

# Core Service Report

## Hospice Care

Consumer Category:  
**With / At Risk of Health Conditions**

Primary Consumer Group:  
**Persons Who Are  
Terminally Ill**



February 2007

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## COMPANION REPORTS

In addition to the information included in this report, a report of the other core services (80 in total), community leader key informant interviews, United Way - First Call for Help staff focus groups, consumer snapshots, and e-survey of United Way funded executive directors, board presidents, and United Way Community Investment staff are available at <http://www.uws.org>.

## ACKNOWLEDGEMENTS

We are grateful to the multiple public and private funders, provider agencies, experts in the various fields of interest, and staff of United Way of Greater Cleveland for their assistance, support, information, and insight.

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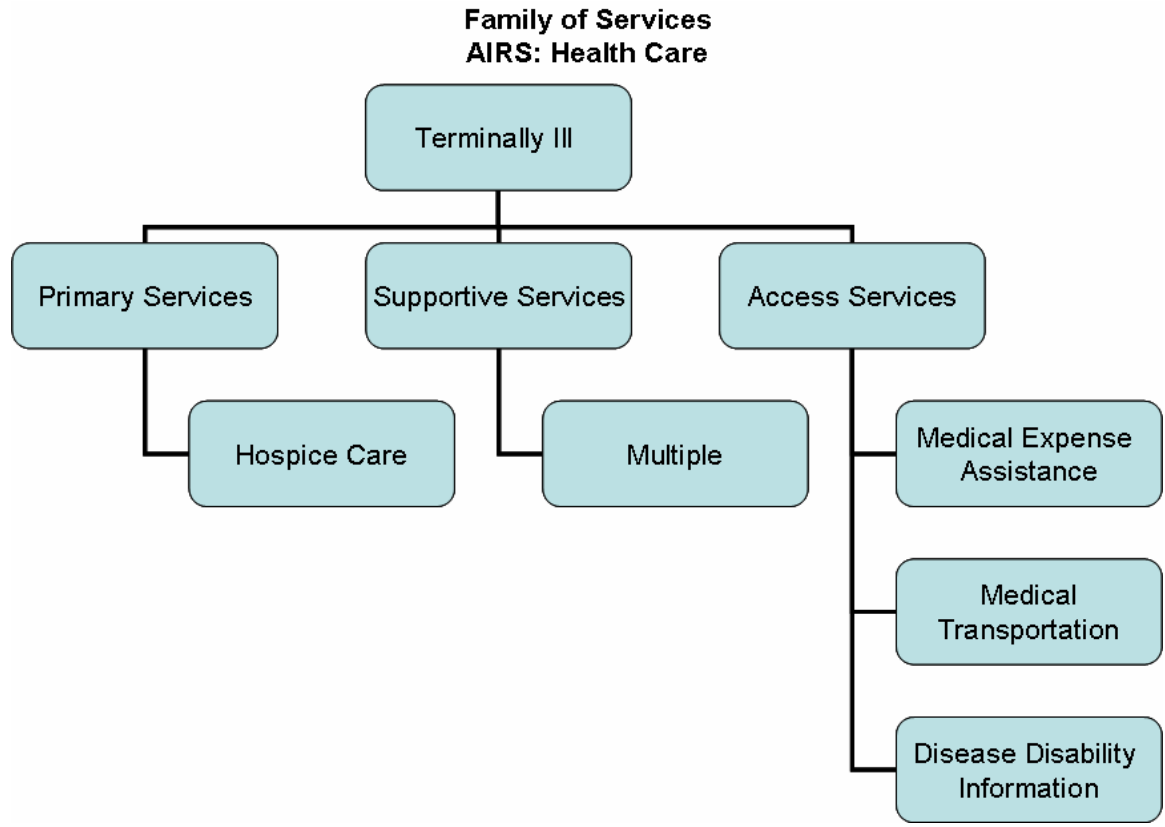
# SNAPSHOT

**AIRS Code Level I: Health Care (L)**  
**AIRS Code Level II: Specialized Treatment (LT)**  
**Core Service: Hospice Care (LT-300)**

**Investment Committee: Health & Caring for All and Senior Success**  
**Cluster: Basic Subsistence; Supportive Services and Rehabilitation/Specialized Treatment**

**AIRS Definition:** Programs that provide a full range of supportive services for terminally ill people in the final stages of their illnesses and for their families. Services may include medical care, pain and symptom management, home nurse visitation, case management, emotional and spiritual support, and bereavement services for the patient and members of the family. In the United States, in order to qualify for Medicaid or Medicare reimbursement, an individual must have a life threatening illness and must be certified by their physician to have entered the last six months of life. Hospice care may be provided at home, in a freestanding hospice facility, a hospice unit of a hospital, or in long-term care facilities such as nursing homes.

Hospice Care is the only core service in the family of services for the terminally ill. In addition, three other services help consumers access the service. (See figure below.)



*Core Service Environment*

Death and dying have changed dramatically for Americans over the past century. Life expectancy has increased by almost three decades, from 47 years in 1900 to 75 years in 2000. At the turn of the last century, death occurred commonly at any age and was usually an acute event that came within days or weeks of the initial onset of an illness. Now, most Americans are healthier in every phase of life and live in relatively good health into old age. Improved public health and medical treatments have translated into far fewer deaths from acute causes such as childbirth or infections. Death in older age is most often a result of chronic conditions. Given the trajectory of these types of diseases, prolonged periods of disability, dementia, and frailty shape the last years of life for a large part of the population. There are other significant changes in death and dying in America. Most Americans come to the end of their lives in hospitals, and paid professionals, rather than family members, provide most of the visible and costly health care.

There are many public policy issues concerning hospice care, but two key concerns are Medicare reimbursement rates, and education of the public and health care professionals about the importance of hospice and end-of-life issues. Medicare is the main financing mechanism for medical services in the last phase of life and covers 83 percent of all who die in the U.S. Although reimbursement rates have increased over the years, they are mostly based on the types of medicines, treatments, and services available 20 years ago. (For example, therapeutic chemotherapy, a treatment recognized as a best practice, often is too expensive to provide given current reimbursement rates). National hospice organizations are also strongly emphasizing policies that address hospice education, both for practitioners and for potential patients. The current supply of specifically trained palliative care nurses and physicians is not enough. Additionally, the general public is neither discussing nor well enough informed about what hospice is and how it can help them. Education in both of these areas is viewed as highly important.

*Core Service Consumers*

The target population addressed in this core service report is terminally ill people in the final stages of their illness, and their families.

Over the years, Americans have increasingly turned to hospice. Enrollment has risen from about 1,000 per year in 1975, when hospice care was introduced in the United States, to 700,000 in 2000.

More and more Americans are using hospice. In 1985, there were 1,545 hospice programs serving 158,000 patients; in 1994 there were 2,312 programs serving 340,000 patients; in 2000 there were 3,100 programs serving 700,000 patients; and in 2004 there were 3,650 programs serving 1,060,000 patients. This increase in enrollment was made possible in large part by congressional approval of hospice care as a separate Medicare benefit in 1982. The typical hospice recipient is elderly, white, with family, and lives in a private or semi-private residence. Cancer and, to a lesser extent, other chronic diseases are the primary admission diagnoses to hospice. However, the proportion of cancer admissions is decreasing. Other primary admission diagnoses include heart disease, Alzheimer's, cerebrovascular disease, and chronic obstructive pulmonary disease. Race and ethnicity affect use of hospice care. African-Americans, as well as other patients in medically under-served communities, do not use palliative and hospice care services as often as other groups do. Less than 10 percent of all hospice patients are African-Americans.

In Cuyahoga County in 2002, 15,177 individuals died from all causes (Ohio Department of Health, 2004a). Specifically, from 2000-2002, 15,938 individuals died from diseases of the heart, 10,563 from cancers, 2,628 from cerebrovascular diseases, 1,756 from chronic lower respiratory diseases, 1,232 from diabetes mellitus, 866 from Alzheimer's disease, and 875 from kidney diseases (Ohio Department of Health, 2004b).

Between 2000 and 2005, 81,450 deaths occurred in Cuyahoga County. Seventy percent of them were estimated to be predictable deaths and the annual average of predictable deaths was 11,403. This number is expected to decrease to 10,870 for the period 2010 to 2015, and then increase to 11,417 during 2025 to 2030 as baby boomers reach the end of their lives.

*Core Service Delivery*

The definition of hospice care for this report is the same as the AIRS definition.

Taking a holistic approach to death and dying, hospice is a program for both the dying individual and his or her family. As opposed to curative treatments, hospice utilizes medical care focused on comfort (palliative care) in combination with counseling for the individual and the bereaved family, with many services provided in the home. Hospice is a philosophy of care that considers the dying patient and family as one unit and focuses on relieving symptoms (palliation) rather than attempting to cure underlying disease. Hospice encompasses many types of services, but includes both medical services, assistance with activities of daily living (ADLs), and counseling. This kind of palliative care can be provided in a variety of places—a private residence, a nursing home, assisted living, or a hospice facility. A unique characteristic of hospice care is that it is multifaceted and looks to address not only physical symptoms, but also psychological, emotional, and spiritual needs. Support for family members continues after the patient's death; one-year bereavement services are a standard hospice benefit. Hospice care providers (doctors, nurses, social workers, therapists, aides, pastors, and volunteers) work as a cooperative team with terminally ill patients and their families, with the patients at center of decision making. Volunteers are an important hospice service resource, accounting for 10 percent of all hours provided in hospice programs.

Recent major studies looking at death and dying in America concluded that dying in America is unnecessarily painful and isolating; physicians do not understand patients' wishes; and it is costly. Additionally, people have come to fear a technologically over-treated and protracted death and dread the prospect of abandonment and untreated physical and emotional stress. Most people want to die at home, though only about a quarter actually do. About 50 percent of Americans 65 and older die in hospitals, often after stays in intensive care units, visits to multiple physicians in the months before death, and expensive life-prolonging treatments. Patients' preferences often are not the deciding factor in where they die; this is more often determined by the availability of hospice care or the practice habits of medical care providers.

Based on United Way - First Call for Help's database, there are 9 hospice programs in Cuyahoga County operating from 14 different sites, 1 of which is government run and 8 are nonprofit. In FY 2004 (July 2003 to June 2004), United Way funded one of the providers. Over the same five-year period, United Way - First Call for Help had a total of 96 requests for information about hospice services. Of these requests, they were able to make referrals to 96 percent of callers.

According to the National Home and Hospice Care Survey 2000 (National Center for Health Statistics 2004), Medicare is the primary source of payment for 79 percent of hospice

discharges. Medicaid was the primary source of payment for only 5 percent of hospice services. While Medicare information is not available at the county level, nationally, in 2005, 3 percent or about \$9.75 billion of Medicare’s \$325 billion budget was spent on hospice care (Kaiser Family Foundation, 2005).

As of May 11, 2006, over \$18 million in revenues for hospice care programs has been identified countywide. Ninety-seven percent of funding was from government sources, two percent from federated fund raising organizations, and the remainder from foundations and United Way of Greater Cleveland. Note: total revenue does not include Medicare funds because county-specific funding information is not available for this program, which is administered at the federal level.

Medicare and Medicaid reimburse hospice providers at a per diem rate based on four levels of care in which all hospice services are to be absorbed. In Cuyahoga County, the 2006 reimbursement rate from Medicare (and Medicaid observes the same rules) is as follows: for routine home care -- \$128.43; for continuous care -- \$749.57; for general inpatient -- \$570.72; and for inpatient respite -- \$132.43. Private insurers generally use a “fee for service” model. Payment levels differ.

*What Works; What Doesn’t*

Hospice care often impacts individuals by providing better pain control, addressing emotional and spiritual issues associated with end of life, and allowing individuals to die in a setting they prefer. Additionally, hospice educates and supports death with dignity whereby patient’s choices are discussed and acted upon. Hospice programs also address the emotional and spiritual issues of bereaved family members.

There is significant literature demonstrating what works in hospice care. Best practices include appropriate timing of intervention (which is often well before most individuals choose to turn to hospice), a coordinated and multidisciplinary approach to care, and effective education on the role of hospice. Uncoordinated care and a “one-size-fits-all” model of care do not work in hospice. Ethnic minorities utilize hospice less than caucasians.

According to an article published in the *Journal of the American Medical Association*, hospice care and advance directives can save between 25 percent and 40 percent of health care costs during the last month of life (Emanuel, 1996).

Hospice is accredited by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), established in 1951. Since 1996, the American Board of Hospice and Palliative Medicine (ABHPM) has offered physicians certification in palliative care. The Hospice and Palliative Nurses Association (HPNA) has provided this certification since 1994.

*Gap Analysis*

The estimated universe of possible consumers is 9,094 including both realized access (3,706) and unrealized access (5,388).

# I. FOREWORD

## INTRODUCTION

United Way of Greater Cleveland (UW), in partnership with the Cuyahoga County Board of Commissioners, has initiated a large scale core service planning process to generate data and engage in community-wide dialogue about the community's safety net of core service and consumer needs in the Greater Cleveland area. In addition, UW envisions this process as an opportunity to better understand its role in the community and its long term capacity to improve the lives of Greater Clevelanders.

The primary goal of the Cuyahoga County core service research is to identify consumer needs and assess whether there are service gaps/duplications on a community-wide level. The findings from this research will guide future funding decisions at UW, and they will also be used to stimulate dialogue with other funders and groups in the community. United Way intends to continue to fund a broad array of "safety net" services that are important to the Greater Cleveland area. But it is hoped that the research findings will inform how UW dollars may be dispersed to have the greatest impact on current realities, needs, and priorities in the Greater Cleveland community.

## METHODOLOGY

United Way contracted with MCS Consulting Service, LLC, to conduct the core service research, which focuses on both the consumers served and services provided. (See Attachment 1 for list of members of the research team.) The research team has obtained information about each core service from multiple data sources. At the end of the research process there will be substantial information available for some services and less for others, which will provide a clearer picture of what information *is* available and where there are *significant gaps*.

The questions addressed are:

- Including public policies, what are the environmental influences that are impacting both service consumers and the capacity for service delivery?
- Who are the service consumers? What are the factors that lead to a need for services? How many consumers are there? How many have there been in the past several years and what factors influenced the historic trend line? What are the projected numbers for the future? What is their demographic profile? Where do they reside? How many are receiving services funded by government and/or United Way?
- What is the philosophy that drives service delivery? Has it changed? What does the service consist of? Who provides the service?
- What are the funding sources? What are the annual revenues from government sources, federated fund raising organizations, foundations, and United Way of Greater Cleveland? What are the historic government funding trends and what is projected for the future? What is the reimbursement amount?
- What works and what doesn't work in service delivery?
- Are there service gaps, duplication, under-utilization?



The primary information sources used for this report are:

- Results of 20 focus groups with 159 direct service staff of United Way member agencies and non-members, and key informant interviews with 93 experts in the respective service areas (February 2005). Participants were asked about consumer populations that are increasing and those with unmet needs; they provided insight about specific service gaps and duplication, as well as services they perceive to be outdated or under-utilized.
- United Way Program Report data for FY 2004 (July 2003 to June 2004). Each year United Way member agencies submit information to their respective investment committees on each funded core service they provide. Among other things, this information includes a demographic profile of the consumers served, the zip codes where the consumers reside, and all revenue sources that support the service. The research team has aggregated this information for each core service.
- United Way - First Call for Help call data (2000 to 2004) - United Way - First Call for Help provides a 24/7 information and referral service through its 211 telephone line. The research team analyzed data from its large database, which includes the names of service providers for most core services, the activities they provide and the zip codes in which they and those they serve are located, the number of calls received, and whether the need was met or unmet. Unmet needs are those for which there was no resource to reference.
- Literature reviews on service trends and issues as well as best practices (i.e., what works/ what doesn't work in service delivery), including impact on the individual/family and on the community.
- Searches for information on public policies that are currently impacting consumers or service delivery.
- U.S. Census and American Community Survey data for various time periods.
- Data from funders on actual consumer populations and funding levels.

(See Attachment 2 for technical notes on the research methodology as well as limitations of the data.)

## II. THE CORE SERVICE ENVIRONMENT

### CORE SERVICE ENVIRONMENT

Death and dying has changed dramatically for Americans over the past century. Life expectancy has improved dramatically, and people are dying of different diseases and causes than they did at the beginning of the last century. In 1900, the average life expectancy was 47 years. Illness, disability, and death were common at every age. Death was usually an acute event, and most commonly was a result of pneumonia, tuberculosis, diarrhea and enteritis, and injuries. Death usually followed after days or weeks of an acute onset; few people lingered for many years with worsening disabilities arising from an eventually fatal chronic illness. Families bore the bulk of medical expenses and were the main caregivers, especially women. People generally lived their final days at home among family members.

Now, most Americans are healthier in every phase of life and live in relatively good health into old age. Improved public health and medical treatments have translated into far fewer deaths from acute causes such as childbirth or infections. In 2000, the average life expectancy for Americans was about 75 years (77 for women and 73 for men), 28 years longer than at the beginning of the previous century. Biomedical breakthroughs, public health initiatives, and social changes may reduce mortality further and increase the length of life (National Center for Health Statistics and the Centers for Disease Control, 2001). Most people now are dying from heart disease, cancer, stroke, chronic respiratory disease, injury, and diabetes. Given the trajectory of these types of diseases, prolonged periods of disability, dementia, and frailty shape the last years of life for a large part of the population. There are other significant changes in death and dying in America. For older individuals, payment for most medical expenses for end-of-life care comes from Medicare. Most Americans come to the end of their lives in hospitals rather than at home, and paid professionals provide most of the visible and costly health care. Americans will usually spend two or more of their final years disabled enough to need help with routine activities of daily living because of chronic illness (Lynn & Adamson, 2003).

Chronic diseases—such as heart disease, stroke, cancer, and diabetes—are among the most prevalent, costly, and preventable of all health problems. Chronic diseases often can have prolonged and eventually life-limiting courses of illness, and they have generally accepted characteristics, though each characteristic may not be applicable to each disease. They usually last a long time, are generally non-infectious in origin (though AIDS is often considered a chronic disease), and are unlikely to be cured. Seven of ten Americans who die each year die as a result of a chronic disease (CDC, 2005). Nine out of ten older adults who die when covered by Medicare have one or more of these conditions in their final year of life. Most older adults are relatively healthy; however, nearly all can expect to be chronically ill for an extended period at the end of their lives (Lynn & Adamson, 2003).

With most deaths occurring as a result of chronic disease, many people will reach a point when medical technology may be able to keep them alive, but it can neither restore their health nor even improve their condition. At that point, patients and families face difficult choices about the kind of care they want. A major study published in 1995 in the *Journal of the American Medical Association* looked at this issue. Entitled “Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments” (SUPPORT), this study is the largest, most widely publicized research project examining end-of-life care in the United States to date. SUPPORT

found that dying in America is unnecessarily painful and isolating; physicians do not understand patients' wishes; and it is costly. In 1997, an Institute of Medicine report entitled "Approaching Death in America: Improving Care at the End of Life" underscored that "people have come to both fear a technologically over-treated and protracted death and dread the prospect of abandonment and untreated physical and emotional stress" (Last Acts, 2002).

The hospice movement is designed to address these issues. Taking a holistic approach to death and dying, hospice is a program for both the dying individual and his or her family. As opposed to curative treatments, hospice utilizes medical care focused on comfort (palliative care) in combination with counseling for the individual and the bereaved family, with many services provided in the home. Utilization of hospice has been increasing dramatically over the past decades.

A key demographic trend that will affect the core service environment for hospice care is the aging baby boomer generation, the largest age cohort. In addition to the sheer number of older adults who may be consumers of hospice, the characteristics of baby boomers (more educated and focused on consumer choice and satisfaction than past generations) will also increase need and demand for hospice care. A dramatic rise in use of hospice care is expected with the aging of this population.

**PUBLIC POLICY ISSUES**

***NATIONAL***

Medicare and Medicaid

Medicare is the main financing mechanism for medical services during the last phase of life. Medicare covers the medical expenses of 83 percent of all people who die in the United States. The way that Medicare allows for and reimburses hospice is one of the most important public policy issues affecting this core service. Over the past decade, the Centers for Medicaid and Medicare have promoted the availability of the benefit of hospice care to providers and beneficiaries. In December 2003, Congress passed the Medicare Modernization Act of 2003. The hospice provisions were designed to improve access and make hospice care more available to patients and families earlier in their illnesses, including (a) an educational consult for patients who would be appropriate for hospice but have not yet been referred, (b) contracting for core or specialized nursing services, (c) nurse practitioners not employed by hospice to continue caring for patients under hospice, and (d) a rural hospice demonstration project to evaluate care delivery (Radulovic & Person, 2004).

While access to hospice services has become easier, trends in hospice reimbursement are of considerable concern. Medicare and Medicaid reimburse hospice providers on a per diem rate based on four levels of care in which all hospice services (including prescriptions, counseling, respite, home care visits, etc.) are to be absorbed. The per diem rate is intended to allow for variation over an average length of stay in a hospital. However, reimbursement rates were set approximately 20 years ago and, while there have been some increases based on an index rate, they have not been modified to account for advances in technology, pharmacology, or other medical treatments that are now best practices in standards of palliative care. Additionally, trends in short hospice lengths of stay and a lack of increase in reimbursement rates are requiring providers to absorb more costs. As a Milliman, USA report (2001) states:

As the average length of hospice service shrinks, intensive service days required at the onset of hospice enrollment and during the last phase of a terminal illness comprise a higher percentage of days, resulting in a higher per patient per day cost. Financial losses occur as the per-diem costs increase and reimbursement stays steady.

The same report noted that providers' costs often exceed reimbursements by 10-20 percent (Milliman, 2001). Hospices often depend on charitable giving and community support to fill in the gap in reimbursement from Medicare and Medicaid. A report released on March 10, 2006, from RAND Corporation and the Medicare Payment Advisory Committee confirmed that first and last days of service require higher expenditures, suggesting that the Centers for Medicaid and Medicare may move toward increasing reimbursement for those days (National Hospice and Palliative Care Organization, 2006).

Specifics of funding and reimbursement will be discussed in Section IV of this report.

### Last Acts

The Robert Wood Johnson Foundation in 2002 funded the Last Acts study to look at death and dying in the U.S. This thorough study produced a variety of suggestions around public policy for hospice care. Below is a list of these issues:

- Make quality end-of-life care a priority for national health policy.
- Make end-of-life care a special priority in aging policy.
- Support public/private initiatives to meet the needs of family caregivers.
- Encourage policies to enhance consumers' knowledge of the options for quality care near the end of life.
- Promulgate policies that encourage advance care planning and out-of-hospital.
- Ensure that in the absence of advance directives, family surrogacy is recognized and used in the best interests of dying people.
- Set state targets for the numbers of doctors and nurses with palliative care training needed to care for the state's critically ill and dying patients, and work with state-funded educational institutions to achieve them.
- Encourage requirements for continuing medical and nursing education about end-of-life care
- Establish good pain management policies that tackle the problem of under-treatment of pain.
- Encourage coordination of health services programs used by dying people of all ages to promote continuity of care.
- Require that hospitals and nursing homes establish palliative care services—using appropriately trained multidisciplinary teams, meeting quality standards, and encouraging contracting with hospice—as a condition of their participation in Medicare and Medicaid.
- Reassess the rules and regulations that apply to nursing homes where rehabilitation is the mission and allow greater flexibility in caring for dying residents.
- Support the provision of hospice services in government-run institutions—prisons, jails, mental hospitals, and so on.
- Change the Medicare hospice eligibility criteria to allow Medicare beneficiaries to qualify for the hospice benefit by diagnosis rather than an estimate of a six-month prognosis of terminal illness.



- Support large-scale demonstrations of promising models of coordinated end-of-life care that are likely to show better quality of life for patients and families, as well as cost savings.
- If these demonstrations warrant, revise Medicare and Medicaid benefits to cover the clinical, counseling, and support services essential to high-quality end-of-life care.
- Collect data to assess quality, cost, and access to end-of-life care in a variety of settings.
- Develop evidence-based palliative care clinical protocols (Last Acts, 2002).

#### Other Policy Issues

Hospice education, both for practitioners and for potential patients, is another key public policy issue. The current supply of specifically trained palliative care nurses and physicians is not enough. Additionally, the general public is not fully aware of what hospice is. Education in both of these areas is viewed as highly important.

### **III. THE CORE SERVICE CONSUMERS**

#### **DEFINITION OF TARGET POPULATION**

The definition of the target population for this core service report is terminally ill people in the final stages of their illness, and their families.

#### **DEMOGRAPHIC CHARACTERISTICS**

Over the years, Americans have increasingly turned to hospice. Enrollment has risen from about 1,000 per year in 1975, when hospice care was introduced in the United States, to 700,000 in 2000. This increase in enrollment was made possible in large part by congressional approval of hospice care as a separate Medicare benefit in 1982. Since Medicare covers almost every American 65 and older, and since 75 percent of Americans who die are in that age group, hospice became a covered benefit for the vast majority of dying Americans. To qualify, a patient must have a life expectancy of six months or less and must forgo curative treatments. Medicaid also pays for care near the end of life, largely through funding of long-term-care services for low-income people. Medicaid's role in paying for hospice is relatively small and follows Medicare's rules (Last Acts, 2002).

The 2004 National Home and Hospice Care Survey provides important information about the users of hospice:

- In 2000, 80 percent of hospice patients were 65 and older.
- The typical hospice recipient was elderly, white, with family, and lived in a private or semi-private residence. Individuals 65 and over made up 80 percent and whites 84 percent of the hospice discharge population. There were no significant differences among discharges by sex, and they were equally likely to be married or unmarried. Eight-five percent lived with family members. Seventy-six percent lived with a primary caregiver, and that primary caregiver was most often (81 percent of the time) a relative (42 percent of the time their spouse).
- Cancer and, to a lesser extent, other chronic diseases were the primary admission diagnoses to hospice. However, the proportion of cancer admissions has decreased from 75 percent in 1992 to 58 percent in 2000. Other primary admission diagnoses included heart disease (7 percent), Alzheimer's (2.7 percent), cerebrovascular disease (2.7), and chronic obstructive pulmonary disease (4.4 percent).
- Most hospice patients had functional limitations. Seventy-one percent received help for at least one activity of daily living (ADL), 71 percent were incontinent, 82 percent had mobility limitations, 70 percent used a hospital bed, and 51 percent used oxygen.

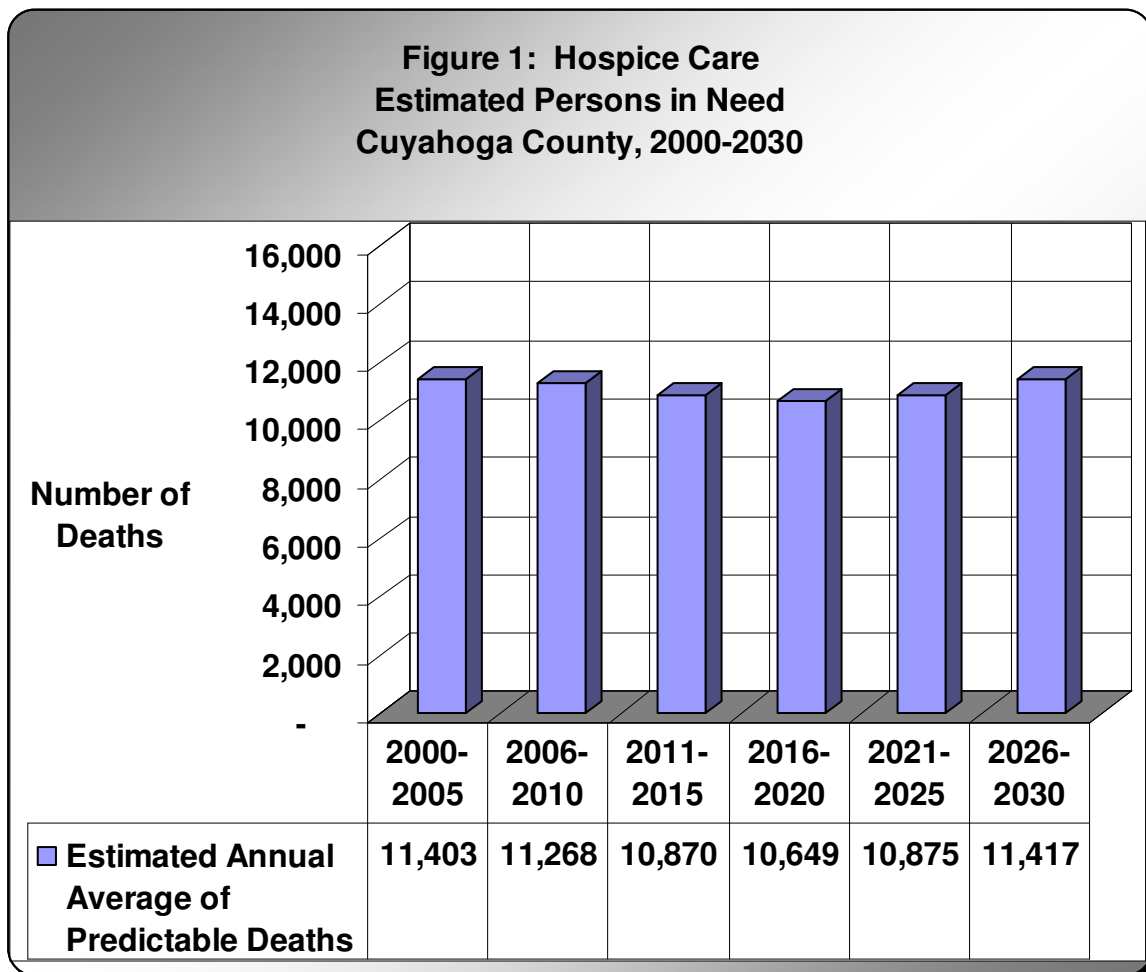
Race and ethnicity affect use of hospice care. African-Americans, as well as other patients in medically under-served communities, do not use palliative and hospice care services as often as other groups. Less than 10 percent of all hospice patients are African-Americans (Robert Wood Johnson Foundation, n.d.).

In Cuyahoga County in 2002, 15,177 individuals died from all causes (Ohio Department of Health, 2004a). Specifically, from 2000-2002, 15,938 individuals died from diseases of the heart, 10,563 from cancers, 2,628 from cerebrovascular disease, 1,756 from chronic lower respiratory diseases, 1,232 from diabetes mellitus, 866 from Alzheimer's disease, and 875 from

kidney diseases (Ohio Department of Health, 2004b). The older population of Cuyahoga County is projected to increase substantially as the baby boomer cohort ages in coming decades, and so the number of individuals who would potentially need hospice services is expected to increase.

*Estimated Persons in Need*

Between 2000 and 2005, 81,450 deaths occurred in Cuyahoga County. Of these, 70 percent were estimated to be predictable deaths (57,015) and the annual average of predictable deaths was 11,403. (See Figure 1.) This number is expected to decrease to 10,870 for the period 2010 to 2015, and then increase to 11,417 during 2025 to 2030 as baby boomers reach the end of their lives.



Sources:

\* Ohio Department of Development, Office of Strategic Research. (March 2003). Projections of Births, Deaths, and Natural Increase by Sex. Projections of deaths are in 5 year increments. We divided by 5 to get annual averages.

\*\* Connor, S. (1999). New initiative transforming hospice care. *The Hospice Journal*, 14(3/4): 193-203. Seventy percent of annual deaths are predictable and therefore possible users of hospice.

It is recognized that this is a conservative estimate of those who could be consumers of hospice because family members also benefit. However, this estimate begins to give some clarity to the need for hospice services in Cuyahoga County.

## REALIZED ACCESS TO SERVICE

Realized access to service is represented by the number of consumers actually served. It includes the actual number of consumers reported by agencies funded by United Way and by government funders from which it was possible to obtain data. Thus, it is an underestimate of actual numbers of consumers receiving service.

In FY 2004, United Way funded hospice care for 3,706 individuals from Cuyahoga County. (See Attachment 3.) Medicaid funded hospice for 1,714 individuals, and Ryan White Title I for 8 hospice patients. Medicare information was unavailable.

United Way funded 58 percent females and 42 percent males. Ryan White Title I funds served primarily males (6 individuals, or 75 percent of all clients reported). Gender information was unavailable for Medicaid clients.

Hospice clients funded by United Way were 81 percent Caucasian, while Medicaid-funded clients were 71 percent Caucasian, and Ryan White Title I, 38 percent. Fifty percent of clients funded by Ryan White Title I were African-American, United Way, 18 percent, and Medicaid, 35 percent. Of clients reporting to be Hispanic, United Way had 0.6 percent, Medicaid had 1.5 percent, and Ryan White Title I had 12.5 percent.

Income information for hospice clients was unreported by programs funded by UW, Medicaid, and Ryan White Title I.

Of the hospice clients funded by United Way and residents of Cuyahoga County, 44 percent lived in the Cleveland and 48 percent lived in the suburbs. For Medicaid-funded clients, 29 percent lived in Cleveland, and 71 percent lived in the suburbs. No data was available for Ryan White Title I. (See Attachment 4.)

## IV. CORE SERVICE DELIVERY

### CORE SERVICE DEFINITION

The core service definition for this report follows the AIRS definition. Hospice programs provide services that may include medical care, pain and symptom management, home nurse visitation, case management, emotional and spiritual support, and bereavement services for the patient and family members. In the United States, in order to qualify for Medicaid or Medicare reimbursement, an individual must have a life threatening illness and must be certified by his or her physician to have entered the last six months of life. Hospice care may be provided at home, in a freestanding hospice facility, a hospice unit of a hospital, or in long-term care facilities such as nursing homes.

### BACKGROUND ON CORE SERVICE

Hospice is a philosophy of care that considers the dying patient and family as one unit and focuses on relieving symptoms (palliation) rather than attempting to cure underlying disease. Hospice encompasses many types of services, but includes medical services, assistance with activities of daily living (ADLs), and counseling. A unique characteristic of hospice care is that it is multifaceted and looks to address not only physical symptoms, but also psychological, emotional, and spiritual needs. Support for family members continues after the patient’s death— one-year bereavement services are a standard hospice benefit.

In the late 1960s, the recognition that some patients were “dying” and thus not appropriately treated with aggressive interventions was a radical one in American health care and spawned the hospice movement in the 1970s (Lynn & Adamson, 2003). In the traditional medical model of care for individuals with life-limiting diseases, the doctor was the decision maker and treatment was most often focused exclusively on curing the patient, often at the expense of quality of life. In hospice, care providers (doctors, nurses, social workers, therapists, aides, pastors, and volunteers) work as a cooperative team with terminally ill patients and their families, with the patients at center of decision making. Volunteers are an important resource in hospice services accounting for 10 percent of all hours provided in hospice programs (National Hospice and Palliative Care Organization, 2005b).

Focus is on palliative treatment (or comfort care), pain management, and symptom control as opposed to medical interventions focused on curing the patient. Even within the past 30 years there have been significant changes in the way hospice care is provided. Initially, a transition model of care using aggressive treatments was provided up to a specific point, and then individuals made the sharp transition to being terminal and beginning hospice. This type of care did not address the needs of patients who might recover or remain stable. Chronically ill individuals often have ambiguous medical prognoses: they may be sick enough to die but also could live for many years. The trajectory model of hospice care is increasingly being viewed as a leading practice. In this model of care, as a disease progresses toward becoming terminal, palliative or comfort care increases while reductions in disease modifying or curative treatments are made (Lynn & Adamson, 2003). However, if hospice care is paid for through Medicare Part A (the hospital benefit), as most hospice is, the patient electing hospice must forgo curative treatments for the specified terminal disease (other diseases can continue to be treated), though he or she could return to regular Medicare benefits (American Hospice Foundation, 2005). As

noted in the public policy section of this report, this is an important issue to be addressed in the structure of Medicare and Medicaid benefits.

Again, since most hospice care is funded at least partially through Medicare, understanding the hospice benefit under Medicare is essential. The following are the types of services covered under the Medicare hospice benefit:

- Physician services;
- Nursing care;
- Medical equipment;
- Medical supplies;
- Medication for pain relief and symptom control;
- Short-term care in a hospital;
- Respite care (up to five days at a time);
- Physical, occupational and speech therapy;
- Home health aide and homemaker services;
- Social work services;
- Dietary counseling; and
- Bereavement services (Taking Care of Mom and Dad, n.d.).

Most people want to die at home, though only about a quarter actually do. About 50 percent of Americans 65 and older die in hospitals, often after stays in intensive care units, visits to multiple physicians in the months before death, and expensive life-prolonging treatments. Another 20 to 25 percent die in nursing homes, and this proportion is growing; only 25 percent die at home (Last Acts, 2002).

Hospice services are provided most often at home (though they can be in a medical center, long term care facility, etc.). A National Hospice Foundation study found that 80 percent of individuals say they want to die in their homes, and 75 percent of hospice patients actually do die at home (National Hospice and Palliative Care Organization, n.d.a). *Where* people die—and what kind of end-of-life care they receive—may be less a reflection of their wishes and more influenced by local doctors' practice habits and the availability of hospice services. People use hospice services earlier in the course of illness if they live in areas that have more hospital beds, more hospice services, and more general practitioners. They are less likely to die in hospitals if they live in areas where nursing homes and hospices are more available. Patients' preferences often are not the deciding factor in where they die (Last Acts, 2002).

The use of hospice care has increased significantly for all types of diseases (historically used mostly by cancer patients). The number of hospice programs and hospice patients has grown substantially in recent decades. In 1985, there were 1,545 hospice programs serving 158,000 patients, in 1994 there were 2,312 programs serving 340,000 patients, in 2000 there were 3,100 programs serving 700,000 patients, and in 2004 there were 3,650 programs serving 1,060,000 patients (National Hospice and Palliative Care Organization, 2005b).

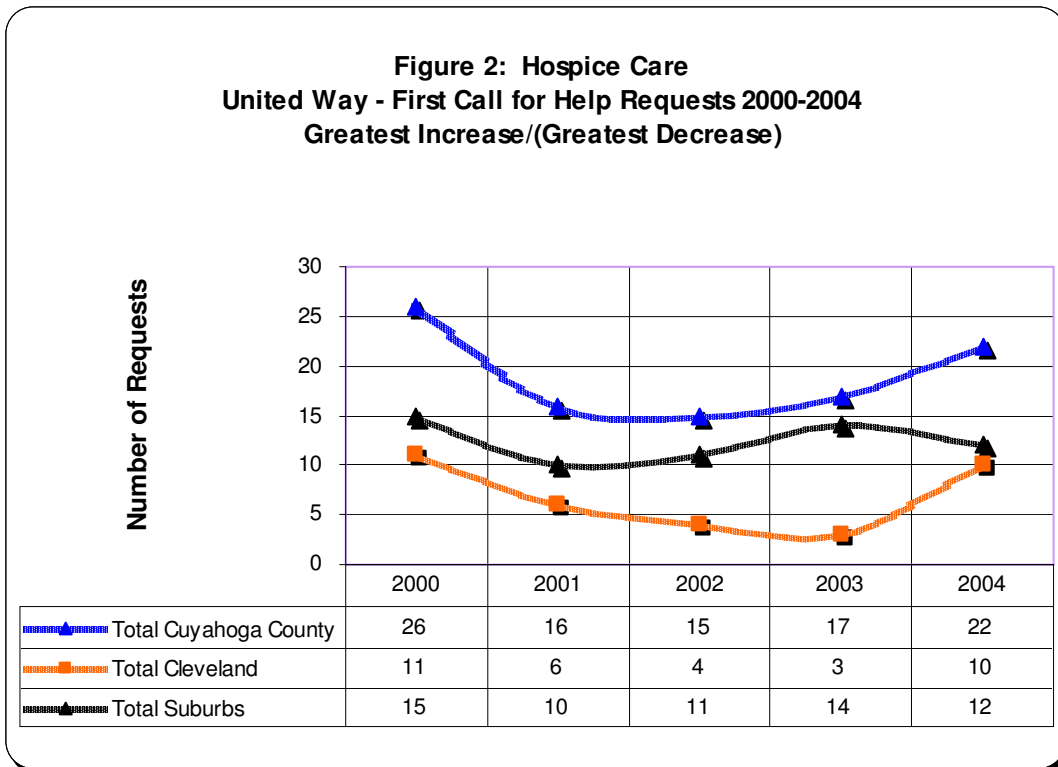
The potential number of persons who could utilize hospice care is far greater than the number that actually does, perhaps as great as 70 percent (Conner, 1999). In addition, according to the National Home and Hospice Care Survey of 2004, the majority of hospice care discharges did not receive timely care. Sixty-three percent of discharges received hospice care for less than 30 days before death (considered by some experts to be the minimum to achieve benefit from hospice; others recommend 60 days at minimum). The average length of service was 46.9 days

(down from 84.0 days in 1994) and the median length of service was 15.7 days (down from 27.4 days in 1994) (National Center for Health Statistics, 2003).

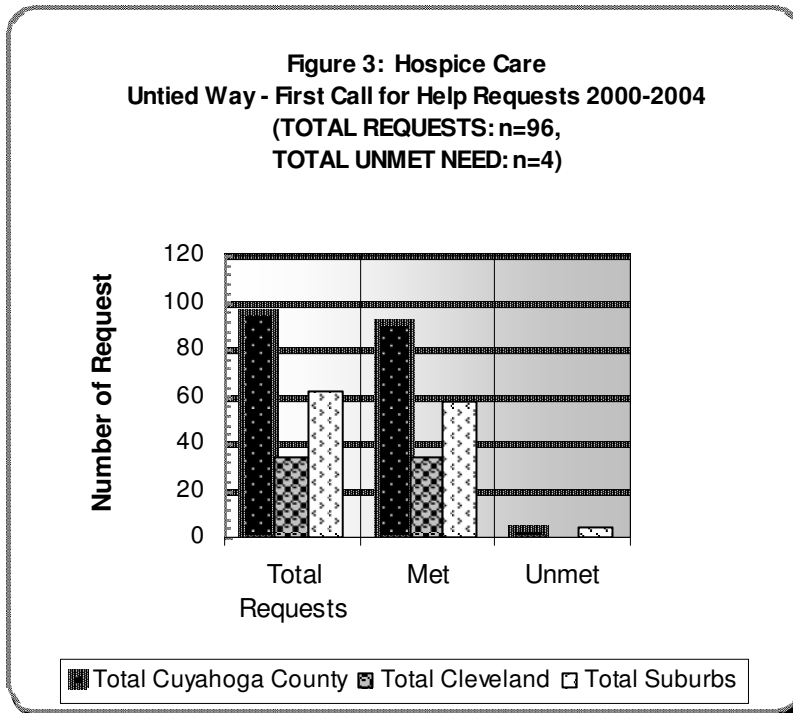
*United Way - First Call for Help Call Data*

Based on United Way - First Call for Help's (FCFH) database (February 2005), there are 9 hospice programs operating from 14 different sites, 1 of which is government run and 8 are nonprofit. In FY 2004 (July 2003 to June 2004), United Way funded one of the providers. (See Attachments 5 and 6.) Note that the FCFH list only includes some of the Hospice programs. For example, none of the for profit hospice programs are included. Some of these are included in the footnote to Attachment 5.

United Way - First Call for Help call data shows a decrease in the number of total requests for hospice programs in the county: from 26 in 2000 to 22 in 2004 (a 15 percent decrease) with a 9 percent decrease in Cleveland (11 to 10 requests) and a 20 percent decrease in the suburbs (15 to 12 requests). This is not necessarily indicative of a need for service, however. No zip code had an average number of calls greater than one for the five-year period. (See Figure 2 and Attachment 7.)



Over the same five-year period, United Way - First Call for Help had a total of 96 requests for information about hospice services. Of these requests, they were able to make referrals to 96 percent of callers, but four callers could not be referred to a provider that matched their needs. Callers with unmet needs were from the suburbs. (See Figure 3 and Attachment 8.)



**FUNDING OF CORE SERVICES**

*Major Government Funders*

The major sources of government funding for hospice are:

- Medicaid;
- Medicare; and
- Title I of the Ryan White CARE Act.

*Medicare and Medicaid*

As discussed in Section II under Public Policy, Medicaid and Medicare are sources of funding for hospice. According to the National Home and Hospice Care Survey 2000 (National Center for Health Statistics 2004), Medicare is the primary source of payment for 79 percent of hospice discharges. Medicaid was the primary source of payment for only 5 percent of hospice services. While Medicare information is not available at the county level, payments have been increasing substantially at the national and state levels. Nationally, in 2005, 3 percent or about \$9.75 billion of Medicare’s \$325 billion budget was spent on hospice care (Kaiser Family Foundation, 2005). In FY 2003, Medicare reimbursements in Ohio for hospice were \$249 million, in FY 2004 they were \$295 million, and in FY 2005 they were \$341 million (Centers for Medicaid and Medicare Services, n.d.).

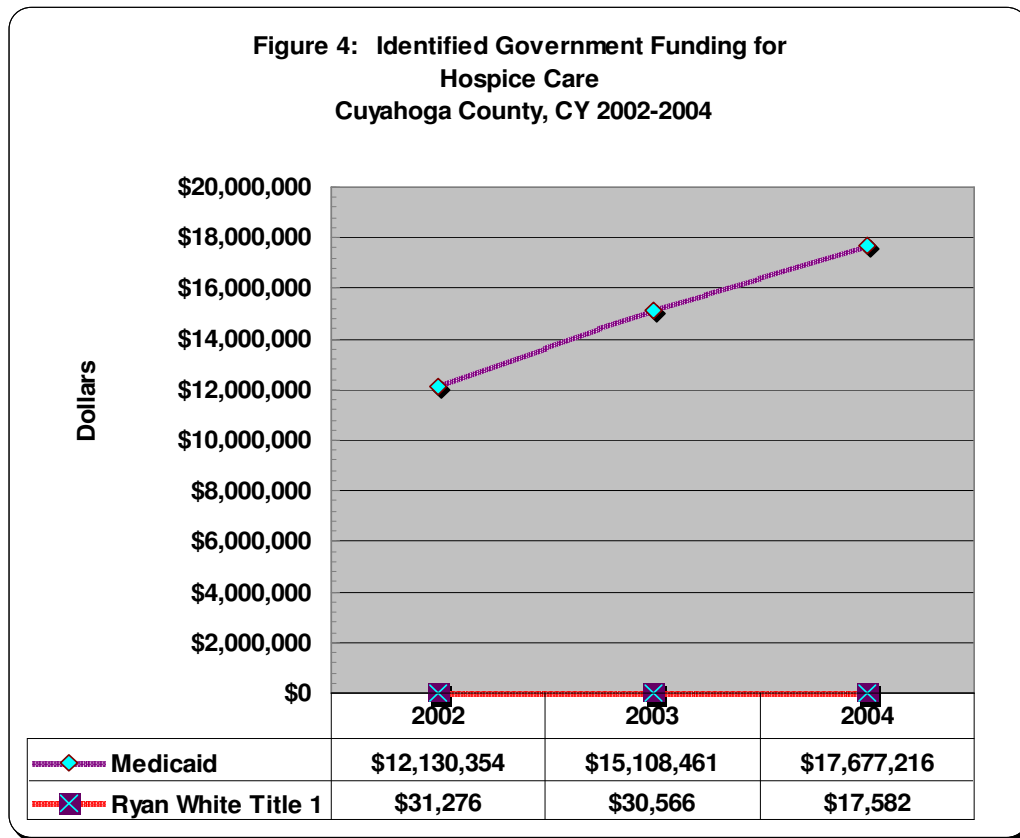
*Title I of the Ryan White CARE Act*

Authorized under the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and administered by the Department of Health and Human Services Health Resources and Services Administration, Ryan White Title I funds provide emergency assistance to eligible metropolitan areas (EMAs) that are most severely affected by the HIV/AIDS epidemic. Formula grants are based on the number of living cases of AIDS, and discretionary grants are available. To be

eligible, an area must have reported at least 2,000 AIDS cases during the previous five years and have a population of at least 500,000. Ryan White Title I funds can be used for many different kinds of outpatient and ambulatory health services, including hospice. Local Title I HIV Health Services Planning Councils make allocation decisions. In FY 2006, \$301 million was allocated nationally from Title I. In 2006, Cleveland received \$3.349 million: \$1.793 million in formula grants and \$1.314 in supplemental funding with another \$214,208 for Minority AIDS Initiative funding.

*Trends of Government Funders*

In Cuyahoga County between 2002 and 2004, Medicaid funding for hospice care increased by more than \$5.5 million (or 46 percent). Funding for Ryan White Title I funds decreased in the same time period by almost \$14,000 (or 44 percent). (See Figure 4.)



Source: Medicaid and Ryan White Title I

**IDENTIFIED REVENUES**

As of May 11, 2006, over \$18 million in revenues for hospice care programs has been identified countywide. Note: this does not include Medicare funds because county-specific funding information is not available for this program, which is administered at the federal level. Sources of information include information from foundations; federated fundraising organizations; regional, county and municipal government; and United Way of Greater Cleveland. (See Table 1.)

**Table 1: Identified Annual Revenue for Core Services: Countywide and United Way of Greater Cleveland Hospice Programs, 2003/2004.**

Funder	Period	A		B	
		Identifiable Total Dollars Countywide		Total Dollars UW-Funded Agencies (Actual FY2004)	
		Amount	% of Total (A)	Amount	% of Total (B)
<b>Total - Contributions and dues (less UW designations)</b>			<b>0.00%</b>	<b>1,895,839</b>	<b>3.78%</b>
Cleveland Foundation, The	2004	11,042		14,050	
McGregor Foundation, The	2004	28,000			
Murphy Foundation, The John P	2004	5,000			
Other Private Foundations - Not Elsewhere Classified				25,000	
Eaton Charitable Fund	2003	16,000			
Key Foundation	2003	340			
Other Corporate Foundations - Not Elsewhere Classified				25,000	
<b>Total - Foundations &amp; Trusts</b>		<b>60,382</b>	<b>0.33%</b>	<b>64,050</b>	<b>0.13%</b>
<b>Total - Special Events - Growth</b>			<b>0.00%</b>	<b>183,865</b>	<b>0.37%</b>
Combined Federal Campaign				10,540	
Jewish Community Federation	2004	400,000			
<b>Total - Federated Fundraising Organizations</b>		<b>400,000</b>	<b>2.18%</b>	<b>10,540</b>	<b>0.02%</b>
United Way of Lake County				65,000	
<b>Total - Other United Ways</b>		<b>0</b>	<b>0.00%</b>	<b>65,000</b>	<b>0.13%</b>
HIV Services Planning Council Ryan White Title I	2004	17,582		12,200	
<b>Subtotal Cuyahoga County Funding Sources</b>		<b>17,582</b>	<b>0.10%</b>	<b>12,200</b>	<b>0.02%</b>
Medicaid	2004	17,677,216		2,347,195	
Medicare				39,902,323	
Other Private Insurer				3,755,513	
<b>Subtotal Third Party Payee/Direct Bill</b>		<b>17,677,216</b>	<b>96.48%</b>	<b>46,005,031</b>	<b>91.76%</b>
<b>Total - Contracts/grants from government organizations</b>		<b>17,694,798</b>	<b>96.58%</b>	<b>46,017,231</b>	<b>91.78%</b>
Private Pay/Fee for Service				938,878	
<b>Total - Program Service Fees</b>		<b>0</b>	<b>0.00%</b>	<b>938,878</b>	<b>1.87%</b>
<b>Total - Investment Income</b>			<b>0.00%</b>	<b>585,253</b>	<b>1.17%</b>
<b>Total - All Other Revenue</b>			<b>0.00%</b>	<b>211,057</b>	<b>0.42%</b>
<b>Subtotal Non - UWGrCle Support</b>		<b>18,155,180</b>	<b>99.09%</b>	<b>49,971,713</b>	<b>99.67%</b>
<b>Total - UWGrCle designations applied to program</b>		<b>140,220</b>	<b>0.77%</b>	<b>140,220</b>	<b>0.28%</b>
<b>Total - UWGrCle investment committee allocation</b>		<b>25,923</b>	<b>0.14%</b>	<b>25,923</b>	<b>0.05%</b>
<b>Subtotal UWGrCle Support - 4001, 4701 &amp; 4703</b>		<b>166,143</b>	<b>0.91%</b>	<b>166,143</b>	<b>0.33%</b>
<b>Total Support/Revenue</b>		<b>18,321,323</b>	<b>100%</b>	<b>50,137,856</b>	<b>100%</b>

## REIMBURSEMENT/COST

As noted in Public Policy under Section II, while access to hospice services has become easier, trends in the reimbursement of hospice are of considerable concern. Medicare and Medicaid reimburse hospice providers at a per diem rate based on four levels of care in which all hospice services are to be absorbed. The levels of care are routine home care, continuous care, general inpatient, and inpatient respite. The reimbursement rates for these levels of care are in part determined by a wage index that differs by state and by county. In Cuyahoga County, the 2006 reimbursement rate from Medicare (and Medicaid observes the same rules) is as follows: for routine home care – \$128.43; for continuous care – \$749.57; for general inpatient – \$570.72; and for inpatient respite – \$132.43. These 2006 rates were about one percent lower than 2005 rates due to changes in the wage structure index (National Hospice and Palliative Care Organization, 2005c). The president’s 2007 budget also calls for reductions in the payment

updates for hospice by 0.4 percent (a reduction in the Medicare budget of 2007 of \$40 million, and \$550 from 2007-2011) (HFMA, 2006).

While Medicare is the primary source of funding for hospice care, most private health insurers have established an all-inclusive model for reimbursement, although with discounted rates below those established by Medicare. There appear to be no insurers still billing at a per service model. Private insurers generally use a “fee for service” model, meaning the hospice programs either bill the insurance company for each service rendered, or they bill the patient who must submit the bills to the insurance company. Coverage and payment levels differ, but many insurance plans have a lifetime ceiling for hospice benefits.

## V. WHAT WORKS; WHAT DOESN'T

### IMPACT ON INDIVIDUALS/FAMILIES

Hospice care often impacts individuals by providing better pain control, addressing emotional and spiritual issues associated with end of life, and allowing individuals to die in a setting they prefer. Additionally, hospice educates and supports death with dignity whereby patient's choices are discussed and acted upon. Hospice programs also address the emotional and spiritual issues of bereaved family members.

#### *What Works*

For hospice services, the timing of interventions is important. Preferably, intervention is made at the point when the patient is known to be terminal. Experts suggest that the greatest benefit of hospice services to the family is realized when there are actually several months of hospice involvement. Having patients and their families understand hospice care well before they may need it is a best practice (WebMD, 2005).

In 1997, the Robert Wood Johnson Foundation initiated the Last Acts campaign to improve end-of-life care. A basis of the campaign was that experts and the public generally agree that the best end-of-life care treats the whole person—body, mind, and spirit. In 1997, Last Acts published its Precepts of Palliative Care, which describe for health professionals five areas key to delivering high-quality end-of-life care. In summary, they are:

- Respecting patient goals, preferences, and choices;
- Providing comprehensive caring;
- Utilizing the strengths of interdisciplinary resources;
- Acknowledging and addressing caregiver concerns; and
- Building systems and mechanisms of support (Last Acts, 2002).

Per another report that looked at cancer care (produced by the Robert Wood Johnson Foundation), providing palliative care and treatment at the same time are possible and even desirable. Additionally, programs that “promoted excellence” had the following typical features:

- Ongoing communication among patients, families, and providers;
- Advanced care planning and patient-centered decision making that is iterative and reflective of patients' values and preferences;
- Formal assessment and treatment of physical and psychosocial symptoms;
- Care coordination (also known as case management) to streamline access to services and monitor quality care;
- Spiritual care;
- Anticipatory guidance in coping with illness and issues of life completion and life closure;
- Crisis prevention and early crisis management;
- Bereavement support;
- An interdisciplinary team approach to care; and
- 24/7 availability of a clinician who is knowledgeable about the case (Robert Wood Johnson Foundation, 2003).

Certification of health professionals is a leading practice. Appropriate care for dying people requires a team of health professionals trained in end-of-life care. While certification in palliative care is now available for physicians and nurses, few who offer this care have specialty training. For both physicians and nurses, certification programs in palliative care help to set standards of quality care and provide clinicians who can serve as change agents and leaders in the field of end-of-life care and within their institutions (Last Acts, 2002).

Cultural competence is a leading hospice practice. Research shows that ethnic minorities access hospice care significantly less often than Caucasians. In part, this has been attributed to the lack of cultural competence among hospice staff. In their efforts to provide culturally appropriate end-of-life care, hospices should have established intervention plans aimed at increasing cultural competence among hospice staff. An effective practice for addressing some cultural competency issues is peer mentoring. Peer mentoring, whereby trained patients educate other patients, offers a culturally sensitive way to tell dialysis patients about their condition and treatment options. In cultural groups with oral rather than written traditions, this person-to-person approach appears to encourage discussion about living wills (advance directives) and end-of-life decision making. The benefits were most pronounced in African American subjects for whom significant improvements in their comfort discussing such directives, subjective well-being, and anxiety levels were also seen (American Journal of Kidney Disease, 2005).

#### *What Doesn't Work*

A “one size fits all” model for end-of-life palliative care doesn't work. In the last year of life, there are distinct patterns of function decline for different diseases that indicate the need for different approaches to palliative care. Different diseases have different trajectories, and even the same disease can be manifested in significantly different ways for individual patients. People usually assume a terminal illness when thinking about the end of life, yet only 23 percent of Americans die of cancer—the most common illness with a distinct terminal phase. Most, particularly those who are chronically ill, are not diagnosed as “terminal,” yet they may also need palliative care (Department of Health and Human Services, 2003). Thus, strategies that continue to educate physicians, families, and patients about the value of hospice should be employed.

Not talking about end-of-life care doesn't work. According to the Robert Wood Johnson's Last Acts study, despite many recent improvements in end-of-life care and greater public awareness of it, Americans at best have no better than a fair chance of finding good care for their loved ones or for themselves when facing a life-threatening illness. In most states, too few patients are accessing hospice and palliative care services; there are too few professionals trained in pain management and palliative care; and there are too many patients dying in hospitals and nursing homes—in pain—rather than at home with their families (Last Acts, 2002).

Uncoordinated care for hospice does not work. The current health care delivery system is organized by setting: nursing home, hospital, home, and doctor's office. This determines how insurance pays bills, providers meet patients, and regulations are applied. Each care provider generally works in only one setting. Patients needing chronic care change settings often and may do so for several years; however, they have an overriding need for continuity of care, both across settings and throughout the changing challenges of worsening illness (Lynn & Adamson, 2003).

Ignoring patients' physical pain does not work. A self-reported survey conducted by the American Hospital Association (AHA) in 2000 found that only 42 percent of U.S. hospitals

reported offering formal pain management programs, and 23 percent and 14 percent offered formal hospice or palliative care programs, respectively (Last Acts, 2002). More than 20 percent of residents die in nursing homes—a figure projected to double by 2020. Adequate pain management for seriously ill and dying nursing home residents is essential to achieving high quality end-of-life care (Last Acts, 2002). Ignoring pain is an inappropriate and unethical practice. According to a comprehensive national study conducted in 1999, nearly one sixth of nursing home patients are in daily pain, and more than 40 percent of residents who were in pain at their first pain assessment were still in severe pain 60 to 180 days later. Another study found that many dying nursing home residents who are in daily pain receive either inadequate pain treatment or none at all (Last Acts, 2002). Medical experts agree that at least 90 to 95 percent of all serious pain can be safely and effectively treated; yet at least half of dying patients report being in pain. For the patient, unrelieved pain is oftentimes crippling; it triggers a range of problems that include depression, social isolation, disturbed sleep, decreased mobility, falls, difficulty in thinking clearly, and loss of appetite. Unrelieved pain is costly to society in both direct and indirect ways, and it can ruin the patients' and their families' quality of life (Last Acts, 2002).

## IMPACT ON COMMUNITY

Hospice programs can have significant cost savings, and produce quality community dialogue around end-of-life issues.

According to an article published in the *Journal of the American Medical Association*, hospice care and advance directives can save between 25 percent and 40 percent of health care costs during the last month of life (Emanuel, 1996). In 1995, Lewin-Value Health, Inc. (VHI), a Washington-based health care consulting firm commissioned by the National Hospice Association, documented that, nationally, for every dollar Medicare spent on hospice, it saved \$1.42 in Part A and Part B expenditures (looking at Medicare hospice and non-hospice users with cancer). Greatest savings occurred in the last month of life, when costs for non-hospice care averaged \$3,900 more than costs for the comparative hospice group (Center to Advance Palliative Care, 2002). Another study by the Health Care Financing Administration and the Social Security Administration in 1997 demonstrated that, for Medicare, hospice had a significantly lower per day reimbursement cost (\$111), compared with a skilled nursing facility (\$426), and a hospital stay (\$2,002) (Lycan, 2004).

The following findings are also important to consider about hospice care:

- Eighty-three percent of people who die each year are eligible for Medicare.
- At least one-third of all Medicare expenditures go to care for an eventually fatal illness (Center to Advance Palliative Care, 2002).
- Medical care at the end of life consumes 10-12 percent of the total health care budget and 27 percent of the Medicare budget (Emanuel, 1996).

Finally, compared to traditional care for the terminally ill, hospice care and the use of advance directives such as living wills and medical powers of attorney that explain the extent to which people want life-sustaining medical treatments could save up to 10 percent of the cost of care in a patient's last year of life, 10 to 17 percent in the last six months, and 25 to 40 percent in the final month. Experts and consumers alike believe that honoring a terminally ill patient's treatment preferences is a critical element of high-quality end-of-life care (Last Acts, 2002).

## ACCREDITATIONS/STANDARDS/CERTIFICATIONS

### *Hospice Programs*

Hospice is accredited by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), established in 1951. The standards for hospice programs were developed in 1986 and are found under JCAHO Accreditation for Home Care Organizations. Standards are updated every two years to improve clarity and reduce duplication. Accreditation has several benefits: (1) improves patient care, (2) strengthens community confidence, (3) provides professional consultation and enhances staff education, (4) may substitute for Medicare and Medicaid certification, (5) fulfills licensure requirements in several states, (6) is recognized by insurers and other third parties, (7) attracts professional referrals, (8) enhances financing capabilities, and (9) may reduce liability insurance coverage.

Accreditation by the Joint Commission is recognized nationwide as a “seal of approval” which indicates that an organization meets certain quality standards. The accreditation process is voluntary, so it up to an organization to pursue accreditation. To earn and maintain accreditation, an organization must undergo an on-site survey by a Joint Commission survey team at least every three years. (Joint Commission of Accreditation of Healthcare Services, 2005)

The Accreditation Commission for Health Care (ACHC) has a hospice accreditation program. ACHC accredits standard hospice services, in-patient services, and pharmacy services.

Additionally, the Community Health Accreditation Program, Inc. (CHAP) accredits hospice programs. CHAP has “deeming authority” by the Health Care Financing Administration (HCFA) of the U.S. Department of Health and Human Services. The federal government recognizes CHAP hospice standards as meeting or exceeding federal standards for participation in Medicare.

Additionally, all hospice programs that bill for services under Medicare and Medicaid hospice benefits must be licensed by the state of Ohio.

### *Hospice Physicians and Nurses*

Since 1996, the American Board of Hospice and Palliative Medicine (ABHPM) has offered physicians certification in palliative care. Certification is an acknowledgment of a physician’s expertise, attitudes, and skills as they apply to good palliative care. Additionally, the American Board of Internal Medicine has agreed to apply to the American Board of Medical Specialties for approval of a subspecialty certificate in hospice and palliative medicine (American Board of Hospice and Palliative Medicine, 2005). As the Accreditation Council for Graduate Medical Education does not yet accredit palliative medicine residencies or fellowships, a limited number of these programs currently exist (Last Acts, 2002). The Hospice and Palliative Nurses Association (HPNA) has provided this certification since 1994. To be certified, CHPNs must demonstrate both knowledge and competency in hospice and palliative nursing. Finally, accreditation standards for medical schools now include the mandate to cover end-of-life care; however, the requirement contains no clear standards for that instruction.

*Other Standards*

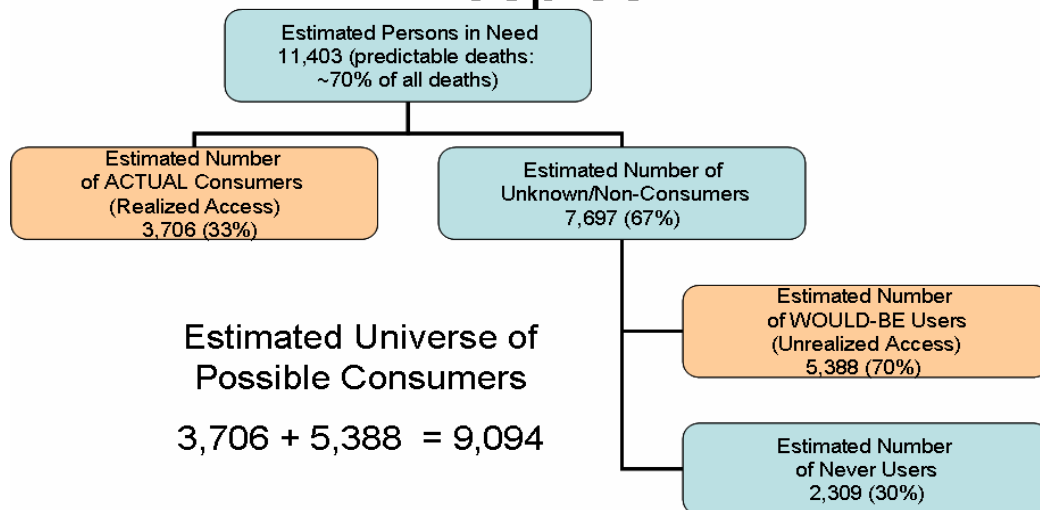
The National Consensus Project for Quality Palliative Care developed “Clinical Practice Guidelines for Quality Palliative Care in 2004.” These guidelines were established to promote consistent and high quality care, and to guide the development and structure of new and existing palliative care services. These guidelines are applicable to specialist-level palliative care delivered in a range of treatment settings, as well as to the work of providers in primary treatment settings where palliative approaches to care are integrated into daily clinical practice (National Consensus Project of Quality Palliative Care, 2004). These guidelines cover eight domains of care: physical, psychological, psychiatric, social, spiritual, cultural, imminently dying patient, and ethical and legal.

## VI. GAP ANALYSIS

The following is the formula for arriving at the estimated universe of possible consumers for Hospice Care:

- A conservative estimate of 11,403 persons in Cuyahoga County need hospice, which is based on the number of deaths estimated to have been predictable (e.g., not a result of an accident or sudden illness) in Cuyahoga County in 2000. This is based on Connor's (1999) estimate that 70 percent of annual deaths are predictable and, therefore, possible users of hospice.
- Approximately 3,706 had realized access to hospice services. This leaves a net estimate of 7,697 persons who are either receiving services from unaccounted-for sources or are not receiving hospice. ( $11,403 - 3,706 = 7,697$ )
- The study by Connor (1999) also noted that the potential number of person who could utilize hospice care is far greater than the number that actually does, perhaps as great as 70 percent. Applying this to the estimated number of unknowns results in 5,388 would-be users, or those who have unrealized access. ( $7,697 \times 70\% = 5,388$ )
- Including both realized (3,706) and unrealized (5,388) access, the estimated universe of possible consumers for hospice is 9,094. (See Figure 5.)

### Figure 5- Consumer Estimates: Hospice



#### *Service Site Index*

There is no Service Site Index because of the nature of this service.



### *Service Capacity*

One study found that only 30 to 35 percent of all individuals who would benefit from hospice actually do utilize the service (Simpson, 2003). This percentage was consistent with this core service report's findings (35 percent were estimated to have realized access in Cuyahoga County). There are many reasons for this disparity, including lack of knowledge in patients and family, physicians, and other caregivers, and concerns about "giving up" on the patient (Jennings, Ryndes, D'Onofrio, & Baily, 2003). Cultural beliefs also can contribute to an inequitable utilization of hospice for some racial and ethnic groups. While the proportion of persons of color is growing, research shows that ethnic minorities access hospice care significantly less often than Caucasians. For example, African Americans are aware of the discrimination they encounter in the health care system and are more likely to distrust their health care providers, and this affects their attitude towards hospice. They are more likely to question the motives underlying referral to hospice and other physician decision-making at the end of life and may be concerned that hospice care will be of lower quality than hospital care (Jennings et al., 2003). This has also partially been attributed to the lack of cultural competence among hospice staff (Doorensob and Schim, 2004). Finally, financial reimbursement for hospice care requires a diagnosis that predicts a life expectancy of six months or less, which may limit individuals' ability to access hospice services.

Since the delivery of hospice services is not limited to a specific physical space, the capacity to deliver hospice services will be related to the numbers of trained personnel, the development of the skill sets essential to consistent high quality hospice and palliative care in a variety of settings—hospitals, nursing homes, primary care settings, rehabilitation settings, home health care programs, and others (Pitorak & Amor, 2002).

## VII. SUMMARY

In summary, there are several major findings from the research on hospice programs:

- Death and dying have changed dramatically for Americans over the past century. Life expectancy has increased by almost three decades, from 47 years in 1900 to 75 years in 2000. Death in older age is most often a result of chronic conditions. Given the trajectory of these types of diseases, prolonged periods of disability, dementia, and frailty shape the last years of life for a large part of the population.
- There are many public policy issues concerning hospice care, but two key concerns are Medicare reimbursement rates, and education of the public and health care professionals about the importance of hospice and end-of-life issues.
- Recent major studies looking at death and dying in America concluded that dying in America is unnecessarily painful and isolating; physicians do not understand patients' wishes; and it is costly. Additionally, people have come to fear a technologically over-treated and protracted death and dread the prospect of abandonment and untreated physical and emotional stress. Most people want to die at home, though only about a quarter actually do.
- Most Americans come to the end of their lives in hospitals, and paid professionals, rather than family members, provide most of the visible and costly health care.
- Medicare is the primary source of payment for 79 percent of hospice discharges. Medicaid was the primary source of payment for only 5 percent of hospice services. Nationally, in 2005, 3 percent or about \$9.75 billion of Medicare's \$325 billion budget was spent on hospice care (Kaiser Family Foundation, 2005).
- As of May 11, 2006, over \$18 million in revenues for hospice care programs has been identified countywide.
- There is significant literature demonstrating what works in hospice care. Best practices include appropriate timing of intervention (which is often well before most individuals choose to turn to hospice), a coordinated and multidisciplinary approach to care, and effective education on the role of hospice.
- Uncoordinated care and a "one-size-fits-all" model of care do not work in hospice.
- The estimated universe of possible consumers is 9,094 including both realized access (3,706) and unrealized access (5,388).

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## ATTACHMENTS

### Attachment 1: Researcher List

# MCS

## CONSULTING SERVICE

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## Attachment 2: Technical Notes

### Technical Notes: Methodology, Caveats, Limitations of Data

The following provides descriptions, definitions, methodologies, caveats, or limitations of data for the following components of the core service reports:

- Unit of Analysis
- First Call for Help Data
- Funding Information for Core Services
- Consumer and Financial Data: Caveats
- Gap Analysis Methodology & Limitations
- Service Site Index

#### Unit of Analysis

The core service is the unit of analysis. United Way of Greater Cleveland either funds or could fund 80 core services. These are the object and subject of the research, specific to Cuyahoga County. A separate report has been developed for each service. It must be noted that the aggregate of any quantifiable data across all of the reports does not comprise a picture of the totality of health and human services in Cuyahoga County because there are many more than 80 services that comprise the community's safety net.

The unit of analysis for estimates of service consumers is the individual, the family, or the household.

#### United Way - First Call for Help Data

For most core services, United Way First Call for Help (FCFH), the community's resource and referral service data, was used in tables that show the number of service providers and service sites, the geographic location of service providers by zip code, the service area by zip code as reported by providers of the respective services, and to show unmet need and greatest increase/decrease in calls received by FCFH for a particular core service.

It is important to remember that FCFH receives calls from a variety of sources that include people calling on behalf of a prospective consumer such as social workers, provider agencies, relatives, etc. Not all calls come directly from a prospective consumer, so some of the zip codes are for hospitals and business addresses, although the numbers for these zip codes are relatively small.

Calls also may be from people who are not interested in receiving a service, but wish instead to make a contribution to a program such as clothing, household items, food, books, crafts supplies, etc.

Because, in many instances, FCFH codes its data with a different level of core services than the 80 core services identified by the United Way Community Investment staff as fundable services, it was necessary to develop a crosswalk. This crosswalk was used for a number of services,

however, seven services did not have a match in the FCFH database. The staff of United Way - First Call for Help gave explanations which follow each core service):

- Adolescent/Youth Counseling: A caller asking about help with their troubled teenager would be referred by the type of counseling rather than age. (Example: counseling for drugs, family, sexual abuse, etc.)
- Advocacy: FCFH does not receive calls from people about advocacy.
- Child Care: Calls are directed to Starting Point.
- Condition Specific Rehabilitation Services: FCFH would refer caller back to their primary care physician for a referral.
- Early Intervention for Mental Illness: FCFH does not receive calls for this, but if they did, they would refer to the county's Help Me Grow program.
- Family Support Centers: FCFH defines data by specific service rather than type of agency. Depending on the call, the caller may be referred to General Counseling or Early Intervention for Infants and Toddlers with Disabilities, and so on.
- Preschools: Calls are directed to Starting Point.

A different match was used for other services that had no crosswalk.

- Medical Transportation and Senior Ride: FCFH uses "Paratransit" as they do not differentiate between senior transportation, medical transportation, and transportation for the disabled.
- Outpatient Mental Health Facilities: FCFH uses "Mental Health Drop-in Centers."

It must also be noted that, for the most part, the FCFH database does not include for-profit agencies. In the case of home health care providers, we contacted the Long Term Care Ombudsman for a more complete list of provider agencies which includes for-profit organizations.

There were several instances where the FCFH database did not code a United Way-funded agency with the core service for which they were receiving funding. In these instances, the agency was added manually to the Service Provider Table along with their site locations. The core services with the respective United Way of Greater Cleveland agencies that were added are:

- Case/Care Management – Care Alliance, Cystic Fibrosis, Epilepsy Foundation, Golden Age Centers
- Comprehensive Outpatient Substance Abuse Treatment – The Covenant
- Disease/Disability Information – The Muscular Disease Society of Northeastern Ohio
- Early Intervention for Infants and Toddlers with Disabilities – United Cerebral Palsy
- Medical Expense Assistance – North Coast Health Ministry
- Medical Transportation (Paratransit in FCFH) – Kidney Foundation of Ohio
- Senior Centers – Catholic Charities Services Corporation, Jewish Community Center of Cleveland, Jewish Family Service Association of Cleveland, University Settlement House.
- Volunteer Development – Neighborhood Leadership Institute

It must also be noted that when numbers are low for trend data reported, the high percentages are slightly exaggerated.

## **Funding Information for Core Services**

We collected financial information for each core service on a countywide level from multiple sources including major government funders, foundations, federated fund raising organizations, and United Way of Greater Cleveland. While we were successful in gathering a substantial amount of data, there is much that has not been collected. It must also be noted that even if we had all major public and private funding gathered, this would not create a total picture of health and human service funding in Cuyahoga County because there are more than 80 core services provided. The following provide highlights of data collected and some of the limitations for each source. It is important to note that funding in each source is changing and represents point in time amounts. The typical period for trend data, when available, is 2002, 2003, and 2004. Note: some services are funded by private insurance or other self-pay arrangements.

### *Foundation Funding*

We attempted to obtain foundation funding amounts for each core service from the latest annual report or 990 PF (foundation tax return to the IRS) of each major foundation that funds social services in Greater Cleveland. Wherever a description of the grant purpose was given, we used our best judgment to match the grant to the appropriate core service. If the grant fell within more than one core service area, it was not listed. When no description was given, the grant was treated like a general operating grant and assigned to a core service only when the mission of the grant recipient fell mainly within one particular core service. In-kind donations, grants for capital and equipment expenses and administrative salaries were not used. When grants were \$10,000 or greater, they were listed by name of the foundation. All others were placed under Other Foundations and not listed. Typically, we did not attempt to provide trend financial data for foundation funding of core services because of the changing nature of funded programs from year to year.

### *Federated Funding Sources*

We approached the major federated funders of core services in Greater Cleveland for funding and consumer information. Some data provided was for a single point in time; others provided three years of trend data. We often had to do a cross walk of United Way of Greater Cleveland funded core services against those funded by federated agencies to agree on the services.

### *Government Funding*

We approached every major government funder for funding amounts for each core service and also did Internet searches for some federal government sources. Due to the constant state of change in government funding, it is important to note that the data provided is a snapshot in time and that many of the programs funded in 2004 have changed definition, are funded through different revenue sources, or no longer exist at all due to a lack of funding. This is particularly true of Community Development Block Grant dollars which have decreased due to shifting federal priorities.

Every effort was made to appropriately match government funding data to the correct core service area; however, this was not always possible as frequently the service definitions were not a one-to-one match. It was necessary, in some instances, to take the closest match or use the sore service which represented a majority of the services being provided.

In other cases, it was not possible to select a specific core service. An example is Medicaid in which Medicaid-defined services crossed over more than four core services in some instances. In cases where Medicaid is a significant source of revenue, the data was entered as an

aggregate total at the appropriate AIRS level. These aggregates are footnoted under the appropriate funding table.

Every effort was made to include data from municipalities. However, many did not respond after repeated requests for information. We would like to thank those who took the time to help with this project.

#### *Medicaid Funding*

A significant portion of Medicaid funding was NOT entered under the countywide total in the core service reports for two reasons: first, because many of the Medicaid services are not a one-to-one match with United Way core services, and second because some Medicaid services fall into more than one AIRS Level 1 categories. In the first instance, Medicaid funding was entered as an aggregate total at the AIRS 1 level, and in the second instance Medicaid funding was entered as an aggregate total under Third Party Payee/Direct Bill in the combined Master Revenue file of funding across all nine AIRS Levels. They are as follows:

#### **Entered as Aggregate Total Under Appropriate AIRS Level**

- Medicaid Service - Home Care (\$17,787,703 in 2004) - Falls into AIRS 1 Health Care and includes the following core services: daily living aids and home health care.
- Medicaid Service - CADAS (\$8,522,183 in 2004) - Falls into AIRS 1 Health Care and includes the following core services: comprehensive outpatient substance abuse treatment, residential substance abuse treatment programs, substance abuse education and prevention.
- Medicaid Service - Therapy (\$2,257,394 in 2004) - Falls into AIRS 1 Health Care and includes the following core services: condition specific rehabilitation, and speech & hearing.
- Medicaid Service - CMH (\$67,773,487 in 2004) - Falls into AIRS 1 Mental Health Care & Counseling and includes the following core services: supportive therapies, adolescent/youth counseling, children's residential treatment facilities, early intervention for mental illness, general counseling services (outpatient mental health facilities), and psychiatric day treatment.

#### **Entered as Aggregate Total Under Third Party Payee/Direct Bill**

- Medicaid Service - Inpatient Hospital (\$188,329,269 in 2004) - Falls into two different AIRS 1 categories: Basic needs and health care. It includes the following core services: condition specific rehabilitation and medical expense assistance.
- Medicaid Service - Waiver (\$128,921,354 in 2004) – This category included all PASSPORT services. Since we reported PASSPORT separately, in order to avoid duplication, we deducted the PASSPORT total of \$52,676,048 from this number and reported the remaining \$76,245,306. This total falls into AIRS 1 Basic Needs, Health Care and Individual & Family Life and includes the following core services: adult day care, home-delivered meals, home health care and in-home assistance.
- Medicaid Service - Habilitation (\$55,550,307 in 2004) - Falls into AIRS 1 Health Care and Individual & Family Life and includes the following core services: condition specific rehabilitation services, early intervention for infants and toddlers with disabilities/delays, and residential living options for people with disabilities.

#### *United Way of Greater Cleveland Funding*

Financial data for core services funded by United Way of Greater Cleveland was for FY 2004 (July 2003 to June 2004). It included allocations through the community investment committees

and donor designations that United Way funded agencies applied to the respective core services. It is important to note that not all United Way funded agencies applied donor designated gifts, which are unrestricted, to the core service for which they receive United Way funding. It did not include donor designations that non-United Way funded agencies used for any of the 80 core services.

*United Way Agency Revenues*

Annually United Way-funded agencies submit revenue budgets to United Way for each funded core service. This information for FY 2004 is reported. However, all of the agency data may not be included in the countywide data as agencies may have assigned dollars from unrestricted grants to a specific core service, or allocated a portion of grant monies that fell within two or more core service areas. It was not always possible to match countywide government or foundation funding with that reported by the agencies and that gathered from other funding sources.

**Consumer and Financial Data: Caveats**

The following applies to revenue sources on tables and graphs and their corresponding consumer data used in the consumer demographics and zip code tables.

*All Core Services*

Data was self-verified by the funder/provider. Whenever data provided by a funder appeared to be inconsistent or incorrect, an attempt was made to contact the funder. If the funder responded, the data was either adjusted according to their instructions, or the reason for discrepancies footnoted. If they did not respond, or if they said it was correct, the data was left as submitted.

Demographic and zip code data provided by the funder/provider is frequently taken from consumer intake forms which may have missing or incomplete data, or from provider agency databases which contain data entry errors or incomplete consumer intake forms. Whenever possible, the funder was asked for corrected data. In cases where a correction was not possible, the data was counted as either unknown or missing. The usage of these terms is footnoted at the bottom of each table and is explained more fully in the Gap Analysis section of this attachment.

It was not always possible to get information in the format requested as each funder tracks data differently, using different service definitions, terminology and variables. Wherever possible, data was matched to a consistent report format.

When a funder could not provide consumer demographics, but could provide an estimated percentage of consumers by category, we took the total number of consumers and applied the percentages to come up with estimated numbers for the consumer tables. For example, Medicaid tracks individual recipients throughout the year, entering new data if there is a change, each time a claim occurs. Thus, a consumer who has a birthday between claims will appear in the system for that year with two different ages.

To resolve this, the percentage of consumers in each age range was determined for the total number of duplicated consumer ages. Those percentages were then applied to the total number of unduplicated consumers for the year in order to reach a total number of unduplicated consumers for each age range.

The time periods for both revenue and consumers vary by funder/provider. United Way Program Report data is for FY 2004 (July 2003 to June 2004). Other funder/provider data is for either a January to December or July to June fiscal year.

### **Gap Analysis Methodology & Limitations**

Based on Anderson's (1964) seminal needs assessment model, realized access is defined as the number of consumers who receive service while unrealized access is the estimated number of consumers who need and would utilize a service, but are not currently receiving it. This could be considered the service gap. Unrealized consumer access to services drives the need for change in the social service delivery system. Ensuring unrealized consumer access to services requires new models of service delivery related to access, effective use of resources, data management, and funding. There were multiple steps used to conduct a gap analysis:

- *Estimate of persons in need of the service:* Unless local research was conducted to determine need for a given service, this estimate was obtained by either using U.S. Census data for Cuyahoga County or applying percentages from national studies and reports to the census data. All references and percentages are footnoted in the respective graphs or tables. In most cases this percentage was also applied to actual 1990 Census figures and population projections 2005 through 2015 that were done by the Ohio Department of Development.
- *Estimate of number of ACTUAL consumers in the public systems (realized access):* Data submitted to United Way by funded agencies was aggregated to determine the number of consumers for each core service. The period was FY 2004, which is July 2003 through July 2004.
  - In some cases data was "unknown," defined as data not collected by agency because no tracking system was available or the type of service delivered made it difficult (i.e., group presentations, telephone information and referral, and drop-ins). This also represents data not completed by consumers either deliberately or inadvertently on intake forms.
  - In other cases, data was missing that, for United Way data, represented computational errors or incorrect completion of online reports. For all other data, "missing" represents data funders/providers were unable to provide.
  - There was no check of the accuracy of data submitted by agencies.
  - Major government funders were asked to provide information about the number of consumers for the respective core services that they funded. In most cases, services were not defined in the same way as the United Way core services which are based on the Alliance for Information and Referral Systems (AIRS) taxonomy. To accommodate these differences, customized crosswalks were developed.
  - We assumed that the numbers of consumers across funding sources were not unduplicated and thus made a judgment about which numbers would be the best estimate of an unduplicated number.
  - The estimate of consumers is not inclusive since it does not include numbers of consumers who use their personal resources to pay for services, nor for other private resources such as insurance or agency fundraising. In addition, it was not always possible to obtain information from some government funders.
- *Estimate of number of "unknown/non-consumers":* This is the difference between the estimated number of actual consumers and the estimate of persons in need.

- *Estimate of number of “would-be users” (unrealized access):* This is the estimate of persons who would use a service if it were available, typically based on research.
- *Estimate of number of “never users”:* This is the difference between the estimated number of unknown/non-consumers and would-be users.
- *Estimate of “universe of possible consumers”:* This is the total of those actually receiving the service (realized access) and those would-be users (unrealized access).

We recognize that this is not a perfect method for assessing either realized or unrealized access to core services. However, we opted to use an imperfect method rather than no method to demonstrate both the complexity and the usefulness of quantifying realized and unrealized access to services as a first step toward a more rigorous methodology. In the business sector this would be a form of market analysis. We also recognize that actual consumer numbers are not unduplicated across funders, or across core services. Thus, there is much work yet to be done to gain realistic estimates of needs.

The numbers we provided are on a countywide level. We recognize that there could be, and often are, differences by demographics and geographical area. In the Actual Consumer Demographics attachment, we have identified the profile of the base consumer group from census, but have little on the estimated persons in need. Occasionally, there is information from other research that describes differences among different racial, ethnic, gender, age, or income groups that is discussed in the narrative. There is also inconsistent information for consumers funded by various governmental bodies. In other words, some funders provided demographic data and others did not. In the Actual Consumer Zip Codes attachment, we have also attempted to identify the geographic profile of the estimated persons in need and actual consumers. However, this information has the same limitations as the demographics.

### **Service Site Index**

For many services a service site index was developed. It provides a ratio of estimated consumers per service site on a countywide level and for each zip code within the county. The ratio is based on the number derived from the gap analysis described in the previous section and on the number of providers who reported to United Way – First Call for Help whether a specific service site includes a given zip code in its service area. A provider site is located in a single zip code, but could serve multiple zip codes. The ratio is a measure of potential service accessibility by estimated universe of service consumers per zip code area. This measure does not include the capacity of providers to offer the service, for example, the number of consumers that can be served on a daily basis. It is only capturing whether there is a possibility of being a consumer. The lower the ratio, the greater is the chance of receiving service. The index also gives an indication of which zip codes have higher ratios which means that consumers have a lower probability of receiving a service as well as any patterns in zip codes that have high percentages of African Americans, Asians, or Hispanics. A map is also attached which provides a graphic picture of the estimated consumers by zip code.

Based on the numbers of providers that report to FCFH whether they serve a given zip code, we had assumed that there would be greater variability across zip codes. In reality, many report that they serve the entire county. Thus the variability across zip codes is often primarily because of differences in the population numbers rather than in service sites that offer service in a given zip code.



## Specific Service Issues

### *Senior Services*

“Senior Centers” was used as a catch-all category when the funder-defined service covered more than one senior success core service and could not be accurately allocated among the separate core services. Often, funding for transportation and home-delivered meals was not broken out from senior activities and supportive services at the municipal level, so it was placed under Senior Centers. Because the core services for congregate and home-delivered meals and senior ride were tracked separately, funding for these core services was not included under Senior Centers to avoid duplication of resources, even though senior center activities can and do include congregate meals.

Senior Ride includes disabled individuals of all ages as well as seniors for most funders with the notable exception of Western Reserve Area Agency on Aging (WRAAA) that requires an individual to be 60 years of age or older in order to receive services. If the transportation service was not provided by a senior center, the number of consumers reflects the number of riders using the system and contains duplicates (e.g. paratransit).

Home improvement/accessibility data includes programs for low-income families and people of all ages with disabilities, as well as seniors.

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### Attachment 3: Actual Consumer Demographics

Core Service: Hospice Care LT-300					
PERIOD	Total County Average Resident Deaths (%) <sup>*</sup>	Estimated Persons in Need	Actual Number/Percent of Consumers by Funding Source <sup>***</sup>		
			Estimated Average Predictable Deaths (%) <sup>**</sup>	UW Program Report Data Cuy Cnty Only 67% (%) 7/1/2003-6/30/2004	Medicaid (%) 2004
<b>TOTAL</b>	<b>16,290</b>	<b>11,403</b>	<b>3,706</b>	<b>1,714</b>	<b>8</b>
<b>Percent</b>	<b>100.0%</b>	<b>70.0%</b>			
<b>GENDER</b>					
Male	49.3%	N/A	41.9%	0.0%	75.0%
Female	50.7%	N/A	58.1%	0.0%	25.0%
Unknown Data <sup>****</sup>			0.0%	0.0%	0.0%
Missing Data <sup>*****</sup>			0.0%	100.0%	0.0%
<b>RACE<sup>*****</sup></b>					
White alone	N/A	N/A	80.6%	70.7%	37.5%
Black or African American alone/combination	N/A	N/A	17.7%	34.9%	50.0%
Asian alone/combination	N/A	N/A	0.2%	0.3%	0.0%
American Indian and Alaska Native alone/combination	N/A	N/A	0.0%	0.1%	0.0%
Native Hawaiian and Other Pacific Islander alone/combination	N/A	N/A	0.0%	N/A	N/A
Some other race alone/combination	N/A	N/A	0.0%	0.1%	12.5%
Unknown Data <sup>****</sup>			1.6%	N/A	N/A
Missing Data <sup>*****</sup>			0.0%	0.0%	0.0%
<b>HISPANIC<sup>*****</sup></b>	<b>N/A</b>	<b>N/A</b>	<b>0.6%</b>	<b>1.5%</b>	<b>12.5%</b>
<b>AGE</b>					
0-4	N/A	N/A	0.5%	0.6%	
5-9	N/A	N/A	0.3%	0.0%	
10-14	N/A	N/A	0.2%	0.0%	100.0%
15-19	N/A	N/A	0.2%	0.0%	
20-34	N/A	N/A	0.5%	20.5%	
35-54	N/A	N/A	7.2%	0.0%	
55-64	N/A	N/A	10.7%	0.0%	
65-74	N/A	N/A	16.4%	84.4%	0.0%
75+	N/A	N/A	64.0%	0.0%	0.0%
Unknown Data <sup>****</sup>			0.0%	0.0%	0.0%
Missing Data <sup>*****</sup>			0.0%	0.0%	0.0%
<b>INCOME<sup>*****</sup></b>					
<b>Average Household Size</b>					
\$0-\$9,999	N/A	N/A	0.0%	0.0%	0.0%
\$10,000-\$14,999	N/A	N/A	0.0%	0.0%	0.0%
\$15,000-\$19,999	N/A	N/A	0.0%	0.0%	0.0%
\$20,000-\$29,999	N/A	N/A	0.0%	0.0%	0.0%
\$30,000 and above	N/A	N/A	0.0%	0.0%	0.0%
Unknown Data <sup>****</sup>			100.0%	0.0%	0.0%
Missing Data <sup>*****</sup>			0.0%	100.0%	100.0%
<b>Totals</b>	<b>N/A</b>	<b>N/A</b>	<b>100.0%</b>	<b>100.0%</b>	<b>100.0%</b>

### Attachment 3: Actual Consumer Demographics (continued)

<p>* Ohio Department of Development, Office of Strategic Research. Projections of Births, Deaths and Natural Increase by Sex. 5 year projections divided by 5 to obtain annual averages.</p>
<p>** Seventy percent of annual average deaths based on research: Connor, S. (1999). New initiatives transforming hospice care. <i>The Hospice Journal</i>, 14(3/4): 193-203. Seventy percent of annual deaths are predictable and therefore possible users of hospice.</p>
<p>***Note: Consumers could be funded by more than one funding source; thus the columns are not necessarily mutually exclusive.</p>
<p>****Unknown Data - Represents data not collected by agency because no tracking system is available or type of service delivered makes it difficult (i.e., group presentations, telephone information and referral, and drop-ins). Also represents data not completed by clients either deliberately or inadvertently on intake forms.</p>
<p>*****Missing Data - For United Way Data - represents computational errors or incorrect completion of online report. For all other data - represents data funder was unable to provide.</p>
<p>*****The race categories and data utilize US Census SF4 "Race Iterations," which allow for multiple races to be selected by census respondents. As a result, totals will add to &gt; 100% of population. Universe is "Total Races Tallied." Except "White Alone", all racial categories are "... alone or in combination with some other race". This method isolates and minimizes the non-minority population ("White alone").</p>
<p>*****Hispanic - Amount in this field is from data provided by clients on intake forms and may not be accurate as clients may either deliberately or inadvertently provide incomplete data, or data may not be collected by the agency.</p>
<p>*****The U.S. Census reports income by household or family, not individuals. Estimates by income category were derived by applying the ratio of total county population (1,393,978) to total households (571,606) = 2.4. The number of households in each income category was multiplied by 2.4 to arrive at an estimate of individuals by income category. The assumption is that the average household size applies to each income category, which may result in more conservative estimates for children, and the "old old," which may actually have larger proportions of persons in the lower income categories.</p>

### Attachment 4: Actual Consumer Zip Codes

Core Service: Hospice Care LT-300						
Period	City/Town (% Cleveland)	Total County Average Resident Deaths (%) <sup>*</sup> 2000 to 2005	Estimated Persons in Need	Actual Number/Percent of Consumers by Funding Source <sup>***</sup>		
			Estimated Average Consumers of Predictable Deaths (%) <sup>**</sup> 2000 to 2005	UW Program Report Data (%) 7/1/2003-6/30/2004	Medicaid (%) 2004	Ryan White Title I (%) 2004
<b>TOTAL</b>		<b>16,290</b>	<b>11,403</b>	<b>3,706</b>	<b>1,714</b>	<b>8</b>
<b>Percent</b>		<b>100.0%</b>	<b>70.0%</b>			
44017	Berea	N/A	N/A	2.0%	2.3%	0.0%
44022	Bentleyville	N/A	N/A	1.2%	0.7%	0.0%
44040	Gates Mills/Mayfield Village	N/A	N/A	0.1%	0.0%	0.0%
44070	North Olmsted	N/A	N/A	0.9%	2.0%	0.0%
44101	Cleveland (100%)	N/A	N/A	0.0%	0.0%	0.0%
44102	Cleveland/Brooklyn (95%)	N/A	N/A	1.5%	4.3%	0.0%
44103	Cleveland (100%)	N/A	N/A	1.8%	3.3%	0.0%
44104	Cleveland (100%)	N/A	N/A	0.6%	1.2%	0.0%
44105	Cleveland/NewburghHts/GarfieldHts (75%)	N/A	N/A	1.4%	1.9%	0.0%
44106	Cleveland/Cleveland Hts (60%)	N/A	N/A	10.3%	5.0%	0.0%
44107	Lakewood/Cleveland	N/A	N/A	2.6%	3.6%	0.0%
44108	Cleveland/Bratenahl (90%)	N/A	N/A	0.8%	1.4%	0.0%
44109	Cleveland/Brooklyn Hts (96%)	N/A	N/A	1.9%	2.1%	0.0%
44110	Cleveland/East Cleveland (98%)	N/A	N/A	0.5%	1.8%	0.0%
44111	Cleveland (100%)	N/A	N/A	1.0%	0.7%	0.0%
44112	East Cleveland/Cleveland	N/A	N/A	1.8%	4.1%	0.0%
44113	Cleveland (100%)	N/A	N/A	0.9%	2.2%	0.0%
44114	Cleveland (100%)	N/A	N/A	0.1%	0.4%	0.0%
44115	Cleveland (100%)	N/A	N/A	0.9%	0.1%	0.0%
44116	Rocky River	N/A	N/A	0.6%	1.1%	0.0%
44117	Euclid/Cleveland	N/A	N/A	1.4%	3.0%	0.0%
44118	ClevelandHts/UniversityHts/ShakerHts	N/A	N/A	0.8%	0.6%	0.0%
44119	Cleveland/Euclid (50%)	N/A	N/A	21.3%	2.0%	0.0%
44120	Shaker Hts/Cleveland	N/A	N/A	1.9%	2.6%	0.0%
44121	University Hts/South Euclid	N/A	N/A	0.6%	0.5%	0.0%
44122	Beachwood/Highland Hills/ShakerHts	N/A	N/A	4.9%	8.4%	0.0%
44123	Euclid	N/A	N/A	0.4%	0.0%	0.0%
44124	Pepper Pike/MayfieldHts/Lyndhurst	N/A	N/A	4.8%	3.6%	0.0%
44125	Valley View/Garfield Hts	N/A	N/A	2.2%	2.2%	0.0%
44126	Fairview Park/Cleveland	N/A	N/A	0.2%	0.1%	0.0%
44127	Cleveland (100%)	N/A	N/A	0.2%	0.4%	0.0%
44128	Warrensville Hts/Cleveland	N/A	N/A	0.8%	1.6%	0.0%
44129	Brooklyn/Parma/Cleveland	N/A	N/A	0.8%	4.4%	0.0%
44130	Parma/Cleveland	N/A	N/A	1.3%	4.9%	0.0%
44131	Independence/Seven Hills/BrooklynHts	N/A	N/A	0.3%	0.1%	0.0%
44132	Euclid	N/A	N/A	0.6%	0.2%	0.0%
44133	North Royalton	N/A	N/A	0.5%	2.2%	0.0%
44134	Parma/Cleveland	N/A	N/A	2.1%	4.8%	0.0%
44135	Cleveland/Linndale (90%)	N/A	N/A	0.5%	4.4%	0.0%
44136	Strongsville	N/A	N/A	0.7%	1.3%	0.0%
44137	Maple Hts/Cleveland	N/A	N/A	0.8%	2.1%	0.0%
44138	Olmsted Twp/Olmsted Falls	N/A	N/A	1.3%	0.4%	0.0%
44139	Bentleyville/Glenwillow/Solon	N/A	N/A	2.0%	2.5%	0.0%
44140	Bay Village	N/A	N/A	1.2%	0.1%	0.0%
44141	Brecksville	N/A	N/A	0.2%	0.0%	0.0%
44142	Brookpark/Cleveland	N/A	N/A	0.5%	0.5%	0.0%
44143	Highland Hts/Richmond Heights	N/A	N/A	3.3%	2.9%	0.0%
44144	Brooklyn/Cleveland	N/A	N/A	0.3%	0.5%	0.0%
44145	Westlake	N/A	N/A	2.3%	7.6%	0.0%
44146	Walton Hills/Oakwood/Bedford	N/A	N/A	2.4%	3.2%	0.0%
44147	Broadview Hts	N/A	N/A	0.4%	1.3%	0.0%
44149	Strongsville			0.0%	0.1%	0.0%
Unknown Cuyahoga County Zip Codes*****				7.9%	0.0%	0.0%
Missing****				0.0%	0.0%	100.0%
Unknown*****				49.3%	0.0%	0.0%
<b>Total Cuyahoga County*****</b>		<b>N/A</b>	<b>N/A</b>	<b>100.0%</b>	<b>106.5%</b>	<b>0.0%</b>
<b>Total Known Cleveland</b>		<b>N/A</b>	<b>N/A</b>	<b>43.7%</b>	<b>31.1%</b>	<b>0.0%</b>
<b>Total Known Suburbs</b>		<b>N/A</b>	<b>N/A</b>	<b>48.4%</b>	<b>75.4%</b>	<b>0.0%</b>
<b>Unknown &amp; Missing</b>				<b>49.3%</b>	<b>0.0%</b>	<b>100.0%</b>

### Attachment 4: Actual Consumer Zip Codes (continued)

* Ohio Department of Development, Office of Strategic Research. Projections of Births, Deaths and Natural Increase by Sex. 5 year projections divided by 5 to obtain annual averages.
** Seventy percent of annual average deaths based on research: Connor, S. (1999). New initiatives transforming hospice care. <i>The Hospice Journal</i> , 14(3/4): 193-203. Seventy percent of annual deaths are predictable and therefore possible users of hospice.
*** Note: Consumers could be funded by more than one funding source; thus the columns are not necessarily mutually exclusive.
****Missing Data - represents computational errors or incorrect completion of online report.
*****Unknown Data - Represents data not collected by agency because no tracking system is available or type of service delivered makes it difficult (i.e., group presentations, telephone information and referral, and drop-ins). Also represents data not completed by clients either deliberately or inadvertently on intake forms.
***** Totals vary because of rounding. County total population 1,393,978 does not correspond to the total of zip codes because some zip codes include data from adjacent counties

**Attachment 5: Profile of Core Service Providers – 2005**

<b>PROFILE OF CORE SERVICE PROVIDERS - 2005</b>		
<b>Source: United Way - First Call for Help Refer Database February 2005</b>		
	Count	Sub-Count: UW-Affiliated
Total Number of Providers	9	1
Number of Providers by Type		
Nonprofit	8	1
For-profit	-	-
Government	1	-
Other	-	-
Total Number of Service Sites	14	4
Number of Service Sites per Provider		
1	8	-
2 – 5	2	1
6 – 10	-	-
11+	-	-
Geographical Location of Service Sites, by ZIP Code		
44017 – Berea		
44022 – Bentleyville	-	-
44040 – Gates Mills/Mayfield Village	-	-
44070 – North Olmsted	-	-
44101 – Cleveland	-	-
44102 – Brooklyn/Cleveland	-	-
44103 – Cleveland	-	-
44104 – Cleveland	-	-
44105 – Newburgh Hts/Garfield Hts	-	-
44106 – Cleveland Hts/Cleveland	-	-
44107 – Cleveland/Lakewood	1	-
44108 – Cleveland/East Cleveland	-	-
44109 – Cleveland/Brooklyn Hts	-	-
44110 – Cleveland/Bratenahl	-	-
44111 – Cleveland	-	-
44112 – Cleveland/East Cleveland	-	-
44113 – Cleveland	-	-
44114 – Cleveland	2	-
44115 – Cleveland	-	-
44116 – Rocky River	1	1
44117 – Cleveland/Euclid	-	-
44118 – Euclid/University Hts	-	-
44119 – Cleveland/Euclid	-	-
44120 – Cleveland/Shaker Hts	1	1
44121 – University Hts/South Euclid	-	-
44122 – Orange/Warrensville Hts	-	-
44123 – Euclid	1	-
44124 – Pepper Pike/Mayfield Village	-	-
44125 – Valley View/Garfield Hts	-	-
44126 – Cleveland/Fairview Park	-	-
44127 – Cleveland	-	-
44128 – Cleveland/Warrensville Hts	-	-
44129 – Cleveland/Brooklyn/Parma	-	-
44130 – Cleveland/Parma	-	-
44131 – Seven Hills/Brooklyn Hts	1	-
44132 – Euclid	1	-

Attachment 5: Profile of Core Service Providers - 2005 (continued)

<b>PROFILE OF CORE SERVICE PROVIDERS - 2005</b>		
<b>Source: United Way - First Call for Help Refer Database February 2005</b>		
	Count	Sub-Count: UW-Affiliated
44133 – North Royalton	-	-
44134 – Parma/Cleveland	-	-
44135 – Cleveland/Linndale	3	1
44136 – Strongsville	-	-
44137 – Maple Hts/Cleveland	1	-
44138 – Olmsted Twp/Olmsted Falls	-	-
44139 – Bentleyville/Glenwillow/Solon	-	-
44140 – Bay Village	-	-
44141 – Brecksville	-	-
44142 – Cleveland/Brookpark	2	1
44143 – Highland Hts/South Euclid	-	-
44144 – Brooklyn/Cleveland	-	-
44145 – Westlake	-	-
44146 – Walton Hills/Oakwood/Bedford	-	-
44147 – Broadview Hts	-	-
44149 – Strongsville	-	-

**Attachment 6: Providers and Functions – 2005**

Service Providers & Functions	
Source: United Way - First Call for Help Refer Database February 2005	
Agency	Services
Cleveland Clinic Foundation	Hospice
Holy Family Home	Care For Terminally Ill Cancer Patients
<b>Hospice of the Western Reserve</b>	<b>Hospice Care - Assisted Living and Nursing Facilities/Residential and In-Home Care</b>
Malachi House	Hospice And Home Care For Indigent/Terminally Ill
Montefiore	Hospice Services
Parma Community General Hospital	Hospice
Southwest General Health Center	Hospice
United States Department of Veterans Affairs	Home Health Care
Visiting Nurse Association Healthcare Partners of Ohio	Hospice

**Bold** represents agencies funded by United Way for this service. There are several additional hospice providers who service all or part of Cuyahoga County including: New Life Hospice, Odyssey Hospice, Harbor Light Hospice, Harbinger Hospice, Heartland Hospice. All but one of these hospice programs are for profit. In addition, several area nursing homes have announced plans for developing hospice programs: Lutheran Home, Harborside Healthcare, and Legacy Group. Although Holy Family Home is listed above as “Care for the Terminally Ill,” it has just obtained licensure and certification as a hospice program. There are several additional hospice programs: Hospice of Medina County, Care Corp, VNS Akron, and AseraCare that serve in the counties surrounding Cuyahoga County. Malachi House is noted in the list above; however, it is a volunteer residence group home providing 24 hour charity care for terminally ill, and works closely with various hospice programs to provide hospice services. (Stricklin, reviewer, 2006)

**Attachment 7: United Way - First Call for Help Hospice Care Requests – 2000-2004: Greatest Increase/Greatest Decrease**

LT-300 Hospice Care								
United Way - First Call for Help Requests 2000-2004								
Greatest Increase/(Greatest Decrease)								
Zip Code		TOTAL REQUESTS					%Change*	Avg. #
		2000	2001	2002	2003	2004	00&04	Calls 00-04
44111	Cleveland	1	0	1	0	2	100%	1
44125	Valley View/Garfield Hts	1	0	0	0	2	100%	1
44122	Beachwood/Highland Hills/Shaker Hts.	1	2	0	0	0	(100%)	1
44139	Bentleyville/Glenwillow/Solon	1	0	0	0	0	(100%)	0
44144	Brooklyn/Cleveland	1	1	1	0	0	(100%)	1
44104	Cleveland	3	0	0	0	0	(100%)	1
44108	Cleveland/Bratenahl	2	0	0	0	0	(100%)	0
44105	Cleveland/Newburgh Hts/Garfield Hts	2	1	0	1	0	(100%)	1
44112	East Cleveland/Cleveland	2	0	2	1	0	(100%)	1
44107	Lakewood/Cleveland	1	0	0	1	0	(100%)	0
44134	Parma/Cleveland	3	1	1	0	0	(100%)	1
44110	Cleveland/East Cleveland	3	0	0	0	1	(67%)	1
44131	Independence/Seven Hills/Brooklyn Hts	2	0	0	0	1	(50%)	1
44124	Pepper Pike/Mayfield Hts./Lyndhurst	2	0	0	0	1	(50%)	1
<b>**Total Cuyahoga County</b>		<b>26</b>	<b>16</b>	<b>15</b>	<b>17</b>	<b>22</b>	<b>(15%)</b>	<b>19</b>
<b>**Total Cleveland</b>		<b>11</b>	<b>6</b>	<b>4</b>	<b>3</b>	<b>10</b>	<b>(9%)</b>	<b>7</b>
<b>**Total Suburbs</b>		<b>15</b>	<b>10</b>	<b>11</b>	<b>14</b>	<b>12</b>	<b>(20%)</b>	<b>12</b>
* Extremely high percentages are due to low numbers.								
** These totals do not reflect the sum of the numbers above which are the zip codes reflecting the greatest increase or decrease. Rather, they are the total of calls from ALL zip codes many of which do not appear on this table.								

**Attachment 8: United Way - First Call for Help 2000-2004: Unmet Need**

LT-300 Hospice Care					
United Way - First Call for Help Requests 2000-2004					
Unmet Need					
Zip Code		TOTALS 00-04			%
		Requests	Met	Unmet	Unmet
44129	Brooklyn/Parma/Cleveland	1	0	1	100%
44112	East Cleveland/Cleveland	5	3	2	40%
44120	Shaker Hts/Cleveland	6	5	1	17%

<b>*Total Cuyahoga County</b>	<b>96</b>	<b>92</b>	<b>4</b>	<b>4%</b>
<b>*Total Cleveland</b>	<b>34</b>	<b>34</b>	<b>0</b>	<b>0%</b>
<b>*Total Suburbs</b>	<b>62</b>	<b>58</b>	<b>4</b>	<b>6%</b>

**FCFH DATA NOTES**

**Met** = service request resulting in referral to an organization. (Does not mean agency was able to provide the service.)

**Unmet** = service request for which there was no referral.

**Note:** Zip Codes shared by Cleveland and surrounding suburbs whose boundaries fall 50% and greater within the city of Cleveland are highlighted and totaled as Cleveland. Others are totaled as Suburbs.

\* These totals do not reflect the sum of the numbers above which are the zip codes reflecting unmet need in 2004. Rather, they are the total of calls from ALL zip codes some of which do not appear on this table.



**United Way of  
Greater Cleveland**

1331 Euclid Avenue

Cleveland, Ohio 44115

[uws.org/CoreServicesPlanning](https://uws.org/CoreServicesPlanning)