

The Changing Landscape of Caregiving

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Long-Term Care Assistance

- The national need for LTC care assistance will increase by 30-50% in the next 15-20 years.
- The need in Florida will be even greater as the 65+ population grows from 19% to 24% of the total population.
- The number needing assistance in Florida will grow from about 300,000 to over 500,000 in 2020.
- Nationally, the numbers increase from 5.2 million to about 7.5 million.

Long-Term Care Assistance (cont'd)

- 45 million+ individuals provide caregiving services for adult family members and friends. The total value of these services exceeds \$300 billion annually. The productivity loss to employers, however, is \$30 billion.
- Caregiving is difficult, demanding work, especially for those providing 20 hours of care a week or more and caregivers of persons with dementia.
- It is also very rewarding work with many emotional and spiritual benefits.

Long-Term Care Assistance (cont'd)

- The number of available caregivers, both paid and unpaid, will not keep up with the increasing number of people age 65+ and under age 65 (40%) in need of assistance.
- Families (kinship groups) are smaller and the caregiving labor force is rapidly falling behind the rising demand.
- Families are about half as large as they were 50/60 years ago. Most (80%) caregiving is now provided by family and friends.

Role of Family Caregivers

- Typically, caregivers are 46-year-old working women who spend 20 hours per week providing care to their 77-year-old mothers.
- Thirty-four percent of them care for their mothers, while 11% care for a grandmother and another 10% care for a father.
- Many older care recipients are widowed and more than half (53%) live alone.
- Nearly half of all caregivers say they provide eight hours or less of care per week, and one in five say they provide more than 40 hours of care per week.
- The average length of caregiving is 4.3 years.

Role of Family Caregivers (cont'd)

- Caregiving is a balancing act with competing priorities. Nearly 40% of family caregivers have children under age 18 at home, while six-in-ten caregivers work outside the home.
- Caregivers report that their most frequent unmet needs are:
 - finding time for themselves (35%)
 - managing emotional and physical stress (29%)
 - and balancing work and family responsibilities (29%)

Role of Family Caregivers (cont'd)

- The financial impact of caregiving on the caregivers is substantial, with the financial burden of caregiving averaging \$12,500 per year.
- Non-spousal caregivers spend about \$200 per month out-of-pocket on home modifications, medications, groceries and other expenses.
- Those who provide the most intensive caregiving spend significantly more—about \$324 per month.
- Over their lifetime, family caregivers who provide intense personal care, for several years lose about \$659,000 in lost wages, pensions, earned interest, employer matched retirement saving and Social Security benefits.

Role of Paid Home-Care Workers

- On average, wages for paid in-home workers are just \$8.50 an hour--\$1.50 less than the wages paid to a certified nursing assistant in a nursing home.
- Paid in-home workers rarely have access to health insurance and are not entitled to federal earned income tax credits. They often work several different jobs to make ends meet.
- Ninety-three percent of in-home workers are women, and since one-third have children under age 18, child care is frequently a concern.

Role of Paid Home-Care Workers (cont'd)

- As a result of poor wages, minimal training, poor supervision and few opportunities for advancement, vast numbers of direct-care workers leave their jobs within the first few months of employment.
- This high rate of turnover compromises care, which dependent on consistent, ongoing relationships. It also points to a looming crisis.
- Over the next decade, the demand for direct-care workers is going to grow enormously as our population ages and more people living with disabilities choose to live in the community.

Impairment Levels

- The declining IADL disability rate will not have much of an affect on the level of need for LTC over the next 20 years.
- ADL (more serious impairments) disability rates are not declining significantly and the older population is growing fast—from 36 million 65+ to 77 million by 2040.
- The percentage with dementia is increasing as the number of age 80+ grows faster than the 65+ groups as a whole.

Assistive Technology

- Some of the growing gap between the need for LTC help and available caregivers can be filled through improvements in greater access to assistive technology and better design features on products and housing.
- We need more public funding for AT research and for increasing access to available devices.
- Greater immigration could also play a role.

Growth in Labor Force

- To maintain the current ratio of LTC workers to the population age 85 or older, the number of LTC 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.
- The paid LTC workforce would need to grow, at a minimum, by more than 2% per year between 2000 and 2050. This rate of growth in the LTC labor force is possible; but during this time period, the working-age population is expected to increase only 0.3% per year.

Growth in Labor Force (cont'd)

- For LTC, retaining and attracting new workers will require real changes to overcome its current negative image. Changing the image of the work will require changing the culture surrounding the work environment and the nature of the work itself—this may mean changing duties, responsibilities and supervisory structure.
- Likely to necessitate substantial advances in labor-saving technologies and increases in wages
- Without fundamental changes in how care is organized and delivered, the LTC system of the future could be worse than it is today.

Wellspring Alliance Program

A model for changing the culture and work roles and responsibilities in LTC:

- 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 management to support their goals.

Wellspring Alliance Program (cont'd)

- 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 staff turnover.
- 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.

State and Federal Policies Related to Caregiving

- State/federal Medicaid waiver-funded home- and community-based services include **respite services**
- **The National Family Caregiver Support Program** (AOA--\$140 million annually) allows funding for vouchers to purchase services (HCE), a variety of respite arrangements and direct payments to family members to provide respite or personal care services.

State and Federal Policies (cont'd)

- A few states (**California's IHSS Program**) use state general revenue funds to pay spouses and other relatives to provide respite and personal care.
- **Cash and Counseling Demonstration Programs** in Arkansas, New Jersey and Florida since 2001 and now in six more states; based on German model of consumer-directed care (CDC) implemented in 1994.

State and Federal Policies (cont'd)

- Several states use **tax deductions and credits** to provide financial support to caregivers (federal tax policy is moving in this direction).
- **Family and medical leave** (federal and state policies)—California now requires paid leave for employees in firms with more than 50 employees.

State and Federal Policies (cont'd)

- Assisting and supporting in-home workers:
 - **Increasing access to health insurance** for home care workers—subsidies and access to public insurance programs.
 - Targeted **wage enhancements**.

Ethic of Care

- We also need a major change in the general culture and our hierarchy of values—caregiving needs to be more highly valued and an ethic of care is needed to resist the total domination of market values (profits and shareholder value), which has created distortion in the U.S. healthcare system and the larger society.
- The U.S. healthcare system is extremely expensive, but its outcomes in terms of morbidity/mortality rates, medical errors and access are not terribly impressive.
- Health care policy and practice must be shaped by more than corporate priorities—by a rejuvenated “ethic of care.”