A Citizens League Research Report Prepared for the Minnesota State Council on Disability

Seniors with Disabilities in 2030

Getting Ready for the Aging Boom

A final report by the Citizens League Committee on Seniors with Disabilities

Phil Riveness and Emily Anne Tuttle, co-chairs

September, 1999

CITIZENS LEAGUE 708 S. 3rd St., Suite 500, Minneapolis, MN 55415 ph: 612/338-0791 fax: 612/337-5919 info@citizensleague.net www.citizensleague.net

×

Seniors with Disabilities in 2030

Getting Ready for the Aging Boom

TABLE of CONTENTS

| Executive Summary | I |
|--|----|
| Introduction | 5 |
| Section I: Seniors, Disabilities and Demographics. | 7 |
| Section II: Conclusions and Recommendations | 13 |
| Healthcare | 15 |
| Long-term Care | 18 |
| Housing | |
| Transportation | |
| Appendix: Work of the Committee | 29 |

As the 21st century approaches, the aging of the baby boom generation is receiving a great deal of attention. By the year 2030, our society will be much more heavily composed of individuals over the age of 65 than ever before. This demographic shift will have a profound impact on everything from family relations to state budgets.

The purpose of this report is to examine a subset of Minnesota's aging population those with disabilities, and specifically their service needs in the areas of healthcare, long-term care, housing and transportation. These are crucial components of independent living for a growing population of individuals with both late-life and lifelong disabilities.

This report combines an understanding of those services currently available with what the demographic trends tell us about future demand, and then outlines recommendations for system improvements that will allow the state to better prepare for a growing population of seniors with disabilities.

The state of Minnesota must begin planning now, because it simply cannot continue on its current path. If the spending patterns of the 1990s were to be continued through the year 2030, the growth of our senior population would increase state spending on health and human services to 65 percent of the total budget.¹

What is Disability?

There are many different ways to define disability, but perhaps the most common is "the inability to perform at least one task of independent daily living." Today people with disabilities make up a large and diverse

group, that includes those with physical and developmental disabilities, speech, hearing

and visual impairments, chemical dependency and mental illness.

The Demographics

There is a critical lack of comprehensive, up-to-date statistical data about people with disabilities in Minnesota. The most recent statewide study to collect data about individuals with disabilities in Minnesota was done more than 20 years ago.

However, there is a general consensus that the overall <u>rate</u> of disability in the United States, and most industrialized countries, is declining. Meanwhile, the <u>actual number</u> of people with disabilities is expected to increase due to the dramatic growth of the 65+ population. The number of Minnesotans over the age of 65 with chronic disabilities is expected to almost double from 135,058 in 1995 to 265,207 in 2030.²

Conclusions & Recommendations

Conclusion #1: There is an urgent need for more comprehensive, up-todate information.

There needs to be a current and regularly updated source of demographic information about the number, condition and location of older adults and seniors with disabilities in Minnesota. There also needs to be one comprehensive, reliable source of information about the type and amount of services available to seniors with disabilities. Finally, we need more information about the unique aging process experienced by individuals with lifelong disabilities.

Conclusion #2: In order to meet the needs of a growing and diversifying population of seniors with disabilities, there must be increased collaboration among the various

¹ Implications for State Spending of Minnesota's Projected Demographic Trends to 2030. Minnesota Taxpayers Association, 1998.

²Project 2030 Briefing Book, Minnesota Department of Human Services, 1998.

sectors of the disability community and between the disability community and the senior community.

collaboration and This increased coordination should begin with state agencies. The legislature should consider structural changes in the various state entities that work with seniors and individuals with disabilities in order to better align policy development and service delivery according to a social model of care. The numerous private advocacy and service organizations that address the needs of seniors and individuals with disabilities must also increase their collaboration by sharing information, jointly developing services and better serving people with dual diagnosis.

Conclusion #3: As frequent users of our healthcare system, seniors with disabilities would benefit significantly from an increased emphasis on chronic-care and the continued deinstitutionalization of healthcare delivery.

The healthcare industry must be encouraged to place greater emphasis on chronic care. In order to continue moving towards this goal, information systems will have to be adapted to allow for information sharing between an individual's numerous care providers, while protecting privacy. Additionally, medical education programs must place a greater emphasis on disabling conditions and diseases, geriatrics, chronic care, and aging with a disability, and the social service and health care industries must increasingly incorporate the use of technology beyond the hospital or clinic setting.

Conclusion #4: The long-term care industry has the potential to provide a wide range of individualized services that allow people to continue living independently longer. However,

these services need to become more widely available and the industry will have to overcome a long-term labor shortage that is currently expected to last well into the next century.

Long-term care options, such as assisted living services, can, and should, be made more affordable and available, by providing them in existing structures and separating the cost of housing from the cost of services. Long-term care providers should be given greater flexibility to use existing facilities and resources in new ways, in order to better meet the changing needs of However, even with greater seniors. flexibility, the realities of a shrinking workforce will require Minnesotans to increasingly meet the need for long-term care through care networks at the family, community and neighborhood level. Furthermore, long-term care options must become more affordable, and individuals assume greater must begin to responsibility for financing their own longterm care.

Conclusion #5: In order to remain living independently in the community, seniors with disabilities need housing that is accessible, affordable and connected to services.

In order to encourage more accessible development, the guidelines for dispersing grant funds from the Livable Communities Act should be amended to favor programs that include accessible housing. Overall, housing programs funded wholly or in part by public funds should give enhanced consideration to proposals featuring units that are fully accessible and/or have accessibility features. Finally, and perhaps, most importantly, increased efforts must be made to educate consumers, builders, developers, architects and city planners about the need for accessible, life-cycle housing. Conclusion #6: While Metro Mobility provides a significant amount of accessible transportation for residents of the Twin Cities, there is a need for additional options that are also affordable and unrestricted

In order to enhance customer service at Metro Mobility, the Metropolitan Council should consider investing in more advanced technology that allows for better vehicle tracking and communication. Additionally, the taxi industry should be brought into the business of providing transportation for seniors with disabilities and existing providers should consider utilizing mixed fleets, in order to serve the community more efficiently.

Conclusion #7: There is a significant need for more comprehensive transportation service in Greater Minnesota.

The MnDOT Office of Transit needs to take a more proactive approach to developing public transit systems in those counties that currently have none. New and existing transportation services need to be more closely aligned with the needs of the customer, in terms of hours and days of operation. In order to better meet the need for transportation to regional centers, the state should provide tangible incentives to encourage the development of multi-county and regional transportation systems in Greater Minnesota. As the 21st century approaches, the aging of the baby boom generation is receiving a great deal of attention. By the year 2030, our society will be much more heavily composed of individuals over the age of 65 than ever before. This demographic shift will have a profound impact on everything from family relations to state budgets.

The task here is to examine a subset of Minnesota's aging population - those with disabilities, and specifically their service needs in the areas of healthcare, long-term care, housing and transportation. These are crucial components of independent living for a growing population of individuals with both late-life and lifelong disabilities.

By combining an understanding of those services currently available with what the demographic trends tell us about future demand, this report outlines recommendations for system improvements that will allow the state to better prepare for a growing population of seniors with disabilities.

In any attempt to plan for the future, there are numerous unknowns. What services will seniors with disabilities want and/or need in the year 2030? What medical conditions or service delivery issues will have been made obsolete by advances in technology? While there are no definitive answers to these question, one of the goals of this report is to stimulate thought and discussion about these issues now instead of waiting for the year 2030 to arrive.

What happens if we do nothing?

Put simply, the state of Minnesota cannot continue on its current path.

• By the year 2030, individuals over the age of 65 will constitute 23 percent of the state's population, up from 12

percent in 2000. The number of seniors with disabilities is expected to almost double to 265,000.³

- In 1997, Minnesota spent \$221 per capita on the Medical Assistance program for aged and disabled basic care, long-term care facilities, long-term care waivers and homecare. If we were to continue spending the same amount per client through the year 2030, these services would consume \$4,128 per capita, after adjusting for inflation.⁴
- In 1997, the state spent 19 percent of its total budget on health and human services. If the spending patterns of the 1990s were to be continued through the year 2030, the growth of our senior population would increase state spending on health and human services to 65 percent of the total budget.⁵

Obviously, these budget projections are unsustainable. Yet this report highlights the need for even more comprehensive services in many areas. Therefore, the emphasis must be on more innovative, flexible, locally-controlled and costeffective ways to provide needed services.

Additionally, it will become increasingly important to prevent as much late-life disability as possible. This will require researching and disseminating information through creative partnerships of public health professionals, community agencies and health insurance organizations.

³Project 2030 Briefing Book, Minnesota Department of Human Services, 1998.

⁴Implications for State Spending of Minnesota's Projected Demographic Trends to 2030. Minnesota Taxpayers Association, 1998.

⁵Implications for State Spending of Minnesota's Projected Demographic Trends to 2030. Minnesota Taxpayers Association, 1998.

Who is a "senior"?

For the purpose of this report, a senior is someone over the age of 65. It is important to note, however, that there are other definitions of "senior." For example, for public housing programs, anyone 62 or older is a senior. Other programs and organizations use definitions ranging from 55 to 65.

In the future, it will be increasingly important to look beyond numerical age when determining who is and who is not a senior. For example, many cultures recognize someone as an "elder" at an earlier age than mainstream society. Individuals with life-long disabilities may experience the effects of aging earlier than those without a disability. On the other hand, many people are living healthier longer and the term senior may not yet be appropriate for a healthy, active 68 year old. By the year 2030, the definition of senior will hopefully be based much more on functional ability than numeric age. However, this is likely to pose a challenge for the numerous social service agencies and funding systems that use age to easily determine eligibility.

What is disability?

There are many different ways to define disability. Perhaps the most common is "the inability to perform at least one task of independent daily living." Some studies distinguish between disability and severe disability, whereby an individual who has <u>difficulty</u> performing tasks of independent daily living is considered to have a disability while an individual who <u>is unable</u> to perform tasks of independent daily living is considered to have a severe disability.

Under the Americans with Disabilities Act (ADA), a person is considered to have a disability if (a) there is a physical or mental impairment that substantially limits one or more of the major life activities; (b) there is a record of such an impairment; or (c) the individual is regarded as having an impairment.

The U.S. Census Bureau uses yet another definition for disability, placing those with disabilities in one of three categories: mobility-limited, self-care limited, or work-disabled. A person with a mobility limitation has a physical or mental health condition lasting for six or more months that makes it difficult to go outside the home alone. A person with a selfcare limitation has a health condition lasting for six months or more that makes it difficult to care for oneself or move around inside the home. Finally, a person who is work-disabled has a health condition lasting for six months or more that restricts or prevents choice of jobs or prevents a person from working at least 35 hours a week.

Under any of these definitions, people with disabilities make up a large and diverse group, which includes those with physical and developmental disabilities, speech, hearing and visual impairments, chemical dependency and mental illness. These common classifications of disability follow what is called a <u>medical model</u>, which categorizes people with disabilities according to condition or impairment.

A second model is the <u>social model</u>, which measures disability according to what are known as activities of daily living (ADLs) and instrumental activities of daily living (IADLs). This model is more useful for determining service levels because it focuses on what services an individual actually needs help with, regardless of why they need the help.

Examples of ADLs are bathing, dressing, grooming, eating, toileting and transferring. Meanwhile, cooking, light and heavy housework, grocery shopping, using the telephone, managing money and paying bills are all examples of IADLs. One way to distinguish between the two is that ADLs are more personal care activities while IADLs are more household tasks. Therefore, an individual that is IADLimpaired often needs a lower level of services and can live more independently, while an individual who is ADL-impaired needs a higher level of services and lives less independently.

In addition to the numerous ways of defining and categorizing disability, seniors with disabilities can also be broken down into two clear subgroups: those with lifelong disabilities and those with late-life disabilities. A senior with a lifelong disability is someone who was either born with a disability or acquired one early in life and is now past the societal benchmark of age 65. A late-life disability is one that is acquired with or after the onset of aging, either through something traumatic like a stroke or more gradual such as loss of mobility. These two sub-populations share many similar characteristics, yet there are also aspects unique to each experience. Seniors with lifelong disabilities and seniors with late-life disabilities are likely to have different family supports, monetary resources and personal outlooks that impact their need for services.

The Demographics

There is a critical lack of comprehensive, up-to-date statistical data concerning people with disabilities in Minnesota. The most recent statewide study to collect this information was done more than 20 years ago. "The Assessment of Disability in Minnesota," conducted from 1976-1978, was coordinated by the Minnesota Department of Economic Security's Division of Vocational Rehabilitation, "to provide human service agencies in Minnesota with detailed information useful

Preventing the Leading Cause of Late-Life Disability

There are several disabling conditions or diseases that are closely related to aging. These include arthritis, Parkinson's disease. Ahlzeimer's and stroke. Stroke is the leading cause of late-life disability in the United States and the leading cause of nursing home admissions. The risk of stroke doubles with every decade after age 55. In Minnesota alone, there are an estimated 12,000 new strokes every year. Among stroke survivors, only one-third recover to independence, while one-third require significant help with daily living and one-third become totally dependent on others.

However, stroke is one disabler where there are opportunities for prevention and reduced disability. Risk factors for stroke include high blood pressure, cigarette smoking, heart disease and diabetes. Treating these conditions can reduce a person's risk of having a disabling stroke. There are also several warning signs or symptoms of stroke, including sudden numbness or weakness of the face, arm or leg, especially on one side of the body, sudden confusion, trouble speaking or understanding, and sudden trouble seeing in one or both eyes. Additionally, sudden trouble walking, dizziness, loss of balance or coordination and sudden severe headache with no known cause are also warning signs of a stroke. Taking these warning signs seriously and seeking immediate medical attention can reduce the likelihood of disability or death resulting from stroke. There have been numerous advances in the treatment of stoke, particularly when an individual receives treatment within three hours of the stroke's onset. (Source: National Stroke Association).

for efficient planning, evaluation and resource allocation."⁶

The study found that, in 1976, 30 percent of all Minnesotans with functional disabilities were over the age of 65. Additionally, 55.2 percent of all Minnesotans with functional disabilities lived in the Metro area, 9 percent lived in Region 10 (Olmsted, Winona and Wabasha counties) and 8 percent lived in Region 3 (St. Louis, Lake and Cook counties). All other regions had less than 5 percent.

Finally, the study reported that 60 percent of those with functional disabilities had physical disabilities; 13 percent had hearing disabilities; 5 percent had visual disabilities; 3 percent had developmental disabilities (mental retardation, cerebral palsy, epilepsy, dyslexia, and autism); over 2 percent had a mental illness; over I percent had speech impairments; and I percent had an addictive disorder.

While this statistical information about people with disabilities is more than twenty years old, the Minnesota Department of Human Services' Project 2030 Aging Initiative has collected valuable, and up-to-date, demographic forecasts regarding seniors with disabilities as a subset of the larger senior population.

The overall <u>rate</u> of disability in the United States, and most industrialized countries, is believed to be declining.⁷ However, the <u>actual number</u> of people with disabilities is expected to increase due to the dramatic growth of the 65+ population. The number of Minnesotans over the age of 65 with chronic disabilities is expected to almost double from 135,058 in 1995 to 265,207 in 2030.⁸

A comparison of disability rates by age group shows that disability becomes more common with age. According to the 1990 census, in Minnesota, 10 percent of men and 10 percent of women 65-74 years old have a functional disability, compared to 29 percent of men and 40 percent of women 75 and older.⁹

Among seniors, IADL-impairment (difficulty performing household tasks) is much more common than ADLimpairment (difficulty with personal care). In 1995, 109,000 Minnesotans over the age of 65 were IADL-impaired while only 26,000 were ADL-impaired. These numbers are both projected to double by the year 2030.¹⁰

Projections have also been made regarding the geographic distribution of seniors across the state. It should be noted, however, that these county by county projections are for the entire senior population. The exact geographic distribution of seniors with disabilities is unknown.

In 1997, 6-13 percent of the population in and around the Twin Cities metropolitan area was over the age of 65. By 2025, Hennepin and Ramsey counties are projected to have seen a 50-75 percent growth in the number of residents over the age of 65, while the surrounding counties are projected to grow by 100-350 percent. Olmsted and Beltrami counties are also

⁶The Assessment of Disability in Minnesota.

Minnesota Department of Économic Security.

⁷Interntational Evidence on Disability Trends among the Elderly. Waidmann and Manton, 1998.

⁸Project 2030 Briefing Book, Minnesota Department of Human Services, 1998.

⁹Project 2030 Final Report, Minnesota Department of Human Services, 1998.

¹⁰Project 2030 Briefing Book, Minnesota Department of Human Services, 1998.

| | <u> 1995</u> | <u>2010</u> | <u>2030</u> | <u>2050</u> |
|---------------|--------------|-------------|-------------|-------------|
| IADL-Impaired | | | | |
| 65-74 | 25,083 | 29,055 | 53,089 | 45,047 |
| 75-84 | 42,174 | 45,673 | 85,330 | 78,490 |
| 85+ | 42,040 | 59,272 | 75,140 | 132,210 |
| TOTAL | 109,297 | 134,000 | 213,559 | 255,747 |
| ADL-Impaired | | | | |
| 65-74 | 9,256 | 10,722 | 19,592 | 16,624 |
| 75-84 | 10,839 | 11,738 | 21,930 | 20,172 |
| 85+ | 5,743 | 8,097 | 10,266 | 18,062 |
| TOTAL | 25,838 | 30,557 | 51,788 | 54,858 |

Estimates of Chronic Disability in Minnesota's Senior Population

Source: Manton, Corder and Stallard, 1997, from MDHS Project 2030 Briefing Book.

expected to see growth anywhere from 100-350 percent.¹¹

In contrast, several counties in Greater Minnesota that had 19-26 percent of their population over the age of 65 in 1997, areexpected to see increases of less than 15 percent or in some cases, even losses of 15 percent, by the year 2025. These counties are clustered primarily along Minnesota's southern and western borders.¹²

These growth projections are based on the belief that people generally age in place. For example, the Twin Cities metropolitan area is currently home to a large percentage of the state's baby boomers. These individuals are expected to remain in the area as they age, thereby increasing the senior population of the area over the next 30 years. This, in part, explains the tremendous growth projections for the

¹¹Project 2030 Data Report: Population Profiles: County and Regional Data, Minnesota Department of Human Services, 1998.

¹²Project 2030 Data Report: Population Profiles: County and Regional Data, Minnesota Department of Human Services, 1998. suburban counties. Meanwhile, several of Greater Minnesota's southern and western counties currently have large senior populations, but fewer baby boomers. Therefore, over the next 30 years, as today's seniors pass away, there will be fewer baby boomers growing into old age to take their place. These counties are expected to see a decline in their senior population.

Increasing Diversity

Minnesota's senior population is not only expected to grow rapidly over the next 30 years, but it is also forecasted to become more diverse. While Minnesota's population of racial and ethnic minorities will still be a young population in 2030, minority elders are expected to become a larger portion of the growing population.

Between 2000 and 2030, African American, Hispanic, Asian and Native American seniors will grow from 1.5 percent of Minnesota's 65+ population to 4.5 percent. African Americans will continue to be Minnesota's largest group of minority seniors, but the number of Asian American elderly is expected to grow significantly. And while there are currently a very small number of Hispanic and Native American seniors in Minnesota, they are expected to grow by 372 percentand 300 percent, respectively, over the next 30 years.¹³

Despite this growth, Minnesota will still have a relatively small number of seniors from minority communities. However, the potential exists for these individuals to have a significant impact on the demand for services. First of all, members of particular minority groups experience different rates of disability. For example, the incidence of stroke is 288 per 100,000 people for African Americans, while it is only 179 per 100,000 people for whites.¹⁴

Secondly, Minnesota's minority seniors are concentrated in particular areas of the state. Therefore, counties such as Hennepin, Ramsey and Olmsted can expect to see a much larger growth than the statewide projections suggest. Additionally, as a group, seniors from Minnesota's minority communities are more likely to be lowincome and therefore eligible for various public programs and benefits. And finally, while many of Minnesota's minority seniors are currently cared for solely by family members, this is expected to change. As recent arrivals assimilate to life in Minnesota and younger members of the community increasingly join the workforce, we can expect greater utilization of services for seniors.

This growth in the number of people needing services is not the only factor to consider, though. It is also important to note that elders from Minnesota's minority communities may bring different values and expectations to the issues of aging and disability. While many of the service needs are similar, there will be a growing need for cultural awareness and sensitivity in the delivery of services.

Projected Growth in the Senior Population of Metro-Area Counties, 1995 - 2025



Source: McMurry, from Building Toward the Senior Boom, Wilder Research Center.

¹³Project 2030 Data Report: Population Profiles: African American, American Indian, Asian American and Hispanic Elders. Minnesota Department of Human Services, 1998.

¹⁴Stroke Facts. The National Stroke Association.

Section II: Conclusions and Recommendations

By definition, seniors with disabilities require some level of assistance with activities of daily living in order to remain living independently in the community. The areas of healthcare, longterm care, housing and transportation are particularly important for independent living, and therefore the focus of the following conclusions and recommendations.

Conclusion #1: There is an urgent need for more comprehensive, up-to-date information.

 There needs to be a current and regularly updated source of demographic information about the number, condition and location of older adults and seniors with disabilities in Minnesota.

This information was last collected in the mid-1970s! Since that time, the best available data has been acquired by extrapolating from national data or applying old percentages to updated census numbers. Minnesota's policy makers need better information in order to plan for the future and properly direct public resources. Service providers need it to more completely serve their regions.

 There needs to be one, comprehensive, reliable source of information about the type and amount of services available to seniors with disabilities.

Currently, the "word on the street" and the "official version of things" just don't match up. Conversations about transportation, housing and alternatives to nursing home placement reveal countless anecdotes about service a, b or c being unavailable in community x, y or z. This is particularly true in regards to Greater Minnesota, but it also applies to certain services in the Twin Cities area. However, research inquiries to Area Agencies on Aging around the state and a variety of service providers in the Twin Cities fail to substantiate the shortage or crisis suggested by these anecdotes.

This disconnect between the "word on the street" and the "official version of things," could be caused by a number of factors. For starters, when investigating services for seniors with disabilities, one discovers a wide range of programs and services, operated by the public, private and nonprofit sectors, that are all intended to help people live more independently. It does not take long to realize, however, that there is a great deal of fragmentation and no single point of accountability. The variations in size, area of service, eligibility, funding source, fees charged and services provided are unending.

One frequently proposed solution to this fragmentation is the creation of a single point of access. But that is not necessarily the best way to ensure that all those who need services are connected to them. Calling for a single point of access is actually misidentifying the problem. The current problem is not multiple points of access, but the fact that these multiple points of access actually access multiple pools of information. Therefore, what services an individual ultimately receives is determined, in part, by which access point they started at.

What Minnesotans really need are multiple points of access to a single body of knowledge; to a comprehensive system that will present all possible options and necessary services, no matter where the original point of access. For example, a seventy-five year old woman who is losing her hearing should be able to call the Senior Linkage Line, her county human services office, or the Minnesota Foundation for Better Hearing and Speech and receive the same referrals from all three.

There needs to be more information about the unique aging process experienced by individuals with life-long disabilities.

The aging process is believed to begin earlier and progress faster for individuals with lifelong disabilities, and often includes the onset of a second disability. Unfortunately, there are very few medical professionals that understand the impact of the aging process on an individual already living with a disability.

Individuals with lifelong disabilities not only experience a different aging process from a medical perspective, but from a social and economic one as well. For example, many individuals with developmental disabilities face the loss of parental caregivers and are forced to access the social service system for the first time at age 55 or 60. From an economic standpoint, many individuals with life-long disabilities have been unable to acquire retirement savings during their working years due to asset limitations related to Medicaid eligibility. The increasing life expectancy of individuals with disabilities will force us to consider the question, "what is retirement for someone with a disability?"

Conclusion #2: In order to meet the needs of a growing and diversifying population of seniors with disabilities, there must be increased collaboration among the various sectors of the disability community and between the disability community and the senior community.

Individuals who are both over the age of 65 and living with a disability are in a unique position. They are essentially straddling two communities. While they stand to benefit from the services of both, they are often not recognized as full members of either. There are numerous social service and advocacy organizations, both nationally and in Minnesota, that work with people with disabilities. However, the emphasis of many of these organizations is on one of two age groups: children with disabilities and their special education needs or working-age adults and the challenges they face in entering the workforce. Few disability organizations focus on the needs of people over the age of 65, in part because advances in medical technology are just now allowing large numbers of individuals with disabilities to live this long.

There are also many advocacy organizations and social service providers that work specifically with seniors. However many people fail to see seniors, even those living in a nursing home or using a hearing aid, as people with disabilities. For too long, the inability to complete tasks of independent daily living has been viewed as a "normal" part of aging. Therefore, many seniors with disabilities are just simply thought of as old.

In the past, efforts to push seniors and younger individuals with disabilities together for the sake of easing service delivery have failed to look beyond their common needs to recognize their differences in areas such as taste in music, food and entertainment. Understandably, few individuals with disabilities want to be thought of as old prematurely and few seniors want to be thought of as having a disability.

Therefore, there will be challenges to increasing collaboration and coordination. There is a real "silo" mentality among the various disability and senior groups, in both the public and nonprofit sectors. The disability community and the aging community have long seen themselves as two distinctly different groups. They have different ways of thinking about disability and even use different terminology in many cases. This silo mentality is contrary to the idea of a social model of care, and, over the next thirty years, it will become increasingly detrimental to individuals in need of assistance.

Recommended First Steps

I) Increased collaboration and coordination should begin at the state level. The legislature should consider structural changes in the various state entities that work with seniors and individuals with disabilities in order to better align policy development and service delivery according to a social model of care.

Currently, there are at least six different public sector offices that deal with disability: the Governor's Council on the Developmentally Disabled and the Governor's Council on Technology for People with Disabilities, both within the Department of Administration, State Services for the Blind within the Department of Economic Security and the Deaf and Hard of Hearing Services Division within the Department of Human Services, as well as the State Council on Disability and the Ombudsman for Mental Illness and Mental Retardation. The existence of multiple offices continues to unnecessarily divide the disability community into narrow categories.

Likewise, there needs to be increased coordination between the Department of Health and the Department of Human Services when it comes to services for seniors. For example, the Department of Health licenses and regulates long-term care providers, including nursing homes, housing with service providers, and home health agencies. Meanwhile, the Department of Human Services (DHS) reimburses these providers for services to Medicaid recipients. 2) The numerous private advocacy and service organizations that address the needs of seniors and individuals with disabilities must also increase their collaboration by sharing information, jointly developing services and better serving people with dual diagnosis.

<u>Healthcare</u>

The issues of healthcare access, cost and quality are too large and complex to be fully addressed here. However, the committee did tackle several healthcare issues of specific concern to seniors with disabilities.

Conclusion #3: As frequent users of our healthcare system, seniors with disabilities would benefit significantly from an increased emphasis on chronic-care and the continued deinstitutionalization of healthcare delivery.

According to a recent study conducted for the American Association of Retired Persons (AARP), 10 percent of individuals with disabilities who are over the age of 50, have three or more hospital visits a year, compared to 1 percent of nondisabled individuals over 50. Additionally, 34 percent of individuals with disabilities who are over the age of 50 have 20 or more doctor visits a year, compared to just 3 percent of nondisabled individuals over 50.¹⁵

These hospital and doctor visits are being made within a healthcare system that is based on an acute model of care. This is demonstrated and reinforced by the allocation of research dollars, focus of medical education, and compensation of

¹⁵Midlife and Older Americans with Disabilities: Who Gets Help?, The Public Policy Institute, AARP, 1998.

doctors with various specialties, as well as the reimbursement system.

Acute care views "problems in terms of illness and solutions in terms of cure."¹⁶ It is often focused on the short-term solution to the immediate problem. For an individual with a chronic disability this short-term, quick-fix approach often results in the numerous return visits demonstrated by the above statistics. Ultimately, this system results in cost shifting between various programs, payers and providers.

Chronic care, on the other hand, requires the use of interdisciplinary teams and attempts to manage care across settings in coordination with the other medical professionals and care providers involved with a given patient. It requires sharing information, focusing on long-term functional goals, and empowering the individual to be part of the decision making process. Chronic care also attempts to anticipate the next stage of disability progression and to minimize, prevent, or delay that progression, thereby allowing individuals to maintain their functional abilities longer and preventing the need for high-cost services in the future. Overall, a chronic care approach helps create a desirable balance between a medical model of care and a social model of care.¹⁷

One positive shift in the health care industry that is already underway is the deinstitutionalization of healthcare delivery. The number and type of settings in which care and treatment can be provided is expanding. Care that was once provided only in a hospital, doctor's office or nursing home can now be provided in a home or community setting, thanks to the expansion

¹⁶The Chronic Care Challenge. The National Chronic Care Consortium, 1999.

¹⁷Innovations and Issues in Clinical Integration: Improving Systems for MSHO Clients. Minnesota Senior Health Option, 1997. of home healthcare and advances in medical technology.

By the year 2030, technology will have further changed the face of healthcare delivery in ways that are virtually unimaginable today. However, it will be important to recognize the potential danger of stratification along the lines of technology haves and have-nots.



Recommended First Steps

I) The healthcare industry must be encouraged to place greater emphasis on chronic care.

This will be a long-term process, requiring systemic change in multiple areas. Chronic care requires a group of providers who are trained differently, a longer term outlook for determining success or failure, an information system that supports doctors and a reimbursement system that rewards success. The process must start with infrastructure changes, which should then be reinforced by a new payment system.

2) In order to continue moving towards a chronic care model, we must have better information systems that allow for information sharing, while still protecting privacy.

Currently, the health care industry uses information primarily for billing, record keeping and regulatory compliance. Increased efforts should be made to utilize the mass of information gathered from patients to create a more comprehensive picture of that individual's unique situation, in terms of health status, social supports, financial resources, etc., while still protecting individual privacy.

3) Minnesota's professional education programs, including those training social workers, doctors, psychologists and policy makers, must do more to prepare students for the realities of an aging society. In particular, medical education programs should place a greater emphasis on disabling conditions and diseases, geriatrics, chronic care, and aging with a disability. Each year, the University of Minnesota graduates only about 2 geriatricians and 6-12 nurse practitioners trained in gerontology. Currently, there is no geriatrics requirement in the medical curriculum, and medical students continue to see older people primarily in hospitals and other acute care settings.¹⁸

This is not necessarily a call solely for more specialists, though. By the year 2030, individuals over the age of 65 will equal almost one-quarter of the state's population. Every medical professional and social worker, no matter what their role or specialty, can expect to see more individuals over the age of 65.

4) The social service and health care industries must increasingly incorporate the use of technology beyond the hospital or clinic setting.

2030's seniors will be more technologically-literate than any previous cohort of seniors. Basic communication technologies, such as the telephone, internet and successor technologies, can and should be used more effectively to answer questions or monitor patients.

The use of home adaptation devices and telemedicine also offer a great deal of potential for improving the lives of seniors with disabilities.

There are barriers to increased and improved use of technology, though. Currently, these barriers include the lack of reimbursement for medical professionals who spend time providing care by phone or email, and the confidentiality concerns raised by the use of these technologies.

¹⁸ Dr. Robert Kane, Testimony to Citizens League Committee, May, 1999.

Long-term Care

It was not long ago that living with family or entering the local nursing home were the only options for individuals needing longterm care. Today, however, there are numerous alternatives to the traditional nursing home, including homecare, assisted living, adult foster care and adult day care. In many cases, these alternatives are less expensive, more desirable and more appropriate to the individual needs of a given person.

Conclusion #4: The long-term care industry has the potential to provide a wide range of individualized services that allow people to continue living independently longer. However, these services need to become more widely available and the industry will have to overcome a long-term labor shortage that is currently expected to last well into the next century.

There are very few areas of the state where entering the local nursing home remains the only option for someone needing long-term care. However, the full array of options is by no means available everywhere, and in reality, probably never will be. But while every resident won't have every option, every resident should have at least some options.

One example of a long-term care option that needs to become more universally available is assisted living. Assisted living facilities typically resemble apartment complexes where residents have small, private living quarters and can receive services ranging from meals, social activities and housekeeping to personal care and medical treatments. This is an ideal option for those who can no longer live alone, but do not require the 24 hour care provided by a nursing home. Despite the fact that new assisted living facilities are popping up around the state, even saturating the market in some areas, there is a strong need for greater access to this option. Currently, assisted living facilities are not an option for many Minnesotans because they are either too expensive or there is no facility nearby.

In addition to location and cost, an ongoing labor shortage can be expected to limit the availability of long-term care options in the future. Minnesota's long-term care industry is already experiencing a severe labor shortage, and demographic trends suggest it will only worsen with time. Over the next 30 years, Minnesota's working-age population is expected to grow at a much smaller rate than its senior population. Therefore, the long-term care industry will have to compete for workers against other industries offering higher pay for easier work.

The trend towards community and homebased care only adds to the strain of a dwindling labor pool. While home and community-based services are highly beneficial and attractive, they are also more labor intensive than institutionally based services. Home care requires workers to travel from one recipient's home to another, thus reducing the number of people each worker can serve in a given time period.

Long-term care providers, from homehealth agencies, to nursing homes and assisted living facilities, are going to have to make some significant changes in order to attract and retain the workforce they need to serve their expanding clientele. Currently, jobs in both institutional and community based long-term care require hard, unglamorous work for very low pay. And there are no easy solutions. Wages are severely limited by the reimbursement rates set by Medicare and private health insurance companies, and the personal hygiene tasks with which individual clients need assistance are an unalterable part of the job.

Recommended First Steps

I) Assisted living services can, and should, be made more affordable and available, by providing them in existing structures and separating the cost of housing from the cost of services.

Assisted living services do not have to be provided in new facilities built specifically for this purpose. They can be provided successfully and cost effectively in any setting where there is a grouping of people needing services.

Public housing complexes are one model of just that. Since they give priority to housing low-income seniors and individuals with disabilities, public housing complexes are home to numerous individuals needing assistance with ADLs and IADLs. Without diverting from their primary mission of providing housing, public housing agencies are collaborating with external service providers to provide assisted living services within their buildings. This allows public housing residents to age in place, adjusting the level of service they receive as their functional ability changes. It also allows for economies of scale because the service providers can care for a number of individuals without traveling from place to place.

Secondly, separating the cost of housing from the cost of services allows lowincome seniors to use their own resources, such as Social Security, to pay their rent, while accessing whatever public programs they might be eligible for to cover the service component. When these two components are billed together, many public assistance programs, which are intended to pay for care, not housing, cannot be applied.

2) The Department of Health should give long-term care providers greater flexibility to use existing facilities and resources in new ways, in order to meet changing needs.

Not only will the needs and wants of seniors be changing over the next 30 years, but so will their location. The areas of Minnesota that currently have large proportions of seniors are the same areas expected to see minimal growth or an actual decline by the year 2030. This means that we must find ways to meet the needs of today's seniors without making rigid and expensive brick and mortar investments. Instead we must find ways to alter existing structures and resources to meet changing needs as the years go by.

These efforts might be modeled after a pilot program currently being conducted at the Lyngblomsten Care Center in St. Paul. Based on a Swedish model of care, the Lyngblomsten Service House was created by remodeling a portion of the existing, traditional nursing home. The new Service House provides all levels of care to nine individuals living in efficiency apartments on site and another six individuals living in the community. A small staff of generalists, composed primarily of licensed practical nurses and trained medication aides, does everything the residents need, including cooking meals in their kitchenettes, doing laundry, monitoring medications, and administering treatments and therapies.

Because it has no restrictions on the level of care needed, the Service House concept allows residents to age in place. As an individual's needs increase, they can remain where they are, with their current care providers, instead of being transferred to a nursing home or other facility.

The Lyngblomsten Care Center created the Service House after asking themselves how they could best use their existing facilities to meet the changing needs of today's seniors, while still bringing in enough money to pay the bills. These are exactly the questions every long-term care provider and facility should be asking. How can they adapt what they have to keep up with changing needs? Unfortunately, the Lyngblomsten Care Center had to go through the process of applying for more than 70 waivers from the Department of Health in order to create the Service House. This type of extensive regulation, which focuses on structures and procedures rather than care outcomes. impedes innovation and should be reviewed.

3) Given the realities of a shrinking workforce, long-term care responsibilities are going to have to be met increasingly through care networks at the family, community and neighborhood level.

This will require some trade-offs. Care networks at the family, community and neighborhood level should yield programs that are innovative, flexible and tailored to local needs. In exchange, we will have to accept the fact that not every community will have the same mix of services.

Increased family and community provided care is something that is very difficult for the state to create. Much will depend on individual initiative, planning and responsibility. However, there are ways for the public sector to enable or encourage this type of care-giving.

One potential model can be found in a unique program that is currently being used in 17 Minnesota counties. The Consumer

Support Grant Program allows individuals currently receiving services through the Alternative Care, Medical Assistance Home Care, Personal Care Attendant or Developmental Disability Family Support Grant programs to receive a grant equal to the state's share of funding for the program they are currently in. Individuals can then use their Consumer Support Grant to purchase their own services from an agency of their choice, family or friends. Programs such as this, which give the recipient more choice and control over their care, while bringing family and friends into the mix whenever possible, should be explored and developed.

Simultaneously, community supports must be established to protect and assist families in securing their own care. This should include training for individuals and families on how to evaluate a potential employee, training programs for informal and formal caregivers, and an affordable system for providing workers compensation, payroll support and access to background checks.

4) Long-term care options must become more affordable, especially for middle-income individuals who do not qualify for public programs and subsidies yet cannot afford to pay for all of their care needs themselves.

One possibility to consider is a broadbased sliding-scale fee system, where individuals pay a certain percentage of their income for home care. Current financial assistance programs are directed at lowincome individuals and have a sharp cut-off point that leaves many lower-middle income seniors without any assistance.

5) Individuals must begin to assume greater responsibility for financing their own long-term care.

Currently, there is a misperception that long-term care costs will be covered by Medicare and ordinary health insurance, but in many cases they won't.¹⁹ This misperception and a lack of solid financial planning results in too many seniors depleting whatever long-term care benefits they have, along with their own assets, and then turning to Medicaid, the healthcare program for low-income individuals of all ages. Currently, more than 50% of longterm care costs are picked up by Medicaid²⁰, which is funded by a combination of state and federal dollars. The reality is that by 2030, Minnesota will be unable to afford the 400 percent increase in projected costs.²¹

The are numerous areas that the public, private and nonprofit sectors should explore, develop and promote in order to encourage individuals to assume greater financial responsibility. These include increased education about financial planning, improved long-term care insurance products and reverse mortgages, the expanded inclusion of long-term care insurance as an employee benefit, increased use of charitable annuities, and tax credits for families already caring for their senior members.

<u>Housing</u>

All of the talk of home health care, community-based services and independent living often neglects the most basic ingredient - individuals must have a home in which to receive this care. For seniors with disabilities this is not as easy as it may sound. **Conclusion #5:** In order to remain living independently in the community, seniors with disabilities need housing that is accessible, affordable and connected to services.

The majority of our current housing stock, both old and new, lacks even the most basic accessibility features, in terms of architectural and interior design and location to services. Without a redirection of housing development and sensible housing rehabilitation, our housing stock will be unable to meet the changing needs of our aging population.

While people are becoming more and more familiar with the concept of accessible design, they don't often incorporate it into their own homes until it becomes absolutely necessary.²² The homes currently being built for today's 40 and 50 years olds (who are 2030's seniors) will not allow their owners to age in place.

The current trend in housing construction is towards large, multi-level homes on the outskirts of the metropolitan area. These are often too large for a senior with a disability to maintain and are very rarely barrier-free. Furthermore, residents have to have a car to access basic services such as a grocery store, bank, post office or drug store, not to mention some of the more specialized services needed by a senior with a disability.

Existing housing can be renovated to accommodate the needs of an individual with a disability, and there are programs in place to help finance such renovations. The Minnesota Housing Finance Agency offers two programs that help people finance accessibility improvements to their homes. Projects might include building a

¹⁹Survey: Baby boomers ignore long term care needs. Star Tribune, June, 1999.

²⁰Survey: Baby boomers ignore long term care needs. Star Tribune, June, 1999.

²¹400% increase projected by Project 2030 Final Report. Minnesota Department of Human Services, 1998.

²²Jane Hampton, Testimony to Citizens League Committee, May, 1999.

ramp, adding a bedroom and bathroom to the first floor, and widening doorways. However, these programs can only help a limited number of people each year.

Meanwhile, thirty years is a long time in terms of housing development, and we have the opportunity to build entire communities between now and 2030 that are accessible to individuals with disabilities. Including accessibility features in the original construction of a home is significantly less expensive than having to renovate the home at a later date. Additionally, many of the features that make a home accessible fall into the category of "universal design." These are design features such as lower light switches, higher electrical outlets, and wider doorways that inhibit no one and make a house more accessible to everyone from children to seniors.

Creating more of this type of housing is primarily a matter of public education. Home buyers and builders must continue to be educated about what is and what is not "accessibility" or "universal design" or "barrier free." Equally important, though, is convincing people that disability can happen to anyone. Consumers must begin to plan ahead, for their own inevitable aging and the very real possibility that they will acquire some sort of disability as they age.

It is important to remember, though, that accessibility is an issue for all residences, not just single family homes. While 31% of Minnesotans over the age of 60 who own their own home have functional limitations, 44% of seniors renting at market rate and 49% of seniors renting with a subsidy have functional limitations.²³ Public housing high-rises are one source of accessible, rental housing for low-income seniors, but a large number of individuals are competing for affordable units on the private market.

In addition to accessibility, affordability is a major housing concern for older adults and seniors with disabilities. Individuals age 50 and older who are living with a disability are much more likely to be low-income than individuals age 50 and over without a disability. Among those with a disability, 19 percent have incomes below the poverty line (which was \$8,050 per year for a single individual in 1998) and 24% are below 150% of the poverty line, compared to 7 percent and II percent, respectively, for those without a disability. And while, half of the nondisabled population over 50 have incomes 300 percent of the poverty line or greater, only a quarter of those with disabilities have this much income.24

Recommended First Steps

I) The guidelines for dispersing grant funds from the Livable Communities Act should be amended to favor programs that include accessible housing.

The Livable Communities program is designed to encourage housing development that is affordable, mixed-use, lifecycle, pedestrian-friendly and transit-Unfortunately, while the oriented. program is one of the only government tools available to influence housing development in the Twin Cities, it fails to specifically encourage the development of accessible housing. This represents a great deal of lost potential because individuals with disabilities, and particularly seniors with disabilities, would benefit greatly from this type of affordable housing, if only it were accessible on the interior. For example, an individual that lives in a mixeduse development would have easy access

²³The Future of Senior Housing in the East Metro Area: A Report to East Metro SAIL. Wilder Research Center, 1999.

²⁴ Midlife and Older Americans with Disabilities: Who Gets Help?, The Public Policy Institute, AARP, 1998.

to a grocery store, bank and post office, thus reducing the need to depend on Metro Mobility for transportation to these locations.



2) Housing programs funded wholly or in part by public funds should give enhanced consideration to proposals featuring units that are fully accessible and/or have accessibility features.

3) Increased efforts must be made to educate consumers, builders, developers, architects and city planners about the need for accessible, lifecycle housing.

This might include better utilization of the Parade of Homes, existing awards for builders and the Home & Garden section of the newspaper.

Transportation

In many ways transportation services are the glue that holds all of the pieces together, in both the metro area and Greater Minnesota. Transportation is the key to allowing seniors with disabilities to live independently and to providing access to a wide range of other services.

The Twin Cities has one large, regional provider of paratransit services specifically for individuals with disabilities. Additionally, about half of the regular route bus fleet is equipped with accessibility features. This is supplemented by a variety of for-profit providers of accessible transportation and several small community-based transportation services.

In Greater Minnesota, the cities of Duluth, East Grand Forks, Moorhead, Rochester, and St. Cloud also have paratransit service. In the smaller towns and rural areas of Greater Minnesota, where there is public transit the vehicles are lift equipped. However, there are no separate systems specifically for individuals with disabilities. Greater Minnesota also depends heavily on a variety of small transportation programs run by nonprofits and numerous volunteer driver programs.

Conclusion #6: While Metro Mobility provides a significant amount of accessible transportation for residents of the Twin Cities, there is a need for additional options that are also affordable and unrestricted.

In the Twin Cities area, paratransit services for individuals unable to use the regular route bus system are provided by Metro Mobility. Operated by the Metropolitan Council, under the requirements of the ADA, Metro Mobility's demand service provided a total of 667,979 rides in 1998²⁵, at a cost to the rider of \$2 per one-way trip (\$2.50 during peak hours).

Not everyone who needs a ride on Metro Mobility is always able to get one, though. In 1998, Metro Mobility's official trip denial rate was 3.5 percent.²⁶ However, the committee heard testimony and received feedback that Metro Mobility rides are much more difficult to get than this statistic suggests. These comments were closely aligned with an acknowledgment made recently by the program's general manager, that "riders are expressing a lot of frustration at the difficulty of scheduling rides when they need them, particularly during peak travel times in the morning and late afternoon."²⁷

At first glance, the obvious solution is to expand Metro Mobility service. However, that seems unlikely to happen given the high cost of providing paratransit services. In 1997, Metro Mobility received a budget allocation of \$18.5 million from the state's general fund.²⁸ The cost per trip of operating Metro Mobility is approximately \$16.²⁹ After the passenger's \$2 fare, this results in a \$14 public subsidy for every one-way trip on Metro Mobility.

Expanding Metro Mobility is not the only option, though. At the heart of the complaints about transportation is the fact that when an individual cannot schedule a ride on Metro Mobility, they often have no place else to turn. Many paratransit riders hark back to the day when the Twin Cities had numerous transportation services certified to provide paratransit service. An individual would call their favorite provider and if they couldn't schedule the ride, the individual just called the next company on the list until one could schedule the ride. With today's single paratransit system, when Metro Mobility says "no," many people have no place else to call.

The Metro Transit bus system does provide public transit to some individuals with disabilities, and at a discounted fare of 50 cents per one-way trip. Currently, about half of the regular-route fleet is equipped with accessibility features, and all buses are scheduled to be accessible by the year 2004. However, a recent needs assessment conducted for the Metropolitan Council concluded that while the increasing accessibility of regular route buses will allow some current Metro Mobility riders to ride the regular route system, it will do little to reduce the overall demand for Metro Mobility service.³⁰

²⁵ Metro Mobility News, February, 1999.

²⁶ Metro Mobility News, February, 1999.

²⁷ Metro Mobility News, February, 1999.

²⁸ Metropolitan Council's Americans with Disabilities Act (ADA)/ Specialized Transportation Services(STS) Needs Assessment. March, 1999.

²⁹Metropolitan Council's Americans with Disabilities Act (ADA)/ Specialized Transportation Services(STS) Needs Assessment. March, 1999.

³⁰Metropolitan Council's Americans with Disabilities Act (ADA)/ Specialized Transportation Services(STS) Needs Assessment. March, 1999.

In addition to Metro Mobility and the accessible routes of Metro Transit, there are only a few other options for seniors with disabilities that cannot or do not drive themselves. The first option would be purchasing service from one of the Twin Cities' numerous private providers of accessible transportation. However, these services are significantly more expensive than Metro Mobility. For example, out of four different private transportation companies, the average round-trip cost for a ride that is ten miles each way, is \$62.31 For many, this cost limits the use of private transportation to situations where the trip is absolutely necessary, and for others it eliminates the option altogether.

A second transportation alternative for seniors with disabilities is to contact a nonprofit community-based service. These services receive financial support from a variety of sources, including Area Agencies on Aging and the United Way, and they serve as an essential gap-filler. However, they tend to use their limited resources primarily for transportation to medical appointments. These services often cannot help someone trying to go to the grocery store, library or theater.

Recommended First Steps

I) In order to enhance customer service at Metro Mobility, the Metropolitan Council should consider investing in more advanced technology that allows for better vehicle tracking and communication.

2) The taxi industry should be brought into the business of providing transportation for seniors with disabilities. Taxis are more affordable than the private providers of accessible transportation and, with enough supply, they allow maximum independence and spontaneity. Currently, there is only one taxi company in the Twin Cities that operates accessible vans, and they only have two. This results in the same need to call ahead for a reservation, for which there is a \$15 minimum charge. This is the same requirement the company has for any reserved ride, though.

Bringing the taxi industry into the business of providing transportation for seniors with disabilities will require more than just accessible vehicles, though. For example, people with visual impairments, hearing impairments or developmental disabilities are often physically capable of utilizing a traditional taxi, but are hindered by other barriers, such as difficulty communicating with the driver. These non-physical barriers must also be addressed in order to make taxis a viable alternative.

3) Transportation providers should consider utilizing mixed fleets, including both accessible vans or buses and sedans. Lift-equipped vehicles are the most expensive to own and operate, yet not every passenger with a disability needs these extra features. For example, the Ramsey County Red Cross operates a transportation service using 11 sedans and 6 lift-equipped vans. The operating costs of this system is approximately \$10 per trip for the sedans and \$18 per trip for the liftequipped vans.³²

Conclusion #7: There is a significant need for more comprehensive transportation service in Greater Minnesota.

There are currently 75 public transit systems in Greater Minnesota, 59 of which

³¹ Phone conversations with R&D Transportation, Northland Transportation, Key Transportation and D.S.T.S., Inc.

³² American Red Cross of the St. Paul Area Transportation Program.

are county or multi-county systems and 12 that are municipal only.³³ These systems provide a valuable service to riders of all ages and abilities, but are particularly important to seniors with disabilities.

Public transportation systems in Greater Minnesota receive approximately 65 percent of their annual operating costs and 80 percent of their capital costs from federal and state funds. The remaining amounts are raised locally using fare collections, general county or city revenue, grants and even fundraising efforts.³⁴

With this 65/35 funding system, Greater Minnesota's small transit systems operate at what appears to be a very reasonable cost. For example, Heartland Express in Mower County had a total operating budget of \$337,522 in 1997 and transported 59,644 passengers, for a cost per passenger of \$5.66. Roseau County Area Transit had a total operating budget of \$81,815 in 1997 and a total ridership of 13,141, for a cost per passenger of \$6.23.³⁵

Unfortunately, the majority of these systems have limited hours and days of operation, as well as limited areas of service. Service is commonly available Monday through Friday from approximately 8 a.m. to 5 p.m., but evening and weekend service is rare. Additionally, many public transit services are restricted by city or county lines and therefore do not provide transportation to the state's regional centers, such as Rochester or Mankato. This is a critical missing link for seniors with disabilities who often require the specialized medical care only available in larger communities.

More importantly, though, there are too many counties in Greater Minnesota that have no public transportation. Currently, eight counties have no public transit service at all, and another 13 have municipal service within their borders, but no county-wide system.³⁶

Recommended First Steps

I) The Office of Transit needs to take a more proactive approach to developing public transit systems in those counties that currently have none.

This is part of their mission, according to Minnesota Statutes, Section 174.21, which includes "[providing] access to transit for persons who have no available alternative mode of transit."³⁷ Currently, the office works with Greater Minnesota communities that approach them expressing an interest, but does not take steps to encourage communities to begin or expand services.

In order to take a more proactive approach and help create county-wide service in the 21 counties that currently have none, the numerous public and private organizations that serve people with disabilities must assist the Office of Transit in acquiring greater financial resources from the legislature.

2) Transportation services need to be more closely aligned with the needs of the customer.

³⁶MnDOT 1998 Transit Report. ³⁷MnDOT 1998 Transit Report.

³³Donna Allen, Director, Office of Transit, MnDOT. Testimony to Citizens League committee. May, 1999.

³⁴Donna Allen, Director, Office of Transit, MnDOT. Testimony to Citizens League committee. May, 1999.

³⁵ MnDOT 1998 Transit Report.

For many transportation providers in Greater Minnesota, this will require a reconsideration of cost-benefit breakdowns, hours and days of operation, and areas of service.

3) In order to better meet the need for transportation to regional centers, the state should provide tangible incentives to encourage the development of multi-county and regional transportation systems in Greater Minnesota.

####

Background for Study

The process of aging is both a blessing and curse. With aging comes (at least hopefully) increased wisdom, self-confidence, and very often a slower, more enjoyable pace of life.

Unfortunately, we also know that as people age, their functional ability tends to deteriorate. One-third to one-half of all people over the age of 65 have a certified disability.

Thanks to medical advances, the *rate* of disability among older people has actually gone down compared with past generations. However, due to demographic trends, the overall *number* of people with disabilities is growing and will continue to increase as a result of the huge wave of aging baby boomers.

As the number of people with disabilities increases, so too must the systems designed to care for and otherwise support these individuals. By many accounts, the current system falls short of meeting the demands of today, and is ill-equipped to meet the rapidly growing needs of tomorrow.

Charge to Committee

In an effort to begin setting service benchmarks and improving support systems for people with disabilities, this committee should:

- provide a status report on the health care, transportation, day support services and alternatives to nursing home residency for people with disabilities, and determine ability to meet growing demand in the future;
- breakdown and analyze the number and types of people (particularly seniors) with disabilities looking for trends that might inform policy makers and the private market on how to meet future needs;
- breakdown and analyze the service needs of seniors with disabilities, and their utilization of existing services; particularly according to geographic regions of the state;
- make recommendations regarding system improvements to health care, transportation, day support services and alternatives to nursing home residency for people with disabilities, so the state is better prepared to handle the coming aging of baby boomers.

Committee Membership

The Seniors and Disability Study Committee was co-chaired by Phil Riveness and Emily Anne Tuttle. A total of 33 individuals took an active part in the work of the committee. In addition to the chairs, they were:

Toni Baker Elizabeth Bergman Sue Carter Ellie Emanuel Beth Fondell Rob Fulton Beth Gendler Jean Greener John Hagman Jan Imsland Dianna Krogstad Diane Loeffler Joan Lynch Amy McQuaid Lila Moberg Curt Nelson Bob Nethercut Mary Jean Overend Bob Provost Ann Roscoe Anne Rozga Jim Scheu John Selstad Barbara Sporlein Bob Teetshorn Tom Teigen Candace Tillquist Eileen Weber Michael Weber Katie White Joan Willshire

Meetings and Resource Testimony

The committee met for the first time on April 19, 1999 and concluded its deliberations on July 12, 1999. The committee met ten times, studied a large and varied amount of printed materials and heard from the following resource speakers:

Donna Allen, Director, Office of Transit, MnDOT Janet Anderson, Program Director, Lyngblomsten Service House Shahla Espinosa, CLUES Spanish Speaking Elders Program Jane Hampton, President, Accessibility Design Bob Held, Director, Division of Continuing Care for the Elderly, DHS Helen Hyllested, the Advocacy Center Dr. Bob Kane, Director, U of M Center on Aging Steve Lund, Executive Director, Minnesota Homecare Association Adrienne Mason, Courage Center Speakers Bureau Eddie Rogers, Courage Center Speakers Bureau Barbara Sporlein, St. Paul Public Housing Agency Jim Varpness, Director, Division of Aging and Adult Services, DHS Bee Vu, Institute for Education and Advocacy Mary Walker, Volunteers of America - Senior Resources Mary Youle, Director of Housing & Community Services, Minn. Health & Housing Alliance

Meeting Space

Meeting space was generously donated by the Minnesota Hospital and Healthcare Partnership. The League greatly appreciates such in-kind contributions to its study committees.

Staffing

This report was prepared by Kristine Lyndon. Research and other committee tasks were performed by David Chadwick. Administrative support was provided by Trudy Koroschetz and Gayle Ruther.

WHAT THE CITIZENS LEAGUE IS

The Citizens League promotes the public interest in Minnesota by involving citizens in identifying and framing critical public policy choices, forging recommendations and advocating their adoption.

The Citizens League has been an active and effective public affairs research and education organization in the Twin Cities metropolitan area for more than 40 years.

Volunteer research committees of League members study policy issues in depth and develop informational reports that propose specific workable solutions to public issues. Recommendations in these reports often become law. Over the years, League reports have been a reliable source of information for governmental officials, community leaders, and citizens concerned with public policy issues of our area.

The League depends upon the support of individual members and contributions from businesses, foundations, and other organizations throughout the metropolitan area.

| OFFICERS 1998-99 | 1998-99 BOARD OF DIREC | 1998-99 BOARD OF DIRECTORS | |
|---------------------------|------------------------|----------------------------|--|
| President | John Adams | Susan Heegaard | |
| George Latimer | Mary Anderson | William Johnstone | |
| Vice President | Marcia Avner | Lani Kawamura | |
| Matthew Ramadan | Scott Brener | Steve Keefe | |
| Secretary | Andy Brown | Sean Kershaw | |
| Gary Cunningham | Mike Christenson | Barbara Lukermann | |
| Treasurer | Calvin Clark | Gene Merriam | |
| Christine Roberts | William Diaz | Tony Morley | |
| | James Dorsey | Pam Neary | |
| | Sally Evert | David Olson | |
| | Linda Ewen | Randy Peterson | |
| | Laurel Feddema | Orlan Thorbeck | |
| | Suzanne Fuller-Terrill | Emily Anne Tuttle | |
| | Peter Gove | Robert Vanasek | |
| | Marie Grimm | Jane Vanderpoel | |
| | Jean Harris | Lee Pao Xiong | |
| STAFF | PAST PRESIDENTS | Ũ | |
| Executive Director | Mary Anderson | Jean King | |
| Lyle D. Wray | Charles S. Bellows | Stuart W. Leck, Sr. | |
| Finance Director | Francis M. Boddy | Greer E. Lockhart | |
| Philip Jenni | Alan R. Boyce | Barbara Lukermann | |
| Research Associates | John Brandl | Becky Malkerson | |
| Kristine Lyndon | Ronnie Brooks | John W. Mooty | |
| David Chadwick | Mike Christenson | Arthur Naftalin | |
| Ronald Wirtz | Charles H. Clay | Charles Neerland | |
| Administrative Staff | Eleanor Colborn | Norman Newhall, Jr. | |
| Trudy Koroschetz | Rollin H. Crawford | Wayne H. Olson | |
| Editor, Minnesota Journal | Carl "Buzz" Cummins | Leslie C. Park | |
| Dana Schroeder | Waite D. Durfee | Malcolm G. Pfunder | |
| | Kent Eklund | Wayne Popham | |
| | John F. Finn | James R. Pratt | |
| | Richard J. Fitzgerald | Leonard F. Ramberg | |
| | David L. Graven | John A. Rollwagen | |
| | Walter S. Harris, Jr. | Charles T. Silverson | |
| | Peter A. Heegaard | Archibald Spencer | |
| | James L. Hetland, Jr. | Thomas H. Swain | |
| | Terry Hoffman | Peter Vanderpoel | |
| i | B. Kristine Johnson | Frank Walters | |
| | Verne C. Johnson | John W. Windhorst | |
| | William Johnstone | | |

RECENT CITIZENS LEAGUE REPORTS

These reports are the product of the League's unique program of citizen-based research. To order copies, use the form in this report.

| What's on the Public Agenda? | 5-99 |
|---|--------------------|
| A New Wrinkle on Aging: Baby Steps to 2030 | 12-98 |
| Help Wanted: More Opportunities than People | 11-98 |
| A Competitive Place in the Quality Race: Putting the Univ. of MN in the Top Five | 1-98 |
| It Takes a Region to Build Livable Neighborhoods | 2-97 |
| Straight "A"s for Minnesota's Schools | 2-97 |
| Compete Globally, Thrive Locally: What the Public Sector Should do | 9-96 |
| Building a Legacy of Better Value: Choose Reform, Not Declining Quality | 8-15-95 |
| Effective Transit: Invest in access to jobs and services | 1-95 |
| The Case for a Regional Housing Policy in the Twin Cities Metropolitan Area | 5-94 |
| Minnesota's Budget Problem: A Crisis of Quality, Cost and Fairness | 7-13-93 |
| Results for Citizens, Options for Officials | 6-16-92 |
| Reform the Electoral Process, Restore the Public Trust | 5-28-92 |
| The Party Caucus: An Inquiry | 4-5-91 |
| New Regional Approaches to Library Services: Long Overdue | 2-25-91 |
| Large Trucks: A Small Piece of A Larger Problem | 1-24-91 |
| Remaking the Minnesota Miracle: Facing New Fiscal Realities | 10-8-90 |
| Because That's Where the Money Is: Why the Public Sector Lobbies | 6-28-90 |
| Does the System Maltreat Children? | 4-3-90 |
| | 11-16-89 |
| Losing Lakes: Enjoyment of a Unique Metropolitan Resource is Threatened | 11-8-89 |
| Access, Not More Mandates: A New Focus for Minnesota Health Policy | 9-21-89 |
| Community: A Resource for the '90s | 7-25-89 |
| The Metropolitan Council: Strengthening Its Leadership Role | 3-23-89 |
| | 12-16-88 |
| | 11-17-88 |
| | 10-20-88 |
| Stopping AIDS: An Individual Responsibility | 5-09-88 |
| The Public's Courts: Making the Governor's Nominating Process Statutory | 1-28-88 |
| | 12-17-87 |
| Cooperatively-Managed Schools: Teachers as Partners | 8-05-87 |
| The New Weigh to Recycle | 5-22-87 |
| First Class Property Tax System | 4-27-87 |
| Start Right with "Right Start": A Health Plan for Minnesota's Uninsured | 2-24-87 |
| | 10-28-86 |
| Commitment to Focus: More of Both | 8-27-86 |
| State Civil Service: People Make the Difference | 6-12-86 |
| It's Only a Game: A Lottery in Minnesota | 2-11-86 1-08-86 |
| AdaptabilityThe New Mission for Vocational Education | 11-22-85 |
| | |
| Power to the Process: Making Minnesota's Legislature Work Better | 9-19-85 |
| Accountability for the Development Dollar | 6-20-85 |
| | 11-28-84 9-25-84 |
| A Larger Vision for Small Scale Agriculture | 6-07-84 |
| The Metro Council: Narrowing the Agenda and Raising the Stakes | 5-30-84 |
| The Region's Infrastructure: The Problem Isn't What You Think It Is | 4-24-84 |
| Meeting the Crisis in Institutional Care: Toward Better Choices, Financing and Results | 2-07-84 |
| A Farewell to Welfare | 11-03-83 |
| Homegrown Services: The Neighborhood Opportunity | 3-02-83 |
| Use Road Revenue for the Roads That Are Used | 12-15-82 |
| Workers' Compensation Reform: Get the Employees Back on the Job | 10-26-82 |
| Thought Before Action: Understanding and Reforming Minnesota's Fiscal System | 9-22-82 |
| The CL in the Mid-80s Making Batter Use of Existing Housing: A Pental Housing Strategy for the 1080s | 5-19-82 |
| Making Better Use of Existing Housing: A Rental Housing Strategy for the 1980s | 5-04-82 |
| Rebuilding Education to Make It Work | 3-24-82 |
| A Positive Alternative: Redesigning Public Service Delivery Paying Attention to the Difference in Prices: A Health Care Cost Strategy for the 1980's | |
| raying recention to the Difference in Thees. A freath care cost brancy for the 1900's | |

For titles and availability of earlier reports, contact the Citizens League office at 612/338-0791

RECENT CITIZENS LEAGUE STATEMENTS

These statements update the League's positions on key issues. No charge for a copy of League statements.

| | 11-24-97 |
|---|------------------|
| Letter to the Board of Regents at the University of Minnesota:re:General College | 4-10-96 |
| Regional Challenges and Regional Governance | 4-8-93 |
| Health-Care Access for All Minnesotans | 2-20-92 |
| | 12-11-91 |
| Light Rail Transit: The Regional Transit Board's Proposal to the 1991 Minnesota | |
| Legislature | 1-24-91 |
| Letter to Legislature from Community Information Committee re: | |
| Financing at the University of Minnesota | 4-07-89 |
| Statement on Changing the Fiscal Disparities Law | 1-15-88 |
| Statement to the Governor & Legislature on Transportation Financing in 1988 | 1-04-88 |
| | 10-12-87 |
| Statement to University of Minnesota Regents re: Commitment to Focus | 7-7-87 |
| Statement to Governor and Legislature on Innovation and Cost Control | 4-8-87 |
| | 10-30-86 |
| Letter to Regional Transit Board re: Metro Mobility Price Competition Ideas | 6-12-86 |
| Testimony to Legislature on Bloomington Stadium Site Bill | 2 - 20-86 |
| Letter to Regional Transit Board re: Policy Committee's Study of Metro Mobility | 12-6-85 |
| Statement to House Tax Subcommittee on Fiscal Disparities | 10-31-85 |
| Statement to Legislature on Preserving Metropolitan Tax-Base Sharing | 9-6-85 |
| Statement to Legislature & Metro Council on Bloomington Development Proposal | 8-15-85 |
| Statement to Metropolitan Council on Organized Collection of Solid Waste | 4-24-85 |
| Statement to Metropolitan Council on Long-Term Care | 3-8-85 |
| Statement on Transit Alternatives | 1-23-85 |
| Statement on Solid Waste Disposal | 1-21-85 |
| Statement to Tax Study Commission | 8-22-84 |
| Statement on Light Rail Transit | 4-6-84 |
| Statement to Legislative Study Committee on Metropolitan Transit | 12-15-83 |
| Statement to Governor's Tax Study Commission | 11-22-83 |
| Statement to Minnesota's Highway Study Commission | 9-29-83 |
| Statement on the Metropolitan Council's Proposed Interim Economic Policies | 8-29-83 |
| Statement to Minneapolis. Charter Commission: Proposal to have Mayor as | 8-11-83 |
| non-voting member of Council | |
| Statement to Metropolitan Council & Richard P. Braun, Commissioner of | 7-21-83 |
| Transportation on Preferential Treatment in I-35W Expansion | |
| Statement to Members, Steering Committee on Southwest-University | 7-19 - 83 |
| Avenue Corridor Study | |
| Statement to Commission on the Future of Post-Secondary Education in Minnesota | 6-22-83 |
| Statement to the Metropolitan Health Board | 6-20-83 |
| Appeal to the Legislature and the Governor | 4-26-83 |
| Citizens League Opposes Unfunded Shifts to Balance Budget | 12-1-82 |
| Longer-Term Spending Issues Which the Governor and Legislature | |
| Should Face in 1982 | 1-18-82 |
| Statement Concerning Alternatives to Solid Waste Flow Control | 1-12-82 |
| Amicus Curiae Brief in Fiscal Disparities Case, filed | 12-17-81 |
| Statement to the Minnesota State Legislature Regarding the Reconstruction Project | 12-14-81 |
| Letter to the Joint Legislative Commission on Metropolitan Governance | 11-13-81 |
| Statement to Metropolitan Health Board on Phase IV Report | 11 - 4 - 81 |
| Statement to Metropolitan Council on I-35E | 9-24-81 |
| Statement to Minneapolis Charter Commission | 7 - 6-81 |
| Letter to Metropolitan Council re CL Recommendations on I-394 | 6-23-81 |
| - | |

CITIZENS LEAGUE PUBLICATIONS

PRICE LIST

Use the coupon below to order any reports or statements and copies of:

Minnesota Homestead Property Tax Review 1998
(October 1998 issue of the Minnesota Journal) \$2.00

| • | 1999 Public Affairs Directory | Members | Non-members |
|---|-------------------------------|---------|-------------|
| | 1 copy | \$15.00 | \$20.00 |
| | 2 - 10 copies, each | \$12.00 | \$16.00 |
| | 11 copies or more, each | \$9.00 | \$12.00 |

Postage and Handling: \$1.50 1st copy; \$1.00 each additional copy

STUDY COMMITTEE REPORTS

| 1 copy | FREE | \$10.00 |
|-------------------------|--------|---------|
| 2 - 10 copies, each | \$5.00 | \$ 9.00 |
| 11 copies or more, each | \$4.00 | \$ 8.00 |

(*There is no charge for A New Wrinkle on Aging: Baby Steps to 2030.)

CITIZENS LEAGUE PUBLICATIONS

ORDER COUPON

| Quantity | Publication | Cost |
|------------------|--|---------|
| | | \$ |
| | | \$ |
| | | \$ |
| | Subtotal: | \$ |
| | Postage & Handling: (PAD only) | \$ |
| | Total: | \$ |
| Ship to: Name | | |
| Address | | |
| City, St, Zip | | |
| Phone | | |
| Form of payment: | Check enclosed: Credit ca VisaMaster CardDiscover | |
| | Exp | o. Date |

I am interested in receiving Citizens League membership information:_____

Return form to: Citizens League, 708 So. Third St, Ste 500, Minneapolis, MN 55415 or fax: (612) 337-5919