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Special Need Trusts - Caring for Special Loved Ones Under Unique Circumstance - PSU 2011

Welcome and thank you for attending. I would especially like to extend a special thank you to Angela Kirby-Wehr, Director and Mike Miklos of PaTTAN.

On a personal note, this past June I met one of my life goals in presenting this seminar at the Annual Million Dollar Round Table conference in Atlanta, Georgia. MDRT is made up of the top 1% Financial Professionals in the world. MDRT feels this is an important subject for it's top Financial Professionals, then you must realize that this is an incredibly important seminar for you. I hope all of you are having a good meeting. Be a sponge and soak up all the knowledge and ideas you can. Network and ask questions. But don't go home and try to implement all the great ideas you hear. Pick one or two of the best and implement them in your practice. You are the best advocate for your child.

How many here are parents, professionals, educators? Is there a category I have missed?

Today you have a unique experience you will be able to share with your friends, co-workers, clients and relatives. Today you met the original "Shadie" Insurance man!

There are over forty-six million disabled adults and children in the US. There is no greater service you can provide for your clients and our society than helping them

prepare for the care and financial security of their Special Needs Child (SNC). No one has a lease on life. One of the worst types of phone calls I get, typically goes like this:” Mr. Shadie, I am seventy-five years old and I have just been diagnosed with cancer. Can you help me provide for the secure future of my fifty-two year old disabled son?” What a difficult position to be in as a financial professional! So many options are now off the table with Mom’s age and poor health. While my focus here is Autism, my principles apply to all disabilities and the critical needs of your clients.

This picture is of my current family at Disney and taken on the fifth anniversary of Claire’s death (my late wife and Alex’s adoptive mother). While Alex’s receptive language is quite good, his expressive is not. But as you can see, even though he is at his favorite place on earth, he is pained by the remembrance of this horrible date. He remembers on his own.

Alex was adopted at three months from a local Catholic Adoption Agency. Autism was unknown to Claire and me. It reared its ugly head after his DPT shot at eighteen months. Normal development was suddenly and seriously arrested. Notice the difference in Alex’s face in these two pictures.

I married Brenda Eaton on August 20, 2005. Brenda is the Autism Coordinator for a professional public educational organization. We met at the National Autism Conference in 2003. She did not like me at first. She told her friend that I didn’t have a clue, so I went out and got my clue, CLU.

Her natural son, Brendan demonstrates the wide spectrum of Autism. Alex is socially disconnected except for his immediate family and family friends. Brendan is very outgoing and engaging, although when he was younger, he was also socially disconnected. Brendan's and Alex's success represent a lot of hard work, on the average of 2,000 to 2,500 hours of one on one instruction each year. Alex has done this for seventeen years! Both have made tremendous success in their own way Each child is valuable and has his hidden talents and skills. It is the parent's, teacher's and therapist's job to find and develop these hidden abilities.

You need to listen. We all do. God gave us two ears and one mouth for a reason. I tell you these things so that you will have sympathy for your special needs clients and so you can reach them and understand their daily dilemmas. Remember "Rain Man"? How many of you saw it? Dustin Hoffman did an outstanding job. But don't typecast. Every child with a disability is different. When you meet one child with Autism, you have met one child with Autism. They are not "Rain Man".

The Corpus Callosum is the network of nerves that connects the two halves of the brain. Many cognitive injuries and disabilities can be traced to problems with the Corpus Callosum.

The real Rain Man had tremendous recall for dates, days in history, important days of the week and historical facts, but he couldn't dress, bathe, or feed himself. He had no Corpus Callosum, no functionality between his two halves. Every disabled person is different and unique as the individual snowflakes. To help your clients, you need to be sensitive to this. Every parent of a disabled child is looking for the silver bullet, the magic

cure. Hope should never end or be taken away. Many professionals are guilty of this mortal sin. I can give you many brutal personal examples (e.g. Woman Pediatrician-College Fund). Be aware of this when planning. Always be positive. Alex's third professional diagnoses, at age four, was that he would never speak and due to self injurious behaviors, would be institutionalized by age five. As his parents, we would have none of this. Today Alex can communicate his needs. He is a whiz on the computer searching for his favorite areas of enjoyment (Disney, Universal Studios, music, Halloween, etc.). Be aware and complimentary of parents' pride in what their child can do. If you run into a negative environment (parent or professional) tell them they need to read with sensitivity and understanding Helen Keller's life story. Better yet buy them her book.

On average, 70% of women have 40% more Corpus Callosum than men. They also have 30% more grey matter. That's why they are better multi-taskers. How about the guy, who is late for supper because he was out at happy hour with the boys? He thinks he has the perfect alibi, but she is taking it all in, eyes, clothes, slurred speech, and nervousness – He's Toast! "Joke – Lecture – the evils of drinking". By the way, my Dad gave me two pieces of great advice, for a happy marriage. The two most important words in a marriage are "Yes Dear!" If you are upset about something, chew on it until Sunday night. Never ever get into an argument with your wife on a Friday. Enjoy your weekend first. I found that to be very good advice. But unfortunately I learned to listen to my Dad's advice after a failed first marriage.

This following information is taken from a prior Main Platform speaker, Allan Pease. His book “Why Men Don’t Listen and Women Can’t Read Maps” is an easy read and has some great insights into the brain and the difference between men and women. Autism is four times more prevalent in boys than girls. The CDC reports show an average of 1 in 100 children has Autism. The actual number is probably higher. It is the fastest growing disability in the world. There is no known cause or cure and worse, no standard of care. Be aware of the child’s disability effects and signs, so that when you reach out to help a family, you will be knowledgeable, sensitive and warmly welcomed.

Children with Autism tend to be obsessive compulsive. Men (Fathers / Grandfathers and Grandmothers) have a much more difficult time dealing with the child’s disability. Men tend to be more focused. “Let’s get to the point. There must be a cure; all we have to do is find it! Where is the silver bullet?” Grandmothers are famous for “He’ll grow out of it. He’s just a little slow”. In my case, my Grandmother used to tell me I was slow too.

Men are better drivers at night because of their singular focus. Women have better peripheral vision, but this can lead to distractions. They have a more difficult time driving at night. Mothers often have much guilt over their child’s disability, even in our case of adoption. Sometimes you may know a family and approach them and not be welcomed when you offer to help. Denial is a big part of dealing with a disability. Stay in contact and be ready to help, when needed, but don’t be pushy. There is a 70% divorce rate among these families. Many times you will run into difficulties because of bad undercurrents in the marriage. Always insist both parents are present when you meet.

Having this knowledge and perspective on families and their SNC will help you understand, make you more of a positive force to direct the family in making these hard decisions and helping them deal positively with the inevitable future. You need to be the quarterback or leader of their financial team made up of their CPA, Attorney, Banker, Stock Broker, Advocate, Guardian and Trust Officer.

The lawyers now have their say. NEW YORK LIFE Disclaimer: “This seminar is for informational purposes only. Neither New York Life nor any of its Agents or Employees are in the business of giving tax, legal, or accounting advice. Attendees should consult with their own professional advisors to determine the appropriateness of any course of action.”

Having children changes your life. Having a child with special needs brings ...

- Added challenges
- Unique joys
- Complex financial and emotional concerns

Caring for an individual with special needs requires patience, dedication, and sometimes unique skills. Ensuring the continued wellbeing of your loved one, in the event you are no longer able to provide care, is one of the most important steps you can take.

Statistics

- Disabled Americans

- 15% adults
 - 42 Million adults
- 6.1% children under age of 18
 - 4 Million children

All with special needs that will likely stretch over their lifetime

Just Suppose ...

- You have two children ...
 - One with special needs one without special needs
- At your death you want to treat your children equally.
 - Intestate
 - Will/living trust

The increase in disabilities is growing at a staggering rate. We are becoming more aware of the needs of these families and the importance of future, possible changes, flexibility, and thorough financial planning.

I run into many families who have spent thousands on a living trust. Be careful of Living Trust seminars. They can be costly and useless, and actually destroy the design and functionality of the SNT. Be careful of scams. Parents of SNC are a ripe commodity for scams and unscrupulous charlatans.

Just suppose:

You have a \$500,000 estate

- No special needs planning
- ½ to each child, John and Joe
- Joe has special needs
 - John pays off house, buys car, takes a vacation, and saves some of his \$250,000
 - Joe loses all of his inheritance for services that otherwise would be covered by government programs

Fair?

Probably not ...

Why not leave all to John and have John take care of Joe?

Taking care of Joe:

- Sounds great ... but ...
 - What if John gets sued?
 - What about John's creditors?
- What if John gets married (marital rights of new spouse)?
- What if John dies?
- What if John becomes disabled?
- What if John just wants/needs the money?

- What if John just can not handle money well

What if John is Unwilling/Unable ...

My experiences:

- IRS story (Brother's Lien)
- Divorce story (New wife had no time for disabled Brother-in-Law)
- Embezzlement story (Brother used money to pay his bills, gambling problem)
- Sound planning is so important. We are making plans that must operate in a different environment forty, fifty, sixty or more years from now.

All can be bad outcomes ...

Not to mention the psychological and emotional pressures on John to take care of Joe.

Are there any other options for caring parents, relatives and other loved ones?

Yes but first the financial issues

Long term planning

1. Be knowledgeable (about specific disabilities)
2. Do a good fact finder. Get copies of important documents.

3. Be flexible, you are dealing in a highly emotional area.
4. Be aware of income, capital gains and death taxes. (see #2 above)
5. Be cautious, sympathetic and sensitive. (see #3 above)
6. When the plan is being finalized, recommend to bring in the extended, interested family and caretakers to participate.
7. Focus on the letter of intent.

The plan needs to involve the financial team and needs to be in writing. You don't want any misunderstandings later on.

- **Financial demands - immediate and intimidating.**
- **More so if one parent has to leave workforce to care for loved one.**
- **What if one parent can't face issues and leaves?**
- **Need to explore federal and state programs.**
- **National Institute of Health – www.nih.gov**
- **Social Security – www.ssa.gov**
- **Medicare/Medicaid (programs vary by state)**

The parents are the child's best advocate, but they won't be around forever. Encourage parents to advocate for their child and not to be intimidated by elitist professionals at any level. No one knows their child better!

Remember the 70% divorce rate among special needs families. Many just flee because they get tired of the fight! The stress level many times is unbearable.

Government Assistance?

- If your child can qualify for government assistance the financial burden will be lessened.

- Qualify – for what?

-SSI and Medicaid

- **When will special needs child qualify?**

-Now

-Future

- Supplemental Security Income (SSI)
 - Program for “needy” disabled individuals
 - If you Qualify for SSI = “*categorical eligibility*” for Medicaid in many states.

- Definition of disabled for children:

“... child must have a medically determinable impairment that causes marked and severe functional limitations. The impairment must have lasted or be expected to last for a continuous period of at least 12 months or be expected to result in death.”

- Don’t just consider income of disabled child.

- Based on a Social Security formula, income and resources of parents are “deemed” and therefore considered in determining a disabled child’s SSI benefit.

- All the parents’ income is not counted

Grandmother dies and left her old \$5K life insurance policy to Joe. He loses all of his services. He loses his placement. This loss creates a traumatic situation for him and he becomes quite depressed. Depression in the SNC leads to much higher mortality rates. This is why many SNC are uninsurable. I have been successful in getting children with Autism insured, when I can show that depression is not an issue and that they are in a good, healthy, productive environment.

Many times it takes years for Social Security to catch up. I have seen many instances where the family gets a huge bill years later for services rendered. (My own experience with savings bonds)

- Parents with means can cover needs

- Most or all needs

- Supplemental needs

- Either way parents must plan for future.

- Qualify during parent’s life?

- Planned properly ... special needs child should qualify after parents death.

Remember we are planning for thirty, forty, fifty or even more than sixty years out!

Individuals with Disabilities Education Act (IDEA)

- The act requires that children with disabilities receive:
 - Free appropriate public education
 - As close to home as possible with children who do not have disabilities
 - Supplemental services (speech therapy, advocates, classroom aides, interpreters, etc)
 - An assessment to determine the child's needs

Most times these critical services are only available locally through the public welfare and the educational sector and cannot be privately purchased. Most rural areas or military environments are totally lacking in any service.

What happens when parents die?

- If assets (resources) or income are left to special needs child ...

- Special needs child's resources and income must be used before governmental programs will cover most expenses.

Once inheritance is used ...

- **What is covered?**
- Only the basics
 - Food

- Clothing
- Shelter
- Benefits at or below poverty level.

What is not covered?

- Anything else ...

In the Navy this was known as “Three Hots and a Cot!”

What is not covered:

- Eyeglasses
- Transportation
- Hobby, recreation
- Computer, electronics, cable
- Furniture, TV
- Personal care items, comb, toothbrush, etc.
- Plus many other items.

Parents’ Dilemma:

- Leave assets to special needs child to be used up before government benefits take hold.
- Disinherit special needs child
- Leave assets to other family member
- Remember the issues here

- Or ...

Special Needs Solution:

- Create a “special” type of trust (SNT).
- A Special Needs Trust – designed to:
 - Only provide for extras.
 - For child’s lifetime.
 - At child’s death to other heirs.
- Requires extremely competent experienced legal counsel to draft document(s).
- How does it work?

New or existing life insurance is an effective way to fund the testamentary trust at some future time. A second to die policy is very cost effective. Often it is funded by Grandparents and by other family members, who may be in a better financial situation than the parents and have a deep, emotional desire to help. If economics is an issue, use convertible term but make sure you convert within the contract period and that the term can be converted to a second to die policy. If using universal life, make sure you also use the guaranteed death benefit, no lapse rider. But do this carefully and get a signed statement to protect yourself that the clients understand they must make the required premium payments on time to avoid lapse. Other policies from other “insurable interest” parties can be used. Pensions, IRAs, annuities, investment accounts are all valid. Be careful of real estate, stocks or bonds, as they have special situations and requirements.

Involve an interested and a knowledgeable stock broker. Make sure the beneficiary on the policies and contracts read exactly as it appears in the SNT and estate documents (e.g. The Special Needs Trust for Joseph Smith).

You must make sure that the asset used is stable at the time it is needed and not subject to volatile market conditions. Guaranteed death benefits and cash value riders on variable annuities are mandatory to avoid this problem. A solid, knowledgeable, financially astute and stable trustee is also a paramount need. Have contingent trustees, custodians and guardians, in case someone can't serve.

Complex Solution:

- Laws are complex and may vary by state
 - Laws can change (built in flexibility)
 - Trust requires special language
- Disabled child has no discretion or access
 - Non-assignable
 - Not revocable by disabled child
 - Not payable to disabled child's estate at death
 - Spendthrift clause

Most states have special laws that require the assets to revert back to the state upon the death of a SNC. This generally applies to a Trust setup as a result of a court award for an abuse (e.g. classroom), malpractice or accident etc. Competent legal counsel is extremely important.

Important Steps To Take:

Many organizations and experts in the field of special needs individuals suggest some important steps to take.

Most recommend a basic check list of “to dos”.

- Get help.
- Apply for all programs.
- When you pass away:
 - Adequate funds for the family and the special needs child.
 - Properly safeguard assets – special needs child.
- Designate advocate/guardian.
- Select future living accommodations.
- Prepare a letter of intent.

Knowledgeable lawyers, trustees, advocates and guardians are extremely important.

Remember we are planning for an event far into the future.

Get Help ...

Competent Legal Counsel

Before we review the list, The MOST important issue to address is ...

Seek and retain competent experienced counsel ...

Experienced in special needs issues ...

Familiar with all laws ...

State and Federal

Guidelines – choosing counsel

- Experience in Special Needs planning.
- Understanding that both state and federal laws apply.
- Knowledge of all state and federal assistance programs.
- Understanding of state specific Medicaid rules.
- Knowledge of estate planning wills, trusts etc.
- Keeps current on federal and state law changes.
- Aware of advocacy referrals to assist clients.

Important Steps To Take:

- Get help.
- Apply for all programs.

Trustees, parents, siblings, advocates and guardians must keep up on programs available and changes in the regs and laws, as well as new proven interventions.

Get Help ...

Apply for All Programs

- SSI
- Medicaid
- Medicare
- State and local programs
- Programs from local charitable organizations

I had a case one time where the child became terminally ill. So I recommended to the Parents to seek the help of our local Make-A-Wish Foundation. This was greatly appreciated by the family. Being on the Board of our local Make-A-Wish chapter and burying three of my wish children, also taught me there are worse problems in life than Autism and disabilities.

Important Steps To Take:

- Get help.
- Apply for all programs.
- When you pass away:
 - Adequate funds for the family and the special needs child.
 - Properly safeguard assets – special needs child.

Remember competent advisors, especially the Estate Attorney.

Get Help ...

Issues in Your Estate Planning

When You Pass Away

- Adequate funds for
 - Special needs child
 - Other family members
- Properly safeguard assets for your special needs child – *Special Needs Trust*

Be aware of future legal changes. Sometimes it is an administrative regulation (regs) change. A competent, researched estate lawyer is mandatory. Advocacy is extremely important. Your knowledge is powerful!

Issues In Special Needs Trust

- Created by parent, grandparent or legal guardian during their life or at their death.
- Beneficiary can have NO control and NO discretion over assets or income in trust
- Special needs child's estate can not be the beneficiary of the trust
- The trustee, during the life of the child **MAY** distribute “for the benefit” of the special needs child but ...

-No income

-No cash

-No assets convertible to cash

- Cannot provide any benefits that could, in any way cover the necessities of food, shelter or clothing
- Provisions for flexibility of the trust to change to comply with changes in programs and laws
- Provision for successor trustees
- Provision to distribute the trust to remainder beneficiaries if attacked by government programs for re-imburement

Have competent legal counsel always available to review and adjust Trust documents and the will for future changes. (See the Estate Planning Website for an Estate Attorney in your area - www.naepc.org)

- Special needs trust can be formed
- Inter-vivos (during life of the parents)

-Track record may be helpful to future trustee

-Relatives gift or bequeath assets

-May involve other siblings

-Estate Inclusion

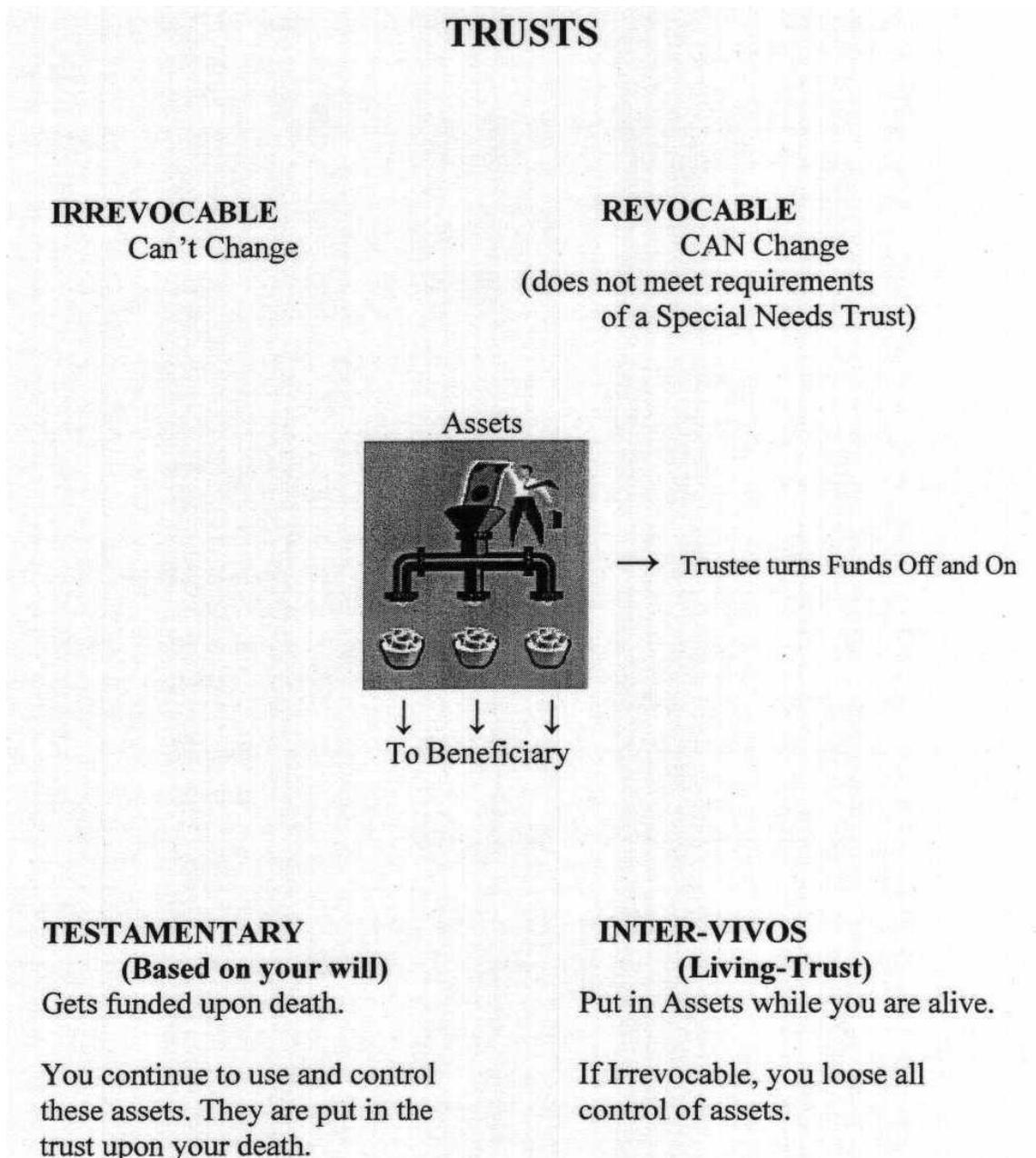
- Testamentary (by provisions of will or living trust)

-Comes into being at the death of the parent(s)

-Planning can be more contemporary

The SNC can have both types of trusts depending on funding – future and current.

Testamentary and Inter-vivos



Locate advocacy and support groups for advice, support and help for the family. Support is ongoing and necessary for special needs families.

Important Steps To Take:

- Get help
- Apply for all programs.
- When you pass away:
 - Adequate funds family and special needs child.
 - Properly safeguard assets – special needs child.
- **Designate advocate/guardian.**

Get Help ...

Designate Advocate/Guardian

- Disabled child will need advocate to make certain your child gets the services and education they are entitled to.
- May need Guardian (probably after the parents' deaths).
- Plan for the future of other minor beneficiaries.

Important Steps To Take

- Get help

- Apply for all programs.
- When you pass away:
 - Adequate funds family and special needs child.
 - Properly safeguard assets – special needs child.
- Designate advocate/guardian.
- **Select future living accommodations.**

Plans are for long into the future and must be flexible.

Get Help ...

Considerations For Future Living Accommodations

- Where will your disabled child live?
 - Will he/she be able to stay at home?
 - What will need to be done to make home more “friendly”?
 - What special care will be needed?
 - Equipment
 - Basic living needs
 - Education
 - Care Giver Issues

Sometimes there are multiple disabilities.

Important Steps To Take

- Get help
- Apply for all programs.
- When you pass away.
 - Adequate funds family and special needs child.
 - Properly safeguard assets – special needs child.
- Designate advocate/guardian.
- Select future living accommodations.
- **Prepare a letter of intent.**

Get Help ...

Prepare a Letter of Intent

- While not a legal document it gives guidance to future guardians and trustees as to how the parents would like their special needs child treated once they are dead.
 - A letter of intent is used to express parents' wishes, rather than be an enforceable agreement. If enforceable, it would take away the discretionary nature of the special needs trust
- Comprises instructions to the trustee and guardian regarding the type and level of care you would want provided

This is a very important task and document, often overlooked. Remember the earlier slide and Alex at Disney. Everyone needs a vacation. What does their child like? Make sure the guardian, trustee, advocate and lawyer have copies.

Don't Forget!

- Competent counsel
- Apply for all Programs
- Estate and financial planning
- Special needs trust

-Inter-vivos (living) trust

-Testamentary (in will) trust

- Letter of intent

Use this as your checklist in helping your clients. Long Term Care (LTC) insurance becomes an important part of the long term financial plan. There could be a future depletion of needed SNT assets for parents' if LTC needs aren't covered. The SNT is a lucrative market for you and very often will result in multiple ongoing sales. But I caution you, do not rush the process. Remember to do a detailed fact finder. When you formulate the plan, you must meet with the financial team and the extended family with permission and input of the parents.

There is peace of mind for the family and great satisfaction for you in the wonderful and noble, humanitarian service you have provided. (Show the \$100 bill again)

You can make the SNC's life worth something and help them reach their full potential.
Wouldn't you want this for your child?

Children with Autism are very literal. (e.g. "leave the door ajar", "in the meantime", The story of Jonah and the Whale, Sunday School, first grade)

Here are some wonderful websites to help.

- **Social Security**
[-www.socialsecurity.gov](http://www.socialsecurity.gov)
[-www.ssa.gov](http://www.ssa.gov)
- **The Special Needs Network**
[-www.tsnn.org](http://www.tsnn.org)
- **National Institute of Health**
[-www.nih.gov](http://www.nih.gov)
- **Special Needs Advocate for Parents**
[-www.snapinfo.org](http://www.snapinfo.org)
- **The Exceptional Family Member Program for military families**
**[-www.militaryhomefront.dod.mil/portal/page/mhf/MHF/MHF HOME 1?
section_id=20.40.500.570.0.0.0.0](http://www.militaryhomefront.dod.mil/portal/page/mhf/MHF/MHF_HOME_1?section_id=20.40.500.570.0.0.0.0)**
- **National Information Center for Child and Youth with Disabilities**
[-www.nichcy.org](http://www.nichcy.org)
- **SAFE – Supporting Autism & Families Everywhere Ph: 1-877-510-SAFE**
[-www.autismsafe.org](http://www.autismsafe.org)

- **PA Health Law Project – Atty. David Gates Ph: 1-800-274-3258**

-www.phlp.org

- **PaTTAN**

- **-www.pattan.net**

- **PA DPW**

-www.dpw.state.pa.us

- **Parent to Parent of PA - Brenda Eaton-Shadie**

-www.parenttoparent.org

- **National Association of Estate Planners & Councils (NAEPC)**

-www.naepc.org/

Go and do some of this wonderful work. Fulfill your soul while you fill your bank account.

Thank you again.

