

# LEGISLATIVE & DEMOGRAPHIC DEVELOPMENTS



New York State Bankers Association  
September 15, 2022  
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# Practice & Perspective

Trusts & Estates Attorney with focus on special needs planning and special needs trust administration. Represent families and fiduciaries across New York.

Not for profit Board Activity and Professional Activity

Parent of an 18 year old young man with Autism Spectrum Disorder (f/k/a Asperger's Syndrome)



# Today's Discussion

SECURE Act and Proposed Regulations in the Special Needs Trust context

The Special Needs Trust Act of 2022

Supported Decision Making (SDM) in New York

Demographic Activity and Impact on Trust Administration and Practical Planning Advice



# SECURE ACT & PROPOSED REGULATIONS



## SECURE Act

- Stretch IRA gone except for certain beneficiaries
  - Maximum 10-year payout
- EDBs (Eligible Designated Beneficiaries) - life expectancy payout still available
  - Spouse
  - Disabled individual
  - Chronically ill individual
    - Properly drafted SNTs
  - Minor Children
  - Beneficiary less than 10 years younger
- 10 year rule upon death of EDB



## Disabled Individual

- IRC Section 72(m)(7)
- Age 18 and older
  - Unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment that can be expected to result in death or to be of long-continued and indefinite duration
  - Adult disability rules apply to some minors (18-21)
- Under age 18
  - Medically determinable physical or mental impairment that results in marked and severe functional limitations expected to result in death or to be of long-continued and indefinite duration

# SECURE ACT – Proposed Regulations

- Non-AMBT issues of note
  - 10 Year Rule. Non-EDBs (Expect there will be comments requesting simpler implementation)
    - If owner dies prior to his or her RBD, then non-EDBs are subject to the 10-year rule.
    - If the owner dies on or after his RBD, then non-EDBs are subject to both the 10-year rule and regular stretch distributions during the pendency of the 10 years.
  - Minor Child Reaches Majority at age 21.
    - All children in all states regardless of state laws on defining the age of majority.
  - Defining Disability for EDB Status for adults
    - Beneficiary deemed disabled by the SSA as of the death of the account owner is the only safe harbor.

# SECURE ACT – Proposed Regulations

- Defining Disability for EDB Status – Minor Children
  - Someone who does not have an SSA disability determination has a disability if that individual as of the date of death of the account owner:

(1) *“ has a medically determinable physical or mental impairment that results in **marked and severe functional limitations** and that can be expected to result in death or to be of **long-continued and indefinite duration**. (Emphasis added); and*

(2) Provide documentation of disability to the plan administrator or IRA custodian by October 31<sup>st</sup> of year following year of death.

*Note: The Proposed Regulations do not specify the nature of this documentation, nor do they outline what if any requirements an administrator or custodian would need to meet in verifying disability for EDB purposes. Comments provided to the Treasury as well as on the fact that many disabilities are not patently evident in young children although they exist as a matter of fact.*



# Social Security Administration Safe Harbor

- Social Security Disability Income (SSDI)
- Supplemental Security Income (SSI)
- Age 18 and older
  - Unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or last for a continuous period of not less than 12 months
- Under age 18
  - Medically determinable physical or mental impairment, which results in marked and severe functional limitations, and can be expected to result in death or last for a continuous period of not less than 12 months

# Disability Determination

- Not the proper role of the plan administrator
- Many disabled individuals will not qualify as EDBs
  - Insufficient work records
    - Stay at home parent
  - Excess resources
    - SSI \$2,000 resource limitation
    - Deemed income until age 18
    - Minor and family must be indigent
  - SSA determination not made until at least age 18
- Should be an alternative way to determine disability

# Disability Determination

- ABLÉ safe harbor
  - Medical certificate of disability
    - Individual retains underlying documentation
    - HIPAA
  - Licensed health care provider
    - Similar to procedure establishing SECURE CI status
- State agency or contractor
  - Determine disability for individuals who have not yet been determined disabled by SSA
  - Use same definition of disability

# SECURE ACT – Proposed Regulations

- Defining Chronic Illness for EDB Status
  - Proposed Regulations reinforce the definition of chronic illness which was slightly modified from the IRC 7702 definition (Assistance with 2 ADLs “which is reasonably expected to be lengthy in nature”).
  - Confirms documentation requirement by October 31 of the year after the year the account owner dies, but here, unlike with the definition of disability, the Proposed Regulations require that documentation “Include a certification from a licensed health care practitioner.”

## Trusts for EDBs

- See-through trust
  - Trust beneficiaries treated as account owner's beneficiary
  - Valid under state law
  - Irrevocable or will become irrevocable on death of account owner
  - Beneficiaries are identifiable
  - Specified documentation requirements are met
  - Conduit or accumulation trust
- Applicable Multi-Beneficiary Trust (AMBT)
  - Trust with more than one beneficiary
  - All beneficiaries are designated beneficiaries
  - At least one beneficiary is DC/I

# SECURE ACT – Proposed Regulations

- Applicable Multi-Beneficiary Trusts (AMBTs)
- Defined as: (1) A see-through trust with more than one beneficiary; (2) all of the trust beneficiaries are designated beneficiaries (i.e. individuals); and at least one trust beneficiary is disabled or chronically ill.
- Regs create Type I and Type II AMBTs:
  - Type I: Terms of the Trust provide that the trust will be divided immediately upon the death of the account owner into “separate trusts” for each beneficiary. Division is a special exception of the separate accounts rule for Type I AMBTs which generally (the separate accounts rule) doesn’t apply to Trusts.
  - Type II: The terms of the Trust identify one or more individuals who are disabled or chronically ill and who are entitled to benefits during their lifetimes **and** the terms of the trust must provide that no ***individual*** (other than a disabled or chronically ill beneficiary) has any right to the account owner’s interest in the retirement account until the death of all of the disabled and/or chronically ill beneficiaries.



## Type II AMBT/SNT

- Accumulation trust
- No distributions to anyone other than D/CI during lifetime
  - No distributions are required to be made to D/CI
- On death of D/CI trust passes to individual beneficiaries

## Type II AMBT/SNT

- Payments for third parties
  - Distributions to others which benefit DC/I should not violate AMBT rules
    - For benefit of D/CI
    - Travel to visit DC/I
    - Travel with DC/I
  - POMs
    - Primary v. sole benefit
    - Should be permitted to have derivative benefits to others
    - Sole benefit rule applies only to first party trusts
      - Type II AMBT is third party SNT

## SECURE ACT – Proposed Regulations

GOOD NEWS: Special Rule for Type II AMBTs:  
The remainder beneficiaries of a Type II AMBT are disregarded for purposes of determining the Applicable Distribution Period for RMDs payable to the disabled or chronically ill beneficiary or beneficiaries of the Type II AMBT.

BAD (but expected) NEWS: Still can not name charities as first tier remainder beneficiaries of Supplemental Needs Trusts. Doing so would result in loss of AMBT status and the EDB status.

# THE SPECIAL NEEDS TRUST IMPROVEMENT ACT OF 2022

Introduced in the Senate & The House  
Expected to be part of the EARN Act

# Special Needs Trust Improvement Act of 2022

Introduced in the Senate June 16, 2022 – S. 4426

Introduced in the House July 29, 2022 – H.R. 8625

Allows charitable organizations to be named as remainder beneficiaries of Third-Party Supplemental Needs Trusts without adverse impact on use of the EBD's life expectancy for minimum distribution purposes.

Special Needs Alliance Advocacy responsible for this introduction.

# Special Needs Trust Improvement Act of 2022

Bipartisan Support

Expected to be a part of SECURE 2.0/EARN Act after the election

Recognition of both primary source of wealth transfer and need for funding for Service Delivery Agencies





# SUPPORTED DECISION MAKING

Enacted July 26, 2022

Effective 90 days after Regulations are issued and placed in the State Register. Likely Q4 2023.

S. 7107-B

A. 8586

# Supported Decision Making (SDM)

## What is it? - National Trend

- Alternative to guardianship
  - Due process concerns
  - Common misconception that all disabled individuals need a court-appointed guardian
  - Right to make own decisions is critical to autonomy
  - Less restrictive
- Individual with disability selects advisors or supporters to help gather information, make and communicate decisions
- Individual does not give up right to make his own decisions
- Can be used in conjunction with advance directives
- Over 20 states have adopted SDM legislation, including New York

## Supported Decision Making Agreements (SDMAs)

- Areas of support needed - financial, health care, living arrangements, etc.
- Who will provide support - trusted people in that person's life
- Type of support needed - gathering information, weighing alternatives, consequence of decisions, communicating to others
- How support will be provided - in person, Facetime, text, group meetings, etc.
- Acceptance by third parties who might otherwise refuse to deal with someone, or question such person's ability to enter into a contract

# New York's Approach to SDM

2015 – NY's Developmental Disabilities Planning Council (DDPC) issued an RFP for a five-year Supported Decision-Making Pilot Grant.

Purpose of the pilot was to develop and distribute educational materials and to pilot supported decision-making with people with IDD in New York.

Look to inform reforms to NYS law to advance the use of SDM as an alternative to Guardianship.

# New York's Approach to SDM

Supported Decision-Making New York (SDMNY)

<https://sdmny.hunter.cuny.edu/> was the consortium of collaborating institutions which was awarded the grant. Hunter/CUNY served as the lead agency for the consortium, which included the New York Alliance for Inclusion and Innovation, and the ARC of Westchester County.

# New York's Approach to SDM

SDM designed a Facilitation Model for two groups of individuals with IDD:

**Diversion Pilot** – Offers SDM to divert those “at risk” of Guardianship away from Guardianship

**Restoration Pilot** – offers SDM to those with Guardianship orders with the aim to restore their decision-making rights by terminating the Guardianships. (Handled with oversight and support from DRNY)



# SDMAs in NY – The “Big Four”

**Which** areas a DM wants decision support in (i.e. financial matters, health care, living arrangements, etc.)

**Who** is chosen to provide that support (trusted persons in the DMs life)

**What** kinds of support (gathering information, helping to weigh alternatives or possible consequences, communicating decisions to others); and

**How** support will be provided (face-face meetings, group meetings, text, Facetime, etc.)

# SDMNY Roles: DM

Using the term decision-maker to refer to the individual with IDD engaged in the process was key for setting expectations for the individuals themselves, their supporters and third parties.

The DM drives the process and is the center of it. The DM voluntarily adopts SDM, identifies areas where support is welcome, identify and invite supporter involvement, and advise supporters how to provide decision support.

# SDMNY Roles: The Facilitator

- The facilitator is key to the process and has proven to be a difficult role to sustain.
- Facilitators are trained volunteers. They assist the DMs to consider what kinds of decisions they want help with making, who they want decision support from, what kind of support they want and how it is to be provided. They also assist the DM with communicating to their identified and preferred supporters.

# SDMNY Roles: The Facilitator

There is one philosophical qualification for the Facilitator:

Believing in the value of individuals with IDD making decisions about their own lives.

Formal qualifications are:

- (1) Completion of the SDMNY Facilitator Training (2 days)
- (2) Computer skills sufficient for reporting and communicating with SDM staff

# SDMNY Roles: The Mentor

Provide Guidance as well as technical and emotional support to facilitators as well as review draft SDMAs.

Qualifications:

- (1) Completion of Facilitator Training;
- (2) Successful Facilitation Experience with at least one DM through the creation of an SDMA.

# SDMNY Roles: The Supporter

- Typically a family member, friend, paid service provider staff selected by the DM who pledge to provide support as described in the agreement, to refrain from acting as a substitute DM, to avoid conflicts of interest and not to exert undue influence.

# NY's Legislation

- Contains a presumption of capacity unless that adult has a legal guardian, appointed by a court of competent jurisdiction, whose granted authority is in conflict with the proposed SDMA.
- Presumption of capacity can only be rebutted by clear and convincing evidence.
- Capacity includes capacity with decision-making support and/or accommodations.
- A diagnosis of intellectual, developmental, or other disability shall not constitute evidence of incapacity.
- The manner in which an adult communicates with others shall not constitute evidence of incapacity.

# NY's Legislation

- Sets forth the duties, responsibilities and authority of supporters (including how to resign).
- Sets forth the formation and term of the agreement.
- Sets forth the format for revocation and amendment of the agreement.
- Provides expansive definition of who can be chosen to be a supporter (i.e. anyone is eligible unless an order of protection has been issued by the Court against the supporter on request or on behalf of the DM or the local department of social services has found that the supporter has committed abuse, neglect, financial exploitation or physical coercion against the supporter).



# NY's Legislation

- Codifies the facilitation process (as defined by future regulations to be promulgated by the NYS Office for Persons with Developmental Disabilities). OPWDD has until July 26, 2023 to promulgate regulations.
- **Sets forth the required contents of the agreement but specifically does not provide a statutory form.**
- Defines the legal effect of decisions made with support and third-party obligations

# Expectations of Third Parties

- Who are the third parties?
  - Health Care Providers
  - Financial Institutions
  - Vendors
  - Any other provider or entity that interfaces with the DM

# How do we prepare for implementation?

- Focus on Sections 82.11 and 82.12 of the Mental Hygiene Law.
- Attestation
- Training
- Liability Limitation

# Themes and Expectations

- Court system is over-burdened. This legislation gives an “out” to Guardianship Judges to send families out of the court system looking for the least restrictive alternative.
- Parents are often shamed by disability rights advocacy groups, the courts, guardians ad litem and state agencies by framing the conversation around restricting the rights of their children and focusing on dignity of risk. This is all happening at a time when demographics are particularly challenging.

# Graying of America

- 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

# Beneficiaries with Special Needs

- 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
  - One in 54 children have an autism spectrum disorder



## HELP

National Staff Shortages in Service Delivery System

Nursing Homes can't fill to capacity

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





Wage compression and the need for private dollars needed to supplement service delivery.

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 that mean for families and Trustees?



Thank you! Questions?



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