

## The Employment Journey: A Focus on Informed Choice

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**STUDY OVERVIEW:** This study provides an in-depth analysis on the concept of informed choice and how making informed choices can contribute to improved employment outcomes. This study will explore the legal and policy context for fostering informed choice for all individuals, and the impacts of systemic initiatives furthering meaningful informed choice.

### Introduction

In concert with the Institute for Community Inclusion (ICI) at UMass Boston, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) identified potential topical areas for policy white papers that influence employment outcomes and services for individuals served by state intellectual and developmental disability (I/DD) agencies. This is the fourth white paper in a series of five papers.

To determine priority areas for the white papers, ICI and NASDDDS convened discussions with advisory team members and self-advocates, identifying potential topics aligned with the high-performing states model for increasing employment. The high-performing states model draws from extensive research in states that achieve measurable success with systems change initiatives. The seven key elements that are essential to improving and achieving employment success and that guide the structure of the model are 1) Leadership, 2) Strategic Goals and Operating Policies, 3) Financing and Contracting Methods, 4) Training and Technical Assistance, 5) Interagency Collaboration, 6) Services and Service Innovation, and 7) Employment Performance Measurement and Outcome Data.

The first white paper addressed what was being learned from the implementation of the Centers for Medicare & Medicaid Services (CMS) 2011 guidance on prevocational services and employment. The second paper addressed “Support Coordination: Strategies that Impact Employment Outcomes and Services for Individuals Served by State Intellectual/Developmental Disability Agencies.” The third paper reviewed multi-system collaboration to support employment and community engagement outcomes during different transformative life stages of individuals with I/DD.

This paper highlights the leadership and values elements of the framework through exploration of how states can build a foundation for informed choice. It also explores the history and legalities that surround the concept of supported decision-making as one tool to support informed choice, and how, when exercised, both of these concepts can lead to a more self-determined, higher-quality life for people with I/DD.

Figure 1: High-Performing States Framework



## What is informed choice and supported decision-making (SDM)?

Informed choice starts with the assumption that all people have the right to make choices and decisions about their lives. This is a founding principle in society that is critical for the independence and happiness of all people. In its purest sense, informed choice means having the decision-making authority to make a voluntary, well-considered decision that is based on options, information, and understanding. The person making the informed choice is in the driver's seat during the decision-making process and is free to make a decision about whether or not they wish to accept the options and considerations that have been put forth. Being afforded the ability to make an informed choice leaves a person feeling empowered, independent, and in control. Making choices in our daily lives provides us all with a sense of value, and more importantly, it is a right that no one should lose on the basis of a disability.

**It is important to involve people in decisions even when they do not use speech as their main means of communication. Person-centered planning techniques assist us in listening to people in different ways other than only relying on the human voice.**

State I/DD agencies seek to maximize the independence of the people they support. This means empowering individuals to make choices, and increasing their self-determination and independence so that they can enjoy the full protection of their rights. To accomplish these goals, state agencies have been focusing on an approach to policy and training that puts the person at the center of all discussions. In addition, many states seek to support maximum opportunities for self-direction. When individuals with I/DD need assistance or support, states also seek to ensure that the individual's best interests are the forefront of all decisions made on their behalf.<sup>1</sup> In these instances, a variety of legally recognized tools may formally support an individual in decision-making.

One such tool is supported decision-making (SDM). Texas was the first state to recognize SDM as a substitute for guardianship in 2015. SDM enables people with disabilities to ask for support from people they know and trust, as we all do on a daily basis. Just like people without disabilities, people with I/DD have the right to receive assistance from one or more trusted friends, family members, professionals, or advocates to help them understand the situations they face and the choices and options they have, so they can make their own decisions.

SDM can be purely informal (something done without legal sanction), or it can be done with legal enforceability between the person with I/DD and a trusted third party. Such formalized SDM relationships may be pre-existing relationships to which the state gives legal recognition, or they may be new relationships created for the purpose of providing state-sanctioned support.<sup>2</sup>

Research demonstrates that self-determination and the right to make choices are key elements for a meaningful and independent life.<sup>3</sup> SDM, as a strategy to support and enhance informed choice, has been shown to increase self-determination in individuals with disabilities. SDM leads to higher employment at increased wages and greater community integration, as well as increased health, welfare, and safety.<sup>4</sup>

**Gathering advice and input from trusted allies is part of what we do on a daily basis to support our decision making. We all use people around us, available information, and other forms of support to make big and small decisions. Some people use a significant amount of support and others use less, based on our needs, preferences, and the types of decisions at hand.**

**This process mirrors what happens for most adults when they make decisions such as whether to get car repairs, sign legal documents, or 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. (Terrill, Campanella, & Melda, 2014).**

<sup>1</sup> Retrieved from [www.in-control.org.uk/](http://www.in-control.org.uk/)

<sup>2</sup> Kohn, N. A., Blumenthal, J. A., & Campbell, A. T. (2012). Supported Decision-Making: A Viable Alternative to Guardianship?

<sup>3</sup> Blanck, P., & Martinis, J. (2015). The Right to Make Choices: The National Resource Center for Supported Decision Making.

<sup>4</sup> Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little (in press).

## Informed Choice Starts with Person-Centered Planning

When state systems cultivate informed choice using SDM as a tool, they often use person-centered planning (PCP) to guide that process. PCP is an approach that focuses on the person's strengths and challenges, and keeps the job seeker in the driver's seat and in control of their own decision-making.

PCP supports people at any age to have lives like people without disabilities: lives that provide independence, choice, and informed decision-making, and include goal setting. Everyone should have the freedom to plan a real life, have authority over personal resources, and contribute to their community. For example, most adults without disabilities are employed, join spiritual and/or social groups, and have friends. These opportunities enhance the lives of people with disabilities in the same way.

Linking plan goals with the principles of self-determination becomes paramount in PCP. The components of an effective PCP process and informed choice go hand in hand, and are essential tools for compliance with CMS regulations regarding PCP (42 CFR § 441.725). It all starts with the person being the focal point. They should be empowered to direct the job-search process, and engaged in designing their PCP plan.

States should ensure the efficacy of their PCP processes by offering choices in a manner that the person understands, providing information in plain language and with the use of assistive technology when needed. Supporting people to have varied experiences also can be an essential part of ensuring informed choice. To make a truly informed choice, especially about employment, people need to have varied experiences and information. These experiences should be in different types of work settings and jobs that are based on what is important to that person and on their interests using a person-centered assessment.

A job can mean many things, including a way to earn money and be productive. For most people, a job is also a vehicle for greater access to community participation, personal relationships, and enhanced quality of life. At the core of person-centered career planning is the belief that the job seeker is the primary decision maker about their employment path. A state's policies can help support a stronger job match when those policies ensure that a person's wants, needs, abilities, and dreams are considered in the job development process.

## Intersection of Supported Decision-Making and Self-Determination

The Administration on Intellectual and Developmental Disabilities and the Administration on Aging, two program components of the Administration for Community Living (ACL), jointly awarded a cooperative agreement to the Quality Trust for Individuals with Disabilities to build a national training, technical assistance, and resource center to explore and develop supported decision-making as an alternative to guardianship.

The [National Resource Center for Supported Decision-Making \(NRC-SDM\)](#) has been at the forefront of educating about and increasing access to SDM. They have applied SDM in groundbreaking legal cases, developed evidence-based outcome measures, and advocated for changes in law, policy, and practice to increase self-determination, showing SDM to be a valid, less restrictive alternative to guardianship.

In ACL's blog post titled *Preserving the Right to Self-Determination: Supported Decision Making*, ACL states that "Supported decision-making starts with the assumption that people with intellectual and developmental disabilities and older adults with cognitive impairment should retain choice and control over all the decisions in their lives. It is not a program. Rather, it is a process of working with the person to identify where help is needed and devising an approach for providing that help. Different people need help with different types of decisions. For some, it might be financial or health care decisions. Others may need help with decisions surrounding reproductive rights or voting. Some may need help with many types of decisions, while others need help with only one or two."<sup>5</sup>

The solutions also are different for each person. Some people need one-on-one support and discussion about the issue at hand. For others, a team approach works best. Some people may benefit from situations being explained pictorially. The key is that the process is centered on the person to whom the decisions

<sup>5</sup> Retrieved from <https://acl.gov/news-and-events/acl-blog/preserving-right-self-determination-supported-decision-making>

apply, and it enables the person to make decisions based on their wants and preferences.

The National Gateway to Self-Determination defines self-determination as a “characteristic of a person that leads them to make choices and decisions based on their own preferences and interests, to monitor and regulate their own actions and to be goal-oriented and self-directing.” SDM and self-determination are fundamental rights that intersect and afford all people lifestyle options, the opportunity for fair compensation, and full participation in community life.<sup>6</sup>

The Self-Determination Principles outlined in the Developmental Disabilities Assistance and Bill of Rights Amendments of 2000, as noted below, suggest that both the abilities of the person and the opportunities presented by the environment contribute to the degree of self-determination that can be expressed. An individual with I/DD, with assistance:

- » Has the ability and opportunity to make choices and decisions;
- » Has the ability and opportunity to exercise control over services, supports, and other assistance;
- » Has the authority to control resources and obtain needed services;
- » Has the opportunity to participate in and contribute to their communities;
- » Has the support, including financial, to advocate, develop leadership skills, become trained as a self-advocate, and participate in coalitions and policy-making.

The National Council on Disabilities report *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities* states that people with I/DD who exercise greater self-determination, who are “causal agents” with more control over their lives, have better life outcomes and quality of life. This includes being more independent, more integrated into their communities, better problem-solvers, better employed, healthier, and better able to recognize and resist abuse. People with I/DD learn through the process of making decisions, and self-determination can also be learned. As one interviewee explained, “It’s not about protecting someone. It’s about teaching them how to best protect themselves.” The positive outcomes of self-determination are consistently shown across studies,<sup>7</sup> and demonstrate the link between self-determination and employment, independent living, and community inclusion.<sup>8</sup>

## What Does the Data Tell Us?

The National Council on Disability has stated: “As a nation, we are essentially working in the dark when describing adult guardianship practice. Data and research are scant to nonexistent. Many courts and states do not know the number of adults under guardianship in their jurisdiction, let alone the demographics.”<sup>9</sup> National Core Indicators (NCI), a collaborative effort between NASDDDS and the Human Services Research Institute, is a notable exception to this. The purpose of the program, which began in 1997, is to support NASDDDS member agencies to gather a standard set of performance and outcome measures that can

Figure 2: Self-Determination



<sup>6</sup> Moore, R., & Friedman, M. (2017). The Role of Informed Choice in Advancing Competitive Integrated Employment. (Journal of Vocational Rehabilitation).

<sup>7</sup> Wehmeyer, Palmer, Rifenbark, & Little, 2014; Powers et al., 2012; Khemka, Hickson, & Reynolds, 2005; Wehmeyer & Palmer, 2003; Shogren, Wehmeyer, & Schwartz, 1997 & 1998; Wehmeyer, Kelchner, & Reynolds, 1996.

<sup>8</sup> Nota, L., Ferrarri, L., Soresi, S., & Wehmeyer, M. L. (2007). Self-determination, social abilities, and the quality of life of people with intellectual disabilities. Journal of Intellectual Disability Research, 51.

<sup>9</sup> National Council on Disability. (2018). Beyond Guardianship: Toward Alternatives That Promote Greater Self-determination for People with Disabilities, p. 65.

track their own performance over time, to compare results across states, and to establish national benchmarks.

NCI has completed many publications focused on the rights of people with disabilities, and NCI data suggests that the national prevalence of guardianship among individuals who receive services from state I/DD agencies is approximately 42.9% (2017-2018 In

Person Survey (IPS)). One of these publications, *What Do NCI Data Reveal About the Guardianship Status of People With I/DD?*, explores the characteristics and outcomes of people with intellectual and developmental disabilities who have full or partial guardianship compared to those without guardianship. The brief also poses some starting points for examining the need for guardianship reform and the ways in which supported decision-making can be expanded and alternatives instituted. Some of the impacts of guardianship noted in the brief include:

- » A person is denied the ability to be a causal agent in his/her life and often “feels helpless, hopeless, and self-critical”
- » “Low self-esteem, passivity and feelings of inadequacy and incompetency” associated with loss of autonomy and self-determination also result in decreased functioning
- » Being subject to guardianship may affect subjective well-being including physical and mental health (National Core Indicators Data Brief, 2019).

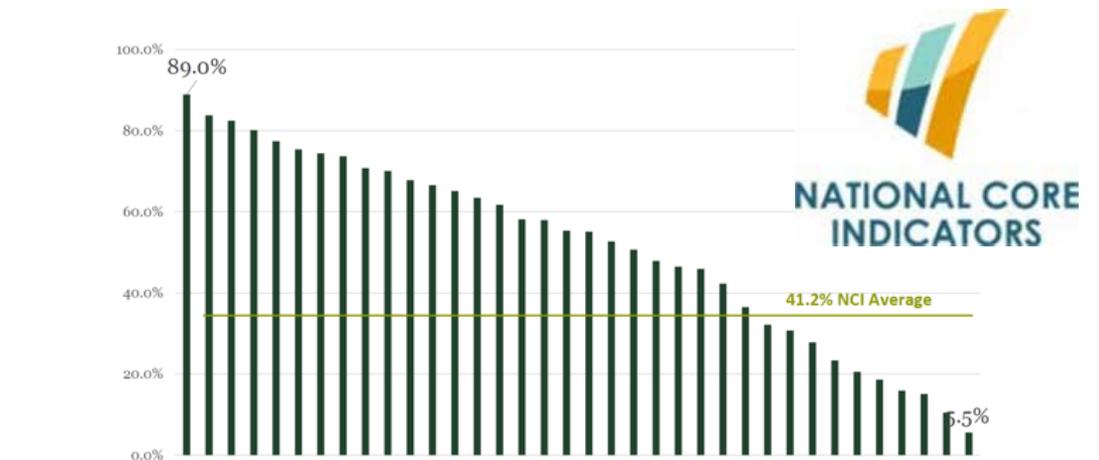
Further, in another NCI data brief, [What Do NCI Data Tell Us about the Characteristics and Outcomes of Young Adults Receiving Services](#), findings indicate that:

- » Young adults were significantly more likely than their older counterparts to have a legally appointed guardian/conservator (a person who is legally granted partial or full authority to make decisions on behalf of the individual) and to be under full guardianship or conservatorship.
- » Young adults with I/DD say they need assistance finding, maintaining, or changing jobs or accessing education/training. Employment outcomes substantiate this need for support: Just 18% of young adults with I/DD were currently employed in community employment, the same percentage as for those 26 and older. Additionally, a significantly greater proportion of young adults reported that they were not working and wanted a job when compared to individuals 26 and older.

NCI data suggest that the population of young adults who have most recently entered the adult support system are still in transition to a self-determined adult life, and have support needs that do not appear to be present to the same degree in those who are older.

To exercise our rights, we need to be able to make choices. Once an individual reaches the “age of majority” and becomes an adult, they are assumed to be legally capable of making decisions and taking certain legal actions. Presumed competency is a foundational principle in our democracy.<sup>10</sup> Everyone, regardless of their

## Percentage of respondents with guardianship by state (Full, limited or unknown level)



All relationships shown in this presentation are significant at the  $p < .001$  level. Data are not weighted. Total sample: 25,671 respondents from 36 states including DC. Averages are averages of cases (not averages of state averages).

Source: [https://www.nationalcoreindicators.org/upload/core-indicators/NCI\\_GuardianshipBrief\\_April2019\\_Final.pdf](https://www.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf)

<sup>10</sup> American Bar Association Commission on Law and Aging and American Psychological Association: Assessment of Older Adults with Diminished Capacity: A

limitations, needs opportunity, experience, and support to make well-informed decisions. Unfortunately, these typical practices of autonomous decision-making are not always available for people with I/DD. In many cases when people with disabilities need support or encouragement to make decisions, there is a default in our systems to encourage a petition for guardianship. Many professionals and school systems recommend that people with I/DD seek guardianship when they turn 18 years of age without even exploring other options.

## Legal Tools that States Have Used

As mentioned earlier, SDM generally occurs when people with disabilities use friends, family members, and professionals to help them understand the everyday situations they face and choices they must make. This allows them to make their own decisions without the need for a substitute decision maker, such as a guardian. This is just one legal tool available (in most states) along a continuum of decision-support strategies.

### Power of Attorney

A power of attorney is a written document executed under state law that allows a person or persons to represent or act on the behalf of another person (called the principal) in personal or business affairs or other legal matters. Some states also allow powers of attorney for health-care decisions.

### Special Needs Trust

A special needs trust is a trust that can be established for the benefit of a person with a disability. The assets in this kind of trust can only be used in restricted ways, but they allow the person with a disability to have access to funds that might otherwise disqualify them from a variety of benefits programs. The money or property in a trust is managed by a trustee, who determines how to manage the trust for the beneficiary or beneficiaries in accordance with the terms of the trust.

### Representative Payee

A representative payee is a person or an organization appointed by the Social Security Administration to manage benefits for a Social Security beneficiary who is unable to manage or direct the management of those benefits. The representative payee must use the benefits to pay for the needs of the beneficiary and save any benefits not needed to meet current needs.

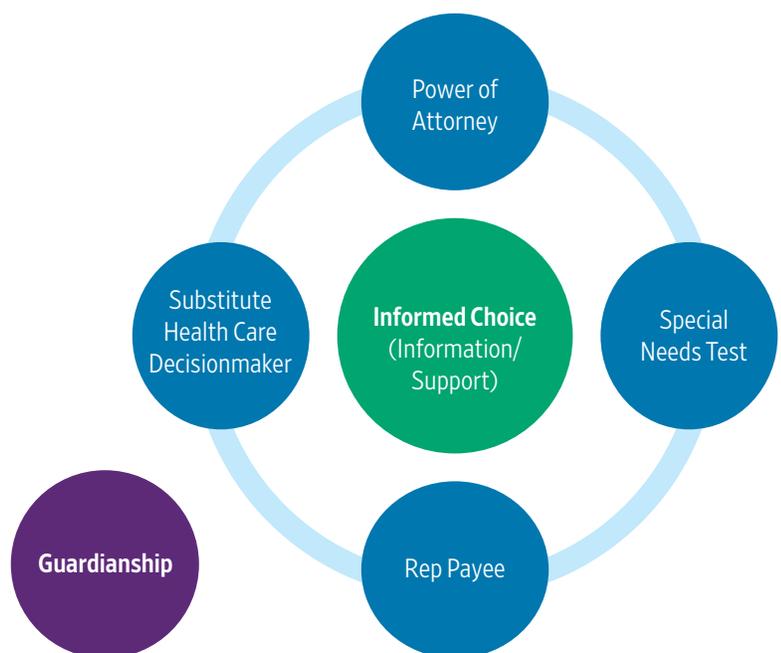
### Substitute Health Care Decision Support

A substitute health care decision maker provides “informed consent” for a person to proceed with a medical treatment, procedure, or even examination.”<sup>11</sup>

### Guardianship

Guardianship reflects state law, and has a profound impact on the people subject to it, as well as on their families and communities.<sup>12</sup> According to the joint position statement of AAIDD and the Arc of the United States, “[t]he appointment of a guardian is a serious matter for two reasons:

**Figure 3: Possibilities in the Decision-Making Process**



**\*Regardless of the legal tools in place, all individuals should be provided with any information and support they need to make an informed choice and allow their preferences to be known.**

Handbook for Lawyers, 5–8. Last modified March 25, 2005.

<sup>11</sup> National Council on Disability. (2018). *Beyond Guardianship: Toward Alternatives That Promote Greater Self-determination for People with Disabilities*, pp. 124-128.

<sup>12</sup> National Council on Disability. (2018). *Beyond Guardianship: Toward Alternatives That Promote Greater Self-determination for People with Disabilities*, Executive Summary.

1. It limits a person's autonomy, that is, the person's choice of how to live and from whom to receive support to carry out that choice;
2. It transfers the person's rights of autonomy to another person, a guardian."<sup>13</sup>

According to the National Guardianship Association, "Guardianship, also, referred to as conservatorship, is a legal process, utilized when a person can no longer make or communicate safe or sound decisions about his/her person and/or property or has become susceptible to fraud or undue influence."<sup>14</sup>

There are two types of guardianship: limited and plenary. Although both types of guardianship typically cover the person or their property, state and local laws vary across the country.

Limited guardianship occurs when a judge decides that a person can exercise some rights, but not others, on their own. Plenary guardianship, also known as general guardianship, occurs when a judge determines that an individual lacks capacity to exercise any of their rights, and the plenary guardian becomes the guardian of both person and property. This type of guardianship gives the appointed guardian power to make all decisions for a person with I/DD, and comprises about 90% of all types of guardianship proceedings.

A 2011 briefing paper for the Guardianship Summit Roundtable further explains the impact of guardianship: "In the language of human rights, guardianship deprives a person of 'legal capacity,' which means not only that he/she no longer has the right to make decisions, but that he/she is not a person who will be recognized as a legal actor, that is, a person whose decisions are entitled to legal recognition. Indeed, the 1987 Associated Press report that triggered the modern guardianship reform movement said guardianship 'un persons' an individual."<sup>12</sup>

## Federal Activity and Informed Choice

The right to make informed choices is reinforced under federal law through the Americans with Disabilities Act, which secures the basic civil rights of people with disabilities, including self-determination, community integration, and the right to receive accommodations to participate in governmental programs and employment. Other federal laws also support informed choice. The Individuals with Disabilities Education Act mandates transition planning to assist young adults with disabilities to make choices as they enter adulthood. The Rehabilitation Act mandates that the individual participate in the individualized plan for employment and decisions regarding employment.

In 2014, CMS established standards for the settings in which Medicaid-reimbursed home and community-based services (HCBS) may be provided (42 C.F.R. § 441.301). These regulations focus heavily on the rights of people receiving Medicaid supports to make informed choices. They require state systems to focus on both big and small decisions in a person's life. The regulations state that "the Person Centered Planning Process provides necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make informed choices and decisions."

These HCBS regulations appear to be deliberate in ensuring that individuals have support in decision making and do not default to a global use of the term "guardian." In fact, even when legal decision-making authority has been conveyed to someone else, the regulation requires that "In instances where state law confers decision-making authority to the individual representative, the individual will lead the service planning process to the extent possible."

The US Department of Justice (DOJ) notes that individuals may be hesitant to consider employment in integrated settings. This hesitation is often a result of being segregated in sheltered workshops, told they cannot work in integrated settings, tracked away from competitive integrated employment, steered to segregated settings directly from school, left out of the competitive labor market for long periods of time, or given scant information about supported employment services, integrated employment settings, or how individuals with disabilities can work in jobs in the community.

<sup>13</sup> Retrieved from <https://aaid.org/news-policy/policy/position-statements/guardianship>

<sup>14</sup> Retrieved from <https://www.guardianship.org/what-is-guardianship/>

Thus, the DOJ has taken a strong position about what is required for someone to be able to make an “informed choice.” In their 2011 statement on integration, DOJ defines these requirements as follows: Individuals must be provided the opportunity to make an informed decision. Public entities must take affirmative steps to remedy this history of segregation and prejudice in order to ensure that individuals have an opportunity to make an Informed Choice. Such steps include:

- » providing information about the benefits of integrated settings;
- » facilitating visits or other experiences in such settings;
- » offering opportunities to meet with other individuals with disabilities who are living, working and receiving services in integrated settings, with their families, and with community providers.
- » making reasonable efforts to identify and addresses any concerns or objections raised by the individual or another relevant decision-maker.<sup>15</sup>

## State-level Best Practices

States are working on many policies and procedures to ensure people are being supported within their systems, and have a voice in making informed choices about their everyday lives. States continue to redesign systems to ensure that these pursuits are fully realized for everyone being supported through measures of health and safety, dignity, autonomy, and self-determination. SDM continues to be an emerging powerful option to help people understand and make choices that can have lasting impacts on the rest of their lives. Below are some examples of state policies and activities that have strengthened informed choice and decision-making.

### *Disability Rights Maine (DRM)*

DRM received a National Resource Center on Supported Decision Making grant funded by the Administration for Community Living. As reflected in Maine’s grant report (<http://supporteddecisionmaking.org/sites/default/files/sdm-cop-2016-maine.pdf>), “Through training, outreach, and representation, DRM quickly learned that many individuals facing guardianship do not know the basic fundamentals about what guardianship is. Accordingly, they did not know about due process and their rights before, during, and after guardianship proceedings. Because of this, they often did not know how their decisions could lead to guardianship or that they had any ability to contest guardianship.”

While autonomy and self-determination are important to individuals facing guardianship, individuals transitioning into adulthood still worry that contesting guardianship will disappoint their parents. This fear often overwhelms the person’s desire for autonomy. Further, by not fully understanding guardianship, they perceive contesting guardianship as contesting their parents’ involvement in their lives. Most individuals think guardianship is SDM because they are often told that guardianship is “help” or “assistance” rather than substitute decision-making.

Maine ties this work into planning for employment through the person-centered planning manual ([www.maine.gov/dhhs/oads/provider/developmental-services/documents/PCPManualpdf.pdf](http://www.maine.gov/dhhs/oads/provider/developmental-services/documents/PCPManualpdf.pdf)). According to the manual, the Maine Office of Aging and Disability Services (OADS) is committed to supporting career development and meaningful employment for all working-age individuals who receive services.

OADS is required under the Employment First Maine Act (Sec. A-1. 26 MRSA c. 39) to offer customized, individual employment services as the “first and preferred service option” before other day services. At least annually, the person and their planning team must talk about the benefits of working, services available to go to work, and access to supports such as career planning, vocational rehabilitation, work incentive counseling, and long-term support on the job. Concerns and barriers should be identified and planned support to address them included within the PCP.

If the person says they do not want to pursue work, then the team should respectfully try to learn more. It may be possible to share information that will assist the person in making an informed choice about starting

<sup>15</sup> Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.* Retrieved from [http://www.ada.gov/olmstead/q&a\\_olmstead.htm](http://www.ada.gov/olmstead/q&a_olmstead.htm)

on a pathway to employment, including volunteer opportunities to gain work experience, career planning, or meeting with a Work Incentives Counselor.

### District of Columbia

The District of Columbia (DC) passed the Disability Services Reform Amendment Act in 2018. The law has three parts: 1) There is a new formal complaint process for people to use when unhappy with their Department on Disability Services (DDS) supports or providers. 2) No new people can be committed to guardianship in DC. People who are committed now can choose whether they want to remain committed or not, and will have this choice at their hearing. Ending commitment will not change any DDA supports a person gets. 3) People can use a new form called a Supported Decision-Making Agreement to name a supporter to assist with making decisions.

To implement and uphold this law, both the Department on Disability Services (DDS) and DC Public Schools are offering an array of supports that begin while a person is in school and continue as they are supported by DDS. The public school system is focusing on students understanding the stake

they have in making decisions about their futures. The district has developed an SDM question and answer document to help educators prepare students to make the best decisions possible.

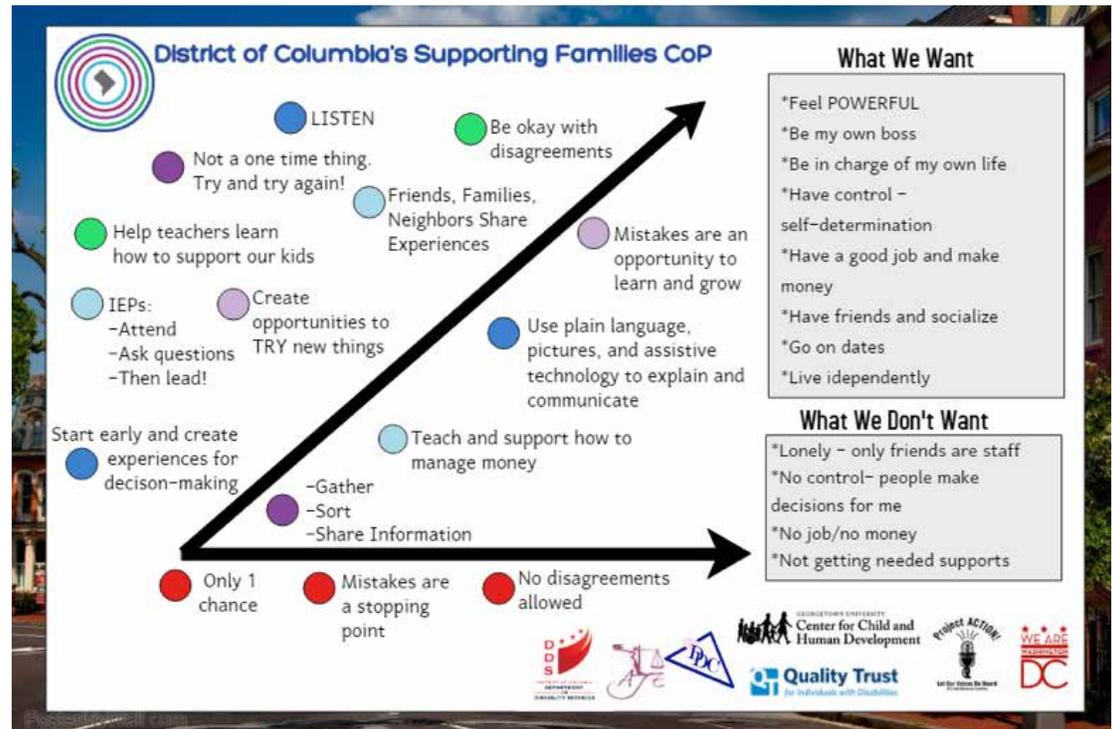
DC Public Schools have also developed a self-advocacy course to teach students how to be aware of their needs and their disability as they transition to post-secondary opportunities. Students will participate in a variety of activities aimed at developing their decision-making skills and preparing them to take an active role in their future.

Schools are preparing students for self-advocacy by:

- » Ensuring students are enrolled in the self-advocacy course.
- » Engaging students in problem-solving activities that encourage them to think critically about their decisions.
- » Explaining the Transfer of Rights and the Individual Education Program (IEP) process to students.
- » Encouraging students to take on key roles in their school IEP meetings to demonstrate an active awareness of their educational strengths and needs.
- » Counseling students on ways to make the best decisions and showing them the costs and benefits to each of the options before them.

DC Public Schools also published What Happens When My Child Has an IEP and Turns 18? This document describes SDM and educational power of attorney. DC DDS has also added a section to their website dedicated to decision-making rights for people with I/DD.

### Washington DC Decision Making Trajectory



DC DDS ensures that people make an informed choice when planning for employment through PCP, and created a document that helps case managers access a person's interest and progress towards employment (<https://dds.dc.gov/publication/assessing-employment>). This document explains the importance and expectations of work, and outlines the reasons that having a job increases overall quality of life.

### **New York**

The New York Office for People with Disabilities (OPWDD) has taken an expansive approach in educating stakeholders through its Supported Decision-Making New York (SDMNY) effort ([sdmny.org](http://sdmny.org)). SDMNY is a 5-year project funded by the New York State Developmental Disability Planning Council (DDPC) that demonstrates how SDM can be used as an alternative to guardianship for people with I/DD.

The facilitation process includes three phases and a written agreement (the Supported Decision-Making Agreement, or SDMA). Each phase is aimed at determining which areas the person with I/DD (the "Decision-Maker," or DM) wants support in (e.g., financial matters, health care, living arrangements, etc.); who he or she wants to support him or her; what kinds of support he or she wants (gathering information, helping to weigh alternatives or possible consequences, communicating decisions to third parties, etc.); and how he or she wants to receive that support (face-to-face meetings with individual supporters, a "circle of support" for important decisions, use of Skype and other technology for communication, etc.).

**The premise of this project is that "We believe that every person has the right to make his or her own decisions, regardless of disability, and to have those decisions legally recognized. This belief is reflected in the United Nations Convention on the Rights of Persons with Disabilities that posits legal capacity as a human right. We understand that no one makes decisions entirely in a vacuum, that we all engage in some kind of supported decision - making, and that people with intellectual disabilities may simply need more, or different kinds of supports in order to make their decisions."**

The following represents the three phases:

- » **Phase 1:** The facilitator works with the DM to learn about how he or she communicates, makes decisions, what kinds of decisions are likely to arise in the long and short term, and who are the important people in the DM's life from whom she or he may choose trusted supporters.
- » **Phase 2:** The facilitator works with the supporters the DM has chosen, educating them about SDM, and helping them "reposition" from people who make decisions for the DM, to supporting her or him in making her or his own decisions, including consideration of the "dignity of risk."
- » **Phase 3:** The facilitator works with the DM and her or his chosen supporters to negotiate the SDMA, and to ensure that all parties understand their roles, obligations, and responsibilities. Then the facilitator prepares a draft of the SDMA that all parties review and may alter, and oversees the signing of a final version.

Part of having an informed choice and making decisions about supports in NY is to know about the Pathway to Employment service. This is a person-centered employment planning and support service that provides assistance for individuals to obtain, maintain, or advance in competitive employment or self-employment. This service offers instruction and training in job readiness skills and develops a plan for achieving competitive, integrated employment at or above the New York State minimum wage. Within 12 months, the outcomes of this service are documentation of the participant's stated career objective, and a detailed career plan used to guide individual employment supports.

### **Wisconsin**

The Wisconsin Board for People with Developmental Disabilities (BPDD) received a National Resource Center on Supported Decision Making grant funded by the Administration for Community Living. As reflected in Wisconsin's grant report, (<http://supporteddecisionmaking.org/sites/default/files/sdm-cop-2016-wisconsin.pdf>), it was learned that the language the agency uses is very important for encouraging informed choice. When SDM is promoted, it should be considered as "one of several options in legal decision making," rather than labeled as "an alternative to guardianship." If it is described as the latter, it sounds as

though guardianship is the standard, and it normalizes the process of guardianship. Consistency in messaging across the entire state was also noted as important when it comes to explaining the options around support and decision-making.

Wisconsin signed into law a Supported Decision-Making Bill (AB 655). This law makes several changes to state policy:

- » Defines SDM as “a process of supporting and accommodating an adult with a functional impairment to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the self-determination of the adult.”
- » Allows the person to enter into a formal agreement with a “supporter.”
- » Provides an SDM agreement form.
- » Ensures that the person with a disability retains all decision-making rights and authority.
- » Includes provisions that protect a person from inappropriate actions by the supporter or misuse of the SDM agreement.
- » Requires judges to consider whether SDM has been attempted for an individual prior to granting guardianship.
- » Requires schools to talk to parents about SDM as an alternative to guardianship.

**Education also needs to be framed around the concept of dignity of risk. There needs to be recognition that people with and without disabilities make mistakes, and the right to make decisions is not contingent on the quality of decisions made or whether another person would make that same decision. Rather, understanding and negotiating risk is an essential component of learning how to make decisions.**

**Decision - making is a skill, and everyone needs practice.**

To implement this law, the Wisconsin Department of Health Services, which includes the Division of Long Term Care, has taken a broad approach to planning and educating stakeholders on the benefits of SDM. The approach is predicated on the foundations of self-determination and choice. Wisconsin’s guide speaks to “being able to make choices about your life and how crucial it is for independence and happiness of all people, including those with disabilities. Regularly involving young people with disabilities in decision-making results in adults who are able to make informed decisions and direct their own lives. People with intellectual disabilities who have more opportunities to make choices make better decisions. The more someone makes their own decisions, the better they can learn new skills, including problem solving, goal-setting, and taking more responsibility.”

According to the 2010 Department of Health Services Handbook, Guardianship of Adults, “We all learn by making mistakes. When a person is denied the right to take risks, he or she is also denied the opportunity to learn and grow. The Department of Health Services strives to create better supports so people with disabilities can lead more independent lives as being able to make choices about your life is crucial for the independence and happiness of all people.”

## Conclusion

States are using many different strategies to advance and enforce the rights of individuals with disabilities and increase awareness. To support these values and rights, state I/DD systems and their partners are:

- » Ensuring a robust person-centered process.
- » Administering policies, services, and models of support that empower individuals with disabilities to make informed decisions about their life that protect their rights while ensuring their safety and privacy.
- » Conducting outreach and providing training on individual rights and developing advocacy skills.
- » Developing fully accessible and informational websites to house information and connect people to

**“We are our choices.”  
~ Jean - Paul Sartre**

resources that promote SDM and the right to make an informed choice.

- » Developing materials in many formats as well as tools to help a person understand the right to make an informed choice, as well as normalizing the fact that all people seek help with making and implementing decisions.

Freedom to make choices is a human right. We all have the right to make choices to the best of our abilities and the concept of informed choice is universal to everyone. People with disabilities, especially people with I/DD, often do not get to make their own choices. However, with the right supports, individuals with I/DD can engage in informed choice and increase their self-determination, leading to more empowered and satisfying lives.

## Resources

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Wisconsin Alternative to Guardianship Guide

[https://wi-bpdd.org/wpcontent/uploads/2018/06/Supported\\_decision\\_making\\_booklet\\_final.pdf](https://wi-bpdd.org/wpcontent/uploads/2018/06/Supported_decision_making_booklet_final.pdf)

Wisconsin Board for People with Disabilities Supported Decision-making Toolkit

<https://wi-bpdd.org/index.php/supporteddecision-making/>

Wisconsin Arc Future Planning Tool (includes guided questions for supported decision-making)

<https://futureplanning.thearc.org/landing>

Supported Decision-Making FAQ (summary of questions and answers about SDM in Wisconsin)

[http://wi-bpdd.org/wp-content/uploads/2018/09/SDM\\_FAQ\\_final.pdf](http://wi-bpdd.org/wp-content/uploads/2018/09/SDM_FAQ_final.pdf)

Washington State's Informing Families / Alternatives to Guardianship <https://informingfamilies.org/topic/alternatives-to-guardianship/>

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