The Next Generation of Freedom and Self-Determination: Moving Support Decision-Making from Theory to Practice

Supported Decision-Making and the ABLE Act, "Achieving Better Life Experience"

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TRULY Achieving A Better Life Experience: Supported Decision-Making and the ABLE Act

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FIRST PRINCIPAL

What's Your Favorite Right?

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RIGHTS=CHOICE

"I am my choices. I cannot not choose. If I do not choose, that is still a choice. If faced with inevitable circumstances, we still choose *how we are* in those circumstances."
- Jean Paul Sartre

"We were not promised ease. The purpose of life . . . is not ease. It is to choose, and to act upon the choice. In that task, we are not measured by outcomes. We are measured only by daring and effort and resolve."
- Stephen R. Donaldson

CHOICE=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, p. 440).

BENEFITS OF SELF-DETERMINATION

People with greater self determination are:

- More independent
- More integrated into their communities
- Healthier
- Better able to recognize and resist abuse

(Khemka, Hickson, & Reynolds, 2005; Wehmeyer, Kelchner, & Reynolds, 1996; Wehmeyer & Schwartz, 1998).

Think About It

- What REALLY integrates us into our communities?
- How do we REALLY interact with our friends, neighbors, and neighborhoods?

REALLY Think About It

True community integration means being integrated into all facets of the community, INCLUDING the financial sphere.

It's NOT just where you live

It's HOW you live

And Yet

"[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

ENTER ABLE

- Like 529 Accounts for Education
- Allows for creation of ABLE Account where money can be withdrawn, tax free, to pay for expenses like housing, transportation, healthcare
- Amount in account does affect eligibility for Social Security or Medicaid/Medicare

QUESTION-ABLE

Who Decides How The Money Is Spent?

THE WHOLE POINT

Purpose of the ABLE Act is:

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

Making it Achieve-ABLE

If Increased Self-Determination=Improved Health, Increased Independence, and Better Quality of Life . . .

Shouldn't ABLE Accounts Increase Self-Determination?

And Yet: 2,000 Years and Counting

- **Ancient Rome**: "Curators" appointed for older adults and people with disabilities.
- **5th Century Visigothic Code**: "people insane from infancy or in need from any age . . . cannot testify or enter into a contract"
- **Feudal Britain**: divided people with decision-making challenges into "idiots" and "lunatics" and appointed "committees" to make their decisions

Guardianship In The US

"Plenary" or "Full" Guardianship

- Gives the Guardian power to make ALL decisions for the person.
- Used in the VAST majority of cases

"As long as the law permits plenary guardianship, courts will prefer to use it." (Frolik, 1998)

Studies

- More than 90% of guardianships reviewed were plenary (Teaster, Wood, Lawrence, & Schmidt, 2007).
- 87% of guardianships reviewed were plenary (Lisi, Burns, & Lussenden, 1994).
- 54% of the cases reviewed resulted in plenary guardianship but almost no difference between "plenary" and "limited" guardianship (Millar & Renzaglia, 2002).

The Problem

"**The typical ward has fewer rights than the typical convicted felon** . . . . By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen."

(House Select Committee on Aging, H.R. Rpt. 100-641 (opening statement of Chairman Claude Pepper))

More Studies

People under guardianship can experience "**significant negative impact** on their physical and mental health, longevity, ability to function, and reports of subjective well-being"

(Wright, 2010, p. 354)

Think About It

In a Special Needs Trust:

Who Decides How The Money is Spent?

Making ABLE…Able

Supported Decision-Making:

"People with disabilities use friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions without the "need" for a guardian."

(Blanck & Martinis, 2015).

That's A Lot Of Words For

Getting help when its needed

Just like you and me

It's Value-ABLE

"Supported Decision-Making has the potential to increase the self-determination of older adults and people with disabilities, encouraging and empowering them to reap the benefits from increased life control, independence, employment, and community integration" (Blanck & Martinis, 2015)

It's A Paradigm, Not A Process

There is no "one size fits all" method of Supported Decision-Making.

Can include, as needed and appropriate:

- Informal support
- Interpretation based on knowledge of person
- Written agreements, like Powers of Attorney, identifying the support needed and who will give it
- Formal Micro-Boards and Circles of Support

Just One Example

Power of Attorney giving agent decision-making authority **but requiring Supported Decision-Making:**

"It is my and my agent's intent that we will work together to implement this Power of Attorney. That means that I should retain as much control over my life and make my own decisions, with my agents support, to the maximum of my abilities. I am giving my agent the power to make certain decisions on my behalf, but my agent agrees to give primary consideration to my express wishes in the way she makes those decisions."

Financial 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."

Making it Access-ABLE

- The "Student Led" IEP
- "Informed Choice" in Vocational Rehabilitation
- "Person Centered Planning" in ISPs

ARE ALL SUPPORTED DECISION-MAKING. ALL CAN PROVIDE FINANCIAL SELF-DETERMINATION SKILLS AND TRAINING!

The Goal is Reach-ABLE

Every person the "causal agent" in his or her life, TRULY a part of his or her community!

- We all need help making decisions
- People with disabilities may need more or different help but have the SAME rights

Join the Conversation

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

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About this Project

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More Information and Contact

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Supported Decision Making and the ABLE Act

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June 17, 2015

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Personal Introduction to the ABLE Act

- Disinherited our youngest son as a newborn
- Set him up for a life of poverty so that he can receive benefits as an adult
- Attended first NDSS Capitol Hill Day and learned about ABLE
- Fortunate enough to witness the historic House vote after 5 years of advocating
- Learned that our system of supports and services for individuals with disabilities is deeply flawed

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Confusing Messages from SSI

- Must declare inability to work in order to be deemed eligible for SSI
- SSI is the gateway to Medicaid
- BUT, Medicaid provides employment support through LTSS
- Artificially low asset and income limitations, leaving beneficiaries consigned to poverty
- System incentivizes and discourages work at the same time

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ABLE and Asset and Income Limitations

- Effectively raises the SSI asset limitation to $100k
- Does not address state income limitations
- Encourages work and savings by allowing income to be deposited into ABLE accounts up to $14k per year
- Amounts to a work and economic self-sufficiency incentive

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Myths of ABLE and Supported Decision-Making

- "But my adult child doesn't understand money"
- "My loved one will lose benefits if he has too much income"
- "She needs a trustee to make financial decisions for her"
- "His assets will count against him in determining eligibility for benefits"
- "She is vulnerable to scam artists so she nee guardianship"

The majority of people with intellectual and/or developmental disabilities can manage their own affairs with informal assistance and guidance from family, friends, and others.

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Alternatives to Guardianship

- Power of Attorney
- Durable Power of Attorney
- Management of Community Property
- Money Management
- Social Security Representative Payment Program
- Trusts

Individuals may communicate wishes, decisions, like and dislikes in nontraditional ways which can include actions rather than language. Friends, family member or others who are trusted by the individual, can help to interpret those decisions.

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QUESTIONS?

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The Able Act: A New Path to Self-Determination

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JUNE 17, 2015

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ABLE Account: Beyond Supplemental Needs Trusts

- Trusts allow individuals with disabilities or families to set aside funds for an individual with a disability without impacting eligibility for Medicaid.
- Not all people can afford the cost of setting up and maintaining a Supplemental Needs Trust.
- Do not allow for purchase of anything that Medicaid paid for (hence "supplemental")
- Limited utility for those who really need more of what Medicaid pays for.

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What ABLE Can Pay For

A "qualified disability expense" means any expense related to the designated beneficiary as a result of living a life with disabilities.

Expenses for **education**; housing; **transportation; employment training and support; assistive technology** and **personal support services**; health, prevention, and wellness; financial management and administrative services; legal fees; expenses for oversight and monitoring; funeral and burial expenses.

Other expenses as defined in the regulations.

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Access to Medicaid Preserved

ABLE accounts are disregarded for the purposes of determining if a person meets the asset limit for Medicaid.

Having an ABLE Account does not impact Medicaid eligibility.

- ABLE account intended to supplement – not supplant- Medicaid benefits.

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Use ABLE when Medicaid says..

- That's not medically necessary
- That's not the most cost-effective way to meet your need
- You only need this much service to meet your assessed need
- You don't meet the eligibility criteria for that service or support

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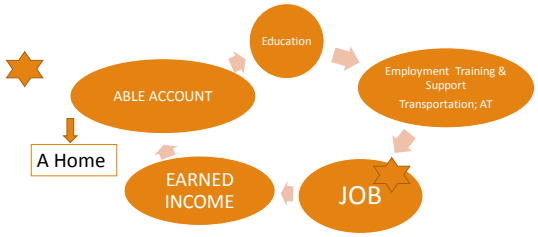
Path Out of Poverty



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Self-Directed Supports Under Medicaid Waiver

- Community Support Services (alternative to institution/nursing home)
- Individualized Budgets – capitated funding model
- Can more easily choose the services you need and choose/hire your own provider
  - Can choose any service available under the program – if can show the service will help you meet an assessed need and/or achieve an outcome in your plan.
  - More flexibility in who can be a provider of Medicaid funded services
  - Use of a fiscal intermediary who acts as co-employer of record, handles administrative tasks related to hiring your own support staff
- Can decide how much to pay for service to varying degrees (safeguards in place; state rates sometime dictated; limits/prohibition against paying for outcomes)

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Self-Directed Supports Under Medicaid Waiver

- **Still only have the resources Medicaid would otherwise allocate to you.**
- Includes a principle of "responsibility" to contribute (i.e. work) but this is often not emphasized in favor of the emphasis on choice and control. ***Rewards and incentives for working still lacking.***
- Largely has meant if a person has a legal guardian, the guardian is in control of the budget.
- True self-determination means we utilize **supported** (not substitute) decision-making.

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ABLE as Extension of Supported Decision-Making & Self-Determination

- People with individual budgets under Medicaid waivers often have a support broker to assist them with making a plan for how they will use their budget to meet their needs and achieve their goals.
- Support brokers are not case managers (not gatekeepers of resources)
- The funds have been allocated to the person – the focus is on how to best use them.
- ABLE Account is very similar.

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ABLE as Extension of Supported Decision-Making & Self-Determination

- Support Broker can help person **braid** ABLE resources with a Medicaid Individual Service Plan that is funded by an Individualized Budget. ABLE can help when a plan or budget is limited because:
- Something is deemed "not medically necessary" (can't spend I-budget on that)
- Your I-budget won't buy as much of a service as you really need
- The I-budget can't be used for that expense (not covered under Medicaid waiver)

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Combining Individual Budget under Medicaid Waiver and ABLE Account

- Support Brokers is critical assistant
- Trusted family, trusted friends, circle of support also critical
- A financial advisor is also important – for planning contributions to and withdraws from an ABLE account over time
- Remember, the goal in life is not to have to buy all of the support we need!

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Questions or Comments?

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Questions for Discussion

1. Financial decision-making is a set of knowledge and skills that should be learned based on education and experience over the course of life (child – adults – older adult). Should these skills be part of IEPs, IPEs, and individual support plans?
2. As a parent, what could be done to advance financial decision-making skills?
3. The beneficiary is the ABLE account owner. Some families are concerned their son or daughter does not have the skill or experience to manage the account. What options for support do you suggest as alternatives to guardianship?
4. How would you recommend states support the development of skills to be an account owner?
5. From a legal perspective, what are ways to formalize supported decision-making for an ABLE account owner?
6. Can you envision an individual having an ABLE account and a Special Needs Trust? If so, why and how would an individual utilize a Trust versus an ABLE account?

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