

## The Caregiver: A Growing Role in America

As the American population continues to age and life expectancy increases, the need for family caregivers is increasing. This paper takes a closer look at specific examples of caregiving and the tremendous opportunities to provide much needed support to this growing population. Benefit advisors, in particular, can bring a fresh perspective to employers who are looking for programs and resources to support caregiving employees.

A family caregiver is typically someone who is responsible for the daily needs of another person. Daily needs can be physical and emotional. They also often include financial support for persons unable to care for themselves due to illness, injury or disability.

A 2009 study conducted jointly by The National Alliance for Caregiving and AARP found that over 65 million people in the United States were serving as unpaid family caregivers to an adult family member, a child with special needs or a friend. If they haven't already done so, employers would be well advised to take notice of this growing trend. Given the numbers, it is likely many workers are devoting time to caregiving responsibilities. The pressures felt by this group of working caregivers could be showing up as stress related illnesses, higher utilization of health care, decreased productivity, higher absences, and a feeling of helplessness – not knowing where to turn.

#### **Group Insurance**

January 2013

#### **Case Study**

See Page 7 to learn about Kimberly-Clark's Family Caregivers Network.

Caregiving also can have a dramatic impact on employee retention. According to the National Center for Caregiving, in any given year 18 to 23 percent of caregivers cut back their work hours or leave the workforce altogether to provide care full-time.

#### **Feeding the Sandwich Generation**

There is a new and growing generation of employees to consider when developing and promoting benefits programs and resources. The Sandwich Generation, typically those working adults ranging in age from 40-60 years old, is struggling to juggle the needs and care of both their children and aging parents.

This trend is only expected to increase as the Sandwich Generation's parents continue to age. In addition, the needs of the generation's children are not just confined to those under the age of 18. More and more adult children are now returning home due to the economic downturn and poor job prospects once out of college.

The National Alliance for Caregiving was established in 1996 to focus on the growing issues of family caregiving. Together with ReACT, a coalition of corporations and organizations dedicated to addressing these challenges at the employer and employee level, the Alliance released results of a study on Best Practices in Workplace Eldercare.

Employer representatives were asked which programs they would like to provide if budgets and resources were not an issue. Respondents offered the following:

- Increase the number of subsidized days of home care
- Provide more paid days off
- Provide assistance on long-term care decisions
- Expand seminar programs and caregiving topics
- Start a geriatric care management program
- · Provide more paid hours of time for caregivers to support each other

While adding all of these options may seem a lofty goal given today's economy, there are existing options for employers and brokers to explore together. Group or voluntary life insurance benefits and Employee Assistance Programs are excellent programs that can start to fill the gap.

#### The importance of life insurance

As a senior partner with North Star Resource Group, Minneapolis, Joe Fox works hard to educate his clients on the importance of life insurance and making sure families are protected. He offers employers tips for educating the Sandwich Generation.

A typical life insurance conversation revolves around how much coverage an employee should have in place. "Today, that's not good enough," states Fox. "Asking employees to consider what they want

- Nearly one in four families provide some form of caregiving
- Caregiving reduces work productivity by 18.5 percent
- This lost productivity costs employers \$30-50 billion per year

Caring for the Caregiver, TIAA CREFF, 2012.

for themselves and their families is more appropriate," he explains. With help from carriers, employers can quantify and qualify the value of life insurance to employees so they can, in turn, share the information with their families.

Without family life insurance planning, the Sandwich Generation could be on the line for the care of their grandchildren and their parents. And, it is not likely they have prepared for such responsibility.

"Employer-provided life insurance benefits can take the burden off this generation," says Fox. He also recommends employers consider offering voluntary life insurance benefits that employees can purchase for family members – or opening the benefits up for purchase by family members.

#### Addressing the stress of caregiving

Stress levels of the Sandwich Generation are on the rise. MHN, a San Rafael, CA firm offering Employee Assistance Programs (EAP) and behavioral health services, is seeing an increase in calls from employees who are trying to balance caregiving responsibilities and are looking for guidance.

"We are seeing more and more people with young children at home also caring for their parents," says Lisa Lydon, Supervisor, Clinical Services, Direct Care Services for MHN. "This generation is also dealing with feelings of guilt often associated with not knowing how to balance taking care of themselves, the kids and the parents (or grandparents) all at the same time."

"They are stressed out and overwhelmed, don't know what to do, and are looking for help in the moment. We are there to provide resources and let them know that what they are feeling is completely normal," says Lydon.

MHN can assist early in the decision-making process by helping employees consider how three generations living under one roof will impact the family dynamic and identifying what direct care services, as well as resources within the community, are available. For example, when an employee needs help getting a parent to a doctor appointment during the day, MHN can share how to find transportation resources – and provide support in developing an action plan. This collaborative approach helps employees stay at work, remain productive, and feel more in control of the situation.

Lydon's team also helps employees navigate health plan offerings. "Caregiving comes in many forms and employees often don't realize the support health plans offer," explains Lydon. Self-care is another concern for caregivers. MHN refers them to support groups in the community so they have a place to turn when they need relief or encouragement.

Ten tips for family caregivers:

- 1. Choose to take charge of your life, and don't let your loved one's illness or disability always take center stage.
- 2. Remember to be good to yourself. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
- 3. Watch out for signs of depression, and don't delay in getting professional help when you need it.
- 4. When people offer to help, accept the offer and suggest specific things that they can do.
- 5. Educate yourself about your loved one's condition. Information is empowering.
- 6. There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.
- 7. Trust your instincts. Most of the time they'll lead you in the right direction.
- 8. Grieve for your losses, and then allow yourself to dream new dreams.
- 9. Stand up for your rights as a caregiver and a citizen.
- 10. Seek support from other caregivers. There is great strength in knowing you are not alone.

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EAP providers such as MHN can help employees deal with life stress and change, but employers need to let them know the resource is available. Typically EAPs are underutilized. Employers that spend time considering how existing programs and resources can offer support to the generation trying to balance the needs of children and parents will benefit in the long run by helping these employees remain healthy, at work and productive.

As Lydon points out, "We can help employees find ways to cope and reframe their home and family situation from a negative to a positive."

#### Caring for a dependent with special needs

The Centers for Disease Control and Prevention estimate that one in every 88 children in the U.S. has autism or an autism spectrum disorder<sup>1</sup>, and the number's on the rise. According to the National Business Group on Health (NBGH), the incidence of autism increased 556 percent between 1991 and 1997.<sup>2</sup> A diagnosis of autism is now more common than childhood cancer, juvenile diabetes and pediatric AIDS combined, says the NBGH.

Families who have dependents with autism experience a number of challenges while trying to understand and meet the needs of their children. The emotional toll can be significant – anxiety and depression rates are high among parents of these special needs children. The financial toll is beyond staggering; caring for and providing treatment for a dependent with autism can cost more than \$3 million over a lifetime.

Facing a lifetime need, these families need a team of supporters to look to for benefits, community resources, and legal, financial and estate planning.

#### A supportive team suits up at diagnosis

The increased awareness of autism presents opportunities to serve families with special needs dependents. Benefits advisors, especially, can be key players on the support team – helping employers understand the impact of autism on employees. Providing care for children with autism can result in lost productivity, increased absenteeism, work limitations, and have a negative effect on overall health and well-being.

An employer's health plan can track and report when autism is diagnosed. Notification of the diagnosis to an employer should trigger a first wave of communication and outreach to the family, starting with the employer's Employee Assistance Program (EAP) or behavioral health plan.

<sup>&</sup>lt;sup>1</sup> CDC, http://www.cdc.gov/NCBDDD/autism/data.html, March 2012.

<sup>&</sup>lt;sup>2</sup> National Business Group on Health, "Autism: Facts for Employers," April 2010.

MHN, a San Rafael, CA firm offering EAP and behavioral health services, launched their Autism Center (AC) in 2010. The innovative case management program partners with families facing the challenges that accompany an initial diagnosis of autism and may continue throughout the life of the child.

"Children with autism and their families require a variety of services," says Amel Whitaker, LMFT, Clinical Supervisor, National Clinical Operations for MHN's AC. "We coordinate member care by helping the family navigate the various autism-related systems. This includes medical, educational, community, and state resources, maximizing the child's benefits in the health plan, and exploring alternate funding sources when benefits are limited."

The health and well-being of the family is equally important. "We take a holistic approach to the family's overall well-being because we view the family as the greatest contributor to the child's progress," explains Whitaker. "We assess their coping skills, how resilient they are, and determine if they have support from extended family which optimizes the child's care."

When families receive a diagnosis of autism, employers need to be ready to step up and share a summary of all available benefits says Greg Zibricky, a financial services professional for over 27 years. Zibricky formed Provider Group in 1999 to offer traditional planning services with a focus on special needs planning. His understanding of the issues, and commitment to special needs planning, run close to home. Zibricky's now 19-year-old son, Aaron, has autism.

"Gaining an understanding of the benefits available from the employer is a first step," explains Zibricky. "If an employer offers legal or financial planning services, these resources can guide parents in drafting a will with a special needs trust. Funding a trust with insurance proceeds, versus naming the dependent with autism as a beneficiary, protects the assets and long-term financial support of the dependent."

#### Rally the resources

Benefits advisors can help employers gather and identify all potential resources for employees with autistic dependents. To get started, review the employer's current benefits programs, then reach out to each benefits provider and ask them to document the full scope of resources they have available for families with special needs dependents. Below is a sampling of potential resources:

- Health insurance benefits recommended therapies and coverage
- Managed behavioral health plans outreach care coordination
- Employee Assistance Programs counseling, educational resources, and referrals to community resources

Autism is a complex developmental disability that typically appears during the first three years of life and affects a person's ability to communicate and interact with others. Autism is defined by a certain set of behaviors and is a "spectrum disorder" that affects individuals differently and to varying degrees. There is no known single cause of autism, but increased awareness and funding can help families deal with the disorder.

Source: http://www.autism-society.org/about-autism/

- Group and voluntary term, whole, and universal life policies trust and immediate need funding
- Legal services access to attorneys and estate planning services
- Financial planning services access to Certified Financial Planners

#### A parent's recommendations

In addition to the resources provided by employee benefits programs, Greg Zibricky recommends these resources in his book "F.A.M.I.L.Y. Autism Guide: Your Financial Blueprint for Autism:"

- Autism Society of America www.autism-society.org
- Autism Speaks www.autismspeaks.org
- The National Autism Resource and Information Center www.autismnow.org
- Medicaid www.medicaid.gov
- U.S. Social Security Administration www.ssa.gov
- The Special Needs Alliance www.specialneedsalliance.org

# Case Study

### A case study of caregiving and supportive resources in action

For more than 20 years, consumer essentials manufacturer Kimberly-Clark has encouraged the formation of employee network groups around common interests and concerns. The company believes the groups help to better understand and meet employees' needs.

The Family Caregivers Network (FCN) is one of eight employee network groups currently thriving within the Kimberly-Clark workforce. Nancy Brown-Koeller, Technical Lead, Market Research, co-founded the FCN in 1996 and remains active on the leadership committee. "The FCN was formed and nurtured by volunteers and remains so today," explains Brown-Koeller. The volunteers are still responsible for all regular job responsibilities. "Kimberly-Clark provides budget and permission to use campus facilities, but the group uses their own time and talents to run the network."

Joel Hopper, ITS Business Partner, Retail Data Services, Customer Development has been the FCN chairperson since 2010 and a volunteer member of the FCN for 10 years. In 2013, he will be the event leader. As a volunteer member of the FCN leadership, Joel works to promote awareness around the challenges facing caregivers and the national and community resources available to them.

"Caregivers tend to have similar challenges," says Hopper. "They also tend to not self-identify as caregivers." This can be a challenge in itself. When caregiving for a loved one is considered a normal part of their role, individuals may not be reaching out for support. "The FCN developed a Caregiver Starter Kit to help people understand they must take care of themselves, too," explains Hopper. The very existence of such a kit reinforces that employees are not alone in their situation and that support is available.

Using the collaborative networking tool SharePoint, a FCN volunteer created a comprehensive website for Kimberly-Clark caregivers to find and share resources. "Last year we developed branded communications and a monthly email to draw employees to the site and help raise awareness about the FCN," says Hopper. The site offers national and community resources, news about FCN events, and links to Kimberly-Clark's Employee Assistance Program. "Partnering closely with ValueOptions, our EAP provider, and the Aging Disability Resource Center (ADRC) has been instrumental in keeping resources and support flowing to caregivers in need."

Kimberly-Clark and the FCN recognize the importance of EAPs and the benefits they bring to caregivers. "They have the expertise and in-depth knowledge to help caregivers with their specific situation," explains Hopper. In addition, Hopper works with a county caregiving coalition trying to leverage EAP contacts within the area to benefit all employers and caregivers. "The mission is to share the knowledge and provide more awareness and support," says Hopper.

For the FCN, it's all about education and awareness. "We conduct four forums each year, bringing in speakers on targeted topics," says Brown-Koeller. In 2013, monthly lunch and learns are being planned by the volunteer committee. As Brown-Koeller sees it, the FCN has played a critical role in opening everyone's eyes to the scope – and the needs – of caregiving. "Child care resources were well understood, but resources for those dealing with elders, dependents with specials needs, critical illness were not." The FCN has been instrumental in filling those gaps.

#### Sources:

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- Zibricky, Greg, "F.A.M.I.L.Y. Autism Guide: Your Financial Blueprint for Autism," Networlding Publishing, June 2012.

St. Paul-based Minnesota Life, one of the country's largest group life insurers\*, offers basic and voluntary group life insurance programs to help address the financial needs of more than 5 million U.S. employees. The insurer also offers its group clients access to the services of MHN, a San Rafael, CA firm offering Employee Assistance Programs (EAP) and behavioral health services. For more information, contact your Minnesota Life regional group sales manager or client relationship advisor or call our Group National Sales office at 1-800-606-LIFE (5433).

\* Leading writers of group life insurance based on 2011 insurance in force, as reported by A.M. Best in July 2012.

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