

# Introduction

This report presents the findings of an assessment of end of life needs and services in Michigan. Commissioned by the Cancer Prevention and Control Section of the Division of Chronic Disease and Injury Control in the Michigan Department of Community Health (MDCH), the assessment was conducted by an independent contractor from March through October, 2004.

The impetus for the project was twofold. First, public health consultants in the Cancer Prevention and Control Section recognized end of life as a legitimate state public health issue, having participated with a variety of partners in a number of efforts to advance end of life care in Michigan. They shared the common concern about the impact of unstable funding sources on program sustainability. Second, research scientists at the Centers for Disease Control and Prevention (CDC) validated end of life as a national public health issue (Rao, Anderson, & Smith, 2002). In October 2002, with the Association of State and Territorial Chronic Disease Program Directors (CDD), the CDC launched a process to identify public health roles and priorities for addressing end of life needs. A Michigan physician leader and an MDCH consultant participated as stakeholders in that process.

As CDC and CDD partners worked to compile input about public health roles and priorities, leaders in the Cancer Prevention and Control Section at MDCH decided that a sensible next step would be to assess end of life needs and services in Michigan. This report presents the findings from that state assessment and is formatted for ease of use as a practical resource.

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## Project Objectives

The end of life needs assessment was designed to accomplish these objectives:

- Justify end of life as a public health concern or not.
- Identify critical unmet needs in end of life care in Michigan.
- Assess and describe current end of life infrastructure, projects, and programs in Michigan.
- Examine the potential for an expanded role related to end of life for the Michigan Department of Community Health.
- If the analysis supports it, justify and propose a structure for an end of life function for MDCH.

## Methodology

Multiple sources of information were used to assess end of life needs and services in Michigan. These include:

- Semistructured interviews with stakeholders and hospice contacts;
- Mortality statistics from death certificates for the year 2002;
- Data from the end of life component of the 2001/2002 Special Cancer Behavioral Risk Factor Survey;
- Michigan scores from national and state reports related to end of life; and
- Strategic plans of statewide coalitions in Michigan.

### Stakeholder Interviews

The first people interviewed were professionals in both public and private sectors whose roles involve people at the end of life or issues that affect them. The contractor generated a master list of potential stakeholder contacts. Priorities were identified with input from the director of the state hospice organization and from public health consultants in the MDCH Cancer Control and Prevention Section. Interview subjects were contacted first by e-mail with a message that explained the project. The contractor then phoned them to schedule interviews. Only one subject declined to participate.

The contractor conducted 40 semistructured interviews in person and 10 by telephone. She also facilitated one focus group with

seven hospice directors. The interview subjects represent these affiliations (some are classified more than once):

- Michigan Commission on End of Life Care (5)
- Statewide end-of-life-related coalitions (8)
- Health-related trade associations and nonprofits (7)
- Health-related academic programs (6)
- Aging service network (5) and long term care (6)
- Model programs—palliative care, end of life decision-making, long term care (11)
- Mental health and developmental disability services (4)
- Community end-of-life coalitions (4).

Stakeholders were invited to discuss end of life issues and activities in their organizations and to offer input about these topics:

- How to define end of life for policy and program purposes
- Unmet end of life needs in Michigan
- Strengths of efforts and obstacles to progress.

Of the 40 stakeholders who were interviewed in person, 32 were asked to look at a list of core issues and select the three top priorities for the state. (These were core issues identified by the Michigan Commission on End of Life Care.) Stakeholders in this subset are evenly distributed among these affiliations: the Michigan Commission on End of Life Care, statewide coalitions, trade associations and nonprofits, academic programs, aging services, long term care, and model programs.

Interviews averaged 90 minutes. The contractor took thorough notes during each session and transcribed them as soon as possible, usually within 24 hours. The stakeholders who were interviewed in person received a copy of the notes to review. About half responded, and a small number of them offered minor edits.

## Hospice Director Interviews

The second group of informants interviewed was hospice administrators and clinical managers who deal with end of life issues every day. The 57 contacts represent 84% of the hospices listed in the membership database of the Michigan Hospice and Palliative Care Organization as of June 2004. Together they serve all counties in the state except Chippewa. Hospice directors were contacted first by e-mail with an introduction to the project and then by phone to schedule an interview. One person declined to participate and four others were unable to find the time.

Hospice contacts served as the main source of information about end of life programs and services in Michigan communities. They were asked for input on the following:

- The availability of palliative care services in area hospitals;
- Pre-hospice services and models;
- Community end of life coalitions and their activities;
- Strategies for consumer and professional education; and
- Services for caregiver support.

Hospice directors were invited to identify vulnerable populations in their areas and to discuss unmet end of life needs and related obstacles. They also were asked about the state of pain management, informed decision-making, and timeliness of hospice referrals.

The contractor conducted the interviews by telephone; they averaged 45 minutes. She took thorough notes during each session and transcribed them as soon as possible.

### Mortality Statistics

During the period of the needs assessment, the most recent year for which full mortality data was available from death certificates was 2002. The Vital Records and Health Data Development Section of the MDCH provided files including:

- Number of deaths by age, cause, and place of death for all residents and by race/ethnicity;
- Place of death by age, race, ethnicity, and cause for 1990 and 2002;
- Number of deaths by age, cause, marital status, and where pronounced;
- Place of death by county; and
- Number of deaths with any mention of selected diseases as an underlying or related cause of death by race and place of death.

### Special Cancer Behavioral Risk Factor Survey

In 2001 the MDCH commissioned the Michigan Public Health Institute (MPHI) to conduct a Special Cancer Behavioral Risk Factor Survey (SCBRFS). It was a telephone survey that targeted Michigan residents aged 50 and older. An end of life component collected input from a sample of respondents who had been involved in the care of a close family member or friend who died of a terminal illness. The survey over sampled African Americans so results could be generalized to the entire African American

population in the state. In 2002 additional interviews were conducted with African Americans and also with Native Americans, Hispanics, and Arab Americans so results could be generalized for each of these special population groups.

The end of life SCBRFS includes questions about these factors:

- Cancer vs. non-cancer diagnosis;
- Pain levels, medication use, and relief;
- Place of death and place of residence during the last three months of life; and
- Hospice versus non-hospice care.

MPHI provided a number of tables that show relationships among combinations of these variables for the general population and by ethnic group. Examples include:

- Average pain level by place of residence for final three months;
- Hospice use by cancer versus non-cancer diagnosis; and
- Place of residence compared to place of death.

## Other Resources

In addition to interview input, the contractor collected and reviewed these resources:

- Recommendations for public health activities related to end of life issues, from a joint project of the Centers for Disease Control and Prevention and the Association of State and Territorial Chronic Disease Program Directors;
- Descriptions of end of life projects and activities in other states;
- Recommendations for improving end of life care from the Institute of Medicine and Last Acts;
- Strategic plans from Michigan coalitions related to end of life issues;
- National and state reports and data on end of life needs, infrastructure, and services;
- Research reports and articles in professional journals; and
- Input from presentations at professional conferences related to palliative care, hospice, cancer, caregiving, and dementia.