SUPPORTED DECISION-MAKING
Creating a Continuum of Choice
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Supported Decision-Making: Creating a Continuum of Choice, is the result of the collaboration among disability organizations to educate about an emerging best-practice concept known as Supported Decision-Making (SDM). Our organizations’ work has deepened our understanding that individuals with disabilities and aging adults are just like everyone else. They are diverse individuals with unique wants and needs for whom inclusion, accessibility, and self-determination are beneficial and result in enhanced community engagement.

For some people making their own choices can be difficult. For these situations, Tennessee currently has some processes for support including conservatorships or Power of Attorney. While these options are useful, they are also limiting, because each appoints other people to make decisions on behalf of the individual. These are one-size-fits-all options that do not necessarily fit all. SDM offers an internationally recognized framework that broadens the continuum of choice when assisting individuals with disabilities and aging adults who need help making decisions.

Furthermore, the system of services and supports for people with disabilities and people who are aging has shifted in recent years. It has moved from the “most restrictive” (think developmental centers, nursing homes, sheltered workshops and segregated classrooms) to “least restrictive” (think supported employment, supported living, and other community living supports). Therefore, it makes sense that our government systems assisting people with life choices make the same shift to a less restrictive alternative. SDM provides that option.

We appreciate the opportunity to share more information about SDM with individuals, families, educators, professionals, and community organizations. Your engagement and feedback is invaluable, as we work toward making SDM a viable decision-making model in Tennessee.
CREATING A CONTINUUM

“The [conservatorship] system is designed as a last resort, applied only when an individual lacks capacity to make decisions. However, there is reason to believe that [conservatorships] are imposed on many individuals without sufficient evidence of their decision-making incapacity and that in some cases, disability alone appears to be used as a sufficient justification for the imposition of [conservatorship].”

— Nina Kohn, David M. Levy Professor of Law and Associate Dean for Research at Syracuse University College of Law

Our democracy was founded on the protection of an individual’s right to live out their values and preferences. No two people are exactly alike or have the same wants and needs. This includes adults with intellectual or developmental disabilities and aging adults. However, under current Tennessee law, adults who need help making decisions and their families have limited options for assistance.

A conservatorship or power of attorney are the typical legal approaches to assist people who need help making life decisions. However, both of these options require designation of ‘incapacity’ for the individual and a removal of rights. This makes our current choices “one-size-fits-all” solutions that are not appropriate for many people with disabilities and aging adults. Supported decision-making offers an option that is focused on tailored assistance that maintains individual rights and dignity. It enables improved individual well-being and enhances civic participation and employment, which benefits our entire community.
The Jenny Hatch Story

“Just because people have a disability does not mean they need a [conservatorship]. Many times they just need a little help.”

—Jenny Hatch

By most standards Margaret “Jenny” Hatch led an independent life. She is a high school graduate, lived in her own home, worked at a job she loved, and volunteered in many political campaigns. But, because she has Down syndrome, Jenny faced a conservatorship petition that would take away her right to make choices.

In 2012, following a bicycle accident, her parents obtained a temporary conservatorship from the court. Jenny was then placed in a group home. There they took away her cell phone and laptop and wouldn’t let her go to her job or see her friends. Jenny felt like a prisoner and longed for independence.

After a year long fight in court, Jenny won back her right to make her own decisions. Using supported decision-making, Jenny now lives and works where she wants, sees who she chooses, and encourages others to do the same.
What is Supported Decision-Making?

Supported decision-making (SDM) is a nationally-recognized process for assisting people with life choices, without removing an individual’s independence or self-determination. SDM may be a good fit for a variety of people, including:

- People in their 20s and 30s who have relied on parents to represent them in the past and are now expanding their support circles to include siblings, friends, and other community supports.

- People whose parents are planning for the future by bringing to the table the next generation of supporters – often an individual’s siblings who know their values and how they express themselves.

- Older individuals working to avoid institutionalization by making sure their network of supporters know and respect their preferences.

In practice, SDM is how adults typically make decisions. Rarely does anyone make important life choices without the input of family, friends, or in some cases a trained professional. If you have ever asked your doctor to just ‘spell it out in simple language’ or asked your parents for advice about buying a car, you have used SDM informally. For people with disabilities and aging adults SDM is very similar; it simply provides a framework and guidance for this process. Formally recognizing this framework is critical, and in some states the framework is part of state law and thus provides legal recognition for their supporter (see page 10).

Timberley & Tonya Mouat

Often when students with disabilities turn eighteen, school districts and parents lean towards conservatorship because they think that’s the only option they have. When Tonya Mouat read the information on conservatorship, she felt that she would be stripping away her daughter’s rights. “It was important to raise both my girls to make decisions and live independently,” states Mouat. “Right now Timberley needs a little extra support.” Tonya and Timberley have found a supported decision-making contract to work for them. So far Timberley has used her mother’s help to select classes to graduate high school and to prepare for college. Tonya has found this to be a solution to ensure that her daughter’s voice is always heard.
How Does Supported Decision-Making Work?

The supported decision-making (SDM) process provides information and guidance for assisting someone in making their own choices. First, individuals in need of assistance designate their ‘supporters,’ or the people they want to help them make their decisions. Once supporters have been identified, both parties enter into a voluntary agreement, often documented in a form.

When the agreement is signed, the supporter’s role is to help individuals understand their options, so an informed decision can be made. In the presence of the individual, the supporter may assist in accessing or gathering information relevant to a particular decision, including medical, financial, educational, or treatment records. The supporter may also assist in communicating a decision once it’s made by the individual.

The supporter cannot use the role to make any decisions on behalf of the individual with a disability or aging adult. The supporter is like a “resource librarian,” gathering and interpreting information, but with no power over the person being assisted. Furthermore, at any time the individual may reject their supporter’s advice. To minimize opportunities for exploitation and to clarify the relationship between individuals using SDM and their supporters, proposed legislation should address these issues explicitly.

“It helps me because I have [my] mom on my side always. If I don’t want it, I can say, ‘No.’ It’s better than [conservatorship].”

— Timberley Mouat

Timberley Mouat photo courtesy of Disability Rights TX
When Ryan King turned 18, his parents were told they had to become his conservators, so they could support him through his transition to adulthood. For years, Ryan worked independently, managed his own finances, and had dreams of owning his own business. His parents saw no need for Ryan to have conservators and asked the Court to remove the order.

The Court refused. It was not the outcome his parents desired. “We wanted Ryan to do what Ryan wants,” stated his mother, “to have that opportunity, just like everyone else in society.” His father continued, “The decision process is part of being whole...We want Ryan to be whole.”

Ryan’s parents repeated their request and after 15 years of conservatorship, Ryan won the right to direct his own life. The SDM process has been a better fit for Ryan’s wants, needs, and skills for as he says, “Independence is fun.” Ryan’s story highlights the need for options so families can find the appropriate supports for their loved one’s unique needs.

“Everybody needs help sometimes. Nobody in this world knows everything...Whether you have a disability or don’t, you should include everyone in day-to-day activities...and choices”

—Ryan King

SDM in Action: Ryan King and his parents
THE CASE FOR SDM

PROTECTION OF INDIVIDUAL RIGHTS

Some people with disabilities and aging adults want or need assistance making big life decisions, but they do not need someone else to make those decisions on their behalf. While other mechanisms exist – conservatorship, powers of attorney – supported decision-making (SDM) is unique, because it allows the individual to retain the right to be the final decision-maker. Other existing options remove that right by design, because they presume incapacity of the individual. These options make sense in some cases, but for a person who is capable of making decisions with support they go too far.

In recognition of this need, and the obligation to protect individual rights to the fullest extent possible, across the nation states are looking to SDM. Put simply, SDM replaces substituted decision-making with supported decision-making.

PROMOTION OF SELF-DETERMINATION & SELF-SUFFICIENCY

Our democracy was founded on the protection of individuals’ right to live their values and preferences. However, under Tennessee law, all available options for individuals with disabilities and aging adults who need help making decisions also restrict individual self-determination. For example, people can lose their right to choose who they can spend their time with, where they live, or they work. SDM provides a framework for assistance while maintaining independence for the individual, therefore allowing for self-determination and ultimately increased self-sufficiency. Studies show that people with greater self-determination are healthier, more independent, well-adjusted, and better able to recognize and resist abuse.

Benefits of Self-Determination

Self-determination is a combination of attitudes and abilities that leads people to make choices and decisions based on their own preferences and interests. Self-determination should not be confused with self-sufficiency.

Greater self-determination correlates with people with disabilities:

- being healthier and more independent
- being better able to recognize and resist abuse
- having positive post-secondary outcomes
- being employed and earning higher wages
- participating in self-advocacy
Enhanced independence that leads to civic engagement and employment, in turn benefits entire communities. Currently, Tennesseans with disabilities are an untapped workforce resource. With the employment rate of individuals with disabilities disproportionately low (28%) compared to all Tennesseans (75%).

Research also suggests that, when denied self-determination, people experience low self-esteem, passivity, and feelings of inadequacy and incompetency, decreasing their ability to function. People under conservatorship can experience significant negative impacts on their physical and mental health, longevity, ability to function, and reports of subjective well-being. Furthermore, studies show that maintaining autonomy is an important component of mental health. Complete loss of status as an adult member of society can act as a self-fulfilling prophecy by intensifying existing disabilities. In light of the profound benefits of independence and our national commitment to freedom, the addition of supported decision-making (SDM) to a continuum of choice allows for the maintenance of individual rights and self-determination when possible.

“Independence is important to me because if you’re out on your own you could just basically be free.”

— Dawn Carlton

**EXPANSION OF OPTIONS FOR FAMILIES**

Families want what is best for their loved ones, and when a loved one needs support making decisions, families are often encouraged to obtain a conservatorship or power of attorney. Though these are currently the most widely-accepted options for people with disabilities and aging adults who need decision-making support, they remove individual rights, even if the person is not incapacitated. SDM will provide an option for individuals and families to tailor supports to the needs of their loved one, while retaining a buffer of care and assistance. For some families, this may be
a good step to explore prior to obtaining a conservatorship; for others, it may avert the need for a conservatorship all together.

SDM offers a lower cost alternative for providing support to individuals with disabilities and aging adults who need assistance making decisions. A conservatorship is often very expensive, sometimes thousands of dollars once the court and attorney fees are paid. The removal of a conservatorship is also very difficult and an added expense to individuals or their family. SDM has no court costs or processing fees, so it offers an option that maintains the individual’s rights while dramatically reducing financial burden for families.

**PROVIDES LEAST RESTRICTIVE ALTERNATIVE**

Governments have a legal obligation to provide mechanisms that allow people with disabilities to be in control of their own lives to the greatest extent feasible. The Supreme Court has long espoused a Least Restrictive Alternative principle. This doctrine generally states that government must achieve its goals by the narrowest means available when individual rights and liberties are concerned, by doing only what is necessary for the health and welfare of individuals. In 1974, this principle was first applied to mental health law in the context of involuntary institutionalizations, and since then has increased in prominence.

> “I don’t feel comfortable with a conservatorship where my son will never be able to make his own decisions, but I also want to guide him through difficult parts of life. Moe can read at a high level, but often struggles with comprehension. This makes complex situations such as renting an apartment or applying for benefits difficult for him. Supported decision-making would give Moe the support team he needs and achieve the goal of his being as independent as possible.”
> — Stacie Price, Attorney & mother of a child with a disability

By not offering less restrictive options to conservatorships, states are failing to achieve the Least Restrictive Alternative principle. Every time a court grants an unnecessary conservatorship it is violating that principle. Lending strong support to this argument is the United Nations Convention on the Rights of Persons with Disabilities, adopted in 2006, which recognizes in Article 12 that persons with disabilities have the right to make their own decisions and that governments have the obligation to support them in doing so. Article 12 calls for a switch in perception from a focus on disabilities to abilities, and from protection to support. Supported decision-making, then, is a viable tool that governments can use to meet their legal obligations to individuals with disabilities and aging adults.
“I have an adult daughter with a disability and we have a limited conservatorship over her. Although I believe that conservatorship was and is the right choice for our family, I do wish there had been more information available when we were making the decision. You are groomed that conservatorship is what you do when your child turns eighteen, but that shouldn’t be the only option.”

— Julie Sullivan, mother of an adult child with a disability

To implement supported decision-making (SDM) as a formal mechanism, states have begun adopting legislation. Texas, Virginia, Maryland, Massachusetts, North Carolina, New York, and Washington, D.C., have all already begun implementing or examining SDM as an option in their state. In 2015, Texas passed SDM legislation that is already having a tremendous impact on individuals and families there, such as Timberley and Dawn. By adding SDM to Tennessee Code, our state has an opportunity to be a leader in this movement as well.

Legislation provides a common definition of SDM that can be understood by multiple stakeholders, including those who may advise families and individuals (schools, lawyers) and those who may interface with individuals as they make big life decisions (banks, landlords, service providers). Furthermore, it provides common parameters to protect the individual’s privacy, identity, and right to be free from coercion and exploitation.

Why Legislation in Tennessee?

Tennessee Code already states that the “court has an affirmative duty to ascertain and impose the least restrictive alternatives upon the person with a disability...” Adding supported decision-making in Title 34 will create a continuum of options to consider before or along with conservatorship. This will result in broadening choices to better meet the individual needs of Tennesseans with disabilities and aging adults. Furthermore, once implemented, SDM is not permanently binding and a conservatorship can be pursued if necessary.
Conclusion

Tennesseans with disabilities and aging adults have diverse values, needs, levels of functionality, and preferences, yet in our state there are one-size-fits-all solutions that are a poor fit for many. If Tennessee provides an option to conservatorship and power of attorney that creates a continuum of choice, more individuals could retain their independence and freedom, and our state will acquire a more engaged and participatory citizenry.

In the words of Jenny Hatch, “I don’t need a guardian. I just need a little help.” Jenny was able to create a support system to do that: friends and professionals she chose, helping her in the way she directed. Tennesseans deserve the same chance for a nuanced continuum of choice that protects their freedom and independence as individuals with disabilities and aging adults.

“I could show the doctors who I really was, that I could speak up for myself….To have people look at me the way I want them to look at me feels great.”

— Gabby Castro

SDM in Action: Gabby Castro
RESOURCES

NATIONAL

American Bar Association
http://www.americanbar.org/groups/disabilityrights/resources/article12.html

The Arc of the United States
https://futureplanning.thearc.org

Autistic Self Advocacy Network
http://autisticadvocacy.org/tag/supported-decision-making

National Resource Center for Supported Decision-Making
www.supporteddecisionmaking.org

www.supporteddecisions.org

STATE

The Arc Tennessee
www.thearctn.org

Tennessee Disability Pathfinder
www.familypathfinder.org

TennesseeWorks
www.tennesseeworks.org
CITATIONS

2 http://supporteddecisionmaking.org/
7 Jennifer L. Wright, Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA, 33 Int’l J.L & Psychiatry 350, 358 (2010).
8 http://www.tennesseeworks.org/data-dashboard/
14 See id.
17 See id.
“THERE IS NOTHING I HAVE ACHIEVED...WITHOUT THE LOVE AND SUPPORT OF SPECIFIC INDIVIDUALS WHO REACHED OUT TO EMPOWER ME... THERE IS NOTHING I HAVE ACCOMPLISHED WITHOUT REACHING OUT TO EMPOWER OTHERS.”

—Justin Dart

For more information on how to make Supported Decision-Making a viable decision-making model in Tennessee, contact:

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