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Supported Decision-Making: Protecting Rights, Ensuring Choices

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Introduction¹

How would you feel if you had no say in where you live or work, on what you can spend money, or with whom you can spend time? The denial of such fundamental freedoms—the building blocks of Life, Liberty and the pursuit of Happiness—without extraordinarily compelling reasons violates our bedrock moral and legal codes. To safeguard liberty, for example, we pledge that “it is better that ten guilty persons escape than that one innocent suffer”² and provide evaluations and treatment for those thought to be incompetent to stand trial.

And yet, for over 2,000 years people with challenges in decision-making have been placed under guardianship, resulting in another person having “substantial and often complete authority over [their] lives,”³ frequently including control of their finances, living conditions, social freedoms, and medical care.⁴ Despite efforts to reform guardianship laws and proceedings, and a national trend toward increasing the autonomy of those affected, the number of adults under guardianship appears to have risen substantially in

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the last twenty years.⁵

This article introduces Supported Decision-Making, an alternative to guardianship where people make their own decisions, without a guardian, while receiving the help they need and want to do so. Supported Decision-Making protects and enhances the “principal prerogative all people have to make their own decisions and direct their own lives to the maximum of their abilities” and can improve life outcomes like health, independence, safety, and employment.⁶

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

On September 25, 1987, a House Select Committee held hearings titled *Abuses in Guardianship of the Elderly and Infirm: A National Disgrace*. Summarizing the Committee’s findings, Chairman Claude Pepper famously stated:

The typical ward has fewer rights than the typical convicted felon By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception . . . of the death penalty.⁷

Decades of research performed before and after Representative Pepper’s pronouncement has shown that people subjected to overbroad or undue guardianship—guardianships imposed on those who can use less-restrictive alternatives to make their own decisions⁸—can suffer negative life outcomes.⁹ This is because guardianship decreases self-determination by taking away a person’s legal right to make decisions. Self-determination “describe[s] actions that enhance the possibilities for people to control their lives.”¹⁰ People exercise self-determination by making life choices—decisions “casual and critical that determine where, how, and with whom they live life.”¹¹

When people are denied self-determination, their performance across-the-board can suffer, leading them to “feel helpless, hopeless, and self-critical.”¹² Thus, it is easy to understand how overbroad or undue guardianship can cause a “significant negative impact on . . . physical and mental health, longevity, ability to function, and reports of subjective well-being.”¹³ In short, once a Judge appoints someone to make their life choices, “[w]hy . . . should they attempt a task that they have been told they are incompetent to perform?”¹⁴

Consequently, policymakers, scholars, and some courts have recognized that “even when it is functioning as intended [guardianship] evokes a kind of ‘civil death’ for the individual, who

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is no longer permitted to participate in society without mediation through the actions of another if at all."¹⁵ Consistent with the Americans with Disabilities Act and other law and policy mandating independence and community integration,¹⁶ legislatures, courts, and policymakers have acknowledged the need to identify and implement less-restrictive alternatives to guardianship that protect and advance the self-determination of older adults, people with disabilities, and others with challenges in decision-making.¹⁷

Supported Decision-Making has recently emerged as "an alternative to and an evolution from guardianship"¹⁸ with the potential to protect fundamental rights, increase self-determination, and improve life outcomes. While there is no one-size-fits-all model of Supported Decision-Making, it occurs when people choose trusted friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions.¹⁹ In this way, it 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."²⁰

Supported Decision-Making relationships can be "of more or less formality and intensity," including informal support by people who "speak with, rather than for, the individual with a disability,"²¹ formal "micro-board[s] . . . and circles of support"²² and other relationships offering varying types of support for various types of decisions. However, all Supported Decision-Making relationships share three common elements:

1. The recognition that the person has the right to make his or her own decisions;
2. The acknowledgment that the person can enter into a decision-making process or relationship without surrendering his or her right to make decisions; and
3. The understanding that the person may need assistance in making or communicating decisions "through such means as interpreter assistance, facilitated communication, assistive technologies and plain language."²³

Through these relationships, people may "receive support 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."²⁴

Conclusion

Supported Decision-Making is increasingly being encouraged and adopted by courts,²⁵ legislatures,²⁶ and policymakers²⁷ as a less-restrictive alternative to guardianship. In contrast to overbroad or undue guardianship, Supported Decision-Making can increase self-determination by ensuring that the person retains life control to

the maximum extent possible. Thus, instead of “divest[ing] the individual of the ability to make crucial self-defining decisions,”²⁸ Supported Decision-Making “retains the individual as the primary decision maker, while recognizing that the individual may need some assistance . . . in making and communicating a decision.”²⁹ By doing so, it empowers people to be “causal agents”³⁰ in their lives, able and authorized to make their own life choices, with access to the improved life outcomes research has correlated with greater self-determination, such as increased and enhanced independence, employment, community integration, and safety.³¹

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² William Blackstone, 2 Bl. Com. c. 27, margin page 358, *ad finem*, cited in, *Coffin v. United States*, 156 U.S. 432, 456 (1895).

³ Judge David Hardy, *Who Is Guarding the Guardians? A Localized Call for Improved Guardianship Systems and Monitoring*, 4 NAELA J. 1, 7 (2008).

⁴ See, e.g., Sens. Gordon H. Smith & Herb Kohl, S. Spec. Comm. on Aging, *Guardianship for the Elderly: Protecting the Rights and Welfare of Seniors with Reduced Capacity* 7 (2007) (“[W]hen full guardianships are imposed, all of one’s fundamental rights are transferred to the guardian.”); *Guardianships: Little Progress in Ensuring Protection for Incapacitated Elderly People: Hearing Before the S. Spec. Comm. on Aging, 109th Cong.* 3-4 (2006) (statement of Barbara D. Bovbjerg, Dir. Of Education, Workforce, and Income Security Issues) (discussing possible loss of rights).

⁵ See, Winsor C. Schmidt, *Guardianship: Court of Last Resort for the Elderly and Disabled*. Durham, NC: Carolina Academic Press (1995); Sandra L. Reynolds, *Guardianship Primavera: A First Look at Factors Associated with Having a Legal Guardian Using a Nationally Representative Sample of Community-Dwelling Adults*. 6

Aging and Ment. Health, 109-120 (2002); Brenda K. Uekert, Richard Van Duizend, R., Adult Guardianships: A "Best Guess" National Estimate and the Momentum for Reform. In *Future Trends in State Courts 2011: Special Focus on Access to Justice* (2011). Retrieved from http://www.guardianshipcert.org/files/publicpolicy/Uekert_Van_Duizend_Adult_Guardianships.pdf (last visited June 3, 2015).

⁶ 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); Peter Blanck & Jonathan Martinis, 'The Right to Make Choices': The National Resource Center for Supported Decision Making, 3 Inclusion 24-33 (2015).

⁷ H.R. Rep. No. 100-641, at 1 (1987).

⁸ See, Jonathan Martinis, Peter Blanck, and Iris Gonzalez, Brief for Amici in *In Re: Guardianship of the Person and Estate of Ryan Keith Tonner, an Incapacitated Person*. Case No. 14-0490 (Tx, 2015); Margaret "Jenny" Hatch, Samantha Crane, and Jonathan Martinis, Unjustified Isolation is Discrimination: The Olmstead Case Against Overbroad and Undue Organizational and Public Guardianship, 3(2) Inclusion 65, 67 (2015).

⁹ See, e.g., 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); 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, 354 (2010); Nina A. Kohn, Jeremy A. Blumenthal & Amy T. Campbell, Supported Decision-Making: A Viable Alternative to Guardianship?, 117 Penn St. L. Rev. 1111, 1119 (2013) [hereinafter "Kohn et al."].

¹⁰ Michael L. Wehmeyer, Self-Determination and Individuals with Severe Disabilities: Re-examining Meanings and Misinterpretations, 30 Res. & Prac. for Persons with Severe Disabilities 113, 119 (2005) (internal quotations omitted).

¹¹ Martinis, Blanck, & Gonzalez, *supra* note 8 at 10.

¹² Edward Deci, Intrinsic Motivation 208 (1975).

¹³ Wright, *supra* note 9, at 354.

¹⁴ Bruce J. Winick, The Side Effects of Incompetency Labeling and the Implications for Mental Health Law, 1 Psychol., Pub. Pol'y & L. 6, 18 (1995).

¹⁵ 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).

¹⁶ See, e.g., Americans With Disabilities Act, 42 U.S.C. § 12101 et seq. (2006); *Olmstead v. L.C.*, ex rel. Zimring, 527 U.S. 581 (1999).

¹⁷ See, e.g., Kohn et al., *supra* note 9, at 1115-1120.

¹⁸ See Admin. for Cmty Living. U.S. Dep't of Health & Human Servs., Funding Opportunity HHS-2014-ACL-AIDD-DM-0084, Supported Decision Making, available at <http://www.grants.gov/web/grants/view-opportunity.html?oppId=256168> (last visited June 3, 2015).

¹⁹ Blanck & Martinis, *supra* note 5.

²⁰ Quality Trust for Individuals with Disabilities, Supported Decision-Making: An Agenda for Action (2014), available at <http://jennyhatchjusticeproject.org/node/264> (last visited June 3, 2015).

²¹ Dinerstein, *supra* note 15, at 10.

²² Kohn et al., *supra* note 9, at 1123.

²³ Dinerstein, *supra* note 15, at 10-11.

²⁴ Salzman, *supra* note 9, at 306.

²⁵ See, *In re Peery*, 727 A.2d 539, 540 (Pa. 1999) (guardianship terminated because the person had a "circle of support to assist her in making rational decisions"); *In re Dameris L.*, 956 N.Y.S.2d 848, 856 (N.Y. Sur. Ct. 2012) (guardianship terminated because person was "able to engage in supported decision-making"); *Ross v. Hatch*, No. CWF120000426P-03, slip op. at 7 (Va. Cir. Ct. Aug. 2, 2013), available at http://jennyhatchjusticeproject.org/docs/justice_for_jenny_trial/ (petition for permanent guardianship denied in favor of Supported Decision-Making relationship the person had developed).

²⁶ See, e.g., Volunteer-Supported Decision-Making Advocate Pilot Program, Tex. Gov't Code Ann. § 531.02446 (2009) (expired on Sept. 1, 2013); H.B. 39 (Tx. 2015) (amending Texas Estate Code to recognize Supported Decision-Making as a less-restrictive alternative to guardianship; require that Courts find that less-restrictive alternatives are not feasible before imposing a guardianship; and authorizing Supported Decision-Making agreements); H.J.Res. 190, Reg. Sess. (Va. 2014).

²⁷ See Admin. for Cmty Living. U.S. Dep't of Health & Human Servs., Funding Opportunity HHS-2014-ACL-AIDD-DM-0084, Supported Decision Making, available at <http://www.grants.gov/web/grants/view-opportunity.html?oppId=256168> (last visited June 3, 2015).

²⁸ Salzman, *supra* note 9, at 291.

²⁹ Dinerstein, *supra* note 15, at 10.

³⁰ Wehmeyer, *supra*, note 10, at 115.

³¹ See, e.g., Karrie A. Shogren et al., Relationships Between Self-Determination and Postschool Outcomes for Youth with Disabilities, 4 J. Special Educ. 256 (2015); Laurie Powers et al., My Life: Effects of a Longitudinal, Randomized Study of Self-Determination Enhancement on the Transition Outcomes of Youth in Foster Care and Special Education, 34 Child. & Youth Services Rev. 2179 (2012); Janette McDougall et al., The Importance of Self-Determination to Perceived Quality of Life for Youth and Young Adults with Chronic Conditions and Disabilities, 31 Remedial & Special Educ. 252 (2010); 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). ■

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