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**Progressing Towards Empowering Caregivers and Planners with
Special Needs Planning Resources**

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Abstract

Many factors come into play when families plan for the future of their special needs family members. Trying to balance family, emotional, educational, financial, governmental, and legal factors can be a daunting task for any family. Due to the overwhelming nature of this type of planning, many families fail to plan for the financial future of their children, grandchildren, or relatives with developmental disabilities. The rising number of children and adults with disabilities presents an opportunity for financial planners to add value in the lives of their clients by helping them sort through key issues. Two focus groups have been completed and participants are currently being recruited for additional group sessions in order to assess the educational needs of the special needs community. The results will aid in developing educational modules to serve as a resource for financial planners and caregivers.

Progressing Towards Empowering Caregivers and Planners with Special Needs Planning Resources

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 (Erickson & Lee, 2008; 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 (Barker, Page, & Meyer, 2003; Grassi, 2008).

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. (Erickson & Lee, 2008). 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.

Special Needs Families Overwhelmed

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.

Education and the Financial Planner's Role

The literature demonstrates 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.

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. Outreach through the use of educational training modules can further this goal.

Special Needs Focus Groups

Focus groups are currently being utilized to delve deep into the concerns and needs of special needs families to better determine their educational needs. 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). Quantitative methods have been employed previously by Lauderdale (2009) and gaps were left to be filled to determine the educational needs of the special needs families. Focus groups will permit insight into stories and experiences of families dealing with special needs planning issues. Success stories and stories of frustration will be useful to bridge the gap between families that have already found a way to plan financially and those that have been unable or unwilling to do so.

Currently, two focus groups have been conducted and additional participants are being recruited 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. After establishing

participants' knowledge of planning resources and identifying common gaps, educational modules will aid in increasing awareness and provide support to both caregivers and planners.

Methodology

The focus group sessions employ qualitative research methods described by Krueger and Casey (2009), Templeton (1994), and Greenbaum (1998). Methods will include the bifurcation of groups, formulation of participant criteria and screening procedures, development of discussion guides, recruitment of participants, moderation of focus group sessions, participant debriefing, moderator and research team debriefing, transcription and content analysis of focus group data, and preparation of research report. These research measures will be followed by the creation of educational modules.

The purpose of this study is to determine whether care givers feel that they are aware of and comfortable with navigating through the myriad of financial tools, estate planning tools, and government entitlements to take full advantage of the available benefits. After determining the current awareness and desires, educational tools 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.

Sample

The families are segmented into two groups to generate discussions of successes and problematic experiences in planning financially for special needs loved ones. The two segments are 1) those that have completed some financial planning for their special needs family member and 2) those that have not completed any planning. Potential participants are randomly selected from current membership of family support groups as well as accepting personal nominations.

Only one member from a family is permitted to participate. The desired size of the groups is four to six individuals. The researchers estimate that it will take approximately two to three groups of each segment to achieve saturation.

An email screening questionnaire was developed to establish qualifying criteria. This helps to prequalify the individuals that agree to participate. A single interviewer conducts all of the email screening questionnaires. Additional correspondence via email is sent to confirm participation. Over-recruiting is employed to account for no-shows and cancellations.

One focus group session for each group has been conducted. Four participants were present for both sessions.

Measures & Procedure

We have conducted two focus group sessions thus far. A professional moderator was secured to direct the sessions. A monetary incentive of \$30 was provided to recruit participants through a grant from The CH Foundation. A discussion guide was developed for the focus group by researchers in order to ensure that questions were free of emotional biases and also to ensure that the questions reflected the desired outcomes. Questions were formulated to determine present and future concerns in administering care, planning arrangements and desired training for special needs education. The study adheres to research guidelines involving human subjects and was approved by Texas Tech University's Institutional Review Board.

The focus group sessions are currently being conducted on Texas Tech University campus. The Marriage & Family Therapy clinic is equipped for the focus group meetings with a viewing room with a two-way mirror. The same moderator is used to lead the focus group discussions. The sessions are observed through a two-way mirror, and researchers take notes and

assist the moderator with the direction of questions and time management. Participants were asked to fill out a questionnaire prior to starting the session. At the end of each session, participants are debriefed and given compensation for their time.

Initial Findings after Two Focus Group Sessions

When analyzing the sessions, we examine not only the answers to questions but try to identify common themes throughout each discussion. Among the two focus group sessions conducted thus far, it is apparent that females are the primary caregivers, consistent with findings in previous research (Lauderdale, 2009). This presents an area of concern, as there may be an overreliance on females as sole caregivers. Identifying an alternative caregiver in the event that the primary caregiver (usually the mother) is unable to administer care is a major concern among the participants.

As mentioned above, both married and unmarried females are predominantly the primary caregiver for a special needs child or relative (Lauderdale, 2009). One of the participants, a father who cares for two special needs children alongside his wife states that “more fathers than not, are disconnected.” Even when males are supportive of their special needs children they are usually not as knowledgeable of the daily tasks and responsibilities that come with a disabled child. As mothers or other family members take on a caregiver role, they bear all the responsibility and find it difficult to identify others who are able to provide care in the future.

The dominant theme arose when asked, “what is your greatest fear for your special needs loved one?” Consistently the answer revolved around concerns about when the parent or guardian dies. Then what? The common frustration is finding someone who will love and not take advantage of their loved one, someone who also has the financial capacity and the time to

navigate through all the special needs planning information. Great fears were shared in both groups regardless of how much planning had been completed. One parent said, “I haven’t really prayed about this, but I’ve thought it. It would be good if he (her son) passed on before I did. And that’s not something that is medically in his future, but just thinking about what I have to set up for him, how do I trust that these people are going to be there for him? How do I know they’re actually going to help and not hurt him? He doesn’t fight back. He could be abused so easily and it’s terrifying...I’ve never voiced this to anyone--that’s not what you want to hear a mom say, so...” Even when other children are present in the home, parents (mothers) do not want to burden them with caring for the special needs sibling or they do not feel that their other child or children are capable of administering proper care. They view finding another caregiver to be a scary and somewhat hopeless situation.

Regarding financial management, of the eight participants, four had some estate planning in place. No one has a complete plan in place. One participant sees government benefits and her extended family as the only source of future financial needs. Another participant stated that she had a trust in place but she didn’t know how long it would last for her loved one. A majority of the focus group participants did not have a will, letter of intent or guardianship in place. Concerning professional services, about 25 percent have obtained therapy for their loved ones. Furthermore, in both groups, it was apparent that there initiative is lacking to get estate documents in place. Perhaps it is due to the overwhelming demands of daily care and an on-going to do list in seeking services for their loved ones. However, for wills and guardianships, the common theme arose that they would set up the documents, but they do not have a name to put in the blank to take care of their loved one.

Additionally, the participants expressed frustration in identifying experts in the special needs field. They are aware that they have to visit with an attorney or a financial planner for many issues, but some want specific names of those professionals in their community. Many indicated frustration that they continue to send on a scavenger hunt to find answers and run into dead ends from time to time. For example, when a participant sought out an estate planning attorney for a guardianship case they were told that he/she does not do guardianship proceedings. Financial planners may be able to assist in gathering a team of experts in this area through referrals.

Implications

After all of the focus group sessions are completed, researchers will know more about the implications. To address the need for an alternative caregiver, especially in the case of single-parent households, it may be important to develop support groups or provide training for siblings. While the parents with other children in the household said that they did not want to burden their other children with a care giving role, it may be necessary to take advantage of immediate family members. This can provide the peace of mind that they would lack in having no one in place. One suggestion is to include other children in the daily care of the disabled child. Heller & Kramer (2009) cites that having siblings of disabled loved ones interact with each other will better facilitate a future care giving role. Also, having a 'special needs care' notebook with information pertinent to the special needs loved one may also instill peace of mind in relinquishing care.

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