



# **Supported Living:**

**A Cost Effective Model of Independent Living for  
People with Disabilities**

**Massachusetts Rehabilitation Commission  
Elmer C. Bartels, Commissioner  
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## Background

Increasingly, state and federal government are moving towards programs and policies that support people with disabilities and elders in the community rather than in institutional settings such as nursing facilities. In addition to responding to the preferences of these individuals, this shift to community-based long-term care addresses the need for cost containment, as well as meeting federal and state court mandates.

- **Cost Savings:** In many instances, community-based care can be provided more cost-effectively than care in a nursing facility or institution. The Commonwealth's August 2001 report on Long Term Care<sup>1</sup>, for example, found that elders with similar needs were served at a cost to Medicaid of \$34,100 in a nursing facility but only \$6,329 in the community. The report also found that Massachusetts had a Medicaid nursing facility utilization rate 65% higher than the national average.
- **Olmstead:** Since the Supreme Court decision *LC. v. Olmstead*, states have been under increasing legal pressure to offer community-based alternatives to elders and adults with disabilities living in nursing facilities and institutions rather than risking legal suits.
- **Preferences and Needs:** Research indicates most elders and adults with disabilities prefer to remain in the community rather than receive care in a nursing facility. For example, one study finds that 30% of elders being treated in the hospital for a serious illness said they would rather die than live permanently in a nursing facility<sup>2</sup>. New federal data shows that nearly 20% of those living in Massachusetts nursing homes would prefer to live in the community and are ready to be discharged<sup>3</sup>.
- **Positive Health and Happiness Outcomes:** Research shows improved health and happiness outcomes when individuals with disabilities live in the community and control the provision of their services. Research comparing the satisfaction of people with physical disabilities receiving personal care services with a traditional-agency directed model versus a consumer-directed model found that those who directed their own services were more satisfied<sup>4</sup>. Further, a 2002 Agency for Healthcare Research and Quality study found that four out of five program recipients reported that consumer-directed services improved their lives<sup>5</sup>.



Loretta Rolland ribbon cutting ceremony

<sup>1</sup> Executive Order #421 Report on Long Term Care; Governor Jane Swift; August 2001, page 13.

<sup>2</sup> Journal of American Geriatric Society July 1997 as cited in Executive Order #421 Report on Long Term Care; Governor Jane Swift; August 2001; page 17.

<sup>3</sup> [www.cms.hhs.gov/states/mdsreports](http://www.cms.hhs.gov/states/mdsreports)

<sup>4</sup> Rehabilitation Research and Training Center on Medical Rehabilitation and Health Policy, 1998. [www.lsi.ukans.edu/apps/riil/review.asp?73](http://www.lsi.ukans.edu/apps/riil/review.asp?73)

<sup>5</sup> Research Information on Independent Living, Volume 2, Issue 10. [www. Getriil.org/counseling\\_evaluations.htm](http://www.Getriil.org/counseling_evaluations.htm)

## Supported Living Model

Over the last four decades, the Massachusetts Rehabilitation Commission (MRC) has developed models and programs to cost-effectively support people with disabilities in the community. MRC programs are designed with consumer input and provide for personal choice, empowerment and integration. **Supported Living** is one service model that efficiently and cost-effectively assists people with disabilities to live successfully in the community. The model is based on a philosophy of individual choice and empowerment, with consumers making informed choices and taking personal responsibility for those choices. Supported living has prevented institutionalization for hundreds of individuals and assisted others in moving from a nursing facility or state institution into the community.

Supported living is a model of community based supports, not a funding stream. Supported living services can be and are currently funded through a broad variety of sources, including MRC's Turning 22 Program, Statewide Head Injury Program, Nursing Home Transition Grant, Rolland Settlement and Adult Supported Living Program. Any public or private funding stream can be used or directed to provide this service.

MRC's Adult Supported Living Program, which began in 1986, provides one example of the use of the supported living model. The program provides case management services to individuals with physical disabilities to assist them to live independently in their community of choice. In addition to a physical disability, eligible consumers must have a cognitive or emotional disability that prevents them from effectively managing their support services independently. For example, someone who has Multiple Sclerosis may experience both physical and cognitive disabilities. Without appropriate assistance, such an individual would be at risk in the community and likely end up in a nursing home.

### Case Management

Case management is the core service provided by MRC's Adult Supported Living Program (SLP). Under SLP, MRC contracts with community-based vendors to provide the case management services. The case manager works with the eligible participant to **jointly** develop a support services plan to address the specific areas of daily living in which the individual needs assistance. The plan includes areas such as: help with managing the personal care assistance (PCA) program, housing search, household management, financial management, transportation, health care and recreation. MRC pays primarily for case management services. All of the participant's other needs for support are met through using existing local and state-funded services coordinated by the case manager. For example, if a participant identifies a need for transportation assistance, the case manager helps the consumer in identifying local public transportation or taxi vouchers, rather than paying for the transportation services through the program. This cost-effective model ensures non-duplication of services and an efficient use of existing resources.

## Supported Living Participants

MRC also implements the supported living model in the Turning 22 Program. The following provides the demographics for participants in the Turning 22 and Adult Supported Living Programs. Although these individuals all have significant disabilities, the model has assisted them in living successfully and independently in the community.

### Primary Disability

The following chart lists the eight most prevalent primary disabilities among participants:

*Table A - Primary Disability*

Primary Disability	Number	Percentage
Brain Injury	5	2%
Cerebral Palsy	38	26%
Multiple Medical Problems	14	10%
Multiple Sclerosis	17	12%
Muscular Dystrophy	11	8%
Spina Bifida	9	6%
Spinal Cord Injury	14	10%
Stroke	15	10%
Other <sup>6</sup>	23	16%
<b>Total</b>	<b>146</b>	<b>100%</b>

### Gender

The program is nearly equally populated with men and women.

*Table B - Gender*

Gender	Number	Percentage
Female	78	53%
Male	68	47%
<b>Total</b>	<b>146<sup>7</sup></b>	<b>100%</b>

### Ethnicity

As illustrated in the table below, 85% of program participants have been White. The second largest group is Hispanic.

*Table C - Ethnicity*

Ethnicity	Number	Percentage
American Indian or Alaskan Native	1	0%
Black or African American	8	6%
Latino/Hispanic	11	8%
Other	4	3%
Unavailable	3	2%
White	118	81%
<b>Total</b>	<b>145</b>	<b>100%</b>

<sup>6</sup> Includes seizure disorder, post-polio and others.

<sup>7</sup> This represents the total number of participants in the program to date.

## Age

More than 65% of the participants are between 23 and 55 years of age.

*Table D - Age*

Age	Number	Percentage
Less than 20 years	2	1%
20-22	7	5%
23-33	39	27%
34-44	25	17%
45-55	32	22%
56-66	27	19%
67 years and older	14	9%
<b>Total</b>	<b>146</b>	<b>100%</b>

These demographics do not capture the complexities faced by many of the Supported Living Program participants. Such individuals often have several disabilities, few or no family supports, as well as emotional/behavioral issues that may be directly or indirectly related to their disability. The following stories illustrate both the challenges faced by program participants, as well as their success moving into the community with the assistance of the supported living model.

### **Supported Living Success Story: Mr. D**

Mr. D is a 45 year-old man with Multiple Sclerosis. His disability has progressed to the point where he uses a wheelchair for mobility and requires assistance transferring. When referred to the program, he was living in a nursing facility in New Bedford and disliked institutional living immensely. He ended up in the nursing home after his PCA injured her back and was no longer able to assist him. Mr. D also had interpersonal/behavioral difficulties related to his disability, making it difficult for him to hire and maintain a sufficient number of PCAs. The VNA provided assistance but could not provide adequate home health aide coverage.

Because Mr. D's disability had worsened, a significant amount of planning was required to assist him in moving back to the apartment he had retained while in the nursing facility. This included:

- Establishing case management services
- Obtaining approval for increased PCA hours
- Identifying placement in a day health program
- Obtaining approval for a new wheelchair
- Procuring additional durable medical equipment

Once back in his apartment, Mr. D was thrilled to be home!

### **Mr. D Cost Comparison**

State-funded community-based care costs:

- Case Management: 7 hours per week @ \$47 per hour = \$17,108 annual
- Personal Care: \$429 per week = \$22,308<sup>8</sup>
- Housing: \$3,072<sup>9</sup>
- Adult Day Program: \$10,400<sup>10</sup>

Total annual community based care costs: \$52,888

Total nursing facility cost for Mr. D: \$56,000<sup>11</sup>-\$87,000<sup>12</sup>

**Annual Savings: \$3,112 - \$34,112**

**10 Year Savings: \$31,120 - \$341,120**

### **Supported Living Success Story: Mr. L**

Mr. L is a 23 year-old white male with a spinal cord injury due to a motor vehicle accident. Mr. L is a "Rolland Class" member who is served by the MRC. His accident occurred on September 9, 2002 in which he sustained a spinal cord injury resulting in quadriplegia. Mr. L was also diagnosed with seizure-related activity along with depression and traumatic brain injury. He was admitted to the Boston Medical Center where he underwent spinal surgery on September 11, 2002. He remained there for two months until he was transferred to the Avery Manor Nursing Facility for on-going rehabilitation. Mr. L became known to the MRC and was evaluated for community placement in April of 2003.

With the assistance of a Supported Living Program case manager, Mr. L completed the following tasks in order to transition back into the community:

- Mr. L applied for and secured a one bedroom, wheelchair accessible apartment in Fall River.
- Medical practitioners in this area were identified and appointments were made in a timely fashion.
- Personal care assistance services were applied for and put into place
- An adaptive equipment needs assessment took place and equipment was purchased and delivered prior to his discharge from the nursing facility. These items included an air mattress to protect his skin integrity, a recliner chair, bed, motorized wheelchair, automatic door opener, a Hoyer lift and Lifeline. Mr. L has expressed an interest in using a voice-activated computer and a referral has been made for an assistive technology (AT) evaluation.

<sup>8</sup> PCA hours have increased but were not available.

<sup>9</sup> Estimate of maximum subsidy provided to two-bedroom state-assisted public housing unit.

<sup>10</sup> Estimated annual costs of Adult Day Health Program.

<sup>11</sup> Massachusetts Extended Care Federation as cited in Boston Globe January 22, 2003.

<sup>12</sup> GE Financial Survey as reported in Kiplinger's Retirement Report March 2004

Mr. L is a strong self-advocate. He recently acknowledged his need for some assistance with anger management and coping with his frustration, given the magnitude of the adjustments he has made and continues to make. Toward that end, he receives counseling from Family Services of Fall River.

It has been just a little more than seven months since Mr. L moved into the community. He has come a very long way in dealing with the numerous issues with which he has faced. He schedules his own medical appointments, manages his PCA's and keeps himself busy with friends and family. He recently completed an application to attend college classes. He is able to stay on top of his medical issues as they occur, for example, noticing when he might require medical treatment for a developing infection.

### **Mr. L Cost Comparison**

State-funded community-based care costs:

- Case Management: 5 hours per week @ \$47 per hour = \$12,220 annual
- Personal Care: 58 hours per week plus overnight: \$38,787
- Housing: \$1,476<sup>13</sup>

Total annual community based care costs: \$52,483

Total nursing facility cost for Mr. L: \$56,000-\$87,000

**Annual Savings: \$3,517 - \$34,517**

**10 Year Savings: \$35,170 - \$345,170**

### **Supported Living is Cost-Effective**

Not only is the supported living model effective, it is cost-effective as well. In 2003, the Adult Supported Living Program and Turning 22 Program provided case management services using the supported living model for 121 individuals. On an average weekly basis, participants received between 3 and 8 hours of case management services. The number of hours is dependent upon the individual's circumstances and may change over time, depending on their personal needs.

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<sup>13</sup> Estimate of maximum subsidy provided to one-bedroom state-assisted public housing unit.

The following chart represents the costs of case management and personal care assistance for SLP participants in 2003:

**Table E - Supported Living Program Costs in 2003**

<b>Program Component</b>	<b>Number People</b>	<b>Number annual hours</b>	<b>Total annual costs</b>	<b>Costs Per Person</b>
Case Management	121	17,322	\$770,101	\$6,551
Personal Care Assistance	102	323,960	\$3,299,816	\$32,351 <sup>14</sup>
			<b>\$4,069,917</b>	<b>\$38,902</b>

### Comparison of Supported Living Program Costs with Nursing Facility Costs

The current annual cost of a nursing facility stay for one individual is \$56,000<sup>15</sup> - \$87,000<sup>16</sup> depending on various sources. The annual cost of the Massachusetts Hospital School is \$85,892. In 2003, the average cost to the Commonwealth of supporting an individual in the Adult and Turning 22 Supported Living Programs was \$41,974<sup>17</sup>. This is \$14,000 - \$45,000 *less* than nursing facility costs, a 25% cost savings at minimum, and nearly \$44,000 less than the Massachusetts Hospital School, a cost savings of more than 50%.

**Table F - Supported Living Program and Nursing Facility Costs 2003**

<b>Component</b>	<b>Supported Living Program</b>	<b>Nursing Facility Costs</b>	<b>Massachusetts Hospital School</b>
Case management	\$ 6,551	Included in total	Included in total
Personal care assistance	\$32,351	Included in total	Included in total
Housing	\$ 3,072 <sup>18</sup>	Included in total	Included in total
<b>Total Costs</b>	<b>\$41,974</b>	<b>\$56,000 - \$87,000</b>	<b>\$85,892<sup>19</sup></b>
<b>Difference from SL</b>	<b>\$0</b>	<b>\$14,026 - \$45,026</b>	<b>\$43,918</b>

Of those consumers included in this data, 37 came from the Massachusetts Hospital School, resulting in an annual savings of more than \$1.6 million. Another 18 were referred from nursing facilities, with 50 more at risk of moving into such a facility, resulting in an annual savings of an additional \$1 million or more. Over ten years, savings exceed \$25 million for just more than 100 individuals.

<sup>14</sup> Case management services are paid for directly by the program. PCAs are paid with Medicaid funds through DMA.

<sup>15</sup> Massachusetts Extended Care Federation figures, as cited in Boston Globe January 22, 2003.

<sup>16</sup> GE Financial Survey as reported in Kiplinger's Retirement Report March 2004.

<sup>17</sup> Includes costs of housing subsidy as well as PCA and case management.

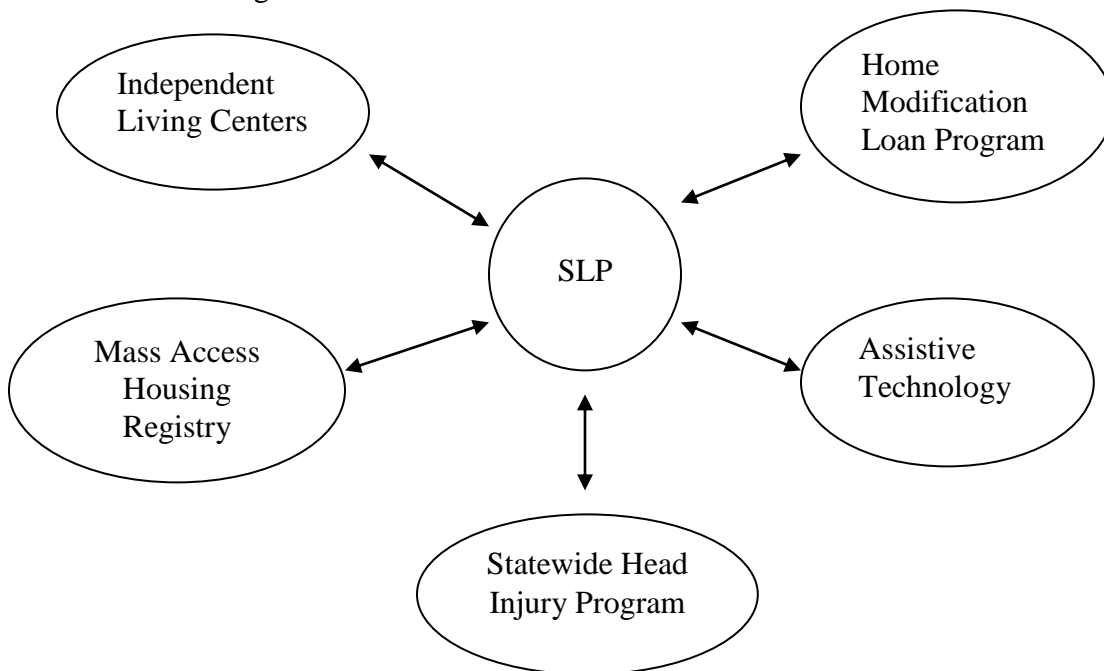
<sup>18</sup> Massachusetts Department of Housing and Community Development; Division of Asset Management.

<sup>19</sup> Cost per day is \$397.65, thus an annual cost of \$145,142; however students on average currently spend only 216 days on-site.

It is important to note that the comparison used in this document represents the average annual cost of a nursing facility; many of the SL program participants were in *more* expensive facilities due to the specific nature or complications of their disability.

### Other Key Supports

As previously described, the Supported Living model does not work in isolation. The model relies on a variety of services to enable a consumer to live independently in the community. A number of these services are also provided through MRC programs including: Independent Living Centers, the Mass Access Housing Registry, SHIP, Assistive Technology and the Home Modification Loan Program.



### Independent Living Centers

Independent Living Centers (ILCs) are private nonprofit agencies committed to assisting people with disabilities to live independently in the community. Massachusetts has 11 ILCs serving people with disabilities. At least 51% of an ILC Board of Directors and staff must be individuals with disabilities. Unlike many human services programs with targeted recipients, ILCs serve people regardless of their type of disability. All ILCs provide the following core services: peer counseling, skills training, advocacy and information and referral. Every service is provided in the context of the independent living philosophy, a philosophy that promotes advocacy for services and options to maximize self-reliance and self-determination in all of life's activities. ILCs also advocate to the community at large to make services accessible to all people with disabilities, whether they seek ILC services or not. This is accomplished through technical assistance, training and community awareness education.

ILCs assist participants in the Supported Living Program in numerous ways. Some SLP consumers were referred by the ILC peer counselors working with consumers. Some of the ILCs also administer PCA programs. On behalf of Medicaid, they assess the number of PCA hours needed by the participant and provide skills training in hiring and managing PCAs. Some

ILCs have recreation and support programs for participants to utilize. The ILC can help consumers learn to advocate for themselves – even if the participant is also using supported living case management – and to become an active member of their community.

In some instances, people living in nursing facilities require some assistance to move into the community but do not require the on-going supports such as the case management provided by the SLP. ILCs can assist these individuals in making the move back to the community. The following story provides one such example.

### **Supported Living Success Story: Ms. K**

Ms. K is a 47 year-old woman with severe arthritis. She uses a power wheelchair for mobility. She was living in a nursing home in Chelmsford when contacted by an ILC peer counselor about living in the community. Ms. K ended up in the nursing facility when she separated from her boyfriend who was also her primary caregiver. Ms. K has a college degree and had been previously employed in human services.

Ms. K worked with her peer counselor to develop a plan of action for moving back into the community. Components in the plan included:

- Identifying affordable, wheelchair accessible housing near public transportation
- Obtaining adaptive equipment including a speakerphone, new wheelchair and a hospital bed
- Obtaining standard household items such as furniture and dishes
- Hiring personal care assistants

Ms. K received assistance identifying available housing units, obtaining and completing housing applications. She was evaluated for the Personal Care Assistance (PCA) program and, once approved, trained to hire and manage the PCA. Once a housing unit was identified, Ms. K worked with her peer counselor to arrange transportation to visit the unit. Ms. K was provided with some funds for the security deposit. Ms. K has been living successfully in the community since the Fall of 2001.

#### **Ms. K Cost Comparison**

State-funded community-based care costs:

- Personal Care: 52 hours weekly<sup>20</sup> plus overnight = \$35,555
- Housing: \$3,072<sup>21</sup>

Total annual community based care costs: \$38,627

Total nursing facility cost for Ms. K<sup>22</sup>: \$39,533

**Annual Savings: \$907**

**Ten Year Savings: \$9,070**

<sup>20</sup> Hourly rate is \$10.36; overnight is paid at two hours.

<sup>21</sup> Estimate of maximum subsidy provided to two-bedroom state-assisted public housing unit.

<sup>22</sup> Annual average nursing facility costs; it is likely Ms. K's actual costs were higher given his needs.

## **Statewide Head Injury Program**

The Statewide Head Injury Program (SHIP) is part of the Community Services Program of the MRC. SHIP is the public program in the Commonwealth that identifies, cultivates and develops resources and services for Massachusetts residents who have sustained an externally caused traumatic brain injury. Since 1985, this has been accomplished through training, program development and service coordination activities.

SHIP has been successful in creating a network of community-based service providers and supports that assist individuals in maintaining or increasing their level of independence at home, work and in their communities. SHIP provides a broad range of services specifically targeted to persons with brain injuries, including:

- Assistive technology
- Community-based supports for independent living
- Head Injury centers
- Individual treatment and therapy services
- Social/Recreation program
- Substance abuse treatment

The supported living model is one of the services offered by the program. SHIP consumers served under this model have cognitive disabilities which require case management assistance to live successfully in the community, but they do not necessarily have physical disabilities, such as required in the Adult Supported Living Program described earlier. This SHIP service is very highly individualized and can only serve 25-30 individuals. These consumers live in their own apartment or in congregate settings. They receive as little as five to ten hours of case management per month to as much as eight hours of case management per day, depending on their disability, cognitive level and other types of needs.

Whether receiving five hours per month or eight hours per day, the cost of supporting these consumers in the community is substantially less than any institutional setting. The cost per person ranges from \$22,000 to \$30,000<sup>23</sup>, saving the Commonwealth from \$11,000 to \$47,000 per person, annually.

## **Mass Access Housing Registry**

The Supported Living model requires participants working with their case managers to locate affordable, and often, wheelchair accessible housing. The Mass Access Housing Registry is a free program assisting people with disabilities to find rental housing in Massachusetts, primarily accessible and barrier-free housing. The Mass Access database keeps track of accessible and affordable apartments throughout the state and maintains current information about their availability.

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<sup>23</sup> Not including publicly funded housing subsidy

Developed by the MRC, the program is now based at Citizens Housing and Planning Association (CHAPA). CHAPA's core task on the Mass Access program is working with housing managers to maintain up-to-date housing and vacancy information. The Mass Access program was initiated in 1995 and for the first five years, people searching for housing needed to contact an Independent Living Center (ILC) to learn about available apartments. Today, this information is available via the Internet through a website at [www.chapa.org](http://www.chapa.org), as well as through the ILCs.

### **Assistive Technology Program**

As previously illustrated in the examples of Mr. D and Mr. L, many SLP participants benefit from assistive technology. From specialized wheelchairs and telephones to environmental control units, AT devices assist the individual with a physical disability to be more independent. This not only promotes self-reliance and self-esteem, but potentially saves money because consumers require less assistance to live independently.

MRC's Assistive Technology Program was created in 1999 to enable individuals with significant disabilities to access assistive technology devices and training. Assistive technology (AT) devices and services help to maximize an individual's control over their environment and achieve self-determined goals. The ability to use AT to perform such tasks as check or letter writing, money management, shopping, controlling the home environment and communication improvement are anticipated outcomes. The AT program compliments another MRC services for individuals going back to work, available through the MRC's Vocational Rehabilitation Services Program.

MRC contracts with three organizations for the provision of AT assessments, purchase and set-up of equipment, training and follow-up. These organizations (Mass. Easter Seals, United Cerebral Palsy of Berkshire County and CLASS, Inc.) provide services on a regional basis and have sample AT devices on-site for use in evaluation and training.

### **Conclusion**

The Supported Living model, as illustrated here in several MRC programs, has been proven to assist people with severe and multiple disabilities to successfully live in the community.

Supported living:

- Promotes independence and self-reliance
- Meets the needs and preferences of the participants
- Results in significant cost savings compared to institutional alternatives

Data from two MRC programs indicates that on average, at **minimum**, the Supported Living model can result in \$14,026 of savings to the Commonwealth, per individual. Reaching out to only 100 of the estimated 8,000 individuals in nursing homes who prefer to live in the community and are ready to be discharged<sup>24</sup>, the state could potentially save nearly \$1.5 million on an annual basis. There is no formula to estimate the significance of the human impact here but the improvement in the quality of life of these consumers cannot be undervalued. When one considers the savings, if 50% or more of this group could be assisted to live in the community using the Supported Living model, the savings would indeed be quite significant.

This document was prepared with the assistance of the following experts:

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<sup>24</sup> [www.cms.hhs.gov/states/mdsreports](http://www.cms.hhs.gov/states/mdsreports)