

Progressing Towards Empowering Caregivers and Planners with Special Needs Planning Resources

This paper details the prevalence of disabilities and the challenges faced by those who care for individuals with special needs. It highlights a survey in progress to residents primarily in the West Texas region, posing demographic questions, financial questions and questions related to the presence of a disability within the family. Learning modules will be developed to enhance the knowledge base of financial planners and caregivers.

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Special needs planning has become more important and prominent as the amount of children and adults with disabilities has increased in the past few years (The American Community Survey, 2007; Saposnek, Perryman, Berkow & Ellsworth, 2005). Within the area of special needs planning, it is vital that financial planners, including those planners who specifically engage in estate planning, to be knowledgeable about the varying degrees of disabilities, the family issues that may develop during the course of planning for their clients, and the laws that affect planning in this area. Suffice to say, special needs planning does not solely involve recommending and then implementing a special needs trust, even though trusts can be a valuable planning tool.

Although there has been some research that has centered on assessing the needs of the special needs community, many care givers are still unaware of the resources which may benefit their disabled loved ones. A survey has been distributed to assess the needs of the special needs community. Financial planners have the opportunity to be involved in one of the most burgeoning areas of the field and the chance to increase their client base through comprehensive special needs planning.

Literature Review

Current Disability Statistics

Over 75 percent of special needs adults are without employment (Grassi, 2008). In 2007, the earnings in a household with at least one working disabled person was approximately \$38,400. However, this number is slightly lower (\$31,500) for households with an individual or individuals with a mental disability. Only 17 percent of working-age individuals receive Social Security Income. Furthermore, households containing at least one family member with a mental disability are also marked by the highest poverty rate, 32 percent, within the U. S. (The American Community Survey, 2007). Findings from Emerson (2007) also show in many cases poverty precedes becoming disabled, as the environment and economic status of those caring for their loved ones is oftentimes not conducive for providing adequate care. In fact, disabled individuals face a higher poverty risk in developed countries more so than non-disabled individuals partly due to lower workforce participation and the cost of care.

When defining children with disabilities, it includes a broad scope. Disorders range from asthma and food allergies to spectrum disorders such as autism and Asperger's Syndrome, with autism becoming prevalent across the nation (Graetz, 2010; Sharpe & Baker, 2007; Saposnek et al., 2005). Sharpe & Baker (2007) discuss significant factors that increase the likelihood of financial pressures due to caring for a child with autism, and cites an annual projected growth rate of 10 to 17 percent in the United States. These factors include the type of medical intervention utilized and having unreimbursed out-of-pocket expenses.

Financial planners can anticipate that the needs of clients with disabled loved ones will be different for each family, based on the type of disability and severity of that disability. While the financial planner cannot obtain all the information relevant to the various disabilities individuals face, when it comes to disorders such as autism, the planner and his or her support team needs to address the individual with the disability, not the group of individuals with the disability (Graetz, 2010; Grassi, 2008). There is no one size fits all in Special Needs planning. Each individual's quality of life is different than the next and unique financial plans needs to reflect this important aspect.

Planners should also anticipate an increase in the number of clients with special needs children if they have not seen such effects already. It is important to consider that the advances in medical technology are, for the first time, allowing children with disabilities to outlive their parents. Also, according to the National Institute on Aging

(2008), more parents are living into their 90's and 100's than ever before. Considering the vastness of the baby boomers, the demand for special needs planning shows no signs of slowing down. An informed background on the planning issues that may arise will help financial planners and estate planners better help clients make informed decisions, while building confidence and trust from clients' perspective.

Diagnosis of these types of disabilities varies in the impact it has on the household. Oftentimes spouses grow apart as a result of the pressure of 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). The divorce rate for parents with a special needs child is over 90 percent partly due to the inability of one or both spouses to adjust to the possibly new and ongoing demands of caring for a child with special needs (Grassi, 2008; Kraus, 2005). In the event that marital problems do persist and clients end their marital relationship, the planning for the child may be in jeopardy if proper arrangements were not in place prior to the separation or divorce. 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 at the death of the caregiver(s) (Kraus, 2005). Financial planners will be better equipped and able to impart knowledge upon clients who may be unaware of the typical, yet detrimental family issues which arise.

Families caring for loved ones with a mental disability face lifetime financial and emotional demands. Costs arise from intervention strategies involving counselors, therapists, schools (or a combination of the three), health care, pressure to leave the labor market, in addition to the normal expenses associated with caring for a child (Graetz, 2010; Heller & Kramer, 2009; Grassi, 2008; Sharpe & Baker, 2007; Thomas, 2005; Gould 2004). While these costs may fluctuate with time in either direction, depending on the type and severity of the disability, a cost that clients may not consider are those associated with children with disabilities reaching adult-age, as life expectancy is increasing with advanced medical techniques. Caring for a loved one with a disability also inhibits community activities, such as dining out (Graetz, 2010). Realizing and being cognizant of the fact that many families deal with multiple issues can assist the financial planner with more holistic Special Needs planning.

It may be overwhelming for clients to think about future planning needs when current needs seem more urgent. Planners may find it beneficial to avoid inundating their clients with information regarding special needs provisions. Over two decades ago Heller and Factor (1987) found that a majority of parents having a child with a disability had no future financial planning arrangement for their child and more recent literature and research shows that this is still an impediment among families (Graetz, 2010; Smith & Tobin, 1989). Many of these parents lacked interest in receiving information, perhaps due to feeling overwhelmed at the thought of receiving information and having to decipher through such information.

Currently, there are more resources and much more information that can be attained, so it is likely that parents are still or even more overwhelmed by the information that is available to them. Therefore it is vital that planners do not add to the strain clients may already be facing by giving them too much information at one time. Again, it is important that planners address future planning issues in addition to present issues so that their clients are prepared for (or at the very least, not surprised by) the emotional and financial challenges ahead.

While the vastness and complexity of information regarding special needs planning can be intimidating, it is imperative to engage the special needs community in order to promote awareness of services and resources available for the well-being of disabled individuals. Within the family, grandparents are often involved in providing non-monetary and monetary support but many caregivers do not involve siblings of those with disabilities in the overall planning process (Graetz, 2010; Heller & Kramer, 2009). Elder law attorneys are among professionals equipped with the training to assist with the legal needs of elderly adults with disabilities (Arnason, Fish & Rosenzweig, 2001). Since the majority (53 percent) of adults with disabilities in the U.S. includes those 75 years old and older, having more resources available can better assist with planning.

Special Needs Community Survey

Currently a survey is being developed to assess the issues and unique needs of the special needs community with the intention to develop and make resources more readily attainable and available (Lauderdale & Stebbins, 2009). Within this survey are questions which address the extent of care giver knowledge, including what they want to know and how they would like to receive information. The survey covers demographic and socio-graphic information as well as estate planning provisions, trusts and government benefits. While there have been studies, seminars and trainings developed to support caregivers, there has been little research on developing educational tools to aid both planners and caregivers (Heller & Caldwell, 2006). After gauging survey participants' knowledge of planning resources, including any gaps in knowledge, educational modules can aid in increasing awareness and provide support to both caregivers and planners.

Methodology & Partial Results

The survey was created primarily to assess and determine how comfortable care givers are with special needs planning resources (Lauderdale & Stebbins, 2009). It is important to note that most of the survey respondents are from the West Texas community due to grant limitations. However, there are plans to expand beyond West Texas in future studies.

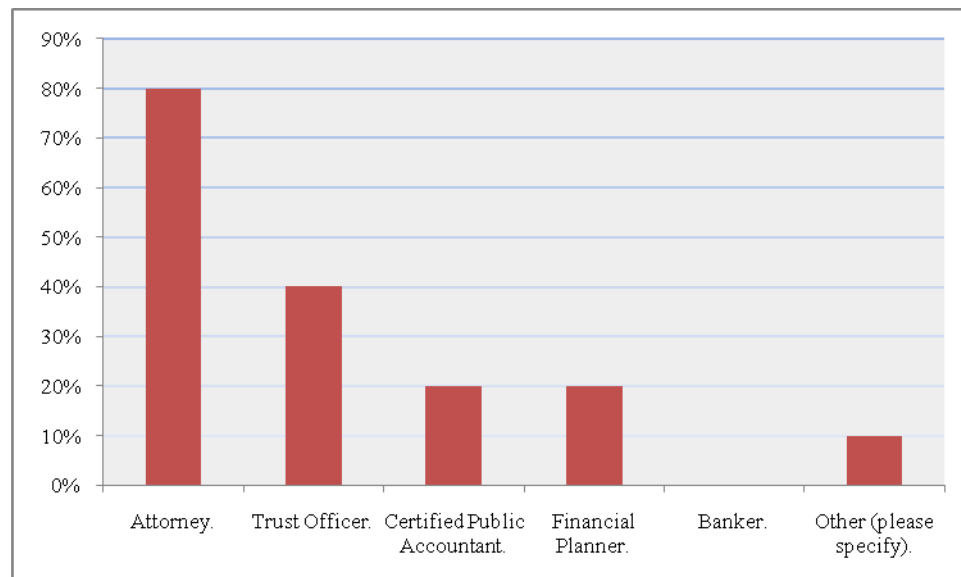
The participants are asked to give some basic demographic questions, including age, gender, presence of disability, ethnicity, socioeconomic status and educational level, in addition to questions used to determine if the respondent is actually a care giver for someone with special needs. Financial questions are asked to determine benefits eligibility, and the participants are asked to rate their understanding of the various types of entitlements. Questions within the last segment of the survey ask about education tools which would lessen the gap in care giver knowledge (Lauderdale & Stebbins, 2009).

The survey was created online using Survey Monkey. Participants were recruited through the use of list serves and sent originally to existing community groups in West Texas that offer support for individuals who care for someone with special needs, as well as faculty, staff and students of a large university in West Texas. The support groups include the Burkhart Center for Autism Education and Research, the South Plains Autism Network (SPAN), and Better Understanding of Down Syndrome (BUDS). The survey link was emailed to these support groups and the snowballing technique was used to forward the link to any potential participants. Thus far we have 15 partially completed and 70 fully completed. A copy of the survey is attached in Appendix A.

Consistent with the literature, the results thus far show that a majority of caregivers are parents and the majority of the children being cared for are males. The majority of the respondents are married and female, with some college education. Almost 83% of the respondents were Caucasian, with 14% Hispanic, 2% African-American and 1% other.

The need for financial planners to intercede can be seen from some of the survey responses. From the results reported, we can see that a majority (71%) of the respondents who have written a will have some sort of guardianship in place for the child in the event that the caregiver is not able to provide care. However, over 65% of the respondents in the survey have not created a will. Furthermore, over 85% of the respondents have not sought advice from financial professionals regarding their loved one(s). But among those who have consulted a financial professional, only 20% sought the advice of a planner, as seen in Figure 1.

Figure 1
Professionals Consulted by Respondents.

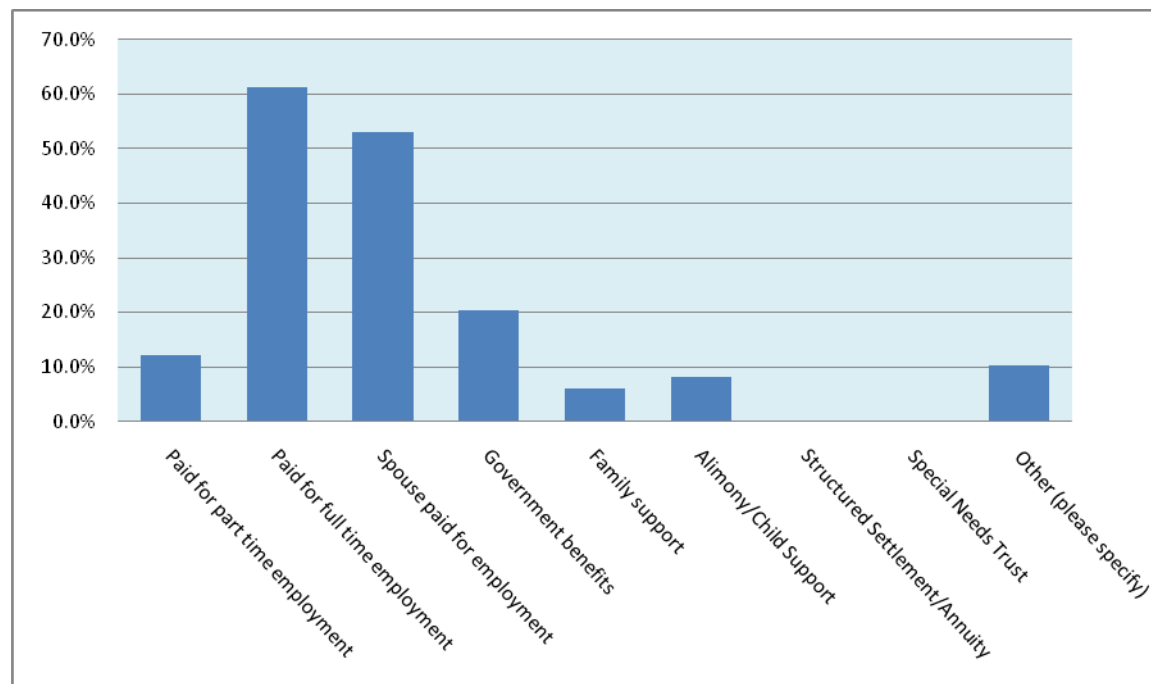


In addition to these results, it has been reported that a majority (60%) of respondents thus far are unsure if they have adequate finances to care for the special needs individual for the duration of their life and 21% not enough. This result further explains why over 90% would like to know more about special needs trusts, among other resources such as government benefits and estate planning provisions. Moreover, after receiving diagnosis of a loved

one with a disability, 42% of the respondents wanted to seek out information through books and online resources and 22% wanted to speak to a professional about the diagnosis.

As demonstrated by the Figure 2 below, a majority of caregivers receive income and financial support through full-time employment and spouse employment. However, thus far in the survey, none of the respondents have reported a special needs trust as a source of financial support.

Figure 2
Current Source of Income & Financial Support.



Discussion

Although data collection is incomplete, there are several weaknesses that may impede the results. Selection bias is one of the limitations with the survey since our recruitment method involves sending emails to existing support groups in the community. Many of the respondents—who are also promoters of the survey—are those who have already been seeking assistance with planning. Thus, we are likely missing a population of people who are not a part of organizations that are designed as a support system to families with special needs. In addition, it is apparent that computer access for survey participants is necessary, which limits our outreach. We are considering other methods to reach out to those in the local community as well the use of focus groups to further develop a comprehensive assessment of needs.

The literature and our survey project demonstrate that the financial planner should be very clear in his or her role. The planner is usually not an attorney and should not hold himself as an expert in the field (Sharpe & Baker, 2007). Rather, the planner should work hard to gain a good, general knowledge of the “big picture” that is special needs planning. They should actively seek out other members of the community that can fill niche roles such as Life Insurance agents, attorneys, CPA’s, and even government program representatives. For example, another interesting find among the survey results was that 79 percent of respondents are married. Perhaps working with a marriage and family therapy professional can broaden outreach efforts. Also, a recent study involving adults with autism shows that support services, like those in the community, have been helpful to many families (Graetz, 2010).

Education is tantamount in any area of financial planning, but even more pressing when it comes to special needs planning. Heller (2000) and Smith & Tobin (1989) found that both families and professionals lack the necessary information on regulations, rights and benefits to make effective choices for their children. By understanding the factors which affect this area, the regulations, eligibility requirements and current tax laws, financial and estate planners can better understand the structuring of special needs trusts based on the interaction

between Medicaid, Medicare, social security and other income resources (Sharpe & Baker, 2007). However, planners do not have to bear the full burden of collecting and gathering information pertinent to special needs individuals. If clients are already aware and informed about the tools and resources that can aid their loved ones in maintaining total financial well-being, then planners can focus on implementing their plans. The survey and outreach discussed can further this goal.

Once a special needs knowledge base is developed and the appropriate contacts are made, the planner will see an increase in their client base. Also, when planners are past the initial phase of developing their business in the special needs area, they may want to consider pro bono work and determine how it fits into their business model. Steve Rhatigan, of ArcherCare, and a pioneer in the Special Needs planning field can attest to that.

Conclusion

As with parents, a planner's introduction into the world of special needs can often be overwhelming. Planners must take a step back and consider their role in the estate planning process. If financial planners strive to take and maintain a holistic view of the planning process, bearing in mind the vastness of resources available, their clients will see their goals realized. Use resources that are already in place and tested. For example, MetLife, another pioneer in special needs planning, has established a help desk exclusively for special needs families. Using such resources wisely provides opportunities for financial planners to leave an indelible mark.

Grassi (2008) asserts that it takes more than just a financial planner or attorney to meet the needs of clients with a special needs child. The special needs cohort often consists of a financial planner, attorney, insurance agent, special education teachers, counselors and/or therapists. Once the planner has uncovered all of the resources (e.g. financial, educational, etc.) available to special needs families, then and only then, can they move forward with the planning process. Planners will want to assist families with cost benefit analysis such as work versus child care, and be able to perform other calculations that aid clients in sorting through the many difficult decisions they will face. This process will be much more fluid if both caregivers and planners are on the same page. The special needs community assessment survey in progress can lead to better decisions for both financial planning professionals and special needs caregivers.

Appendix

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.

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
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).

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Endnotes

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Figure 1
Professionals Consulted by Respondents.

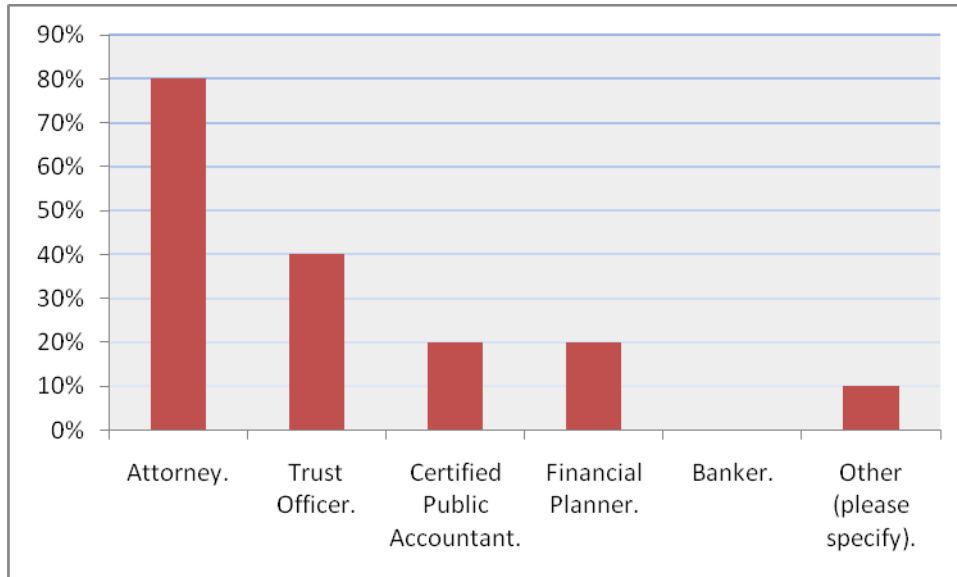


Figure 2
Current Source of Income & Financial Support.

