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# *Envisioning the Possibilities*

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2022**

*Envisioning  
the Possibilities*

# A SMS Parent's Perspective on Guardianship and Estate Planning

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# Agenda

- Introduction
- Guardianship
- SSI and SSDI
- Medicaid Health Insurance
- Home and Community Based Services (aka Medicaid Waiver Programs)
- ABLE Accounts
- Special Needs Trusts
- Resources

# Introduction



- Our daughter, Laura, age 37, was diagnosed with Smith-Magenis Syndrome at age 12
- She has been living in a Medicaid HCS group home with 3 other women for the past 10 years
- My wife, Mary, and I are her legal guardians
- She currently receives/has:
  - Supplemental Security Income/SSI (used to pay room and board)
  - Texas HCS (used for residential services and day program)
  - Medicaid Health Insurance
  - ABLE Account
  - Special Needs Trust

**They grow up fast! School is 18 years,  
Adult Life could be 60 or 70 years!**



# Why seek government assistance for your special needs child?



- Most of our kids won't be able to support themselves
- They will most likely outlive us by 20-30 years or more!
- The cost of care can be astronomical
  - Daytime support services can run more than \$100k per year
  - A group home can run from \$140k-\$300k per year
  - The lifetime cost of care for a individual with special needs can be as high as \$2.4 million
- Individuals with special needs can work and still receive government assistance but know the rules!

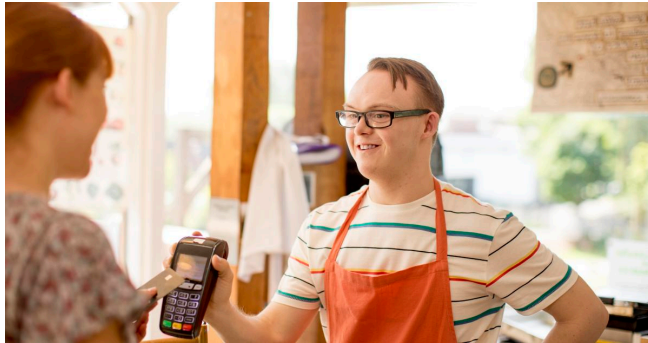
# What is Guardianship?



- When your child turns 18, they legally become an adult, with the right to make independent decisions about **all** aspects of their life
- For SMS families, parents may need to continue to provide the same kind of guidance and help you always have
- Guardianship ensures that you have the legal right to make these important decisions for your child after they become an adult
- A guardian is appointed by the probate court to make decisions for another person
- A guardian is authorized to make informed personal and financial decisions as defined by a court order
- By court order, a guardian can be appointed as full or limited

# Goals of a Guardianship

- Protect your special needs child/adult
- Maintain/improve their quality of life
- Advocate for them





# Reasons for Seeking Guardianship



- Medical reasons
- Financial decisions
- Contracts
- Decisions about programs, records, etc.
- Administrative convenience
- Placement decisions
- What will happen when we (the parents) are no longer around?

## Why Avoid Guardianship?

- Promote independence, dignity, freedom of choice
- Avoid public declaration of “incompetency”
- People deal with guardian – not the person
- Expense – attorney fees, hearings, evaluations, etc.



# “Alternatives” to Guardianship

- Durable Power of Attorney for Health Care
- Durable Power of Attorney
- ABLE account
- Special Needs Trust



# What is SSI?



- SSI stands for Supplemental Security Income
- It's one of the most important Federal programs for people with disabilities
- It's a “means-tested” program – eligibility is based solely on financial need and not on work history
- SSI is administered by the Social Security Administration but paid through general revenues appropriated by Congress
- Provides monthly cash assistance to people with limited income and resources
  - Resource limit is \$2,000 per individual

## SSI Disqualification



- Does your child with SMS currently have more than \$2,000 in their name?
- Would your child with SMS inherit more than \$2,000 if you or your spouse died today (say from your life insurance, 401k, IRA or will)?
- If you have living relatives, could your child with SMS potentially inherit more than \$2,000 from them?
- If you answered "yes" to any of these questions...

# SSI Qualification Action Steps



- Consider making changes to your will and any family member's will that names your child with SMS as a beneficiary
  - Name a Special Needs Trust instead of your child
- Also consider changes to your IRA and 401k beneficiaries so that your child with SMS is not a named beneficiary
- Don't forget about life insurance policies that name your child as a beneficiary
- Consider opening an ABLE account and/or a Special Needs Trust

## Why Apply for SSI at Age 18?



- Parents' income and resources are no longer considered in determining eligibility
- Financial benefit of up to \$841/month (2022)
  - Reduced benefits if living with parents or others unless paying fair share of rent and food
  - <https://www.ssa.gov/ssi/spotlights/spot-one-third-reduction.htm>
- **In most states, Medicaid uses the same eligibility criteria as SSI**

# SSDI



- SSDI stands for Social Security Disability Insurance
- SSDI eligibility is based on a person's work history or based on a parent's work history after a parent dies or retires
- SSDI beneficiaries are also eligible for Medicare regardless of age
- Individuals can received both SSI and SSDI



## Social Security Disabled Adult Child (DAC)

- An adult with IDD who became disabled before age 22 may be eligible for “disabled adult child” benefits if their parent is deceased or starts receiving retirement or disability benefits and if the adult child has never worked a substantial amount



# Medicaid



- Medicaid is free health insurance for people or families with low income
- Medicaid is a federal-state program and varies state to state
- Medicaid covers 1 in 5 Americans and serves diverse populations
- Medicaid covers a broad range of health and long-term services
- Most Medicaid enrollees get care through private managed care plans
- **In most states, SSI beneficiaries are automatically eligible for Medicaid**

# Medicare



- Medicare is health insurance for people over 65, people younger than age 65 with certain disabilities and dialysis patients
- Medicare is administered through the Social Security Administration but receiving Medicare is not tied to receiving Social Security
- Medicare does not cover all medical expenses or the cost of most long-term care
- More health providers accept Medicare than Medicaid
- Some people qualify for both Medicaid and Medicare

# Medicaid Waiver Services aka Home and Community Based Services (HCBS)



- Benefits designed to help people remain in their home and community
- Gives family caregivers the tools to do their job
- Programs vary by state and don't transfer!
- States can have multiple wait or "interest" lists with potentially long wait times
- **Ask to get on your state's various wait lists ASAP and make sure to check-in periodically to keep your place in line**

# ABLE Accounts



- Are tax-advantaged savings accounts for individuals with disabilities
- Accounts are state specific but eligible individuals are not obligated to enroll in their state of residence
- Contributions can be made by any person but are limited to \$16,000 per year (2022)
- Contributions will not adversely affect eligibility for most means-tested benefits such as Medicaid or SSI
- Funds from an ABLE account can help designated beneficiaries pay for “qualified disability expenses” (QDE) typically using a check or debit card
  - e.g., food, education, housing, job coach, transportation, legal fees

# ABLE Account Medicaid Recapture Provision



- In the event the account owner passes away, ABLE assets are passed on to the owner's estate following the payment of any outstanding qualified disability expenses, funeral expenses, Medicaid claims and estate taxes of the deceased.

# Special Needs Trust (SNT)



- A SNT is a trust that holds funds for your child with special needs but preserves their eligibility for needs-based government benefits such as Medicaid and SSI.
- **It's important to work with a Special Needs Attorney to create a SNT because incorrect language can disqualify a trust**
- SNTs can be created as part of your will (testamentary trust) or a separate trust document (a stand-alone trust)
- An SNT must have a trustee – someone to manage the trust and make decisions about how to invest and spend the money
- To open a SNT account, your SNT must have its own Tax Identification Number (TIN) or Employer Identification Number (EIN) assigned by the IRS
- Once the trust is funded, the trustee will be required to file a 1041 tax return for the SNT each year

# Don't Forget to Plan for the Future!!



- **Your Will**
  - 68% of Americans don't have a will
  - For families with Special Needs children, your will is best done by a Special Needs Attorney
  - To allow your child to continue to receive SSI and Medicaid, don't name them as a beneficiary
- **Durable Power of Attorney (DPOA)**
  - Allows someone to manage your affairs if you become incapacitated
- **Healthcare Proxy**
  - Allows your designee to serve as your healthcare advocate
- **Advance Directive (i.e., a living will)**
  - Details your wishes should you be involved in a medical emergency



# Eligibility

- SSI - <https://www.ssa.gov/ssi/text-eligibility-ussi.htm>
- SSDI – <https://www.ssa.gov/benefits/disability/qualify.html>
- Medicaid - <https://www.medicaid.gov/medicaid/eligibility/index.html>
- Medicare – <https://www.hhs.gov/answers/medicare-and-medicaid/who-is-eligible-for-medicare/index.html>



# Resources

- A Smith-Magenis Guidebook: Exploring Adult Residential Living  
<https://www.prisms.org/education/publications-and-resources/>
- The ARC Resource Directory -  
<https://futureplanning.thearc.org/professionals/landing>
- Benefits Checkup - <https://benefitscheckup.org>
- Medicaid Waiver Pgms - <http://medicaidwaiver.org/index.html>
- ABLE National Resource Center - <https://www.ablenrc.org/>



The logo for 'prisms' features the word in a bold, lowercase, sans-serif font. The letter 'i' is replaced by a vertical DNA double helix structure. Above the top of the DNA helix is a small, white, semi-circular icon with radiating lines, resembling a prism or a lens. The entire logo is centered on a solid blue background.

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