

# Special Needs Planning Workshop

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# Moira S. Laidlaw's Bio

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- Partner, Shamberg Marwell Hollis Andreycak & Laidlaw, P.C., concentrate practice in Elder Law and Special Needs Planning
- Co-Chair, Guardianship Committee of the Westchester County Bar Assoc.
- Executive Committee Member of the Elder Law and Special Needs Planning Section of the New York State Bar Association
- Certified Elder Law Attorney from the National Elder Law Foundation, which is an American Bar Association accredited program
- B.A. from UC Berkeley in 1991 and J.D. from Rutgers Law School in 1994 (*Rutgers Law Review*)
- Admitted in New York, Connecticut and New Jersey



# Disclaimer

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- This is an overview – not a complete statement of the law and is not to be considered legal advice
- If you have any questions, contact Moira S. Laidlaw, Attorney at Law, at (914) 666-5600 or [mlaidlaw@smhal.com](mailto:mlaidlaw@smhal.com)



# Overwhelming Intersection of Law and Regulation

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- ❑ Social Security Law
- ❑ Department of Health Regulations
- ❑ Internal Revenue Code
- ❑ Estates, Powers, and Trusts Law
- ❑ Surrogate's Court Procedure Act
- ❑ General Obligations Law
- ❑ Mental Hygiene Law

# Recent Study of 11 Steps Taken by Parents of Child with I/DD

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- **Located Knowledgeable Attorney** 57.7%
- **Discussed Future Plan for Child with Family** 53.6%
- **Discussion Future Plan for Child with Child** 53.1%
- **Identified Successor to Current Caregiver** 48.2%
- **Established Powers of Attorney and HCP for Caregiver(s)** 44.8%
- **Established SNT** 42.8%
- **Established Guardianship** 41.5%
- **Researched Residential Program** 30.7%
- **Made Residential Plans** 26.8%
- **Created Letter of Intent** 26.3%
- **Taken steps toward Securing Residential Placement** 23.5%



# Overview of Presentation

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- Define the estate planning and trust options
- Review guardianship laws
- Provide information on government programs and community resources



# Defining the Estate Plan

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- Planners Win:
  - All of our laws (somewhat unfairly) reward families that do **advance** planning
- A coordinated plan is needed for:
  - Parents
  - Children with Intellectual or Development Disabilities
  - Grandparents Potentially



# Defining the Estate Plan

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- Parents:
  - Will, Trust, Power of Attorney and Health Care Advance Directives
    - Helps avoid guardianship **for parents**
    - Helps avoid program ineligibility for child
  - Coordination of Asset Beneficiary Designations with the Estate Plan
  - Letter of Intent
  - Assess Financial Risks to the Plan



# Estate Planning Documents

## Types and Effectiveness

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Effective Immediately  
Upon Signing

Effective Upon Disability  
or Loss of Competence

Death

Durable POA

Health Care  
Proxy/Living Will

Will

Trusts



# Power of Attorney

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- Allows agent to manage financial affairs
- Critically important document in avoiding adult guardianship proceeding
- NOTE: expires immediately on death of principal



# Power of Attorney

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- New Power of Attorney Statute
  - Gifting powers need to be documented in a special Gift Rider
- Recent Power of Attorney Case Law
  - Implied Best Interest
    - Gifting to Reduce Estate Taxes
  - Express Best Interest
    - Save on Cost of Nursing Home Care needs to be affirmatively set forth in Gift Rider



# Health Care Advance Directives

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- Preplanning:
  - Health Care Proxy
  - Living Will
  - HIPPA Authorization
- If Potential Triggering Medical Condition:
  - Do Not Resuscitate Order
  - Medical Order for Life Sustaining Treatment
    - Type of Non-Hospital DNR Order



# Last Will and Testament

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- Only effective upon death - may be changed at any time in your life as long as you have legal capacity
  
- Names beneficiaries of assets:
  - Specific Bequests
  - Residuary Estate
  
- Nominates fiduciaries:
  - Executors
  - Trustees potentially
  - Guardians for Minors

# Assets Governed by a Will aka Probate Assets

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- Financial Assets and Real Property:
  - titled only to the decedent or held as tenants-in-common
  
- Tangible Personal Property
  
- Business Interests
  - LLC interests, C or S Corp. shares, general partnerships and sole proprietorships
  - **Note:** Business agreements with co-owners may dictate valuation and transfer upon death or disability



# Non-Probate Assets

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- IRAs or Qualified Retirement Accounts
- Life Insurance
- Annuities (Qualified or Non-Qualified)
- Certain Bank Accounts
  - JTWRORS, POD OR TOD
- Real Property
  - Tenancy by the Entirety
  - Joint Tenancy with Rights of Survivorship
  - Life Estates
- Trust Assets
- Any other assets with a “Designated Beneficiary”



# Trusts

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- ❑ A trust is a relationship among a Grantor, Trustee and Beneficiaries
- ❑ Must be documented in writing and duly acknowledged
- ❑ Trusts can be created inside Wills (testamentary trusts) or during lifetime in a separate trust agreement (inter vivos trusts)





# Special Needs Trust (SNT)

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- ❑ Estate planning vehicle that permits funds to be segregated in order to meet the needs of a disabled beneficiary without impacting the beneficiary's receipt of government means-tested programs
- ❑ The major purpose of the trust is to provide goods and services which are not provided by Medicaid or other government programs
- ❑ Synonymous with “Supplemental Needs Trust” and can be used interchangeably



# Types of Special Needs Trusts

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- Third Party Trusts
- First Party Trusts
- Pooled Trusts



# Third Party SNT

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- Any individual **other than the beneficiary** can place funds into a Third Party SNT for the benefit of the disabled beneficiary without impacting the beneficiary's receipt of government means-tested benefits
- Funds do not have to be paid back to the State to repay Medicaid benefits after a child's death because the trust assets were never the property of the child
- **Caveat:** Parent cannot fund trust until the child is **over 21**



# Third Party SNT

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- The trust can be intervivos or testamentary
  - Benefits to intervivos trusts:
    - Other family members can leave assets to that trust because it has already been established
    - Avoids court involvement
    - Can list the trust as a designated beneficiary on certain assets
  - Benefit to testamentary trusts:
    - Delays administration and can be changed anytime before parents passes away



# Third Party SNT

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- Common types of assets used to fund the trust:
  - Cash
  - Non-Retirement Investment Accounts
  - Life Insurance
  - Real Estate
  - Retirement Accounts



# Third Party SNT

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- Beneficiaries of a Third Party SNT:
  - Primary beneficiary: individual with I/DD
    - Growing thoughts about making other children beneficiaries at same time
  - Contingent beneficiary: other children/family members



# SNT Trustees

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- Trustees of an SNT will generally use the trust assets and income to purchase goods and services which will supplement the basic items of support which are provided by programs of governmental assistance
- Cash payments to the trust beneficiary will be considered income for Medicaid purposes and should be avoided



# SNT Trustees

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- ❑ Pay for education, vocational training, hobbies, transportation and vacations
- ❑ Could purchase a car, television, assistive devices, computers, stereo, appliances, etc.
- ❑ Can pay for professional services including social workers, accountants, lawyers, therapists, housekeepers, etc.
- ❑ Pay for medical expenses and devices which are not covered by the Medicaid program
- ❑ Housing (purchase a house or coop, pay rent, supplement rent payments)





# SNT Trustees

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- NOTE: The SSI Program will consider “in kind” distributions of food and shelter as unearned income, which will reduce the cash payment to the SSI recipient
- A properly drafted trust will give the trustee the discretion to make payments for food or shelter if the trustee makes the determination that the welfare of the trust beneficiary is better served by the distribution even if it results in a reduction or denial of public benefits

# NON-SNT Trust Options for Parents' Planning

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- For children with long term needs that aren't presently known, a general discretionary trust may be a better planning solution in the parents' estate plan than a standard SNT
- Trusts can be developed in a very family specific and child centered way with the assets still protected from government assistance if a child's needs ever develop in that way – trigger SNT – but they don't have to start out as SNTs



# Letter of Intent

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- Can provide guidance to the guardians, trustees and the courts as to your hopes and desires for your child
- Not legally binding, but will provide valuable guidance to caregivers and financial advisors about your wishes for your child



# Letter of Intent

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- ❑ 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 and training
- ❑ Religious training and preferences
- ❑ Preferences and history regarding residential environment and social environment
- ❑ Behavioral issues and management
- ❑ Final arrangements



# Risk Factors for Trust Funding

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- Market corrections that could lead to lower asset values for parents and grandparents
- Disabling event for parent could compromise income and savings projections
- Long term care expenses for parents and/or grandparents could compromise funding for the child with I/DD
  - Nursing Home Care (currently \$500/day)
  - 24 hour in-home care (currently \$250-400/day)
- Untimely death of parent



# Ways to Hedge Risk

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- Obtain **neutral** professional guidance to develop risk tolerance and appropriateness of certain insurance products, such as life, long term care and disability insurance
- Generally recommend financial advisors using an asset under management model rather than a commission/brokerage model
- Fiduciary standard is higher with Registered Investment Advisors
- Educational Training: Chartered Financial Analyst versus Certified Financial Planner



# First Party SNT

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- A trust in which the beneficiary's own funds are used to fund the trust
  - Funds may come from the beneficiary's savings, an inheritance mistakenly not directed to a Third Party SNT, retirement plan or proceeds from a lawsuit

# First Party SNT

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- The disabled individual must be under the age of 65 and must be disabled as the term is defined in the Social Security law
- Funds can only be used for benefit of the person with I/DD
- Have a provision for payback to the state of all Medicaid benefits expended after the death of the individual
- Until recently, the trust could only be established by the individual with I/DD's parent, grandparent, legal guardian, or a court. Can now be created by person with I/DD as long as have legal capacity.





# First Party SNT

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- Payback provision:
  - Upon the death of the disabled beneficiary all remaining trust principal and accumulated income must be paid back to Medicaid to reimburse Medicaid for all benefits paid to the disabled beneficiary during his or her lifetime.
  - Following the payment to the state, any additional assets remaining in the trust, if any, are distributed to the named contingent beneficiaries of the Trust



# First Party SNT

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- Special Applications May Be Required:
  - Trustees of First Party SNTs may have to make special applications to expend trust funds that are either over ten percent of the trust fund or so non-routine that the expenditure could be viewed as improper
  - Why? Because of the payback provisions. The state wants to make sure that the trust fund is not inappropriately dissipated
  - None of these rules apply to Third Party SNTs

# Pooled Trusts: Managed by Non-Profit Licensed Trust Companies

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- ❑ In a pooled trust, the assets of many individuals are managed by a non-profit agency which maintains separate accounts for each beneficiary
- ❑ Pooled trusts can be a useful tool for Medicaid planning purposes as they can be used to shelter resources and income from consideration by Medicaid
- ❑ Pooled trusts are almost always funded with the disabled person's own funds (“first party” money)



# Pooled SNT

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- ❑ Pooled trusts cannot distribute funds directly to the trust beneficiary but can pay a third party for items for the beneficiary or can pay bills directly
- ❑ The trust must contain language indicating that payments will not replace or reduce the person with I/DD's Medicaid benefits



# Pooled SNT

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- These trusts are usually utilized where there is no family member to act as a trustee or when the beneficiary is over the age of 65.
- NOTE: If the beneficiary is over the age of 65, there is a penalty period for assets transferred to the Pooled Trust for Medicaid nursing home benefits



# Pooled SNT

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- Balance **RETAINED BY THE POOLED TRUST** on death, technically for the “benefit of other disabled persons” (really to defray overhead)

# Defining the Estate Plan for the Child with I/DD

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- Once 18, all parental authority over health and finances expires
- Child needs their own legal documents or protection through Guardianship
- **Legal** capacity needs to be assessed to know which path to pursue



# Capacity for Child with I/DD

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- In New York State, individuals are assumed to be legally competent to make their own personal, medical and financial decisions upon attaining the age of 18
- What is legal capacity?
  - Varies for Wills versus Advance Directives
  - To sign advance directives, a person needs to understand the nature and consequences of signing the document





# Order of Preference for Legal Plan for Child with I/DD

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- **First Choice:** Advance Directives signed by child with I/DD if possible
- **Second Choice:** SCPA 17A Guardianship if qualify
- **Third Choice:** MHL Article 81 Guardianship otherwise



# 17-A Guardianship

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- New York's Surrogate's Courts offer an accessible guardianship process which authorizes parents and other caregivers to make important life decisions for individuals with disabilities after reaching the age of 18 and continuing throughout the duration of the disability



# 17-A Guardianship

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- The 17-A Guardianship proceeding can be brought on the behalf of any individual with an intellectual or developmental disability having an onset prior to age 22, or on behalf of individuals with traumatic head injury sustained at any age
- If parents believe an Article 17-A Guardianship is appropriate, the process should be undertaken six (6) months prior to a child's 18<sup>th</sup> birthday



# 17-A Guardianship

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- Three step process:
  - Prepare the Petition and accompanying documents
  - Completion of Office of Children and Family Services Form 3909
  - Secure proof of the disability in the form of a physician's affirmation and a licensed psychologist's affidavit (or two physician's affirmations).



# 17-A Guardianship

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- Once the documents are filed with the Surrogate's Court the Court will schedule a hearing that the individual with the disability will attend
- In most cases a Guardian Ad Litem will be appointed by the Court to represent the interests of the person with the disability



# 17-A Guardianship

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- Once the Surrogate's Court has the hearing and reviews all documentation they can appoint a guardian of the person, the property or both and issue "Letters of Guardianship"
- An Article 17-A Guardianship is very broad and covers most decisions that are usually made by a parent for a child such as financial and healthcare decisions



# 17-A Guardianship

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- Note that a Guardian of the Property has ongoing property management and reporting responsibilities including:
  - Collecting all of the persons property and depositing it in a Court-supervised account
  - Requesting Court approval for any withdrawal from such account
  - Preparing and filing and Annual Report of account activity



# Recent Guardianship Developments

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- 17-A Guardianships have been subject to criticism by a number of disability rights advocates, the concern being that the process for establishing guardianship does not sufficiently protect the due process rights of the individual with the disability
- Though to be about protecting parents, not necessarily the person with I/DD





# Recent Guardianship Developments

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- Advocates are concerned that the 17-A statute is designed to grant guardianship based on a diagnosis and does not require the Court to determine whether there are certain powers that the Guardian should not be granted
- Advocates argue that Article 81 Guardianships are a better approach because the Court concentrates on functional limitations rather than diagnosis



# Article 81 Guardianship

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- Article 81 of New York's Mental Hygiene Law historically used for guardianship proceedings where a person has LOST capacity and facing imminent harm
- This type of guardianship is filed in the Supreme Court Guardianship Part of the county of residence



# Article 81 Guardianship

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- Unlike Article 17-A Guardianship, this type of guardianship is very individualized and specific regarding decisions the guardian has the power to make and which rights remain with the person with the disability



# Article 81 Guardianship

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- Petition
- Order to Show Cause
  - Appoints lawyer for AIP and/or Court Evaluator
- Hearing
- Notice of Settlement of Order followed by  
Notice of Entry of Order
- Commission Issues Thereafter
- Reports Due Annually



# ABLE Accounts

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- Allows those with disabilities to save for qualified disability expenses without the risk of losing their benefits from assistance programs like SSI and Medicaid
- NOTE: NY ABLE accounts are exempt from tax on its earnings and distributions, **provided the funds are used to pay for qualified disability expenses**
  - Earning on non-qualified withdrawals may be subject to federal income tax and a 10% federal penalty, as well as state and local income taxes.



# ABLE Accounts

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- Qualified disability expenses include:
  - Education
  - Housing
  - Transportation
  - Employment training and support
  - Assistive technology
  - Personal support services
  - Health
  - Financial management
  - Legal fees
  - Funeral and burial expenses
  - Other expenses approved by the Treasury

# ABLE Account Eligibility

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- There are two ways to be considered an *eligible individual* per the NY Able website:
  - A disability must be present before age 26, and the individual must be entitled to SSI or Social Security Disability Insurance (SSDI) because of his or her disability, **OR**
  - a disability must be present before age 26 **AND AT LEAST ONE OF THE FOLLOWING** requirements must be met:
    - The individual has a written diagnosis from a licensed physician documenting a medically determinable physical or mental impairment which results in marked and severe functional limitations, that can be expected to last for at least a year or can cause death, **OR**
    - The individual is classified as blind (as defined in the Social Security Act), **OR**
    - The individual has a disability that is included on the Social Security Administration's List of Compassionate Allowances Conditions



# ABLE Accounts

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- An ABLE account can be opened by:
  - An eligible individual
  - A parent or legal guardian of an eligible individual
  - A person granted Power of Attorney on behalf of an eligible individual
- An eligible individual will be both the NY ABLE account owner AND beneficiary
- NOTE: Anyone can contribute to an eligible individual's NY ABLE account





# ABLE Accounts

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- Limits:
  - One ABLE account is allowed per beneficiary
  - Maximum amount that can be deposited during any year is \$15,000 (contributions are not tax deductible)
  - Maximum account balance is \$100,000 (if over \$100,000 is in the account there will be a suspension of SSI benefits)



# ABLE Accounts

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- Upon termination of the account there is a required payback for Medicaid services received by the beneficiary regardless of the source of the account funds



# Program Eligibility

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- Health Insurance, Service Coordination and Long Term Care:
  - Medicare
  - Medicaid (means tested)
- Income Support:
  - SSDI
  - SSI (means tested)
- Housing
  - Private Pay (such as POINT)
  - Various state and county programs (means tested)



# Medicare

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- Federal Rules and Regulations
- Health Insurance for Aged and Disabled
- Not Means Tested
- Available to most people over 65 and to a disabled person



# Medicaid

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- Means Tested Health Insurance for Disabled, Aged and Blind (“DAB”)
- Funded by federal, state and local government
- Governed by network of state and federal laws and regulations
- County Administered
- Means Tested
  - \$15,150 in Countable Assets
  - Income spenddown can be protected by utilizing pooled income trusts if receiving Community Medicaid



# Social Security Disability Income

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- Federal rules and regulations
- Disabled Adult Child (“DAC”) eligible based on PARENTS’ earnings
  - Caveat: If person with I/DD marries, could jeopardize eligibility
- Disability must have manifested before the age of 22
- Not Means Tested



# Social Security Income

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- Federal rules and regulations
- Means Tested
  - \$2,000 Asset limit
- Income of \$735 per month, reduced by other income sources and certain types of in kind support

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# What To Do Now

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- **Now:**
  - Create estate plan for parents and any grandparents; start to spend down child's assets if over limits for means tested programs
  - Start the family discussions
  - Research Residential Housing
  - Submit Front Door Application with OPWDD
    - Two part process:
      - Medicaid (financially based)
      - OPWDD (disability based)
    - Apply Online or In Person (Get Proof!)



# What To Do Later

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- **At age 15:** Start to research residential housing options, if needed, to secure waiting list position
- **At age 17:** Apply for Guardianship if needed OR prepare to sign advance directives as soon as child turns 18
- **At age 18:**
  - Apply for DAC benefit under SSDI
  - Apply for SSI
  - Apply for Medicaid if haven't done so already



# Agency and Community Resources

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- **OPWDD** (Office for People With Developmental Disabilities)
  - <https://opwdd.ny.gov/welcome-front-door/resource-booklet>
- **The ARC of Westchester**
  - <https://www.arcwestchester.org>
- **ACCES-VR** (Adult Career & Continuing Ed Services – Vocational Rehabilitation)
  - White Plains District Office: (914) 946-1313
- **POINT** (Pursuing Our Independence Together)
  - Contact Barbara Greene, director, at (914) 761-0600, ext. 175
- **Aging Life Care Association**
  - <https://aginglifecare.org>



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*Thank you*

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