

An Equal Right to Make Choices: Supported Decision-Making

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Questions

What's your favorite right?

You're probably thinking, "There *really are* stupid questions," but humor us. What's the right that makes you feel the proudest, the most like a full, equal, and valued member of society? Free speech? Voting? Life, liberty, and the pursuit of happiness?

What do all of those rights have in common?

Choice.

Free speech is the right to choose what to say, voting the right to choose our representatives, and Americans are free to choose the life they lead, the liberty they exercise, and the happiness they pursue. The Right to Make Choices² traces a through line across our rights, making them effective rather than aspirational, giving us the power to decide for ourselves what to do, where to go, and who to meet.

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² Peter Blanck & Jonathan Martinis, *'The Right to Make Choices': The National Resource Center for Supported Decision Making*, 3 Inclusion 24-33 (2015).

Clinicians call this power *self-determination*. People who are self-determined are “the primary causal agent in [their] lives,”³ making and implementing “decisions easy and hard, silly and significant that make us who we are and shape our life course.”⁴

Research has consistently found that when people with disabilities are more self-determined, they have better lives. People with disabilities who exercise their Right to Make Choices are more likely to be independent, employed, integrated into their communities, and safer.⁵

Here’s another stupid question: Are your rights worth anything if you’re not allowed to exercise them? If someone could say “you have the right to speak, but you will say only what I tell you,” or “you have the right to associate, but you will only see who I allow you,” would they even be rights?

History

For two thousand years, that’s exactly what society has said to people with developmental disabilities – people with “chronic” disabilities like intellectual disability, cerebral palsy, epilepsy, and autism that manifest before age 22 and result in limitations in 3 or more major life function.⁶ In Ancient Rome, if you were “feeble-minded,” a *curator*

³ Michael Wehmeyer & Michelle Schwartz. *Self-Determination and Positive Adult Outcomes: A Follow-Up Study of Youth with Mental Retardation or Learning Disabilities*. 63(2) *Exceptional Children*, 245-255 (1998).

⁴ Jonathan Martinis, ‘*The Right to Make Choices*’: *How Vocational Rehabilitation Can Help Young Adults With Disabilities Increase Self-Determination and Avoid Guardianship*, 42 *J. Voc. Rehab.*, 221, 222 (2015)

⁵ e.g., Wehmeyer & Schwartz, *supra* note 3; Ishita Khemka *et al.*, *Evaluation of a Decision-Making Curriculum Designed to Empower Women with Mental Retardation to Resist Abuse*, 110 *Am. J. Mental Retardation* 193 (2005).

⁶ Idaho Code 66-402(5)

was appointed to control your life.⁷ In feudal Britain, “idiots” and “lunatics” were placed under *committees* who made decisions for them.⁸

America continues this historical pattern through *guardianship* and *conservatorship*. In Idaho, when a court finds that a person with developmental disabilities is “unable to manage some financial resources or meet some essential requirements for physical health or safety,” it may appoint a *conservator* to make financial decisions for the person, a *guardian* to make non-financial decisions, or both.⁹

The Problem of Overbroad and Undue Guardianship

From Justinian Rome to today’s Boise, this process has been considered a societal good where “all parties were on the same side in seeking the well-being of the respondent,”¹⁰ and is often recommended by teachers, medical professionals, and attorneys as “standard procedure” when people with developmental disabilities turn 18.¹¹ Because of this, society has not closely examined whether guardianship is *truly* necessary or beneficial.¹²

⁷ R. Fleming & C. Robinson. *Care of Incompetent Adults: A Brief History of Guardianship*. 30 *The Arizona Attorney* 16-42 (1983).

⁸ J. Regan. *Protective Services for the Elderly: Commitment, Guardianship and Alternatives*. 13 *William and Mary Law Journal* 569-622 (1972).

⁹ Idaho Code 66-405. Hereafter, guardianship and conservatorship will be referred to as “guardianship.”

¹⁰ Jennifer Wright, *Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA*. 33 *Int’l J.L. & Psychiatry* 350, 352 (2010).

¹¹ Jameson, *et al.*, *Guardianship and the Potential of Supported Decision Making with Individuals with Disabilities*. *Research and Practice for Persons with Severe Disabilities*, 40(1), 36-51 (2015).

¹² Blanck & Martinis, *supra* note 2.

Before going further, it is important to note that we are not calling for the end of guardianship; guardianship is certainly appropriate in some circumstances. Rather, we are concerned with *overbroad or undue guardianship* – guardianships imposed upon people who are able to direct their own lives or that restrict more rights than necessary.¹³

People subjected to overbroad and undue guardianship can suffer “significant negative impact on their physical and mental health, longevity, ability to function, and reports of subjective well-being.”¹⁴ Such guardianships “not only divests the individual of the important right to self-determination but also marginalizes that person and removes him or her from a host of interactions involved in decision making.”¹⁵

Research suggests that many, if not most, guardianships are overbroad or undue.¹⁶ Even though most state laws, including Idaho’s, state that guardianships should be limited to the life areas where people cannot make their own decisions,¹⁷ the vast majority are *plenary*, where the guardian is given the power to make all decisions in all areas.¹⁸ One commenter refers to plenary guardianship as “civil death” because, in a legal sense, the person ceases to exist: he or she can only interact with society through a guardian.¹⁹ Hence, in the words of Congressman Claude Pepper:

¹³ Martinis, *supra* note 4.

¹⁴ Wright, *supra* note 10,

¹⁵ Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*. 81 *University of Colorado Law Review*, 157-244 (2010) (“Salzman 2010”).

¹⁶ *e.g.*, Salzman 2010, *supra* note 15.

¹⁷ *e.g.* Idaho Code 66-401.

¹⁸ *e.g.* Teaster, *et al.*, *Wards of the State: A National Study of Public Guardianship*. 37 *Stetson Law Review*, 193-241 (2007).

¹⁹ Robert Dinerstein, *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*, 19 *Hum. Rts. Brief* 8, 9 (2012).

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 . . . the most punitive civil penalty that can be levied against an American citizen, with the exception, of course, of the death penalty.²⁰

Nevertheless, overbroad and undue guardianships are sought and ordered with alarming regularity.²¹ This is no doubt because of the continuing view of guardianship as a protective process, saving the person from him or herself.²² After all, the theory goes, without guardians, people with developmental disabilities might sign or buy something they shouldn't or enter into inappropriate relationships.

Reread that last sentence. Now think about your life. Have you signed the endless papers thrust in front of you at a mortgage closing or before surgery without reading them? Have your friends influenced you to do silly or dangerous things? Have you made impulse purchases you shouldn't? If you answered "yes" to any of those, do *you* need a guardian?

Have you dated the wrong person and learned what a good relationship is? Made poor choices and learned lessons from them? Most importantly, would you be who, what, and where you are today if you were not allowed to make the "bad choices" that taught you what good ones are? So, exercising your Right to Make Choices made you a better, stronger, smarter person, didn't it?

As best illustrated by the recent National Core Indicators study, the same is and

²⁰ H.R. Rep. No. 100-641, at 1 (1987).

²¹ Salzman 2010, *supra* note 15.

²² *e.g.* Wright, *supra* note 10.

can be true for people with developmental disabilities. Among other things, that study compared the quality of life of people with developmental disabilities who had guardians to that of people with similar abilities and limitations who did not. The study found that those without guardians were more likely to have paid jobs, live independently, have friends, date, and practice their religion.²³

Supported Decision-Making as an Alternative to Overbroad and Undue Guardianship

In the last decade, legislatures, policy makers, and courts have searched for alternatives to overbroad and undue guardianship that keep people in control of their lives to the maximum of their capabilities. Increasingly, they have turned to Supported Decision-Making (SDM).²⁴

SDM occurs when people work with friends, family members and professionals “to help them understand the situations and choices they face so they may make their own informed decisions.”²⁵ Accordingly,

SDM mirrors how most adults make daily decisions—whether to get car repairs, sign legal documents, consent to medical procedures, review financial documents, and the like. In each instance, individuals seek advice, input, and information from knowledgeable friends, family, or professionals.²⁶

²³National Core Indicators Study (2017), available at <http://www.nationalcoreindicators.org/charts/>

²⁴ Nina Kohn, Jeremy Blumenthal & Amy Campbell. *Supported Decision-Making: A Viable Alternative to Guardianship?* 117 PENN ST. L. REV. 1111 (2013).

²⁵ Blanck & Martinis, *supra* note 2.

²⁶ Quality Trust for Individuals with Disabilities, *Supported Decision-Making: An Agenda for Action*. (2014). Available at:

SDM relationships are individualized to the person’s abilities, preferences, and needs. They can include informal support by people who “speak with, rather than for, the individual with a disability;”²⁷ legal relationships like Powers of Attorney and Advanced Directives that identify the life areas where the person wants support, the type of support the person wants, and who will provide it; formal “micro-board[s] . . . and circles of support”²⁸ and everything in-between. By working with their supporters, people are empowered to “understand relevant information, issues, and available choices, to focus attention in making decisions, to help weigh options, to ensure that decisions are based on [their] own preferences, and . . . to interpret and/or communicate [their] decisions to other parties.”²⁹

Recent SDM milestones include:

- The “Justice for Jenny” case, the first trial holding that a person with developmental disabilities had the right to use SDM instead of being subjected to a permanent, plenary guardianship;³⁰
- The creation of the National Resource Center for Supported Decision-Making, “a national training and technical assistance center” dedicated to advancing knowledge and use of SDM, through a grant from the U.S.

http://bbi.syr.edu/news_events/news/2014/02/Supported%20Decision%20Making-2014.pdf

²⁷ Dinerstein, *supra* note 19.

²⁸ Kohn et al., *supra* 24.

²⁹ Leslie Salzman, *Guardianship for Persons with Mental Illness – A Legal and Appropriate Alternative?*, 4 St. Louis U. J. Health L. & Pol’y 279, 289-93 (2011).

³⁰ Ross and Ross v. Hatch, Circuit Court of Newport News, Virginia, Case No. CWF-120000-426 (2013). Information about the case, including transcripts and court orders, can be found at www.JennyHatchJusticeProject.Org

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- Texas' legislation recognizing SDM as an alternative to guardianship and granting legal status to SDM relationships and agreements;³²
- The Virginia Secretary of Health and Human Services recommending that state law recognize SDM as a "legitimate alternative to guardianship;"³³
- SDM projects in Vermont, New York, North Carolina, South Carolina, Maine, Nevada, Indiana, Delaware, Wisconsin, and other states; and
- The American Bar Association³⁴ and National Guardianship Association;³⁵ publishing articles and position papers calling for the use of SDM before imposing guardianship.

Supported Decision-Making Under Idaho Law

SDM is consistent with Idaho law. As mentioned, Idahoans with developmental disabilities may only be placed under guardianship if they are "unable" to manage their financial resources or meet their health and safety needs. Ask yourself this not-so-stupid question: How can you know if people are *truly* unable unless something has been tried to enable them to manage their resources, health, and safety?

The answer in nearly all cases is: you can't. Thus, under Idaho law, people with developmental disabilities cannot be placed under guardianship unless there is evidence

³¹ U.S. Admin. for Cmty Living. Funding Opportunity [HHS-2014-ACL-AIDD-DM-0084](#).

³² See, e.g., Tex. Est. Code § 1002.031; Tex. Est. Code § 1101.101(a)(D) & (E);

³³ Va HJR 190 (2014)

³⁴ Jonathan Martinis. *Supported Decision-Making: Protecting Rights, Ensuring Choices*. 36(5) Bifocal 107-110 (2015).

³⁵ National Guardianship Association. *Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making*. (2015). Available at: http://www.guardianship.org/documents/NGA_Policy_Statement_052016.pdf

that attempts to enable them to manage their financial resources and/or meet their health or safety needs, like SDM, have failed. Our position is consistent with that of the National Guardianship Association which stated “Alternatives to guardianship, including supported decision making, should always be identified and considered whenever possible prior to the commencement of guardianship proceedings.”³⁶

Supported Decision-Making in Action: Vermont

In 2016, Vermont became the first state to make a system-wide commitment to SDM. Vermont’s SDM Task Force brought together people with disabilities, families, and representatives of the medical, legal, educational, employment, advocacy, mental health, aging, and developmental disabilities communities with the goal of decreasing overbroad and undue guardianship by infusing SDM principles and practice throughout the systems serving people with disabilities.

The Task Force is built on the Culture of Coordinated Support (CCS) model.³⁷ CCS involves people, professionals, providers, and agencies coordinating and collaborating on service planning and provision, rather than each entity operating in a “vacuum.” As a result, all parties are able to plan for and provide effective, efficient supports that enhance each other’s strengths rather than unknowingly duplicating or nullifying efforts. For example, attorneys and Judges will work with agencies and providers to help people with disabilities identify supportive people and organizations, rather than reflexively advocate

³⁶ National Guardianship Association, *supra* note 35.

³⁷ See, Jessalyn Gustin & Jonathan Martinis. *Change the Culture, Change the World: Increasing Independence by Creating a Culture of Coordinated Support*. Apostrophe Magazine (2016). Available at: www.apostrophemagazine.com

for or order guardianship. Health care providers will collaborate with developmental disabilities agencies to secure needed supports instead of recommending guardianship to “solve problems” those supports can address. Schools, service agencies, and providers will work together to help young adults plan for and implement the supports they need to learn independent living skills.

State and system-wide use of SDM is the key to CCS. This is because SDM is or should be incorporated into most, if not all, of the services and supports used by people with disabilities. “Informed choice” in Vocational Rehabilitation, “informed consent” in medical care, the “student-led IEP” in Special Education, “person centered planning” in Medicaid services, and attorneys’ ethical obligations to clients with “diminished capacity” all involve professionals helping people with disabilities understand the situations and choices they face, so they can make their own decisions – the *very definition* of SDM.

Using SDM as a “common tongue” across systems and agencies, Vermont has launched several pilot projects designed to decrease over-reliance on overbroad and undue guardianship and support people to direct their own independent, self-determined lives. These include:

- A collaboration between a developmental disabilities agency, the Public Guardian, and attorneys to identify people currently under guardianship who could direct their own lives with appropriate support, help them plan for and implement needed supports, and then request that the court remove their guardianships;
- Schools, Vocational Rehabilitation Agencies, a self-advocacy organization, and provider agencies working together to identify young adults at risk of guardianship

and help them plan for and implement the services and supports they want and need to direct their own lives;

- State evaluators coordinating with the Public Guardian and state aging and disability agency to develop evaluation guidelines that focus on people's functional ability to make decisions, with or without support.
- State provider agencies developing policies and practices to allow people to work with supporters to apply for and review services.

Conclusion

While SDM has the potential to help people with disabilities reap the research-proven benefits of self-determination – including increased employment, independence, health, and safety³⁸ – two millennia of overbroad and undue guardianship loom overprotectively before that goal.

To reach the promise of SDM, attorneys and Judges, professionals and providers must team with people and families to recognize, respect, and protect *everyone's* Right to Make Choices with the support they need and want to do so. When that happens, your favorite rights – whatever they are – will, at long last, be equal rights.

³⁸ Blanck & Martinis, *supra* note 2.