THE VALUE OF LONG-TERM CARE IN OHIO: PUBLIC DOLLARS AND PRIVATE DEDICATIONS

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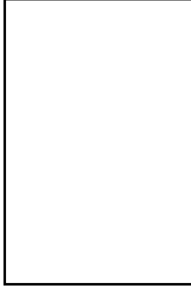
May 2003



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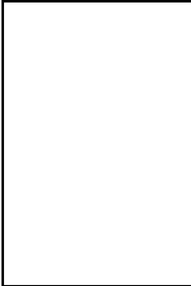

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Executive Summary

In Ohio, for 1999[1], we estimated that about 153,000 older people (age 65 and older)[2] were so disabled as to require long-term care. Of this total, a little less than half (about 76,000) were receiving care in Ohio's long-term care institutions. The remaining 77,000 were receiving care at home. About 26,000 of those who received their care at home had some of their care publicly funded by either a home and community-based Medicaid waiver (PASSPORT Program) or by local tax levies approved specifically for care of older people with disabilities. The remainder of the care was largely uncompensated care provided by family members.

Another 274,000 older persons were moderately disabled. Although the moderately disabled could take care of their basic needs, they still needed help with shopping, meal preparation, chores around the house, and money management. Almost all people with moderate disablilities live in the community and receive their care from family, friends, and neighbors or limited purchased services.

It is also estimated that the overall economic value of long-term care to these 153,000 severely disabled and the 274,000 moderately disabled older Ohioans reached almost 10 billion dollars. Of this total, the value of family care accounted for about half; 29.0 percent ($2.9 billion) was in the form of publicly funded services, mostly nursing home care funded by Medicaid; and 20.6 percent came from private sources, mostly out-of-pocket payments to nursing homes by older persons or their families.

Because such a large amount of care and its financing are currently provided in older persons' homes by the family, and because demographic and economic trends indicate difficulty in maintaining family home care at this high level as the older population ages, the State of Ohio could become economically vulnerable to increasing costs. These increases are due not only to health care inflation and growth in the number of disabled older Ohioans, but also to a growing proportion of older persons in need of publicly supported services.

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[1]Unless otherwise stated, the figures in this report are for calendar year 1999.

[2]"Older people" in this report always refers to persons 65 years and older.

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We are grateful to Heather Menne, a student in the Master of Gerontological Studies program at Miami University between 1999-2001 for her help at various stages of this project.

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Background

The soaring cost of state-funded long-term care services to older adults is currently one of the most urgent issues facing Ohio, as well as all other state governments throughout the United States. These increases are due mainly to growing numbers of people in the oldest age brackets, where need for long-term care is most prevalent; concentration of state-funded long-term care in nursing homes--a very expensive type of long-term care; and the increased overall impairment level of nursing home residents in recent years (Sahyoun, Pratt, Lentzner, Dey, & Robinson, 2001).

The State of Ohio, along with the federal government, spent about 2.6 billion dollars to finance long-term care services to older Ohioans in long-term care institutions, and another 5 million dollars to perform survey certification and ombudsman services. In contrast, the state spent 173 million dollars to care for individuals 65 years and older in their homes. Ohio's public expenditures for long-term care must be seen in a context that includes expenditures by other government programs, by private insurers, by older people and their families, and by charitable organizations. We also should consider the economic value of care provided by older people's family and friends and will examine possible present and future income lost to caregivers because they may reduce employment to perform the caregiver role. This report will provide estimates of the number of older people in Ohio receiving long-term care and identifies:

1) Whether they are receiving formal care:
   a. in an institution;
   b. in the community; or
   c. receiving informal care from family, friends, and neighbors in the community

2) The value of care provided in each setting; and

3) Who paid for the care.

In addition, this report will discuss whether Ohio can continue with its present policies, given an expected and unprecedented increase in the number of older people as well as disabled, older people in the next 50 years.

No single private or public agency collects all of the data needed to examine the issues identified above. Many agencies collect part of the data, but significant gaps remained, for which estimates were made. Data were collected from the Ohio Departments of Health, Job and Family Services, and Aging; the Ohio General Assembly; the Office of Budget and Management; and United Way of Ohio. In addition, data were collected from each county government in Ohio to determine if they had a levy funded program; where the levy funded services for older people take place in the county; and whether the services could be classified as long-term care. We also examined data from several national surveys to estimate various parameters.

Ascertaining the number of people receiving long-term care in nursing homes or from community-based formal agencies was

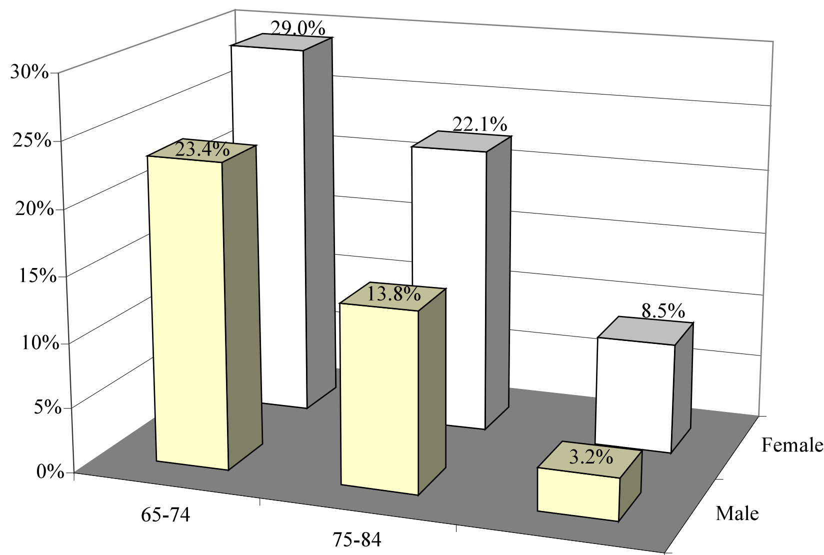
a relatively straightforward task, even though the data were collected by several agencies and sometimes were not strictly comparable. The most difficult aspects of this study were estimating the number of people who needed long-term care and were receiving it from informal sources, such as family and friends, and then estimating the economic value of that care. Without estimates of the economic value of informal care, we would substantially overstate the role of government-funded long-term care.

A Brief Description of Ohio's Older Population

Using the 2000 Census, we estimated that there were about 1.5 million persons age 65 and older residing in Ohio in 1999; 60 percent of this population was female. Over half (52 %) were among the youngest old, 65 to 74, and 12% were 85 years old or older. Figure 1 presents detailed age and gender distributions of Ohio's older population.

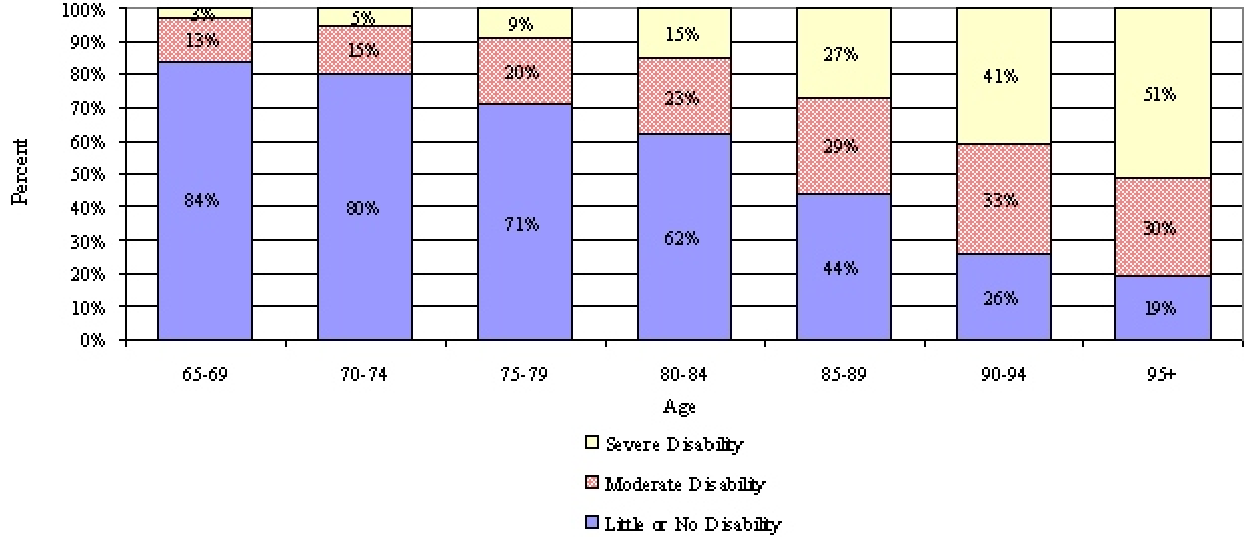
From earlier studies (Kunkel & Applebaum, 1992; Mehdizadeh, Kunkel & Ritchey, 2001) we learned that the extent of disability increases with age and women in general are more likely to be disabled than men at every age. Figure 2 presents the prevalence of disability in the U. S. population and the progression of disability as the population ages. Combining the information from Figures 1 and 2 allows us to estimate the proportion of Ohio's older population with disability.

Figure 1
Ohio's 65+ Population Distribution by Age and Gender in 1999 (1.5 Million Persons)



Source: U.S. Census Bureau. Census of Population and Housing, 2000. Retrieved 2002, from http://www.odod.state.oh.us/research.htm.

Figure 2
Estimated Percentage Distribution of U.S. Population by Disability Status and Age



Source: Mehdizadeh, S., Kunkel, S., and Ritchey, N. (2001). *Projections of Ohio's Older Disabled Population: 2015 to 2050.* Oxford, OH: Scripps Gerontology Center, Miami University.

Who Needs Long-Term Care?

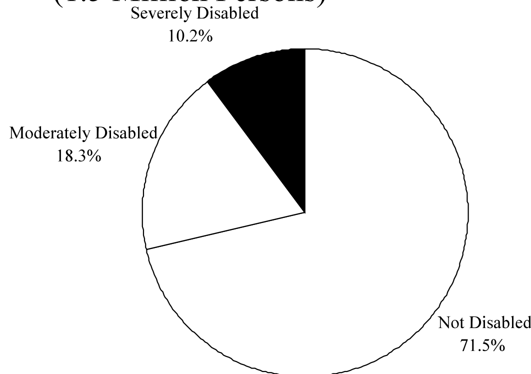
What Proportion of Ohio's Older Population Needs Long-Term Care?

There were 1.5 million older people in Ohio in 1999. Only an estimated 10 percent were so disabled that they could not care for themselves; another 18 percent required some help with shopping, preparing meals, and doing heavy chores around the house.

Sometimes the concern over the number of disabled older people in need of care and the staggering cost of long-term care, whether it is paid privately or publicly, overshadows the overwhelming proportion of older people who are functionally intact and have remained active in their later years. These individuals, by participating in civic, volunteer, and work activities, are contributing to their communities. Figure 3 shows that there were 1.5 million older people in Ohio in 1999. Only an estimated 10 percent were so disabled that they could not care for themselves; another 18 percent required some help with shopping, preparing meals, and doing heavy chores around the house. The remaining 72 percent had little or no disability. It is the care needs of one out of every ten older Ohioans who are so disabled that they need regular assistance with some

activities and the almost two out of every ten that require some assistance that we will examine in this report.

Figure 3
Proportion of Ohio's 65+ Population by Disability Status
(1.5 Million Persons)



Source: Calculated by authors based on the information in Chart 1 and 2.

We began with the assumption that need for long-term care is related to disability. Nearly all older people who receive sustained long-term care services need not only health care, but also assistance with activities of daily living (ADLs) such as eating, bathing, dressing, remaining continent, and transferring in and out of bed or a chair. They also may need help with instrumental activities of daily living (IADLs) such as meal preparation, shopping, housekeeping, placing telephone calls, managing money or using transportation. Cognitive impairment, such as inability to remember one's home address or to take medication, also is related to the need for assistance. We assumed that older people who had at least one ADL impairment, or at least two IADL impairments were moderately disabled, and those who had at least two ADL impairments, including cognitive impairment, were severely disabled requiring either institutional care or substantial long-term care services at home.

Where Do People With Disabilities Receive Care?

Based on Ohio's 1999 estimated older population, by five-year age-gender categories, [authors' calculations using census 2000 data and five-year age-specific disability rates developed for the *Projections of Ohio's Older Disabled Population 2015 to 2050*, (2001)] we estimated that about 153,000 Ohioans age 65 and older were severely disabled and in need of long-term care services (see Table 1). About 274,000 more were moderately disabled and needed some assistance regularly (Table 2). Next we examined the data on the number of people receiving care in various types of long-term care programs. A total of 76,000 severely disabled older people were in nursing homes, homes for the aged, or residential care facilities. We estimated that nearly all of the remaining 77,000 people with severe disability received some care in the community from informal providers such as family, friends, neighbors or purchased formal care (although the national surveys show there are unmet needs in the community; e.g. the National Long-Term Care Survey, 1995). Of the estimated 77,000 older people receiving care in the community, 16,600 also received case-managed care from PASSPORT (Ohio's 2176 Medicaid waiver program) and 9,300

Table 1
Estimated Number of Older Ohioans with Severe Disability in Need of Long-Term Care and the Value of Services, by Type of Provider, 1999

Provider	Persons Served*		Economic Value of Services	
	Number	Percent	Thousands of Dollars	Percent
Long-Term Care Institutions				
Nursing homes, residential care facilities, homes for the aged	75,924	49.7	3,667,576	56.4
Subtotal	**75,924**	**49.7**	**3,667,576**	**56.4**
Community-Based Services				
Out of pocket	50,862	33.3	132,630	2.1
PASSPORT	16,625	10.9	173,564	2.6
Local property tax levies designated for home care services	9,353	6.1	28,954	0.4
Other			12,691	0.2
Subtotal	**76,840**	**50.3**	**347,839**	**5.3**

Estimated Value of Informal Care

Provider	Number	Percent	Thousands of Dollars	Percent
Informal Care				
Family, friends, neighbors	**58,168**[a]	**36.3**	**2,490,476**	**38.3**
Total	**152,764**	**100.0%**	**6,505,891**	**100.0%**

*For a detailed explanation of the estimates see Table B-1 in Appendix B.

[a] These numbers not included in the total since this care is often supplemented by formal care.

Table 2
Estimated Number of Older Ohioans with Moderate Disability in Need of Long-Term Care and the Value of Services, by Type of Provider, 1999

Provider	Persons Served*		Economic Value of Services	
	Number	Percent	Thousands of Dollars	Percent
Long-Term Care Institutions				
Residential care facilities	5,218	1.9	136,894	
Subtotal	**5,218**	**1.9**	**136,894**	**4.0**
Community-Based Services				
Local government home care services (tax levies)	1,746	0.6	5,404	0.2
Out of pocket	266,635	97.5	748,711	22.1
Other state and federal programs			45,832	1.4
Subtotal	**268,381**	**98.1**	**799,947**	**23.7**
Informal Care				
Family, friends, neighbors	**132,580**[a]	**48.5**	**2,444,516**	**72.3**
Total	**273,599**	**100.0%**	**3,381,357**	**100.0%**

*For a detailed explanation of the figures see Table B-2 in Appendix B.

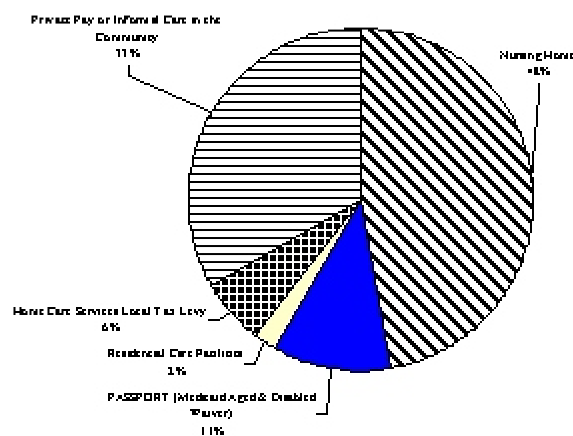
[a] These numbers not included in the total since this care is often supplemented by formal care.

persons yearly received home and community-based services funded by local property tax levies[3]. Some older people also received limited services from other types of programs: Options for Older Persons; the Administration on Aging's Eldercare Initiative administered by Area Agencies on Aging; programs funded by the United Way; and Home Health Agencies following hospitalization.

About half of Ohioans with severe disability received their care in long-term care institutions. Approximately 11 percent received home and community-based care, paid by Medicaid case-managed care, and another six percent received similar care in the community paid by local property tax dollars specifically approved for this purpose. Three out of every ten severely disabled persons were cared for in the community solely by home care agencies paid by the recipient or her/his family.

As Figure 4 shows, about half of Ohioans with severe disability received their care in long-term care institutions. Approximately 11 percent received home and community-based care paid by Medicaid case-managed care, and another six percent received similar care in the community paid by local property tax dollars specifically approved for this purpose. Three out of every ten severely disabled persons were cared for in the community solely by home care agencies paid by the recipient or her/his family. In contrast, almost all of the moderately disabled older persons, except for a relatively small number who live in residential care facilities, are residing in the community and receiving informal care (Figure 5).

Figure 4
Setting of Care Services for Ohio's Severely Disabled Persons, 1999
(Estimated 152,764 Persons)



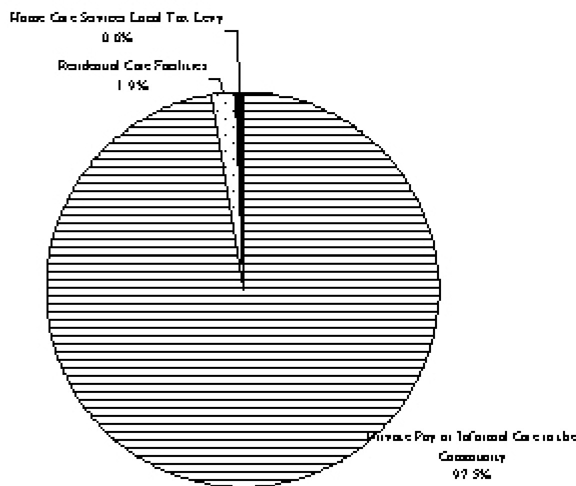
Source: See Table B-1 and notes in Appendix B.

In Ohio, the amount of Medicaid long-term care dollars spent on home and community-based care has increased steadily from nearly 39 million dollars in 1990 to almost 196 million in 1999. This is a significant increase (400%) in terms of dollars spent on community-based long-term care, and in the number of individuals (230% increase) who received care in the community (Mehdizadeh & Atchley, 1992). However, in

[3] Ohio is practicing local support for in-home services through the use of county property taxes. These locally supported in-home services have less stringent financial and disability eligibility requirements. Almost half of Ohio's counties supplemented aging services in this way.

comparison to other states, Ohio is ranked 43rd in the proportion of Medicaid long-term care dollars spent on home and community-based care (Burwell, Eiken, & Sredl, 2002).

Figure 5
Setting of Care Services for Ohio's Moderately Disabled Persons, 1999
(Estimated 273,599 Persons)



Source: See Table B-2 and notes in Appendix B.

How Much Does It Cost To Care For People With Disabilities?

The Total Economic Value of Long-Term Care to Ohio's Older Disabled Persons

The economic values assigned to institutional care and formal community-based care were computed from reports submitted by the organizations providing services. Most of these reports came from three Ohio Departments: Health, Job and Family Services, and Aging. To estimate the value of informal services, we multiplied the number of people we estimated to be receiving such services by average weekly service hours and hourly pay rates obtained from several large national surveys of community-based care. We also considered including the estimated value of current and future income loss by caregivers because some caregivers had to reduce employment.

The total economic value of long-term care to older people in Ohio was almost $10 billion. When this total was broken down by type of care, the value of institutional care was about $3.8 billion, the value of community-based formal services was $1.1 billion, and the value of care provided by family, friends, and neighbors was nearly $4.9 billion.

We estimated that the total economic value of long-term care to older people in Ohio was almost $10 billion in 1999 (see Table 3). When this total was broken down by type of care, the value of institutional care was about $3.8 billion, the value of community-based formal services was $1.1 billion, and the value of care provided by

family, friends, and neighbors was nearly $4.9 billion. Thus, in terms of economic value, by far the largest component of long-term care was informal care provided in the home, followed by the value of care in institutions. The value of community-based formal long-term care services accounted for the smallest proportion of the total.

Table 3
Total Value of Long-Term Care Services in Ohio by Source of Support, 1999

Source of Economic Support	Total Value* (in Thousands of Dollars)	Percentage of Total by Source
Long-Term Care Institutions		
Medicaid	2,154,727	21.8
Private pay (no insurance)	1,094,232	11.1
Medicare	449,933	4.5
Long-term care insurance	39,861	0.4
Other	65,717	0.6
Subtotal	**3,804,470**	**38.4**
Community-Based Formal Services		
Private pay	881,341	8.9
PASSPORT	173,564	1.8
Home care local government (tax levies)	34,358	0.4
Other state and federal programs	48,589	0.4
Medicare	3,850	---
Charitable assistance (United Way)	6,084	0.1
Subtotal	**1,147,786**	**11.6**
Informal Care	**4,934,992**	**50.0**
Total	**9,887,248**	**100.0%**

*For a detailed explanation of the figures see Table B-3 in Appendix B.

Sources of Economic Support for Formal Long-Term Care Services

In per capita terms, the State of Ohio's public long-term care expenditure for the population age 65 and over was $1,915 of which $1,554 came from the Medicaid program. The private per capita contribution to long-term care expenditures for formal and informal services was $4,685.

When economic support for long-term care services was broken down into institutional care and community-based care, by source of economic support (see Table 3), we saw that Medicaid and Medicare were used primarily to fund care in institutions and medical home care. Long-term care insurance also funded a very small proportion of institutional care. Although the newer long-term care insurance policies have provisions that allow home care, there is no single source that tracks that information. Private charitable assistance played a very minor role in long-term care, mostly by funding nursing home care for residents of sectarian homes for the aged, and the United Way providing $6 million for home and community-based care. Formal home-delivered long-term care was funded by Medicaid (PASSPORT) and by the property tax levy programs. The Older Americans' Act also paid for home care services at a very modest level, (0.2%) particularly in comparison with the total value of economic support for long-term care.

Economic support for long-term care services to older people is either public or private. Table 4 shows that, of the total $4.9 billion of long-term care services provided by organizations, almost $2.9 billion (58%) came from public sources and almost $2.1 billion (42%) from private sources. In per capita terms, the State of Ohio's public long-term care expenditure for the population age 65 and over was $1,915 of which $1,554 came from the Medicaid program. The private per capita contribution to long-term care expenditures for *formal* and *informal* services was $4,685.

Medicaid was the most important public source, accounting for over 81 percent of public funding for long-term care. Medicare accounted for 16 percent of public funding; the remainder was shared by funding from state and local governments, the Older Americans' Act, and Social Services Block Grants, in that order.

Private economic support of long-term care came in the form of formal or informal care, formal care accounting for 29.7% of private support. Formal care had two components: the out of pocket costs paid by older people or their families to long-term care institutions, and the value of privately purchased assistance for housekeeping, shopping, transportation, and financial management services by older consumers or their families. Doty, Jackson, and Crown (1998) estimated that, on average, a disabled person residing in the community purchases four hours of services per week. This was followed by long-term care insurance (0.4%), continuing care residential care contracts (0.2%) and private charitable assistance (0.1%). The value of informal care provided by family, friends and neighbors, if such services had to be purchased, represents 70.3% of private support.

Table 4
Sources and Value of Support for Long-Term Care for Moderately and Severely Disabled Persons in Ohio, 1999

Source	Amount in Millions of Dollars*	Percentage of All Long-Term Care Payments
Public		
Medicaid	2,328,291	23.6
Medicare	453,784	4.6
All other state and federal expenditures	87,950	0.8
Subtotal	**2,870,025**	**29.0**
Private		
Payments by elderly individuals or their families	1,975,573	20.0
Long-term care insurance	39,861	0.4
Continuing Care Residential Care contracts	17,731	0.2
Charitable organizations	6,084	---
Other	42,982	0.4
Subtotal	**2,082,231**	**21.0**
Informal Care	**4,934,992**	**50.0**
Total	**9,887,248**	**100.0%**

*For a detailed explanation of the figures see Table B-4 in Appendix B.

Value of Services Provided by Informal Caregivers

Informal caregivers are family members, friends, and neighbors who assist disabled older adults with transportation, meal preparation, housework, money management, continuous supervision, and personal care. Agencies or formal caregivers (e.g., Area Agencies on Aging, and home health agencies) are more likely to provide nursing care, physical therapies, and adult day care. In appraising the value of the services provided by informal caregivers, we should assess both the value of the services performed and the probable income lost because of caregiving.

To place a monetary value on the services provided by informal caregivers, we had to estimate the number of hours of care received by each disabled older person per week, as well as the economic value of this

service had it been performed by a paid[4] provider. Based on national home care data sources, we learned that not all disabled older people, irrespective of impairment status, have a primary caregiver. In fact, 24 percent of severely disabled and over 50 percent of moderately disabled older persons in the community had no primary caregiver (1995 National Long-Term Care Survey, authors' calculation). Some older people with no primary caregiver rely on the goodwill of friends and neighbors, or faith based/charitable organizations to meet their needs. Since a certain level of benevolence exists among members of a community, irrespective of age, we did not attempt to put a value on these acts of kindness. Among those who had caregivers, some received care only a single day of the week, while others received help every day of the week. The unit cost of service is based on Ohio's average unit cost reimbursement for home care services in the PASSPORT program, a conservative estimate.

To estimate the hours of care received by a chronically disabled older person we reviewed several sources. In a previous study, based on the Channeling Demonstration Survey of Informal Caregivers, we estimated that the average hours of care received per person per day was approximately 5 hours for moderately disabled and 7.5 hours for severely disabled persons (35 hours and 52.5 hours per week, respectively) (Mehdizadeh and Atchley, 1992). A review of more recent data, such as the National Alliance for Caregiving Survey in 1997, found that individuals designated as moderately disabled on average received a total of 36 hours a week and those defined as severely disabled received about 80 hours of care per week (National Alliance for Caregiving and the American Association of Retired Persons, 1997). The work by Doty, Jackson, and Crown (1998) based on the 1989 National Long-Term Care Survey and its companion, The Caregiver Survey, found that the average number of hours of weekly help by informal caregivers for individuals with all disability levels was 52.7 hours per week. Those with fewer than two impairments in Activities of Daily Living received about 28 hours of care per week from the primary caregiver alone (Doty, Jackson, & Crown, 1998).

It appears that the average number of hours of informal care a person with moderate disability (one or no ADL impairments and at least two IADL impairments) receives has remained stable since 1982, around 35 to 36 hours per week. However, there is an increase in the number of hours of care severely disabled persons receive. This increased need for assistance could be the result of shorter and fewer nursing home stays. Nationally, in 1985, about 18 percent of nursing home residents were discharged to the community; by 1997 almost one out of every three were discharged to the community. The average length of stay for short stays also dropped from 89 days in 1985 to 45 days in 1997 (Sahyoun, et al, 2001). We found similar patterns of nursing home utilization in Ohio. Following a group of newly admitted nursing home residents for 24 months between 1994 and 1996, we learned that about 47.6 percent left within the first three months, and another 15.7 percent were released to the community within the next three months. Those who

[4] Although residents of long-term care institutions have caregivers who visited them, attended their care conferences, and assisted in their care, we have not included the value of this care in the total value of informal caregiver services.

remained in a nursing home beyond 9 months rarely returned to the community (Mehdizadeh, Applebaum, & Straker, 2001).

We calculated the number of persons, at each impairment level, who had a regular caregiver. Then, we multiplied the number of hours of weekly service at a given level of disability by the number of community recipients at each level of disability, and multiplied that total by 52 weeks in a year to arrive at an estimated total of 362 million hours of informally provided care. The total economic value of this care at $13.50 an hour was estimated at $4.9 billion. In estimating the value of informal care we selected the most conservative approach in several ways:

First, we did not include the value of informal care provided to residents of long-term care institutions. While we know families participate in residents' care management, decision making, do their laundry, and manage their finances, we attributed these contributions to family responsibility and commitment.

Second, for disabled older people in the community, whether they received formal services or not, we only counted the value of the care provided by the primary caregiver, if there was one. If the care was distributed among several children, siblings, or friends and neighbors with no designated primary caregiver, we did not put a dollar value to that care. Again, we attributed that care to the intergenerational exchange among members of a family or community that takes place now and perhaps will continue in the future.

Third, we only accounted for the value of the primary caregiver's care and assumed all other informal care, such as that by faith based or charitable organizations will continue in the future based on the goodwill of these organizations toward their community members irrespective of the member's disability or age.

Fourth, we used the Medicaid home and community-based waiver reimbursement rate for the value of each hour of service. Medicaid often has a lower reimbursement rate compared to privately purchased or levy reimbursed rates resulting in conservative estimates.

The Value of Lost Income Due to Caregiving

Caregiving responsibilities will most often occur when women, who had left the labor market to raise a family, return to employment.

The overwhelming majority of caregivers are women (72.5% according to The 1997 National Alliance for Caregiving Survey; 73.5% according to The Caregiver Companion of the 1989 National Long-Term Care Survey). Caregiving responsibilities will most often occur when women, who had left the labor market to raise a family, return to employment. The average age of a caregiver varies from 46 in the National Alliance for Caregiving Survey to 60 in the 1989 Caregiver Companion of the National Long-Term Care Survey. There has been concern that women at this stage of employment, while trying to establish and accumulate work history, might be adversely impacted by caregiving responsibilities if they have to

reduce or terminate employment. Examining this matter, we will first review the employment status of the caregivers, then we will explore whether they made adjustments to employment level, and finally, compare these adjustments with their peers with no caregiving responsibilities. The caregiver companion of the 1989 National Long-Term Care Survey showed that only 31 percent of caregivers were employed. The proportion describing themselves as employed was much higher (64%) in the 1997 National Alliance for Caregiving Survey. About half of the employed caregivers mentioned that they had to make adjustments to their work schedule, a fewer number had to reduce work hours or take a leave of absence, and a very few passed on a promotional opportunity (Doty, Jackson, & Crown, 1998; The National Alliance for Caregiving & The American Association of Retired Person, 1997). In a study by Pavalko and Artis, the authors examined the connection between employment and caregiving. What is unique about their study is the data that was utilized for the analysis. Most other studies relied on the surveys of caregivers, Pavalko and Artis used the National Longitudinal Survey of Mature Women for 1984 and 1987. They found, as in other studies, that employed women, when assuming caregiving responsibility, are more likely to reduce or stop employment, and this pattern does not reverse when the caregiving responsibilities end. Yet the most intriguing finding is that "… although women who start caregiving are more likely to reduce hours or exit the labor force, the work and demographic characteristics that most strongly affect employment reductions are similar to those that affect women's employment reductions more generally. Thus, older caregivers and those less satisfied with their job are more likely to reduce hours, but this is also true for non-caregivers. This suggests that the exit process among caregivers is similar to that among non-caregivers, but occurs at a more rapid pace" (Pavalko & Artis, 1997, p. S177). Based on this study's findings, we decided not to include lost current or future income as part of the informal caregiving value.

Although the impact on the current and future income of the caregivers due to caregiving responsibilities may be uncertain, caregivers at the lower end of economic scale and those receiving an hourly wage will feel the impact of lost work hours. Since these caregivers have the least flexible work arrangements, and often no retirement benefits aside from Social Security and Medicare, the lost income could be substantial for them.

Finally, some studies have shown that caregivers often pay for additional expenses such as special foods and clothing, home modifications, utilities, and transportation that are not included in the value of informal care. Estimates of these out of pocket expenses vary widely and are dependent on the economic status and needs of both the caregiver and the care recipient. Since these expenses are not traditionally included in the value of informal care, we chose to exclude them also.

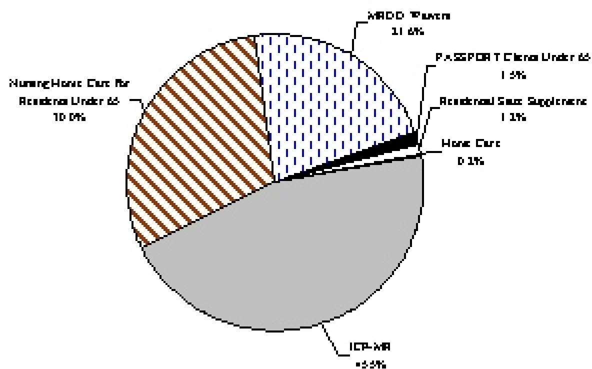
Other Disabled Populations in Ohio

This study focused on the long-term care needs of Ohio's population 65 years and older. Other groups of Ohioians, although under 65, are equally disabled and require long-term care. Estimating the preponderance of disability among the under 65 population is

more difficult for two reasons: first, there is no national survey to guide us in determining the prevalence of disability among this population; second, many of the younger disabled individuals are recognized as disabled in terms of *inability to maintain gainful employment*, although they can perform activities of daily living. Perhaps another scale reflecting the care needs of this population is yet to be developed. Even though we are not able to provide an estimate of the number of persons with disabilities younger than 65, we will briefly discuss public funding for long-term care of this segment of the population. Undoubtedly, the value of family caregiving is several times the public funds available for the long-term care of this population.

Various state and federal programs spent a total of almost 1.2 billion dollars to care for disabled people under 65 years old or those with mental or developmental disabilities. One such group is those with cognitive disability, as well as those requiring 24-hour supervision. From this group, the Residential State Supplement (RSS) program supported those who met eligibility criteria. Some individuals under 60 with physical disability received home care services under a Medicaid waiver (Disabled/ Physical Disabled). Almost all the care delivered to residents of Ohio's ICF-MR facilities and the care provided to the 10 percent of the nursing home residents under 65 and the PASSPORT clients between the ages of 60 and 64 were paid for by Medicaid or one of the Medicaid waivers (See Figure 6).

Figure 6
Other State and Federal Expenditures for Persons with Mental or Developmental Disabilities of all Ages or Disabled Persons Under 65
(Total Expenditures: $1,191,513,000)



Source: Ohio Department of Job and Family Services, (2001).
PASSPORT MIS System, Ohio Department of Aging

Is Ohio Prepared For The Care Needs Of An Aging Population?

Can Ohio Continue with Its Present Policies in the Future?

This study found that a large proportion of the economic support for long-term care took the form of informal care provided by family and friends. As a result,

government programs limited their liabilities to about 29 percent of the total economic value of long-term care to older people. Government funding is focused largely on institutional care; only a small proportion is devoted to community-based care. Conversely, private long-term care focuses on care at home by families and friends; formal service providers play a relatively smaller role, despite the substantial increase for PASSPORT and funding by a large collection of local, state, and federal government programs.

In the future, a greater proportion of the older population will reach the advanced ages at which the need for long-term care is greatest. In 1999, about 12 percent of the 65 and over population were 85 years or older. By 2050, this segment of the older population will grow to 34 percent of the total older population.

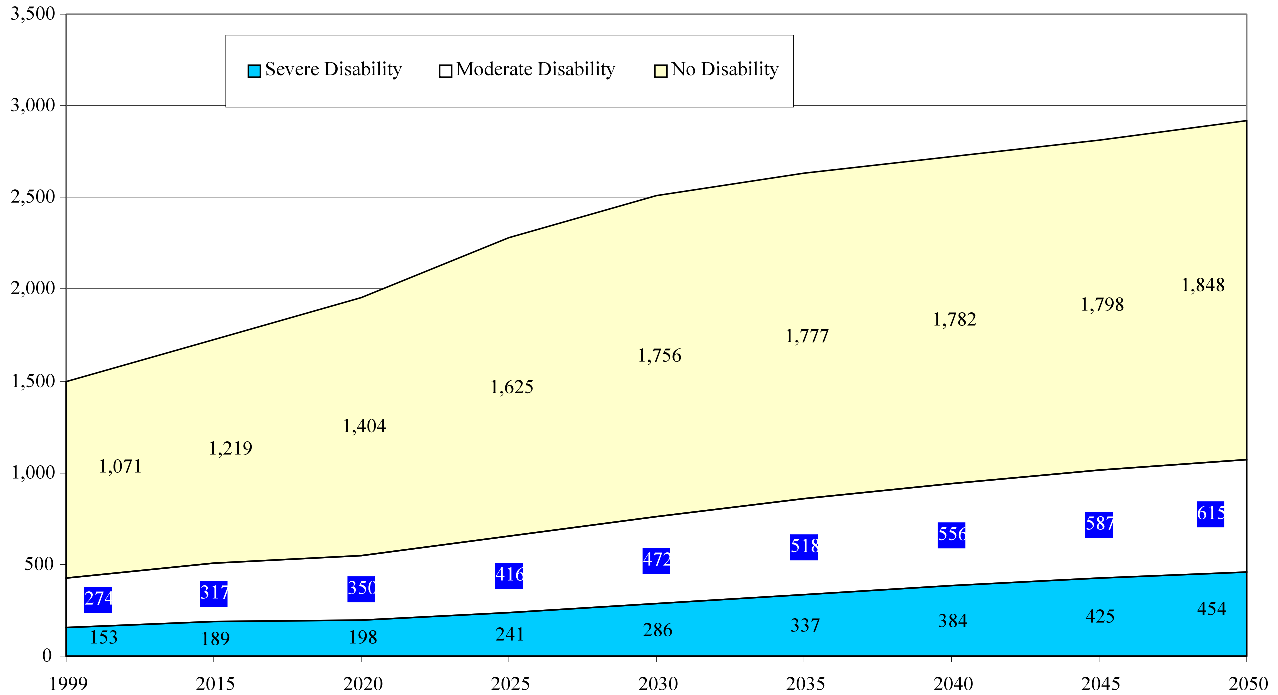
In the future, a greater proportion of the older population will reach the advanced ages at which the need for long-term care is greatest. In 1999, about 12 percent of the 65 and over population were 85 years or older. By 2050, this segment of the older population will grow to 34 percent of the total older population (Figure 7). As we discussed earlier, the prevalence of disability increases with age. The projected disabled population in 2050 is about 1.1 million, up from 426,000 in 1999. Although the immediate future generation of older persons can rely on larger numbers of children for help, families in the future may find it more difficult to maintain the high levels of support for long-term care that we observed here because of the growing trend for all adult members of households to be in the labor force. Also, there will be fewer children to provide care for older family members due to smaller family sizes. Thus, sharing the caregiving responsibility with siblings may be less feasible in the future. Greater geographic mobility also means that adult children are likely to be unavailable to provide care. As a result, state government not only will be faced with a rapidly growing number of disabled older persons, a greater proportion may need publicly funded formal services. Even if there were not budgetary constraints, there are questions about whether there will be an adequate workforce to care for the increased number of disabled older people.

How Can Ohio Prepare for Its Aging Population Given the Current Budgetary Challenges Today?

Ohio must educate the public on both the likelihood of needing long-term care and the cost of that care. Most people are not aware of the potentially catastrophic cost of long-term care. Further, they often believe they are covered for long-term care services either by their health care benefits, Medicare or Medicaid. As part of this educational effort, the state needs to promote personal financial responsibility and perhaps provide greater incentives for Ohioans to purchase long-term care insurance.

Ohio should make care management available to all families, irrespective of financial eligibility for publicly assisted care. Since long-term care decisions often are made in crisis, those with the financial means

Figure 7
Projection of Ohio's Older Population by Year and by Level of Disability (in thousands) 1999-2050



Source: U.S. Census Bureau. Census of Population and Housing, 2000.
Available: http://www.odod.state.oh.us/research.htm. (Date retrieved: June 25, 2002)
Mehdizadeh, S.A., Kunkel, S.R., & Ritchey, P.N. (2001). Projections of Ohio's Older Disabled Population 2015-2050. Oxford, OH: Scripps Gerontology Center, Miami University

to pay for care, at least initially, could benefit from care management. This could allow families to evaluate all options and examine how they can select the appropriate care setting, given their financial resources, and the length of time such services might be needed.

Ohio should expand community-based long-term care services and allow for flexibility and consumer choice. Currently, over 80% of the state's long-term care dollars are spent caring for disabled persons in nursing homes. Although nursing homes are serving an increasingly acute and disabled population, some nursing home residents could be cared for in a less restrictive environment such as assisted living or in the community.

As discussed, the most conservative estimates show that about half of all long-term

care expenditures were paid by the primary caregivers. **In the future there will be a larger number of moderate and severely disabled persons relying on a shrinking pool of informal caregivers**. A system should be in place to assist, train, and provide respite to these informal caregivers. These supportive services will decrease caregiver burden and help caregivers to provide care longer, thus potentially reducing the cost to the state for institutional care.

In response to the Supreme Court decision in the Olmstead case, and under the direction of Governor Taft, the State of Ohio has engaged in a comprehensive assessment of the state's service delivery system to learn about consumer preferences on where and how they receive long-term care services. Not surprisingly, the state found that it is facing a challenge with consumers who desire choice, control and autonomy, and Ohio's historical practice of over-reliance on institutional care rooted in Medicaid policy. Ohio's *Access for People with Disabilities* study reports on the findings and steps that the state of Ohio must take in order to be more responsive to consumers' desire for community-based services. The state should not lose sight of these recommendations given the current challenging budgetary times.

Finally, **the state should continue to support environmental modifications required by the Americans with Disabilities Act which accommodate disabled persons by providing a better fit between a person and his/her environment**. Moderately disabled individuals can continue to live independently, if they have access to public transportation, community services such as libraries, and businesses such as stores, restaurants, and doctors' offices.

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APPENDIX A

Estimating the Value of Informal Care

Of the estimated 426,363 disabled persons living in Ohio in 1999, 152,764 were classified as severely disabled (had at least two ADL impairments) and the remaining 273,599 as moderately disabled (one ADL or at least two IADL disabilities). If we assume that all the nursing home residents and 30 percent of residential care facilities residents in Ohio are severely disabled (The National Center for Assisted Living, 2002), then 76,840 severely impaired persons {152,764 – (72,197 older residents of nursing homes+ 3,727 severely disabled residential care facility residents respectively)} and 268,381 moderately disabled persons {273,599 –5,218 moderately disabled residents of residential care facilities} were living in the community. Therefore, the number of non-institutional disabled older persons was used as the basis of determining estimated hours of care by caregivers (Mehdizadeh, Kunkel, & Ritchey, 2001).

As might be expected, not all persons with disability have a primary caregiver. These individuals rely on occasional help from neighbors, family members, church and other charitable organizations and often their needs are not met. An analysis of the "helpers" section of the 1995 National Long-Term Care Survey revealed that more than 24 percent of those designated as severely disabled had no primary caregiver, a small proportion, almost 7 percent, received help one day a week, and a little over two-thirds received help everyday. Even fewer of the moderately disabled had a primary caregiver. More than half had no caregiver, 13 percent received help about one day a week and over 36 percent received help on daily basis (Table A-1).

The number of hours of care received by a disabled person was related to the extent of disability. By examining the Channeling Demonstration Informal Caregiver Survey, the 1989 National Long-Term Care Survey, the 1997 National Alliance for Caregiving Survey, and the "helpers" section of the 1995 National Long-Term Care Survey, we learned that although the number of hours of care over a 15 year time span was not identical, it was consistent. Table A-2 presents a comparison of the data from these surveys. The data on the number of weekly hours of care for moderately disabled persons ranged from 31.5 to 36.5 hours a week. We are using an average of 34 hours a week in this study. The average weekly hours of care for severely disabled persons were more variable over time, ranging from 52.5 to 80 hours a week. We are using a weekly average of 66 hours. We calculated that the total hours of care for the 58,168 severely disabled persons were 184,479,746 hours and 181,075,275 hours for the 132,580 moderately disabled persons, excluding those with no primary caregivers.

Next it was necessary to establish the unit cost of each hour of service provided. The unit cost of each service varies considerably from one area to another in Ohio, and unit costs for some services were not available. We used the average unit cost paid by the PASSPORT program across the state ($13.50) to estimate the value of the informal care provided. The value of informal care for severely disabled persons was $2,490,476,000 and $2,444,516 for moderately disabled.

Although a large percentage of nursing home residents receive help in the facility from family and friends, these costs were not included in our calculations.

A person who chooses to be a caregiver for a relative, a friend, or a neighbor always loses leisure time or work time. Previous studies have noted serious economic impacts on employees and their employers as a result of caregiving. Because our focus here was on the economic impact to the state if formal care were substituted for informal care, these costs were not included. Participation in caregiving tasks also causes some stress and fatigue, but we chose not to place a monetary value on these negative aspects of caregiving. By the same token, we did not evaluate in monetary terms the satisfaction that one feels from assisting an aging parent or an older friend. These mental and physical health aspects of caregiving probably have economic implications, but we had no basis for estimating them.

Table A-1
Percent of Disabled Older Persons With Primary Caregivers

Disability Level	No Primary Caregiver	Primary Caregiver: Once a week	Primary Caregiver: Several times a week
	(Percent)	(Percent)	(Percent)
Severely Disabled	24.3	6.7	69.0
Moderately Disabled	50.6	13.1	36.3

Source: The National Long-Term Care Survey, 1995.

Table A-2
Average Weekly Hours of Care by Primary Caregivers in Different Studies

Surveys	Severely Disabled	Moderately Disabled
Channeling Demonstration Informal Caregivers	52.5	35.9
1989 NLTCS*	52.7	---
National Alliance for Caregiving	80.0	36.5
Helper Section of 1995 NLTCS	57.3	31.5
Average used in this study	66.0	34.0

*Average hours of care for recipients at all disability levels.
Source: The National Long-Term Care Survey, 1995.

APPENDIX B

Detailed Tables

Table B-1
Estimated Number of Older Ohioans with Severe Disability in Need of Long-Term Care and the Value of Services, by Type of Provider, 1999

Provider	Persons Served		Economic Value of Services	
	Number	Percent	Thousands of Dollars	Percent
Long-Term Care Institutions				
Nursing homes, residential care facilities, homes for the aged	75,924[a]	49.7	3,662,573[b]	56.4
Ombudsman Services and Nursing Home Certification Survey			5,003[c]	
Subtotal	**75,924**	**49.7**	**3,667,576**	**56.4**
Community-Based Services				
Out of pocket	50,862[j]	33.3	132,630[k]	2.1
PASSPORT	16,625[d]	10.9	173,564[e]	2.7
Local property tax levies designated for home care services	9,353[f]	6.1	28,954[g]	0.4
Options for Elders	NA		238[h]	
ElderCare Initiative	NA		242[i]	
United Way	NA		6,084[l]	0.1
Home health agencies	NA[m]		3,850[n]	
Alzheimer's respite			2,277[o]	
Subtotal	**76,840**	**50.3**	**347,839**	**5.3**
Informal Care				
Family, friends, neighbors	58,168[p]	36.3	2,490,476[q]	38.3
Subtotal	**58,168**	**36.3**	**2,490,476**	**38.3**
Total	**152,764**	**100.0%**	**6,505,891**	**100.0%**

Please see note section at the end of this Appendix.
NA: not available

Table B-2
Estimated Number of Older Ohioans with Moderate Disability in Need of Long-Term Care and the Value of Services, by Type of Provider, 1999

Provider	Persons Served		Economic Value of Services	
	Number	Percent	Thousands of Dollars	Percent
Long-Term Care Institutions				
Residential care facilities	5,218[r]	1.9	136,894[s]	
Subtotal	**5,218**	**1.9**	**136,894**	**4.0**
Community-Based Services				
Out of pocket	266,635[y]	97.5	748,711[z]	22.1
Local property tax levies designated for home care services	1,746[t]	0.6	5,404[u]	0.2
Older American Act	NA		19,993[v]	0.6
Social Services Block Grants	NA		12,297[w]	0.4
Senior Community Services Block Grants	NA		13,542[x]	0.4
Subtotal	**268,381**		**799,947**	**23.7**
Informal Care				
Family, friends, neighbors	132,580[aa]	98.1	2,444,516[bb]	72.3
Subtotal	**132,580**	**98.1**	**2,444,516**	**72.3**
Total	**273,599**	**100.0%**	**3,381,357**	**100.0%**

Please see note section at the end of this Appendix.
NA: not available

Table B-3
Total Value of Long-Term Care Services in Ohio by Source of Support, 1999

Source of Economic Support	Total Value (in Thousands of Dollars)	Percentage of Total by Source
Long-Term Care Institutions		
Medicaid	2,154,727[cc]	21.8
Medicare	449,933[dd]	4.5
Private pay (no insurance)	1,094,232[ee]	11.1
Long-term care insurance	39,861[ff]	0.4
Continuing Care Retirement Community contracts	17,731[gg]	0.2
Other	42,983[ii]	0.4
Nursing home survey certification, ombudsman services	5,003[c]	---
Subtotal	**3,804,470**	**38.4**
Community-Based Formal Services		
Medicare	3,850[n]	
Private pay	881,341[k+z]	8.9
PASSPORT	173,564[e]	1.8
Home care funded by property tax levies	34,358[g+u]	0.2
Older Americans Act	19,993[v]	0.1
Senior Community Block Grants	13,542[x]	0.1
Social Service Block Grants	12,297[w]	0.1
Charitable assistance (United Way)	6,084[l]	---
Alzheimer's respite	2,277[o]	---
Options for elders	238[h]	---
ElderCare Initiative	242[i]	---
Subtotal	**1,147,786**	**11.6**
Informal Care	**4,934,992[q+cc]**	**50.0**
Total	**9,887,248**	**100.0%**

Please see note section at the end of this Appendix.

Table B-4
Sources of and the Value of Support for Long-Term Care for Moderately and Severely Disabled Persons in Ohio, 1999

Source	Amount in Millions of Dollars	Percentage of All Long-Term Care Payments
Public		
Medicaid	2,328,291[dd+e]	23.6
Medicare	453,784[ee+n]	4.6
State and local government	34,358[g+u]	0.4
Older Americans Act	19,993[v]	0.2
Social Services Block Grants	12,297[w]	0.1
Senior Community Services Block Grants	13,542[z]	0.1
Nursing Home Survey Certification, and Ombudsman Services	5,003[c]	--
Alzheimer's respite	2,277[o]	--
ElderCare Initiative	242[i]	--
Options for elders	238[h]	--
Subtotal	**2,870,025**	**29.0**
Private		
Payments by elderly individuals or their families	1,975,573[ff+ll]	20.1
Long-term care insurance	39,861[gg]	0.4
Continuing Care Residential Care contracts	17,731[ii]	0.2
Charitable organizations	6,084[l]	---
Other	42,982[hh]	0.4
Informal Care	**4,934,992**[g+cc]	**50.0**
Subtotal	**7,017,223**	**71.0**
Total	**9,887,248**	**100.0%**

Please see note section at the end of this Appendix.

NOTE: The figures presented in all tables are for the period from January 1 to December 31, 1999; however, Ohio's fiscal year runs from July 1 to June 30. To find the budget allocations for each program, we added one-half of the funds allocated for the period from July 1, 1998 to June 30, 1999 to one-half of the funds allocated for the period from July 1, 1999 to June 30, 2000.

a. The estimated number of persons age 65 and older living in nursing homes, residential care facilities, and homes for the aged in Ohio in 1999. The number of persons residing in nursing homes (including the beds licensed as nursing home beds in homes for the aged) met the severely disabled definition used in this table. However, the number was adjusted downward by 10% (based on the age distribution of nursing home residents in March 95; March 96; March 97; and March 98) to exclude those residents that are under 65 years old. The number of persons residing in residential care facilities was adjusted based on national statistics on the extent of disability among Assisted Living Facility residents (The National Center for Assisted Living, 2002). It should be noted that residential care facilities in Ohio encompass Assisted Living facilities. **Source**: The 1999 Annual Survey of Long-Term Care Facilities, Ohio Department of Health.

b. Total payments by all sources to nursing homes, residential care facilities, and homes for the aged. The patient days for each facility and source of payment type were multiplied by the appropriate per diem rate and summed to arrive at this figure. **Source**: The 1999 Annual Survey of Long-Term Care Facilities, Ohio Department of Health.

c. This figure represents the quality of care monitoring (ombudsman, plus the survey and certification of nursing facilities). **Source**: Ohio Department of Aging 1999 Annual Report, 2000; the Amended Substitute House Bill 215 (Ohio General Assembly 1997, p. 1157, and the Amended Substitute House Bill 283 (Ohio General Assembly 1999, p. 736.

d. Total number of person-years (rather than individuals) who received long-term care services through the PASSPORT program. The figures are adjusted to include only the 65+ population served by this program in 1999. **Source**: PASSPORT Management Information System, Ohio Department of Aging.

e. Total budget allocations for the PASSPORT program. The total budget appropriation of $196 million was adjusted to include only the 65+ population served by the PASSPORT program in 1999. **Source**: PASSPORT Management Information System, Ohio Department of Aging, the Amended Substitute House Bill 215 (Ohio General Assembly 1997, pp. 1036-37), and the Amended Substitute House Bill 283 (Ohio General Assembly 1999, pp. 687-88).

f. Number of person-years (if each person was using the services every day of the year) with severe disability who received home care services funded by local elderly care levies. Ohio county commissioners have been asking voters for their approval of property taxes to be used for providing home care for individuals who meet a certain level of impairment. In Hamilton county, one of the first counties that instituted this kind of tax levy, 75% of service recipients are defined as severely disabled; 14% moderately disabled; and 11% with lower levels of impairment.

Source: Council on Aging of Southwestern Ohio.

g. Total local tax levy dollars used for providing long-term care services to severely disabled persons in the state. Only 75% of such dollars are entered here to account for the care expenditure for the severely disabled portion of those who received such services. **Source**: Individual reports from county commissioner's offices.

h. Options for Elders. **Source**: Ohio Department of Aging. 2000. 1999 Annual Report.

i. ElderCare Initiative. **Source**: Amended Substitute House Bill 215, p. 1035, and the Amended Substitute House Bill 283, p. 687.

j. Estimated number of severely disabled persons receiving home-based services and paid out of pocket. **Source**: Authors' calculation based on the study by Doty, Jackson, & Crown, 1998.

k. Estimated out of pocket expenditures for home-based services provided to severely disabled persons. **Source**: Authors' calculation based on the study by Doty, Jackson, & Crown, 1998.

l. United Way contributions to home-based services**.** **Source**: Reports from individual United Way agencies in Ohio.

m. Number of individuals receiving home health care. The Annual Survey of Certified Home Health Care Agencies, the only source of information in the state for this data, is not designed to determine the number of unduplicated, over 65 years old service recipients. **Source**: The 1999 Annual Survey of Certified Home Health Care Agencies, Ohio Department of Health.

n. Total Medicare reimbursement for service recipients over 65 years old, to Ohio's Home Health Care Agencies. Other payers are either reflected in "e", or "k". **Source**: The 1999 Annual Survey of Certified Home Health Care Agencies, Ohio Department of Health.

o. Alzheimer's respite. **Source**: Ohio Department of Aging, 2000. 1999 Annual Report.

p. Total number of severely disabled older people in the community minus the 24% who had no caregivers. **Source**: Authors' calculation based on The 1995 National Long-Term Care Survey.

q. The estimated value of the care provided to severely disabled persons by informal caregivers. Detailed explanation is provided in Appendix A.

r. The number of persons residing in residential care facilities are divided into moderately and severely disabled based on national statistics on the extent of disability among assisted living facility residents. The survey of assisted living residents shows that, in 1999, 42 percent of residents were impaired at a level comparable to moderately disabled, 30 percent were as disabled as the severely disabled in this study. Less than one-third (28%) had lower levels of impairment (The National Center for Assisted Living, 2002). It should be noted that residential care facilities in Ohio encompass assisted living facilities. **Source**: The 1999 Annual Survey of Long-Term Care Facilities, Ohio Department of Health.

s. Residential care facility expenditures. **Source**: The 1999 Annual Survey of Long-Term Care Facilities, Ohio Department of Health.

t. Number of person years with moderate disability who received home care services funded by local elderly care levies. Ohio county commissioners have been asking voters for their approval of property taxes to be used for providing home care for individuals who meet a certain level of impairment. In Hamilton county, one of the first counties that instituted this kind of tax levy, 75% of service recipients are defined as severely disabled; 14% moderately disabled; and 11% with lower level of impairment. **Source**: Council on Aging of Southwestern Ohio.

u. Total local tax levy dollars used for providing long-term care services to moderately disabled persons in the state. Only 14% of such dollars are entered here to account for the care expenditure for the moderately disabled portion of those who received such services. **Source**: Individual reports from county commissioner's offices.

v. Older Americans' Act. **Source**: Ohio Department of Aging, 2000. 1999 Annual Report.

w. Social Service Block Grant. **Source**: Ohio Department of Aging, 2000. 1999 Annual Report.

x. Senior Community Services Block Grant. Ohio Department of Aging. 2000. 1999 Annual Report.

y. Estimated number of moderately disabled older persons who received home-based services and paid out of pocket. **Source**: Authors' calculation based on the study by Doty, Jackson, & Crown, 1998.

z. Estimated out of pocket expenditures for home-based services provided to moderately disabled persons. **Source**: Authors' calculation based on the study by Doty, Jackson, & Crown, 1998.

aa. Total number of moderately disabled older persons in the community minus 50.6% who had no caregivers. **Source**: The 1995 National Long-Term Care Survey, based on authors' calculation.

bb. The estimated value of the care provided to moderately disabled persons by the informal caregivers. A detailed explanation is provided in Appendix A.

cc. Medicaid payment to nursing homes. This figure is calculated based on 90 percent of Medicaid patient days (65+ residents only) multiplied by the average statewide Medicaid nursing home reimbursement rate of $125. **Source:** The 1999 Annual Survey of Long-Term Care Facilities, Ohio Department of Health.

dd. Medicare payment to nursing homes. This figure is calculated based on 90 percent of Medicare patient days (65+ residents only) multiplied by the average statewide Medicare nursing home reimbursement rate of $224.75. **Source:** The 1999 Annual Survey of Long-Term Care Facilities, Ohio Department of Health.

ee. Private (self) payment to nursing homes. This figure is calculated based on 90 percent of private pay nursing home patient days (65+ residents only) multiplied by the average

statewide self pay nursing home rate of $135. In addition, this figure includes 90 percent of payments to residential care facilities. **Source:** The 1999 Annual Survey of Long-Term Care Facilities, Ohio Department of Health.

ff. Long-term care insurance payments to nursing homes. This figure is calculated based on 90 percent of long-term care insurance patient days in nursing homes (65+ residents only) multiplied by the average statewide long-term care insurance nursing home reimbursement rate of $135. **Source:** The 1999 Annual Survey of Long-Term Care Facilities, Ohio Department of Health.

gg. Continuing Care Retirement Community (CCRC) contract payments to nursing homes. This figure is calculated based on 90 percent of CCRC patient days multiplied by average statewide self pay nursing home rate ($135). **Source:** The 1999 Annual Survey of Long-Term Care Facilities, Ohio Department of Health.

hh. Nursing home survey certification expenditures. **Source**: Ohio Department of Aging. 2000. 1999 Annual Report, 2000, Amended Substitute House Bill 215 , and Amended Substitute House Bill 283.

ii. Other payments to nursing homes. This figure is calculated based on 90 percent of the patient days with a payment source identified as "other", multiplied by average statewide self-pay nursing home rate ($135). **Source:** The 1999 Annual Survey of Long-Term Care Facilities, Ohio Department of Health.