Promises Made, Goals Unmet

Federal law says what millions of people with disabilities already know: they face severe disadvantages and barriers to working, saving money, getting an education, and being active members of their communities. Even though the same laws say that physical and mental disabilities “in no way diminish” their right to be full and equal members of society, people with disabilities “continually encounter various forms of discrimination,” including:

- Outright intentional exclusion;
- Overprotective rules and policies;
- Exclusionary qualification standards and criteria; and
- Lesser services, programs, activities, benefits, jobs, or other opportunities.

On July 26, 1990, President George H.W. Bush signed the American with Disabilities Act (ADA) saying, “Let the shameful wall of exclusion finally come tumbling down.” Yet, almost 30 years later, millions of people with disabilities still struggle against obstacles that

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prevent them from achieving the “equality of opportunity, full participation, independent living, and economic self-sufficiency” promised by the ADA, including:

- **Unemployment.** People with disabilities are more than twice as likely to be unemployed as those without disabilities;  

- **Underemployment.** People with disabilities earn approximately $10,000 less per year than those without disabilities;  

- **Poverty.** People with disabilities are more than twice as likely to live in poverty than those without disabilities; and  

- **Loss of Rights and Opportunities.** People with disabilities are often ordered into guardianship and lose their rights to make financial and life decisions.  

These problems can be even worse for people with disabilities who receive public benefits such as Social Security Disability Insurance (SSDI), Supplemental Security Insurance (SSI), Medicare and Medicaid. Due to federal rules limiting how much money they can have, people with disabilities are often afraid to work (or work to their full potential) because they could lose the health care, financial, food, and housing supports they need. As a result, people

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9 StatsRRTC, 2014.
receiving public benefits do not have the same opportunities to earn, save and spend money, socialize, or participate in the community as people without disabilities.

This paper discusses ways people with disabilities may take more control over their finances and lives by opening and managing an ABLE Account. In so doing, they may also develop the skills and receive the supports they need to achieve the independence, community participation, and quality of life promised by the ADA.

**Equal Rights, Equal Expectations, and Self-Determination**

The ADA was a life-changing event for people with disabilities. Two centuries after the Declaration of Independence said that all people are created equal and decades after women and people of color were guaranteed equal protection under the law, people with disabilities finally had the same legal rights as everyone else. For the first time, over 40,000,000 American citizens could expect to take part in “the Nation’s proper goals” including “full participation, independent living, and economic self-sufficiency.”

In 1999, the U.S. Supreme Court ruled that the ADA guarantees people with disabilities the right to live, work, and socialize in their communities. In the famous *Olmstead* case, the Court said “institutional placement of persons who can handle and benefit from community settings” prevents people with disabilities from taking part in “everyday life activities.” For example, before *Olmstead*, millions of people with disabilities had to give up their freedom and

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14 *Olmstead*, 527 U.S. at 601.
live in institutions to receive health care, “while persons without mental disabilities can receive the medical services they need without similar sacrifice.”

Put simply, before the ADA and *Olmstead*, people with disabilities did not have the same rights to lead the same type of lives as people without disabilities. Afterward, millions of people could choose where they live and work, who they spend time with, and what they do. This “Right to Make Choices” – which most people without disabilities take for granted – is known as *self-determination*.

When people are *self-determined*, they are their own “causal agents:” they make the decisions and take actions that shape their lives. Decades of studies have shown that people with disabilities who are more self-determined are more likely to be employed, independent, safer, and participate in community activities. In other words, self-determination is a key to people with disabilities achieving the “full participation, independent living, and economic self-sufficiency” promised and protected by the ADA and *Olmstead*.

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15 *Olmstead*, 527 U.S. at 601.
16 *e.g.*, Blanck & Martinis, 2015.
A Sad Irony

In the wake of the ADA and Olmstead, more and more people with disabilities began looking for and taking part in opportunities to work and participate in their communities.19 Millions of people with disabilities now use financial and medical support programs like SSDI, SSI, Medicare and Medicaid to live independently to the maximum of their capabilities.20 These public benefits help people with disabilities receive the medical care and other supports and services they need without giving up the “participation in community life they could enjoy.”21

Unfortunately, many public benefits come with a sad irony: the same services that can help people with disabilities live in the community may also prevent them from being full and equal members of their communities. People receiving means-tested public benefits like SSI, Medicaid, food stamps, and others generally cannot have more than $2,000 in money and other resources such as bonds and insurance policies. Many people misunderstand Social Security Administration rules and fear that they could lose the benefits they need to live in the community if they go over the “$2,000 cliff.” 22 As a result, far too many people with disabilities do not work at all, earn as much as they could, save money,23 or take part in activities the Olmstead Court

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21 *Olmstead, 527 U.S.* at 601.

22 For information about Social Security Administration rules, eligibility, and work, see [www.choosework.ssa.gov](http://www.choosework.ssa.gov)

23 Morris, Rodriguez, & Blanck, 2016.
identified as important parts of community life, including “social contacts . . . economic independence, educational advancement, and cultural enrichment.”

**The ABLE Act: A Pathway to Participation**

In 2014, Congress passed, and President Obama signed, the Achieving a Better Life Experience (ABLE) Act. ABLE helps people with disabilities “have a decent quality of life” by empowering them to earn, save, and spend money while keeping the public benefits they need. When people with disabilities are eligible for the ABLE program, they may open ABLE Accounts. They, or anyone on their behalf, may deposit up to $15,000 per year into their Account and continue to receive their benefits. ABLE Accounts grow tax-free and people can have up to $500,000 in their Accounts. However, if people receive SSI and have more than $101,999 in their Accounts, their SSI benefits will be suspended until their balance falls below that amount. Even then, they will continue to receive Medicaid benefits as long as they are otherwise eligible for Medicaid.

People with disabilities are eligible for the ABLE program if their disabilities began before they turned 26 and they receive SSI or SSDI. People whose disabilities began before they turned 26, but who do not receive SSI or SSDI, may still be eligible for the ABLE program if they meet other criteria established by the Social Security Administration. The ABLE National

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24 *Olmstead*, 527 U.S. at 601.


26 Account limits vary by state. See, [www.ablenrc.org](http://www.ablenrc.org) for information on state ABLE programs.


Resource Center provides information and resources to help people explore whether they are or could be eligible for the ABLE program.²⁹

People may withdraw money from their ABLE Accounts to pay for many “qualified disability expenses,” including:

- Housing;
- Medical care and support;
- Employment training and support;
- Transportation;
- Education;
- Community and recreation programs, activities, and experiences;
- Personal support services;
- Assistive technology;
- Health and wellness;
- Financial management and services;
- Funeral and burial expenses; and
- Other “basic living expenses.”³⁰

In that way, ABLE Accounts can give people with disabilities a “pathway to participation” in their communities by helping them work, take part in community activities, and have a higher quality of life. Consider this scenario: a person who receives SSI and Medicaid never worked because she was afraid of losing her benefits. She opens an ABLE Account, gets a job that she would not have gotten before, and puts her salary into her Account. As long as her

²⁹ See, www.ablenrc.org
³⁰ Morris, Rodriguez, & Blanck, 2016.
countable income does not exceed the limits set by the Social Security Administration, she will continue to receive her SSI benefits.\textsuperscript{31} She then uses some of the money in her ABLE Account to pay for transportation, living expenses, and community activities, which she could not have afforded before, while continuing to receive the financial and health benefits she needs. She also uses money in the Account to pay for job training, which helps her get a promotion and earn more money. She continues to put her salary into her Account and withdraws money to have more community experiences and get more job training, while continuing to receive public benefits. She may then repeat this cycle, advancing in employment and improving her quality of life, with the hope of getting better and higher paying jobs that provide health care and retirement benefits.\textsuperscript{32}

This is just one example showing the potential impact and uses of an ABLE Account. The ABLE National Resource Center provides information and resources that can help people with disabilities explore ways to use ABLE accounts, including best practices and real-world examples of people who used ABLE Accounts to maximize their opportunities and independence.\textsuperscript{33}

**ABLE Accounts and Supported Decision-Making: Developing Self-Determination**

ABLE Accounts also give people with disabilities the opportunity to make their own financial and life decisions. A person with an ABLE Account has the legal right and responsibility to manage it. Put another way, unless the person is under guardianship, he or she

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\textsuperscript{31} For information about income limits and opportunities to use work incentives to offset income, see, \url{www.choosework.ssa.gov}.


\textsuperscript{33} See, \url{www.ablenrc.org}
decides when to deposit and withdraw money from the Account and how to spend it. These decisions – how much to save, what to spend money on, and what activities to take part in – are essential to the “community life” promised and protected by the ADA and *Olmstead.*

When people make these types of life decisions, they have more control over their lives and more self-determination. When people with disabilities are more self-determined, they are more likely to be employed, independent, and active in their communities. Therefore, owning and managing an ABLE Account can have a positive impact on a person with disabilities’ quality of life.

Parents and professionals may be concerned about a person with disabilities making financial and other life decisions. They may believe that the person does not have the knowledge or skills to “create and manage a budget, set and manage savings goals, and track disbursements” without their input and assistance. Others may feel pressure to seek guardianship and assume the authority to make all financial and other decisions for the person.

However, ABLE Accounts not only give people with disabilities the right to make decisions about budgets, deposits, and withdrawals, they also give them the opportunity to seek and use the help they need to do so. Therefore, parents and professionals may help people with disabilities learn about, make, and carry out informed decisions about their ABLE Accounts –

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34 Morris, Rodriguez, & Blanck, 2016.
35 *Olmstead,* 527 U.S. at 600-601.
37 *e.g.,* Blanck & Martinis, 2015.
38 Morris, Rodriguez, & Blanck, 2016, p. 27.
just like they receive help managing their budgets and lives. Every day, people with and without disabilities ask for and receive advice and assistance from friends, family members, and professionals to help them make budgeting, saving, spending, and other life decisions. This process is known as Supported Decision-Making (SDM).

While there is no “one-size-fits-all” model of SDM, it generally occurs when people work with people they trust, who help them understand the situations and choices they face, so they can make their own decisions. In that way, SDM mirrors “what happens for most adults when they make decisions such as whether to get car repairs, sign legal documents, and consent to medical procedures: they seek advice, input, and information from friends, family, or professionals who are knowledgeable about those issues, so they can make their own well-informed choices.”

“Many, if not most,” people with disabilities can use SDM to:

- Understand the issues and their possible choices;
- Consider their options and choose the ones they want;
- Ensure that their decisions are based on their personal preferences and values; and
- Communicate their decisions to others and advocate for their decisions to be honored.

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40 e.g. Blanck & Martinis, 2015.
43 e.g. Dinerstein, R. (2012). Implementing legal capacity under article 12 of the UN convention on the rights of persons with disabilities: The difficult road from guardianship to supported decision-making. Human Rights Brief, 19, 8.
SDM “retains the individual as the primary decision maker, while recognizing that the individual may need some assistance.” For that reason, SDM is recognized by people with disabilities, families, professionals, and many courts and legislatures as a way to empower people to make their own decisions, direct their lives, avoid unnecessary guardianship, and build self-determination. Consequently, using SDM to manage an ABLE Account can help people with disabilities learn and practice the skills they need to achieve “increased life control, independence, employment, and community integration.”

Using ABLE Accounts and Supported Decision-Making: Strategies for Self-Determination

As shown, ABLE Accounts offer people with disabilities opportunities to learn and use SDM. However, the actual practice of SDM will be different for each person because everyone has different abilities, needs, and interests. Therefore, “the most important thing you can do is explore and identify when the person wants support, who the person wants support from, and how the person wants to be supported. Think of it as the Golden Rule of Supported Decision-Making: Support Others the Way they Want to be Supported.”

Consider the person we discussed, above. There are many decisions she must make, including:

- Whether, and what type, of ABLE Account to open;

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46 Blanck & Martinis, 2015.
▪ How to manage her work, income, savings, and spending to ensure that she continues to receive the SSI and Medicaid benefits she needs;
▪ How much money she should put into her ABLE Account;
▪ When and how much she should withdraw from her ABLE Account;
▪ The job training to take and pay for with her ABLE Account funds;
▪ How much she should budget each month for living expenses and other necessities from her ABLE Account; and
▪ Whether and what kind of community, recreational, and other experiences she should take part in using ABLE Account funds.

While these decisions involve her ABLE Account, they go far beyond “just” financial matters. She must consider and make choices that go to the heart of the independent living experience, encompassing “social contacts, work options, economic independence, educational advancement, and cultural enrichment.” Using SDM, she can work with the friends, family members, and professionals in her life to identify and weigh her options, and choose the ones that are best for her. At the same time, she will be learning and practicing the skills she needs to “(A) make informed choices and decisions; and (B) achieve equality of opportunity, full inclusion and integration in society, employment, independent living, and economic and social self-sufficiency” to the maximum of her capabilities.

48 *Olmstead*, 527 U.S. at 601.
While no two people will use SDM in the exact same way, there are many tools and guides that can help people with disabilities explore and identify the life areas and decisions where they want support, the people they want support from, and the types of support they want.

- The Missouri Stoplight Tool\(^{50}\) and When do I Want Support?\(^{51}\) can help people with disabilities identify the life areas and decisions where they want support;
- The Supported Decision-Making Brainstorming Guide\(^{52}\) can help people with disabilities explore and identify the types of support they want to use;
- Supported Decision-Making Teams: Setting the Wheels in Motion\(^{53}\) has practical tips and worksheets to help people with disabilities identify areas of support, potential supporters, and ways they can work together.
- The National Resource Center for Supported Decision-Making\(^{54}\) provides educational materials, resources, and model forms that can help people with disabilities, their families, and supporters learn about SDM and create


\(^{54}\) National Resource Center for Supported Decision-Making, www.supporteddecisionmaking.org
individualized SDM plans, agreements, Powers of Attorney, and Advanced Directives.\textsuperscript{55}

**Case Study: The National ABLE Alliance Model**

It is important to remember that there is no “one and only way” to use SDM, for ABLE Account decisions or anything else. At its heart, SDM is about sharing information between a person with disabilities, his or her supporters, and others as needed to help the person understand, consider, and make decisions. This can include:

- People with disabilities sharing information about their financial and other goals and needs while a supporter gives them information on state ABLE programs that may best suit them;
- People with disabilities completing an ABLE Account application while their supporters help them understand the process and consider investment options;
- People with disabilities sharing information about their monthly bills while their supporters give them information about how they may use their ABLE Accounts to create and balance their monthly budgets;
- People with disabilities sharing information about their work goals while their supporters give them information about available job training programs so they can make a plan to save and budget money in their ABLE Accounts to pay for the ones they want; and

\textsuperscript{55} \url{http://supporteddecisionmaking.org/content/resource-library}
People with disabilities sharing information about community activities they are interested in while their supporters give them information on available opportunities so they can budget money in their ABLE Accounts to pay for them.

All of these decisions require 3 things: (1) information from the person with disabilities about his or her goals, needs, and interests; (2) information from the person’s supporters about his or her options; and (3) information from the person’s ABLE Account about available funds and ways to save or allocate the funds needed to achieve the person’s goals and meet his or her needs. The person may then use SDM to consider this information and make decisions.

While people can use SDM to manage their ABLE Accounts across the country, this case study uses the example of the National ABLE Alliance, which is made up of 17 ABLE programs, to demonstrate how SDM and ABLE Accounts can work together. Under its model, people with disabilities may identify and share information with supporters to help them make decisions about saving, budgeting, and spending their ABLE Account funds. Because the ABLE Act allows people to open an ABLE Account from any state program that accepts outside residents into its program, people do not have to live in an Alliance state to open an ABLE Account from an Alliance state.

The 17 Alliance programs have set up a system where people with disabilities can name an “Authorized Individual” to receive information about their Accounts or take certain actions regarding their Accounts. The information that an Authorized Individual can receive, and actions

he or she may take, depend on the “level” of access granted by the person with disabilities. There are 4 levels of access a person with disabilities can give:

- Level 1 allows the Authorized Individual to request and receive information about the Account and receive duplicate Account statements;
- Level 2 allows the Authorized Individual to have Level 1 access, contribute money to the Account, and move Account money among Investment Options;
- Level 3 allows the Authorized Individual to have Level 1 and 2 access and withdraw money from the Account;
- Level 4 allows the Authorized Individual to have Level 1, 2, and 3 access, transfer Account ownership of the account to a member of the person with a disabilities’ family, and close the Account if necessary.58

The different levels recognize that people with disabilities have different abilities, needs, and interests: some may only want minimal support while others want friends, family members, and professionals to help them in several ways. By working with their Authorized Individuals and choosing their levels of access, people with disabilities can give and get the information they need to make decisions about their ABLE Accounts and life activities.

Consider, again, the person we discussed earlier. She must make decisions about work, education, and community activities. She also must budget her ABLE Account funds to make sure she can take part in those activities while also having money to pay for her living expenses. If she opens her ABLE Account with one of the 17 Alliance programs, she can choose one or

more Authorized Individuals to support her and the way they will provide that support. For example:

- If she gives her supporter Level 1 access, he or she would have access to her Account information, including how much money is in the Account. She could then work with her supporter to identify activities and programs she is interested in and create a budget so she can afford them. The supporter could also monitor the Account and work with her so she can reach her financial and life goals.

- If she gives her supporter Level 2 access, he or she will be able to receive information about her Account and contribute to it. She could then work with her supporter to identify and save toward a specific goal. The supporter would be able to help her create and save toward a budget and monitor her progress.

- If she gives her supporter Level 3 access, he or she will be able to receive information about the Account, contribute to it, and withdraw from it. She could then work with her supporter to identify programs and activities she is interested in. The supporter would be able to help her make a budget and save money toward her goals, while monitoring the Account and adding to it as needed. Once the necessary funds are available, the supporter could withdraw money and pay any necessary fees on her behalf.

- If she gives her supporter Level 4 access, he or she will be able to share and receive information and provide support on all budgeting, saving, spending, and Account management issues. The supporter could then help her manage the Account, including setting saving and spending goals or limits, monitoring
progress, contributing or withdrawing money, and identifying other potential supporters and Account managers.

The National Alliance’s “level system” empowers people with disabilities to customize the support they receive to their abilities, needs, and interests. They can then use SDM with their chosen supporters, in their chosen ways, to understand, make, and communicate financial and life decisions as they work toward their goals for “increased life control, independence, employment, and community integration.”

Conclusion

For people with disabilities, it can be a long and hard road from “lesser services, programs, activities, benefits, jobs, or other opportunities” to “equality of opportunity, full participation, independent living, and economic self-sufficiency.” ABLE Accounts, used in tandem with SDM, can empower people with disabilities to make their own financial and life decisions, earn, save, and spend money while keeping their public benefits, and, at long last, achieve the independence, inclusion, and “decent quality of life” promised by the ADA and Olmstead. 

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59 Blanck & Martinis, 2015.  
60 42 U.S.C. § 12101(a)(5).  