

Representing the Special Needs Family: What You and Your Clients Need to Know

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Demographics - Seniors

- 55 million Americans over age 65
 - 17% of the population
 - 25% of these people will live past 90
 - 10% will live past 95
- By 2050, over 65 population expected to increase to about 73 million
 - 10,000 a day
 - 22% of the population
 - Fastest growing segment is age 85 and older
- Over 6 million Americans diagnosed with Alzheimer's Disease
 - By 2050, this number will triple
 - 250,000 people under age 65

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Demographics – Individuals with Disabilities

- More than 60 million Americans are living with a disability
 - 18% of U.S. population
 - One in six children ages 3 to 17 have a developmental disability
 - As of 2023, one in 35 children are diagnosed with an autism spectrum disorder

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Demographics – Birth Rate/Work Force and Need for Caregivers

- US Birth Rate has fallen 20% since 2007
- Lower birth rate = smaller work force
- Smaller workforce + aging population will put fiscal pressure on social insurance programs like Social Security and Medicaid which are generally paid for through tax revenues.
- Watch for the need to have private dollars principally fund support and care for seniors and those with disabilities across all domains.

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What we are already seeing....

- National Staff Shortages in Service Delivery System
- Nursing Homes can't fill to capacity and are purposefully downsizing
- Agencies can't provide support to individuals with disabilities
- Families are responsible for oversight
- No long-term plan that lasts beyond an election cycle
- Families feeling guilt, shame and entitlement

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What we are already seeing....

- Wage compression and the need for private dollars needed to supplement service delivery
- Changing of philosophy about purpose of and use of publicly funded system
- Trust Administrators will be asked more and more to pay for caregivers, comm hab staff, case managers and advocates to navigate the system
- People will find themselves without choice if there is wholesale reliance on the Medicaid funded system
- What does this mean for families and Trustees

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Objectives for Special Needs & Long-Term Care Planning Professionals

- Many of our clients(and us) are wrestling with the same challenges: planning for the time when parents are no longer able to provide the same level of oversight and support.
- Alternatives are limited: other family members/friends, Medicaid funded supports, and privately-paid supports. Technology can provide solutions in some areas and individuals with disabilities may develop greater independence, but a safety net will always be necessary.
- There is no single solution or game plan.
- Objective is to identify and articulate the challenges, help families think through available resources, and encourage them to take steps in those areas that they can control, especially augmenting private sources of funding the needs of those with disabilities.

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Estate and Financial Planning to Address the Need for Private Funding

- Maintain Private funds
 - Trust arrangements – usually Third Party Supplemental (Special) Needs Trusts – can be used to hold and manage funds for an individual with a disability without disrupting eligibility for and access to Medicaid and other public benefits
- Reconsider Medicaid/Entitlement Planning for Seniors
- Funds to provide both necessities and quality of life enhancements
- Funds to hire aides and advocates to provide assessments and to help navigate a complicated service delivery system
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Estate and Financial Planning to Address the Need for Private Funding

Revise expectations about how private funds and funds left in trust 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
- Hiring of Private advocates when no family members are willing and able to serve
- Normalize private payment for access to care and to buy choice

- Consider providing financial support to disability service providers. Agencies continue to struggle with inadequate reimbursement rates for staffing and other services. -- Special Needs Trust Improvement Act of 2022 (SECURE 2.0)

- The "funding formula" will be different for each family-help them think "outside the box."

Funds to hire aides and advocates to provide assessments and to help navigate a complicated service delivery system

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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)

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EMPOWERING AGENTS

- Legal authority to receive information and make decisions - more than just an inclination to help
- Considering guardianship and alternatives to guardianship:
 - Guardianship
 - 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, but insufficient in practice

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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

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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
- Adequate Funding. New Paradigm.
- 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

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Service Delivery – Then & Now

- The changing population demographics, and the resulting increase in support needs, are occurring at a time of great organizational changes for providers of support services, and funding for those services.
- In the past, supports and services were available from larger, integrated organizations and direct support was provided by highly educated and trained staff; and they had smaller case loads.
- While these changes were designed in part to provide more flexibility and choice for individuals with disabilities and their families, many find the new system harder to manage.

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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 Disability Service Organizations
- Changes in funding and organizational makeup
- The impact of those changes on service providers, especially in the area of residential supports and staffing

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THE SERVICE DELIVERY SYSTEM: THEN AND NOW

- 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

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PROVIDING FINANCIAL SUPPORT TO THE AGENCIES THAT SUPPORT OUR FAMILY MEMBERS - REMINDER

- 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

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KEY POINTS TO HIT HOME

- Systemic Concerns in Service Delivery
- Legal Authority/Advocacy (Guardianship/Advance Directives/Supported Decision Making)
- Supplemental Needs Trusts for Asset Management and Support
- Behavioral Financial Decisions
- Expectation Setting for Families, Siblings, Next Gen

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Questions/Discussion?



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