level. As this program expanded, it found efficiencies and was able to achieve results with higher staff to patient ratios.

5. HOW IS THE PROGRAM PAID FOR?

The program is paid through a contract with the Facey Medical Group, who uses the funds from their risk-based contract to support this effort.

6. ARE THERE ANY KEY ENABLING POLICY DECISIONS/CONSIDERATIONS THAT HAVE SUPPORTED THE PROGRAM?

This particular program relies on private contracts, so federal and state policy impacts are minimal. The initial program was funded in 2014 by a grant from the UniHealth Foundation.

7. WHAT ARE KEY PROGRAM IMPACTS?

Facey reviews the program's financial outcomes each year, using a pre/post methodology. The net savings, after the cost of supporting the program, totaled more than \$19,000 per patient per year. There was a 64% reduction in bed days in 2021, and past years have seen reductions of more than 80 percent.

8. FOR MORE INFORMATION:

- ➔ [Serious Illness Approaches by ACOs: Facey Medical Group](#)

FEATURED PROGRAM

Advocate Aurora Health^{xii}

ORGANIZATIONAL TYPE:	Integrated health care system, with large medical groups, hospitals, continuing health division and other services, operating under a total cost of care contract with Medicare Advantage plans
SERIOUS ILLNESS FOCUS:	Home-based primary and palliative care
GEOGRAPHY:	Chicago, Illinois
DESCRIPTION:	Advocate Aurora Health (AAH) assumed responsibility for total cost of care under an ACO and multiple contracts with Medicare Advantage plans. Recognizing that a care management approach alone to manage complex patients was insufficient, AAH built out its home-based palliative care program, later combining it with its home-based primary care program, to meet those needs and prevent avoidable crises.

1. HOW DID THE PROGRAM GET STARTED?

AAH implemented a home-based palliative care program, which began in 2012, as part of its Continuing Health/Post-Acute Division, to assist in managing total cost of care for their ACO and full-risk contracts. With the implementation of the total cost of care contracts, AAH started a complex care management initiative. However, they soon realized that

the care management approach was not making enough of a difference for their most frail and complex patients, and a more supportive approach was needed. They investigated solutions and identified home-based palliative care as an optimal approach. In 2015, they also implemented a visiting physician program for patients who were totally homebound and unable to travel to a primary care office.

In 2021, in the wake of the COVID-19, the home-based palliative care program was merged with the home-based primary care program, meeting the needs of homebound patients exactly where they are.

2. HOW IS THE PROGRAM MAINTAINED WITHIN THE LARGER INITIATIVE AND DID LEADERS DECIDE TO HIRE DIRECTLY OR COLLABORATE TO DEVELOP CAPACITY?

Like most home-based care programs, this program is sustained on the strength of its outcomes. In AAH's case, they run the data every month and share it widely. This includes not only utilization and cost metrics, but also quality metrics, such as high rates of hospice referral, longer hospice length-of-stay, and the closure of the specific gaps in care that drive Star ratings. It's difficult to object to actual data that shows the "double whammy" of higher quality at lower cost.

That said, program costs are scrutinized, and the program is asked to do more within their existing staffing and budget. To expand without compromising their impact, the AAH program has implemented virtual monitoring for their high-risk patients and added virtual visits.

3. WHO IS SERVED BY THE PROGRAM AND HOW ARE THEY IDENTIFIED?

The program largely gets referrals from the physicians and the ambulatory care managers. The care managers often use the Epic risk score to identify patients, but also flag a patient when any of the care team recognizes that they need "something even more intense." Occasionally, Community Health Workers in AAH's other programs identify patients who can benefit from the program and make referrals.

The program maintains its own intake staff, who make sure that the patient's insurance is one that is under a risk contract, and that the patient understands what the program provides so they can make an informed choice.

4. HOW IS THE PROGRAM STAFFED?

The program comprises 21 nurse practitioners, 11 registered nurses, and 7 social workers, overseen by two Medical Directors. They contract with companies for in-home diagnostics (labs, radiology, urine toxicology screening, and EKGs) and they pull in spiritual care from the community, or from AAH's hospice, as needed.

The program is part of the Continuing Health Division and coordinates with the Division's eleven other programs, such as AAH's skilled home health program, home infusion, hospice

etc., integrating the care and communicating regularly, so that all needs are covered across the programs.

5. HOW IS THE PROGRAM PAID FOR?

Home medical visits are billed to insurance directly, but the deficit is covered by the system since the ROI is met with the reduction in utilization and total cost of care.

6. ARE THERE ANY KEY ENABLING POLICY DECISIONS/CONSIDERATIONS THAT HAVE SUPPORTED THE PROGRAM?

The ACO and private contracts with Medicare Advantage enable the program. Other flexibilities, such as waiver of the three-day requirement for skilled nursing admissions and video visits, have been of benefit to the program and their patients. Even so, new state policies regarding pre-screening of all skilled nursing admissions by a single vendor has led to time delays.

7. WHAT ARE KEY PROGRAM IMPACTS?

The AAH home-based program has reduced the total cost of care for its patients by 35%, based on pre/post analyses, which, as noted, are calculated monthly. In addition, the program has a strong positive impact on the system's physicians, who were overburdened by the volume of calls and issues for their high-need patients before the referral is made.

8. FOR MORE INFORMATION:

→ [How a Full-Risk Payment Model Powers an Illinois Home-based Palliative Care Program](#)

Sharp HealthCare Transitions Program^{xiii}

ORGANIZATIONAL TYPE:	Integrated health care system with large medical groups, hospitals, and hospice care, as well as risk-bearing financial arrangements through their own Medicare Advantage plan and other risk-based contracts.
SERIOUS ILLNESS FOCUS:	Patient and family-education focused intervention
GEOGRAPHY:	Southern California
DESCRIPTION:	Leaders in Sharp's Medical Group realized that the historic and reactive acute care model of disease management was permitting unnecessary hospitalizations. Outpatient physicians could identify who were more likely to be admitted to the hospital than to make their next ambulatory appointment. Within a Medicare Advantage contract, the Hospice and Palliative Care leader created an intervention, focusing heavily on patient and family education and anticipatory guidance, through an intensive phase of 6-8 weeks, and then a long-term "maintenance" phase of ongoing monitoring. This intervention, the Transitions Program, cut hospitalizations for these patients by more than half, and also cut length-of-stay by half for those that were admitted.

1. HOW DID THE PROGRAM GET STARTED?

Daniel Hoefler, MD, a leader in the Sharp Rees-Steely Medical Group, was quick to recognize a gap in the care of some of their older patients. Their physicians knew that these patients would wind up in the hospital, but they just didn't have anything to provide, there was no ongoing skilled need, no rehabilitation need, and they were not ready for hospice. Because of this gap, these patients would wind up in the hospital, simply because there was no other option for support. With the incentives and flexibilities created under the Medicare Advantage contract, Dr. Hoefler and his colleague Suzi Johnson developed the Transitions Program to fill this gap, focusing originally on those with heart failure, but now taking a wider range of patients. The purpose was to stop the revolving door of hospitalization. By preventing primary admissions, the concept of preventing readmissions has no meaning.

2. HOW IS THE PROGRAM MAINTAINED WITHIN THE LARGER INITIATIVE AND DID LEADERS DECIDE TO HIRE DIRECTLY OR COLLABORATE TO DEVELOP CAPACITY?

The home-based palliative care program is sustained through a financial arrangement with Facey Medical Group, which reviews the program's performance each year and decides to continue the arrangement. Interestingly, the original champion left soon after the relationship was established, but because

of those continuing solid outcomes, the home-based program remains within the risk-based contract's operations.

As leadership continues to change, the question of maintaining the relationship continues to be raised. Not only are the quality and cost outcomes a key reason that the program is sustained, but also because of the program's moral value and alignment with the Providence mission and ministry, it is recognized as "the right thing to do" for high-need patients.

As noted, the internal relationship was not the first choice of FMG, but they found that their palliative care colleagues were able to deliver high-quality, impactful care better than a vendor solution. Nonetheless, in other parts of the Providence system, interest in outside vendor relationships continues, and the home-based program must continue to prove its value.

3. WHO IS SERVED BY THE PROGRAM AND HOW ARE THEY IDENTIFIED?

The Transitions Program gets referrals from physicians, primarily PCPs, within the Medical Group. There are no triggers or algorithms. Instead, physicians are asked to identify who they believe are most likely going to be using the hospital to manage their care needs. Physicians are quite capable of recognizing who is at-risk and needs this program; one short-cut is if a patient is eligible for a Physicians Orders for Life-Sustaining Treatment (POLST) according to national guidelines, then they would be eligible for the Transitions Program.

The Transitions Program served as the model when implementation of California SB-1004^{xiv} began and developed more formal eligibility criteria from the Transitions Program experiences.

4. HOW IS THE PROGRAM STAFFED?

The Transitions Program is largely staffed by nurses and social workers, with a physician who oversees the staff and a chaplain who provides additional support; a palliative care pharmacist had been on the team in the past, and a palliative nurse practitioner will be added soon.

The nurse is responsible for educating the patient and family on what to expect as their illness progresses, and what to do when symptoms arise. Transitions also uses Hospital Avoidance (HA) kits for heart failure, COPD and dementia. For example, a COPD patient will have a nebulizer, oxygen, steroids and antibiotics on hand at all times; this “Home ER” is started at the very first signs of decompensation, whether at 2:00 am or any holiday, thus potentially avoiding a hospitalization. A Green/Yellow/Red card guides patients and caregivers when to start the HA kit and call the 24-hour nurse hotline. Used appropriately, and in combination with continued care from their primary provider, patients are able to address their chronic illness without avoidable inpatient care.

5. HOW IS THE PROGRAM PAID FOR?

The program is supported by the Sharp Health System. In return, the system sees the value through prevention of primary admissions, avoided re-admissions, shortened length-of-stay, as well as in significant gains in patient and family satisfaction. Performance under risk-based contracts has also been quite favorable.

6. ARE THERE ANY KEY ENABLING POLICY DECISIONS/CONSIDERATIONS THAT HAVE SUPPORTED THE PROGRAM?

The existence of the Medicare Advantage (MA) contract gave Sharp the right “sandbox” to try something different with their advanced elderly patients. Later the Pioneer Accountable Care Organization (ACO) and the creation of their own MA plan expanded that sandbox. Without such value-based mechanisms, there would be no financial ability to support and monitor high needs patients. Once post-acute care ends, they would be left to their own devices, with no source of information and no support, thus defaulting to their previous care standards, which contributed to readmissions.

Over the course of the last 15 years since the Transitions Program was developed, the Sharp system has developed other home-based care programs, but these lack a palliative approach, and usually mandate that the patient be home-bound.

7. WHAT ARE KEY PROGRAM IMPACTS?

The Transitions Program had their cost savings results published in 2016 (citation below), saving more than \$14,000 per patient in the month prior to death, and just under \$25,000 per patient while on the program compared to usual care. These savings come from reducing hospitalizations by more than 50%, and for those who were admitted, a significant reduction in length of stay and readmission rates plummeting to one-third compared to usual care. An updated study and publication are now underway.

8. FOR MORE INFORMATION:

- [Effect of a Home-Based Palliative Care Program on Healthcare Use and Costs](#)
- [Center to Advance Palliative Care Case Study: Sharp Healthcare](#)

KEY TAKEAWAYS

Embedding serious illness programs within broader risk-based, population-health payment models where many populations are included

- When building a targeted program to serve individuals with serious illness within overall population risk-taking, **it is important to cultivate champions at multiple levels of leadership and to develop a persuasive, data-driven elevator pitch for the program**, recognizing that leadership will likely evolve over time
- **Recognize and model for the fact that existing billable programs** (such as certified home health care or physician

visits) **can be leveraged to fund components of initiatives focused on people with serious illnesses**

- **Develop clear internal referral mechanisms** that detail how care managers or other staff can refer to the program to serve individuals with serious illness, so that resources can be targeted to those where the impact can be greatest. Similarly, maintain clear step-down or discharge criteria so that the program can maintain availability for new patients

Reaching populations with serious illness at home

Most people with limitations in their activities of daily living must also manage multiple chronic conditions.^{xvi} One study of homebound adults in the United States found that completely homebound individuals had nearly double the number of chronic illness as non-homebound individuals and were dramatically more likely to have been hospitalized in the last 12 months (52.1% compared to 16.2%)^{xvii} than non-homebound individuals. Related, a meta-analysis of transportation barriers to care and impacts on health noted that patients who face the highest disease burdens face greater barriers to transportation than other populations.^{xviii} The COVID-19 pandemic presumably exacerbated these difficulties; preliminary data analysis showed that in 2020, the proportion of community-dwelling

homebound adults aged 70 years or older substantially increased, particularly among Black non-Hispanic and Hispanic/Latino individuals.^{xix}

In light of these dynamics, several programs have developed to provide supportive care in order to meet and serve individuals more effectively. The programs described in this section will provide details on how such individuals are identified and what type of care is provided in the home. While the prior section also discussed several programs that provide home-based medical care, the programs featured in this section will highlight a wider range of home-based care delivery, exploring how care is delivered optimally in this non-traditional clinical setting.

FEATURED PROGRAM

TigerPlace^{xx}

ORGANIZATIONAL TYPE:	Intermediate care facility, with longstanding partnership with the University of Missouri-Columbia Sinclair School of Nursing
SERIOUS ILLNESS FOCUS:	All; anyone with a serious illness who is able to remain at home is served at TigerPlace
GEOGRAPHY:	Columbia, Missouri
DESCRIPTION:	TigerPlace is an aging in place community that is currently being operated through a collaboration between Americare and the University of Missouri-Columbia Sinclair School of Nursing.

1. HOW DID THE PROGRAM GET STARTED?

In 1996, nursing faculty and administrators from the University of Missouri-Columbia convened to design strategies to implement long term services and supports that were cost-effective. Ultimately, the state passed two pieces of legislation to establish TigerPlace^{xxi} and enable residents to live in an apartment-like setting with services offered within the setting. In this model, the TigerPlace apartment is the resident's home.

2. HOW DO YOU DETERMINE WHETHER CARE IS OPTIMALLY DELIVERED AT HOME?

Individuals who are considering moving into TigerPlace are comprehensively assessed before entering the program.

Staff from the Sinclair School of Nursing report that they often begin conversations with community members who do not necessarily need services imminently but may require services at a future date. Prior to entry, individuals are assessed clinically and for other types of needs, including social supports such as nutrition, housing needs, and transportation. All residents are encouraged to participate in advanced care planning at the outset and at least once a year thereafter. A menu of care services is available to be added or removed as needed for residents' increasing healthcare needs or temporary recovery services. This allows residents to age in the place of their choosing with advancing services if and when needed. When individuals are contending with illness that are no longer addressable by medical support

available at TigerPlace, program staff will collaborate with external palliative care and hospice partners to determine an appropriate course of action.

3. ARE THERE ANY EXTRA STEPS YOU TAKE WITH YOUR WORKFORCE TO ENSURE OPTIMAL CARE DELIVERY IN-HOME?

In addition to a robust set of clinically experienced staff at multiple levels (detailed further below), TigerPlace has also leveraged technology to ensure optimal care delivery at home. Sensors are embedded throughout the environment to provide an early warning system that prompts clinical staff to proactively identify and assess residents if care needs have changed. Sensors include motion sensors, bed sensors, stove temperature sensors, and gait/fall detection sensors.^{xxii} The sensors have been installed to minimize visibility and staff have been trained on how to interpret and act upon information from these sensors.

4. WHO IS SERVED BY THE PROGRAM AND HOW ARE THEY IDENTIFIED?

TigerPlace is open to any eligible seniors, pending availability; the program is self-pay which impacts who can enroll. Individuals can use long term care insurance for their room and their own funds for other supports. The program markets to eligible individuals in the surrounding area.

5. HOW IS THE PROGRAM STAFFED?

TigerPlace clinical supports include a mix of registered nurses (RNs), licensed practical nurses (LPNs), nursing aides/students from the University, medication technicians, a social worker and physical therapists to serve the 66 residents who reside at TigerPlace. At any given time, there tend to be three nursing aides to provide scheduled care and to respond to individual residents who do not have scheduled care. In the evening, there are two aides for the entire facility and two overnight as well. Because of the partnership with the University, there is a lot of teaching and refining of the model that guides how care is delivered by staff. Staff also receive regular trainings related to serious illness on topics such as advanced care planning, dementia care, palliative care, and hospice.

6. HOW IS THE PROGRAM PAID FOR?

At present, the program is primarily supported through self-pay. In the mid-1990s, researchers who founded the program conducted a study to evaluate whether Medicare and/or Medicaid could support an aging in place model of care for individuals living in low-income housing. Unfortunately, the

study showed at that time that there was not a viable fiscal structure to sustain the model ongoing. The facility does try to make use of individuals' long-term care insurance and health insurance for applicable services when appropriate. Stakeholders involved in the program have also begun to have conversations with stakeholders from Missouri state government agencies to consider other strategies for financial sustainability and access for broader populations.

7. ARE THERE ANY KEY ENABLING POLICY DECISIONS/CONSIDERATIONS THAT HAVE SUPPORTED THE PROGRAM?

The initial legislation that established the program was key to its success. As it relates to challenges, stakeholders flagged that in Missouri, there is not full practice authority for advanced practice registered nurses (APRNs). Under typical models, nurses must contact a physician first before issuing a medical order, which can delay the ability to activate needed treatment. Other research conducted in Missouri (separate from TigerPlace) found that in models where APRNs have a full scope of practice, they can implement orders in real time, thereby reducing time delays and the potential for miscommunication. Stakeholders flagged a need for this type of flexibility in order to supplement the workforce in general, noting declining numbers of geriatricians nationally.^{xxiii} A study of 16 nursing homes in Missouri found that APRNs that were brought into 16 nursing homes, reduced avoidable hospitalizations and improved the quality of care for residents.^{xxiv}

8. WHAT ARE KEY PROGRAM IMPACTS?

TigerPlace has been extensively evaluated over the years given the partnership with the University. One comprehensive analysis of the TigerPlace program and its aging in place model over a multi-year period (2011-2019) found several notable outcomes: TigerPlace residents were able to maintain a longer length of stay in the community at a higher level of function. Additionally, residents demonstrated improved outcomes in cognition, depression, activities of daily living, and incontinence compared to a similar population that was not residing at TigerPlace.^{xxvi}

9. FOR MORE INFORMATION:

- ➔ [University of Missouri Sinclair School of Nursing TigerPlace](#)
- ➔ [TigerPlace, A State-Academic-Private Project to Revolutionize Traditional Long-Term Care](#)

Housecall Providers^{xxvii}

ORGANIZATIONAL TYPE:	A home-based medical practice, owned by CareOregon
SERIOUS ILLNESS FOCUS:	Primary care, palliative care, and hospice care
GEOGRAPHY:	Portland, Oregon
DESCRIPTION:	Housecall Providers offers primary care, community-based palliative care, and hospice care to individuals residing in Oregon. The program works closely with the community to identify highly at-risk adults who can benefit from the services offered by the program. The program focuses on four unique populations: the homebound elderly; people with physical and developmental disabilities; people with complex medical, behavioral health and other health-related social needs; and people facing the end of life.

1. HOW DID THE PROGRAM GET STARTED?

Housecall Providers was started by Dr. Benneth Husted in 1992 as a home-based primary care practice to provide medical care to home-bound individuals. The model built upon Dr. Husted's early experiences with her father, who was an osteopathic physician who visited frail elderly individuals at home when they could no longer attend office visits. Dr. Husted saw the need for this type of model at scale in Portland, Oregon and rapidly built the program to serve 100 patients. In 2009, the program added hospice services. In 2017, the Housecall Providers became a part of CareOregon, a non-profit healthcare organization that largely serves Medicaid populations in the state. Through this partnership, Housecall Providers integrated the CareOregon community-based palliative care program into their service offerings.

2. HOW DO YOU DETERMINE WHETHER CARE IS OPTIMALLY DELIVERED AT HOME?

Housecall Providers has a very strong referral network to proactively identify individuals who would be well suited for its service offerings. Referral partnerships often come from the "home" setting, thereby ensuring that individuals are best suited to be served in that setting; for example, Housecall Providers receives a large number of referrals from adult care home programs in Portland and 60% of the people it serves reside in some form of congregate care setting, such as assisted living, memory care, senior living, or adult care homes. The program also maintains relationships with specialists, such as oncology services, so that these providers can refer individuals who may be facing housing or other health-related social need challenges to the Housecall Providers program to provide wraparound services.^{xxviii}

3. ARE THERE ANY EXTRA STEPS YOU TAKE WITH YOUR WORKFORCE TO ENSURE OPTIMAL CARE DELIVERY AT HOME?

The Housecall Providers programs use an interdisciplinary team in order to share workload and reduce the burnout that can be experienced from serving highly medically and socially complex individuals. The program also uses outreach specialists, with specific responsibility for coordinating housing, transportation, and food related services, which are often critical for individuals being able to remain at home while receiving treatment. The program has also leveraged technology to assist with the home-based model; they use a technology that integrates GIS mapping and schedule functionalities to logistically support place-based supports. The team uses telemedicine capacities when meeting in person is not possible and offers remote patient monitoring technology for some patients.^{xxix}

4. WHO IS SERVED BY THE PROGRAM AND HOW ARE THEY IDENTIFIED?

The target population for Housecall Providers is four highly at-risk adult populations: the homebound elderly; people with physical and developmental disabilities; people with complex medical, behavioral health and social determinant challenges; and people at the end of life. Housecall Providers works closely with community-based organizations serving at-risk populations to identify individuals who could benefit from engagement with Housecall Providers. Additional patients are identified from referrals through primary and specialty care providers for community-based palliative care and hospice services.

In 2022, Housecall providers served 1,585 primary care patients, 276 individuals with its Advanced Illness Care Program, and 534 Hospice patients. The primary care population has a median age of 80, while the advanced illness care program serves individuals with an average age of forty-five.

5. HOW IS THE PROGRAM STAFFED?

Each service line within Housecall Providers entails a unique staffing model designed to support the patient population. The primary care program utilizes a provider-led, team-based model with nursing, care coordination, social work and spiritual care represented within a single team. Additional needed health services, such as radiology and lab services can be arranged with community providers. The community-based palliative care program is staffed by a team of nurses and social workers, who work in tandem teams to support a caseload of patients. A social health and housing specialist supports the health-related social needs of patients. Additional supports are provided by an outreach specialist and intake coordinator. The hospice program is staffed by Board-Certified Hospice and Palliative Medicine Physicians, registered nurses, social workers, spiritual care supports, hospice aides, massage therapists, music thanatology professionals, and volunteers. All three service lines also have a dedicated clinical manager and supervisors. Staff receive training specific to pain and symptom management, communication in the context of serious illness, as well as additional training on Motivational Interviewing and Trauma Informed Care.

6. HOW IS THE PROGRAM PAID FOR?

Housecall Providers accepts Medicare, Medicaid, and commercial insurances to support the care provided. The program is also included in several value-based contracts.

7. ARE THERE ANY KEY ENABLING POLICY DECISIONS/CONSIDERATIONS THAT HAVE SUPPORTED THE PROGRAM?

In 2012, Housecall Providers was invited by Senator Ron Wyden to participate in a CMS Demonstration Project called Independence at Home (IAH). This project was designed to test the effectiveness of delivering comprehensive primary care services at home and whether doing so improves care. This policy initiative, which involved other participants across the country, formally evaluated the program and in so doing, reinforced the tremendous cost savings and positive outcomes associated with the program (noted below), that have helped with its ongoing sustainability. In 2021 Housecall Providers became a participant in the CMS ACO REACH payment demonstration program^{xxx} which will continue for

at least five performance years. More recently, Oregon has received approval for an 1115 waiver that will involve additional funding for health-related social needs, which will likely align with many of the services that Housecall Providers seeks to offer and coordinate. Lastly, in 2021 the Oregon Legislature approved HB 2981^{xxxi} which requires Medicaid Coordinated Care Organizations^{xxxii} to develop and make accessible to Medicaid beneficiaries palliative care services.

8. WHAT ARE KEY PROGRAM IMPACTS?

In both 2015 and 2016, Housecall Providers was first in the nation for cost-savings realized through the Independence at Home demonstration project; in 2015, the program posted a \$25 million savings to the federal Medicare program and a 32% savings over a control group.^{xxxiii} In addition to cost savings, Housecall Providers measures patient satisfaction and quality measures across service lines, with examples including preventive services in primary care, individualized care plans in community-based palliative care, and visits within the last days of life for hospice care.

9. FOR MORE INFORMATION:

- [Results of the National Medicare Study, Independence at Home, Validate Housecall Providers' Service Model](#)
- [Who Will Care for Society's Forgotten?](#)
- [House Calls Could Provide a Remedy for Soaring Health Care Costs](#)

FEATURED PROGRAM

University of California San Francisco (UCSF) Care at Home^{xxxiv}

ORGANIZATIONAL TYPE: Health System

SERIOUS ILLNESS FOCUS: Home-based primary care and palliative care

GEOGRAPHY: San Francisco, California

DESCRIPTION: The UCSF Care at Home Program provides primary care and longitudinal palliative care within private homes and assisted living settings to older adults in the San Francisco Bay Area.

1. HOW DID THE PROGRAM GET STARTED?

The UCSF Care at Home Program began in 1999 and was funded through a philanthropic donation to teach medical students about home health care. Through this process, it became apparent that there was little follow up after home visits and patients often did not have access to ongoing primary care. The donor then made a second donation to expand the program to provide ongoing care to home-bound individuals. Currently, the program is part of the Office of Population Health and Accountable Care within the UCSF system.

2. HOW DO YOU DETERMINE WHETHER CARE IS OPTIMALLY DELIVERED AT HOME?

The patients served by the UCSF Care at Home program are home-limited due to physical, psychiatric, or cognitive disability. By providing in-home care, both in private homes and at assisted living facilities, the UCSF Care at Home program facilitates access to care for a population that has difficulty accessing services in traditional settings. The Care at Home Program provides both an initial home visit to assess patient need, as well as ongoing primary care through home visits.

3. ARE THERE ANY EXTRA STEPS YOU TAKE WITH YOUR WORKFORCE TO ENSURE OPTIMAL CARE DELIVERY AT HOME?

Before care is initiated, UCSF Care at Home staff conduct an initial telephone call with prospective patients in order to provide background on the program and answer any questions before entering their home. Staff then conduct an initial home visit that entails a comprehensive medical assessment as well as an evaluation of the home environment, such as home safety, cleanliness, durable medical equipment functionality, and social supports in the home or nearby. These considerations become a part of the person's ongoing care plan and team

members will facilitate connections to community resources as needed to address environmental issues impeding care.

4. WHO IS SERVED BY THE PROGRAM AND HOW ARE THEY IDENTIFIED?

The target population for the UCSF Care at Home program is home-limited adults, primarily over 65, in the San Francisco Bay Area. The approximately 400 patients served by the program are the medically complex and frail. Individuals are referred to the Care at Home Program through hospital and primary and specialty care settings in the community, as well as through community-based organizations.

5. HOW IS THE PROGRAM STAFFED?

The UCSF Care at Home Program consists of two interdisciplinary teams made up of medical providers (Physicians and Nurse Practitioners), Registered Nurses and Social Workers. These teams are supported by administrative and operational support teams and overseen by a Medical Director. Many of the medical providers on the UCSF Care at Home team have board-certification in both palliative care and geriatrics. Training on home care medicine is provided to all staff and formal workflows guide the operations of the program.

6. HOW IS THE PROGRAM PAID FOR?

As described above, the UCSF Care at Home Program was founded through a philanthropic donation. Philanthropy continues to serve as a source of funding, though the UCSF Care at Home program accepts Medicare, Medicaid and supplemental insurance coverage. Additionally, UCSF Health supports program operations, including salaries of operations and clinical staff.

7. ARE THERE ANY KEY ENABLING POLICY DECISIONS/CONSIDERATIONS THAT HAVE SUPPORTED THE PROGRAM?

None identified.

8. WHAT ARE KEY PROGRAM IMPACTS?

The UCSF Care at Home program reviews a number of indicators to determine their impact, including hospitalizations, the use of hospice care, the completion of advanced directives and if patients passed away in their place of choice. Notably, in 2018, UCSF Health data, reviewed by program leaders, showed

that patients utilizing the UCSF Care at Home program had approximately 70% fewer inpatient admissions, 65% fewer ED visits and nearly 70% less observation stays than those patients who were not utilizing the Care at Home Program. According to program operations, additional data review showed a 30% decrease in hospitalizations, including inpatient and Emergency Department utilization when comparing the six months prior to program enrollment to the six months after program enrollment.

9. FOR MORE INFORMATION:

→ [Providing Primary Care to Homebound Patients: UCSF Health's Care at Home Program \(Case Study\)](#)

FEATURED PROGRAM

Alivia Care, Inc.

ORGANIZATIONAL TYPE: Non-profit organization

SERIOUS ILLNESS FOCUS: Hospice and palliative care

GEOGRAPHY: Florida and Georgia

DESCRIPTION: Alivia Care Inc. is a community-based hospice and palliative care organization serving North Florida and Southern Georgia. The organization operates a hospice program, community-based palliative care services, pediatric palliative care, hospital-based palliative care consults, a Program of All Inclusive Care for the Elderly (PACE) program, and a home health organization. Alivia Care participates in a number of value-based payment initiatives, including the ACO REACH program run through the CMS Innovation Center.

1. HOW DID THE PROGRAM GET STARTED?

Alivia Care, formerly known as Community Hospice & Palliative Care, began in 1979 as a community-based Medicare hospice program. Senior leaders flagged several areas of challenge and potential opportunity over the years, including a desire to serve patients beyond the hospice length of stay, to reach people in more rural communities, and to serve individuals enrolled in Medicaid. Over the years, leaders would seek out opportunities to test out program expansions, including participating in the [CMS Medicare Care Choices Demonstration](#). In the late 2010s, the board and leaders of Community Hospice & Palliative Care began a strategic planning process that culminated in the formation of Alivia Care Inc. in 2020. The strategic intent of Alivia Care, Inc. was to support additional programs and services across the continuum of serious illness care, including but not limited to hospice care. Alivia Care currently operates in 35 counties across Florida and Georgia and saw 18,000 Medicare hospice patients in 2022.

2. HOW DO YOU DETERMINE WHETHER CARE IS OPTIMALLY DELIVERED AT HOME?

Alivia Care starts with the premise that most people prefer to receive care at home and almost 96% of Alivia Care patients are cared for in their homes. Their PACE program, which provides adult day health services in the community as an alternative to a nursing home level of care, is one programmatic strategy the organization uses to help people remain in the community. Alivia Care also developed several specialized inpatient units in the event that someone residing at home requires a brief inpatient level of care; this is offered as an alternative to hospitalization. The team works closely to determine and continuously update the array of interventions that can be delivered in the specialized unit vs the hospital.

3. ARE THERE ANY EXTRA STEPS YOU TAKE WITH YOUR WORKFORCE TO ENSURE OPTIMAL CARE DELIVERY AT HOME?

Alivia Care pairs technology and people-oriented strategies to deliver care at home. In addition to standard assessments of homes for fall risks (as one example), Alivia Care offers a technology-enabled intervention to allow hospice patients to express whether they are having a good or bad day at home so that the team can intervene proactively if needed and will expand its use to other lines of services in 2024. The organization has also sought to create on-demand resources so that people can stay in their homes even during an urgent moment of need. Several years ago, they discovered that it was easier for patients to directly contact their nurses at 2 a.m. rather than 2 p.m. when nurses would be seeing other patients. In response, they created a virtual care navigation center where individuals can immediately access a nurse any time of day for emergency situations. There are workflows such that if individual or their families call a certain number of times, it will activate an in-person visit to their home.

Because of the distributed nature of working in homes, Alivia Care has also refined its staff to patient ratios to reflect the realities of travel time. Staff are dedicated by geography and in more rural areas, staff have smaller caseloads to account for the extended travel time.

4. WHO IS SERVED BY THE PROGRAM AND HOW ARE THEY IDENTIFIED?

Alivia Care has invested in representatives to communicate with local partners like hospitals to share information about the array of service offerings at Alivia Care. In the course of this work, they identified that many local providers needed education on the nature of serious illness care work, including what hospice entails, or weren't necessarily sure which Alivia Care program would be most appropriate for their patients (e.g. PACE or palliative care or hospice). Alivia Care now offers referral partners the opportunity to send their patients directly to Alivia Care's virtual navigation center. Representatives of the center assess individuals and recommend the right service option. This partnership takes some of the burden off of referral partners to be familiar with the intricacies of all serious illness care options.

5. HOW IS THE PROGRAM STAFFED?

Alivia Care employs different staffing models for its various business units. The care navigation center helps liaise and coordinate across those units. Within

the navigation center, there is a Patient Access Support unit, which is staffed with non-clinicians who can provide an overview or informational session to prospective patients and may initially triage incoming calls among current patients. Depending on needs, a Medical Assistant or Licensed Practical Nurse (LPN) can provide initial care navigation. For higher acuity needs, an individual will be escalated to a registered nurse (RN), one of whom is always on-call at the navigation center. For the palliative care programs, both the community-based services and inpatient care, Alivia Care relies upon nurse practitioners, with social workers also augmenting care in the community. The hospice program also brings in physician leaders, with specific expertise in palliative care.

6. HOW IS THE PROGRAM PAID FOR?

Alivia Care reports that most of the palliative care work currently remains fee-for-service (FFS). Alivia Care also holds a number of value-based care contracts to support its services and recently joined the ACO REACH program to bring value-based payment design to serve Medicare FFS beneficiaries. Of the pediatric programs provided by Alivia Care (care management, palliative care and hospice, only the pediatric hospice care program is presently insurance reimbursable. The care management and palliative care programs are funded as a community benefit which is supported through fundraising and operating dollars.

7. ARE THERE ANY KEY ENABLING POLICY DECISIONS/CONSIDERATIONS THAT HAVE SUPPORTED THE PROGRAM?

Alivia Care has sought to participate in various CMS Innovation Center demonstrations testing new forms of reimbursement. A challenge is that many of these demonstrations require extensive reporting or upfront investments to sustain operations. The organization is hopeful about potential expansions of the PACE program like the Elizabeth Dole Home Care Act of 2023, which would enable the Veteran's Administration to use PACE programs.

8. WHAT ARE KEY PROGRAM IMPACTS?

As described above, Alivia Care participated in the CMS demonstration of the Medicare Care Choices

Model (MCCM). This demonstration allowed Medicare beneficiaries to receive supported care services from selected hospice providers, while continuing to receive services provided by other Medicare providers resulted in improved outcomes. Beneficiaries were 29% more likely to enroll in the Medicare hospice benefits and 26% less likely to be admitted to the hospital. These changes resulted

in a 14% reduction of Medicare expenditures from the date of MCCM enrollment through death. Additionally, MCCM improved quality of end-of-life care received, as beneficiaries were 26% less likely to receive aggressive life-prolonging treatment in the last 30 days of life and spent an additional six days at home in the period between MCCM enrollment and death.^{xxxv}

KEY TAKEAWAYS

Reaching populations with serious illness at home

- **Strong relationships with community-based organizations and health care providers** are critical to proactively identify populations in need of home-based care, ideally prior to an urgent moment of need
- Home can have many different meanings, from assisted living to nursing homes, to shelters; because these “homes” are structured differently, it may be useful to differentiate service lines and staffing compositions to respond to the home-based service setting (e.g. care for unstably housed individuals living with serious illness should ideally include supports to identify longer-term housing supports, which may not be necessary for assisted living residents)
- In such programs, technology like remote patient monitoring can offer all-hours visibility into individuals’ needs and enable swift intervention to maintain living at home; similarly, technology that integrates mapping with scheduling eases the logistical challenge of maintaining appointments at disparate home locations

CHALLENGE

Addressing health equity through faith-based partnerships

Research has clearly demonstrated that significant disparities exist during serious illness, including in access to hospice care, in participation with advanced care planning, and may exist in access to specialty palliative care, particularly non-Hispanic blacks.^{xxxvi} One meta-analysis of available literature surfaced several predominant reasons for these disparities such as personal or cultural values that conflict with serious illness services and mistrust of the US healthcare system.^{xxxvii}

Despite these entrenched, systemic and attitudinal barriers to care, qualitative research has also shown that faith communities can play an important role alongside

care systems as sources of information and support as people consider health care decisions in life-threatening situations.^{xxxviii, xxxix} This bridging role may be especially critical for populations that experience cultural or personal concerns with care related to serious illness and/or mistrust of healthcare institutions. The featured programs in this section reflect various practices and models that are implementing and testing this evidence-based approach: that faith-based organizations can help facilitate access to care to address serious illness and center health equity in such efforts.

FEATURED PROGRAM

AC Care Alliance, Advanced Illness Care Program (AICP) ^{xi}

ORGANIZATIONAL TYPE:	Community-based organization collaboration
SERIOUS ILLNESS FOCUS:	Advance care planning, access to social supports and community linkages, whole-person care
GEOGRAPHY:	Alameda County, Contra Costa County, San Francisco County, Santa Clara County, San Mateo County and Los Angeles County, California
DESCRIPTION:	The AICP program provides people living with serious illness, as well as their caregivers, with a trained Care Navigator, to provide information, tools, training, and emotional support, while connecting them with practical resources, across five cornerstones: health needs, spiritual needs, advance care planning, caregiver needs, and social needs. Care Navigators, through a series of 5-12 phone and in-person meetings over a six-month period, help families by connecting them to resources to fill unmet needs, while empowering them to communicate effectively with their health care providers.

1. HOW DID THE PROGRAM GET STARTED?

C-TAC played a key and important role in the formative years of the AC Care Alliance (ACCA). C-TAC leadership reached out to the Pastor of one of the ACCA founding churches, Allen Temple Baptist Church, to discuss and solicit its support in convening a region-wide Interfaith Network Consultation/Needs Assessment of diverse faith leaders across Northern California. The key goals were to better understand opportunities and challenges to support family caregivers in communities of faith and to consider early talks around building

a model of care that could be replicated nationally. Drawing on a strong relationship with a hospice marketing professional who worked to reach Black, Latinx and Asian populations with information about hospice and palliative care the ACCA and its AICP began.

The initiative soon grew to involve five Hub congregations with input from past leaders of the Sutter Health's Advanced Illness Management program and continued partnership with the University of California Davis School of Nursing, as ACCA's evaluation and strategic planning partner, faith leadership and

community engagement, the Care Navigator AIC program began to develop. Presently, formal training is available for Care Navigators and other Care Team members on advanced illness, palliative and hospice care, social supports, advance care planning, caregiver support and privacy/HIPAA requirements. These formal trainings were developed across collaborators and through the experience of the ACCA leadership team. Participation with and from health care organizations, such as Kaiser Permanente and Lifelong Clinics continue to expand as the model of care seeks to build capacity as a health care, total care collaborative, while becoming more aware of the spiritual and emotional concerns of their patients and participants.

2. HOW DOES THE PROGRAM ADDRESS EQUITY AND BUILD TRUST?

This AICP has benefitted from strong leadership by the faith and health leaders involved, who play instrumental roles throughout the planning, implementation, and improvement phases. On the health care organization's side, there must be strong commitment to benefit the individual families (rather than the needs of the organization or provider), and a respect for the assets of the target community. The ACCA also hires and trains staff that reflect the Black and Brown communities it predominately serves. Building trust and self-efficacy is crucial for long-term sustainability within communities where medical mistrust is real.

3. WHO IS SERVED BY THE PROGRAM AND HOW ARE THEY IDENTIFIED?

The AICP program began by “upreach” (not outreach) to congregants, many of whom self-identified or raised a concern about someone with a serious illness or caregiver distress. Today, the program works with more than 40 faith communities, and also accepts referrals from anyone eligible. Over 55% of ACCA-AICP's referrals presently come from health care systems, which ACCA engages deeply to inform and educate via faith-based congregations. The program also continually trains Care Navigators, drawing on congregants from the participating communities and qualified applicants in the field.

4. HOW IS THE PROGRAM STAFFED?

The program comprises 15 Care Navigators, 2 Care Team Supervisors, a Program Administrator, Regional Director, Assistant and Senior Director, Executive Director/CEO and Public Health back-office support team members.

5. HOW IS THE PROGRAM PAID FOR?

The program is paid for through grants and foundation support, with supplemental financial support from participating health care organizations (e.g., Kaiser Permanente Community Benefits, Stanford Community Benefit). The services are all provided free of charge to the families served.

6. WHAT ARE KEY PROGRAM IMPACTS?

The AICP has proven that the faith community, as a trusted messenger, can play a significant role in the care of families facing serious illness. For example, according to the program operators and UC Davis School of Nursing Evaluation Team, 55% of the participants have completed an advance directive (compared to only 15% nationally). In addition, there was an average of 3.5 referrals to social service providers per participant, and preparation for more effective clinician visits was completed in over 35% of the Care Navigator visits.

7. FOR MORE INFORMATION:

➔ [AC Care Alliance](#)

FEATURED PROGRAM

Louisville Community Care Project ^{5,xli}

ORGANIZATIONAL TYPE: Community collaborative

SERIOUS ILLNESS FOCUS: All types of serious illness

GEOGRAPHY: Louisville, Kentucky

DESCRIPTION: The Louisville Community of Care Project provides support to individuals with serious illness in Louisville, KY to access healthcare, transportation, nutrition and other health-related social supports. The program centers faith leaders as healthcare ambassadors linking individuals to Community Health Workers who are reflective of the population that they serve.

1. HOW DID THE PROGRAM GET STARTED?

Louisville is a community with tremendous healthcare needs and a high prevalence of serious illness, disproportionately high compared to other surrounding areas. For example, approximately 40% of the adult population in Jefferson county (where Louisville is based) has hypertension;^{xlii} and the Louisville community experienced a 40% increase in homelessness between 2018 to 2021.^{xliii} Despite these needs, faith-based leaders in the community working closely with C-TAC reported that lack of information about care related to serious illness and mistrust of traditional medical institutions meant that such services are largely under-utilized.

These conversations paved the way for a more formal partnership to improve access to care for Louisville residents engaged in faith-based communities facing serious illness. In 2022, faith-based leaders in Louisville; Assessia Health, a care coordination organization; and the Norton Institute for Health Equity began a formal collaboration to pilot test a process through which faith-based leaders would identify individuals in need of care to address their serious illness, refer them for a baseline assessment, and then facilitate access to ongoing services. The University of Louisville will be evaluating the pilot.

2. HOW IS THE PROGRAM ADDRESSING HEALTH EQUITY AND BUILDING TRUST?

The Louisville Community of Care model incorporates the spiritual needs of the individual at the center of the care

model. Faith leaders play a key role in facilitating access to care by serving as a trusted advisor to individuals who experience mistrust in the healthcare system or face barriers to accessing care.

In addition to faith leaders directly facilitating access to care, the Louisville Community of Care Model incorporates a number of community partners who participate in planned events in the community to publicize the program. Each of these events has a distinct purpose, for example one recent event focused on mental health awareness, but all events are open to the community and can serve as a way to link individuals to the program.

3. WHO IS SERVED BY THE PROGRAM AND HOW ARE THEY IDENTIFIED?

The target population for the Louisville Community of Care Project is anyone with a serious illness residing in Louisville (zip code 40203). Within this zip code, 42% of the black population has an annual income below the federal poverty guideline.^{xliiv} Faith leaders play a key role as healthcare ambassadors in identifying individuals with serious illness who could benefit from a multidisciplinary approach to care and referring them for follow-up assessment and ongoing care management.

4. HOW IS THE PROGRAM STAFFED?

As described, faith leaders serve as healthcare ambassadors linking individuals to the Community of Care Project. Once

[5] The Louisville Community of Care Project has not yet been formally evaluated but is testing an evidence-based presumption – that faith-based connections and leadership can facilitate access to during serious illness.

an individual is engaged, their primary point of contact is a Community Health Worker (CHW) who completes an assessment and links individuals with needed medical care and services to support health-related social needs. Researchers from University of Louisville will be evaluating the program ongoing.

5. HOW IS THE PROGRAM PAID FOR?

Currently the faith leaders involved in the project receive a small honorarium; CHW resources are provided in-kind through the Norton Institute for Health Equity. Additional community partners are contributing services such as legal aid services, transportation, and caregiver supports. The hope is that an evaluation will demonstrate financial viability by showing that the program facilitates access to community-based care in order to prevent avertable inpatient utilization. The hope is that the results from this research effort can be used to make a case for ongoing investment with payers in the region.

6. WHAT ARE THE KEY PROGRAM IMPACTS?

This program has not yet been formally evaluated. The University of Louisville is in the midst of finalizing an institutional review board submission to formally evaluate the program and will be considering a range of potential impacts such as improved quality of life, access to care related to serious illness, and potentially costs.

7. FOR MORE INFORMATION:

- ➔ As of publication of this resource, the program is still at an initial pilot phase. For more information, please contact C-TAC at info@thectac.org

KEY TAKEAWAYS

Addressing health equity through faith-based partnerships

- ➔ Before launching a new initiative to address healthcare disparities during serious illness, **it is critical to engage community partners to define needs and co-design programs**; this up-front work ensures community buy-in and credibility
- ➔ **It is important for health care partners to be cross trained on the spiritual care dimensions of care and vice versa** to create bi-directional understanding of the two supportive systems that serve individuals with serious illness
- ➔ **Language is especially important:** consider terminology like “upreach” vs outreach that resonates with community partners and does not reinforce an overly medicalized entry to care
- ➔ **Build in an active advisory structure and feedback loop** between and among all parties to continuously reinforce positive dynamics and mutual understanding
- ➔ **Identify, if possible, an evaluation partner up-front**; many of these initiatives – especially during the planning phase – are philanthropically funded. A strong evaluation focus at the outset will articulate the case for ongoing investment from payers, health systems or policymakers

CHALLENGE

Meeting the needs of pediatric populations facing serious illness

On an annual basis in the United States, over 45,000 infants, children, and adolescents die, with nearly 20,000 additional deaths among individuals aged 20 to twenty-four.^{xlv} Pediatric populations and their families face unique concerns when it comes to serious illness and serving them well merits a different approach. The fact of serious illness faced by young or very young individuals may present different spiritual or emotional concerns for loved ones and caregivers, and require specialized expertise in Child Life services, family

counseling, and other services. In addition, when younger populations face serious illness, it may be on account of rare diseases that require specialized, more difficult to access treatment. All of this additional context, means that programs to address pediatric serious illness ideally should be designed differently, involving a more active role for family members and siblings in the treatment and support, among other modifications.

FEATURED PROGRAM

Ryan House ^{xlvi}

ORGANIZATIONAL TYPE: Health Care Delivery System

SERIOUS ILLNESS FOCUS: Pediatric respite, palliative, and hospice care

GEOGRAPHY: Phoenix, Arizona

DESCRIPTION: Ryan House is one of only three dedicated houses that provides respite, palliative and hospice care services to the pediatric population in the United States. Recognizing that the needs of children and families are different than the needs of adults, Ryan House provides specialized care to children with life-limiting illness and at end of life.

1. HOW DID THE PROGRAM GET STARTED?

Ryan House is named for Ryan Cottor. Ryan was diagnosed with Spinal Muscular Atrophy when he was eight months old with a prognosis that he would not live past the age of two. At the time, Ryan's family was living in England and received support services from an organization called Helen House that provided pediatric respite, hospice, and palliative care. When the family returned to the United States, they were searching for similar services and came to learn that no services were available. The family learned that there was not a similar model of care in the United States, due in part to a lack of reimbursement for respite services.

The family began talking about their experience and made connections with the CEOs of Hospice of the Valley and St. Joseph's Hospital. Ryan House received a donation of land from St. Joseph's Hospital and the facility was built by Hospice

of the Valley to house both Ryan House on the first floor and an adult hospice unit on the second floor. Raising funds through community support provided the remainder of the funding used to open Ryan House.

2. WHO IS SERVED BY THE PROGRAM AND HOW ARE THEY IDENTIFIED?

Ryan House serves the pediatric population, primarily ages 0-18 and runs an alumni program for individuals who have survived past childhood. Patients are generally identified by community physicians and referred to Ryan House when they have received a life limiting diagnosis and the physician certifies that they are not expected to survive into adulthood. Patients are also able to self-refer to Ryan House for respite services, as long as eligibility criteria are met. Ryan House has approximately 300 children who are enrolled in respite

services and are generally retained as patients throughout their lifespan. Hospice services are driven by physician referrals and on average, 50 children per year receive hospice services through Hospice of the Valley at Ryan House.

3. HOW IS THE PROGRAM STAFFED?

As patients utilizing Ryan House services are medically complex, the program is overseen by medical directors, who are board-certified in hospice and palliative medicine and are part of the inpatient and outpatient Palliative Care Team at Phoenix Children's Hospital and the pediatric hospice medical directors for Hospice of the Valley. The facility is staffed by a team of nurses and certified nursing assistants overseen by a nursing director. A child life specialist and music therapists are also part of the direct care teams. Clinical nurse liaisons provide intake services, for initial and ongoing admissions for respite services. An executive director and four development staff participate in fundraising and development efforts for sustainability. A shared staffing model with Hospice of the Valley provides access to social work, chaplain, and bereavement services. Additionally, volunteers support the activities provided to children and families.

All staff receive training specific to pediatrics and are oriented and trained on a hospice philosophy. All staff are also encouraged to obtain a specialized hospice and palliative certification from their respective disciplines.

4. HOW IS THE PROGRAM PAID FOR?

Inpatient hospice services are reimbursed through the usual daily rates for hospice services via insurance. The respite services that are provided to families are not currently reimbursable. These services are supported through grant and fundraising efforts, costing approximately \$3 million per year.

5. ARE THERE ANY KEY ENABLING POLICY DECISIONS/CONSIDERATIONS THAT HAVE SUPPORTED THE PROGRAM?

As reimbursement is not currently available for pediatric respite care, there are only three facilities that currently provide these services in the United States. By contrast, the United Kingdom maintains at least 44 freestanding facilities providing pediatric palliative and hospice care.^{xvii} The primary barrier in the United States appears to be the reimbursement structures, as hospice reimbursement alone does not cover all operational costs associated with running more comprehensive programs.^{xviii} Ryan House has been advocating for the

reimbursement of pediatric respite with on-site palliative care under licensed hospice services, which would support longer term financial stability.

6. WHAT ARE KEY PROGRAM IMPACTS?

Studies of programs for terminally ill children have often found that parents and siblings experience better outcomes when children are served outside of a hospital setting (such as home).^{xlix} Inpatient hospice facilities, can offer an intermediate option between home and hospital, with additional medical supports than would be available in a home setting. While inpatient hospice options for children are very limited in the United States, studies of such programs in the United Kingdom found that parents and other loved ones experience relief when accessing programs that are uniquely tailored to the considerations of children. One study of Ryan House showed that families are significantly more likely to use inpatient hospice services for end-of-life care when pediatric-specific facilities are available.^l Ryan House also surveys on the quality of the services rendered and any improvements in quality of life and stress to the families accessing services.

7. HOW DOES THE PROGRAM MEET THE UNIQUE NEEDS OF CHILDREN FACING SERIOUS ILLNESS?

Ryan House tailors its services to meet the needs of children and their caregivers and families. Ryan House offers therapeutic supports specifically designed for children such as art, music, pet interactions, hydrotherapy and more. Additionally, Ryan House's pediatric respite care program offers around-the-clock care to children, thereby potentially enabling caregivers/family members to meet the needs of other siblings, and connects kids with one another in a medically safe environment.^{li} Ryan House's partner, Hospice of the Valley, adds additional supports to its hospice program including counseling support for all family members and quarterly workshops for siblings living alongside a brother or sister facing a life-limiting illness. This program also uses specially designed programs^{lii} to provide bereavement support for entire families and for adults that have lost an only child.

8. FOR MORE INFORMATION:

- ➔ [“If We Build It, Will They Come?” A Cohort Study of Family Utilization of a Pediatric-Specific Hospice Home](#)
- ➔ [Ryan House: Relief for Caregivers of Children with Life-Limiting Conditions](#)

FEATURED PROGRAM

CompassionNet ^{liii}

ORGANIZATIONAL TYPE: Health System

SERIOUS ILLNESS FOCUS: Perinatal and Pediatric Palliative Care

GEOGRAPHY: Upstate New York

DESCRIPTION: CompassionNet is a community-based pediatric and perinatal palliative care program, serving children and youth diagnosed with a potentially life-threatening illness, and their families. Upon referral, CompassionNet's interdisciplinary care team works closely with the family and health care team to address the child and family's physical, emotional, psychosocial, and spiritual needs to enhance their quality of life. CompassionNet provides care across the disease trajectory, and when indicated, care at end of life. Bereavement supports are also offered for up to three years following the death of a child.

1. HOW DID THE PROGRAM GET STARTED?

CompassionNet began in 2001 as a collaboration with Excellus/Blue Cross Blue Shield, as a part of a local home care and hospice organization. In 2010, CompassionNet expanded to include perinatal palliative care. CompassionNet is part of Rochester Regional Health.

2. WHO IS SERVED BY THE PROGRAM AND HOW ARE THEY IDENTIFIED?

The program serves families caring for a child through age 21, who have been diagnosed with a potentially life-threatening illness as well as families expecting the birth of a child with a serious medical condition. Children are identified through direct referrals to the CompassionNet program, often at the time of diagnosis, primarily through local children's hospitals, medical specialists, and community pediatricians. Eligibility is based on the child's medical diagnosis/disease trajectory, in addition to their enrollment in a health insurance plan managed by a participating provider or support through philanthropic entities. Since the program's inception, over 2,700 patients and their families have been served, with the current annual program census at approximately 500 children and their families.

3. HOW IS THE PROGRAM STAFFED?

CompassionNet is staffed by an interdisciplinary pediatric palliative care team of social workers, pediatric nurse

practitioners/nurses, child life specialists, and board certified pediatric palliative care physicians. In addition to care from the core interdisciplinary team, CompassionNet offers additional support through collaborative partnerships with community providers, such as music and art therapy, and counseling.

4. HOW IS THE PROGRAM STAFFED?

CompassionNet is provided by Rochester Regional Health's home care agency and is sponsored by the Lifetime Healthcare Companies (Excellus BlueCross BlueShield and Univera Healthcare) outside of normal insurance benefits and supported through generous local community partners. The services CompassionNet provides are free of charge to families and additional funds are raised through philanthropy efforts.

5. WHAT ARE KEY PROGRAM IMPACTS?

CompassionNet strives to alleviate suffering for the child who has been diagnosed with a potentially life-threatening illness and their family. The program is patient/family-centered, providing ongoing medical, psychosocial, and emotional support throughout the trajectory of the child's illness. The team works closely and extensively with families to develop goals of care for the child and family with a care plan based on informed decision making with respect for diversity, equity, and inclusion.

The comprehensive nature of the CompassionNet program broadens options to support the child and family's goals of

care, including meaningful input into location of death. A study published in the Journal of Palliative Medicine noted a significant cost savings for CompassionNet program participants who died at home, with an estimated cost of care associated with death at home (\$121,111) versus death in the hospital (\$200,500).^{iv} CompassionNet regularly surveys patients and their families using multiple survey formats to assess their satisfaction with the program.

6. HOW DOES THE PROGRAM MEET THE UNIQUE NEEDS OF CHILDREN FACING SERIOUS ILLNESS?

CompassionNet recognizes that pediatric palliative care patients have needs that are significantly different than adults. CompassionNet's home and community-based Child Life Specialists provide care within a developmental framework to assess and address the unique needs of the child with life-threatening illness and their siblings through play, preparation, education, and self-expression interventions. Their unique role continues to make a significant impact on the well-being of the child and their sibling(s).

The CompassionNet team provides expert pediatric palliative and end-of-life care when a child is nearing end of life, and uniquely supports a child nearing end of life at home by enabling a 24/7 best practice care model. Children and families are beautifully cared for before, during, and after the death of a child by expert clinically trained medical and psychosocial providers. Immediately following the death of a child, the team continues to provide support, which often includes compassionate care of the child who has died and promotes opportunities for ongoing legacy making, including hand and footprints, photography, and securing meaningful keepsakes. The program continues to offer bereavement support to the family for up to three years following the death of the child.

7. FOR MORE INFORMATION:

- [Costs of Care and Location of Death in Community-Based Pediatric Palliative Care](#)
- [The Epidemiology of Community-Based Pediatric Palliative Care: A Descriptive Study](#)

KEY TAKEAWAYS

Meeting the needs of pediatric populations facing serious illness

- **Children have fundamentally different needs related to socializing, development, and emotional support than adults and this does not change even when children face life-limiting illness;** it is essential to provide specialists in Child Life Services and to build in socialization opportunities and child-oriented activities such as art and aquatherapy
- **Families, caregivers, and siblings require their own specialized supports** within such programs throughout the duration of treatment and during bereavement
- With additional complex needs to be met, **pediatric programs necessitate more resource-intensive care.** However, current payment systems dramatically underfund whole family care, so resources to support pediatric respite and palliative care will need to be supported through other means (e.g. planned philanthropy) until such time as policy changes enable more comprehensive reimbursement



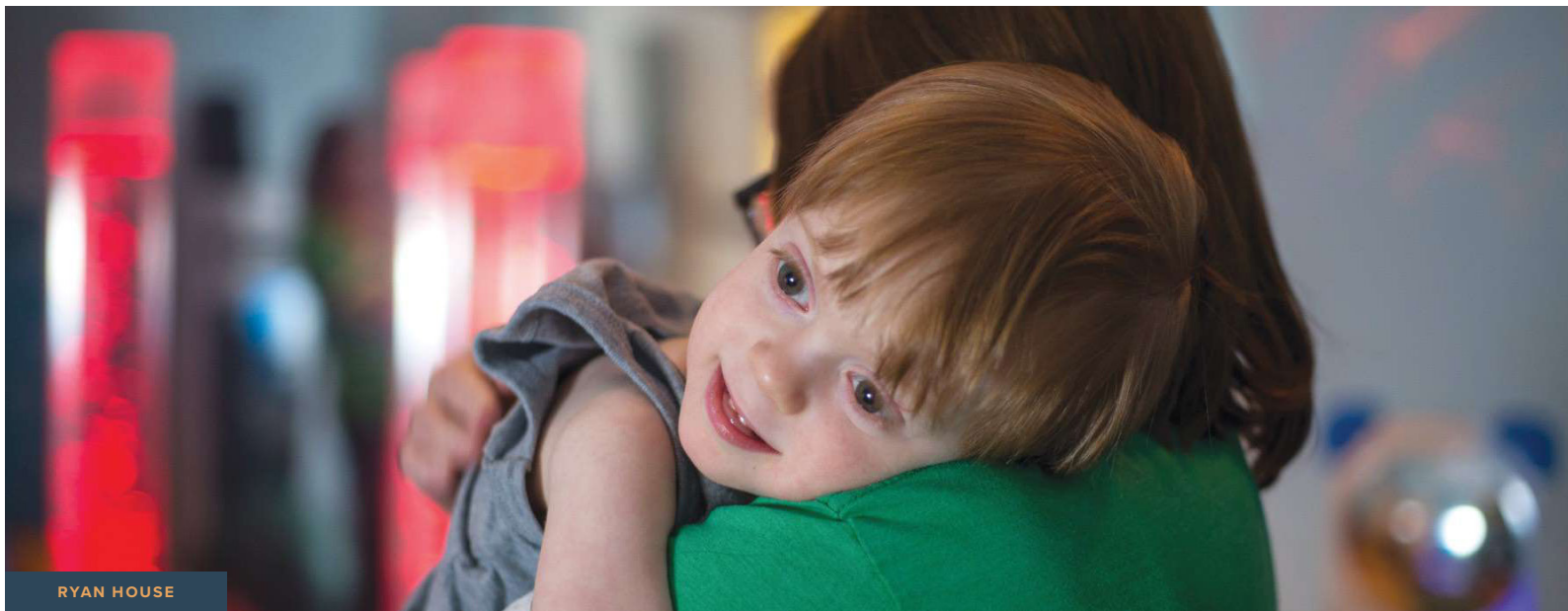
UCSF CARE AT HOME



HOUSE CALL PROVIDERS



COMPASSIONNET



RYAN HOUSE



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APPENDIX

Program Alignment with C-TAC Core Principles

ORGANIZATION	Care is person- and family-centered, improving quality of life	Care is inclusive – reducing inequities and disparities, and removing barriers to access and to quality care	Each person’s physical, social, psychological, and spiritual needs are assessed on an ongoing and standardized basis.	A care plan is developed, using shared decision making, based on those needs and the persons individual goals and preferences
Facey Medical Group of the Providence Health Care System	✓	✓		✓
Advocate Aurora Health	✓	✓	✓	✓
Sharp HealthCare Transitions Program	✓	✓	✓	✓
TigerPlace Intermediate Care Facility	✓	✓	✓	✓
Housecall Providers	✓	✓	✓	✓
UCSF Care at Home	✓	✓	✓	✓
Alivia Care	✓	✓	✓	✓
AC Care Alliance	✓	✓	✓	✓
Louisville Community of Care	✓	✓	✓	✓
Ryan House	✓	✓	✓	✓
CompassionNet	✓	✓	✓	✓

ORGANIZATION	Care is provided by a qualified core interdisciplinary team, with additional team members as needed	Care is accessible 24/7 (using technology as appropriate) and available throughout the continuum of a serious illness (including in the home when appropriate)	Care is comprehensive, coordinated, with seamless transitions, and with integration of clinical and community-based services and supports for the person and family caregiver(s)	Payment is value-based, available to qualified organizations of any size, and includes risk adjustment, upfront investment, accountability, standardized metrics, and quality improvement, and covers both clinical and social services
Facey Medical Group of the Providence Health Care System	✓		✓	✓
Advocate Aurora Health	✓	✓	✓	✓
Sharp HealthCare Transitions Program	✓	✓	✓	✓
TigerPlace Intermediate Care Facility	✓	✓	✓	
Housecall Providers	✓	✓	✓	✓
UCSF Care at Home	✓	✓	✓	
Alivia Care	✓	✓	✓	✓
AC Care Alliance			✓	
Louisville Community of Care	✓		✓	
Ryan House	✓	✓		
CompassionNet	✓	✓	✓	



C+TAC

COALITION TO TRANSFORM
ADVANCED CARE