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Financial Therapy and Planning for Families with Special Needs Children

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This study examines factors associated with the likelihood of having a plan that includes a special needs trust among families that have disabled minor children. Descriptive analyses indicate that the top two reasons families provide for not having a plan are the inability to save and no perceived need. Among families that do indicate having a plan, most do not include a special needs trust. Multivariate analyses reveal that professional involvement (financial, legal, and mental health professionals) is a key factor to increasing the likelihood of having a plan with a special needs trust. Families that have met with a financial advisor are 23 times more likely, and families who are encouraged to create a plan by a mental health professional are almost 3 times more likely, to have a plan that includes a special needs trust. Results from this study suggest that financial therapists are uniquely positioned to educate and ensure that appropriate plans are in place to provide for the future of children with special needs.

Keywords: financial therapy; special needs financial planning

INTRODUCTION

Financial therapy is the study of cognitive, emotional, behavioral, relational, economic, and integrative aspects of financial health (Grable, McGill, Britt, 2010). Financial therapy encompasses the intersection where finances and emotions meet and is particularly relevant in cases where financial decisions are required and where circumstances surrounding these decisions are highly emotional. Planning the future for children with special needs requires several decisions, including financial decisions, within a highly emotional context. Financial therapy may provide an ideal approach to future planning for families that have special needs children.
All families need to plan for the future of their children in case the parents predecease their children while they are minors. Parents who have children with disabilities (special needs families) face additional complex challenges when trying to prepare for the future. In most families, the expectation is that children will attain financial and social independence at some point after reaching the age of majority. When defining children with special needs, disabilities cover a broad scope, both mental and physical. Disorders range from mobility disabilities to spectrum disorders, such as autism and Asperger’s Syndrome, with autism becoming prevalent across the nation (Graetz, 2010; Sharpe & Baker, 2007; Saposnek, Perryman, Berkow, & Ellsworth, 2005). With most special needs diagnoses, parents must plan for partial or complete dependency extending throughout the child’s life span. Further, special needs families need to plan to provide financial support for multiple generations, as well as address how to provide continuity of care when one generation passes on (Grassi, 2008; Nadworny & Haddad, 2007).

Over two decades ago, Heller and Factor (1987) found that the majority of parents having a child with a disability had no future financial arrangement for their child and more recent literature shows that adequate planning is still an impediment among special needs families (Graetz, 2010; Lauderdale, Durband, Scott, & Springer 2010; Smith & Tobin, 1989). Even though planning is vital for special needs families and the implications for not planning impact multiple generations, parents are still not formalizing plans. A comprehensive special needs plan encompasses financial aspects, legal planning matters, emotional concerns, while also taking into consideration the social and family support needs (Hoyt & Pollock, 2003; Nadworny & Haddad, 2007). A Special Needs Trust (SNT), also known as a Supplemental Needs Trust, can provide resource protection through management and spendthrift shelter, allow for guardianship due to incompetence (either current or anticipated), and most importantly can prevent disqualification of government assistance due to asset ownership (Caudill, 2009). SNTs serve as the fundamental component of a plan (Grassi, 2008).

Special needs planning is vital, but is typically not present within families that have special needs children. An SNT is a crucial planning tool for families with disabled, permanently dependent offspring, as it provides resource protection, guardianship provision, and preservation of government assistance. The purpose of this study is to examine factors that are associated with having a plan that includes a special needs trust. Understanding the factors associated with explaining planning variation among special needs families can provide insight into what interventions may be associated with increasing planning among these families. The decision to have a plan is conceptualized as being influenced by both human capital and motivational factors. In order to better assist special needs families in meeting their planning needs, it is useful to understand which of these factors is most associated with having a plan that includes a special needs trust. Results from this study can be used by financial and mental health professionals who come in contact with special needs families to improve plan status, both in terms of plan adoption and quality.
BACKGROUND INFORMATION/LITERATURE REVIEW

The Need for Special Planning

Planning for the future of special needs loved ones has always been a necessity; however, due to the higher incidence of diagnosed disabilities, longer life spans attributable to medical advancements, increasing long-term care costs, and the reduction of government support, the importance of special needs planning is paramount (Erickson & Lee, 2008; Hoyt & Pollock, 2003; Nadworny & Haddad, 2007; Saposnek et al., 2005). Families caring for disabled loved ones face lifetime financial and social/emotional demands. Costs may arise from intervention strategies involving counselors, therapists, schools (or a combination of the three), and a multitude of health care providers; all of these expenses are on top of the traditional expenses associated with caring for a child. Pressure for a parent to leave the labor market arises many times when excessive appointments must be attended with therapists, doctors, and teachers, when care providers are not able to manage behavioral issues of the child, or when excessive illnesses remove the child from school (i.e., leaving the parent to take care of them and miss work). The decision to leave the labor market must be carefully balanced with the need to provide healthcare coverage (Graetz, 2010; Heller & Kramer, 2009; Grassi, 2008; Sharpe & Baker, 2007; Thomas, 2005; Gould 2004).

Heller (2000) and Smith and Tobin (1989) found that both families and professionals lack the necessary information on regulations, rights, and benefits to make effective choices for their children. Understanding the consequences of poor planning and lack of planning is critical. Special needs families require appropriate guidance and very few professionals are trained in both the technical (i.e., financial and legal) and emotional aspects of planning. Families usually need to seek the help of a combination of professionals (e.g., financial planners, estate planners, and mental health professionals) who understand the regulations, eligibility requirements, current tax laws, as well as the social and emotional issues that are associated with planning for this particular target audience. Financial advisors and attorneys will pay particular attention to the interaction between Medicaid, Medicare, Supplemental Security Income (SSI), Social Security Disability Income (SSDI), and other income resources (Sharpe & Baker, 2007). It is important to consult attorneys in advance of implementing other strategies to ensure that strategies do not inadvertently establish potential barriers to government benefits or estate planning objectives (Stone, 2006). But the social and emotional aspects tend to be overlooked by many professionals.

While creating a comprehensive financial plan, nearly everyone should consider addressing components of asset acquisition planning, liability and insurance planning, savings and investment planning, employee benefits planning, tax planning, retirement planning, and estate planning (Gitman & Joehnk, 2008). A special needs plan should be comprehensive in nature and, at a minimum, include several documents, including legal (e.g., a will, special needs trust, power of attorney or guardianship) and non-legal (e.g.,
letter of intent), as well as financial planning tools. In Figure 1, Nadworny and Haddad (2008) present a planning model that combines a traditional planning pyramid with a special needs planning pyramid to create the comprehensive special needs plan. Starting from the foundation up, the plan is segmented into legal and estate planning, risk management/insurance protection, cash reserves, cash management and budgeting, and wealth distribution. From a legal and financial standpoint, proper planning must be in place to balance and manage the resources available to the individual while maintaining eligibility for the government entitlements that he/she qualifies to receive, Medicaid long-term care in particular (Grassi, 2008; Jackins, Blank, Shulmna, & Onello 2010).
Figure 1. Comprehensive Special Needs Planning
Traditional Planning Pyramid + Special Needs Planning Pyramid = Comprehensive Special Needs Planning (Nadworny & Haddad, 2008, p. 14)
Special Needs Planning Uniqueness

Planning for the special needs child has two main focuses: financial support for the child’s future and continuity of the child’s care to provide necessary social and emotional support. While all parts of a special needs comprehensive plan are important, the special needs trust in coordination with a good estate plan is crucial to fulfilling the financial needs of a disabled person. Although the plan can be funded in a variety of ways depending on the family’s financial position, the trust is essential to properly implement the plan (Grassi, 2008; Hoyt & Pollock, 2003; Nadworny & Haddad, 2008; Stevens, 2002). Since parents generally know what their child needs more than anyone else, a letter of intent provides instructions to the guardian and trustee to facilitate the best continuity of care for the disabled child (Moore & Landsman, 2010).

The only reliable method to ensure that an inheritance actually has a chance of being available to a person with a disability when he or she needs it is through the utilization of a Special Needs Trust (Rhatigan, n.d.). Special Needs Trusts (SNT) are most commonly referred to as the “legal centerpiece” of a special needs plan (Enea, 2008). They are designed to control resources for the disabled individual that may struggle with management of assets, but more importantly to supplement existing government benefits (Rhatigan, n.d.; Rosenberg, 2000). SNTs are utilized to title assets in the name of the trustee rather than the name of a mentally or physically disabled individual, while allowing them to still qualify for federal and state government means-based entitlements, such as SSI and Medicaid.

Other estate planning documents, including a last will and testament, general durable power of attorney for financial affairs, durable medical power of attorney, and guardianship, are important to discuss with a qualified attorney. Wills are an important tool for everyone, regardless of disability, and guardianship for minor children needs to be addressed in the will as well (Gitman & Joehnk, 2008; Grassi 2008). All wills with the intent to transfer assets to a disabled individual, including wills for parents, grandparents, friends and others, should state that the gift is directed to the SNT and not the special needs individual, otherwise benefits may be taken away (Grassi; Hoyt & Pollock, 2003; Nadworny & Haddad, 2008; Stevens, 2002). Generally, in order to maintain benefits, no gifts should be made outright to a special needs person, including life insurance death benefits and other accounts, such as retirement and payable on death (POD) accounts. This requires the coordination of other people’s estate plans when others are trying to help.

A letter of intent, also known as a special letter of instruction, is an important non-legal estate planning tool necessary to provide for continuity of care in the event that a parent is no longer able to care for a special needs child, be it through death or incapability (Greenbaum, 2007; Hoyt & Pollock, 2003; Nadworny & Haddad, 2008; Stevens, 2002). Some professionals believe this document is a catalyst to encourage planning by demystifying the planning process and breaking it down into simple, yet lengthy details (Nadworny & Haddad). This self-drafted document includes biographical, legal, financial, support considerations, and other information. Biographical information typically includes:
personal demographics, personal and family medical history, current medical and health information, important daily living routines, emotional considerations, and personality traits of the disabled child. Legal information needs to be provided on both the parents and disabled child and includes: the location of documents such as wills, trusts, powers of attorney, as well as information on guardianship plans, any potential inheritances to be received, and final arrangements, if any. Financial information regarding the location and existence of bank accounts, insurance policies, government benefits, and the contact information for any financial advisors and government benefit agents should also be included. To maintain the disabled individual's support structure, information must be included about family members, therapy plans, social and recreation information, professional support contacts, government care support, and contact information for friends. Other details one wishes to provide regarding hopes, dreams, and a vision for their child's future should be incorporated into the letter of intent (Hoyt & Pollock, 2003; Nadworny & Haddad, 2008; Stevens, 2002). This document is ever-changing, can range from a few pages, to multiple binders, and serves to facilitate a transition that is as seamless as possible, addressing both financial and social/emotional aspects of the child’s life (Etmanski, Collins, & Cammack, 2002).

**Social and Emotional Considerations**

Proper comprehensive special needs planning includes much more than simply addressing the financial and legal concerns of the family. Families, communities, churches, therapists, educational peers, and other friends provide invaluable support to families and special needs individuals (Hoyt & Pollock, 2003; Nadworny & Haddad, 2008; Stevens, 2002). Diagnosis of disabilities has a huge impact on the household and varies based on the type of disability. Davis (2003) also suggested that older parents with deteriorating health face greater concerns with the need to plan.

Typically, a parent's greatest fear for the future of their special needs child involves “what will happen when I am no longer able to care for my child or am no longer alive to care for them?” (Davis, 2003; Lauderdale et al., 2010). Parental concerns arise regarding how their children will be financially supported, where they will live, who will take care of them, who they will socialize with, and how they can maintain everything they are doing right now (Lauderdale et al.). Other parental fears include the child's financial independence, employability, and the ability for the child to live independently (Davis, 2003). Most of these fears are justified. Over 75% of special needs adults are unemployed (Grassi, 2008). Furthermore, one-third of all households containing at least one family member with a mental disability live below the poverty threshold (The American Community Survey, 2007). Some parents have unrealistic expectations of the future of their child, while many parents harbor anger, grief, and guilt; all of which can hinder planning (Grassi, 2008).

Marital and other family relational issues arise from the stressors of raising a special needs child (Sharpe & Baker, 2007). Spouses often grow apart as a result of the pressure of...
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raising a child with a disability (Krauss, 2005). Parents argue over many things concerning their special needs child (e.g., treatment strategy for child) and they are encouraged to seek the help of professionals before engaging in long-term planning (Saposnek et al., 2005). Researchers agree that the divorce rate for parents with a special needs child, reported to be as high as 90%, is substantially higher than traditional families (Grassi, 2008; Kraus). In the event that marital problems do persist and the marriage ends, financial planners should advise funding a special needs trust prior to a divorce to avoid unnecessary financial battles and, more importantly, to ensure that the child is provided for throughout his life and upon death of the caregiver(s) (Kraus).

Family and other social support, both financially and emotionally, play an important role in providing for special needs children. Within the family, grandparents are often involved in providing social/emotional and financial support. Many families fail to plan because they reason that other siblings are available to take care of their special needs child (Davis, 2003). Even though siblings are relied upon much of the time, many caregivers do not involve siblings of those with disabilities in the overall planning process (Graetz, 2010; Heller & Kramer, 2009). All relevant parties need to be appropriately integrated to prevent catastrophic errors that can ultimately lead to the loss of social support and government financial support. This integration includes family members understanding the proper way to give gifts or leave inheritances to disabled loved ones. Maintaining the social support structure can be crucial to providing stability of care for the special needs loved one (Nadworny & Haddad 2008).

Summary

Most special needs families are not currently properly planning for their children’s futures. The consequences are potentially catastrophic (Lauderdale et al., 2010). Special Needs Trusts remain vital to planning for disabled individuals in order to protect government benefits eligibility, manage assets, and provide care continuity when guardianship is deemed necessary (Stone, 2006). By keeping the social/emotional consequences to a minimum, letters of intent are also valuable tools to help transition care providers with as little stress on the special needs child as possible. Parents have many concerns about the social/emotional and financial effects of dying before their special needs child. These concerns can serve as motivation to create and implement a special needs plan. Trusted professionals, such as financial planners, attorneys, and mental health professionals, should recognize the unique needs of special needs families and can play a significant role in both encouraging and creating a suitable special needs plan.

STUDY BACKGROUND AND RESEARCH FRAMEWORK

All families (especially those with children) need to have a plan in place to address the risk of premature death. Families that have children with special needs must also consider the additional costs and requirements associated with disabilities that require lifetime dependency, thus planning for these families is imperative. Special needs plans typically include both financial (i.e., covering costs for dependents) and social aspects (i.e.,
covering care for dependents). There are many financial and legal products available that are appropriate for managing this type of risk.

Choosing to make a plan requires human capital input. Human capital refers to an individual’s knowledge and skills (Shultz, 1961). With regard to special needs planning, an individual’s knowledge can influence the ability to recognize (a) that a plan is needed and (b) that professional assistance (e.g., lawyer, financial planner) may be required. Motivation can be viewed as the impetus for action and the process that initiates goal-directed behavior (Maslow, 1943). In terms of special needs planning, motivation may be observed through a sense of urgency, concern for the dependent's future well-being, and the degree of complexity regarding the dependent's disability. The decision maker must be able to recognize that a plan is needed, have access to the knowledge required to create a plan, and have the motivation to implement the plan. The basic framework used to help identify factors that discriminate planning behavior among families that have children with special needs is as follows:

\[
\text{Special Needs Plan Status} = f(\text{knowledge, motivation})
\]

Access to knowledge can come from the decision maker's own stock of human capital and/or it can be acquired from another person (e.g., consulting one's social network or hiring professional expertise). Motivation may arise from a sense of urgency, concern, and/or the degree of complexity associated with the child's particular disabilities.

**METHODS**

**Data**

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 December 10-23, 2008. Surveys were administered to a nationwide sample of 580 American adults who are their household’s primary or shared financial decision maker and have a minor child with special needs living in the household. Data from the 10-minute survey were collected using an online format and samples are adjusted to be representative of the total adult U.S. population based on region, age within gender, education, household income, race/ethnicity, and propensity to be online.

**Measures**

The dependent variable used in the regression models was plan status. Two items within the data were used to determine the attributes of the regressand. First, the household must have indicated a positive response to the question, "Do you have a plan in place to cover the cost of care for your child with special needs when you are no longer here?" Within this subcategory, households were further classified into two groups: those that had a special needs trust as part of their plan and those who did not. Since a special
needs trust is nearly always indicated for families that have children with disabilities, the dependent variable was coded as 1 for families with a plan that includes a special needs trust and 0 if otherwise.

To capture human capital related to knowledge, two aspects must be considered: the respondent's own human capital and his/her access to the human capital of others. Own human capital indicators available in the data were the respondent's level of education, age, gender, and race. Education provides a measure of attained human capital and age provides a measure of experience. In terms of financial decision making, previous literature finds that males tend to have higher levels of financial literacy and minorities tend to have lower levels (Huston, 2010; Chen & Volpe, 2002). It was hypothesized that parents with greater stocks of human capital (i.e., college educated, older) would be more likely to have a plan.

Access to rented human capital is assessed through the response to the following question: "Have you spoken to a financial advisor about how to cover the expenses of your child with special needs when you are no longer here?" It was hypothesized that parents who had consulted with a financial advisor may have an increased ability (i.e., afforded through garnering expert advice) and would be more likely to have a plan.

Motivation for having a plan includes urgency, concern, and complexity. Respondent age and health were used to assess urgency. It was hypothesized that older parents, and/or those worried about their own health, may be more motivated to ensure a plan is in place.

Concern about the welfare of their child upon parental death was measured using eight variables stemming from the question, "How concerned are you regarding each of the following in the event that your child with special needs lives longer than you?" The eight items were coded into two variables: social/emotional concerns and financial concerns.

Social concerns were represented through the inclusion of four items:
1. “My child would no longer have a support system.”
2. “My child would not be able to live independently.”
3. “My child’s emotional needs would not be able to be met.”
4. “My child will become a burden to others.”

Financial concerns were represented by the remaining four items:
1. My child would not be able to be financially independent.
2. My child will not be able to afford their basic needs.
3. My child will not be able to cover additional costs created by their special needs.
4. My child will become a ward of the state.

Respondents were asked to rate each of the eight concerns on a Likert scale with the values from 1 (not at all concerned), 2 (somewhat concerned), 3 (concerned), 4 (very concerned), and 5 (extremely concerned). The social/emotional and financial concern variables ranged in value from 4 (not at all concerned) to 20 (extremely concerned). If the
total score was 16 or higher (i.e., very concerned or extremely concerned), the variable was coded as 1 to represent concern, and 0 otherwise. This threshold was chosen to represent respondents who had the most concern.

It was hypothesized that concern about either social/emotion or financial issues increases the motivation to have a plan. Concern was also captured through income. Relatively wealthy families (proxied by income because no wealth indicators were available) had an increased need to ensure appropriate allocation of wealth upon death. It was hypothesized that wealthier families may be more motivated to have a plan.

Complexity as a motivating factor was captured through the type of disability the child had. Disability classifications in the data were physical (i.e., ambulation, hearing, and visual), mental, and other. If a respondent chooses more than one category, the disability type was coded as multiple disabilities. It was hypothesized that parents that have a child with multiple disabilities may be more motivated to have a plan. Complexity was also measured by controlling for the additional cost associated with their special needs child. Higher costs may motivate parents to have a plan.

Analysis

Descriptive statistics, for the variables used to represent the knowledge and motive concepts, provided initial evidence of potential predictors of plan status. Logistic regression models were used to estimate the impact of knowledge and motivation factors in determining plan status. Within the subgroup of households that self-reported having a plan, another logistic regression was used to examine the role of human capital in explaining variation in plan quality. Understanding which of these elements are most associated with increasing the odds of having a plan will aid in identifying those families who are most likely to need attention.

RESULTS

Descriptive Statistics

Table 1 presents the descriptive statistics for the dependent and independent variables used in the study. Less than four out of ten families that had a special needs child self-reported having a plan. Of those that indicated having a plan, 25% (10% of whole sample) had a plan that includes a special needs trust. In terms of own human capital, families with a plan that included a special needs trust had the highest proportion of college educated respondents (63%). Mean age across the plan status groups was similar (38-41 years old). Families with no plan have the lowest proportion of male respondents (36%). The proportion of race does not appear to have had much variation across the plan status categories. In terms of access to expert human capital, the majority (88%) of families with a plan that includes a special needs trust had consulted with a financial advisor, while families with no plan had the lowest access to expert human capital reported (7%).
In terms of motivational factors, there appears to be little variation with regard to urgency (as evidenced by respondent age and concern about health). Families with a plan that included a special needs trust had the highest frequencies of both social/emotional and financial concerns (70% and 60%, respectively) and the highest proportion of household income of $100,000 or more (61%). Complexity appears to be greater for families that had plans, including a special needs trust. These families had the largest proportions of children with multiple disabilities (37%) and high monthly costs associated with their special needs children (51%).

Table 1
Descriptive Statistics by Plan Status

| Variable                              | Total Sample | PLAN with SNT | PLAN no SNT | NO PLAN |
|---------------------------------------|--------------|---------------|-------------|---------|
|                                      | N=580        | 10%           | 28%         | 62%     |
| Have a Plan                           | 38%          | ---           | ---         | ---     |
| Education: High School (or less)      | 29%          | 9%            | 18%         | 37%     |
| Some Post-Secondary                   | 36%          | 28%           | 43%         | 34%     |
| College (or more)                     | 35%          | 63%           | 39%         | 28%     |
| Respondent Age                        | 38.8         | 39.8          | 40.9        | 37.7    |
| Gender (male)                         | 44%          | 63%           | 55%         | 36%     |
| Race: White                           | 67%          | 63%           | 64%         | 69%     |
| Black                                 | 10%          | 11%           | 14%         | 9%      |
| Hispanic                              | 19%          | 26%           | 18%         | 19%     |
| Other                                 | 3%           | <1%           | 4%          | 4%      |
| Consult Financial Planner             | 26%          | 88%           | 47%         | 7%      |
| Health (very/extremely concerned)     | 27%          | 38%           | 25%         | 27%     |
| Emotional/Social Concern              | 27%          | 70%           | 22%         | 27%     |
| Financial Concern                     | 29%          | 60%           | 27%         | 29%     |
| Household Income: <$35,000             | 31%          | 14%           | 21%         | 39%     |
| $35,000-$99,999                       | 40%          | 25%           | 40%         | 43%     |
| $100,000 or more                      | 29%          | 61%           | 39%         | 19%     |
| Type of Disability: Mental             | 28%          | 27%           | 20%         | 32%     |
| Physical                              | 26%          | 20%           | 43%         | 20%     |
| Other                                 | 29%          | 16%           | 24%         | 34%     |
| Multiple Disabilities                 | 17%          | 37%           | 14%         | 15%     |
| Monthly Cost ($500 or more)           | 21%          | 51%           | 21%         | 17%     |
Table 2 shows the results from variables asked only of those families who self-reported having a plan in place. Information was available regarding who encouraged and who helped to create the plan, as well as a various plan elements. In addition to providing frequencies for all families who self-report having a plan, frequencies are also shown for those with a special needs trust and those without. Families that had a special needs trust had the highest frequency of being encouraged to develop a plan by a professional (46%), with the greatest frequency of encouragement coming from mental health professionals (19%). The majority of families without a special needs trust plan received encouragement from non-professionals (81%), themselves, family, or friends. In terms of help with plan creation, about half of families with a special needs trust had assistance from either a lawyer or a financial advisor when creating their plan, compared to less than half of that frequency (22%) for families with no special needs trust.

| Table 2                                                                 |
|-------------------------------------------------------------------------|
| Descriptive Statistics for Families with a Plan                         |
| All                       | PLAN with SNT | PLAN no SNT |
| N=222 (38%)          | 25%        | 75%        |
| Who encouraged you to create a plan?                                   |
| Financial Advisor         | 5%         | 3%         | 5%         |
| Lawyer                    | 6%         | 12%        | 3%         |
| Mental Health Professionals | 8%         | 19%        | 5%         |
| Other Professionals       | 7%         | 12%        | 6%         |
| Non-professionals         | 74%        | 54%        | 81%        |
| Who helped you to create a plan?                                       |
| Financial Advisor         | 16%        | 25%        | 12%        |
| Lawyer                    | 14%        | 26%        | 10%        |
| Mental Health Professionals | 5%         | 8%         | 5%         |
| Other Professionals       | 9%         | 9%         | 9%         |
| Non-professionals         | 56%        | 32%        | 64%        |
| What elements are in your plan?                                        |
| Special Needs Trust       | 25%        | 100%       | 0%         |
| Life Insurance Policy     | 65%        | 60%        | 67%        |
| Will                      | 55%        | 47%        | 58%        |
| Another Type of Trust     | 8%         | 2%         | 10%        |
| Annuity                   | 20%        | 30%        | 17%        |
| Investment Account        | 30%        | 33%        | 29%        |
| Savings Account           | 45%        | 64%        | 39%        |
| Gov’t Assistance Program  | 20%        | 33%        | 16%        |
| Other                     | 7%         | 0%         | 9%         |
Table 3 provides information that was asked only of families who did not self-report having a plan in place. About a third of these families indicated that they did not have a plan because of financial reasons, nearly one in five reported that they did not feel a plan was necessary to have, and just over one of every ten families stated that they did not know how to get help to create a plan or that family members would care for their child in the event of death. Roughly one of every twenty families indicated that they were either too busy with the needs of their child or that they were confident the government would take care of their child’s financial needs.

| The main reasons for not having a plan | N=358 (62%) |
|---------------------------------------|-------------|
| I am unable to devote extra savings to a plan at this time | 32%         |
| I have not felt I need a plan, even if my child lives longer than I do | 18%         |
| I have family members who will care for my child when I am no longer here | 15%         |
| I do not know where to turn for help creating a plan | 12%         |
| I am too busy dealing with the day-to-day needs of my child | 6%          |
| I am confident the government will cover the cost of care for my child | 5%          |
| I have not felt I need a plan, I do not expect my child to outlive me | <1%         |
| Other | 12%         |

**Regression Results**

Logistic regression was used to determine the impact of knowledge and motivational factors on predicting the likelihood of having a plan that includes a special needs trust. The regression included the variables representing own human capital (i.e., education, age, gender, and race), rented human capital (i.e., met with financial advisor), urgency (i.e., age and health), concern (i.e., social/emotional, financial, and income), and complexity (i.e., multiple disability and special needs cost). The results for the statistically significant variables are provided in Table 4.

In terms of knowledge, none of the variables representing the respondent’s human capital produced statistically significant results, but using an expert’s human capital (i.e., financial advisor) yielded the strongest predictor in the model in terms of both variance explanation (Std. Beta = 0.76) and magnitude of effect (Odds Ratio = 23.01). Families who consulted with a financial advisor were 23 times more likely to have a special needs trust compared to families who did not have access to an expert’s human capital.
Social/emotional concerns for the child (upon parental death) and having a child with multiple disabilities (rather than one disability) appear to be the two most significant motivating factors. Parents who were very or extremely concerned about social/emotional aspects of their child’s life after their death were ten times more likely to have a special needs trust compared to families with less concern about these issues. Similarly, families who had a child with multiple disabilities tripled the odds of having a plan that includes a special needs trust.

Table 5 presents logistic regression results from an additional model limited to the families who self-reported that they have a plan in place, either with/without a special needs trust. To explain variation in plan status (i.e., have a plan with a special needs trust or some other (inferior) plan), human capital factors regarding professional involvement were included in the model. Motivational factors were not included in this model because all families in this subsample indicate having a plan. The objective of this analysis was to determine which human capital factors influence plan quality. To control for the respondent’s own human capital, education (college educated vs. other education levels) was used. Professional involvement was included in terms of both encouragement and plan creation assistance. Four groups of professionals were specified—financial advisor, lawyer, mental health professionals (e.g., therapist, psychological counselor, or social worker), and other professionals (e.g., physician, other medical professionals, accountant, and insurance agent) in relation to non-professional (e.g., self, spouse, relative, or friend) encouragement or assistance. The strongest result from the regression was from encouragement by mental health professionals both in terms of explanatory power (Std. Beta = 0.45) and magnitude (Odds Ratio = 15.83). Among families who report having a plan, those who were encouraged by a mental health professional were nearly 16 times more likely to have a plan that
includes a special needs trust. Although encouragement from lawyers and financial advisors did not significantly differ from being encouraged by non-professionals, both do have an impact through assistance. Among families with a plan, the odds of having a special needs trust were nearly tripled if a financial advisor, and more than quadrupled if a lawyer, helped to create the plan. Being encouraged by other professionals or being helped by either mental health or other professionals was no different than being encouraged or helped by non-professionals. Families with plans that have parents who were college educated were nearly three-and-a-half times more likely to have a plan that includes a special needs trust.

### Table 5

| Variable                              | Coefficient | Odds Ratio | Std. Beta |
|---------------------------------------|-------------|------------|-----------|
| College Educated                      | 1.2292***   | 3.42       | 0.36      |
| Encouraged by Financial Advisor       | ---         | ---        | ---       |
| Encouraged by Lawyer                  | ---         | ---        | ---       |
| Encouraged by Mental Health Professionals | 2.6137**   | 15.83      | 0.45      |
| Encouraged by Other Professionals     | ---         | ---        | ---       |
| Helped by Financial Advisor           | 0.9968*     | 2.71       | 0.22      |
| Helped by Lawyer                      | 1.4820**    | 4.40       | 0.35      |
| Helped by Mental Health Professionals | ---         | ---        | ---       |
| Helped by Other Professionals         | ---         | ---        | ---       |
| Max-rescaled R-Square                 | 0.28        |            |           |

***p<0.001, **p<0.01, *p<0.05

### DISCUSSION

Results from this study confirm that the majority of families are not planning for the future of their special needs children when they are no longer able to care for them. Among parents that have taken the step to create a plan, most are not ideal, in that they do not include a SNT. The SNT is deemed to be the legal centerpiece of an appropriate special needs plan. An SNT helps address parents’ financial and social/emotional concerns for their children (Grassi, 2008). This study provides evidence to suggest that financial and mental health professionals play a substantial role in increasing the odds of ensuring that special needs families have adequate plans.

Among families indicating having a plan in place, findings from this study add insight into professional involvement with the planning process. Mental health professionals play a key role in ensuring families have plans with SNTs. Training mental health professionals to understand crucial elements of a plan (i.e., the importance of the need for a SNT) could be an effective method of increasing not only the incidence of having a plan, but also ensuring plan quality. Assisting in the creation of a letter of intent is a way that mental health professionals can help initiate the planning process. Results indicate...
financial advisor and attorney participation is associated with having a quality plan that includes a SNT. Educating those that have an opportunity to encourage families on the importance of planning and the importance of seeking out a financial advisor or attorney to assist in plan creation, can result in better outcomes for special needs children. Referrals are an important element in the planning process. Mental health professionals, financial therapists, financial advisors, and attorneys need to work together to encourage and create quality plans for families with special needs children. Given the results from this study, it would seem that a financial therapist would be the ideal professional to guide a family through the special needs planning process. A financial therapist would be uniquely positioned to not only understand the importance and complexity, but also the crucial social and emotional barriers associated with families facing the daunting task of having to create a plan for their special needs child.

Among families who do not have a plan, one of every five families indicate they do not think it is necessary to plan and more than one of every ten families indicate not knowing where to turn for help. It is particularly disturbing that a third of these families indicate they do not have a plan due to their lack of ability to save. This may stem from a misconception regarding the requisite wealth to establish a special needs plan, as many components of a plan do not require current savings. This descriptive result regarding the perceived lack of ability to save as a deterrent in having a plan is particularly interesting when compared to the logistic results indicating that income level does not play a statistically significant role in predicting plan status among special needs families. These results would suggest that while income and financial concerns do not appear to explain variation in plan status, the ability to save may have a role. In any case, many types of SNTs are available that appeal to all levels of wealth. Life insurance is also a common method of being able to fund a trust, alleviating the need for current savings. A letter of intent is a crucial component and requires no savings to implement as part of a comprehensive special needs plan.

Results from this study are somewhat limited by the nature of the secondary data used for the analysis. Information regarding the specific type of financial advisors (i.e., CFP®, CPA®, compensation structure, etc.), increased sample to allow for differentiation among mental health professions (therapist, social worker, etc.), and additional data regarding timing and referral circumstances would have provided more insight into the process that is most successful for families to create an optimal special needs plan. Having a plan in place is conceptualized as being a function of both knowledge (i.e., one’s own and/or access to expert human capital) and motivation (i.e., urgency, concern, and complexity). Results from this study suggest that expert knowledge (i.e., meeting with a financial advisor) is the most important factor associated with having a plan that includes a SNT. Previous research has established urgency as a motivational factor (Davis, 2003); however, findings from this study suggest that urgency is less important than the other motivation factors included in the model. Results from this study indicate that concern (particularly social/emotional) and complexity (children with multiple disabilities) are important motivators to establishing a plan. The approach used in this study to
conceptualizing special needs planning—that plan status is a function of both knowledge and motivation—can be helpful for financial therapists to recognize in their own work with current and potential clients with special needs children. Both knowledge and motivation play a key role in predicting which families will have an adequate plan in place for their special needs child. In particular, families who have met with a financial professional, those who are most concerned about the social and emotional welfare of their child (beyond parental death), and those with a multi-disabled child are most likely to have a plan (with SNT) in place. A financial therapist can reach out to special needs families to inform them about the financial and legal aspects required, while simultaneously attending to the overwhelming barriers imposed by the social and emotional considerations that are involved with special needs planning.

There are many obstacles to special needs planning because it is often perceived as cumbersome, overwhelming, complex, and intimidating. Education designed to address the emotional, as well as the financial aspects of special needs planning, needs to be developed. Financial therapists are uniquely positioned to lead the special needs planning process through a combination of encouragement and creation. A combination approach coordinated by a professional trained in both financial and therapeutic matters may increase the likelihood that special needs families have a plan in place over and above the odds evidenced by these professions separately. A financial therapeutic approach can help to bridge the gap that currently exists between the financial/legal and mental health professions. In addition, an approach that embraces the intersection and overlap between financial/legal and social/emotional aspects can specifically address the barriers that often prevent special needs families from initiating and completing the planning process. Families with special needs children have a lot to cope with. If more financial therapists can market and provide services to these families, perhaps these professionals can not only increase the number of families with adequate plans in place, but also provide seamless and integrated financial and emotional support services to these families. Families with special needs children have planning needs that may be most successfully addressed through the benefits provided by the financial therapy profession.
REFERENCES

Caudill, A. (2009, June). Funding Special Needs Trust with Retirement Benefits. *Journal of Financial Service Professionals, 63*(4) 15-17.

Chen, H. & Volpe, R.P. (2002). Gender differences in personal financial literacy among college students. *Financial Services Review, 11*, 289-307.

Davis, S. (Ed.) (2003). *A Family Handbook on Future Planning*. Chicago: The Arc of the United States and Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Department of Disability and Human Development, College of Applied Health Sciences, University of Illinois at Chicago. Retrieved from http://internet.dssc.uic.edu/forms/psu/Future_Planning_Family_Handbook_2003.pdf

Enea, A. (2008). The ABC’s of SNTs (Special Needs Trusts). *Westchester Bar Journal, 35*, 25-33.

Erickson, W., & Lee, C. (2008). *2007 Disability Status Report: United States*. Ithaca, NY: Cornell University Rehabilitation Research and Training Center on Disability Demographics and Statistics.

Etmanski, A., Collins, J. & Cammack, V. (2002). *Safe and Secure: Six steps to creating a good life for people with disabilities*. Vancouver, B.C.: Planned Lifetime Advocacy Network.

Gitman, L. & Joehnk, M. (2008). *Personal Financial Planning*. Mason, OH: Thomson South-Western.

Gould, E. (2004). Decomposing the effects of children’s health on mother’s labor supply: Is it time or money? *Health Economics, 13*(6), 525–541.

Grable, J., McGill, S., & Britt, S. 2010. The financial therapy association: A brief history. *Journal of Financial Therapy, 1*(1).

Graetz, J. E. (2010). Autism grows up: opportunities for adults with autism. *Disability & Society, 25*(1): 33-47.

Grassi, S. G. (2008). Special Planning Is Needed for Families with a Special-Needs Child. *Journal of Practical Estate Planning, 39*-51.

Greenbaum, J. (2007). *Life Planning for Adults with Development Disabilities: A guide for parents and family members*. Oakland, CA: New Harbinger Publications, Inc.

Heller, T. & Kramer, J. (2009). Involvement of Adult Siblings of Persons With Developmental Disabilities in Future Planning. *Intellectual and Developmental Disabilities, 47*(3): 208-219.

Heller, T. (2000). Supporting Adults with Intellectual Disabilities and Their Families in Planning and Advocacy: A Literature Review. *Physical & Occupational Therapy in Geriatrics, 18*(1), 59-73. Retrieved April 9, 2009, from the University of Delaware.

Heller, T. & Factor (1987, November). Elderly parents caring for disabled adult offspring: Issues in permanency planning. Paper presented at the 40th Annual Scientific Meeting of The Gerontological Society of America. Washington, DC.

Hoyt, P. & Pollock, C. (2003). *Special People Special Planning: Creating a safe legal haven for families with special needs*. Oviedo, FL: Legacy Planning Partners.

Huston, S.J. (2010). Determining who is financially literate: Evidence from the 2009 Financial Literacy Assessment Survey. *Academy of Financial Services Proceedings.*
Financial Therapy and Planning for Families with Special Needs Children

Jackins, B., Blank, R., Shulman, K. & Onello, H. (2010). Managing a Special Needs Trust: A guide for trustees. Brookline, MA: DisABILITIESBOOKS, Inc.
Kraus, M.B. (2005). Special Needs Planning in the Family Court: Planning is Important Even When Life Doesn't Go the Way We Plan. Family Court Review, 43(4), 607-611.
Lauderdale, M., Durband, D., Scott, J. & Springer, N. (2010). Special Needs Training: A focus group study. Paper presented at The Academy of Financial Services Conference, Denver, CO.
Maslow, A.H. (1943). A Theory of Human Motivation. Psychological Review, 50(4), 370-396.
Moore, R. & Landsman, R. (2010). Estates, gifts and trusts portfolios: Planning for disability: Portfolio 816. The Bureau of National Affairs: Tax Management, Inc.
Nadworny, J. & Haddad, C. (2007). The Special Needs Planning Guide: How to prepare for every stage of your child's life. Baltimore, MD: Paul H. Brooks Publishing Co.
Rhatigan, S. (n.d.). Special Needs Trust. Center for Lifelong Planning for Individuals with Cognitive Disabilities. Retrieved from http://www.cllp.org/financial/SpecialNeedsTrust.pdf
Rosenberg, J. (2000). Supplemental Needs Trusts for People with Disabilities: The development of a private trust in the public interest. The Boston University Public Interest Law Journal, 10, 91-151.
Saposnek, D. T., Perryman, H., Berkow, J., & Ellsworth, S. (2005). Special Needs Children in Family Court Cases. Family Court Review, 43(11), 566-577.
Schultz, T.W. (1961). Investment in Human Capital. The American Economic Review, 51(1), 1-17.
Sharpe D.L. & Baker, D. L. (2007). Financial Issues Associated with Having a Child with Autism. Journal of Family and Economic Issues, 28(2), 247-264. Retrieved April 27, 2009, from ABI/INFORM Global database. (Document ID: 1276430161).
Smith, G. & Tobin S. (1989). Permanency planning among older parents of adults with lifelong disabilities. Journal of Gerontological Social Work, 14, 35-59.
Stevens, B. (2002). The ABC's of Special Needs Planning. Phoenix, AZ: The Stevens Group, LLC.
Stone, C. (2006). In the Blink of an Eye: Special Needs Planning. Journal of Financial Planning, 19(10), 64-74
Thomas, T. (2005, April 11). Planning Gap Children With Seen For Special Needs. National Underwriter, 8, 32.