Supported Decision-Making, the ABLE Act, and Managing Money

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Article of Faith

"In this great and prosperous nation, everyone deserves shot at the American Dream"

- Representative Ander Crenshaw

Article of Faith: EVERYONE has the Same Goal

We **ALL** want "a foundation that will foster a lifetime of opportunity and happiness."

"Many of the means to achieving those outcomes are the same: enrollment in post-secondary education, vocational training programs, experiencing work, and developing social networks that foster long-term meaningful relationships and opportunity for continued growth."

- Gustin, 2015

The Goal: Self-Determination

- Life control
- People's ability and opportunity to be "causal agents . . . actors in their lives instead of being acted upon"

- Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000

Benefits of Self-Determination

People with disabilities who have more self determination are more likely to:

- Live independently
- Be employed
- Be integrated into their communities
- Be able to recognize and avoid abuse

- Khemka, Hickson, & Reynolds, 2005; O'Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998

Why Is This Important?

- Estimated number of adults under guardianship has **tripled** since 1995- Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011.
- Why? Perception that people with disabilities cannot "take care of themselves in a manner that society believes is appropriate" - Kapp, 1999

How Did You Get To Self-Determination?

If you're a person without disabilities, how did YOU

- Develop short/long term goals
- Develop financial literacy, budgeting
- Identify opportunities for saving and spending
- Get a job

"Most likely all of these experiences happened with support, either from your family or mentors."

Gustin, 2015

Sad Fact

- **People without disabilities**: "students . . . and families typically navigate with the assistance of a guidance . . . and the parent's personal experience"
- **People with disabilities**: "Figuring out who the different service provider representatives are and what their roles are can take on a life of its own that often overwhelms families, mostly because the different service systems are not always clear on what their roles are or get into territorial role definitions that impact forward progress and planning."

- Gustin, 2015

The Problem: Lack of Coordination

The "fragmented system of services . . . contributing to the failure . . . to prepare [people with disabilities] for the future." - Katsiyannis, deFur, & Conderman, 1998

"Too often, systems serving [people] with disabilities operate in "silos," focused only on what they provide and unaware of what others do. Worse, some providers engage in territorial "battles" that duplicate or cancel out others' efforts." – Gustin & Martinis, 2016 www.ApostropheMagazine.Com

The Goal

- Bring together people with disabilities and the agencies and providers that support them to provide effective, efficient supports and services – Gustin & Martinis, 2015
- Supports and services should coordinate and build on each other, so that there is no ONE agency or program charged with doing EVERYTHING – Martinis & Gustin, 2017
- Financial Planning, then, should be built in to ALL the person's supports and services - Martinis & Harris, 2019

Building Financial Skills At Home

- Start Early
- Encourage children to take responsibility for money and make financial decisions
  - Offer the chance to do extra chores to earn more allowance or opportunities
  - Give choices on how to spend money
  - Build self-determination and decision-making skills and teach children to *expect* to make financial decisions - Martinis, 2014

Building Financial Skills At School

- Create "I Statement" IEP goals focusing on building self-determination and financial skills.
- Instead of a goal saying that the student will improve his or her math skills, consider an I Statement like this one:

  "I will improve my math skills by working with my teacher to create model budgets where I choose what to spend money on and add and subtract money to balance my budget. Each month, I will be able to manage and balance budgets with more money."
- Student must take responsibility and make decisions about *how* the budget looks, *what* he or she is budgeting for, and the *things* to "buy."
- Student must work with his or her teacher to create and manage the budget, the student also practices seeking and using support to make decisions.
- As a result, the student builds math, financial, SDM, and self-determination skills.

Building Financial Skills Transition Planning

- Transition Services must help students as they move toward “post school lives”
- Should include “independent living,” “community participation,” “adult living objectives,” and “daily living skills.”
- Shouldn’t this include financial planning? How can the student truly be a part of the “community” or live independently without them?

Building Financial Skills Transition Planning

- The Youth Transition Project (YTP) focuses on improving students' self-determination and independent living skills including money management – Benz, Lindstrom, & Yovonoff, 2000
- YTP students work with a transition team to help them access services and supports for post-school employment, financial, and other independent living skills.
- After completing the program, 67% of YTP students graduated with a standard high school diploma, much higher than the less than the national graduation rate;
- Two years after graduation, 71% were in competitive jobs much higher than the national average – Wagner, 2003.

Building Financial Skills
Vocational Rehabilitation

Some Services VR provides:

- Assessments;
- Counseling;
- Education and vocational training; and
- "Other goods and services deemed necessary for the individual to achieve an employment outcome"

-34 C.F.R. § 361.48 (2001).

Building Financial Skills Vocational Rehabilitation

VR can provide financial management supports as part of your IPE.

- For example, some need to manage complex medical needs and living expenses to get and hold a job.
- VR can provide “Assessments” to help people learn the help they need
- VR can provide “education and training” to help people budget their money to meet their expenses so they can keep working
- VR can provide “benefits counseling” to help people stay on track and not put their Medicaid/SSI/SSDI at risk

Building Financial Skills
Person Centered Planning

- Person Centered Plans should include supports and services related to “community participation, employment, income and savings, health care and wellness, education and others” - https://www.medicaid.gov/medicaid/hcbs/downloads/1915c-fact-sheet.pdf
- Medicaid Waivers and other PCPs can provide counseling and support to help people make financial decisions and manage their money to meet their needs and live as independently as possible.

Managing Money
A Sad Fact

"[P]eople with disabilities cannot have a decent quality of life with limited financial resources and modest government support."

- Forbes Magazine, "Are Tax-Free ABLE Accounts The Right Financial Solution for People with Disabilities," 12/4/14

When You Receive Public Benefits

- To live independently, many people rely on public benefits like Medicaid, SSI, and SSDI
- To qualify for Medicaid/SSI, you generally may not have more than $2,000 of countable assets. Earnings of more than the substantial gainful activity (SGA) level can also affect eligibility for these programs.
- If families provide financial or “in-kind” support, the person may be disqualified or have benefits reduced.

How Can People With Disabilities Save Money

Because of the "means test"

- People with disabilities fear working because if they make too much, they can lose their benefits
- Families are discouraged from supporting for fear of causing the person to lose benefits
- People with disabilities must "spend down" assets they receive or they can lose benefits.
- As a result, people with disabilities often cannot afford housing or must live in dangerous or substandard conditions - "Priced Out in 2008: The Housing Crisis for People with Disabilities," by Technical Assistance Collaboraive, Inc., Consortium for Citizens with Disabilities Housing Task Force."

Enter ABLE

Achieving a

Better

Life

Experience

What It Is

- Like 529 Accounts for Education
- Family, friends can contribute up to $14,000 per year into an ABLE account
- ABLE account money can be withdrawn, tax free, to pay for housing, transportation, healthcare and other expenses
- Money in an ABLE account **does not** affect eligibility for Social Security or Medicaid/Medicare (if there is $102,000 or more in the account, SSI benefits will be suspended, but still receive Medicaid).

Eligibility for ABLE

An ABLE Account can be established for or by any individual with a disability, including:

- An individual eligible for SSI or SSDI due to blindness or disability.
- An individual who WOULD be eligible under disability criteria for SSI/SSDI, even if
  - S/he has not been found eligible
  - S/he WOULD NOT be found eligible due to income.

Establishing Eligibility

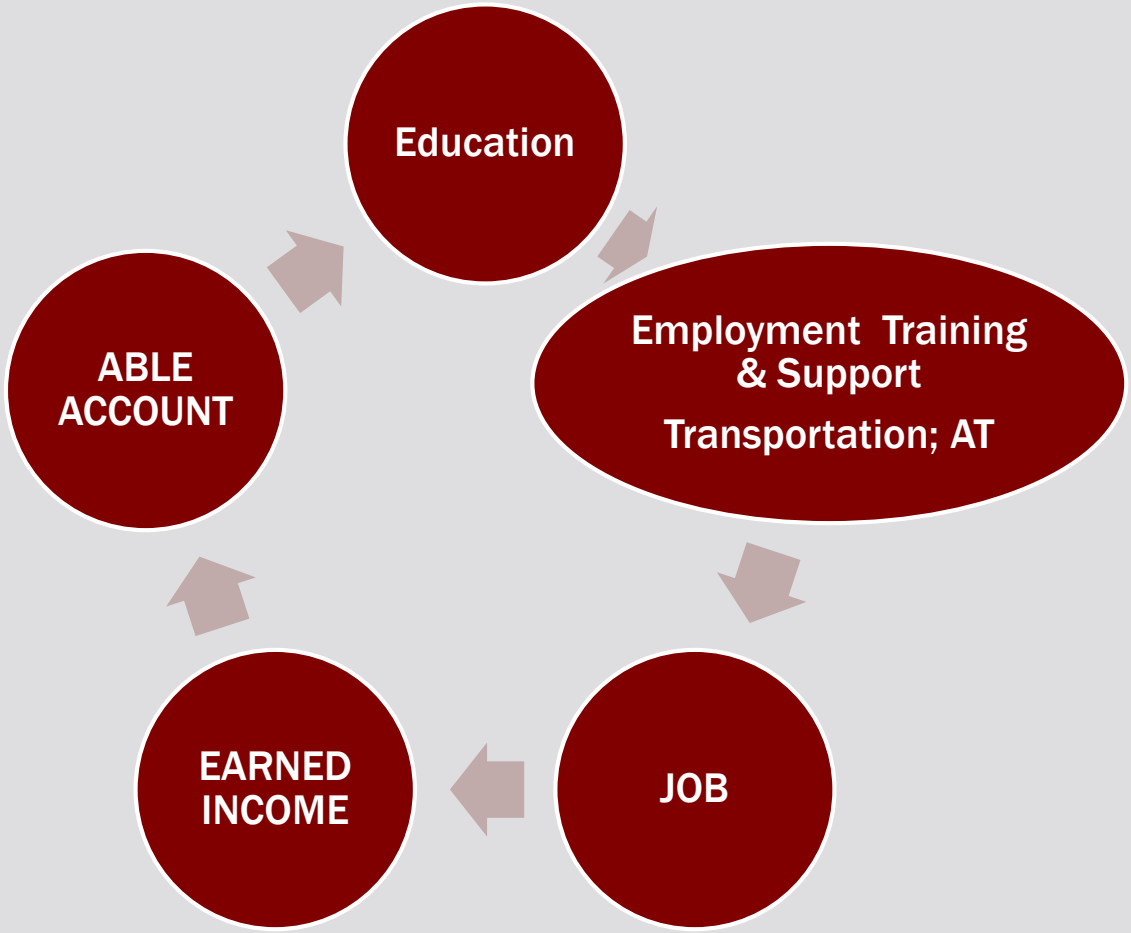
- Is designed to be done by filling out a tax form with a Dr certification saying the person has a disability that would make him or her eligible for SSI or SSDI
- States can set up their own ABLE accounts but you don't have to live in the state to open an account
- For summaries of state ABLE programs, see: www.ableNRC.org

Specifically

ABLE Account funds can be used for:

- **Education**—including tuition for preschool thru post-secondary education, books, supplies, and educational materials related to such education, tutors, and special education services.
- **Housing**—including rent, mortgage payments, home improvements and modifications, maintenance and repairs, real property taxes, and utility charges.
- **Employment Support**—including expenses related to obtaining and maintaining employment, including job-related training, assistive technology, and personal assistance supports.
- **Health**—including premiums for health insurance, medical, vision, and dental expenses, habilitation and rehabilitation services, durable medical equipment, therapy, respite care, long term services and supports, and nutritional management.
- **Transportation**—including the use of mass transit, the purchase or modification of vehicles, and moving expenses.
- **Other Life Necessities**—including clothing, activities which are religious, cultural, or recreational, supplies and equipment for personal care, community-based supports, communication services and devices, adaptive equipment, assistive technology, personal assistance supports, financial management and administrative services, expenses for oversight, monitoring, or advocacy, funeral and burial expenses.

A Path Out of Poverty



The Whole Point

Purpose of the ABLE Act is:

"supporting individuals with disabilities to maintain health, independence, and quality of life."

ABLE Accounts and Self-Determination

In ABLE Accounts, the person with disabilities decides how the money is spent

Doesn't that sound like a job for Supported Decision-Making?

Using SDM with ABLE

- The National ABLE Alliance, made up of 17 ABLE programs, allows people to identify an "Authorized Individual" to receive information about the account and take certain actions
- The "Authorized Individual" can then support the person to make decisions about saving, budgeting, and spending their ABLE Account funds.
- The ABLE programs in the Alliance are Alaska, Arkansas, Colorado, the District of Columbia, Delaware, Illinois, Iowa, Indiana, Kansas, Minnesota, Montana, Nevada, North Carolina, New Jersey, Pennsylvania, and Rhode Island. https://savewithable.com/home.html

Doesn't That Sound Like:

The Student Led IEP?

Informed Choice in VR?

Person Centered Planning?

Managing Money
Spending Authority

I will not buy, sell, manage, or otherwise take or exercise any interest in any tangible property or item costing or worth more than $X without my agent's agreement. For example, if I want to buy or sell a car for $20,000, I would need my agent to agree or the sale could not go through.

In making decisions whether or not to buy, sell, manage, or otherwise take or exercise any interest in any tangible property or item costing or worth more than X, **my agent and I will discuss the situation and give consideration to my express wishes before my agent decides whether or not to agree**.

Managing Money
Banking Authority

I agree that my agent will be listed as a joint account holder on all bank or other financial institution accounts – including checking and savings accounts, as well as credit and debit cards – that I have or open while this power of attorney is in effect.

I agree that I will not withdraw more than $X from any account, write a check for more than $X, or otherwise cause more than $X to be withdrawn from or charged to any account unless my agent agrees.

In making decisions whether or not to agree to write checks, withdraw money from my accounts or charge money to my accounts, my agent and I will discuss the situation and **give consideration to my express wishes before my agent decides whether or not to agree.**

Managing Money
"Growth Clause"

"My agent and I will review this [Power of Attorney/Advanced Directive/Plan] to see if it **should be changed or cancelled at least every _____**. However, unless my agent and I change the power of attorney, I cancel it, my agent resigns, or either I or my agent dies, the [ ] will continue."

Bringing It Together: A Coordinated Support Plan

- **Review**! Go through each area of the individual's financial life.
  - Example: Employment, Savings, Spending, Budgeting, Benefits
- **Brainstorm**! Does the person need support in these areas?
  - If so, talk about what support could help, who could provide it, and how
- **Write**! As you develop support solutions, create a written plan for the person and team to use
- **Attach**! Include it as part of the person's IEP, ISP, IPE, and other plans

Making It Happen
Steps in Supported Decision-Making

Listen and Think

- Supported Decision-Making should always be based on the person's strengths, needs, and interests.
- Start by encouraging the person to think about decisions he or she makes now and those the person needs help to make.
- RESOURCE: When Do I Want Support: https://www.aclu.org/other/when-do-i-want-support

Making it Happen
Steps in Supported Decision-Making

Identify Opportunities and Challenges

- Explore the types of support the person wants to use.
- Talk about the support he or she uses now. If one way of supporting the person works wells, think about trying it for other life areas.
- If you're not sure what to try, brainstorm about ways to give and get support
- RESOURCE: The "Supported Decision-Making Brainstorming Guide:" http://supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf

Making It Happen: Steps in Supported Decision-Making

Find Supporters

- Connect with the people, professionals, agencies, and organizations that can provide the support the person wants.
- Consider support from programs like Special Education, Vocational Rehabilitation, Medicaid Waiver, Centers for Independent Living.

Making It Happen
Steps in Supported Decision-Making

Coordinate Support

- Work with the person, supporters, professionals, and agencies to develop a Supported Decision-Making plan laying out who will support the person and how the person will use that support.
- RESOURCE: "Setting the Wheels in Motion": http://supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf

Making It Happen: Steps in Supported Decision-Making

Put it in Writing

- Not Just a "Supported Decision-Making Agreement," whether or not that is required by state law
- All plans – IEP, ISP, IPE, etc – should indicate the support the person uses, who will provide it, when, and how

Join the Conversation

National Resource Center for Supported Decision-Making: SupportedDecisionMaking.Org

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