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.

1. 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.

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.”\(^1\)

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 a coordinated Interdisciplinary Team (IDT) comprised of doctors, nurses, clinicians, social workers, chaplains, grief counselors, and integrative therapists (art, music, massage) that helps patients avoid the costly acute care system. The IDT’s focus is to support patients’ and families’ health, well-being, dignity, and quality of life every step of the way.

\(^1\) 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.

Updated 12/12/2016
The comprehensive IDT patient evaluation is based on the National Consensus Project for Quality Palliative Care, thus patient/family needs are assessed and documented by the Domains.\(^2\) In the hospital and ambulatory setting, new consultations or referrals are most often seen first by a physician. The social worker (SW) assessment is done either concomitant with the physician visit or our preference is for the social worker to visit in the next transition setting, such as the home. This provides greater insight in the home for safety and caregiving needs. In the home and community-based settings, initial and follow-up assessments may be completed by the physician or the APN, also using the Domains of care. Many of these visits may be longitudinal from assessments initiated in other sites. The comprehensive interdisciplinary patient evaluation is reviewed on a weekly basis in Interdisciplinary Team (IDT) meetings for outpatients or, in the case of a hospital setting, in the daily huddles. This allows further discussion of patient/family needs. The team identifies community resources that will be utilized to provide a holistic, sustainable plan of care. The IDT allows the integration of community partners such as behavior health specialists, physical therapists or a Parish nurse. The team attempts to integrate the members of the patient’s own faith community or hospice chaplaincy for spiritual support.

In 2015, JourneyCare served 7,921 adult hospice patients, 4,150 adult palliative patients, 122 pediatric hospice patients, and 210 pediatric palliative patients. Having never turned anyone away due to inability to pay, JourneyCare provided $3 million in uncompensated care to patients who were under- or uninsured or needed family support services in 2015. Rates of uncompensated care are highest among the pediatric patient population, nearly 50% of whom cannot afford their complex care.

2. **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.**

Hospice and palliative care, at their roots, are co-created by patients and clinicians, as the main goal of both types of care is to increase the quality of life for each patient, however that quality uniquely translates for each individual. In order to assist with this co-creation, JourneyCare uses multiple methods to learn from and communicate with patients and their families. An integrated team—including patients, family, clinicians, integrative therapists, social workers, clergy, volunteers and grief counselors—meets weekly to discuss patient care and wishes.

Two documents, available in English and Spanish, aid all involved in meeting the wishes of patients:

1. **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.

2. **Five Wishes**: This document is a living will, filled out by the patient or a representative, that lets a person’s family and doctors know who they want to make healthcare decisions for them, what kind of treatment they do and don’t want, how comfortable they want to be, and so on. It is written in everyday language and helps start and structure important conversations about care in times of serious illness.

Additionally, JourneyCare is routinely in line with—if not outperforming—state and national benchmarks for overall patient care. A monthly review takes place with our Quality Management Board Committee, and information is disseminated at interdisciplinary group, staff, leadership, and board meetings. We also hold quarterly quality assessment and improvement meetings, where a committee introduces and reports on performance improvement projects. Most recently, JourneyCare identified areas with the most opportunity for improvement and added them to our dashboard of key quality indicators: 1) family confidence in doing what is needed for the patient; 2) family confidence in knowing enough about medications; and 3) clinical measures for pain, nausea, shortness of breath (dyspnea), and anxiety (i.e., what is measured is patients who had a symptom intensity of ‘4’ out of ‘10’ or higher, and the % whose symptoms were brought down at least 1-2 levels within 48 hours).

In June 2014, JourneyCare hired its first director devoted to service excellence, who was charged to enhance the JourneyCare’s customer service. The system that grew since then—and which is now managed by our Director of Patient & Family Experience—goes beyond compliance, offering a constant communication loop, enabled by software, to automate, track, and trend provision of services—both to be commended and improved. The system provides a methodical and timely tool that increases access to patients and loved ones, allows JourneyCare to respond with service excellence within a defined timeline, and measures improvement over time.

**This constant communication loop allows** JourneyCare’s beneficiaries to voice and co-create such things as (but not limited to):

- Timeliness of medicine and medical equipment delivery
- Staff attitude and performance of duties
- Patient and loved ones’ wishes for enhanced quality of life
- Response time of JourneyCare staff and services
3. **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:

- Advocate Christ Medical Center
- Advocate Good Shepherd Hospital
- Advocate Hope Children’s Hospital
- Advocate Lutheran General Children’s Hospital
- Advocate Sherman Hospital
- Alexian Brothers Behavioral Health Hospital
- Ann & Robert H. Lurie Children’s Hospital of Chicago
- Centegra Hospital – McHenry
- Centegra Hospital – Woodstock
- Loyola Medical Center
- Northwest Community Hospital
- Northwestern Lake Forest Hospital
- Northwestern Memorial Hospital
- Presence St. Joseph Hospital
- Rush University Medical Center
- St. Alexius Medical Center
- University of Chicago Medical Center
- University of Illinois Hospital and Health Sciences System

4. **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:**

In 2015, JourneyCare provided $3 million in uncompensated care to adult and pediatric patients, which includes care for under- or uninsured patients and family support services. These two categories of need remain JourneyCare’s highest priorities.
UNCOMPENSATED CARE
The Patient Assistance Fund provides both uncompensated care and comfort and joy services. Uncompensated care is provided based on a financial assessment to those who cannot pay for their care. 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 2015, over half of JourneyCare’s 234 pediatric patients in hospice or palliative care had no form of payment and needed uncompensated care. Finally, comfort and joy services provide supplementary financial support to help meet a basic need (like gasoline for family visitation) or fulfill an end-of-life wish.

2015 DATA:
- Number of clients served: 176
- Total amount budgeted by your organization for the program: $3,025,000
- Percent that program budget is of total agency budget: 3.5%
- 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%

FAMILY SUPPORT SERVICES
Thanks to philanthropic support, family support services and programs (listed below) 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 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.

2015 DATA:
- Number of clients served: 6,251
- Total amount budgeted by your organization for the program: $658,000
- Percent that program budget is of total agency budget: 1.0%
- 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 Counseling** by our professional counselors helps youth and adults with the challenging journey of illness, death and grief by providing individual and group counseling, and an annual grief support summer camp program designed to help children and teens cope with the death of a loved one.

**2015 DATA:**
- Number of clients served: 5,853
- Total amount budgeted by your organization for the program: $707,000
- Percent that program budget is of total agency budget: 1.0%
- 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.

**2015 DATA:**
- Number of clients served: 544
- Total amount budgeted by your organization for the program: $112,000
- Percent that program budget is of total agency budget: < 1.0%
- 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.

**2015 DATA:**
- Number of clients served: 436
- Total amount budgeted by your organization for the program: $88,000
- Percent that program budget is of total agency budget: < 1.0%
- 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%