

**Will**



**Anyone Care?**



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Leading the Paradigm Shift in  
Developing Arizona's Direct Care Workforce

*Recommendations from the  
Citizens Workgroup on the Long-Term Care Workforce  
to  
Governor Janet Napolitano*

*April 2005*

## Who Will Care For Us? *Will anyone care? This is the simple but compelling*



*question we all must answer. The future portends exponential growth in the aging and disabled population in Arizona; of this there is little doubt or disagreement. Considering the fact that, even today, we face a crisis in the long-term care workforce—it is abundantly clear that we must build a new paradigm to create a stable and capable work force sufficient to meet the dramatic surge in the projected demographics of care in Arizona.*

**G**overnor Janet Napolitano embraced this challenge, issuing an Executive Order, called Aging 2020, in March 2004 to all state departments requiring them to plan for the significant increase in Arizona's aging population by the year 2020. At that time she also created the Citizens Work Group on the Long-Term Care Workforce, empowering knowledgeable citizen leaders in the aging and disability networks to further study the issue of the direct care workforce. This report is an interim analysis following eight months of deliberation on key areas impacting the viability of the direct care workforce. In this report you will find summarized some of the best thinking on the future of the long-term care (LTC) workforce, projections on where Arizona may be headed and why, and suggestions for potential strategies for ensuring meaningful access to LTC services for the state's elderly and disabled residents who will require assistance in the future.

The problem we face is not simply one of demand or workforce supply. The more fundamental, long-term dilemma is how to develop a committed, stable pool of front line workers who are willing, able, and prepared to provide high caliber care to people with long-term care needs. Both the short- and long-term problems must be addressed if we are to design quality systems of care to meet the needs of elders and people with chronic disabilities.

A stable, professional workforce is the key for ensuring quality of care. This challenge cannot be met through public policy alone, nor does the market place have the ability to meet the increasing labor demands in its current state. We must strategically work toward an environment characterized by coordinated public policy, improved and fair reimbursement, and a spirit of partnership among public and private stakeholders. This is the key to ensuring the viability of the long-term care system. Our commitment to the dignity of human life must be translated into the political will to develop systems that both serve those in need and care for the caregiver.

# Table of Contents

<b>Executive Summary</b> _____	i
<b>Introduction</b> _____	1
<b>Demand for Direct Care Workers</b> _____	3
Changing Population Demographics... _____	3
Increasing Rates of Disability... _____	4
New Directions in Settings of Care _____	5
Long-Term Care Expenditures Increase... _____	5
Medicare and Medicaid as Funding Sources... _____	5
Nursing Home Residents Require Higher Levels of Care _____	6
High Vacancy and Turnover Rates... _____	7
Special Considerations for Rural Arizona _____	7
Unique Challenges in Providing Long-Term Care in Rural Areas _____	8
Changing Demographics of Family... _____	9
<b>Supply of Direct Care Workers</b> _____	11
Demand Outpaces Supply... _____	11
Arizona Is No Exception... _____	11
Long-Term Care Must Compete With Other Sectors... _____	11
Compensation Gap Widens... _____	12
Informal Caregivers Are the Backbone... _____	13
Regulation, Education and Roles Are Inconsistent _____	14
<b>Conclusion</b> _____	15
<b>CWG Appointed Members</b> _____	17
<b>Endnotes</b> _____	18

# Executive Summary

## History

Governor Janet Napolitano acknowledged the need to address the growing aging population in the state of Arizona through several important strategic planning initiatives this past year. In March of 2004, Governor Napolitano issued an Executive Order for state agencies to plan for “Aging 2020”. Recognizing the increasing concern of Arizona citizens for the development of a capable and compassionate workforce to meet the needs of this dramatically increasing segment of the Arizona population, the Governor also appointed a Citizens Work Group on the Long-Term Care Workforce (CWG), which began its work in April of 2004.

In creating the CWG, the Governor appointed a wide range of concerned citizens and professionals from the private sector to address this issue. The unique characteristic of the CWG is that it includes the perspective of citizens whose thinking was not limited by governmental constraints or provider self interests. It was hoped that the CWG would think “out of the box” and provide creative solutions to a mounting problem, providing the Governor with a new paradigm for programmatic and policy recommendations related to workforce development in the long-term care service delivery system.

The Citizens Work Group learned that there were other workforce initiatives in place actively addressing the shortage of licensed health care professionals, including the Campaign for Caring and the Governors Task Force on the Nursing Shortage. Thus, the CWG chose to focus its attention to a particularly important unmet need... the development of the paraprofessional direct care workforce. As we quickly came to realize, the role of the direct care worker is critical to the system of care, but largely overlooked in a healthcare system that directs the lion’s share of its attention to acute care providers. For these reasons, our goal has been to address the current and future gap between the demand for, and supply of capable, “hands on”, unlicensed support persons in both informal and formal care giving settings.

## Process

The CWG established three key subcommittees: *“Promising Practices in Recruitment and Retention”*; *“Data and Demographics on the Long-Term Care Workforce; and “Education and Training Needed for Direct Care Workforce Development.”* These working groups met over the last year and have involved more than 50 citizens and stakeholders in dialogue, all working toward thoughtful solutions to address the workforce crisis.

The thoughts and recommendations presented in this report all deserve further public dialogue. Issues of feasibility, cost, timing, and even political will, must be considered. This is an initial report designed to help define the circumstances that underlie the Governor’s concern about long-term care workforce capacity, and to increase awareness of the issue among government officials and the general public. In the months ahead, the CWG will continue its research and analysis, seek further public input and move to the dialogue forward to refine and develop strategies for implementation of the recommendations included in this report.

## Guiding Principles

The Citizens Work Group felt strongly that guiding principles should drive the development of recommendations to improve and enhance the direct care workforce. These are very much in keeping with the existing principles inherent in several state plans, including that of the

Department of Economic Security (DES), the Arizona Health Care Cost Containment System (AHCCCS), and the Department of Health Services (DHS)-and are also embodied in similar form in the draft AGING 2020 plan.

**Each of our recommendations has one of the following guiding principles at its core...**

- Promotion of Person-Centered Care Practices in Long-Term Care Service Delivery
- Parity in Wages and Benefits for Direct Care Workers
- Acknowledgement of the Intrinsic Value of Caregivers and Direct Care Worker Role
- Recognition of Cultural Diversity and the Unique Needs of Rural and Urban Service Delivery Networks
- Implementation of On-Going Strategic Planning to Meet Current and Forecasted Workforce Needs
- Assurance of Both Access to Care and Quality of Care in Long-Term Care Settings

## **Recommendations**

These recommendations are the “first step” considerations of the Citizens Workgroup. They are made following serious deliberation and reflect a citizen’s perspective, made with the “perfect” not just the “possible” in mind. Based on the belief that those entrusted with the care of our fellow citizens should themselves earn a livable wage, we recognize that this is only a starting point, and that the direct care workforce shortage is part of a larger problem involving both the long-term and acute care systems. Our fundamental hope is that policymakers will begin to pursue a systematic strategy that addresses the essential elements of a system of care.

Compensating direct care workers with a livable wage and benefits and providing a more rewarding work environment benefits all stakeholders. Provider agencies should direct their management and financial resources away from their historical focus on recruitment and disciplinary actions, and toward training, support, and retention that results when direct care workers are viewed as a respected members of the care team.

Family caregivers should have the resources and support at hand to perform their role competently. Care recipients should receive consistent assistance from capable and compassionate caregivers whose attention is focused solely on their care.

1) **State agencies must establish and implement policies to support informal/family caregivers to ensure that the demand for professional caregivers does not outweigh supply and thus exacerbate the financial challenge already facing an overburdened system.** If this vital component in the long term care system breaks down, the demand for professional caregivers will far outweigh the supply. ***To protect and support caregiving families, specific recommendations include:***

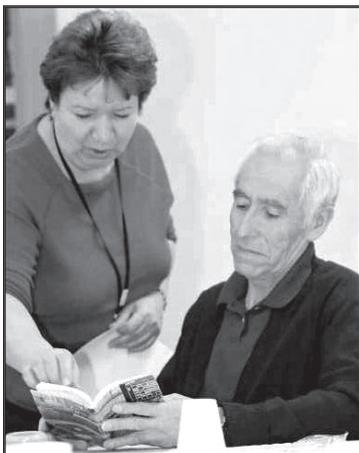
- Expand payment to family members including spouses, parents and grandparents of minor children (AHCCCS to obtain a federal waiver).
- Make affordable high quality respite care available to all.
- Establish an annual tax credit to offset cost of care, supplies and equipment.
- Expand within Arizona provisions of the federal Family Medical Leave Act, that allow caregivers time off for caregiving.

- Support “Cash and Counseling” Consumer Directed Care Programs.
  - Establish one-stop information centers for family caregivers.
- 2) **State agencies responsible for regulating oversight of direct care workers must develop a standardized, uniform and universal training curriculum.**
- *The training curriculum should be flexible in order to accommodate career pathways, and the modules should allow for basic and advanced training for homemakers, personal care and CNAs.* Additional modules that address the needs of special populations would allow what we now consider to be direct care workers to become “**direct support professionals.**”
  - *State approved credentialing and oversight of the universal curriculum must occur.* Arizona must continually review the appropriateness of the curriculum to changing realities of the workplace. All training entities should be approved and reviewed for delivery of the curriculum as designed including competency testing. There should be a monitoring process to ensure credibility of training and a disciplinary process and sanctions should be in place for violations.
  - *Direct support professional’s credentials must be portable.* This allows the direct support professional to seek immediate employment placement with a variety of providers, and assures the employer of the skill sets of the employee in addressing the needs of the clients assigned to them.
  - *The state must cost out the training curriculum and delivery methodologies.* State agencies must receive and provide sufficient payment to address the identified costs. There could also be consideration of the provision of training to family caregivers on a sliding fee basis, as well as a modest tuition payment for the direct support professional.
- 3) **Plans developed by state agencies that serve elders and people with disabilities should be modeled on the concept of person-centered care,** and should include projects to enhance direct care workforce recruitment and retention in community-based long-term care settings that meet the unique care needs of both the client and worker. Both the direct care worker and care recipient report significantly higher satisfaction in settings which emphasize this paradigm of service delivery. Regulation, public protection, individual choice and need must all be balanced.
- 4) **One state agency should be identified as the focal point for resource development for health care workforce initiatives, and designated to play a proactive role in seeking state, federal and private grants to further develop arizona’s direct care workforce.** Arizona has missed opportunities to respond to any number of public and private labor force initiatives over the past few years, and must immediately ramp up efforts to position our state to receive such awards. There should also be a single repository of state data on aging, disability and health care and workforce. The Citizens Work Group faced significant challenges in finding current and accurate state and local data, and acknowledges these gaps in this report.
- 5) **State policy must require and fund health insurance and benefits for direct care workers in long term care settings,** by establishing this as part of the base for determining provider reimbursement rates. This policy could be developed as a “pass through” system, and might also be provided through participation in Healthcare Group of Arizona. Clearly, the lack of health and other benefits for entry level workers, the negative impact of poor health on attendance, and the cost of health benefits have a cumulative negative impact on the retention of workers in the long term care workforce.

- 6) **Public and private sector employers must fundamentally re-evaluate the wages paid to the direct care workforce and balance this with the value of the services they provide.** The direct care workforce shortage is in no small part due to low wages paid. The offset to the cost of higher wages will be the lower cost of turnover, and the increase in continuity of care. Wages should be commensurate with the import of service provided, training and certification requirements. The state should also monitor the implementation of the Fair Labor Standards Act in all state contracts and subcontracts for the delivery of human services. This will help ensure fair wages, and overtime compensation in Arizona's direct care marketplace—key factors in workforce retention.
- 7) **Funding for pilot projects to enhance direct care workforce recruitment and retention in long term care should be identified.** There should be consideration of a web-based model and other promising practices in recruitment nationwide. The State of Arizona must expand the avenues to inform both potential workers and individuals needing care about options for employment and care services. Support for projects focusing on education and training for direct care workers—emphasizing the role of secondary, vocational, and community college educational opportunities—should also be identified.
- 8) **The state should mount a public awareness campaign to promote the image and profile of the direct care workforce.** Public and private partnerships could be leveraged to promote this critical segment of the long term care profession. The campaign could center around “AZCares”, or some other theme, focusing on paraprofessionals. Such an effort could also include press, public service announcements, awards, proclamations, publications, posters, and public education.
- 9) **The state should continue to support and develop preventative health care programs.** Data suggest that age alone is not the only significant driver in the need for long term care services. Clearly, rising rates of disability and functional impairment will exacerbate the demand for long term care. (Examples include osteoporosis, diabetes and falls prevention programs.)
- 10) **Support the incorporation of long-term care workers into existing professional associations, or the creation of an association dedicated to the direct care worker in the long-term care setting.** The private/non-profit sector, including educational institutions, long-term care providers and advocacy organizations should include direct care workers. There is a great need for the “worker voice” in the development of direct care worker initiatives, and this would link Arizona's direct care workers to other national advocacy efforts.

# Introduction

National data on the long-term care workforce is not hard to find. In fact, the challenge for the Citizen's Work Group on Long-Term Care Workforce was to reconcile the myriad of reports, projections, trends and forecasts and reach consensus on Arizona's likely future. Using a combination of national, state and, where possible, county data, this report provides an overview of the current status of the long-term care workforce, and attempts to project what the future might look like. In creating this report, it also became quite evident that, as one Committee member put it; "our forest is missing some trees." Indeed, creating a framework for assessing needs and resources may be the first step in developing reliable and valid information about the strengths and needs of our communities and crafting public policies that support both those who need our care and those who provide it.



Direct care workers are found in a variety of settings that have evolved to meet the diverse needs of care recipients. Defining these care settings frames how we think about them, how we fit them into a continuum of care and how we finance care delivery. Within the long-term care industry, this variety of settings is matched by an equally broad range of direct care worker roles and titles. For purposes of this report, we use the term *direct caregiver* in a generic sense that encompasses a range of roles, both paid and unpaid, in a variety of settings (see Figure 1). To simplify the variety of settings, we group nursing homes with assisted living facilities under the rubric of *institutional settings*, and differentiate this group from home and community-based service (HCBS) settings. HCBS settings, including unlicensed group homes and private residences, are referred to as *community settings*. Within each setting, direct caregivers perform a variety of roles, requiring various levels of educational preparation and regulatory oversight. Because the roles and titles often overlap, there may be multiple titles for what is essentially the same caregiving role.

The challenges we face in ensuring a stable pool of committed workers may be conceived in three inter-related dimensions including factors that influence *demand*, factors that influence *supply* and the setting-dependent factors that mediate the *process* of caregiving. This report focuses on a review of the factors driving **demand** for care, and concluding with a summary of the issues that impact the current and future **supply** of long-term care workers. Despite what we know about population demographics and the driving forces of demand and supply, generating accurate long-term estimates for this dynamic and evolving system is a considerable challenge. The long-term care industry has long structured itself on the presumption of an endless supply of low-income workers, but the changing dynamics of population, workers and models of care are converging to create a very different future.

**Figure 1**  
**The Myriad Titles of**  
**Direct Care Providers**

Homemaker/Housekeeper  
Personal Care Aide/Attendant  
Certified Nursing Assistant (CNA)  
Family Caregiver  
Nurses' Aide/Patient Care Assistant  
Licensed Practical Nurse (LPN)  
Volunteer Caregiver  
Home Health Aide  
Registered Nurse (RN)

Past experience generally provides the basis for forecasting future long-term care workforce demand and supply. Coupled with an aging population, it's logical to stop there when thinking about the future. However, projections should not be based solely on historical data. The impact of technology, improved health status of seniors and data on trends in disability rates suggest that the impact of the baby-boom generation will be significant, but not insurmountable.<sup>1</sup> Historical models which forecast long-term care needs and workforce demand within the broader context of the acute care sector do not reflect emerging trends and demand for emerging models of care which embrace a more holistic, community-based approach. While the focus of this report is the long-term care workforce, addressing the current crisis requires that we think more broadly about these issues.



# Demand for Direct Care Workers

## *Increasing Demand for Care Drives the Demand for Direct Care Workers*

Future demand projections for long-term care are generally based on population age demographics, disability rates, expenditures for long-term care and the availability of informal caregivers, as shown in Figure 2. (Fishman, et al;<sup>2</sup> Davis and Dawson;<sup>3</sup> HHS/ASPE<sup>4</sup>)

### Changing population demographics fuel the demand for care

Arizona's changing population demographics are commonly cited as one of the most significant public policy issues facing the state over the next 20 years. As one of the fastest growing states in the nation, Arizona has seen its population increase by 40% between 1990 and 2000, when the Census Bureau put the total at 5,130,632. Arizona is currently, and will continue to be, among the top ten states in terms of the number of older residents as the 60+ population grows from the current 875,000 representing 17% of the population, to just under 3 million, or 26% of the population in 2050.<sup>5</sup> Changes in population demographics related to aging are driven primarily by the baby boom generation, migration of retirees to the state and, to some degree, by longer life expectancy<sup>6</sup> (Gober, 2002). Most older Arizonans will reside in urban counties, but rural counties will also experience significant growth in the over-60 segment of their population. In 2000, residents over the age of 60 already accounted for 30% of the population in Mohave County and 32% in Yavapai County. By 2050, over 25% of the residents in eight of Arizona's 15 counties will be over the age of 60.<sup>7</sup> Currently, Caucasians account for 85% of the over-60 population, however the percentage of African-American and Hispanic elders is increasing, with growth over the next 40 years projected to be 300% and 600% respectively.<sup>8</sup>

**Figure 2**  
**Factors Influencing Demand**

- Population demographics—namely aging—and increasing disability rates among middle-aged adults.
- Changes in the extent and nature of disabilities that limit activities of daily living for care recipients.
- Availability of private resources as a result of broad economic changes in wealth formation and savings.
- Availability of private long-term care insurance.
- Changes in family structure that will increasingly shift the burden of care to formal systems and paid caregivers.

While Arizona is in the 'top-ten' when it comes to the age of our population, we are not alone in this trend. In a recent report to Congress, the Department of Health and Human Services states "the aging 'baby boomer generation' will be the most significant factor increasing the demand for long-term care services over the next half century."<sup>9</sup> Currently, some 15 million individuals utilize nursing facilities, assisted living and home care services on a national level, a number that is expected to grow to 27 million in 2050. Most of this increase will be driven by the growth in the number of elderly in need of such care, a population that is poised to double from approximately 8 million in 2000 to 19 million in 2050.<sup>10</sup>

## Increasing rates of disability accelerate the demand for care



Because the incidence of disability accelerates with age,<sup>11</sup> it's easy to understand how these demographics can lead to the conclusion that aging is the key factor driving demand for care and for more direct care workers. However, recent research has questioned the methodology and assumptions used to generate estimates and projections of the demand for both long-term care and health care in general in the future, noting specifically that “the aging of the population is too gradual a process to rank as a major cost driver in health care.”<sup>12</sup> Fueled by a growing epidemic of obesity, disability rates are on the rise, reversing the downward trend that has been in place since the mid 1980s. According to the U.S. Department of Commerce Census Brief on disabilities, one in five Arizonans experience some kind of disability and one in ten experiences a severe disability. (December 1997) While the full range of causes isn't clear, the implications for the capacity of the long-term care sector to respond to the demand for disability-related care could lead to future nursing home populations that are as much as 25% higher that they would otherwise have been.<sup>13</sup> For Arizona, this could translate to increased expense for nursing home care in the neighborhood of \$100 million annually.

In addition to the elderly and disabled adults, the long-term care system also serves the state's developmentally disabled citizens. Approximately 1.5% of the population is diagnosed with a developmental disability and many of these Arizonans require long-term care assistance. The ADHS Division of Developmental Disabilities reports that about 60% of the care they support is provided in the home setting, and 28% of clients receive only support coordination, not actual services.<sup>14</sup> Current forecasts of the need for home and community-based services for persons with developmental disabilities (DD) indicate a 9 to 10% annual increase, translating into the need for over 30,000 direct care providers by 2016.

The Department of Economic Security provides non-medical, home and community-based support services for the elderly and developmentally disabled. The number of clients currently served in these programs is approximately 13,000, with a waiting list of 658 additional clients. The Department currently lists 146 contract service provider organizations. In addition to the formal system of care, informal reports add an estimated 15,000 persons living in unlicensed community settings. While these estimates have not been formally documented, they represent a significant and ongoing need for caregivers.

### **Figure 3: Key Facts about People with Developmental Disabilities**

- About 95% of facilities for the DD population are community based, but represent 60% of the beds because of other institutional care (Beauregard and Potter 1992)
- About half of the DD population is admitted into institutional care after the age of 40 and about 2/3 of persons with DD who are 65+ are in nursing homes or other long-term care facilities that are not specially designated for DD. (Altman 1990)
- Those with impairments in the most Activities of Daily Living reside in state institutions and those with the fewest impairments are in small private or public facilities. (Cunningham and Muller 1990)
- Although the reasons may differ, service needs are similar across age groups. (Altman 1995)

## New direction in settings of care

Nationwide, the long-term care industry includes nearly 120,000 agencies, ranging from small, single-site non-profits to massive, for-profit corporations. These agencies provide services in a variety of institutional, home-based, and community based settings. The capacity of Arizona's long-term care network has been diminished, with most experts citing financial viability as a key factor in the closure of most care settings. In 1999 there were 188 licensed skilled nursing facilities in the state, but in 2005 the number had dropped to 137.<sup>15</sup> Offsetting the decrease in formal systems of care is an increase in informal – and often unlicensed – care settings. While these settings demand a similar number of workers, their degree of oversight and required level of training is highly variable. Figure 4 summarizes the various types of facilities and their client capacity.

## National long-term care expenditures increase exponentially

Even as lower-cost home and community-based care expands, nursing home care expenditures continue to grow. In 1980 aggregate nursing home expenditures totaled \$17.7 billion, and out-of-pocket costs accounted for 40% of the total. By 2002, the tab for nursing home care had risen to \$103.2 billion, and while the out-of-pocket percentage had fallen to just 25% of the total, that 25% is significantly higher than the total expenditure in 1980. In 2002, private health insurance picked up just 7.5% of the total, while Medicare accounts for 12.5% and Medicaid remains the single largest source of nursing home funding, accounting for 49.3% of total expenditures.<sup>17</sup>

## Medicare and Medicaid are the primary sources of funding for direct care workers

The Arizona Long-Term Care System (ALTCS) provides for long-term care services for persons who meet financial and medical eligibility criteria. Two sub-populations of persons enrolled in the ALTCS program include the Elderly and Physically Disabled (EPD) and the Developmentally Disabled (DD). Care may be provided in either an institutional setting (nursing

**Figure 4: Settings, Services and Skill Levels in Arizona<sup>16</sup>**

• <b>Licensed Skilled Nursing Homes</b> .....	<b>137</b>
Approx. 13,500 beds, est. 87% occupancy	
• <b>Licensed Adult Day Health Care Settings</b> ....	<b>27</b>
Range of 20 - 100 clients	
• <b>Licensed Assisted Living Centers</b> .....	<b>187</b>
10 or more clients	
> Directed Care Centers:	117
> Personal Care Centers:	49
> Supervisory Care Centers:	21
• <b>Licensed Assisted Living Homes</b> .....	<b>1289</b>
10 or fewer clients	
> Directed Care:	1262
> Personal Care:	18
> Supervisory Care:	9
• <b>Adult Foster Care</b> .....	<b>209</b>
Unknown number of clients	
> 11 in rural areas	
> 165 in Maricopa County	
> 29 in Pima County	
> 4 in Yavapai County	
• <b>Unclassified Respite Facilities</b> .....	<b>6</b>
• <b>Licensed Behavioral Health Facilities</b> .....	<b>681</b>
• <b>Group Homes for the Developmentally Disabled</b> .....	<b>872</b>
• <b>Intermediate Care For Mentally Retarded Facilities</b> .....	<b>12</b>
• <b>Private/Residential</b> .....	<b>Unknown</b>
Person receiving care in own home	

home) or through home and community-based services (HCBS). Like the Arizona Health Care Cost Containment System (AHCCCS), the ALTCS program is funded through a combination of federal Medicaid funds and state matching funds. Like other states, enrollment in these programs has increased substantially and Arizona faces a significant challenge in funding the AHCCCS and ALTCS programs.

Most people think of Medicaid/AHCCCS as a public insurance program for low-income children and women. While this is true for the absolute number of people served, the costs associated with the long-term care components are disproportionately higher. Nationally children and non-elderly adults account for 74% of Medicaid's enrollment but just 29% of its costs. The elderly, blind and disabled account for 26% of enrollment, but 71% of Medicaid costs. The elderly and disabled accounted for 70% of the increase in Medicaid spending between 2002 and 2003.<sup>18</sup> Thus the impact of funding cuts in public insurance programs is likely to exacerbate the workforce shortage by creating instability in the financing and delivery of care throughout the system.

### **Nursing homes residents require higher levels of care**

A recent study of Arizona's nursing home residents<sup>19</sup> found on average, over 27,300 individuals were admitted to Arizona nursing homes each year. A demographic profile of nursing home residents shows that the majority of patient admissions are among white, English-speaking women over the age of 75. However, the population is far from homogeneous and can be categorized into three distinct subgroups:

- *Post-Acute* – this subgroup is primarily composed of individuals who are admitted to a nursing home for less than 90 days, generally following a hospitalization in an acute care facility, and accounts for almost 75% of all admissions;
- *Chronic-Care* – individuals in this subgroup are predominantly those clients who are admitted from non-hospital settings and remain for longer than 90 days; and,
- *Transitional* – representing those individuals who transition between the hospital and the nursing home, staying longer than 90 days, or who are initially admitted from a non-hospital setting but are subsequently admitted to a hospital.

These subpopulations share some characteristics, but what is more noteworthy are the distinct differences in their care needs. For example, residents admitted on a post-acute basis are significantly more likely (20%) to be taking in excess of 12 medications in comparison to the transitional subpopulation (14%) and the chronic-care subpopulation (10%). Post-acute residents are also significantly more likely to be receiving physical/occupational therapy and to indicate higher levels of pain, but significantly less likely to exhibit signs of depression, dementia/Alzheimer's disease, incontinence and short- and long-term memory loss. The skill mix and training of direct care workers, especially those providing basic care, often does not reflect the different types of client populations for whom they may be providing care.



**Figure 5: Factors Influencing  
Processes of Care—The Changing Nature of Direct Care Work**

- Changes in the roles that industry employers assign to direct care workers, including the restructuring of work tasks and delegation of tasks to less-skilled or more specialized workers.
- Changes in the structure of the long-term care industry and the types of provider institutions, reflecting a less institutionalized and more community-based mix of services.
- Potential changes in regulatory standards, including quality standards for nursing homes and home health agencies or stronger regulation of assisted living and other residential care providers.
- The role of technology in aiding both paid and unpaid caregivers, through monitoring or assistive devices.

### **High vacancy and turnover rates contribute to the national workforce crisis**

Continued high turnover rates exacerbate the demand for health care workers. Industry-wide turnover rates increased from 8% to 2001 to 11% in 2003, ranging from a low of 6% among physician assistants to a high of 39% among nursing aides. Occupations with some of the highest turnover rates (nursing aides, phlebotomists, registered nurses) also have some of the highest rates of projected future demand.

The situation among paraprofessional caregivers is an even greater cause for concern. Eight out of every ten hours of paid care received by a long-term care client is provided by a “direct-support” paraprofessional: a home health aide, personal care attendant, or certified nurse’s aide. These direct-support staff members are the primary delivery system for long-term care, yet more than 40 states now report critical shortages of paraprofessionals. Turnover rates range between 40% and 100% annually. (2003 American Health Care Association Workforce Report)

Vacancies and turnover rates within the paraprofessional caregiver workforce are high for several reasons. First, the quality of direct-care jobs tends to be extremely poor with low wages, limited benefits and lack of respect cited as major factors in worker dissatisfaction with job quality. Second, other market sectors offer preferable job alternatives for workers at the lower end of the wage scale. Frontline worker jobs in long-term care are largely viewed by the public as being physically and emotionally demanding, paying low-wages and lacking in respect. Despite the challenges they face, many workers take pride in the care they provide and find their interactions with clients highly rewarding. The truth likely lies somewhere in the middle, and is no doubt heavily influenced by the working environment, which is both demanding and rewarding. The challenge is to match the rewards—both financial and social—with the demands of the job, and it is our failure to meet this challenge that is fueling the current shortage of workers.

### **Special considerations for rural Arizona**

Ten of Arizona’s fifteen counties are designated as rural. Current funding formulas reimburse services provided in these counties at a lower rate than their urban counterparts. The rural

setting places increased demands on care systems and caregivers, and relies heavily upon informal caregivers. Providing services in the rural setting is more expensive on a per-person basis because it is difficult to achieve economies of scale. However, specific cost differences have not been quantified and further study of formal and informal care systems is needed to determine the precise cost of rural long-term care.

### Unique challenges in providing long-term care in rural areas

- Costs to provide in-home care and assisted living are higher in comparison to similar services in urban areas, but lower than skilled nursing facility costs. Care recipients also prefer home or community-based care settings that allow them to remain engaged to the greatest degree possible with their family and their community.
- Geography and weather conditions increase travel time for caregivers who must drive long distances over rough roads to reach clients, even before any care is provided. For home health care, Medicare currently provides for a maximum travel time of 45 minutes, which is not realistic in many rural areas.
- Systems of care in rural areas rely more heavily on informal systems to supplement limited formal systems of care. Only with local networking and knowledge of community care needs can the sense of satisfaction and ownership that sustains informal care systems develop.
- Formal care systems in the more remote rural areas are often absent or fragmented, and care providers must often rely upon novel and creative approaches to ensure that adequate assistance is obtained.
- The viability of assisted living homes operating in rural areas is tenuous and these care settings often close due to lack of business skills, low census, economic status of residents and inability to leverage economies of scale.
- Rural counties have the highest percentage of seniors, and the highest percentage of the oldest old, age 85 and over. Yavapai and Mohave counties lead the state with over 27% of their population over the age of 60.<sup>20</sup>
- Nationally and in Arizona there is wide disparity in the poverty rate for older persons. Poverty increases with greater rurality, from 12.8% for rural counties adjacent to a metro area to 20.6% in non-adjacent, completely rural counties.<sup>21</sup>

In addition to the more general challenges faced by rural areas, rural areas also face problems specific to the development of a viable health and long-term care workforce. Where technology such as telemedicine could be used to maintain contact with isolated rural elders, limited funding and educational opportunities often preclude its use. Caregiving in rural areas also requires extensive travel which, in the absence of affordable child care and reliable transportation, precludes many otherwise qualified workers from joining the long-term care workforce. This situation is exacerbated by the low population density that artificially depresses standard productivity measures which form the basis for reimbursement, making the wages for these workers even less attractive.





Finally, many rural areas are far more dependent upon public funding such as Medicaid/AHCCCS/ALTCS to support their long-term care systems. Corporate and private funding sources are limited and the competition for private donations is intense. There is also less capacity for individual donations from rural residents and less incentive for private urban donors to give to causes which primarily serve rural areas.

### **Changing demographics of the family and informal networks of care**

The availability of informal unpaid caregivers 30 to 50 years from now depends upon a number of factors, but the most significant factor is the changing size and composition of families. Current population estimates project significant declines in the number of workers that will be supporting each Social Security recipient, from approximately 5:1 in 1960, to 3:1 in 2000 and 2:1 in 2040. The ratio of workers to dependents (defined as the number of individuals under 18 plus those over 65 years of age) is even more dramatic, reaching a 1:1 ratio by 2050.<sup>22</sup> today's seniors are more likely to live alone as they get older, reflecting fewer children, longer life expectancy and increased divorce rates since the 1960s.<sup>23</sup>

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# Supply of Direct Care Workers

## *The Long-Term Care Workforce Supply Is Insufficient*

### **Demand will outpace supply everywhere**

Nationally, the growth of new health care jobs is projected to outpace growth in other job sectors by a margin of 2:1. Over the next ten years projected job growth in the health care sector is forecast to be nearly 30%. The largest percentage increase is projected for medical assistants, where the 57% increase will translate into approximately 187,000 new jobs. Responding to the preference for home-based care, home health aides are projected to increase by 47.3% and nursing aides by 23.5%. In terms of the absolute number of new jobs created, registered nurses top the list with projected 560,000 new jobs.<sup>24</sup> The impact of the nursing shortage is reflected in a major campaign sponsored by the Arizona Hospital and Healthcare Association. Dubbed the Campaign for Caring, this multi-million dollar initiative addresses attraction, education and retention in an effort to address the shortage of health care professionals primarily in the acute care setting.<sup>25</sup>

**Figure 6**

### **Factors Influencing Supply**

- The availability of jobs in other sectors of the economy.
- Competition for workers from other areas of the health care system.
- Changing population demographics and a growing 'dependency ratio.'
- The availability of stable, reliable and affordable child-care for low-income workers.
- The availability of education and training for increasingly complex direct caregiving roles.

### **Arizona is no exception to the shortage**

Within Arizona projections are consistent with national trends where, according to Bureau of Labor Statistics (BLS) estimates, by 2010 direct care worker jobs in long-term care settings should grow by about 800,000 jobs, or roughly 45%. According to estimates developed by the HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE), by 2010 the demand for direct care workers in long-term care settings will become even greater as the baby boomers reach age 65. ASPE estimates project the demand for direct care workers to grow to approximately 5.7-6.6 million workers in 2050, an increase in the current demand for workers of between 3.8 million and 4.6 million (200% and 242% respectively). This increase in demand will be occurring at a time when the supply of workers who have traditionally filled these jobs is expected to increase only slightly.<sup>26</sup>



### **Long-term care must compete with other sectors for direct care workers**

Health care in the United States has been perceived to be in a state of perpetual crisis for the past 30 years, fueled by the inherent tension between the expansion of medical services for a growing population and the need to control rising costs. Since

direct care positions cannot be replaced by technology, nor moved offshore, direct caregiving is projected to be the one of the nation's fastest growing occupations over the next decade. As a market sector, the delivery of health care is labor intensive, requiring highly educated workers, but with relatively less benefit derived from gains in productivity. Because it is a relatively concentrated employment market, salaries have not increased commensurate with the increase in demand for services.<sup>27</sup>

Arizona is below the national average for health care related employment, despite the fact that the health care sector has been, and will continue to be, one of the fastest growing segments of Arizona's economy. (Source: Western Blue Chip Economic Forecast, 2004)



- In 1970, approximately 23,000 people in the state worked in health care jobs, representing 4.1% of total jobs. In 2003, about 200,000 Arizonans worked in health care, representing 8% of total jobs.
- According to the Arizona Board of Regents, approximately 10% percent of state wages, or \$2 billion, was generated through health care jobs in 2002. In the future, the great majority of the fastest growing occupations in Arizona will be in health care and related fields.
- In the 1988-2000 period, employment in the Arizona health care sector grew 58%, while the population grew 46%, resulting in a net per capita growth rate of 8%, significantly lower than the national per capita growth rate of 21%.
- Roughly 42% of Arizona health care workers are employed in ambulatory health services (physician offices, outpatient clinics, etc.), 27% are employed by hospitals and 21% in the long-term care sector.
- 86% of direct care workers in the long-term care setting are women, and most are between the ages of 25 and 54.
- Ethnic minorities are under-represented in the licensed healthcare professions. In 1998 just 6% of active practitioners were Hispanics at a time when Hispanics represented 22% of the general population. However, approximately 30% of direct care workers are women of color.

### **The compensation gap widens the care gap**

Assuming full-time, year-round employment, average gross annual income in 2003 was \$21,050 for nursing aides, orderlies and attendants; \$19,180 for home health aides; and \$17,020 for personal and home care aides. Often what is not paid to workers in direct wages is balanced by a higher percentage of compensation paid in benefits. However, this is not the case for direct care workers. The cost of benefits for personal care workers in 2001 was \$1.88 per hour, compared to \$8.73 for lower-wage workers employed by state and local governments. The lower benefit cost reflects both their low wages and the fact that direct care workers are much less likely to have health insurance. According to The U. S. General Accounting Office, home care aides and nursing assistants employed by nursing homes are more than twice as likely to be uninsured than other workers. (Report on Nursing Workforce, 2001)

For direct care workers, market demand has not translated into higher market wages. Between 1992 and 2000 the percent increase in hourly wage for fast food workers was 45%, while the wage increase for personal and home care aides was only 12%. Nationally, about 12% of workers earn incomes that are below the poverty level, however among direct care workers that figure jumps to almost 20%. Consistent with the profile of the direct care worker, one in three nursing home and home health aides are single parents receiving food stamps. Because the wages are low, these front line workers are also challenged in their personal lives with issues of reliable transportation and stable childcare. Bottom line: the physical and emotional demands of these jobs are not being matched by wages and other benefits. The result is dissatisfaction, high turnover, high vacancy rates, and poor quality of care.

### **Informal caregivers are the backbone of support for an aging population**

Informal care provided by family and friends is a major element within the realm of caregiving. Despite the critical role of informal caregiving, not much is known about it and it is generally not included in economic statistics.<sup>28</sup> In fact, much of what we know about informal caregivers is based on national data developed by non-profit groups and other advocates. What we do know is that informal caregivers provide the majority of long-term care services in the U.S. In 2000, there were 22 million unpaid informal caregivers aiding 14 million elderly persons in the U.S. These numbers are projected to increase to approximately 40 million individuals caring for approximately 28 million Americans in 2050.<sup>29</sup>

#### **A Snapshot of the Informal and Volunteer Caregiver<sup>31</sup>**

- Among informal caregivers, 69% say they help one person.
- While approximately half of all caregivers say they provide eight or fewer hours of care per week, nearly 20% report providing more than 40 hours of care per week.
- The average length of care giving is 4.3 years.
- Similar to the profile of nursing home residents, most individuals who receive informal care are female (65%) and are more likely to be single/widowed (42%).
- Approximately 80% of informal care recipients are over the age of 50, with the remaining 20% between 18-49 years of age.

The long-term care industry has been structured on the presumption of a seemingly endless supply of low-income workers. Now that this decades-old presumption is no longer valid, unprecedented pressure is placed not only on the formal, paid health care delivery system, but also on informal volunteers and family caregivers. Many Arizona residents express concerns about becoming a caregiver for an aging or disabled parent or spouse. A statewide survey of 40-59 year-old Arizonans found that



75% of respondents were concerned about their ability to care for an elder parent or relative. Almost 80% were optimistic about growing older themselves.<sup>30</sup>

The value of informal caregiving goes far beyond nurturing and social support that enables people who need care to remain in their homes. Economic estimates based on 2003 data find that not only do informal caregivers—family, friends and volunteers—supplement the health care workforce and provide the majority of long-term care services in the U.S., in 2003 they provided services with an estimated market value of \$257 billion. According to a 2004 National Family Caregivers Association



report on caregiving, an estimated 490,000 caregivers in Arizona provided a total of 523 million hours of care with an estimated annual market value of \$4.6 billion.<sup>32</sup>

### **Regulation, education and roles are inconsistent**

Regulation and licensure vary with the degree of education, training and responsibility along the continuum of roles, and the diversity of titles is driven in some degree by the reimbursement levels ascribed to each level of care by third party payors. The fragmentation of caregiving roles and settings is reflected in the inconsistencies found in training requirements within the formal, paid system and missed opportunities for training that would benefit informal caregivers and the recipients of their caregiving efforts. In addition, workforce fragmentation may result in over- or under-regulation of caregivers.

While some degree of training would likely benefit all levels of caregivers, not all caregiving needs to be regulated. For areas that are, and should be subject to oversight, the challenge we face is balancing the risk to the care recipient with the unintended consequences of regulatory burden. Standardization of nomenclature for titles and settings would help to clarify levels of care and establish appropriate regulatory oversight that is based on both the needs of care recipients and the risk posed to them as potentially vulnerable individuals.

# Conclusion

In essence, there are not enough direct care workers to meet current or future demand for care in Arizona. Here we reiterate some of the reasons for that gap and offer recommendations to improve the direct care workforce capacity and supply.

## 1. The demand for care continues to be driven primarily by changing population demographics, including factors related to age, disability and geography.

### *Recommendations:*

- One state agency should be designated as a focal point for identifying federal grant source opportunities for health care workforce initiatives, and to coordinate resource development and support. Workforce initiatives must clearly identify rural and urban factors, and special needs and costs of recruitment and retention of direct care workers in both formal and informal long-term care settings.
- Plans developed by state agencies that serve elders and people with disabilities should be modeled on the concept of person-centered care, and should include projects to enhance direct care workforce recruitment and retention in community-based long-term care settings that meet the unique care needs of both the client and worker.
- The state legislature and governor should continue to support preventative health care programs, as data suggest that age alone is not the only significant factor in the need for long-term care services. Disability services must also be made available and accessible to mitigate the effect of rising rates of functional impairment that will exacerbate the demand for long-term care.

## 2. Family and informal caregivers are the essential foundation of the long-term care service delivery system.

### *Recommendations:*

- State agencies, in particular DES and AHCCCS/ALTCS, should develop and implement policies that support informal and family caregivers, and direct care workers as part of the larger continuum of care. These efforts should include the creation and maintenance of one-stop information centers/clearinghouses for family caregivers, in collaboration with private organizations who share the agencies' goal of supporting these informal caregivers.
- Recognizing the economic value of informal caregivers and the need for further development of respite programs, the state legislature should consider adopting an annual tax credit to offset the cost of care, supplies and equipment for family caregivers.



## 3. Recruitment and retention of direct care workers in institutional settings is impaired by a working environment that is unattractive due to low salaries, poor image, significant physical demands and few opportunities for advancement.

*Recommendations:*

- The public, private, and non-profit sectors should collaboratively undertake a public awareness campaign to promote the image and value of the direct care workforce. State plans, including those developed by DES, DHS, AHCCCS/ALTCS and the Department of Commerce should delineate action steps in support of this effort.
- State agencies that administer long-term care contracts should exercise appropriate oversight to ensure that contracted providers are held accountable to wage and benefit standards, including FLSA compliance, for direct care workers in long-term care settings. Publicly funded organizations should adopt “promising practices” that focus on culture change in long-term care settings that enhance worker satisfaction and retention, and these factors should be included in state agency oversight and for determining provider reimbursement rates.
- The private/non-profit sector, including educational institutions, long-term care providers and advocacy organizations should support the incorporation of long-term care workers into existing professional associations, or the creation of an association dedicated to the direct care worker in the long-term care setting. There is a great need for the “worker voice” in the development of direct care worker initiatives, and this would link Arizona’s direct care workers to other national advocacy efforts.



**4. Educational preparation, caregiver roles and responsibilities and regulatory oversight are inconsistent both with each other, and with the needs of care recipients.**

*Recommendations*

- The Interagency Council on Long-Term Care, in collaboration with other interdisciplinary planning entities within state government, should develop and adopt a standardized universal training curriculum for direct care workers based on a modularized, tiered curriculum.
- To increase the capacity and supply of the direct care workforce, state and local government agencies should, under state government direction, collaborate with public and private educators and long-term care leaders to promote working partnerships between long-term care providers, high schools, vocational schools, community colleges and workforce investment boards.

# Citizens Work Group on the Long-Term Care Workforce Group Members

## **Kathleen Collins Pagels**

Executive Director, Arizona Health Care Association  
CWG Chair

## **Richard H. White**

President, Arizona Interfaith Network  
CWG Co-Chair

## **Melanie K. Starns**

Policy Advisor on Aging  
Staff Liaison – Office of Governor Janet Napolitano

## **Subcommittee Chairs**

**Jill Rissi**, Associate Director for Research and Policy, St. Luke's Health Initiatives

**Guy Mikkelsen**, CEO, Foundation for Senior Living

**Margaret "Peg" Harmon**, CEO, Catholic Community Services, Tucson

---

### **Gene C. Blue**

President/CEO, The Arizona OIC

### **Sherri Collins**

Executive Director  
Arizona Commission for the Deaf

### **Kathleen Collins Pagels**

Executive Director  
Arizona Health Care Association

### **Sheriolyn Curry**

Executive Director, Comfort Keepers

### **Bonnie Danowski**

Family Caregiver, Valley Interfaith Project

### **Gwen Dean**

Director of Attendant Care, ABIL

### **Frances Baker Dickman, Ph.D., J.D.**

Community Member

### **Luis A. Enriquez**

Director, Adult Education, Workforce  
Development, Friendly House

### **Meg Fenzi**

Regional Director, Northern AZ Region  
Alzheimer's Association

### **Carmen Green**

Deputy Director  
Arizona Commission for the Deaf

### **Marguerite Harmon**

CEO, Catholic Community Services

### **Pat Harris**

Director, Health Care Education  
Maricopa County Community Colleges

### **Jill Harrison**

Director, Area Agency on Aging  
Western Arizona Council of Governments

### **Nita Kauffman**

Community Member  
Developmental Disability Network

### **Steve Lacy**

Ombudsman Coordinator  
Area Agency on Aging, Region 1

### **Anne McKinley**

Community Outreach, Gerontology  
Yavapai College

### **Guy Mikkelsen**

Executive Director  
Foundation for Senior Living

### **Mahdi Ochoa, MBA**

Vice President of Prevention and Family  
Services, Valle del Sol, Inc.

### **Denise Pederson**

Director, Cochise County Aging/Social Services

### **Jill Rissi**

Assoc. Director for Research and Policy  
St. Luke's Health Initiatives

### **Michael Roberts**

Government Relations Director  
Paralyzed Veterans of America

### **Cynthia Russell, Ph.D.**

Dean of Samaritan College of Nursing  
Grand Canyon University

### **Anthony Spillman**

**Ritch Steven**  
State President, AARP

### **Richard H. White**

President, Arizona Interfaith Network

### **Olan Williams**

# Endnotes

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