



# FEATURE: ESTATE PLANNING & TAXATION

By **Ann Koerner** & **Martin M. Shenkman**

## Effective Planning for a Family With Special Needs Considerations

Collaborative professional practice is essential

**T**he importance of collaborative professional practice is essential when consulting with families with special needs considerations.

Too often, practitioners view this issue as merely planning for children with special needs, but the number of clients affected is much broader. An “individual with special needs” from a planning perspective can be broadly defined as anyone who requires support of another to achieve a defined quality of life. This includes individuals challenged by developmental disability, mental illness, physical disability and altered functional abilities due to aging. The sheer number of clients affected is staggering. Estimates indicate that there are 61 million Americans living with chronic illness and disability, and six out of 10 adults have chronic illness.<sup>1</sup>

### Common Situations

Common client situations that practitioners may face include:

1. A family with an adult child who’s still being supported by parents, and the parents don’t wish to leave funds outright to their adult child due to cognitive challenges, physical disabilities, addiction or alcohol issues. A commonly overlooked challenge for these families is planning for the disabilities of both the adult child and the parental care giver. This requires addressing not only financial issues and trusts for the adult child but also aging and

disability planning for the parent.

2. A family that can’t define the level of care that their child with a developmental disability (for example, Down syndrome, autism) requires over his lifetime with aging (for example, does he need 24/7 care?). The level of care may change over time with life transitions as well as the associated cost projections.
3. A family that’s having difficulty determining the role of successor generations or has an absence of family/friends to fill roles of power of attorney/guardian or successor caregiver. This phenomenon is growing as more families are fractured, and the traditional intact family is less than half of family units. Addressing a particular client’s situation will require assembling various fiduciary building blocks and estate-planning techniques. For example, an institutional trustee might be named successor trustee in a revocable trust along with a trust protector to monitor the institutional trustee. In other situations, a combination of family and other trustees and/or a committee of trust protectors can be used in varying combinations.
4. A family that’s having difficulty identifying care needs with age—and the need for modified housing, paid caregivers and end-of-life care for essential parent caregivers. Each of these factors may change over time. Too often, clients falsely believe that a child or other person will take care of whatever is necessary. They often do this without consideration of the challenges to the potential child or other individual or geographic challenges if the individual moves.
5. A family that hasn’t been able to identify, access and maximize all available third party and community benefits. These are quite complex and often require the guidance of an attorney and special needs benefits consultant.
6. A family that’s at odds with each other regarding the vision for how family funds should be used in the

**Ann Koerner** is president and founder of National Care Advisors in Morgan Hill, Calif., and **Martin M. Shenkman** is an attorney in Fort Lee, N.J.





future. The reality is that few families with these challenges have sufficient funds to meet everyone's needs, so triage is required and challenging on many levels.

7. A family having difficulty developing a housing and care transition plan over their loved one's life. While the input of the traditional advisor team of attorney, CPA and wealth manager is important, the guidance of a special needs care manager, and perhaps other specialists, will be critical.

### Demand for Services

With effective, personalized fact finding, financial planners and estate-planning attorneys will understand that more family clients than not have some degree of special needs considerations. The market for high quality planning services is significant and growing. The reality is that in too many cases, these issues aren't being addressed. As the population continues to age, the demands for better, personalized, comprehensive and collaborative planning services will grow.

Approximately one in five adults in the United States—43.8 million or 18.5%—experiences mental illness in a given year. Approximately one in 25 adults in the United States—9.8 million or 4%—experiences a serious mental illness in a given year that substantially interferes with or limits one or more major life activities.<sup>2</sup> Autism rates are one in 59 based on Centers for Disease Control and Prevention studies.<sup>3</sup> An estimated 2.47% of children in the United States have autism spectrum disorder, according to a new analysis of data from the U.S. National Institutes of Health.<sup>4</sup> About 56.7 million people—19% of the population—had a disability in 2010, according to a broad definition of “disability,” with more than half of them reporting the disability as severe, according to a comprehensive report on this population released by the U.S. Census Bureau.<sup>5</sup>

### Collaboration

Best practice for special needs financial and estate planning must incorporate essential information regarding future care and a quality-of-life plan for the individual family member with special needs as well as the long-term needs of all family members. Financial planners and estate-planning attorneys should collaborate with a highly skilled special needs nurse consultant as the comprehensive plan is developed.

This isn't simple, as the financial and estate-planning

teams often face barriers to including other professionals in their professional practice. Many advisors simply won't collaborate because they want to protect their client relationship, maximize their billing and avoid discussions that may be outside of their routine practice. The traditional planning team must expand to include the specialists to deal with aging, disability and other challenges if their model is to provide best practices ser-

In most cases, the wealth advisor requires the input of the care manager and a care plan with dollar cost estimates to realistically forecast financial results for a particular client.

services to their clients. In addition to providing excellent comprehensive services to clients, collaboration also mitigates practice risk for all professionals.

### Consulting/Analysis Services

The following consulting and analysis services are essential:

1. Consulting with the family/client to define their vision for future care and quality of life for the special needs individual over his life time, including:
  - a. Home transitions
  - b. Caregiver transitions
  - c. Medical management
  - d. Financial management
  - e. Socialization management
2. Projection of the expected real-life costs of care and quality-of-life needs over lifetime, including models that encompass a range of possible outcomes that can be factored into the plan.
3. Analysis of the specific line item costs of the vision, based on today's dollars and circumstances.
4. Identification of third-party benefits that will be available to assist with the costs of care—such as Social Security, Medicare and Medicaid waiver programs.



## FEATURE: ESTATE PLANNING & TAXATION

5. Projection of the involvement of family members as caregivers and management of affairs.
6. Written analysis of vision.
7. Expenditure plan models (cost models) that define the monthly recurring costs and large purchases specific to the defined vision.
8. Integration of the costs and cash flow sources into a financial model or forecast to help project likely outcomes over the life expectancies of all involved and, if necessary, increasing cash flows (via a more aggressive investment allocation or a working person staying in the workforce longer), cutting expenses, etc. This type of analysis can also be enhanced with

Tools such as life insurance policies can be extremely helpful to make sure that resources are available for the special needs individual without impacting the share of the estate available to siblings.

sensitivity analysis or “what if” scenarios to address reasonable variables that should be factored into the planning.

9. Plan for annual review of the care plan, as life is dynamic. This is true not only for financial results but also for the progression or remission of the functional challenges if that’s feasible, changes in family dynamics or loss of a caregiver.

This care and quality-of-life plan is documented and incorporated into the estate and financial plan so that successors have essential information. The information contained in the plan and cost projections inform the financial planner and attorney regarding the objectives and goals for the overall comprehensive plan for the family. In most cases, the wealth advisor requires the input of the care manager and a care plan with dollar cost estimates to realistically forecast financial results

for a particular client. It’s not enough to use generalized assumptions, provided by family caregivers, when the client faces a specific illness or challenge.

Frequently, this step of the process is omitted, and the attorney drafts estate-planning documents based solely on a limited office interaction with her client. Too often, the planning is document-focused when these clients commonly need practical multi-disciplinary guidance. Steps seemingly as simple as consolidating financial accounts and automating bill payment to reduce costs and risks of identity theft could be vital for these clients.

### Projecting Long-Term Care Needs

Parents and primary family caregivers often don’t have the ability to objectively project the long-term line item care needs for their loved one with special needs over life expectancy. Common inaccuracies include:

- Underestimating the need and private pay costs for 24/7 care and supervision.
- Tailoring that care to be realistic within the client’s financial needs (for example, a lower level of care or staggered care).
- Difficulty analyzing the true costs of housing, transportation and socialization support.
- Lack of knowledge about the value of third-party benefits.
- Inaccurate projection of funding levels for designated trust accounts to accomplish goals within the scope of available resources.
- Consideration for the needs of other family members. This is critical. If for example, one child is expected to care for a second child, what about the needs of the caregiving sibling? If all financial resources are devoted to the child with challenges, the disillusioned sibling may not be willing to provide the care anticipated.

A skilled special needs nurse consultant can lead the parents and family through important determinations to address these aspects of the future care and quality of life needs accurately.

Common missed considerations include the value of dependent Social Security benefits as parents age, the role of siblings as successor caregivers/managers of care and the value of means-tested benefits such as Supplemental Security Income, Medicaid and Medicaid



waiver programs. Planning for parent retirement and elder care funds as well as sibling financial support frequently isn't discussed within the scope of special needs planning.

### Estate-Planning Process

On completion of a well-developed care plan, decisions regarding the value of establishing a special needs/supplemental needs trust (SNT) and the appropriate funding level for the trust become readily apparent. Also, bear in mind that not all clients with challenges necessarily need SNTs. Some simply don't qualify or receive governmental benefits, so an SNT isn't necessary. Nonetheless, specialized planning and a trust, albeit one that doesn't meet the strictures of an SNT, might be essential.

Guardianship and power of attorney designations should also be a part of the estate-planning process.

Tools such as life insurance policies can be extremely helpful to make sure that resources are available for the special needs individual without impacting the share of the estate available to siblings.

Financial planners and estate-planning attorneys frequently note that families don't complete intake forms and fact-finding documents. Successful collaborative special needs planning incorporates a service model in which parents are allowed to express their vision without having the additional burden of writing their own documents, researching costs and developing the transition plans over lifetime. The professional team consulting with the family should designate a leader to make sure that the plan is documented, legal documents are executed and the financial/investment plan is implemented. Consider a more free-form meeting with open-ended questions, and let the conversation evolve. If there's a tendency to focus on typical points that need to be addressed, for example, who should be your client's executor, the client may not reach the level of comfort to open up about sensitive and difficult facts.

### Benefits

The return on investment for collaborative practice for special needs planning is justified through the following benefits:

1. Legal documents that reflect the plan and are developed with flexible language that allows for

modification as unexpected life challenges arise for the family.

2. A financial plan that allows for quality of life for all family members, not just the individual with special needs.
3. Maximization of all third-party benefits and community resources that have value to the funding of the care and quality of the life plan.
4. Long-term professional support and resources as life transitions are necessary.

One to two months of maximized dependent Social Security benefits or Medicare/Medicaid benefits can easily justify the additional cost of adding the special needs nurse consultant to the planning team. It's also important that the professional fees for the attorney and financial planner are transparent and that clear objectives and goals for consulting services are identified.

High-net-worth (HNW) families face these planning issues as well. For these clients, the issue that's paramount to most, financial resources, isn't important, but there are numerous other concerns that make their planning just as specialized and challenging. HNW clients have to address additional difficult questions, such as how much is the maximum amount to bequeath to an SNT. Should it be capped at \$2 million, \$5 million or something else?

HNW families also have the same challenges regarding successor caregivers, finding quality, reliable staff and management of the care needs consistent with the quality-of-life vision that their resources will allow.

For effective, best-in-class special needs planning, the unique professional expertise of the special needs nurse consultant, attorney and financial planner must come together. Professionals who develop this type of collaboration with specific practice expertise find that their clients' objectives and goals for quality of life are well served over time. The outcome is worth the additional effort. 

### Endnotes

1. [www.cdc.gov/media/releases/2018/p0816-disability](http://www.cdc.gov/media/releases/2018/p0816-disability); [www.cdc.gov/chronic-disease/resources/infographic/chronic-diseases](http://www.cdc.gov/chronic-disease/resources/infographic/chronic-diseases).
2. [www.nami.org/learn-more/mental-health-by-the-numbers](http://www.nami.org/learn-more/mental-health-by-the-numbers).
3. [www.cdc.gov/hcbddd/autism/data](http://www.cdc.gov/hcbddd/autism/data).
4. [www.cbsnews.com/news/u-s-autism-rates-appear-to-be-stabilizing/](http://www.cbsnews.com/news/u-s-autism-rates-appear-to-be-stabilizing/).
5. [www.census.gov/newsroom/releases/archives/miscellaneous/cb12-134.html](http://www.census.gov/newsroom/releases/archives/miscellaneous/cb12-134.html).