Maintaining independence of seniors and those with disabilities through unpaid caregivers and informal supports

Mobilization Plan for Self-Reliance and Independence Community Solutions Team

United Way of Dane County
October, 2006

I. Problem Statement

The population of seniors in Dane County has grown over the past ten years and will grow at an even faster rate over the next 10 years. And, the life expectancy of people with disabilities continues to increase. Our community is faced with a rapidly growing problem: how can we continue to help seniors and people with disabilities stay in their homes without available resources growing at the same rate?

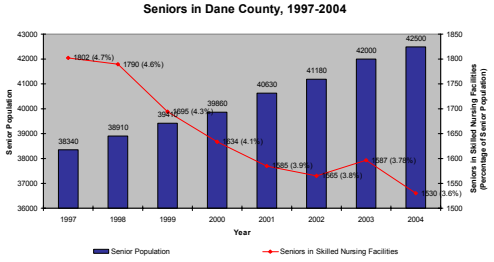
The United Way of Dane County is committed to helping seniors and those who are disabled remain as independent as they choose, as expressed in its Agenda for Change: "Seniors and people with disabilities are able to stay in their own homes."

Over the past two decades public policy has minimized the number of nursing home beds while providing financial support to allow more individuals to stay in the community. Over time, the resources for community-based care have increased substantially, but have not kept pace with demographic changes. While local home health agencies have experienced an increase of 66% in their patients, the number of family and unpaid caregivers is increasing, and their role is as important to the quality of life of seniors and people with disabilities as it has ever been.

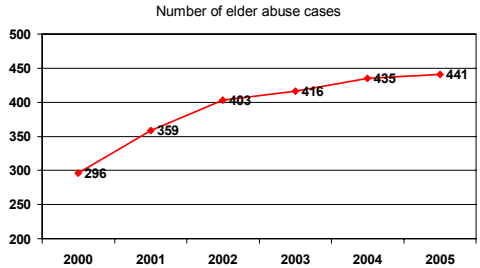
In the face of increasing numbers and a changing economy, the Self-Reliance and Independence Community Solutions Team sees a solution in the support of family/unpaid caregivers—helping them to find existing resources, build their knowledge and competence in the caregiving role, and provide support.

Measures

3.6% of seniors now in skilled nursing facilities



Elder abuse in Dane County grows 50% over 6 years



Why it matters

1. The elderly and persons with enduring mental health or physical disabilities live longer and happier lives if they are able to live in the home of their choice. The broad culture honors and respects the wishes of seniors and those with disabilities to live as independently as possible. (The annual cost of institutionalization is $53,600).
2. The growth in the number of seniors is outpacing the capacity of private and tax-supported institutional care. Significant growth in the senior population is anticipated as the baby-boomers age.
3. 38% of seniors need help to remain independent; 80% of the in-home care is provided by family/unpaid caregivers.
4. We estimate 42,000 unpaid caregivers in Dane County. We also recognize there may be more who are trying to care for loved ones long distance. Caregivers are also aging—49% of people in their sixties are caring for a parent--as their parents live longer and those with disabilities live longer.
5. Helping seniors and those with disabilities raises many situational and individual issues. How the caregiver and loved one resolve these issues depends on myriad factors: health, emotions, the number and quality of circles of support, nutrition, relationships between family members, lack of family, cultural norms, financial resources, and personalities.
6. Caregivers are typically unskilled and unaware of services available to them. They may not know how to provide care until they are abruptly faced with a family member in need of care. Then they are suddenly in need of information and guidance.
7. Unpaid caregivers are helping both seniors and those with disabilities--both are our target populations.
8. Stress in caregivers increases stress in whole families, and can create unhealthy family relationships. Evidence suggests support for caregivers creates healthier relationships, and reduces isolation for both the caregiver and the loved one.

Background–articulation of the problem

National research

The National Family Caregivers Association (NFCA) has done extensive research on this topic and estimates that there are more than 50 million people in the United States who provide care for a chronically ill, disabled, or aging family member or friend each year. The average length of time a person acts as a caregiver is 8 years. [1]

Population of caregivers

- 21% of the US adult population provides unpaid care to an adult family member or friend. They report poorer health than the general population and experience a downward spiral of health which deteriorates in relation to the amount of time they spend caregiving and the intensity of the caregiving. [2]

- Caregiving is no longer predominantly a women's issue. Men now make up 44% of the caregiving population. Caregivers providing care for a family member over the age of

[1] This information from the National Family Caregivers Association was compiled from a wide variety of resources.
[2] "Caregiving in the U.S.", National Alliance for Caregiving, , July 2006

50 routinely underestimate the length of time they will spend as caregivers—only 46% expect to be caregivers longer than two years.[3]

- Most women will spend 17 years caring for children and 18 years helping an elderly parent.[4]

- 30% of family caregivers caring for seniors are themselves aged 65 or over; 15% are between the ages of 45-54.[5]

- 44 million people are providing unpaid care to a loved one or friend with cancer, sometimes around the clock.[6]

Economics

- Family/unpaid caregivers cover up to 80% of the in-home care provided in the United States. The value of the services family caregivers provide for "free" is estimated to be $306 billion year; twice as much as is actually spent on homecare and nursing home services combined ($158 billion).[7]

- Caregiving families tend to have lower incomes than non-care giving families. 43% of Caregiving families have household incomes under $30,000. [8]

Impact of Caregiving

- Elderly spousal caregivers with a history of chronic illness themselves and experiencing stress have a 63% higher mortality rate than their non-caregiving peers. [9]

- Family caregivers experiencing extreme stress have been shown to age prematurely. This stress can take as much as 10 years off a caregiver's life.[10]

- The stress of family Caregiving for a person with dementia has been shown to have an adverse effect on a person's immune system for up to three years after their Caregiving ends thus increasing their chances of developing a chronic illness themselves.[11]

- Family caregivers who provide care 36 or more hours weekly are more likely to experience symptoms of depression or anxiety. For spouses the rate is six times higher; for those caring for a parent, the rate is twice as high.[12]

- 72% of caregivers said they had not gone to the doctor for themselves as often as they should—caregivers often miss their own routine appointments, eat poorly, and can't sleep.[13]

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3 NFCA Survey 2000 and Met Life Mature Market Institute, 1999
4 101 Facts on the Status of Working Women
[5] US Department of Health and Human Services, 2001.
[6] National Foundation for Cancer Research
[7] Peter S. Arno, "Economic Value of Informal Caregiving," 2002
[8] NFCA Survey, 2000
[9] Journal of the American Medical Association, December, 1999.
[10] Peter S. Arno, "Economic Value of Informal Caregiving, 20006.
[11] Proceedings of the National Academy of Sciences, June 2003.
[12] American Journal of Public Health, 2002.
[13] National Alliance for Caregiving, July 2006

Caregiving and Work

- American businesses loses as much as $34 billion each year as a result of their employees' need to care for loved ones 50 years of age and older.[14] 62% of businesses have to make workplace accommodations. This is particularly difficult for those who are in hourly wage jobs, where caregivers have to balance taking care of a loved one with the loss of family income.

- Family caregivers comprise 13% of the workforce.[15]

- Both male and female children of aging parents make changes at work in order to accommodate caregiving responsibilities. Both have modified their schedules, come in late and/or leave early; and altered their work-related travel.[16]

- In 2000, a typical working family caregiver lost $109 per day in wages and health benefits because of the need to provide care at home.[17]

- Women caregivers average 11.5 years out of the paid labor force; men average 1.3 years.[18]

Caregiving and Healthcare

- Family caregivers provide 80% of homecare services.[19]

- In 2000, 50% of caregivers reported that different providers gave different diagnoses for the same set of symptoms and 62 % reported that different providers gave other conflicting information. 44% of physicians believe that poor care coordination leads to unnecessary hospitalization, and 24% says it can lead to unnecessary nursing home stays.[20]

- Family caregivers who acknowledge their role are more proactive in reaching out for resources and talking with their loved one's doctor than non-acknowledged caregivers.[21]

- Over 40% of family caregivers provide some type of nursing care for their loved ones, such as giving medications, changing bandages, managing machinery, and monitoring vital signs.[22]

- One-third of family caregivers who change dressings and manage machines receive no instructions.[23]

- Caregiving for a disabled or ill spouse for 9+ hours per week increased the risk of coronary heart disease for women in a study of 54,412 women.[24]

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[14] Met Life study. 2006.
[15] Administration on Aging, DHHS, 2002
[16] Met Life Mature Market Institute, June, 2003.
[17] American Council of Life Insurers, March, 2000.
[18] 101 Facts on the Status of Working Women.
[19] US Agency for Healthcare Research and Quality, November, 2000.
[20] Johns Hopkins University, December, 2002
[21] NFCA Survey, 2001.
[22] NFCA Survey, 2000, and United Hospital Fund, 1998.
[23] Henry J. Kaiser Family Foundation Wide Circle of Caregiving, 1998.

- Caregivers of the disabled are often poorly trained and at risk of injury for both themselves and their loved ones. 40% of caregivers of those who are disabled injured themselves while lifting and handling their dependents. 20% of the patients were injured, too.[25]

Local research

- The number of caregivers in Wisconsin is estimated at 520,561, providing 558 million hours of caregiving, with an annual market value of $4,913,000. [26]

- According to DHHS, family caregivers comprise 13% of the workforce—this translates to 36,000 family caregivers in Dane County.

- According to National Alliance on Caregiving, 96,000 adults in Dane County are caregiving (21%).

- Dane County has 7 home health agencies providing community-based care that served 3,160 patients in 1995. In 2004 these same agencies served 5,261 patients--a 66% increase. During the same period, nursing home beds decreased to 1,899 (from 2,384) and the occupancy rate decreased from 91.5% to 87.3%.[27]

- Key findings from the Taskforce on the Aging in Dane County[28] on caregiving included
  - Most caregivers don't realize that caregiving is a job
  - Residents of Dane County need to "wake up and realize the scope of this problem"
  - Health care professionals often don't realize the importance of the existence of the family caregiver
  - The taskforce recommended employers offer paid time off for caregivers to attend educational programs, increase their skills, and receive needed support.

[24] Lee, Colditz, Berkman and Kowachi, American Journal of Preventive Medicine, 2003, vol. 24.
[25] Brown, Mulley, Department of Medicine, St. James University Hospital, Leeds, UK.
[26] NFCA statistics developed in conjunction with Peter S. Arno, Dept. of Epidemiology and Population Health, Montefiore Medical Center and Albert Einstein College of Medicine.
[27] WI Dept. of Public Health, 1995 and 2004
[28] Task Force on the Aging of Dane County, November, 2004

II. National Research—Best Practices

A. Caregiver Education and Support Programs[29]

"A growing body of evidence indicates that caregiver education and support programs can delay nursing home placement and reduce the health care costs of care recipients. Therefore, although caregiving can be stressful, its effects can be mitigated at least partially by participating in education and support programs."

Highlights

1. To accommodate caregivers' needs and schedules, offer a range of caregiver education and support programs to be available in any community.
2. Training should be targeted to specific groups
    a. Caregivers for persons with particular health problems who need specialized information.
    b. Caregivers who might otherwise not participate in a general education program.
    c. Caregivers for those with severe disabilities who need information delivered to them by teleconferencing, the internet, or in-person. Caregivers of persons with milder disabilities will avail themselves of community-based programs, and welcome the opportunity to socialize and have a respite.
    d. Adult children of persons needing care, who have different needs from spouses of such persons, particularly in psychological and emotional issues.
    e. Same-gender groups, which can encourage richer and franker discussion.
    f. Persons of different racial and ethnic backgrounds, whose caregiving is affected by their own cultural norms—besides language and translation, cultural norms affect the pace and timing of interventions. Also on most health status indicators, African American and Latino elderly are less healthy than white elderly.
3. After recruitment of participants to training programs, it is important to screen potential participants—to identify individuals who might not be appropriate participants and refer them to alternative sources.
4. Monitor program implementation—evidence suggests even seasoned clinicians can benefit from supervision and evaluation. Program evaluation should be routine. The choice of outcome measures should be guided by the goals of the program.
5. Caregivers should be training in safe lifting and handling of those who are disabled.
6. Provision of respite on-site during caregiver training is more successful in encouraging caregivers to participate in training than providing respite at home.

B. In gaining access to services[30]

1. Information to caregivers about available services, assistance in gaining access to these services, and directly linking clients to services increases the utilization of services and has a positive impact on caregivers.
2. Increasing the caregiver's knowledge of available services, the recipient's disease, and caregiver challenges and solutions—however, information-only services have not shown evidence of positive mental or physical health-related outcomes.

[29] Family Caregiver Alliance, National Center on Caregiving
[30] Center for Advanced Study of Aging Services, University of California at Berkeley, American Society on Aging Conference 2002

3. Respite care—both day care and in-home respite--enables caregivers to be temporarily relieved from their caregiving responsibilities, and decreases the negative effects of caregiving. Respite care on-site during training programs increases the likelihood that caregivers will participate in programming.
4. Supplemental services, to complement the care provided by caregivers include
    a. Home modification and adaptive equipment
    b. Assistive devices
    c. Chores/personal care
    d. Medication management
    e. Home delivered meals
    f. Legal assistance
5. Individual counseling, organization of support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their caregiving roles.
6. Support groups have shown to be helpful by providing knowledge and enhancing informal support networks, but less evidence of their effectiveness in improving caregiver mental and physical health or ability to manage their caregiving situation.
7. Multi-component counseling programs improved feelings of competence, increased knowledge of community services and how to access them, and lowered rates of depression

C. Proactively engaging physicians[31]

Programs that link physicians to their patients' caregivers were highly effective in increasing the quality of life for the recipient, caregiver, and ultimately decreased extra work for the physicians' offices. Caregivers were included in the physician care and consultation of loved ones. Physicians proactively asked if their patients were caregivers of others.

III. Data Review

Our community engagement

In a survey in spring, 2006, of United Way of Dane County donors partner agencies, service recipients and interested community members, 818 people responded, and the highlights of our findings include (complete survey results are on Attachment B):

a. Addressing the emotional and mental health needs of their loved ones, and determining when and how to seek out alternative living arrangements were most needed.
b. The services most needed were
    - Accessing the professional trained and paid caregivers, resources, volunteers, and opportunities for social interaction
    - Adult day care so family/unpaid caregivers are able to maintain their jobs
    - Respite care to allow caregivers a break

In a participative exercise in summer, 2006, involving 318 Key Club donors at 13 major companies in Dane County, participants ranked these strategies as most important for independence of seniors and those with disabilities:

[31] National Association of Area Agencies on Aging, September 2004

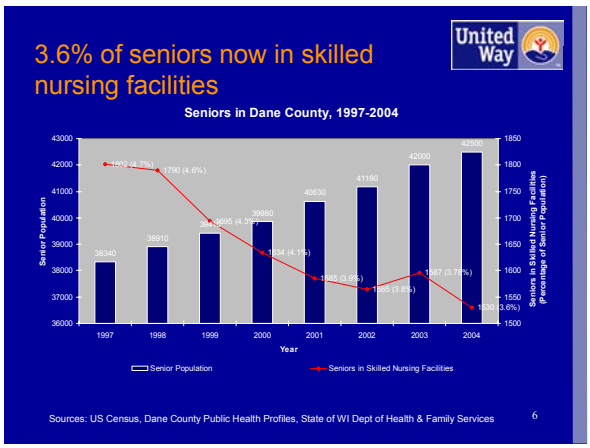
1. Adult day care so family/unpaid caregivers are able to maintain their jobs.
2. Training on the emotional and mental health needs of those in their care
3. Training to help family/unpaid caregivers learn when and how to seek out alternative living arrangements
4. Information and referral about community resources, volunteers, and opportunities for social interaction.

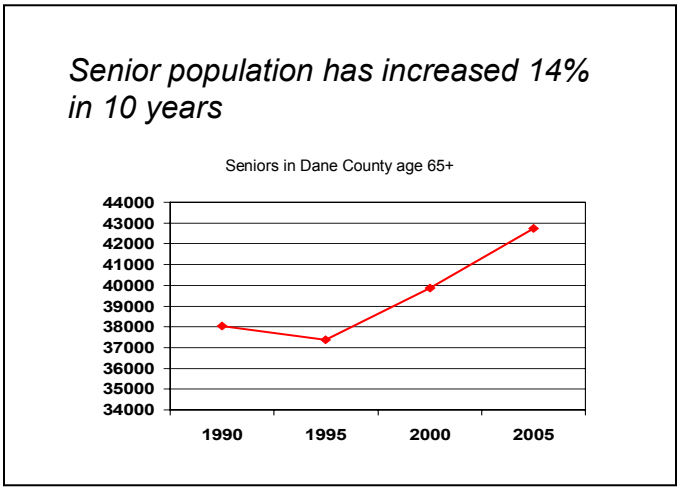
The Labor Community also conducted community engagement on Labor Day, 2006, and ranked their priorities as

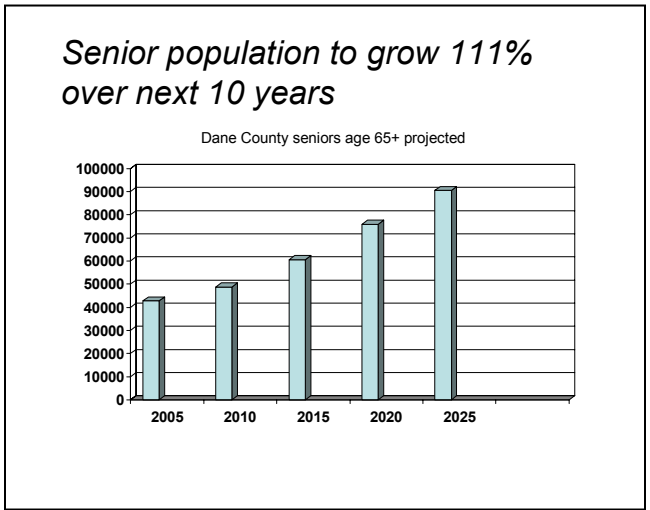
1. Adult day care so family/unpaid caregivers are able to maintain their jobs
2. Information and referral about community resources
3. Respite care to allow family/unpaid caregivers a break

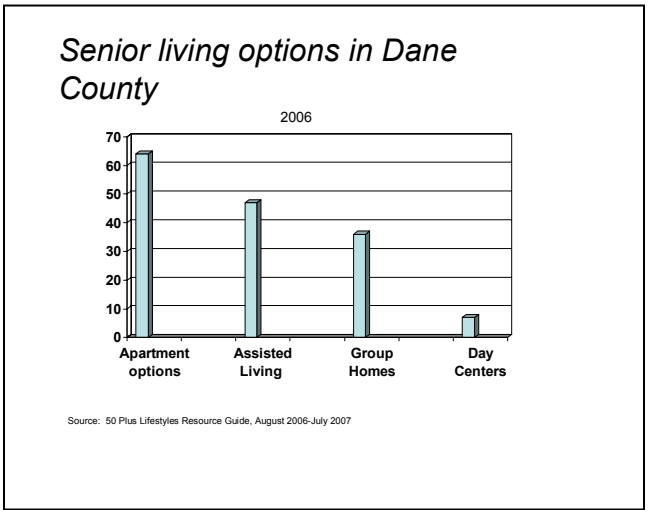
Our 2005 focus groups with people of color produced Impact Reports for the Latino, African American, Southeast Asian, and Native American communities. In summary, we learned that for these groups, institutionalization of elders is rarely, if ever, considered an option because of cultural deference and respect these communities pay to their elders and the responsibility and accountability of the family for their elders, religious influences, and finances.

United Way 2-1-1 (the non-emergency phone number to get help and give help) is not seen as an information and referral resource for those seeking help with seniors or people with disabilities. Of the 60,000 calls received this year through August in 2006, only 139 sought help with senior issues, and only 1 call requested help with a disability.







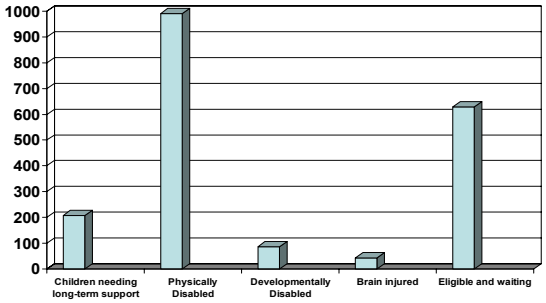


*Paid Caregivers in South Central Wisconsin**

Total paid caregivers	11,018
Share of total workforce	2.4%
Median wage	
Nursing Aides, Orderlies, and Attendants	$8.91
Home Health Aides	$7.95
Personal and Home Care Aides	$7.22
Number of Nursing Homes	55

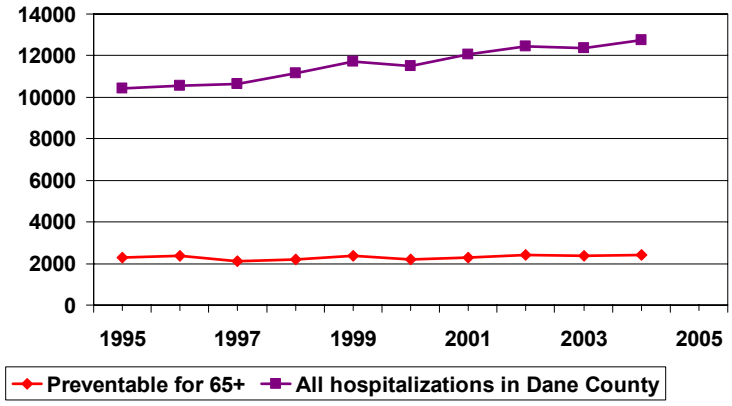
Source: Center on Wisconsin Strategy, 2001 data, includes Columbia, Dane, Dodge, Jefferson, Marquette, and Sauk Counties

2283 people with disabilities receiving medical assistance, another 628 eligible and waiting



Source: Dane County Human Services, 2004

Preventable hospitalizations for seniors averages 2000+ annually



Dane County Public Health data

IV. Hypothesis

Increased support to family/unpaid caregivers will increase the community's capacity to provide care to seniors and people with disabilities, allowing these groups to stay in their homes longer, lessening the strain on the community of the aging population.

Our goal: Maintain 96% of seniors in the community, in the homes of their choice.

Special note:

1. We recognize that nursing home care may be the most appropriate and desirable place for someone, short-or long-term.
2. While our goal measures seniors in the community, we have chosen to focus on family/unpaid caregivers because we know a substantial number are caring for those with disabilities, some of whom receive a medical assistance to help them remain in the community.

V. Strategies and Resources

Family and other unpaid caregivers receive adequate information, respite and other supports to enable them to continue in their caregiving role.

Over the next 5 years, United Way of Dane County will focus on these strategies for unpaid/family caregivers:

1. Increase the availability of "just-in-time" training; insure that training addresses the practical needs, as well as emotional and mental health of both loved one and caregiver.
2. Increase respite programs for the family/unpaid caregivers, including adult day care.
3. Encourage programming that provides emotional support for caregivers and reduces the caregiver's social isolation.
4. Increase information and referrals through United Way's 2-1-1 database. Market United Way 2-1-1 as a way to get information on caregiving issues and obtain referrals for more specific questions.
5. Help caregivers access professional caregivers and supplemental services through referrals and subsidies.

VI. Results and Measures

Strategy	*Time frame--begins*	*Anticipated results*
1. Increase the availability of training for caregivers	1st quarter, 2007	Monthly training for caregivers available
2. Increasing information and referrals through United Way 2-1-1.	1st quarter, 2007	Increase calls related to needs of seniors and those with disabilities to 10% of total calls. (Approximately 8,000) by 2012.
3. Increase respite programs, including adult day care	1st qtr. 2008	Respite care available for 10% of population
4. Programming to provide emotional support for caregivers, reducing their social isolation	1st qtr. 2009	On-going programming available for all demographics: spousal caregivers, children of seniors, parents of those with disabilities, Latino, African-American, Southeast Asian, LGBT. Reduce elder abuse by 30% by 2012.
5. Link caregivers to professionally trained /paid caregivers through referrals and subsidies.	1st qtr. 2010	Create sustainable subsidies for low-income population to access paid/professional caregivers.

Results of Caregiver Survey

Seniors and people with disabilities are able to stay in their homes.

In Dane County, there are over 42,000 unpaid caregivers[32], usually family members, providing care to seniors and people with disabilities and helping them stay in their homes. United Way of Dane County, in partnership with the Area Agency on Aging's Caregiver Alliance, turned to our community for help prioritizing ways to support caregivers in their important roles.

From mid-April to mid-May, 2006, we conducted an online survey and invited donors, partner agencies, service recipients and interested community members to share their perspectives. Our request was met with an overwhelming response from 818 people and provided United Way with new information to strengthen support to Dane County's caregivers. By helping caregivers provide assistance to seniors and people with disabilities in Dane County, we are advancing the Agenda for Change by creating lasting solutions for individuals at risk of losing their independence.

We asked three main questions about ways to support caregivers.

1. Training is valuable for family/unpaid caregivers to be the most effective in caring for their loved ones

The training topics our survey participants found most needed were:

- 21.7% - Emotional and mental health needs of the people they are caring for
- 21.7% - When and how to seek out alternate living arrangements (such as senior housing, assisted living, etc.)
- 18.0% - Taking care of their own emotional and physical needs as caregivers
- 15.5% - Financial and legal planning, including day-to-day money management
- 13.7% - Managing medications and medical appointments
- 7.8% - Personal care and hygiene
- 1.6% - Other

2. Services also support family/unpaid caregivers in their efforts.

The services our survey participants found most important were:

- 24.9% - Information and referral about available community resources, volunteers, and opportunities for social interaction.
- 23.9% - Adult day care so family/unpaid caregivers are able to maintain their jobs
- 22.4% - Respite care to allow family/unpaid caregivers a break
- 16.6% - Clearinghouse of information to access paid professionals who can provide in-home services that require special skills (like giving shots)
- 7.3% - Peer support groups for family/unpaid caregivers to talk with others in similar situations
- 3.5% - Outreach to employers to help them understand issues family/unpaid caregivers face

[32] National Family Caregiver Association, 2003, estimate made with Census data

- 1.3% - Other

3. Paid/professional caregivers (such as people who work for respite services and in-home health professionals) also play key roles in helping seniors and people with disabilities remain independent.

The issues related to paid/professional caregivers that our survey participants found most important were:

- 36.8% - Ensuring that all paid/professional caregivers are appropriately/adequately trained
- 29.4% - Providing subsidies so family/unpaid caregivers can afford to utilize the services of paid/professional caregivers
- 25.7% - Increasing the pool of trained paid/professional caregivers
- 6.6% - Conducting employee recruitment in communities of color to increase the number of culturally-competent paid/professional caregivers
- 1.5% - Increasing the number of paid/professional caregivers able to provide specific services

We also asked for additional thoughts and comments. The community responded:

- For a middle-aged person with elderly relatives, this is one of the scariest personal issues, because of finances and tough decisions. The issue crosses geographical boundaries where adult children or other family members do not live near the person needing care.
- … I think that a great focus should be placed on help for unpaid or family caregivers. Many of them start out as a caregiver thinking it will be a short-term solution, or not very difficult, and have sadly underestimated the commitment of themselves emotionally. The best caregiver is one who can also take time for, and care for, themselves.
- This is becoming increasingly important as our population ages. I have been in the situation where I chose to place my mother in very expensive assisted living quarters because I had no way of providing the care she needed to stay at home.
- How can we make caregiver work “desirable”? How can we ensure good training and a decent wage? How can we prioritize having people with a sensitive and caring nature consider this work?

To better understand the survey results, we asked 5 demographic questions.

1. How are you connected to the issue of caregivers?

- 50.1% - I am an interested/concerned community member
- 32.7% - I am (or was in the past) a family/unpaid caregiver or paid/professional caregiver or I am (or have been) a recipient of caregiver services
- 9.8% - Other
- 7.3% - I am employed for a community non-profit (but not as a paid/professional caregiver)

2. How did you hear about this survey?

- 70.5% - I was invited by an email to Rosenberry Society, Key Club or Alexis de Tocqueville Society
- 11.1% - I was invited by an email to United Way volunteers
- 7.5% - I was invited at the Caregiver Luncheon or a Caregiver Support Group Meeting

- 6.5% - I was invited by an email to staff and volunteers of nonprofit organizations
- 3.1% - Other
- 0.9% - I saw a link on United Way of Dane County's website (www.unitedwaydanecounty.org)
- 0.4% - I was invited as a service recipient of a non-profit organization

3. Gender:

- 56.2% - Female
- 42.0% - Male
- 1.8% - Preferred not to answer

4. Age:

- 59.2% - Age 35-54
- 22.9% - Age 55-64
- 11.1% - Age 18-34
- 6.0% - Age 65+
- 0.8% - Preferred not to answer
- 0% - Under age 18

5. ZIP Code:

- 52.1% - Madison ZIP codes
- 7.1% - Sun Prairie (53590)
- 6.5% - Verona (53593)
- 6.2% - Middleton (53562)
- 3.7% - Oregon (53575)
- 3.2% - Waunakee (53597)
- 2.2% - McFarland (53558)
- 1.9% - Stoughton (53589)
- 1.8% - DeForest (53532)
- 1.6% - Cottage Grove (53527)

13.7% - Other area ZIP code