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Iowa State Profile Tool: An Assessment of Iowa's Long-Term Support System

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Iowa State Profile Tool: Executive Summary

The Iowa State Profile Tool is a comprehensive, high-level assessment of Iowa's progress toward a balanced long-term care[1] system – a system that relies less on institutional services and provides greater opportunities for the in-home and community-based services that most people prefer. This report includes long-term support for people of all ages and disability types and is based on a variety of state and federal data sources and interviews with public and private leaders in Iowa's long-term care system.[2] The Iowa State Profile Tool describes all publicly funded long-term care programs and presents data regarding:

- Estimated demand for long-term care (i.e., age and disability rates)
- Expenditures and number of people served in public programs
- Number of people using privately funded long-term support, where available

It also describes the degree to which Iowa's system has eight system components found in states that have reformed their long-term care systems:

- **Consolidated state agencies** – a single agency for both institutional and community services that coordinates policies and budgets to promote community options;
- **Single access points** – a clearly identifiable organization managing access to a wide variety of community supports, ensuring people understand the full range of available options before receiving more restrictive services;
- **Institution supply controls** – mechanisms such as Certificate of Need requirements that enable states to limit or reduce institutional beds;
- **Transition from institutions** – outreach to identify residents who want to move and assistance with their transition to the community;
- **A continuum of residential options** – availability of support services in a range of options from mainstream single-family homes and apartments to integrated group settings for people who need 24-hour supervision or support;
- **HCBS infrastructure development** – recruitment and training to develop a sufficient supply of providers with the necessary skills and knowledge to encourage consumer independence;
- **Participant direction** – people who receive HCBS having primary decision-making authority over their direct support workers and/or their budget for supports;
- **Quality management** – an effective system that: a) measures whether the system achieves desired outcomes and meets program requirements and b) identifies strategies for improvement.

This executive summary presents trends that emerged from spending and utilization data and briefly describes the state's status for all populations regarding the eight system components.

[1] We use the phrases "long-term care" and "long-term support" interchangeably and use a definition developed by the Georgetown University Long-Term Care Financing Project: "Assistance with essential, routine tasks of life – such as bathing, getting around the house, and preparing meals – provided to people who need this assistance because of physical or mental conditions or disability." This assistance can include therapies or equipment to improve a person's functional capacity. (Rogers, Susan and Komisar, Harriet "Who Needs Long-Term Care?" Georgetown University Long-Term Care Financing Project: May 2003)

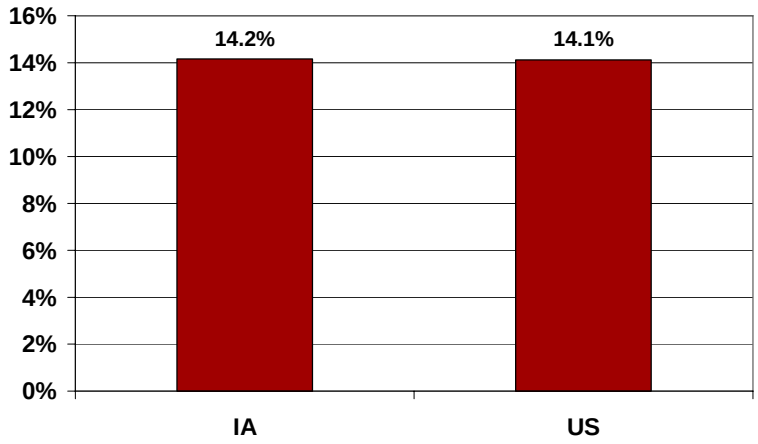
[2] See the Bibliography and Appendix A for a list of data sources and individuals interviewed for this report.

Iowa State Profile Tool: Executive Summary

Data Trends

When both age and disability rates are considered, Iowans are about as likely to need long-term care as other Americans, as shown Chart ES.1 below. One of every seven Iowans (14.2%) has a disability.[3] This conclusion may be a surprise because Iowa has a high proportion of people age 65 and older, and older adults are more likely to need long-term care than younger individuals. However, Iowa's seniors have a low disability rate, which largely offsets the high percentage of older adults.

Chart ES.1: Percentage of Total State Population with Disabilities, 2007



Sources:
U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for population
U.S. Census Bureau, American Community Survey, 2007 "Table B18002. Sex by Age by Disability Status for Civilian Noninstitutionalized Population 5 Years and Over" September 23, 2008 for community disability data
U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2007* Undated for nursing facility data

Iowa serves more people with disabilities and older adults in large facilities than almost any other state, when controlling for state population (See Table ES.1). Iowa is second to North Dakota in the number of nursing facility residents per 1,000 people age 65 or older. On a single day in 2008, approximately 9,700 individuals would not be in a nursing facility if Iowa's utilization was the same as the national average.[4] Iowa is third to Mississippi and Arkansas in the number

[3] U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for population; U.S. Census Bureau, American Community Survey, 2007 "Table B18002. Sex by Age by Disability Status for Civilian Noninstitutionalized Population 5 Years and Over" September 23, 2008 for community disability data; and U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2007* Undated for nursing facility data

[4] U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for population age 65 or older; and U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2007* Undated for nursing facility data

of people with developmental disabilities served in residential facilities of 16 or more individuals.[5] In contrast, Iowa has a relatively low rate of state mental health hospital utilization.[6]

Table ES.1: Residents of Institutional Long-Term Care Facilities per 100,000 State Residents

	Nursing Facilities	Facilities with 16 or more residents with developmental disabilities	State Mental Health Hospitals*
Date for Most Recent Data	**June 30, 2008**	**June 30, 2007**	**June 30, 2006**
Iowa	853	55.1	7.4
United States	457	20.7	15.6

* For state mental health hospitals, United States data are based on 43 states that reported data.

Sources:
U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for population age 65 or older. Population data for 2007 were used because they were the latest available.
U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2008* Undated for nursing facility data
Prouty, Robert W.; Alba, Kathryn; Lakin, K. Charlie (eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007* University of Minnesota Institute for Community Integration: August 2008
National Association of State Mental Health Program Directors Research Institute, Inc. "State Mental Health Agency Profiling System: System: 2007" October 2008

The high institutional utilization affects people with disabilities of all ages. Children in Iowa are more likely to live in nursing facilities and intermediate care facilities for people with mental retardation (ICF/MR) than children in other states (See Table ES.2).[7] In addition, the use of institutions for children with serious emotional disturbances has increased in recent years.[8]

Federal, state, and local governments dedicated approximately $2.2 billion in State Fiscal Year (SFY) 2008 to provide supports and services to Iowans with disabilities and older Iowans.[9] The $2.2 billion estimate does not include county expenditures for community mental health services outside the Medicaid program, because the authors were not able to develop an estimate for

[5] Prouty, Robert W.; Alba, Kathryn; Lakin, K. Charlie (eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007* University of Minnesota Institute for Community Integration: August 2008

[6] National Association of State Mental Health Program Directors Research Institute, Inc. "State Mental Health Agency Profiling System: System: 2007" October 2008.

[7] Prouty, Robert; Smith, Gary; Lakin, K. Charlie (eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006* University of Minnesota: August 2007; U.S. Centers for Medicare & Medicaid Services, *Medicaid Statistical Information System (MSIS) State Summary Datamart*, data obtained December 2008; and U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008

[8] Data provided November 2008 by Iowa Medicaid Enterprise

[9] Most data were provided upon request by the Department of Education, the Department of Elder Affairs, the Department of Human Services, the Iowa Department of Public Health, and Iowa Vocational Rehabilitation Services. Data for some programs were obtained from Iowa Department of Management *Iowa Fiscal Year 2010 Report* January 28, 2009.

these expenditures. An estimate was available for county-based, non-Medicaid spending for people with developmental disabilities.[10]

Table ES.2: Children under age 21 in Institutions for which National Comparison Data are Available, per 100,000 Population under 21

	State Developmental Disabilities Institutions, Residents on June 30, 2006	Nursing Facilities, Medicaid beneficiaries, Oct. 2005 – Sept. 2006
Iowa	**9.8**	**9.0**
United States	1.7	5.8

Sources:
Prouty, Robert; Smith, Gary; Lakin, K. Charlie (eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006* University of Minnesota: August 2007 for developmental disabilities institution data
Thomson Reuters analysis of data from the U.S. Centers for Medicare & Medicaid Services, Medicaid Statistical Information System (MSIS) State Summary Datamart, data obtained December 2008, for nursing facility data
U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for population data

Table ES.3 shows the amount of spending in SFY 2008 for five population groups defined by either age or type of disability. Many public long-term care programs are targeted to one or two of these population groups. This report is organized according to these five groups.

As in most states, Medicaid is the major long-term care funding source, with 64% of total spending. Special Education is also a significant funding source (See Chart ES.2). While it is not typically considered part of long-term care, the education system provides significant assistance to children with disabilities. Long-term care spending has increased by approximately 4.1% per year from SFY 2006 through SFY 2008.[11] Real per capita spending, controlling for inflation and population growth, increased by 0.4% per year from $735 to $740 per state resident.[12]

[10] Braddock, David; Hemp, Richard; Rizzolo, Mary C. *The State of the States in Developmental Disabilities: 2008* Preliminary Report from University of Colorado, Department of Psychiatry and Coleman Institute for Cognitive Disabilities: 2008

[11] Most data were provided upon request by the Department of Education, the Department of Elder Affairs, the Department of Human Services, the Iowa Department of Public Health, and Iowa Vocational Rehabilitation Services. Data for some programs were obtained from Iowa Department of Management *Iowa Fiscal Year 2010 Report* January 28, 2009 and Iowa Department of Management *Iowa Fiscal Year 2008 Report* January 30, 2007.

[12] Thomson Reuters analysis based on data from Table ES.2; U.S. Department Of Labor, Bureau of Labor Statistics "Consumer Price Index for All Urban Consumers (CPI-U), Midwest Region" January 26, 2009; and U.S. Census Bureau, Population Division "Annual Population Estimates, Estimated Components of Population Change, and Rates of the Components of Population Change for the United States, States, and Puerto Rico: April 1, 2000 to July 1, 2008" December 22, 2008

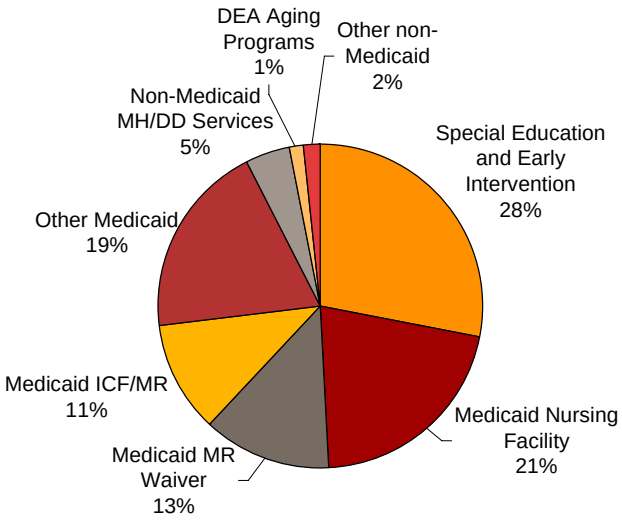
Table ES.3: Public Long-Term Care Spending in Iowa by Target Population in millions, SFY 2008

	2008
Children with Disabilities*	$839
Adults with Mental Retardation	$558
Older Adults**	$533
Adults with Mental Illness***	$160
Adults with Physical Disabilities	$133
Total	$2,223

Sources:
See Tables 4.1, 5.1, 6.1, 7.1, and 8.1 for a complete list of sources.

* Children were defined as people age 18 or younger, except for special education and home health. All special education expenditures were counted as spending for children. For home health, children were defined as under age 21 because service limits change significantly at that age.
** Older Adults were defined as people age 60 or older.
*** Data for adults with mental illness do not include non-Medicaid mental health services provided through counties.

Chart ES.2: Iowa Expenditures for Long-Term Care and Support, SFY 2008



Sources:
See Tables 4.1, 5.1, 6.1, 7.1 and 8.1 for a complete list of sources

Compared to other states, Iowa spends a higher proportion of Medicaid long-term care dollars on institutional services. A little less than two-fifths of Medicaid long-term care spending was for home and community-based services in FFY 2007 (See Table ES.4).[13]

[13] Data provided by the Department of Human Services, Iowa Medicaid Enterprise and Burwell, Brian; Sredl, Katherine; and Eiken, Steve *Medicaid Long-Term Care Expenditures in FFY 2007* Thomson Reuters September 28, 2008.

Table ES.4: Percentage of Medicaid Long-Term Care Expenditures Used for Community Services, FFY 2007

	Total	Services for Older Adults and People with Physical Disabilities	Services for People with Developmental Disabilities
United States	42%	31%	63%
Iowa	**38%**	**26%**	**50%**

Source: Thomson Reuters analysis of data provided by the Department of Human Services, Iowa Medicaid Enterprise and Burwell, Brian; Sredl, Katherine; and Eiken, Steve *Medicaid Long-Term Care Expenditures in FFY 2007* Thomson Reuters September 28, 2008. Iowa expenditures do not include an assessment that Intermediate Care Facilities for people with Mental Retardation (ICF/MR) are required to pay to the state.

However, Iowa has increased utilization of Medicaid community services and decreased institutional utilization since 2004 (See Table ES.5).[14]

Table ES.5: Change in Utilization of Iowa Medicaid Long-Term Care Services with the Largest Number of Participants, SFY 2004 and SFY 2008

	2004	2008	Average Annual Percentage Change
Institutional Services			
Nursing Facility Participants	20,792	21,023	0.3%
Nursing Facility Days	5,091,688	4,636,441	-2.3%
ICF/MR Participants	2,346	2,154	-2.1%
ICF/MR Days	786,981	711,343	-2.5%
Home and Community-Based Services (all data are number of participants)			
Home Health Nursing	17,073	20,670	4.9%
Elderly Waiver	8,035	11,826	10.1%
Home Health Aide	6,134	6,622	1.9%
Mental Retardation Waiver	7,618	10,695	8.9%
Ill & Handicapped Waiver	2,123	2,695	6.1%

Source: Data provided by the Department of Human Services, Iowa Medicaid Enterprise

Eight System Components

Consolidated State Agency

The Iowa state agencies that fund long-term supports tend to be organized around funding sources rather than common services, so multiple agencies pay for similar services using different methods. On a positive note, Iowa's organizational structure is not based on diagnosis, providing a structure within a funding source (such as Medicaid) to coordinate services for all individuals with long-term support needs. Many states that have reformed their long-term care system (e.g., Oregon, Minnesota, Washington and Vermont) established a single agency

[14] Data provided by the Department of Human Services, Iowa Medicaid Enterprise

responsible for planning and delivery of services.[15] Some of these states have taken the additional step of creating a single organization for the full range of disabilities, to align services with individuals' functional needs regardless of diagnosis.[16]

Single Access Point

For most populations, the person's initial contact for services varies based on funding source and service. An exception is for adults with developmental disabilities, for whom the county Central Point of Coordination (CPC) is a single access point for all publicly funded services. In addition, there is no standard process to help people navigate the system and no independent assessment to ensure people know about all options before choosing services. Iowa has started several initiatives to improve information and assistance, such as LifeLongLinks, Iowa COMPASS, 2-1-1, and the Iowa Family Caregiver Hotline. However, funding for sustainability of these initiatives is uncertain.

Institutional Supply Controls

Iowa has a Certificate of Need requirement for institutional long-term care services, including nursing facilities and intermediate care facilities for people with mental retardation (ICF/MR). New beds must be reviewed by the State Health Facilities Council, whose members are appointed by the Governor. In addition, between SFY 2001 and SFY 2005, Iowa awarded grants to nursing facilities that agreed to reduce bed capacity and to provide home and community-based services such as respite, assisted living, and adult day care.[17]

Since SFY 2004, nursing facility capacity has declined by almost 1,200 beds while ICF/MR and psychiatric medical institutions for children (PMIC) capacity changed by only a few beds.[18] Market forces and individual provider decisions have contributed to these trends, in addition to the state policies described above. For mental health services, stakeholders expressed concern about a lack of inpatient psychiatric beds and post-acute beds to help people in crisis.

Transition from Institutions

Iowa's most significant effort to help long-term institutional residents move to community settings is the Money Follows the Person Demonstration, which is targeted to people moving from ICF/MR.[19] While there is no specific initiative for other populations, stakeholders indicated nursing facilities have increased the number of short-term admissions by providing more Medicare-funded rehabilitative services and ensuring people return home after rehabilitation is complete.

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[15] Eiken, Steve *Promising Practices in Long Term Care Systems Reform: Common Factors of Systems Change* Medstat: November 9, 2004 and Kane, Rosalie A.; Kane, Robert L.; Priester, Reinhard; Homyak, Patricia *Research and State Management Practices for the Rebalancing of State Long-Term Care Systems: Final Report* University of Minnesota: June 2008

[16] Kane, Rosalie A.; Kane, Robert L.; Priester, Reinhard; Homyak, Patricia *Research and State Management Practices for the Rebalancing of State Long-Term Care Systems: Final Report* University of Minnesota: June 2008

[17] House File 655, chapter 64, section 249H.6, subs. 5, 79th General Assembly (2001)

[18] Data provided by the Iowa Department of Inspections and Appeals, November 2008

[19] Iowa Department of Human Services, Iowa Medicaid Enterprise "Partnership for Community Integration & Money Follows the Person" Application submitted November 2006

Iowa State Profile Tool: Executive Summary

Continuum of Residential Options

States that have reduced their reliance on institutional services have provided a variety of alternative options for housing and supports, including group residential settings and single-family homes and apartments. The availability of one residential option, assisted living, has increased significantly in recent years. By 2008, Iowa's supply of assisted living beds – controlling for the older adult population – was greater than the national average in 2007, the latest data available. Iowa had 36 beds per 1,000 people age 65 or older, compared to a national average of 26.[20] In contrast, several stakeholders said there was an inadequate supply of residential options that combined long-term housing and supports for people with mental illness and for people with challenging behaviors related to dementia or brain injury.

To improve access to homes and apartments, the Iowa Finance Authority and several service agencies have worked together to address housing issues. Initiatives include:

- A 30% set-aside in the Qualified Allocation Plan for Low Income Housing Tax Credits[21]
- An online Housing Registry that identifies accessible, affordable housing; describes the properties; and provides links to information and referral services
- Training to agencies so they can help people with disabilities can access available housing resources.[22]

HCBS Infrastructure

Iowa's efforts to increase the supply of home and community-based services vary across populations and services, reflecting different service gaps. The Department of Human Services, Mental Health and Disability Services division has worked on:

- Crisis services to provide alternatives to emergency room and inpatient care; [23]
- Implementation of evidence-based practices and
- Improved recruitment and retention of psychologists and psychiatrists, which are in especially low supply in Iowa.

For long-term care services for older adults, the Iowa Finance Authority operates an Affordable Assisted Living program to expand access to assisted living and an HCBS Revolving Fund Loan that assists providers that will provide adult day services, respite, and other services.[24] For people with mental retardation, the Department of Human Services, Iowa Medicaid Enterprise Iowa plans to provide incentives for community providers to expand services and for ICF/MR providers to diversify their services as part of the Money Follows the Person Demonstration.[25]

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[20] Thomson Reuters analysis of data provided by Iowa Department of Inspections and Appeals November 2008; Mollica, Robert; Sims-Kastelein, Kristin; and O'Keeffe, Janet *Residential Care and Assisted Living Compendium: 2007* November 30, 2007; and U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008

[21] Iowa Department of Human Services, Iowa Medicaid Enterprise "Systems Readiness Assessment" part of application for the Federal Systems Transformation Grant Revised September 29, 2005

[22] Iowa Department of Human Services, Iowa Medicaid Enterprise "MFP Housing Inventory Report" September 4, 2007

[23] *Ibid.*

[24] Iowa Finance Authority "IFA Programs" Undated

[25] Iowa Department of Human Services, Iowa Medicaid Enterprise *Operational Protocol for Iowa's Money Follows the Person Grant* (Revised February 26, 2008)

One issue that affects all populations is the challenge of recruiting and training health and long-term care workers and reducing turnover among these workers. Iowa has pursued multiple strategies on a cross-disability basis to increase recruitment and retention as described in Section 3: Workforce.

Participant Direction

The Department of Human Services, Iowa Medicaid Enterprise has implemented participant-direction in all Medicaid home and community-based services waivers serving adults. Waiver participants who choose to direct their services are given a budget based on a determination of their needs and then can use their budget to obtain necessary, cost-effective services that are not specified in the waiver. Participants can also directly employ their direct support workers, rather than use an agency. In addition, Iowa started a pilot for participant-directed mental health services using a Community Reinvestment Fund established as part of the Iowa Plan, the managed behavioral health program.[26]

Quality Assurance

This report did not evaluate the quality of Iowa's long-term support services, but summarized plans for monitoring or ensuring quality. States that reformed their long-term support systems have had comprehensive quality management plans, but the content of those plans varied significantly among the states.

Two types of quality assurance efforts were summarized in this report:

- Licensure or other requirements that certain long-term care providers must meet in order to operate, regardless of who pays for their services
- Quality management by state agencies that manage particular funding streams such as Medicaid home and community-based services waivers, special education, and Older Americans Act funding.

The Department of Human Services, Iowa Medicaid Enterprise and the Department of Elder Affairs both took steps to improve their quality management in 2008.

[26] Koyanagi, Chris; Alfano, E; and Carty, L. *In the Driver's Seat: A Guide to Self-Directed Mental Health Care* Bazelon Center for Mental Health Law and UPENN Collaborative on Consumer Integration: February 2008

Iowa State Profile Tool
Introduction

As in many states, Iowa faces important decisions regarding public long-term support services, which comprise a significant portion of state and county budgets. This State Profile Tool provides important information that can inform decision-making about long-term care for people of all ages and disability types in a single document.[1]

This report is a comprehensive, high-level assessment of Iowa's progress toward a balanced long-term care system – a system that relies less on institutional services and provides greater opportunities for the in-home and community-based services that most people prefer. It describes all major publicly funded long-term care programs and shows recent utilization and expenditures data for these programs. It also includes demographic data that policy makers can use to measure demand for long-term care, and includes information on privately funded long-term supports where available (primarily for institutional services). In addition, this report describes the degree to which Iowa's system matches several system characteristics found in states that have reformed their system to encourage home and community-based services. These system components associated with rebalancing are listed on the following page.

The Iowa State Profile Tool is based on the model State Profile Tool developed by the Healthcare Business of Thomson Reuters (then known as Thomson Medstat) for the U.S. Centers for Medicare & Medicaid Services (CMS) in 2006.[2] In September 2007, CMS awarded grants to Iowa and nine other states to produce similar profiles. The Iowa Department of Elder Affairs contracted with Thomson Reuters to compile the data, conduct the analysis, and complete this report.

Methods

The Iowa State Profile Tool is based on a variety of state and federal data sources and interviews with public and private leaders in Iowa's long-term support system. The authors analyzed several national sources that provide data about each state's long-term supports. We also collected data from Iowa state agencies and the Iowa State Association of Counties regarding utilization and spending for public long-term care programs, focusing on the years from State Fiscal Years (SFY) 2004 through 2008 to show recent trends.

For qualitative information, the authors reviewed state laws, regulations, policy documents, and research reports regarding Iowa's system and interviewed public and private stakeholders in Iowa's long-term care system. Appendix A lists the people interviewed.

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[1] We use the phrases "long-term care" and "long-term support" interchangeably and use a definition developed by the Georgetown University Long-Term Care Financing Project: "Assistance with essential, routine tasks of life – such as bathing, getting around the house, and preparing meals – provided to people who need this assistance because of physical or mental conditions or disability." This assistance can include therapies or equipment to improve a person's functional capacity. (Rogers, Susan and Komisar, Harriet "Who Needs Long-Term Care?" Georgetown University Long-Term Care Financing Project: May 2003)

[2] Eiken, Steve; Nadash, Pamela; and Burwell, Brian *Profile of Pennsylvania: A Model for Assessing a State Long-Term Care System* Thomson Medstat: December 2006

Iowa State Profile Tool
Introduction

Organization of the Profile

The profile begins with a Background section that provides an overview of the long-term care system, including: 1) demographic indicators of long-term support demand; 2) service utilization and expenditure data; and 3) important historical and political characteristics. The next section provides an overview of state and local long-term care administration: describing the roles government agencies, the legislature, and consumers and families have typically played in changes to publicly funded supports. A third section highlights efforts to improve the recruitment and retention of the long-term care workforce, a significant challenge for all long-term care services.

The bulk of this report describes the long-term support delivery systems for major population groups – defined by either age or type of disability – that account for most people who need home and community-based services. In the Federal grant, Iowa selected five groups required by CMS: older adults, people with physical disabilities, people with developmental disabilities, people with mental illness, and children with disabilities. These population groups reflect how programs are organized, and this report's organization is not intended to imply that people only fit within one of these groups. Thousands of Iowans fit in multiple groups and could be served in multiple service systems (e.g., an older adult with a mental illness).

For each population group, we present information on the range of available home and community supports targeting that group. Any notable gaps in coverage are discussed, whether a lack of needed services or people ineligible for service. The profile also presents data on demographic and utilization trends for each population group related to the state's rebalancing efforts. Finally, each population is profiled from the perspective of eight system components that have been previously identified in states that have rebalanced their long-term support system, i.e., reduced institutional utilization and increased access to home and community-based services.[3] The eight components are:

1. **Consolidated state agencies** – a single agency for both institutional and community services that coordinates policies and budgets to promote community options;
2. **Single access points** – a clearly identifiable organization managing access to a wide variety of community supports, ensuring people understand the full range of available options before receiving more restrictive services;
3. **Institution supply controls** – mechanisms such as Certificate of Need requirements that enable states to limit or reduce institutional beds;
4. **Transition from institutions** – outreach to identify residents who want to move and assistance with their transition to the community;

[3] See, for example: Crisp, Suzanne et al. *Money Follows the Person and Balancing Long-Term Care Systems: State Examples* Medstat: September 29, 2003; Eiken, Steve and Heestand, Alexandra *Promising Practices in Long Term Care System Reform: Colorado's Single Entry Point System* Medstat: December 18, 2003; Horvath, Jane and Thompson, Rachel *Promising Practices in Long Term Care System Reform: New Hampshire's Community-Based Service System for Persons with Developmental Disabilities* Medstat: December 5, 2003; Justice, Diane *Promising Practices in Long Term Care System Reform: Vermont's Home and Community Based Service System* Medstat: September 8, 2003; Justice, Diane and Heestand, Alexandra *Promising Practices in Long Term Care System Reform: Oregon's Home and Community Based Services System* Medstat: June 18, 2003; Mullen, Dorothy et al. *Promising Practices in Long Term Care System Reform: Pennsylvania's Transformation of Supports for People with Mental Retardation* Medstat: March 3, 2003; Reinhard, Susan C. and Fahey, Charles J. *Rebalancing Long-Term Care in New Jersey: From Institutional toward Home and Community Care* Milbank Memorial Fund: March 2003.

5. **A continuum of residential options** – availability of support services in a range of options from mainstream single-family homes and apartments to integrated group settings for people who need 24-hour supervision or support;
6. **HCBS infrastructure development** – recruitment and training to develop a sufficient supply of providers with the necessary skills and knowledge to encourage consumer independence;
7. **Participant direction** – people who receive HCBS having primary decision-making authority over their direct support workers and/or their budget for supports; and
8. **Quality management** – an effective system that: a) measures whether the system achieves desired outcomes and meets program requirements and b) identifies strategies for improvement.

Iowa State Profile Tool
Section 1: Background

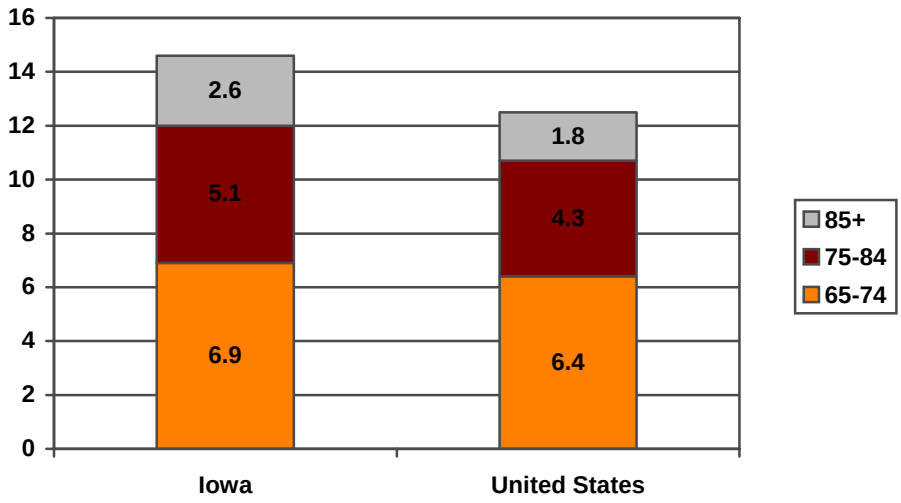
Iowa's long-term care system is shaped by several factors, including: the state's demographic makeup, historical service utilization patterns, and its political and organizational structure. This section describes these factors and how they have shaped Iowa's system.

Demographic Data

A combination of age and disability data indicates Iowans are about as likely to need long-term care as other Americans. While Iowa is one of the oldest states in the nation, older Iowans are less likely to have disabilities than other older Americans. For people under age 65, Iowa's disability rate is similar to the national rate. These data are explained further below.

More than one of every seven Iowans was age 65 or older in 2007, the latest data available from the U.S. Census Bureau. Iowa ranked fifth in the percentage of residents age 65 and older. More importantly, Iowa has a particularly high percentage of people age 85 and older (See Chart 1.1).[1] This "oldest old" cohort is more likely to need long-term care. In 2007, for example, people age 85 and older are 12 times as likely to be in a nursing facility as people age 65-74.[2]

Chart 1.1: Percentage of Population Age 65 or Older, 2007



Source:
U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008

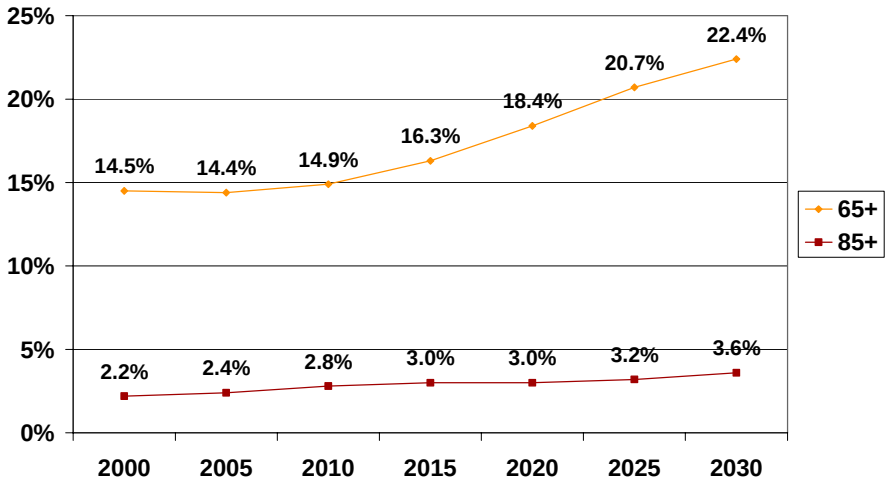
The number of Iowans age 65 and older increased by less than one percent per year since 2000, while the number of people age 85 and older has grown by more than two percent per

[1] U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008

[2] Thomson Reuters analysis of U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 and U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2007* Undated

year. The populations in both age groups are expected to grow by 1-2% per year through 2030 (See Chart 1.2). In 2030, 22% of Iowans will be age 65 or older, and 3.6% will be age 85 or older.[3]

Chart 1.2: Older Iowans as a Percentage of State Population, 2000 - 2030



Sources:
U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for 2000 and 2005 data
U.S. Census Bureau, Population Division "Interim Projections of the Population by Selected Age Groups for the United States and States: April 1, 2000 to July 1, 2030" April 21, 2005 for 2010 – 2030 data

A low disability rate among older adults offsets Iowa's relatively high older adult population. The U.S. Census Bureau's American Community Survey estimates that Iowa had the fifth smallest disability rate for people age 65 or older in community settings in 2007.[4]

Since the American Community Survey only includes non-institutionalized individuals, the number of nursing facility residents on a single day in 2007 (June 30) was added to estimate a disability rate for the entire older adult population.[5] This analysis assumes all nursing facility residents have a disability.[6] As Chart 1.3 shows, older Iowans were less likely than other older Americans to have disabilities.

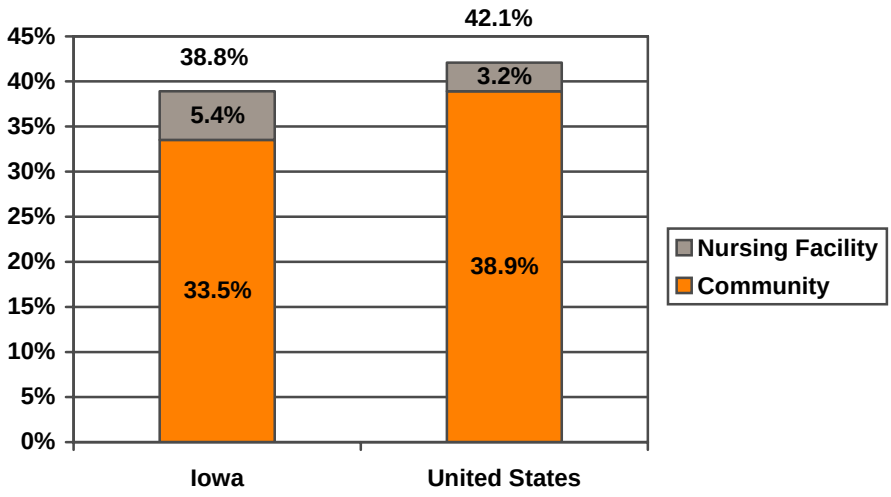
[3] Data for 2010 – 2030 were obtained from U.S. Census Bureau, Population Division "Interim Projections of the Population by Selected Age Groups for the United States and States: April 1, 2000 to July 1, 2030" April 21, 2005.

[4] U.S. Census Bureau, American Community Survey "Table R1803. Percent of People 65 Years and Over With a Disability" September 23, 2008.

[5] Nursing facility data were obtained from U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2007* Undated.

[6] The Census Bureau defines disability as a long-lasting sensory, physical, mental, or emotional condition or conditions that make it difficult for a person to do functional or participatory activities such as seeing, hearing, walking, climbing stairs, learning, remembering, concentrating, dressing, bathing, going outside the home, or working at a job. (U.S. Census Bureau, *American Community Survey and Puerto Rico Community Survey: 2007 Subject Definitions* Undated)

Chart 1.3: Percentage of Persons Age 65 or Older with a Disability, 2007

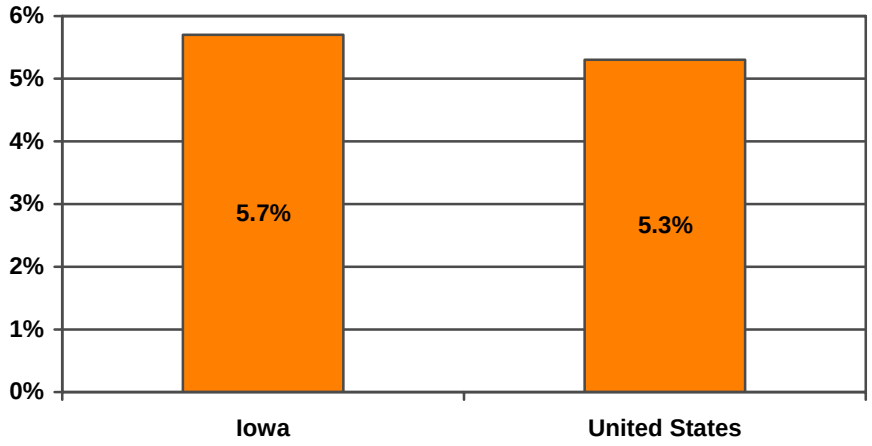


Sources:
U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for population age 65 and older
U.S. Census Bureau, American Community Survey, 2007 "Table B18002. Sex by Age by Disability Status for Civilian Noninstitutionalized Population 5 Years and Over" September 23, 2008 for community disability data
U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2007* Undated for nursing facility data

Chart 1.4 combines data from the first two charts to estimate aging-related long-term care need as a proportion of total population. Approximately 5.7% of Iowans were both age 65 or older and 1) in a nursing facility or 2) in the community with a disability in 2007. Such individuals were an estimated 5.3% of the national population.[7]

[7] U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for population age 65 and older; U.S. Census Bureau, American Community Survey, 2007 "Table B18002. Sex by Age by Disability Status for Civilian Noninstitutionalized Population 5 Years and Over" September 23, 2008 for community disability data; and U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2007* Undated for nursing facility data

Chart 1.4: People Age 65 or Older with a Disability as a Share of Total Population, 2007

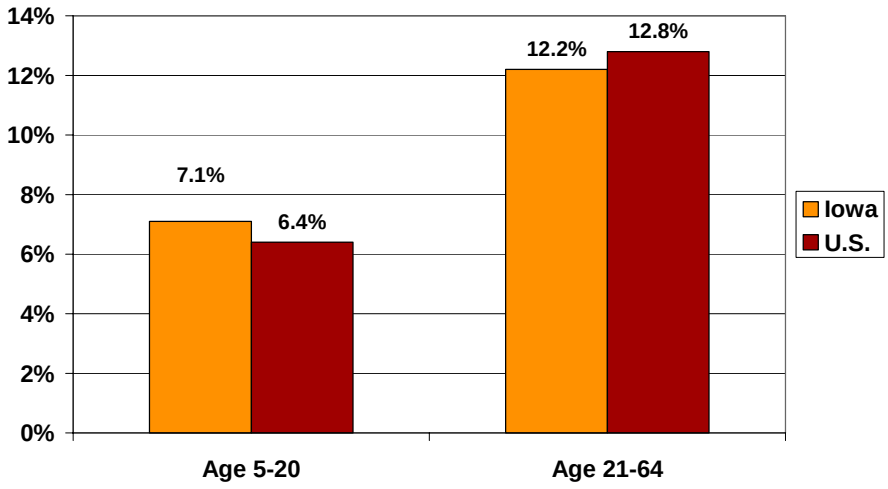


Sources:
U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for population age 65 and older
U.S. Census Bureau, American Community Survey, 2007 "Table B18002. Sex by Age by Disability Status for Civilian Noninstitutionalized Population 5 Years and Over" September 23, 2008 for community disability data
U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2007* Undated for nursing facility data

For people under age 65, the American Community Survey estimates suggest Iowa had a higher than average percentage of children age 21 and under with disabilities, and a lower than average percentage of adults age 21-64 with disabilities (See Chart 1.5).[8]

[8] U.S. Census Bureau, American Community Survey, 2007 "Table B18002. Sex by Age by Disability Status for Civilian Noninstitutionalized Population 5 Years and Over" September 23, 2008 for community disability data

Chart 1.5: Percent of People Under Age 65 with Disabilities, 2007

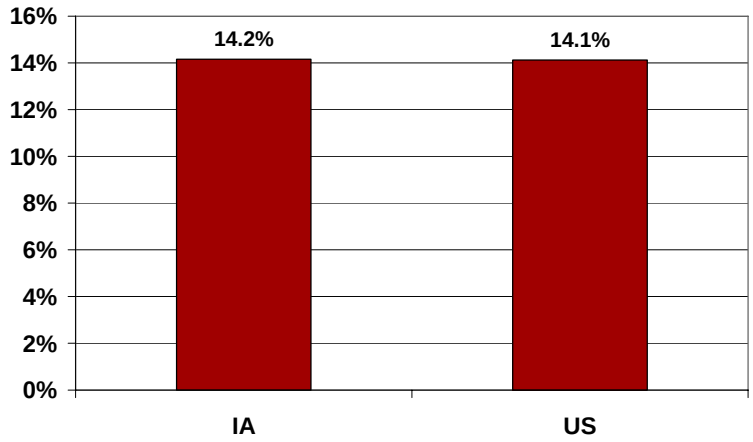


Sources:
U.S. Census Bureau, American Community Survey, 2007 "Table B18002. Sex by Age by Disability Status for Civilian Noninstitutionalized Population 5 Years and Over" September 23, 2008 for community disability data
No source was used for institutional data because a small portion of this age group uses institutional services.

Chart 1.6 shows the estimated proportion of total state population with disabilities in 2007. When data for all age groups are included, the disability rate for Iowans was close to the national disability rate. One of every seven Iowans (14.2%) has a disability.[9]

[9] U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for population; U.S. Census Bureau, American Community Survey, 2007 "Table B18002. Sex by Age by Disability Status for Civilian Noninstitutionalized Population 5 Years and Over" September 23, 2008 for community disability data; and U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2007* Undated for nursing facility data

Chart 1.6: Percentage of Total State Population with Disabilities, 2007



Sources:
U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for population
U.S. Census Bureau, American Community Survey, 2007 "Table B18002. Sex by Age by Disability Status for Civilian Noninstitutionalized Population 5 Years and Over" September 23, 2008 for community disability data
U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2007* Undated for nursing facility data

Service and Utilization Patterns

This section provides a brief overview of service and utilization data to provide perspective regarding Iowa's long-term care system and how it similar or different to other state systems. It begins with data on institutional services for all payer sources to show the degree to which state residents use institutional services, regardless of payer source. (Similar data on community services are not available). An overview of all public funding for long-term support is next, followed by an analysis of Medicaid expenditures and utilization data. Medicaid receives particular attention because it is the largest payer of long-term support services in the country.[10]

Institution Utilization

Iowa serves more people with disabilities and older adults in large facilities than almost any other state, when controlling for state population. Iowa is second to North Dakota in the number of nursing facility residents per 1,000 people age 65 or older.[11] Iowa is third to Mississippi and Arkansas in the number of people with developmental disabilities served in residential facilities

[10] Georgetown University, Long-Term Care Financing Project "National Spending for Long-Term Care" February 2007

[11] U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for population age 65 or older; and U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2007* Undated for nursing facility data

of 16 or more individuals.[12] As Tables 1.1 and 1.2 demonstrate, relatively high utilization is common in Midwestern states, but Iowa's rates for these types of facilities are above average for the region.

Table 1.1: Nursing Facility Residents per 1,000 Residents Age 65 or Older, June 30, 2008

	Nursing Facility Residents per 1,000 65+ population
Iowa	**58.1**
South Dakota	56.1
Nebraska	53.0
Minnesota	49.6
Illinois	48.2
Missouri	47.4
Wisconsin	43.2
United States	36.4

Sources:
U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for population age 65 or older. Population data for 2007 were used because they were the latest available.
U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2008* Undated for nursing facility data

Table 1.2: Number of People with Developmental Disabilities Living in Facilities with 16 or more residents, per 100,000 Residents June 30, 2007

	State Institutions	Non-State Large Facilities	Total
Iowa	**19.2**	**35.9**	**55.1**
Illinois	20.0	28.1	48.1
Nebraska	19.0	13.3	32.3
Missouri	16.0	4.7	20.7
United States	12.4	8.3	20.7
South Dakota	19.8	0.0	19.8
Minnesota	0.8	18.0	18.8
Wisconsin	8.5	9.6	18.1

Source:
Prouty, Robert W.; Alba, Kathryn; Lakin, K. Charlie (eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007* University of Minnesota Institute for Community Integration: August 2008

For people with serious mental illness, however, Iowa has a relatively low rate of state hospital utilization. Further, most people have short stays in the state hospitals, unlike some states

[12] Prouty, Robert W.; Alba, Kathryn; Lakin, K. Charlie (eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007* University of Minnesota Institute for Community Integration: August 2008

where these facilities provide long-term services.[13] Table 1.3 shows utilization data for state-operated mental health hospitals.

Table 1.3: Number of People in State Hospitals for People with Mental Illness per 100,000 Residents, last day of SFY 2006

	State MI Hospital Residents per 100,000
Iowa	**7.4**
Minnesota	7.7
Wisconsin	8.5
Illinois	9.0
United States	15.6
Missouri	23.4
South Dakota	32.3

* United States data are based on 43 states. Nebraska was one of seven states that did not report data.

Source:
National Association of State Mental Health Program Directors Research Institute, Inc. "State Mental Health Agency Profiling System: System: 2007" October 2008.

Total Public Spending

Federal, state, and local governments dedicated approximately $2.2 billion in SFY 2008 to provide supports and services to Iowans with disabilities and older Iowans.[14] Chart 1.7 shows how this funding was distributed among service programs. The $2.2 billion estimate does not include county expenditures for community mental health services outside the Medicaid program, because the authors were not able to develop an estimate for these expenditures. An estimate was available for county-based, non-Medicaid spending for people with developmental disabilities.[15]

Table 1.4 shows the amount of spending in SFY 2008 for five population groups defined by either age or type of disability. Many public long-term care programs are targeted to one or two of these population groups. This report is organized according to these five groups.

[13] National Association of State Mental Health Program Directors Research Institute, Inc. "State Mental Health Agency Profiling System: System: 2007" October 2008.

[14] Most data were provided upon request by the Department of Education, the Department of Elder Affairs, the Department of Human Services, the Iowa Department of Public Health, and Iowa Vocational Rehabilitation Services. Data for some programs were obtained from Iowa Department of Management *Iowa Fiscal Year 2010 Report* January 28, 2009

[15] Braddock, David; Hemp, Richard; Rizzolo, Mary C. *The State of the States in Developmental Disabilities: 2008* Preliminary Report from University of Colorado, Department of Psychiatry and Coleman Institute for Cognitive Disabilities: 2008

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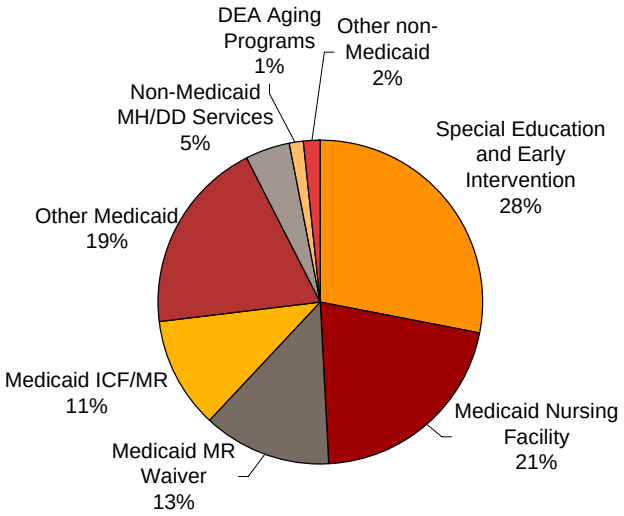
Table 1.4: Public Long-Term Care Spending in Iowa by Target Population in millions, SFY 2008

	2008
Children with Disabilities*	$839
Adults with Mental Retardation	$558
Older Adults**	$533
Adults with Mental Illness***	$160
Adults with Physical Disabilities	$133
Total	$2,223

* Children were defined as people age 18 or younger, except for special education and home health. All special education expenditures were counted as spending for children. For home health, children were defined as under age 21 because service limits change significantly at that age.
** Older Adults were defined as people age 60 or older.
*** Data for adults with mental illness do not include non-Medicaid mental health services provided through counties.

Chart 1.7: Iowa Expenditures for Long-Term Care and Support, SFY 2008

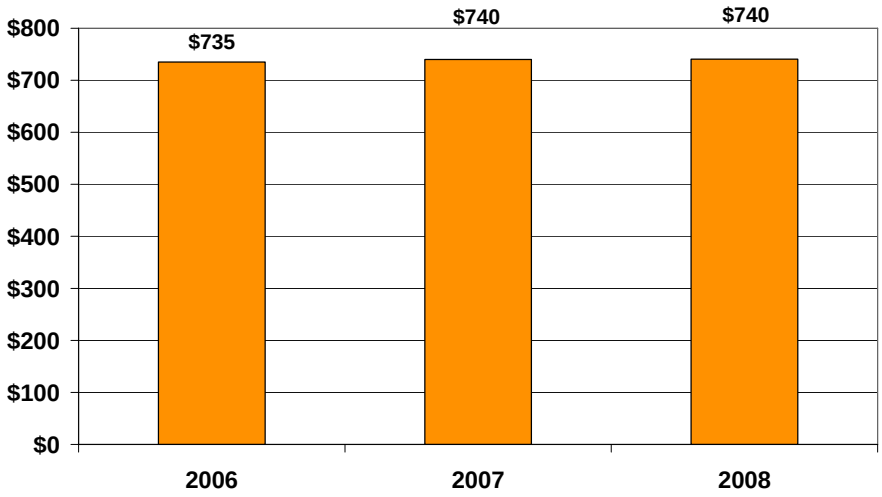


Sources:
See Tables 4.1, 5.1, 6.1, 7.1 and 8.1 for a complete list of sources

As in most states, Medicaid is the largest long-term care funding source, with about 64% of total spending. Special Education is also a significant funding source. While it is not typically considered part of long-term care, the education system provides significant assistance to children with disabilities. When the children transition to adulthood, long-term support programs such as Medicaid home and community based services waivers provide some of these services.

Long-term care spending has increased by approximately 4.1% per year from SFY 2006 through SFY 2008.[16] When controlling for inflation, real expenditures increased by 0.9% per year.[17] Total state population grew 0.6% during that time,[18] so per capita spending increased by only 0.4% per year, from $735 to $740 per state resident (See Chart 1.8).

Chart 1.8: Real Per Capita Expenditures in Iowa for Long-Term Care and Support



Sources:
See Tables 4.1, 5.1, 6.1, 7.1 and 8.1 for expenditures data sources
U.S. Department Of Labor, Bureau of Labor Statistics "Consumer Price Index for All Urban Consumers (CPI-U), Midwest Region" January 26, 2009 for inflation data
U.S. Census Bureau, Population Division "Annual Population Estimates, Estimated Components of Population Change, and Rates of the Components of Population Change for the United States, States, and Puerto Rico: April 1, 2000 to July 1, 2008" December 22, 2008 for population data

The authors further examined Medicaid data because of its large role in long-term care and because states have greater control over Medicaid policy than they do over special education.

Medicaid Expenditures and Utilization

Iowa's Medicaid program spent $1.4 billion in SFY 2008 on long-term support services for older adults, people with disabilities, and people with serious mental illnesses. This figure includes Federal, state, and local expenditures (See Chart 1.7 above).[19] Iowa Medicaid data was

[16] Most data were provided upon request by the Department of Education, the Department of Elder Affairs, the Department of Human Services, the Iowa Department of Public Health, and Iowa Vocational Rehabilitation Services. Data for some programs were obtained from Iowa Department of Management *Iowa Fiscal Year 2010 Report* January 28, 2009; Iowa Department of Management *Iowa Fiscal Year 2009 Report* January 15, 2008; and Iowa Department of Management *Iowa Fiscal Year 2008 Report* January 30, 2007

[17] Thomson Reuters analysis based on inflation data from U.S. Department Of Labor, Bureau of Labor Statistics "Consumer Price Index for All Urban Consumers (CPI-U), Midwest Region" January 26, 2009

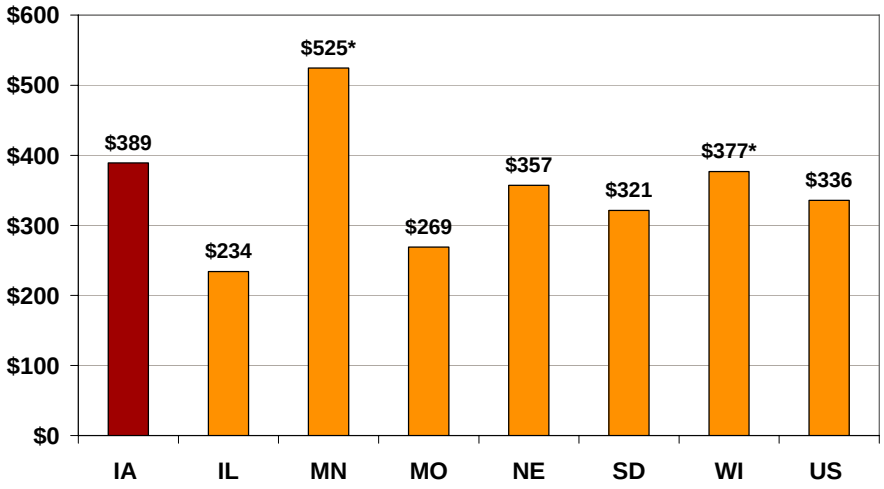
[18] U.S. Census Bureau, Population Division "Annual Population Estimates, Estimated Components of Population Change, and Rates of the Components of Population Change for the United States, States, and Puerto Rico: April 1, 2000 to July 1, 2008" December 22, 2008

[19] Data provided by Department of Human Services, Iowa Medicaid Enterprise

compared to the national average and data from neighboring states to identify how Medicaid spending and utilization in Iowa compares to other states.

Iowa Medicaid long-term care expenditures per state resident were 16 percent above the national average in Federal Fiscal Year 2007 (See Chart 1.9 below), and greater than a majority of neighboring states. This state comparison data does not include mental health expenditures, because the available data sources for all states do not identify Medicaid mental health expenditures.[20]

Chart 1.9: Medicaid per Capita Spending for Long-Term Care (Not Including Mental Health Services), FFY 2007



Iowa ICF/MR expenditures do not include an assessment that ICF/MR providers are required to pay to the state.

* Data do not include large managed long-term care programs in Minnesota and Wisconsin

Source: Burwell, Brian; Sredl, Katherine; and Eiken, Steve *Medicaid Long-Term Care Expenditures in FFY 2007* Thomson Reuters: September 28, 2008.

Most Medicaid long-term care data were examined separately for 1) older adults and people with physical disabilities and 2) people with mental retardation and other developmental disabilities.[21] Different dynamics affect spending for each group. Older adults and people with physical disabilities are more likely to use in-home services for only part of the day, while people with developmental disabilities are more likely to need around-the-clock support in residential settings.

[20] Burwell, Brian; Sredl, Katherine; and Eiken, Steve *Medicaid Long-Term Care Expenditures in FFY 2007* Thomson Reuters: September 28, 2008

[21] Many people prefer the term “intellectual disability” instead of “mental retardation”. The phrase “mental retardation” is used in this report to reflect the phrase used in Federal and state laws and regulations that authorize services for these individuals. We use the phrase “developmental disabilities” when the described policy or program applies to all developmental disabilities, including mental retardation.

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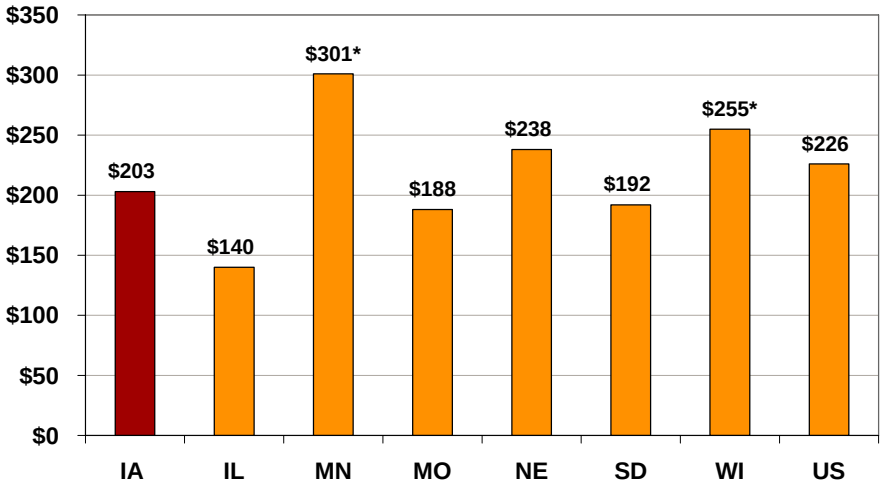
Despite high nursing home utilization and a large older adult population, Iowa was below average in per capita spending for older adults and people with physical disabilities in FFY 2007 (See Chart 1.10 below).[22] Iowa Medicaid services included in this chart include nursing facility care, home health care, and services from the Elderly Waiver, the Ill and Handicapped Waiver, and the Physical Disability Waiver. Two factors explain Iowa's lower-than-average expenditures:

1. A large number of Iowans and their families pay privately for nursing facility care[23]
2. Iowa has one of the lowest nursing facility average costs in the country. This in turn results in an average Medicaid rate for nursing facilities that is low compared to other states.[24]

Chart 1.10: Medicaid per Capita Spending for Long-Term Care for Older Adults and People with Physical Disabilities, FFY 2007



* Data do not include large managed long-term care programs in Minnesota and Wisconsin

Source: Burwell, Brian; Sredl, Katherine; and Eiken, Steve *Medicaid Long-Term Care Expenditures in FFY 2007* Thomson Reuters September 28, 2008

In contrast, Iowa had the ninth highest per capita spending for services for people with developmental disabilities in 2007 (See Chart 1.11 below).[25] Average payment rates are below

[22] Burwell, Brian; Sredl, Katherine; and Eiken, Steve *Medicaid Long-Term Care Expenditures in FFY 2007* Thomson Reuters: September 28, 2008

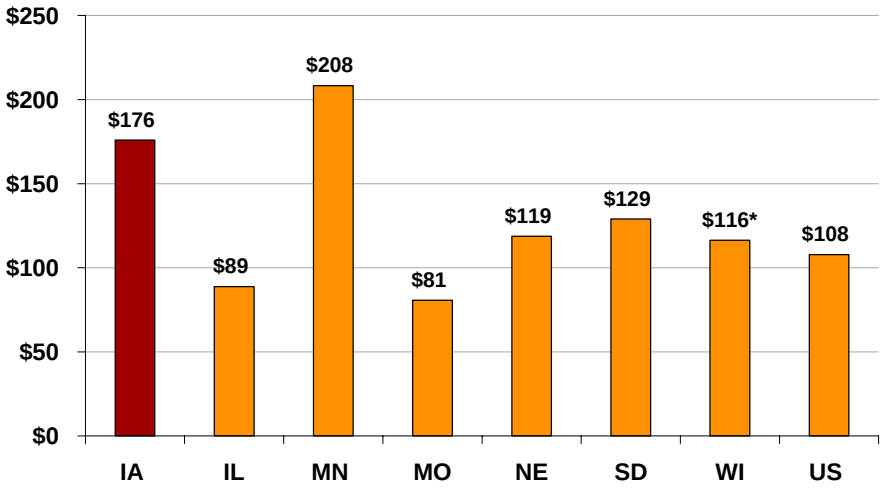
[23] U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2008* Undated

[24] Eljay, LLC *A Report on Shortfalls in Medicaid Funding for Nursing Home Care* American Health Care Association: October 2008 and Grabowski, David C.; Feng, Zhanlian; Intrator, Orna; Mor, Vincent "Medicaid Nursing Home Payment and the Role of Provider Taxes" *Medical Care: Research and Review* 65(4): 514-527. August 2008

[25] Thomson Reuters analysis of data provided by the Department of Human Services, Iowa Medicaid Enterprise and Burwell, Brian; Sredl, Katherine; and Eiken, Steve *Medicaid Long-Term Care Expenditures in FFY 2007* Thomson Reuters September 28, 2008. Iowa ICF/MR expenditures do not include an assessment that ICF/MR providers are required to pay to the state.

average, but Iowa is third in the country in people with developmental disabilities served under Medicaid. Iowa serves a relatively large number of people in both ICF/MR and in its waiver for people with mental retardation.[26]

Chart 1.11: Medicaid per Capita Spending for Long-Term Supports for People with Developmental Disabilities, FFY 2007



Iowa ICF/MR expenditures do not include an assessment that ICF/MR providers are required to pay to the state.

* Data do not include a large managed long-term care program in Wisconsin

Source: Thomson Reuters analysis of data provided by the Department of Human Services, Iowa Medicaid Enterprise and Burwell, Brian; Sredl, Katherine; and Eiken, Steve *Medicaid Long-Term Care Expenditures in FFY 2007* Thomson Reuters September 28, 2008. Iowa ICF/MR expenditures do not include an assessment that ICF/MR providers are required to pay to the state.

The percentage of long-term care spending devoted to community services has often been used as a measure of "balance": the degree to which a state Medicaid program supports community services as well as institutional supports. A little less than two-fifths of Medicaid long-term care spending was for home and community-based services in FFY 2007 (See Table 1.5). Like most states, Iowa has been spending more money on institutional services while most individuals say they would prefer in-home services.[27]

[26] Thomson Reuters analysis of data from the Department of Human Services, Iowa Medicaid Enterprise and Prouty, Robert W.; Alba, Kathryn; Lakin, K. Charlie (eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007* University of Minnesota Institute for Community Integration: August 2008

[27] Stowell-Ritter, Anita *Iowa Long-Term Care: A Synthesis of Consumer and Provider Research* AARP: October 2003

Table 1.5: Percentage of Medicaid Long-Term Care Expenditures Used for Community Services, FFY 2007

	Total	Services for Older Adults and People with Physical Disabilities	Services for People with Developmental Disabilities
Minnesota*	63%	47%	84%
Wisconsin*	46%	31%	77%
Missouri	45%	31%	77%
United States	42%	31%	63%
South Dakota	39%	11%	80%
Iowa	**38%**	**26%**	**50%**
Nebraska	38%	22%	68%
Illinois	31%	25%	38%

* Data do not include large managed long-term care programs in Minnesota and Wisconsin

Source: Thomson Reuters analysis of data provided by the Department of Human Services, Iowa Medicaid Enterprise and Burwell, Brian; Sredl, Katherine; and Eiken, Steve *Medicaid Long-Term Care Expenditures in FFY 2007* Thomson Reuters September 28, 2008. Iowa ICF/MR expenditures do not include an assessment that ICF/MR providers are required to pay to the state.

Since 2004, utilization for Medicaid institutional services has decreased while Medicaid community services have increased (See Table 1.6). While the number of nursing facility beneficiaries increased slightly, length of stay also decreased and the number of Medicaid-funded days of care declined.[28]

Table 1.6: Change in Utilization of Iowa Medicaid Long-Term Care Services with the Largest Number of Participants, SFY 2004 and SFY 2008

	2004	2008	Average Annual Percentage Change
Institutional Services			
Nursing Facility Participants	20,792	21,023	0.3%
Nursing Facility Days	5,091,688	4,636,441	-2.3%
ICF/MR Participants	2,346	2,154	-2.1%
ICF/MR Days	786,981	711,343	-2.5%
Home and Community-Based Services (all data are number of participants)			
Home Health Nursing	17,073	20,670	4.9%
Elderly Waiver	8,035	11,826	10.1%
Home Health Aide	6,134	6,622	1.9%
Mental Retardation Waiver	7,618	10,695	8.9%
Ill & Handicapped Waiver	2,123	2,695	6.1%

Source: Data provided by the Department of Human Services, Iowa Medicaid Enterprise

[28] Data provided by the Department of Human Services, Iowa Medicaid Enterprise

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Historical and Political Factors

In interviews with stakeholders, three characteristics frequently emerged that are particularly important to understanding Iowa's long-term support system:

- A state organizational structure based on funding sources
- A large county role in funding and administration
- Recent system reforms to encourage and improve community services

State Organization by Funding Source

Many states that have reformed their long-term care system (e.g., Oregon, Minnesota, Washington and Vermont) established a single agency responsible for planning and delivery of services.[29] Some of these states have taken the additional step of creating a single organization for the full range of disabilities, to align services with individuals' functional needs regardless of diagnosis.[30] As described in the Section 2: System Administration and Management, in Iowa several state government entities are involved in service planning, funding, and delivery.

The Iowa state agencies that fund long-term supports tend to be organized around funding sources rather than common services, so multiple agencies pay for similar services using different methods. For example, both the Iowa Department of Public Health and the Department of Elder Affairs pay for in-home services to help people ineligible for Medicaid remain in their homes. Also, the Iowa Department of Human Services has three organizational units with significant roles in services for people with disabilities and people with mental illness: the Mental Health and Disability Services division, the Iowa Medicaid Enterprise, and the Field Operations unit that operates state institutions. On a positive note, Iowa's organizational structure is not based on diagnosis, providing a structure to coordinate services for all individuals with long-term support needs.

Another organizational challenge is fragmentation between system planning and day-to-day management. The entities responsible for service planning have limited ability to implement the plans. For example, the Senior Living Coordinating Unit includes leadership from all three service funding agencies and a licensing agency and is responsible for long-term care planning. However, there is no requirement to coordinate policy development and implementation.[31] Similarly, the Department of Human Services' (DHS) Mental Health and Disability Services Division and the MHMRDDBI Commission approve county plans for serving adults with disabilities and/or mental illness, but a review of MHMRDDBI Commission documents and information from stakeholder interviews suggest the DHS Iowa Medicaid Enterprise, which manages the largest funding source for these individuals, plays a small role in the planning process.

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[29] Eiken, Steve *Promising Practices in Long Term Care Systems Reform: Common Factors of Systems Change* Medstat: November 9, 2004 and Kane, Rosalie A.; Kane, Robert L.; Priester, Reinhard; Homyak, Patricia *Research and State Management Practices for the Rebalancing of State Long-Term Care Systems: Final Report* University of Minnesota: June 2008

[30] Kane, Rosalie A.; Kane, Robert L.; Priester, Reinhard; Homyak, Patricia *Research and State Management Practices for the Rebalancing of State Long-Term Care Systems: Final Report* University of Minnesota: June 2008

[31] Iowa Senior Living Coordinating Unit *2008 Annual Report* January 15, 2009

Iowa State Profile Tool
Section 1: Background

Large County Role

Iowa's 99 counties play a significant role in financing and setting policy for services for adults with chronic mental illness, mental retardation, and other developmental disabilities. County governments differ in their ability and desire to fund services, so there is variation across the state in what services are available and how they are furnished. This variety can be a source of both innovation and frustration – some counties provide effective services while others struggle to meet participants' needs.

The state share of funding for mental health and disability services has grown since 1995, when the legislature set a limit on the county property tax levy for mental health and disability services. Starting in SFY 1997, the state has provided property tax relief to counties and required counties to lower their property tax revenue by the amount of property tax relief. Since 2000, the property tax relief has been $88.4 million.[32] Each year the state adds additional funding based on projected spending growth. Further, counties can obtain Federal Medicaid funds for services in the Medicaid State Plan or a home and community-based services waiver that are provided to Medicaid-eligible individuals. The use of Medicaid also provides a greater policy role for the state because Medicaid policies and available services must be consistent statewide.[33]

State law requires counties to provide services to people with mental illness and people with mental retardation.[34] Services for people with disabilities, including brain injuries, physical disabilities, and autism, are optional unless the person also has mental retardation. As a result of a long-standing mandate for a limited population, people with mental retardation do not have to endure the lengthy waiting lists for services that exist in many states. However, people with other conditions have more limited service options.

Recent System Reforms

Iowa has made progress in recent years to expand opportunities for people of all ages to live independently in the community. Initiatives in the last five years include:

- Implementation of participant-directed services in all Medicaid home and community-based services waivers that serve adults[35]

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[32] Iowa State Association of Counties *2008 County Financial Overview* January 2008 and Iowa Department of Human Services, Mental Health and Disability Services *Alternative Distribution Formulas Workgroup Documents: Disability System Funding* November 28, 2006. The Iowa Department of Management's *Iowa Fiscal Year 2010 Report* (January 29, 2009) lists total property tax relief at $95 million, but $6.6 million of that amount is used for the state share of Medicaid services for children with mental retardation.

[33] HCBS waivers provide states the option to waive the statewideness requirement. A state could do this to make services available only in specific counties, for example. However, once a service is available, policies related to that service must be consistent statewide. (U.S. Centers for Medicare & Medicaid Services *Application for a 1915(c) Home and Community-Based Services Waiver [Version 3.5]: Instructions, Technical Guide and Review Criteria* January 2008)

[34] Iowa State Association of Counties *2007 New County Officers Manual: The ABC's of County Government* 2007. Counties are not required to pay for services for people who move into the county, unless that person went without services for more than one year. People who move to Iowa from out of state, and people who have left state institutions, are "state cases" who services are state funded.

[35] Iowa Department of Human Services, Iowa Medicaid Enterprise "Systems Readiness Assessment" part of application for the Federal Systems Transformation Grant Revised September 29, 2005

- Developing more than 1,500 housing units for low-income people with disabilities[36]
- Starting the Children's Mental Health Waiver to provide community alternatives to Psychiatric Medical Institutions for Children[37]
- Establishing habilitation services in the Medicaid State Plan under the new Section 1915(i) of the Social Security Act.[38] Iowa is the only state in the nation using the 1915(i) option.
- Starting the Money Follows the Person Demonstration, which provides an enhanced Federal matching rate for people who move from an institution to a home or apartment[39]
- Establishing LifeLongLinks (http://www.lifelonglinks.org), an online information and assistance resource for older adults with links to resources for all people who need long-term support

Several stakeholders said there was a widespread commitment among people involved in the long-term care system to provide quality services and continue to improve the system.

[36] Iowa Department of Human Services, Iowa Medicaid Enterprise "MFP Housing Inventory Report" September 4, 2007

[37] Iowa State University, Child Welfare Research and Training Project for the Iowa Department of Human Services "Iowa Department of Human Services, CMH Waiver" May 3, 2007

[38] Iowa Department of Human Services, Iowa Medicaid Enterprise "HCBS Habilitation Services Program" Undated

[39] Iowa Department of Human Services, Iowa Medicaid Enterprise "Partnership for Community Integration & Money Follows the Person" Application submitted November 2006

Iowa State Profile Tool
Section 2: System Administration and Management

The state agencies in Iowa that administer long-term supports tend to be organized around funding sources rather than common services, so multiple agencies pay for similar services using different methods. Coordination of the different funding streams occurs at the local level, among county agencies and other local organizations. In addition, separate entities often are responsible for planning and service delivery, with planning by commissions that involve state staff and other stakeholders and service delivery managed by individual state agencies.

This section provides some basic information on Iowa's management of long-term supports. It starts with a basic overview of the state and local entities involved. It then describes the complicated funding structure for mental health and disability services for adults under age 60, which is important for understanding the system described in subsequent sections of this report. The report then describes an important recent organizational change, the 2006 re-establishment of the Mental Health and Disability Services division with the Department of Human Services (DHS). The section concludes with an overview of the roles of the state legislature and participants in system planning and policy development.

Organizational Structure

Iowa's umbrella human services agency, DHS, administers most long-term supports. DHS has three divisions with significant roles in services for older adults, people with disabilities, and people with mental illness:

- The Mental Health and Disability Services Division, which licenses community mental health centers and administers state and federal grants
- The Iowa Medicaid Enterprise, the designated State Medicaid Agency
- The Field Operations unit that operates state institutions for people with mental retardation and mental illness[1]

While DHS provides most funding for long-term supports, six additional agencies play important roles in the system:

- The Department of Education oversees special education services, the largest public funding source for services to children with disabilities
- The Department of Elder Affairs manages a variety of long-term supports for people age 60 and older, including nutritional services, case management, and in-home services
- The Department of Inspections and Appeals licenses and/or certifies many long-term care providers, including nursing facilities, ICF/MR, residential care facilities, assisted living, elder group homes, and adult day care
- The Iowa Department of Public Health manages grants to local public health entities for in-home services
- Iowa Vocational Rehabilitation Services assists people with disabilities in obtaining employment and manages independent living grants for people with disabilities
- The Iowa Department of Corrections provides long-term care and mental health services to its inmate population

[1] Iowa Department of Human Services *Organization Summary* October 2008

Some of the state agencies administer grant funding through a network of local agencies, often units of government. The local agencies provide information and assistance; assess functional or clinical eligibility for services; enroll people in service programs; and provide case management or supports coordination to help people obtain necessary services. Local agencies include:

- County-based Central Points of Coordination (CPC), which manage local services for adults with mental health, mental retardation, and developmental disabilities funded by grants from the Department of Human Services, Mental Health and Disability Services division. Multiple counties have the option to pool resources to select a single CPC.
- Local school districts, which provide special education and early intervention services. For specialized services, these districts typically contract with one of 10 regional Area Education Agencies
- Regional Area Agencies on Aging (AAA) that administer state and federal grants to provide services to older adults
- County-based Local Boards of Public Health select a Local Public Health Entity (LPHE) to provide public health services, including in-home services. The Local Public Health Entity can be a unit of county government or another organization such as a hospital with a home health agency.

The Department of Human Services, Iowa Medicaid Enterprise (IME) works with all four types of local organizations described above to provide long-term support services. CPC provide case management for people with mental retardation. Some local school districts have enrolled as Medicaid providers, and can bill IME for medically necessary services provided to a child enrolled in Medicaid. Both AAA and LPHE provide case management for older adults as part of the Elderly Waiver.

Mental Health and Disability Services Financing Structure

County governments play a significant and evolving role in financing services for adults with developmental disabilities and/or mental illness. Local property taxes were the primary funding mechanism for these supports until the mid-1990s, when the state started providing property tax relief to counties.[2] Property tax relief is paid into the Mental Health Property Tax Relief Fund, and counties typically have saved a portion of dollars in that fund for future needs. The state set a limit on county general revenue that could be used for mental health and disability services. This limit is based on the county levy in place before the limit was set (counties could choose to use FY 1994 or 1996 for the baseline). The limit is a hard dollar limit not indexed for inflation or for changes in property values. It has not changed in several years.[3] Counties are still required to provide both community and institutional services to people with mental retardation and chronic mental illness, and have the option of providing services to people with brain injuries and/or people with other developmental disabilities.[4]

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[2] Iowa General Assembly, Legislative Services Agency *History of the County/State Partnership for Mental Health, Mental Retardation and Developmental Disability Services* Undated

[3] Iowa State Association of Counties *2005 County Financial Overview* January 2005; Iowa State Association of Counties *2006 County Financial Overview* January 2006; Iowa State Association of Counties *2007 County Financial Overview* January 2007; Iowa State Association of Counties *2008 County Financial Overview* January 2008; and Iowa State Association of Counties *2009 County Financial Overview* January 2009

[4] Iowa State Association of Counties *2007 New County Officers Manual: The ABC's of County Government* 2007

At the same time the property tax limit was set, state appropriations were established to allow for program growth. These appropriations have increased over time.[5] Some funds are distributed based on counties' population and poverty rates, while others are contingent upon achieving outcomes related to service access and provision of more integrated services such as smaller ICF/MR (10 beds or less) and supported employment. Counties must submit a county management plan for mental health and disability services to receive these state appropriations.[6] County plans were subject to approval by DHS in consultation with the MHMRDDBI Commission.[7] Counties do not need to submit a new plan each year, but can amend the plan with DHS approval. Counties send an annual review to DHS and develop a strategic plan every three years.[8]

Chart 2.1 on the following page shows the trend in the combined total of the county levy and state appropriations. The amount of state and county general revenue dedicated to mental health and disability services increased by an average rate of 3.7% per year from SFY 2004 through SFY 2008.[9] This increase matches the combination of increased inflation and population during that time (3.7%). The inflation rate in the Midwest averaged 3.0% per year, [10] and the number of people age 18 – 64 increased an average of 0.7%.[11]

Between SFY 2005 and SFY 2007, counties withdrew about $29.5 million from the Mental Health Property Tax Relief Fund – more than half the fund balance – to continue or expand services. A state appropriations increase of $12 million in SFY 2008 enabled counties to reduce withdrawals from the fund balance. When withdrawals from the Mental Health Property Tax Relief Fund are included, expenditures increased 4.0% per year on average. Only $24 million remained in the fund as of the end of SFY 2008,[12] and several stakeholders expressed concern that the current funding mechanism is not sustainable.

Stakeholders also noted that counties increasingly used their funding as the non-Federal share for Medicaid services. The Federal government pays approximately 62% of the cost of Medicaid services. Counties pay the other 38% for the services under their county management plan. Medicaid is only available for people who are eligible for Medicaid and who choose necessary services in Iowa's Medicaid State Plan or in a home and community-based services waiver. The use of Medicaid also provides a greater policy role for the state because Medicaid policies and available services must be consistent statewide.

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[5] Iowa Department of Management *Iowa Fiscal Year 2009 Report* January 15, 2008

[6] Iowa State Association of Counties *2007 New County Officers Manual: The ABC's of County Government* 2007

[7] Iowa Code, Section 331.439

[8] Iowa General Assembly, Legislative Services Agency *History of the County/State Partnership for Mental Health, Mental Retardation and Developmental Disability Services* Undated

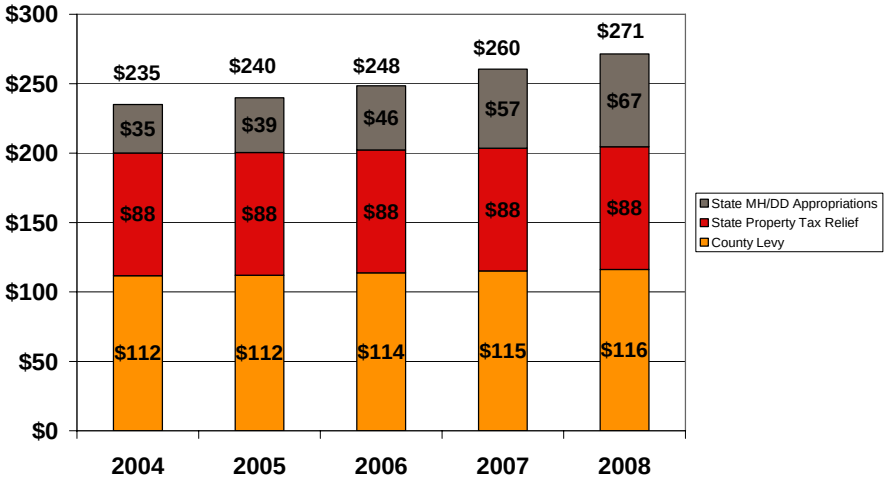
[9] See sources identified under Chart 2.1

[10] U.S. Department Of Labor, Bureau of Labor Statistics *Consumer Price Index for All Urban Consumers (CPI-U), Midwest Region* January 26, 2009. The national Consumer Price Index for All Urban Consumers during this period increased by an average of 3.3% per year (U.S. Department Of Labor, Bureau of Labor Statistics *Consumer Price Index for All Urban Consumers (CPI-U)* January 16, 2009)

[11] U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008

[12] Iowa State Association of Counties *2009 County Financial Overview* January 2009

Chart 2.1. County and State Appropriations for MH/DD Services, in Millions, SFY 2004 - 2008



Sources:
Iowa State Association of Counties *2005 County Financial Overview* January 2005
Iowa State Association of Counties *2006 County Financial Overview* January 2006
Iowa State Association of Counties *2007 County Financial Overview* January 2007
Iowa State Association of Counties *2008 County Financial Overview* January 2008
Iowa State Association of Counties *2009 County Financial Overview* January 2009
Iowa Department of Management *Iowa Fiscal Year 2008 Report* January 30, 2007
Iowa Department of Management *Iowa Fiscal Year 2009 Report* January 15, 2008
Iowa Department of Management *Iowa Fiscal Year 2010 Report* January 28, 2009

Governing Commissions

Three interagency or intergovernmental commissions described below play important roles in long-term services planning and coordination:

- The Senior Living Coordinating Unit (SLCU)
- The Mental Health, Mental Retardation, Developmental Disabilities, and Brain Injury (MHMRDDBI) Commission
- The Governance Group

Senior Living Coordinating Unit (SLCU)

The SLCU includes leadership from three departments that fund services for older adults (Department of Elder Affairs, Department of Human Services, and Iowa Department of Public Health) and the licensing agency (Department of Inspections and Appeals), as well as two

Governor-appointed citizen members.[13] Four legislators are ex-officio members who receive materials and can attend meetings, but cannot vote on SLCU decisions.

Authoring legislation for the SLCU assigned several tasks to improve interagency coordination, including developing a long-range plan for long-term care services; developing common intake procedures and assessment tools; and establishing common definitions of long-term care services.[14] The state has accomplished several positive system changes consistent with the latest Long Range Plan the SLCU released in December 2005,[15] including piloting an evidence-based health promotion program, starting a public awareness campaign on long-term supports, and establishing a rural Program for All-inclusive Care for the Elderly (PACE) project for integrated Medicare and Medicaid services.[16] However, the SLCU has limited authority to implement plans or recommendations, and some planned changes – including common intake and assessment procedures and common definitions of long-term care services – have not come to fruition. Individual agencies maintain responsibility for the programs and funds they administer, and major policy changes such as new assessment tools may need legislative action and/or Federal approval (e.g., for Medicaid services).

The Mental Health, Mental Retardation, Developmental Disabilities, and Brain Injury (MHMRDDBI) Commission

The MHMRDDBI Commission has governing authority for mental health and disability services, in conjunction with the Department of Human Services. State law involves both DHS and the MHMRDDBI Commission in planning and decision-making for mental health and disability services. In some cases, the MHMRDDBI Commission has final decision-making authority. In other cases DHS has final authority.

Unlike the SLCU, the Governor does not determine the full voting membership of the MHMRDDBI Commission. The 16-member Commission includes county supervisors, CPC administrators, provider representatives, advocates, a union representative, family members, and at least one person receiving services. County, CPC, provider, and union representatives are named by the interest group they represent (i.e., county supervisors named by the Iowa State Association of Counties). Like the SLCU, four General Assembly members serve in an ex-officio capacity; receiving information but not having a vote on decisions.[17]

The MHMRDDBI Commission adopts regulations and standards for mental health and disability services providers, including Community Mental Health Centers and case management organizations. The Commission makes the final decision regarding accreditation of community mental health providers, based on information provided by DHS, Mental Health and Disability Services (MHDS) division staff that monitors the providers.[18]

The MHMRDDBI Commission also established rules for county management plans for mental health, mental retardation, and developmental disability services. The county plans, three-year

[13] Senior Living Coordinating Unit *2008 Annual Report* January 15, 2009
[14] Iowa Code, Section 231.58
[15] Senior Living Coordinating Unit *A Long-Range Plan for Long-Term Care in Iowa* December 16, 2005
[16] Senior Living Coordinating Unit *2008 Annual Report* January 15, 2009
[17] Iowa Code, Section 225C.5
[18] Iowa Code, Section 225C.6

strategic plans, and an annual review are prerequisites for state appropriations for mental health and disability services. The Commission reviews the plans, and DHS, MHDS approves the plans (annual reviews are not subject to approval).[19] Every five years, the Commission prepares a five-year plan for state mental health and disability services, based on the county management plans.[20]

Finally, the MHMRDDBI Commission is responsible for setting financial eligibility standards for disability services, including setting rules for any copayments county agencies may require. State law requires that people with incomes lower than 150% of Federal Poverty Level and less than $2,000 of assets be eligible for services, but it appears counties can set different standards if they can afford to serve individuals with higher incomes and assets.

Governance Group

The Governance Group includes directors of seven state organizations to identify and change policies that make it difficult for people with disabilities to obtain employment. The organizations include:

- Iowa Vocational Rehabilitation Services
- The Department of Human Rights, Deaf Services Commission
- The Department of Human Rights, Division for Persons with Disabilities
- The Department of Human Services, Iowa Medicaid Enterprise
- The Department of Human Services, Mental Health and Disability Services division
- The Department for the Blind
- The Developmental Disabilities Council

These organizations signed a Memorandum of Agreement in 2003 to collaborate on employment initiatives. The group meets quarterly and provides oversight for Federal and State initiatives to improve work incentives and provide services to people with disabilities on public programs, including Temporary Assistance for Needy Families.[21]

Recent Change: Establishment of Mental Health and Disability Services Division

An important change in the state's organization of long-term care agencies was the 2006 re-establishment of a division of the Department of Human Services to manage non-Medicaid services for people with disabilities and chronic mental illnesses. The division had been eliminated in 2002. Between 2002 and 2006, some of this division's duties – such as provider monitoring and budget setting – were fulfilled by the MHMRDDBI Commission and other divisions within DHS. Other tasks, especially technical assistance, did not occur.

The Mental Health and Disability Services division administers Federal and state mental health and developmental disabilities grants. It also approves county management plans, based on criteria set by the MHMRDDBI Commission. DHS, including MHDS, also recommends growth

[19] Iowa General Assembly, Legislative Services Agency *History of the County/State Partnership for Mental Health, Mental Retardation and Developmental Disability Services* Undated

[20] Iowa Code, Section 225C.6

[21] Iowa State Rehabilitation Council *2006 – 2007 Annual Report* December 31, 2007

in state appropriations for mental health and disability services as part of the Governor's budget-setting process.[22]

For the past three years, the Mental Health and Disability Services division has focused on implementing evidence-based practices for adults with mental illness and on improving coordination of mental health services. The division provides grants to providers to purchase training and start-up funding to implement evidence-based practices such as cognitive behavioral therapy, supported employment, and integrated dual diagnosis treatment for people with both mental illness and an addiction disorder. The division established two new bureaus for populations whose mental health needs are often underserved: children and older adults. At the time this report was written, the Older Adults Bureau did not yet have staff.

On many topics, the division provides staff support for the MHMRDDBI Commission's decisions. For example, the division recommends standards for community mental health centers and other mental health and disability services, but the Commission has the final decision. The division can recommend accreditation or non-accreditation of a provider based on monitoring activities, but the final decision rests with the Commission.[23]

Legislative Involvement

In addition to the executive branch, the Iowa General Assembly plays an active role in long-term care policy development. The General Assembly is involved in policy changes, in addition to the appropriations role a state legislature has in any state. Major changes, such as starting a new program or changing institutional reimbursement methodology, require legislative approval. Four key pieces of legislation passed in the last 15 years have had a significant effect on the long-term care system:

- House File 2430 in 1994 and Senate File 69 in 1995, which set a limit on county property tax levies for mental health and disability services and authorized property tax relief to increase the state's role in funding these services[24]

- The 2000 Iowa Senior Living Program Act authorized several policies to reduce the need for nursing facility care, including development of a case-mix payment rate for nursing facilities, grants to develop alternative services, and state-funded programs for caregiver support and for home and community-based services for older adults[25]

- The 2005 Iowa Care Act authorized an ambitious set of Medicaid policy changes, some which have not yet been implemented. This law authorized five years of Medicaid payment for services in mental health institutes and the establishment of a home and community-based services waiver for children with severe

[22] Iowa Code, Section 229C.4

[23] Iowa Code, Section 229C.6

[24] Iowa General Assembly, Legislative Services Agency *History of the County/State Partnership for Mental Health, Mental Retardation and Developmental Disability Services* Undated

[25] 2000 Iowa Acts, Chapter 1004

emotional disturbances. Initiatives that have not yet been implemented include a case mix reimbursement system for services for people with mental retardation.[26]

- A 2006 law re-established the division of Mental Health and Disability Services within the Department of Human Services, as described earlier in this section of the report

Consumer Involvement

People who receive long-term support services are involved in systems advocacy through state governing and advisory groups and through independent advocacy to their elected officials. Both governing commissions described earlier in this section, the Senior Living Coordinating Unit and the MHMRDDBI Commission, include members of the population affected by that group's decisions (older adults and people with mental illness or developmental disabilities, respectively). The Department of Human Services and the Department of Elder Affairs also have governor-appointed boards that approve or adopt department regulations and make other decisions with the advice of Department staff (The DHS Council and the Elder Affairs Commission, respectively). Consumers and family members also are involved in short-term task forces to plan and/or implement new initiatives, such as the Money Follows the Person Demonstration.

As in any state, individuals who need long-term supports and their family members also can reach decision makers through independent advocacy. The Governor's Developmental Disabilities Council has helped people with developmental disabilities learn to advocate on their own behalf through initiatives like IDAction (for Iowa Disability Action) and Advocacy University. These initiatives provide training to individuals to help them communicate their wishes and encourage people to participate in the political process, including voter registration. Hundreds of individuals with developmental disabilities come to the State Capitol for the annual Advocating Change Day and provide their perspective directly to their legislators and/or their staff.

[26] Iowa Code, Chapter 249J

Iowa State Profile Tool
Section 3: Workforce

Ensuring an adequate supply of well-trained health and long-term care workers was a repeated area of concern among Iowa stakeholders. People interviewed for this report expressed concern about long-term care workers in the context of an overall shortage of health care workers in Iowa, including physicians, nurses, and psychologists. For example, there are some counties in Iowa where no registered nurses are working.

This shortage is not unique to Iowa. Table 3.1 highlights the estimates of the current supply of select health and long-term care professions from the U.S. Bureau of Labor Statistics with comparisons to neighboring states. The number of workers, controlling for state population, is comparable to neighboring states for most professions.

Table 3.1: Number of Workers per 100,000 State Population for Select Health and Long-Term Care Professions, May 2007

	Registered Nurses	Home Health Aides	Nursing Aides, Orderlies, and Attendants	Personal and Home Care Aides
Iowa	**989**	**339**	**698**	**188**
Illinois	810	187	468	152
Minnesota	1,014	543	565	544
Missouri	958	192	613	271
Nebraska	1,007	228	755	74
South Dakota	1,214	109	721	185
Wisconsin	905	316	625	291
United States	*818*	*277*	*461*	*197*

	Psychologists	Psychiatrists	Mental Health Counselors and Social Workers
Iowa	**30**	**4.4**	**79**
Illinois	39	5.7	60
Minnesota	55	6.0	76
Missouri	23	8.5	68
Nebraska	28	7.3	100
South Dakota	23	3.8	54
Wisconsin	38	6.4	68
United States	*35*	*7.2*	*71*

Source:
U.S. Bureau of Labor Statistics *Occupational Employment Statistics Estimates for May 2007* May 9, 2008 and U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008

Several factors make recruitment and retention of health and long-term care workers more difficult. For direct care workers, low pay and high turnover rates are significant factors, as well

as hindered job mobility from one workplace to another.[1] Although wages for Iowa's direct care workers in 2007 were close to the median national wage, wages are low compared to other employment options. In nursing, some of the biggest challenges are nursing faculty shortages and wages that are low compared to other states.[2] The median wage for a registered nurse in Iowa is below the twenty-fifth percentile nationally, meaning 50% of Iowa registered nurses make less than 75% of registered nurses across the country (see Table 3.2). Among physicians, some of the biggest challenges include high attrition (moving to other states) and lack of geographic dispersion.[3]

Table 3.2: Median Wages for Select Health and Long-Term Care Professions, May 2007

	Registered Nurses	Home Health Aides	Nursing Aides, Orderlies, and Attendants	Personal and Home Care Aides
Iowa	$23.04	$10.14	$10.85	$9.50
United States	$28.85	$9.62	$11.14	$8.89

Source:
U.S. Bureau of Labor Statistics *Occupational Employment Statistics Estimates for May 2007* May 9, 2008

Informal Caregivers

Adding to the workforce crunch are the changing demographics of informal caregivers, who provide most long-term care. Informal caregivers can be a spouse, relative, neighbor, or friend who provides unpaid assistance with daily activities, such as personal care, transportation, or even possibly handling certain delegated medical tasks. Nationally, up to 75% of caregivers are female, with the majority being 35-64 years old.[4] In Iowa, there are an estimated 300,000 informal caregivers at any given time. An estimate of the economic value of informal care is $3.4 billion,[5] about 50% more than the total for all public long-term support spending presented in Section 1: Background.

Informal caregivers are increasingly likely to be juggling care for a loved one with a full- or part-time paying job and their own personal and family care needs. In addition, Iowa has a high labor force participation rate among women, who are most likely to be caregivers. Currently, nearly 67% of women are in the workforce, well above the national average of 59%.[6] In addition, the aging of the baby boom generation is expected to coincide with a decline in the number of people available for caregiving – those in the 35 to 64 age range. Strategies to prepare and support informal caregivers may prove just as important for helping people live in the community as workforce recruitment strategies.

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[1] Iowa Direct Care Worker Task Force *Recommendations for Establishing a Credentialing System for Iowa's Direct Care Workforce* May 2008

[2] *Report of the Iowa Governor and Lieutenant Governor's Nursing Task Force* March 3, 2008

[3] University of Iowa Hospitals and Clinics, *Report of the Task Force on the Iowa Physician Workforce* January 2007

[4] Family Caregiver Alliance *Selected Caregiver Statistics* 2005

[5] Houser, Ari and Gibson, Mary Jo *Valuing the Invaluable: The Economic Value of Family Caregiving*, *2008 Update* AARP Public Policy Institute: November 2008

[6] Pearson, Beth and Gordon, Colin *Women, Work and the Iowa Economy: The State of Working Iowa 2008, Part II* Iowa Policy Project: September 2008

Iowa State Profile Tool
Section 3: Workforce

Current Workforce Initiatives

Iowa has taken several steps to improve recruitment of the health and long-term care workforce, with the Iowa Department of Public Health (IDPH) in a lead planning role. Legislation passed in 2008 requires IDPH to submit reports every two years regarding strategic plans for building and sustaining a health care workforce to the Governor and General Assembly, [7] with the first report planned for January 2010.[8]

Public efforts that have already been implemented related to the long-term care workforce include:

Direct Care Worker Directory: The Department of Inspections and Appeals (DIA) expanded the scope of its Certified Nurse Aide Registry to a Direct Care Worker Registry that also includes people who provide community-based services. Community-based workers are not required to register, but the registry provides an opportunity for agencies to identify qualified workers. Ultimately, the goal is to track all direct care workers using this registry.[9] This change was a joint effort of DIA, IDPH, and the Iowa CareGivers Association, a private non-profit association of direct care workers.

Direct Care Worker Task Force: This task force was established by the General Assembly in 2005 to recommend education and training criteria for direct care workers for all types of disability. Currently, an estimated 75,000-100,000 direct care workers in Iowa have about 40 different job titles.[10] Recommendations include:

- A uniform definition of direct care worker
- A multi-tiered credentialing system, with core competencies that apply to all workers and additional training standards determined by the type of work performed
- A standard curriculum for training direct care workers, including continuing education requirements through courses taught only by certified instructors who are trained in the direct care worker curriculum.[11]

Nurse delegation service: The Department of Human Services, Iowa Medicaid Enterprise, added a nurse delegation service as part of the Money Follows the Person demonstration. As a result, persons transitioning out of ICF/MR under the demonstration can now have the delegation service paid by the Medicaid program. Nurse delegation can alleviate the state's nursing shortage by allowing nurses to delegate certain tasks to direct care workers, such as administration of oral medications or wound care.[12] If nurse delegation can be provided safely and is cost-effective, it may be expanded to other Medicaid Home and Community-Based Services Waiver participants.

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[7] Iowa 82nd General Assembly, House File 2539

[8] Iowa Department of Public Health "Health and Long-Term Care Access Advisory Council" Undated

[9] Iowa Department of Inspections and Appeals "Direct Care Worker Search" Undated

[10] Iowa Direct Care Worker Task Force *Recommendations for Establishing a Credentialing System for Iowa's Direct Care Workforce* May 2008

[11] *Ibid.*

[12] Reinhard, Susan C. *Consumer Directed Care and Nurse Practice Acts* Rutgers University Center for State Health Policy: September 2001

Expansion of Participant-Direction: Participant-directed services, where Medicaid participants choose their own direct care worker and do not work through an agency, are available in all Medicaid Home and Community-Based Services Waivers that serve adults. People who choose participant-direction (called the Consumer Choice Option in Iowa) often recruit family members or friends as their providers, which adds new direct care workers to the system.

Area Health Education Centers (AHECs): In 2007, the University of Iowa College of Nursing and Des Moines University received funding to establish regional AHECs to recruit health care workers in rural and urban underserved areas, expand clinical placement sites, and help retain medical professionals already serving in such areas. Prior to this funding, Iowa was one of only four states in the country not to have AHECs.[13] Presently, there are seven regional AHECs serving 95 of Iowa's 99 counties. Most regions are conducting needs assessments to determine what activities would best serve their areas, such as student mentoring by current health professionals, summer camps for people interested in health professions, or providing hospital tours for students.[14]

Iowa Health Workforce Center: This Center within IDPH staffs the Long-Term Access Advisory Council which coordinates, among other things, health care workforce resources in Iowa.[15] The Center provides online resources related to best practices for recruiting and retaining nurses and promoting health care careers.[16]

Primary Care Recruitment and Retention Endeavor (PRIMECARRE): Established by the legislature in 1994, this program funds the Iowa Loan Repayment Program, which provides grants to offset student loans for various primary care professionals. Those who have worked a minimum of two years in a public or non-profit entity within a federally-designated health professional shortage area (HPSA) can receive repayment awards ranging from $15,000 up to $30,000 per year.[17]

J-1 Visa Waiver Program: This enables foreign medical graduates to stay in the United States and practice in designated underserved areas. The IDPH states that it usually recruits as many doctors as possible, noting that "[t]he maximization of the program…shows that there is significant and ongoing need and difficulty in finding physicians who want to practice in needed specialties and geographic areas in Iowa."[18]

[13] University of Iowa College of Nursing *$2.6 Million Grant Will Improve Access to Care* August 29, 2007

[14] March 2009 phone conversations with Dr. David Plundo, Des Moines University AHEC Project Director; Dr. Kathleen Hanson, University of Iowa AHEC Principal Investigator; and Kristin Wentworth, Executive Director, Northeast Iowa AHEC

[15] Iowa Department of Public Health "Health and Long-Term Care Access Advisory Council" Undated

[16] Iowa Department of Public Health "Iowa Health Workforce Center" Undated

[17] Iowa Department of Public Health "Primary Care Recruitment and Retention Endeavor" Undated

[18] Iowa Department of Public Health, *The Future of Iowa's Health and Long-Term Care Workforce* December 2007

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Iowans are more likely to use nursing facility care than other Americans, and more likely to pay for their own care.[1] Iowa has made several changes in recent years to move the state's system toward home and community-based services. Since 2004, the state has increased use of community services and reduced nursing facility utilization.

Programs and Services

Table 4.1 on the following page shows long-term care expenditures in public programs for older adults with physical disabilities or complex medical needs. There were approximately $533 million in public expenditures for programs providing nursing facility care and alternative services for people age 60 or older in SFY 2008. Medicaid accounted for over 90% of these expenditures. The state Medicaid program spent an additional $34 million for services to adults age 60 or older with mental retardation as described in the Developmental Disabilities section of this report.

Total public expenditures for nursing facilities and alternatives increased an average of 3.7% per year between SFY 2004 and SFY 2008.[2] Real per capita spending, which adjusts data for inflation and the growth of the population age 60 and older, *decreased* by 0.5% per year.[3]

This spending decrease occurred during a time of expanding community services (See Table 4.2). The estimated total number of people served grew 3.7% per year. These data are estimates and double count individuals who receive services from multiple programs. For example, individuals may receive both Medicaid supports and services from the Department of Elder Affairs (DEA) such as nutrition services.[4] Programs serving older adults are further described below.

Medicaid Services

Medicaid nursing facility care accounted for almost three-fourths of public spending for older adults. Nursing facilities provide housing, meals, nursing, rehabilitation, and personal care services to individuals in a licensed residential setting. Options for people ages 60 to 64 are described in Section 5: Services for People with Physical Disabilities. For people age 65 and older, available Medicaid community services are the Elderly Waiver and Home Health Services.

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[1] Where possible, this report defines older adults as people age 60 and older, consistent with the Federal Older Americans Act.

[2] Data provided by Iowa Department of Elder Affairs; Iowa Department of Human Services, Iowa Medicaid Enterprise; and Iowa Department of Public Health, November and December 2008

[3] Thomson Reuters analysis based on inflation data from U.S. Department Of Labor, Bureau of Labor Statistics "Consumer Price Index for All Urban Consumers (CPI-U), Midwest Region" January 26, 2009 and population data from U.S. Census Bureau, Population Division "Annual Population Estimates, Estimated Components of Population Change, and Rates of the Components of Population Change for the United States, States, and Puerto Rico: April 1, 2000 to July 1, 2008" December 22, 2008

[4] The number of unduplicated participants in services funded through the Department of Elder Affairs jumped from 68,929 in 2004 to 107,896 in 2005, when Federal appropriations increased, and then declined slowly in subsequent years when funding was flat and inflation increased costs. People receiving congregate meals and other nutrition services accounted for most of the changes in total participants. (Data provided by the Iowa Department of Elder Affairs, November 2008)

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Table 4.1: Public Long-Term Care Expenditures for Iowans Age 60 and Older, SFY 2004 and SFY 2008

	2004	2008	Average Annual Percent Change	Percent of Total 2008 Expenditures
Medicaid				
Nursing Facility	$359,541,129	$393,090,899	2%	74%
Elderly Waiver	$32,325,957	$63,777,419	19%	12%
Home Health Nursing	$14,759,809	$19,832,016	8%	4%
Home Health Aide	$14,062,977	$15,505,633	2%	3%
Ill and Handicapped Waiver	$213,816	$266,426	6%	0.05%
Other Waivers*	$32,545	$163,253	50%	0.03%
Total Medicaid	**$420,936,234**	**$492,635,646**	**4%**	**92%**
Non-Medicaid				
Elder Affairs – Older Americans Act and State General Fund	$21,231,720	$22,794,250	2%	4%
Elder Affairs – Senior Living Program	$7,489,117	$7,725,609	1%	1%
Public Health – Home Care Aide	$6,902,251	$5,995,133	-3%	1%
Public Health – Nursing	$2,682,788	$2,321,740	-4%	0.4%
SSI State Supplement for Residential Care Facilities	$2,250,564	$1,544,499	-9%	0.3%
Total	**$461,492,674**	**$533,016,877**	**4%**	**100%**

Source:
Data provided in November and December 2008 by the Iowa Department of Human Services and Iowa Medicaid Enterprise; and Iowa Department of Public Health
Iowa General Assembly, Legislative Services Agency, Fiscal Services Division *2005 Session Fiscal Report* August 2005 and Iowa General Assembly, Legislative Services Agency, Fiscal Services Division *2008 Session Fiscal Report* September 2008 for DEA appropriations data

* Other Waivers is the sum of data from the Brain Injury, Physical Disability, and AIDS/HIV Waivers

The Elderly Waiver provides a variety of services for people age 65 or older who qualify for nursing facility care. The most common services are case management, personal emergency response system (PERS), home-delivered meals, consumer-directed attendant care, and homemaker services.[5] From SFY 2004 through SFY 2008, Elderly Waiver participants received waiver services for an average of 23 months.[6]

Home Health Services under Iowa's Medicaid State Plan serve Medicaid-eligible individuals regardless of age. Two home health services tend to provide long-term supports: nursing and home health aide services. Unlike an HCBS Waiver, a person does not need to meet nursing facility level of care criteria to qualify for services, but services must be medically necessary.[7]

[5] Data provided by Iowa Department of Human Services, Iowa Medicaid Enterprise November 2008

[6] Data provided by Iowa Department of Human Services, Iowa Medicaid Enterprise December 2008.

[7] Iowa Department of Human Services, Iowa Medicaid Enterprise *Medicaid Provider Manual: Home Health Services* July 1, 2000

Table 4.2: Number of Iowans Age 60 and Older Receiving Public Long-Term Care Services, SFY 2004 and SFY 2008

	2004	2008	Average Annual Percent Change
Medicaid			
Nursing Facility	18,011	17,378	-1%
Elderly Waiver	8,035	11,826	10%
Home Health Nursing	6,716	7,651	3%
Home Health Aide*	4,133	4,434	2%
Ill and Handicapped Waiver	61	77	6%
Other Waivers**	12	30	26%
Total Medicaid	**32,835**	**36,962**	**3%**
Non-Medicaid			
Elder Affairs – Unduplicated Total	68,929	80,908	4%
SSI State Supplement for Residential Care Facilities***	868	657	-9%
Total**	**102,632**	**118,527**	**4%**

Source:
Data provided in November and December 2008 by the Iowa Department of Elder Affairs and Iowa Department of Human Services, Iowa Medicaid Enterprise. Participant data from the Iowa Department of Public Health were not available for most years. An estimated 10,617 people were served in SFY 2006.

* Home Health Aide was not counted for Total Medicaid or for the overall Total to avoid double-counting these individuals. All home health aide participants must also receive home health nursing.
** Other Waivers is the sum of data from the Brain Injury, Physical Disability, and AIDS/HIV Waivers
*** 2005 data were used in the 2004 column for the SSI State Supplement because 2004 data for unduplicated participants were not available.
**** Total data may include a large number of duplicated participants, as people may receive both Medicaid and Aging Network services.

Non-Medicaid Services

A variety of supports outside the Medicaid program are described below:

Aging Network services: The Department of Elder Affairs (DEA) and regional Area Agencies on Aging provide a variety of services using grants from the Federal Administration on Aging, state General Fund Revenue appropriations, and appropriations from the Senior Living Trust Fund. More than 90% of people served received nutrition services, provided both at congregate dining sites or through home delivered meals. Other common services include case management, transportation, information and assistance, homemaker, chore, and caregiver support.

Public Health Home Care Aide and Nursing Services: The Iowa Department of Public Health, Bureau of Local Public Health Services manages state-funded services provided by county-based Local Boards of Health, or their contracted entities. Elderly Wellness includes home care aide services – assistance with activities of daily living by a personal care attendant – and nursing services. Although the appropriation is named Elderly Wellness,[8] people under age 60

[8] Iowa Department of Management *Iowa Budget Report: Fiscal Year 2010 Report* January 28, 2009

may also receive these services. Participants must be at risk of nursing facility care and unable to access these services through other public programs or private insurance.[9]

State Supplement for Supplemental Security Income (SSI): Iowa provides a few hundred dollars a month for SSI participants who need additional support because of functional impairments. The state supplements are described in Section 5: Services for People with Physical Disabilities because most participants are under age 65.

Other Supports Commonly Used by Older Adults

People who live in the community with long-term care needs often combine and coordinate many different supports to live independently. Older Iowans often receive supports from the following sources, which are described further in Appendix B:

- Income support from Social Security Old Age and Disability Insurance or Supplemental Security Income
- Health insurance, often from Medicare (for people who qualify, Medicaid covers Medicare coinsurance and may provide all health insurance if the person does not qualify for Medicare)
- Housing assistance – including rent and home modification loans - from the local public authority or Iowa Finance Authority
- Local senior transportation services
- Grocery payment from the Food Assistance program (formerly Food Stamps)
- Utility bill payment and weatherization assistance from the Low-Income Home Energy Assistance Program

Demographic and Utilization Trends

This section will first describe nursing facility utilization trends and then discuss trends for Medicaid expenditures, the largest funding source for nursing facility and other long-term care.

Nursing Facility Utilization

As shown in Chart 4.1, older Iowans are more likely to live in a nursing facility than other older Americans. On June 30, 2008, 23,437 Iowans age 65 or older (5% of the total population) lived in a nursing facility. By comparison, nursing facilities served only 4% of people age 65 or older in neighboring states and only 3% in the United States.

The higher rate of nursing facility utilization exists despite Iowa's lower disability rate among older adults (See Chart 1.3 in Section 1: Background). If Iowa's nursing facility utilization was the same as in neighboring states, 5,800 fewer people would have been in nursing facilities. If Iowa's nursing facility utilization reflected the national average, there would have been 9,700 fewer nursing facility residents on June 30, 2008.[10]

[9] Iowa Department of Public Health "Bureau of Local Public Health Services" Undated

[10] U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2008* Undated and U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008

Iowa State Profile Tool
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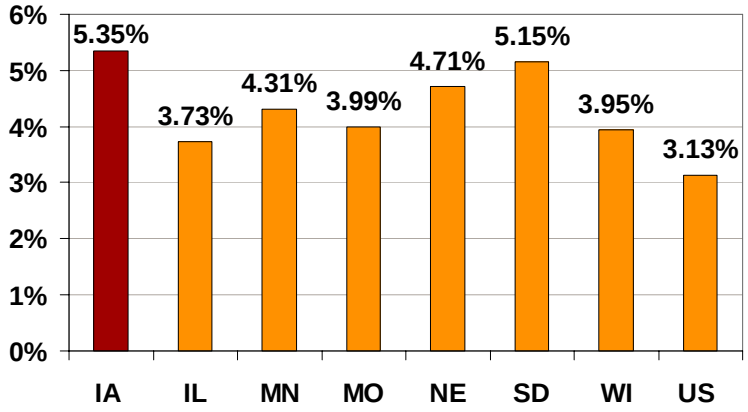
Chart 4.1: Percent of Residents Age 65 or Older in a Nursing Facility, June 30, 2008



Sources:
U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2008* Undated
U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008

Private payment of nursing facility care drives Iowa's high utilization. As shown in Chart 4.2, Iowans are more than 4 times more likely than other Americans to pay for their own nursing facility care, when controlling for the population age 65 or older. Iowa's utilization of the public programs most likely to pay for nursing facility care, Medicaid and Medicare, was closer to the national average.[11]

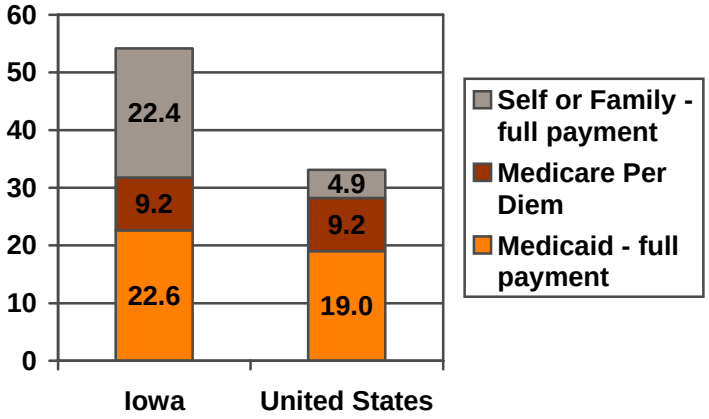
Iowa also has a relatively high number of nursing facility residents with low acuity or functional impairment. In the most comprehensive review of acuity in recent years, Vincent Mor and colleagues analyzed nursing facility assessment data for July 1, 2004 through June 30, 2005 (SFY 2005 for Iowa) from the continental 48 states. Iowa had the seventh highest percentage of residents who met their most inclusive definition of low acuity. Neighboring states also had high proportions of low-acuity residents, as shown in Table 4.3.[12]

[11] U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2008* Undated and U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008

[12] Mor, Vincent; Zinn, Jacqueline; Gozalo, Pedro; Feng, Zhanlian; Intrator, Orna; Grabowski, David C. "Prospects For Transferring Nursing Home Residents To The Community" *Health Affairs* 26:6 (2007): 1762-1771. This is based on the "broad" definition of low acuity, which was defined as people who needed no hands-on assistance with eating, toileting, transferring, and bed mobility and who do not have rehabilitation needs or clinically complex diagnoses that affect Medicare nursing facility reimbursement categories (called RUG-III categories). Iowa ranked fourth when using the narrow definition of low acuity.

Iowa State Profile Tool
Section 4: Services for Older Adults

Chart 4.2: Number of Nursing Facility Residents of All Ages per 1,000 State Population Age 65 and Older by Primary Payer, Second Quarter 2008



Categories do not include people who spend some of their income each month to qualify for Medicaid (spenddown).

Sources:
U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2008* Undated
U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008

Table 4.3: Percent of Long-Stay Nursing Facility Residents (90 days Or more) of All Ages with Low Care Need, SFY 2005

	All Residents	New Admissions
Iowa	16.1%	23.5%
South Dakota	14.5%	21.0%
Missouri	16.6%	20.2%
Wisconsin	16.2%	19.3%
Nebraska	12.8%	18.0%
Illinois	16.1%	17.2%
Minnesota	12.4%	15.3%
Continental 48 States	11.8%	13.5%

Source:
Mor, Vincent; Zinn, Jacqueline; Gozalo, Pedro; Feng, Zhanlian; Intrator, Orna; Grabowski, David C. "Prospects For Transferring Nursing Home Residents To The Community" *Health Affairs* 26:6 (2007): 1762-1771. Data are based on the "broad" definition of low acuity, which was defined as people who needed no hands-on assistance with eating, toileting, transferring, and bed mobility and who do not have rehabilitation needs or clinically complex diagnoses that affect Medicare nursing facility reimbursement categories (called RUG-III categories).

For new admissions, Iowa ranked third in low-acuity residents among new admissions, indicating that a significant minority of people entering nursing facilities (23.5%) had needs that are often met with in-home services or in community residential settings like assisted living.[13]

In recent years overall nursing facility utilization decreased, and the number of private pay and Medicaid-funded residents also declined (See Table 4.4). However, the number of Medicare-funded admissions increased. Medicare pays for nursing facility care only after a hospital admission and for a limited time. The increase in residents with Medicare payment indicates that facilities are providing more short-term rehabilitative care.

Table 4.4: Number of Nursing Facility Residents of All Ages, 2004 – 2008

	June 30, 2004	June 30, 2008	Average Annual Percent Change
All Residents	26,986	25,475	-1.4%
Medicaid – Full Payment	11,064	9,927	-2.7%
Self or Family – Full Payment	10,905	9,802	-2.6%
Medicare Per Diem	3,449	4,055	4.1%

These categories do not include people who spend some of their income each month to qualify for Medicaid (spenddown).

Sources:
U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2008* Undated
U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2004* Undated

Medicaid Expenditures

Despite Iowa's high nursing facility utilization, Iowa's per capita spending for Medicaid nursing facility care and alternatives is 10% below the national average ($203 per capita in Iowa and $226 per capita nationwide).[14] Two factors explain the relatively low spending: high private pay nursing facility utilization described above and relatively low nursing facility rates. Two studies of state Medicaid reimbursement rates listed Iowa among the ten lowest states in nursing facility reimbursement, although some neighboring states such as Illinois and Missouri have lower rates.[15]

Since 2004, Iowa has increased long-term care spending for both nursing facility and home and community-based services (See Chart 4.3). For both types of services, Iowa's expenditures have risen a little more than the national average. Consistent with national trends, expenditures have grown more for community services than for nursing facilities.[16] As described earlier in

[13] *Ibid.*

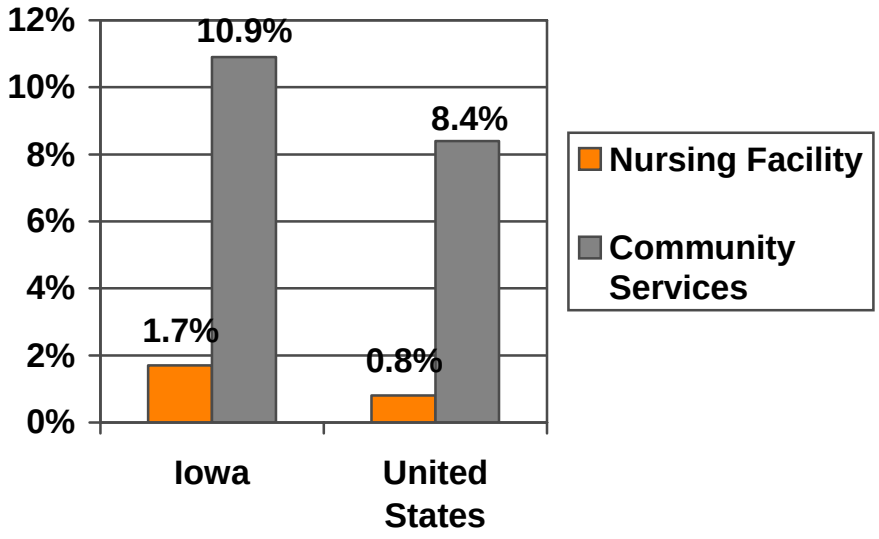
[14] Burwell, Brian; Sredl, Katherine; and Eiken, Steve *Medicaid Long-Term Care Expenditures in FFY 2007* Thomson Reuters September 28, 2008. Iowa expenditures included in this calculation are nursing facility care, home health care, and three HCBS waivers (Elderly Waiver, Ill and Handicapped Waiver, and Physical Disability Waiver)

[15] Eljay, LLC *A Report on Shortfalls in Medicaid Funding for Nursing Home Care* American Health Care Association: October 2008 and Grabowski, David C.; Feng, Zhanlian; Intrator, Orna; Mor, Vincent "Medicaid Nursing Home Payment and the Role of Provider Taxes" *Medical Care: Research and Review* 65(4): 514-527. August 2008

[16] Burwell, Brian; Sredl, Katherine; and Eiken, Steve *Medicaid Long-Term Care Expenditures in FFY 2007* Thomson Reuters September 28, 2008

this section, overall spending declined 0.5% per year, when adjusting for inflation and population growth.

Chart 4.3: Average Annual Increase in Medicaid Long-Term Care Spending for Older Adults and People with Physical Disabilities, Federal Fiscal Years 2004 – 2007



So

urce:
Burwell, Brian; Sredl, Katherine; and Eiken, Steve *Medicaid Long-Term Care Expenditures in FFY 2007* Thomson Reuters September 28, 2008.

Only sixteen states offer waivers specifically for older adults, with a minimum age of 60 or greater. Of these states, Iowa had one of the lowest average spending rates per participant in 2005, the most recent year available. Iowa was above average in number of participants.[17]

Table 4.5: Number of Participants in HCBS Waivers for Older Adults (minimum age 60 or older), 2005

	Number of Participants per 1000 Population Age 65+	Expenditures per Participant
Minnesota	27.5	$8,259
Illinois	19.1	$4,279
Iowa	21.0	$4,132
South Dakota	8.3	$4,659

Source:
Ng, Terence; Harrington, Charlene; and O'Malley, Molly *Medicaid Home and Community-Based Service Programs: Data Update* Kaiser Family Foundation: December 2008
Iowa data based on data received from Iowa Department of Human Services, Iowa Medicaid Enterprise and U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008

[17] Ng, Terence; Harrington, Charlene; and O'Malley, Molly *Medicaid Home and Community-Based Service Programs: Data Update* Kaiser Family Foundation: December 2008

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System Components Associated with Rebalancing

The remainder of this section describes the extent to which Iowa's system of supports for older adults includes eight system components that have been previously identified in states that have rebalanced their long-term support system, i.e., reduced institutional utilization and increased access to home and community-based services. The components are defined in the introduction of this report.

Consolidated State Agency

No single agency in Iowa coordinates planning and service delivery for older adults. Currently, four state agencies have various roles described in Section 2: System Administration and Management:

- The Department of Human Services (DHS), Iowa Medicaid Enterprise
- The Department of Elder Affairs (DEA)
- The Iowa Department of Public Health (IDPH)
- The Department of Inspections and Appeals (DIA)

The Senior Living Coordinating Unit, described in Section 2: System Administration and Management, is responsible for long-term care planning and includes leadership from all four agencies, as well as two citizen members and ex-officio legislative members.[18] Each agency maintains its independent role and policy development is often, but not necessarily, connected to planning.

Single Access Point

Older Iowans have multiple contacts for services, which can vary by funding source and service. In addition, the functional eligibility assessment varies based on funding source and service. A uniform assessment could reduce duplicate assessments for similar services (e.g., if a person needs home health and waiver services), saving staff time and enabling people to receive services more quickly.

There is also no clear resource to help people navigate the service system, to help both public and privately paying individuals learn about the full range of services that are available and address issues that may arise when obtaining and coordinating services. Information and assistance is part of the mission of Area Agencies on Aging, but it is not clear whether they have the capacity to provide the level of assistance some people need on a large scale. LifeLongLinks (http://www.lifelonglinks.org) is an also an important resource. LifeLongLinks is an online portal to multiple referral sources such as Iowa 2-1-1, Compass, and Iowa's Association of Area Agencies on Aging. Iowa's Aging and Disability Resource Center (ADRC) grant has helped improve the coordination of LifeLongLinks and the other resources, although funding for sustainability of these efforts is not certain.

Institutional Supply Controls

Iowa has a Certificate of Need requirement, whereby all additional nursing facility beds must be reviewed by the State Health Facilities Council, whose members are appointed by the

[18] Iowa Code, Section 231.58

Governor. The Council can use a formula in regulation as guidance, but can consider other factors including the availability of other long-term care services. The formula has a relatively high assumption of need for nursing facility beds (in rural areas, 6.6% of 65+ population plus 0.1% of population under 65; a smaller percentage in urban areas).[19]

For several years, Iowa took a more proactive approach to reducing institutional supply: awarding grants to facilities that agreed to provide home and community-based services such as respite, assisted living, and adult day care.[20] Between SFY 2001 and SFY 2005, $54.6 million was appropriated for Nursing Facility Conversion and Long-Term Care Service grants.[21]

Between SFY 2004 and SFY 2008, nursing facility capacity has declined by 0.9% per year (from 31,733 to 30,556),[22] while capacity has increased slightly nationwide.[23] Market forces and individual provider decisions have contributed to this decline, in addition to the state policies described above.

Transition from Institutions

Iowa has no statewide initiative to assist nursing facility residents in moving to other settings. Stakeholders report an increase in short-term admissions to nursing facilities, as facilities provide more Medicare-funded rehabilitative services. The change to a case-mix reimbursement system early in this decade also may have encouraged more short-term admissions, as facilities received less payment for people with lower needs.

All of Iowa's waivers serving adults offer community transition services, which can pay for items people need to set up a household when transitioning after a long institutional stay (e.g., security deposit, furniture), which can make it easier for people to move if they choose to do so.

Continuum of Residential Options

Assisted living is an increasingly available community residential option for older Iowans. Between 2004 and 2008, the number of licensed programs increased 51% and the number of beds almost doubled (See Table 4.6). During the same time period, other licensed facilities decreased.[24] Assisted living capacity has increased even more, up 91% to 15,739 beds.[25] By 2008, Iowa's supply of assisted living beds – controlling for the older adult population – was greater than one estimate of the national average in 2007, the latest data available. Iowa had 36 beds per 1,000 people age 65 or older, compared to a national average of 26.[26]

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[19] Iowa Administrative Code, Chapter 203.5

[20] House File 655, chapter 64, section 249H.6, subs. 5, 79th General Assembly (2001)

[21] Iowa General Assembly, Legislative Services Agency, Fiscal Services Division *2006 Session Fiscal Report* July 2006

[22] Data provided by the Iowa Department of Inspections and Appeals, November 2008

[23] American Health Care Association *Nursing Facility Beds by Certification Type: CMS OSCAR Data Current Surveys, December 2008*

[24] Data provided by Iowa Department of Inspections and Appeals November 2008 except for 2004 assisted living data, which was from Mollica, Robert; Sims-Kastelein, Kristin; and O'Keeffe, Janet *Residential Care and Assisted Living Compendium: 2007* November 30, 2007

[25] Ibid.

[26] Thomson Reuters analysis of data provided by Iowa Department of Inspections and Appeals November 2008; Mollica, Robert; Sims-Kastelein, Kristin; and O'Keeffe, Janet *Residential Care and Assisted Living Compendium: 2007* November 30, 2007; and U.S. Census Bureau, Population Division "Annual Estimates of the Resident

Table 4.6: Change in Number of Residential Long-Term Care Facilities, 2004 – 2008

	Facilities, 2004	Facilities, 2008	Beds, 2004	Beds, 2008
Nursing Facility	418	412	31,733	30,556
Assisted Living (including dementia units)	184	278	8,246	15,739
Residential Care Facility	124	107	4,414	3,861

Source:
All data provided by the Iowa Department of Inspections and Appeals except for 2004 assisted living data, which was from Mollica, Robert; Sims-Kastelein, Kristin; and O'Keeffe, Janet *Residential Care and Assisted Living Compendium: 2007* November 30, 2007

While private pay individuals are particularly driving the assisted living expansion, Medicaid utilization was also increasing. From SFY 2004 to SFY 2008, the number of Elderly Waiver participants receiving Consumer Directed Attendant Care (CDAC) services through an assisted living provider nearly tripled from 315 to 933.[27] In SFY 2008, costs associated with CDAC services provided by assisted living programs were more than 10% of all Elderly Waiver spending, nearly $6.8 million.[28]

For several years, the Iowa Finance Authority (IFA) and other state agencies have worked to expand access to affordable assisted living. IFA has worked with developers and both public and private financing sources to create an Affordable Assisted Living program. In addition, IFA developed toolkits to help developers, program operators, and potential consumers learn more about assisted living. Since the program's inception, at least twenty-one affordable assisted living facilities have been developed.[29]

HCBS Infrastructure

In addition to the Affordable Assisted Living program mentioned earlier, the HCBS Revolving Fund Loan provides help for facilities that will provide adult day services, respite, and other services for older adults.[30] In earlier years, the Nursing Facility Conversion Grants described as part of "Institutional Supply Controls" also provided a means to improve the infrastructure for community supports.

Participant Direction

Policies in place regarding participant-directed services are the same for all HCBS waivers for adults and are described in Section 5: Services for People with Physical Disabilities.

Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008

[27] Data provided by Iowa Department of Human Services, Iowa Medicaid Enterprise November 2008

[28] *Ibid.*

[29] Iowa Finance Authority, "Iowa Affordable Assisted Living Directory" Undated

[30] Iowa Finance Authority, "IFA Programs" Undated

Quality Management

The Department of Inspections and Appeals (DIA), Health Facilities Division licenses and/or certifies several types of long-term care providers, including nursing facilities, assisted living facilities, home health agencies, residential care facilities, and adult day care centers. DIA monitors nursing facilities and home health agencies according to Federal Medicare guidelines, which include an on-site review every 15 months, with an average of once per year. As is common for licensing agencies, DIA does not have sufficient staff to monitor other providers on-site on an annual basis. These providers may receive one monitoring visit over several years. For all providers, DIA will conduct additional monitoring when warranted by concerns regarding quality of care such as a report of substandard care. Providers of these services cannot operate without licensure (for nursing facilities, home health agencies, and residential care facilities) or certification (for assisted living and adult day care).

In addition, each funding source has its own quality management process. The Department of Human Services, Iowa Medicaid Enterprise is currently revising the quality management process for Medicaid home and community-based services waivers – such as the Elderly Waivers – to reflect Federal specifications released in 2008 to improve quality assurance and improvement. The new specifications require states to use aggregate measures to indicate whether a waiver meets the six requirements specified in Federal regulations, including representative samples where sampling is used.[31] Data collection methods include:

- Waiver service utilization and cost data
- A survey of waiver participants regarding their experience in the waiver
- Desk reviews of service plans
- Developing an incident management system to monitor trends in incidents that may indicate abuse and neglect
- Periodic re-enrollment of providers to ensure they continue to meet provider requirements

The state contracts with Iowa State University for some of these quality assurance activities. Whenever requirements are not met, the state will require the responsible party to take corrective action and will monitor whether the corrective action has taken place.[32] In 2008, Iowa Medicaid Enterprise required all waiver providers to complete a self-assessment to document their progress toward developing requested policies and procedures. This self-assessment was followed by extensive provider training to improve provider performance.

For Aging Network and Public Health services, the state agency monitors each local agency managing the programs (Area Agencies on Aging and Local Boards of Health, respectively). The Iowa Department of Elder Affairs is revising its monitoring process for Area Agencies on Aging. The plan calls for a more coordinated annual visit to each AAA and plans to use site visit time efficiently by conducting a review of records related to programs and grants managed by that AAA.[33] The Iowa Department of Public Health reviews local records to ensure the person has received appropriate services and to ensure other funding sources (e.g., Medicare,

[31] U.S. Centers for Medicare & Medicaid Services *Application for a 1915(c) Home and Community-Based Services Waiver [Version 3.5]: Instructions, Technical Guide and Review Criteria* January 2008

[32] Iowa Department of Human Services, Iowa Medicaid Enterprise *Draft 1915(c) Version 3.5 Elderly Waiver Workplan* January 15, 2009

[33] Iowa Department of Elder Affairs *Draft Monitoring Plan* February 2, 2009

Medicaid) were pursued before using public health funding for nursing or home care aide services.

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Iowa has significantly expanded home and community-based services in recent years for adults with physical disabilities, a population that several stakeholders said has historically been underserved. Nursing facility utilization continued to increase, however. The rise in nursing facility utilization is consistent with national trends[1] and may reflect rising disability rates found nationally for people age 18 – 64.[2]

When compared to other states, Iowa provides home health agency services, including skilled nursing and home health aides, to a large number of people. Many states use less medically involved services such as personal care or attendant care to serve this population at a lower cost and in a manner that encourages participant independence.

Programs and Services

Table 5.1 on the following page shows long-term care expenditures in public programs for adults with physical disabilities. There were approximately $133 million in public expenditures for long-term care for age 18 through 59 with physical disabilities in SFY 2008. Medicaid, especially nursing facility care, accounted for almost 90% of spending. Expenditures had increased an average of 6.5% per year since SFY 2004.[3] Real per capita spending, which adjusts data for inflation and population growth, grew 2.7% per year.[4] As Table 5.2 illustrates, the total number of people served grew 1.7% during this time to over 17,000 individuals.[5] This figure is an estimate and double counts individuals who receive services in multiple programs. Programs serving adults with physical disabilities are further described below.

Medicaid Services

Depending on one's condition and circumstances, an adult with a physical disability may be eligible for several service options as a substitute to nursing facility care, the primary institutional service (which was described in Section 4: Services for Older Adults). Four Medicaid home and community-based services (HCBS) waivers serve adults with physical disabilities, and home health benefit also provides long-term care. Medicaid community services are described below in order of number of participants:

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[1] U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2004* Undated and U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2008* Undated

[2] Adams, PF; Barnes, PM; Vickerie, JL *Summary Health Statistics for the U.S. Population: National Health Interview Survey, 2004* U.S. Centers for Disease Control and Prevention, National Center for Health Statistics: Vital Health Statistics 10(238) November 2008 and Adams, PF; Barnes, PM *Summary Health Statistics for the U.S. Population: National Health Interview Survey, 2004* U.S. Centers for Disease Control and Prevention, National Center for Health Statistics: Vital Health Statistics 10(229) August 2006

[3] Data provided between November 2008 and March 2009 by the Iowa Department of Human Services, Iowa Medicaid Enterprise; the Iowa Department of Human Services, Children and Family Services; and Iowa Vocational Rehabilitation Services

[4] Thomson Reuters analysis based on inflation data from U.S. Department Of Labor, Bureau of Labor Statistics "Consumer Price Index for All Urban Consumers (CPI-U), Midwest Region" January 26, 2009 and population data from U.S. Census Bureau, Population Division "Annual Population Estimates, Estimated Components of Population Change, and Rates of the Components of Population Change for the United States, States, and Puerto Rico: April 1, 2000 to July 1, 2008" December 22, 2008

[5] Data provided between November 2008 and March 2009 by the Iowa Department of Human Services, Iowa Medicaid Enterprise; the Iowa Department of Human Services, Children and Family Services; and Iowa Vocational Rehabilitation Services

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Table 5.1: Public Long-Term Care Expenditures for Iowans Age 18 – 59 with Physical Disabilities, SFY 2004 and SFY 2008

	2004	2008	Average Annual Percent Change	Percent of Total 2008 Expenditures
Medicaid				
Nursing Facility	$54,204,029	$68,227,178	6%	51%
Brain Injury Waiver	$5,454,163	$13,748,096	26%	10%
Home Health Nursing	$9,040,604	$12,190,953	8%	9%
Home Health Aide	$8,093,964	$10,489,421	7%	8%
Ill and Handicapped Waiver	$6,393,838	$10,019,277	12%	8%
Physical Disability Waiver	$1,644,580	$3,572,416	21%	3%
AIDS/HIV Waiver	$325,493	$478,938	10%	0.4%
Total Medicaid	**$85,156,672**	**$118,726,280**	**9%**	**89%**
Non-Medicaid				
Vocational Rehabilitation*	$4,787,898	$3,740,193	-6%	3%
SSI State Supplement for In-Home Health Related Care**	$8,225,610	$7,634,503	-2%	6%
SSI State Supplement for Residential Care Facilities**	$5,377,185	$3,344,015	-11%	3%
Total	**$103,547,364**	**$133,444,991**	**6.5%**	**100%**

Source:
Data provided between November 2008 and March 2009 by the Iowa Department of Human Services, Iowa Medicaid Enterprise; the Iowa Department of Human Services, Children and Family Services; and Iowa Vocational Rehabilitation Services

* Vocational Rehabilitation spending is an estimate based on the percentage of participants with physical impairments was multiplied by total expenditures
** Data for the Supplemental Security Income State Supplements for In-Home Health Related Care (IHHRC) and for Residential Care Facilities (RCF) include expenditures for people with other conditions. For IHHRC, data were provided for all participants regardless of age. For RCF, data were available for people age 18 – 59, but not available by type of disability.

- Home Health Services under Iowa's Medicaid State Plan serve Medicaid-eligible individuals regardless of age. Two home health services tend to provide long-term supports: nursing and home health aide services. Home health provides the only Medicaid-funded option for people who are on a waiting list for a Medicaid home and community-based services waiver. Unlike a HCBS Waiver, a person does not need to meet nursing facility level of care criteria to quality for services, but services must be medically necessary.[6]

- The Ill and Handicapped Waiver provides a variety of services for children and adults who qualify for nursing facility care. Most people enter this waiver during childhood, but approximately half of participants are adults age 18 or older. Adults are only eligible if they are not financially eligible for Supplemental Security Income benefits. People who meet SSI financial eligibility criteria

[6] Iowa Department of Human Services, Iowa Medicaid Enterprise *Medicaid Provider Manual: Home Health Services* July 1, 2000

instead receive services in one of the other waivers.[7] The most common service in this waiver was respite, which accounted for $7.5 million of the $19.3 million in expenditures during SFY 2008 (for people of all ages). Other common services were home delivered meals, homemaker, Consumer Directed Attendant Care (CDAC) and Personal Emergency Response System (PERS). 1489 individuals of all ages were on the waiting list as of December 2008 with anticipation of a one year delay from application to waiver services provision.[8]

Table 5.2: Number of Iowans Receiving Public Long-Term Care Services Targeted to People Age 18 – 59 with Physical Disabilities, SFY 2004 and SFY 2008

	2004	2008	Average Annual Percent Change
Medicaid			
Nursing Facility	2,485	2,963	4%
Brain Injury Waiver	372	822	19%
Home Health Nursing	4,689	5,678	5%
Home Health Aide*	1,416	1,704	5%
Ill and Handicapped Waiver	1,034	1,355	7%
Physical Disability Waiver	446	815	16%
AIDS/HIV Waiver	48	53	3%
Total Medicaid	**9,074**	**11,686**	**7%**
Non-Medicaid			
Vocational Rehabilitation**	3,505	2,622	-6%
SSI State Supplement for In-Home Health Related Care***	1,669	1,455	-3%
SSI State Supplement for Residential Care Facilities***	2,253	1,871	-9%
Total	**16,501**	**17,634**	**1.7%**

Source:
Data provided between November 2008 and March 2009 by the Iowa Department of Human Services, Iowa Medicaid Enterprise; the Iowa Department of Human Services, Children and Family Services; and Iowa Vocational Rehabilitation Services

* Home Health Aide was not counted for Total Medicaid or for the overall Total to avoid double-counting these individuals. All home health aide participants must also receive home health nursing.
** For Vocational Rehabilitation, 2005 data were used for the 2004 column because 2004 data for unduplicated participants were not available.
*** Data for the Supplemental Security Income State Supplements for In-Home Health Related Care (IHHRC) and for Residential Care Facilities (RCF) include expenditures for people with other conditions. For IHHRC, data were provided for all participants regardless of age. For RCF, data were available for people age 18 – 59, but not available by type of disability. 2005 data were used for the 2004 column because 2004 data for unduplicated participants were not available.

[7] Data provided by Department of Human Services, Iowa Medicaid Enterprise November 2008

[8] Iowa Department of Human Services, Iowa Medicaid Enterprise *2008 Monthly Slot and Waiting List Data* December 2008

- The Brain Injury Waiver serves individuals with a brain injury due to accident or illness.[9] The waiver offers a comprehensive list of services ranging from in-home to residential options. The most common services are case management, supported community living, and respite. Supported community living is defined as assistance to help people meet daily living needs and is provided in the person's home. The average wait from time of application to receipt of services is one year with approximately 578 individuals of all ages on the waiting list as of December 2008.[10]

- The Physical Disability Waiver serves individuals between the ages of 18 and 64 who qualify for nursing facility care and do not qualify for the other waivers, which provide more robust benefit packages. The consumer or representative must be able to hire, direct and fire the services providers to qualify for the waiver.[11] Only four services are available: consumer directed attendant care (CDAC), personal emergency response system (PERS), home or vehicle modification and specialized equipment. Approximately 1000 individuals are on the PD waiting list as of December 2008 with a one year timeframe from application to services provision.[12]

- The AIDS-HIV Waiver serves individuals regardless of age with a diagnosis of AIDS or an HIV infection. Only 53 people used this waiver in SFY 2008. The most commonly used services are CDAC and home delivered meals, but a comprehensive array of other services are available. This waiver does not have a waiting list.[13]

Non-Medicaid Long-Term Support Services

A variety of supports outside of the Medicaid program are described below.

Vocational Rehabilitation: The Vocational Rehabilitation program helps adults and youth with disabilities prepare for and obtain employment. The Federal Department of Education, Rehabilitation Services Administration (RSA) provides 78.7% of Vocational Rehabilitation funding and the state provides the rest.[14] In SFY 2005, Iowa Vocational Rehabilitation Services (IVRS) reduced its contracting for difficult to serve individuals to increase efficiency. In the subsequent three years, IVRS reported a 14% per year increase in number of individuals placed in employment (from 1438 to 2148) while incurring a substantial decrease in funding from $13,999,702 in SFY 2005 to $10,716,884 in SFY 2008 (6.5 percent per year).[15] At the same time, some stakeholders reported IVRS is not able to serve some individuals who are particularly difficult to serve because of high functional impairments.

[9] Iowa Department of Human Services, Iowa Medicaid Enterprise *Brain Injury Waiver Information Packet* Last revised March 10, 2006

[10] Iowa Department of Human Services, Iowa Medicaid Enterprise *2008 Monthly Slot and Waiting List Data* December 2008

[11] Iowa Department of Human Services, Iowa Medicaid Enterprise *Physical Disability Waiver Information Packet* Last revised March 10, 2006

[12] Iowa Department of Human Services, Iowa Medicaid Enterprise *2008 Monthly Slot and Waiting List Data* December 2008

[13] *Ibid.*

[14] Iowa Vocational Rehabilitation Services "About Vocational Rehabilitation Services" Undated

[15] Data provided by Iowa Vocational Rehabilitation Services November 2008

Independent Living Services: IVRS also administers Federal independent living grants from RSA. IVRS distributes the Federal grants – and $250,000 in state dollars starting in SFY 2008 – to seven Centers for Independent Living (CILs). The seven CILs provide the Federally defined core services of information and referral, peer support, independent living skills training, and individual and systems advocacy. IVRS provides these services in several counties where CILs are not operational.

State Supplement for Supplemental Security Income (SSI): Iowa provides a few hundred dollars a month for certain SSI participants with a need for long-term supports. Up to $289.45 per month in state funds are available for people in licensed residential care facilities that provide room, board, and personal assistance but do not provide nursing care. When added to Federal SSI, the total payment was $926.45 in 2008. The provider receives most of the payment for care-related expenses, but the resident is able to keep a personal needs allowance of $91 for personal expenses. Up to $480.55 per month in state funds is available for people who need care in their own homes (called in-home health related care), for a total payment of $1,117.55 for an individual. Payment is based on the actual cost of care necessary up to the maximum.[16]

Public Health Home Care Aide and Nursing Services: These services are described in Section 4: Services for Older Adults and primarily serve individuals over 60. However, every Iowan is eligible for these services if an assessment verifies the need and resources are available, with priority given to low income individuals.

Other Supports Commonly Used by People with Physical Disabilities

People who need long-term care often need to combine and coordinate many different supports to live independently. Adults with physical disabilities often receive supports from the following sources, which are described further in Appendix B:

- Income support from Social Security Disability Insurance or Supplemental Security Income
- Health insurance, often from Medicare (Medicaid covers Medicare coinsurance and may provide all health insurance if the person does not qualify for Medicare)
- Housing assistance – including rent and home modification loans - from the local public authority or Iowa Finance Authority
- Local paratransit services
- Grocery payment from the Food Assistance program (formerly Food Stamps)
- Utility bill payment and weatherization assistance from the Low-Income Home Energy Assistance Program
- Loans to purchase assistive technology from the IowaAble Foundation

Demographic and Utilization Trends

Iowans under age 65 were slightly more likely to use nursing facility care than other Americans under age 65 in 2008, but less likely to use nursing facilities than residents of three nearby states (See Table 5.3). The number of nursing facility residents under age 65 has increased 5% since 2004 (from 1,962 on June 30, 2004 to 2,063 on June 30, 2008). At the same time, the

[16] U.S. Social Security Administration *State Assistance Programs for SSI Recipients, January 2008* 2008

national increase was 8%.[17] The national increase in nursing facility use is consistent with a national increase in the disability rate for adults under age 65. The proportion of Americans age 18 – 64 in the community who needed help in activities of daily living increased from 0.9% of the population in 2004 to 1.0% in 2007.[18] Reliable state-level disability prevalence data over time is not available because the source we used for state-level disability prevalence, the U.S. Census Bureau's American Community Survey, has changed its methodology in recent years.

Table 5.3: Nursing Facility Residents per 1,000 Residents Age 18 - 64, 2004 and 2007

	NF Residents Under Age 65 per 1,000 population, June 30, 2004	NF Residents Under Age 65 per 1,000 population, June 30, 2008*
Illinois	1.40	1.50
Missouri	0.99	1.17
Nebraska	0.85	0.90
Iowa	**0.78**	**0.81**
South Dakota	0.72	0.77
United States	0.70	0.74
Minnesota	0.68	0.57
Wisconsin	0.57	0.56

* 2008 data on residents were compared to 2007 population data, because 2007 was the most recent year with population estimates by age

Sources:
U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for population age 65 or older
U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2008* Undated for June 30, 2008 nursing facility data
U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2004* Undated for June 30, 2004 nursing facility data

Data from 2006 indicate that Iowans under age 65 were about as likely to use Medicaid-funded nursing facility care as adults under age 65 in other states (See Table 5.4).[19] However, between SFY 2006 and SFY 2008 the number of Medicaid-funded nursing facility residents age 18 to 64 increased 16%. Similar national data are not available and it is possible Iowans in this age group are now more likely to use Medicaid for nursing facility care.

[17] U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for population; U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2008* Undated and U.S. Centers for Medicare & Medicaid Services *Minimum Data Set 2.0 Active Resident Information Report: 2nd Quarter 2004* Undated for nursing facility data

[18] Adams, PF; Barnes, PM; Vickerie, JL *Summary Health Statistics for the U.S. Population: National Health Interview Survey, 2007* U.S. Centers for Disease Control and Prevention, National Center for Health Statistics: Vital Health Statistics 10(238) November 2008 and Adams, PF; Barnes, PM *Summary Health Statistics for the U.S. Population: National Health Interview Survey, 2004* U.S. Centers for Disease Control and Prevention, National Center for Health Statistics: Vital Health Statistics 10(229) August 2006.

[19] U.S. Centers for Medicare & Medicaid Services *Medicaid Statistical Information System State Summary Datamart* Data obtained December 2008

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Table 5.4: Medicaid Nursing Facility Residents per 1,000 State Residents Age 21 – 64: Daily Average in Federal Fiscal Year 2006

	Age 21 – 44	Age 45 – 64
Illinois	0.65	3.41
Missouri	0.48	2.62
Nebraska	0.33	2.18
South Dakota	0.25	1.89
Iowa	**0.25**	**1.66**
United States	*0.23*	*1.65*
Wisconsin	0.14	1.24
Minnesota	0.14	1.17

Source:
U.S. Centers for Medicare & Medicaid Services *Medicaid Statistical Information System State Summary Datamart* Data obtained December 2008

Iowa serves a relatively high number of people with physical disabilities and brain injuries and spends a relatively low amount per participant in its Medicaid home and community-based services waivers. Data from the most recent state comparison sources are in Table 5.5. When compared to the 25 states with waivers just for physical disabilities, Iowa was fifth in 2005 in the number of participants relative to state population. Among 23 states with waivers for people with brain injuries, Iowa was second in 2006 in the number of participants. In both cases, Iowa was third to last in average expenditures per participant. The exception to the rule is the small waiver for people with HIV/AIDS, which serves a relatively small number of people (close to the median among the states) and has relatively high expenditures per person.[20]

Table 5.5: Comparison of Iowa HCBS Waivers for People with Physical Disabilities or Brain Injuries, Most Recent Data Available

	Number of States	Rank of Iowa in Number of Participants per 100,000	Rank of Iowa in Expenditures per Participant
Brain Injury (2006 data)	23	2nd (27.8)	22nd ($13,192)
HIV/AIDS (2005 data)	15	12th (1.4)	6th ($7,312)
Physical Disability (2005 data: Ill & Handicapped and Physical Disability Waivers)	25	5th (89.8)	23rd ($6,367)

Source:
Ng, Terence; Harrington, Charlene; and O'Malley, Molly *Medicaid Home and Community-Based Service Programs: Data Update* Kaiser Family Foundation: December 2008 for physical disability and HIV/AIDS waivers
Data received from Iowa Department of Human Services, Iowa Medicaid Enterprise in November 2008 for Iowa physical disability waivers
Hendrickson, Leslie and Blume, Randall *Issue Brief: A Summary of Medicaid Brain Injury Programs* Rutgers Center for State Health Policy: March 2008 for brain injury waivers (2006 data)

[20] Ng, Terence; Harrington, Charlene; and O'Malley, Molly *Medicaid Home and Community-Based Service Programs: Data Update* Kaiser Family Foundation: December 2008 for physical disability and HIV/AIDS waivers; Iowa Department of Human Services, Iowa Medicaid Enterprise for Iowa physical disability waivers; and Hendrickson, Leslie and Blume, Randall *Issue Brief: A Summary of Medicaid Brain Injury Programs* Rutgers Center for State Health Policy: March 2008 for brain injury waivers.

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System Components Associated with Rebalancing

The remainder of this section describes the extent to which Iowa's system of supports for persons with physical disabilities includes eight system components that have been previously identified in states that have rebalanced their long-term support system, i.e., reduced institutional utilization and increased access to home and community-based services. The components are defined in the introduction of this report.

Consolidated State Agency

There is no discreet state agency or commission responsible for planning and service delivery for people with physical disabilities. The Department of Human Services, Iowa Medicaid Enterprise (IME), is close to a consolidated state agency because it administers most publicly funded services. IME has worked to bring all parties together to plan systems improvements (not just for people with physical disabilities), using funding from a series of Real Choice Systems Change grants from the Centers for Medicare & Medicaid Services.

Additional entities have planning responsibilities that affect people with physical disabilities. The Senior Living Coordinating Unit provides a forum for agencies to embrace a common vision and jointly plan for systems improvement with an emphasis on HCBS services. While the SLCU focuses on services for older adults, people with physical disabilities often use the same services (e.g., nursing facility, home health, and attendant care). In a few regions, AAAs and CILs have worked together to improve services for both populations. The Brain Injury Council has developed a long range plan for people with brain injuries, proposing a coordinated approach among multiple agencies.[21]

Single Access Point

The contact for services varies based on funding source and service, and some stakeholders described the process for obtaining services as frustrating. For nursing facility and home health services, the first assessment is conducted by the provider. For Medicaid services, the first contact is often a financial eligibility worker,[22] who may not be aware of options from other funding sources. There is no clear contact person to ensure a person is aware of all options – regardless of funding source – before choosing services.

Three information and assistance resources are available for people with disabilities who request assistance. Iowa COMPASS provides statewide information and referral for persons with disabilities and their families. The service is provided by the Center for Disabilities and Development at the University of Iowa Children's Hospital. Information is available online or through phone contact. People can also receive information and assistance by calling 2-1-1, which is administered by the United Way and funded by the Department of Human Services. Finally, information and assistance is one of the core services of Centers for Independent Living (CILs) and available from Iowa Vocational Rehabilitation Services where CILs are not available.

[21] Iowa Department of Public Health *Iowa Plan for Brain Injury: 2007 – 2010* 2007

[22] Iowa Department of Human Services, Iowa Medicaid Enterprise "LTC Facilities: What are the steps to follow for the new Long Term Care Assessment Process for Medicaid level of care?" July 12, 2005

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Institutional Supply Controls

Policies in place to reduce nursing facility capacity are described in Section 4: Services for Older Adults.

Transition from Institutions

As described in Section 4: Services for Older Adults, there is no specific initiative to help people leave nursing facilities.

Continuum of Residential Options

The state housing agency, Iowa Finance Authority, and several service agencies have worked together to address housing issues. The Iowa Finance Authority (IFA) has established an online Housing Registry that identifies accessible, affordable housing; describes the properties; and provides links to information and referral services. IFA also provided training to agencies working with people with disabilities so that they could access available housing resources.[23]

To encourage the building of new accessible, affordable housing, IFA established a 30% set-aside in the Qualified Allocation Plan for Low Income Housing Tax Credits. This means 30% of units developed with funding from these credits must be accessible and properties must have a plan to provide supportive services.[24] Also, IFA administers the Home and Community Based Services Rent Subsidy Program, a state-funded program for Medicaid waiver individuals who are on a waiting list for another type of rent subsidy.[25] The rent subsidy program has paid approximately $300,000 per year since SFY 2005 for housing for an average of 342 adults per year age 18 – 59.[26]

Two residential care facilities are options for people with physical disabilities: residential care facilities and assisted living. Residential care facilities serve people with disabilities regardless of diagnosis, and are funded through a state-funded supplement to the Supplemental Security Income program. They typically provide housing and limited personal assistance, and not sufficient services for people who would otherwise need nursing facility care. Assisted living facilities can provide more support, but typically serve older adults. Assisted living is not an option in Medicaid home and community-based services waivers for Iowans under age 65.

HCBS Infrastructure

Other than the initiatives described in Section 3: Workforce, there is no initiative for developing provider capacity for people with physical disabilities. Home health plays a significant role in Iowa's Medicaid program. In 2005, Iowa was first in Medicaid home health participants as a proportion of state population (8.2 per 1,000 state residents, compared to the national average

[23] Iowa Department of Human Services, Iowa Medicaid Enterprise "MFP Housing Inventory Report" September 4, 2007

[24] Iowa Department of Human Services, Iowa Medicaid Enterprise "Systems Readiness Assessment" part of application for the Federal Systems Transformation Grant Revised September 29, 2005

[25] Iowa Department of Human Services, Iowa Medicaid Enterprise "MFP Housing Inventory Report" September 4, 2007

[26] Data provided by Iowa Finance Authority

of 3.1).[27] Home health can be an effective substitute for nursing facility care, but also can provide more support than is necessary. In other states, a personal care service in the state Medicaid Plan provides similar services to home health aides and in a less expensive model that encourages participant independence.

Participant Direction

The Department of Human Services implemented participant-direction in all Medicaid home and community-based services waivers serving adults, with support from a Robert Wood Johnson Foundation Cash & Counseling Grant. Waiver participants who choose to direct their services are given a budget based on a determination of their needs and then can use their budget to obtain necessary, cost-effective services that are not specified in the waiver. Participants can also directly employ their direct support workers, rather than use an agency. Iowa introduced an innovative approach for providing necessary financial management services by partnering with credit unions and banks, rather than disability service providers.

The original Cash & Counseling program was implemented in three states to compare the traditional model of agency-directed personal care services with a consumer directed approach where consumers manage the budget and determine the mix of goods and services. An evaluation using a randomized, controlled trial found people who directed their services had better outcomes than people who wanted to direct their services but did not have that option.[28]

Quality Assurance

The quality management process for nursing facilities, home health agencies, and Medicaid home and community-based services waivers, described in the Section 4: Services for Older Adults, also applies to services for adults under age 60 with physical disabilities.

[27] Ng, Terence; Harrington, Charlene; and O'Malley, Molly *Medicaid Home and Community-Based Service Programs: Data Update* Kaiser Family Foundation: December 2008 and U.S. Census Bureau, Population Division "Annual Population Estimates, Estimated Components of Population Change, and Rates of the Components of Population Change for the United States, States, and Puerto Rico: April 1, 2000 to July 1, 2008" December 22, 2008

[28] Phillips, Barbara; Mahoney, Kevin; Simon-Rusinowitz; Schore, Jennifer; Barrett, Sandra; Ditto, William; Reimers, Tom; Doty, Pamela *Lessons From the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey Final Report* June 2003

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Section 6: Services for People with Mental Retardation

Unlike most states, Iowa does not have a single service system for people with developmental disabilities. This section describes the system for people with a mental retardation diagnosis,[1] which serves most individuals with developmental disabilities. People with other developmental disabilities often receive services described in Section 5, Services for People with Physical Disabilities, such as the Ill and Handicapped Waiver and the Brain Injury Waiver. Some individuals with significant disabilities do not fit into any existing service program, most notably people with autism spectrum disorders.[2] Many people with autism qualify for services in the mental retardation system, but many others do not. The number of people diagnosed with these disorders has increased rapidly in recent years, making this gap more apparent.

Iowa is one of the leading states in the number of people with mental retardation receiving supports.[3] One reason is that Iowa has long mandated that county governments provide "treatment, training, instruction, care, habilitation, support, and transportation of persons with mental retardation."[4] Since 1995, the state has taken a greater role in paying for these services while counties have continued to have management responsibility.

Programs and Services

Table 6.1 on the following page shows long-term support expenditures for adults age 18 and older with mental retardation. Data for children under age 18 are included in Section 8, Services for Children with Disabilities. Total spending for developmental disability services was approximately $558 million in SFY 2008.[5] Medicaid accounted for over 90% of expenditures.

Funding for adults with mental retardation had increased 9.3% per year since SFY 2004. The estimated spending does not include the change in non-Medicaid dollars spent by counties for services for people with mental retardation. At the time this report was written, we were not able to obtain an estimates non-Medicaid expenditures for multiple years. Real per capita spending, which adjusts data for inflation and population growth, grew 5.4% per year.[6]

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[1] Many people prefer the term "intellectual disability" instead of "mental retardation". The phrase "mental retardation" is used in this report to reflect the phrase used in Federal and state laws and regulations that authorize services for these individuals. We use the phrase "developmental disabilities" when the described policy or program applies to all developmental disabilities, including mental retardation.

[2] The autism spectrum includes autism, Asperger's disorder, and other pervasive developmental disabilities.

[3] Prouty, Robert W.; Alba, Kathryn; Lakin, K. Charlie (eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007* University of Minnesota Institute for Community Integration: August 2008

[4] Iowa Code 222.60

[5] Data provided in November 2008 by the Iowa Department of Human Services and Iowa Vocational Rehabilitation Services and Braddock, David; Hemp, Richard; Rizzolo, Mary C. *The State of the States in Developmental Disabilities: 2008* Preliminary Report from University of Colorado, Department of Psychiatry and Coleman Institute for Cognitive Disabilities: 2008

[6] Thomson Reuters analysis based on inflation data from U.S. Department Of Labor, Bureau of Labor Statistics "Consumer Price Index for All Urban Consumers (CPI-U), Midwest Region" January 26, 2009 and population data from U.S. Census Bureau, Population Division "Annual Population Estimates, Estimated Components of Population Change, and Rates of the Components of Population Change for the United States, States, and Puerto Rico: April 1, 2000 to July 1, 2008" December 22, 2008

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Table 6.1: Public Long-Term Care Expenditures for Adults with Developmental Disabilities, SFY 2004 and SFY 2008

	2004	2008	Average Annual Percent Change	Percent of Total 2008 Expenditures
Medicaid				
ICF/MR, age 18 – 59	$186,747,953	$211,090,407	3%	42%
ICF/MR, age 60+	$10,519,610	$15,465,807	10%	3%
MR Waiver, age 18 – 59	$133,813,430	$242,412,277	16%	48%
MR Waiver, age 60+	$6,777,383	$15,851,648	24%	3%
MR Targeted Case Management, age 18+	$16,263,677	$23,316,088	9%	5%
Total Medicaid	**$354,122,054**	**$508,136,227**	**9%**	**91%**
Non-Medicaid				
Non-Medicaid Developmental Disabilities Services*	n/a	$45,950,316	n/a	8%
Vocational Rehabilitation**	$4,955,895	$3,868,795	-6%	0.7%
Total	**$359,077,948**	**$557,955,338**	**n/a**	**100%**

Sources:
Data provided in November 2008 by the Iowa Department of Human Services and Iowa Vocational Rehabilitation Services and Braddock, David; Hemp, Richard; Rizzolo, Mary C. *The State of the States in Developmental Disabilities: 2008* Preliminary Report from University of Colorado, Department of Psychiatry and Coleman Institute for Cognitive Disabilities: 2008

* Non-Medicaid developmental disabilities services include county and state appropriations for supports provided through county-based Central Points of Coordination. 2008 data were based on a 2006 estimate provided by Iowa Department of Human Services to Braddock, *et al*. Estimates for other years were not available.
** Vocational Rehabilitation spending is an estimate based on the percentage of participants with cognitive impairments multiplied by total expenditures

As Table 6.2 on the following page illustrates, the total number of people who received Medicaid services grew 2.1% during this time 10,752 individuals.[7] The overall number of people served decreased by a small amount because of changes in the vocational rehabilitation system. This figure is an estimate and double counts individuals who receive services in multiple programs. The programs listed in these tables are described below.

Medicaid Services

Intermediate Care Facilities for people with Mental Retardation (ICF/MR) provide housing, habilitation, and medical services. Iowa has two state-operated ICF/MR, Glenwood and Woodward, which together served 597 people of all ages in SFY 2008 and accounted for 46% of all ICF/MR expenditures. In SFY 2008, Iowa had 137 private ICF/MR.[8] The majority of these

[7] Data provided in November 2008 by the Iowa Department of Human Services and Iowa Vocational Rehabilitation Services

[8] Data provided November 2008 by Iowa Department of Inspections and Appeals

facilities are licensed for four to eight residents, but there are several facilities that serve 16 or more people.[9]

Table 6.2: Number of Iowans Receiving Public Long-Term Care Services Targeted to Adults with Developmental Disabilities, SFY 2004 and SFY 2008

	2004	2008	Average Annual Percent Change
Medicaid			
ICF/MR, age 18 – 59	1,982	1,807	-2%
ICF/MR, age 60+	109	118	2%
MR Waiver, age 18 – 59*	5,336	7,689	10%
MR Waiver, age 60+*	196	415	21%
MR Targeted Case Management, age 18+	7,795	8,827	3%
Total Medicaid	**9,886**	**10,752**	**2%**
Non-Medicaid			
Non-Medicaid Developmental Disabilities Services**	n/a	n/a	n/a
Vocational Rehabilitation	3,629	2,712	-9%
Total	**13,515**	**13,464**	**-0.1%**

Sources:
Data provided in November 2008 by the Iowa Department of Human Services and Iowa Vocational Rehabilitation Services

* MR Waiver was not counted for Total Medicaid or for the overall Total to avoid double-counting these individuals. All MR Waiver participants age 18+ must also receive targeted case management.
** Non-Medicaid developmental disabilities services include county and state appropriations for supports provided through county-based Central Points of Coordination. Estimated participants were not available by funding source.

The Mental Retardation (MR) Waiver offers a wide array of services as an alternative to ICF/MR. Most participants receive supported community living, which provides up to 24 hours of supports in a person's home or in a community residential setting of up to five people. Other common services are respite, transportation to day supports, and day supports (day habilitation, pre-vocational services, and supported employment). The MR waiver increased rapidly in SFY 2005 when day habilitation was added and enrollment increased by 1,550 people.[10]

Targeted case management is provided to all adults on the MR waiver and to other individuals who meet criteria for the state plan targeted case management service. Case management helps people identify and obtain necessary services to support independent community living, including MR waiver services and supports from other funding sources.

Non-Medicaid Supports:

Services through counties: Counties receive a combination of state and Federal revenue and can raise a limited amount of property tax revenue for mental health and developmental

[9] Iowa Department of Inspections and Appeals *Entities Book* August 7, 2008
[10] Data provided by Iowa Department of Human Services, Iowa Medicaid Enterprise.

disabilities services. Counties are required to provide services for people with mental illness and mental retardation, but not for people with other developmental disabilities.[11] For people with mental retardation, counties are financially responsible for the non-Federal share of Medicaid targeted case management, ICF/MR, and MR Waiver services. Counties also must provide services for people ineligible for Medicaid supports, and services that are ineligible for Medicaid reimbursement such as housing and supports in Residential Care Facilities for People with Mental Retardation (RCF/MR).[12]

Counties must appoint a Central Point of Coordination (CPC) to manage expenditures according to a county management plan for mental health and developmental disability services. Some counties pool their resources to fund a single CPC, which may be one or more individuals.[13]

Vocational Rehabilitation: The Vocational Rehabilitation program helps adults and adolescents with disabilities prepare for and obtain employment. The Federal Department of Education, Rehabilitation Services Administration (RSA) provides 78.7% of Vocational Rehabilitation funding and the state provides the rest.[14] This program is described further in the Section 5: Services for People with Physical Disabilities.

State Supplement for Supplemental Security Income (SSI): As described in Section 5: Services for People with Physical Disabilities, Iowa provides a few hundred dollars a month for SSI participants who need additional support because of functional impairments.

Other Supports Commonly Used by People with Mental Retardation

Other supports commonly used by individuals with mental retardation/developmental disabilities include the following programs. Services are based on income, need, residential setting or a combination of the criteria. Individuals living with families may need additional family support services.

- Income support from Social Security Disability Insurance or Supplemental Security Income
- Health insurance from Medicare or Medicaid
- Housing assistance – including rent and home modification loans - from the local public authority or Iowa Finance Authority
- Grocery payment from the Food Assistance program (formerly Food Stamps)
- Utility bill payment and weatherization assistance from the Low-Income Home Energy Assistance Program
- Loans to purchase assistive technology from the IowaAble Foundation

[11] Iowa State Association of Counties *2007 New County Officers Manual: The ABC's of County Government* 2007

[12] Iowa Department of Human Services, Mental Health and Disability Services *Statewide - Persons Served by Age Group, Population Group and Service, FY 2007* January 29, 2008

[13] Iowa Department of Human Services, Mental Health and Disability Services *Uniform Application FY 2008 – State Plan: Community Mental Health Services Block Grant* August 31, 2007

[14] Iowa Vocational Rehabilitation Services "About Vocational Rehabilitation Services" Undated

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Demographic and Utilization Trends

Among the 50 states and Washington D.C., Iowa is among the top five states in many measures of utilization, when controlling for state population. In 2007, Iowa ranked third to North Dakota and Wyoming in the number of people with developmental disabilities receiving Medicaid-funded services, almost twice the average utilization rate (See Table 6.3).[15]

Table 6.3: Number of People with Developmental Disabilities Receiving Medicaid-Funded Services, per 100,000 State Population, June 30, 2007

	HCBS Waiver	ICF/MR	Total
Iowa	**324.7**	**71.0**	**395.7**
South Dakota	327.7	19.8	347.5
Minnesota	280.8	48.3	329.1
Wisconsin	223.2	18.9	242.1
Nebraska	186.2	32.8	219.0
United States	*166.3*	*32.0*	*198.3*
Missouri	142.8	17.4	160.2
Illinois	99.6	71.7	171.3

Source:
Prouty, Robert W.; Alba, Kathryn; Lakin, K. Charlie (eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007* University of Minnesota Institute for Community Integration: August 2008 and data from Iowa Department of Human Services, Iowa Medicaid Enterprise

As Tables 6.4 and 6.5 illustrate, Iowa provides a high number of both large institutional services and services in small settings. In 2007, Iowa was third in the number of people with developmental disabilities served in facilities of 16 beds or more, following Mississippi and Arkansas. Iowa's rate of 55.1 per 100,000 of persons with developmental disabilities living in facilities of 16 or more is higher than the rate in any neighboring state (See Table 6.4).[16] Iowa ranked sixth in the number of people served in settings with six or fewer residents. These data include ICF/MR, group homes, and people receiving services in their own homes or their family members' homes, if the services provide up to 24 hours of support (See Table 6.5).[17]

Utilization trends are changing as waiver enrollment has increased rapidly and ICF/MR residents and days have decreased by two percent per year from SFY 2004 to SFY 2008 (See Table 6.2 on page 58).[18]

[15] Prouty, Robert W.; Alba, Kathryn; Lakin, K. Charlie (eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007* University of Minnesota Institute for Community Integration: August 2008 and data from Iowa Department of Human Services, Iowa Medicaid Enterprise

[16] *Ibid.*

[17] *Ibid.*

[18] Data provided by Iowa Department of Human Services, Iowa Medicaid Enterprise in November 2008

Table 6.4: Number of People with Developmental Disabilities Living in Facilities with 16 or more residents, per 100,000 State Population June 30, 2007

	State Institutions	Non-State Large Facilities	Total
Iowa	**19.2**	**35.9**	**55.1**
Illinois	20.0	28.1	48.1
Nebraska	19.0	13.3	32.3
Missouri	16.0	4.7	20.7
United States	*12.4*	*8.3*	*20.7*
South Dakota	19.8	0.0	19.8
Minnesota	0.8	18.0	18.8
Wisconsin	8.5	9.6	18.1

Source:
Prouty, Robert W.; Alba, Kathryn; Lakin, K. Charlie (eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007* University of Minnesota Institute for Community Integration: August 2008

Table 6.5: Number of People with Developmental Disabilities Receiving Services in Residential Settings with Six or Fewer Residents, per 100,000 State Population, June 30, 2007

	Community Settings	ICF/MR	Total
Minnesota	229.5	11.7	241.2
Iowa	**194.8**	**8.0**	**202.8**
South Dakota	201.5	0.0	201.5
Wisconsin	196.2	0.0	196.2
Nebraska	149.7	0.0	149.7
United States	*98.5*	*6.4*	*104.9*
Missouri	70.0	0.2	70.2
Illinois	56.5	1.6	58.1

Source:
Prouty, Robert W.; Alba, Kathryn; Lakin, K. Charlie (eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007* University of Minnesota Institute for Community Integration: August 2008

System Components Associated with Rebalancing

The remainder of this section describes the extent to which Iowa's system of supports for persons with developmental disabilities includes eight system components that have been previously identified in states that have rebalanced their long-term support system, i.e., reduced institutional utilization and increased access to home and community-based services. The components are defined in the introduction of this report.

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Consolidated State Agency

The Department of Human Services, Iowa Medicaid Enterprise is close to a consolidated state agency because it manages 90% of publicly funded services, including institutional and community supports. However, state-level planning responsibility for services for adults with developmental disabilities is divided among the Mental Health and Disability Services (MHDS) division and the MHMRDDBI Commission, who approve county management plans for local developmental disability services.[19] The county funding formula and history are described in detail in Section 2: System Administration and Management. While the administration is divided roughly based on funding source, financing structures for both Medicaid and non-Medicaid services allow savings from institutional services to be reinvested in community services. For people with a county of legal settlement (explained under "Single Access Point" below), the county pays the non-federal share for both types of service. Iowa Medicaid Enterprise has this responsibility for people without a county of legal settlement.

Single Access Point

The local county offices serve as the Central Points of Coordination (CPC) for access to mental retardation services. Counties either directly provide or purchase Targeted Case Management Services to help people obtain necessary supports, including assistance outside of long-term support, such as housing. The CPC concept gives individuals with mental retardation and their families a clear access point of entry at the local level.

The role of CPCs is complicated by the fact that people move from county-to-county within the state. The county responsible for payment – called the county of legal settlement – is often different from the county in which a person lives. For example, if a person starts receiving services in a rural county and then moves to an urban county with a greater array of services, the rural county is responsible for services unless the person does not use services for a full year. Also, if a person moves to Iowa from out of state and needs services within a year, that person has no county of legal settlement and the state is responsible for services.[20] In both cases, the CPC in the county of residence conducts assessment and utilization management. Further complicating matters, counties use different assessment tools to determine functional strengths and needs and inform service planning.[21] The county of legal settlement arrangement removes the incentive for counties to reduce services in the hope that people with mental illness or developmental disabilities leave the county. However, it can delay access to services when there is confusion regarding which county is responsible for a person's services. [22]

As described in Section 5: Services for People with Physical Disabilities, Iowa COMPASS provides a statewide information and referral resource to help individuals, families and agencies to locate disability resources.

[19] Iowa Code, Section 331.439

[20] Iowa Code Section 252.16

[21] Iowa Department of Human Services, Iowa Medicaid Enterprise "Partnership for Community Integration & Money Follows the Person" Application submitted November 2006

[22] Iowa Department of Human Services, Mental Health and Disability Services *Uniform Application FY 2008 – State Plan: Community Mental Health Services Block Grant* August 31, 2007

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Institutional Supply Controls

There is a Certificate of Need requirement for facilities serving individuals with developmental disabilities. The process is described in the Section 4: Services for Older Adults. Since there is not a strong market for new ICF/MR beds, the Certificate of Need control is less relevant than for Nursing Facilities. The number of ICF/MR beds increased slightly between SFY 2004 and SFY 2008, from 3,110 to 3,127 beds.[23]

Iowa is one of only 10 states that have not closed a state institution for people with developmental disabilities since 1960, and there are no plans to close either of the two facilities. However, Glenwood and Woodward are smaller than in previous decades. On June 30, 2007, they served 597, 34% as many people as served on June 30, 1982.[24]

Transition from Institutions

Iowa plans to help 528 individuals move from ICF/MR to community living over five years as part of the Money Follows the Person Demonstration. This demonstration enables Iowa to draw a higher percentage of Federal funds for services to people during their first year out of an institution.[25] As of February 2009, eleven people had moved from ICF/MR.[26] As in many states, the demonstration has started slowly as the state needed to develop the program infrastructure necessary to implement the demonstration.

Before the demonstration, Iowa had been transitioning individuals from the state institutions. One of the terms of the 2004 consent decree following a lawsuit brought by the Department of Justice regarding quality of care at the Resource Centers was development of transition plans to transition residents to the community. As of 2006, DHS had been exceeding its goal to transition approximately 12 individuals per year from each Center to community settings.[27]

Continuum of Residential Options

The MR Waiver enables people to receive supports in a variety of settings. The Supported Community Living service is defined to encourage integrated housing options such as a family home or a person's home or apartment. Services must be in "the typical and preferred living unit and may include one to four persons", with a special certification process for serving five people. All living situations are required to be integrated into the community. Services are provided in the family home, guardian's home or community setting but not the home of the provider. If services are provided in apartment complexes, people without disabilities must occupy the majority of living units.[28]

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[23] Data provided November 2008 by Iowa Department of Inspections and Appeals

[24] Prouty, Robert W.; Alba, Kathryn; Lakin, K. Charlie (eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007* University of Minnesota Institute for Community Integration: August 2008

[25] Iowa Department of Human Services, Iowa Medicaid Enterprise "Partnership for Community Integration & Money Follows the Person" Application submitted November 2006

[26] Data provided February 2009 by Iowa Department of Human Services, Iowa Medicaid Enterprise

[27] Iowa Department of Human Services, Iowa Medicaid Enterprise "Partnership for Community Integration & Money Follows the Person" Application submitted November 2006

[28] Iowa Department of Human Services, Iowa Medicaid Enterprise *Mental Retardation Waiver Information Packet* Last revised March 10, 2006

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Section 5: Services for People with Physical Disabilities describes a variety of initiatives to expand residential options for people with disabilities, which can include people with mental retardation. Stakeholders report these options are still not common for people with mental retardation, reflecting a long-standing practice of using group settings for this population. As part of the Money Follows the Person Demonstration, DHS plans to provide training to case managers to increase their knowledge regarding housing options, including rent subsidies. This training is one step toward increasing awareness of housing options that have not traditionally been used in state developmental disabilities service systems.

HCBS Infrastructure

Several stakeholders expressed concern regarding the relatively high number of Iowans in ICF/MR. As part of a 2005 Real Choice System Transformation grant, the Department of Human Services, Iowa Medicaid Enterprise initiated a planning process to reduce populations served by ICF/MR and to increase utilization of waiver and community services. Reasons for ICF/MR utilization identified in this process included an underdeveloped HCBS provider network and a lack of awareness of community alternatives. The Money Follows the Person Operational Protocol was designed to address these barriers, including an allocation of $60 million to provide an incentive for community providers to expand services and for ICF/MR providers to diversify their services.[29]

Participant-Direction

The MR Waiver includes participant direction, as described in Section 5: Services for People with Physical Disabilities. All MFP participants will have the choice of the Consumer Choices Option in their transition planning.

Quality Management

The Department of Inspections and Appeals (DIA), Health Facilities Division licenses ICF/MR and residential care facilities. Providers of these services cannot operate without licensure. DIA monitors ICF/MR according to Federal Medicare guidelines, which include an on-site review every 15 months, with an average of once per year. As is common for licensing agencies, DIA does not have sufficient staff to monitor other providers on-site on an annual basis.

Iowa's state-operated ICF/MR, Glenwood and Woodward, have been under investigation by the United States Department of Justice, Civil Rights Division with written findings submitted to the Governor on July 9, 2002.[30] The Department of Justice findings outlined numerous quality issues and recommendations related to both facilities. Quality issues have been reported on an ongoing basis and have recently received media coverage with concerns expressed by advocacy groups.

Section 4: Services for Older Adults describes Iowa's quality management activities related to Medicaid Waiver services, including the Mental Retardation Waiver.

[29] Iowa Department of Human Services, Iowa Medicaid Enterprise *Operational Protocol for Iowa's Money Follows the Person Grant* (Revised February 26, 2008)

[30] Boyd, Ralph F. *Investigation of Woodward State Resource Center and Glenwood State Resource Center* United States Department of Justice, Civil Rights Division: July 9, 2002

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Iowa's mental health system is particularly fragmented, with aspects of state system management divided among two divisions of the Department of Human Services and the MHMRDDBI Commission. The fragmentation continues at the local level, where county governments play a significant funding and service coordination role for adults age 18 and older, but not for children. The separation of the adult and children's systems further complicates planning the transition to adulthood for youth with serious emotional disturbances. This section will focus on the system for adults with mental illness, while services for children with serious emotional disturbances are described in Section 8: Services for Children with Disabilities.

Several stakeholders expressed concern about the capacity of the mental health system. On a per capita basis, Iowa has fewer psychiatrists and psychologists than most states. Long-term supports were also considered inadequate, especially residential services that combined housing with supports to help people manage their mental illness. The lack of supports reportedly leads to more hospitalizations and in some instances to behaviors that require law enforcement involvement. The state has taken steps to improve the system by starting pilots to implement evidence-based practices such as assertive community treatment, supported employment, and integrated treatment for people with both addiction disorders and mental illness.

Programs and Services

Table 7.1 on the following page shows public mental health expenditures. There were approximately $160 million in public expenditures for adults with mental illness in SFY 2008. This figure includes acute services – such as psychiatrist and psychologist visits and hospitalizations – and long-term care services such as residential supports, day treatment, and psychiatric rehabilitation. Both types of services are included because it is difficult to distinguish between acute and long-term care spending in the available data. Two of the largest funding streams – the Medicaid managed care plan and non-Medicaid services provided through counties – provide both types of support. Services can range from a few counseling sessions to intensive residential services, depending on a person's needs.

The $160 million figure is a low estimate because the authors were not able to identify the amount of state and local mental health spending outside of the Medicaid program. As is common in other states,[1] funding outside of the Medicaid program plays a significant role in mental health services. Many individuals with mental illness either are not eligible for Medicaid or have difficulty demonstrating their eligibility because of inadequate documentation of their disability and/or financial status.[2] In addition, some mental health services are not eligible for Medicaid reimbursement.

To provide mental health and other disability services to Iowans with low incomes, Iowa distributes state appropriations and Federal Social Services Block Grant funds ($12.5 million total)[3] to counties according to formulas detailed in state law. In addition, counties dedicate a portion of their property tax levy to mental health and developmental disability services.

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[1] Shirk, Cynthia *Medicaid and Mental Health Services* George Washington University, National Health Policy Forum: October 23, 2008

[2] See Eiken, Steve and Galantowicz, Sara *Improving Medicaid Access for People Experiencing Chronic Homelessness: State Examples* Thomson Medstat: March 29, 2004 for more information about barriers to establishing Medicaid eligibility.

[3] Iowa Department of Management *Iowa Budget Report: Fiscal Year 2010 Report* January 28, 2009

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Counties can use some of the state and local funds to pay the non-Federal share of Medicaid-eligible services for people enrolled in Medicaid.[4] Counties report total spending for mental health services ($88.7 million in SFY 2004 and $107.4 million in SFY 2008),[5] but do not report how much of that amount is used to match Federal Medicaid funds.

Table 7.1: Public Expenditures Targeted to Adults with Mental Illness, SFY 2004 and SFY 2008

	2004	2008	Average Annual Percent Change	Percent of Total 2008 Expenditures
Medicaid				
Iowa Plan (managed behavioral health care premiums)	$49,358,278	$61,046,457	5%	38%
State Plan Habilitation*	$0	$36,849,774	n/a	23%
State Plan Rehabilitative Services*	$30,308,635	$2,749,332	-45%	2%
Total Medicaid	**$79,666,913**	**$100,645,563**	**6%**	**63%**
Non-Medicaid				
Mental Health Institutes**	$46,987,929	$56,249,211	5%	35%
Community services provided through counties***	n/a	n/a	n/a	n/a
Correctional institutions****	n/a	n/a	n/a	n/a
Vocational Rehabilitation*****	$4,213,910	$3,065,029	-10%	2%
Total	**$130,868,752**	**$159,959,803**	**5.1%**	**100%**

Source:
Magellan Health Services *Iowa Plan Monthly Report, October 2008* November 18, 2008 for Iowa Plan data
Iowa Department of Human Services, Iowa Medicaid Enterprise *Title XIX Report of Expenditures: Fiscal YTD Totals as of June 30, 2004* June 27, 2004 for rehabilitative services data
Data for other services provided between November 2008 and March 2009 by the Iowa Department of Human Services, Iowa Medicaid Enterprise; Iowa Department of Human Services, Field Operations; Iowa Vocational Rehabilitation Services; and Iowa Department of Corrections.

* State Plan Rehabilitative Services expenditures decreased significantly between 2004 and 2008 because Iowa reduced available rehabilitative services. Iowa established the habilitation service to replace services previously provided as part of the Medicaid State Plan rehabilitative services benefit.
** Mental Health Institutes receive some Medicaid reimbursement – for people age 65 and older and as part of IowaCare, a Research and Demonstration Waiver authorized under Section 1115 of the Social Security Act.[6] The IowaCare payments are similar to Disproportionate Share Payments in other states, which are provided to hospitals that serve a large portion of uninsured individuals. Mental Health Institutes are listed separately because they are an important part of the mental health system, and are listed under non-Medicaid services because they also receive funding from counties.
*** Community services provided through counties are funded by a combination of Federal grants, state appropriations, and county property tax revenues. Counties also pay the cost of Mental Health Institute care.
**** Correctional institutions do not track spending for particular individuals, so no expenditures data is available regarding spending for mental health services.
***** Vocational Rehabilitation spending is an estimate based on the percentage of participants with mental impairments multiplied by total expenditures. Data for SFY 2004 were not available, so SFY 2005 data were used.

[4] Iowa State Association of Counties *2007 New County Officers Manual: The ABC's of County Government* 2007

[5] Iowa Department of Human Services, Mental Health and Disability Services *Statewide – Expenditures by Service and Disability, FY 2008* March 27, 2009 and Iowa Department of Human Services *Statewide – Expenditures by Service and Disability, FY 2004* December 1, 2005

[6] Iowa Department of Human Services, Iowa Medicaid Enterprise *State of Iowa 1115 Waiver (Iowa Care) 2007 Annual Report: July 1, 2006 – June 30, 2007* October 31, 2007

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Table 7.2 shows the number of people receiving public mental health services from different funding streams. Data includes people insured for Medicaid mental health services in the Iowa Plan, whether or not they used services during the year. A total number of people served was not calculated because the data on the previous page likely count individuals more than once. Programs serving adults with mental illness are further described on the following page.

Table 7.2: Number of Iowans Receiving Public Long-Term Care Mental Health Services Targeted to Adults, SFY 2004 and SFY 2008

	2004	2008	Average Annual Percent Change
Medicaid			
Iowa Plan (average eligible adults per month)	96,525	108,545	3%
Habilitation*	0	3,241	n/a
Rehabilitative Services*	3,720	0	n/a
Total Medicaid	**96,525**	**108,545**	**3%**
Non-Medicaid			
Mental Health Institutes (unduplicated admissions over a year)**	1,721	1,523	-4%
Community services provided through counties***	33,723	33,034	-0.5%
Correctional institutions (inmates with serious and persistent mental illness)	n/a	2,640	n/a
Vocational Rehabilitation****	2,311	2,876	8%

Sources:
Magellan Health Services *Iowa Plan Monthly Report, October 2008* November 18, 2008 for Iowa Plan data
Iowa Department of Human Services, Iowa Medicaid Enterprise *Title XIX Report of Expenditures: Fiscal YTD Totals as of June 30, 2004* June 27, 2004 for rehabilitative services data
Iowa Department of Human Services, Mental Health and Disability Services *Persons Served - Unduplicated by Age and Population Group, FY 2004* December 1, 2005 and Iowa Department of Human Services, Mental Health and Disability Services *Persons Served - Unduplicated by Age and Population Group, FY 2008* March 10, 2009 for grant-funded services provided through counties.
Data for other services provided in November and December 2008 by Iowa Department of Human Services, Iowa Medicaid Enterprise, Iowa Vocational Rehabilitation Services, and Iowa Department of Corrections

* The number of people receiving habilitation and rehabilitative services were excluded from the Total Medicaid calculation to prevent double-counting. People who received these services were often enrolled in the Iowa Plan. The number of State Plan Rehabilitative Services participants decreased significantly between 2004 and 2008 because Iowa reduced available rehabilitative services. Iowa established the habilitation service to replace services previously provided as part of the Medicaid State Plan rehabilitative services benefit.
** Mental Health Institutes receive some Medicaid reimbursement – for people age 65 and older and as part of IowaCare, a Research and Demonstration Waiver authorized under Section 1115 of the Social Security Act.[7] The IowaCare payments are similar to Disproportionate Share Payments in other states, which are provided to hospitals that serve a large portion of uninsured individuals. Mental Health Institutes are listed separately because they are an important part of the mental health system, and are listed under non-Medicaid services because they also receive funding from counties.
*** Community services provided through counties are funded by a combination of Federal grants, state appropriations, and county property tax revenues. Counties also pay the cost of Mental Health Institute care. Counties appoint a Central Point of Coordination to manage expenditures according to a county management plan for mental health and developmental disability services. Counties use most available funds within Medicaid to draw Federal matching funds for Medicaid-eligible services to Medicaid-eligible participants.
**** Vocational Rehabilitation data for SFY 2004 were not available, so SFY 2005 data were used.

[7] Iowa Department of Human Services, Iowa Medicaid Enterprise *State of Iowa 1115 Waiver (Iowa Care) 2007 Annual Report: July 1, 2006 – June 30, 2007* October 31, 2007

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Medicaid Services

Most Medicaid-funded mental health services are provided through the Iowa Plan, a statewide managed behavioral health care plan operating under a waiver authorized by Section 1915(b) of the Social Security Act, which allows states to limit individuals' ability to choose providers. The Iowa Plan serves most Medicaid participants, with exceptions for people with limited Medicaid benefits (e.g., Medicaid only pays Medicare premiums); people who need to spenddown part of their income to qualify for Medicaid; people enrolled in state institutions for people with developmental disabilities; and people age 65 or older.[8]

Table 7.3: Number of Adults Receiving Long-Term Care Mental Health Services as part of the Iowa Plan, SFY 2004 and SFY 2008

	2004	2008	Average Annual Percent Change
Inpatient Hospital Admissions	4,210	4,005	-1%
Inpatient Hospital Days	*18,772*	*18,919*	*0.2%*
Residential Behavioral Treatment (mental health or substance abuse)*	779	653	-6%
Community Psychiatric Support Services	2,376	3,065	7%
Home Health Nursing	702	739	1%
Psychosocial Rehabilitation	436	580	7%
Assertive Community Treatment	178	272	11%
Intensive Mental Health Outpatient Psychiatric Services	166	90	-14%
Clubhouse/Drop-In Centers	140	72	-15%
Targeted Case Management	3,469	3,117	-3%

Source:
Data provided December 2008 by Iowa Department of Human Services, Iowa Medicaid Enterprise

* 2005 data were used for this service because the billing code changed during FY 2004 and double-counting of participants was possible for that year.

The Iowa Plan provides most mental health services, including inpatient hospitalization and psychiatrist and psychologist services. It does not include prescription drugs. Table 7.3 presents utilization data for a variety of supports that could be considered long-term care, which is defined in this report as "assistance with essential, routine tasks of life."[9] Although most hospitalizations are short-term, hospitalizations are included because they may be necessary due to inadequate supports. The data suggest a general decline in hospitalizations and in residential services, and increases in several types of non-residential supports.

The Department of Human Services, Iowa Medicaid Enterprise contracted with Magellan Health Services to administer the Iowa Plan. The contract is subject to a request for proposal process every five years, including in 2009. The contract is a joint contract between Iowa Medicaid

[8] People age 65 or older are scheduled to be added to the Iowa Plan in Calendar Year 2009 (Iowa Department of Human Services, Iowa Medicaid Enterprise *Request for Proposals for the Iowa Plan for Behavioral Health* December 31, 2008)

[9] Rogers, Susan and Komisar, Harriet "Who Needs Long-Term Care?" Georgetown University Long-Term Care Financing Project: May 2003

Enterprise and the Iowa Department of Public Health, Division of Behavioral Health, which administers substance abuse prevention and treatment programs. The joint contract provides the opportunity to better coordinate services from both systems for people with both addiction disorders and mental illness.

The Iowa Plan does not include one long-term support service, habilitation, which is assistance in developing and maintaining self-help, socialization, and adaptive skills. Habilitation can be provided in a person's home, on a job site, or in day service settings certified by Iowa Medicaid Enterprise or accredited by one of several national organizations that set standards for long-term support services. Iowa provides habilitation services on a fee-for-service basis as a Medicaid State Plan service.

Iowa is the only state using an option authorized in Section 1915(i) of the Social Security Act to provide State Plan home and community-based services for people who need long-term supports but do not qualify for institutional care. Iowa's habilitation service is available for people who meet a definition of chronic mental illness established in Iowa's administrative regulations.[10] Individuals must have received intensive psychiatric treatment such as emergency services, partial hospitalization or inpatient hospitalization; and who have meet at least two of the following five criteria for at least two years:

- "Is unemployed, or employed in a sheltered setting, or have markedly limited skills and a poor work history.
- "Requires financial assistance for out-of-hospital maintenance and may be unable to procure this assistance without help.
- "Shows severe inability to establish or maintain a personal social support system.
- "Requires help in basic living skills such as self-care, money management, housekeeping, cooking, or medication management.
- "Exhibits inappropriate social behavior that results in demand for intervention."[11]

Iowa established the habilitation service to replace services previously provided as part of the Medicaid State Plan rehabilitative services benefit. CMS and the Federal Health and Human Services Office of Inspector General had concluded that many services were habilitative, i.e., they helped a person develop new skills, and that the rehabilitative services benefit was for restoring a person to a previous level of function.[12]

Non-Medicaid Long-Term Support Services

Supports that are typically outside of the Medicaid program are described below.

Mental Health Institutes: Iowa has four state-operated mental health hospitals across the state. The mental health institutes are primarily used for stays of a few days or weeks when there is not another facility willing and able to serve the individual. The exception is a portion of the Clarinda Mental Health Institute that is a nursing facility for older adults with serious mental illness. While over 2,000 people of all ages (including children under age 18) were voluntarily or

[10] 441 Iowa Administrative Code Chapter 22

[11] Iowa Department of Human Services, Iowa Medicaid Enterprise *Application for 1915(i) HCBS State Plan Services* 2006

[12] U.S. Department of Health and Human Services, Office of the Inspector General *Audit of Iowa's Adult Rehabilitation Services Program* March 2005

involuntarily committed to the institutes in SFY 2008, only 223 people where there on June 30, 2008.

Iowa's Medicaid program covers services in mental institutes for people under age 21 and age 65 and older. The Medicaid program typically does not allow individuals age 22 to 64 in mental health hospitals to enroll in Medicaid. The Mental Health Institutes receive some Medicaid funds as part of IowaCare as described in Table 7.2 above. In addition, county governments must pay mental health institutes for involuntary commitments for people who have legal settlement in that county (as described below).

Services through counties: As described earlier in this section, counties receive a combination of state and Federal revenue and can raise property tax revenue for mental health and developmental disabilities services. For people with mental illness, counties are financially responsible for the cost of involuntary commitments to mental health institutes and are responsible for services a person may need after admission. The responsibility for institutional payment provides an incentive for counties to offer community mental health services to people who cannot afford them, including people ineligible for Medicaid.

Counties must appoint a Central Point of Coordination (CPC) to manage expenditures according to a county management plan for mental health and developmental disability services. Some counties pool their resources to fund a single CPC, which may be one or more individuals.[13] CPCs are a single access point for public, non-Medicaid mental health services and are responsible for contracting with community mental health centers and other safety net community mental health providers. Common services provided by counties include case management, psychiatric treatment, prescription drugs, psychotherapy, and combinations of housing and supports – both in facilities such as licensed residential care facilities and in supervised apartments.[14]

Several stakeholders expressed concern about inequities among counties. Counties' ability to pay for services varies according to property values, not need for publicly funded services. In SFY 2008, county levies ranged from 20 cents (Louisa County) per $1,000 of property value to approximately $2.80 per $1,000 value (Jasper County).[15] Since state dollars are distributed to counties with greater poverty rates,[16] state appropriations partially address these inequities. In addition, counties naturally make different decisions on how to spend available dollars on mental health and developmental disabilities services. While counties are required to provide mental health services, no set of core services are defined and the availability of services can vary significantly.

Vocational Rehabilitation: The Vocational Rehabilitation program helps adults and youth with disabilities prepare for and obtain employment. The Federal Department of Education, Rehabilitation Services Administration (RSA) provides 78.7% of Vocational Rehabilitation

[13] Iowa Department of Human Services, Mental Health and Disability Services *Uniform Application FY 2008 – State Plan: Community Mental Health Services Block Grant* August 31, 2007

[14] Iowa Department of Human Services, Mental Health and Disability Services *Statewide - Persons Served by Age Group, Population Group and Service, FY 2007* January 29, 2008

[15] Iowa State Association of Counties *2008 County Financial Overview* January 2008. Accessed September 2008

[16] Iowa State Association of Counties *2007 New County Officers Manual: The ABCs of County Government* 2007

funding and the state provides the rest.[17] This program is described further in Section 5: Services for People with Physical Disabilities.

State Supplement for Supplemental Security Income (SSI): As described in Section 5: Services for People with Physical Disabilities, Iowa provides a few hundred dollars a month for SSI participants who need additional support because of functional impairments.

Corrections: As in many states, thousands of people with mental illness are involved in the corrections system. As of December 31, 2007, 3,581 inmates in correctional facilities had a mental illness. Most of these individuals (2,640) had serious and persistent mental illness. As Chart 7.1 illustrates, the corrections system houses many more individuals with serious mental illness than the mental health institutes. The number of inmates diagnosed with mental illness has grown more than 20% since 2005, but that growth is attributed to improved identification of mental illness, not an increase in prevalence.[18] An additional 6,840 offenders were under community supervision (e.g., probation, parole, work release, and substance abuse treatment correctional facilities) on October 15, 2007. Only 59% of these individuals were currently receiving mental health treatment, suggesting there is room for improving access to community services for these individuals.[19]

The Iowa Department of Corrections has worked to improve treatment for offenders with mental illness in recent years, and continues to examine ways to improve services. Each inmate is assessed upon arrival for all health needs, including mental health, and the prison system's database includes a comprehensive medical record so assessment information is available on an ongoing basis. In addition, Iowa has established three levels of intensive mental health treatment services in the facilities. In 2008, 520 beds in special needs units provided increased psychiatric, psychological, and social work services. An additional 74 beds are available with more medical care: 28 transitional or sub-acute beds and 46 acute hospital beds.[20]

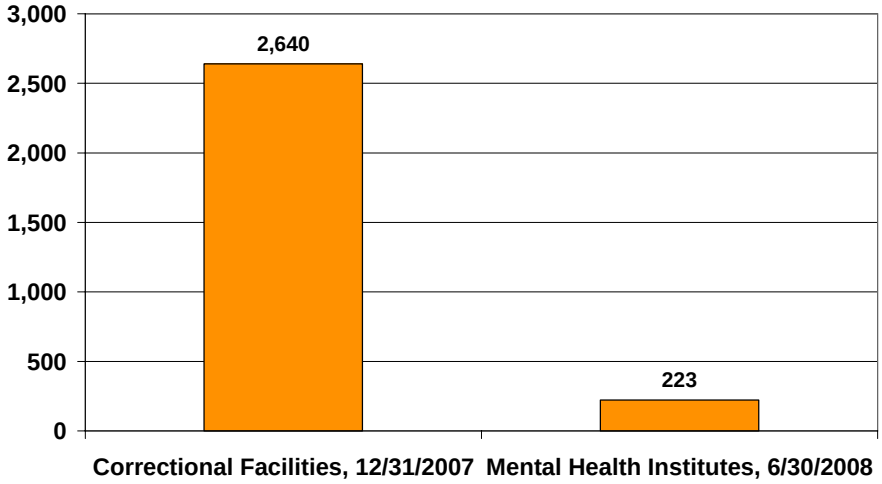
[17] Iowa Vocational Rehabilitation Services "About Vocational Rehabilitation Services" Undated

[18] Data provided in December 2008 by Iowa Department of Corrections

[19] Iowa Department of Corrections *Mentally Ill Offenders in Community-Based Corrections* April 2008

[20] The Durrant Group and Pulitzer/Bogard and Associates *State of Iowa Systemic Study for the State Correctional System: Phase II Report* April 29, 2008

Chart 7.1: Individuals with Serious and Persistent Mental Illness in State Facilities



Source:
Data provided in December 2008 by Iowa Department of Corrections and Iowa Department of Human Services

Other Supports Commonly Used by People with Mental Illness

People who need long-term care often need to combine and coordinate many different supports to live independently. Adults with mental illness often receive supports from the following sources, which are described further in Appendix B:

- Income support from Social Security Disability Insurance or Supplemental Security Income
- Health insurance, often from Medicare (Medicaid covers Medicare coinsurance and may provide all health insurance if the person does not qualify for Medicare)
- Housing assistance from the local public authority or Iowa Finance Authority
- Grocery payment from the Food Assistance program (formerly Food Stamps)
- Utility bill payment and weatherization assistance from the Low-Income Home Energy Assistance Program

Demographic and Utilization Trends

Iowans with mental illness were less likely to be in state institutions than people in other states as shown in Table 7.4 below.[21] In addition, Iowa state hospitals have a lower readmission rate than other states, so people discharged from a hospital are less likely to return within 30 days (Table 7.5).[22]

[21] National Association of State Mental Health Program Directors Research Institute, Inc. "State Mental Health Agency Profiling System: System: 2007" October 2008

[22] U.S. Substance Abuse and Mental Health Services Administration *2006 CMHS Uniform Reporting System Output Tables* October 2, 2007

Table 7.4: Number of People in State Hospitals for People with Mental Illness per 100,000 Residents, last day of SFY 2006

	State MI Hospital Residents per 100,000
Iowa	**7.4**
Minnesota	7.7
Wisconsin	8.5
Illinois	9.0
United States	15.6
Missouri	23.4
South Dakota	32.3

* United States data are based on 43 states. Nebraska was one of seven states that did not report data.

Source:
National Association of State Mental Health Program Directors Research Institute, Inc. "State Mental Health Agency Profiling System: System: 2007" October 2008

Table 7.5: Percentage of Adults Age 18 or Older Discharged from State Hospitals for People with Mental Illness Readmitted within 30 Days, 2006

	Percentage of Readmissions
Wisconsin	16.7%
Illinois	10.6%
United States	*9.4%*
Minnesota	7.7%
South Dakota	7.3%
Missouri	6.2%
Iowa	**5.2%**
Nebraska	3.3%

Source:
U.S. Substance Abuse and Mental Health Services Administration *2006 CMHS Uniform Reporting System Output Tables* October 2, 2007

While the proportion of people in state hospitals is low, the rate of hospital *admissions* to psychiatric units, both public and private, is slightly above average.[23] As stated above, Iowa's Mental Health Institutes are primarily short-stay facilities, so the number of admissions is greater than the state hospitals' census as of June 30.

[23] U.S. Substance Abuse and Mental Health Services Administration *2006 CMHS Uniform Reporting System Output Tables* October 2, 2007

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Table 7.6: Psychiatric Hospital Utilization per 1,000 Residents, 2006

	People Served per 1,000
South Dakota*	2.95
Wisconsin	2.38
Iowa	**2.25**
*United States***	*2.01*
Missouri	1.44
Nebraska	1.01
Illinois*	0.68
Minnesota	0.52

* United States data is based on 39 states that reported both admissions to both publfic and private hospitals. South Dakota and Illinois were among states that did not report private hospital admissions, so data for these states include only state hospital admissions.

Source:
U.S. Substance Abuse and Mental Health Services Administration *2006 CMHS Uniform Reporting System Output Tables* October 2, 2007

Iowans are more likely to use all public mental health services, which are primarily community mental health services. As shown in Table 7.7, more than 2% of all Iowans used public mental health services in 2006. This percentage includes services administered by county Central Points of Coordination and Medicaid-funded services.[24]

Table 7.7: Public Mental Health Services Penetration Rate (Percent who Received Services), 2006

	Percent of State Population Served
Iowa	**2.25**
United States	*1.99*
Minnesota	1.58
Wisconsin	1.57
South Dakota	1.45
Nebraska	1.42
Missouri	13.0
Illinois	1.29

Source:
U.S. Substance Abuse and Mental Health Services Administration *2006 CMHS Uniform Reporting System Output Tables* October 2, 2007

[24] U.S. Substance Abuse and Mental Health Services Administration *2006 CMHS Uniform Reporting System Output Tables* October 2, 2007

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Section 7: Mental Health Services

System Components Associated with Rebalancing

The remainder of this section describes the extent to which Iowa's system of supports for persons with mental illness includes eight system components that have been previously identified in states that have rebalanced their long-term support system, i.e., reduced institutional utilization and increased access to home and community-based services. The components are defined in the introduction of this report.

Consolidated State Agency

There is no discreet state agency or commission responsible for planning and service delivery for mental health services. Responsibility for planning and service delivery is divided among two divisions with the Department of Human Services – Mental Health and Disability Services and Iowa Medicaid Enterprise – and the governor-appointed MHMRDDBI Commission, as described in Section 2: System Administration and Management. At the local level, administration is divided between county-based Central Points of Coordination (CPC) and Medicaid behavioral health managed care contractor. In addition, the most visible presence in an area may be the community mental health center, which provides services under contract with CPC.

While the administration is divided roughly based on funding source, financing structures for both Medicaid and non-Medicaid services would allow savings from institutional services to be reinvested in community services. Counties are responsible for the non-Federal share of admissions to Mental Health Institutes[25] and for community mental health services. The Medicaid managed care contractor is responsible for most Medicaid mental health services, with two important exceptions. First, counties pay the non-Federal share for Medicaid habilitation services, even for people who receive other Medicaid services through the managed care contractor. Second, prescription medications are not part of the managed care contract.[26]

Single Access Point

Both CPC and the Medicaid managed care contractor are access points for publicly funded services, depending on which entity is responsible for payment. They assess need for services and approve utilization for both community and institutional care. Each has an incentive to ensure a person is aware of all options, regardless of funding source. Counties have the option to contract with the Medicaid managed care contractor, which would provide a single entity responsible for all services.[27]

Because there are two organizations involved depending on service and funding source, confusion can occur for people whose Medicaid eligibility status changes frequently. This can be more common for people with serious and persistent mental illness because the individuals may not provide necessary information to maintain eligibility, or may lose eligibility if involved in the criminal justice system even for a short amount of time.[28] In addition, there is no uniform

[25] Some services from Mental Health Institutes are eligible for Medicaid reimbursement as described in the notes for Table 7.2.

[26] Iowa Department of Human Services, Iowa Medicaid Enterprise *Request for Proposals for the Iowa Plan for Behavioral Health* December 31, 2008

[27] *Ibid.*

[28] Eiken, Steve and Galantowicz, Sara *Improving Medicaid Access for People Experiencing Chronic Homelessness: State Examples* Thomson Medstat: March 29, 2004

assessment among CPC or between CPC and managed care contractors, so people may need multiple assessments to receive services from both funding sources.

The role of CPC is complicated by the fact that people move from county-to-county within the state. The county responsible for payment – called the county of legal settlement – is often different from the county in which a person lives. For example, if a person starts receiving services in a rural county and then moves to an urban county with a greater array of services, the rural county is responsible for services unless the person does not use services for a full year. Also, if a person moves to Iowa from out of state and needs services within a year, that person has no county of legal settlement and the state is responsible for services.[29] In both cases, the CPC in the county of residence conducts assessment and utilization management. The county of legal settlement arrangement removes the incentive for counties to reduce services in the hope that people with mental illness or developmental disabilities leave the county. However, it can delay access to services when there is confusion regarding which county is responsible for a person's services. [30]

Institutional Supply Controls

Institutional supply controls are less important for Iowans with mental illness than they are for other populations that have high institutional utilization. Iowa's Mental Health Institutes serve a relatively small number of people and individuals typically have short stays, as described earlier in this section. Stakeholders expressed more concern about a lack of institutional capacity: specifically, inpatient psychiatric beds and post-acute beds to help people in crisis. Iowa has a Certificate of Need requirement for acute care hospitals that includes psychiatric beds, but there are no requirements specifically limiting psychiatric beds.[31]

Transition from Institutions

There is little need for a specific initiative to help people leave Iowa's Mental Health Institutes, since short-term stays are already common and readmission rates are low compared to other states.

Continuum of Residential Options

People with serious or chronic mental illness are often eligible for housing assistance, and can benefit from a great deal of work Iowa has done to improve access to affordable housing, which is described in Section 5: Services for People with Physical Disabilities.

Several stakeholders said there was an inadequate supply of residential options that combined long-term housing and supports. Data from the Iowa Plan on residential mental health and/or substance abuse treatment (See Table 7.3 above) indicate use of existing residential treatment options decreased by six percent per year between SFY 2004 and SFY 2008. The supply of residential care facilities, which provide a lower level of care than residential treatment providers and serve people with disabilities regardless of diagnosis, declined three percent per year from

[29] Iowa Code Section 252.16

[30] Iowa Department of Human Services, Mental Health and Disability Services *Uniform Application FY 2008 – State Plan: Community Mental Health Services Block Grant* August 31, 2007

[31] Iowa Administrative Code Section 203.1

5,620 to 4,939.[32] Stakeholders said the facilities that do exist often do not have staff trained to work with people with serious and persistent mental illness, such as training to deescalate challenging behaviors.

HCBS Infrastructure

Since it was reestablished in 2006, the Department of Human Services, Mental Health and Disability Services (MHDS) has taken several steps to improve the community mental health system's capacity. In 2007, the General Assembly passed legislation requiring MHDS to establish workgroups of state staff and a variety of stakeholders to recommend improvements in the following areas:

- Identifying a set of core mental health services to be available in all counties
- Revising accreditation standards for community mental health centers
- Implementing evidence-based practices
- Changing the formula for distributing state appropriations to counties[33]

MHDS has worked with counties, community mental health centers, and other stakeholders to implement pilots of three evidence-based practices promoted by the U.S. Substance Abuse and Mental Health Services Administration: assertive community treatment, supported employment, and integrated dual diagnosis treatment for people with both mental illness and addiction disorders. MHDS also established pilots of crisis safety net services to provide alternatives to emergency room and inpatient care.[34] Funding to continue the pilots is uncertain because of budget constraints.

Iowa has a particularly low supply of psychiatrists and psychologists. Data regarding the number of providers and efforts to improve recruitment and retention are described in the Section 3: Workforce.

The Iowa Plan includes another mechanism for improving the community mental health infrastructure. If there are cost savings from the managed care program, up to 2.5% of the state's payment to the managed care provider can be added to a Community Reinvestment Fund. The managed care contractor and the Department of Human Services, Iowa Medicaid Enterprise determine pilot projects and additional new services to fund using Community Reinvestment dollars. If a pilot is successful and funding is available, a new service or program model can be expanded statewide. The Iowa Plan provides several services using this fund, including community support services, peer supports, and residential services for substance abuse treatment.[35]

Participant Direction

Iowa started a pilot for participant-directed services using the Community Reinvestment Fund described above. Participants receive an individual budget of up to $2,000 that they can use for

[32] Data provided November 2008 by Iowa Department of Inspections and Appeals. Data include all licensed residential care facilities (RCF), including RCF/MI that specifically target people with mental illness.

[33] Iowa Department of Human Services, Mental Health and Disability Services *Uniform Application FY 2008 – State Plan: Community Mental Health Services Block Grant* August 31, 2007

[34] *Ibid.*

[35] Iowa Department of Human Services, Iowa Medicaid Enterprise *Background of the Iowa Plan* Undated

services or items that can lead to employment or increased independence. The managed care contractor must approve proposed expenditures. The budget is managed by a psychosocial rehabilitation provider, which also provides staff to help people develop and implement a plan to use their individual budget.[36]

Quality Management

The Department of Human Services, Mental Health and Disability Services (MHDS) division accredits many community mental health providers, including community mental health centers, psychosocial rehabilitation providers, and case management organizations. These providers cannot operate without MHDS accreditation. Accreditation staff review providers each year to determine whether they meet standards in statute or that the MHMRDDBI Commission set in regulation.

Quality management processes in addition to provider accreditation vary by funding source. For services managed by counties, each county must describe its quality management plan as part of the county management plan for mental health and disability services.[37] Central Points of Coordination provide local quality management according to the county plan. Counties must submit to MHDS an annual review of their county management plan that identifies measurable outcomes that indicate the system is becoming more individualized. Every three years each county must submit a strategic plan that identifies measurable goals and objectives to improve the mental health and disability system.[38]

For Medicaid services, the contract with the Iowa Plan requires a comprehensive quality improvement plan that is updated annually. To assess quality, the contractor must conduct surveys of people receiving services and of providers to measure their experience with the managed care contractor. The contractor also must analyze claims and other administrative data to identify providers that are outliers – i.e., that approve or prescribe an unusually large or small amount of services per participant. Each year, the Department of Human Services, Iowa Medicaid Enterprise and the contractor work together to identify five quality improvement initiatives with measurable outcomes to implement in the upcoming year. The contractor must then implement the initiatives, measure results, and report what changes occurred the following year.[39]

[36] Koyanagi, Chris; Alfano, E; and Carty, L. *In the Driver's Seat: A Guide to Self-Directed Mental Health Care* Bazelon Center for Mental Health Law and UPENN Collaborative on Consumer Integration: February 2008

[37] Iowa Department of Human Services, Mental Health and Disability Services *Uniform Application FY 2008 – State Plan: Community Mental Health Services Block Grant* August 31, 2007

[38] Iowa Code Section 331.439

[39] Iowa Department of Human Services, Iowa Medicaid Enterprise *Request for Proposals for the Iowa Plan for Behavioral Health* December 31, 2008

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Section 8: Services for Children with Disabilities

Entitlements to a broad array of Medicaid and public education services create a comprehensive services continuum for children with disabilities that decreases dramatically when youth transition to the adult services world. Through the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program, Medicaid-eligible children are able to receive any medically-necessary service including services outside Iowa's Medicaid State Plan. Part B of the Federal Individuals with Disabilities Education Act (IDEA) requires local school districts to offer educational services to children with disabilities age 3 – 22.[1] For children under age three, the Early ACCESS Integrated System of Early Intervention Services (IDEA Part C) offers eligible infants and toddlers and their families supports and services. Iowa implemented a family-centered philosophy in services delivery – where families have a role in decision-making, planning and services delivery – for children with disabilities starting in the late 1980s and early 1990s with Early ACCESS and the Child Health Specialty Clinics.[2]

However, entitlements are not a guarantee of community services. Children in Iowa are more likely to live in nursing facilities and ICF/MR than children in other states, and the use of institutions for children with serious emotional disturbances is rising.[3] Stakeholders interviewed reported an inadequate supply of behavioral health services, and an increasing awareness of the need for behavioral health services. Finally, families are not always aware of all service options. Families receiving one type of service may not know about necessary services available outside the range of responsibility of a program-specific case manager.

Programs and Services

Table 8.1 on the following page shows long-term supports spending for children with disabilities from SFY 2006 through SFY 2008. Special education data includes Federal grants, state appropriations, and spending by local school districts. This table starts with SFY 2006 data because special education data for all payers was not available for earlier years. There were approximately $839 million in public expenditures for supports for children with disabilities in SFY 2008. This figure includes both acute and long-term mental health services because available data do not separate acute and long-term care spending. Expenditures had increased an average of 3.0% per year since SFY 2006.[4] When adjusting for inflation and a small decline in the number of children, real per capita spending decreased 0.1% per year.[5]

The definition of a child varies based on program criteria. Special education includes services from birth through a youth's 22nd birthday or high school graduation, whichever comes first. We defined children as people under age 18 for most Medicaid long-term support services because county responsibility for the non-Federal share of some of these services begins at age 18. For home health, we used under age 21 to define children's services. Home health is a common service used under EPSDT and the maximum number of hours available changes at age 21.

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[1] Individuals with Disabilities Education Improvement Act of 2004, Public Law 108-446, 108th Congress

[2] Information provided by Child Health Specialty Clinics December 2008

[3] See Table 8.1

[4] See sources identified in Table 8.1

[5] Thomson Reuters analysis based on data in Table 8.1; inflation data from U.S. Department Of Labor, Bureau of Labor Statistics "Consumer Price Index for All Urban Consumers (CPI-U), Midwest Region" January 26, 2009; and population data from U.S. Census Bureau, Population Division "Annual Population Estimates, Estimated Components of Population Change, and Rates of the Components of Population Change for the United States, States, and Puerto Rico: April 1, 2000 to July 1, 2008" December 22, 2008. The 0.1 percent decrease in real per capita spending is true whether the number of children is based on people under age 18 or people under age 21.

Iowa State Profile Tool
Section 8: Services for Children with Disabilities

Table 8.1: Public Expenditures to Support Children with Disabilities in Iowa, SFY 2006 and SFY 2008

	2006	2008	Average Annual Percent Change	Percent of Total 2008 Expenditures
Special Education (includes early intervention)	**$585,319,735**	**$624,631,185**	**3%**	**74%**
Medicaid Mental Health				
Psychiatric Medical Institution for Children (PMIC)	$25,011,016	$34,331,115	17%	4%
Remedial Services*	$0	$38,894,092	n/a	5%
Rehabilitative Services*	$44,693,031	$0	-100%	0.0%
Iowa Plan (managed behavioral health care premiums)	$39,080,877	$34,274,914	-6%	4%
Children's Mental Health Waiver	$876,328	$4,354,981	123%	0.5%
Targeted Case Management	$1,241,860	$2,579,801	44%	0.3%
Habilitation	$0	$13,043	n/a	0.0%
Total Medicaid Mental Health	**$110,903,112**	**$114,443,902**	**2%**	**14%**
Medicaid Mental Retardation				
ICF/MR	$24,423,391	$23,520,544	-2%	3%
MR Waiver	$26,172,681	$24,349,523	-4%	3%
Targeted Case Management	$5,775,935	$6,782,537	8%	0.8%
Total Medicaid Mental Retardation	**$56,372,007**	**$54,652,604**	**-2%**	**7%**
Medicaid Physical Disability				
Nursing Facility	$5,201,397	$6,952,739	16%	0.8%
Home Health Nursing	$13,024,360	$17,002,573	14%	2%
Home Health Aide	$4,665,241	$3,467,931	-14%	0.4%
Ill and Handicapped Waiver	$8,265,883	$9,012,634	4%	1%
Brain Injury Waiver	$2,154,657	$3,525,418	28%	0.4%
Total Medicaid Physical Disability	**$33,302,454**	**$39,961,296**	**10%**	**5%**
Total Medicaid	**$200,577,573**	**$209,048,802**	**2%**	**25%**
Other Non-Medicaid				
Child Health Specialty Clinics	$2,640,475	$3,304,872	12%	0.4%
Children-At-Home Program	$433,212	$433,212	0%	0.1%
Family Support Subsidy	$1,503,222	$1,503,222	0%	0.2%
Total	**$790,474,217**	**$838,921,293**	**3.0%**	**100%**

Source:
Data provided in November and December 2008 by the Iowa Department of Human Services and Iowa Department of Education
Magellan Health Services *Iowa Plan Monthly Report, October 2008* November 18, 2008 for Iowa Plan data
Iowa Department of Human Services, Iowa Medicaid Enterprise *Title XIX Report of Expenditures: Fiscal YTD Totals as of June 30, 2006* June 25, 2006 for rehabilitative services data
Iowa Department of Human Services, Iowa Medicaid Enterprise *Title XIX Report of Expenditures: Fiscal YTD Totals as of June 30, 2008* June 29, 2008 for remedial services data
Iowa Department of Public Health *Annual Report and Budget Summary: 2007* Undated for Child Health Specialty Clinics data

* State Plan Rehabilitative Services expenditures decreased significantly between 2004 and 2008 because Iowa eliminated four categories of services for children (family centered program, family preservation, group treatment therapy, and treatment foster family care) and replaced them with Remedial Services.

Iowa State Profile Tool
Section 8: Services for Children with Disabilities

Table 8.2 on the following page presents data from SFY 2006 and SFY 2008 regarding the number of children who received long-term support. These data include children who are insured for Medicaid mental health services in the Iowa Plan, but who may not have used services. A total number of children served was not calculated because the data below likely count thousands of individuals more than once. The programs listed on Tables 8.1 and 8.2 are described below.

Education System

The education system is the largest service system for children with disabilities. Part B of the Federal Individual with Disabilities Education Act (IDEA) requires local school districts to provide services and supports to children ages 3-21 under Part B to help children learn in the least restrictive environment. In addition, Iowa provides developmental and supportive services to infants and toddlers under age three with disabilities or developmental delays through education agencies in the Early ACCESS program, which is funded in part by Federal grants under Part C of IDEA.

Iowa's Early ACCESS program serves infants and toddlers and their families through a family-centered system of services coordination and developmental and supportive services. It is based on a partnership between families with eligible infants and toddlers, the Iowa Departments of Education, Public Health, Human Services and the University of Iowa Child Health Specialty Clinics as well as numerous community agencies. The number of children served under Early ACCESS has increased substantially in the past four years (from 2,331 in SFY 2004 to 3,547 in SFY 2008) in children while the Part B program has decreased an average of two percent per year (from 73,637 to 67,390). The majority of funding is from state and local education agencies. Federal grants accounted for 23% of special education funding in SFY 2008.[6]

Early ACCESS utilizes an Individualized Family Service Plan (IFSP) which relies on the family as the driving force in identifying team members serving the child and family from across agencies and developing child and family goals. When the child transitions to Part B services at age three, s/he moves into a child-centered system with the Individual Education Program (IEP) serving as the child's educational blueprint. Planning for the child's adult life is required to begin at age 14 with formal transition planning to discuss learning, living and working in the community.[7] Transition planning includes preparing the individual and family for the reduced benefit set available for adults.

Ten regional Area Education Agencies (AEAs) provide therapies and other specialized staff resources for the Iowa's 362 school districts, and are paid by the local districts. Medicaid is an important partner for medically necessary Medicaid services provided to Medicaid-eligible children.

[6] Data provided November 2008 by Iowa Department of Education

[7] 281 Iowa Administrative Code 41.43

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Table 8.2: Number of Children in Iowa Receiving Public Long-Term Supports, SFY 2006 and SFY 2008

	2006	2008	Average Annual Percent Change
Special Education (ages 3 – 21)	71,394	67,390	-3%
Early Intervention (ages 0 – 2)	2,932	3,547	10%
Total Special Education	**74,326**	**70,937**	**-2%**
Medicaid Mental Health			
Psychiatric Medical Institution for Children (PMIC)	959	1,968	43%
Remedial Services*	0	11,851	n/a
Rehabilitative Services*	9,982	0	-100%
Iowa Plan (average eligible children per month)	174,318	181,670	2%
Children's Mental Health Waiver*	260	662	60%
Targeted Case Management (fee-for-service)	270	675	58%
Total Medicaid Mental Health	**175,547**	**184,313**	**2%**
Medicaid Mental Retardation			
ICF/MR	239	216	-5%
MR Waiver**	2,214	2,589	8%
Targeted Case Management	2,395	2,833	9%
Total Medicaid Mental Retardation	**2,634**	**3,049**	**8%**
Medicaid Physical Disability			
Nursing Facility	80	81	1%
Home Health Nursing	6,258	7,341	8%
Home Health Aide	570	481	-8%
Ill and Handicapped Waiver	1,166	1,263	4%
Brain Injury Waiver	220	344	25%
Total Medicaid Physical Disability	**8,294**	**9,510**	**7%**
Other Non-Medicaid			
Child Health Specialty Clinics	4,012	6,598	28%
Children-At-Home Program	616	616	0%
Family Support Subsidy	378	378	0%

Source:
Data provided between November 2008 and January 2009 by the Iowa Department of Human Services, Iowa Department of Education and Iowa Department of Public Health
Magellan Health Services *Iowa Plan Monthly Report, October 2008* November 18, 2008 for Iowa Plan data
Iowa Department of Human Services, Iowa Medicaid Enterprise *Title XIX Report of Expenditures: Fiscal YTD Totals as of June 30, 2006* June 25, 2006 for rehabilitative services data
Iowa Department of Human Services, Iowa Medicaid Enterprise *Title XIX Report of Expenditures: Fiscal YTD Totals as of June 30, 2008* June 29, 2008 for remedial services data

* The number of people receiving remedial, rehabilitative, and Children's Mental Health Waiver services were excluded from the Total Medicaid calculation to avoid double-counting. Most children who received these services were enrolled in the Iowa Plan and/or received fee-for-service targeted case management.
** The number of people receiving MR Waiver services was excluded from the Total Medicaid Mental Retardation calculation to avoid double-counting. Most MR Waiver participants also receive targeted case management.

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Medicaid Services

Most Medicaid services for children with disabilities have been described in previous sections of this report. This section lists available long-term support services and programs, and provides additional information related to children's utilization of these services. Services are listed in the same target population categories used in Tables 8.1 and 8.2.

Mental Health Services:

- Psychiatric Medical Institutions for Children (PMIC) provide inpatient behavioral treatment for children under age 21. PMICs served one of every 430 children in SFY 2008. Stakeholders indicated PMICs were the only option for many children with serious emotional disturbances until the Children's Mental Health Waiver began in SFY 2006.

- The Children's Mental Health Waiver serves children diagnosed with a serious emotional disturbance and subsequent needs requiring a hospital level of care.[8] It started in SFY 2006 as part of the IowaCare initiative.[9] Respite, in-home family therapy and family and community supports are the services used by most participants. Children also receive fee-for-service targeted case management, which is funded through the Medicaid state plan. Since the waiver started in SFY 2006, it has grown from 260 people to 662 people in SFY 2008. During that time, the number of children receiving PMIC services doubled from 959 to 1968, but expenditures increased by less than 40%. It is possible that average length of stay decreased as children were able to move from PMIC and receive supports in-home with waiver services.[10]

- Remedial services are services to build skills to help decrease mental health symptoms, including crisis intervention. They can also include development of strategies to help the family cope with the child's symptoms and help the person manage his or her behavior. Remedial services are part of Iowa's Medicaid State Plan rehabilitative services benefit. Remedial services started in 2007 to replace four categories of rehabilitative services after CMS and the Federal Health and Human Services Office of Inspector General had concluded that many services were habilitative, i.e., they helped a person develop new skills, and that the rehabilitative services benefit was for restoring a person to a previous level of function.[11]

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[8] Iowa Department of Human Services, Iowa Medicaid Enterprise *Children's Mental Health Waiver Information Packet* Last revised February 18, 2006

[9] Iowa Department of Human Services, Iowa Medicaid Enterprise *State of Iowa 1115 Waiver (Iowa Care) 2007 Annual Report: July 1, 2006 – June 30, 2007* October 31, 2007

[10] Data provided November 2008 by Iowa Medicaid Enterprise

[11] U.S. Department of Health and Human Services, Office of the Inspector General *Iowa Medicaid Payments Claimed for Children's Remedial Services* January 16, 2009. The word "remedial" is unusual for State Plan services but refers to language in Section 1905(a)(13) of the Social Security Act, which authorizes "diagnostic, screening, preventive, rehabilitative services, including any medical or remedial services (provided in a facility, a home, or other setting) recommended by a physician or other licensed practitioner of the healing arts within the scope of their practice under State law, for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level"

- As described in Section 7: Mental Health Services, the Iowa Plan is a managed care arrangement that provides inpatient hospitalization, psychiatrist, psychologist services, targeted case management, and other mental health services. It does not include some mental health supports, including remedial services, PMIC, and the children's mental health waiver.[12]

Services for children with mental retardation:

Medicaid provides the same services as are available for adults and described in Section 6: Services for People with Mental Retardation: ICF/MR, the MR Waiver, and targeted case management. Children under age 18 account for 24% of the Medicaid MR Waiver population and 10% of the ICF/MR population.[13]

Services for children with physical disabilities or brain injuries:

Medicaid provides the same services as are available for adults and described in Section 4: Services for Older Adults and Section 5: Services for People with Physical Disabilities: nursing facility care, home health, Ill and Handicapped Waiver, and Brain Injury Waiver.

To comply with Federal Early and Periodic Screening, Diagnosis and Treatment (EPSDT) requirements, Iowa has higher service limits for children under age 21. There is no explicit limit for private duty nursing, although services must be medically necessary.[14] In SFY 2008, private duty nursing accounted for $6.4 million of the $17.0 million spent on home health nursing for children.[15] The remaining $10.6 million was for intermittent nursing services for children with medically predictable recurring needs.[16] As mentioned in Section 5: Services for People with Physical Disabilities, many states use less medically involved services such as personal care or attendant care to serve these individuals.

Other Non-Medicaid Services

Two additional programs in the Department of Human Services provide small grants to families with disabilities. The Family Support Subsidy, administered through DHS Child and Family Services Division provides families of children with disabilities a monthly stipend to purchase needed services. The Children at Home Program provides small grants based on individual requests from families and is administered locally. Regulations for the Family Support Subsidy Program and the Children-at-Home Program have been consolidated under a new regulatory Chapter F, Comprehensive Family Support.[17] Funding for both programs, and the number of

[12] Iowa Department of Human Services, Iowa Medicaid Enterprise *Request for Proposals for the Iowa Plan for Behavioral Health* December 31, 2008

[13] Data provided by Iowa Medicaid Enterprise

[14] Iowa Department of Human Services, Iowa Medicaid Enterprise *Medicaid Provider Manual: Home Health Services* July 1, 2000

[15] Data provided by Iowa Medicaid Enterprise

[16] Iowa Department of Human Services, Iowa Medicaid Enterprise *Medicaid Provider Manual: Home Health Services* July 1, 2000

[17] Iowa DHS General Letter No.16-F-2; December 12, 2008

families served, in both programs have remained at the same level with no changes until funding reductions that affected a number of programs in SFY 2009.

The University of Iowa Child Health Specialty Clinics (CHSC) are an important resource to children and families and a central point of coordination for numerous programs. The clinics are a significant part of the Children with Special Health Care Needs program funded by Federal Maternal and Child Health Block Grants authorized by Title V of the Social Security Act. Services are delivered through a system of community based regional centers. The CHSC also works in partnership with Medicaid's EPSDT program and the Ill and Handicapped Waiver. CHSC adopted the family-centered philosophy in the 1990s and continues to refine its programs within that framework. The CHSC is the main clinical triage and evaluation resource for children referred for severe emotional disorders under a U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) System of Care Grant in northeast Iowa.

The program structure is currently undergoing a redesign process to move from a direct care provider structure to one that enables and coordinates multiple service efforts. In addition, for several years CHSC has been expanding its staff complement of parent consultants – parents of children with disabilities who assure that families and providers have links to community services. The Parent Consultant Network supports families in the Early ACCESS program, Medicaid home and community-based services waivers; the Early Hearing, Detection, and Intervention program; the Iowa Department of Public Health's Health and Disease Management Program; and the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) System of Care grant in northeast Iowa.[18]

The Child Health Specialty Clinics served 6,598 children in 2008 and reported a higher proportion of direct care visits for mental/behavioral health. Some behavioral health services are provided through the use of telehealth technology so that families can access services in their own communities which may lack the specialty providers.

Other Supports Commonly Used by Children with Disabilities

People who need long-term care often need to combine and coordinate many different supports to live independently. Children with disabilities often receive supports from the following sources, which are described further in Appendix B:

- Income support from Supplemental Security Income
- Health insurance, often from Medicaid
- Local paratransit services
- Other supports for low-income families as necessary, such as housing assistance, food assistance, and energy assistance

Demographic and Utilization Trends

The number of children in Iowa has been declining by less than one percent per year since 2000, and is expected to decrease – although at a slower rate – over the next 20 years. If disability rates remain constant, the need for services could decline gradually (See Table 8.3).

[18] Data provided by University of Iowa Child Health Specialty Clinics

Table 8.3: Number of Iowans under Age 21, 2000 - 2030

	2000	2005	2010	2015	2020	2025	2030
Population Under Age 21	875,168	847,446	835,639	822,451	811,461	793,990	774,385
Percent of Total Population	29.9%	28.5%	27.8%	27.2%	26.9%	26.5%	26.2%

Sources:
U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for 2000 and 2005 data
U.S. Census Bureau, Population Division "Interim Projections of the Population by Selected Age Groups for the United States and States: April 1, 2000 to July 1, 2030" April 21, 2005 for 2010 – 2030 data

Table 8.4 compares Iowa's institutional utilization to the national average, where state comparison data are available. Iowa has a relatively high proportion of children in state institutions for people with developmental disabilities (Glenwood and Woodward) and in nursing facilities. Data comparing Iowa to most states regarding children in other institutions – such as private ICF/MR and psychiatric treatment facilities – are not available. Similarly, data sources for community supports for children that include a majority of states also are not available.

Table 8.4: Institutional Utilization Data Regarding Children under Age 21, per 100,000 Population under 21

	State Developmental Disabilities Institutions, Residents on June 30, 2006	Nursing Facilities, Medicaid beneficiaries, Oct. 2005 – Sept. 2006	Nursing Facilities, Medicaid-funded days, Oct. 2005 – Sept. 2006
Iowa	**9.8**	**9.0**	**2,187**
United States	1.7	5.8	909

Sources:
Prouty, Robert; Smith, Gary; Lakin, K. Charlie (eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006* University of Minnesota: August 2007 for developmental disabilities institution data
Thomson Reuters analysis of data from the Centers for Medicare & Medicaid Services, Medicaid Statistical Information System (MSIS) State Summary Datamart for nursing facility data
U.S. Census Bureau, Population Division "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007" May 1, 2008 for population data

System Components Associated with Rebalancing

The remainder of this section describes the extent to which Iowa's system of supports for children includes eight system components that have been previously identified in states that have rebalanced their long-term support system, i.e., reduced institutional utilization and increased access to home and community-based services. The components are defined in the introduction of this report.

Consolidated State Agency

Multiple agencies support children with disabilities, reflecting the complex needs of children with disabilities. Advocates and state agencies noted that the complexity of children's needs often requires coordination across systems and causes blurring of agency responsibilities. The

redesign of CHSC to support behavioral as well as physical health services is one example of this recognition. The Early ACCESS program is another example, using a services coordination model that crosses boundaries and coordinates services from all funding sources in partnership with families. In addition, the newly established Children's Bureau in the Department of Human Services, Mental Health and Disability Services division will provide another avenue for system planning across funding streams.

Single Access Point

The education system serves as primary access points for the majority of children and youth. Most programs operate parallel processes without a uniform assessment process. Children and families may or may not be referred to other services based on program philosophies and skills and knowledge of case managers. For example, stakeholders reported the Medicaid managed behavioral health care system has enhanced access to acute services but long-term supports remain difficult to access or – in some areas – are non-existent.

The CHSC serve as an assessment point for multiple programs such as Early ACCESS, EPSDT screening, and the Ill and Handicapped Waiver, and therefore perform some of the functions of a single access point. The CHSC are strengthening their efforts to provide more support to families and providers in assessment and coordination and access of needed services. For example, the CHSC Medical Home model is an effort to improve coordination of medical services by primary care physicians who have links to community services.

For children under age 3, the Early ACCESS program for infants and toddlers provides an entry point model where the Departments of Education, Public Health, Human Services and the Child Health Specialty Clinics as well as numerous local agencies have entered into cooperative agreements making agencies responsible for coordinating their services delivery rather than the families coordinating agencies. Families identify service needs across programs through a coordinated assessment process and the written IFSP directs the efforts of service providers based on family strengths and goals. This model is not available for older children so families transition into the network of multiple fragmented programs with the family performing the linking and communication functions.

Institutional Supply Controls

The supply control mechanisms for ICF/MR, nursing facilities, and psychiatric hospitals were described in previous sections. In addition, there is a moratorium on nursing facility beds targeted for children. The authors are not aware of specific institutional supply controls for PMIC. The number of PMIC beds decreased six percent from SFY 2004 to SFY 2005, from 529 to 498 beds, and then increased gradually to 532 in SFY 2008.[19]

Transition from Institutions

Initiatives to help people move from institutions have been described in other sections of this report, and the authors are not aware of additional initiatives specific to children. It is a difficult decision for families to make when selecting institutional care for a child. It is oftentimes the only option available or the care demands are so overwhelming the family can no longer provide what is needed.

[19] Data provided November 2008 by the Iowa Department of Inspections and Appeals

The number of PMIC admissions increased sharply when the Children's Mental Health Waiver began in 2006, while expenditures did not increase as quickly. One possibility is that children are able to leave PMIC earlier than before.

Continuum of Residential Options

In-home services and family supports are essential elements of the continuum for children with disabilities and their families. When these supports are not sufficient, community residential options can provide important opportunities to serve children and youth in the least restrictive setting possible. Residential services where supports and therapies are available 24 hours a day are most common for children and youth with serious emotional disturbances. The Iowa Plan paid for residential treatment for 232 children and youth in SFY 2008, including mental health and substance abuse treatment. In addition, the Mental Retardation Waiver offers a residential-based Supported Community Living service that served 48 children and youth under age 18 in SFY 2008.[20] Several stakeholders said there were not enough community residential options for children with challenging behaviors, which reportedly contributes to the demand for PMIC services.

HCBS Infrastructure

The HCBS infrastructure for children is the sum of multiple service systems based on specific populations, which are described in other sections of this report. As described above under "Consolidated State Agency", a few initiatives have examined the system across the established systems, such as the Early ACCESS program for children under age three and the SAMHSA System of Care Grant, which provides behavioral health services and while building upon the established CHSC structure that has typically served children with physical impairments.[21]

Participant Direction

As described in Section 5: Services for People with Physical Disabilities, the Department of Human Services implemented participant-direction in all Medicaid home and community-based services waivers except the Children's Mental Health Waiver, with support from a Robert Wood Johnson Foundation Cash & Counseling Grant. For children enrolled in a waiver, participant-direction means parents or guardians can directly employ direct support workers or use an individual budget to obtain necessary, cost-effective services not specified in the waiver.

Quality Management

Many services for children with disabilities are also provided to adults. For these services, quality management processes have been discussed in previous sections of this report. For example, the Department of Inspections and Appeals licensed ICF/MR, home health agencies, and nursing facilities; while the Department of Human Services, Mental Health and Disability Services division accredits several types of mental health and mental retardation services providers. For children served in Medicaid home and community-based services waivers, the process is described in Section 4: Services for Older Adults.

[20] Data provided November and December 2008 by Iowa Department of Human Services, Iowa Medicaid Enterprise

[21] Iowa Department of Human Services *Offer #401-HHS-013: Mental Health and Disability Services* Undated budget narrative for SFY 2010 proposal

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For special education and early intervention services, Federal law requires a State Performance Plan submitted to the U.S. Department of Education that evaluates implementation of requirements and describes improvement measures. The state must assess its performance related to indicators developed by the U.S. Department of Education regarding outreach, the use of the least restrictive educational environment, graduation rates, suspensions and expulsions, complaints, and mediations. Iowa uses a participatory process where stakeholders including families are involved in the process. The teams established for IEP and IFSP planning serve a quality management function on an individualized basis. Each IEP or IFSP meeting must review progress and services delivery in relation to goal achievement.

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Prouty, Robert; Smith, Gary; Lakin, K. Charlie (eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006* University of Minnesota: August 2007. Accessed November 2007 at http://www.rtc.umn.edu.

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Appendix A

Appendix A: Stakeholders Interviewed for the Iowa State Profile Tool

Greg Anliker, Iowa Department of Elder Affairs

Robert Bacon, University of Iowa, Center for Disabilities and Development

Cindy Baddeloo, Iowa Health Care Association/Iowa Center for Assisted Living

John Baldwin, Iowa Department of Corrections

Julie Beckett, Family Voices

J Bennett, Iowa Department of Inspections and Appeals

Jane Borst, Iowa Department of Public Health

Anthony Carroll, AARP Iowa

Shelly Chandler, Iowa Association of Community Providers

Eileen Creager, Department of Human Services

Di Findley, Iowa CareGivers Association

Dawn Francis, Iowa Statewide Independent Living Council

Eugene Gessow, Department of Human Services

Christine Grundmeyer, Auxi HealthServices

Becky Harker, Iowa's Developmental Disabilities Council

Ann Harrmann, Coalition for Family and Children's Services

Donna Harvey, Hawkeye Valley Area Agency on Aging

Linda Hinton, Iowa State Association of Counties

Deb Johnson, Iowa Department of Human Services

Dean Lerner, Iowa Department of Inspections and Appeals

John Lee, Iowa Department of Education

John McCalley, Iowa Department of Elder Affairs

Julie McMahon, Iowa Department of Public Health

Judy Naber, Iowa Department of Public Health

Tom Newton, Iowa Department of Public Health

Liz O'Hara, University of Iowa, Center for Disabilities and Development

Jean Oxley, Iowa Senior Living Coordinating Unit

Dr. Allen Parks, Iowa Department of Human Services

Dana Petrowsky, Iowa Association of Homes and Services for the Aging

Sylvia Piper, Iowa Protection and Advocacy Services

Ann Riley, University of Iowa, Center for Disabilities and Development

Rik Shannon, Iowa's Developmental Disabilities Council

Jennifer Steenblock, Iowa Department of Human Services

Margaret Stout, National Alliance on Mental Illness (NAMI) Iowa

Dan Strellner, Abbe

Kathy Sutton, Iowa Department of Inspections and Appeals

Lisa Uhlenkamp, Iowa Health Care Association/Iowa Center for Assisted Living

Lloyd Vanderkwaak, ChildServe

Jennifer Vermeer, Iowa Department of Human Services

Dr. Debra Waldron, University of Iowa, Child Health Specialty Clinics

Bob Welsh, Iowa Senior Living Coordinating Unit

Mark Wheeler, Iowa Association for Home Care

Brian Wilkes, University of Iowa, Child Health Specialty Clinics

Ben Woodworth, Iowa Department of Public Health

Stephen Wooderson, Iowa Vocational Rehabilitation Services

Beverly Zylstra, Iowa Department of Inspections and Appeals

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Appendix B: Other Programs Serving Older Adults and People with Disabilities

While this profile focused on long-term supports, many other supports are vital to older adults and people with disabilities living in the community. For example, programs that provide income support, health care, transportation, and housing can be essential for a person's quality of life. As a result, changes in these programs can affect the ability of individuals to live in the community and therefore affect Iowa's rebalancing efforts.

This appendix describes common support programs, with Iowa-specific data as available. The programs are grouped according to the supports they provide. Medical programs are listed first, because of the close coordination that is often necessary between the health and long-term care systems. Substance abuse treatment programs are then described, followed by programs that provide basic necessities everyone needs in daily life: housing, food, income, energy assistance, and transportation.

Medical Programs

People with disabilities and older adults can have significant health needs that affect community living. As a result, Medicare and Medicaid are important sources of medical care. In addition, state-funded programs can help people with prescription drug payments, and the Department of Public Health facilitates several additional programs that assist targeted populations.

Medicare

Medicare is a federal health insurance program available for almost all people age 65 or older and for many people with disabilities. Since its beginning, Medicare services have been divided into two components that are financed differently. Part A is funded by payroll taxes and covers hospital care and related services (e.g., post-acute nursing facility admissions). Part B is funded by participant premiums and covers physician and other outpatient services. Medicare is available as fee-for-service health insurance or through managed care organizations that cover both Part A and B (Medicare Advantage).

As of July 2007, 498,863 Iowans received Medicare coverage.[1] Since 2004, the number of Medicare enrollees has increased about one percent per year. A majority of this increase was in the number of people under age 65 with disabilities, which increased from 59,496 to 66,639 (3.9 percent per year). The number of people age 65 or older increased 0.5 percent per year from 425,803 to 432,224.[2]

Effective January 1, 2006, Medicare added a prescription drug benefit, called Medicare Part D. This benefit is available either through stand-alone Prescription Drug Plans or through Medicare

[1] U.S. Centers for Medicare & Medicaid Services *Medicare Aged and Disabled by State and County as of July 1, 2007* Undated

[2] Thomson Reuters analysis of U.S. Centers for Medicare & Medicaid Services *Medicare Aged and Disabled by State and County as of July 1, 2007* Undated; U.S. Centers for Medicare & Medicaid Services *Medicare Enrollment – Aged Beneficiaries as of July 2004* Undated and U.S. Centers for Medicare & Medicaid Services *Medicare Enrollment – Disabled Beneficiaries as of July 2004* Undated

Iowa State Profile Tool
Other Programs

Advantage plans that cover drugs along with other Medicare services. People who enroll for the program must pay a monthly premium that varies according to the plan they choose. A subsidy is available for people with low income and resources.[3] As of January 2009, 335,617 Iowans were enrolled in stand-alone plans or Medicare Advantage.[4]

Medicaid (Medical Assistance)

Medicaid provides health and long-term care services for older adults, people with disabilities, and low-income families with children. Many people with disabilities and older adults receiving Medicaid also are eligible for Medicare. These dual eligible individuals use Medicare for medical needs such as hospital and physician services. Medicaid covers co-payments, deductibles, and services that Medicare does not cover.

Prescription Drug Donation Program

The Iowa Department of Public Health manages the Prescription Drug Donation Repository Program, which began in May 2007. The program authorizes medical facilities and pharmacies to re-distribute donated prescription drugs and supplies that might otherwise be destroyed. Drugs may be donated by pharmacy providers, physicians, and individuals if sealed in their original packaging. In calendar year 2008, the program helped over 3,000 low-income Iowans receive an estimated 428,000 doses of medications valued at nearly $647,000.[5]

Prescription Drug Payment

The Iowa Department of Public Health administers two programs that pay directly for prescription drugs. The AIDS Drug Assistance Program pays for drugs to treat AIDS for low-income individuals who are not fully covered by Medicare, Medicaid, or other insurance. Participants must have AIDS or an HIV infection and meet financial eligibility criteria. The ADAP program is funded primarily by a Federal grant under the Ryan White CARE Act, with state funds enabling additional people to be served.[6] Total expenditures for AIDS and Hepatitis prevention and treatment was $5.2 million in State Fiscal Year 2008 compared to $4.3 million in State Fiscal Year 2004. A $750,000 increase in Federal funds in 2008 caused most of the increase.[7] The state-funded Prescription Services program offers free treatment for people with a sexually transmitted disease or a tuberculosis infection. Funding has decreased an average of four percent per year, from $172,674 in State Fiscal Year 2004 to $147,357 in State Fiscal Year 2008.[8]

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[3] U.S. Social Security Administration, *Getting Help with Medicare Prescription Drug Plan Costs* February 2009

[4] U.S. Centers for Medicare & Medicaid Services *Total Medicare Beneficiaries with Drug Coverage by Stand-Alone PDP, Medicare Advantage, RDS, and Creditable Coverage by State as of February 1, 2009* February 1, 2009

[5] Iowa Department of Public Health "Donated Prescription Drugs Aid Thousands of Iowans" February 6, 2009

[6] Iowa Department of Public Health *Guidelines for Ryan White Title II Programs* January 2007

[7] Iowa Department of Public Health *2008 Annual Report and Budget Summary* Undated and Iowa Department of Public Health *2005 Annual Report and Budget Summary* Undated

[8] Iowa Department of Public Health *2008 Annual Report and Budget Summary* Undated

Iowa State Profile Tool
Other Programs

Diagnosis-Specific Programs

The Iowa Department of Public Health (IDPH) operates several programs that provide screening, community education, and in some cases ongoing treatment to people with specific diagnoses that may cause disability. IDPH also contracts with the University of Iowa, Center for Disability and Development to provide an eight-week called "Living Well with a Disability" that helps people set personal goals to promote health and wellness. Specific conditions currently targeted by IDPH programs include:

- Asthma
- Brain Injury
- Cancer
- Congenital and Inherited Disorders
- Diabetes
- Heart Disease and Stroke
- HIV/AIDS
- Hepatitis[9]

Substance Abuse Prevention and Treatment

The Iowa Department of Public Health also provides funding for substance abuse prevention and treatment. For SFY 2008, IDPH received $6.0 million for prevention efforts, a 1.4 percent per year decrease from SFY 2004 funding of $6.4 million. IDPH received $27.8 million in SFY 2008 for substance abuse treatment efforts, a five percent per year increase from $22.7 million in SFY 2004.[10] Funding amounts include both state appropriations and Federal grants from the U.S. Substance Abuse and Mental Health Services Administration. As described in Section 7: Mental Health Services, IDPH contracts with the Iowa Plan managed care contractor to manage substance abuse treatment funds, which can facilitate integrated treatment for people with both mental illness and an addiction disorder.

Housing Assistance

Public housing programs targeted to people with disabilities or older adults are described below. Most programs are funded by the federal department of Housing and Urban Development (HUD) and operated locally by city and county Public Housing Authorities (PHAs). In addition to the programs mentioned here, several community development programs support the development of affordable housing, and can be used to improve or increase housing for people with disabilities and older adults. Examples include: the Low-Income Housing Tax Credit; the Community Development Block Grant; the HOME Investment Partnerships Program; and the Mortgage Insurance for Nursing Homes, Intermediate Care, Board & Care and Assisted-living Facilities Program.

[9] Iowa Department of Public Health "What We Do – Profiles of IDPH Programs, Services, and Activities" Undated

[10] Iowa Department of Public Health *2008 Annual Report and Budget Summary* Undated and Iowa Department of Public Health *2005 Annual Report and Budget Summary* Undated

Iowa State Profile Tool
Other Programs

Section 8 Housing Choice Voucher Program

The Section 8 program pays part of a low-income household's rent. Eligible households are put on a waiting list until new vouchers are available or a family leaves the program. When vouchers become available, people select their housing among landlords that accept the public housing authorities' payment standard. The PHA pays this standard, minus a minimum monthly rent. The household pays the minimum rent, typically 30 percent of income.[11]

A portion of Section 8 vouchers are reserved specifically for people with disabilities. Mainstream Vouchers can be paid to any landlord that accepts Section 8 vouchers. Designated Housing Vouchers and Certain Development Vouchers can help people with disabilities access housing developments that target older adults.[12]

Home and Community-Based Services Rent Subsidy Program

The Home and Community Based Services (HCBS) Rent Subsidy Program provides housing assistance for people on a Medicaid HCBS Waiver who are on a waiting list for Section 8 vouchers or other rent subsidies.[13] This state-funded program served 565 people in SFY 2008, a two percent per year increase from 532 in SFY 2005. In other years, the program has served as many as 625 people. Program expenditures were $609,573 in SFY 2008 and have been above $600,000 each full year that IFA has administered the program.[14]

Section 202 Supportive Housing for the Elderly Program

Section 202 is one of several HUD programs that encourage development of affordable housing, rather than directly fund rent. This program provides interest-free capital to develop and rehabilitate housing structures, and offers rental assistance for five years to cover the difference between operating costs and the residents' rental payments. Residents are expected to pay 30% of their income for rent. Funds do not have to be repaid if the project serves low-income people age 62 or older for at least 40 years.[15]

Section 811 Supportive Housing for Persons with Disabilities

The Section 811 program is similar to Section 202, but serves people with disabilities. The requirements are the same as for Section 202, except eligible residents must have at least one household member age 18 or older with a physical or developmental disability or chronic mental illness.[16]

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[11] U.S. Department of Housing and Urban Development *Housing Choice Vouchers Fact Sheet* Undated

[12] U.S. Department of Housing and Urban Development *Vouchers for People with Disabilities* Undated

[13] Iowa Partnership for Community Integration: Housing Subcommittee *Housing Inventory Report* September 4, 2007

[14] Data provided December 2008 by Iowa Finance Authority

[15] U.S. Department of Housing and Urban Development *Section 202 Supportive Housing for the Elderly Program* November 8, 2007

[16] U.S. Department of Housing and Urban Development *Section 811 Supportive Housing for Persons with Disabilities* November 8, 2007

Iowa State Profile Tool
Other Programs

Emergency Shelter Grants

The Emergency Shelter Grants fund projects that operate, increase, and improve the quality of emergency shelters. Grants can also be used to provide transitional housing and social services for homeless people or to provide funds to prevent homelessness.

Supportive Housing Program

The Supportive Housing Program funds the development, rehabilitation, and operation of supportive housing services to help homeless persons live more independently. It is designed to provide residents of the program with housing stability, improved skill sets and/or incomes, and increased control over decision-making.[17]

Shelter Plus Care Program

The Shelter Plus Care Program provides rental assistance for long-term housing and support for homeless people with disabilities and their families. Grantees may target particular conditions such as serious mental illness, substance abuse, or AIDS.[18]

Single Room Occupancy (SRO) Program

The SRO program helps refurbish single room occupancy space and provides rental assistance for homeless people. HUD works in conjunction with PHAs and building owners to provide rent subsidies for 10 years for homeless individuals in these dwellings.[19]

IowaAble Loan Programs

The Iowa Able Foundation helps people with disabilities and older Iowans obtain low-interest loans for home modifications and/or assistive technology such as wheelchairs, communication devices, and vehicle modifications. The foundation is supported in part by a grant from the U.S. Department of Education.[20] Between SFY 2004 and SFY 2008, 106 people have received loans from local banks or credit unions through the Iowa Able Foundation. Total loans were $660,531 during this time.[21]

Nutrition Services

The Federal Supplemental Nutrition Assistance Program (formerly called the Food Stamp Program) pays for groceries for households that meet income and asset requirements, including many older adults and people with disabilities. Eligible groceries include most foods, but

[17] U.S. Department of Housing and Urban Development *Supportive Housing Program* March 21, 2008
[18] U.S. Department of Housing and Urban Development *Shelter Plus Care Program (S+C)* March 21, 2008
[19] U.S. Department of Housing and Urban Development *Single Room Occupancy Program (SRO)* March 21, 2008
[20] Iowa Able Foundation "History of the Iowa Able Program" Undated
[21] Data provided by the Iowa Able Foundation in November 2008

exclude meals made for immediate consumption, alcohol, dietary supplements, and pet food.[22] The average monthly number of people receiving food assistance increased rapidly between 2004 and 2006, from 179,179 to 225,717, an average increase of 12 percent per year. In 2006, an estimated 71% of eligible Iowans participated in the program.[23] In addition, older adults can receive congregate meals and home delivered meals through the Iowa Department of Elder Affairs as described in Section 4: Services for Older Adults.

Income Support

Most older adults and people with severe disabilities receive monthly income support from the federal Social Security Administration. Most adults age 65 and older receive the traditional Social Security benefit for retired workers and their surviving spouses and children, Old Age and Survivors Insurance. Two additional benefits serve people with disabilities whose impairments affect their ability to work. The Disability Determination Services Bureau in Iowa Vocational Rehabilitation Services reviews applications for disability benefits and makes recommendations to the Social Security Administration regarding eligibility.[24]

Social Security Disability Insurance

People who have worked a minimum number of quarters in the United States and paid into the Social Security system are eligible for Social Security Disability Insurance (SSDI). The required minimum varies depending on the person's age at the onset of disability. The payment also varies according to the person's income before the disability. SSDI benefits are also available for the disabled person's spouse and dependent children. The number of Iowans receiving SSDI benefits increased from 70,250 in December 2003 to 78,428 in December 2007, an average increase of 2.7 percent per year.[25]

Supplemental Security Income

People who have not worked enough to qualify for SSDI can obtain Supplemental Security Income (SSI), which has a lower benefit than SSDI. In December 2007, 44,249 Iowans received SSI Iowa. The number of participants has increased 1.6 percent per year since December 2003, when there were 41,579 participants.[26] Like many states, increases the monthly SSI payment with a state-funded supplement.[27] A person can qualify for the state supplement, but not for SSI, if his or her income is greater than the SSI benefit but lower than the total of SSI and the state supplement.

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[22] Iowa Department of Human Services, *Food Assistance, Employee's Manual, Title 7, Chapter A, Participant Use of Benefits* December 17, 2004

[23] Cunnyngham, Karen E.; Castner, Laura A.; and Schirm, Allen L. *Empirical Bayes Shrinkage Estimates of State Food Stamp Program Participation Rates in 2004-2006 for All Eligible People and the Working Poor* February 2009

[24] Iowa Department of Management *Iowa Budget Report: Fiscal Year 2010 Report* January 28, 2009

[25] U.S. Social Security Administration *Annual Statistical Supplement, 2008* 2009 and U.S. Social Security Administration *Annual Statistical Supplement, 2004* August 2005

[26] *Ibid.*

[27] For most people, this supplement is $22.00 per month for an individual. Higher state supplements, from $142 to $480.55 per month for an individual, are provided for people who live with a dependent person, receive in-home health related care, or live in certain facilities.

Iowa State Profile Tool
Other Programs

Energy Assistance

Many low-income individuals, including older adults and people with disabilities, are unable to pay heating bills in winter months. Two types of energy assistance are available, both administered by the Iowa Department of Human Rights. The Low-Income Energy Assistance Program (LIHEAP) pays a portion of the heating bills and educates consumers about energy conservation and weatherization.[28] The number of people receiving LIHEAP has increased 0.9 percent per year since SFY 2004, from 82,431 to 85,338 individuals. Expenditures increased $33.5 million to $47.9 million during this time, reflecting higher energy prices in SFY 2008.[29]

The Weatherization Assistance Program installs cost-effective improvements to homes, including repairing and improving heating systems and installing insulation.[30] In SFY 2008, 1,712 homes were weatherized, a two percent per year decrease from SFY 2004. The number of homes weatherized has fluctuated from 1,700 and 2,100 homes per year in recent years. Available funding for weatherization increased during that time from $10.8 million to $13.4 million.[31]

Transportation Services

The authors were not able to identify state-funded programs specifically for people with disabilities or older adults. Some human services programs provide transportation, however. For example, Area Agencies on Aging provide transportation among many services for older adults. Also, transportation is a service in five Medicaid home and community-based services waivers, and Medicaid provides transportation for almost all its services to people who need transportation assistance. An interdepartmental Transportation Coordination Council is planning a transportation brokerage system as part a Systems Transformation Grant from the U.S. Centers for Medicare & Medicare Services, which would include multiple funding streams in an effort to improve coordination, reduce administrative expense, and therefore improve access to transportation services.[32]

[28] Iowa Department of Human Rights "Bureau of Energy Assistance" Undated

[29] Data provided November 2008 by Iowa Department of Human Rights

[30] Iowa Department of Human Rights "Bureau of Weatherization" Undated

[31] Data provided November 2008 by Iowa Department of Human Rights

[32] Iowa Department of Human Services, Iowa Medicaid Enterprise "Systems Readiness Assessment" part of application for the Federal Systems Transformation Grant. September 29, 2005

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Appendix C: Maps Showing Local Variation in Service Delivery

Many individuals noted dramatic differences in service availability across the state, a phenomenon common among states. This appendix uses a series of maps to show local or regional variation in spending for several types of publicly funded services:

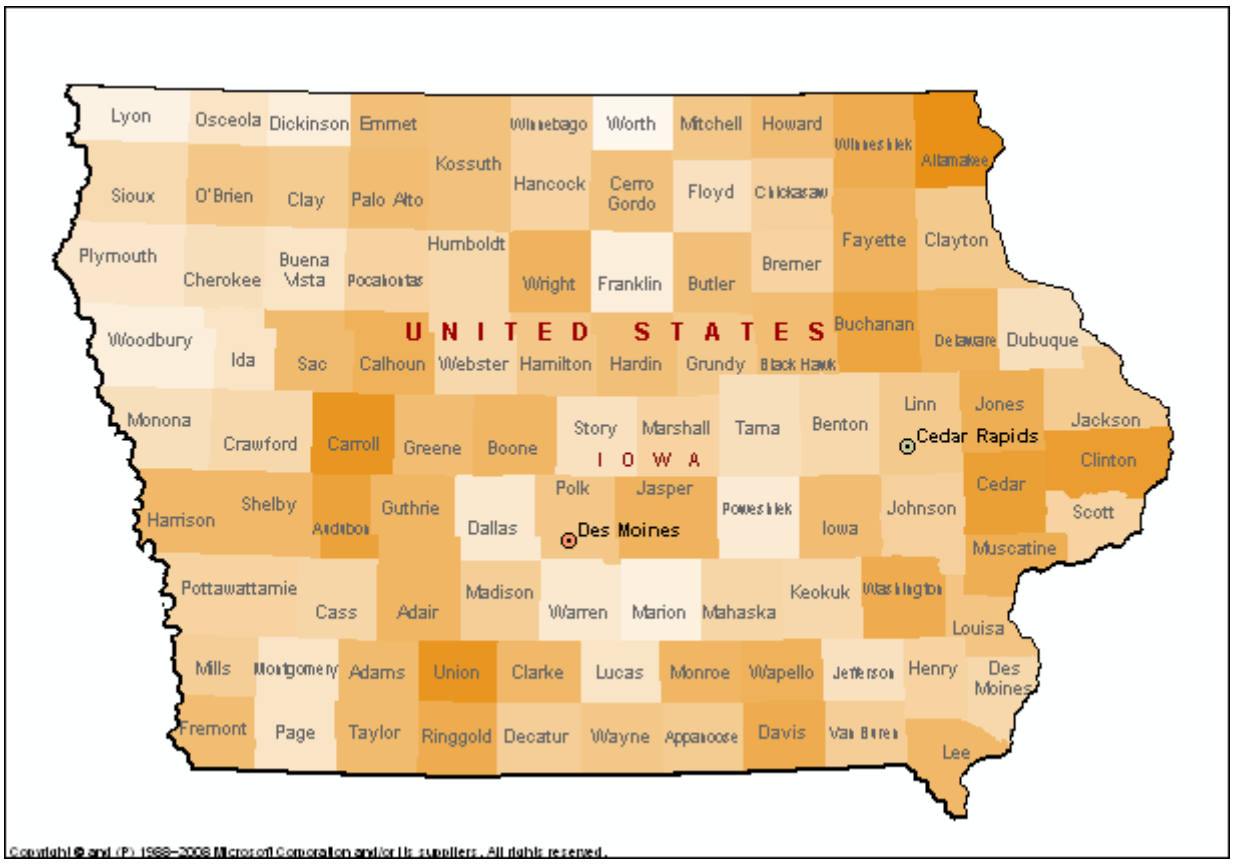
1. The Mental Retardation Waiver
2. The Ill and Handicapped Waiver
3. The Brain Injury Waiver
4. Home health nursing
5. Assisted Living in the Elderly Waiver (provided under the Consumer Directed Attendant Care option)
6. In-home paraprofessional supports for older adults, the sum of spending for multiple services including:
    - 6a. Elderly Waiver Consumer-Directed Attendant Care (CDAC), not including assisted living
    - 6b. Medicaid State Plan Home Health Aide
    - 6c. Homemaker
7. Home delivered meals for older adults
8. Adult day care for older adults
9. Respite for older adults

Several maps (6, 6c, 7, 8, and 9) combine multiple funding sources available for long-term care: Medicaid, the Senior Living Program, Title III of the Older Americans Act, and Elderly Wellness funding through the Iowa Department of Public Health. These maps show total public support for common long-term care services in different regions of the state. Data are presented according to regional Area Agencies on Aging because the Department of Elder Affairs did not have expenditures data available at a county level.

The final map in this appendix (Chart C.10) documents local variation in the percentage of people age 65 or older, a common demographic indicator of long-term care demand. A map was not developed for the other indicator of long-term care demand used in this report – disability rates – because reliable local data were not available for many counties.

Iowa State Profile Tool
Local Data Maps

Chart C.1: Mental Retardation Waiver per Capita Expenditures by County of Legal Settlement, SFY 2008



MR Waiver: Dollars per Person

$180

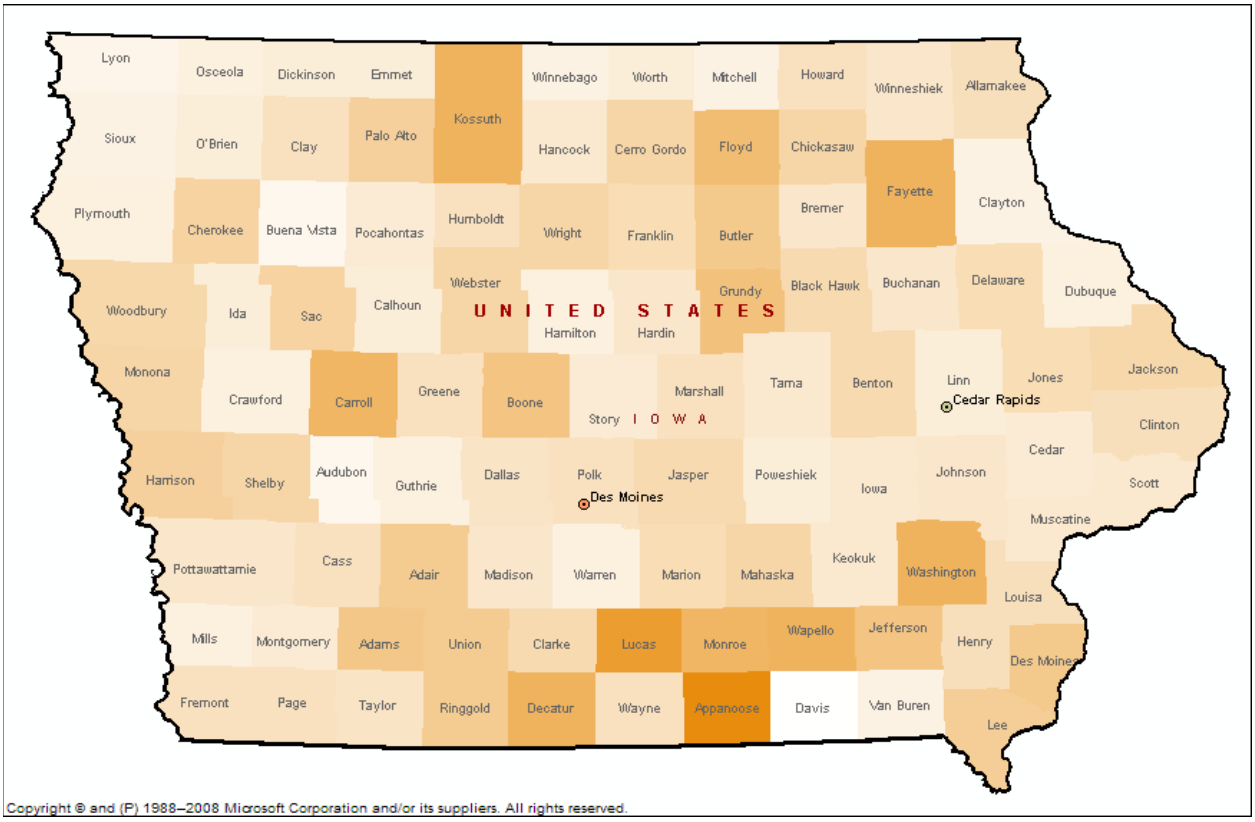
$100

$20

Sources:
Data provided November 2008 by Iowa Department of Human Services, Iowa Medicaid Enterprise
U.S. Census Bureau, Population Division "2007 Population Estimates Program: Table 6. Sex by Age" March 2008
(2007 is the most recent year for which Census data is available on county level)

Iowa State Profile Tool
Local Data Maps

Chart C.2: Ill & Handicapped Waiver per Capita Expenditures by County of Residence, SFY 2008



I&H Waiver: Dollars per Person

$24

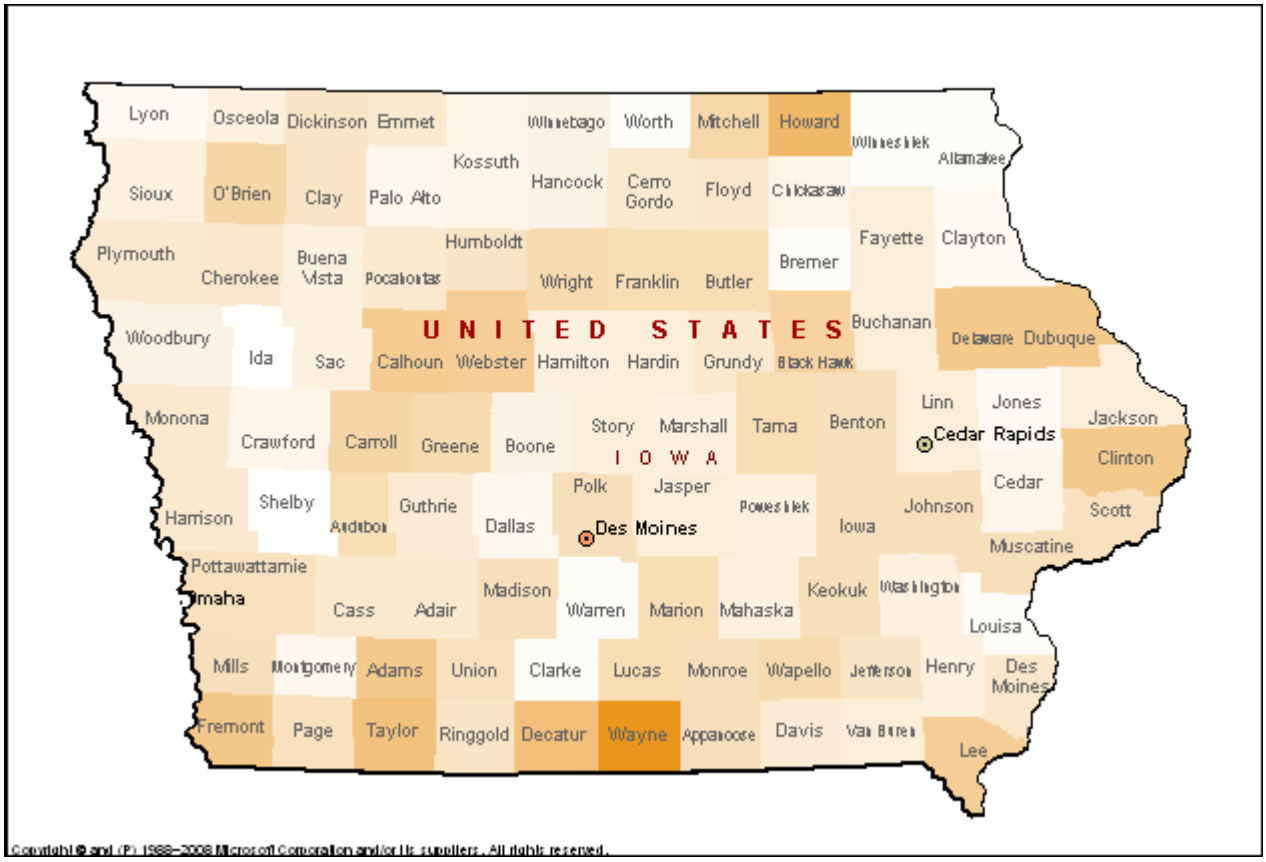
$12

$0

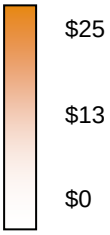
Sources:
Data provided November 2008 by Iowa Department of Human Services, Iowa Medicaid Enterprise
U.S. Census Bureau, Population Division "2007 Population Estimates Program: Table 6. Sex by Age" March 2008
(2007 is the most recent year for which Census data is available on county level)

Iowa State Profile Tool
Local Data Maps

Chart C.3: Brain Injury Waiver per Capita Expenditures by County of Legal Settlement, SFY 2008



BI Waiver: Dollars per Person



Sources:
Data provided November 2008 by Iowa Department of Human Services, Iowa Medicaid Enterprise
U.S. Census Bureau, Population Division "2007 Population Estimates Program: Table 6. Sex by Age" March 2008
(2007 is the most recent year for which Census data is available on county level)

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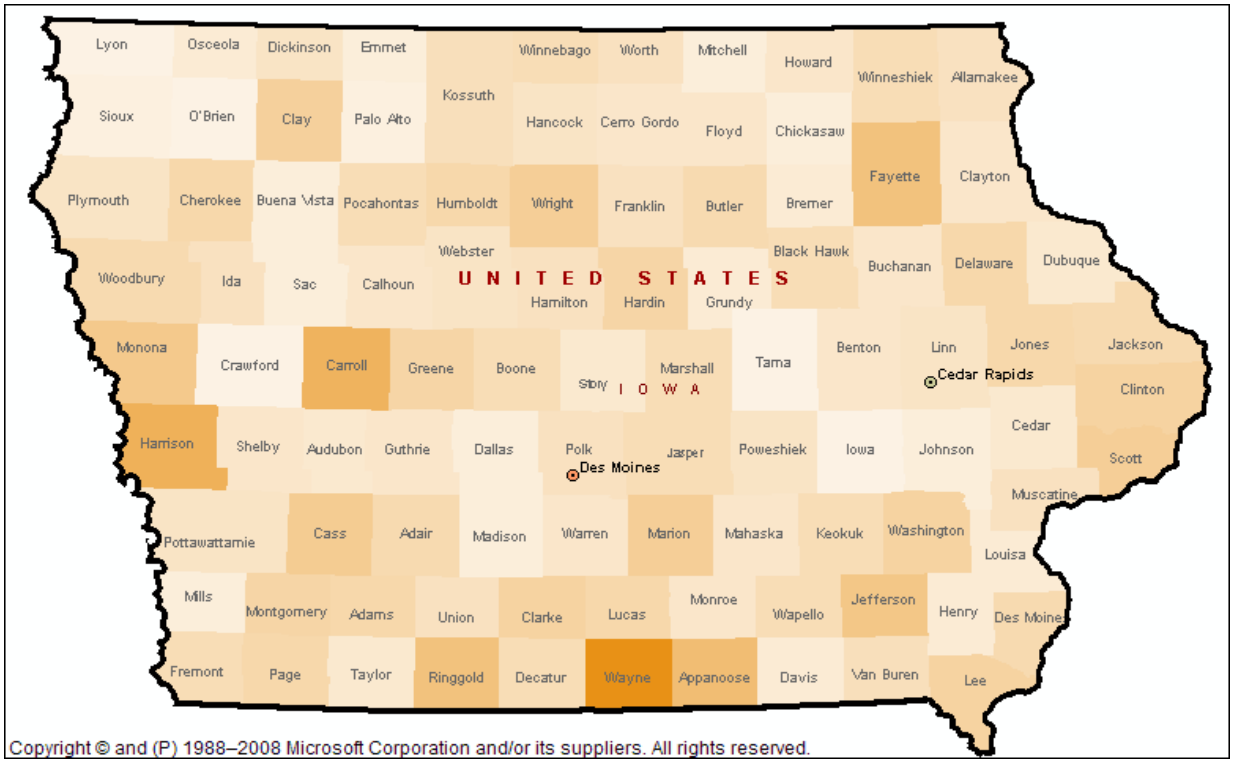
Chart C.4: Public In-Home Nursing Expenditures per Capita by County of Residence, SFY 2008



In-Home Nursing: Dollars per Person

$65

$36

$7

Note:
Public nursing expenditures include Medicaid State Plan home health nursing, the nursing component of the Iowa Department of Public Health Elderly Wellness program, and nursing services in Medicaid home and community-based services waivers

Sources:
Data provided November 2008 by Iowa Department of Human Services, Iowa Medicaid Enterprise and Iowa Department of Public Health
U.S. Census Bureau, Population Division "2007 Population Estimates Program: Table 6. Sex by Age" March 2008 (2007 is the most recent year for which Census data is available on county level)

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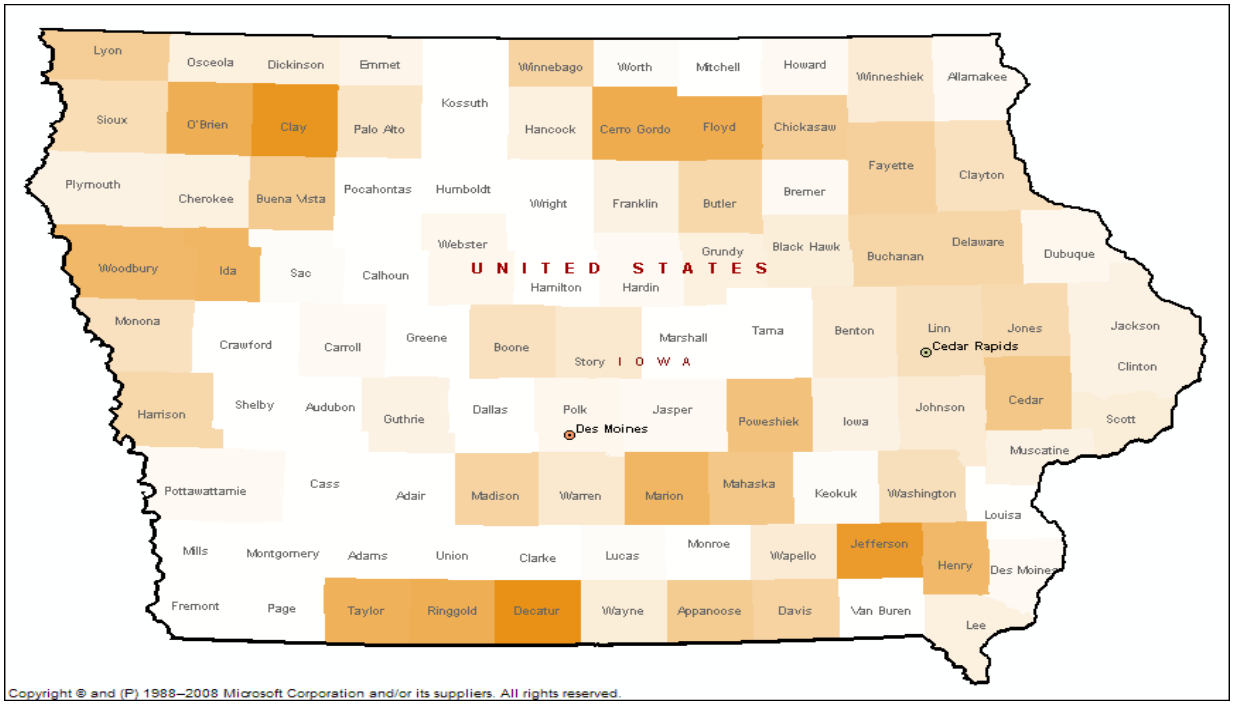
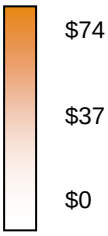
Chart C.5: Elderly Waiver Expenditures for Consumer-Directed Attendant Care through an Assisted Living Provider per Person age 65 or Older, by County of Residence, SFY 2008



Assisted Living: $s per Person 65+



Sources:
Data provided November 2008 by Iowa Department of Human Services, Iowa Medicaid Enterprise
U.S. Census Bureau, Population Division "2007 Population Estimates Program: Table 6. Sex by Age" March 2008
(2007 is the most recent year for which Census data is available on county level)

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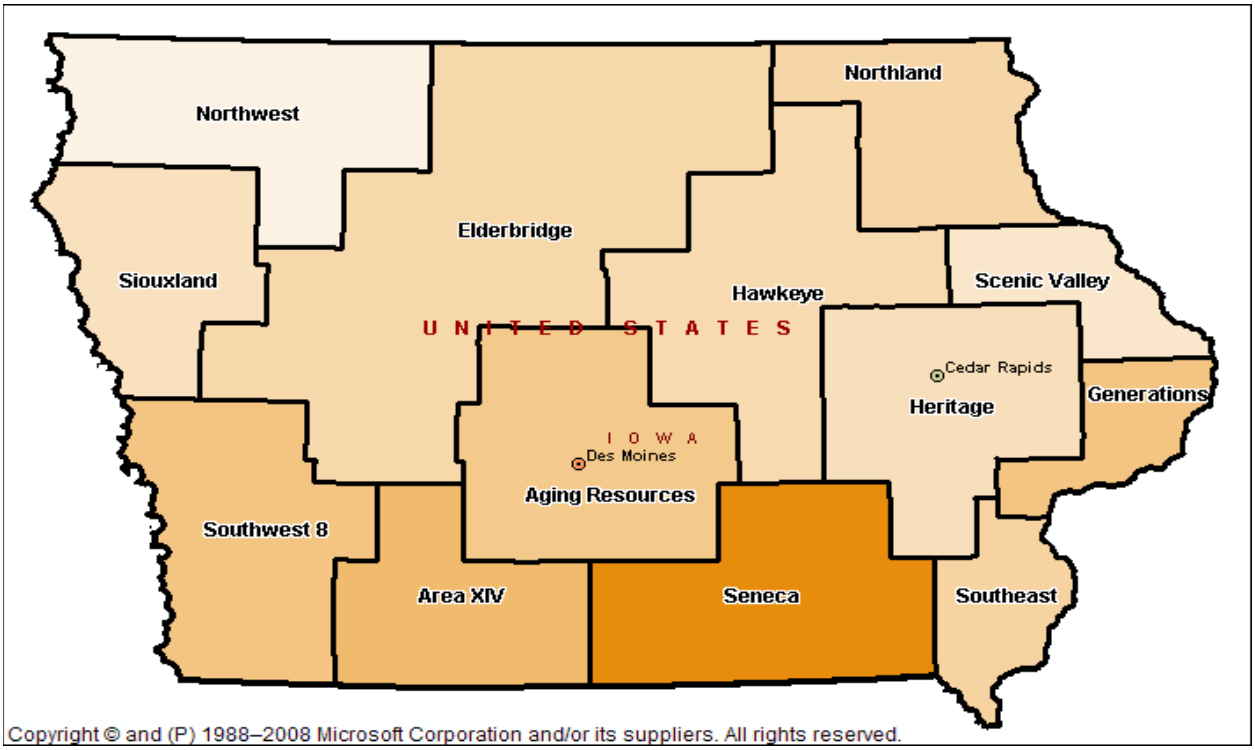
Chart C.6: Public Expenditures for Home-Based Paraprofessional Supports for Older Adults per Person age 65 or Older by Area Agency on Aging, SFY 2008



Home-Based Paraprofessional: $ per Person 65+

$251

$161

$70

Sources:
Data provided November 2008 by Iowa Department of Human Services, Iowa Medicaid Enterprise; Iowa Department of Public Health; and Iowa Department of Elder Affairs
U.S. Census Bureau, Population Division "2007 Population Estimates Program: Table 6. Sex by Age" March 2008 (2007 is the most recent year for which Census data is available on county level)

Home-based paraprofessional services expenditures for older adults include Medicaid State Plan home health aide for people age 60 or older, the home care aide component of the Iowa Department of Public Health Elderly Wellness program, and paraprofessional services provided by the Medicaid Elderly Waiver and/or the Aging Network that often provide services in a person's home: homemaker, chore, personal care, and consumer-directed attendant care (not including assisted living). The next three charts show distribution of spending for home-based paraprofessional services with the highest cost.

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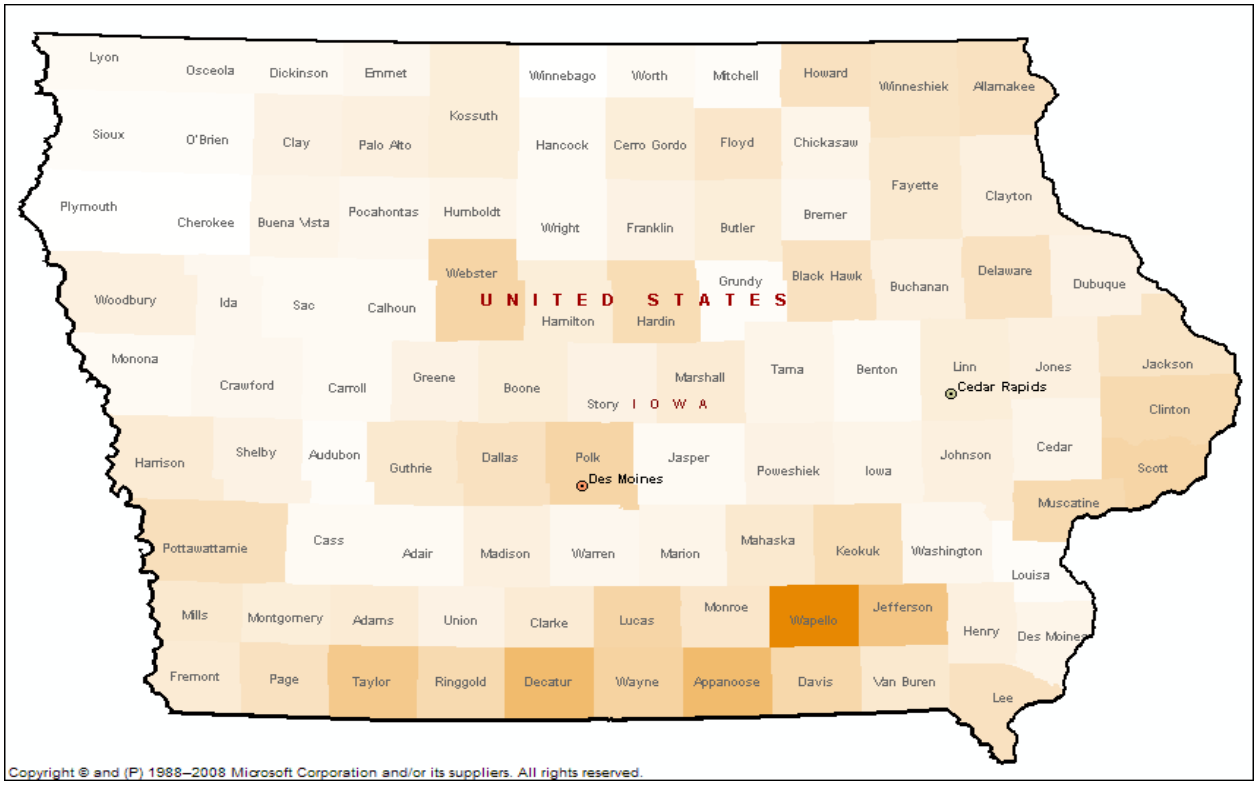
Chart C.6a: Elderly Waiver Expenditures for Consumer-Directed Attendant Care (not including Assisted Living Providers) per Person age 65 or Older, by County of Residence, SFY 2008



CDAC Non-Assisted Living: $s per Person 65+

$300

$150

$0

Sources:
Data provided November 2008 by Iowa Department of Human Services, Iowa Medicaid Enterprise
U.S. Census Bureau, Population Division "2007 Population Estimates Program: Table 6. Sex by Age" March 2008
(2007 is the most recent year for which Census data is available on county level)

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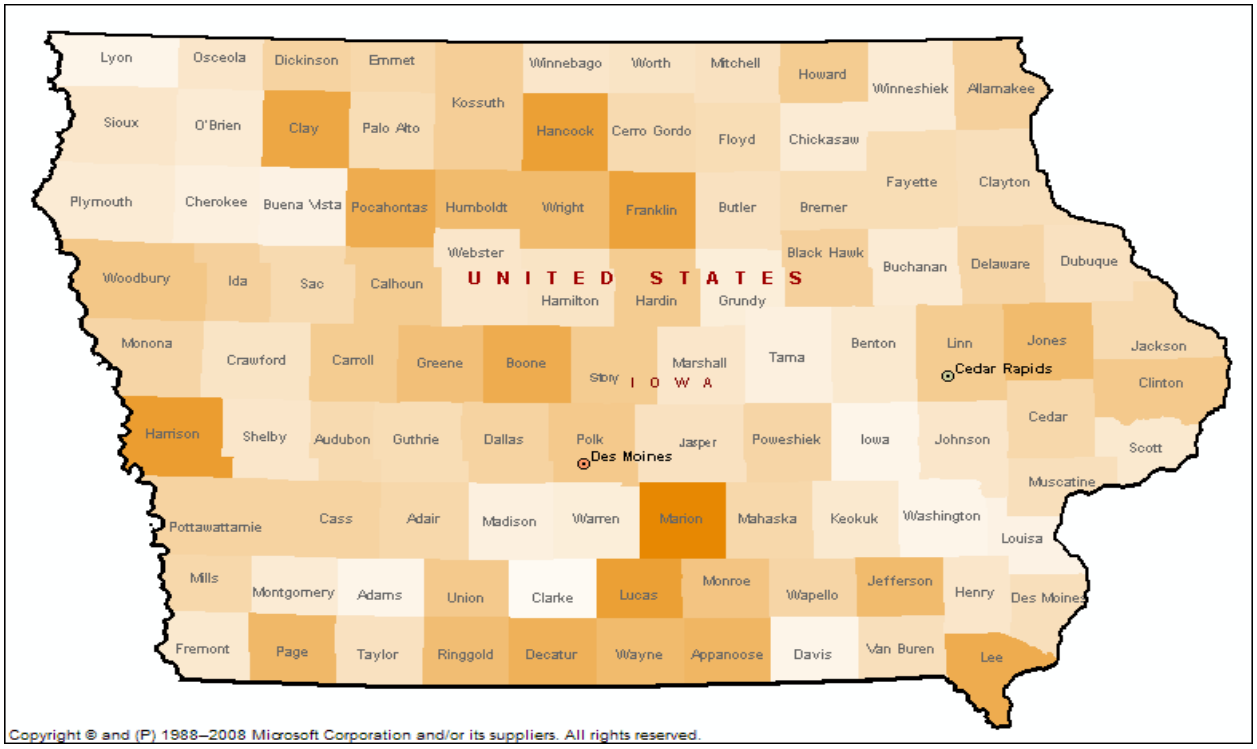
Chart C.6b: Medicaid State Plan Home Health Aide Expenditures for Older Adults per Person age 65 or Older by County of Residence, SFY 2008



Home Health Aide: Dollars per Person 65+

$99

$52

$5

Sources:
Data provided November 2008 by Iowa Department of Human Services, Iowa Medicaid Enterprise
U.S. Census Bureau, Population Division "2007 Population Estimates Program: Table 6. Sex by Age" March 2008
(2007 is the most recent year for which Census data is available on county level)

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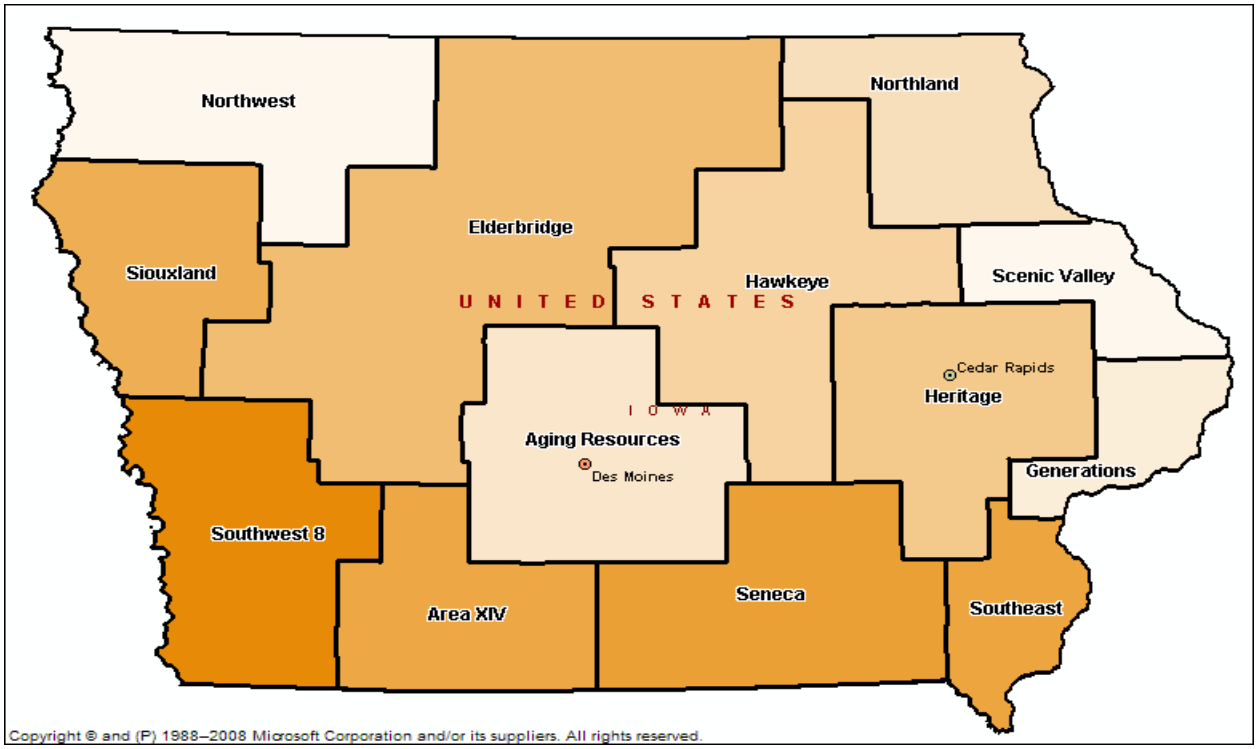
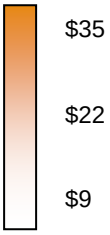
Chart C.6c: Public Homemaker Expenditures for Older Adults per Person age 65 or Older by Area Agency on Aging, SFY 2008



Homemaker Services: Dollars per Person 65+



Note:
Homemaker expenditures include services funded by the Medicaid Elderly Waiver and the Aging Network.

Sources:
Data provided November 2008 by Iowa Department of Human Services, Iowa Medicaid Enterprise and Iowa Department of Elder Affairs
U.S. Census Bureau, Population Division "2007 Population Estimates Program: Table 6. Sex by Age" March 2008 (2007 is the most recent year for which Census data is available on county level)

Iowa State Profile Tool
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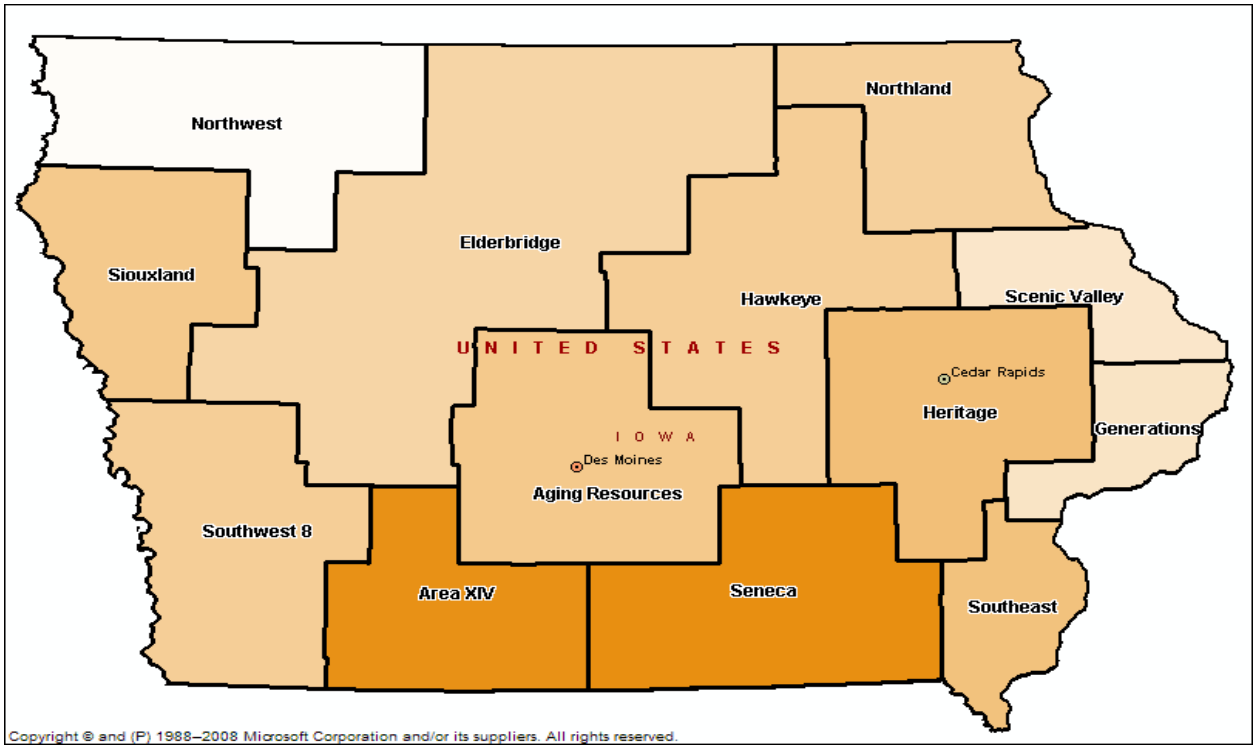
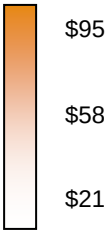
Chart C.7: Public Home Delivered Meal Expenditures for Older Adults per Person age 65 or Older by Area Agency on Aging, SFY 2008



Home Delivered Meals: Dollars per Person 65+



Note:
Home delivered meal expenditures include meals funded by the Medicaid Elderly Waiver and the Aging Network.

Sources:
Data provided November 2008 by Iowa Department of Human Services, Iowa Medicaid Enterprise and Iowa Department of Elder Affairs
U.S. Census Bureau, Population Division "2007 Population Estimates Program: Table 6. Sex by Age" March 2008 (2007 is the most recent year for which Census data is available on county level)

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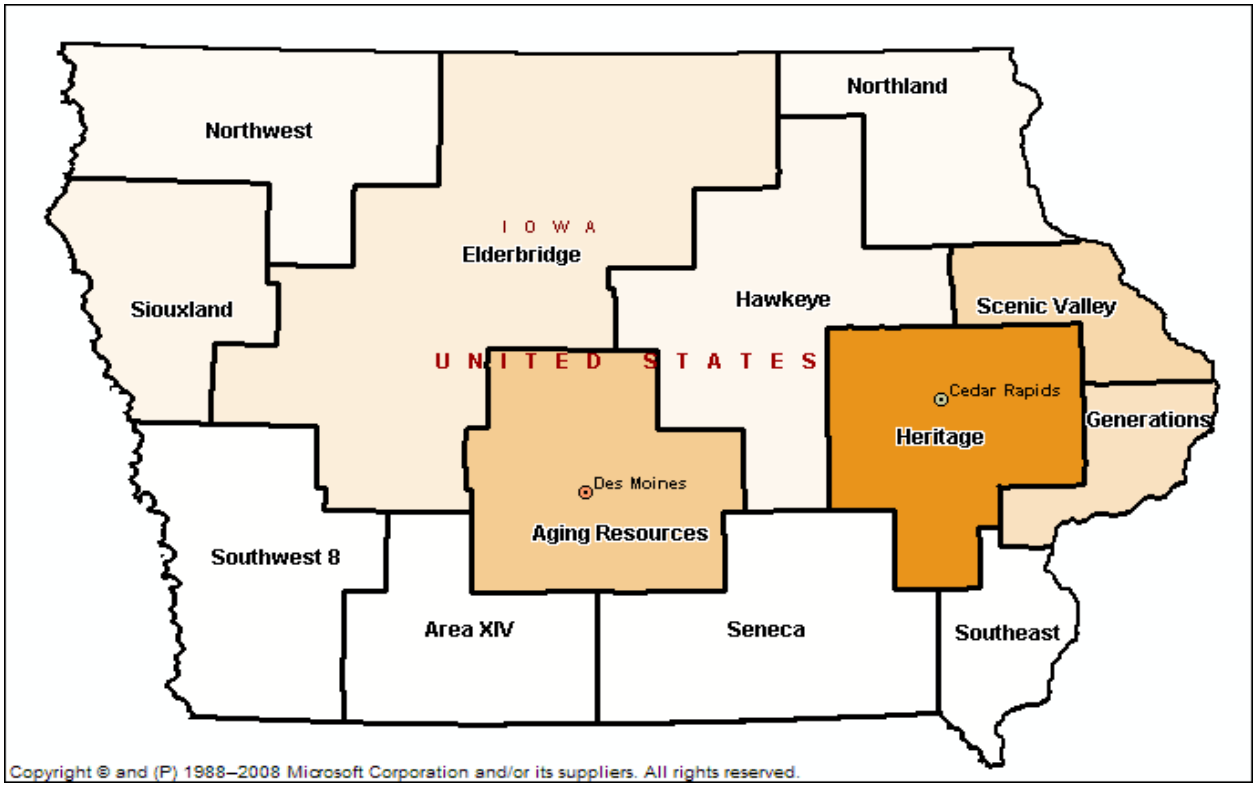
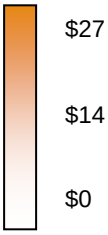
Chart C.8: Public Adult Day Care Expenditures for Older Adults per Person age 65 or Older by Area Agency on Aging, SFY 2008



Adult Day Care: Dollars per Person 65+



Note:
Adult day care expenditures include adult day services funded by the Medicaid Elderly Waiver and the Aging Network.

Sources:
Data provided November 2008 by Iowa Department of Human Services, Iowa Medicaid Enterprise and Iowa Department of Elder Affairs
U.S. Census Bureau, Population Division "2007 Population Estimates Program: Table 6. Sex by Age" March 2008 (2007 is the most recent year for which Census data is available on county level)

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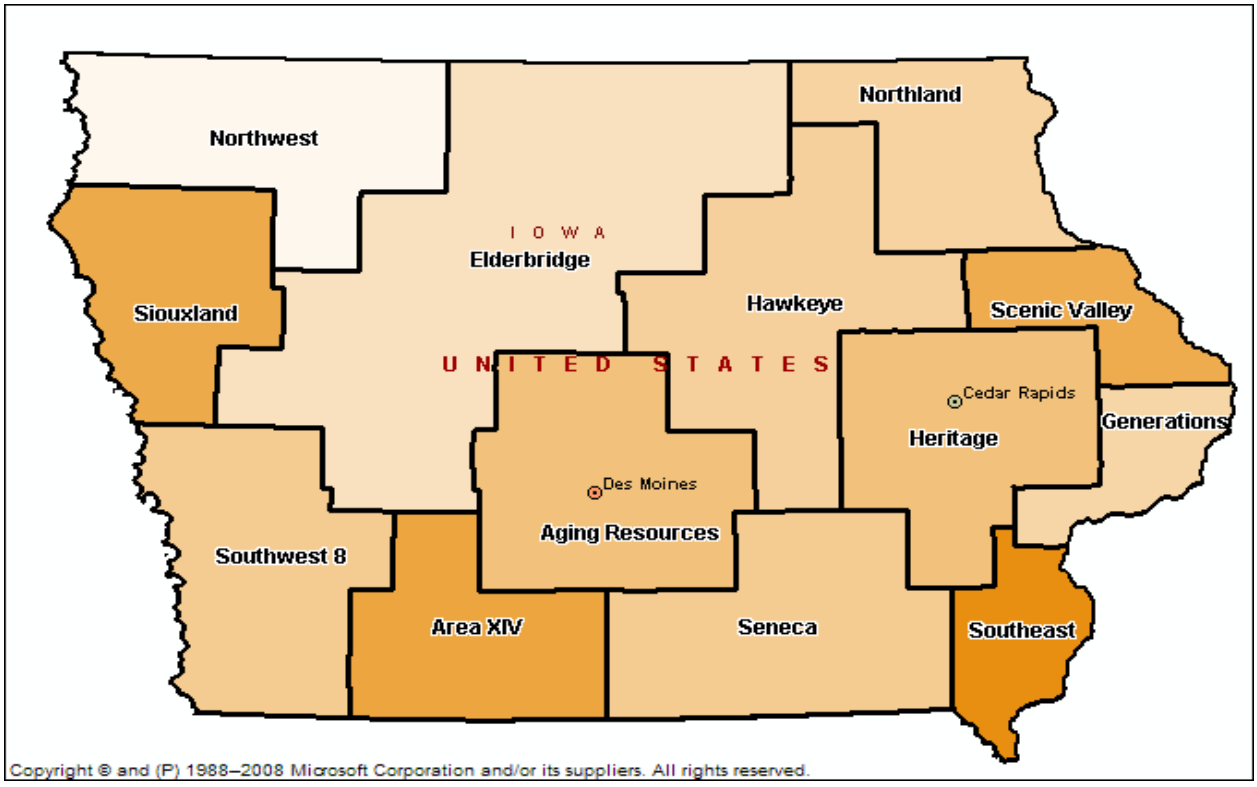
Chart C.9: Public Respite Expenditures for Older Adults per Person age 65 or Older by Area Agency on Aging, SFY 2008



Respite Services: Dollars per Person 65+

Note:
Respite expenditures include all respite services funded by the Medicaid Elderly Waiver and the Aging Network.

Sources:
Data provided November 2008 by Iowa Department of Human Services, Iowa Medicaid Enterprise and Iowa Department of Elder Affairs
U.S. Census Bureau, Population Division "2007 Population Estimates Program: Table 6. Sex by Age" March 2008 (2007 is the most recent year for which Census data is available on county level)

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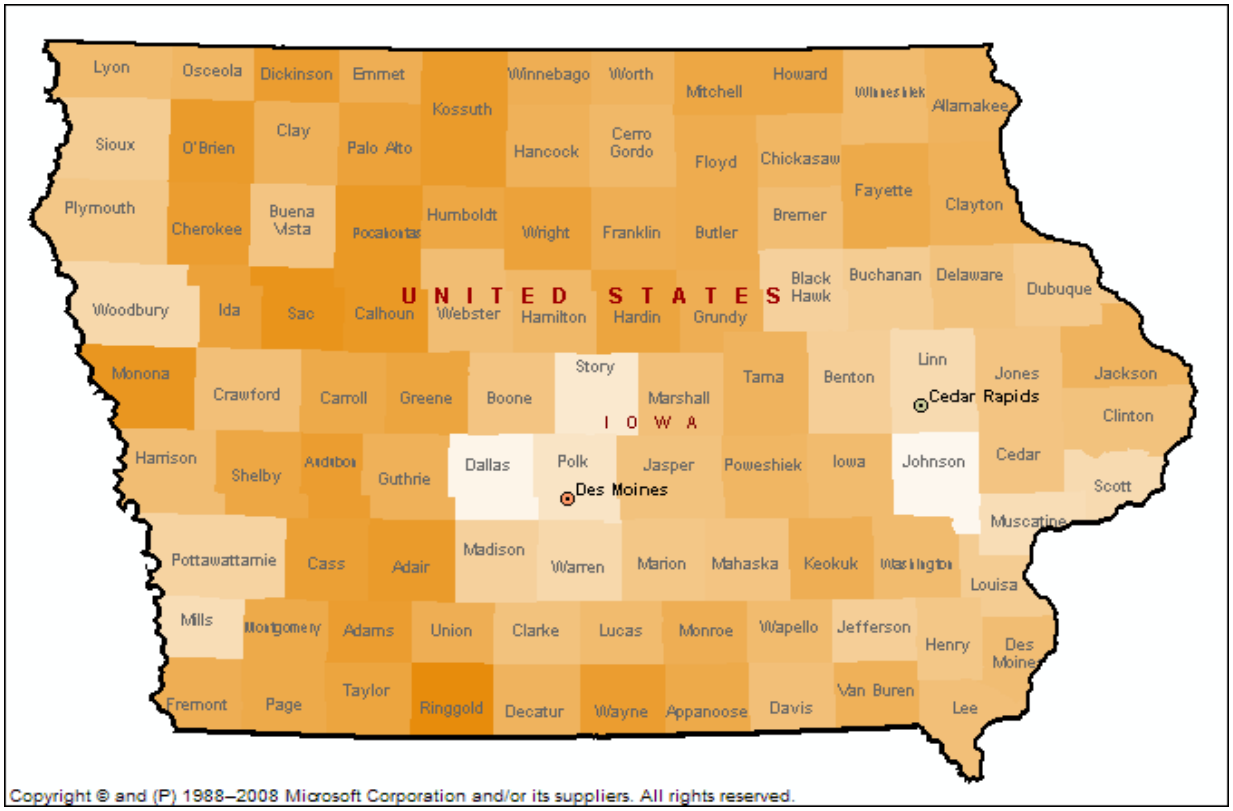
Chart C.10: Percent of Population Age 65 or Older by County of Residence, 2007



Percent 65+ Per County

24%

16%

8%

Sources:
U.S. Census Bureau, Population Division "2007 Population Estimates Program: Table 6. Sex by Age" March 2008 (2007 is the most recent year for which Census data is available on county level)