

## **Special Needs Financial Planning: Assessing Community Awareness**

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## Abstract

Individuals with special needs may not be taking advantage of all of the options available to obtain the financial support to live a rich, full life. The government provides a myriad of entitlements such as Medicare, Medicaid, Social Security Income, Social Security Disability Income, and the ability to create special needs trusts. The complexity of the interactions between these options can create confusion for care givers of those with special needs.

Current research in the area focuses on the emotional challenges faced by family and friends with little attention paid to the financial aspects of caring for a person with special needs. Commercial literature explaining the financial options is available, but much of the information presented is at an advanced level.

The purpose of this study is to determine whether care givers feel that they are aware of and comfortable with navigating through the government entitlements to take full advantage of the available benefits. After determining the current awareness and desires, an educational tool will be created to address the needs of the community with the goal of improving quality of life for care givers and individuals with special needs.

# **Special Needs Financial Planning: Assessing Community Awareness**

Note: This study received IRB approval on February 22, 2009 and is currently in progress.

## **Introduction**

Approximately 20% of Americans self reported to have a disability in 2006 (Disability, 2006). This percentage includes permanent/developmental disabilities such as mental retardation, acquired disabilities such as a traumatic brain injury, and organic disabilities such as mental illness. These individuals may not be taking advantage of all of the options available to obtain the financial support to live a rich, full life. The government provides a myriad of entitlements such as Medicare, Medicaid, Social Security Income, Social Security Disability Income, and the ability to create special needs trusts. The complexity of the interactions between these options can create confusion for care givers of those with special needs.

This study attempts to determine if care givers for individuals with special needs are aware of the financial benefits available. A survey is used to assess care givers awareness of the benefits available and if it would be beneficial to learn more. If a need is found, an educational tool will be created to teach care givers about the various benefits available. The goal of the educational tool will be to increase the quality of life for both the care givers and the individuals with special needs.

## **Literature Review**

Current research in the area focuses primarily on the emotional challenges faced by family and friends with little attention paid to the financial aspects of caring for a person with special needs (Roberts & Lawton, 2001; Sharpe & Baker, 2007). Sharpe & Baker (2007) discuss

significant factors that increase the likelihood of financial pressures due to caring for a child with autism. These factors include the type of medical intervention utilized and having unreimbursed out-of-pocket expenses.

Commercial literature explaining the financial options is available, but much of the information presented is at an advanced level of financial sophistication that might not be accessible to the average reader. Parents of children with special needs are not satisfied with the current commercial literature on financial benefits (Stallard & Lenton, 1992). This limited availability of information results in increased search costs for the parents and an inability to take full advantage of the resources available.

Academic research on the complexity of health insurance issues and the relationship between Medicaid and special needs trusts is available, but the wide array of other government entitlements has yet to be definitively addressed (Kraus, 2005; White, 2002). This gap in the literature could be addressed with an overview of benefits available. One in-depth study on autism explores the nuances of the financial benefits available for an autistic child, however the results are not generalizable to other types of special needs such as Down's Syndrome (Sharpe & Baker, 2007).

Individuals with special needs are enjoying increasingly longer lives due to advances in health care (Lefley & Hatfield, 1999). In addition, caregivers tend to put off planning for the care of their disabled children until the last minute (Bigby & Ozanne, 2004), possibly due to the reluctance to accept mortality (Lefley & Hatfield, 1999).

In addition to individuals with special needs losing their parent, caregiver, and quality of life when the parent predeceases the individual with special needs, the lack of information on special needs care could mean people are unable to take full advantage of the available benefits.

If this study determines that there is a need, the creation of a special needs planning educational tool could help increase the quality of life for individuals with special needs.

### **Methodology**

This study is part one of a project funded by The CH Foundation. The Foundation supports research and community outreach benefiting the communities of West Texas. Part One of the grant is to conduct a needs assessment of the community.

A voluntary online survey, Appendix A, evaluates the awareness and needs of the community. The subjects are first asked if they actually care for someone with special needs to screen out unqualified subjects. The remainder of the survey is split into four areas: Demographic questions, financial questions to determine eligibility for certain benefits, special needs questions to determine what areas the subjects want to know more about, and the final portion of the survey determines the most beneficial type of education tool(s). An additional category of questions on family therapy needs is also asked but these questions but will be utilized in a study to follow.

The subjects are caregivers for those with special needs. Community groups in West Texas offering support for caregivers for someone with special needs such as the South Plains Autism Network (SPAN), Better Understanding of Down Syndrome (BUDS), and the Burkhart Center for Autism Education and Research are the primary source of subjects. Using list serves, the members of these groups were contacted via email to fill out the survey and were asked to forward the survey to anyone else that they knew who might be interested.

The purpose of this study is to determine whether care givers feel that they are aware of and comfortable with navigating through the government entitlements to take full advantage of the available benefits.

## Current Results (Study in progress)

The first question used skip logic to remove unqualified respondents from the survey. Currently, 67 people have started the survey, and after the removal of the 6 respondents that were not caregivers, the survey had an 80.6% completion rate.

The caregivers themselves were on average 40 years old with an average salary of \$46,004, 80.8% Caucasian, 86.5% female, and 86.9% were caring for their own child. Interestingly, 76.5% were married, which is markedly different from previous research in the area that predicts a divorce rate of greater than 90% in parents of a child with special needs (Kraus, 2005). This may be due to a limitation of the study in that respondents are largely recruited through support groups located in the socially conservative panhandle of Texas. The current survey also does not ask the respondents if they have been divorced, which may also account for the difference.

The individuals with special needs were on average 30.79 years old with a range of less than a year old to 99. Two respondents were independent, meaning they cared for themselves. 70.6% were male and 29.4% were female.

Initial reaction, as illustrated in Table 1, to the diagnosis of the disability shows that the financial impact was rarely the first thing a caregiver thought of which might explain the lack of commercial literature available on financial planning.

Table 1.

*Rank how the following applies to your initial reaction to the diagnosis of your loved one*

	1	2	3	4	5
Concern about the quality of life for your child	<b>42.2%</b>	6.7%	4.4%	15.6%	31.1%
The overall emotional impact on your family	11.6%	<b>37.2%</b>	23.3%	23.3%	4.7%
The emotional impact on you as a caregiver	6.8%	27.3%	<b>47.7%</b>	18.2%	0.0%
The financial impact on your family	8.5%	19.1%	23.4%	<b>27.7%</b>	21.3%

This result is interesting as financial distress has been shown to have a large impact on the emotional well-being and harmony of a family (Grable, Britt, & Cantrell, 2007; Vinokur, Price, & Caplan, 1996). 55% of the respondents did not expect the individual with special needs to ever be able to financially support themselves and 62.3% did not know if financial support would be in place if they were to pass away before the disabled individual.

As a needs assessment, the telling story came from asking respondents how confident they felt with their knowledge about different financial planning tools as illustrated in Table 2.

Table 2.

*I feel confident with my knowledge about \_\_\_\_\_ . (1=Strongly Agree, 5=Strongly Disagree)*

	1	2	3	4	5
Medicare/Medicaid	16.1%	<b>32.1%</b>	26.8%	23.2%	1.8%
Social Security Income/Social Security Disability Income	17.9%	<b>33.9%</b>	32.1%	14.3%	1.8%
Government benefits programs overall	27.3%	<b>45.5%</b>	12.7%	12.7%	1.8%
Special needs trusts	28.6%	<b>42.9%</b>	12.5%	14.3%	1.8%
The duties of a trustee	26.8%	<b>37.5%</b>	16.1%	14.3%	5.4%
Financial planning for special needs	30.9%	<b>40.0%</b>	12.7%	10.9%	5.5%

When asked what they wanted to learn more about, the majority wanted to learn about special needs trusts as illustrated in Table 3.

Table 3.

*What area(s) of special needs planning would you like to know more about?*

Medicare	37.3%
Medicaid	52.9%
Social Security Income	47.1%
Social Security Disability Income	68.6%
<b>Special Needs Trusts</b>	<b>90.2%</b>
Guardianship	54.9%
Letters of Intent	80.4%

Additional questions were asked to determine the most appropriate educational tool. The results are illustrated in Table 4, with 98.6% of the participants indicating a willingness to take a pre-test, an immediate quiz after the training, and another post-test 6 months after receiving the training.

Table 4.

*How would you like to receive training? Please check all that apply.*

In a classroom	40.4%
At home	38.5%
By myself	23.1%
With others	36.5%
Paper/Pencil and books	28.8%
<b>Electronically/Internet</b>	<b>76.9%</b>
Other	11.5%

### **Conclusion**

The lack of information readily accessible to the average person creates an environment where people are unable to take full advantage of the government entitlements available. The result is a lower quality of life for both the caregivers and the individuals with special needs. While there are limitations to the study, the results show that the caregivers of individuals with special needs want to learn more about the financial tools available for special needs planning.

The limitations include the fact that a majority of the respondents were reached through different support groups for caregivers. These individuals may be more likely to seek help and be more receptive to training than others. In addition, the respondents are all from the panhandle of Texas, an area that may not represent the entire population. Also, because the survey was administered online, the respondents may be more comfortable (and have access to) the internet.

### **Overall Grant Timeline**

Part One of the grant is currently in progress and the researchers plan to close data collection December 2009. Part Two of the grant will fund the creation of an educational tool for special needs caregivers to help them identify areas of financial planning that they need to capitalize on more. Based on the results of the needs assessment, particularly the method of delivery and areas of interests, the researchers plan to start developing the educational tool in

January. Summer 2010, the educational tools will be delivered during Part Three. A pre-test and a post-test will be conducted to verify the education tools are successful in reaching the participants. Fall 2010, the final phase of the grant will analyze the educational tools and modify them based on feedback of the participants as well as the pre and post-test analyses.

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## Appendix A: Special Needs Assessment Questions

1. Are you a caregiver for someone with a disability?
  1. Yes, I financially care for someone with a disability.
  2. Yes, I physically care for someone with a disability.
  3. Yes, both physically and financially.
  4. No
  
2. How is the person(s) with a disability related to you? If you care for more than one, please check all that apply. (If your son has a disability, you would check 'Your Child'.)
  1. Your Spouse/Partner.
  2. Your Parent.
  3. Your Child.
  4. Your Brother/Sister.
  5. Your Grandchild.
  6. Other (please specify).
  
3. How old is the person(s) with a disability?
  
4. What is their gender? If you care for more than one, please check the number of each gender that applies.

Male(s).	1	2	3+
Female(s).	1	2	3+
  
5. What type of disability do they have?
  1. Autism.
  2. Cystic fibrosis.
  3. Down syndrome.
  4. Epilepsy.
  5. Low vision.
  6. Poor hearing.
  7. Other (please specify).
  
6. Is someone lined up to be primary care-giver should you no longer be able to care for the person with a disability?
  1. Yes.
  2. No.

3. I don't know.
7. Do you ever expect the individual with special needs will be financially independent?
    1. Yes.
    2. No.
    3. Mixed Yes and No (only if you care for more than one).
  8. Will there be enough financial support available to care for the person with a disability throughout his or her life?
    1. Yes.
    2. No.
    3. I don't know.
  9. Have you consulted a professional for financial advice regarding caring for a person with a disability?
    1. Yes.
    2. No.
  10. Which type of professional(s) did you consult?
    1. Attorney.
    2. Trust Officer.
    3. CPA.
    4. Financial Planner.
    5. Banker.
    6. Other (please specify).
  11. Do you have a letter of intent outlining the future care plan for the individual with special needs?
    1. Yes.
    2. No.
  12. Do you have a will?
    1. Yes.
    2. No.
  13. Does your will include a guardianship provision naming someone to care for the individual with special needs?
    1. Yes.
    2. No.

3. N/A because I am not the legal guardian.

14. Does your will name a trustee to care for the finances of the individual with special needs?

1. Yes.
2. No.

15. Please complete the following statement using the terms given on each line and circle the number that corresponds to the accuracy of the statement. I feel confident with my knowledge about \_\_\_\_\_. 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, 5 = Strongly Agree.

		<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly Agree</b>
a.	Medicare/ Medicaid.	1	2	3	4	5
b.	Social Security Income/ Social Security Disability Income.	1	2	3	4	5
c.	Government benefits programs overall.	1	2	3	4	5
d.	Special needs trusts.	1	2	3	4	5
e.	The duties of a trustee.	1	2	3	4	5
f.	Financial planning for special needs.	1	2	3	4	5

16. What resource have you primarily used to learn about government benefits and/or special needs trusts?

1. Internet
2. Attorney
3. Financial Planner
4. Medical Doctor
5. Social Worker
6. Library/Bookstore
7. Other (please specify)

17. What area(s) of special needs planning would you like to know more about? Please check all that apply.

1. Medicare
2. Medicaid
3. Social Security Income
4. Social Security Disability Income
5. Special Needs Trusts
6. Guardianship
7. Letters of Intent
8. Other (please specify)

18. How would you like to receive training? Please check all that apply.

1. In a classroom.
2. At home.
3. By myself.
4. With others.
5. Paper/Pencil and books.
6. Electronically/Internet.
7. Other (please specify).

19. Would you be willing to take a pre-test before training, a quiz immediately after the training, and an assessment 6 months after the training to help us improve the training process?

1. Yes
2. No

20. What is the highest level of education you have completed?

1. Grade School.
2. High school diploma/GED.
3. Trade School.
4. Some College.
5. College Degree.
6. Graduate Degree.
7. Professional Degree.

21. What is your current marital status?

1. Married.
2. Single.
3. Divorced.
4. Widowed.
5. Separated.

22. How old are you?

23. What is your gender?

24. What is your race?

1. Caucasian.
2. Hispanic.
3. African-American.
4. Asian.
5. Other (please specify).

25. What is your zip code?

26. How did you learn of your loved one's diagnosis?

1. Pre-natal testing (e.g., sonogram, amniocentesis).
2. At birth/w/Doctor evaluation.
3. After birth/w/follow-up testing.
4. Other (please specify).

27. Rank how the following applies to your initial reaction to the diagnosis of your loved one: Each number may only be used once.

a.	Concern about the quality of life for your child.	1	2	3	4	5
b.	The overall emotional impact on your family.	1	2	3	4	5
c.	The emotional impact on you as a caregiver.	1	2	3	4	5
d.	The financial impact on your family.	1	2	3	4	5

28. After receiving my loved one's diagnosis, I wanted:

1. To speak to another parent of a child with the same diagnosis.
2. To speak to a professional about the diagnosis.
3. To speak to no one.
4. To read/gather information from books/online.

5. Other (please specify).

29. Have you ever met with a mental health professional to manage the stress of being the caregiver to your loved one or to discuss the general impact on your family?

1. Yes.
2. No.

30. What type of professional did you go to?

1. Social Worker.
2. Family Therapist.
3. Licensed Professional.
4. Counselor.
5. Psychologist.
6. Pastor/chaplain.
7. Don't know/remember.
8. Other (please specify).

31. If you were to seek out family therapy services, would you want to work with someone who also had a personal experience with a loved one with special needs?

1. Yes.
2. No.
3. Not necessarily.

32. What is your monthly household take home (after taxes) income?

33. What are your current sources of income/financial support? (Please check all that apply.)

1. Paid for part time employment
2. Paid for full time employment
3. Spouse paid for employment
4. Government benefits
5. Family support
6. Alimony/Child Support
7. Structured Settlement/Annuity
8. Special Needs Trust
9. Other (please specify)

34. How much of your monthly household income goes towards providing for a person with a disability (including insurance, therapy, medical expenses, etc.)?

1. None.

2. Less than one half.
3. About one half.
4. Over one half.

35. Does this individual have a special needs trust?

1. Yes - I am the trustee.
2. Yes - someone else is the trustee.
3. No.
4. I don't know.

36. What other source(s) of income does the person with disability have access to?

37. What types of problems, if any, have you or your family experienced with your job(s) due to caring for an individual with a disability?

38. If family therapy services were NOT free, what could you pay for an appointment?

1. \$0
2. \$10
3. \$20
4. \$40
5. Other (please specify).