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A family-based organization for people with intellectual and developmental disabilities



The Arc®

New York

Stronger Together!

Passing the Baton: Planning the Transition of Oversight and Advocacy to Siblings and Other Caregivers



Panel Presenters

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THE SERVICE DELIVERY SYSTEM: THEN AND NOW

- The dilemma presented by the aging of the caregiver population
- Past supports and services available from organizations like Wildwood
- Changes in funding and organizational makeup, with a movement towards managed care
- The impact of those changes on service providers, especially in the area of residential supports and staffing

THE SERVICE DELIVERY SYSTEM: THEN AND NOW

- One sibling's story: first hand experience with "Self Direction" under the OPWDD program
- More flexible funding is designed to support more individuals living in their own home, including:
 - reimbursement for many household expenses
 - more generous hourly rates for staff
 - support for community based activities
- But... more responsibility for oversight and administration by family members and other advocates

THE OBJECTIVES OF “TRANSITION PLANNING 2.0”

- Empowering advocates
- Educating the successors
- Estate and financial planning so that there will be financial resources to supplement services and support the providers (understanding the public/private partnership)

EMPOWERING AGENTS

- Legal authority to receive information and make decisions - more than just an inclination to help
- Considering guardianship and alternatives to guardianship:
 - Article 17A and Article 81 proceedings
 - Powers of Attorney and Health Care Proxies
 - Understanding what is (and what is not) expected when siblings and others assume these roles
- Supported Decision Making: valuable in aspiration, moving ahead, but currently insufficient

EDUCATING THE SUCCESSORS

- For the siblings and other advocates:
 - Attend ISP/care planning meetings (in person/by phone)
 - Visit a residence to meet staff and professional providers
 - Read copies of service and care plans
 - Think realistically about what you can offer
- For the parents and other caregivers:
 - Prepare a letter of intent/life care plan: write it down!
 - Hire a care manager to help create a record
 - Think realistically about what you should expect
- For everyone: honest and open discussion makes for smooth transitions

PROVIDING FINANCIAL RESOURCES TO SUPPLEMENT CARE

- Siblings and other caregivers cannot be expected to provide the same level of time and attention that a parent provides
- Revise expectations about how funds left for family members with disabilities will be used:
 - Trips to Disney World are fun, but my brother will need someone to help him get his car repaired
 - Yankees tickets are great, but my sister needs someone to help interview and select new staff

ESTATE AND FINANCIAL PLANNING TO ADDRESS THE NEED FOR PRIVATE FUNDING

- Trust arrangements – usually Supplemental (Special) Needs Trusts – can be used to hold and manage funds for an individual with a disability without disrupting access to Medicaid and other public benefits
- It is easier to ask family members and others to agree to assume some level of responsibility when you have taken steps to ensure that private dollars will be available to assist:
 - Funds to provide both necessities and quality of life enhancements
 - Funds to hire aides and advocates to provide assessments and to help negotiate a complicated service delivery system

PROVIDING FINANCIAL SUPPORT TO THE AGENCIES THAT SUPPORT OUR FAMILY MEMBERS

- Needs will not diminish with the passing of the caregiver. To the contrary, as individuals with disabilities age their needs will often increase
- Agencies continue to struggle with inadequate reimbursement rates for staffing and other services
- Without private financial support, agencies will be able to do less

SOME OF US WILL PLAY MULTIPLE, SEPARATE ROLES...

