

**Critical Resources  
for Special Needs Families:**



**Creating a Blueprint  
for Your Loved One's Future**

*Presented by:*

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**Negotiating Disability "Systems"**





## The Adult DD System in NJ: The 30 Second Version

- Eligibility & Assessment (Medicaid, 21+, NJ CAT)
- Waiver Enrollment (Supports or Community Care Program)
- Support Coordination Selection
- Plan Development (Choosing Services & Providers)
- Monthly & Annual Reviews (Amendments as Needed)
- Ongoing Maintenance of Eligibility
- Transition to Different Program (SP to CCW or SP/CCW to MLTSS)



## Disability Planning: Start with the Key Questions

- What, if anything, must change within the next 30 days?
- What, if anything, should change within the next year?
- What, if anything, should change within the next five years?
- What events will trigger the need for other changes?
  
- What supports are needed?
- Where will the supports be needed?
- How will the supports be funded?
  
- **Is this plan sustainable?**



## Disability Planning: Overview

- Care Coordination
- Supports for Daily Living
  - Residential “placement” v. In-Home services
- Employment/Day Services
- Self Determination, Choice, Capacity/Assisted Decision-Making
- Financial Planning



## Care Coordination

- Think broadly about care coordination to ensure all areas are covered:
  - ❖ Medical care --- HMO
  - ❖ Behavioral health care --- HMO (currently)
  - ❖ DDD supports/services --- DDD waiver program
  - ❖ MLTSS supports/services --- MLTSS/Medicaid through HMO
  - ❖ Internal provider agency care coordination



## Care Coordination

- Support Coordination Selection
  - ❖ Any willing and qualified provider
  - ❖ Boggs Center resource available
  - ❖ Use your resources
  
- Understand the SCA's role in both the short and long term
  - ❖ Planning issues
  - ❖ SCA --- Individual/Family --- Service Provider --- DDD
  
- Change providers if not satisfied!



## Supports for Daily Living

- Where will you live?
  - ❖ Next Month
  - ❖ Next Year
  - ❖ 5 Years/10 Years/20 Years
  - ❖ Known triggers that will change this
  
- Understand the options – and keep up to date, as these will change over time!
  - ❖ Traditional “residential placement” models
  - ❖ In Home Services
  - ❖ New Supported Living Models



## Supports for Daily Living

- Choosing a Residential Service Provider – Know What To Look For
  - ❖ The Tale of Bedspreads & Flowers
  - ❖ Engagement is Everything
  - ❖ Culture Matters
- Maintaining Quality with a Residential Service Provider
  - ❖ Remember that you have a ROLE in this
    - ❖ DDD’s Quality Plan
    - ❖ Federal & State Monitoring, including SCAs
    - ❖ Board of Directors, Committees, Fundraising, etc.

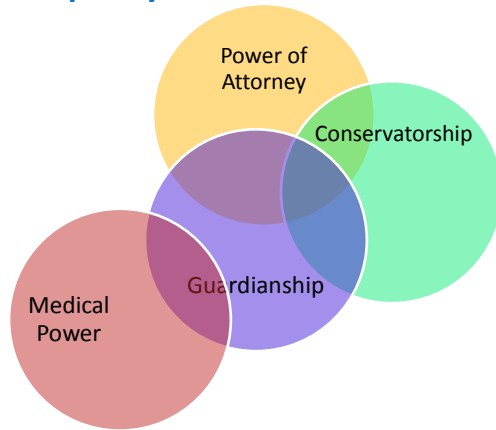


## Employment/Day Services

- What Does It Mean to be an “Employment First” State?
- What Options Exist?
  - ❖ Employment
  - ❖ Pre-Employment, Developing Skills
    - ❖ Day Habilitation
    - ❖ Prevocational Training
    - ❖ Career Planning
    - ❖ Community Inclusion & Community-Based Supports
  - ❖ A Combination of the Above
  - ❖ Retirement
- Choosing Quality Providers – Know What to Look For

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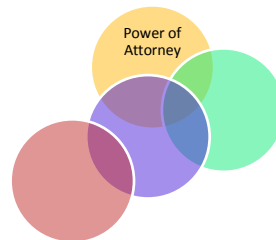
## Substituted Capacity



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## Power of Attorney - Financial

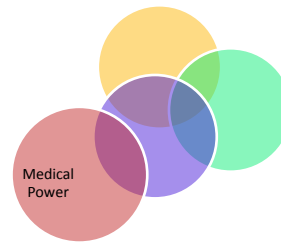
- Inexpensive
- Voluntary
- Revocable
- Immediate or “Springing”



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## Medical Power – Health Care

- Inexpensive
- Voluntary
- Revocable
- Immediate or “Springing”

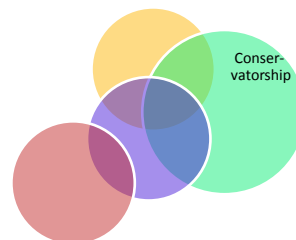


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## Conservatorship - Financial

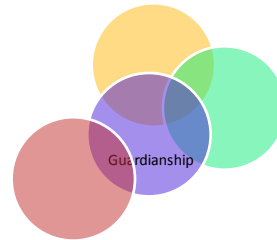
- Expensive
- Voluntary
- Court ordered
- Irrevocable



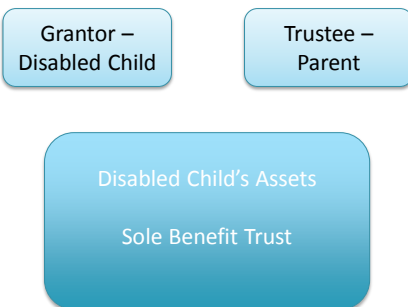
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## Guardianship

- Expensive
- Involuntary
- Court Ordered
- Irrevocable



## First Party Trust – Special Needs Trust – d4A Trust



### Elements

- Child or proxy create
- Under 65
- Notice NJ Medicaid on formation
- Notice to spend more than \$5000
- Sole Benefit Of Rule
- Payback on death

### Usage

- PI Award
- Unplanned Inheritance
- Adult On-Set Disability

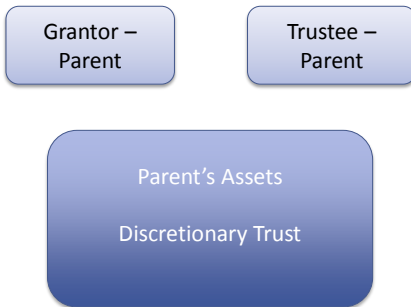
### Taxation

- Grantor Trust





## Third Party Trust – Supplemental Benefits Trust – Discretionary Trust



### Elements

- Parent create
- Private Trust – no Medicaid oversight
- Discretionary
- No Payback on death

### Usage

- Estate planning
  - Inter-Vivos
  - Testamentary
- Life Insurance Planning

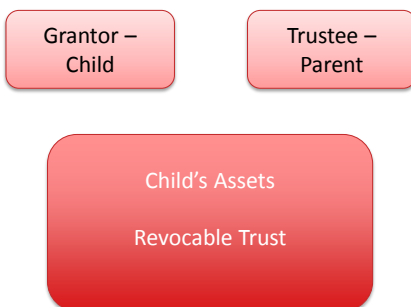
### Taxation

- Grantor Trust
- Non-Grantor Trust
  - Distributions are DNI to beneficiary (SSI)
- Gift Tax

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## Revocable Trust



### Elements

- Child create
- Revocable Trust – no Medicaid, tax or asset protection advantage
- Discretionary

### Usage

- Third party management

### Taxation

- Grantor

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## ABLE Accounts - Achieving a Better Life Experience (ABLE) Act

### Benefits:

- Contributions can be made by anyone (including individual, family) Funds can be used for education, housing, transportation, employment training and support, assistive technology and personal support services, health, financial management and administrative services, legal fees, funeral and burial expenses, and other expenses
- Up to \$100,000 which does not count toward the SSI resource limit of \$2,000

### Limitations:

- Only one ABLE account can be established for an individual
- Disability must occur before age 26
- Annual contributions by individuals are limited to \$15,000 per year
- If an ABLE account exceeds \$100,000, the beneficiary would no longer be eligible for SSI benefits.

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## Taxation and Planning

### Income:

- Grantor Trust
- Non-Grantor Trust

### Gift:

- Annual Exclusion
- Lifetime Exemption
- Sec. 2503(e) Payments for Medical Care

### Estate:

- Unequal Allocation
- Life Insurance Trust

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## Other Considerations

- Fiduciaries (Guardian and Trustee)
  - Successors
  - Corporate v. Individual
- Residential Decisions
- Care Plan – Current and Future Needs

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## Creating A Blueprint

- Start with the key questions
- Know your options
- Prioritize
  - ❖ Care Coordination
  - ❖ Engaged Caregivers
  - ❖ Sustainability
- Stay focused on what you can impact
- Expect (plan for) change
- Revise, revise, revise!

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## Resources

- *Supports Program Policies & Procedures Manual*, NJ DDD
- *Community Care Waiver (CCW) Policies & Procedures Manual*, NJ DDD
- *Selecting A Support Coordination Agency: Making Choices, Becoming Empowered - A Guide for Families*, Boggs Center
- *Evaluating Your Family Member's Support Coordination Services*, Boggs Center
- *Participant Statement of Rights & Responsibilities*, NJ DDD
- *Participant Enrollment Agreement*, NJ DDD



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## Questions

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