THE TORN SECURITY BLANKET

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MetLife

Children and Adults with Special Needs and the Planning Gap

The Increased Need for Financial Guidance for Caregivers and Their Families

Metropolitan Life Insurance Company, New York, NY 10166

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MetLife Center for Special Needs Planning℠

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INTRODUCTION

The 2011 *Torn Security Blanket* survey undertaken by MetLife's Center for Special Needs Planning follows the foundation laid by the group's ground-breaking study of parents caring for children with special needs in 2005. Building upon this first look at caregivers' concerns six years ago, the latest survey creates a more in-depth and comprehensive picture of the financial and day-to-day challenges that the families of children and adult dependents with special needs face, as well as where they see increased need for support services and professional guidance. The current survey of more than 1,000 caregivers arrives at a pivotal time for these families with special needs as the nation's financial resources are stretched – assistance programs at the local, state and federal levels are either being cut, limited or reassessed – and these changes are acutely felt by caregivers. A major goal of this new study is to help families which have dependents with special needs – along with the broader special needs community – understand what resources are currently available and what steps can be taken by caregivers to help secure their dependent's financial future.

One area where the study shows that caregivers are struggling and are looking for more assistance is special needs planning. For families caring for dependents with special needs, financially related planning can feel even more daunting because of its *apparent* complexity and the emotions involved. The 2011 *Torn Security Blanket,* and the accompanying Basic Financial Guidance for Caregivers at the end of this report aims to provide the perspective that planning for dependents with special needs is feasible and within reach for families across the income spectrum.

The 2005 *Torn Security Blanket* report found that 60 percent of parents did not believe that their dependent with special needs would ever be financially independent. Despite this, most had not completed a plan for their dependents' future – but this lack of action is not a reflection of a lack of concern. In addition to their understandable time pressures, many parents attributed this lack of planning to the fact that when they did seek information they had trouble finding guidance related explicitly to planning for special needs. In fact, two-thirds said they found very little planning information that focused on dependents with special needs, and more than half said that what information did exist was difficult to access.

So, what changes has the special needs community seen more than five years after this inaugural report? What planning concerns still need to be addressed?

The availability of information on special needs planning appears to have improved over the years, with the percentage of caregivers saying there is too little financially related planning information dropping from 66 percent in 2005 to 59 percent in 2011. Still, while access to information has gotten better – thanks in part to increased use of Internet resources – caregivers' *understanding* of the data hasn't changed as much. For example, there are still only 21 percent of caregivers familiar with the steps needed to plan for lifetime financial assistance for their dependents. There is also good news; the 2011 report shows that there have been significant steps in the right direction. Many are now recognizing that caregivers may need guidance provided by professionals dedicated specifically to the special needs community. And caregivers are showing interest in such resources as well, with two-thirds of respondents saying that they would be interested in attending an employer-sponsored workshop about special needs planning and 69 percent saying that access to a special needs planner through their employer would be very helpful to them.

The 2011 *Torn Security Blanket* findings – along with insights from interviews conducted with caregivers – convey emphatically that taking care of, and shaping the future of, a dependent with special needs is a sometimes frustrating and challenging, yet rewarding experience. Resources may be stretched and need to be bolstered, but help is available. The saying that knowledge is power was never truer than in the case of the special needs caregiver.

METHODOLOGY AND SAMPLE CHARACTERISTICS

To contact the caregivers of dependents with special needs, the MetLife Center for Special Needs Planning worked with the GfK Custom Research North America to conduct an online survey.

A total of 1,004 panelists agreed to participate in the survey, which was conducted from May to June 2011. The margin of error for this survey is 3.2%. In addition, researchers conducted 18 in-depth online interviews with caregivers of special needs dependents.

The majority (78 percent) of caregivers responding to the survey had one dependent with special needs; 13 percent indicated they had two such dependents, while four percent indicated they had four or more. Many of the dependents with special needs were adults, with 41 percent being age 18 or older. This is a significant change from the 2005 study, when only 27 percent of dependents were 18 and older, but an older cadre of dependents was expected with the second *Torn Security Blanket*, since its focus was expanded beyond parents to all caregivers. Almost a third (32 percent) of respondents cared for dependents between the ages of 5 and 12, while 18 percent had dependents ages 13 to 17.

Dependents typically had more than one type of special need. In 2011, about four in ten dependents experienced developmental (45 percent) or emotional (42 percent) difficulties. About a third (32 percent) of dependents had some form of cognitive disability. More dependents were reported to have medical or physical disabilities in 2011 than 2005 – with 35 percent of dependents with medical disabilities and 34 percent of dependents with physical disabilities. In general, caregivers did not find out about their dependent's special needs until later in life (75 percent), though one in four became aware of the dependent's special needs when he or she was born.

Participants in the survey represented a cross-section of life circumstances. On average, the caregivers were about 43 years old, more than half were employed, and 42 percent had at least some college education. Average annual household income was $54,400.

Caregiver Demographics

Age	
Under 34	22%
35 to 49	52%
50 to 64	24%
65 or older	2%
Marital Status	
Married	72%
Single	7%
Divorced	14%
Separated	4%
Widowed	3%
Employment Status	
Employed Full-time	39%
Employed Part-time	14%
Self-Employed	3%
Homemaker	25%
Unemployed	7%
Retired	6%
Student	3%
Other	3%
Household Income	
Under $50K	62%
$50K to $75K	21%
$75K or more	17%
Education	
High school or less	26%
Some college	42%
College graduate	25%
Postgraduate	7%

INFORMATION HAS BECOME EASIER TO FIND, BUT MORE GUIDANCE IS NEEDED

Between work and caring for their dependent with special needs, caregivers face many demands on their time, which is why the search for information can be so frustrating.

While caregivers are becoming more adept at finding the information about caring for a dependent with special needs, sifting through these mountains of data to find what is applicable to their families is still a difficult and time-consuming process.

Many of the issues that caregivers face begin with the need for information – and the lack thereof. They need medical information to understand how to care properly for their dependent's special needs, educational information to ensure the best schooling possible, and planning financial information to ensure that that their financially related needs are met in the future. Sorting through all this information without the benefit of professional guidance and determining what is useful and what isn't can be a challenge to even the most sophisticated caregiver.

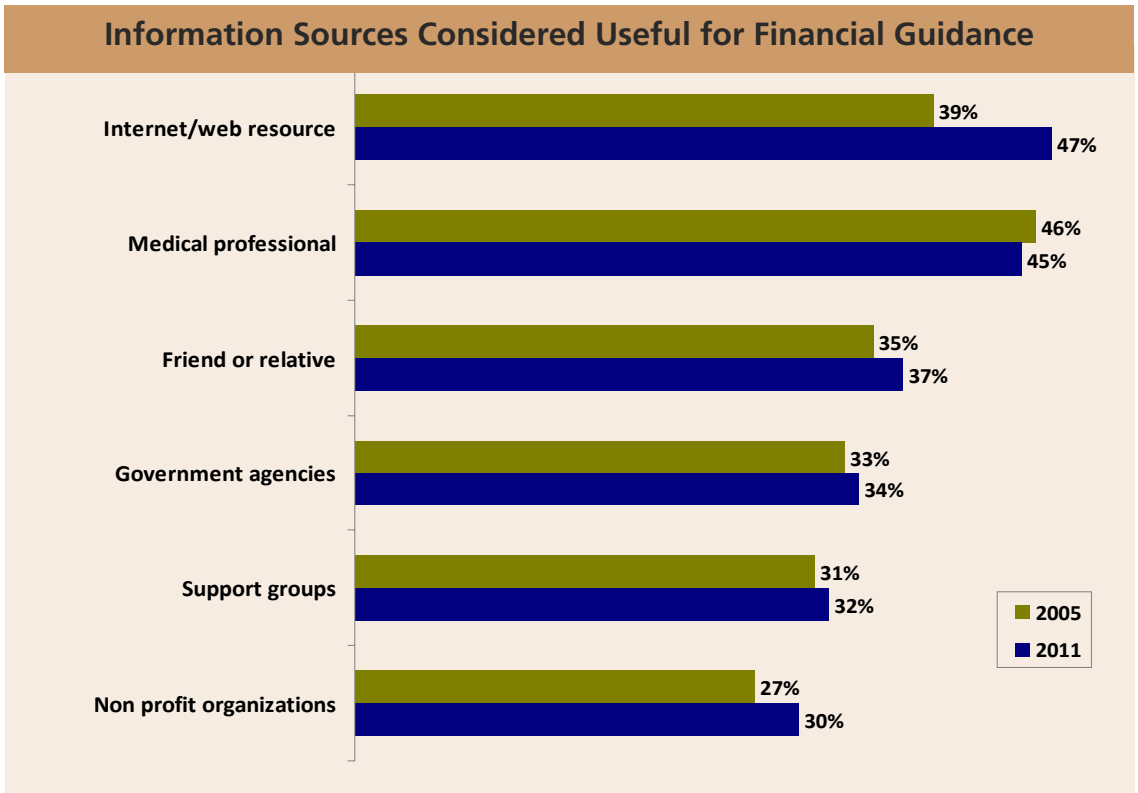
"How reliable is this information? Is it about some government program that Congress is fighting about and could be changing very soon? If one site says one thing and another says something different, which one's right?"

Caregiver from Indiana

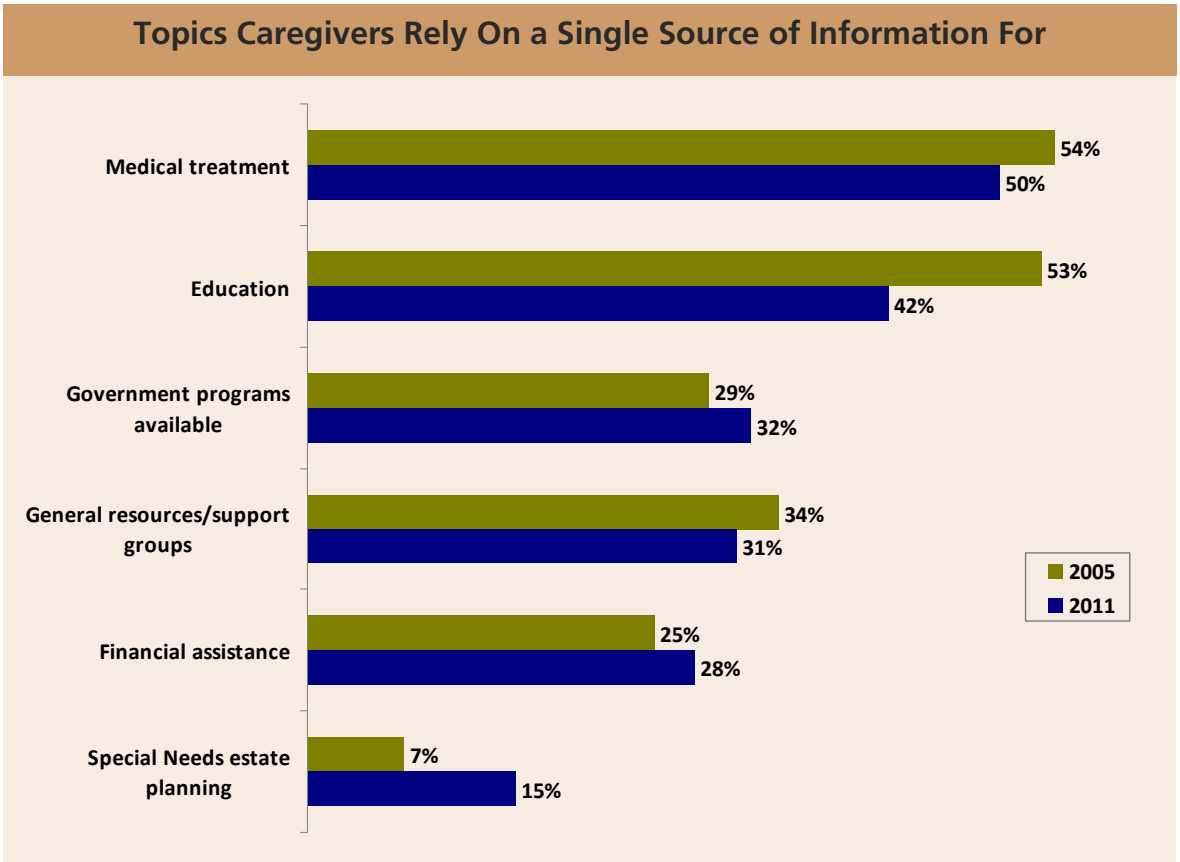
"Broken links, endless phone menus, no one ever returns my calls, workers lie to me about what programs are available, just lots of red tape. It seems that more often than not they design it so people get discouraged and give up."

Caregiver from New Jersey

Over the years, the Internet has made finding such information quite a bit easier. Almost half of caregivers (47 percent) view Internet and web resources as the most useful source for special needs financial guidance, up from 39 percent in 2005. The Internet surpassed medical professionals as the most useful source of information for financial guidance for dependents with special needs – it came in at 45 percent in 2011. But as an information resource, the Internet is not without its issues. As one caregiver from New Jersey stated, "The Internet can be helpful, but many issues are state-specific, so articles from other states, while interesting, may not apply."

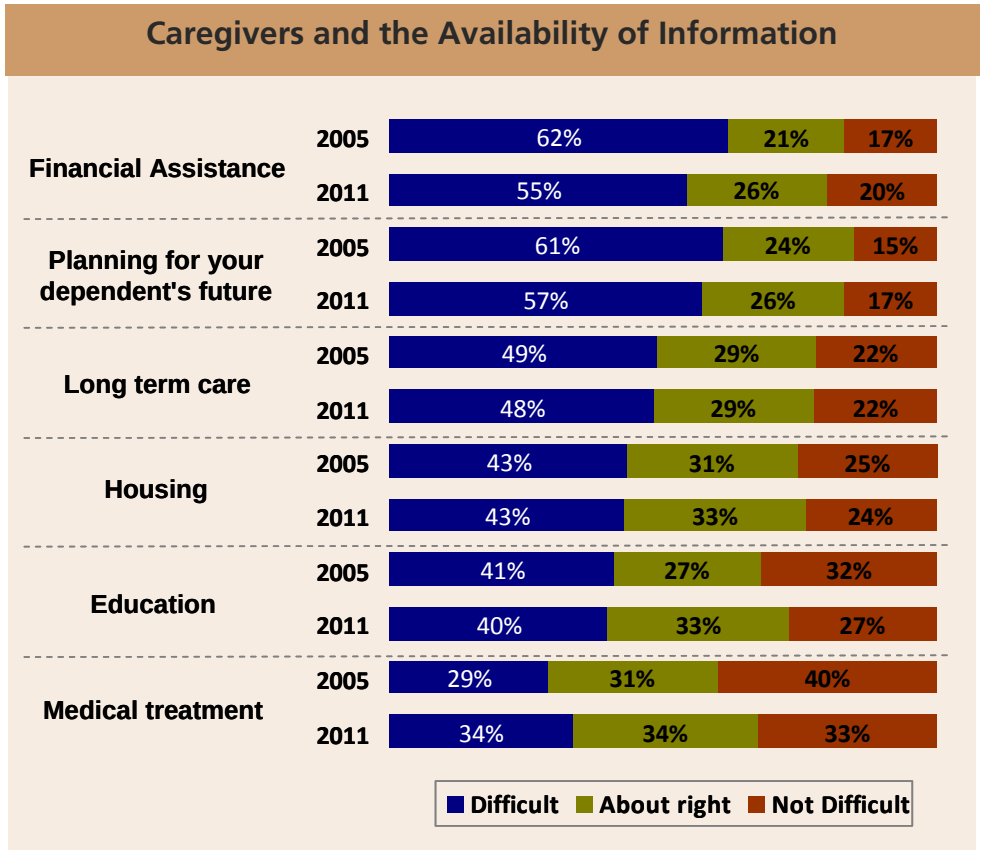


The search for information and direction about financial assistance (benefits and support provided by government agencies) and special needs planning (preparation for future financial needs) has proven to be especially frustrating for caregivers – although there are some signs it's getting better. Caregivers are still less likely to use a single source for financial information than they are for medical or educational information – perhaps pointing to dissatisfaction with the information that is available about relevant financial topics, and the need to go to several places before finding meaningful guidance. For instance, while half of caregivers reported using a single source of information for medical information, only 28 percent said they used a single source for financial assistance information. One area where the trend line is improving is estate planning. Today, 15 percent of caregivers use a single source of information for special needs estate planning, more than doubling from 7 percent in 2005.



When asked about how much data was available and how easily accessible that data was, survey respondents were likely to find information on financial assistance and planning less available than information on medical treatment. For example, when asked about obtaining data regarding medical treatments, just 38 percent of respondents said that there is too little information available and 34 percent said that it is very difficult to get the information they need. In contrast, almost three in five (59 percent) of caregivers said that there is too little information available about financial assistance and 55 percent said that it is very difficult to find.

While financial assistance still remains well behind topics such as medical treatment, these responses represent improvements when compared to where the topic stood in 2005. Then, 66 percent of respondents said that there was too little information on financial assistance and 62 percent said it was difficult to find. In the latest survey, caregivers also report an increase in available information when planning for a dependent's future care; the number of respondents describing the amount of information as "about right" increased from 28 percent in 2005 to 33 percent in 2011.



Caregivers are either not getting enough financially related planning information or not getting the guidance they need to make use of the information that they do receive. Many caregivers who have not yet prepared for their dependent's financial future are unsure what steps they need to take to do so. "Knowing where to start [is an issue]. I'm sure there is lots of information out there, but finding it is another matter altogether," said one respondent from Florida.

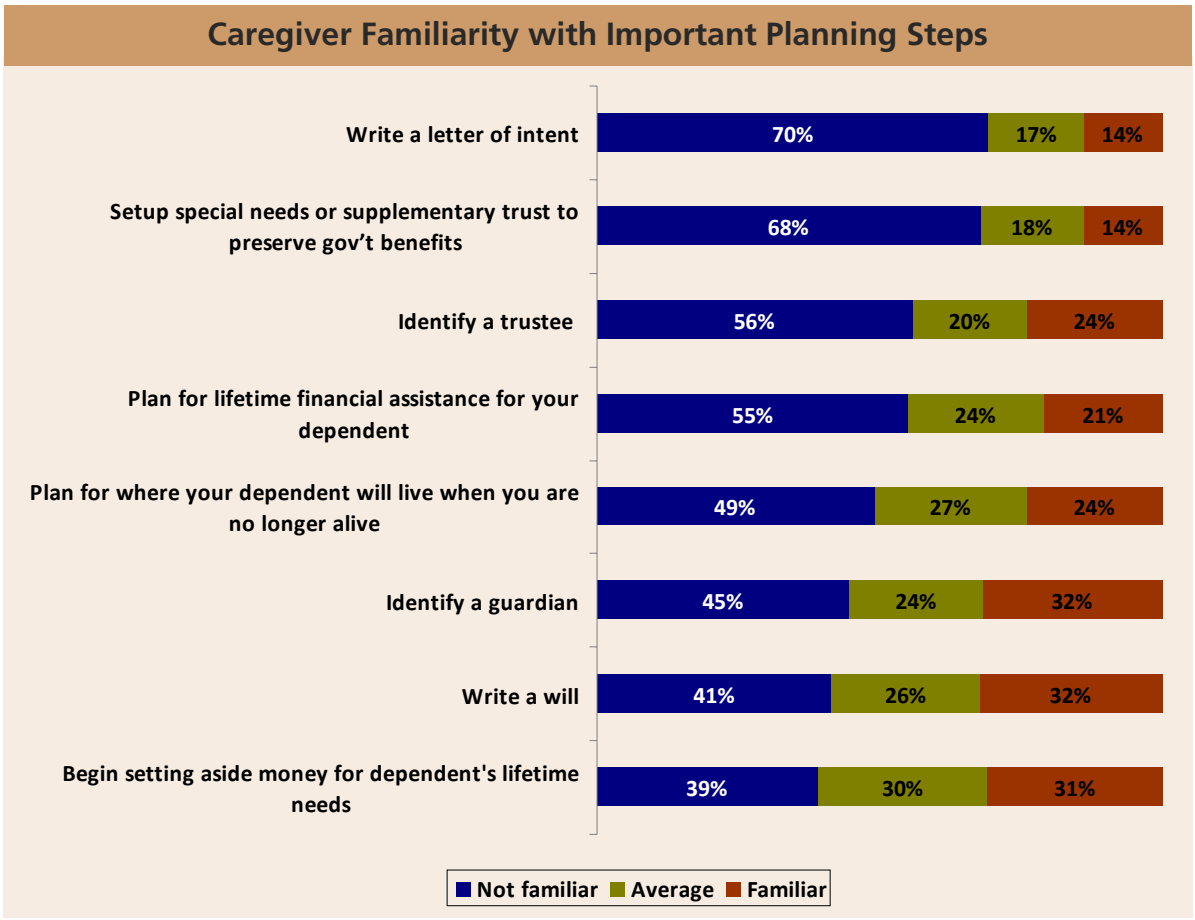
When asked about a variety of financial tasks, today's caregivers appear to be as unfamiliar with the most important steps as they were in 2005. In 2011, more than half (56 percent) of caregivers said they are unfamiliar with steps needed to identify a trustee to oversee their dependent's financial holdings in the future – the same percentage as in 2005. Also unchanged in 2011, 55 percent said they weren't sure how to set-up a plan for lifetime financial assistance for their dependent.

"I haven't begun seeking information because it seems overwhelming and I'm afraid I won't be able to understand everything."

Caregiver from California

Even in areas where caregivers have made significant strides, a knowledge gap remains. Less than one-third (27 percent) of caregivers are familiar with the steps involved in identifying a guardian, someone qualified to act as a representative for their dependent. This was down from 32 percent in 2005. That leaves almost half (49 percent) of caregivers who are unfamiliar with how to identify a responsible and successful guardian.

> ***"The only thing we have done is begin setting aside money for her lifetime needs. I did not realize all this needed to be done. We were going to get Wills done this year. After seeing this list I can see we need to get busy."***
>
> *Caregiver from Minnesota*



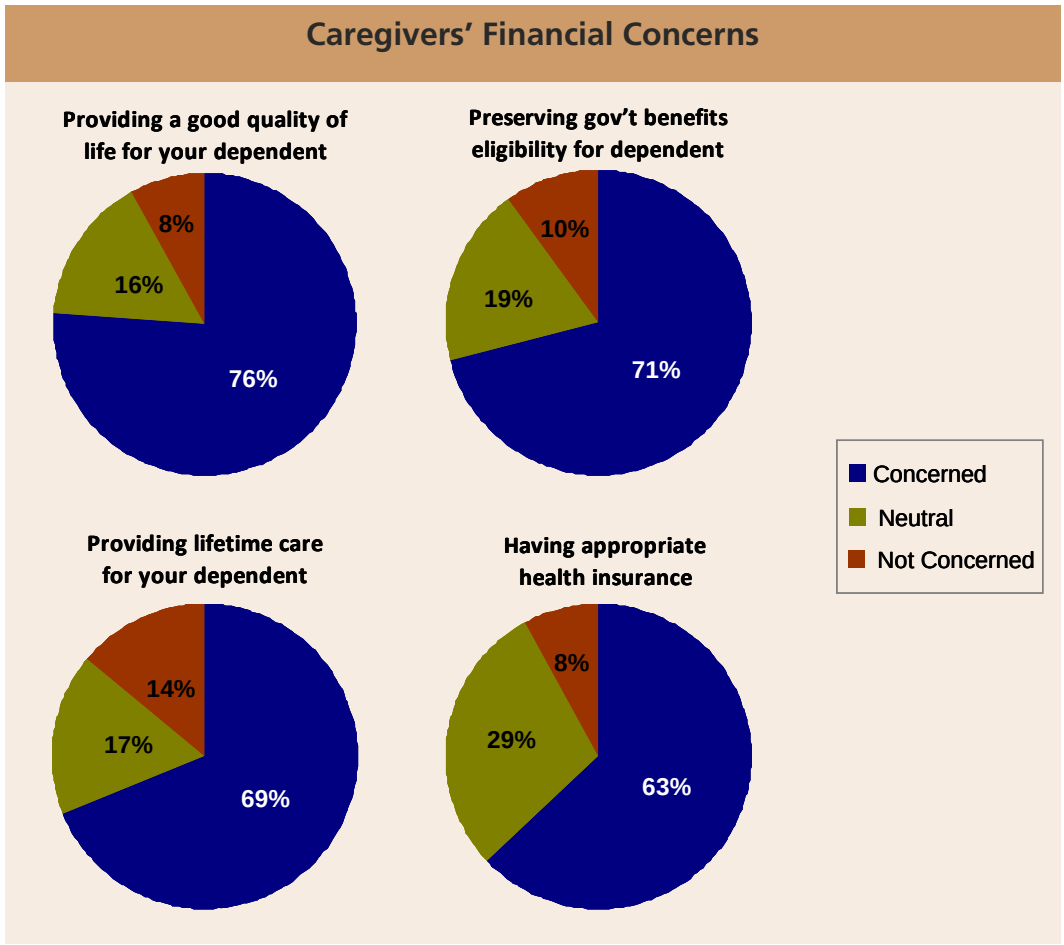
LACK OF TIME AND KNOWLEDGE LEADS TO PLANNING INERTIA

Caregivers' lack of familiarity with financially related planning tasks does not indicate a lack of concern on their part. In fact, many caregivers said that they are very concerned about financial security – both for their family's overall financial health, as well as for their dependents' future. Almost three-quarters (71 percent) of caregivers said that they are very concerned about having enough money to make ends meet, down slightly from 73 percent in 2005. Caregivers also expressed serious concerns about job security (61 percent) and having enough money for a parent to stay at home (59 percent).

And while immediate financial concerns seemed to be a dominant area of focus, caregivers have long-term financial concerns as well. Almost two thirds (64 percent) said they are very concerned about outliving their retirement income, while 63 percent are very concerned about having enough money for college.

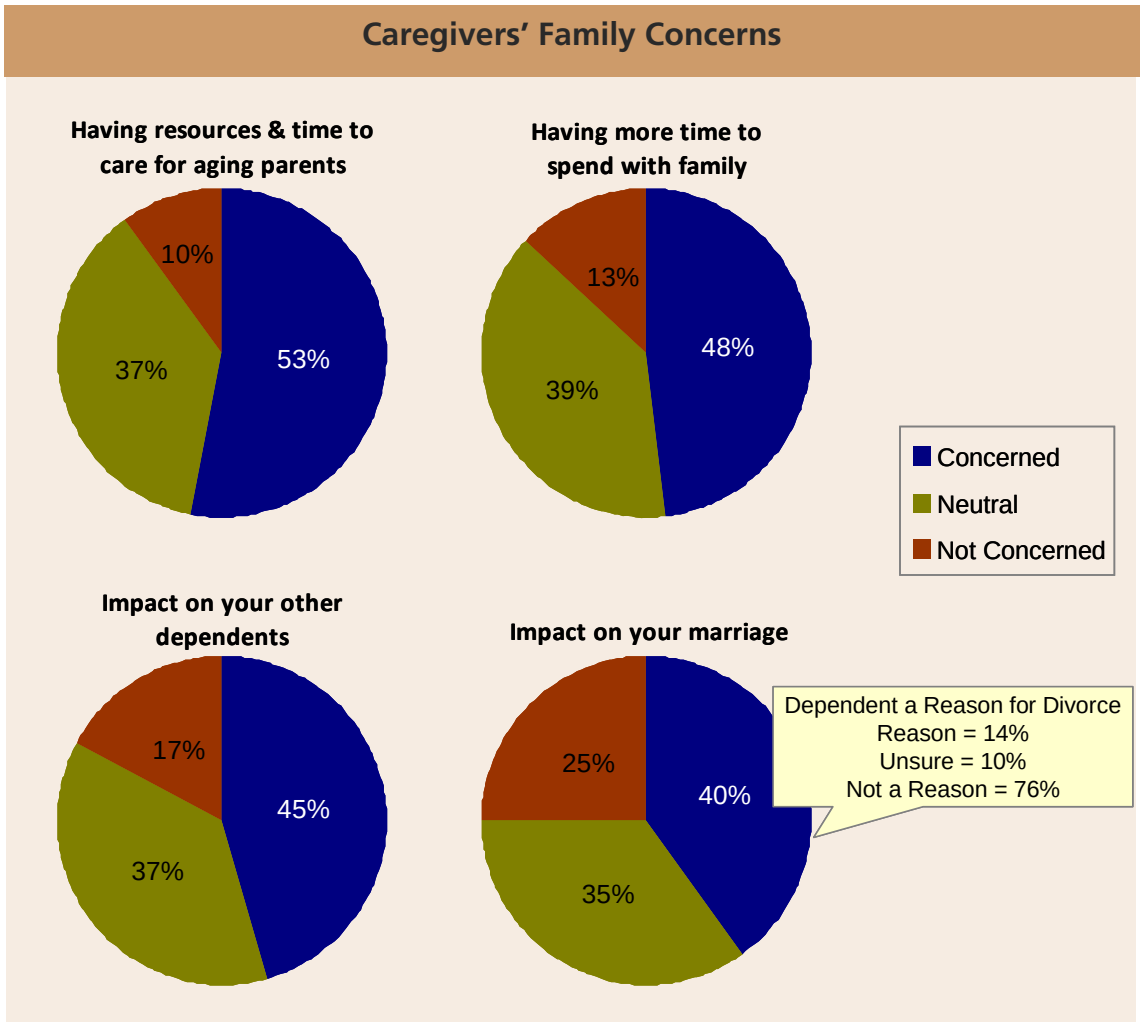
Caregivers are concerned about the financial security of their families and their dependents, both in the short-term and the long-term.

With more immediate concerns holding their attention, caregivers have had to push-off their attempts to secure their dependents' future – in spite of their own concerns.



In comparison to six years ago, caregivers are becoming more worried about their dependent's future financial security, while quality of life – still a major focus for many – is becoming less of a concern. When considering unforeseen events – such as a job loss or the unexpected death of a caregiver – 69 percent of caregivers said that they are very concerned about being able to provide lifetime care for their dependents with special needs, up from 64 percent in 2005. Meanwhile, the percentage of caregivers worried about providing a good quality of life for their dependent dropped slightly from 80 percent in 2005 to 76 percent in 2011, perhaps indicating that while caregivers consider both issues to be important, financial concerns are moving more to the forefront.

Despite all the concerns, though, there is a discernible current of optimism flowing from many caregivers regarding their dependent's future quality of life. One caregiver from Florida said of her dependent, "I expect her to have a long and happy life. She will always have issues, but with help she should be able to live a relatively 'normal' life . . . When this first happened we didn't have any expectations. The doctors weren't sure she would survive much less what her brain function would be. As she continues to grow leap[s] and bounds in her progress, we are hopeful for her and her future." Another caregiver from Minnesota had similar expectations for the dependent's quality of life, but expressed some planning concerns: "I think her quality of life will be good, since she is developmentally delayed, but she needs assistance to make the right decisions. I feel guilty because she has no brothers or sisters, so when we are gone she will be alone . . . My expectations have not changed in the past years, but I worry about it more since we are getting older. I realize there is a lot we need to do because I don't want to make things harder for my daughter when we are gone."

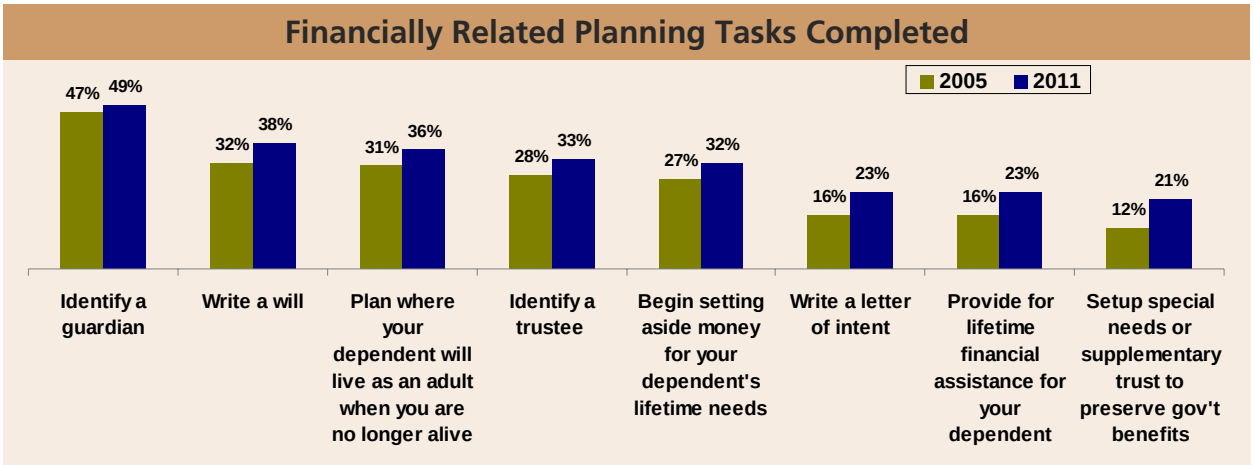


Despite the obvious concerns that caregivers have about the future, very few have completed planning for their dependent's care and financial security. While caregivers are moving in the right direction – seven in ten have completed at least one planning task – many have yet to address crucial gaps in their future arrangements. Relatively unchanged from six years ago, slightly less than half (49 percent) of caregivers have identified a guardian for their dependent.

In qualitative interviews many respondents said they see identifying a guardian and/or trustee as the most important preparation they have to make for the dependent's future. "For us, it was identifying a guardian. We want to make sure that, should something happen to us, our daughter will be taken care of by my brother and his wife and not just become a ward of the state," said a caregiver from Florida. Another respondent from Indiana noted: "Setting the trustee. Nothing you've set up matters if the person who's supposed to see to it doesn't. We made sure we chose someone who we know we can trust and have complete faith in and who knows and loves our son and our son loves him."

> ***"We have started to set aside money for my son's future. I worry about his financial situation as an adult. We do have a Will in place. I want to set up a trust, trustee and guardian.***
>
> ***The reason we have not is it feels so overwhelming and starts stress on top of everything else going on. It is very important I know. I need more support in this area."***
>
> *Caregiver from California*

Caregivers showed more progress compared to six years ago with other planning tasks: 38 percent have written a Will, up from 32 percent in 2005; 36 percent have planned for future housing, up from 31 percent; and 32 percent have identified a trustee, up from 28 percent. The greatest area of growth was in the number of caregivers setting up special needs trusts – nearly doubling from 2005 with 21 percent having completed this task. Again, the uncertainty that many caregivers feel is likely keeping them from doing more to prepare for the future. As one caregiver from Florida said, "We have a Will and have identified a guardian. We also have begun setting money aside for our daughter's future. We started setting aside money for all our children when they were born. . . . This is where it gets uncertain for us. There is not a lot of help out there with these things and it's hard to know where to start."



COMMON MISCONCEPTIONS AND BLOCKS IN PLANNING

In addition to not knowing where to start, some caregivers are struggling with day-to-day finances and don't feel that they have enough money to plan for the future. For instance, one caregiver from South Carolina says: "I really haven't looked into any of this; it is kind of depressing to even think about savings or future money because I rarely have anything extra at the end of the month and can't seem to find a job anywhere." And another caregiver from Oregon echoes this reality: "With [a] SSD check every month to live on, I just don't know what kind of financial planning we could do with that little money when all of it goes to monthly necessities."

Not knowing where to begin preparing for dependent's future care is just one of several barriers in a caregiver's path –

misconceptions are another side effect that caregivers experience as a result of not having clear special needs financial guidance.

However, many of the tasks with which caregivers struggle, such as writing a Will, can be done at relatively low cost and with few assets, as long as caregivers have the proper tools and guidance. For example, according to the MetLife Center for Special Needs Planning, caregivers have several options for setting up a special needs trust that can be tailored to meet their current financial situations. As outlined at the beginning of this report, they can choose to add funds to the trust over time, slowly growing the account, or they can choose to fund it at a later time with their life insurance benefits or estate assets. Knowing that a special needs trust doesn't require thousands of dollars to set-up would likely make a difference to special needs caregivers, such as one respondent from Pennsylvania, who believes a special needs trust is beyond reach because: "…there is no money left after paying bills, groceries. If I knew I could start a special needs trust unfunded, I would be more likely to create one."

Another task that can appear daunting to caregivers, but can be simplified with some guidance, is the Letter of Intent. Caregivers may be surprised to find out that they don't have to fill out complicated forms or legal documents in order to create a Letter of Intent – that it can be structured and formatted to fit their needs. While not a legally binding document, the letter of intent can be an invaluable tool for providing direction to the person or persons who will care for their dependent after caregivers are no longer able to do so. It should detail a dependent's medical history, daily care needs, housing and services, as well as any specific wishes and expectations about the dependent's future.

Along with such concerns, caregivers also cited a number of emotional reasons for resisting certain tasks related to finances. For some, such as this respondent from South Carolina, it was about not wanting to think about certain circumstances: "I really don't like to think about writing a Will as I am only 28, and it seems so morbid, but I know that tragedy can strike at any age, and it would be the responsible thing to do." Other caregivers experienced anxiety about deciding who might be able to care for their dependent in the future. As one respondent from Minnesota noted, "I have thought about getting her a guardian and trustee but am struggling with who to ask. It is a difficult decision because I want someone that will

not take advantage of her. I also don't know how they [the trustee or guardian] will feel about taking on this responsibility." Other statements from caregivers also show that they are concerned about the potential burden they may place on other family members. "It was hard to take away from other family members to set up a living trust," said a caregiver from Indiana. "Even though they understand that more is needed for him, it felt 'wrong' and we didn't like having to do it."

While these emotional blocks are understandable, speaking to family members or seeking the professional guidance of a special needs planner can help caregivers to move forward. Special needs planners and other financial professionals often have the experience necessary to talk through caregivers' concerns, and help find objective solutions.

WORK-LIFE BALANCE REMAINS A STRUGGLE

While there have been advances in special needs planning – i.e., available information, government programs and medical advances – the reality is that the daily care needed from caregivers has remained fairly consistent since the last report. Specifically, while 60 percent of dependents with special needs required some form of medication or medical intervention on at least a daily basis six years ago, that number has dropped only modestly to 55 percent. As the majority of dependents with special needs require medical care on a daily basis, it's not surprising that caregivers continue to spend a significant portion of their week tending to the special needs of their dependents. While on average caregivers spent 26.6 hours on care, one-third of caregivers reported that their families spend more than 40 hours a week tending to their dependent's special needs, level with the 32 percent that reported the same in 2005.While all caregivers reported spending a significant amount of time caring for their dependent, there were some notable differences on the amount of time spent when comparing types of disabilities. According to the survey, caregivers of dependents with a medical (37 percent) or physical (38 percent) disability were less likely to spend more than 40 hours a week on care than caregivers of a dependent with a cognitive (43 percent) or developmental (42 percent) disability. This may be in part due to the fact that cognitive and developmental disabilities can be more pervasive in their effect on a variety of behaviors, and require more attention from the caregivers on a day-to-day basis.

Families must spend significant amounts of time and money to care properly for a special needs dependent.

Although they may receive assistance through a private or public program, they still face a significant resource burden.

"…there is always a careful balance between therapy, giving him the attention and time he needs, work, spending time with other children and spouse, household chores, errands and it goes on and on."

Caregiver from Pennsylvania

These 40 hours – the same amount spent on a full time job – are taking a toll on many caregivers, as half (49 percent) say that it has been difficult to balance work and family life. Just 20 percent of caregivers say that it has not been difficult. Some caregivers report that they've had to choose lower paying or part-time positions in deference to their responsibilities to their dependents with special needs. For instance, one caregiver from New Jersey says, "Due to (my dependent's) needs, I chose not to return to work after she was born, so have been out of the work force for 25 years.

"It has definitely been challenging, but it has also taught me to have more patience. I used to be quick tempered but have found that you just can't be with a special needs child. It has taught me more compassion as well. The negatives could be the dynamic it can cause between spouses – with one feeling the need to be tough and the other feeling the need to be softer. Finding that balance is hard."

Caregiver from Florida

This has impacted our finances tremendously." What's more, relief doesn't seem to increase with income – i.e., monetary resources do not have a major impact on the amount of time families spend caring for their dependents day-to-day.

Also consistent with the 2005 report, caregivers remain concerned about the impact that caring for their dependent with special needs could have on their other children and their marriage. In 2011, 40 percent of caregivers reported concern about the impact of caregiving on their marriage, up from the 35 percent that said the same six years ago. And, this year, 45 percent of caregivers reported concern about the impact on other children, roughly consistent with the 42 percent that cited the same concern in 2005. One caregiver from Tennessee echoes these findings: "Because [my dependent's] behavior is so unpredictable, we have a hard time having any time just for us or time for our other child. [Our dependent] can be very jealous of her brother and will act out if she feels that she is missing something."

Yet, while the impact on the lives of those caring for a special needs dependent has not changed in six years, what has changed is the provider of health insurance coverage they receive. And, it's changed for the worse in terms of having private health insurance. According to the 2011 study, just 43 percent of dependents are currently covered by private health insurance, down from 49 percent in 2005. Meanwhile, the number of dependents covered by Medicaid, the federal health insurance program, has risen notably; rising from to 41 percent in 2005 to 52 percent in 2011. In comparison to families covered by federal insurance, another 28 percent of dependents with special needs are now covered by state-sponsored health insurance programs.

While the majority (63 percent) of families pay less than $250/month out-of-pocket on their dependent's medical care (not including premiums), this can still represent a serious strain on a family's resources and one that appears to be increasing. On average, caregivers in 2011 spend about $426/month on medical care, rising significantly from the $326/month that parents spent in 2005, and suggesting an overall increase in healthcare costs over the last six years.

AVAILABLE RESOURCES NOT KEEPING UP WITH NEEDS

Today, less than 3 in 10 families report that they receive a support service; most either do not know why they are not receiving support services or don't qualify. Therefore not surprisingly, families of dependents with special needs have a fairly low level of satisfaction with the support they currently receive from various sources and agencies. Specifically, local and federal government agencies received the lowest levels of satisfaction, with only 25 percent and 26 percent of respondents saying they were satisfied with their services. Employers received a relatively favorable rating, with 39 percent of caregivers saying they were satisfied with services provided. The highest level of approval of all the agencies listed in the survey went to school districts, though less than half (42 percent) of respondents said they were satisfied with the service provided – highlighting the overall displeasure of caregivers with the kinds of support that they receive.

The level of assistance and services currently provided by private and public agencies at various levels has simply not kept up with the demands of special needs caregivers and dependents.

Caregivers are dissatisfied and would like to receive more assistance. At the same time, some of the problems may trace back to caregivers' difficulties in locating and leveraging available resources.

In qualitative interviews, it's clear that the perceived deterioration in services is top of mind for many caregivers. For instance:

- ***"I have seen counseling services disappear due to budget cuts. There has been a loss of employees in some agencies. I feel for the families who are just starting to look for help for their children. The resources just aren't out there. Things have definitely gotten worse."*** *Caregiver from California*
- ***"Funding has become less available. The wait lists for housing and other services are long, and the chances of our daughter reaching the top of the list in her lifetime look grim. . . Housing with state funding is virtually non-existent in [my state]."*** *Caregiver from New Jersey*
- ***"Case management is not what it was in the beginning. My case manager does not do too many in-home support visits anymore."*** *Caregiver from Tennessee*

Perhaps explaining the satisfaction with educational resources, when asked what types of services are currently being received by the family, education topped the list. In 2011, 29 percent of caregivers report that they receive educational advocacy, 26 percent receive help outside the home and 24 percent get help in the home. A smaller number (18 percent) of families receive Medicare waivers, and just 9 percent have respite care.

In terms of education, the majority (63 percent) of special needs students are educated in public schools, and almost two-thirds (63 percent) of caregivers report that they are satisfied with their services. Of those special needs students educated in public schools, many (44 percent) are in an inclusion class, while less than one-fifth (19 percent) of special needs students in public schools are educated in a self-contained class.

EMPLOYERS CAN BE A VALUABLE PLANNING RESOURCE

Families of dependents with special needs are uncertain where they should go for financial guidance and education – often relying on non-professional resources such as the Internet.

They are eager to receive more assistance in this area and would appreciate their employers stepping in with workshops and/or other assistance.

The first *Torn Security Blanket* study revealed a major issue, namely that families of dependents with special needs were not taking the appropriate steps to prepare for their children's financial health after a parent's death – despite the majority believing that their dependent would never be financially independent. And in 2011, the needle has not moved significantly; families of dependents with special needs require additional, specialized guidance when it comes to financial matters, but they don't seem to know where to turn for that assistance. One caregiver from Florida says: "We haven't really done this yet, and there's not a particular reason why. I guess it really boils down to not knowing where to start. Her school teacher and counselor have provided us with some basic information, but that's it. There really needs to be lists of who to contact in our area for parents who don't know who to turn to, where to go and/or what to do."

Yet, despite this need for help, relatively few caregivers turn to financial professionals with a special needs focus or seek specialized assistance as sources of financial information. The percentage of caregivers identifying insurance agents (14 percent) and financial planners (13 percent) as a useful source of financial guidance or advice remain relatively low, though they are up significantly from 2005 levels.

To help them get started, caregivers are interested in receiving workplace assistance related to special needs planning. Over two-thirds say that access to a special needs planner would be helpful if provided by their employers, while 64 percent would welcome employer-sponsored workshops on special needs planning and access to legal services. Almost three-fourths (75 percent) of caregivers are likely to attend workshops about special needs planning if offered by their employer, while roughly one-quarter rate workshops about special needs planning (26 percent) and access to a special needs planner (24 percent) as the "most helpful." Popular topics for these special needs planning workshops include government benefits (67 percent) and Social Security/Social Security Disability Insurance (55 percent). Other topics of interest include establishing a special needs trust (44 percent), guardianship (42 percent), housing options (40 percent) and transition planning (36 percent).

Topics of Interest for Special Needs Planning Workshop	
Government benefits	67%
Social Security/SSDI	55%
Establishing a special needs trust	44%
Guardianship/Power of Attorney	42%
Housing options	40%
Transition Planning	36%
Other	5%

CONCLUSION

Caregivers of dependents with special needs are aware that their families face unique challenges that make setting up future care plans especially important. Loss of income, disability or even the unexpected death of a caregiver can severely change the shape of a dependent's life. Most families are simply unprepared to grapple with the complicated and difficult decisions they must often make to protect their dependent's future. While the situation has improved somewhat over the past six years, far too many caregivers need more specialized resources to guide them through the process.

As the 2011 survey results demonstrate, caregivers continue to be overwhelmed by the amount of data they must sift through and interpret to get answers. Often spending, on average, 27 hours a week to ensure that medical and educational needs are met, caregivers simply don't feel they have the spare time or resources to search the Internet and make informed financial decisions. As a result, many delay or simply never complete the preparations for their dependent's future. This, despite the fact that many expect that their dependent will always need some form of support services or special care.

Increasing the availability and accessibility of special needs information is just part of the solution. The 2011 *Torn Security Blanket* study shows that caregivers want and need access to dedicated special needs planning resources and want financial guidance. While the Internet has helped many caregivers self-educate on special needs issues, there is a hunger for more personal guidance and support – even with foundational tasks such as writing a Will and/or identifying a guardian. Feeling that they lack such support, special needs caregivers are facing a significant planning gap. It threatens their dependents' financial security – and often caregivers' work-life balance. While some important progress has been made over the past six years – both in awareness of needs and in the availability of specialized resources – much work remains.

In an era of budget cuts, many families have seen services for dependents disappear. They have also struggled to balance the competing demands of work and caregiving. To close the planning gap, caregivers will need new financial tools and resources - including assistance and guidance from non-profits, community groups and employers – that help them protect their families' future.

About MetLife's Center for Special Needs Planning

The MetLife Center for Special Needs Planning[SM] works with national non-profits and individuals to help support the mutual goal of helping individuals with special needs. The Center is dedicated to helping families plan for the future of dependents with special needs. Helping you answer those questions, directing you to the right resources, and just being there as a resource and advocate for you, is an important part of what we do. If you'd like to find out more or you'd like to be referred to a local MetLife Special Needs Planner, please call 1-877-638-3375, or visit our website at www.metlife.com/specialneeds.

MetLife's Special Needs Planners are Financial Services Representatives and do not provide legal or tax advice.

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About GfK

GfK Custom Research North America is part of the GfK Group, one of the world's largest and most prestigious market research organizations, operating in more than 100 countries. Headquartered in New York City, with 10 offices in the U.S., GfK Custom Research North America provides full-service market research and consulting services in the areas of Customer Loyalty, Product Development, Brand & Communications, Channels, Thought Leadership, Innovation, and Public Affairs.

Basic Financial Guidance For Caregivers

Below are 10 steps to help caregivers get started in preparing for the financial future of their dependent with special needs. Each circumstance is unique, so caregivers should consider their own situation carefully.

1

Plan for future medical, educational and housing needs for your dependent.
Start by thinking about what your dependent's needs will be in the future – and develop your financial strategy based on these projections. Will they need weekly/daily medical treatments? Will they need funds for college? Would they live in a group home or need their own space?

2

Review beneficiary designations.
To continue to receive federal aid, dependents with special needs cannot have any assets in their name (cash, art, jewelry) that is worth more than $2,000. Check with close friends and family to see if they have designated your dependent to receive any inheritance or insurance benefits from their estate– if they have, it's important that they leave this amount to your dependent's special needs trust (see number eight on this list for information on trusts). Don't let well-intentioned friends and family unknowingly cause your dependent to lose access to valuable resources.

3

Have a family meeting to discuss your dependent's future needs.
Just as caring for a dependent with special needs is a family affair, so is financially related planning. With the thoughts that you have prepared on your dependent's special needs throughout their life, meet with your family members to discuss their concerns and options for future care. This is also a good time to broach the beneficiary designation issue discussed above.

4

Speak with a special needs financial professional and create a team of professionals to assist you in planning.
Once you have determined the current and future financial needs of your dependent with special needs, it's important to pull together a support team that can help guide you through the variety of options available to you and your family. The composition of the team may vary depending on your unique situation, but it could include an attorney, a health professional and a school guidance counselor, among others.

5

Contact local nonprofit organizations for additional resource support.
Your local nonprofit may be able to provide resources that can help with planning or that supplement the standard services provided by government agencies. To find out what services may be available, you may want to begin with the list of national non-profits below. A good starting place is to first contact a nonprofit dedicated to your dependent's special need.

6

Apply for government benefits.

Government benefits – such as Medicaid and Social Security (www.ssa.gov) – may help provide for your dependent's needs in the form of medical treatments and supplies, equipment, financial assistance and more. Visit your local Social Security Office to find out what benefits your dependent may qualify for; call or visit their website first to find out what documents you should have with you for your visit.

7

Prepare your Last Will and Testament (review and update periodically).

A Will declares how you want your estate to be distributed and allows you to select a guardian for your dependent when you pass away. It may be especially important to prevent automatic asset distributions directly to a person with special needs, and to be cognizant to not leave your dependent with special needs any assets in excess of $2,000 (as discussed in number two above.)

8

Consider setting up a special needs trust.

This allows caregivers a way to provide for their dependent's care and quality of life, without disqualifying them for federal assistance. Trusts can be set up either funded or unfunded, and must be overseen by a guardian – often the dependent's caregiver and/or a bank trust officer. Funds can be contributed gradually over the years, or the trust can be designated as a beneficiary of an inheritance or life insurance policy. The money in the trust must be used to enhance the dependent with special needs quality of life, and can help to supplement standard services and benefits provided by government agencies.

9

Apply for guardianship and conservatorship, if applicable.

Caregivers must apply for a guardianship or conservatorship to maintain legal control over financial and healthcare decisions once a dependent reaches the age of 18. This can take up to a year in some states, so it's best to start this process when the dependent turns 17. There are different levels of guardianship and conservatorship available, depending on the dependent's capabilities and needs. For example, a limited guardianship could be solely for financial or healthcare-related decisions.

10

Prepare a Letter of Intent.

Although not legally binding, this document is important for providing direction for the person or persons who will care for your dependent with special needs and should be stored with other vital documents, such as your Will. Thinks of it as a "letter to the caregiver" – it can cover day-to-day care routines such as what medical assistance is needed, as well as quality of life guidance such as what entertainment and activities should be provided.

Representative Sample of Non-Profit Organizations

The MetLife Center for Special Needs Planning[SM] has worked with representatives from the following non-profit organizations.*

The Arc
www.thearc.org
(800) 433-5255

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

Autism Society
www.autism-society.org
(800) 3AUTISM / (800) 328-8476)

The Autism Society increases public awareness about the day-to-day issues faced by people on the Autism spectrum, advocating for appropriate services for individuals across the lifespan and providing the latest information regarding treatment, education, research, and advocacy.

Huntington's Disease Society of America (HDSA)
www.hdsa.org
(800) 345-HDSA / (800) 345-4372

HDSA a national non-profit voluntary health agency who provides vital support, information and educational services to improve the lives of those affected by Huntington's Disease (HD), offer resources and guidance for HD families and promotes and supports research to find a cure for HD.

LA Goal
www.lagoal.org
(310) 838-5274

L.A. GOAL's educational, vocational, and recreational programs provide opportunities for adults with developmental disabilities to increase their independence and employability. Through its art and outreach activities, L.A. GOAL educates the community about the abilities of people with developmental disabilities.

National Down Syndrome Congress (NDSC)
www.ndsccenter.org
(800) 232-NDSC / (800) 232-6372

NDSC provides information, advocacy and support concerning all aspects of life for individuals with Down syndrome.

National Organization for Rare Disorders (NORD)
www.rarediseases.org
(203) 744-0100 /
Toll free: (800) 999-6673
(voicemail only)

NORD is dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

TASH
www.tash.org
(202) 540-9020

TASH is a civil rights organization for, and of, people with mental disability, autism, cerebral palsy, physical disabilities and other conditions that make full integration a challenge. An organization of members concerned with human dignity, civil rights, education, and independence for all individuals with disabilities.

Tuberous Sclerosis Alliance (TS Alliance)
www.tsalliance.org
(800) 225-6872

TS Alliance promotes and supports research and medical efforts to find a cure for tuberous sclerosis complex (TSC), assists people and families affected, educates the public about those affected by TSC and the benefits of increased investment in TSC research for related disorders such as Autism, Epilepsy, and

United Cerebral Palsy (UCP)
www.ucp.org
(800) 872-5827

United Cerebral Palsy (UCP) educates, advocates and provides support services to ensure a life without limits for people with a spectrum of disabilities.

***These organizations are not affiliated with MetLife.**