



Community Health Care Report 2017

NAME OF ORGANIZATION: JourneyCare

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MISSION OF THE ORGANIZATION: JourneyCare's mission is to enrich lives through expert and compassionate care. Its vision is to transform lives by building a community where exceptional palliative, supportive, and end-of-life care is accepted, expected, and available to all.

Identify the high risk/underserved and/or disadvantaged populations in the community(ies) that you serve and describe specifically the actions you have taken, based on relevant assessment data, to increase their accessibility of health services.

JourneyCare provides hospice and palliative care to urban, suburban and rural populations. Patients facing advanced illness and their families are often vulnerable due to the physical, emotional and financial stress related to serious illness. Our pediatric patient families, in particular, may be in financial distress because a parent must leave a job to care for the child.

The JourneyCare service area covers a ten-county region in northern Illinois (including Boone, Cook, DeKalb, DuPage, Kane, Kendall, Lake, McHenry, Will, Winnebago) including underserved urban, suburban and rural areas therein. JourneyCare delivers services most often in the home but also in the nursing facility or inpatient care setting – wherever the patient calls home. Since the majority of patients prefer to be at home with family, providing services in the home can help prevent unnecessary hospital or doctor visits – especially when a patient must rely on public transportation – allowing patients to avoid the costly acute care system. JourneyCare maintains five hospice inpatient carecenters located in Arlington Heights, Barrington, Chicago, Glenview and Woodstock. Patients also have access to care support 24/7.

JourneyCare's core services include: hospice for those nearing the end-of-life; palliative care for those with serious and complex illnesses; and grief support for those coping with the death of a loved one. These programs serve both adults and children and are delivered by an interdisciplinary team (IDT) comprised of doctors, nurses, social workers, chaplains, certified nursing assistants, grief counselors, and integrative therapists (art, music, massage). The IDTs meet weekly to discuss/coordinate patient cases and to address the medical issues of the patient as well as psycho/social and pre-bereavement needs of patient and family.



Based on the individual care plan developed in collaboration with the patient and family, the team helps to identify community resources needed and coordinates care with other community partners such as primary care physician, behavior health specialists, physical therapists or a Parish nurse. Social workers, in particular, help patients navigate the healthcare system, access community resources to assist low-income families and address psycho-social needs that are the result of advanced illness.

In 2016, JourneyCare served 7,409 adult hospice patients, 4,153 adult palliative patients, 120 pediatric hospice patients, and 262 pediatric palliative patients. Having never turned anyone away due to inability to pay, JourneyCare provided more than \$3 million in uncompensated care to patients who were under- or uninsured or needed family support services in 2016. Rates of uncompensated care are highest among the pediatric patient population, nearly 50% of whom cannot afford their complex care.

Mount Sinai’s Icahn School of Medicine published research findings that show that hospice enrollment “lowers Medicare expenditures, rates of hospital and intensive care unit use, 30-day hospital readmissions, and in-hospital death. Building upon prior studies of hospice and palliative care that have demonstrated higher quality and improved patient and family satisfaction, this finding suggests that hospice and palliative care are critical components in achieving greater value through health care reform: namely, improved quality and reduced costs.”¹

Describe specifically the strategies you have used to gather input from high risk, underserved and/or disadvantaged population and their leaders as a basis for program or service development.

The hospice and palliative care model focuses on the family as the unit care. One of the pillars of hospice and palliative care is effective patient/family communication with the team. The plan of care is developed in conjunction with the patient and family to reflect their wishes. Two documents, available in English and Spanish, aid all involved in meeting the wishes of patients:

Caring Essentials: This mini-binder is a tool unique to our agency that serves as a crucial guide for patients and families. It serves as a medication tracker, teaching tool, and a **communication channel** between the patient/family and their care team. After a patient is admitted, each *Caring Essentials* binder is **customized** for each patient, taking into account their specific disease and symptoms. Its ultimate purpose is twofold: 1) promote clear communication between the family—the “eyes and ears” when we’re not there—and 2) to empower the caregiver by creating confidence.

¹ A Morrison Amy S. Kelley, Partha Deb, Qingling Du, Melissa D. Aldridge Carlson and R. Sean, Number of Different Lengths-Of-Stay Hospice Enrollment Saves Money For Medicare And Improves Care Quality Across A Number of Different Lengths-Of-Stay, *Health Affairs*, 32, no. 3 (2013): 552-561.



Five Wishes (available in 20 languages): This document, written in everyday language, serves as a workbook designed to help guide discussions about difficult decisions and preferences for care. It also serves as a power of attorney form. Completed by the patient or a representative, the document helps a patient's family/decision-maker and doctors understand who they want to make healthcare decisions for them, treatment preferences, specific wishes, etc.

Evaluation: JourneyCare regularly evaluates its programs by participating in the CAHPS program administered by the Centers for Medicare and Medicaid (CMS). JourneyCare's Vice President of Quality and Compliance oversees this process for JourneyCare. Two months following the death of a patient, the family receives a family satisfaction survey to measure satisfaction with care in four domains. Results are tabulated and used to determine additional training, program adjustments needed, etc.

This constant communication loop allows JourneyCare's beneficiaries to provide feedback on areas such as:

- Staff attitude and performance of duties
- Response time of JourneyCare staff and services
- Communication clarity (e.g., increase patient/family education and empowerment; manage expectations of staff and services; transparency between beneficiaries and staff)
- Timeliness of medicine and medical equipment delivery

Describe specific partnerships with other providers and community-based organizations to promote continuity of health care for high risk/underserved and/or disadvantaged populations.

JourneyCare collaborates with hospitals, physicians, long-term care communities, social service agencies, churches, institutions of higher education and other community organizations to provide the best possible care for our patients and families. We are appreciative of the following strategic partnerships:

Centegra Health System
Northwest Community Hospital
Northwestern Memorial Hospital
Northwestern Lake Forest Hospital
Rush University Medical Center
University of Chicago Medicine

JourneyCare is also an active member of the Greater Illinois Pediatric Palliative Care Coalition that advocates for reimbursement for pediatric palliative care in Illinois and provides education and technical assistance to other providers around Illinois.

Provide two examples of how you have used the community-oriented approach to program development specified in the attached principles to develop a program of service for high risk/underserved and/or disadvantaged populations specified in the guidelines. Include in each



description components of the current program and the following quantitative information for the most recent year available:

UNCOMPENSATED CARE

In 2016, JourneyCare provided more than \$3,100,000 in uncompensated care most of which is attributed to the Patient Assistance Fund (charity care for under- or uninsured patients and patient/family support services that have no reimbursement mechanism). These two categories of need remain JourneyCare's highest priorities.

Charity Care and Charitably Funded Programs

JourneyCare's Patient Assistance Fund covers uncompensated services such as charity hospice and palliative care for patients who are uninsured/underinsured and do not have the resources to pay. It also includes hospice and palliative care services not reimbursed by private or government insurance or other payor as well as services that have little or no reimbursement mechanism. These services include palliative care for seriously ill children, integrative therapies (art, music, massage, pet, thanatology), bereavement support to the community, special Jewish care services and a veteran's program. As a mission-driven organization, JourneyCare provides these services as part of the comprehensive, patient-centered plan of care for patients. JourneyCare has never turned anyone away because of inability to pay.

In addition, JourneyCare's Comfort & Joy services provide financial support to help patient families meet a basic need (e.g., gasoline to enable a family member to visit) or fulfill an end-of-life wish (e.g. trip to a baseball game). JourneyCare also regularly provides community education on issues related to advanced illness at no charge.

The majority of uncompensated care is provided to pediatric patients, many of whom have exhausted their insurance benefits and whose families cannot undertake such a financial burden. In calendar year 2016, almost half of JourneyCare's 329 pediatric patients in hospice or palliative care received some form of uncompensated care.

2016 DATA:

CHARITY CARE AND COMFORT & JOY PROGRAM

Number of clients served: 228

Total amount budgeted by your organization for the program - \$1,600,000

Percent that program budget is of total agency budget: 1.8%

Percent of program budget that is directly reimbursed by third party payers: 0%

Percent of program budget that is covered by public/private grants: 100%

PATIENT/FAMILY SUPPORT SERVICES

Thanks to philanthropic support, support services and programs are *offered at no charge* to our patients, their family members and communities in our 10-county service area in northern Illinois (Lake, McHenry, Cook, DuPage, Kane, Kendall, Winnebago, DeKalb, Will, and Boone).



Complementary/Integrative Therapies include art, massage, pet therapies and two music programs: music therapy for relaxation, stress relief and life review and music-thanatology using harp and voice to soothe patients in the active stage of dying.

2016 DATA:

Number of clients served: 3,906

Total amount budgeted by your organization for the program: \$731,000

Percent that program budget is of total agency budget: 0.8%

Percent of program budget that is directly reimbursed by third party payers: 0%

Percent of program budget that is covered by public/private grants: 100%

Adult and Child Bereavement Services provides support to help children and adults with the challenging journey of illness, death and grief by providing individual and group counseling, a grief support summer camp program designed to help children and teens cope with the death of a loved one and outreach to family members following the death of loved one.

2016 DATA:

Number of clients served: 8,685 (patient family and community members)

Total amount budgeted by your organization for the program: \$130,000 (community)

Percent that program budget is of total agency budget: 0.1%

Percent of program budget that is directly reimbursed by third party payers: 0%

Percent of program budget that is covered by public/private grants: 100%

The **Jewish Care Services** (JCS) program honors individual cultural and religious traditions of Jewish hospice patients and their families.

2016 DATA:

Number of clients served: 403

Total amount budgeted by your organization for the program: \$92,000

Percent that program budget is of total agency budget: 0.1%

Percent of program budget that is directly reimbursed by third party payers: 0%

Percent of program budget that is covered by public/private grants: 100%

The **Veterans Program** is registered through the National Hospice and Palliative Care Organization (NHPCO) and the Department of Veterans Affairs (VA) *We Honor Veterans* collaboration and offers training to staff and the community on veteran needs at the end of life.

2016 DATA:

Number of clients served: 1,052

Total amount budgeted by your organization for the program: \$93,000

Percent that program budget is of total agency budget: 0.1%

Percent of program budget that is directly reimbursed by third party payers: 0%

Percent of program budget that is covered by public/private grants: 100%