

WHAT'S SO SPECIAL ABOUT SPECIAL NEEDS TRUSTS

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WHY SPECIAL NEEDS PLANNING?

75% of parents worry about how their special needs child will have financial support

But...

WHY SPECIAL NEEDS PLANNING?

- ▶ 88% have not set up any trust
- ▶ 84% have not written letters of instruction
- ▶ 49% have not named a Guardian

TYPES OF DIAGNOSES

Physical	Developmental
<ul style="list-style-type: none">▶ Muscular Dystrophy▶ Multiple Sclerosis▶ Cerebral Palsy	<ul style="list-style-type: none">▶ Down Syndrome▶ Autism▶ Processing Disorders
Behavioral	Sensory Impaired
<ul style="list-style-type: none">▶ ADD▶ Bi-Polar Disorder▶ Oppositional Defiance Disorder	<ul style="list-style-type: none">▶ Blind▶ Deaf▶ Visual/Hearing Impairment

RAISING A CHILD WITH SPECIAL NEEDS

- Autism (Autism Speaks)
 - Average annual cost = \$60,000
- Down Syndrome (CDC)
 - 12X the medical costs of a nondisabled child
- Cerebral Palsy (MMWR)
 - Lifetime Expenses = \$921,000

COSTS ASSOCIATED WITH SPECIAL NEEDS

- Lost Wages
- Special Education Services
- Developmental Assistance
- Occupational Therapy
- Speech Therapy
- Physical Therapy
- Medical Equipment
- Habilitation Services

FAMILY GOALS

Maintain Quality of Life

- ▶ Educational Access
- ▶ Standard of Care
- ▶ Family Supports
- ▶ Recreation
- ▶ Vacation

Maintain Benefits

- ▶ Medicaid
- ▶ Supplemental Security Income
- ▶ Housing Assistance

SUPPLEMENTAL SECURITY INCOME

Medical Qualifications

- ▶ Physical or mental condition
- ▶ Severely limiting activity
- ▶ At least one year, or
- ▶ Expected to result in death

Financial Qualifications

- ▶ Less than \$2,000 in assets
- ▶ No more than \$841 income*
- ▶ Earned vs. unearned income

TYPES OF INCOME

- ▶ Earned Income: wages, some royalties
- ▶ Unearned Income: Social Security benefits, state disability payments, interest/dividend income, child support
- ▶ In-Kind Income: food & shelter received at no cost or less than FMV to applicant
- ▶ Deemed Income: income of others used to compute SSI benefits

WHAT'S NOT INCOME?

- ▶ First \$20 received in any month
- ▶ First \$65 of earned income in any month
- ▶ One-half remaining earned income in any month
- ▶ Income tax refunds
- ▶ Loans applicant must repay
- ▶ Money spent by others on applicant's expenses other than food & shelter

PARENTAL DEEMING

- ▶ Parental income is deemed to child
- ▶ Child Support = Child's unearned income (2/3)
- ▶ Parental Deemed Income = Child's unearned income
- ▶ Upon 18th Birthday
 - ▶ Parents' income no longer deemed to child
 - ▶ If living with parents = one-third benefit reduction
 - ▶ In-Kind Support & Maintenance

MEDICAID

- ▶ SSI connected Eligibility
- ▶ Income Based Eligibility
- ▶ Waiver Programs
 - ▶ Income Waivers based on child's income only
 - ▶ 1915(c) Waivers
 - ▶ Wait Lists
- ▶ Texas Programs – Check other States!

PLANNING TIMELINE

- Childhood Medicaid Benefits Available?
- If not, prepare for potential benefits after 18th birthday.
- Will a guardianship/conservatorship be necessary at 18?
- If not, what planning can beneficiary engage in?
- Parents estate planning – what is the best option?

MEET THE JOHNSONS

- Grampa Bill
- Mom Sarah
- Sally
- Tommy
- Step-Dad Fred
- Grandma Dottie



CASE STUDY – THE JOHNSONS

- ▶ Tommy (7 years old) lives with his mother, sister, and step-father
- ▶ Sally is Sarah's & Fred's child and has no special needs
- ▶ Tommy was diagnosed with Autism at age of 4
- ▶ Tommy's grandparents, Bill & Dottie, are very involved in his day to day life and want to help provide for Tommy
- ▶ Tommy receives OT, ST, and BT weekly
- ▶ Prognosis = severe limitation for life

CASE STUDY – THE JOHNSONS

What's the Plan?

- Does Tommy qualify for SSI?
 - Now or after 18?
- Does Tommy qualify for any Medicaid program?
 - Now or after 18?
- Will Tommy need a guardianship?
- What kind of planning can Tommy's parents do to help?
- What about Grampa Bill and Gramma Dottie?

CASE STUDY – THE JOHNSONS

Does Tommy qualify for SSI?

- ▶ Sarah makes \$1,500/month
- ▶ Fred makes \$2,000/month
- ▶ Tommy's legal father pays \$250/month in child support for Tommy
- ▶ Parents Earned Income = \$3,500/month
- ▶ Tommy's Unearned Income = \$166.67/month (2/3 child support)

CASE STUDY – THE JOHNSONS

Does Tommy qualify for SSI?

- ▶ Parental Income = Gross Income less...
 - ▶ \$420/nondisabled child credit
 - ▶ \$20 any income
 - ▶ \$65 earned income
 - ▶ Max SSI Benefit (\$841/\$1261)
- ▶ Divide earned income in half
- ▶ No divisor for unearned income

CASE STUDY – THE JOHNSONS

Does Tommy qualify for SSI?

- ▶ Parental Deemed Income = Child's Unearned Income
- ▶ Reduce gross income by credits
 $\$3,500 - \$420 - \$20 - \$65 = \$2,995$
- ▶ Divide Earned income in half
 $\$2,995 / 2 = \$1,497.50$
- ▶ Reduce by Max SSI Benefit
 $\$1,497.50 - \$1,261.00 = \underline{\$236.50 \text{ parental deemed income}}$

CASE STUDY – THE JOHNSONS

Does Tommy qualify for SSI?

- ▶ Tommy's Income
 - ▶ \$236.50 deemed income (unearned income)
 - ▶ \$166.67 unearned income (2/3 of child support)
 - ▶ Tommy's total unearned income = \$403.17
 - ▶ Tommy's countable income = \$383.17 ($\$403.17 - \20)
- ▶ SSI Max Benefit (2022) \$841
 - ▶ $\$841 - \$383.17 = \$457.83$
Tommy's SSI = \$457.83

CASE STUDY – THE JOHNSONS

Does Tommy qualify for SSI?

- ▶ When Tommy turns 18...
- ▶ Tommy's Income
 - ▶ \$250 unearned income (child support)
 - ▶ Over 18 – NO 1/3 reduction
- ▶ SSI Max Benefit (2022) \$841
 - ▶ $\$841 - (\$250 - \$20) = \611
Tommy's SSI = \$611?

CASE STUDY – THE JOHNSONS
Does Tommy qualify for SSI?
Tommy's SSI = \$611? No!

- ▶ Tommy lives at home = ISM
 - ▶ SSI reduces benefit by 1/3 (\$280)
- ▶ Tommy's Benefit
 - ▶ \$611 - \$280(ISM) = \$331

Tommy's SSI = \$331

CASE STUDY – THE JOHNSONS
Other Planning Considerations

- ▶ Guardianship?
- ▶ Tommy's parents' estate plans?
- ▶ Grandparents?

CASE STUDY – THE JOHNSONS

- ▶ Child Support
- ▶ Tommy's parents divorced
- ▶ Tommy's grandparents want to help support him

SPECIAL NEEDS TRUSTS & ABLE ACCOUNTS

SPECIAL NEEDS TRUST

First Party	Third Party
<ul style="list-style-type: none"> ▶ Grantor = Beneficiary ▶ Created by parent, grandparent, guardian, court OR <u>beneficiary</u> (2016) ▶ Beneficiary <65 ▶ Medicaid Payback ▶ §1396p(d)(4)(A) ▶ §1396p(d)(4)(C) 	<ul style="list-style-type: none"> ▶ Grantor ≠ Beneficiary ▶ No restrictions on who creates or can add property (other than beneficiary) ▶ Beneficiary = any age ▶ NO Medicaid Payback ▶ Supplemental Needs Trust

SPECIAL NEEDS TRUST

Testamentary	Stand-Alone
<ul style="list-style-type: none"> ▶ Trust funded at time of Grantor's death ▶ Will or Revocable Living Trust ▶ No concern about outside funding ▶ No disability/creditor protection to grantor 	<ul style="list-style-type: none"> ▶ Trust funded at time of execution ▶ Irrevocable Trust ▶ Outside Funding ▶ Creditor Protected ▶ Disability protection to grantor

SPECIAL NEEDS TRUST

- Improve Beneficiary's quality of life
- Cannot pay for services provided by Medicaid
- Cannot pay for food & shelter without partial loss in SSI
 - ISM – In-kind support & maintenance
 - 1/3 reduction in benefit (\$280)

SPECIAL NEEDS TRUST - DISTRIBUTIONS

- Therapies not covered by Medicaid
- Social activities & hobby expenses
- Legal services
- Phone services
- Television
- Furniture
- Clothing
- Travel

SPECIAL NEEDS TRUST - PARTIES

- Trustee
 - Grantor?
 - Family Member?
 - Trust Company?
 - Other options?
- Care Manager
 - Coordinates & supports Trustee & Beneficiary
 - Monitors beneficiary's needs
 - Coordinates appointments, medications, and day to day needs of beneficiary

SPECIAL NEEDS TRUST - PARTIES

- **Trust Protector**
 - Oversees Trustee - has ability to change Trustee
 - Protects trust from future changes
 - POMS
 - Medicaid Regulations
 - Statutory Changes
 - Who?

ABLE ACCOUNT

Achieving a Better Life Experience Act

- ▶ Tax deferred savings account (529A)
- ▶ Disability diagnosis <26
- ▶ Money in account ≠ asset
- ▶ Distributions from account* ≠ income to SSI/Medicaid recipient
- ▶ Anyone can contribute
 - *Qualified Medical Expenses*

ABLE ACCOUNT

Limitations

- ▶ Annual input = annual gift tax exemption*
- ▶ Up to \$100,000 = Maintain SSI Eligibility
- ▶ Up to \$370,000 = Maintain Medicaid eligibility**
- ▶ Subject to Medicaid Payback!
- ▶ 529 → 529A rollover allowed
- ▶ Should not replace Special Needs Trust
- ▶ Can work with Special Needs Trust

*unless beneficiary has earned income
 **This amount varies state to state, check other states

CASE STUDY – THE JOHNSONS

PUTTING IT ALL TOGETHER....

- ▶ **Special Needs Trust**
 - ▶ Child Support – 1st party SNT
 - ▶ Stand-alone SNT
 - ▶ Tommy's Parents
 - ▶ Tommy's mother's/step-father's estate plan
 - ▶ Tommy's father's estate plan
- ▶ Guardianship/Conservatorship @ 18?
- ▶ ABLE account?

HELPFUL RESOURCES

- www.ssa.gov (Social Security Administration)
- www.cms.gov (Center for Medicaid & Medicare Services)
- Yourtexasbenefits.com (Texas Health & Human Services)
- www.p2pusa.org (Parent to Parent)
- www.ablenrc.org (ABLE Account general info)
- www.texasable.org (Texas ABLE program)
- www.kidswaivers.org (State Medicaid Waivers)

THANK YOU!

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