

# Caregivers and long-term care needs in the 21<sup>st</sup> century: Will public policy meet the challenge?

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**L**ong-term care is hands-on assistance provided to people who need help with fundamental daily activities such as bathing or eating, over a substantial period of time. This type of assistance is labor intensive and is provided by family, friends, and volunteers, as well as by hired personnel. Most people with long-term care needs (83 percent) live in their own home; among those living at home, the majority (78 percent) does not hire any help.<sup>1</sup> Families are critical in providing most long-term care, even when care is purchased.<sup>2</sup>

Over the next 15 years the number of people who need long-term care is expected to increase by 30 percent. Soon thereafter, the number of people likely to need long-term care is expected to increase even more dramatically. Estimates of the long-term care population suggest that the number of people with long-term care needs will more than double between 2000 and 2050. Government estimates suggest that the number of people using paid long-term care services—in a nursing facility, alternative residential care (such as assisted living) facility, or at home—could nearly double, increasing from 15 million in 2000 to 27 million in 2050.<sup>3</sup>

Given the sizable increase in the number of people who may need long-term care in the future, it is important to ask: will there be enough paid caregivers and family caregivers to meet projected long-term care needs? Currently, many persons who need long-term care have a number of family members available to provide care or have a significant pool of caregivers available for hire. However, as this paper will show, after 2015 the number of people likely to need long-term care will increase substantially faster than the number of people available either as family or as paid caregivers. Families will need more support to supplement their efforts and more paid caregivers will be necessary to provide this support.

If the market does not respond to meet these needs soon, policy makers, working with payers and providers of long-term care services, may need to find ways to encourage workers to remain in the long-term care labor force, encourage a larger share of the labor force to seek employment in the long-term care sector, and enhance how long-term care providers work with families to expand the capacity of family caregivers. Family caregivers need all the help they can get to provide care, including purchasing modifications to the home, purchasing labor-enhancing and labor-saving technologies, and figuring out how best to integrate paid caregivers into their homes. Paid caregivers will also be necessary for those who do not have any family available to provide care. Since 2015 is slightly more than a decade away, it is not too soon to start working towards fundamentally improving the efficiency and effectiveness of how care is delivered.

This paper reviews trends and identifies public policy issues that must be addressed to meet the demand for long-term care in the future. The next section examines the anticipated growth in the demand for long-term care. This is followed by an overview of recent trends in the supply of long-term care. The last section of the paper articulates the kinds of changes necessary to ensure an adequate supply of paid and family caregivers to meet the demand for assistance.

### **In the face of declining disability rates, will demand for long-term care really increase?**

The observation that disability rates among older people have been declining since the mid-1980s has generated some confusion about long-term care needs in the future.<sup>4</sup> A review of 16 studies conducted in the 1990s on disability or functioning trends among people age 65 or older suggests that for most of the 1980s and nearly half the 1990s, disability rates did decline substantially. Among the different studies, the average annual decline in the proportion of people age 65 or older with any disability ranged from 0.92 percent to 1.55 percent.<sup>5</sup>

The largest share of the decline was among people reporting limitations in instrumental activities of daily living (IADLs) and not in activities of daily living (ADLs).<sup>6</sup> IADLs include such activities as light housekeeping, managing money, shopping, and managing medications. ADLs consist of activities such as eating, dressing, bathing, using the toilet, transferring from bed to chair, or moving about. In several of the studies, the proportion of the older population with limitations in ADLs did not decline, and in two studies the proportion with ADL limitations increased.<sup>7</sup>

Although a decline in IADL-type limitations affect the needs of individuals and their families, IADL-type limitations do not necessitate the most intensive type of long-term care. Moreover, in private insurance and public programs that target benefits to people with functional limitations, insurance claims or public assistance benefits are often not triggered until limitations exist in two or more ADLs. Thus, the decline in IADL-type disability rates over the past decade has probably had only a modest impact on altering the demand for the most intensive hands-on assistance.

Furthermore, a decline in disability rates among people age 65 or older does not necessarily translate into a decline in the number of people who need help. The research showing the largest decline in limitations is based on the National Long-Term Care Survey. Researchers using this survey report that the proportion of people age 65 or older with any (ADL or IADL) disability declined from 26.2 percent in 1982 to 19.7 percent in 1999.<sup>8</sup> Although this is a nearly 25 percent decline in the disability rate, the fact that there were more people age 65 or older in 1999 resulted in a slight increase (1.5 percent) in the total number of older people with disabilities.

While the population age 75 or older is at substantially greater risk of needing long-term care than most everyone else, it is important to keep in mind that nearly 40 percent of the long-term care population is under the age of 65.<sup>9</sup> During most of the period in which disability rates among older people were declining, the disability rate among the population age 18 to 44 was increasing.<sup>10</sup>

There is disagreement on whether disability rates among older people will continue to decline. There is even more disagreement as to how much.<sup>11</sup> Historically, disability trends have varied considerably, declining rapidly during some years, increasing in others, and holding constant in most.<sup>12</sup> Nevertheless, there have been a variety of changes that would suggest that the overall long-term trend in the future would be towards further reductions in disability rates.<sup>13</sup> For example, there have been considerable changes in the nature of work as well as in working conditions over the past 25 years which are likely to result in far more people leaving the labor force at older ages with far less serious chronic and disabling conditions related to their work. Moreover, advances in medical care have not only resulted in more effective treatments for many chronic conditions but also treatments with fewer debilitating side effects. In addition, disability rates have been found to be inversely correlated with education, and future generations of older people are more likely to have acquired more education.<sup>14</sup>

A countervailing trend, however, is the fact that larger proportions of older and younger people are obese and not exercising. Moreover, substantial proportions of society still smoke cigarettes and drink excessive amounts of alcohol. Obesity, lack of exercise, smoking, and alcohol abuse are among the controllable risk factors for developing chronic and disabling conditions.<sup>15</sup> Furthermore, the prevalence of a variety of dementias, which primarily first affect people in their 70s, has been increasing.<sup>16</sup>

It is difficult to speculate on what will happen with overall disability rates, let alone disability rates for ADL-type limitations. However, so far, many of the advances have had a larger impact on moderating the level of assistance needed for IADL-type limitations than on lessening the amount of care needed to assist those with ADL limitations. Advances in pharmacology, better information and the opportunity to quickly analyze the potential for drug interactions has had a profound impact on reducing drug-related effects.<sup>17</sup> The growing market for canes, walkers, scooters, and lifts has resulted in design improvements in the assistive devices that make it easier for people to maintain mobility, functionality, and independence. Physical changes imposed on structures and public transportation to comply with the Americans with Disabilities Act, have also helped considerably.

Technological advances and design features on products that make life easier for everyone also make it possible for some people to avoid or delay needing help with IADLs. For example, direct deposits of Social Security and pension payments, along with on-line banking, make it easier to manage money without having to venture down to the bank. Microwave ovens, on-line grocery shopping, and advances made in packaging prepared meals make food shopping and meal preparation easier. The technologies that brought about wireless home security systems are now being used to dispense medications and monitor health without necessitating a trip to the physician's office. Mobile phones, global positioning units, and direct lines to a person with informational resources are technologies now being used that may enable a person to remain independent longer.

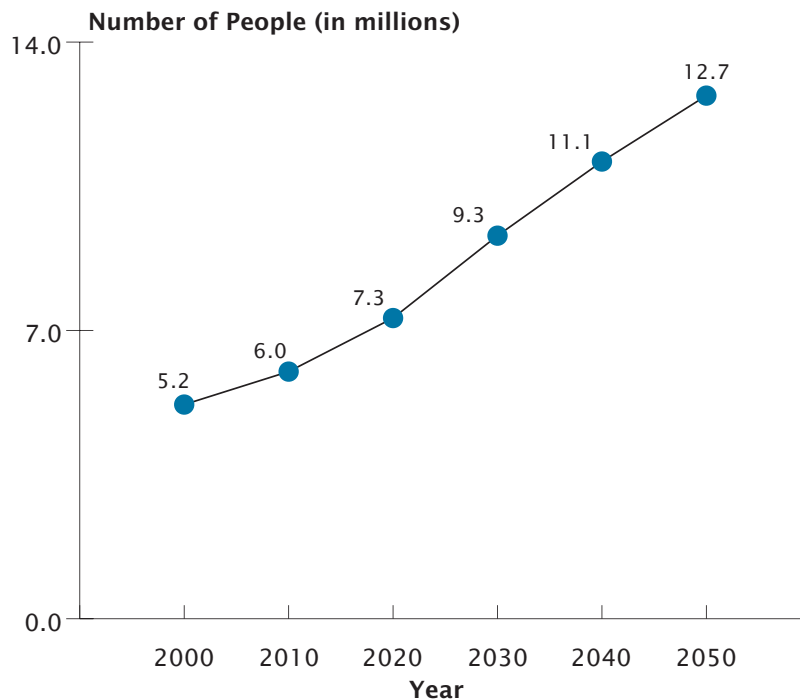
As the nature of needs change, tools that are readily available to help remain independent may no longer be sufficient. A grab-bar in the shower, for example, can be very effective at enabling independence but only for people with the capacity to lift their legs or with substantial strength in their arms. A grab-bar is less helpful to those with limited physical strength or cognitive difficulties that necessitate ongoing atten-

tion. Avoiding or delaying ADL-type limitations may require substantial breakthroughs in medicine, pharmacology, and technology.

In 2000, an estimated 9.5 million people of all ages needed assistance with either IADL or ADL limitations.<sup>18</sup> About 55 percent or 5.2 million people had limitations in ADLs (see Figure 1). If prevalence of ADL limitations by age were to remain the same, reflecting no change in ADL-type disability rates, then there could be as many as 12.7 million people in 2050 with limitations in ADLs who need hands-on assistance from others.<sup>19</sup> In order for the number of people of *all ages* with ADL-type limitations in 2050 to remain essentially what it is today, the proportion of the population with ADL limitations would need to be nearly half of what it is today. In part, this is because the population age 85 or older, which is the population at greatest risk of needing assistance, is expected to more than quadruple during this time period (increasing 356 percent between 2000 and 2050).

Figure 1

**Estimated Population with ADL Limitations through 2050 (Assuming Current Prevalence)**



SOURCE: Author's calculations using age-specific prevalence rates from the National Center on Health Statistics Health Interview Survey, 1999, applied to intermediate population projections from the U.S. Census Bureau, National Population Projections, <http://www.census.gov/population/www/projections/natsum-T3.html>.

## In the face of rising demand, will the supply of caregivers increase?

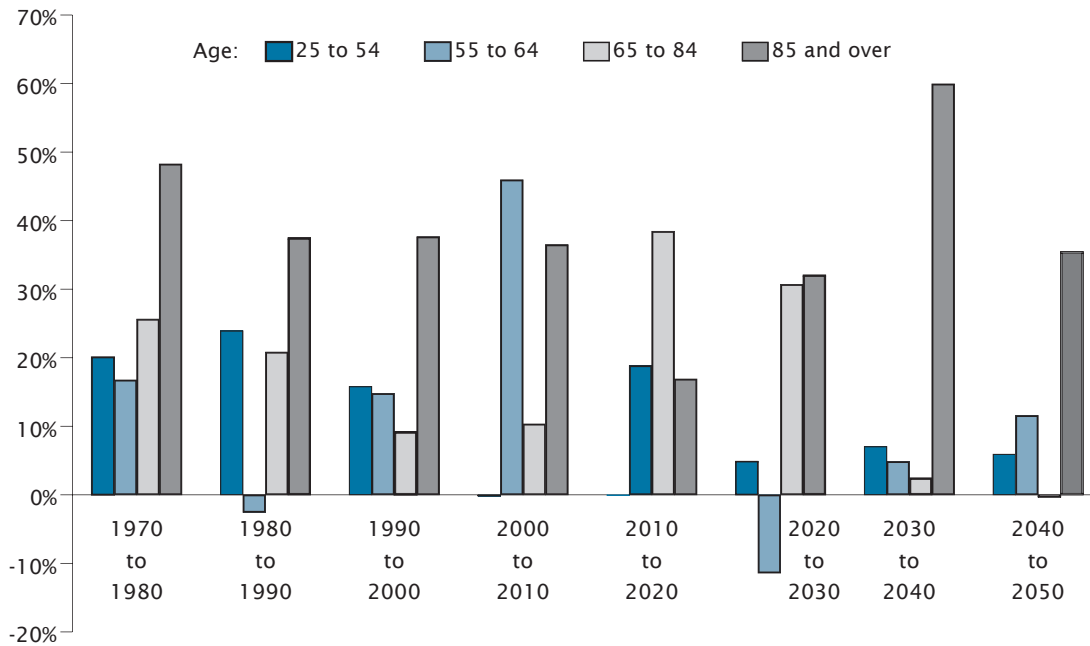
Over the past two decades there has been a surge in the supply of paid and unpaid caregivers and long-term care providers. Depending on the particular birth year, the total fertility rate of cohorts (defined by birth year) of women who in 2000 were age 85 or older varied from about 3.7 to 4.0 per woman.<sup>20</sup> In addition, from 1985 to 2000, the number of nurses and nurses' assistants providing long-term care increased nearly 31 percent.<sup>21</sup> Over a similar time period (1988 to 2000) the number of home health aides increased nearly 68 percent.<sup>22</sup>

During this time, the number of home and community-based long-term care providers increased substantially faster than the population that needed long-term care,<sup>23</sup> faster than the rate of growth in the overall population, and faster than the growth in the population at greatest risk of needing assistance—people age 85 or older.<sup>24</sup> For example, from 1990 to 1997, the number of home care agencies increased 89 percent, and from 1991 to 1999 the number of assisted living beds increased 114 percent.<sup>25</sup> Between 1978 and 1997, the number of adult day care centers increased 1,233 percent.<sup>26</sup>

Hence, during a period in which people age 65 or older had a relatively large number of adult children, there were also significant increases in the number of long-term care providers and paid caregivers. Over the next 50 years, however, there will be fewer adult children per parent than there are today. Compared with 50 years ago, women are having fewer children, and more women are not having any children at all.<sup>27</sup> By 2050, fertility rates among cohorts age 85 and older will range between 1.8 percent and 3.0 percent—considerably less than fertility rates of 3.7 to 4.0 percent for most cohorts of women age 85 or older in 2000.<sup>28</sup>

In the future, the labor force, on a whole, will not be growing as fast as either the long-term care population or the population at greatest risk of needing long-term care (people age 85 or older). As a point of comparison, during the 1970s, 1980s, and 1990s, the population age 85 or older increased about 40 percent, while the population age 25 to 54 increased nearly 20 percent (see Figure 2). In the first decade of this century, the population age 85 or older is expected to increase by a similar amount (37 percent) but the population age 25 to 54 is not expected to increase at all.<sup>29</sup>

Figure 2  
 Percentage Change in the Population by Age Over Each Decade  
 (Actual Past and Projected Future)



SOURCE: Author's calculations using data from U.S. Bureau of the Census, Decennial Census for 1970 to 2000 and Projections for 2010 to 2050.

In the face of a severely tight labor force among entry level workers, employers may seek to retain and recruit older workers. Workers age 55 and older have already demonstrated a greater willingness than previous generations of older workers to remain in the labor force longer; this age group is currently among the fastest growing.<sup>30</sup> Long-term care work, as currently structured, is among the lowest paid; it is also physically demanding.

After 2015, the number of people needing long-term care is likely to increase substantially. At that time, the overall labor force relative to the size of the population is likely to be smaller than it is today. This will put substantial pressure on families seeking help with long-term care, as well as long-term care providers and the federal-state Medicaid program. Families are likely to bear the brunt of hard choices as they struggle to provide assistance and organize paid providers to help them take care of their loved one(s). An adult child is likely to be pressed into service and that child is likely to have fewer siblings to turn to for respite. Increasingly, stepchildren will be a part of the already complex tapestry of family caregiving.<sup>31</sup>

Along with the demand for assistance from family members there will be increased demand for paid caregivers. Preferences for care at home or in the community will put upward pressure on the wages of long-term care workers. Higher labor costs will ensure additional financial pressures both on families and on the Medicaid program. To maintain the current ratio of long-term care workers to the population age 85 or older, the number of long-term care workers would need to more than double; increasing from an estimated 1.9 million workers in 2000 to at least 4.0 million in 2050.<sup>32</sup> The paid long-term care workforce would need to grow, at a minimum, by more than two percent per year between 2000 and 2050. This rate of growth in the long-term care labor force is possible, but during this time period the working-age population is expected to increase only 0.3 percent per year.<sup>33</sup>

Doubling the number of long-term care workers will entail encouraging a disproportionate number of people into the long-term care workforce. Such measures will require concerted efforts to not only attract but retain long-term care workers. Moreover, the field of long-term care is not alone in this challenge. Other industries have acknowledged that they will experience serious labor shortages if they are not proactive. They too, through their trade associations and lobbying connections have begun searching for private and public ways to encourage a disproportionate share of the labor force to enter their field as well.

For long-term care, retaining workers as well as attracting new workers will require making real changes to overcome its current negative image. Changing the image of the work will require changing the culture surrounding the work environment and probably changing the nature of the work itself.<sup>34</sup> Changing the work may mean changing the duties, responsibilities, and supervisory structure.<sup>35</sup> It will likely necessitate substantial advances in labor-saving technologies and also require increases in wages.<sup>36</sup> Without fundamental changes in how care is organized and delivered, the long-term care system in 2050 could be worse than it is today.

### **How can public policy encourage supply to meet demand?**

Many policy leaders have come to recognize the importance of expanding the long-term care workforce.<sup>37</sup> Influenced by the labor force concerns of hospitals and nursing homes, commissions have been organized in at least 35 states.<sup>38</sup> Several states have undertaken specific initiatives related to increasing wages, altering staffing requirements, and financing additional training. At the federal level, the U.S. Congress requested that the Secretaries of Labor and Health and Human Services identify the causes of the long-term care labor shortfalls and make rec-

ommendations as to how to address the anticipated demand for long-term care in the future.<sup>39</sup> The Secretaries responded with a long list of specific recommendations directed at finding new sources of workers; providing effective post-secondary education and on-the-job training for current workers; or improving working conditions by providing more career opportunities, increasing compensation, and lightening the workload. The Secretaries also identified 36 initiatives or programmatic efforts already underway within their two departments to address these issues.<sup>40</sup>

The specific recommendations provide a comprehensive list of options. However, it is difficult to cull from this list a sense of what will be effective at changing current circumstances or, more importantly, a blueprint for change. Missing from their discussion is the list of fiscal and regulatory incentives that will encourage and support the proposed efforts to improve how care should be organized and delivered.

### ***Change can happen on its own***

High turnover rates are symptomatic of unhappy workers and turnover rates have been reported to be quite high (exceeding 100 percent) among most long-term care providers.<sup>41</sup> High turnover rates make recruitment more pressing and retention even harder. Some providers have been working hard on making changes to engage long-term care workers in ways that will increase their tenure and reduce turnover. While many providers have been quite successful, their efforts have not yet turned into an industry-wide set of changes.

A look at the Wellspring Alliance suggests that market-based change is possible.<sup>42</sup> Wellspring Innovative Solutions, Inc. is an alliance of 11 freestanding independent nursing homes in eastern Wisconsin.<sup>43</sup> Concerned at the time about the emerging power of managed care providers, the nursing homes and home health agencies forged an alliance to initially enable them to more effectively compete within the managed care environment.

The threat from managed care never materialized, yet the alliance continued. They now have two interdependent goals: to improve the quality of care and to improve the working environment to help retain workers and make it easier to recruit new workers.

Through a deliberative process, the Wellspring Alliance questioned the existing structure and then developed a plan to re-engineer how care is provided and how staff at different levels should relate to one another. They then worked at changing the administration, staffing, and manage-

ment to support their goals. By providing direct-care workers with the skills they need and giving them a real voice in how their work should be done, the nursing homes have been able to make strides in improving their performance on federal nursing home quality surveys and reducing staff turnover.<sup>44</sup> Surveys and studies underscore the importance of valuing workers, particularly in the context of letting them have a voice in the care of their patients or clients.<sup>45</sup>

### ***Change can be encouraged through public policies***

The changes that transpired through the Wellspring Alliance occurred in the absence of public policy interventions. However, through licensure, accreditation standards, and reimbursement policies, public policy can encourage providers of long-term care to reexamine and restructure how they deliver care.

Redefining the job description of the long-term care worker, redefining the training necessary, and redesigning how public programs pay for long-term care can go a long way towards creating better jobs and ensuring better care.<sup>46</sup> The more that families value the long-term care worker, the more valuable the workers will be to long-term care facilities and organizations. The more valuable long-term care workers are to long-term care facilities and organizations, the more willing workers will be to enter the field and the more likely they will be to stay.

Greater labor costs will also encourage providers to invest in labor-saving or labor-enhancing technologies. Public policies that support the basic research or even the application of a particular technology can also support development by recognizing the costs of these technologies in reimbursement rates. Payers of long-term care, particularly Medicaid and private insurance, should have a fiscal incentive to better understand the potential of labor-saving and labor-enhancing advancements. Given the relative importance of government as a buyer of long-term care, it makes sense to think of investing in labor-saving technologies as a public enterprise in much the same way in which investments are made in the biomedical, defense, and space industries. Similar to the role played in these sectors, the government could support the research undertaken to develop the technology, finance and evaluate demonstration projects, and purchase technology that proves effective. In addition, public funding could be used to encourage, test, and evaluate alternative ways of organizing and delivering long-term care. Demonstration projects can be an effective way to test approaches to organizing and delivering care and in some cases bring about market changes faster than would have occurred if left solely to the market.

Given the slow growth in the labor force and the anticipated shift in family structure, it is not too soon to start seriously encouraging new technologies and the evolution of a new paradigm for organizing and delivering long-term care in people's homes as well as in institutions.

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## About the Project

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