

Family Caregivers: Blueprint for Action in Santa Clara County 2014

Who are Family Caregivers?

Family caregivers—unpaid relatives, partners and friends—are the backbone of the long term care system. Up to 80% of all assistance to older adults with chronic care conditions is provided by family members and friends even when there is paid help in the home. In Santa Clara County, there are over 306,000 family caregivers or about 1 in 5 households. The estimated annual economic value of unpaid care by families is over \$2.3 billion dollars for Santa Clara County (SCC) – more than all publicly funded long-term care services combined.

17% to 35% of family caregivers see their health as 'fair' to 'poor'

40% to 70% of caregivers have clinically significant symptoms of depression

adult children, caregiving is a juggling act between their own families, parents and work.

Over half of the current family caregivers in the county are adult children. Almost two-thirds are holding down full or part-time employment in addition to providing an average of 20 hours a week of assistance to an older adult – typically a parent(s). Caregiving is a long-term job with the majority of families providing care for 3 years or longer. For these mostly

Why are Family Caregivers Important?

Family caregivers provide services that would take a multidisciplinary team to accomplish. From coordinating care to performing healthcare tasks to organizing social activities, family caregivers assume these roles, often involving complex sets of instructions or activities, with little to no training or guidance.

Family caregivers are the largest long-term care work force in the county. While use of family caregivers appears to be free to health care professionals and policy makers, it comes with a cost: poorer health and mental health; less time for a primary caregiver to socially engage with immediate family and friends and lost productivity in the workplace. For employed caregivers who trim their hours or quit work to take care of a relative, the financial impact can be devastating: lost income, fewer Social Security credits, retirement savings deferred can mean a loss of up to \$300,000.

What Do Family Caregivers Provide?

- ✓ Medication management
- ✓ Care coordination
- ✓ Bill paying
- ✓ Wound care
- ✓ Medical equipment operations
- ✓ Health insurance advocate
- ✓ Incontinence management
- ✓ Health decisions assistance
- ✓ Food for special diets preparation
- ✓ Personal care
- ✓ Financial management
- ✓ Household tasks
- ✓ Transportation
- ✓ Emotional support
- ✓ Ostomy care
- ✓ Family member coordination
- ✓ Home test kits administration
- ✓ Social activities organizing

We need family and friends to assist older adults as they age in place, but shortages of family caregivers looms. Over half of family caregivers in Santa Clara County are adult children between the ages of 45-64, members of the baby boomer generation. Up until now, the numbers of family members in their peak caregiving years (45-64) have kept pace with those needing the most assistance – older adults over age 80. Currently there are 7 family caregivers to 1 older adult over 80 needing assistance. But due to shrinking family size and other societal factors, by the time baby boomers will likely need assistance in 2030, that ratio will drop to 4 to 1. In 2050 when 70% of all baby boomers will likely need assistance, the ratio drops further to 3 caregivers to 1 older adult over 80.

The Demographics of Santa Clara County Are Changing

In the fifties and sixties, communities retooled for the wave of children born after World War Two with building family communities with schools, parks, roads, recreation and library facilities. And now, those same demographics that dictate the next big wave of older adults means that communities once again need to retool for aging in place.

Santa Clara County is aging at the same rate as the rest of California: currently there are 280,000 individuals (15.7%) over the age of 65 in 2010. In 2030, that percentage is expected to rise to 25% or one in four residents. One of the fastest growing age groups are those over age 75 – with an anticipated 35% increase in the next decade – a group that has the highest risk for functional impairments that required assistance.

One of the most costly diseases to provide care for—Alzheimer’s disease and related dementias—is expected to almost double between 2015 and 2030, from 33,000 to 58,600 individuals in the county. Caring for an individual with Alzheimer’s disease or other cognitive impairment extracts an especially high financial and emotional cost on the families, with estimate of upwards of \$100,000 per year for services provided by formal and informal supports.

And like the rest of the state, the county is diverse in terms of ethnicity, identified LGBT community, unequal access to services due to geography and income disparity between the very wealthy and those with lower or stagnant wages employed largely in the service sector. While the aging network has acknowledged and has risen to meet some of those challenges, it is chronically under-resourced for the task and has suffered budget cuts in recent years.

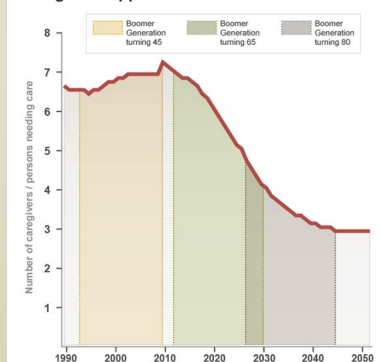
Family caregivers most at risk include those who live in areas with less services; are older spousal caregivers with their own health

Santa Clara County—like all counties across the country—are facing two colliding demographic challenges in the future: the dramatic rise in the number of older adults and the precipitous fall in the number of family caregivers.

You Take Care of Mom, But Who Will Take Care of You?

Family caregivers provide the majority of long-term services and supports (LTSS). But the supply of family caregivers is unlikely to keep pace with future demand. The Caregiver Support Ratio is defined as the number of potential family caregivers (mostly adult children) aged 45-64 for each person aged 80 and older—those most likely to need LTSS. The caregiver support ratio is used to estimate the availability of family caregivers during the next few decades.

Caregiver Support Ratio



In 2010, the caregiver support ratio was more than 7 potential caregivers for every person in the high-risk years of 80-plus.

In 2030, the ratio is projected to decline sharply to 4 to 1, and it is expected to further fall to less than 3 to 1 in 2050.

POLICY ACTION: Rising demand and shrinking families to provide LTSS call for new solutions to the financing and delivery of LTSS and family support.

Source: D. Friedboil, L. Feinberg, and A. Houser, The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers (Washington, D.C.: AARP Public Policy Institute, August 2013). www.aarp.org/research/policy

problems; are lower middle-income and don't qualify for MediCal HCBS but cannot afford to pay for services; are living with and caring for an adult with dementia or other cognitive impairment; or who are lacking English language skills to easily access services.

What Caregiver Support Services Are Available in Santa Clara County?

It is important to define caregiver support services as those interventions that directly related to the caregiver's own identified needs through assessment. Caregiver support services may include: caregiver assessment; care planning/consultation; counseling; family meetings; training on direct care skills and management of behaviors associated with cognitive impairments; benefits counseling; referral to service programs of benefit to caregivers and care recipients; information about chronic health conditions; caregiver self-care; legal and financial planning; respite; informal support organizing; support groups, and; technology assessment.

Publicly funded caregiver support services in the county are largely financed through the National Family Caregiver Support Program (Title III-E, Older Americans Act) at slightly over \$600,000 per year through allocations by the California Department of Aging. Administered by SourceWise, the Area Agency on Aging for the county, SourceWise and a small number of service providers provide more intensive services to approximately 500 family caregivers and information and education to an average of 4500 caregivers per year under Title III-E funding.

In addition to services provided with Title III-E funding, there are voluntary health organizations like the Alzheimer Association and the Parkinson's Association, numerous adult day programs, private care managers, home care agencies, churches, senior centers, hospitals and health centers who may provide some similar services (typically support groups and education programs). But while reporting on the numbers served by these entities is not required, it would be safe to state that a very small percentage—likely less than 10%—of family caregivers receive any formal support from the current network within any given year.

What Are Communities Doing to Prepare For The Next Age Wave?

Around the country, communities are leading the way in innovative programs and policies that ideas that promote age-friendly communities, fund needed services, support employed caregivers, change practice within healthcare to incorporate family caregivers and look to technology for new products and services to make caregiving easier.

First and foremost, any strategy related to aging in place must recognize the critical role of family caregivers and fully incorporate them as partners—and providers—in care.

Efforts have included creating a living laboratory for testing new services and technologies through the Institute for the Future in Sarasota Florida where 32% of its residents over age 65. Others focused on how neighborhoods can be service centers that build on formal and informal supports with the birth of the Village movement in Beacon Hill Massachusetts. Cities have come together for making age-friendly communities like the current effort just launched in Los Altos, as part of the global movement towards age-friendly cities.

In states like Ohio, the majority of counties (69 counties) have levied additional taxes to underwrite expanded senior services of more than \$140 million statewide in 2009. Added with other property tax dollars, local communities combined with the counties raise annually over \$166 million for services such as meals, transportation, respite, in home assistance and other supportive services. In 2009, 90% of the levies on the ballot passed by an average of 67% voting yes.

Other communities like San Francisco passed the [Family Friendly Workplace Ordinance \(2013\)](#) for employees who are caregivers or parents to request a predictable and flexible schedule and prohibit employment discrimination based on the employee's status as a caregiver or parent.

Paid sick days legislation has passed in cities such as Seattle, San Francisco, Portland, Washington DC, Jersey City and the state of Connecticut. Paid sick days allow employees to take a paid day for their own illness or that of a family member. Only half of all employees in the U.S. have paid sick leave.

While California took the lead in passing the first Paid Family Leave Act in the country, more marketing needs to be done so employed caregivers in the county are aware of its benefits. And nationally, some major businesses have banded together to form ReACT (Respect A Caregiver's Time) as a resource to the business community to investigate and promote best practices in workplace for employed caregivers.

Other metropolitan areas have invested in changing healthcare practice such as the Next Step in Care program. Developed by the United Hospital Fund and tested by 45 teams in hospitals, home care agencies, nursing home rehab facilities and hospice programs in New York City, Next Step in Care provides training and mentoring to health providers on including family caregivers in person and family centered transitional care.

Recently Rhode Island passed the Family Caregivers Support Act (2013) that requires a caregiver assessment that would identify problems the caregivers or care recipients might have and develop a plan to address those issues. This is required for all Medicaid funded long term services and supports in the state. On the state level in California, legislation was passed to develop a universal assessment instrument for home and community based services in 2012. The universal assessment instrument is now in development and expected to pilot test in 2015.

Another key trend in supporting family caregivers is the rapid development of products and services to improve care in the home. Many new developments are using technology to coordinate formal and informal supports, increase and improve compliance with health maintenance tasks for chronic disease management, increase social interactions for home-bound older adults and distance monitoring of older adults in their homes. Consumer products are also undergoing a remarkable change with ageless design, improved care products that are easier to use in the home and home design for maintaining independence.

Some local organizations such as Aging 2.0 in San Francisco and the Palo Alto Medical Foundation's David Druker Center for Health Systems Innovation are promoting development of innovations to improve the lives of older adults and their families. The translation of these innovations into the hands and daily routines of family caregivers is just starting. Education for both family caregivers and for the aging network on emerging products, how they effectively manage or solve caregiving problems and support for their use is only just beginning.

How Could Santa Clara County Increase Support For Family Caregivers?

1. Public funding is limited and its use must be both effective and efficient. The county should review current use of Title III E family caregiver support funds to ensure that interventions found most effective for promoting skill-building, decreasing stress and offering consumer choice for respite are targeted those most in need based on data from a caregiver assessment.
2. Community funders should provide resources so service providers can coordinate education and training programs to ensure that a range of model skill building and educational programs are offered across the county and to the diverse communities within the county. Some additional training would most likely be required for providers to teach skill-building classes and for materials. Information about training programs should be centralized on an online calendar that provides easy access for families to locate training locally and throughout the Bay Area region.
3. Policy makers at the county and local community level should increase resources or repurpose existing funds for targeted family caregiver services. Targeted funding should meet outcome objectives for improving skills, decreasing stress and promote choice in respite options based on evidence-based and models programs that include:
 - universal caregiver assessment and action plans to target limited resources to those most at risk and to establish outcomes for services;
 - short term groups to decrease caregiver stress and anxiety using vetted models;
 - skill-building classes for caregivers in direct care, decision making and management of difficult behaviors using vetted models;
 - providing respite that honors family choice and direction
4. The County Board of Supervisors should initiate a countywide plan for excellence in supporting family caregivers, similar to efforts in San Francisco and in the multiple states that created state plans for Alzheimer's disease. Family caregivers cut across all chronic care conditions and should have an integrated approach to support across county departments and services.
5. The County Board of Supervisors should create, with the support of community funders, a Blue-Ribbon Panel of leaders from business, services, researchers and consumers to examine the challenges and best practices to support employed caregivers and make recommendations for actions that would enable family caregivers to remain in the workforce.
6. City and county policy makers should pass ordinances that promote workplace flexibility, provide protection from discrimination for family caregivers and provide paid sick days for employees.
7. All planning efforts and responses to federal, state and private initiatives in long-term services and supports by the county should include family caregivers in a formalized process within the service design.

What is the Cost Benefit of Investing in Family Caregiver Supports and Services?

Changes in health care policy point to incentives that reward keeping older adults in the community, in their home, engaged and active for as long as possible. It is also the overwhelming preference of all adults to age in place. For those older adults with chronic conditions that limit function, reimbursement incentives drive identification and care management of high-risk older adult in their homes. The desired outcome for health care is to invest in better care management in order to prevent more costly care: trips to the emergency room or hospital, use of Medicaid waiver home and community based services or placement in a nursing home.

Partnering with family caregivers and investing in assessment, care planning, skills training and interventions to decrease stress, strengthen and extend the abilities of family caregivers. Data-driven programs that utilize best practices in combination with specific interventions have begun to bend the cost curve in preventing usage of more costly public services. In Washington State, use of an in-depth caregiver assessment and consultation process has “resulted in a statistically significant delay in the use of Medicaid LTC services.” (Family Caregiver Support Program: A Report on the FY 2012 Expansion, Aging and Disability Services Administration, State of Washington, January 2012)

But even with better health care management, the silent assumption is made that there will be family caregivers willing and able to assist or provide care at home and to step in when needed for managing other life tasks for the older adult.

Summary

While the county is known for youthful innovation, the truth is that Santa Clara County is aging at the same rate as the rest of California. The last 20 years have been marked by growth in the middle-aged adult population and children. The next 20 years the growth is projected for the senior population and young adults.

Now and in the future, the main providers of assistance to an older adult will continue to be family and friends . . . so now is the time to invest in the services that have shown evidence to both improve the well-being for family caregivers and for whom they care, but also to delay the movement into more costly public services. Services need to be expanded but they also need to be data driven with clear outcomes, target families most at risk and follow through with vetted models for interventions.

Half of family caregivers are in the workforce and the county needs to champion caregiver-friendly workplaces. Santa Clara should be a leader in high quality family caregiver services and workplace flexibility for employed caregivers. And finally, the county as the world leader in technology innovation should also lead in making sure that family caregivers are incorporated into the translation of new technologies and community developments Adding these components will ensure that the county will be an attractive, family-friendly place to live and work at any age.

About This Paper

This paper was commissioned by the Health Trust of Silicon Valley to Family Caregiver Alliance, National Center on Caregiving, in San Francisco. In preparation, literature review was conducted on research and evaluation of caregiver interventions, scaled use of caregiver assessment and services in other states, focus group and key informant interviews with service providers in Santa Clara County, review of local and state funding strategies for services for older adults and background study of leadership issues within the county network of aging services.

Family Caregiver Alliance was founded in 1977 *to improve the quality of life for family caregivers through services, education, research and public policy.* FCA provides direct services to family caregivers of cognitively impaired adults with Alzheimer's, Parkinson's and related dementia and other chronic care conditions. FCA established the National Center on Caregiving to advance the development of high-quality, cost effective policies and programs for caregivers in every state in the country. It serves as a central resource on caregiving and long term care issues for policy makers, service providers, media and family caregivers throughout the country.

