COMMUNITY HEALTH NEEDS ASSESSMENT PROJECT
THE UNDER-SERVED OF CAPE COD
Co-sponsored by Cape Cod Healthcare and the Barnstable County Department of Human Services

With assistance from
Cape Cod Child Development Programs
Falmouth Human Services
Health Care of Southeastern Massachusetts
Hospice of Cape Cod
JRI Health
Lower/Outer Cape Community Coalition
Massachusetts Department of Public Health
Massachusetts League of Community Health Centers
O'Neill Center/NOAH Shelter
Outer Cape Health Services
Provincetown AIDS Support Group
Visiting Nurse Association of Cape Cod

September 1998
Total Population with Age Distributions
Barnstable County: 1970-2010

Source: Massachusetts Institute for Social and Economic Research (MISER), UMASS Amherst, December 1994
EXECUTIVE SUMMARY
1998 Community Health Needs Assessment Project

Background

The Community Health Needs Assessment Project (CHNAP) evolved from a number of different interests and origins that came together to work for a common goal of assuring that every Cape Codder has access to competent, appropriate, primary medical care without financial or other barriers.

One such origin was the recognition by the Community Benefits Council (CBC) of Cape Cod Hospital that a comprehensive needs assessment was necessary to insure that future decisions about health care delivery should be data-driven.

Another such origin was the Barnstable County Health and Human Services Advisory Council's (BCHHSAC) Task Force on Health, which was convened in 1992 to address gaps in primary care services. This task force later became the Cape Cod and the Islands Community Health Network, in partnership with the Massachusetts Department of Public Health, and studied several issues that serve as indicators of access to primary care: adequacy of prenatal care, breastfeeding, child immunization, and health care for the homeless.

These two major forces in the Cape's health and human services field were joined at the table to conduct the CHNAP by: the Cape Cod Child Development Programs; Falmouth Human Services; Health Care of Southeastern Massachusetts; Hospice of Cape Cod; JRI Health; the Lower/Outer Cape Community Coalition; the Massachusetts Department of Public Health; the Massachusetts League of Community Health Centers; the O'Neill Center/NOAH Shelter; Outer Cape Health Services; Provincetown AIDS Support Group; and the Visiting Nurse Association of Cape Cod.

Previous studies on Cape Cod (namely, those conducted by Harvard in 1957, Brandeis in 1981, and the Barnstable County Department of Human Services in 1995) have already identified disparities among residents of the Cape in terms of income, housing, employment, transportation, and health care. Anecdotal information about barriers to access and gaps in primary care services has existed for several years but had not been systematically validated through study of the populations who were most directly affected.

By contrast, the CHNAP was designed to provide a voice for under-served populations. The CHNAP began in the fall of 1997 to study accessibility to health services by under-served and
under-represented groups of Barnstable County. At a time of much structural and organizational change within the health services system of Cape Cod, the CHNAP provides important benchmark information upon which the current health care delivery system may be evaluated and future health care policies and programs may be built.

The CHNAP explored four health-specific areas: dental care, medical care, mental health services and preventive health services for certain groups of the year-round populations of Cape Cod.

The CHNAP is unique in the recent history of Cape Cod. Similar to The Human Condition - A Study of the Human Environment on Cape Cod, collaborative research enlisted the support and participation of a wide range of health and human service organizations on Cape Cod. However, the CHNAP process included the partnership and collaborative participation of dozens of grassroots organizations. We also used many community organizing techniques. Many community volunteers participated in efforts to involved under-served residents of Cape Cod in the survey research and community forums. Because of this diversity of institutional and community support, therefore, the CHNAP was particularly successful in reaching under-served and previously under-represented populations. This is truly a study of the community, by the community.

Research Question

The CHNAP provides a comprehensive response to the research question posed at the outset of the study:

If you or a household members feels sick or needs preventive health care, is there a place for you that:

You can get to?
You can afford?
Speaks your primary language?
Gives you quality care?
Understands your culture?
Treats you with respect?
Incorporates your feedback into services?
Provides linkages with other services?
Populations Studied

The CHNAP was designed to examine the health care access experiences of population groups on Cape Cod that were not included or were under-represented in previous research such as *The Human Condition - A Study of the Human Environment on Cape Cod* (1995) and the Barnstable County Needs Assessment Study (1981). For the purposes of this study under-served and under-represented people include:

- People living in low-income households.
- Cultural and linguistic minorities.
- Uninsured and under-insured people.
- People who have only seasonal employment, who are self-employed, or who are unemployed.
- Gays, lesbians, bisexuals, and people who are transgender.
- People without access to public or private transportation.
- Homeless people.
- People living in physical isolation
- People with disabilities.

Approaches to Data Collection

*Community Engagement.* The CHNAP began with a process of community engagement that served to guide the data collection methods. Anecdotal information collected through interviews with key stakeholders guided and directed the project by focusing attention on population groups that most likely experience problems with access to care. This information also focused attention of the project on elements or aspects of the health care system that would most likely pose barriers to access for those populations studied.
Following, and as a result of, the community engagement process, it was determined that the CHNAP would study the health care access experiences of selected populations by conducting survey research, convening seven community forums throughout Barnstable County, and examining socio-demographic data. Through this approach, we intended the survey research to collect information from the populations that we thought experienced problems in accessing health care. In addition to the survey research, the purpose of the community forums was to elicit comments from a broad spectrum of the community on the affordability, accessibility, and perceived quality of health care services. We examined socio-demographic data to understand trends in population demographics, significant health status problems, and the distribution and availability of health care resources on Cape Cod.

**Community Health Care Survey.** Trained volunteers conducted the Community Health Care Survey at more than 100 sites in February/March 1998. We designed it to collect systematically quantifiable data on the size and scope of the health care access problems of under-served populations on Cape Cod. Survey questions queried the health condition of members of the household, health insurance status, income, housing, household/family structure, use of the hospital emergency room, and demographics profile of the members of the household. We collected data from 1,075 households. This included surveys printed in English, French, Portuguese, and Spanish.

**Community Forums.** Other aspects of the inquiry into access to health care for under-served populations did not lend themselves to examination through a formal survey approach. While the survey research served to quantify the size and scope of the problem, another approach was needed to assess the depth of the problems faced by people on Cape Cod as they sought medical, dental, mental health, and preventive care. A public forum offered an opportunity to collect data that complemented and enhanced the findings of the survey research, while not being limited to those who were the focus of the survey research. We held seven community forums at key geographic locations across Cape Cod in March 1998, and recorded all the comments that were offered. The forums provided a structured approach to gathering and recording the range of anecdotal accounts of barriers to access that others had not documented in a formal way before this study.

**Socio-demographic data.** Selected demographic, health status indicator, and health care access and utilization data were collected and analyzed in order to provide a
context in which the CHNAP population groups were studied. These data provide a framework for interpreting and understanding the CHNAP Community Health Care Survey and Community Forums.

**Poverty Levels**

**Barnstable County and Massachusetts: 1989**

<table>
<thead>
<tr>
<th>Category</th>
<th>Barnstable County</th>
<th>Massachusetts</th>
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</thead>
<tbody>
<tr>
<td>Population below 100% of poverty</td>
<td>7.5%</td>
<td>8.9%</td>
</tr>
<tr>
<td>Population below 200% of poverty</td>
<td>21.7%</td>
<td>21%</td>
</tr>
<tr>
<td>Children &lt;18 years of age below 100% of poverty line</td>
<td>11.3%</td>
<td>12.9%</td>
</tr>
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Key Findings

1. **Barriers to Access**

   **Affordability**

   Affordability was the major barrier to access to health care on Cape Cod.

   - For the groups studied, there were significant difficulties paying for even common health care services — especially dental care and mental health therapy.
   - Many were unable to afford dental or medical insurance.
   - For those with insurance, there was difficulty paying for insurance deductibles or co-payments.
   - Many had difficulty paying for prescription medications.
   - Having insurance coverage does not guarantee availability of, access to, or adequacy of services.
   - Unaffordable health insurance and unaffordable services result in inadequate care.
   - Lack of parity for mental health coverage may result in premature termination of services.
   - Accessible dental services are limited due to cost and distance.
   - The high cost of medications prevents people from filling prescriptions and/or taking medications as directed.
Hours of Operation

Hours of operation are a very BIG problem for many household — especially working people and working families.

- Getting time away from work to go to health care — without disciplinary action — is often impractical regardless of the costs involved in the health care.

- There is often a lack of transportation during working hours even though a car is “available.”

- The cost of taking time away from work to take care of personal or family health care is too great.

- The availability of primary care health services is limited by location, the time services are open and available, and the participation of the provider in a particular health plan.

Transportation

- Many health care services are clustered in and around the Hyannis and Falmouth Hospital area on Cape.

- There is limited public transportation to and from health care services for many portions of the Cape’s population, and this is a significant barrier to accessing these services.

Location

- Beyond the geographic location problem cited above, study participants -- especially racial/cultural/ethnic minorities -- cited feeling unwelcome or intimidated in some areas.

- The lack of physical accommodation at health services creates access problems for people with disabilities.
• As cited above, the availability of primary care health services is limited by location, the time services are open and available, and the participation of the provider in a particular health plan.

Lack of Information

• What services are available, and where are they located? There is a severe lack of information to answer this question across the Cape. The result is that people do not know how to find and access services that will respond to their needs.

Bad Experiences and Discrimination

• Bad prior experiences in attempting to access health care services on Cape Cod acts as a barrier to trying again.

• Some respondents felt discriminated against when they were told doctors were not accepting new patients.

• Bad experiences include feelings of disrespect for ethnicity, culture, income status, etc. Feelings of discrimination due to race, ethnicity, culture, sexual identity, HIV/AIDS status, and other factors were common. Members of cultural, ethnic, and sexual minorities experience insensitivity, discrimination and a general lack of respect when receiving services.

• The lack of medical interpreter services (ASL, Haitian Creole, Portuguese, and Spanish) limits access to health care and results in inadequate care, or leads to inappropriate requests for others to interpret.

• Whether real or imagined, the study revealed general feelings of not getting adequate health care.
• The lack of communication and cooperation among providers limits the quality of care received.

### Children in Fair-to-Poor Health

**In Underserved Populations: % of Children**

<table>
<thead>
<tr>
<th>Category</th>
<th>% of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Linguistic Minority</td>
<td>11%</td>
</tr>
<tr>
<td>3 or More Children</td>
<td>10%</td>
</tr>
<tr>
<td>Seasonal-Only Work</td>
<td>8%</td>
</tr>
<tr>
<td>Cultural/Ethnic Minority</td>
<td>8%</td>
</tr>
<tr>
<td>Non-emergency ER Use</td>
<td>7%</td>
</tr>
<tr>
<td>Single-Parent</td>
<td>7%</td>
</tr>
<tr>
<td>&quot;Working Poor&quot;</td>
<td>7%</td>
</tr>
<tr>
<td>Underemployed</td>
<td>6%</td>
</tr>
<tr>
<td>On State or Federal Plan</td>
<td>6%</td>
</tr>
</tbody>
</table>

2. **Health Condition**

• The study results confirm prior research and demonstrates that those individuals and groups who experience barriers to accessing health care experience a poorer health status than the general population.

• Interruptions in the continuity of care — particularly after hospitalization — affects health outcomes.

• Half the population groups we surveyed report their children in only fair/poor health.
• Non-English speaking households report children in only fair-to-poor health at twice the rate (11%) as the average household surveyed.

• Over 40% of adults are reported in only fair-to-poor health for a variety of reasons, including aging related illness. However, this percentage is higher than would be expected due only to aging.

• One third of the groups surveyed reporting only fair-to-poor adult health were non-elderly/senior groups.

3. Health Insurance

Coverage

• Nearly two-thirds — 62% — of households surveyed had someone without medical insurance coverage in the past year.

• Only 40% of the households surveyed had everyone covered, and that was for medical care, not dental care.

• 82% of the households surveyed said they had someone without dental care insurance.

• The main sources of health insurance are for households surveyed were:
  State or Federal Programs
  Employers Insurance Plans

• When asked how long they had gone without health insurance, the two most frequent responses from survey respondents were:

  1. "More than three months"; and

  2. "Never had health insurance.”
Reasons for No Insurance

The inevitable consequence to the lack of health insurance is that many people go without care because they cannot afford it.

• The most frequently cited reason by survey respondents for the lack of health insurance was “Costs too much.”

• The second most frequently cited reason for the lack of health insurance by survey respondents was an employment related issue — job change, not yet eligible, self-employed, etc.

• People not eligible for state and federal health insurance programs cannot afford private health insurance.

• The cost of insurance deductibles and co-payments was reported to be a major barrier to accessing health care.

• When asked how much survey respondents could afford to pay for “adequate, low-cost health insurance,” the most frequent response was “up to $25 per month.” Many respondents, however, said they would not be able to pay anything at all, and advocated for “free care” or a “sliding fee scale” for services.

4. Use of Hospital Emergency Rooms

Because of barriers in the health care system, hospital emergency rooms are used for a wide spectrum of care — from primary to emergency — with three results: 1) the care given is often inappropriate in terms of price and medical expertise to address the medical needs that brought the patient there in the first place; 2) non-emergency care creates bottlenecks in the system, and lessens its flexibility and readiness for the truly emergency care; and, 3) referrals to other treatment or aftercare are often inadequate. There is lots
of evidence that the Emergency Room is being used as a substitute for an after-hours medical clinic.

**Emergency Room Use**

- Overall, 30% of households surveyed used the emergency room for an “accident or injury.”

- 13% of households surveyed used the emergency room for “a serious illness.”

- Many respondents used the emergency room for admittedly non-emergency reasons. For those who used the Emergency Room for non-emergency needs, the most often cited reasons were:

  1. “The doctor’s office/clinic was closed”;

  2. “No health insurance”;

  3. “Can’t afford to pay for the services”;

  4. “Don’t know where else to go for services;” and

  5. “Have no regular place to go (doctor or clinic)”. 
• Adults using the Emergency Room for non-emergency care were, in general, those adults reporting a poorer health status.

5. Referrals

Referrals by Health Care Professionals

Referrals by health care professionals are critical to making health care and the continuity of care work on Cape Cod, with its combination of urbanized and rural areas and its 15 separate and distinct communities.

• Less than one-third of households surveyed (30%) reported being referred by a health care professional.
• Over half of the households surveyed reported no referrals (56%).

• People reported being frustrated by the lack of choices on the Cape and the lack of responsiveness to their input.

• Alternative/holistic health providers are viewed as positive complements that need to be better integrated into the provision of preventive and curative health services.

• Physical and mental health are not adequately integrated within the care-giving systems.

• The lack of comprehensive services to address life-long disabilities, chronic diseases, and pain management results in inadequate care and negative health outcomes.

• Health, human services, and schools need to coordinate information and services better so that people do not "fall through the cracks."

• Family and friends are the most common source of health care advice or information on services.
Conclusions

The CHNAP study demonstrates that there is a significant number of year-round Cape Cod residents who lack access to health care who experience one or more barriers to care. The specific consensus conclusions of the CHNAP Steering Committee are provided below.

<table>
<thead>
<tr>
<th>Summary Conclusions</th>
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<tbody>
<tr>
<td>• Access to primary care is inequitable on Cape Cod</td>
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<tr>
<td>• Dental care for MassHealth recipients and the uninsured is largely inaccessible</td>
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<td>• Affordable mental health services are lacking</td>
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<td>• Health care options are increasingly limited</td>
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<tr>
<td>• The severity of problems experienced in accessing health care is directly related to the numbers of barriers encountered</td>
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<table>
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<tr>
<th>Identified Access Barriers</th>
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<tr>
<td>• Affordability of health care is an issue for people living in poverty as well as working people</td>
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<tr>
<td>• Barriers to access to primary care go beyond issues of affordability</td>
</tr>
<tr>
<td>• People lack knowledge and information about health care services or benefits</td>
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<tr>
<td>• Public transportation to services is impractical and inadequate given location of some services</td>
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<tr>
<td>• Hours of operation for some services are not convenient</td>
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<tr>
<td>• People have difficulty taking time off from work to go for services</td>
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<tr>
<td>• There are inadequate interpretation services for non-English speaking people</td>
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<tr>
<td>• There is a lack of respect for cultural uniqueness of minority residents</td>
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<tr>
<td>• People with disabilities experience barriers to access to care</td>
</tr>
<tr>
<td>• People have bad experiences with services which relate to satisfaction with the quality of care received and their willingness to use services again</td>
</tr>
<tr>
<td>• The limitations associated with managed care pose barriers to people with insurance</td>
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Access-Related Observations about the Health Care System

- Some programs and services are effective and accessible but are not meeting the needs of all Cape Codders
- Health care services are uncoordinated and fragmented; follow-up care is inconsistent
- Services for some conditions (e.g., Lyme Disease, chronic illness and long-term disability) are ineffective
- Holistic, preventive and complementary therapies are inadequately integrated with mainstream medicine
- Emergency rooms are frequently used for non-emergency services
- People are hospitalized for conditions that should be managed and controlled in primary care settings to prevent hospitalization

The ability of an individual to access primary health care services is a key indicator of overall access to care. The lack of affordable and accessible primary care services not only can affect the health of the individual, but it can also place significant stresses on the health care system and health care costs through preventable use of hospitals and emergency rooms. The findings of this study indicate that there are significant problems with access to primary care for selected populations of Cape Cod.

Vision

A vision of an accessible system of health care emerges from these findings. The CHNAP Steering Committee believes that the following characteristics are a minimum set for a system of primary health care that ensures equitable access for all residents of Cape Cod:
<table>
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<tr>
<th>Characteristics of an Accessible Health Care System</th>
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<tbody>
<tr>
<td>• Primary health care services are located such that they are geographically accessible to the population with adequate public transportation</td>
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<tr>
<td>• Primary care services are affordable either through health insurance or a sliding fee scale for uninsured, self-paying individuals</td>
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<tr>
<td>• Office hours are convenient for all segments of the population</td>
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<tr>
<td>• People have a choice of primary care providers that are culturally and linguistically competent</td>
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<tr>
<td>• Information about health care services and benefits needs is readily available</td>
</tr>
<tr>
<td>• The system of primary care is designed to accommodate population growth and changing demographics</td>
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<tr>
<td>• Systems and patterns of practice are established that ensure that appropriate referrals for specialty, ancillary, and follow-up services are made</td>
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<tr>
<td>• The health care system provides a continuum of comprehensive services that addresses the medical, dental, mental health, and preventive care needs of the population</td>
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**Next Steps**

This report serves as a reference document and catalyst for action for policy makers, planners, health care professionals, and consumers interested in achieving equity of access to health care, in general, and primary care, in particular, for residents of Cape Cod. Some of the barriers identified in this report are amenable to change on the local level, while elimination of others will be facilitated by policy changes at the state and federal levels.

Great strides have been made in improving access to health care in Massachusetts through the expansion of the MassHealth program to include many more families. Massachusetts is one of the few states in the nation where all children are eligible for low-cost health insurance coverage for primary care services through MassHealth for Children or the Children’s Medical Security Plan. More outreach and education about these sources of health insurance would reduce the number of individuals for whom lack of health insurance is a barrier to obtaining care.
While affordability issues are being addressed, this report clearly indicates that there are other barriers experienced by people for whom insurance/affordability are not overriding issues. The growing minority population reported in this study that they experience language and discrimination barriers. These can best be resolved locally through a concerted effort to attract and/or train bi-lingual health professionals and to enhance the cultural competence and communication skills of health care providers.

Many people in this study reported barriers to health care which fall under the rubric of convenience. The chief barriers among these are the location of services and hours of operation. The data on emergency room use for non-emergency purposes reported both in the community health care survey and in utilization data reported by the two hospitals suggest in the communities in which these hospitals are located (Barnstable and Falmouth), people are using the emergency room in the absence of another source of care. While this use of the hospital emergency room is more frequent for people without health insurance, it is also a significant issue for people with insurance also. This suggests that the problem extends beyond issues of affordability.

The CHNAP is a study both of the community and by the community. The CHNAP was designed to provide an opportunity for people who were under-represented in previous studies of health care to share their experiences in accessing care. The segments of the Cape Cod community that were the focus of this study are active participants in the resolution of the access problems identified herein.

In this context, the next step of the CHNAP Steering Committee will be to convene another series of community forums to share the study findings and to invite the recommendations for programs, services, and policies to achieve equity of access for all residents of Cape Cod. A secondary report of those recommendations will be released upon the completion of the forums.