

**Special Needs Caregivers:  
An Increased Need for Support and Professional Guidance**

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## **Abstract**

Planning for families with special needs dependents can be complex and overwhelming. The purpose of this study is to gauge the preparedness of parents and guardians (caregivers) of disabled minor and adult dependents with regard to the future, to identify stressors currently faced by caregivers, and to pinpoint ways that professionals can best assist special needs families. In summary, most caregivers have not planned for the event when they are no longer alive or able to care for their dependent and caregivers currently face great amounts of both financial and emotional stressors. Less than one-fourth of caregivers have completed a letter of intent and of those that have not completed a letter, 70% are unfamiliar with the planning tool. A great place for a family to start planning is to begin drafting a letter of intent that serves as a blue print to provide continuity of care in their absence. Both financial planners and therapists are uniquely qualified to guide caregivers in this part of the planning process.

## **Introduction**

Planning for a dependent's future is essential; however, the need is substantially elevated for dependents with special needs. Failing to plan affects quality of life and can cause considerable trauma to special needs dependents because lack of planning leads to disruption in continuity of care (Lefly, 1999; Smith, Hatfield, & Miller, 2000; Rajput, 2001). Clients with special needs dependents are more prevalent than many realize. While estimates vary, the 2010 American Community Survey determined approximately 12% of noninstitutionalized civilians in the United States (8% of population under the age of 65) suffer from disability including difficulty with hearing, vision, cognition, ambulation and self-sufficiency.

Caregivers of disabled dependents are not planning for the financial and emotional future of their children due to varying reasons from unawareness to unwillingness to face their own mortality (Smith et al., 2000). Less than four out of ten families have a plan in place for their special needs dependent in the event they are unable to continue caring for them. Of those with a plan, only one-fourth of them have a plan that includes a crucial element, a special needs trust; resulting in less than 10% of special needs families having optimal plans (Lauderdale & Huston, 2012).

The purpose of this study is to gauge the preparedness of parents and guardians (caregivers) of disabled minor and adult dependents with regard to the future, to identify stressors currently faced by caregivers, and to pinpoint a starting place where professionals can best assist families with special needs dependents. Preparedness encompasses both familiarity with, and completion of, crucial planning steps. Stressors include lack of information as well as socio-emotional and financial concerns. Results from this study can be used by financial and

mental health professionals to improve caregiver preparedness and reduce stressors where possible when dealing with clients that have special needs dependents.

## **Background Information**

### *The Need for Planning*

Comprehensive financial planning is important for all families and general planning commonly includes evaluating the impact on loved ones such as children and grandchildren (Pabón, 2005). Planning for special needs dependents is not an option; it is a necessity (Rajput 2001). Maintaining the dependent's quality of life depends on it. Most special needs dependents rely on their parent's financial, physical, and emotional support to function. When the parent is no longer able to provide assistance, the children are left with whatever means and support passed to them through wills and trusts from their parents (Pabón, 2005). Losing a lifelong caretaker prematurely occurs often and many times will permanently traumatize a special needs dependent. "Management of this transition and [determining] who or what services replace parental care are crucial issues for families and service systems" (Bigby, 1996).

Expenses related to children can quickly consume a substantial portion of a family's budget. Having children with special needs compounds the expenses and far exceeds the costs associated with typical healthy children (Pabón, 2005). Additionally, caregivers have to plan to provide for two generations of expenses, since disabled children are now expected to outlive their parents (Bigby, 1996). Clients need to plan for longer life expectancies because of medical advancements (Rajput, 2001). Many disabilities are frequently associated with comorbidity

medical issues that take additional time and money to care for (Rajput 2001). In addition to medical expenses, one must account for costs related to therapy and intervention strategies with schools and counselors. Balancing work and caring for a special needs dependent is taxing and may require the caregiver to leave the labor force and forego income (Gould, 2004; Graetz, 2010; Grassi, 2008; Heller & Kramer, 2009; Sharpe & Baker, 2007; Thomas, 2005).

Costs and complexity vary with types of disability. For example, with some physical disabilities gainful employment that results in financial self-sufficiency may be possible which reduces the need for additional financial planning. On the other hand, mental disabilities almost always require substantial planning. Disabilities can be classified in many different ways. For instance, mental disability are classified as: developmental (e.g. mental retardation, autism, Down's syndrome, and Fragile X) and mental illness (e.g., schizophrenia, manic depressive and schizo-affective disorders). Mental disabilities usually prevent one from functioning in a normal environment (Rajput, 2001).

#### *Failure to Plan*

Special needs planning involves blending complex financial, legal and social/emotional details (Harmon, 2000; Rajput, 2001; Thorp, 2002; Vogel, 2003). Caregiver's knowledge about the need to plan and how to plan is crucial to achieving a plan (Pabón, 2000). However, researchers have confirmed that there is a lack of easily accessible and understandable information available to parents (Heller, 2000; Lauderdale, Durband, Scott & Springer, 2010; Pabón, 2000; Rajput, 1998; Smith & Tobin, 1989).

Most families are not formalizing plans which can be catastrophic (Lauderdale et al., 2010; Lauderdale & Huston, 2012). In addition to the obvious financial implications, other potential social/emotional consequences for the dependent include: failure to trust others in a reasonable time frame, resistance of services, as well as considerable trauma because continuity of care is lacking (Lefly, 1999; Smith et al., 2000)

Researchers document a variety reasons for the failure to plan. Lack of accessible and understandable information and lack of professional assistance has been cited for decades (Heller, 2000; Smith & Tobin, 1989). Other social/emotional barriers include parent's inability to accept their own mortality, interdependence with offspring, unattractive residential options, difficulty giving up long term caregiving routines, fear of safety, and denial/hope they will get better (Lauderdale et al., 2010; Lauderdale & Huston, 2012; Smith et al., 2000).

### *Stressors*

Researchers analogize the diagnosis of a child's disability to the grieving process one experiences when loved one dies (Norton & Drew, 1994). The whole family dynamic is impacted by a dependent with special needs and siblings and spousal relations are affected. Some research reports divorce rates as high as 90% (Kraus, 2005); however others actually recognize that it in some cases it may bring spouses closer (Norton & Drew, 1994). In any divorce, having children involved always adds a layer of complexity regarding custody and living arrangements; however, additional complications arise when a dependent has special needs (Kraus, 2005).

Providing care and management for a disabled dependent can be very exhausting, highly emotional, and painful for many families (Harmon, 2000). Norton & Drew (1994) note particular problem areas for children with autism to include: bonding issues, sleep pattern problems,

unpredictable behavior, necessity for routine, splinter effects, need for respite care and financial matters. With the exhaustion and emotional drain comes a great need for respite care regardless of the disability type; however the frequency of need may vary (Norton & Drew, 1994).

Relationships with siblings are complex as well. Many caregivers feel guilty because more time and finances are directed towards the disabled siblings. While mothers want siblings to be the key caretaker after their death, they wonder if the sibling will be able or choose to do so (Pruchno, Patrick, & Burant, 1996; Smith et al., 2000). Explicit and appropriate planning can alleviate the worry as well as protect the disabled dependent.

#### *Where Do Professionals Fit In?*

Professional help is needed for both encouragement and creations of plans (Lauderdale & Huston, 2012; Smith et al., 2000). Professionals such as financial planners and therapists are uniquely positioned to assist with encouragement and completion of, at least part of, the plan (Lauderdale & Huston, 2012). Attorneys are required for drafting some of the documents (e.g., wills and trusts), but most of special needs planning can be conducted by non-attorneys. An attorney will need to confirm that the strategies are appropriate and do not inadvertently disqualify the dependent from any government benefits, but this can be accomplished when they draft the necessary documents (Stone, 2006).

Very little attention has been paid to the efficacy or implementation of plans (Bigby, 1996). Families are more likely to have a quality plan when they receive assistance from financial professionals to create a plan (Lauderdale & Huston, 2012). Research also shows that encouragement to plan by mental health professionals results in plans that include a special needs trust, the legal centerpiece to a special needs plan (Lauderdale & Huston, 2012).

More planners are needed to assist the underserved market of special needs families but appropriate knowledge is necessary due to the complex nature of planning (Harmon, 2000; Pabón, 2000; Rajput 2001). Seventy percent of special needs financial planners have a family member with a disability (Pabón, 2000; DeSimone, 2003).

Professionals working with special needs families must have empathy, sincerity, and patience (Pabón, 2000; Vogel, 2003). Planners and therapists need to assume a role in helping clients make decisions vital to children's future (Rajput 2001); however, they must be prepared for a roller coaster of emotions when working with these caregiver clients (Harmon, 2000). When working with families that have special needs dependents, financial therapists should be prepared for the first meeting to be more about getting to know the client, the family, in terms of their emotional and financial well being. It is helpful to start with a list of questions to assess the current situation and to be prepared for a long list of questions from the parents in response (Staebell, 2000).

### *Letter of Intent*

A letter of intent is an important non-legal estate planning tool necessary to plan for transition of caregivers in the event that a parent is no longer able to care for a special needs child (Greenbaum, 2007; Hoyt & Pollock, 2003; Nadworny & Haddad, 2008; Stevens, 2002). Some people refer to the letter of intent as special letters of instruction which mirrors the name of an estate planning tool, side letter of instruction. These letters of intent essentially serve the same purpose but tend to be much more detailed when disabled dependents are involved. While they are not legally binding documents, judges rarely ignore them when admitted for evidence of



intent of will or trusts (Thorp, 2002). Letters of intent should also include a caregiver's hopes, dreams and vision for the dependents future which can be emotionally draining and uplifting at the same time.

A letter of intent is an ideal place for a financial therapist to start working with a family to create a road map or a blue print for a transition when it is chosen or becomes necessary (Thorpe, 2002). Letters of intent lay out the needs, care instructions, and communicates crucial information for one assuming responsibility. No two letters are the same and some become binders while others use online tools. They are dynamic documents and must be updated as circumstances change (Nadworny & Haddad, 2008; Stevens, 2002).

Appropriate information includes: contact information of family members, medical professionals, legal representatives, financial representatives (and even those that should be avoided). Specific details of the disability should include a descriptive history and current status. Personal information such as likes/dislikes, entertainment preferences, dietary needs, medical issues, and religious affiliations are important elements to include. Letters of intent also contain financial and legal information. Financial information includes employment records, assets/liabilities, and any benefits received. Legal issues include information about the existence and location of wills, trusts, and other similar documents (Davis, 2003; Rajput, 2001; Thorp, 2002). Finally, information regarding guardianship/conservatorship/advocate of the estate and the person is crucial; however, financial therapists should be very aware that this is often the barrier that prevents many from initiating or completing the planning process.

**\*\*\*\*To provide an applied approach to benefit attendees, note that sample letters of intent and further discussion will be provided during the presentation of this paper if accepted.\*\*\*\***

## **Methodology**

Data used in this study are from a proprietary survey sponsored by an insurance company and collected by a third party market research firm from May to June, 2011. The survey was administered online to a nationwide sample of 1004 caregivers of minor and adult dependents with special needs. Panel participants were screened to include parents having dependents with special needs.

## **Results**

Table 1 presents descriptive statistics for the respondent (caregiver) demographics. Approximately three out of four caregivers are under the age of 50 with a mean age of 43. Almost three fourths of caregivers (34%) have had at least some college, graduated from college or completed postgraduate work. Caregivers are predominantly married heterosexual women with income and net worth less than \$50,000. Over half (56%) of the caregivers also work either full time, part time, or are self-employed.

While all caregivers (1004) have at least one dependent with a disability, approximately one out of five (22%) have more than one child with disability. The majority (52%) of the dependents are expected to be financially reliant on their caregivers for the rest of their lives. Table 2 presents descriptive demographic statistics on the 1264 dependents of the caregivers. Over 40% of the dependents are already 18 years or older. Dependents typically have more than one type of disability. Almost half (45%) of the dependents face developmental challenges and one third (32%) cognitive disabilities. Emotional disorders affect 42% of the dependents. Approximately a third of dependents experience medical and/or physical disabilities.

Caregivers appear to be dissatisfied with the usefulness of resources available to them for financial guidance. Table 3 presents sources considered useful for financial guidance. Internet

and medical professionals account for the two most useful resources for financial guidance. An alarming 45% of caregivers found financial guidance useful from their medical professionals. About one out of three caregivers found that friends/relatives and/or government agencies were useful.

Table 4 shows crucial planning steps and whether caregivers completed the step and if they have not completed the step, how familiar they are with the critical steps. Less than half of all caregivers have completed any one step. Less than four of ten (38%) caregivers have completed a will. Almost eight out of ten have not completed a letter of intent, special needs trust, or established a plan for financial assistance for the dependent's lifetime. Approximately one third of respondents have started setting aside money for the dependent(s), identified a trustee, and established a residential plan for the dependent. Almost half (49%) have identified a trustee. Caregivers that have not completed steps were also asked if they are familiar with, neutral, or not familiar with the planning step. Not a single planning step has familiarity by more than one third of the non-planners. Letter of intent had highest not familiar response, with almost three out of four (70%) not familiar with letters of intent. A close second was special needs trust where 68% of non-planners are not familiar with the step.

Both financial and family concerns are prevalent among special needs caregivers. Table 5 presents caregivers concerns separated into two categories, financial and family/emotional. At least two out of five caregivers have concerns in all areas. Financial concerns weigh heaviest on these caregivers. In terms of financial concerns, providing lifetime care of dependents and appropriate health insurance were selected by over 60% of respondents, while concern for quality of life and preserving government benefits were both selected by more than 70% of caregivers. Family and emotion concerns are also substantial. Approximately one-half of the

respondents are concerned about having to care for aging parents and/or want for more family time together. Approximately two out of five caregivers are also concerned about the impact that caring for their special needs dependent(s) has on their marriage and other dependents within the family.

### **Discussion**

Caregivers lack preparedness in the event they are no longer able to care for their disabled dependent. Not only do they lack explicit planning, those that have not completed steps lack familiarity with what they should be doing to plan. Perhaps the most important step with regard to emotional stability of the dependent is to complete the letter of intent. Even if a caregiver has designated a guardian, if they do not know how to provide continuity of care the dependent will suffer. Less than one-fourth of caregivers have completed a letter of intent and those that have not completed a letter have the highest incidence of unfamiliarity (70%).

Caregivers of special needs dependents are stressed. Current emotional and family stresses are burdensome. Most of these caregivers are in the sandwich generation and have concern about their own aging parents. Results regarding stress within spousal relationships as well as the impact on siblings is consistent with previous literature. The divorce rate among couples with a special needs child has been reported as high as 90% (Kraus, 2005). Although this appears not to be the case with the data used in this study, it is important to note that these results are self-reported and there may be a social desirability bias in terms of placing the blame on a special needs child.

The future of their dependent(s) provides substantial stress for caregiver's. Concern for providing on-going quality of life for their dependent is of greatest concern, and continuity of care is a critical determining factor. Most steps of a special needs plan do not require a large

monetary investment and some require no money at all. Planning at any level will potentially reduce overall stress of caregivers regarding the future wellbeing of their dependent.

Professionals can initiate the planning process by working with clients to create a letter of intent. Financial therapists are uniquely positioned to assist in the process because of their expertise in developing relationships with their clients that address social and emotional dimensions in addition to the financial elements involved in the planning process. One of the greatest stumbling blocks in the process tends to be identifying a guardian, and family dynamics plays a significant role in this decision making process. Financial planners that do not feel comfortable addressing non-financial planning tasks, such as letters of intent, should consider referring clients to therapists to assist in obtaining improved financial and emotional outcomes for their clients.

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## Tables

**Table 1. Descriptive Statistics of Respondent (Caregiver) Demographics**

Variable	Total Sample <i>N=1004</i>
Education:	<i>High School (or less)</i> 26%
	<i>Some Post-Secondary</i> 42%
	<i>College (or more)</i> 32%
Respondent Age	43
Gender (female)	79%
Household Income:	<i>&lt;\$30,000</i> 32%
	<i>\$30,000-\$50,000</i> 29%
	<i>\$50,000-\$74,999</i> 21%
	<i>\$75,000 or more</i> 17%
Employment Status:	<i>Full Time</i> 39%
	<i>Part Time</i> 14%
	<i>Self-Employed</i> 3%
	<i>Homemaker</i> 25%
	<i>Unemployed</i> 7%
	<i>Retired</i> 6%
	<i>Student</i> 3%
	<i>Other</i> 3%
Sexual Orientation:	<i>Heterosexual</i> 94%
	<i>Gay, Lesbian, Bisexual, Transgender</i> 4%
	<i>Preferred not to answer</i> 3%
Marital Status:	<i>Married</i> 72%
	<i>Single Never Married</i> 7%
	<i>Domestic Partners</i> 9%
	<i>Divorced</i> 14%
	<i>Separated</i> 4%
	<i>Widowed</i> 3%
Household's Net Worth:	<i>&lt;\$50,000</i> 57%

\$50,000-\$99,999	12%
\$100,000 or more	22%
<i>Preferred not to respond</i>	9%

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**Table 2. Descriptive Statistics of Dependent Demographics**

Variable	Total Sample
	<i>N=1264</i>
Dependent Age:	<i>5-12</i> 32%
	<i>13-17</i> 18%
	<i>18 or older</i> 41%
Type of Disability (all that apply):	<i>Developmental</i> 45%
	<i>Emotional</i> 42%
	<i>Cognitive</i> 32%
	<i>Medical</i> 35%
	<i>Physical</i> 34%

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**Table 3. Descriptive Statistics of Sources Considered Useful for Financial Guidance**

<b>Variable</b>	<b>All</b> <i>N=1004</i>
Internet/Web	47%
Medical Professional	45%
Friend or Relative	37%
Government Agencies	34%
Support Groups	32%
Non Profit Organizations	30%

**Table 4. Descriptive Statistics of Important Planning Steps**

*N=1004 (100%) for Completed; Familiar with and Not Familiar with is only of those Not Completed*

	Completed	Familiar With	Not Familiar With
Letter of Intent	23%	14%	70%
Special Needs Trust	21%	14%	68%
Identify a Trustee	33%	24%	56%
Plan for Lifetime Financial Assistance for Dependent	23%	21%	55%
Plan Where Dependent is to Live When You are No Longer Alive	36%	24%	49%
Identify a Guardian	49%	32%	45%
Write a Will	38%	32%	41%
Begin Setting Aside Money for Dependent's Lifetime Needs	32%	31%	39%

**Table 5. Descriptive Statistics of Caregivers Concerns**

*N=1004, whole sample*

<b>Variable</b>	<b>Concerned</b>	<b>Not Concerned</b>
<b>Financial</b>		
Providing a Good Quality of Life for Your Dependent	76%	8%
Preserving Government Benefits Eligibility for Dependent	71%	10%
Providing Lifetime Care for Your Dependent	69%	14%
Having Appropriate Health Insurance	63%	8%
<b>Family and Emotional</b>		
Having Resources and Time to Care for Aging Parents	53%	10%
Having More Time to Spend with Family	48%	13%
Impact on your Other Dependents	45%	17%
Impact on Your Marriage	40%	25%