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Long-term Supports in Massachusetts: A Profile of Service Users

Prepared by:

Office of Long-Term Support Studies
Darlene O'Connor, Ph.D.
David Centerbar, PhD
Cheryl Cumings, MPA
Valerie Konar, MBA
Eliza Lake, MSW
Faith Little, MSW
Wendy Trafton, MPH

Center for Health Law and Economics
Stephanie Anthony, JD, MPH
Robert Seifert, MPA
Jean Sullivan, JD

In cooperation with:

Executive Office of Health and Human Services, Office of Disability Policies and Programs
Jean McGuire, PhD
Laurie Burgess, MS

Executive Office of Elder Affairs
Eleanor Shea-Delaney, MPA
Sandra Albright, LICSW

Office of Medicaid
Corrinne Altman Moore, MPA
Lauren Almquist, MBA

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Long-Term Supports in Massachusetts
A Profile of Service Users

The attached profile of long-term supports in Massachusetts has been developed to support the work of the Massachusetts Long-Term Care Financing Advisory Committee (LTCFAC). The LTCFAC was established in January 2009 to identify strategic options for the future financing of care for elders and individuals with disabilities in Massachusetts. The LTCFAC's charge is to advise the state regarding public and private long-term care financing options, identify strategic concerns regarding the options, and assist in prioritizing options that will help the state build a roadmap for change (Committee documents, 2009).

This profile is designed to provide critical background information on the size of the current and future populations needing long-term care in Massachusetts, their service needs, utilization, and gaps in service. The profile also includes information about the public and private payments for long-term care. In order to help focus the work of the LTCFAC and this profile, we first discuss the populations covered and our rationale for using the term "long-term supports" rather than long-term care.

Background

When it emerged as a term of art in the 1960s, long-term care was defined by what it was not. It was not the acute care for which most health insurance and the federal Medicare program had been designed, nor was it primary medical care focused on diagnosis and treatment of medical conditions. Long-term care was defined as "the provision of a range of services to individuals who require assistance with daily activities because of chronic illnesses and functional impairments" (Noelker and Harel, 2001). It was the care provided when medical or rehabilitative goals were no longer achievable, when Medicare and health insurance ceased coverage.

Although many individuals received such support from their families, the reimbursable component of long-term care was focused on institutional settings (particularly nursing facilities and intermediate care facilities for persons with mental retardation—ICFs-MR). This happened "haphazardly" rather than by design (Holstein and Cole, 1996, Noelker and Harel, 2001). The federal Medicare program, developed in 1965, was specifically focused on coverage of medical services. Although skilled nursing facility services were covered, they were limited to short-term, post-acute situations. In contrast the Medicaid program, a joint federal-state program for indigent persons, included a mandate for nursing facility services along with medical services. Because the cost of nursing facility services was high, many individuals, particularly older adults, became impoverished in the course of paying for long-term care and eventually qualified for Medicaid through a process known as "spending down".

In the early 1970s, as states began to see their Medicaid budgets grow, largely due to the explosion in costs for long-term care, a focus on alternatives to institutionalization emerged. States offered such supports initially through state-funded programs but gradually began to use the Medicaid program to cover personal care assistance, durable medical equipment, and longer-term home health services. In 1981, federal legislation specifically authorized the use of Medicaid home and community-based services (HCBS) waivers to enable states to offer HCBS to individuals who, in the absence of such services, would require long-term institutionalization.

Because of its early history, the term "long-term care" came to be associated with institutional supports. Moreover, because access to long-term care was contingent on a determination of "medical necessity," the term "care" became associated with a medical approach to assisting individuals to meet their long-term needs. Increasingly, the disability community has advocated the use of the term "long-term supports" when discussing the type of supports needed to assist people of all ages with disabilities to perform self-care and everyday tasks over an extended period of time. For this reason, throughout this profile we have used the term long-term supports (LTS). Although this term may be interpreted by some as more expansive than traditional long-term care, in the context of this profile, our focus is still on those institutional or community-based supports that assist people of all ages with disabilities to meet their daily needs.

The focus of LTS is not on where services are provided or a specific disability type or age group. Rather, LTS refers to a wide variety of goods and services that assist with the routine tasks of daily living that persons without disabilities would typically do for themselves. Examples of such services include:

Everyday tasks: These are activities that are necessary for any individual to live a healthy and productive life integrated in the community. Some of these activities, such as shopping, laundry, money management, and housekeeping may be completed on a weekly or less frequent basis. Others, such as meal preparation, managing medications, and using the telephone may be needed on a daily basis. In addition to those who need direct physical assistance with these activities, individuals with intellectual disabilities, brain injuries, or mental illness may need skills training to assist them in learning how to perform these activities or to relearn skills that may have been lost. In addition, individuals who need direct physical assistance or training to perform these activities frequently also require assistance with scheduling appointments and identifying, accessing and participating in community-based activities, as well as respite for themselves or family members

In the professional literature, these activities are often referred to as "Instrumental Activities of Daily Living" or IADLs. Many people with disabilities need assistance with some or all of these everyday tasks, but even those without disabilities—particularly those with adequate financial resources—may prefer to pay for others to assist with some of these activities. To avoid covering supports for those who may want but may already have the resources for adequate support, many public programs and most private long-term care insurance will pay for assistance with these activities only for individuals who also demonstrate a functional need for assistance with more intensive self-care tasks.

Self-care tasks: Self-care tasks are activities of a more personal nature that affect the individual's care of their own body. Examples include bathing, dressing, using the toilet, getting in and out of bed, moving within the home, and eating. In the professional literature, these activities are referred to as Activities of Daily Living or ADLs. Support may be physical "hands-on" assistance or stand-by assistance such as talking the person through the various steps of the activity when an individual has a severe intellectual disability or other cognitive disability such as chronic mental illness, brain injury or dementia. This is often called "cueing" or "supervision". Research suggests that those with a need for assistance with self-care tasks generally have more significant disabilities although individuals with either set of needs may be at risk of poor health outcomes and long-term institutionalization if community services are not provided. Some LTS programs will only pay for

such supports when an individual needs physical assistance with such activities while other programs offer coverage to individuals who need stand-by assistance due to a cognitive disability.

Medical/Health services: Long-term care does include some medical services such as nursing, physical and occupational therapy, and home health aides. There is often not a clear line between when these services are considered traditional medical services and when they fall under long-term care. Sometimes support with self-care and everyday tasks is bundled within a package of medical services or is so tightly linked with medical outcomes that it has fallen within the coverage of traditional health insurance. This is usually the case when services are provided during a recovery phase following an acute medical crisis.

Medical services are typically considered outside the sphere of LTS when they are offered to individuals whose needs are "chronic" and not likely to improve. The greatest overlap with LTS is with "post-acute" services, e.g. home health and skilled nursing facility services following a hospitalization. However, these services often cannot be effectively separated from LTS in studies of utilization or payment. For example, home health aides and home nursing services are not identified within payments systems in a way that permits separation of post-acute services from long-term supports; consequently most analyses of payment for LTS include home health services even though it is recognized that this is an overstatement of LTS expenditures.

Similarly, services such as preventive medical care and mental health services have such an impact on LTS that they are sometimes discussed as part of an overall system of LTS, particularly when developing models that integrate primary, acute and long-term care (like Special Needs Plans or the Program of All-inclusive Care for the Elderly). In the context of such integrated care initiatives, it can be impossible to distinguish medical from long-term care services.

Other supports: Many other supports are important to enable people with disabilities to participate fully in their communities. Accessible housing is essential for individuals with mobility disabilities; individual educational plans are critical for individuals with learning disabilities; peer counselors are often important for some people with acquired brain injuries, mental illness or other disabilities; and many technological innovations (such as medical equipment, hearing or visual aids, communication devices, service animals, and home adaptations) are needed by individuals who would then need no other assistance with everyday tasks or self-care. These supports are sometimes covered as traditional medical services and tend to fall within the scope of LTS only when provided to individuals who demonstrate need with self-care or other everyday tasks. While such services are not the primary focus of discussions related to financing LTS, they are part of the overall environment that supports people to live healthy and productive lives, and important elements of a community's ability to accommodate the needs of children, adults and elders with disabilities.

As a framework to guide the work of the LTCFAC, we developed the graphic on the next page. The shaded arrow gradually transitions from light to dark, suggesting the increasing degree to which the supports fall within standard definitions of LTS.

Long-Term Supports (LTS) help people with disabilities meet their daily needs and improve the quality of their lives over an extended period of time

LTS may be provided at home, in community settings, or in institutional facilities

Range of Long-Term Supports*

Medical services	Support for everyday tasks	Support for self-care tasks
Supports can include: • Primary / preventive health care • Acute care • Post-acute care • Home health (post-acute) • Mental health • Hospice • Early intervention	**Supports can include:** • Homemaker • Chore • Laundry • Shopping • Meal preparation • Home-delivered meals • Bill payment • Emergency response • Transportation • Skills training • Care coordination	**Supports can include:** **Community** •Adult day health • Personal care attendant • Home health (long term) • Residential supports • Respite care **Institutional** • Nursing facility • Intermediate care facilities/MR • Chronic & rehabilitation hospitals

Education, employment and housing services also are necessary components of successful community living for people with disabilities of all ages

*See appendix for comprehensive list of services

Disability vs. Long-Term Supports

While many elders and individuals with disabilities need assistance with everyday tasks or self-care, this is not true for all people with disabilities. For purposes of estimating the Massachusetts population needing long-term supports, the American Community Survey (ACS) was the most useful source of data available. However, the ACS variable for identifying disability uses a very broad set of categories from which respondents can self-identify. The categories include the following and are not mutually exclusive:

- Vision or hearing disability (blindness, deafness, or a severe vision or hearing impairment)
- Difficulty learning, remembering or concentrating (lasting 6 months or more)
- Difficulty working at a job or business (lasting 6 months or more; identified only for individuals age 15 and older)
- Substantial limits in one or more basic physical activities (such as walking, climbing stairs, reaching, lifting, or carrying)
- Difficulty going outside the home alone to shop or visit a doctor's office (lasting 6 months or more, identified only for individuals age 15 and older)
- Self-care disability (difficulty dressing, bathing, or getting around inside the home; lasting 6 months or more)

Within each of these categories there are almost certainly individuals needing long-term supports; however, with the exception of the last category, all categories have the potential to include individuals who do not need such support. In order to approximate the population needing long-term supports for this profile, we selected those individuals needing assistance with mobility or self-care, the last three in the above list. This amounts to two-thirds of the population with disabilities and approximately 10% of the total population in the state. This is the method also used by the state of Maryland in developing the profile of its LTS population.

Though imperfect, the ACS maps closely though not exactly to other age-specific measures of disability. The LTS disability indicator determined by the ACS captures a higher portion of the elder population compared with a study by Manton and others (Manton, K.G., Gu, X., et al, 2006) which grouped elders based on needs for assistance with IADLs and ADLs. By including mobility disability from the ACS profile, the LTS item estimates that one-third of the elder population needs LTS, compared with only 19% identified as needing assistance with ADLS or IADLs in the Manton study. In relation to school-aged children, data from the ACS identifies a similar population to that reported by the Massachusetts Department of Education and Special Education (2% in ACS vs. 3.1% from DESE) needing assistance due to physical, developmental, or medical conditions (excluding disabilities specific to learning.)

It is important to note that the ACS is not applied to children under age five. At such early ages, it is often not clear whether the child will need long-term supports, and standard measures such as self-care needs do not apply since most children need assistance with self-care up to age five. Consequently, children under age five are not included in the estimates of the population used in this profile; however, they do appear in the estimates of service utilization and expenditures.

Section I of this profile includes data on the total population with disabilities, and compares it with the population needing long-term supports (based on the proxy of individuals needing assistance with mobility or self-care.) Section II provides additional depth on the population needing long-term supports. Section III provides data on LTS service utilization, primarily identified through reports of public programs. Section IV provides estimates of unmet need for LTS based on national studies and state-specific surveys. Finally, Section V provides data on payments related to LTS, compiled with assistance from the Massachusetts Executive Office of Health and Human Services and the Executive Office of Elder Affairs.

Part I

Estimates of the Population with Disabilities

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TN:1

Estimated Number of People Age 5+ with A Disability in Massachusetts and the U.S By T*ype of Disability*.

	U.S.		Massachusetts	
	# Individuals	%	# Individuals	%
Total Population Age 5+	280,925,288	100.0	6,074,669	100.0
Population with ANY Disability:	43,796,933	15.6	895,772	14.7
TYPE OF DISABILITY:				
Self-Care disability (dressing, bating, getting around)	9,957399	22.7	209,987	23.4
Vision or Hearing disability	12,512,188	28.6	249,446	27.8
Difficulty Getting Out disability	14,447,585	33.0	300,868	33.6
Difficulty Learning/Remembering	17,666,637	40.3	375,848	42.0
Difficulty Working	24,889,266	56.8	508,078	56.7
Difficulty with Physical Activity	27,850,401	63.6	551,719	61.6

Note: Individuals may report having more than one type of disability.

Source: 2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.

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TN:2

The MA population age 65 and older will increase dramatically by 2020

Current and Projected MA Total Population 5 Yrs and Older by Age Group

Age Group:	2007 (Estimate)	2015 (Projected)			2020 (Projected)		
	Estimate*	Projected**	Change	% Change	Projected**	Change	% Change
5 – 15	885,827	894,063	8,236	**+0.9**	896,853	11,026	**+1.2**
16 – 20	470,777	441,304	-29,473	**-6.3**	440,621	-30,156	**-6.4**
21 – 34	1,151,480	1,284,883	133,403	**+11.6**	1,288,286	136,806	**+11.9**
35 – 44	985,722	846,105	-139,617	**-14.2**	838,398	-147,324	**-14.9**
45 – 54	992,930	989,385	-3,545	**-0.4**	889,778	-103,152	**-10.4**
55 – 64	724,203	867,690	143,478	**+19.8**	919,506	195,303	**+27.0**
65 – 74	417,039	566,961	149,922	**+35.9**	656,655	239,616	**+57.5**
75 – 84	308,894	289,544	-19,350	**-6.3**	331,175	22,281	**+7.2**
85 +	137,797	168,943	31,146	**+22.6**	171,987	34,190	**+24.8**
Total 5 +	6,074,669	6,348,878	274,209	**+4.5%**	6,433,259	358,590	**+5.9**

*2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.
**U.S. Census Bureau, State Interim Population Projections by Age, 2004-2030.

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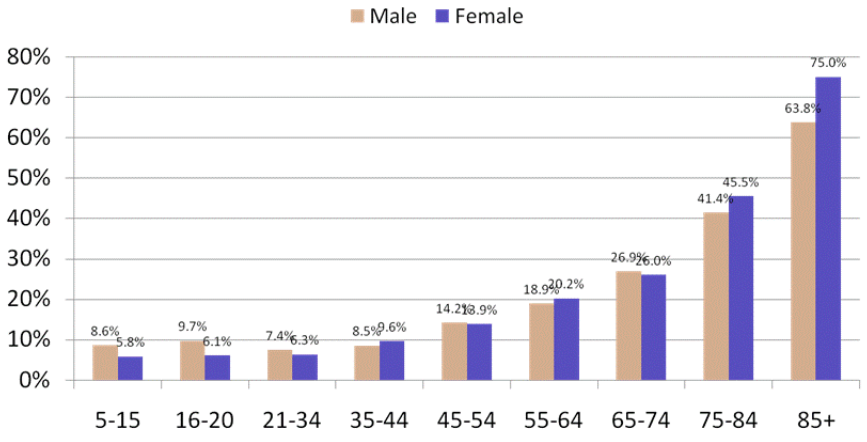
3

TN:3

For men and women, disability tends to increase by age

Incidence of People with Disabilities Age 5+ by Age Group and Gender, Massachusetts (2007)



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Source: 2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.

4

TN:4

15% of the population has a disability. More than half (54%) are age 55 or older.

Estimated Number of Persons Age 5+ with Disabilities in MA and the U.S By *Gender and Age*.

	U.S.		Massachusetts	
	# Individuals	%	# Individuals	%
Total Population	280,925,288	100.0	6,074,669	**100.0**
Population with ANY Disability:	43,796,933	15.6	895,772	14.7
Any Disability by **Gender**:				
Male	20,538,996	46.9	407,920	45.5
Female	23,257,937	53.1	487,852	54.5
Any Disability by **Age**:				
5-15	2,825,595	6.5	64,114	7.2
16-20	1,573,239	3.6	37,598	4.2
21-34	3,999,204	9.1	78,959	8.8
35-44	4,443,183	10.1	89,126	9.9
45-54	6,878,979	15.7	139,515	15.6
55-64	7,818,837	17.9	142,052	15.9
65-74	5,902,757	13.5	110,142	12.3
75-84	6,518,865	14.9	135,515	15.1
85+	3,836,274	8.8	98,748	11.0

Source: 2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.

TN:5

Disability is distributed by race/ethnicity in approximately the same proportion as in the total population.

Estimated Number of Persons Age 5+ with A Disability in Massachusetts and the U.S by *Race and Ethnicity*.

	U.S.		Massachusetts	
	# Individuals	%	# Individuals	%
Total Population	280,925,288	100.0	6,074,669	100.0
Population with ANY Disability:	43,796,933	15.6	895,772	14.7
Any Disability by Race:				
White Alone	33,345,574	76.1	752,241	84.0
Black or African American Alone	6,171,286	14.1	58,126	6.5
Asian Alone	1,087,810	2.5	23,434	2.6
Native American or Alaska Native Alone	481,166	1.1	3,042	0.3
Native Hawaiian or Other Pacific Islander Alone	51,210	0.1	0	0.0
All Other Races / Multiple Races	2,658,887	6.1	58,929	6.6
Any Disability by Ethnicity:				
Spanish/Hispanic/Latino Origin	4,458,702	10.2	80,040	8.9
Not of Spanish/Hispanic/Latino Origin	39,338,231	89.8	815,732	91.1

Source: 2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.

TN:6

Most people with disabilities live in the community

Estimated Number of People Age 5+ with a Disability in Massachusetts and the U.S By *Setting*.

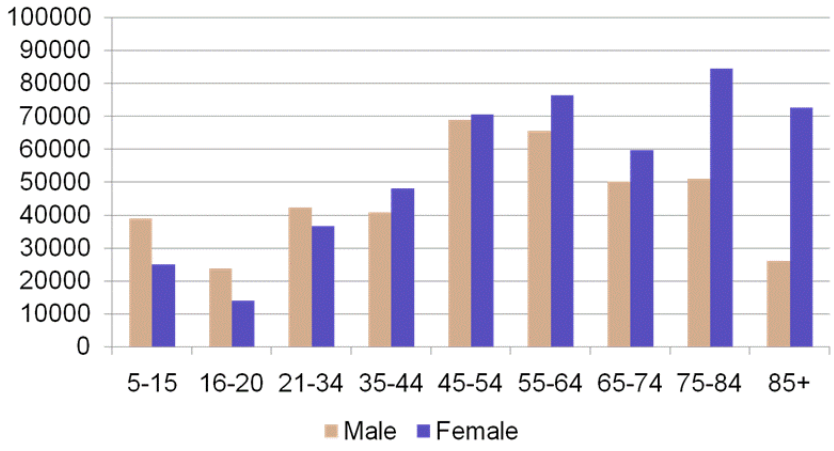
	U.S.		Massachusetts	
	# Individuals	%	# Individuals	%
Total Population	280,925,288	100.0	6,074,669	100.0
Population with ANY Disability:	43,796,933	15.6	895,772	14.7
Any Disability by Setting:				
Non-Institutional Community Settings	40,363,905	92.2	803,989	89.8
Non-Institutional Group Quarters Settings	942,293	2.2	25,897	2.9
Institutional Group Quarters Settings	2,490,735	5.7	65,886	7.4

Source: 2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.

TN:7

After age 35 there are more women with disabilities than men.

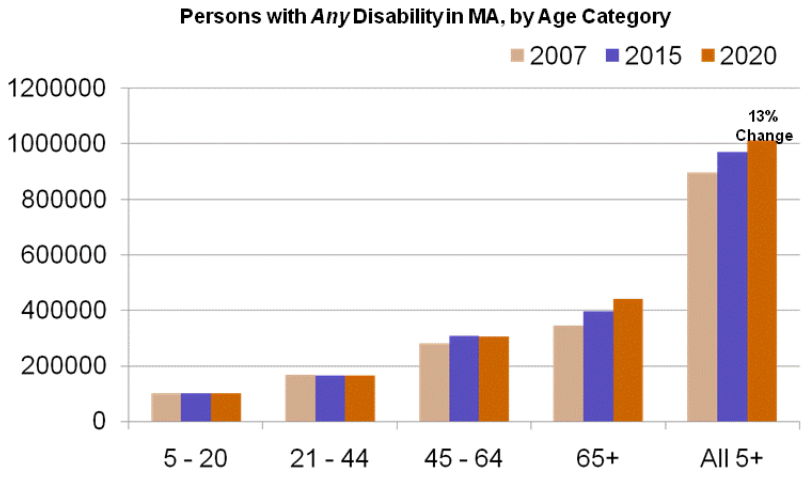
Number of Persons Age 5+ with *Any* Disability, by *Age Group and Gender* in MA (2007)



Source: 2007 American Community Survey, U.S. Census Bureau, tabulations by authors.

TN:8

The number of people with disabilities age 5+ is expected to grow by 13% between 2007 and 2020



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Sources: 1) 2007 American Community Survey (ACS), U.S. Census Bureau, 2) U.S. Census Bureau, State Interim Population Projections by Age, 2004-2030.; tabulations by authors.

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TN:9

The MA population with disabilities will exceed one million persons by 2020

Current and Projected MA Population 5 Yrs and Older with *Any* Disability by Age Group

Age Group:	2007 (Estimate)	2007 Incidence	2015 (Projected)			2020 (Projected)		
	Estimate*	%	Projected**	Change	% Change	Projected**	Change	% Change
5 – 15	64,114	7.2%	64,710	+596	+0.9%	64,912	+798	+1.2%
16 – 20	37,598	8.0%	35,242	-2,354	-6.3%	35,190	-2,408	-6.4%
21 – 34	78,959	6.9%	88,107	+9,148	+11.6%	88,340	+9,381	+11.9%
35 – 44	89,126	9.0%	76,502	-12,624	-14.2%	75,805	-13,321	-14.9%
45 – 54	139,515	14.1%	139,017	-498	-0.4%	125,021	-14,494	-10.4%
55 – 64	142,052	19.6%	170,197	+28,145	+19.8%	180,361	+38,309	+27.0%
65 – 74	110,142	26.4%	149,737	+39,595	+36.0%	173,426	+63,284	+57.5%
75 – 84	135,518	43.9%	127,029	-8,489	-6.3%	145,293	+9,775	+7.2%
85 +	98,748	71.7%	121,068	+22,320	+22.6%	123,249	+24,501	+24.8%
Total 5 +	895,772	14.7%	971,611	+75,839	+8.5%	1,011,597	+115,825	+12.9%

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*2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.
**U.S. Census Bureau, State Interim Population Projections by Age, 2004-2030, tabulations by authors.

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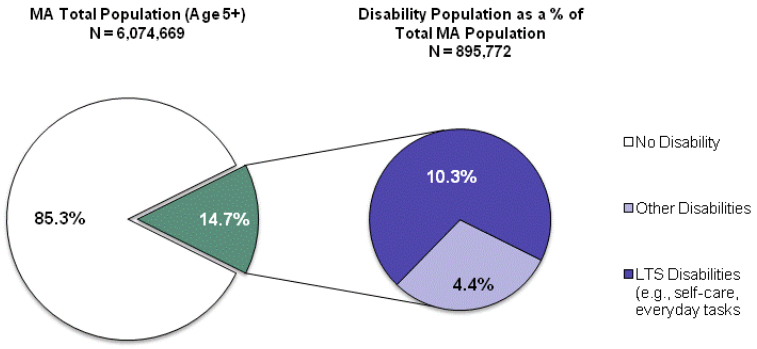
Part II

Estimates of the Population with LTS Disabilities

TN:10

People with disabilities comprise nearly 15% of the total MA population; those with a LTS disability comprise about 10% of the total MA population

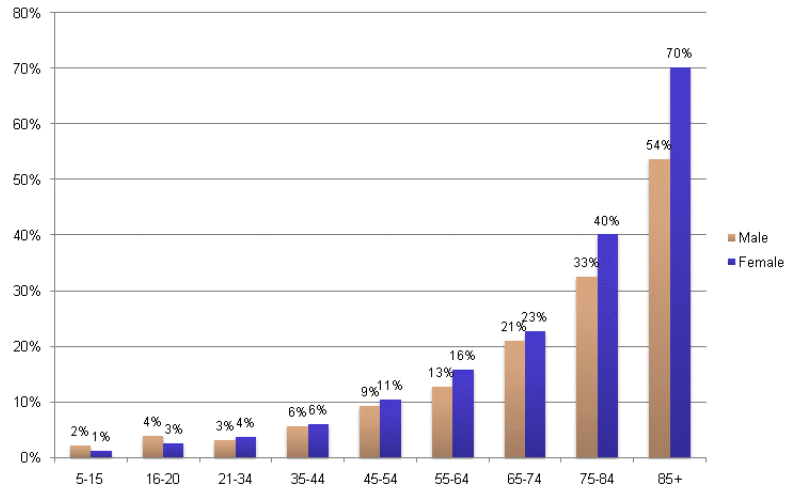


Source: 2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.

TN:11

For men and women, LTS disability increases with age

Incidence of Persons with a LTS Disability by Age Group and Gender, Massachusetts (2007)



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Source: 2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.

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TN:12

LTS disability is distributed by race/ethnicity in approximately the same proportion as the population

Estimated Number of Persons with a LTS Disability and All Individuals Age 5+ in Massachusetts by *Race and Ethnicity*

	Massachusetts		LTS Disability	
	# Individuals	%	# Individuals	%
Total Population Age 5+	6,074,669	100.0	626,280	100.0
Disability by **Race**:				
White Alone	752,241	84.0	532,913	85.1
Black or African American Alone	58,126	6.5	39,351	6.3
Asian Alone	23,434	2.6	15,684	2.5
Native American or Alaska Native Alone	3,042	0.3	2,295	0.4
Native Hawaiian or Other Pacific Islander Alone	0	0.0	0	0.0
All Other Races / Multiple Races	58,929	6.6	36,037	5.8
Disability by **Ethnicity**:				
Spanish/Hispanic/Latino Origin	80,040	8.9	51,179	8.2
Not of Spanish/Hispanic/Latino Origin	815,732	91.1	575,101	91.8

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Source: 2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.

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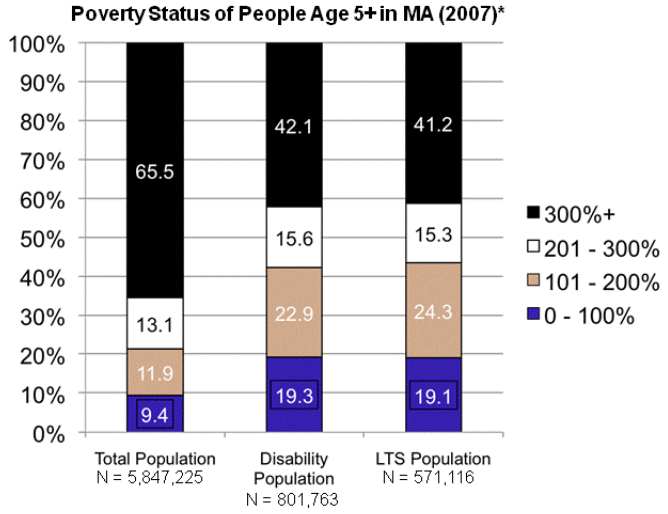
TN:13

Nearly 60% of people with a LTS disability are below 300% of the poverty level, compared to roughly one-third of the total Massachusetts population



*Note: Excludes Group Quarters populations, for whom poverty status data incomplete

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Source: 2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.

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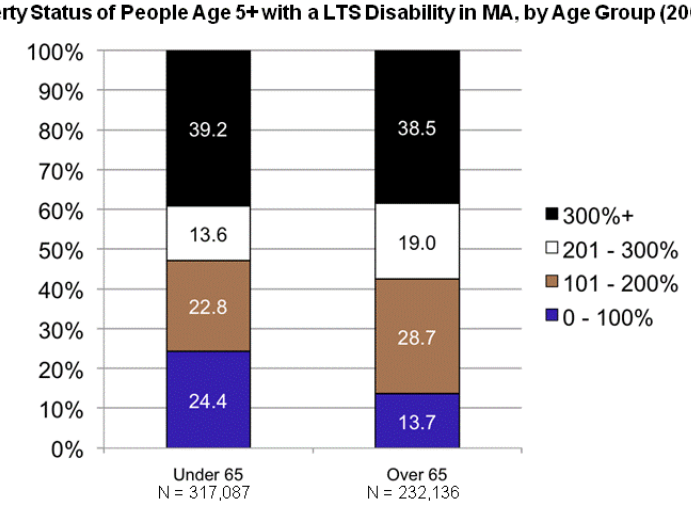
TN:14

Among people with a LTS disability, a greater proportion of those under age 65 are below the poverty level, than are those over age 65



*Note: Excludes Group Quarters populations, for whom poverty status data incomplete

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Source: 2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.

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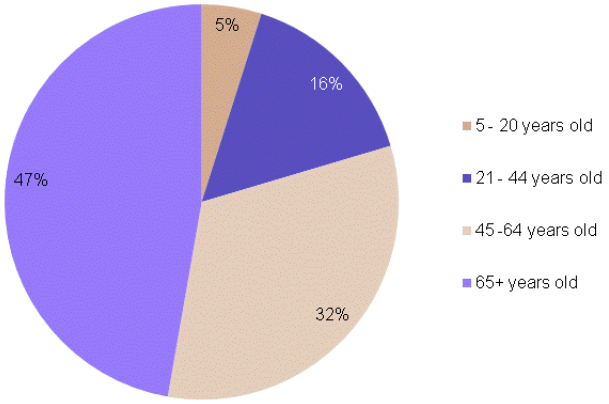
TN:15

Approximately half of the people with a LTS disability are age 65 and older, and half are under age 65

People with LTS Disability in MA, by Age Group (2007)



Total Age 5+ = 626,280

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Source: 2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.

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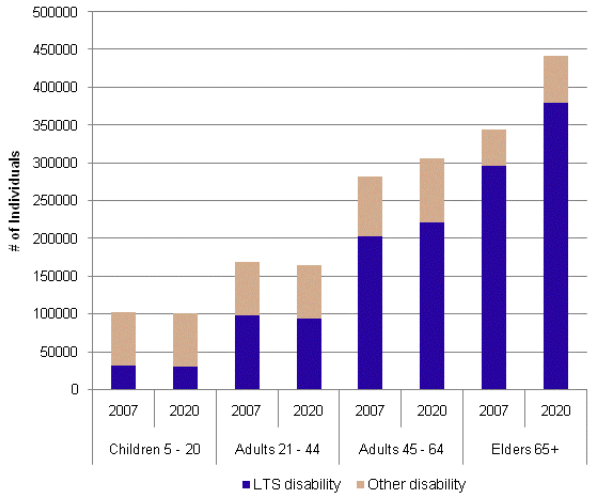
TN:16

The needs for LTS population will increase

Older adults (age 65+) are the fastest growing group, and most likely to need long-term supports

Projected increase in disability populations by age group.



Sources:
Estimates: 2007 American Community Survey (ACS),U.S. Census Bureau, tabulations by authors.
Projections: U.S. Census Bureau, State Interim Population Projections by Age, 2004-2030, tabulations by authors.

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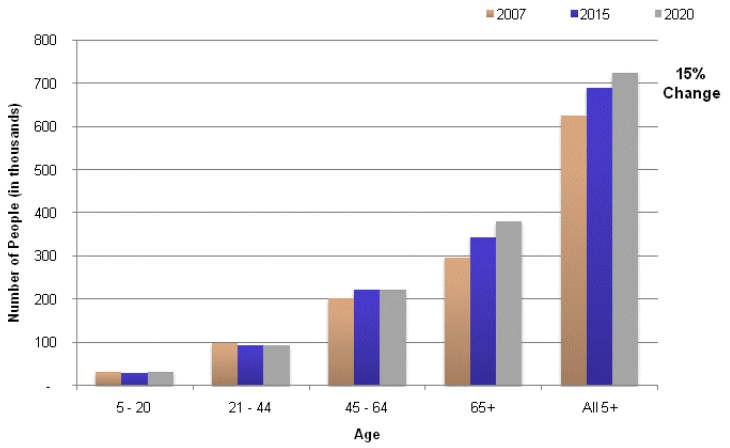
TN:17

The number of people with a LTS disability is projected to grow by 15% from 2007 to 2020 (compared to 6% growth for the total MA population)

People age 5+ with a LTS Disability in MA, by Age Category



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Source: 2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.

19

TN:18

The MA LTS population will increase at a higher rate than the overall population with disabilities

Current and Projected MA *LTS* Disability Population 5 Yrs and Older by Age Group

Age Group:	2007 (Estimate)	2007 Incidence	2015 (Projected)			2020 (Projected)		
	Estimated*	%	Projected**	Change	% Change	Projected**	Change	% Change
5 – 15	15,568	1.8%	15,713	+145	+0.9%	15,762	+194	+1.2%
16 – 20	15,059	3.2%	14,116	-943	-6.3%	14,094	-965	-6.4%
21 – 34	39,622	3.4%	44,212	+4,590	+11.6%	44,329	+4,707	+11.9%
35 – 44	57,529	5.8%	49,381	-8,148	-14.2%	48,931	-8,598	-14.9%
45 – 54	98,402	9.9%	98,051	-351	-0.4%	88,179	-10,223	-10.4%
55 – 64	104,227	14.4%	124,878	+20,651	+19.8%	132,335	28,108	+27.0%
65 – 74	91,570	22.0%	124,489	+32,919	+35.9%	144,183	+52,613	+57.5%
75 – 84	114,425	37.0%	107,257	-7,168	-6.3%	122,679	+8,254	+7.2%
85 +	89,878	65.2%	110,193	+20,315	+22.6%	112,178	+22,300	+24.8%
Total 5 +	626,280	9.7%	688,289	+62,009	+9.9%	722,671	+96,391	+15.4%

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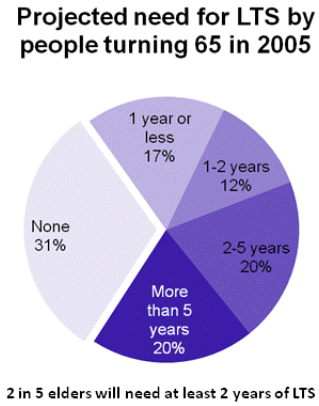
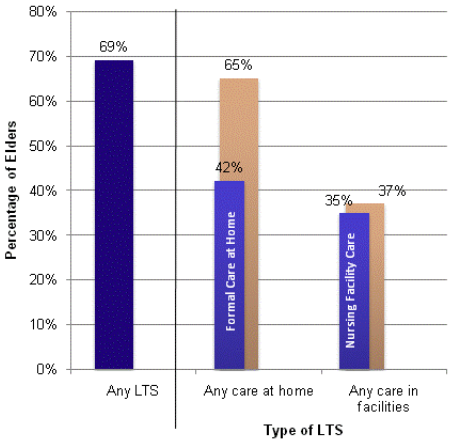
*2007 American Community Survey, U.S. Census Bureau, tabulations by authors.
** U.S. Census Bureau, State Interim Population Projections by Age, 2004-2030,tabulations by authors.

20

TN:19

Most people turning 65 will need LTS in their lifetimes





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Source: P. Kemper et al., "Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?" *Inquiry* 42:335-30 (Winter 2005/06)

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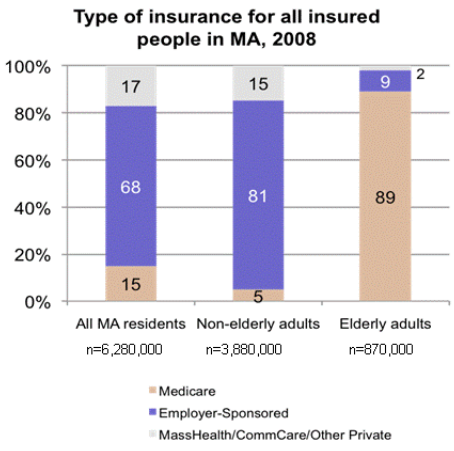
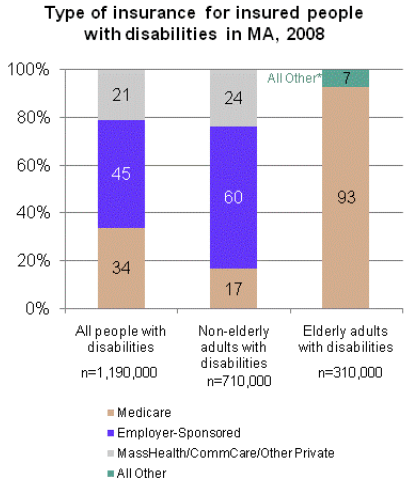
TN:20

Most people in MA, including those with disabilities, have health insurance (which typically does not cover LTS)





Note: Disability status is self-declared. Population figures (n) are estimates, in thousands

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Source: Mass. Division of Health Care Finance and Policy

22

TN:21

How do the ACS data compare with data on need for assistance with daily activities? (an illustration based on elders)

U.S.	2004 - 2005[1]	Est. MA from Nat'l Projections[2]
Total Age 65+	%	Total Age 65+ (863,730)
Nondisabled	**81.0**	699,621
IADL only	2.4	20,730
1-2 ADLs	5.6	48,369
3-4 ADLs	3.8	32,822
5-6 ADLs	3.2	27,639
Institution	4.0	34,549

ACS Est. MA 2007[2]		ACS Est. MA 2007[2]
Total Age 65+ (863,730)		%
Nondisabled (inst. & community)	**519322**	**60.1**
Other Disability (inst.& community), (no Mobility and no Self-Care)	48,536	5.6
Mobility (no Self-Care Disability)	**179,351**	**20.8**
Self Care Disability (Community)	**72,544**	**8.4**
Self Care (Institutional)	**43,977**	**5.1**

Sources:
[1]Manton, K.G., Gu, X., et al. (2006)
[2]2007 American Community Survey (ACS) U.S. Census Bureau, tabulations by authors

TN:22

How do the ACS data compare with data on students with disabilities? (an illustration based on MA public school population)

MA Est. 2007 Pop. Est. with Educational Disabilities data		
Total Age 5 – 20 (Non-Institutional)	N	%
Total Population	**1,349,334***	**100.0**
No Educational Disability	1,183,297	87.7
Specific Learning Disability	59,454	**4.4**
Intellectual/sensory disabilities:: Intellectual, Hard of Hearing, Communication, Vision Impairment, Emotional, Sensory/Deaf-blind, Autism,	65,385**	**4.8**
Physical disabilities: Physical, Health, Multiple Disabilities, Developmental Delay	41,198**	**3.1**

ACS Est. MA 2007		ACS Est. MA 2007
Total Age 5 – 20 (Non-Institutional)	N	%
Total Population	**1,349,334***	**100.0**
No Disability (ACS)	1,251,773*	92.8
Specific Learning Disability	Not identified	**NA**
Other Disability (ACS: Vision/hearing, Working, Learning) and NOT LTS Disability	70,243*	**5.2**
LTS Disability (ACS: Self-care OR Physical OR Going Out)	27,318*	**2.0**

Sources: *2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.
**Massachusetts Department of Elementary and Secondary Education (2008-09).

TN:23

Students with Disabilities (regular and special education students) Enrolled in Public Schools in MA for School Year 2008-2009

Disability	# of Students	% of Total
Intellectual	10,968	6.6
Sensory/Hard of Hearing	1,194	0.7
Communication	28,701	17.3
Sensory/Vision Impairment	544	0.3
Emotional	13,966	8.4
Physical	1,603	1.0
Health	11,525	6.9
Sensory/Deafbliind	219	0.1
Multiple Disabilities	4,780	2.9
Autism	9,793	5.9
Neurological	6,481	3.9
Developmental Delay	16,809	10.1
Specific Learning Disabilities	59,454	35.8
Total	**166,037**	**100.0**

Source: Massachusetts Department of Elementary & Secondary Education (2008-2009)

TN:24

People with disabilities report experiencing more poor health

Quality of Life Among Massachusetts Adults (2007)

	15+ Days of Poor Physical Health		
Group:	**N**	**%**	**95% CI**
Disability Status:			
Disability	1,361	28.0	24.2 – 31.8
No Disability	3,740	3.5	2.7 – 4.2

Source: Mass. Dept. of Public Health, Health Survey Program. A Profile of Health Among Massachusetts Adults, 2007

Part II Summary Points

- There are many types of LTS and they are provided in a variety of settings
- The key factors distinguishing LTS are:
  - Help with everyday tasks or self-care
  - Needed over an extended period of time
- People needing assistance with everyday tasks or self-care are 10% of the total MA population
  - About 1/2 of the people with a LTS disability are elders, and 1/2 are under 65
  - While people of any age may need LTS, need tends to increase with age
- The population needing LTS will grow dramatically between now and 2020
- While most people with disabilities in MA have health insurance coverage, this coverage typically does not cover LTS

Part III
LTS Utilization

TN:25

Most people with a LTS disability live in community settings

People Age 5+ with a LTS Disability in MA, by Setting

	LTS Disability	
	# Individuals	%
Non-Institutional Community Settings	549,287	87.7
Non-Institutional Group Quarters Settings	15,711	2.5
Institutional Group Quarters Settings*	61,282	9.8
All Settings	626,280	100.0

*The ACS data includes individuals in correctional facilities and, therefore, overstates the number in institutions.

Source: 2007 American Community Survey (ACS), U.S. Census Bureau, tabulations by authors.

TN:26

People with disabilities, including those with LTS needs, receive services from various state agencies. Almost all people receive these services in community settings.

Agency	LTS Programs	Unduplicated Number of Individuals Served
DMH	Case management, crisis management, community rehabilitation support, clubhouse, drop in center, day rehabilitation, day, residential, in-patient and out-patient, respite, and educational/employment services	27,594
DDS (DMR)	Service coordination, outreach and education, transportation, Turning 22 program, community residential, facility, individual, family, community day and employment supports.	33,203[b]
EOEA	Home Care Basic, ECOP, and Choices/Frail Elder Waiver	68,880[ab]
VET	Homeless services, suicide prevention, workforce development, outreach	237
MCB	Independent living social services including orientation and mobility, rehabilitation services, specialized services for children, Turning 22 program, bridge program, vocational rehabilitation including assistive technology and employment supports	2,986[a]
MCDHH	Case management, independent living services, communication access and training services,	5,291[a]
MRC	Independent living centers, Turning 22, assistive technology, housing registry, supported living, head injury program, protective services, voc. rehab, employment	40,116[b]
DPH	Early intervention for children with a medical diagnosis that has a high probability of resulting in developmental delay	4,748[a]

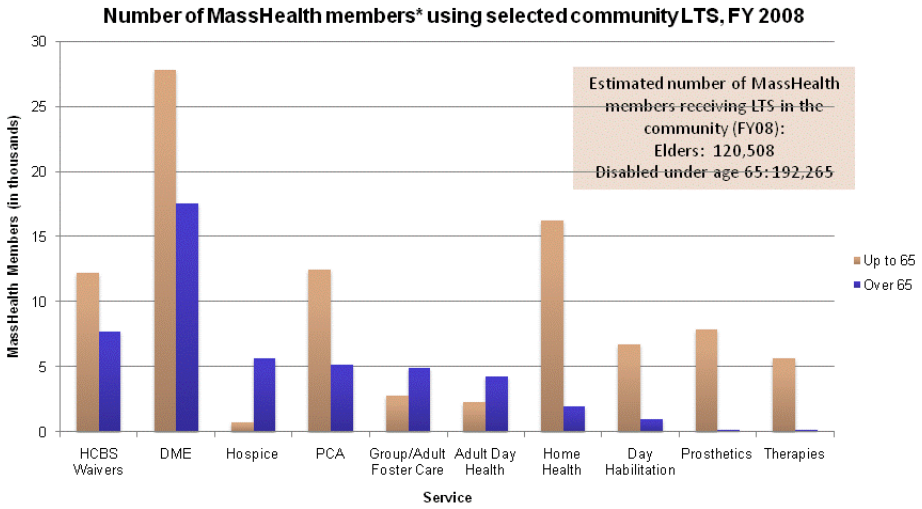
[a]100% of people served are in community settings

[b]Includes HCBS waiver enrollees

Source: MA State Profile Tool, 2009

TN:27

Elder and disabled MassHealth members use a variety of community LTS



*Not unduplicated. HCBS Waiver numbers are estimated, as of 1/09.

Source: MassHealth

TN:28

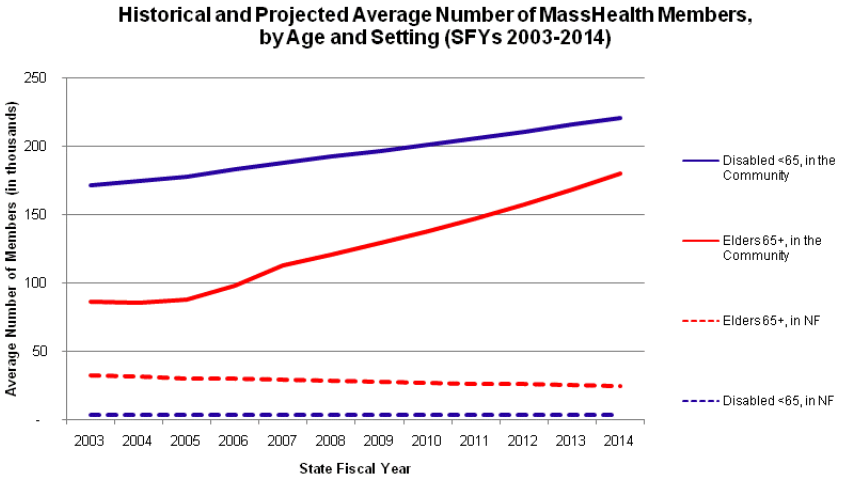
Utilization of MassHealth LTS

	Members		Expenditures ($ in Millions)	
Provider Type	FY2007	FY2008	FY2007	FY2008 Est.
Inpatient Rehab/Chronic	3,187	2,092	265.7	269.90
Outpatient Rehab/Chronic	11,296	7,505	12.7	10.6
Nursing Facilities	44,277	42,336	1,557.9	1,545.9
PCA	15,798	17,584	284.5	315.7
Home Health Agency	17,685	18,141	117.6	135.0
Private Duty Nursing (Indep.)	182	219	6.4	9.6
Adult Foster Care/Group	6,696	7,730	75.1	89.7
Adult Day Health	6,040	6,499	52.9	62.7
Day Habilitation	7,305	7,689	106.6	112.1
Hospice Care	5,855	6,393	87.7	105.30
Therapies	5,535	5,809	2.1	2.1
Early Intervention	7,787	8,045	9.0	9.3
Prosthetics/Orthotics	6,153	8,045	4.4	5.3
DME/Oxygen	44,939	45,291	37.9	37.7
Total	182,735+	183,378+	2,620.4+	2,710.9+

Source: MassHealth Finance Office

TN:29

The number of community-based elder and disabled MassHealth members is projected to continue to increase

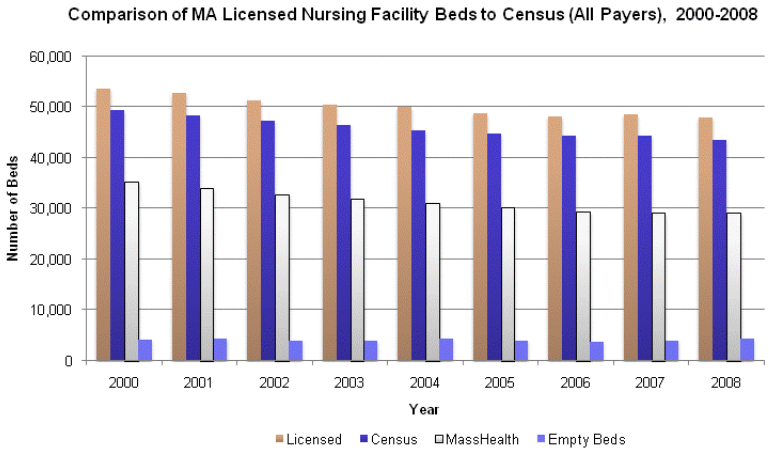


Note: Projections are based on current utilization

Source: MassHealth Finance Office

TN:30

Over the past decade, nursing facility bed availability and average census have decreased

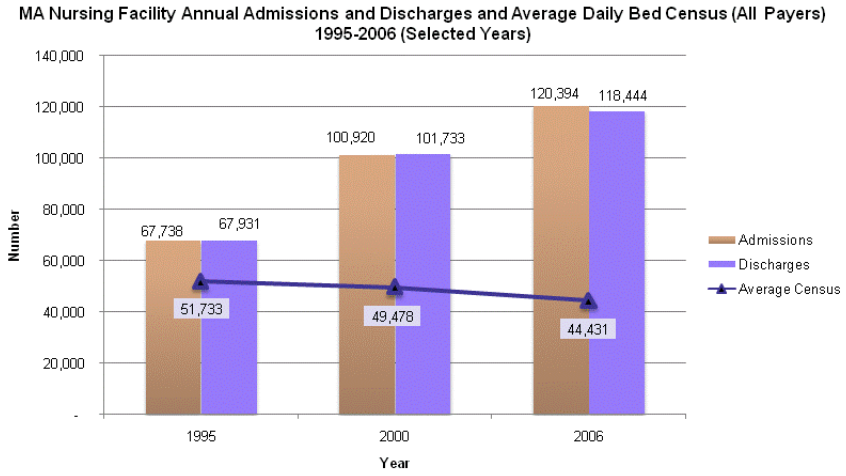


Since 2000, the number of licensed beds has decreased 12%, the census has decreased 14%, and the number of empty beds has increased 5%.

Source: MassHealth Office of Long-Term Care

TN:31

Nursing facility admissions continue to rise, matched by the number of discharges - even as the number of occupied beds in MA falls



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Source: DHCFP nursing facility cost reports, with tabulations by Mass Senior Care Association (admissions & discharges), 2009; MassHealth Office of LTC (census)

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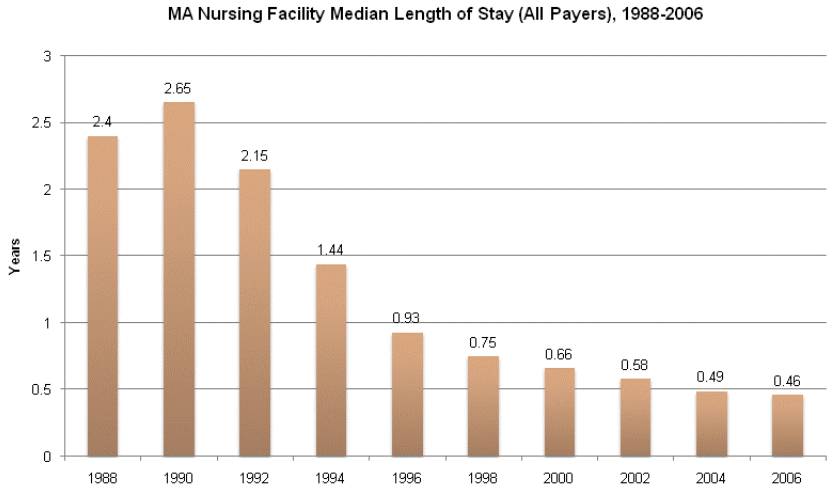
TN:32

The average length of stay in MA nursing facilities has declined steadily since 1990



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Source: State DHCFP, Nursing Facility Cost Reports, 1988-2006

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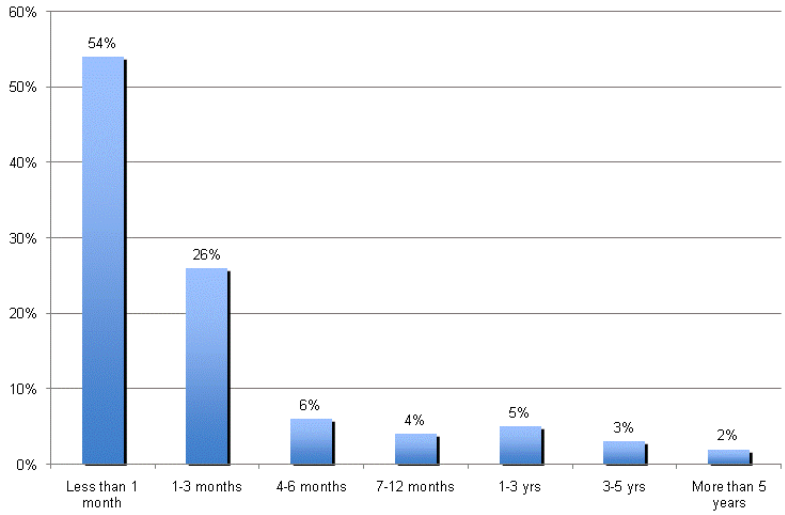
TN:33

Most MA Nursing Home residents have short stays (post acute); these are generally covered by Medicare



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Source: MSCA Admission, Discharge and Length of Stay Survey, February 2008.

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TN:34

Nursing Facility Industry Profile - All Payers

*Number of Facilities:	433
*Urban Facilities:	113
*Number of Licensed Beds (excluding Rest Homes) as of 1/1/08 Census:	47,946
*Average Occupancy as of 1/1/08 Census:	90.9%
Licensed beds in Urban Areas from 1/1/08 Census:	10,902
Average Urban Occupancy from 1/1/08 Census:	91.1%
Percentage For- Profit: From HCFP:	73.35 %
Affiliated with or owned by Management Company:	69.34%
Affiliated with Real Estate Companies:	55.42%
Annual **Medicaid Patient Days SFY 2007:	$10,346,359
Annual **Medicaid Expenditure SFY 2007:	$1,554B
Annual **Medicaid** Patient Days SFY 2006	10,518,752
Annual **Medicaid** Expenditures SFY 2006	$1,555,000,000
***Payer Mix:	
Mass Medicaid	66.9%
Other Medicaid (COB non-MA MCD)	1.3%
Medicare	14.5%
Private/Other	17.4%
Total Industry Revenue (2007) from HCFP	$ 3.659B

* Data source Medicaid January 1, 2008 Census excludes all private & non-participating Medicare facilities
** Data source from MassHealth Finance Office
*** DHCFP cost report

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Source: MassHealth Office of Long-Term Care

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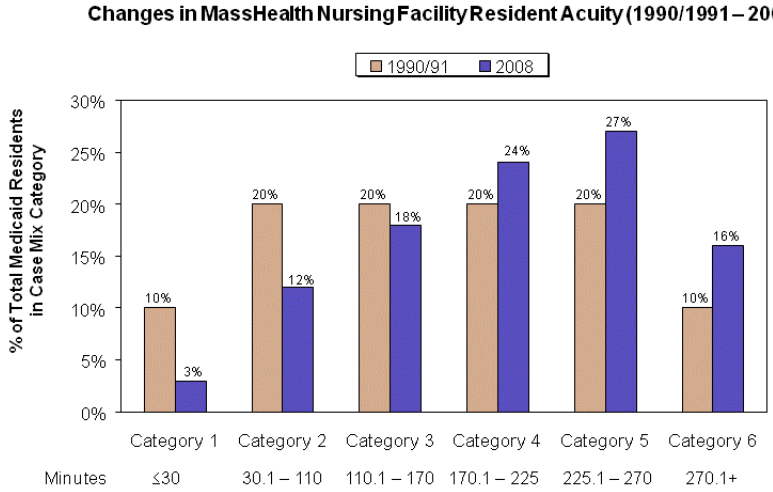
TN:35

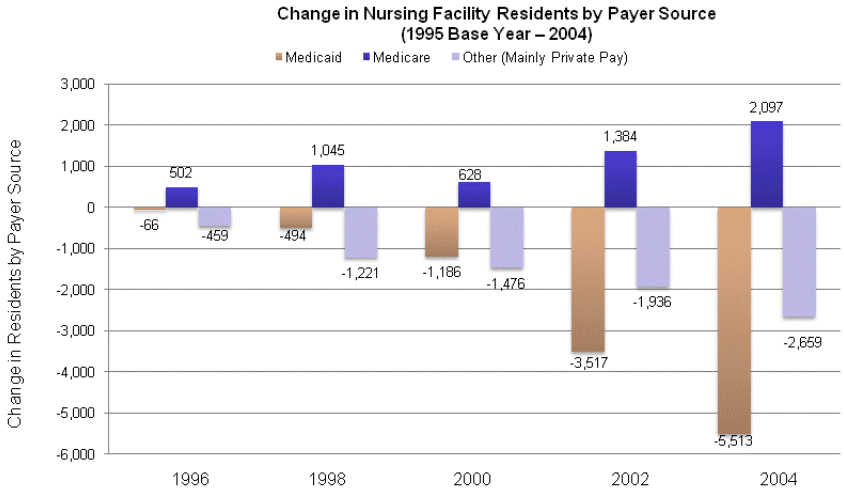
MassHealth nursing facility residents are becoming more frail (1990/1991 – 2008)



Source: Mass. Senior Care Association, 2009.

TN:36

Medicare's proportion of nursing facility residents in MA has increased, while Medicaid's proportion has decreased

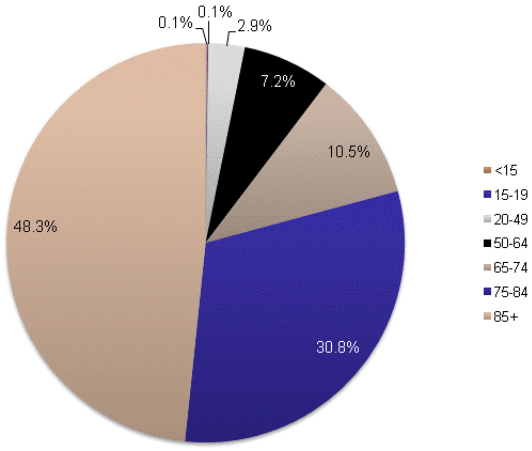


Source: Mass Senior Care Association.

TN:37

90% of all Massachusetts nursing facility residents are 65 years or older; nearly half are 85 years or older.

Age Distribution of Residents in MA Nursing Facilities



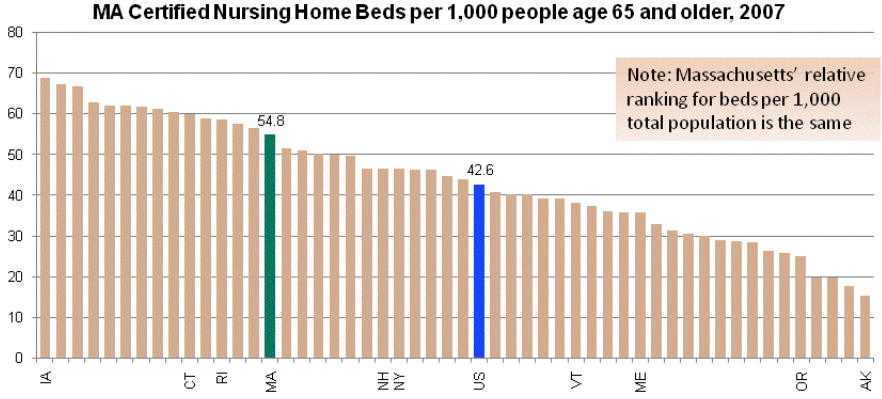
Age	Number
<15	61
15-19	35
20-49	1,268
50-64	3,087
65-74	4,516
75-84	13,288
85+	20,831
Total	**43,086**

Source: MassHealth Office of Long-Term Care

TN:38

In 2007, MA had more nursing home beds per capita than about two-thirds of the states

MA Certified Nursing Home Beds per 1,000 people age 65 and older, 2007



Sources: Kaiser Family Foundation State Health Facts Online; U.S. Census Bureau

Based on current numbers, DPH has recently determined that MA has excess nursing facility beds to meet 2015 need

- MA is projected to have an average daily bed census of 37,657 nursing facility residents in 2015
- Assuming a 95% occupancy rate, this would require 39,639 nursing facility beds
- There are 48,839 beds in the state currently, including 1,572 beds out of service
- Therefore, there would be 10,772 excess beds in 2015

Source: Department of Public Health, 2008.

Part III Summary Points

- Most people needing LTS live in community settings
- Community LTS are provided through MassHealth and a variety of state agencies
- Elder and disabled MassHealth members use a wide range of community LTS
- The number of community-based elder and disabled MassHealth members is projected to increase

Part III Summary Points (2)

- Nursing facility utilization and average length of stay have declined steadily in the past decade
- The overall acuity of MA nursing facility residents has increased due to an increase in the acuity of post-acute nursing facility admissions, which is matched by short-stay discharges
- MA has a higher ratio of nursing facility beds per elder than most states, and a projected excess of over 10,000 beds through 2015

Part IV
Unmet Need for LTS

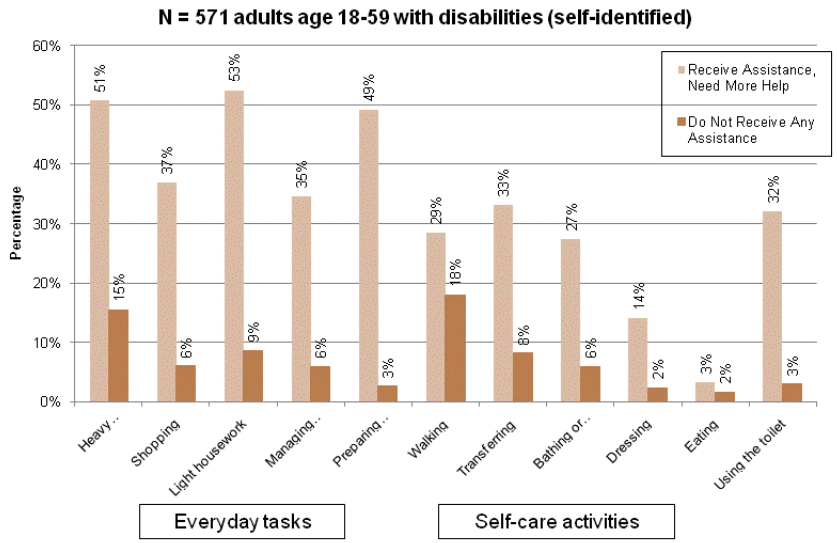
Many people with a LTS disability have unmet needs

- A study of **children** with special health care needs in MA found that over 10% of these children had unmet needs for home health care, mental health care, substance abuse treatment, communication aids and professional care coordination (KS Hill, 2008)
- A study of **adults** with disabilities in MA found that many people with ADL and IADL needs did not receive help (DPH, 2007)
- A national study of dual eligible **elders** (age 65+) found that while 64% receive home care, 55% still have unmet\ need for help with ADLs (Komisar, Feder, Kasper, 2005)

Sources:
Kristen Hill, et al. *Unmet Need among Children with Special Health Care Needs in Massachusetts.* Matern Child Health J (2008) 12.
DPH, *Study of the Unmet Needs of Adults with Disabilities in Massachusetts, 2007.*
Harriet Komisar, Judy Feder, Judith Kasper. *Unmet Long-Term Care Needs: An Analysis of Medicare-Medicaid Dual Eligibles.* Inquiry 42: 171-182 (Sum 2005).

TN:39

In MA, many people who receive assistance with LTS need more help; some people who need LTS receive no assistance at all



Source: DPH, Study of the Unmet Needs of Adults with Disabilities in Massachusetts, 2007

TN:40

Of those in the community needing assistance, only a portion receive help

	Have any difficulty .... (n=571)*	Receive help with .... (n=571)
ACTIVITIES OF DAILY LIVING		
Walking	26.8%	8.8%
Getting in or out of bed or chairs	16.9%	8.6%
Bathing or showering	11.2%	5.2%
Dressing	8.6%	6.2%
Eating	4.8%	3.1%
Using the toilet	4.3%	1.3%
INSTRUMENTAL ACTIVITIES OF DAILY LIVING		
Heavy housework	53.8%	38.4%
Shopping	31.4%	25.3%
Light housework	25.8%	17.1%
Managing money	19.5%	13.5%
Preparing own meals	14.2%	11.5%

*The number of unweighted cases varies from 568-571, depending on the number of missing cases.

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Source: DPH, Study of the Unmet Needs of Adults with Disabilities in Massachusetts, 2007

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TN:41

Many of those receiving help still have unmet needs

	Need more help with ...
	Based on those having difficulty*
ACTIVITIES OF DAILY LIVING	
Getting in or out of bed or chairs	33.2%
Using the toilet	32.1%
Walking	28.5%
Bathing or showering	27.4%
Dressing	14.1%
Eating	3.3%
INSTRUMENTAL ACTIVITIES OF DAILY LIVING	
Light housework	52.5%
Heavy housework	50.8%
Preparing own meals	49.1%
Shopping	36.9%
Managing money	34.6%

* The number of unweighted cases varies depending on how many respondents reported that they had difficulty with a particular ADL/IADL. The numbers vary from 21 (for help eating) to 354 (for heavy housework).

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Source: DPH, Study of the Unmet Needs of Adults with Disabilities in Massachusetts, 2007

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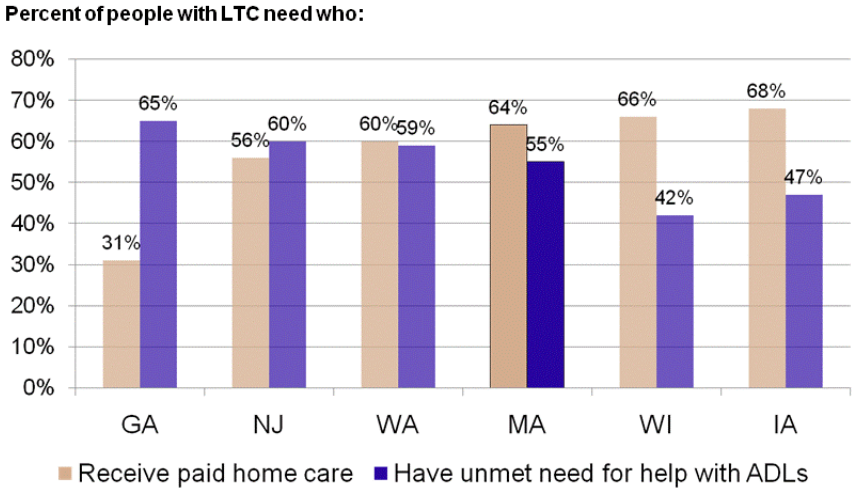
TN:42

Most people with paid help still have unmet needs.



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Source: Komisar, H.L., Feder, J. & Kasper, J.D. (2005).

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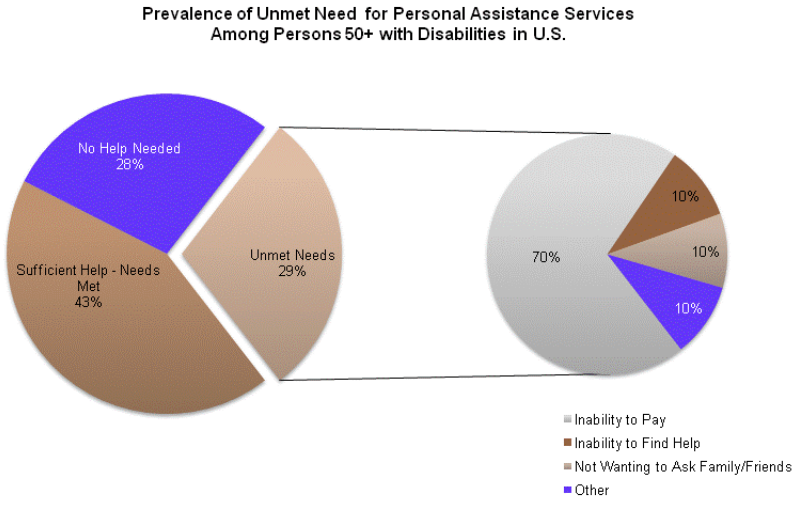
TN:43

Reasons for unmet need include inability to pay or find help, and not wanting to ask friends and family



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Source: Mary Jo Gibson, S. Verma. Just Getting By: Unmet Need for PAS Among Persons 50 or Older with Disabilities. AARP Public Policy Institute.

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TN:44

About 20% of adults with disabilities report unmet needs for case management

Percentage of Adults with Disabilities who needed case management services in the past 12 months

Felt like needed ….	% (n=571)
Help keeping track of services	19.6%
Help finding services	19.5%
Advice about eligibility for public benefit programs	18.3%
Help finding caregivers to help at home	15.2%

Source: DPH, Study of the Unmet Needs of Adults with Disabilities in Massachusetts, 2007

TN:45

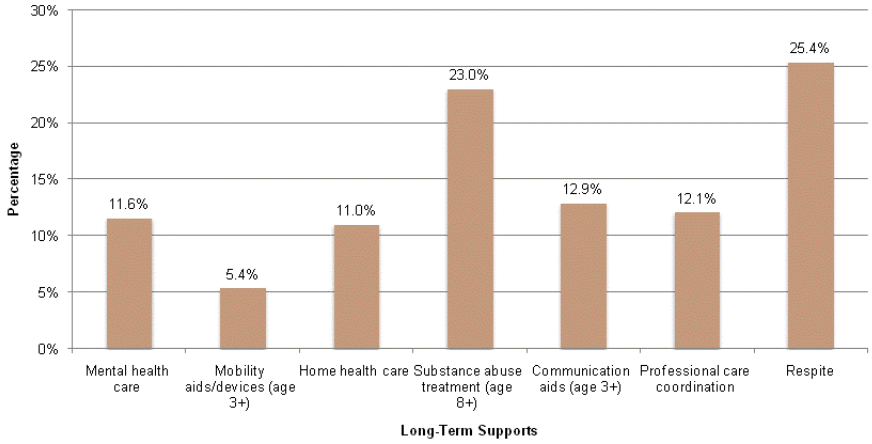
Many children with special health care needs still have unmet needs

	Needs Reported		Unmet needs reported	
LTS	All CSHCN (%)	CSHCN w/more severe needs (%)	All CSHCN (%)	CSHCN w/more severe needs (%)
Mental health care	33.3	53.8	11.6	12.9
Medical Equipment	10.6	14.9	0.3	0.0
Mobility aids/devices (age 3+)	4.9	6.9	5.4	26.5
Home health care	4.3	17.7	11.0	18.3
Substance abuse treatment (age 8+)	2.6	6.6	23.0	11.4
Communication aids (age 3+)	2.5	10.8	12.9	21.0
Professional care coordination	11.0	25.6	12.1	11.4
Eyeglasses/vision care	33.4	37.8	1.7	3.2
Hearing aids/hearing care	5.2	10.0	0.0	0.0

Source: KS Hill, Freeman, LC, Yucel RM, Kuhlthau, KA. Unmet Need Among Children With Special Health Care Needs in Massachusetts. Maternal Child Health Journal (2008) 12: 650-661.

TN:46

Reported Unmet Need among Children with Special Health Care Needs (CHSCN)*

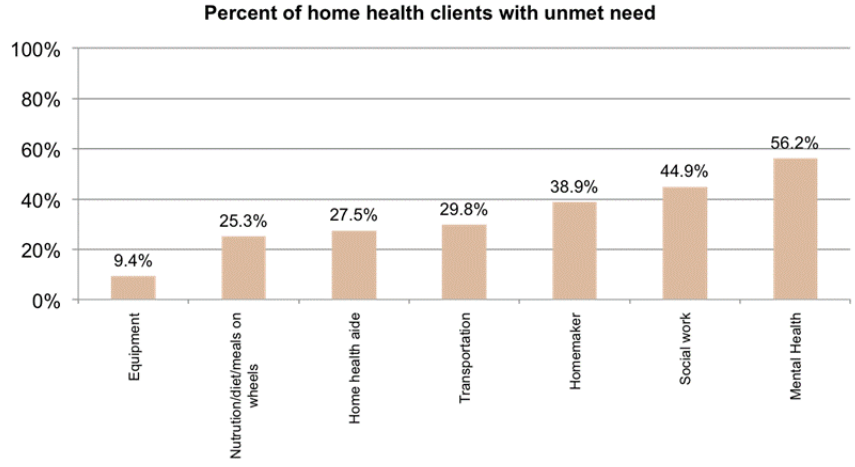


* CSHCN are defined as children who require services beyond that required by children generally because of a chronic physical, developmental, behavioral or emotional condition.

Source: KS Hill, Freeman, LC, Yucel RM, Kuhlthau, KA. Unmet Need Among Children With Special Health Care Needs in Massachusetts. Maternal Child Health Journal (2008) 12: 650-661.

TN:47

More than half of home health clients reported at least one unmet need



Note: Data collected from 2,013 Mass. home health clients from 12 HH agencies. Need reported by specialty nurses.

Source: Cindy Parks Thomas, Susan Payne. "Home Alone: Unmet Need for Formal Support Service Among Home Health Clients." Home Care Services Quarterly, Vol. 17(2) 1998.

Other potential indicators of unmet need

- 1,500 applications were submitted for the 80 autism waiver slots that became available in November, 2007
- Hutchinson settlement plaintiffs have alleged that thousands of people with acquired brain injuries have unmet needs for long-term supports in the community
- Many individuals in nursing facilities have stated a preference for living in the community. They can not leave institutional settings because community-based services are not available to them. On a typical day, 32,000 MassHealth members are residing in nursing facilities.

Gaps in existing access to publicly-funded community LTS contribute to unmet need

- Across state programs, there is uneven access to LTS depending on diagnosis, age and income status
- Only four populations are eligible for any HCBS waiver services:
  - children with autism
  - elders
  - people with mental retardation
  - people with traumatic brain injury
- Individuals who have developmental disabilities (not MR), age into or acquire disabilities (including brain injury) have less or no access to services

TN:48

Gaps in Existing Access to Long Term Supports

Key LTS Availability for Adults with Disabilities Across the Disability Agencies, DMH, EOEA & DPH

Disability or Condition Key Community-Based LTS & where available	Mental Retardation (MR)	Physically Disabled (PD)	Seriously and Persistently Mentally Ill (SPMI)	Acquired Brain Injury (ABI) excluding TBI	Traumatic Brain Injury (TBI)	Develop-mental Disabilities (DD) excluding MR	Multiple Sclerosis (MS)	Autism	>60	Other Adult Onset Disabilities (like Parkinson's)
-HCBS waiver services	DMR				MRC				EOEA	
- 24/7 Residential supports (staffing) including AFC and GAFC	DMR Mass Health		DMH		MRC				Mass Health	
-Case management	DMR	MRC's Supported living program (Limited to 100)	DMH			UMass (as NF to transition out) MRC	DPH		EOEA	
-PCA (limited to hands-on assistance with 2 ADLs and ability to self-direct or surrogate direct)	Mass Health[1]	Mass Health		Mass Health	Mass Health	Mass Health	Mass Health	Mass Health	Mass Health	Mass Health
-Chore/homemaker services (state funded only)	DMR	MRC							EOEA	
-skills training	DMR	ILCs	DMH ILCs	ILCs	MRC	ILCs	ILCs	ILCs	ILCs/ ASAPS	ILCs
-peer counseling	ILCs	ILCs		ILCs		ILCs	ILCs	ILCs		ILCs
-employment supports	DMR	MRC		MRC		MRC	MRC	MRC		

[1] Assumes that any qualifying criteria, including disability and financial criteria for eligibility, are met.

Part IV Summary Points

- Studies in MA show that people with disabilities across all age groups have unmet LTS needs – the degree of unmet need varies by population and service category
- More people receive some assistance, but need more help ("under-assisted"), than receive no assistance at all ("unassisted")
- For people with disabilities age 50 and over, the primary reason for having unmet need for personal assistance services is the inability to pay
- Gaps in access to publicly-funded community LTS, due to program eligibility that varies by diagnosis, age and income, contribute to unmet need

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Part V
LTS Spending

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Nationally, Medicaid and informal caregivers support the majority of LTS

- Of all paid LTS:
  - Medicaid is the primary payer of LTS for people with disabilities of all ages (48.9%)
  - Medicare pays relatively little for LTS (20.4%)
    - Roughly 13% ($42.4 billion) of the $329 billion in total Medicare spending in 2005 was for LTS
    - Of the $42.4 billion, 47% is for skilled nursing facility, 31% is for home health agencies, and 12% is for other fee-for-service LTS (e.g., hospice, DME, rehab hospitals)
  - Private LTC insurance is small (7.2%), but may be able to grow
  - Out-of-pocket expenses are significant (18.1%) and expected to grow by 25-50% by 2015

Though often not counted in LTS expenditures, informal caregivers (unpaid) provide the majority of LTS – one study estimated that informal care equaled 36% of the total value of care for elders

Sources: Georgetown University Long-term Care Financing Project; Congressional Budget Office

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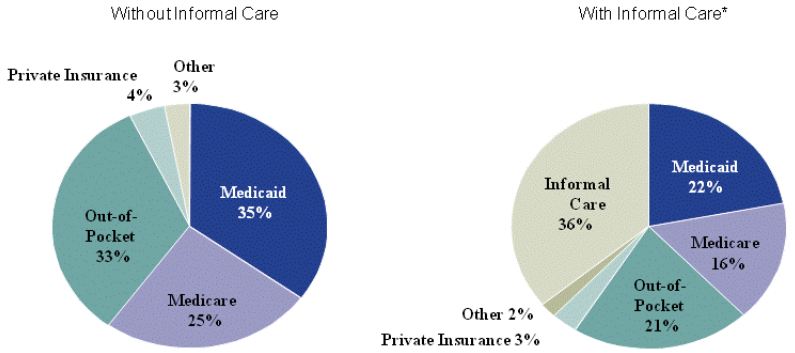
Nationally, unpaid care from family and friends is a larger share than any payer – even Medicaid

Estimated Percentage of Share of Spending for Long-Term Care for the Elderly: with and without informal care



* Values are calculated on the basis of how much such care would cost if it were provided through formal means. Estimates are from Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Administration on Aging, *Informal Caregiving: Compassion in Action* (June 1998), inflated to 2004 dollars.

Note: comparable figures on spending for non-elderly individuals with disabilities are not currently available.

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Source: Hagen, S. Financing Long-Term Care for the Elderly, Congressional Budget Office, April 2004. 63

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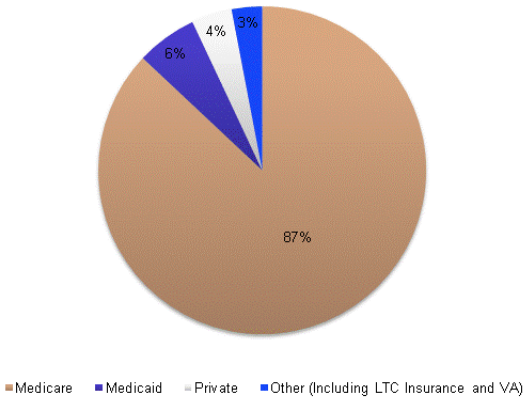
At admission, the vast majority of nursing facility residents' care is paid by Medicare

MA Nursing Facility Payment Source at Admission



Source: MSCA Admission, Discharge and Length of Stay Survey, February 2008.

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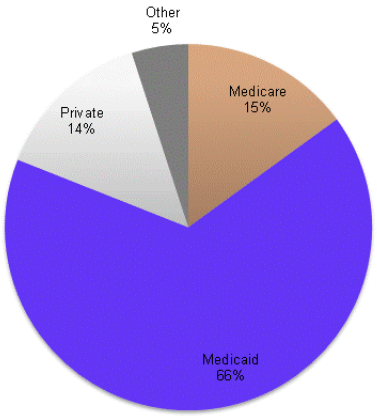
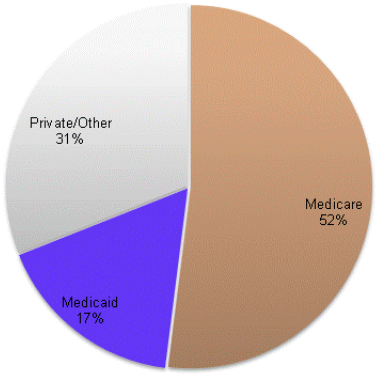
While Medicare remains the primary payer for home health care, nursing facilities are disproportionately dependent on Medicaid

MA Nursing Home Payer Mix



MA Home Health Payer Mix

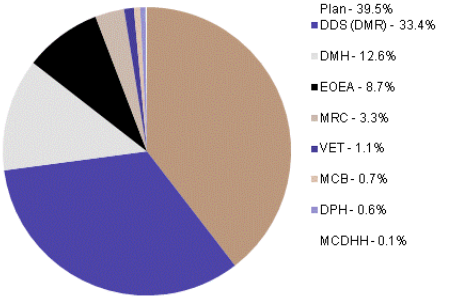


Source: MSCA, February 2008.

TN:52

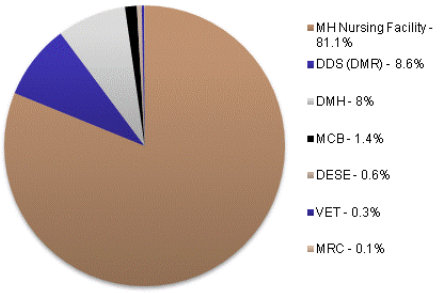
State expenditures for LTS are spread across several agencies

Community Expenditures



Total: $2,887,171,375

Institutional Expenditures



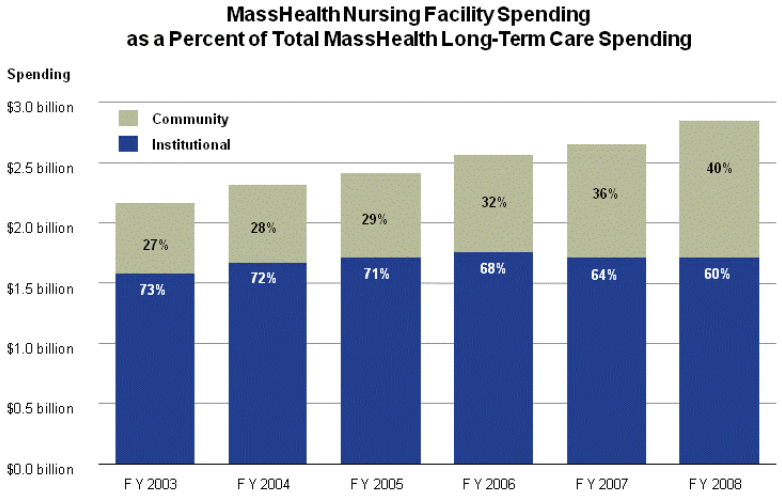
Total: $2,128,539,714

Note: MassHealth collects federal Medicaid matching funds for a significant portion of LTS expenditures made by other agencies for Medicaid members. All $ are SFY08, except for MH Nursing Facility, which is SFY07.

Source: MA Executive Office of Health and Human Services

TN:53

Shift in MassHealth spending from institutions to communities reflects the State's Community First policy



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Source: MassHealth Finance Office. These expenditures do not include spending on HCBS waivers.

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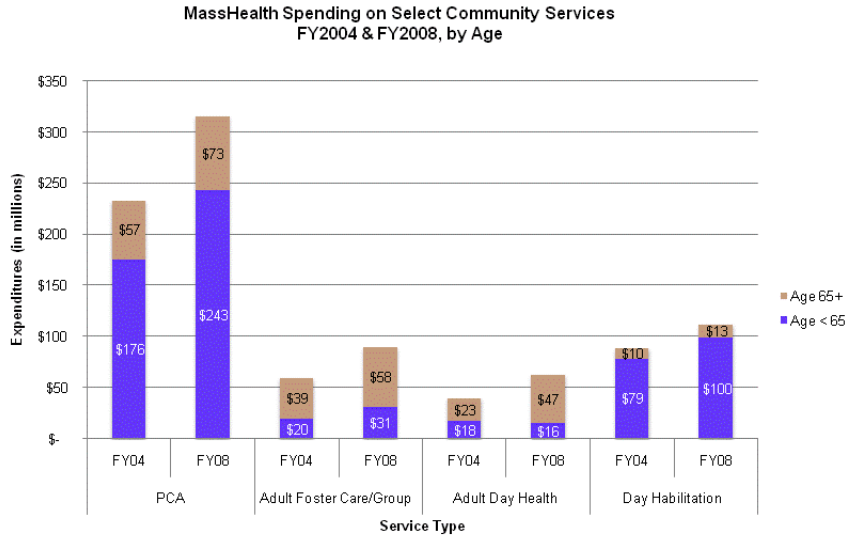
MassHealth spending on selected community LTS has increased substantially over the past five years



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Source: MassHealth Finance Office

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Nationally, out-of-pocket and private expenses are expected to grow by 25-50% by 2015

Out-of-Pocket and Private Expenditures: (proxy for LTS: Nursing Home Care, Home Health Care, and Durable Medical Equipment)

	2006 (Estimate)				2015 (Projected)			
	Amount ($) in Billions				Amount ($) in Billions			
	Out-of-Pocket Payments	Private Health Insurance	Other Private Funds	Total	Out-of-Pocket Payments	Private Health Insurance	Other Private Funds	Total
Home Health Care	5.9	6.0	1.1	13.0	8.6	8.0	1.4	18.0
Nursing Home Care	32.9	9.3	4.6	46.8	48.7	12.2	7.1	68.0
Durable Medical Equipment	13.3	2.9	0.0	16.2	16.5	3.7	0.0	20.2

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Source: National Health Expenditure Projections 2007 - 2017

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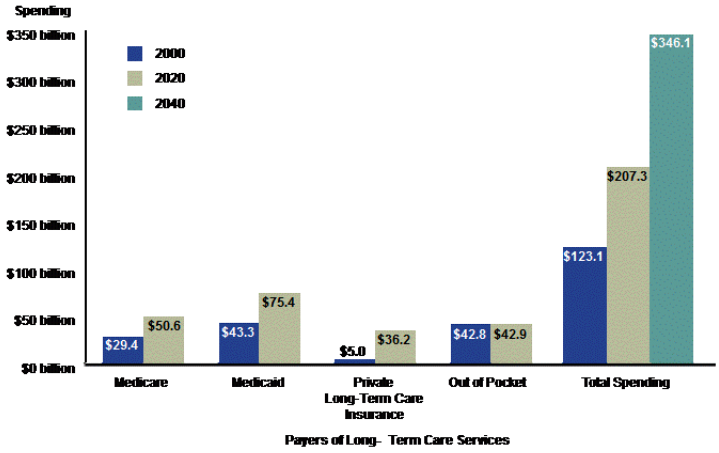
Distribution of payments for LTS

Projected National Spending on Long-Term Care Expenditures for the Elderly, 2000, 2020, 2040 (in 2000 dollars)



Note: comparable figures on spending for non-elderly individuals with disabilities are not currently available.

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Source: Congressional Budget Office (1999)

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Part V Summary Points

- LTS currently are a shared public and private responsibility
- Informal caregivers provide a significant amount of LTS
- Several state programs pay for both community and institutional LTS, although MassHealth pays for the majority of institutional LTS
- Public LTS spending is still weighted heavily toward institutional care, but community LTS is increasing

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Appendix A

Definitions of long-term care supports and services in Massachusetts

Adaptive technology/ Home Medical Equipment: Medical equipment such as hospital beds, wheelchairs, and prosthetics as well as other devices and technology used to allow an individual to remain in their home. May be covered by Medicaid and in part by Medicare or private insurance (www.hcbs.org).

Adult Foster Care/Group Adult Foster Care: A program for frail elderly adults and adults with disabilities who cannot live alone safely. Adults in the program live with trained paid caregivers who provide daily care. The caregiver provides meals, companionship, personal care assistance, and 24-hour supervision.

Care Management: A variety of supportive activities to assist and enable an eligible person to gain access to needed medical, social, educational or other services. Core activities include assessment, coordination and monitoring services. In some programs, the services includes advocacy, gatekeeping, and financial accountability for cost-effectiveness. Various names for such services include case management, service brokerage, service coordination, and targeted case management.

Chore Service: Services needed to maintain the home in a clean, sanitary and safe environment. This service includes heavy household chores such as washing floors, windows and walls, tacking down loose rugs and tiles, moving heavy items of furniture in order to provide safe access and egress.

Chronic Disease and Rehab Hospitals: Non-acute hospitals that provide inpatient and outpatient services. Each facility is licensed and certified by the Department of Public Health.

Companion Service : Non-medical care, supervision and socialization, provided to a functionally impaired adult. Companions may assist or supervise with tasks such as meal preparation, laundry, and shopping and may also perform light housekeeping tasks that are incidental to the care and supervision of the Individual.

Day Services: A daytime community-based program for adults that require a variety of health, social, and related support services in a protective setting (www.hcbs.org).

Early Intervention: A program for children ages 0-3 years that provides family-centered services that facilitate the child's developmental progress.

Grocery Shopping and Home Delivery: Obtaining a participant's grocery order, shopping, delivering the groceries, and assisting with storage as needed.

Home-delivered Meals: Provides well-balanced meals (one or two meals daily) to participants to maintain optimal nutritional and health status. Each meal must comply with established nutrition standards, and be religiously and ethnically appropriate to the extent feasible. Home-delivered Meals service includes the preparation, packaging and delivery of meals by trained and supervised staff.

Home and community based services: Services and other supports to help people with disabilities of all ages to live in the community. Each state has a mix of programs and funding sources. The Medicaid program pays for many of these services in all states. There are also other federal, state and local dollars that fund home and community based services, including the Social Services Block Grant (SSBG), Older

Americans Act (OAA), Education and Rehabilitation funds and State General funds. Various types of services may be provided in the home or in the community to enable individuals to remain in their own home. Assistance is generally provided with the following types of activities:

Activities of Daily Living (ADL's): Basic personal activities which include bathing, dressing, transferring from bed to chair, toilet assistance, mobility and eating;

Instrumental Activities of Daily Living (IADL's) : Services include housekeeping, cooking, shopping, laundry, medication management, money management, and communication; and

Home/Environmental Accessibility Modifications: This service provides physical adaptations to the private residence of the individual or the individual's family that are necessary to ensure the health, welfare and safety of the individual or that enable the individual to function with greater independence in the home. Such adaptations include, but are not limited to:

- installation of ramps and grab-bars;
- widening of doorways;
- door openers;
- modification of bathroom facilities;
- home lifts – internal and external;
- stair climbers;
- environmental control units that can activate TV, stereo, lights, and doors;
- installation of specialized electric and plumbing systems that are necessary to accommodate the medical equipment and supplies that are necessary for the welfare of the participant.

Home Health Aide : Assistance with personal care related home care support to individuals who are recovering from a hospitalization or related acute medical crisis. Home health aide services are primarily a "medical service" authorized for rehabilitation rather than long-term support. However, home health aides assist with many of the same activities that are conducted by personal care attendants, and they are also able to assist with some homemaking activities as long as these are and adjunct to personal, hands-on care.

Homemaker: Services include assistance with shopping, menu planning, laundry, and the performance of general household tasks (e.g., meal preparation and routine household care) provided by a qualified homemaker, when the individual regularly responsible for these activities is absent or unable to manage the home and care for him or herself or others in the home.

Housing with Supportive Services: Housing in the community that provides services that would otherwise be provided in a facility-based setting. These services can include:

Assisted Living: residences that provide a "home with services" and that emphasize residents' privacy and choice (www.hcbs.org);

Congregate Housing: Individual apartments where residents may receive some services, such as a daily meal with other tenants (www.hcbs.org); and

Group Home (also called board and care home): A residence which offers housing and personal care services to a small number of residents, usually 3-16 individuals (www.hcbs.org).

Intermediate Care Facility for the Mentally Retarded (ICFMR): An institution that provides diagnostic, medical, surgical, and/or restorative treatment for persons with mental retardation. Facilities are licensed by the Department of Public Health.

Laundry: Pick-up, washing, drying, folding, wrapping, and returning of laundry.

Medication Support: This service provides support to participants capable of self-administration of prescription and over-the-counter medications. Typically it includes the following services provided by a support worker:

- remind the participant to take the medication;
- check the package to ensure that the name on the package is that of the participant;
- observe the participant take the medication; and
- document in writing the observation of the participant's actions regarding the medication (e.g., whether the participant took or refused the medication, the date and time).

Non-Medical Transportation: Service offered in order to enable waiver participants to gain access to waiver and other community services, activities and resources.

Nursing Facilities: Institutions that provide skilled services, assistance with activities of daily living and nursing services.

Personal Assistance Services (PAS): A range of services provided by a person designed to assist an individual with a disability to perform daily living activities that the individual would typically perform without assistance if the individual did not have a disability. Personal assistants provide a variety of services to individuals who, because of their disability, experience limited mobility or personal care skills.

Respite Care: Services provided to relieve informal caregivers from the daily stresses and demands of caring for a participant in efforts to strengthen or support the informal support system.

Skilled Nursing: A service that must be provided within the scope of the State's Nurse Practice Act by a registered professional nurse. In determining whether a service requires the skills of a nurse, consider both the inherent complexity of the service, the condition of the patient and accepted standards of medical and nursing practice.

Skills Training: Services that include teaching and assistance with developing the skills necessary for independent living in the community.

Transitional Assistance: One-time or short term financial or support services that assist an individual to transition from a facility to community based services.

Transportation: Provided for medical appointments, recreational activities, or other depending on the provider of the service and the scope of services provided by the provider. Does not include transportation provided by community-based residents, but rather supplemental services not included in the price of housing.

Waiver Services (HCBS waiver): The Home and Community Based Service Waivers (HCBS) are programs for low-income Massachusetts residents who qualify for institutional care but want to live at home. The Waivers allow MassHealth members to get needed health care and long-term supports at home rather than in an institution. The goal of the waivers is to help frail elders, people with intellectual disabilities and adults with brain injuries to live safely in their communities and to prevent or delay institutionalization. Services include:

Agency Personal Care
Assistive Technology and Specialized Medical Equipment
Chore Service
Community Transition Services
Companion Service
Day Services
Expanded Substance Abuse Services
Family Support and Training
Grocery Shopping and Home Delivery
Home-delivered Meals
Home/Environmental Accessibility Modifications
Home Health Aide
Homemaker
Individual Support and Community Habilitation
Laundry
Non-Medical Transportation
Respite Care
Residential Habilitation
Skilled Nursing
Supported Employment Services
Supportive Home Care Aide
Supportive Day Program

Related community inclusion and medical services that complement LTS

(These services by themselves are generally not considered LTS and are used by people with disabilities regardless of whether they need LTS. However the services do contribute to the quality of life of persons who also need LTS.)

Advocacy: Assistance to enable individuals to get their needs met. Activities may include actions on behalf of a specific person to address their needs as well as actions to support systemic changes to address societal issues which will improve the lives of all individuals.

Community Education: Inform the community, providers, caregivers, and consumers on barriers, stigma, and solutions for elders and people with disabilities who choose to live in the community.

Education: Informal or formal education for consumers. It can relate to professions, formal degrees, and individual rights.

Eligibility Determination/ Information and Referral: System in which consumers are able to access information pertaining to insurance eligibility and service eligibility that may depend on income, population, and/or disability.

Financial Assistance: Cash allotments or vouchers for a specific population or a specific service that will allow an elder or individual with a disability to live in the community.

Housing: Housing developed, modified, or designated for a specific population with no linked supported services.

Legal Services: Provided to elders or individuals with disabilities to insure that the consumer is receiving services, benefits, and protections that are mandated by law and that they are not discriminated against by a state agency or provider agency based on age or disability.

Medical Service: General physical health services provided to improve or maintain the overall health of an individual. Examples of such services include physicians, hospitals, clinics, laboratory services, prescriptions, and other health-related services.

Mental Health Services - variety of services provided to people of all ages, including counseling, psychotherapy, psychiatric services, crisis intervention, and support groups. Issues addressed include depression, grief, anxiety, stress, as well as severe mental illnesses (www.hcbs.org).

Recreational Services: Services that facilitate meaningful recreation options for involvement in community life.

Vocational/Employment Services: Can include networking services, rehabilitation services, and modification of physical environment all of which take place in an environment in which an elder or individual with a disability is volunteering or employed.

Appendix B

Technical Notes

TN1. Slide 2: "Estimated Number of People Age 5+ with A Disability in Massachusetts and the U.S. By *Type of Disability*"
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html. Tabulations by authors.
This slide focuses on the population estimates for persons age 5+, since the ACS survey only collects disability data on this population. The estimated total population *of all ages* for the U.S. and Massachusetts were 301,621,159 and 6,449,775 respectively in 2007. Note: The counts of persons with each of the six specific disabilities do not sum to the total number of persons with disabilities, since individuals may report more than one disability.

TN2. Slide 3: "The MA Population age 65 and older will increase dramatically by 2020" (Current and Projected MA Total Population 5 Yrs and Older by Age Group)
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html (for population estimates); and, U.S. Census Bureau, Interim State Population Projections by Age and Sex: 2004 -3030, web site, http://www.census.gov/population/www/projections/projectionsagesex.html (for projection estimates). Tabulations by authors. Population projection estimates for persons age 5+ were obtained for each age group from the U.S. Census Bureau for the years 2015 and 2020.

TN3. Slide 4: "For men and women, disability tends to increase by age" (Incidence of People with Disabilities Age 5+ by Age Group and Gender, Massachusetts (2007))
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html (for population estimates); and U.S. Census Bureau, Interim State Population Projections by Age and Sex: 2004 -3030, web site, http://www.census.gov/population/www/projections/projectionsagesex.html (for projection estimates). Tabulations by authors. For each age category within the male and female populations, incidence was calculated as: # people with any disability/# total population.

TN4. Slide 5: "15% of the population has a disability. More than half (54%) are age 55 or older" (Estimated Number of People Age 5+ with Disabilities in MA and the U.S. By *Gender and Age*.)
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html (for population estimates); and U.S. Census Bureau, Interim State Population Projections by Age and Sex: 2004 -3030, web site, http://www.census.gov/population/www/projections/projectionsagesex.html (for projection estimates). Tabulations by authors.

TN5. Slide 6: "Disability is distributed by race/ethnicity in approximately the same proportion as in the total population" (Estimated Number of People Age 5+ with A Disability in Massachusetts and the U.S. by *Race and Ethnicity*.)
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html (for population estimates); and U.S. Census Bureau, Interim State Population Projections by Age and Sex: 2004 -3030, web site,

http://www.census.gov/population/www/projections/projectionsagesex.html (for projection estimates). Tabulations by authors.

TN6. Slide 7: "Most people with disabilities live in the community" (Estimated Number of People Age 5+ with a Disability in Massachusetts and the U.S. by *Setting*)
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html (for population estimates); and U.S. Census Bureau, Interim State Population Projections by Age and Sex: 2004 -3030, web site, http://www.census.gov/population/www/projections/projectionsagesex.html (for projection estimates). The ACS defines settings as follows:
Group Quarters (GQ) facilities: "A GQ facility is a place where people live or stay that is normally owned or managed by an entity or organization providing housing and/or services for the residents. These services may include custodial or medical care, as well as other types of assistance. People in group quarters are usually not related to each other. Group quarters include such places as college residence halls, residential treatment centers, skilled nursing facilities, group homes, military barracks, correctional facilities, and workers dormitories."
Institutional Group Quarters: "Includes facilities under formally authorized, supervised care or custody at the time of interview, such as correctional facilities, nursing facilities/skilled nursing facilities, in-patient hospice facilities, mental (psychiatric) hospitals, group homes for juveniles, and residential treatment centers for juveniles."
Non-institutional Group Quarters: "Includes facilities that are not classified as institutional group quarters, such as college/university housing, group homes intended for adults, residential treatment facilities for adults, workers' group living quarters and Job Corps centers, and religious group quarters."
Non-Institutional Community Settings: The ACS refers to all other housing units not included in Group Quarters facilities as "housing units". Housing units may include a house, an apartment, a mobile home, a group of rooms or a single room, etc.
Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://www.census.gov/acs/www/UseData/Def.htm

TN7. Slide 8: "After age 35 there are more women with disabilities than men." (Number of People Age 5+ with *Any* Disability, by *Age Group and Gender* in MA (2007)
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html. Tabulations by authors.

TN8. Slide 9: "The number of people with disabilities age 5+ is expected to grow by 13% between 2007 and 2020" (People with *Any* Disability in MA, by Age Category)
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html (for population estimates); and U.S. Census Bureau, Interim State Population Projections by Age and Sex: 2004 -3030, web site, http://www.census.gov/population/www/projections/projectionsagesex.html (for projection estimates). Tabulations by authors. Population projection estimates for persons age 5+ were obtained for each age group from the U.S. Census Bureau for the years 2015 and 2020. Following the method reported by Sum et al. (2006), the incidence of disability within each age group was obtained and applied to the projected population estimates for that age group.
Full reference for Sum et al. : Sum, A., Khatiwada, I., Tobar, P., Palma, S., & McLaughlin, J. (2006). The adult disabled population (16-74) in Massachusetts: Its size and demographic/socioeconomic composition in 2003-2004. Report prepared for the Commonwealth Corporation and Massachusetts Rehabilitation Commission, Boston, Massachusetts, March 2006.

TN9. Slide 10: "The MA population with disabilities will exceed 1 million people by 2020" (Current and Projected MA Population 5 Yrs and Older with *Any* Disability, by Age Group)
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html (for population estimates); and U.S. Census Bureau, Interim State Population Projections by Age and Sex: 2004 -3030, web site, http://www.census.gov/population/www/projections/projectionsagesex.html (for projection estimates). Tabulations by authors. This table reports the data generated as described in TN10, as used in that slide.

TN10. Slide 12: "People with disabilities comprise nearly 15% of the total MA population; those with a LTS disability comprise about 10% of the total MA population"
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html. The MA population with ANY disability represents 14.7% of the total population age 5 or older. Of this disability population, 10.3% of people report having at least one of the three "Long-Term Supports" disabilities: difficulty with a physical disability (slide 7, #4), difficulty going outside the home (slide 7, #5), or a self-care (dressing, bathing, or getting around inside the home) disability (slide 7, #6). This definition of Long-Term Supports disability (based on these three ACS disabilities) was also used by the State of Maryland for disability counts "most representative of ADLs and IADLs" (Mood, M. & Cowdry, R. W. (2007) Long-Term Services and Supports in Maryland: Planning for 2010, 2020, and 2030. Maryland Health Commission, December 1, 2007, p. 4, web site, http://www.chpdm.org/publications/ltcPlanning_dec2007.pdf.

TN11. Slide 13: "For men and women, LTS disability increases with age" (Incidence of Persons with a LTS Disability by Age Group and Gender, Massachusetts (2007)
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html. Tabulations by authors. For each age category within the male and female populations with a long-term supports disability (as defined in TN12), incidence was calculated as: # people with a LTS disability/# total population. See TN12 for definition of LTS disability.

TN12. Slide 14: "LTS disability is distributed by race/ethnicity in approximately the same proportion as in the population" (Estimated Number of People with a LTS Disability and All Individuals Age 5+ in Massachusetts by Race and Ethnicity).
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html. Tabulations by authors. See TN12 for definition of LTS disability.

TN13. Slide 15: "Nearly 60% of people with a LTS disability are below 300% of the poverty level, compared to roughly one-third of the total Massachusetts population" (Poverty Status of People Age 5+ in MA(2007))
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html. Tabulations by authors.

TN14. Slide 16: "Among people with a LTS disability, a greater proportion of those under age 65 are below the poverty level, than are those over age 65" (Poverty Status of People Age 5+ with a LTS Disability in MA(2007))
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html. Tabulations by authors.

TN15. Slide 17: "Approximately half of the people with a LTS disability are age 65 and older, and half are under age 65" (People with LTS Disability in MA, by Age Group (2007)

TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html. Tabulations by authors.

TN16. Slide 18: "The needs for LTS population will increase (Projected increase in disability populations by age group)"
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html (for population estimates); and U.S. Census Bureau, Interim State Population Projections by Age and Sex: 2004 -3030, web site, http://www.census.gov/population/www/projections/projectionsagesex.html (for projection estimates). Tabulations by authors. Note: Height of bars represents total estimate (or projection) of people with any disability population age 5+. The blue (lower) portion of each bar represents the estimate (or projection) people with a LTS disability.

TN17. Slide 19: "The number of people with a LTS disability is projected to grow by 15.4% from 2007 to 2020 (compared to 6% growth for the total MA population" (People Age 5+ with a LTS Disability in MA, by Age Category)
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html (for population estimates); and U.S. Census Bureau, Interim State Population Projections by Age and Sex: 2004 -3030, web site, http://www.census.gov/population/www/projections/projectionsagesex.html (for projection estimates). Tabulations by authors. Population projection estimates for persons age 5+ were obtained for each age group from the U.S. Census Bureau for the years 2015 and 2020. Following the method reported by Sum et al. (2006), the incidence of LTS disability within each age group was obtained and applied to the projected population estimates for that age group. See TN5 for full reference to Sum et al. (2006).

TN18. Slide 20: "The MA LTS population will increase at a higher rate than the overall population with disabilities" (Current and Projected MA *LTS* Disability Population 5 Yrs and Older by Age Group)
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html (for population estimates); and U.S. Census Bureau, Interim State Population Projections by Age and Sex: 2004 -3030, web site, http://www.census.gov/population/www/projections/projectionsagesex.html (for projection estimates). Tabulations by authors. This table reports the data generated as described in TN19, as used in that slide.

TN19. Slide 21: "Most people turning 65 will need LTS in their lifetimes"
TN: Source: P. Kemper et al., "Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?" *Inquiry* 42:335-30 (Winter 2005/06). Tabulations by authors.

TN20. Slide 22: "Most people in MA, including those with disabilities, have health insurance (which typically does not cover LTS)"
TN: Source: Mass. Division of Health Care Finance and Policy. Tabulations by authors. Data are from the 2008 Massachusetts Health Insurance Survey, conducted by DHCFP. The survey identifies respondents who have "activity limitations due to health problems." For the elderly category, the "Employer-Sponsored" and "Public or Other Private" coverage types from the survey data are combined into "All Other" because small sample sizes make estimates based on the individual categories unreliable.

TN21. Slide 23: "How do the ACS data compare with data on need for assistance with daily activities? (an illustration based on elders)"
TN: Sources: 1) U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html; 2) Manton, H.G., Gu, X. & Lamb, V.

(2006). Change in chronic disability from 1982 to 2004/2005 as measured in the U.S. elderly population, *PNAS*, *103*, *18374-18379*. The percentages in the left table were reported for the U.S. population for the years 2004/2005. The estimates in the rightmost column in the left table were calculated by applying the Manton et al. percentages to the 2007 ACS population estimates of people age 65+. The table on the right indicates how the number of people in MA in 2007 age 65+ within each LTS group match conceptually onto the IADL and ADL categories from the left table. See TN12 for definition of LTS disability and its constituent components.

TN22. Slide 24: "How do the ACS data compare with data on students with disabilities? (an illustration based on MA public school population)"
TN: Sources: 1) U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html; 2) MA Department of Elementary and Secondary Education (2008-2009).

TN23. Slide 25: "Students with Disabilities (regular and special education students) Enrolled in Public Schools in MA for School Year 2008-2009"
TN: Source: Massachusetts Department of Elementary and Secondary Education (2008-2009). Retrieved from http://www.doe.mass.edu/infoservices/reports/enroll/default.html?yr=sped0607 on April 27, 2009.

TN24. Slide 26: "People with disabilities report experiencing more poor health" (Quality of Life Among Massachusetts Adults (2007))
TN: Massachusetts Department of Public Health (2007). Study of Unmet Needs of Adults with Disabilities in Massachusetts.

TN25. Slide 29: "Most people with a LTS disability live in community settings" (People Age 5+ with a LTS Disability in MA, by Setting)
TN: Source: U.S. Census Bureau, 2007 ACS surveys, web site, http://factfinder.census.gov/home/en/acs_pums_2007_1yr.html. Tabulations by authors. See TN8 for settings definitions. See TN12 for definition of LTS disability.

TN26. Slide 30: "People with disabilities, including those with LTS needs, receive community services from various state agencies. Almost all people receive these services in community settings".
TN: Source MA State Profile Tool, 2009

TN27. Slide 31: "Elder and disabled MassHealth members use a variety of community LTS" (Number of MassHealth members* using selected community LTS, FY 2008).
TN: Source: MassHealth Finance Office. Box in right corner contains estimated number of MH members receiving LTS in the community which was calculated using MH member months for FY08. The data used in the bar graph is FFS unduplicated members. The members are not unduplicated across services.

TN28. Slide 32: "MassHealth utilization of LTS" (from MassHealth Finance Office)
TN: Source: Unduplicated FFS MassHealth members from MassHealth Finance Office dataset updated on 1/16/09.

TN29. Slide 33: "The number of community-based elder and disabled MassHealth members is projected to continue to increase" (Historical and Projected Average Number of MassHealth Members, by Age and Setting (SFYs 2003-2014)
TN: Source: MassHealth Finance Office. All Figures for 2008 through 2014 are projections, not actuals. Data from SFY2003 - SFY2007 were used to project nursing facility utilization by age group and community

or nursing facility cohort for SFY2008 - SFY 2014. All projected years are based on SFY2007 actuals, trended by the SFY2003 - SFY2007 compound annual growth rate (CAGR), and do not reflect utilization changes that occurred after June 30, 2007. Utilization is reflected as average members (Member Months/12) for 65+ (MassHealth members ages 65 and older) and for Disabled, <65 (MassHealth members ages 19 to 64 who have a disability determination). The nursing facility populations shown are MassHealth members in MassHealth paid nursing facility stays, for members who have been in the nursing facility for a minimum of six months. The 65+ community population is all MassHealth members ages 65 and older, minus members who are in long-stay nursing facilities, ICFMRs, or who are enrolled in the 1915c Frail Elder waiver. The Disabled, <65 community population is all disabled MassHealth members ages 19 to 64, minus members who are in long-stay nursing facilities, ICFMRs, or who are enrolled in the 1915c TBI or the 1915c DMR waivers.

TN30. Slide 34: "Over the past decade, nursing facility bed availability and average census have decreased" (Comparison of MA Licensed Nursing Facility Beds to Census (All Payers), 2000-2008)
TN: Source: MassHealth Office of Finance.

TN31. Slide 35: "Nursing facility admissions continue to rise, matched by the number of discharges – even as the number of occupied beds in MA falls" (MA Nursing Facility Annual Admissions and Discharges and Average Daily Bed Census (All Payers) 1995 – 2006 (Selected Years)).
TN: Source: DHCFP nursing facility cost reports, with tabulations by Mass Senior Care Association (admissions and discharges); MassHealth Office of LTC (census).

TN32. Slide 36: "The average length of stay in MA nursing facilities has declined steadily since 1990" (MA Nursing Facility Median Length of Stay (All Payers), 1988 – 2006)).
TN: Source: State DHCFP, Nursing Facility Cost Reports, 1988 – 2006.

TN33. Slide 37: "Most MA Nursing Home residents have short stays (post acute); these are generally covered by Medicare" (Nursing Home Length of Stay for Discharged Residents)
TN: Source: MSCA Admission, Discharge and Length of Stay Survey, February, 2008.

TN34. Slide 38: "Nursing Facility Industry Profile - All Payers"
TN: Source: Office of Long-Term Care.

TN35. Slide 39: "MassHealth nursing facility residents are becoming more frail" (1990/1991 – 2008)(Changes in Medicaid Nursing Facility Resident Acuity (1990/1991 – 2008)
TN: Source: Mass Senior Care Association.

TN36. Slide 40: "Medicare's proportion of nursing facility residents in MA has increased, while Medicaid's proportion has decreased". (Change in Nursing Facility Residents by Payer Source (1995 Base Year – 2004).
TN: Source: Mass Senior Care Association.

TN37. Slide 41: "90% of all Massachusetts nursing facility residents are 65 years or older; nearly half are 85 years or older." (Age Distribution of Residents in MA Nursing Facilities 8/25/06 DPH Reporting)
TN: Source: Office of Long-Term Care.

TN38. Slide 42: "In 2007, MA had more nursing home beds per capita than about two-thirds of the states" (MA Certified Nursing Home Beds per 1,000 people age 65 and older, 2007)
TN: Source: Kaiser Family Foundation State Health Facts Online; U.S. Census Bureau.

TN39. Slide 48: "In MA, many people who receive assistance with LTS need more help; some people who need LTS receive no assistance at all"
TN: Source: DPH, Study of Unmet Needs of Adults with Disabilities in Massachusetts, 2007. Study sample was sub-sample of the Massachusetts Behavioral Risk Factor Surveillance Systems (BRFSS). All respondents were between the ages of 18-59 and answered affirmatively to one of the two following questions about disability: Are you limited in any way in any activities because of physical, mental or emotional problems? Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone. This study does not include individuals living in institutions or individuals who do not have a telephone.

TN40. Slide 49: "Of those in the community needing assistance, only a portion receive help" (Table 3. ADLs and IADLs – having difficulty and receiving help (based on full sample))
TN: Source: DPH, Study of Unmet Needs of Adults with Disabilities in Massachusetts, 2007.

TN41. Slide 50: "Many of those receiving help still have unmet needs"(Table 4. ADLs and IADLs – need more help)
TN: Source: DPH Study of Unmet Needs of Adults with Disabilities in Massachusetts, 2007. See previous technical note (#42).

TN42. Slide 51: "Most people with paid help still have unmet needs."
TN: Komisar, H.L., Feder, J. & Kasper, J.D. Unmet Long-Term Care Needs: An Analysis of Medicare-Medicaid Dual Eligibles. Inquiry 42: 171-182 (Summer 2005). Figures based on study author's analysis of data from the 1999 Survey of Dual Enrollees in Six States. Sample size for MA is 96 dually eligible individuals.

TN43. Slide 52: "Reasons for unmet need include inability to pay or find help, and not wanting to ask friends and family" (Prevalence of Unmet Need for Personal Assistance Services Among Persons 50+ with Disabilities in U.S.)
TN: Source: Mary Jo Gibson, S. Verma. Just Getting By: Unmet Need for PAS Among Persons 50 or Older with Disabilities. AARP Public Policy Institute.

TN44. Slide 53: "About 20% of people with disabilities report unmet needs for case management"(Table 10. Percent who needed case management services in the past 12 months)
TN: Source: Study of Unmet Needs of Adults with Disabilities in Massachusetts, 2007. See TN43. Due to inconsistent terminology usage, individuals in the study were asked about several specific kinds of assistance or services that can be components of case management.

TN45. Slide 54: "Many children with special health care needs still have unmet needs"
TN: Source: KS Hill, Freeman, LC, Yucel RM, Kuhlthau, KA. Unmet Need Among Children With Special Health Care Needs in Massachusetts. Maternal Child Health Journal (2008) 12: 650-661. Study used analysis from the 2001 National Survey of Children with Special Health Care Needs. This survey identifies children with special health care needs as those children who require services beyond that required by children generally because of a chronic physical, developmental, behavioral or emotion condition. The MA sample included 744 children. Children with more severe conditions were selected if screened positive for 2 or more CSHCN Screener items and either of the following: condition affects ability 'a great deal'; or parent rank of severity 8+ (on scale of 0-10).

TN46. Slide 55: "Reported Unmet Need among Children with Special Health Care Needs (CHSCN)*"
TN: Source: KS Hill, Freeman, LC, Yucel RM, Kuhlthau, KA. Unmet Need Among Children With Special Health Care Needs in Massachusetts. Maternal Child Health Journal (2008) 12: 650-661. See TN47 (previous note).

TN47. Slide 56: "More than half of home health clients reported at least one unmet need"(Percent of home health clients with unmet need)
TN: Source: Cindy Parks Thomas, Susan Payne. "Home Alone: Unmet Need for Formal Support Service Among Home Health Clients." Home Care Services Quarterly, Vol. 17(2) 1998.

TN48. Slide 59: "Gaps in Existing Access to Long Term Supports" (Key LTS Availability for Adults with Disabilities Across the Disabilities Agencies, DMH, EOEA, & DPH)
TN: Source: EOHHS, Office of Disability Policies and Programs.

TN49. Slide 63: "Nationally, unpaid care from family and friends is a larger share than any payer – even Medicaid" (Estimated Percentage of Share of Spending for Long-Term Care for the Elderly: with and without informal care)
TN: Source: Hagen, S. (2004) Estimated Percentage Shares of Spending on Long-Term Care for the Elderly, 2004. Washington, DC: Congressional Budget Office. Page 3. Retrieved from https://www.cbo.gov/doc.cfm?index=5400

TN50. Slide 64: "At admission, the vast majority of nursing facility residents' care is paid by Medicare" (MA Nursing Facility Payment Source at Admission)
TN: Source: MSCA Admission, Discharge and Length of Stay Survey, February 2008.

TN51. Slide 65: "While Medicare remains the primary payer for home health care, nursing facilities are disproportionately dependent on Medicaid" (two pie charts)
TN: Source: Mass Senior Care Association.

TN52. Slide 66: "State expenditures for LTS are spread across several agencies (two pie charts)
TN: Source: MA State Profile Tool, 2009. See TN 25. MH Nursing Facility data from MassHealth Finance Office.

TN53. Slide 67: "Shift in MassHealth spending from institutions to communities reflects the State's Community First policy" (MassHealth Nursing Facility Spending as a Percent of Total MassHealth Long-Term Care Spending)
TN: Source: MassHealth Finance Office.

TN54. Slide 68: "MassHealth spending on selected community LTS has increased substantially over the past five years" (MassHealth Spending on Selected Community Services FY2004 & FY2008, by Age)
TN: Source: Unduplicated FFS MassHealth members from MassHealth Finance office dataset updated on 1/16/09.

TN55. Slide 69: "Nationally, out-of-pocket and private expenses are expected to grow by 25-50% by 2015" (Out-of-Pocket and Private Expenditures: (proxy for LTS: Nursing Home Care, Home Health Care, and Durable Medical Equipment)
TN: Source: National Health Expenditures Projections, 2007-2017). Retrieved on February 9,

2009 from www.cms.hhs.gov/NationalHealthExpendData/Downloads/proj2007.pdf

TN56. Slide 70: "Distribution of payments for LTS (Projected National Spending on Long-Term Care Expenditures for the Elderly, 2000, 2020, 2040 (in 2000 dollars).
TN: Source: Congressional Budget Office (1999). CBO Memorandum: Projections of Expenditures for Long-Term Care Services for the Elderly. Washington, DC: Author. Retrieved from www.cbo.gov/ftpdocs/11xx/doc1123/ltcare.pdf

For more information, please contact Dee O'Connor at (508) 856-8148 Darlene.oconnor@umassmed.edu.

100 Century Drive, Worcester, MA 01606
Tel. (800) 842-9375 Fax. (508) 856-6100
www.umassmed.edu/commed
CommMedWebInfo@umassmed.edu