

A Long-Range Plan for Long-Term Care in Iowa

Approved December 16, 2005

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I. OVERVIEW

A – INTRODUCTION

The goal of this plan is to maximize the independence of older Iowans, including older Iowans with disabilities, to enable them to live in their communities of choice for as long as possible and to receive the care they need in the setting they choose by providers they trust at a cost they can afford.

This plan seeks to rebalance Iowa’s long-term care system placing more emphasis on home and community-based services rather than institutional-based services. Iowa also accepts its responsibilities to assure that services are provided in accord with the Olmstead decision in “the least restrictive” and “most integrated setting.”

The Senior Living Coordinating Unit (SLCU) shares the intent of the State General Assembly to ensure all Iowans access to an extensive range of high-quality, affordable, and cost effective long-term living options that maximize independence, choice and dignity.

The SLCU shares with the General Assembly the conviction that Iowa’s long-range plan for long-term care must be comprehensive and provide multiple services and support in home, community-based, and facility-based settings. It is imperative that Iowans have choices and be able to make informed decisions.

The SCLCU recognizes that the state must respect the dignity of its older citizens and the state’s responsibility to be sure that there are safe providers, good choices and a safety net for the most vulnerable.

The Long-Range Plan for Long-Term Care in Iowa begins with a comprehensive educational program that emphasizes the importance of:

- **Healthy Aging**
Iowans must be encouraged to learn the keys to promoting good health at an early age and be encouraged to practice preventive measures.
- **Fiscal Planning**
Iowans must be encouraged to plan for the future, including the appropriateness of long-term care insurance.
- **A Support Community.**
Iowans must be encouraged to recognize the importance of a circle of family and/or friends and encouraged to cultivate such a circle.
- **Planning for the Future.**
Iowans must recognize the personal changes that occur in the aging process and be encouraged to plan ahead.

While this plan focuses on what the state of Iowa needs to do for its citizens, it is recognized that government needs to partner with private, public, economic, social, health, education and faith-based institutions in addressing the various needs of an aging population. This plan recognizes that many Iowans look to their health care and human service professionals, clergy and family members for information and guidance.

Iowa's Long-Term Care Plan, insofar as possible, will utilize the best practices now known. These include, but are not limited to: Developing Choices –Empowering Iowans (nationally known as Cash and Counseling), PACE (Program for All-Inclusive Care for the Elderly), Seamless System, Aging and Disabilities Resource Centers, Case Management, Family Caregiver Support, Home Modification and Universal Design, and Professional Staff Development.

Iowa's Long-Term Care plan recognizes that data shows most Iowans prefer to receive services in their own homes or apartments. However, there is a need for a continuum of care that also includes elder group homes, assisted living programs, residential care facilities, continuing care retirement communities, hospitals, nursing homes and hospice.

Iowa's Long-Term Care plan recognizes that the Medicaid waiver programs, proposed Medicaid State Plan Amendments, Senior Living Trust dollars and general fund appropriations, are essential in assuring that needed services are available to all Iowans. It recognizes that some may be able to manage partial payment based on a sliding fee scale; some may not be able to pay any of the cost.

Iowa's Long-Term Care Plan emphasizes the importance of promoting good health, preventive medicine and health care, based on "best practices" so as to enable Iowans to remain health and independent.

In order for Iowans to have choices, Iowa needs to:

- Develop an extensive network of services to meet the needs of rural and urban citizens.
- Provide persons with an accurate uniform assessment of the level of care appropriate to meet their needs.
- Provide persons with accurate, independent and comprehensive information about the services available that will meet their level of need.
- Connect persons with the professional support needed, in light of their choice, to help develop a care plan.

The Iowa Departments of Human Services, Elder Affairs, Public Health, and Inspections and Appeals plan to utilize and partner with other state departments and with organizations to assure a comprehensive state plan. These include but are not limited to: The Iowa Association of Home Care, Iowa Association of Area Agencies on Aging, The Iowa Council of Health Care Centers, The Iowa Hospital Association, Iowa Nurses Association, Iowa Foundation for Medical Care, Iowa Coalition of Home and Community-Based Services for Seniors, Iowa Pharmacy Association, Iowa Medical

Society, National Association of Social Workers, Iowa Adult Day Services Association, Iowa Hospice Organization, Iowa Health Systems, Iowa CareGivers Association, Iowa Association of Homes and Services for the Aging, Iowa Health Care Association and AARP Iowa.

It is the intent of the SLCU to use this document as a working plan that is constantly used and referred to, to guide our efforts and evaluate results. This Plan is a work in progress. It is the intent of the SLCU to update this plan as often as necessary to reflect what is happening and what is projected for the long-term care system in Iowa.

B – DEMOGRAPHIC DATA

Related to Long-Term Care in Iowa

State Population: (US Census)

- 65+ population (2000) 436,213 (14.9% of population)
- 65+ population projected for 2030 663,186 (22.4%)
- Iowa ranks **second** in the nation for its % of population 85 years or older.
- Iowa ranks **fourth** in the nation for its % of population 65 years or older

Pertaining to persons 65 years or older:

- 8.8 % live at/below **poverty**. National average is 9.7%. Iowa ranks 28th
- 25.9 % live between 101–200 % of **poverty**. National average 23.8%. Iowa ranks 16th.
- 41.4 % live in rural area. National average is 21.7%. Iowa ranks 11th

Use of Home and Community-Based Services

- 4.4% of Medicare Beneficiaries are receiving home health services.
National average is 6.3%. Iowa ranks 43rd
- 0.1% of Medicaid Beneficiaries are receiving services in a Residential Care Setting. National average is 0.2%. Iowa ranks 22nd

Home and Community-Based Resources

- .41 Medicare-Certified Home Health Agencies per 1,000 Age 65+, 2003
National average is .20. Iowa ranks 6th
- .16 Adult Day Facilities per 1,000 Age 65 +, 2001-2002
National average is .10 Iowa ranks 8th
- 10 Residential Care Beds per 1,000 Age 65+, 2003
National average is 26. Iowa ranks 43rd

Nursing Facility Resources

- 82 Nursing Facility Beds per 1,000 Age 65+
National average is 49. Iowa ranks 1st **This ranking is undesirable.**
- 9,579 Long-Term Care beds per Full-Time Employee Ombudsman, 2002
National average is 2,614. Iowa ranks 1st **This ranking is undesirable.**
- 78.5% Occupancy Rate, 2003
National average is 82.6%. Iowa ranks 37th

Nursing Facility Services

- 49.7% residents with Medicaid as Primary Payer, 2003
National average 66.3%. Iowa ranks 51st
- 5.2% residents with Medicare as Primary Payer, 2003
National average 11.3%. Iowa ranks 51st
- 45.1% residents with “Other” as Primary Payer (Mostly Private Pay)
National average 22.4%. Iowa ranks 1st

Most Data: Across The States – Profiles of Long-Term Care: Iowa an AARP Public Policy Institute 2004 publication. **Number 1 ranking is not always the best.** Other data and graphs can be found in Appendix 2 and Appendix 3.

C – 2005 GENERAL ASSEMBLY

The 2005 General Assembly enacted several bills that will enrich long-term care in Iowa.

One of the most significant was House File (HF) 841, the IowaCare Act. This bill, if all parts are approved by CMS (Center for Medical Services), establishes the need for a higher level of care for entry into a nursing home than for eligibility for home and community based waiver services. *This will enable persons to stay in their homes longer and help rebalance long-term care expenditures from institutional care to home care.*

This bill also helps to implement healthy living by providing dietary counseling and smoking cessation rewards. *Helping persons address these issues prior to age 65 will result in healthier older adults and thus reduce the need for long-term care.*

This bill calls for the development of a plan for a case-mix adjusted reimbursement system for persons with mental retardation and developmental disabilities for both institutional-based and community-based services. *It is expected that this will bring Iowa's expenditure for ICF/MR (Institutional Care Facilities for persons with Mental Retardation) more in line with the national average.*

HF 841 creates a Task Force on Indigent Care to identify any growth in uncompensated care and to identify any local funds that are being used to pay for uncompensated care. *This will help identify costs that may be able to be maximized through a match with federal funds.* The Medical Assistance Projections and Assessment Council will examine service costs. *This will help identify any limitations/inadequacies of our present reimbursements.*

Another health transformation in IowaCare concerns the intent to further promote evidence-based medical care practices for the entire Medicaid population by the use of physician and health provider incentive payments. *The intent is to preserve health status and more aggressively treat symptoms among Iowans.*

HF 841 also provides the mechanism (if approved by CMS as anticipated), for case management to be a reimbursable service in the Elderly Waiver program. *This will help to assure that the elderly obtain the services they need for a quality life.*

This bill, the IowaCare Act, sets in motion the exploration of additional opportunities, under the medical assistance program, to assist individuals in transitioning from institutional settings to home and community-based services. *This recognizes person's preference to remain in their home as long as possible.*

HF 781 establishes a Direct Care Worker Taskforce to review the education and training requirements for direct care workers. *It is anticipated that this will provide a mechanism to enhance the quality of direct care workers who are so vital in providing long-term care.*

The legislature passed three bills that seek to improve care in the long-term care system and increase the options available to the elderly and persons with disabilities. HF 585 Assisted Living, HF 587 Adult Day Care and HF 710 Group Homes.

HF 786 enables nursing homes to provide services to persons other than their residents. This bill recognizes that in many communities, particularly in rural Iowa, nursing homes are in the best position to expand services to others beyond their residents. It will also help nursing homes retain their fiscal viability as they broaden the services they extend in a changing culture.

SF 304, the Elder Iowans Act, contains many provisions aimed at improving services. HF 760 addresses Dependent Adult Abuse; HF 821 establishes a Prescription Drugs Assistance Program and SF 272 establishes a Medical Assistance Advisory Council. HF 470 begins to address Mental Health Parity. HF 617 establishes Assisted Living as a service under Home and Community-Based Services. HF 819 provides for an asset disregard for Long-Term Care Insurance and HF 760 addresses the issue of elder abuse. Each of these bills strengthens long-term care in Iowa.

HF 825 reduces the waiting list for home and community-based waiver services and provides a 3% provider rate increase. It also provides funds for staff to study and coordinate the implementation of PACE (Programs of All-inclusive Care for the Elderly.) This bill establishes legislative intent for the long-term care system in Iowa, including the utilization of a uniform assessment process that assures that the services and support are delivered in the most integrated and life-enhancing setting. In addition, this bill establishes the legislative intent that such services and support are provided by a well-trained, motivated workforce. This plan carries out the legislative intent.

The legislature restored \$35.5 million to the Senior Living Trust. These funds serve older adults who have needs for which there are no other funds available.

This plan, if it is to be carried out, needs the support of the General Assembly in the legislation they enact and the funds they allocate.

II. THE PLAN

A – DEVELOP A COMPREHENSIVE EDUCATIONAL PROGRAM

The Long-Range Plan for Long-Term Care in Iowa begins with a comprehensive educational program that emphasizes personal responsibility. With projections that the populations of older Iowans will more than double by 2030, the state of Iowa should institute a comprehensive educational program that emphasizes the importance of healthy aging, fiscal planning, a support community and planning for the future. To this end the Senior Living Coordinating Unit supports:

- 1) Promoting good health, stressing that the time to pay attention to physical exercise, good nutrition and healthy habits is now. The educational system and the business and labor community will be enlisted to join with the health and human service professionals in emphasizing the importance of caring for one's physical and mental health. In addition, older Iowans will be encouraged to engage in appropriate physical and mental activities that maintain their health as well as promote healthy aging.
- 2) Improving participation in the congregate and home-delivered meals programs, the food assistance program, and screening to identify persons at risk of poor nutritional health. The availability and utilization of nutrition counseling will be encouraged through the Medicaid Elderly Waiver, Medicare, private insurance and the Older Americans Act.
- 3) Exploring launching a Long-Term Care Consumer Awareness Campaign such as "Own Your Future," in partnership with the Administration on Aging, the National Governors Association, and the National Conference of State Legislatures. This program will focus on fiscal planning, understanding long-term care insurance, establishing clear legal directions, deciding upon those who can be counted on for help, learning what the community has to offer, making sure one's home remains a good fit and obtaining low- cost options for home modification and repair.
- 4) Encouraging citizens to purchase long-term care insurance policies that meet core standards approved by the state. Encourage employers to explore ways to assist their employees in paying the cost.
- 5) Developing a public guardianship program to assist older Iowans to receive the decision making and legal help they need and seek additional funds for legal assistance programs.
- 6) Promoting advanced planning for one's care, including advance directives, powers of attorney, living wills and wills.
- 7) Enlisting physicians, medical institutions, attorneys, clergy, businesses, labor and social groups to encourage and assist persons in preventing destructive health habits, helping with fiscal planning, developing a support community and planning for the future to include long-term care needs.

B – DEVELOP STRATEGIES FOR HEALTHY AGING

This Plan recognizes the importance of **Healthy Aging**. The SLCU supports:

- 1) Improving the overall health and well being of older Iowans.
- 2) Increasing the emphasis on providing services that contribute towards extending independent lifestyles and healthy aging.
- 3) Promoting the use of community-based and evidence-based prevention programs. This includes but is not limited to health screenings and assessments, home safety evaluations, adult immunizations such as Flu and Pneumonia, education classes on health topics, physical activity programs, and referrals for early interventions as appropriate.
- 4) Partnering with Primary Care Providers using chronic care management to assist older Iowans in managing their chronic disease process.
- 5) Linking older Iowans with needed health services as appropriate.

C – DEVELOP AN EXTENSIVE NETWORK OF SERVICES AND PROVIDERS

The organizational structure of Iowa includes the Senior Living Coordinating Unit (SLCU) and cabinet level groups such as the Aging Services Cabinet. This enables the departments of Elder Affairs, Human Services, Inspections and Appeals, and Public Health to share information and develop policy and plans to meet the long-term care needs in Iowa. Iowa is also fortunate to have an active MH/MR/DD/BI Commission that has a legislative mandate to redesign Iowa's disability system.

An essential part of the Long-Range Plan for Long-Term Care in Iowa is expanding an extensive network of services to meet the needs of its citizens in rural and urban communities. Iowa is fortunate that it has a number of governmental agencies, professional organizations, healthcare and human service providers, area agencies on aging and business and citizen groups which are committed to developing an extensive network of services. The Senior Living Coordinating Unit is committed to working with these groups in a collaborative partnership to provide accessible, affordable, quality services that meet the needs and choices of Iowans.

Finally, Iowa is fortunate in that the IowaCare Act is in development. This legislation, passed by the 2005 General Assembly, will make Iowa the first state in the nation, when final approval from the Center for Medical Services is received, to require a higher level of care for entry into a nursing home than for eligibility for home and community-based services. This will enable persons to stay in their home longer which, according to an AARP study is the preference of 94% of older Iowans.

1. This Plan focuses on the **Home and Supportive Housing**. Within this area SLCU supports:

- a) Enabling persons to remain in their homes and communities.
- b) Exploring ways to make housing more available, affordable and accessible for older Iowans.
- c) Home modification programs.
- d) Universal design standards that are of value to all Iowans.
- e) Building codes which include accessibility and “visitability” standards.
- f) Adaptive technologies which enable persons to live in their own homes more safely.
- g) Affordable Assisted Living options which combine subsidized housing and Medicaid waiver services.
- h) Home-like atmospheres in Independent Living Facilities, Assisted Living Facilities, Elder Group Homes, Adult Day Services, Residential Care Facilities and Nursing Homes.
- i) Developing programs to provide services to Naturally Occurring Retirement Communities (NORC).

2. This Plan focuses on the availability of quality, affordable **Home and Community-Based Services** that enable persons to stay in their homes and communities. The SLCU supports:

- a) Making home and community based services available to all Iowans.
- b) Implementing “Fast Track Eligibility” for Home and Community Based Waiver Services.
- c) Exploring the implications of presumptive eligibility.
- d) Developing “nursing home transition programs” to help persons return to their homes and communities by amending Medicaid waivers or the Medicaid State Plan to include transition dollars and nursing home transition case management.
- e) Implementing the “Money Follows the Person” type funding strategies that allow persons to move from institutional settings to community-based services.

- f) Commissioning a study to assess the costs for home and community-based services for a variety of acuity levels to determine the extent of savings for providing long-term care in the community rather than in an institution.
 - g) Conversion grants, revolving loans and federal tax financed incentives for home and community-based services.
 - h) Utilizing the Elderly Waiver program as a separate component of affordable assisted living programs.
 - i) Increasing the resource limits for Waiver clients who want to stay in their homes so they have enough money to maintain their home.
 - j) Enhancing the capacity of the mental health service system to respond to the needs of older adults.
3. This Plan recognizes the importance of **Caregivers** who enable persons to stay in their homes. The SLCU supports:
- a) Providing individual and group counseling, training, respite services (in-home, adult day services, overnight), linkage to formal care providers, emergency back-up, and transportation assistance for those who assume responsibility for providing long-term care to a person so that the person can remain in their own home.
 - b) Recognizing and building on the cultural differences where many generations live together.
 - c) Creating policies that enhance employer support of caregiver activities.
 - d) The National Family CareGivers Program of the Older Americans Act, recognizing that informal and formal caregivers provide 80% of all long-term care.
 - e) Partnering with the Iowa CareGivers Association, through their Better Jobs Better Care Grant, to ensure that consumer-directed care does not erode the quality and wages of caregivers.
 - f) Exploring standards for oversight of consumer-directed care.
 - g) Tax incentives and tax credits for caregivers.

4. This Plan recognizes the importance of **Direct Care Workers**.

Direct Care Workers are the persons who have direct contact with and provide the needed services to those receiving long-term care. This may include, but not be limited to Registered Nurses, Social Workers, Licensed Practical Nurses, Nursing

Aides, Orderlies and Attendants, and Home Health Aides. The SLCU supports:

- a) Annual cost-of-living provider rate increases.
- b) Enhancing training and education, including expanding the training slots for nurses and paraprofessionals, promoting registered apprenticeships to paraprofessional occupations.
- c) Forgivable loan programs for professionals who stay in Iowa.
- d) Exploring a GI bill for health and long-term care workers.
- e) Investigating and implementing strategies that improve the recruitment and retention of staff employed in the range of long-term care professions.(2h)
This would include addressing inadequate wages and benefits, training and on-the-job support which are the fundamental causes of the direct care worker shortage.
- f) Efforts to broaden the supply of frontline long-term care workers by reaching out to older workers, former Temporary Assistance For Needy Families (TANF) recipients, military personnel transitioning to civilian life, individuals with recent experience providing care to family members, dislocated workers from other industries and young people.
- g) Partnering with the minority communities to promote quality jobs for recent immigrants.
- h) State acuity-based reimbursement plans to be applied to all long-term care options.
- i) Expanding the Iowa Nurse Aide Registry to include other direct care workers and personal assistance.
- j) Encouraging diversity training in long-term care curriculums.

D – Develop Strategies to Strengthen the Network

1. This Plan recognizes the importance of **Quality Care and Safety**. The SLCU supports:

- a) Monitoring all programs and facilities to assure that persons in the long-term care systems are receiving quality care.
- b) Making available information about certification reports, monitoring visits, complaint investigations, and other information valuable to the consumer by websites and/or written reports.

- c) Encouraging all segments of the long-term care system in Iowa to study and implement “best practices.”
 - d) Expanding statewide the Elder Abuse Initiative that provides a holistic, comprehensive system addressing the areas of prevention, detection, intervention and reporting of elder abuse, neglect and exploitation. This initiative also educates individuals at risk, communities, providers and other stakeholders of options and assistance, including legal assistance, services, housing and employment.
 - e) Adopting policies and legislation designed to increase the safety of individuals experiencing abuse, neglect, or exploitation. The legislation would include enhanced criminal penalties for violations against individuals aged 60 or over and disabled adults of any age.
 - f) Increasing the state ombudsman program to be more in line with the national average. (See Data on Page 6 under “Nursing Facility Resources)
2. This Plan recognizes the importance of **Employment and Meaningful Activities**. The SLCU supports:
- a) Expanding the senior employment programs to meet the needs of older Iowans for full and/or part-time employment and encouraging employers to recognize the value of older workers.
 - b) Adopting employee and pension policies which encourage older workers to stay in the work force. This could be accomplished by eliminating penalties for re-employment in IPERS, adopting flexible work schedules, and adapting the workplace to accommodate the needs of older workers.
 - c) Encouraging a state-wide emphasis on Iowa being a place where seniors can stay engaged in activities that nourish their spirits and minds through meaningful life-long learning, volunteerism, employment and recreation.
 - d) Developing standards for communities to be designated as “Senior Friendly.”
 - e) Exploring ways to design roads and highways to accommodate the changing ability of older persons to drive safely.
 - f) Exploring ways to provide the frail elderly with transportation to medical, educational, social, and spiritual activities
 - g) Exploring ways to support volunteers who provide transportation to frail and disabled citizens.

- h) Encouraging communities to plan and involve older Iowans in a variety of activities aimed at utilizing their skills, expanding their interests, and widening their social contacts.
3. This Plan recognizes the importance of **Innovation**. Iowa must be open to new ways of providing long-term care. As the population ages, new ways of serving persons will be imperative. The SLCU would like to see Iowa on the cutting edge of development. The SLCU supports:
- a) Developing innovative projects in long-term care.
 - b) Examining all rules and exceptions to rules to make sure they are not barriers to providing quality imaginative services.
 - c) Developing projects that are resident-centered, using what is called “culture change” and other technique concepts that will make institutions more home like.
 - d) Programs such as the Coming Home Project currently funded by the Robert Wood Johnson Foundation designed to make residential care available for those with limited income.
 - e) Exploring managed care options such as PACE (Programs for All-inclusive Care for the Elderly).
4. This Plan recognizes the importance of **Partnership**. The SLCU realizes it needs the support and assistance of all stakeholders. The SLCU supports:
- a) The collaborative efforts of governmental organizations, the associations and organizations listed in the Introduction, and others in recruiting and training the persons needed to provide quality service.
 - b) The emerging dialogue between the aging and disabilities constituencies, as well as any resulting collaborative initiatives that promise to improve system design to enhance the quality and quantity of services to both populations. (Appendix 6)
 - c) Enlisting interested citizens as advocates.
 - d) The State General Assembly in the adoption of policies, rules and legislation that will strengthen Iowa’s long-term care system and assure that those providing long-term care services in Iowa receive fair compensation.
 - e) A long-term care network of services and providers that will assure the availability of long-term care services that Iowans need.

E – PROVIDE PERSONS WITH AN ACCURATE ASSESSMENT

Persons need to know what level of care is appropriate to meet their needs if they are to make wise choices and if the state is to have an effective efficient long-term care system.

The SLCU recognizes that a key element to an efficient long-term care system in Iowa is providing persons with a validated accurate independent uniform assessment.

The SLCU recognizes it is charged to develop, for legislative review, the mechanisms and procedures necessary to implement a case-managed system of long-term care based on a uniform comprehensive assessment tool. (231.58 4a)

The SLCU recognizes the legislative intent that Iowa should utilize a uniform assessment process.

The SLCU supports plans to implement a universal (uniform) assessment available to all Iowans. This must be an important part of Iowa's long-term care plan.

F – PROVIDE PERSONS WITH INFORMATION TO ENABLE THEM TO MAKE INFORMED CHOICES

The next step in Iowa's long-term care plan is to provide Iowans with the information they need to make an informed choice. Iowans are fortunate that several programs, designed to help Iowans make informed choices are now in place or are being developed. The SLCU supports:

1. The **Aging and Disability Resource Connection** as an integral part of Iowa's long-term care system.

Iowa is one of 43 states that has received a grant to develop an Aging and Disability Resource Connection (ADRC). This project's information and referral system will include an interactive web site and toll-free telephone service utilizing 211, Family Caregiver Program, Iowa COMPASS database, and Case Management Program for the Frail Elderly (CMPFE) seamless system. Its goal is to provide older Iowans and persons with disabilities and those assisting them with the information and resources needed to make informed decisions.

2. The **Consumer Choice Option** program.

The Consumer Choice Option program offers more choices and control to older Iowans and Iowans with disabilities in managing their daily lives. Persons will have the opportunity to decide, based on the assessment of their needs, the help they need, who provides it (they can hire family, friends, neighbors) and when it is provided. Research shows that this program improves the participants' quality of life and increases their satisfaction with the care received. It has

been demonstrated that services cost no more when consumers direct their own care compared to when the consumer receives traditional agency services.

This program might help to address the lack of professional caregivers, particularly in rural areas. This program includes the use of a fiscal agent and an independent support broker/case manager to assure proper management of the funds and the adequacy of the service. The principle of consumer direction is important in the Iowa Plan for Long-Term Care.

G – PROVIDE PERSONS WITH NEEDED SUPPORT

The last part of the Long-Range Plan for Long-Term Care in Iowa is to connect Iowans who choose, with the professional support needed to develop a case plan.

Those who choose Home and Community-Based Services will be provided the opportunity to be connected with a Case Manager who will work with them in the development of a service plan and in arranging for the delivery of all needed services.

The Case Management Program for the Frail Elderly (CMPFE), utilizing the seamless system, assists with the coordination of health and personal care needs of thousands of older Iowans.

A state-wide case management system, with coordinated and uniform administration will assure consistent quality and aid in the effort to re-balance long-term care expenditures.

Those who choose the Consumer Choice Option alternative will be connected with an independent support broker/case manager.

Those who choose an institutional setting can be assured that the appropriate staff person in that setting will work with them to develop a service plan.

The SLCU is committed to making sure that every Iowan receives the support they need to assure that they receive the services they choose and that the service is provided in accord with high standards.

The SLCU is committed to making sure that persons receiving home and community-based services or those who are served in licensed programs receive quality care.

III. EVALUATION BENCHMARKS

The SLCU is committed to evaluating its Long-Range Plan for Long-Term Care in Iowa.

The following benchmarks, set forth by the 80th General Assembly, shall be used in measuring the state's progress relating to this plan.

- A. Reducing the number of nursing home beds per 1,000 for individuals 65 years of age or older.
- B. Increasing the percentage of Medicaid long-term care dollars expended on community-based services.
- C. Increasing the percentage of Medicaid long-term care dollars expended on consumer-directed care.
- D. Increasing the percent of providers having and using consumer satisfaction surveys.
- E. Reducing the use of nursing homes for individuals who have low acuity needs.
- F. Improving provider and consumers satisfaction with the long-term care system.
- G. Increasing the proportion of persons receiving assistance from family caregivers.
- H. Increasing the proportion of Iowans with private long-term care coverage.

IV. AN INVITATION

As stated earlier, “This Plan is a work in progress. It is the intent of the SLCU to update this plan as necessary to reflect what is happening and what is projected for the long-term care system in Iowa.”

The SLCU needs and desires your input. The SLCU invites you to submit in writing any and all suggestions for updating and improving this plan.

In addition, the SLCU invites you to help in the implementation of this plan. It is the hope of the SLCU that you will reread this plan to identify ways you and the associations to which you belong can help. The SLCU invites you to submit in writing what you are willing to do to help make this plan a living reality.

Together, in partnership, the long-term care program for all Iowans can be improved.

The SLCU meets the third Fridays in February, April, June, August, October and December. Your input is welcome. You are invited to share your thoughts in person.

Written comments and requests to be placed on the agenda may be sent to:

Mark Haverland, Chair of the SLCU
Director - Department of Elder Affairs
Jessie Parker Building
510 East 12th Street, Suite 2
Des Moines, Iowa 50319-9025
Mark.haverland@iowa.gov

And to the other members of the Senior Living Coordinating Unit:

Kevin Concannon, Director – Department of Human Services
kconcan@dhs.state.ia.us
Mary Mincer-Hansen, Director – Department of Public Health
mary.hansen@idph.state.ia.us
Steve Young, Director – Department of Inspections and Appeals
syoung@dia.state.ia.us
Dr. Kumsan Song – Citizen Representative
kumsan@netzero.com
Bob Welsh – Citizen Representative
welshbob@aol.com

Non-Voting Members

Sen. Amanda Ragan amanda.ragan@legis.state.ia.us
Sen. Nancy Boettger nancy.boettger@legis.state.ia.us
Rep. David Heaton dave.heaton@legis.state.ia.us
Rep. Lisa Heddens lisa.heddens@legis.state.ia.us

Appendix 1

Background

The purpose of the long-term care system in Iowa is to ensure that aging individuals, including those with disabilities, have the support necessary for physical, emotional, and social well being. Dr. Bill Thomas, a leading pioneer in the growing movement to build a new culture for aging has succinctly articulated this goal by popularizing the vision that no one should be lonely, hopeless or bored as a result of disability or the frailties of aging. Disabled adults and older Iowans should enjoy the freedom to choose from a variety of living and service options which guarantee their dignity, autonomy and independence. A person's limited income and personal resources should not prevent access to the full array of quality services sufficient to provide a safe environment in which to live. The problems that afflict the government and individuals as they face the challenges of being disabled and growing old will yield to the power of Iowans working together. Iowans must join together to accept responsibility for each other's safety and welfare. If we accept collective responsibility for our fellow human beings, we can construct a long-term care system which ensures that all Iowans have access to the services they need to live with their disabilities and to cope with the frailties of aging with maximum dignity and respect.

Iowans and their government are ill prepared for the expense and incapacitation which comes with aging. Most people simply cannot afford to grow old at the same time that more of us are in fact living to advanced ages. 25% of Iowans over the age of 65 live on less than \$856/month. The average retiree has \$30,000 in assets. About two-thirds of Social Security beneficiaries, age 65-plus, rely on their monthly check from Uncle Sam for more than half their income. For about 20% of Americans age 65-plus, Social Security is their only source of income.¹ Those who retire in the next decade will fare no better. Half of Americans do not have pensions. Only 15% of working-age Americans has an individual retirement account and only 22% contributes to a 401(k) plan. Barely 1 in 3 working Americans has saved more than \$100,000 for retirement.² Even among workers 55 and older, 29% have less than \$25,000 put away, while 26% have \$100,000 or more.³ Although household net worth is at an all-time high, most people do not enjoy the abundance. Average net worth per household was more than \$400,000 in 2003. However, the median net worth per household was about \$65,000 (half the households had net worth less than that).⁴ 40 million Americans are paid less than \$10 an hour and 66 percent of the population earns less than \$45,000 a year.⁵ And of course, credit card debt is at historic and alarming highs and inheritance prospects are dim as the current generation of older Iowans are spending themselves into poverty with their own long-term care needs.

¹ "The Great American Retirement Quiz," The Wall Street Journal Online, December 20, 2004.

² "Retirement Finances at Risk," The Christian Science Monitor, March 9, 2004.

³ Eileen Alt Powell, "Saving enough for retirement is no laughing matter," Des Moines Register, Sunday, November 28, 2004, page 3D.

⁴ Gary L. Maydew, "This rising tide is lifting only yachts," Des Moines Register, Monday, April 26, 2004, page 9A.

⁵ Harper's Magazine/September 2004, "Tentacles of Rage," by Lewis Lapham, page 32.

Recent studies indicate that boomers may not fare as poorly as first thought.⁶ Median household wealth at age 67 for those born between 1946 and 1964 will grow from \$448,000 among current retirees to \$600,000 among boomers. With the inflation rate in health care costs and the added years to a person's eventual frailty, however, future generations likely will fare no better than current retirees most of who face financial ruin when faced with the costs of extended long term care. Nursing home costs of \$50,000 (a bargain in most parts of the country) per year will quickly eviscerate most people's income and resources. The average senior spends down to be eligible for Medicaid after only 5 ½ months in a nursing home. The high costs of long term care drive many to desperation. Many seek, often illegally, to hide or transfer assets to avoid spending their own money for long term care. Some even choose to divorce to protect some assets for the surviving spouse. Others refuse services which they need rather than spend their meager resources or accept help. A recent study by AARP, the nation's largest group representing seniors, surveyed 1,000 Iowans 50 and older and held focus groups with consumers and health care providers. Half said they would rather do without long-term care than seek assistance in obtaining care.

Long-term care problems extend beyond aging Iowans themselves. They are a concern to government officials and tax payers as well. The problem for state government is that LTC allocations (\$2.0 billion and rising exponentially) may not be happening in the most efficient manner possible. Medicaid expenditures are growing at an annual rate that exceeds the rate of new state revenues. Far short of this, state government must find ways to limit the resources applied to the care of Iowa's disabled adults and frail elders. Unsustainable trends tend not to be sustained. To no small measure, the re-balancing efforts of this document reflect the reality that no state government can afford to spend whatever it takes to care for those needing long term care in the manner current expenditures are made.

Providers of services to older Iowans also face huge challenges in an unbalanced system. They face pressure from state and federal governments who keep reimbursements low. They deliver some services to low income people at prices which compromise their ability to deliver quality care. The flight of relatively healthy and wealthy individuals into non-nursing home settings leaves the nursing home industry to care for an increasingly frail and poor population. Meanwhile providers of home and community-based services under the Medicaid Waiver program and the state's own Case Management Program for the Frail Elderly receive increasingly limited reimbursement rates and have difficulty expanding their business to serve the number of needy individuals who also want and need care outside of nursing homes.

These are troubling trends for people who can likely expect to live longer and need more care as they do so. The aging population is increasing rapidly and the fastest growing segment is those over the age of 85 – precisely those in most need of long term care. The looming costs of this burgeoning demographic combined with a shrinking workforce of those willing and able to take care of the elderly and disabled require us to do long term

⁶ "How Will Boomers Fare at Retirement?" The Urban Institute for AARP.

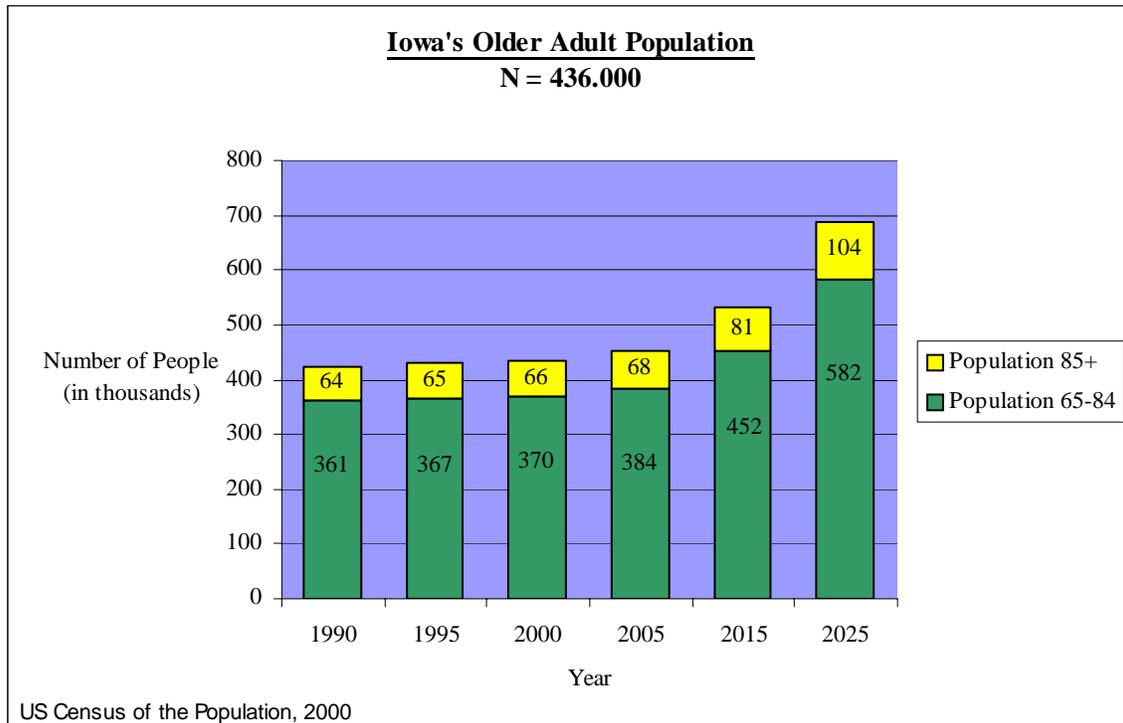
care in the future much more efficiently and effectively. It is recognized that 93 % of older Iowans prefer to remain in their homes and communities as they age and need services and that families remain primarily responsible for long-term care in the United States. The purpose of this long range plan is to lay out some suggestions for change which will enable Iowans and their government to meet the challenges of aging and disability.

The goal of this plan is to maximize the independence of older Iowans to enable them to live in their communities of choice for as long as possible and to receive the care they need in the setting they choose by providers they trust at a cost they can afford.

Appendix 2

Iowa's Aging Population

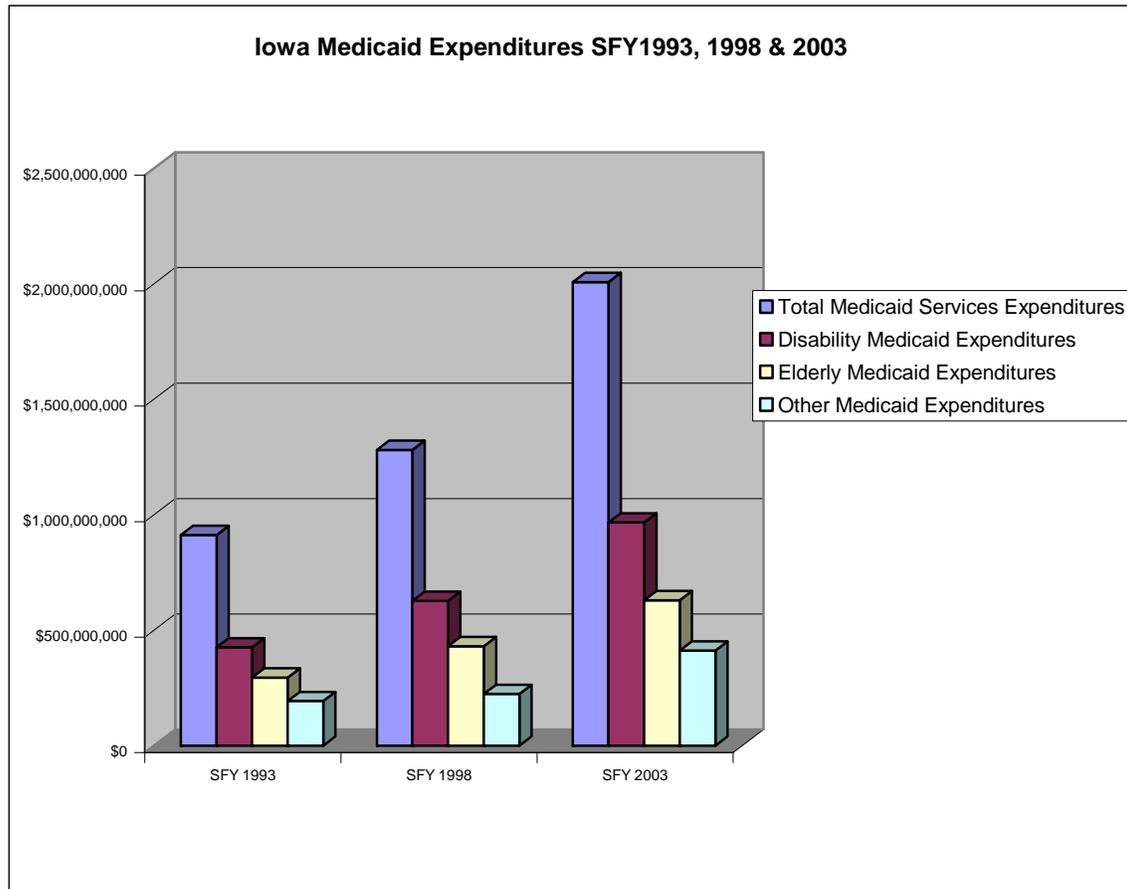
The aging of the American population constitutes an unprecedented demographic event, and Iowa leads the nation as one of the grayest states. The 2000 U.S. Census indicated that 436,000 Iowans are over 65, and this age group constitutes 15% of the state's population. Iowa's aging population is projected to increase by more than 55% over the next 25 years as the Baby Boomers reach and surpass their 65th birthday. By 2025, Iowans over the age of 65 could number almost 686,000 and represent close to one out of every four (22.5%) persons in the State.



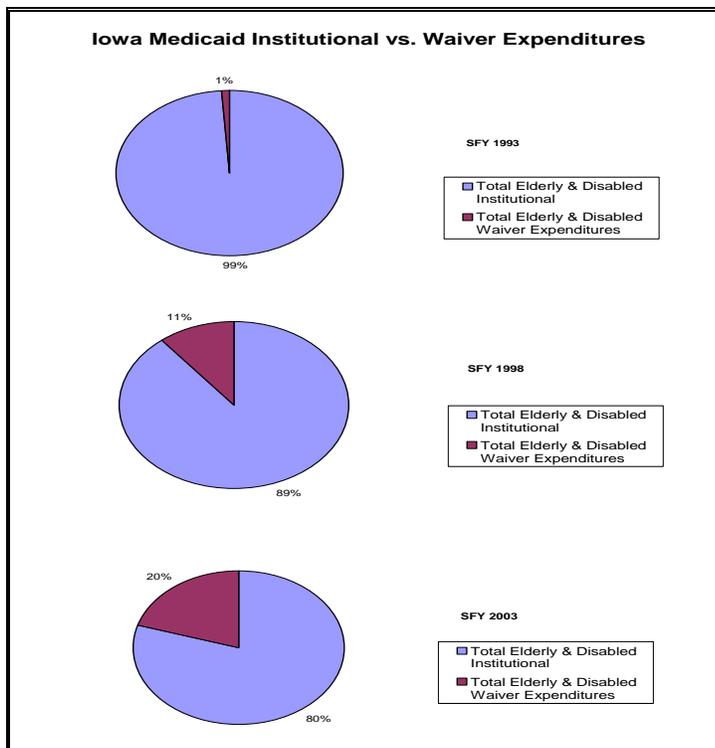
The aging population has become increasingly older. The Census indicates that 233,500 Iowans are over the age of 75. Iowa, along with North Dakota, leads the nation in the percentage of citizens over the age of 85 (Iowa has 2.2%; North Dakota has 2.3%). In the next 20 years, the oldest-old (those over 85 years old) will constitute the fastest growing population group in Iowa, and one out of every six older Iowans actually will be over the age of 85. This particular trend is worth highlighting because the oldest-old are at greatest risk for age-related illnesses and disabilities such as Alzheimer's disease and severe arthritis. As a result, they are more likely to require a spectrum of home, community-based and residential services.

Medicaid spending in Iowa for the old and disabled constitutes nearly 4/5 of total Medicaid expenditures. In 2003, the total spent in the Medicaid budget (both federal and state shares) was \$2,007,826,315. Of this number, \$966,658,633, or 48% was spent on

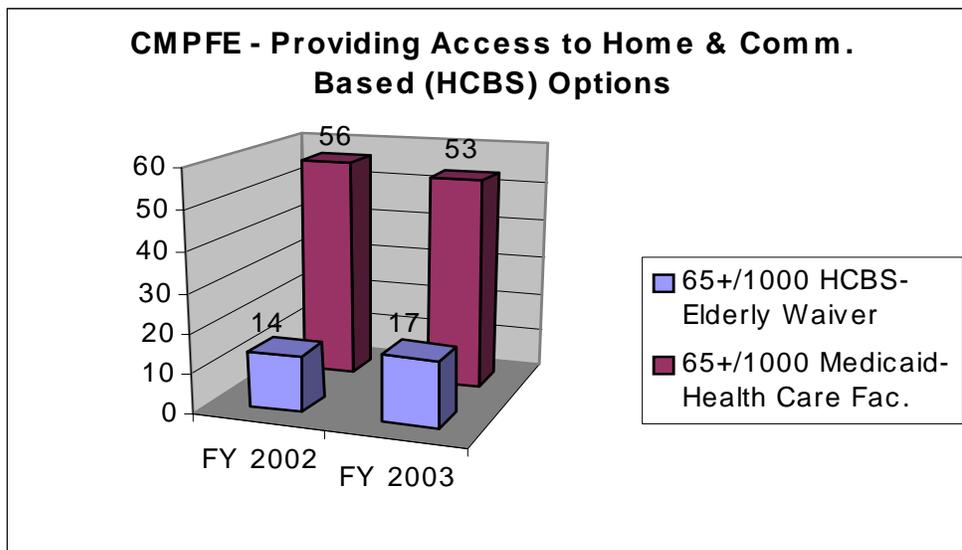
the disability community and \$629,817,495, or 31% was spent on those over 65 years of age. In other words, 79% of Medicaid expenditures were for the disability and elderly populations. The following graph shows that while this ratio has remained fairly constant over the past ten years, the increase in total spending for Medicaid is increasing exponentially, increasing 40% from 1993 to 1998 and 56% from 1998 to 2003.



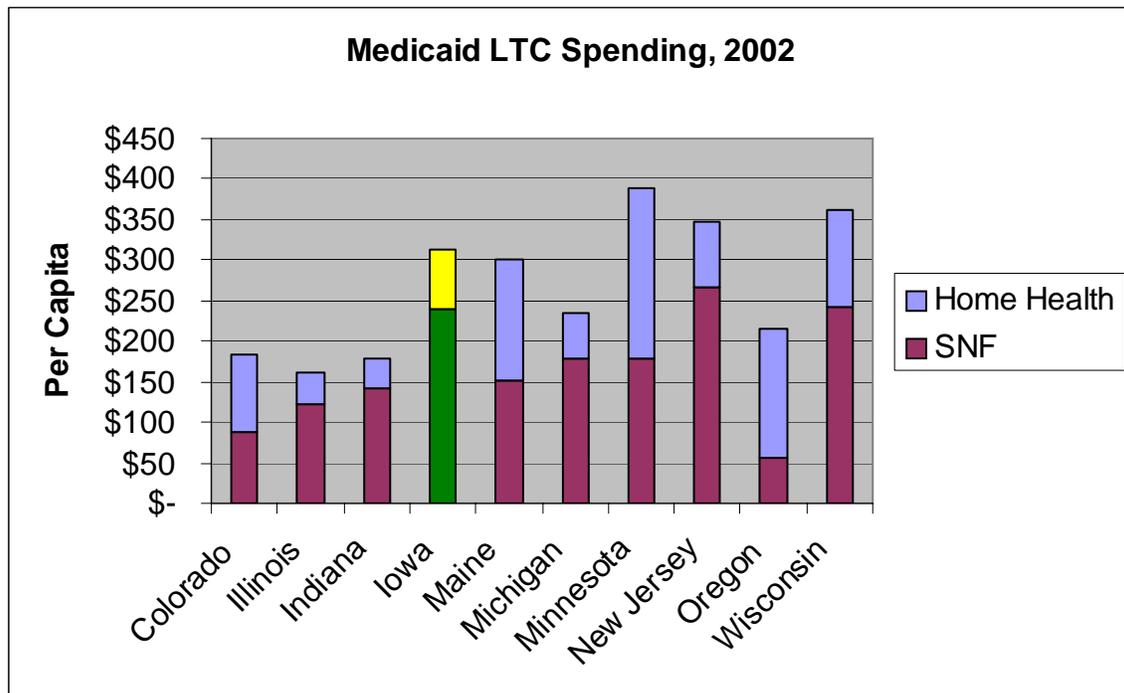
State government in Iowa has initiated several programs over the past several years to address the increasing costs of care to the elderly and disabled. Funded in large measure by the Senior Living Trust, these efforts have included the Case Management Program for the Frail Elderly (CMPFE) and conversion grants to help develop home and community based services. In addition, the Elderly and Disabled Waivers in the Medicaid program have had their desired effect of re-allocating resources away from institutional care and toward services in people’s homes and communities. One measure of this change is a gradual increase in the percentage of Medicaid funds spent for home and community based services in the HCBS Waiver program. The following graph illustrates this trend:



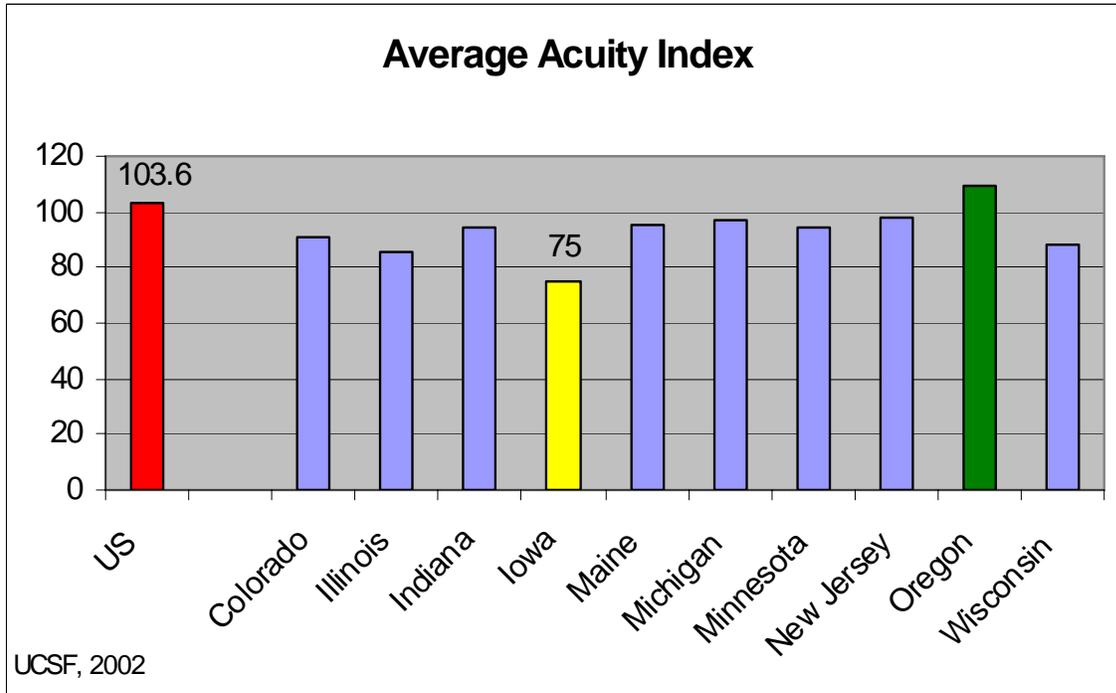
In other words, Iowa along with many other states is experiencing a re-balancing of long term care expenditures. People who once were served in a nursing facility now seem to be receiving needed services in their homes and in homelike settings. As the following graph indicates, the number of people per thousand over 65 in nursing homes is decreasing at the same rate that the ratio for those in home and community based services is increasing:



In spite of this progress, Iowa, like most states, still relies more on institutional care for frail elderly and disabled than on care in home and community based care. Relative to the national average and the nine other states included in this analysis, Iowa has an abundant supply of residential care. For example, the State provides 77 nursing facility beds for older adults, 15 assisted living beds, 33 hospital beds, and 13 residential care beds for every 1,000 older citizens. Of the estimated 59,500 functionally disabled older Iowans, slightly more than 33,000 live in some type of residential care facility. The majority of these, nearly 80%, live in a nursing facility. The Iowa Medicaid program continues to spend more towards institutional-based long-term care when compared to other states.



Polls indicate that people prefer by large margins to age in their homes and communities. Such care is also much less costly for government payers. Effective home health care can also delay or eliminate more costly institutional placement. The goal, then, must be to continue to re-balance the LTC system so that it increasingly favors home and community based care rather than institutional care. Many of the people in nursing facilities in Iowa have an acuity level that suggests that their needs could be met if less institutional alternatives were made available to them. The following graph indicates that the level of care of residents in Iowa nursing facilities is much lower than is common in other states.



Still, it will not be possible for all families to provide the quality services that older Iowans need. Indeed, not all older Iowans even have adequate homes or competent families. Some families will be unable and/or unwilling to provide the free care and lodging which replaces residential care otherwise paid for with tax money. Indeed, as the population of America ages and eventually moves from 12.5% to 20% of the entire population, the cohort of adult children who today account for 80% of their support only increases by 7%. Some older Iowans may even choose to purchase care in a congregate setting to avoid “burdening” their families or because they prefer the security and peace of mind that goes along with purchasing professional care. A significant portion of older Iowans will always reside in institutional settings as they age and become more frail and disabled. Increased attention to the quality and affordability of such institutional care must remain a high priority.

The guiding principles in the LTC system of Iowa must be independence, dignity, choice, affordability and quality. Older Iowans must retain control over their living circumstances. Needing help with Activities of Daily Living (ADLs) and becoming dependent on others for health care must not take away a person’s autonomy, privacy and the freedom to choose which services to receive and where to receive them. Caregivers, whether formal or informal, must always cede to the informed, competent older Iowan’s or disabled adult’s final discretion over the location and extent of services he or she receives.

Money spent in Medicaid:	SFY 1993	SFY 1998	SFY 2003
1. for all Medicaid Services	\$912,736,443	\$1,280,916,908	\$2,007,826,315
2. on the disability population within Medicaid	425,675,632	626,503,421	966,658,633
3. on the elderly population within Medicaid	294,264,231	430,582,296	629,817,495
4. on the elderly population for institutional care	207,065,209	299,331,089	383,893,187
5. on the disability population for institutional care	*N/A	278,404,487	313,350,287
6. on the elderly waiver services	90,424	7,257,712	25,118,681
7. in each of the other waivers	2,297,275	62,440,964	150,711,065
8. in each of the non-elderly waivers for those over 60	39,631	3,688,247	11,047,036

Chart prepared by Department of Human Services
Request for Information (RFI) #4093
March 2004

Appendix 3

AARP did not collect this data but rather brought together a number of different sources into a single place. To see full listing of data please go to the AARP Public Policy Website – Across The States.



ACROSS THE STATES

PROFILES OF LONG-TERM CARE: IOWA



by Mary Jo Gibson
Steven R. Gregory
Ari N. Houser
Wendy Fox-Grage

2004

Introduction

This short state-specific report has been created from the much larger book, *Across the States: Profiles of Long-Term Care 2004*, to facilitate easier access to and distribution of a single state's information on key long-term care issues; national comparisons and state rankings are also provided. To put this information in a broader context, readers also will want to refer to the Overview section of the larger book, a look at key long-term care issues across all of the states.

The state-specific reports excerpt the four-page profile of each state that forms the heart of the larger book. Nine topic areas are covered within these four pages: Demographics; Need for Long-Term Care; Home and Community-Based Services; Home and Community-Based Resources; Nursing Facility Services; Nursing Facility Resources; Long-Term Care Expenditures and Financing; and Trends. In addition, the Long-Term Care Maps section from the larger book, which shows regional patterns for ten indicators, is included in the state-specific reports.

Across the States: Profiles of Long-Term Care 2004, the larger book from which this information is derived, is a compilation of key long-term care characteristics for each state and the District of Columbia. Published biennially for over a decade, the *Across the States* series was developed by the AARP Public Policy Institute to help guide policy discussions among public and private sector leaders in long-term care throughout the United States. It offers a snapshot of each state's long-term care landscape by providing comparable state-level and national data for 85 indicators that are otherwise difficult to find in a single source. The 6th edition of *Across the States* presents the most up-to-date data available at the time of production.

Each state's ranking relative to other states for all indicators is included in each state report. The State Data and Rankings section of the larger book organizes the state data by indicator, so readers can see where all states rank on a specific indicator. Please note that ranking highest does not necessarily imply "doing the best" (e.g., the highest poverty rate), and that not all states are ranked for all indicators due to missing data. In addition, some indicators are not well-suited to being ranked, and caution should be exercised when making comparisons across states.

While a list of sources for the data presented in the four-page profile is included in this version, readers should refer to the Data Documentation section of the larger book for complete information specific to each indicator. That section identifies the original source of data for each indicator, provides a detailed explanation of each indicator, and describes any caveats or limitations that apply to the data. If greater detail is desired, this information is typically available from the source data.

Questions about the state-specific version of *Across the States 2004* or the larger book can be addressed to the AARP Public Policy Institute, Independent Living/Long-Term Care Team, at 202-434-3860. Visit www.aarp.org/ppi for electronic versions of these publications.

DEMOGRAPHICS

Distribution of Population by Age, 2002 & 2020 (Projected)

		50-64	65-74	75-84	85+	Total 65+	Total Population
2002 (%)	State	15.9	7.1	5.4	2.3	14.8	2,952,600
	US	15.6	6.4	4.4	1.6	12.3	289,642,688
2020 (%)	State	18.7	9.8	4.9	2.5	17.1	3,442,704
	US	18.0	9.0	4.5	2.0	15.5	365,963,239
% Change in Population #	State	37.3	61.4	5.4	25.8	35.4	16.6
	US	45.8	78.5	28.8	60.0	58.4	26.3

Population Characteristics	State	Rank	US
Minority/Ethnic Population Age 65+ (%), 2002	3.0	46	17.6
Rural Population Age 65+ (%), 2000	41.4	11	21.7
Bachelor Level Education or Higher Age 65+ (%), 2002	12.3	44	16.7
Household Income Age 65+ (median), 2002	\$23,931	38	\$26,322
Poverty Status Age 65+ (%), 2002			
At/Below Poverty (%)	8.8	28	9.7
101-200% of Poverty (%)	25.9	16	23.8

NEED FOR LONG-TERM CARE

Need for Long-Term Care	State	Rank	US
Men per 100 Women Age 85+ (#), 2002	48.3	22	47.9
Women Age 80+ At/Below Poverty Level (%), 2002	18.9	14	15.1
Persons Age 85+ Living Alone (%), 2002	55.1	15	50.2
Persons Age 65+ with Activity Limitations (%), 2002			
Self-Care Limitations (%)	8.1	31	9.2
Mobility Limitations (%)	16.2	38	18.4
Self-Care or Mobility Limitations (%)	18.1	36	20.1
Sensory Limitations (%)	16.8	25	16.6
Cognitive/Mental Limitations (%)	8.0	44	10.8

Note: The highest data value within each ranking is indicated by a "1."

*The percent change calculation is based on the total number in each age group. For example, the U.S. population age 50-64 was 45,184,259 in 2002 (15.6% of 289,642,688), and was projected to be 65,873,383 in 2020 (18% of 365,963,239). Among persons age 50-64, these population numbers represent a 45.8% increase from 2002 to 2020. See data documentation for an explanation of how rounding affects the calculations.

HOME & COMMUNITY-BASED SERVICES

Livable Communities	State	Rank	US
Homeownership Rate Age 65+ (%), 2002	80.5	27	78.6
Homeowners Age 65+ Paying 30%+ of Income for Housing (%), 2002	15.7	48	22.7
Renters Age 65+ Paying 30%+ of Income for Housing (%), 2002	52.2	40	60.3
Householders Age 65+ in Housing Built before 1960 (%), 2003	52.7	7	41.2
Persons Age 75+ without Driver's License (%), 2000	34.7	17	31.7
Persons Age 70+ without a Vehicle in Household (%), 2002	9.9	44	14.2
Grandparents Age 65+ Raising Grandchildren (% of Age 65+), 2002	1.5	49	4.6

Use of Home and Community-Based Services (HCBS)	State	Rank	US
Medicare Beneficiaries Receiving Home Health Services (%), 2002	4.4	43	6.3
Medicare Home Health Visits per User (average #), 2002	24	36	30
Medicaid Beneficiaries Receiving Services in Residential Care Setting (%), 2002	0.1	22	0.2
Medicaid Home and Community-Based Services Participants per 1000 population, 2001	10.1	11	7.4
Home Health Participants per 1000 population	5.9	7	2.6
Personal Care Participants per 1000 population	NA	NA	1.9
HCBS Waiver Participants per 1000 population	4.2	15	2.9
Aged/Disabled Waiver Participants per 1000 population	1.9	24	1.8
Medicaid Beneficiaries: Persons in Aged/Disabled Waiver Programs as % of Persons in Nursing Homes, 2001	37.7	33	49.5

HOME & COMMUNITY-BASED RESOURCES

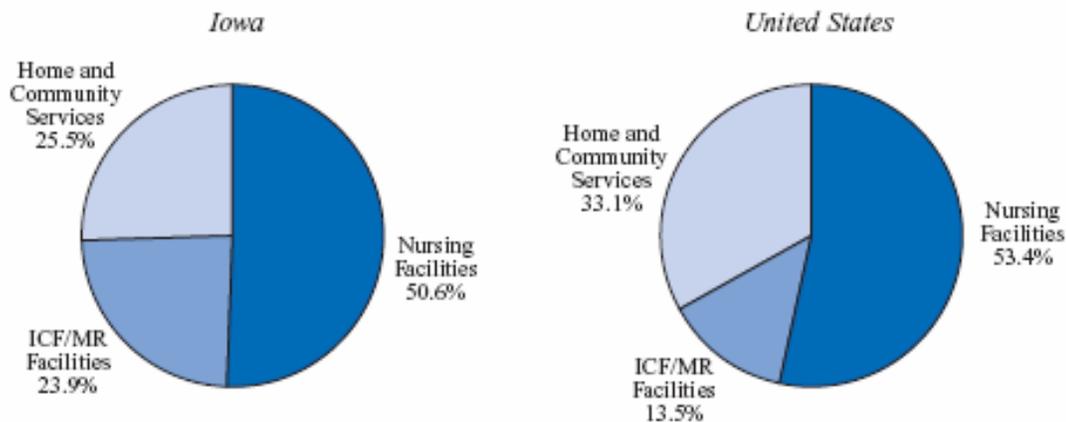
Home and Community-Based Resources Available	State	Rank	US
Medicare-Certified Home Health Agencies per 1,000 Age 65+, 2003	0.41	6	0.20
Adult Day Facilities per 1000 Age 65+, 2001-2002	0.16	8	0.10
Residential Care Beds per 1,000 Age 65+, 2002	10	43	26
Personal & Home Care Aides per 1,000 Age 65+, 2003	13	17	14
Hourly Wage (median), 2003	\$8.31	22	\$7.91
Home Health Aides per 1,000 Age 65+, 2003	15	19	16
Hourly Wage (median), 2003	\$9.01	18	\$8.77

Note: The highest data value within each ranking is indicated by a "1."

NURSING FACILITY SERVICES

Use and Quality of Nursing Facility Services	State	Rank	US
Total Nursing Facility (N.F.) Residents (#), 2003	27,805	20	1,451,672
Nursing Facility Residents (% of Age 65+)	6.4	2	4.0
N.F. Residents with Medicaid as Primary Payer (%), 2003	49.7	51	66.3
N.F. Residents with Medicare as Primary Payer (%), 2003	5.2	51	11.3
N.F. Residents with "Other" as Primary Payer (%), 2003	45.1	1	22.4
Select Nursing Facility Resident Measures, 2004			
Residents with Physical Restraints (%)	3	43	8
"High-Risk" Residents with Pressure (Bed) Sores (%)	9	47	14
N.F. with Deficiency for Actual Harm or Jeopardy of Residents (%), 2002	7.9	47	18.0

Medicaid Spending on Long-Term Services, by Type of Service, 2003



NURSING FACILITY RESOURCES

Nursing Facility Resources Available	State	Rank	US
Total Nursing Facilities (#), 2003	454	11	16,323
Nursing Facility Beds per 1,000 Age 65+, 2003	82	1	49
Long-Term Care Facility Beds per FTE Ombudsman (#), 2002	9,579	1	2,614
Nursing Facility Occupancy Rate (%), 2003	78.5	37	82.6
Direct-Care Nursing Hours per Resident Day (avg.), 2003			
RN Hours per Resident Day	0.4	25	0.4
LPN Hours per Resident Day	0.6	39	0.8
CNA Hours per Resident Day	1.9	45	2.2

Note: The highest data value within each ranking is indicated by a "1."

LONG-TERM CARE FINANCING

Medicaid and State Expenditures	State	Rank	US
Total Medicaid Spending (in millions), 2003	\$2,285	32	\$259,565
Medicaid Long-Term Care Spending (% of Total Medicaid), 2003	42.8	12	32.3
LTC Spending per Capita	\$332	17	\$288
Nursing Facility Spending per Capita	\$168	20	\$154
ICF/MR Spending per Capita	\$79	6	\$39
Home & Community Based (HCBS) Spending per Capita	\$85	29	\$95
Home Health Spending per Capita	\$22	4	\$10
Personal Care Spending per Capita	NA	NA	\$22
HCBS Waiver Spending per Capita	\$63	29	\$64
HCBS Waiver Spending for Aged/Disabled per Capita	\$13	32	\$15
Medicaid HCBS Spending (% of Medicaid LTC Spending), 2003	25.5	37	33.1
State-Funded HCBS Program Spending for Older People (in millions), FY 2002	\$7.3	22	\$1,411.9

Public and Private Payment Rates	State	Rank	US
Medicaid Reimbursement per day for Nursing Facility Care (average), 2002	\$95	40	\$118
Medicare Reimbursement per day for Nursing Facility Care (average), 2002	\$239	38	\$265
Private Pay Rate per day in Nursing Facility (urban average), 2003	\$195	7	\$158
Medicare Reimbursement per Home Health Visit (average), 2002	\$106	45	\$124
Private Pay Hourly Rate for Home Health Aide (urban average), 2003	\$21.77	6	\$18.12

TRENDS

Long-Term Care Trends*	State	Rank	US
Nursing Facility Residents (% change), 1998-2003	-8.4	37	-4.0
Nursing Facility Beds (% change), 1998-2003	-6.4	37	-3.1
Nursing Facility Occupancy Rate (% change), 1998-2003	-2.1	29	-1.1
Medicare Home Health Visits per User (% change), 1993-2002	-25.0	4	-47.4
Medicaid Beneficiaries in Aged/Disabled Waiver Programs (% change), 1996-2001	188.0	14	74.0
Medicaid Total LTC Spending (% change), 1998-2003	59.6	12	41.4
Medicaid Nursing Facility Spending (% change), 1998-2003	56.4	9	30.6
Medicaid ICF/MR Facility Spending (% change), 1998-2003	31.7	9	14.7
Medicaid HCBS Spending (% change), 1998-2003	110.0	17	83.0
Medicaid Spending Other Than LTC (% change), 1998-2003	56.6	32	62.2

Note: The highest data value within each ranking is indicated by a "1."

*Percent change figures are cumulative for the entire time period. Changes may appear especially large when the absolute value for the indicator is relatively low.

Appendix 4

LONG-RANGE CONSIDERATIONS

In addition to the items listed in the Plan, which the SLCU recognizes will take years to accomplish, one or more members of the SLCU have identified the following actions for future consideration.

1. Exploring possible accommodations for high vacancy rates in nursing homes to facilitate a smooth transition to a decreased reliance on institutional care.
2. Exploring ways to allow the expression of legitimate sexual needs of older Iowans and adults with disabilities.
3. Encouraging the long-term care industry to offer expanded opportunities for non-traditional couples to receive equal treatment.
4. Encouraging continuous care retirement communities to expand their services to additional social and economic groups so that more persons can plan well in advance for the decline in physical and mental capacity that often accompanies aging.
5. Examining the statutes and administrative rules which govern the operation of continuous care retirement communities to facilitate their ability to serve older Iowans and protect consumers.

In addition, the following future issues have also been identified for future consideration.

1. **Mental Health:** Older people suffer many undiagnosed and untreated mental health problems. Some of these problems are masked by serious illness and hidden by the normal reaction to the inevitable losses of aging
2. **Rural Concerns:** Rural areas experience a loss of population and economic well-being which make the provision of services difficult.
3. **Financial Responsibility:** Will we continue to require individuals to finance their own long-term care needs or will the public financing of long-term care expand to pay for more than those with virtually no resources (left) to pay for long-term care.
4. **Physical Laborers:** People who labor for a living in jobs which require physical effort often experience more health care needs at an earlier age and are prevented from working longer to compensate for lower life time earnings.

5. **Death & Dying:** Will Americans continue to allow the health care system to extend life without protesting? It is entirely possible that Americans will want to have control over the time and manner of their dying. This presents enormous ethical dangers and dilemmas.
6. **Caregiver Workforce:** The supply of people willing and able to work for the low wages paid caregivers does not begin to meet future demand. Iowa must be able to recruit and retain a new source of people to provide direct care to disabled adults and the frail elderly.
7. **Consumer Education:** People need lots of help making the necessary choices in long-term care. They need encouragement and assistance to plan for their eventual long-term care needs.

Appendix 5

PRIORITIES FROM RE-BALANCING CONFERENCE II

A Re-Balancing II conference was held on November 18-19, 2004 in Des Moines. The conference heard presentations from Josh Wiener, of the Research Triangle Institute on Financing Home and Community Based Services, MaryAm Navaie-Waliser of Visiting Nurses Association of New York on Informal Caregiving, Vince Mor of Brown University on Quality Assurance in Nursing Facilities, and Brant Fries of the University of Michigan on Universal Assessments. The initial day of presentations and break out sessions developed a list of strategies for improving long term living in Iowa. On the final day of the conference, participants selected several of these suggestions as priorities for immediate attention. These priorities will all receive attention over the coming months and years. The top five priorities were to:

1. Ensure most comprehensive application of universal (uniform) assessment tool possible (109 votes).
2. Investigate and implement strategies that improve the recruitment and retention of staff employed in the range of long-term care professions (56 votes).
3. Adopt a state acuity-based reimbursement plan to be applied to all long-term care options (30 votes).
4. Increase the state tobacco tax (26 votes (tie)).
5. Promote advance planning of care; tactics may include advance directives, powers of attorney, public education, outreach to physicians and organized medicine (tie).

The list of additional action items are:

1. Build and strengthen partnership between formal and informal caregivers. Tactics may include transition planning; providing \$ for transition by broadening eligibility criteria for post hospitalization Home Care reimbursement; ensure caregiver assessment in Universal Assessment tool (21).
2. Beginning with all relevant gubernatorial commissions, ensure a constant, inclusive and collaborative dialogue between the Aging and Disability Communities to grow and achieve policy integration (9).
3. Launch broad-based public awareness and outreach campaign to complement Universal Assessment implementation. (8)
4. Ensure that the Universal Assessment tool incorporates questions regarding the availability and reliability of informal care giving services. (6)

Appendix 6

The Aging/Disability Interface in Long-Term Care

There is a close relationship between Iowa's aging and disability populations that needs to be taken into account when considering the redesign of long term supports, especially with regard to Medicaid supports and services. Even though those supports are currently delivered through separate service systems, and even though the Legislature has issued a separate mandate to the MH/MR/DD/BI Commission to undertake redesign of the disability system, the SLCU is cognizant of several important points of intersection between aging and disability needs, basic policy questions, and the politics of Medicaid funding for both populations.

The Demographics of Aging and Disability. People of all ages with disabilities are “the other half” of the population needing long term supports. The U.S. Census indicates that 12% of Iowans, or about 340,000 people, identify themselves as having disabilities. To some extent, this population overlaps with the 436,000 Iowans over 65, as the incidence of disability increases with age. In fact, one third of disabilities reported are linked to Iowans over 65. Besides Iowans over the age of 85, the fastest growing population needing supports is adults with disabilities—due to a great extent to the shared advantage of improved health care.

While most of us assume that aging tends to bring with it a fairly predictable set of physical and cognitive disabilities, there is a new demographic phenomenon emerging that poses new challenges to the long term support system: the aging of people with lifelong or adult onset disabilities not necessarily associated with aging. Once again, improvements in health care no doubt have a great deal to do with this phenomenon. People with cerebral palsy, mental retardation, spinal chord injuries, and other disabilities are living longer, and beginning to knock at the door of the aging services system. The average age of people with developmental disabilities now living at home (generally with family members) is now over 40, and about a half million people with D.D. in the United States are now over age 65. Some Iowans with disabilities have expressed great concern about how well their needs are going to be met in the aging services system.

Separate Service Systems. Up until quite recently, the aging and disability service systems had little occasion for contact, and there was no perceived need for the establishment of any sort of working relationship. While aging services are delivered by area agencies on aging and their provider networks to multi-county service areas, the disability service system is county-based. The aging system is significantly more standardized under the framework of the federal Older Americans Act. Iowa's disability system provides counties with significant discretion over eligibility and the array of services to be made available; this fact, coupled with a general under-funding of the system, results in marked disparities from one county to another. Disability services are funded in part by property taxes; counties assert that equitable access to services, especially in rural areas, will require much more support from State appropriations.

Unlike Iowa's Elderly Waiver, the six HCBS disability waivers have limited availability, resulting in waiting lists that were recently eliminated, at least temporarily, by an additional \$6 million legislative appropriation. Aging advocates point out, however, that Iowans with disabilities on Medicaid waivers tend to be able to access more services than many participants in the Elderly Waiver. How this will affect the emerging population of people aging out of the disability services system remains to be seen. Local service providers are beginning to report their efforts to meet the needs of this new constituency, which has brought them into contact with disability case managers and service providers.

Similar Needs and Issues. Older Iowans and Iowans with disabilities have essentially the same kinds of support needs: home health care and personal assistance, durable medical equipment and assistive technology, and access to prescription drug coverage. Accessibility in housing and transportation are absolutely critical to both groups, and can often mean the difference between the ability to remain independent in the community, and unnecessary or premature institutionalization. Both groups stand to benefit from the U.S. Supreme Court's 1999 *Olmstead* decision, which applies to anyone with a disability, regardless of age, and which decrees that people are entitled to receive long term supports in the most integrated setting consistent with their needs.

Both groups rely heavily on access to the health care system. As noted elsewhere in this Plan, a startling fact is that while the Medicaid groups referred to as the "Frail Elderly" and the "Blind and Disabled" constitute one fourth of all Medicaid participants, they account for three fourths of all spending. Half of Iowa's Medicaid budget goes to long term supports for the two populations. Quality of life for both groups depends not only upon acute care and long term care, but, increasingly, on nutrition, preventive healthcare, and wellness programs that keep people active, focused on personal goals, and resistant to common secondary disabilities like depression.

It is worth noting, though perhaps not surprising, that as the Senior Living Coordinating Unit and the MH/MR/DD/BI Commission consider the array of systemic changes needed to ensure consumer choice, access to quality services, and a continuum of long term supports for all Iowans who need them, they encounter essentially identical issues in both service systems: the same concerns about getting basic information about what is available and help in navigating the system, about simplified access and a streamlined eligibility determination process, and about uniform assessment of individual levels of need, ensuring that everyone gets essential supports. Both populations are demanding more choices, and more control over how resources for their care and support are to be used. Both groups have the same urgent worries about support for family caregivers, and the shortage of trained and motivated direct care workers.

Current Points of Intersection. The spirited public discussion about redesign of the elderly and adult and children's disability systems has raised awareness of these common issues, resulting in both dialogue, and coalition-building around legislation, including the Medicaid budget. The Key Coalition, supported by the Governor's Developmental Disabilities Council, is composed of advocates and providers from both the aging and disability communities, and focuses on statewide advocacy. The Aging and Disability Coalition for Community First has, in addition, been looking at ways to promote joint

educational initiatives and at the possibilities for service collaboration. These Coalitions are driven by a commitment to expansion of home and community based services, momentum for which was enhanced by the passage of the IowaCare Act in the spring of 2005.

Two recent State initiatives offer promising improvements to both service systems. The Aging and Disability Resource Connection/Center project, funded by a grant from the Centers for Medicare and Medicaid Services to the Iowa Department of Elder Affairs, will enable design of a comprehensive, web-based information and referral service for Iowans across the web span, as well as expedited eligibility determination for an array of services through inter-agency sharing of client data bases. A grant from the Robert Wood Johnson Foundation, along with other funding sources, is supporting the design of a self direction option for all Iowa HCBS waiver participants called Developing Choice – Empowering Iowans. Consumers choosing the self direction option will be able to develop an individual budget, with assistance from an independent services broker, which will allow them to make many more decisions about the use of resources available for their supports. Both of these initiatives are being developed with input from both older Iowans and Iowans with disabilities.