

ONE PIECE OF THE PUZZLE: A PRACTITIONER'S GUIDE TO AUTISM-SPECIFIC SPECIAL NEEDS TRUSTS

I.	FOREWORD.....	344
II.	INTRODUCTION.....	344
III.	BACKGROUND INFORMATION	345
	A. <i>Characteristics of Autism Spectrum Disorders</i>	346
	1. <i>Social Interaction</i>	346
	2. <i>Verbal and Nonverbal Communication</i>	347
	3. <i>Repetitive Actions or Interests</i>	347
	B. <i>Other Disorders Associated with ASD</i>	348
	1. <i>Anxiety</i>	348
	2. <i>Epilepsy</i>	348
	3. <i>Mental Retardation</i>	349
	4. <i>Sensory Problems</i>	349
	5. <i>Sleep Disturbances</i>	349
	C. <i>The Significance and Implications of a Broad Spectrum Disorder</i>	350
	D. <i>Available Intervention Therapies to Minimize the Characteristics of ASD</i>	351
	1. <i>Interventions to Support Social-Emotional Needs</i>	351
	2. <i>Interventions to Support Communication</i>	351
	3. <i>Interventions to Support Play</i>	352
	E. <i>Potential Health-Care Considerations for People with ASD</i>	352
	F. <i>The Costs and Other Financial Issues for Families Raising Children with ASD</i>	352
IV.	SPECIAL NEEDS TRUSTS	354
	A. <i>Notable Differences Between Federal and Texas SNT Provisions</i>	355
	1. <i>42 U.S.C.A. § 1396p(d)(4)(A) Special Needs Trusts Requirements</i>	355
	2. <i>Texas Property Code § 142 Special Needs Trusts Requirements</i>	356
	3. <i>Texas Probate Code § 867 Special Needs Trusts Requirements</i>	357
	B. <i>Appropriate Expenses for an SNT to Pay</i>	359
	C. <i>Impact of Medicaid and Social Security Benefits on Creating an SNT</i>	359
	D. <i>The Importance of Constructing a Flexible SNT for an ASD Individual</i>	362

E. <i>The Flexibility Factor: Constructing “On/Off” or “Spigot” SNTs</i>	363
V. USEFUL QUESTIONS FOR PRACTITIONERS TO ASK PARENTS OF ASD CHILDREN.....	364
A. <i>The Who, What, and How of ASD-Specific SNT Planning</i>	364
1. <i>Who Will Be Your Child’s Guardian?</i>	364
2. <i>Who Will Be the Trustee of Your Child’s SNT?</i>	365
3. <i>What Services Will Your Child Need in the Future?</i>	366
4. <i>How Do You Envision Your Child Being Cared for in the Future?</i>	366
VI. CONCLUSION.....	367

I. FOREWORD

In the fall of 1994, my younger brother, Peter, was diagnosed with autism. From the time of his diagnosis, my parents searched constantly for outlets to improve his speech, fine-motor skills, cognitive abilities, and social interaction. Like most parents of autistic children, they focused on the present rather than the future. My parents assume that I will care for my brother should anything happen to them, but this is not the case for every family. Due to the increase in autism diagnoses, there is an ever-growing need for attorneys who can help families with autistic members effectively plan for their loved ones’ futures. My hope is that this article will give such estate planners a glimpse of what life is like for both people with autism and their family members, and help improve those practitioners’ planning strategies accordingly.

II. INTRODUCTION

Autism diagnosis rates are rising. While it is difficult to ascertain the exact percentage of individuals who will be diagnosed with the disorder, one thing is for certain: With chances as high as 1 in 110, Autism Spectrum Disorders (ASD) will affect all of us in some way or another.¹ However, what does the rise in ASD cases mean for the estate planning community?

There is a rapidly growing need for experienced and caring attorneys and financial professionals who can assemble a comprehensive estate and

1. *New Data on Autism Spectrum Disorders*, CENTERS FOR DISEASE CONTROL AND PREVENTION, <http://www.cdc.gov/features/countingautism/> (last updated Mar. 29, 2012). In 2006, the Center for Disease Control and Prevention’s Autism and Developmental Disabilities Monitoring Network (ADDMM) conducted research involving 8% of the country’s eight year-olds and found that the average ASD prevalence within this age group was 9.0 per 1,000, or 1 in 110. *Id.* However, other researchers are reluctant to delegate that high of a percentage to ASD prevalence because of the continual lack of a consistent biological marker with which to diagnose ASD. *See id.*; Carla K. Jackson, *Autism Rates: Government Studies Find 1 in 100 Children Has Autism Disorders*, HUFFINGTON POST (Oct. 5, 2009, 1:52 AM), http://www.huffingtonpost.com/2009/10/05/autism-rates-government-s_n_309290.html.

financial plan for individuals with disabilities. The need in this area stems from several factors, including the move [a]way from institutional placements, advances in medicine which have increased the life expectancy of people with disabilities and the alarming rise in autism, a pervasive life-long disability.²

With a rise in ASD diagnoses, it is likely that all practitioners within this community will be asked to execute a will or trust with an autistic individual in mind. As statistics show a rapid increase in autism, lawyers must be aware that they will be planning for families where ASD impairs a family member more and more.³ As attorneys, what issues must be kept in mind when planning for the future of someone with ASD? Very little is known about ASD and the lack of potential causes or cures presents several interesting challenges for practitioners creating trusts for families or individuals affected by ASD.

This article will address some of the issues associated with a broad-spectrum disorder like ASD. First, background information will be presented in order to develop a strong foundation of what ASD is, what other disorders are associated with it, and other issues families with ASD children face. Next, a brief overview of Special Needs Trusts (SNT) will be tied into the previously discussed ASD information in order to develop an inclusive and ASD-specific SNT framework. Lastly, this article will address some of the questions that parents or grandparents of ASD individuals will likely ask legal professionals when planning for the future of their child. A solution is needed, and the research and assertions within this article will hopefully bring ASD awareness, as well as provide practitioners with helpful guidelines to creating trusts for clients with ASD.

III. BACKGROUND INFORMATION

Autism Spectrum Disorders (ASD) are categorized, along with other pervasive developmental disorders, as a “subclass of mental disorders characterized by distortions in the development of multiple basic psychological functions that are involved in the development of social skills and language.”⁴

2. Frances M. Pantaleo, *Supplemental Needs Trusts*, PRACTICING LAW INSTITUTE, 349 PLI/EST 269, 273 (2009).

3. Cynthia L. Barrett, *The Elder Law Approach to Estate Planning*, AM. LAW INST.—AM. BAR ASS’N CONTINUING LEGAL ED., SH059 ALI-ABA 375, 378 (2003). While it is interesting to think about unique and diverse anomalies that some estate planners face in their careers, it is far more likely that a practitioner will be asked to help a family of an autistic child to plan for that child’s life once the parents pass away, making this article a vector with which to share such information.

4. TEX. HUM. RES. CODE ANN. § 114.002 (West 2005); AM. PSYCHIATRIC ASS’N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 102 (4th ed. 2000). In defining autism and other similar disorders to lay the foundation for the Texas Council on Autism and Pervasive Developmental Disorders, the Texas legislature chose to adopt the definition set forth in the Diagnostic and Statistical Manual of Mental Disorders (DSM), a publication used by psychiatrists, diagnosticians, and other medical professionals to assist in the diagnosis and treatment of ASD. Interview with Sherry Sancibrian, M.S., CCC-SLP, Dir. of Speech-

Autism is more common among children than better-known disorders such as diabetes, Down Syndrome, and spina bifida.⁵ Due to the broadness of the disorder, medical professionals diagnose on a case-by-case basis.⁶

A. Characteristics of Autism Spectrum Disorders

While there is no bright-line rule in place to diagnose someone with ASD, an autistic person will generally demonstrate deficits in three behavioral subsections: (1) social interaction, (2) verbal and nonverbal communication, and (3) repetitive actions or interests.⁷

1. Social Interaction

The typical infant is an inherently social being, responding to their parents' facial expressions and other environmental stimuli.⁸ However, children with ASD have a problem grasping the "give-and-take of everyday human interaction."⁹ Generally, even within the first few months of life, many children with ASD will avoid eye contact, resist attention, and prefer to be alone.¹⁰ Later in development, children with ASD will find it difficult to interpret social cues from family members, teachers, or peers.¹¹ Another problem lies within an ASD diagnosee's inability to properly see things from another person's perspective or effectively place himself in another person's shoes.¹² This characteristic inhibits someone with ASD from being able to predict or understand the actions of others, a sometimes frustrating fact for the individual with ASD and the persons around him.¹³ Though not universal, some people with ASD find it difficult to regulate their emotions.¹⁴ While

Language Pathology, Tex. Tech Univ. Health Scis. Ctr., in Lubbock, Tex. (Sept. 29, 2011).

5. U.S. Dept. of Health and Human Servs., *Autism Spectrum Disorders: Pervasive Development Disorders*, Pub. No. 08-5511, NAT'L INST. OF MENTAL HEALTH 3 (2008).

6. Interview with Sherry Sancibrian, *supra* note 4.

7. U.S. Dept. of Health and Human Servs., *supra* note 5, at 7.

8. *Id.*

9. *Id.* People with ASD do not process social settings the same way normal people do. *Id.* The things we take for granted, like correlating a frown with someone being unhappy, do not register with the majority of autistic persons. *Id.*

10. *See id.*

11. *See id.*

12. *Id.*

13. *See generally* U.S. Dept. of Health and Human Servs., *supra* note 5, at 7. Perhaps the most challenging issue faced by parents and educators of persons with ASD is the social unawareness. *See id.* The inability to make these social and emotional assertions often leaves ASD individuals frustrated with themselves and others. *Id.* Certain therapies are available to aid in the understanding of others' emotions and actions. *Id.*; Interview with Janice Magness, Transition Ctr. Dir., The Burkhart Ctr. for Autism Educ. and Research, Tex. Tech Univ., in Lubbock, Tex. (Sept. 18, 2011) (discussing whether or not there are intervention therapies to minimize the characteristics of ASD).

14. *See* U.S. Dept. of Health and Human Servs., *supra* note 5, at 8.

often deemed to be “‘immature’ behavior,” these emotional outbursts are normally just a result of being in a “strange or overwhelming environment.”¹⁵

2. Verbal and Nonverbal Communication

By the age of three most children have passed the standard language-development milestones, whereas some children with ASD may remain mute their whole lives.¹⁶ Others experience delays and do not develop language skills until as late as ages five to nine.¹⁷ Children who do not speak often use pictures or sign language to communicate, and those who do talk often use language in nontraditional ways.¹⁸ Some of these anomalies include speaking only single words, repeating the same phrase repeatedly, or parroting what they hear others say.¹⁹ Those only mildly affected by ASD may display a large vocabulary, but have difficulty sustaining a conversation.²⁰ The body language of ASD individuals has its own unique quirks; “[f]acial expressions, movements, and gestures rarely match what they are saying.”²¹ “Without meaningful gestures or the language to ask for things, people with ASD are at a loss to let others know what they need.”²²

3. Repetitive Actions or Interests

The repetition of certain motions provides comfort to ASD individuals when placed in an uncomfortable or unfamiliar environment.²³ “ASD children need, and demand, absolute consistency in their environment. A slight change in any routine—in mealtimes, dressing, taking a bath, going to school at a certain time and by the same route—can be extremely disturbing.”²⁴ Such motions might include the flapping of hands or arms, walking on tiptoe, or freezing all motion suddenly.²⁵ These persistent, repetitive behaviors can also take the form of an intense preoccupation with nearly anything: train schedules, vacuum cleaners, numbers, or symbols.²⁶

15. *See id.*

16. *Id.*

17. *Id.*

18. *Id.*

19. *Id.*

20. *See id.* at 9.

21. *Id.*

22. *See generally id.* (proposing that, among other reasons, because of the lack of communication skills, persons with ASD need guidance from advocates to help plan and implement certain aspects of their current and future care needs).

23. *See generally id.*

24. *See id.* at 10 (highlighting the necessity of a constant environment for persons with ASD amplifies the need for a perpetual routine when their primary caregiver(s) are no longer able to provide this setting; thus, their needs can be insured through a trust specific to what they are comfortable with).

25. *Id.*

26. *See id.*

B. Other Disorders Associated with ASD

In order to produce a thoughtful, well-planned trust with an ASD individual in mind, it is important to not only maintain a constant environment for that person, but also investigate other disorders or conditions for which the individual might need care.²⁷ Discussed below are a few of the prevalent comorbid conditions associated with ASD.²⁸ This list is not exhaustive and it is important to keep the line of communication open with the client(s) in order to understand what their child needs or potentially could need on a day-to-day basis.²⁹

1. Anxiety

Studies show that there is a link between ASD and anxiety disorders.³⁰ However, this correlation could be affected by other factors including age, level of cognitive functioning, and degree social impairment.³¹ Regardless of any correlation, many persons with ASD employ psychologists and/or psychiatrists in order to discuss these issues and prescribe certain medications to make the anxiety more manageable.³²

2. Epilepsy

Recently, there has been a growing interest among the autism research community concerning ASD, epilepsy, and possible connections.³³ Although the exact link between autism and epilepsy is unknown, it is evident that there might be a causal relationship between brain function and the two disorders; further studies are still needed to solidify this assertion.³⁴

27. *Id.* at 9.

28. *Id.* (discussing a non-exhaustive list of diseases and disorders that are commonly associated with autism, many for unknown reasons).

29. Telephone Interview with T. Scott Maples, CLTC, Special Care Planner, Partners Fin. Grp., LLP (Oct. 4, 2011) (noting the need for annual reviews of financial planning or trusts for any special needs child in order to establish any physical or emotional changes the child has experienced, and therefore need to be reflected within the long-term planning for the child).

30. Susan W. White, Donald Oswald, Thomas Ollendick & Lawrence Scahill, *Anxiety in Children and Adolescents with Autism Spectrum Disorders*, 29 CLINICAL PSYCHOL. REV. 216, 227 (2009), available at <http://www.sciencedirect.com/science/article/pii/S027273580900004X>.

31. *Id.* at 227–28.

32. Interview with Janice Magness, *supra* note 13.

33. Roberto Canitano, *Epilepsy in Autism Spectrum Disorders*, 16 EUR. CHILD AND ADOLESCENT PSYCHIATRY 1, 61 (2007), available at <http://www.springerlink.com/content/57u4634200n06121/fulltext.pdf>.

34. *Id.* at 62.

3. Mental Retardation

“Many children with ASD have some degree of mental impairment.”³⁵ However, just because doctors diagnose someone with ASD does not mean they are mentally retarded by definition.³⁶ It is quite possible that an autistic person will show no sign of mental retardation at all.³⁷ In most cases, what doctors originally categorize as mental retardation merely reflects current social, behavioral, and communicative difficulties.³⁸ Many individuals with ASD are improperly diagnosed with mental retardation for these reasons, when all they lacked was the primary intake abilities rather than the actual ability to understand and process the information.³⁹ In short, autistic does not necessarily mean mentally retarded, as the general public often believes.⁴⁰

4. Sensory Problems

Imagine a phone ringing, the vacuum cleaner running, or thunder rolling. These are sounds of everyday life for the average person, but these same sounds may create sensory overload for someone with ASD.⁴¹ Researchers hypothesize that ASD renders the brain unable to balance senses appropriately.⁴²

5. Sleep Disturbances

Nearly 86% of children with ASD suffer from sleep disorders.⁴³ Whether these disorders are caused by the ASD itself or other “multiple biological, family, and environmental factors,” is still unknown.⁴⁴ However, compared to the 10-33% of children and 40% of adolescents without ASD that suffer from

35. See U.S. Dept. of Health and Human Servs., *supra* note 5, at 11.

36. Bobby Newman, PhD, BCBA, *What is the Relationship Between Autism and Mental Retardation*, <http://www.asatonline.org/resources/clinician/mental.htm> (last visited Apr. 24, 2012) (stating three criteria used when diagnosing mental retardation: “1. IQ measured to be two standard deviations or more below the mean. 2. Significant adaptive living skill deficits. 3. Onset before age 18 . . .”). See AM. PSYCHIATRIC ASS’N, *DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS* 71 (4th ed. 2000).

37. See generally *Asperger Syndrome Fact Sheet*, NAT’L INST. OF NEUROLOGICAL DISORDERS AND STROKE, http://www.ninds.nih.gov/disorders/asperger/detail_asperger.htm (last updated Apr. 10, 2012) (asserting that milder forms of ASD, such as Asperger’s, do not exhibit manifestations of mental retardation).

38. See Newman, *supra* note 36.

39. See generally *id.*

40. *Id.*

41. See U.S. Dept. of Health and Human Servs., *supra* note 5, at 10.

42. *Id.*

43. Xianchen Liu, et al., *Sleep Disturbances and Correlates of Children with Autism Spectrum Disorders*, 37 *CHILD PSYCHIATRY HUM. DEV.* 179, 189 (2006), available at <http://www.springerlink.com/content/66w37865t47k7344/fulltext.pdf>.

44. *Id.*

sleep disorders, the percentage of ASD children with sleep disorders is very high regardless of the cause.⁴⁵

C. The Significance and Implications of a Broad Spectrum Disorder

Unlike other disorders, such as Down Syndrome, ASD encompasses a wide variety of possible diagnoses across a broad spectrum of severity levels.⁴⁶ There are no physical deformities associated with ASD that would set an ASD child apart from another child, nor is there a “five-point” checklist that medical professionals would look to in making a diagnosis.⁴⁷ Persons with ASD may be completely non-verbal and need 24-hour care, or they might also be college graduates who are totally independent.⁴⁸ There are no typical, “cookie cutter” cases with ASD; every child is different.⁴⁹

Yet another unique aspect of autism is the manner in which professionals diagnose a child with the disorder.⁵⁰ The process of diagnosing a child with ASD can be a long and rigorous ordeal. However, it is crucial for families to receive an accurate ASD diagnosis early in the child’s life, because intervention and care options change dramatically depending on where doctors place a diagnosee on the spectrum and the child’s level of functioning.⁵¹ Typically, although ASD is thought of in the three-pronged characteristic analysis aforementioned, it is the social aspect that prevents most ASD individuals from being “fully integrated into society.”⁵² Even knowing this fact, there is still no one set of recommendations for a parent whose child has ASD.⁵³

45. Stephanie Pappas, *Child Has Sleep Problems? Your Doc May Be Little Help*, MSNBC (Aug. 29, 2011, 9:04:25 AM), http://www.msnbc.msn.com/id/44312172/ns/health-childrens_health/t/child-has-sleep-problems-your-doc-may-be-little-help/#.TqcrRGC4KQM.

46. See generally *Facts About Down Syndrome*, CENTERS FOR DISEASE CONTROL AND PREVENTION, <http://www.cdc.gov/ncbddd/birthdefects/DownSyndrome.html> (last updated June 8, 2011) (comparing ASD with other disorders that can be effectively diagnosed and categorized due to a known genetic mutual or other known cause).

47. Interview with Dr. Wesley H. Dotson, Ph.D., BCBA, Assistant Professor & Dir. of Outpatient Servs., The Burkhardt Ctr. for Autism Educ. & Research, Tex. Tech Univ., in Lubbock, Tex. (Sept. 29, 2011) (discussing the difficulty in making an ASD diagnosis, the time involved and the degree of expertise necessary to make an effective diagnosis for which a therapy plan can be developed so that early intervention can begin).

48. *Id.*

49. *Id.*

50. See MITZI WALTZ, *AUTISTIC SPECTRUM DISORDERS: UNDERSTANDING THE DIAGNOSIS & GETTING HELP* 35–65 (Linda Lamb, 2d ed. 2002); Interview with Dr. Wesley H. Dotson, *supra* note 47 (highlighting the often frustrating and time consuming process that doctors test the social abilities, learning capacity, and behavioral development of a child to diagnose them with an ASD).

51. See Interview with Dr. Wesley H. Dotson, *supra* note 47 (recognizing the importance of an early and accurate diagnosis to reduce the outward manifestations of ASD by improving social awareness and using other therapy techniques).

52. *Id.* Even the most intelligent ASD individuals who have college degrees and are able to live an independent life will experience social difficulties related to the social interaction. See discussion *supra* notes 6–13.

53. Interview with Dr. Wesley H. Dotson, *supra* note 47.

Contrast this assertion with the role the estate planning community will one day play in the lives of families dealing with autism and you will find the reason for this article. Because of the prevalence and broad nature of autism, it is necessary that the persons who will plan for the lives of persons with ASD, long after their primary caregivers are gone, know the struggles and intricacies of an autistic person's life. Furthermore, the broad nature of this disorder means that estate planners will need to realize there is not one recommendation for parents of these children. It is, however, the planner's job to listen to the child's needs and present the parents with a solution, all the while knowing there is not "one" solution.

D. Available Intervention Therapies to Minimize the Characteristics of ASD

While there is no cure for ASD, there are several effective therapies in place to reduce the onset of ASD's characteristics.⁵⁴ Researchers agree that children with ASD "require early intervention, intensive instruction, planned teaching opportunities, and adult support."⁵⁵ There are three typical methods categorized in conjunction with the three major behavioral issues facing children with ASD.⁵⁶

1. Interventions to Support Social-Emotional Needs

There are several means of intervention designed to support the social-emotional development of children with ASD.⁵⁷ Regardless of the structure of the therapy itself, all social-emotional interventions aim to "support a child's connection with another, build strategies for . . . social communication, and facilitate social skills across settings and communication partners."⁵⁸ There are several models of intervention for the improvement of social-emotional needs.⁵⁹

2. Interventions to Support Communication

Children with ASD have communication needs that range from completely nonverbal to those that need little to no communication intervention.⁶⁰ Improvements in communication, verbal or nonverbal, may also support the

54. *What We've Learned About Autism Spectrum Disorder*, CENTERS FOR DISEASE CONTROL AND PREVENTION, <http://www.cdc.gov/features/countingautism/> (last updated Apr. 4, 2011) (discussing typical therapy methods used by practitioners).

55. PATRICIA A. PRELOCK, *AUTISM SPECTRUM DISORDERS: ISSUES IN ASSESSMENT AND INTERVENTION* 348 (2006).

56. See U.S. Department of Health and Human Services, *supra* note 5, at 7–11; see also PRELOCK, *supra* note 55, at 397–538 (comparing the social, communication, and behavioral needs of children with ASD to the social-emotional, communication, and play therapies used by medical professionals to intervene).

57. See generally PRELOCK, *supra* note 55, 345–571.

58. *Id.* at 480.

59. See *id.* at 480–525.

60. *Id.* at 398.

continued development of social and play skills by helping to foster relationships between family members and peers.⁶¹

3. Interventions to Support Play

Both social-emotional and communication skills foster the development of play skills.⁶² Children practice communication skills through game play, and the confidence to play with others allows children with ASD to grow socially.⁶³

E. Potential Health-Care Considerations for People with ASD

In recent years, the American Academy of Pediatrics has recommended that parents of children with disabilities seek a “medical home” for their child.⁶⁴ The biggest challenge for parents of children with ASD is coordinating among the medical personnel that care for their child.⁶⁵ The other interdisciplinary personnel related to a child’s care (e.g. schools, instructors, developmental and mental health agencies and governmental entities) must also be made a part of this routine to construct a plan that encompasses all aspects of the child’s life, whether at school, home, or another site.⁶⁶

F. The Costs and Other Financial Issues for Families Raising Children with ASD

In the years following diagnosis, many families take it one day at a time.⁶⁷ During this “survival mode” stage, parents are left drained from searching for answers for their child; therefore, many parents do not give thought to the future because they are too busy dealing with the present.⁶⁸ However, many

61. *See id.*

62. *Id.*

63. *See generally id.*

64. *Id.* at 542. Noting the importance of continuity that makes ASD individuals comfortable, this assertion states that it is necessary to weave a constant environment throughout all aspects of an ASD person’s life, including the area of both ASD-specific and routine health care. *Id.* The American Academy of Pediatrics, believing the healthcare of children needs to be “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective,” defines medical home as a group of well-trained primary care physicians that manage all aspects of the child’s health, while developing a sense of partnership and mutual responsibility for the child’s well-being with the parents. American Academy of Pediatrics, *The Medical Home*, 110 PEDIATRICS 184, 184 (2002), available at <http://pediatrics.aapublications.org/content/110/1/184.full.pdf+html> (last visited Feb. 7, 2012).

65. PRELOCK, *supra* note 55, at 543. The typical care team for a child with ASD consists of “psychologists, speech-language pathologists, audiologists, occupational therapists,” primary care physicians, and any specialized physician based on the other disorders the child might have. *Id.*

66. *Id.* (reiterating the fact that ASD individuals need not only structure, but also a constant environment filled with persons they can trust).

67. *See* Interview with Dr. Wesley H. Dotson, *supra* note 47 (stating that the shock of an ASD diagnosis paired with handling the physical, mental, and social characteristics leaves parents exhausted and without time to think about what is going on tomorrow, much less the future).

68. *Id.*

medical and legal professionals urge the parents of their patients/clients to briefly step out of the present and begin planning for the future.⁶⁹ Medical professionals meet regularly with parents of ASD children to discuss progress, refigure therapy programs, and assess goals.⁷⁰ Legal consultants should also meet with the family regularly to discuss the development of any special needs trusts (SNT) for the child.⁷¹ Combining both the medical goals of an ASD individual along with a comprehensive financial and legal plan into a SNT will help ensure that a child diagnosed with ASD will be cared for no matter what happens to his/her parents. Many estate planners recommend annual reviews to reassess progress of an individual and any changes that need to be made.⁷²

Before analyzing what specific provisions should be included in an SNT for an ASD child, it is important to recognize the costs associated with raising an ASD child as compared to a child without ASD. This analysis assists practitioners in helping families plan the financial future of their child by demonstrating the costs associated with necessary healthcare, medications, therapies, education, childcare, etc. According to a study published by Harvard School of Public Health in 2006, the average cost of raising a child with ASD into adulthood is \$3.2 million.⁷³ While the parents of an ASD child do not directly cover all of these costs (ASD qualifies some individuals for Medicaid and other U.S. Government benefits), it is still important to note the need for appropriate financial planning and the steadfast protection of assets when preparing an SNT for an ASD child.⁷⁴

Based on this study, the two largest components of these costs are lost productivity and adult care.⁷⁵ In this study, researchers calculated the total cost of autism by adding the direct and indirect costs of the disorder.⁷⁶ “Direct costs measure the value of goods and services used and indirect costs measure the value of lost productivity due to autism.”⁷⁷ Further, it is important to note that

69. *Id.*

70. *See generally Helping Children with Autism: Autism Treatment Strategies and Parenting Tips*, http://www.helpguide.org/mental/autism_help.htm (last visited Feb. 5, 2012) (noting the need to meet regularly with the healthcare professionals in order to allow an ASD person’s healthcare routine to evolve with his progress and changing lifestyle).

71. Telephone Interview with T. Scott Maples, *supra* note 29 (noting the need for annual reviews of financial planning or trusts for any special needs child in order to establish any physical or emotional changes the child has experienced, and therefore need to be reflected within the long-term planning for the child).

72. *Id.*

73. Press Release, Harv. Sch. of Pub. Health, Autism Has High Costs to U.S. Soc’y (Apr. 25, 2006), available at <http://www.hsph.harvard.edu/news/press-releases/2006-releases/press04252006.html>; Michael L. Ganz, MS, PhD, *The Lifetime Distribution of the Incremental Societal Costs of Autism*, 161(4) ARCH PEDIATR. ADOLESC. MED. 343–49 (2007), available at <http://archpedi.ama-assn.org/cgi/content/full/161/4/343>.

74. Tim, *The Cost to Raise a Child and Yet More Autism Disparity*, BOTH HANDS AND A FLASHLIGHT BLOG (Aug. 5, 2009), <http://www.bothhandsandafashlight.com/2009/08/05/the-cost-to-raise-a-child-and-yet-more-autism-disparity/>.

75. Ganz, *supra* note 73.

76. *Id.*

77. *Id.*

the mutually inclusive costs of raising a neurotypical child and an autistic child were not included in these figures, and thus the numbers presented are costs due exclusively to autism.⁷⁸ Focusing on the adult care aspect, the most relevant portion of this study for estate planning purposes is the importance the authors place on detailed financial and legal planning for adulthood.⁷⁹ One way to provide for the future needs of an ASD individual is to create a detailed SNT.

IV. SPECIAL NEEDS TRUSTS

In the past, many families would simply disinherit a mentally disabled family member with the instruction and understanding that the sibling(s) would care for the individual.⁸⁰ It is more advisable that today's professionals inform families that this option endangers the future financial support of the disabled individual.⁸¹ The support of the individual becomes secondary to the potential marital/creditor problems and financial needs of the siblings assigned to care for them.⁸² "Moreover, increasing life spans and decreasing funding of services make it even more critical that funds be specifically earmarked and protected for individuals with disabilities."⁸³

While there are many options for how parents may decide to have their ASD child's needs cared for after they are gone, an SNT is the most well-rounded and sound advice that an attorney can give them.⁸⁴ In 1993, the United States federal government codified the creation of SNTs by enacting the Omnibus Reconciliation Act.⁸⁵ In Texas, SNTs are created pursuant to § 867 of the Texas Probate Code, and § 142.005 of the Texas Property Code.⁸⁶

78. *Id.* (noting that these costs include things such as preventative care visits to pediatricians and other common costs accrued by parents of both autistic and non-autistic children). While this study found that autistic children typically need more preventative care visits, and other common costs are more expensive for autistic children, these costs were nevertheless omitted. *Id.*

79. *Id.* "Perhaps physicians and other care professionals should consider recommending that parents of children with autism seek financial counseling to help plan for the transition into adulthood." *Id.*

80. See Pantaleo, *supra* note 2, at 275–76.

81. *Id.*

82. *Id.* at 276.

83. *Id.*

84. Richard L. Shea, *Special Needs Planning*, TEXAS TITLE 19 (Oct. 27, 2011, 9:27 PM), <http://texastitle19.com/texas-special-needs-trust/>. There are two other viable, but still risky, options besides SNTs that families choose for their ASD child: (1) Give the estate to the brothers and sisters, or (2) Leave an inheritance to the disabled child. With option one, at the parents' death the entirety of the estate is distributed to the child's siblings, with the understanding that they will "take care of" their disabled brother or sister. This could result in the poor management of funds, or even claims against the funds by the siblings' creditors, bankruptcy courts, etc. With option two, the outcome will be the almost certain, negative impact on the child's continued eligibility for publicly-funded benefits, even perhaps rendering the child ineligible for SSI or Medicaid. Both programs encompass a child's ability to access not only essential health care, but many other public assistance programs. *Id.*

85. 42 U.S.C.A. § 1396p(d)(4)(A) (West 1993). "SNT is a trust created for the sole benefit of an individual with a disability under the age of [sixty-five] by the individual's parent, grandparent, legal guardian, or court. The trust must provide that the state Medicaid agency will receive amounts remaining in

A. *Notable Differences Between Federal and Texas SNT Provisions*

When Texas adopted 42 U.S.C.A. § 1396p(d)(4)(A) and codified it into the Texas Probate and Property Codes, a few changes were made.⁸⁷ Below are brief explanations of the definitions and requirements of SNTs under each provision.

1. *42 U.S.C.A. § 1396p(d)(4)(A) Special Needs Trusts Requirements*

The purpose of a SNT is to provide for the beneficiary's supplemental needs only.⁸⁸ For an individual to be the beneficiary of a 42 U.S.C.A. § 1396p(d)(4)(A) SNT (1396 SNT), that individual must fit within the definition of disabled set forth in the statute.

[The individual must be] unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period not less than twelve months. . . . An individual under the age of [eighteen] shall be considered disabled for the purposes of this title if that individual has a medically determinable physical or mental impairment, which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than [twelve] months.⁸⁹

There are five requirements for § 1396 SNTs.⁹⁰ All trusts established under this provision must contain the following: (1) assets of an individual; (2) the individual must be under sixty-five when the trust is created; (3) the individual must be disabled in accordance with the definition provided in 42 U.S.C.A. § 1382c(a)(3)(A)(C); (4) the trust must be established by a parent, grandparent, legal guardian, or court; and (5) the trust must provide for repayment to the state of trust funds equal to the amount paid by Medicaid for the beneficiary upon termination of the trust.⁹¹

the trust upon the individual's death up to the amount paid under the Medicaid program for services to the individual." Bernard A. Krooks & Andrew Hook, *What Attorneys Need to Know About Special Needs Trusts*, ALI-ABA EST. PLAN COURSE MATERIALS J., Oct. 2005, at 6.

86. TEX. PROB. CODE ANN. § 867 (West Supp. 2011); TEX. PROP. CODE ANN. § 142.005 (West 2011).

87. See generally, Helen B. Wils, "Special Needs" Trusts Under the Texas Property Code and The Texas Probate Code, 2-7, Civil Court Ad Litem Institute (Dec. 5, 2003), available at <http://www.texasguardianship.com/Library/SpecialNeedsTrusts.pdf> (setting forth a comparison of the three provisions and noting differences in the definition of incapacity as well as a few differences in the requirements of an SNT).

88. *Id.* at 3 (stating that an SNT cannot be used for basic needs, i.e. food, clothing, shelter, health, support, maintenance, and education). Luckily, for most ASD individuals these basic needs will be covered by state Medicaid and Social Security benefits. *Id.*

89. 42 U.S.C.A. § 1382c(a)(3)(A), (C) (West 2003 & Supp. 2011).

90. See generally Wils, *supra* note 87, at 4 (stating that the requirements of a 1396 SNT are five-fold).

91. 42 U.S.C.A. § 1396p(d)(4)(A) (West 2003 & Supp. 2011).

2. Texas Property Code § 142 Special Needs Trusts Requirements

Texas Property Code Section 142 SNTs (142 SNTs) are created when “a minor has no legal guardian” or when a next of friend or guardian ad litem represents an incapacitated person.⁹² While generally 142 SNTs are created for settlements or judgments in personal injury suits, there are still some instances when these trusts could be applicable to children with ASD.⁹³

The definition of incapacity for 142 SNTs differs substantially from the definition for disabled in § 1396 SNTs. Section 142 SNTs define an incapacitated person as:

A person who is impaired because of mental illness, mental deficiency, physical illness or disability, advanced age, chronic use of drugs, chronic intoxication, or any other cause except status as a minor to the extent that the person lacks sufficient understanding or capacity to make or communicate responsible decisions concerning his person.⁹⁴

There are nine requirements to establish a 142 SNT.⁹⁵

- 1) The minor or incapacitated person must not have a legal guardian . . .
- 2) the applicant must be the next of friend or the court-appointed guardian ad litem . . .
- 3) the trustee must be a trust company or state or national bank having trust powers in Texas . . .
- 4) the trust must provide that the corporate trustee serve without bond . . .
- 5) the minor or incapacitated person must be the sole beneficiary of the trust . . .
- 6) the trust must provide for the distributions of principal, income or both as the trustee determines is reasonably necessary for the health, education, support, and maintenance of the beneficiary, with any income not distributed added to principal.⁹⁶

The most important thing to note about 142 SNTs is that if distributions are made using the above stated “distributive standard,” then the beneficiary will not qualify for state Medicaid assistance.⁹⁷

92. Wils, *supra* note 87, at 4.

93. *Id.* While this form of SNT is generally used for things other than typical life-long planning, it is a great resource for children with ASD who do not have a parent/grandparent advocate willing to plan for them. *Id.* In these cases, the court will appoint a guardian ad litem for the child, and the court can create a trust using the assets of either the parent or grandparent. *Id.*

94. TEX. PROP. CODE § 142.007 (West 2007).

95. See generally TEX. PROP. CODE ANN. §§ 142.001–.004 (West 2007); TEX. PROP. CODE ANN. § 142.005 (West 2007 & Supp. 2011).

96. Wils, *supra* note 87, at 5; see also PROP. §§ 142.001, 142.005(a), (b)(1)–(3), (b)(5).

97. Wils *supra* note 87, at 5. This is important when dealing with ASD individuals because, in many instances, it is very crucial to maintain Medicaid benefits so that the child may continue much needed early intervention therapies, receive necessary medications, and receive other government benefits crucial to the maintenance and care of an ASD child. *Id.* Courts may allow a departure from this language in order to show the necessity of establishing a 1396 SNT and so that Medicaid benefits may be preserved for the beneficiary. *Id.*

7) the trust must provide that the trustee receive reasonable compensation upon application and approval of the court . . . 8) the trust will terminate upon (i) death of the beneficiary; (ii) if the beneficiary is a minor, when the beneficiary reaches the age stated in the trust or the 25th birthday; or (iii) if the beneficiary is incapacitated, on the death of the beneficiary prior to attaining capacity . . . 9) upon termination, the remaining trust estate is distributed to the beneficiary, or if the beneficiary is deceased, to his representative.⁹⁸

3. Texas Probate Code § 867 Special Needs Trusts Requirements

The Texas Probate Code § 867 Special Needs Trust (867 SNTs) adopts a traditional definition of incapacity that aligns more with the § 1396 SNT definition.⁹⁹ An incapacitated person is either:

(A) a minor; (B) an adult individual who, because of a physical or mental condition, is substantially unable to provide food, clothing, or shelter for himself or herself, to care for the individual's own physical health, or to manage the individual's own financial affairs; or (C) a person who must have a guardian appointed to receive funds due the person from any governmental source.¹⁰⁰

To establish an 867 SNT, there must be an existing guardianship established for the individual.¹⁰¹ Texas law allows the inclusion of a special needs provision, which is necessary in case the ward is currently eligible for public benefits or could become eligible in the future.¹⁰² There are approximately eight requirements to establish an 867 SNT that warrant mentioning in this article.¹⁰³ “(1) The trustee must be a financial institution,”¹⁰⁴

98. *Id.* at 5–6; *see also* PROP. § 142.005(b)(4), (b)(6), (e), (g).

99. *See generally* 42 U.S.C.A. § 1382c(a)(3)(A)(C) (West 2003 & Supp. 2011); TEX. PROB. CODE ANN. § 601(14) (West 2003).

100. PROP. § 601(14). ASD individuals could be defined by any of the categories, but when using an SNT as a life planning option, the most likely definition will be (B) to insure that the trust will continue to protect the ASD beneficiary after he or she turns eighteen. *Id.*

101. *See generally* Wils, *supra* note 87, at 8 (noting that for ASD children, it is important that their parents or other guardians establish full guardianship over the child before he or she turns eighteen so as to avoid any issues when trying to establish an SNT).

102. *See generally* Ronald R. Cresswell, *Everything That Can Go Wrong with SNTs and How to Fix It*, Changes and Trends Affecting Special Needs Trusts, Austin, Tex. (Jan. 18, 2006), <http://ebookbrowse.com/everything-that-can-go-wrong-with-snts-and-how-to-fix-it-doc-d152538985>.

103. Wils, *supra* note 87, at 8 (citing approximately eight elements to pay attention to when constructing an 867 SNT).

104. TEX. PROB. CODE ANN. § 867(b) (West 2003) (noting that certain exceptions to this requirement exist); *see* Wils, *supra* note 87, at 8. “If . . . the trust's principal is \$50,000 or less, the court may appoint a person to serve as trustee if the court finds the appointment to be in the ward's best interests.” PROP. § 867(c). “If the value of the trust's principal is greater than \$50,000, the court may appoint a person to serve as a trustee only if (i) no financial institution is willing to serve as trustee; and (ii) the appointment is in the ward's best interest.” PROP. § 867(d); Wils, *supra* note 87, at 8. Before the judge determines that no

“(2) the establishment of the trust is in the ward’s best interest;”¹⁰⁵ “(3) the ward must be the sole beneficiary of the trust;”¹⁰⁶ “(4) the trustee may disburse as much principal or income as the trustee determines necessary for the ward’s health, education, support, and maintenance and any income not distributed shall be added to the principal;”¹⁰⁷ (5) the trustee serves without bond if it is a corporate trustee;¹⁰⁸ “(6) if the trustee is a person rather than a corporate trustee, the trustee must file a bond” in accordance with the conditions established by statute or required by the court;¹⁰⁹ (7) the trustee may receive reasonable compensation from the trust estate upon annual application to the court and the court’s approval;¹¹⁰ and (8) for an incapacitated ward, the trust will terminate on a date determined by the court when the trust is no longer in the ward’s best interest or on the death of the ward.¹¹¹

There are certain admonitions to SNTs. First, there is a legal theory that parents have the primary duty and legal obligation to protect and provide care for their children and to support them financially.¹¹² Of particular importance to long-term planning for an ASD child is the legal assertion that this parental obligation can be “extended and increased beyond the child reaching age eighteen if the child suffers from a disability that begins prior to the age of eighteen and continues on into the child’s adult years.”¹¹³ Should a non-parent trustee ignore this obligation and continue allowing employed or employable parents to use trust funds for daily living expenses, then the trustee can face liability for breaching his or her fiduciary duty.¹¹⁴ Nevertheless, what are appropriate expenses for an SNT to pay?

financial institution is willing to serve as trustee, it must check a list of corporate fiduciaries in Texas. PROB. § 867(e); Wils, *supra* note 87 at 8.

105. PROB. § 867(b) (noting that “best interest” is not defined, nor are factors for determining “best interest” laid out within § 867); Wils, *supra* note 87, at 9.

106. Wils, *supra* note 87, at 9.

107. TEX. PROB. CODE ANN. § 868(a)(2) (West 2003); Wils, *supra* note 87, at 8 (noting that if the trust is dispersed using these principals, it will not qualify as a “special needs trust”). However, the court may modify the terms if it is appropriate for the beneficiary to still receive public benefits or assistance. PROB. § 868(d). In the case of ASD children, as previously mentioned, it is often necessary to receive these government benefits because they either partially or fully cover some of the healthcare costs for ASD treatment.

108. Wils, *supra* note 87, at 9.

109. PROB. § 868(B); Wils, *supra* note 87, at 9. The requirements of a non-corporate trustee bond are that “a trustee must file a bond in an amount equal to the value of the trust principal and protected annual income and in accordance with any other conditions that the court determines.” PROB. § 868(B).

110. PROB. § 868(a)(5) (the amount of compensation is determined in the same manner as compensation of a guardian under § 665 of the Texas Probate Code); Wils, *supra* note 87, at 9. If the court finds that a trustee prudently managed the estate, then the trustee is entitled to 5% of the estate’s gross income and 5% of all money paid out of the estate. TEX. PROB. CODE ANN. § 665 (West 2003).

111. TEX. PROB. CODE ANN. § 871 (West 2003); Wils, *supra* note 87, at 9.

112. See TEX. PROB. CODE ANN. § 777 (West 2003) (providing that a parent who is the guardian of a beneficiary may not use income or “corpus” from the beneficiary’s estate for the beneficiary’s support, education, or maintenance); Deborah Green, *The Top Ten Things to Know About Drafting and Administering SNTs*, 2011 Changes and Trends Affecting Special Needs Trusts, Jan. 27–28, 2011, Austin, Tex., at 3; Wils, *supra* note 87, at 10.

113. Green, *supra* note 112.

114. *Id.*

B. Appropriate Expenses for an SNT to Pay

The amount and frequency by which parents may rely on a trust to pay for everyday needs of their ASD child should be in times of decreased household income and usually not if both parents are employed.¹¹⁵ It may be appropriate for an SNT to help pay for all or part of a house for the entire family or even to make a modification to the home based on the child's disability.¹¹⁶

This raises another important question: How much compensation can a parent or other family member receive from the SNT for providing childcare to an ASD child? There are certain circumstances when it may be reasonable to compensate parents from the trust for childcare.¹¹⁷ Should a parent not be able to work because of the child's disability and should a court find that that parent is the best person to care for the child, then it would be appropriate for a court to allow payment to the parent.¹¹⁸ With an ASD child's need for a consistent environment, this method of childcare may be superior than a constant change in nannies, nurses, or caretakers, if feasible.¹¹⁹ With this situation, the court may require a formal employment contract covering the terms of service, or to have the parent hired by an agency with Medicaid approval to provide for a smoother transition.¹²⁰

C. Impact of Medicaid and Social Security Benefits on Creating an SNT

The general guidelines for Medicaid eligibility were also set out in The Omnibus Budget Reconciliation Act of 1993.¹²¹ To qualify for Medicaid benefits in Texas, as of January 2011, an unmarried individual cannot have more than \$2,022.00 in countable monthly income, and no more than \$2,000 in countable resources.¹²² If an applicant has more "countable assets" than permitted by the particular Medicaid program for which he or she is applying, then the applicant generally has to "spend down" the available resources before qualifying for program assistance.¹²³ Persons with disabilities that may require an SNT are typically assigned to the Community Based Alternative Care sector

115. *Id.*

116. *Id.*

117. *Id.*

118. *Id.* This would be especially appropriate if the parent was a trained professional, i.e. a nurse with experience or a licensed skill that made caring for their child perhaps of better quality than a parent without that training. *Id.*

119. *See generally supra* Part I.

120. Green, *supra* note 112, at 5.

121. Randy Drewett, CELA, *Special Needs Trust Overview*, 2011 Special Needs Trusts, Jan. 27–28, 2011, Austin, Tex., at 3, available at <http://www.texasstatelaw.com/pdfFiles/SNT%20Overview.2011.pdf>.

122. *Id.* at 4.

123. Green, *supra* note 112, at 5. Even if this surplus occurs while the individual is an active participant in a Medicaid program, he or she will still be required to spend down the balance or risk having their assets temporarily frozen. *Id.*

of Medicaid benefits.¹²⁴ The Community Based Alternative Care sector, Home and Community Based Services, Community Living Assistance and Support Services, and the Medically Dependent Children's Program are the programs that "hold that properly paid in-kind support and maintenance expenses are not treated as income to the trust beneficiary"; therefore, a trust beneficiary for this type of program may receive payments for food, clothing, and shelter from another source, such as an SNT.¹²⁵

That being said, it is slightly more complicated for the trustee of an SNT whose beneficiary is also receiving Supplemental Security Income (SSI).¹²⁶ This complication is because of the more complex distribution language found within the SSI rules.¹²⁷ SSI is a federal income supplement program funded by general tax revenues (*not* Social Security taxes).¹²⁸ It is designed to help aged, blind, and disabled people who have little or no income, and it provides cash to meet basic need for food, clothing, and shelter.¹²⁹ As with Medicaid, SSI "benefits are based on the total amount of monthly income a person receives, including, but not limited to, wages earned, payments available through other government assistance programs, gifts of money or property, and the value of 'in-kind' support which can be applied toward food or shelter expenses."¹³⁰

Although there are some differences with SSI income guidelines, the other formalities are more or less congruent with those of the Medicaid rules.¹³¹ "Payments made from a trust are counted as income in the same way under the SSI rules as payments made to or for the benefit of the beneficiary from any other third-party source."¹³² For 2011, the SSI income limitations state that an individual may not receive more than \$647.00 per month in "countable

124. *Id.* Most ASD children or adults would fall under this category of benefits. *Id.*

125. *Id.* at 5–6.

126. *Id.* at 6.

127. *Id.*

128. *Supplemental Security Income*, SOC. SEC. ADMIN., <http://www.ssa.gov/ssi/> (last visited Apr. 5, 2012).

129. *Id.* To find out if your client is eligible for these benefits, the website uses an online survey/screening tool that takes only minutes. *Id.* There are certain disability criteria, asset, and income restrictions to the program. *Id.* After being approved, the client may begin filling out the application for SSI, which is also online. *Id.* More SSI information can be found in Chapter 21 of the Social Security Handbook. *Social Security Handbook: Chapter 21: Supplemental Security Income*, SOCIAL SECURITY ONLINE http://www.socialsecurity.gov/OP_Home/handbook/handbook.21/handbook-toc21.html (last visited Apr. 30, 2012).

130. Green, *supra* note 112, at 6.

131. *Id.* SSI and Medicaid use the same asset restriction guidelines. *Id.* (citing 42 U.S.C.A. § 1396a(a)(10)(A)(ii)(V) (West 2003 & Supp. 2011)). Available resource limit is \$2,000 for an individual. 42 U.S.C.A. § 1396a(e)(14) (West Supp. 2011).

132. Green, *supra* note 112, at 6–7. "Income" . . . is generally regarded as anything the SSI recipient receives in cash, or property readily convertible to cash, or in kind support that can be used to meet his or her needs for food and shelter." *Id.* at 7 (citing 20 C.F.R. §§ 416.1100–.1182).

income.”¹³³ Furthermore, married couples are restricted to a total amount no more than \$1,011.00 per month.¹³⁴

Like Medicaid, SSI utilizes specific rules to count payments of “in kind support and maintenance.”¹³⁵ These specific payments are generally treated “as unearned income and distributions from trusts are” generally dealt with “in the same manner as payments made by third parties.”¹³⁶ Unfortunately, this type of unearned income payment generally “reduces the amount of SSI benefit to the recipient dollar-for-dollar.”¹³⁷

Luckily, there are certain SSI income restriction rules that make in-kind support payments from a trust permissible when paid properly, meaning that this reduction will not go into effect and the beneficiary will not be disqualified from the program.¹³⁸

(1) The One Third Reduction Rule—If a SSI recipient/trust beneficiary lives in the household of another person, and that person provides *both* food *and* shelter to the beneficiary, then the trustee can elect to a one-third reduction of the federal benefit rate as opposed to complete disqualification or dollar-for-dollar reduction of SSI benefits.¹³⁹ (2) The Presumed Value Rule—Applies when the One Third Reduction Rule does not, because the beneficiary is not living with someone who provides food and shelter to them, but the beneficiary receives any support from any source (i.e. payments made from a special needs trust) for these needs.¹⁴⁰ In this case, there is a rebuttable presumption that the cost of housing and food is one-third the federal benefit rate plus \$20.¹⁴¹ The beneficiary may choose to rebut this presumption of maximum value by showing that the actual cost of food and shelter is less than the value provided by the above formula.¹⁴² There is one exception to The One Third Reduction Rule and The Presumed Value Rule.¹⁴³ If the SSI recipient lives with someone whose income is “deemed” to be the beneficiary through the SSI rules (e.g. a

133. *Id.*

134. *Id.* As with Medicaid, the monthly allowance for SSI recipients is typically adjusted yearly in January. *Id.*

135. *Id.* “In-kind support and maintenance is defined by the program as food and shelter that is furnished by or paid for by someone other than the SSI recipient and it includes distributions made from a self-settled special needs trust.” *Id.*

136. *Id.*

137. *Id.*

138. *Id.* The four rules that exempt a recipient from the in-kind support and maintenance payment unearned income payment rule are: 1) The One Third Reduction Rule; 2) The Presumed Value Rule; 3) Business Arrangements; and 4) Rent Subsidy—Pay Presumed Maximum Value Amount Directly to the Landlord. *Id.*

139. See generally Drewett, *supra* note 121, at 21. In 2011, the federal benefit rate for SSI is \$674.00. Green, *supra* note 112, at 8. When the trustee applies the 1/3 deduction, the new monthly SSI payment would be \$674.00–\$224.66 (1/3 of 674.00) = \$449.34. *Id.*

140. Green, *supra* note 112, at 8.

141. Drewett, *supra* note 121, at 22. In 2011, the federal benefit rate is \$674.00, 1/3 of this amount would be \$224.66, and this amount plus \$20 would make the maximum value a rebuttable \$244.66. Green, *supra* note 112, at 8.

142. Drewett, *supra* note 121, at 22.

143. *Id.*

minor who lives in his parents household, where part of the parents' income is attributed to the minor), then the value of food and shelter given to the recipient is not treated as income and, therefore, not subject to a reduction in payment.¹⁴⁴

(3) Rent Subsidy—Pay Presumed Maximum Value Amount Directly to the Landlord—A third party or special needs trust is able to supplement a beneficiary's rent and other costs without the fear of losing SSI benefits, if the beneficiary lives in his own home.¹⁴⁵ If the beneficiary lives in a home owned by another party or landlord that receives direct payment from the trust, then no amount of the subsidized rent paid by the SNT will be seen as income for SSI purposes, and the beneficiary does not risk losing SSI benefits.¹⁴⁶

The preceding points are of utmost importance to trustees administering SNT's because they create a way to provide food and shelter to the beneficiary without substantial loss of the existing SSI benefits.¹⁴⁷ Of course, these food and shelter payments are made in addition to the unlimited payments the trust can make to those who provide "special" or "supplemental" services in caring for the beneficiary.¹⁴⁸ Lastly, because the beneficiary remains SSI qualified, he will also remain qualified for Medicaid, and therefore will have his medical needs taken care of, leaving the remainder of the SNT to cover other needs.¹⁴⁹

D. The Importance of Constructing a Flexible SNT for an ASD Individual

When individuals begin the process of creating a SNT for a loved one with ASD, many of them will consult with a lawyer, potentially with no prior knowledge of estate planning or the legal field and with the fear of deciding what will happen to their special needs child when they are gone.¹⁵⁰ What they will have difficulty conveying to that attorney, however, are the needs their child will have twenty years from now, but they should remember that no one has that ability.¹⁵¹

144. *Id.*

145. Green, *supra* note 112, at 9. "Under a settlement reached in a case with the government over ten [y]ears ago the Social Security Administration agreed to apply a rule to Texas SSI recipients that it had previously only applied in the Seventh Circuit"—the rent subsidy. *Id.* This arrangement exists whenever the recipient pays rent in excess of the presumed maximum value of \$244.66. *Id.*

146. *Id.*

147. *Id.*

148. *Id.*

149. *Id.*

150. It is a difficult concept for any parent or guardian to contemplate what their child's life will be like without them there, and planning for the care of a disabled child is only that much more difficult. Parents with ASD children are just trying to get through the present and need to be comforted by the fact that the practitioner they have chosen can both empathize with their situation and allow them to fully express all of their hopes, fears, and desires for their child to someone capable of granting those wishes.

151. There is so much that is still unknown about ASD and its manifestations, that it would be hard for anyone, even medical professionals, to predict with 100% accuracy what an ASD individual's needs will be even a year from their last consultation. That is why it is important for legal professionals in the estate-planning field to be familiar with this disorder, and understand fully the need for flexibility in order to provide a well-rounded SNT for family members of someone with ASD.

With ASD in particular, because it is such a broad-spectrum disorder, it is of the utmost importance that the language of the trust be flexible enough to encompass any possible progressions or regressions made by the individual.¹⁵² “For this reason, it may be advisable to build flexibility into the documents to permit the trustee to dissolve the trust and/or make outright distributions of cash in the event the beneficiary becomes fully or partially self-sufficient.”¹⁵³ An ASD individual can be protected from many of these situations if the practitioner drafting their SNT utilizes flexible language and “on/off” or “spigot” SNT.¹⁵⁴

E. The Flexibility Factor: Constructing “On/Off” or “Spigot” SNTs

Proper drafting of an SNT results in either a fluid document that melds with the changing needs of an ASD individual, or a rigid, useless piece of paper that prevents an ASD individual from receiving the intended care the loved ones envisioned. The necessary “flexibility can be achieved in the trust language to give the beneficiary [or guardian/power of attorney] a choice about whether or not, and to what extent, he or she will access governmental assistance and use trust property.”¹⁵⁵

Such language is sometimes deemed to be a “spigot” because it gives the trustee the ability to shut off distributions to a handicapped beneficiary and will not interfere with Medicaid or Social Security eligibility payments.¹⁵⁶ By turning the spigot off and on, the trustee risks that the beneficiary might lose or significantly reduce SSI or Medicaid benefits; however, the test for when this action is appropriate is determined by what is in the best interest of the ASD individual.¹⁵⁷ The trustee also needs to weigh the impact of actual distributions

152. Hypotheticals: While it might be considered wishful thinking, what if a cure for Autism is found or a therapy discovered that enabled those with milder forms of ASD to no longer need the protection of a trust, but rather could be fully integrated into society, hold a job, etc.? What if the ASD individual experiences another health related setback or accident that requires even more heightened care and protection from the trust?

153. See Pantaleo, *supra* note 2, at 276.

154. Green, *supra* note 112, at 10. Some practitioners believe that if a disabled child’s healthcare needs are currently covered by the parents’ health insurance, then no special needs provisions needs to be included in a trust because those expenses will be covered and, therefore, there will not be a need to qualify for public healthcare assistance. *Id.* This limiting language could potentially restrict the ability of a trust to adjust to the changing needs of a beneficiary throughout the beneficiary’s lifetime. *Id.*

155. Green, *supra* note 112, at 10; Drewett, *supra* note 121, at 24. An example of a flexible SNT is Master Pooled Trust IV, which allows a trustee to make distributions so long as they do not disqualify the beneficiary from governmental eligibility. Drewett, *supra* note 121, at 24. There are also drafting mechanisms that allow partial or total discretion to trustees. See *id.*

156. William Brown, *How Unusual Family Situations Can be Addressed by Living Trusts* (Jan. 20, 2012, 7:36 AM), <http://www.eldercarematters.com/library/2011/08/article-of-the-week-on-eldercarematters-com-how-unusual-family-situations-can-be-addressed-by-living-trusts/>.

157. David Foster Koth, *Considerations When Choosing and Using Corporate Trustees: Making It Work for Your Client*, 5th Annual Meeting of the Academy of Special Needs Planners (Mar. 12, 2011), <http://www.specialneedsplanners.com/Conference2011/post-meeting/Documents/Session%2010/Session%2010%20Outline.%20David%20Foster%20Koth.pdf>.

for basic needs on the government benefits received by the beneficiary.¹⁵⁸ Without careful monitoring, the ASD individual could lose the government aid that provides for their basic needs.¹⁵⁹ However, if the trust holds a significant dollar amount, this temporary pay cut from the government might be a wise choice in order to pay for the person's other needs.

V. USEFUL QUESTIONS FOR PRACTITIONERS TO ASK PARENTS OF ASD CHILDREN

The parents of an ASD child do not regularly contemplate what will happen to their child once they are gone. They are too busy going to doctor's appointments, therapy sessions, meeting with teachers, and tending to their other children as well as their own careers. It is quite possible that the first time the parents will consider this possibility is when they step into your office to begin planning for their child's future.

What they need then, more than anything, is to be comforted by the fact that you, as a person and as an attorney, do not need the run down of what Autism is or why their child acts the way he or she does (a routine they have no doubt memorized and given to every curious relative, waiter, and stranger on the street). You do not have to be one of those people; you now know what this disorder is and how to help this family. Now, the parents can allow you get to know their child and his or her needs more informally; this allows you to create a customized plan that they can trust. During this initial meeting, there are certain questions that must be answered. The following explanations involve these questions and potential advisory points for you as their attorney.

A. *The Who, What, and How of ASD-Specific SNT Planning*¹⁶⁰

1. *Who Will Be Your Child's Guardian?*

The first question the client should answer is: Who will care for and make the daily decisions for my child once I am gone? Instruct your clients to think about who they envision being able to care for their child on a daily basis and carry out the plans that the parents have for their child. Is this a sibling? Is it an aunt or uncle? Ideally, in order to protect the crucial stable environment that all ASD kids need, it is advisable to name a guardian who has had a significant amount of interaction with the child and knows the day-to-day schedule of the child.¹⁶¹

158. Penny L. Davis, *Special Needs Trusts in Oregon*, West Coast Trust Meeting, June 9, 2006, Portland, Or., at 4, <http://www.theelderlawfirm.com/pdfs/resources.pro.2006.special.needs.trusts.pdf>.

159. *Id.* (highlighting the need to carefully select a capable and knowledgeable trustee).

160. *Adopted from* Pantaleo, *supra* note 2, at 274.

161. See generally TEX. PROB. CODE ANN. § 693 (West 1997); AUTISM CONSORTIUM: GUARDIANSHIPS, <http://www.autismconsortium.org/empowering-families/guardianship-2.html> (last visited Apr. 5, 2012).

It is also important to keep the line of communication open with this person and see if they have the time, energy, and compassion to truly be able to parent the ASD child effectively. In most situations, the sibling of the ASD individual becomes the default choice of guardian because, generally, they are familiar with the ASD individual's routine and parent's wishes.¹⁶²

Now would also be a good time to point out the fact that when an individual in Texas turns 18, they are seen as being capable of making their own decisions despite any pre-existing mental disability.¹⁶³ This is particularly crucial if that individual cannot make the necessary educational decisions for himself and needs a guardian's assistance.¹⁶⁴ Advise your clients to look into this possibility well before their child turns 18.

2. *Who Will Be the Trustee of Your Child's SNT?*

Choosing an appropriate trustee for a supplemental needs trust of a disabled beneficiary is daunting.¹⁶⁵ Due to the potential conflict of interest with trustees who may also be remainder beneficiaries of the trust, it may be advisable to name trustees who are not beneficiaries to serve alone, or joint trustees who are remainder beneficiaries.¹⁶⁶ If the trust assets are likely to be substantial, the family should be carefully advised whether to choose a corporate trustee or co-trustee—especially if no immediate family member has the knowledge to deal with the sophisticated financial matters presented by managing an SNT.¹⁶⁷

If the family chooses not to name other family members as trustees, then in order to maintain the sensitive family equilibrium, the parents may choose to name other family members as “trust advisors.”¹⁶⁸ Trust advisors should be persons who have had significant interaction with the beneficiary and know his needs and desires and give this input to the trustees when decisions are made concerning the beneficiary.¹⁶⁹ For ASD-Specific SNTs, it may be wise to appoint a corporate trustee in place of a family member to keep personal

162. See generally, Guardianship Services, *A Texas Guide to Adult Guardianships*, Tex. Dept. of Aging and Disability Servs., http://www.dads.state.tx.us/news_info/publications/brochures/pub395-guardianship.pdf (last visited Apr. 24, 2012). Parents should understand that if they are not comfortable with appointing one of their other children as guardian over their child with ASD, then there are plenty of other options. Caring for someone with ASD is not for everyone, and the last thing any parent should do is place that responsibility with someone who they do not believe will be able to carry out the duties effectively.

163. THE ARC OF TEXAS: EDUCATION DECISION MAKING YOU'RE YOUR CHILD TURNS 18, http://www.thearcoftexas.org/site/PageServer?pagename=services_transition_further_education (last visited Apr. 5, 2012).

164. *Id.*

165. See generally Michael E. Leonetti, *What to Look for When Selecting a Trustee for Your Estate Plan* (Jan. 1998), <http://www.aaii.com/journal/article/2-what-to-look-for-when-selecting-a-trustee-for-your-estate-plan>.

166. See Pantaleo, *supra* note 2, at 277–78.

167. *Id.* at 278.

168. *Id.*

169. *Id.*

interests and emotions out of the decision-making process as much as possible.¹⁷⁰

3. *What Services Will Your Child Need in the Future?*

While this is a loaded question, it will cause parents to open up about their child's current medical and personal needs, allowing an assessment of the means by which to provide for those same services in the future. As discussed previously, it is likely that Medicaid and Social Security benefits could provide for much of the ASD individual's medical needs, but parents will likely want this reassurance when assessing future needs.¹⁷¹ One suggestion is to have the family calculate the individual's yearly expenses, and then, using a projected lump sum, other things, such as hobbies and future education, can be taken into consideration.¹⁷²

It is possible that meeting with the family will not be enough. A meeting with teachers, therapists, and doctors might also be necessary to fully evaluate the autistic person's future and plan for both foreseeable and unforeseeable events or conditions.

4. *How Do You Envision Your Child Being Cared for in the Future?*

To convey their hopes and desires for their child, a good option for parents is to prepare a "Letter of Intent."¹⁷³ Although not legally binding, this letter will serve as a guide for guardians, trustees, and the courts to help navigate choices concerning the ASD individual's health, welfare, finances, etc.¹⁷⁴ Courts tend to favor the family's wishes as long as they are not illegal or immoral.¹⁷⁵ The Letter of Intent should be reviewed and modified on a regular basis to continually address the evolving issues surrounding the care of the loved one.¹⁷⁶ This letter should convey detailed information regarding the individual with disabilities and the family's wishes and concerns in a way that will be easy for a third party to interpret.¹⁷⁷

170. This is not to say that the trustee should be a droid who is void of emotion, but as already established in this article, ASD is a stressful disorder to deal with and it might be best if a semi-impartial third party with a working knowledge of ASD (and armed with the input of trust advisors) has the final say in financial decisions.

171. See discussion *supra* Part IV.

172. *Meeting the Needs of An Autistic Child*, MERRILL LYNCH, <http://www.totalmerrill.com/TotalMerrill/pages/ArticleViewer.aspx?TITLE=specialneedsspecialadvice> (last visited Apr. 5, 2012).

173. *Id.*

174. *Id.*

175. Kate Moss, *Letter of Intent: A Way to Communicate Your Wishes Into the Future*, <http://www.tsbvi.edu/seehear/archive/intent.htm> (last visited Apr. 5, 2012).

176. See Pantaleo, *supra* note 2, at 278.

177. *Id.*

It is important to note that writing a Letter of Intent will force clients to discuss (often for the first time) the many concerns they have about their child's disabilities.¹⁷⁸ Advise your clients that this can be an emotional experience, and they should be aware of this and plan to work on the letter when they are not feeling overwhelmed.¹⁷⁹ It may also be helpful to work on small portions of the letter over time so each topic is given the necessary time and thought.¹⁸⁰

At minimum, the Letter of Intent should cover the following: medical, educational, and social history; contacts; social agencies; professional advisors; friends and family members who are involved in the child's care and those who should be avoided; employment history or training; religious training and preferences; preferences and history regarding residential environment; preferences and history regarding social environment; behavioral issues and management; and final arrangements.¹⁸¹

Reiterate to clients that this process will not be easy. It takes time to effectively answer these questions, and they should take as much time as necessary. While the subject matter will not be easy to discuss, it is important that clients know they are expressing their feelings to someone who also wants what is best for their child—you, their attorney.

VI. CONCLUSION

Now that you are armed with this information, what is the next step? This article is by no means an exhaustive resource for either ASD or SNT information; however, hopefully it inspired you to learn more about this disorder and other potential planning strategies for persons with ASD. As discussed, there is a very real possibility that a loved one of someone with ASD will approach you and ask how to preserve assets for his or her future. Now you have some knowledge about both ASD and SNTs to use in meetings with future clients, but customization is key.

I strongly encourage you to reach out to your community, both as a concerned member and professional, and speak to a local ASD interest or support group about long-term planning. The members of these groups have questions, but likely no time to seek out an attorney to discuss the answers. A comprehensive presentation for these busy parents would give them an excuse to momentarily step out of the present and begin addressing the future and its potential issues.

178. See Moss, *supra* note 175.

179. *Id.*

180. *Id.*

181. See Pantaleo, *supra* note 2, at 278.

Lastly, there is no hard and fast rule for creating an SNT for someone with ASD. It is crucial that you get to know the family's dynamics, daily routine of the individual, and any other concerns of the parents to create an effective SNT for the ASD individual.

by Katherine Owens